DOROTHY HOUSE HOSPICE CARE

A community-based needs analysis in the Mendip areas of Coleford, Shepton Mallet and Frome.

Report Authors:
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(Community First)
Thank you to Dorothy House Hospice Care for commissioning this important needs analysis and for taking the time to listen to the views of the Mendip community. We heard many positive comments on the door from people who were so grateful that you are listening.

Many thanks to Alex Neale and Katrina Watson, our fantastic Community Organisers who listened to the views of people in the Mendip community with empathy, compassion and good humour – and who had a record number of doors slammed in their face!

Also thank you to the organisations that supported us with this important project including the Community Council for Somerset, Spark Somerset, Frome Medical Practice and the team at Health Connections Mendip, who helped us connect with local groups, including Frome Men’s Shed and Frome and District Day Centre.

Finally, a massive thank you to the residents of Coleford, Shepton Mallet and Frome who kindly opened their doors and shared their experiences with us. You made us laugh, you made us cry and you passionately shared your views on what the Mendip community needs and deserves in terms of life-limiting illness and associated loss and bereavement.
EXECUTIVE SUMMARY

MENDIP NEEDS ANALYSIS

EXECUTIVE SUMMARY:

In June 2018, Community Organisers from Community First carried out a community-based needs analysis in the Mendip communities of Coleford, Shepton Mallet and Frome. This needs analysis was commissioned by Dorothy House Hospice Care and aimed to identify what support was felt to be needed locally in terms of life-limiting illness and associated loss and bereavement.

Community First engaged with Mendip residents through an online survey and face-to-face community engagement, with the initial aim of speaking to 60 residents and 120 completed surveys. The survey was not received well by the Mendip community, who preferred the face-to-face approach, particularly when discussing the sensitive and often taboo subject of dying.

Community First reached a total of 429 people, with 14 responses via the survey, 160 viewed but not completed surveys and 255 face-to-face ‘listenings’. This represents an overall response rate of 63%. Listenings were harvested for quantitative data and feedback was blended into one final dataset for analysis. Listenings were also recorded and analysed for recurring patterns and themes. Listenings were evenly split between Coleford, Shepton Mallet and Frome.

Qualitative Results

Approximately half of all people we spoke to had been affected by a life-limiting illness, the vast majority of these people relayed a historical rather than a current experience. Participants reported receiving support from a variety of sources, including the local hospice (29%), health and social care professionals (24%) and family members (21%). 51% of people who had accessed support or services said they had a ‘very positive’ experience. 75% of people who received support associated with life-limiting illness said that more support would have been helpful.

Around half of all people we spoke to said that they have had a conversation about planning for the end of their life with the remaining half saying that they had not spoken with anyone else about their end of life wishes. The vast majority had spoken with a family member.

Understanding and awareness of Dorothy House was generally good, with 76% of people we spoke to having heard of Dorothy House Hospice Care or expressing some level of understanding around the role of a hospice in end of life care.
EXECUTIVE SUMMARY

Feedback from the Mendip Community

Mendip residents were keen to share their ideas about what support and services they would like to see for their community. Almost a third of Mendip residents felt there was a need for local facilities to support people with life-limiting illness and their families. Some people in Mendip feel they have ‘been forgotten about’ in terms of palliative and end of life care and, whilst many had a good experience with Dorothy House Hospice Care, they also felt that there should be better support, facilities and services locally.

There are significant concerns in the Mendip community about transport provision for terminally ill patients and their families, friends or carers. Logistical support is the ‘flip-side’ of concerns about local facilities and Mendip residents felt that if services could not be provided locally, then support with transport is absolutely essential.

The Mendip community feels that provision of bereavement and support groups is insufficient. Some of the people we spoke to had accessed support groups or bereavement services in the past and felt that support should to be tailored to the individual and available months, possibly even years after a loved one has died.

Mendip residents would like to see better signposting and awareness of the services offered by Dorothy House as well as other local services for people affected by life-limiting illness. Even those that had a personal experience with Dorothy House, felt the hospice should be more visible in the Mendip community, by making the community more aware of the important work it does.

Recommendations

• Mendip residents would like to see local facilities e.g. local hospice, local outreach centre. If this is not possible, a transport solution for patients and loved ones is felt to be essential. Mendip residents would also like to see increased provision of bereavement support. This could be facilitated through a buddy network, helping to alleviate transport issues for those unable to access groups.

• Improve awareness and signposting so Mendip residents know what is available in terms of end of life care. Dorothy House Hospice Care should also consider offering new resources and training to support end of life planning.

• Frome offers an excellent foundation to build upon in terms of existing support networks and community-led solutions which are already in place (e.g. Men’s Shed). Dorothy House Hospice Care could also consider Frome as a potential base of operations in the Mendip area.

• Consider training Dorothy House Hospice Care staff and volunteers in Community Organising techniques. This is a new and innovative way to encourage courageous conversations about living well and dying well, as well as offering a practical solution to building community capacity around life-limiting illness.
INTRODUCTION

INTRODUCTION:
A MENDIP COMMUNITY-BASED NEEDS ANALYSIS.

Dorothy House Hospice Care is a registered charity which provides compassionate care and support for people with a life-limiting illness in Bath, North-East Somerset 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.

For Dorothy House Hospice Care, growing their understanding of community need across their area (including Mendip) is important if they are to realise their new Strategic Plan 2018-25 – Everyday, Everyone - and ensure that everyone in their area has access to outstanding palliative and end of life care.

In June 2018, Community Organisers from Community First carried out a community-based needs analysis in the Mendip communities of Coleford, Shepton Mallet and Frome. This needs analysis was commissioned by Dorothy House Hospice Care and aimed to understand local people’s experiences and help to identify what support was felt to be needed locally in terms of life-limiting illness and associated loss and bereavement.

For Dorothy House Hospice Care, growing their understanding of community need across their area (including Mendip) is important if they are to realise their new Strategic Plan 2018-25 – Everyday, Everyone.
Community Organising

Devizes based charity Community First has over 50 years of experience supporting local communities. As well as running a number of large and established programmes, Community First 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 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 come 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 are able to listen to a diverse range of people and hard-to-reach demographics, including those who are isolated.

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.

Community First has two fully trained Community Organisers Alex Neale and Katrina Watson, with a proven track record of success, having spearheaded and successfully delivered both local and national pilot projects that embrace and utilise Community Organising techniques. These include the Community Organising Volunteer Training Programme, the Mobilisation Fund Programme in 2015-2016 which delivered work around Community Rights and Neighbourhood Planning engagement, Village SOS programme, and Warminster Neighbourhood Plan referendum.
Community First took a digital and face-to-face approach to engaging with local people in the Mendip communities of Coleford, Shepton Mallet and Frome.

Survey & Materials

Working closely with Dorothy House Hospice Care, Community First developed an online survey (see Appendix 1) and a listening sheet which mirrored the questions in the online survey. This listening sheet formed the question structure to gently guide face-to-face conversations with people, allowing a ‘life-for-like’ comparison between the online survey results and face-to-face listenings. Ensuring the listening sheets were aligned with the online survey also meant that listenings could be ‘mined’ or ‘harvested’ for quantitative data, alongside qualitative responses.

As well as offering a useful guide to keep the conversation ‘on track’ and a way of harvesting quantitative data, the listening sheet also helped conversation to flow naturally. As such, not all of the listenings followed the same structure or answered all of the questions available. For some people it was important to talk about their own personal experience and what they felt was needed locally. For those who didn’t have a personal experience to relate to, it allowed them to reflect openly on the subject of life-limiting illness, possibly for the first time.

The Community Organisers used the listening sheet as a guide and made notes for each listening conducted along with demographic information (gender, approximate age category).

Alongside the survey and listening sheet, Community First also worked alongside Dorothy House Hospice Care to produce a printed A5 leaflet (see Appendix 2). This leaflet introduced the Community Organisers and included information about the project, as well as a link to a dedicated landing page on the Community First website with more information on completing the online survey. This ensured that members of the community who were not at home at the time of the face-to-face engagement, still had the opportunity to take part in the project and share their experiences.

The Community Organisers contacted local police stations and PCSO’s prior to the engagement activity to inform them that they would be door-knocking in the area. They also visited Coleford, Shepton Mallet and Frome on Thursday 7th June 2018 to deliver leaflets prior to the engagement activity.
Outreach Activity

As a Wiltshire based charity (with Wiltshire based networks), Community First worked in partnership with similar organisations in Somerset, to ensure access to local networks, both digitally and on the ground in Coleford, Shepton Mallet and Frome. This reduced the likelihood of survey responses from people outside the target audience in Mendip.

In order to target people in the Mendip area, Community First worked alongside ACRE Network partner Community Council for Somerset and local charity Spark Somerset to raise awareness of the needs analysis including the purpose of the project, overall aims and key dates for when the Community Organisers would visit each area. These partners allowed us to share information about the project and the link to the online survey through their contacts and digital networks including email newsletters and social media channels.

Community First also made contact with other key stakeholders and partners in the Mendip area including doctor’s surgeries, medical centres and the Mendip Health Connections team, both to make them aware of the project and to request their support to help us engage effectively and sensitively with the community. This outreach activity resulted in a significant number of listenings with two popular local groups: Frome Men’s Shed and Frome and District Day Centre.

Listening Activity

The Community Organisers followed the below timeline as part of the face-to-face (door-knocking) engagement:

- 7th June 2018 – Leaflet Drop
- 11th June 2018 – Shepton Mallet Community
- 12th June 2018 – Coleford Community
- 14th June 2018 – Frome Men’s Shed
- 14th June 2018 – Frome and District Lunch Club
- 15th June 2018 – Frome Community
- 20th June 2018 – Coleford Community
- 21st June 2018 – Shepton Mallet Hospital

The Community Organisers took a relatively informal approach to sampling. They began canvassing (or door-knocking) neighbourhoods by looking for signs that people were at home (e.g. cars parked in the driveway) or in their gardens. They also looked for local gatherings or group activity in the area. The Community Organisers aimed to hear from a diverse range of people in terms of age, gender and socio-economic status and canvassed a variety of different homes in each area including larger homes, social housing, bungalows and new housing developments.

The Community Organisers aimed to hear from a diverse range of people in terms of age, gender and socio-economic status.
Dorothy House Hospice Care and Community First originally planned to reach up to 60 residents in 4 days of door-knocking and face-to-face community engagement (e.g. lunch clubs, groups) as well as at least 120 responses through the online survey.

After promotion of the survey through Mendip networks and door-to-door activity, it became apparent that whilst people were visiting the survey, the vast majority were choosing not to complete it. The Community Organisers also shared feedback from a Frome Men’s Shed volunteer who deserted the survey as he felt the questions were too generic, covered too many options and didn’t necessarily apply to him.

The Community Organisers also had a variety of comments on the door which indicated that Mendip residents greatly valued the opportunity to talk face-to-face, particularly about a topic which is often upsetting and emotional.

Some of the comments included:

“Thank you so much for coming round and asking, talking, it has felt really good to talk and express myself, sometimes it is good to talk to someone who is not a friend or relative, you have just listened. Sorry for going on.”

“Thank you for the chat today and bringing back all those lovely memories of my dear husband, it has been lovely to tell you a little about him and remember all the good things we did together, not all about the dying.”

“Good on you for coming out and trying to get people to talk about it all. I’m glad Dorothy House are listening.”

Mendip residents greatly valued the opportunity to talk face-to-face, particularly about a topic which is often upsetting and emotional.
As a result of these early findings and the feedback from residents and local people, Community First decided to prioritise face-to-face engagement, with the aim of listening to at least 200 local residents. Community First felt that the survey may have been too impersonal, particularly for people with an experience of life-limiting illness and associated loss and bereavement.

In total the Community Organisers spoke to 255 residents in Coleford, Shepton Mallet and Frome, over three times the total amount of listenings originally planned. The listenings were evenly split between the three target areas. Whilst the survey remained online throughout the duration of the project, we obtained just 14 responses with a further 160 who viewed but did not complete the survey. This represents a response rate of 8% for the survey.

The Community Organisers spoke to 255 residents in Coleford, Shepton Mallet and Frome, over three times the total amount of listenings originally planned.

Response Rate: Summary

In total Community First reached 429 people in the Mendip communities of Coleford, Shepton Mallet and Frome with:

- 255 listenings conducted
- 14 surveys completed
- 160 people viewing but not completing the survey

This represents an overall response rate of 63%.

Listening Figures

<table>
<thead>
<tr>
<th>Date</th>
<th>Location</th>
<th>Listeners</th>
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<tr>
<td>11/06/2018</td>
<td>Shepton Mallet</td>
<td>33</td>
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<td>Coleford</td>
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<tr>
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<td>19</td>
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<tr>
<td>14/06/2018</td>
<td>Frome Lunch Club</td>
<td>25</td>
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<tr>
<td>15/06/2018</td>
<td>Frome</td>
<td>38</td>
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<td>20/06/2018</td>
<td>Coleford</td>
<td>40</td>
</tr>
<tr>
<td>21/06/2018</td>
<td>Shepton Mallet Hospital</td>
<td>50</td>
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Listening Total: 255

Survey Figures

| Completed Surveys | 14 |
| Viewed but not completed | 160 |

Survey Total: 174
 Whilst demographic information was not requested for the survey, Community Organisers were able to record basic demographic data (gender, age category) with permission from residents. As not all people spoken to gave permission for this data to be recorded, some demographic data is missing.

Overall, the gender split of participants was roughly equal, with 55% male and 45% female responses. The slight difference in male/female responses is likely to be due to the 19 listenings conducted at the Frome Men’s Shed, where no females were in attendance.

**Gender**

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<tr>
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<td>45%</td>
<td>55%</td>
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*Percentage of male vs. female listenings conducted (overall)*

**Gender & Age Category**

*Male/female breakdown by age category (overall listenings)*
DEMOGRAPHICS

The Community Organisers spoke to a variety of age groups, however the vast majority of listenings were with people aged 50+. The chart on page 12 shows the breakdown of age categories by gender and is in line with the overall breakdown for age demographics in the Mendip Area.\(^1\)

Whilst the Community Organisers made every effort to speak to people of different age ranges, the listenings were conducted during office hours which meant that a large percentage of people at home during these hours were retired or older people. Similarly, the Community Organisers were keen to hear from people who were active in their local communities (as well as those who were potentially isolated) and attended two local groups, both with a predominantly older audience: Frome Men’s Shed and Frome and District Lunch Club.

Whilst the age range for many of the listenings was largely people aged 50 years and over, this demographic may be more likely to have had a personal experience with life-limiting illness and associated loss and bereavement, potentially adding additional experiences above and beyond what a younger demographic might have to share.

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<th>COLEFORD (%)</th>
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<td>41%</td>
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<tr>
<td>Female</td>
<td>10%</td>
<td>23%</td>
<td>49%</td>
<td>18%</td>
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Tables showing percentage breakdown by gender and age category (by area and overall).

\(^1\) [http://www.somersetintelligence.org.uk/census2011](http://www.somersetintelligence.org.uk/census2011)
Whilst the survey was not well-received by the Mendip community, Community First knew that obtaining quantitative results was an important part of the needs analysis. As such, each listening sheet was carefully harvested for quantitative data, based on statements made by the person being listened to. As the survey data itself was unsubstantial, it was decided to ‘blend’ the survey and the harvested listening datasets together to inform the analysis in this report.

Experiences of Life-Limiting Illness

47% of participants in the Mendip communities of Coleford, Shepton Mallet and Frome said they have previously needed (or are currently receiving) support because they, a family member of a friend currently has or had a life-limiting illness. There was no significant difference in current or historical experience of life-limiting illness by geographical area. In Coleford, Shepton Mallet and Frome, approximately half of all people listened to had a personal experience to share.

Of those who needed support or services associated with life-limiting illness, 83% said they had received support in the past with 17% currently receiving support. Participants reported receiving support from a variety of sources, including the local hospice (29%), health and social care professionals (24%) and family members (21%) or friends (11%).

Of the participants who said they had or are currently receiving support and services, the majority expressed their level of satisfaction with services or support relating to life-limiting illness and associated loss and bereavement, whilst relaying their personal experience.
51% of people who had accessed support or services said they had a ‘very positive’ experience. With an additional 12% having a ‘somewhat positive’ experience. Comments included:

“My girlfriend died and was in Dorothy House she received the best care ever, she was happy in there, we obviously tried to do as much as possible that was on her bucket list. Didn’t manage all of it, but I promised her I would complete them all while she watches over me. I think the care was so good, they explained things clearly to her, which then she was able to tell me about. I am just so pleased that the care and support received from Dorothy House was just lovely and she seemed so happy while she was in there.”

“We had help and support from Dorothy House for 18 months for my wife, while I had acute pancreatitis the care my wife received was brilliant in the day, but not so good in the night.”

“My husband had heart disease, he died at home, we had support from carers, the doctor’s surgery was excellent, our doctor is such a lovely chap. I felt he was very sincere and trusted him with my husband’s life and mine too.”

51% of people who had accessed support or services said they had a ‘very positive’ experience. With an additional 12% having a ‘somewhat positive’ experience.

21% of participants talked about their own experience factually or neutrally and did not express either a positive or negative rating for the service/s received. Some of the people listened to had a ‘very negative’ (4%) or ‘somewhat negative’ (12%) experience. Comments included:

“I needed the support but didn’t receive it, should I say my wife didn’t receive it! My wife passed away just over two years ago, worst day of my life! I’m not sure what happened with the support or should I say lack of support. Yes, people care and offer support (like Dorothy House), but if they haven’t got beds available, then people like my poor wife cannot have a space/bed and that was my wife’s wish. She didn’t want to die at home but was waiting for a bed to become available, but it didn’t.”

“One of my family members needed support, they had cancer and were dying, no beds available to care for them. They ended up dying at home, which was so sad, that is not what she wanted.”

“Had a really bad experience with Dorothy House. I don’t wish to discuss or give money!” [Door slammed in face]
FINDINGS

Of those who received or were currently receiving support for a life-limiting illness and associated loss and bereavement, 74% felt that additional support would have been helpful. A further 26% said they had received adequate support at the time and didn’t feel they needed any additional support.

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End of Life Planning

Of the 269 responses received through the survey or face-to-face engagement, approximately half of Mendip residents answered questions relating to planning for end of life (advanced care planning).

49% of participants said that they have had a conversation about planning for the end of their life with the remaining 51% saying that they had not spoken with anyone else about their end of life wishes. Some of the comments indicated that many people do not know what their own wishes are and don’t want to think about the end of their life or talk about it.

Of those who said they had not had a conversation about end of life planning, some participants acknowledged that talking about it was important but didn’t wish to confront the subject themselves. Some of the participants also felt that talking about end of life wishes and dying was a difficult subject to tackle – even with family members. A handful of participants mentioned trying to talk about end of life wishes with a loved one and being frustrated that they didn’t want to discuss it.

“Some of the participants also felt that talking about end of life wishes and dying was a difficult subject to tackle – even with family members.”

“TJ's difficult to talk about it with dad as he turns it into a joke all the time. I've told him if he won't be serious I'll just pop him in a wheelbarrow and take him down the allotment!”

“I haven't spoken to my kids about my end of life care or support because I can't bear to think about it. No one likes to think about it do they?! I suppose we should all talk about it somehow, but it makes me feel sad.”
Feedback from Mendip residents suggests that having a personal experience with life-limiting illness is a powerful motivating factor behind discussing end of life planning with loved ones. 71% of people who had a personal experience with life-limiting illness said they had already spoken with loved ones about their end of life wishes or made practical plans for the end of their life:

“When it comes to our own end of life care we still haven’t actually spoken about it. We are getting on with living. We don’t want to talk about it, when the Grim reaper comes he comes doesn’t he?! Haven’t got any choice in it. It isn’t a nice discussion to have and so we don’t talk about it even though everything happened with the wife’s brother.”

“My family don’t really know my end of life preferences as I haven’t discussed it. It’s not really spoken about. Perhaps it should be; but I’m here living NOW.”

Through my wife’s short illness, we spoke about both our wishes and dying and plans. We both planned for our funerals at the same time. We both wished we had planned all this before my wife fell ill, it felt rather rushed when we did it and maybe there are a few things we would have done differently.

“My husband and I have discussed our wishes for when our time comes, but I’m sure we only did this once mum was so poorly and realising we hadn’t discussed it properly with her.”

Conversely, only 29% of people who said they did not have a personal experience with life-limiting illness had spoken with a loved one about their end of life wishes.
FINDINGS

Of the participants who said they had a conversation with a loved one about planning for the end of their life, the vast majority (78%) said they had spoken with a family member. 11% reported talking about end of life planning with a friend and a further 7% with a professional.

Top reasons for not discussing end of life wishes or plans with a loved one or professional were:

- Wanting to let whatever happens, happen. “Let fate take its course”
- Not wanting to think about it
- Feeling that it is socially not a culture where we discuss it “stiff upper lip attitude”
- Not having the opportunity to do so or needing support to do so

Awareness of End of Life Services and Support in Mendip

Understanding and awareness of Dorothy House Hospice Care was generally good, with 76% of people we spoke to having heard of Dorothy House Hospice Care or expressing some level of understanding around the role of a hospice in end of life care.

A significant number of people spoke about the fantastic work that Dorothy House Hospice Care does in the community and their own personal experience with the hospice. People spoke passionately about the support they received and praised the patient and understanding care given.
FINDINGS

Some of the positive comments about Dorothy House included:

“I have actually had lots to do with Dorothy House Hospice. They supported myself and my husband. My husband died at the hospice a year ago and they have offered me support after his death too. They never rushed me and are filled with patience. Time is never an issue for them. I feel like the people who work there must go through a magic door where they become filled with sympathy and patience and kindness.”

“Dorothy House are so amazing. So fantastic. What an organisation!”

“Dorothy House and the care team were fantastic, they really cared for both of us, the support we both received was fantastic, treating us so well and making us feel special right up until the day that he passed away. The care that we received at home before he passed away was second to none.”

“I am actually under their care at the moment. I had my diagnosis three weeks ago and within 24 hours Dorothy House had called me and arranged to come and see me. They have been with me the whole time. They come my house to see me at the moment. I can’t tell you enough how good they are to me.”

“I am poorly and really suffering at the moment and it is a real worry, how much longer will I go on for, who will take care of my husband, will we have enough money to care for both of us and one or either of us is able to stay in the house. How much does a place like Dorothy House cost? It is a real worry.”

“I have heard about Dorothy House shops and the Hospice, but not entirely sure what services they offer. I don’t think we could afford to use any of the services that they offer.”

“The shops are really good. I’m not really sure what Dorothy House have on offer, are they a private Hospice? And do you have to pay, it is a real worry, so many people are getting cancer and suffering for years.”

Many people had heard of Dorothy House Hospice Care through the shops or fundraising activities (e.g. bubble rush, motorcycle charity event) and a handful of people actively support the organisation through donations or activities. There was some confusion around the cost of palliative and end of life care and some people were concerned that they couldn’t afford the services offered, even if they needed them:
FINDINGS

24% of people we spoke to in Mendip had not heard of Dorothy House Hospice Care and were not aware of support or services offered by the organisation. Some people associated Dorothy House with the charity shops but did not know exactly what the organisation does or did not connect the shops with the hospice:

“I haven’t heard of Dorothy House Hospice, Winsley, not heard of that either. I have donated to the Dorothy House shops, though but wasn’t aware it was linked to a hospice...It’s very interesting to hear about Dorothy House and link the two.”

“I don’t really know what Dorothy House Hospice do. From what you say they are really good and it would be good for them to advertise that more.”

“I haven’t heard of Dorothy House and I have been around here all my life.”

“I don’t really know much about Dorothy House or the services that they provide, nor do I know about the care that can be given.”

Approximately 20% of participants felt that support and services offered by Dorothy House Hospice care and similar services should be advertised more widely in the Mendip area:

“There really is a need for more awareness of all the services available for life limiting illnesses, maybe a step by step pamphlet with simple instruction and support and advice contact details. Us old people don’t always like to bother the doctors or our friends.”

“I think it would be a really good idea for them to advertise wider and at a local level, in supermarkets, chemists and drop in clinics in smaller villages...”

“I feel there is a need for well-known available support, WHAT IS AVAILABLE!!?”

“Maybe support needs to be more obvious and then people can take it when they want it but somehow feel like they aren’t giving up.”
COMMUNITY FEEDBACK: WHAT SUPPORT IS FELT TO BE NEEDED IN MENDIP?

Regardless of whether they had a personal experience with life-limiting illness, Mendip residents in Coleford, Shepton Mallet and Frome were keen to share their thoughts on what they feel is needed locally in terms of life-limiting illness and associated loss and bereavement. 75% of people who completed the survey or spoke to the Community Organisers face-to-face had ideas about what support and services they would like to see for their community.

Facilities

28% of Mendip residents felt there was a need for local facilities to support people with life-limiting illness and their families. It was felt that more services were being taken away rather than provided, on the whole.

Some people in Mendip feel they have ‘been forgotten about’ in terms of palliative and end of life care and, whilst many had a good experience with Dorothy House Hospice Care, they also felt that there should be better support, facilities and services locally.

Some Mendip residents expressed particular concern about the current availability of beds for people with life-limiting illness.
Many people felt that Mendip area ideally needed its own hospice or, alternatively, a local support centre where patients and families could easily access the care and support they need. Transport was a key issue (see logistics on page 24). Mendip residents do not want to travel long distances to access care, even if they have the means to do so. Some people were also concerned that the distance between Mendip and the nearest hospice might be a potential barrier to visiting loved ones who are dying.

“Support is needed from the government to ensure there are enough beds for dying people to have the palliative care that is needed; it really isn’t good enough that people are not getting the care that they deserve.”

“We are really in need of beds in the Mendip area, to make life easier for the families and easier visiting and to ensure our poor loved ones are not left without visitors.”

“The services are not adequate enough, there should be more beds or other hospices in the Mendip area, other services and more staff in the evenings and weekends.”

“It would of course be so much better if closer to our area, it would be great to have a hospice in the Mendip area. I understand that there is a shortage of beds, our friend, only spent two days in there, because she was waiting for a bed to become available. There should availability of beds and care provision free to everyone that needs it.”

“I would prefer something to be closer here in the Mendip area, so people don’t have to travel quite so far, it’s a little distance out to the hospice, which is fairly difficult to get to from Coleford if you are unable to drive, which means limited visits to a loved one that is staying at the hospice.”

“It would be so good to have more services closer, a hospice, here in the Mendip area would be brilliant.”

“The only thing that I think is needed is more services in our area, more local and central in the Mendip area. I often think about a friend that used the service many years ago, how on earth did they get there and how would I get there, if I had to visit or attend myself one day.”

Some Mendip residents expressed awareness of funding challenges and felt the government should do more to increase provision for end of life care services.
FEEDBACK

People

21% of Mendip residents felt that ‘people centred’ services were needed in the community, mostly local bereavement support and groups to help people who are affected by life-limiting illness and give them the opportunity to talk about how they are feeling.

Some of the people we spoke to had accessed support groups or bereavement services in the past and felt that bereavement support should be tailored to the individual and available months, possibly even years after a loved one has died. A number of people mentioned that they didn’t feel ready for help straight away, but help was not always available later when they were ready to talk.

Similarly, some residents felt that emotional support should be available from ‘day one’ of the illness or diagnosis as well as bereavement support following the death of a loved one.

“I think bereavement support should be offered not just when your loved one has gone, but while we are still caring for them, but they are not the same person they were.”

“Dorothy House were amazing but there is nothing locally. Mum was never the same after dad died and she really needed bereavement support, even if it was just a little local group. There isn’t much going on here and she couldn’t travel that far. If there was local support around loss, then I would probably attend myself.”

“There needs to be more of a support mechanism for those that don’t open up and talk to family members, there should be a place for everyone to have support and counselling if needed from day one of illness.”

“Perhaps bereavement and counselling could be more available for the whole family and maybe it could be an open offer as loss hits people at different times.”

“At the time, I didn’t think I needed any support but over the last six months, I have realised I am in the need for support, all bereavement support should be tailored everyone’s individual needs.”

“I think there is a real need for more in the Mendip area, more bereavement support is needed with less waiting times.”

“I think all three of us could do with a few sessions, counsellors are so expensive, none of us can afford that on our poor wages and being left to pay all the bills etc.”

Mendip residents felt bereavement and emotional support for families affected by life-limited illness should be offered on a flexible and long-term basis (as needed). They also felt the support should be local, so families and relatives do not have to travel too far to access the help they need. Waiting times for counselling and the potential cost of counselling services were also a concern.
 FEEDBACK

Logistics

19% of Mendip residents felt that logistical support was needed locally to support people affected by life-limiting illness. This was almost exclusively related to significant concerns in the Mendip community about transport provision for terminally ill patients and their families, friends or carers. Logistical support is the ‘flip-side’ of concerns about local facilities and Mendip residents felt that if services could not be provided locally, then support with transport is absolutely essential.

“Locally we need better transport to get around or facilities closer to us.”

“Transport is a huge issue with people with life limiting illness, also for family members caring for them, more added pressure on top of everything else”

“‘I would prefer something to be closer here in the Mendip area… it’s a little distance out to the hospice, which is fairly difficult to get to from Coleford if you are unable to drive.’”

“We wouldn’t be able to get to Dorothy House, there is no transport the buses are terrible. I think it would be good to have something easy accessible.”

Dorothy House: Mendip Needs Analysis

Transport is a problem for Mendip residents, particularly for the elderly and for people with illness or mobility problems. Coleford residents are especially geographically isolated. Bus services are infrequent and inadequate, and some people had to travel significant distances to access end of life care or support. This put unnecessary psychological and financial pressure on people who were already struggling with the stress and worry of life-limiting illness. Some people felt that although the care and support they received was outstanding, the stress of traveling to and from the hospice to visit a loved one had a negative impact on their overall experience and made it harder to visit their loved one as often as they would have liked.

“My wife died a couple of years ago it was costing me £60 each visit when she was going to appointments, my wife died at home where she wanted to pass away, but so many hospital appointments to attend and with chemotherapy, several weeks of ongoing appointments, thank goodness, we had the money to be able to get to the appointments, I dread to think what we would have done otherwise.”

“I think it would be really good to have something more local…people that have to visit loved ones and having to travel some distance, the time, the expense and the stress of getting connecting buses, trains and still unable to get to Dorothy House if you can’t drive.”

“I my wife died at home where she wanted to pass away, but so many hospital appointments to attend and with chemotherapy, several weeks of ongoing appointments, thank goodness, we had the money to be able to get to the appointments, I dread to think what we would have done otherwise.”
FEEDBACK

Some Mendip residents had to rely on the goodwill of family members, friends or neighbours to visit loved ones in the hospice and implied they felt like a burden by asking for help with transport.

“The only issue that I felt was transport, I relied heavily on lifts from friends and families, also taxis which are so expensive.”

“I have visited Winsley, it is a lovely place, my cousin was there, the bus route is terrible, so relied on my son to take me there.”

Training & Team Working

A handful of Mendip residents felt that training (3%) and team working (2%) were important factors in supporting people affected by life-limiting illness.

This included education and pastoral support for young people around life-limiting illness and community-based training or advisory sessions to advise people on different options for end of life care.

Some people also felt that better communication between healthcare providers was important.

“I think even more awareness of what is available locally, more education to young people, about life limiting illnesses and bereavement and that it is ok to talk about it, illnesses and death. It would be really great for teachers/lecturers or just the pastoral team trained up to be able to support pupils going through an illness…”

“We should have people from Dorothy House that come out to groups of old people and talk about the different options for end of life care. I don’t think people know what their options are. I certainly wouldn’t know where to start with it all.”

“Perhaps people should be taught in schools how to have a different attitude towards death and illness. Stop it being a stigma. No-one wants to talk about it.”

“I feel that CAHMS is hugely needed, support for Dorothy House and residents, family members including children, it is a huge gap all through services, but I’m sure it should be linked into Dorothy House and better services and support with bereavement and mental health.”

“If they want to know what’s needed they should link in with the hospitals and existing support groups because they have eyes on the ground and have to listen to all of our moans.”

Dorothy House: Mendip Needs Analysis
FEEDBACK

**Signposting & Awareness**

27% of Mendip residents said that they felt that factors other than logistics, people, facilities, training or team working were important. The vast majority of these people felt that better signposting and awareness of the services offered by Dorothy House as well as other local services for people affected by life-limiting illness, was important. Even those that had a personal experience with Dorothy House Hospice Care felt the hospice should be more visible in the Mendip community, by making the community more aware of the important work it does.

“I think Dorothy House should talk more about all the services that are out there on offer, and the options that they are giving people. That way more people will be aware of how to access help and support, also they should be telling the world what good work they do. It’s so valuable and they should advertise that.”

“More awareness about Dorothy House and what it does, I’m only aware since my daughter went for a visit also from my friend. Like it had been kept a secret, but I think it’s important to shout about all the good stuff that it does.”

“They should advertise their services, making us out here know what is on offer, things are not advertised properly, not just Dorothy House but all care services and providers, you have to dig for the information.”

“It would be so much better if the services were better advertised and more local, in case we need them.”

Some people had no knowledge of end of life care including what can be offered, when it can be offered and whether there is a cost involved in accessing care. Some people also felt that knowing more about the work of Dorothy House Hospice Care and end of life support in general, might help people prepare more effectively for the end of their lives, without leaving it until it is too late.

“I do think that the support is fantastic, but I feel that actually people need it sooner - even though they may not realise they know it. It’s hard to explain but I think maybe people don’t realise they need extra support until it’s too late. Perhaps the support needs to be advertised better so that people know what’s out there and how to access it.”

“I have friends that have used Dorothy House, I knew nothing about the services before they used them, I think there needs to be more local services in this area and much more information out there. I am unsure of all that they do, also it must cost a fortune!”

“I think sometimes help and support comes too late, or not at the right time for people.”

“More awareness about Dorothy House and what it does, I’m only aware since my daughter went for a visit also from my friend. Like it had been kept a secret, but I think it’s important to shout about all the good stuff that it does.”
There was a general level of concern amongst Mendip residents for neighbours who do not have family to call on if needed. People asked for more care resources in the community for isolated people without family or friends to care for them. Similarly, some residents we spoke to mentioned how much they rely on their community including neighbours and friends (particularly where family members live far away). They worried about becoming a burden on their current support network if they were diagnosed with a life-limiting illness.

Some people also worried about a potential crisis caused by a loved one falling ill and not being able to take time off work or afford care services for their loved one. These people felt that local services should be sufficient to avoid having to give up work and care for a loved one.

Community Capacity

Despite expressing concerns for their neighbours, residents in Coleford, Shepton Mallet and Frome were evasive when asked how they could support others in the local area affected by life-limiting illness. The vast majority of people in Mendip want to see solutions provided for them. There were a handful of comments relating to sharing experiences with others as a possible route to supporting members of the community:

“I don’t think I would be able to support others, although saying that, perhaps if there were more people that have gone through supporting a loved one through this terrible disease, this process and feeling very alone maybe not so lonely if we spoke to others that have been through it. But I’m still not ready for that yet.”

“I don’t think I am in a position to support or help others, if there was a support group near to me I would like to attend.”

“The only way, I think I can support other people is to discuss what I have been through caring for my dear wife, although some days it is painful to discuss, I just have to try and stay positive and think of all the lovely times we had together.”

Despite expressing concerns for their neighbours, residents in Coleford, Shepton Mallet and Frome were evasive when asked how they could support others in the local area affected by life-limiting illness.
FEEDBACK

There were also several comments from Frome Men’s Shed volunteers who felt the Shed offered a valuable support network for men affected by life-limiting illness:

“This place (Men’s Shed) is a life line for people, we see such a turnaround in them. Isolation is often the biggest cause of people getting unwell. So many men here have such open discussions about their grief and I think men can be underestimated about how much they confide in each other. Sometimes they don’t do any actual project work—they just talk. We never put a timescale on things for this very reason; it gives them the time they need to talk. That’s what makes this so successful.”

“I feel we are in a good position here at the Shed as we are locked into a great network that looks out for one another. So many people are supported here, and we are connected with so many helpful people at the medical centre. They refer people here if needed.”
MENDIP NEEDS ANALYSIS: RECOMMENDATIONS.

Develop Local Services & Solutions

Mendip residents are concerned about the lack of local facilities and support services for people affected by life-limiting illness and would like to see more services provided for them locally. Some of these residents feel they have been forgotten about in terms of palliative and end of life care. Dorothy House Hospice Care could consider offering more practical support locally in the form of an outreach centre, clinic or even a new hospice in the Mendip area.

In a challenging funding environment, Dorothy House Hospice Care may feel that opening a new facility is impractical. In this instance, the organisation should consider developing a co-ordinated and volunteer-led transport solution for the Mendip community to alleviate concerns about access to end of life care. Dorothy House Hospice Care currently has 67 volunteer drivers who support patients and their families to access the hospice using their own cars. While this is an excellent solution, there are just 2 drivers for the whole of the Mendip community, both of these drivers are based in Frome.

Dorothy House Hospice Care could consider approaching local community transport organisations including Mendip Community Transport as a starting point and to build on existing community capacity in terms of transport.

Alternatively, the organisation could consider developing a new Dorothy House Link (volunteer car) Scheme in the Mendip area or investing in a minibus and creating a local community minibus service for families and patients who need regular, free transport to the hospice or local outreach centres. Transport volunteers could potentially be recruited from existing Dorothy House Hospice Care supporters or those who want to ‘give something back’ following a personal experience with the hospice. This also offers families and patients a supportive, understanding driver who they can relate to. Similarly, travelling together in a Dorothy House minibus could offer families and patients the opportunity to talk to others who are going through a similar experience.

Community First can support Dorothy House Hospice Care to establish a new transport service if required. We currently manage one of the most successful community transport services in the country, advising 45 Link Schemes and 21 Community Minibus groups with over 2,000 volunteers locally. We also provide advice, practical support and training for organisations who want to set up a new community minibus group.

Finally, Mendip residents feel that the availability of local bereavement...
and support services is insufficient. Although Dorothy House Hospice Care could consider developing new support groups in rural as well as urban areas, access to transport may be a barrier to attendance, particularly for those who are geographically isolated (e.g. Coleford).

Almost half of the people we spoke to had an experience of life-limiting illness, many of these people lived on the same street or only a short walk from each other. As an alternative to traditional support groups, Dorothy House Hospice Care could consider creating a local befriending or ‘buddy’ network for people experiencing bereavement. Buddies might be people who have experienced the loss of a loved one and be willing to offer peer-to-peer support to a neighbour who is also affected by life-limiting illness. This network of buddies could grow over time on a neighbourhood by neighbourhood basis and offer real volunteer-led community support.

**Improve Awareness & Signposting**

Whilst a large percentage of people had heard of Dorothy House Hospice Care (directly or indirectly), they felt the organisation could be more visible in the community and advertise the services and support offered, more widely. Even in people who were aware of the hospice, there was still some confusion about access to support. Similarly, a quarter of people we spoke to had no knowledge of Dorothy House Hospice Care (beyond the shops) and were unaware of services to support people affected by life-limiting illness.

Overall the Mendip community is relatively uninformed about options, support and services for people affected by life-limiting illness, not just those offered by Dorothy House, but other services including support groups, practical support and counselling. Dorothy House Hospice Care has an opportunity to position itself as the trusted ‘go-to’ organisation in the Mendip community for people who are affected by life-limiting illness or those who need support around end of life planning.

As part of a profile-raising exercise in the Mendip community, Dorothy House Hospice Care could consider reaching out to local health and social care providers, local councils, charities, voluntary groups and the health connections team, to develop a collaborative approach to signposting for life-limiting illness and associated loss and bereavement. Information should be easy to access both online and offline with clear guidance on what services can be offered, when they can be accessed and what (if any) fee is payable.

As well as improving signposting, Dorothy House Hospice Care could also consider developing new resources and training programmes to help local people plan for the end of their life and understand what support is available. An example of this is the Cheshire Living Well Dying Well Partnership which aims to change knowledge, attitude and behaviour towards life, age, death and loss. The partnership offers practical support including funeral planning, future care planning and financial planning as well as advice on how to support others and talk to loved ones about end of life care wishes. The organisation also offers training for people and professionals on important aspects of end of life planning.
Build on Existing Community Capacity in Frome

As previously mentioned, Mendip residents were evasive when asked how they could support people in their community affected by life-limiting illness and said that they would like solutions to be provided for them. Despite this, Community Organisers noticed an underlying concern for and connection between neighbour to neighbour. Given time and with more visibility of services for Mendip residents, this could result in community-led solutions and more involvement from local people in shaping the services they would like to see in future.

Dorothy House Hospice Care is keen to work closely with local people in Mendip and develop community-led solutions to supporting people affected by life-limiting illness and associated loss and bereavement. This is a commendable approach and there is potential, particularly within Frome, to build on existing community capacity.

Frome is a thriving, town in Mendip with a strong community ethos and is well known for its democratic innovation. Since the launch of the Compassionate Frome project in 2013, Frome has seen improved health outcomes for people who were isolated. By employing local health and community connectors and developing a clear picture of existing agencies and community groups, Frome clearly identified gaps for local groups and services including lunch clubs, exercise clubs and Men’s sheds.

The Frome Men’s Shed is a thriving and supportive community of like-minded men who come together to provide emotional and practical support to each other. This group is typically middle-aged or older and many have had an experience with life-limiting illness and associated loss and bereavement. The Men’s Shed provides an emotional outlet for men who might otherwise struggle to speak about their life experiences. Several of the men mentioned that they didn’t know how they could support their community without realising they are already doing it (albeit informally!) This is an example of a local, and effective community-based support network already established in Frome.

Similarly, Frome Community Cars was setup by Frome Town Council and Frome Medical Practice in December 2016 to provide affordable transport for those unable to access local services for a number of reasons including disability. As of April 2018, the service is managed by Mendip Community Transport with a membership base of 300 and 20 committed volunteer drivers. This community-led solution to transport issues demonstrates willingness amongst the Frome community to develop local solutions for local people.

Frome is actively working toward improved community cohesion and building communities at the street level. In 2016-2017 Frome Town Council commissioned a baseline study at the neighbourhood level, to understand what role the Local Council could play in creating more opportunities for resident participation, improved communication and inclusion. The project is ongoing, and the Council hopes to expand this approach to other neighbourhoods in future.

The compassionate and community focused town of Frome offers an excellent opportunity for Dorothy House Hospice Care to develop
new partnerships and community-led solutions for people affected by life-limiting illness. Whilst Frome offers a foundation to build upon, networks should aim to expand outward into surrounding areas so people in Coleford, Shepton Mallet and other Mendip communities do not feel left behind.

Consider Training Staff or Volunteers in Community Organising Techniques

The Community Organising approach offers Dorothy House Hospice Care a new and innovative way of encouraging courageous conversations about living well and dying well, as well as offering a practical solution to building community capacity around life-limiting illness. Dorothy House Hospice Care could consider training key members of staff or volunteers in Community Organising techniques to help the organisation engage effectively with the Mendip community, work with the community to develop solutions and encourage more volunteers to come forward.

Training staff and volunteers in Community Organising techniques (e.g. listening without agenda and encouraging people to embrace projects themselves) also offers the added benefit of finding and engaging local leaders who can support future projects to be more sustainable and locally run.

Social Action Hub Wiltshire + Swindon is one of 20 Social Action Hubs across England, supported as part of the Community Organisers Expansion Programme (2017-2020). The Programme is funded by the Department for Digital, Culture, Media and Sport and led by Community Organisers Ltd.

Social Action Hub Wiltshire + Swindon offers free Community Organising training including how to listen to people, understand the local community and motivate people to take action for a better community. The training, led by qualified Community Organisers Alex Neale and Katrina Watson, is offered free to organisations like Dorothy House Hospice Care and includes the opportunity to work towards ‘qualified’ Community Organiser status.
APPENDICES
1. Have you ever needed support because you, a family member or friend has or has had a life-limiting illness?

A life-limiting illness is an illness where it is expected that death will be a direct consequence of the specified illness. Such illnesses may include, but are not limited to cancer, heart disease, chronic obstructive pulmonary disease, Dementia, heart failure, neurodegenerative disease. People may also refer to this as a terminal illness.

YES  NO

2. Please tick the statement below which best describes your experience in terms of life-limiting illness and associated loss and bereavement.

- I am currently receiving support/services
- I have received support/services in the past
- Not Applicable

3. We would like to know who you have received or are currently receiving support from in terms of life-limiting illness and associated loss and bereavement.

Please tick all that apply:

- Family Member
- Friend/s
- Work Colleague/s
- Health & Social Care Professionals
- Local Hospice
- Local Charity
- Voluntary Group
- Support Group
- Counsellor
- Home Carers
- Not Applicable
- Other
4. How would you rate your overall experience with the local people, organisations or groups who have supported you through your experience of life-limiting illness and associated loss and bereavement?

Please choose the option that best describes your overall experience:

- [ ] Very Negative
- [ ] Somewhat Negative
- [ ] Neither Positive or Negative
- [ ] Somewhat Positive
- [ ] Very Positive
- [ ] Not Applicable

5. Thinking about the support you received through your experience of life-limiting illness and associated loss and bereavement? Do you feel any additional support would have been helpful?

YES  NO

6. Is there anything you would like to tell us about your own experience of life-limiting illness and associated loss and bereavement?


7. What support do you think is needed 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.


8. **Have you ever had a conversation about planning for the end of your life?**

   This planning ahead is sometimes called advance care planning. It may include care preferences, legal issues or personal wishes.

   YES  NO

9. **Who did you have a conversation with?**

   Tick all that apply.

   - [ ] Family Member
   - [ ] Friend
   - [ ] Professional
   - [ ] Not Applicable
   - [ ] Other

10. **What do you think is important to consider when planning for the end of life?**

11. **How do you think you could help support others in the local area with or affected by a life-limiting illness?**

   Continues on next page
12. What do you think needs to be in place for people to support those in their community with or affected by a life-limiting illness?

Tick all that apply.

- Training
- Logistics
- Equipment
- People
- Team Working
- Facilities
- Other

13. Finally, so that we can understand if there are any differences in people's experiences based on where they live in the Mendip area, it would be helpful for us to know where you are based:

- Frome
- Shepton Mallet
- Coleford
- I would prefer not to say
- Other:
Who we are.

Community First (Wiltshire) and Community Council for Somerset (CCS) are registered charities and members of the Action with Communities in Rural England (ACRE) network.

Community Organisers from Community First and Village Agents from CCS are working together to deliver this project in the Mendip area on behalf of Dorothy House Hospice Care.

Community First.
For information about Community First or this project contact:
Alex Neale
aneale@communityfirst.org.uk or;
Ketra Watson
kwatson@communityfirst.org.uk
01380 722475
www.communityfirst.org.uk

Community Council for Somerset (CCS).
For information about CCS, Somerset Village Agents or this project please contact:
Raj Singh
raj@somersetcc.org.uk
01823 331222
www.somersetcc.org.uk

“A society where death is a part of life.”

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

Share your experience and help us understand what support the Mendip community needs in terms of life-limiting illness.
APPENDIX 2 - INFORMATION LEAFLET (INSIDE)

Hello.

We are working with Dorothy House Hospice Care to talk with local people in the Mendip 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 will be door-knocking in your local area on 11th, 12th, 19th & 20th June.

If you have a personal experience with a life limiting illness and associated bereavement, we would be wonderful if we could chat with you about your experience.

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

Not going to be in? Share your experience with us online.

Visit our website to complete the survey:
www.communityfirst.org.uk/dorothy-house

Alex + Karina
Community Organisers

Dorothy House: Mendip Needs Analysis

P39
DOROTHY HOUSE
HOSPICE CARE

A community-based needs analysis in the Mendip areas of Coleford, Shepton Mallet and Frome.

Needs analysis commissioned by Dorothy House Hospice Care, working in partnership with Community First

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