

End of life report:

Evaluation of
non-clinical support

Local health
and care
shaped by you

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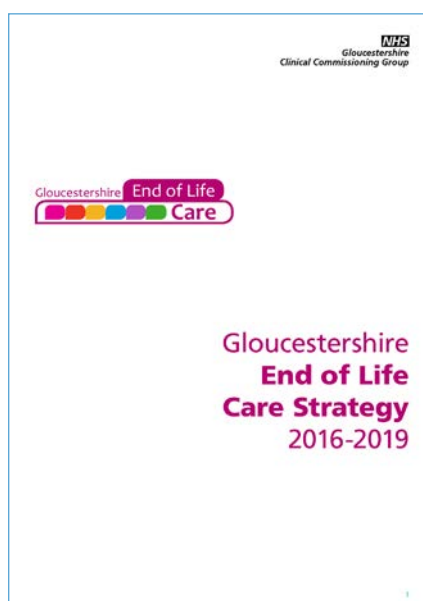
Introduction

Healthwatch Gloucestershire is the county's independent health and care champion. It exists to ensure that people are at the heart of care. A dedicated team of staff and volunteers listen to what people like about local health and social care services, and what could be improved. These views are then shared with the decision-making organisations, so together a real difference can be made. Healthwatch Gloucestershire has been talking to local people about their experiences and views of non-clinical information (not information about their illness or condition but other types of information that would support them through the end of life) and advice around end of life care. This report tells you what people said when we spoke to them about their experiences.



Background

NHS Gloucestershire Clinical Commissioning Group (CCG) and partner organisations are trying to improve end of life care within the county to enable individuals and their families to receive high quality end of life care, irrespective of where they die. In addition, they want to make it easier for people to access the help and services they need earlier in their illness pathway than they do currently. Further they want to respond better to the wishes and needs of patients and their families around where they want to receive end of life care, as well as their preferred place to die.



The End of Life Care Clinical Programme Group is a group of partners that work collaboratively to ensure all people at end of life, their carers and family, receive high quality end of life and palliative care in their preferred place of care and death. Healthwatch Gloucestershire has a seat on this board to ensure the voice of local people is heard and considered at a high level. There has been recognition in this group, that a holistic approach to care was needed to support the person to 'live well' with their condition and to understand 'what is important to them'. Health and care professionals should be able to signpost individuals to appropriate advice and support, provide information and leaflets, and link them into non-clinical local services.

Aims

The aims of the project were to:

- understand and explore in more depth what non-clinical support is available locally and nationally
- understand more fully the types of information required by those at the end of life, their families and carers
- identify gaps in information provision, what is good and what needs to be improved in the way information and support is accessed
- raise awareness of what non-clinical support is available locally and nationally

What we did

We created a survey that could be accessed online as well as completed in hard copy format. This survey was also used as a basis for one-to-one interviews and conversations at engagement events. The survey ran from the 17th August to the 5th October 2018. We spoke to Gloucestershire residents who had accessed support, or who would be looking to access information around end of life support in the future.

Six volunteers supported the project providing around 30 hours of voluntary time.

We attended eight engagement events across the county to speak to people about the project. These included visits to:

- Local hospices
- Support groups for people with long term conditions
- Carers groups
- Death Café
- Lunch Clubs

We also:

- Contacted local voluntary and community groups with information about the project to share with their contacts.
- Had a continuous presence through social media feeds and the website.
- Highlighted the work through local forums.
- Sent hard copies of surveys through to local hospices for them to share with users of their services, their family, unpaid carers and friends.
- Sent surveys to all GP surgeries and other health providers, including acute hospitals.



Who we spoke to

Fifty-two local people completed the survey.

Figure 1 shows the age range of those who took part in the survey.

The majority of respondents were aged between forty-six and seventy-five years old and came from Stroud District (see figure 2 for geographical spread).

“My husband was able to stay in the same home as me towards the end of his life. This was so important to me and to him so that we could be together at the end. I don’t think I would have coped if I had not had that last bit of time with him together. I missed him when he did not live with me.”

“Promised end of life care was virtually non-existent and when it was delivered it was always too little too late. Nothing was good about it.”

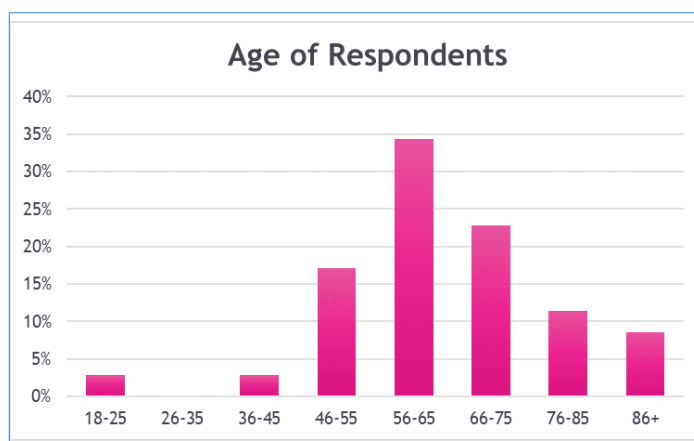


Figure 1

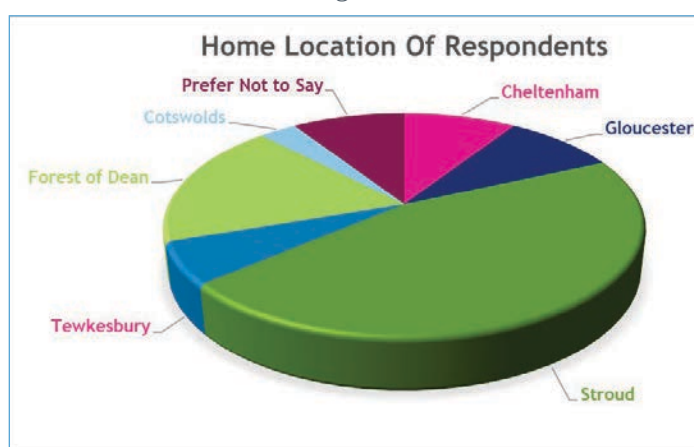


Figure 2

Accessing end of life information

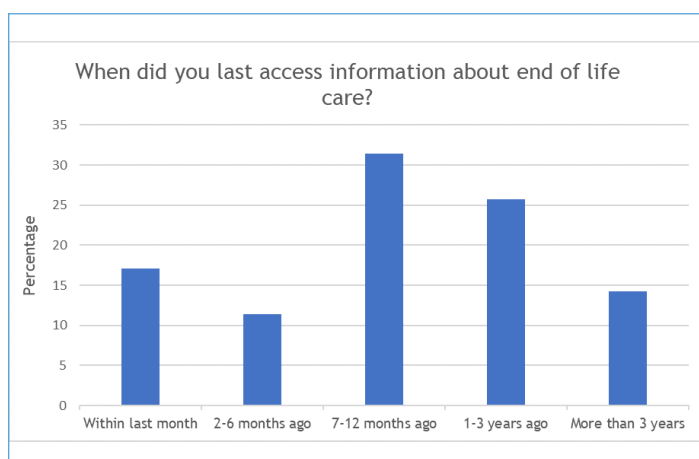


Figure 3

Only two respondents said that they currently cared for someone who was receiving end of life care, and only one respondent was currently receiving end of life care themselves. However, 81% said that they had recently cared for someone who was receiving end of life care.

The majority of people had accessed the information over 7 months ago with 17% accessing information within the last month (see figure 3).

Key findings

Most of those who responded said that they went to medical professionals when they wanted information and support around end of life care, i.e. their community team of palliative care nurses, district nurses etc. (60%), their GP (57%), hospice team (34%) and practice nurse (31%). However, many relied on their friends and family (46%). Others sought information and support from their nursing/care home, or said that they were not aware this information and support existed.

Most people said that they preferred to receive information face-to-face or via a leaflet/book (both 81%). In comparison only 39% preferred to receive it via online or text. Those who mentioned 'other' told us they would like to receive information via the phone or email.

The majority of people said that they want to find hard copies of information in healthcare environments such as the GP surgery (90%), hospital waiting areas (81%) and their local pharmacies (74%). Those who responded 'other' mentioned accessing information from hospices and district nurses.

Some people felt that the following information would have been helpful:

- what psychological and emotional support was available to them
- information on what happened to a person during the last stages of life
- post death advice

Others felt that they had received enough support and information. Having the information in one place was preferred by most people.

20% of respondents had heard of the Your Circle health and social care online directory, with 6% of respondents using it as a source of information.



What people told us

Information people found most helpful

Unpaid carers told us that support for their mental health and emotional wellbeing was one of the most helpful things during the end of life period. Information around accessing NHS Continuing Healthcare (CHC) was also mentioned, as was care and advice provided by the hospices and palliative care teams.



“It’s very difficult as you don’t really know what you need until you need it. However, it was really useful knowing that there are support groups should you need them and knowing who is who with the different professionals and what their role is.”

“Our GPs put into place a lot of support. They put us into contact with our Specialist Palliative Care nurse and our district nurses, who also helped me to organise carers when I could not physically manage the personal care on my own.”

“Advice from professionals about having open discussions with family.”

“Information on what to do after the death of my mother. What to fill in, who to tell, what happens next... it was so overwhelming at a difficult time. I knew a lot of what my mother wanted, but even so it was so hard.”

“My aunt was treated with great care and I was well informed about what was happening. When in hospital the chaplaincy team gave support.”



Information people found least helpful

Some of the participants said that they were given enough information and couldn't think of an unhelpful or a bad piece of information provided to them. Others mentioned that they received conflicting information from some information sources which they found unhelpful. Some people found the amount of information they received was overwhelming and difficult to process.

"It was complex at times, and it was hard to know where to go next. Too much information at once, and no one followed up with us to check all had been well."

"My experience suggest that end of life support did exist in Gloucestershire, the Forest of Dean in particular."

"For me personally I am unlikely to read a load of brochures. Some leaflets that cover the stages of grief have been useful, however the most beneficial was the face-to-face help I received. If the sorts of volunteer organisations I was helped by are not able to be sustained, then groups like CRUSE will be even more stretched and one size does not fit all when you're dealing with human beings!"

"Our experience has been all I could have hoped for at this distressing time after 56 years of happy marriage."



Information people would have found helpful



Thinking about their situation or that of the person they cared for, individuals listed various information and support provisions that they felt would have been useful to help them. In addition, participants told us that they would have liked psychological and emotional support, further information on what happens in the last stages of life including health changes, post death advice including support available, and all this information in the same place. Some felt that they had received enough support and information.

“All information in the same place. A lot of information was contradictory. I got confused easily. The palliative care teams were great and gave me so much information and support. If I hadn't had them, I wouldn't have known where to go. Maybe my GP, but they have so little time in appointments, I don't think they would have helped me much.”

“Questions to ask care team/hospice Drs etc. in the last few days/ hours. Post death advice.”

“Perhaps a bit more information about what was likely to happen as he died, e.g. breathing changes etc.”

“I found information on finding and paying for care particularly hard and complex. Especially around CHC funding. I would have liked to have had all information in one place, and to have had more support for me as a carer.”

“To have a directory relevant to your area that has support services details, a 'handy guide'. To have someone help you through the process emotionally to better understand what to expect. To be offered bereavement support. I and my brother were living out of the area from where my mother died. We were not offered any bereavement support by Gloucester Hospital.”

“More information needed on what to do afterwards. As soon as the funeral was over, people started to not bother with me as much. They went back to their own lives, this was so hard, and I am lonely at times.”



Considerations

Commissioners and providers should:

1. Consider carrying out a review of the information around end of life care currently provided on Your Circle. This should involve working with providers, local people, statutory services and voluntary and community sector organisations to map current provision and to identify what's missing. Similar work has been carried out in Wiltshire: <https://www.yourcareyoursupportwiltshire.org.uk/endoflifecare>
2. Consider improving the information offer for those at the end of their life and their carers and families. This should include clear and accurate information about:
 - funded nursing care and continuing healthcare (CHC), particularly fast track CHC
 - the availability of psychological support
 - what to expect in the latter stages of illnesses
 - what to expect when someone dies, e.g. who to contact, form filling, contacting funeral directors
3. Provide appropriate support and training to health and social care staff (GP's, pharmacists, community nurses, care home staff etc.) so that they are able to refer and signpost individuals to the right support and information at the right time. This could include training on using Your Circle, as the definitive one-stop shop for health and social care information.
4. Ensure that information about end of life care is available in as many formats as possible, including making use of community resources and local health settings as a way of promoting what information and support is available.



“Cheltenham Hospital was very caring and efficient. Local nurses the same.”

“Gloucester Royal Hospital Acute Care staff involved the Palliative Care team. They were wonderful and organised hospice care.”

“Macmillan were fantastic. My district nurses were also a huge support team.”

Next steps

We recognise that we have only heard from a small number of local people who have accessed information around end of life care. Therefore, we do not claim that these findings are representative of the wider population. However, it provides a useful basis on which to build further work that aims to engage with a wider variety of people particularly those from seldom heard communities such as faith groups, the Polish and Chinese communities and those who identify as LGBT.

Most people told us that they would like to access information in the one place. Your Circle provides an ideal platform to host a really comprehensive suite of pages around all aspects of end of life support. Healthwatch Gloucestershire would be happy to work with Commissioners and other key stakeholders to build this resource and to ensure that local people are involved in the process.

This report has been shared with NHS Gloucestershire's Clinical Programme Group so the key messages and considerations can be heard and acted upon.

Thank you

Healthwatch Gloucestershire would like to thank everyone who took the time to contribute their views and experience through the survey and engagement activities. Thanks also to our dedicated volunteers who helped to support the project engagement.



Why not get involved?



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