

End of Life report



Introduction

Healthwatch Wolverhampton are an independent body who act as the public voice in health and social care services. To do this we collect feedback from members of the public in Wolverhampton who have used health and social care services about their experiences. We use that feedback to influence commissioners and service providers to improve services and to recognise areas of good practice.

On this occasion we have been asked by Wolverhampton Clinical Commissioning Group (WCCG) to collect feedback about end of life planning and services. The information gathered from patients / service users will support the work that the CCG and providers are continuing to work on to improve these services across the city and to ensure that patients are given a choice as to how they are involved in their care and to where they wish to die.

Methodology

This project used two different research methodologies with a survey that was largely quantitative and four focus groups that aimed to speak to a range of people from different backgrounds. This report is concerned with the findings from the focus groups.

Focus groups offer an opportunity to explore the answers of the participants in more depth and to build upon themes that are raised during the course of the discussion.

The focus groups spoke to people who were deaf or hard of hearing; dementia support groups and a African Caribbean carers support group. Overall, 53 people took part in the focus groups.

Focus groups were recorded and transcribed. The transcripts were then analysed using thematic analysis that looks for commonalities between the answers that participants gave. As such there are no numbers or percentages assigned to the findings of this section of the project.

Themes

The themes that follow have been drawn from the feedback that was collected during the focus groups.

Ease with discussing end of life

Participants were asked how comfortable they felt with discussing end of life and their wishes and needs. Feelings varied within groups with some saying that they felt uncomfortable with speaking about the end of life. For one participant it was felt that their age was a barrier to them discussing end of life planning commenting that *'I'm not [at ease] with discussing it, I think because I am still relatively young'*. However, one participant said that they felt that young people needed to be able to discuss end of life more openly relating their experience dying in their early 30's. They commented that *'I didn't know anything about this in terms of forms, so it makes me start to think about things' and went on to say 'a lot of young people are unaware of this, do you think this is something that should be promoted to them?'*

Another group that was predominantly made up of older people also made the point that there was a need to ensure that younger people were speaking about end of life and making clear what they would want to happen if they were at end of life because death was not something that only happened to older people. One participant commented that *'at whatever age, death is no barrier to anyone whatsoever'* and another adding that *'when we talk about our age group dying, there are a lot of young people as well.'*

Younger people were not the only participants who were uncomfortable with discussing the end of life. For some participants it was simply something that they had never discussed with their families or with professionals.

One participant said that he had *'never talked to my wife about it'* prior to her death whilst another said that when he tried to discuss it with his daughter, she was not receptive to discussing and he reported that she said *'no, no, no, I don't want to talk about it, Dad'*.

It was also felt by some that talking about what they or a loved one wanted at the end of their life was basically accepting that they were going to die and that this was a difficult thing to do for many people. One participant commented that *'at that stage you are accepting someone's going to die and all that'*.

Others were more comfortable with discussing the end of life and their wishes. For some it was because they pointed out that death was inevitable for everyone with one commenting that *'it's something that's going to happen, we have no choice.'* For one of the participants their faith made a difference to their ability to discuss the end of life saying that *'I do believe in God and pray about it more.'*

For those who were carers for people with dementia, some made the point that it was difficult to know when it was appropriate to talk about end of life. One commented that *'potentially by the time you need to be speaking to someone about it, it's too late and everything you could control has gone.'* Another said that *'as soon as [partner] was diagnosed with dementia, we decided it was time to look to the paperwork'*. However, this was in relation to Power of Attorney rather than in terms of what they wanted for their end of life care.

Importance of family

A consistent theme throughout the discussions was the importance of family support and the involvement of family in making decisions about end of life care and arrangements. One participant told how when they were together with their adult children *'we do very often sit down...we don't dwell on it too long but if there's anything like that it is*

discussed or if anything comes up. They are well aware of what we think.' Another told how his daughter would speak to him about his end of life wishes saying *'my daughter talks to me about when I pass away.'*

For some it was felt that there needed to be agreement amongst family members in order to ensure that end of life wishes or arrangements could be carried out with one commenting *'when you make those decisions, the family know what you want and to a certain degree they've agreed with it. I might come up with something that my daughter says 'that just isn't reasonable.'*

Other people felt that decisions could or should be made by their families. One participant said that *'I didn't want any treatment for things in the past and the wife's been 'no you have to have the treatment, you've got to carry on'. So I've been OK. I'll let the wife decide.'* Another participant told us that they had discussed with their children about what should happen if they were unable to make their own decisions saying, *'make a decision for me, not you.'*

Whilst the involvement of family was seen as important for many and as a source of support when discussing end of life care, some participants had no close family that they could turn to. For one of the participants this was a source of concern as they returned to the issue several times during the focus group. They said *'what I was trying to portray to you when you said families, you see I've got no family. I've relied on my brothers and sisters and they've all gone.'* Another commented that having no family close by meant that when his wife was dying he had nobody that he could seek support from in making decisions about her care when she no longer had capacity. He commented that *'I'm the last of seven, so I've got nobody previous that had gone through this. So, I'd got no help there. My son doesn't live local, I've got a daughter, but we never really discussed it.'*

Understanding of Advance Care Plans

Overall, there was a lack of understanding amongst the participants of what advance care plans were and what they entailed. There were a small number of people who understood them to be concerned with what they wanted to happen with their care as they reached the end of their lives. One commented that *'if it's about advanced care, I'd be looking at a plan for when as a person becomes more poorly.'* There were some that mentioned making plans as to whether they wanted to go into residential care or not with one saying that they *'would prefer a care home... somebody's always there to look after yourself.'* Another mentioned that it was a way of getting *'the quality of care.'*

Some people saw them in terms of whether they had a Do Not Resuscitate instruction in place and this led to a large amount of discussion around their use and how to go about putting one in place. One participant said that they had found that when their wife was dying *'it's more complicated than you think, because [daughter] and I thought that we could just say to the care home 'DNR' you know. [Wife] was at death's door. But you can't, you can't say that. The doctor can sign the form. Well that's what we were told.'* For those participants who had experienced a loved one dying or being in hospital there who had not left an instruction about their treatment there was a feeling that they described as guilt at signing what they considered to be their partners *'death warrant'*. For those that felt that way there had been a lack of explanation about what at DNR was and what resuscitation could mean for their frail relative. One said that they had seen *'my own doctor and he explained.... I was a bit disgusted that nobody [explained the reasons for recommending DNR]'*. Another said that the decision would have been easier if *'they'd explained to me that if they did try to resurrect her it could have broken her bones.'*

Funerals and Wills

For a large number of participants when discussing dying and end of life and the arrangements that they would put in place, sorting out their wills and funerals were the first considerations, not their care at the end of their life. One participant when they were asked what advance care planning mean to them said *'I suppose it's your funeral and what anyone wants. Not just necessarily how you want your funeral to go, whether you want to be cremated, whether you want to be buried.'* A number of participants had either left instructions about their funerals or had already made arrangements with a pre-booked funeral. One said that they had *'already bought my grave'* whilst others discussed the merits of pre-paid funerals. It was commented that *'they talk about your funeral so they ask you the questions.'*

However, nobody in the focus groups had made arrangements that set out their wishes about their end of life care. Although the participants themselves could not be considered to be at the end of their lives, a number did have experience of caring for someone who had died or were caring for someone conditions such as dementia.

There were a number of concerns raised about how binding Advance Care Plans are and if they can be overridden by either family members or medical professionals. One participant commented that *'really it's about your wishes and it doesn't mean that the medical professionals will follow them.'* Another asked *'if the person had an incident where they have lost capacity and a form was already completed saying I want that, that and that, so then they have to follow the form, is that correct?'* One group raised a number of questions about the ways in which the plans were put together, whether they needed to be legally witnessed and how they would be stored such as whether *'you give it to a doctor' or whether 'it goes to the solicitor?'*

Starting the conversation

When asked who they considered responsible for starting the conversation about end of life care participants looked at it in two main ways. Firstly, there was who they would want to speak to them to tell them that they were reaching the end of their lives and secondly who they thought was responsible to start a conversation about what their end of life wishes were.

It was suggested that an individual's GP had a role in speaking to patients about reaching the end of their lives. However, for others it was felt that it was something that should be carried out by a medical professional who was a specialist in end of life or palliative care although nobody in the groups used the term palliative care to describe a specialist medic. For one participant it was felt that non-specialists lacked the skills to deliver the news saying *'I think that when it's come to a point where someone's that sick they need to have someone who is qualified in that field, because sometimes, some of these GPs, the way they talk to their patients about dying, they have no sensitivity at all.'* For another it was felt that GPs were already under enough pressure without having to start end of life conversations saying *'I think they've just got enough on their plates'*. One participant told how they were told that their wife was dying by a doctor *'I was just told to come in because the doctor wanted to see me. And he told me that she was at the end of her life.'* He said that it would have been better if they could *'explain a bit more'* as he was given little information about how long his wife might have left or what would happen with her medical care.

In terms of who was responsible for starting conversations about their end of life care wishes and for planning for after their deaths it was generally felt by participants that it was a personal responsibility with one saying *'it would be the*

person, whoever it affected, ourselves. If that person, they are making the decisions, then it would be that person.'

Some said that they felt that the responsibility for starting the conversation lay with family members of people who were reaching the end of their lives such as their *'husband or wife'* or their *'children'*. Or that it should be other professionals or pastoral support involved in the individual's life such as a *'social worker'* or *'the minister, you know, from church'*.

Where participants said that they would be responsible for starting the conversations themselves it was generally felt that they would benefit from some support to do so because there was uncertainty about how to go about it and who to speak to. However, one participant said that they did not feel that they needed any support because they may not be *'quite sure about what decisions to make or what we need to be putting down.'* Another said that they 'have no idea who to speak to'.

Sources of support

There was a feeling from a number of participants that they lacked knowledge and information about end of life care planning and that they would benefit from more information *'because you can't make a decision if you don't know what the options are'*. For those that were members of the deaf community the need for accessible information was a persistent theme particularly in relation to access to interpreters and written information that was in British Sign Language saying that *'if you've got good English, you are able to understand the information. If you're using BSL it can be very difficult when you need someone to translate that information for you. But it's having that person who's responsible to translate it.'*



Others felt that there was a role for support groups in assisting people to make plans for their end of life care with one saying that *'coming to support groups like this and talking to people is the way forward.'* It was suggested that either existing groups such as carers support groups or condition specific groups could be utilised for advisors to attend to share information. Another suggestion was to have specific support groups that were *'a similar sort of thing to the dementia café where you can come, in my case with my daughter, and the idea of the café... is to discuss end of life. Again with neutral people... instead of talking about dementia you talk about end of life and got people to come and have a chat, an open conversation about the legal side, whatever.'*

It was suggested that for those who had a religious belief that the church could be a source of support and potentially advice for individuals in planning for end of life. One participant said that *'if you were amalgamated to a church you could probably discuss it with the minister there or your pastor.'* Another commented that there was an emotional element to making plans not just about dealing with your estate and *'you could go to church to talk to people'* to get support with the emotional aspects of making plans.

However, this was not the case for all participants as not everyone had a religious conviction with one commenting that as an atheist *'I don't want to talk about going to heaven or wherever. I want, if you like, a neutral position.'*

The Role of Compton

The care given by Compton Care was considered by some participants as a source of support at the end of life as well as providing care at the point of dying. For another participant Compton had also provided counselling for her after the death of her daughter and she said that the counselling had been *'second to none.'* However, one participant said that they felt that the hospice was just where *'you go and spend the rest of your life.'*

Others understood that a hospice was there to provide longer term care for those who were undergoing palliative care, with someone giving an example of a friend who had *'day care at Compton Hospice'* and that *'she said that even though she*

was dying, because they were all there, I suppose what they were doing was taking her mind off [her condition].'

However, the view that a hospice was simply there for people to go to when they were dying may need to the subject of wider information sharing.

District nurses

Very few people had experience of district nurse support for end of life care of their loved ones. There was a feeling that there was no support available for those that were in nursing homes at the end of their lives with a participant saying *'District Nurses don't come into nursing homes. So they are not supported at all.'* They went on to say *'the attitude is that it is a nursing home so therefore, the nursing home should be able to provide all the care that person needs. So somebody can end up going into hospital because the nursing home can't provide the care they need.'*

One participant told that a district nurse had been in to a care home to administer morphine to his dying wife. He said that nobody including the nurse had told him that when morphine was administered it was because his wife was very near to the end of her life saying *'I didn't know it was going to be that soon. Nobody explained to me that when they gave her morphine it'd got to be towards the end to stop her pain.'*

Additionally, there seemed to be some confusion about the role of a district nurse as opposed to social care support with two participants saying that they had refused the district nurse for care of their loved ones because *'the district nurses would come in and get her up and washed and put her to bed. It was going to be at a certain time to get up and a certain time to put her to bed. If you've got people with dementia they either want to get up when they want to get up or they want to stay in bed if they want to. So, it would have created more problems than it solved.'* What they described seemed more likely to actually relate to social care support than nursing care support.

Conclusions

Overall, it seems from the focus groups that there is little understanding of what end of life care is and they see end of life planning as being in relation to what they want to happen after the die in relation to funeral arrangements and wills.

Participants had no knowledge of advance care plans which might be expected for those that were not at end of life or caring for someone that had a life limiting condition. However, for those that were caring for someone who had dementia or other long term life limiting condition it might have been expected that they would have had some knowledge of ACPs.

Although most members of one focus group said that they were comfortable speaking about end of life this was not the case amongst the other groups and many of them said they were not comfortable with discussing it. Discomfort with discussing end of life was not specific to any age group but some felt that there needed to be specific information for younger people as well as those who were older.

Whilst some people said that they were at ease about the idea of discussing their needs at the end of life they were unsure when was appropriate to discuss it and who they could discuss it with outside their own families. Some felt that family was the place that it needed to be discussed and agreed but others wanted access to external advice and support. There was felt that there was a lack of information available for people around end of life planning, and for the deaf and hard of hearing community access to appropriate interpreters and translation was a particular issue.

Although there was generally positive feedback about the work of Compton Hospice there was some evidence that participants believed it to simply be somewhere that people went to die. This suggests that there is scope for broadening the understanding of the role of hospice and what it can offer.

There was little evidence of the use of district nurses at the end of life with some evidence that there may be some confusion between the role of district nurses and social care domiciliary care workers. Where there had been some contact with district nurses communication with family members about their involvement and the care that they are giving was seen as lacking in some cases.

Recommendations

1. There was a feeling that there was not enough information about end of life care and therefore, it is recommended that the CCG considers how it can provide more general information on end of life care including targeted information for younger people. This will help people understand advance care planning and that there is more to consider than funeral planning and wills.
2. For the Deaf community, information needs to be provided in suitable language formats. It is recommended that the CCG works with the Deaf community in order to co-design suitable information and to understand the needs for specialist interpreters at the end of life.
3. Participants felt that there could be a benefit from having specific support groups for end of life planning. Whilst having specific groups on an ongoing basis may not be practicable, it is recommended that the CCG works with voluntary sector support groups to develop relationships and engagement with their members in order to provide more support with end of life care planning.
4. For some participants there had been experiences in relation to DNR's being put in place for their relatives that were not positive due to a lack of understanding of their use and implications. It is recommended that more information is given to individuals towards the end of life and their families on the use of DNR's.
5. For some participants, there had been a lack of communication with them when their relatives were at the end of life and this had a negative impact with them. Therefore, it is recommended that consideration is given to the communication that medical staff have with the families of people who are at the end of life and how they can be kept informed and supported.
6. Whilst the feedback about Compton Care was generally positive there was some lack of understanding of the role of Compton and therefore, it is recommended that consideration is given to how the role of hospice care can be better communicated with the public.
7. There was very little feedback about district nurses at end of life and in some cases a lack of understanding of what their role was. Therefore, it is recommended that consideration is given to how to better communicate with the public what the role of the District Nurse is in relation to end of life care.

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