



Evaluation of the Rapid Response End of Life Service

An
independent
voice for the
people of
Wiltshire

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Key Messages

In order to meet the needs of those people with End of Life care needs (EoLC), Dorothy House Hospice Care and Prospect Hospice deliver a 72-hour rapid response enhanced service. The service provides urgent care at home (up to 24 hours a day for up to 72-hours) for people at the end of life. Healthwatch Wiltshire carried out an evaluation of the service from the perspective of family members whose loved ones were cared for through the service. We carried out 1:1 interviews with family members and spoke to frontline staff delivering the service. The good news is that the family members (including unpaid carers) that we spoke to have very positive things to say about the service.

Healthwatch Wiltshire is an independent organisation which has an important role in assessing the quality of health and social care services today and influencing the design of services for tomorrow.

This is what they told us:

- Relatives of people who had used the service described how grateful and appreciative they were that the service was available to support them and their loved ones.
- The service helped people to die in their preferred place of death, at home.
- The quality of care provided by the hospice healthcare assistants was highly praised by families, who recognised their experience, knowledge and compassion.
- While many people found the move 'on and off' the service to be seamless, this was not the case for everyone.
- Not everyone felt that they knew enough about the dying process, and families would have welcomed more support and information.
- Some people died during the support offered by the service, while others were discharged to other services. Arranging continuing care (following the service) can be difficult and caused delays in discharging people.



In terms of 'learning points' for the service, this feedback is relevant:

- Early signposting and referral to hospice services is appreciated and helps family members feel things are under control. This is not always happening.
- More contact from specialist nurses during final stages, including at weekends, would be welcome.
- Faster access to symptom relief medication (pain/sickness/secretion control) is needed.
- More information for relatives about what to expect in the final days would be appreciated.
- When a person is discharged from the service, more support is needed in finding alternative paid carers, especially ones with experience of end of life care.

"I am so grateful this service exists and that we were able to access it"

Relative

"I will be forever grateful and in their debt for this"

Relative

"The care and support made his passing so much easier, I don't think it would have been as personal in hospital"

Relative

"I could phone, talk, cry and be reassured....it felt like (the hospice) was listening when no one else was"

Relative

“The palliative care nurses were so professional and helpful—I really felt supported”

Relative

“They knew what to do, what to expect, were familiar with the syringe driver, (and) were more confident in looking after someone who was dying. They cared for the family as well as the patient”.

Relative

“So nice they didn't rush away (after the person had died)....but they stayed until they felt you were ready to cope”

Relative



About the service

Health and social care services in Wiltshire are working together to change the way that care is provided for local people who are frail or elderly. This is happening all around the country as part of the Better Care initiative. The aim is that people receive integrated care and support across health and social care with the focus on people being cared for as close to home as possible. The need to be treated at, or as close to home as possible is particularly important for those who are at the end of life.

In order to meet the needs of those with End of Life care needs (EoLC), two of the hospices that serve the people of Wiltshire (Dorothy House Hospice Care and Prospect Hospice) were invited to develop a proposal and subsequently deliver a pilot for a 72 hour rapid response enhanced EoLC service, to provide care at home (up to 24 hours a day for up to 72 hours) for EoL patients.

The aim of the 19-week pilot was to establish demand, capacity and process for an enhanced service for people with EoLC needs. It was designed to prevent inappropriate admissions to hospital and increase timely discharge from hospital, thus reducing unnecessarily prolonged stays.

Each hospice provided a skilled hospice at home carer that was available 24 hours a day (if required) to support any patients within the last year of life who have been assessed as medically stable for discharge or to remain at home with appropriate support.

To enable a seamless service across Wiltshire, the pilot integrated closely with out-of-hours medical services (operated in Wiltshire by Medvivo) and the existing Urgent Care @ Home service, which is coordinated by Medvivo and delivered by carers from MiHomeCare. Joint working with Medvivo enabled the service to be integrated and coordinated across the area.

Depending on what was the most appropriate pathway, the service supported patients to:

- Access appropriate assessments and skilled care in the right place at the right time.
- Remain at home with additional support enabling on-going coping and re-establishing confidence.
- ‘Step up’ to a Community Hospital, Hospice or Intermediate Care Bed.
- Expedite return to home with additional support following acute assessment.
- Die in their preferred place of death.

After the end of the pilot, the service has continued with funding until the end of March 2016. Decisions about the continuation of the service beyond this date have not yet been announced. This evaluation covers both the pilot and the continued service.

The service was delivered to 191 people between December 2014 and December 2015. Prospect Hospice supported 101 people, while Dorothy House Hospice Care provided care to 90 people.

The purpose of the majority of these episodes of care was to manage times where care needs at home increased, and to prevent admission to hospital where this could be safely avoided. Out of the 191 uses of the service, 91% (173 uses) were to prevent admission, and 6% (11 uses) were to discharge patients from acute or hospice settings to care at home.

Healthwatch Wiltshire was asked to evaluate this service from the start of the pilot until December 2015, from the perspective of the families of people who used this service.

End of life care nationally

Nationally, about five hundred thousand people die every year, with three-quarters of these deaths expected¹. In Wiltshire, there are about four and a quarter thousand deaths a year². Care for people at the end of life is especially important, as there is only one chance to get it right for a patient and their family³.

The Leadership Alliance for the Care of Dying People identified priorities for people at the end of life and their families -

- That it is recognised that the person is dying and that this is clearly communicated to the patient and their family, and decisions and actions are made in line with their wishes.
- Sensitive communication by professionals with the patient and their family.
- Being involved in decisions about treatment and care, as much as the person wants to be involved.
- That the needs of relatives and other people important to the patient are identified and met.
- That care individual to the need of the patient is agreed, coordinated and provided with compassion.

The Parliamentary and Health Service Ombudsman identified key areas where people made complaints about End of Life Care⁴. These were not recognising people were dying and not responding to their needs, poor communication, poor symptom control, inadequate out-of-hours services, poor care planning, delays in diagnosis and referrals for treatment.

Having the opportunity to die in a preferred place, often at home, is important to people at the end of life⁵. However, it is not always possible for people to be in their preferred place. Nationally, it is recognised that timely access to free social care at the end of life is a barrier to getting people home from hospital or keeping patients from being admitted unnecessarily⁶.

¹ Actions for End of Life Care: 2014-2016 by NHS England

² End of Life Care Intelligence Network, data from Office for National Statistics (2011-2013)

³ One chance to get it right: Improving people's experience of care in the last few days and hours of life (2014) by the Leadership Alliance for the Care of Dying People

⁴ Dying without dignity: Investigations by the Parliamentary and Health Service Ombudsman into complaints about end of life care (2015).

⁵ What's important to me: A review of choice in end of life care' (2015) by the Choice in End of Life Care Programme Board

⁶ House of Commons Health Committee End of Life Care Fifth Report of Session (2014-15)

Who we spoke to

Relatives or unpaid carers of people who had accessed the 72 hour rapid response enhanced EoLC services ('the service') were contacted by the hospices with information about Healthwatch Wiltshire's evaluation. The information included the background to the evaluation, and methods for taking part. Focus groups were offered, but were not widely taken up. Telephone interviews and home visits were more successful.

Between November 2015 and January 2016, Healthwatch Wiltshire spoke to 16 relatives of people who had used the service. 11 were relatives of people who had used the service from Dorothy House Hospice and 5 family members of people who received the service from Prospect Hospice.

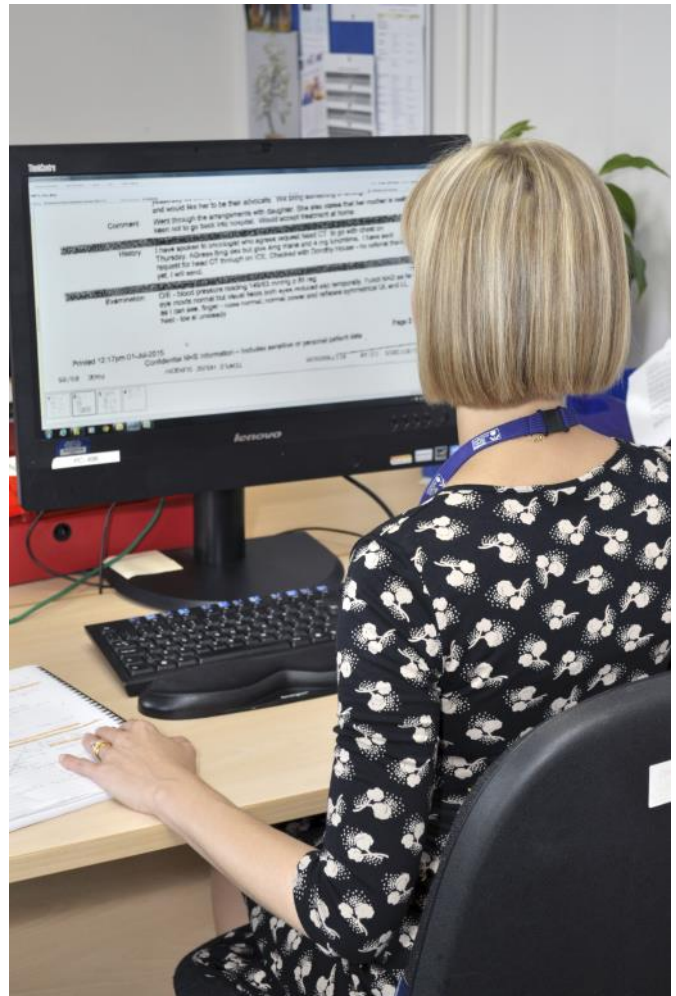
We spoke to staff from the two hospices; four coordinators, two nurse specialists and two healthcare assistants who provided the 72 hour care. We also spoke staff at Medvivo who coordinate the service, the non-specialist Urgent Care @ Home service (which may support patients if there is not enough capacity within the hospices) and the out-of-hours GP service; two coordinators and a manager.

We have also drawn from experiences of people we have spoken to through our other engagement work and issues raised with us by members of the public. Voluntary and community sector organisations who support people at the end of life, or bereaved families, were also given the chance to feed in relevant information.

What people said

Previous use of hospice services

More than half of the relatives reported that their loved one had accessed hospice services in the past, including specialist nurses and therapies offered by the hospices. Other relatives had not used the hospices, and some were unsure about who they were available to and what they had to offer. There was some confusion amongst patients, relatives and some professionals about who can access hospices services.



Accessing the services

It was often the specialist nurses (already known to patients and families) that recognised a deterioration in the patient's condition, or that families were struggling to cope, and who made referrals into the service. Community nurses, care coordinators and GP's were also mentioned as recognising difficulties in managing the situation at home and starting the referral process. In hospitals, ward staff or hospital palliative care teams identified relevant patients, informed patients and families about the service, and made the referrals. For some of the people who we spoke to, the family did not know who had noticed they needed more support, but they were happy to have been contacted by the hospices and offered additional care.

From discussions with staff, and from our wider engagement, we heard some reasons why people turned down the service. Some people were concerned that they would have to pay for the care received through the service. This is not the case, but these people had either not received or not been able to take on board the correct information. Another person turned down the offer of hospice care on the service, as they believed it would end their existing care package, with carers who they knew and wanted continuity with. Again, this may have been based on incorrect information, as the service is designed to be provided alongside existing care packages, to provide additional support.

Care provided by the service

The exact care provided to patients using the service varied based on individual needs of the patients and their relatives. Some relatives reported their loved one receiving overnight care, or a number of visits during the day, while other patients had received 24 hour care. This corresponds with the wider statistics of the service, where over the thirteen months of the scheme, care provided by the service has varied from one visit a day up to 24 hour care.

Staff coordinating the care described trying to match what the patient would require after the end of the service, when they knew. For example, if an application had been made for Continuing Healthcare (CHC) funding for three visits a day, they would offer three visits a day in the time before the CHC care started. They did not want to offer beyond what would be available to the person after the end of the service, to avoid setting unrealistic expectations. However, it is difficult to predict how a persons' condition will progress, and at times staff told us that care was increased to meet changing needs.

The hospice carers were able to be flexible and spend more time with patients and relatives compared to the amount of time that other carers would have been able to provide. This made a huge difference to relatives, who valued the time taken to check on them as well as the patient.

Patients and their families were also able to contact the hospice directly for support or advice. This was very helpful for families, who felt listened to and reassured.



The staff providing the care

People were generally very positive about the hospice carers provided through the service. The specialist palliative trained carers were described as being more knowledgeable, experienced and confident than other carers, and more empathetic. They were described as professional and meticulous, and were able to anticipate and plan for changes in a patient's condition or needs. They were able to manage catheter care, pressure point care and check syringe drivers.

Relatives also described how the carers supported them as well as the patient. This ranged from backing up relatives' calls to other professionals for more symptom relief medication, to practical assistance after the death, such as telephoning the funeral director or laying out the deceased.

Because the carers worked in the hospice when not providing the service, one carer was able to reassure a patient and their family about the inpatient unit, and to check up on them when the patient was admitted for respite care. This was reassuring to the patient and their family.

There were a few less positive comments. In one case, a carer didn't alert the family to a change in the patient's condition, so they missed being present when the person passed away, which was not what they had wanted. In another, a male carer was sent to support a woman who was not comfortable receiving personal care from a male carer. The relative said that they did not feel they could turn him away, but then requested no further men were sent. One family felt that the carer expected them to understand more about the dying process than they did. This relative felt that more information and explanation from the carer would have been helpful.



Knowledge of the service

Not all participants were aware of having used the 72 hour rapid response enhanced end of life care service. This was especially the case where people had received more than 72 hours of care from the service, in addition to care from other sources provided at the same time. When a relative is at the end of life, there are a lot of different professionals involved, and the stress of the situation may have an impact on the amount of information that people are able to take in.

One relative said that if they had known about the service, and other care available at home, then they would have pushed for their loved one to be discharged home sooner, as they had been unhappy at the care received in hospital.

A number of people said that they were unsure of what would happen at the end of the service. Some relatives reported that this has caused them and/or the patient some concern.

The impact of the service

The relatives we spoke to were overwhelmingly positive about the care provided through the service. It enabled people to stay at home and avoid unnecessarily being admitted to hospital, or helped get patients out of hospital and back home, which is what patients and families wanted.

The service also enabled families to spend more quality time with their loved one, while the carers took on the caring tasks. This made a huge difference to families who had previously been so busy doing the tasks required that they weren't able to spend quality time with their relative. With the help from the carers, they were able to "sit, talk and comfort" their relative.

Of the 16 relatives we spoke to, 13 reported that their loved ones had died where they wanted to, at home. Two of the remaining relatives had said that their loved one had originally wanted to die at home, but that when circumstances meant that they needed more support than could be provided at home, they accepted that this was suitable and found positive aspects in the alternative location, such as better pain control or ease of visiting by local friends. One relative said that they would have preferred their loved one to die in the hospice rather than at home, as they thought they would have received faster pain management there.

Family members reported feeling very well supported by the service. Care was put into place very quickly, and families either felt involved in decisions, or were happy not to be involved and that someone else was taking on the responsibility.

Discharge from the service

The service provides care to patients who are close to the end of life (within the last year of life), but this does not always equate to care in the dying phase. Of the 191 total users of the services in 2014-15, 74 people (39%) died during this period of care. Other users were discharged from the service to hospice care, care from the community teams and domiciliary care (either private or council funded, or funded under the Continuing Health Care scheme), residential or nursing care or other care arrangements. It was unclear how many of the people whose relatives we spoke to were using the service when they passed away, as many relatives described other carers who could have been from the hospices or other care providers.

Some relatives had found discharge from the service to alternative care to be an easy process, with one describing the transfer of care as "seamless". However, one relative whose family member had been discharged from the service felt unsupported at this stage. He described feeling in "limbo" as he was left to make decisions and arrangements himself with only the Council's adult social care website for information.



Other experiences

Other services were also discussed, as the service provided by the hospices does not operate in isolation.

GPs played a large part in the end of life experience for many people. Good care from the GP could make a huge difference to patients and relatives at this difficult time, while poor experiences and insensitive communication could be extremely upsetting. Examples of good care included a GP who took the time to talk a family member through possible scenarios, including when things went to plan and where there could be problems. This left the relative feeling more informed and prepared.

Community nurses were often praised as being good, but accessing them could be difficult. There is no overnight (10pm-7am) community nursing cover across the county. Families reported that the community nurses were often busy with routine calls, and unable to respond at the time when the family felt they needed assistance, such as when there was a problem with a syringe driver. Community nurses trained one relative to be able to give injections, which gave the family more control over the situation, while another made a family aware of laundry facilities at the local community hospital, which was greatly appreciated. Some families said that community nurses who did not know the patient were making the applications for Continuing Healthcare funding. They were concerned about whether they were able to accurately tell what the patient needed.

The out-of-hours service was also called upon by a number of participants. Some out-of-hours doctors were described as brilliant, while there were a few issues with doctors not being used to local systems (such as a lack of 24 hour community nurses, and different death verification paperwork between Wiltshire and Swindon). Some relatives felt there was a slow response to calls to the out of hours/access to care service when they called with urgent problems.

Many participants were also receiving domiciliary care from other care providers. Feedback about non-specialist domiciliary carers was mixed. Some were described as excellent, while others were not so highly rated.

The equipment provided by Medequip and other services was appreciated by relatives. It was also appreciated when this could be removed promptly after the patient's death, though this was not always possible. Sometimes equipment was not explained. Two relatives said that they have been given 'just in case' boxes, but these had not been explained to them. They did not know what to do with the boxes, did not know what was in them and told us that they would have appreciated more explanation.

Communication between these other parts of the system was not always clear, and families were sometimes left confused by decisions. One relative said that an out-of-hours doctor had asked for a syringe driver to be put in place, but that community nurses refused, but the reasons were not clear to the family.

Information about a patient's death was not always shared with the necessary people, so some relatives were contacted after a person's death about future care. Other families reported good communication and cooperation between different professionals involved in their relatives' care.



Continuing healthcare (CHC)

Participants reported mixed experiences of accessing CHC funding, which is designed to provide care for people with health (rather than social) care needs. There is a fast-track application process for people who need care at the end of life. Some relatives found the process easier than expected, while others encountered problems. Difficulties included slow decisions caused by incorrect or incomplete paperwork from community nurses, a lack of communication with preferred care agencies and concerns that moving to CHC funded care would require a change in agency which would interrupt the continuity of care staff. This was a particular concern for someone who had a long history with their care agency and very positive relationships with their existing carers.

Families who tried to communicate with the CHC service to get an update on an application or arrange care that met their relatives individual needs were told that the team do not usually communicate with families but work through the community nurses. This is contrary to information provided about the CHC service by the NHS Wiltshire Clinical Commissioning Group on their website⁷, which advises the public to call if they have a query.

Staff told us that their experience was that the decision making part of the CHC process, especially the fast-track, was generally quick once submitted, but the problems came in finding carers able to provide the home care required. Another problem hospice staff perceived was that the community nurses, who make the CHC application, are very busy with a large number of patients on their caseload, and so may struggle to have the time to complete the forms. In some cases, forms were being completed in hospital but not submitted when a patient was discharged through the service, which led to delays while the application was remade by the community team.

One relative told us that she was very concerned that carers who had been arranged through CHC said that they would have to follow their agency protocol if/when the patient stopped breathing, and call an ambulance despite the patient being at end of life. They were especially concerned that this would lead to the patient receiving assisted ventilation, even when they had shared their wishes not to be resuscitated. They contrasted this with the individual centred approach from the hospice carers, which would not have required staff to follow this course of action.



⁷ <http://www.wiltshireccg.nhs.uk/your-health/local-health-services/continuing-health-care>

Access to medication or equipment on prescription

Families reported some problems with accessing the medications their loved one needed. In some cases, this was when health professionals who came and went did not see the patient at their worst, so thought they were more comfortable than they were. If the problems occurred during the time that the additional care was in place, then the extra assistance of the hospice carers was appreciated by families. Because they were there for longer, they saw more of what was happening with the patient and “they could back me [family member] up when I asked for more medication”, or make the call for further medication themselves.

At other times, the medication was prescribed, but was difficult for families to obtain. Pharmacies not always have sufficient stock of controlled medication for collection, and family members reported having to spend time travelling around different pharmacies to try to get medications, when they would have preferred to spend that time with their loved one.

Getting equipment on prescription (such as dressings) was also difficult for some families. The time it took to process the prescription meant that the family frequently ran out before they could get more. Accessing continence products was also a problem for one family, as they were not told they were entitled to them. An assessment for this had been completed but not submitted.



Things that could be changed or improved

Families provided us with this feedback:

- Early signposting and referral to hospice services is appreciated and helps family members feel things are under control. This is not always happening at the moment.
- More contact from specialist nurses during the dying stage, including at weekend.
- Faster access to symptom relief medication (pain/sickness/secretion control).
- More information for relatives about what to expect in their loved ones' final days would be appreciated.
- Where a person is going to be discharged from the service, more support in finding alternative carers, especially ones with experience of caring for people at the end of their life.



What staff told us

The staff we spoke to were very positive about the service. They could see it helping people to remain at home, avoiding unnecessary admissions to hospital and facilitating getting people home if it was their wish to die there.

Hospices reported having very good healthcare assistants available for the scheme, with no problems with staff retention. There were some concerns that the uncertainty whether the service would continue to be funded would negatively impact on staff retention. Frontline staff spoke about the importance of having flexible and understanding coordinators with clinical knowledge.

Challenges for the staff included a lack of capacity to have more than one patient per hospice on the service at once. There was also a lack of cover for staff sickness/leave. There were times when there were a number of people who could have benefitted from the service, but staff had to prioritise who to accept. This meant that those not chosen may have remained in hospital for longer, had an avoidable admission to hospital or received non-specialist care at home.

Both hospices had provided additional training to the non-specialist MiHomeCare carers who usually supported people on the Urgent Care @ Home service, who were called on if the hospices were unable to provide some of the care. However, there was concerns that the turnover of staff at MiHomeCare might have meant that some of the carers had not received this palliative care training.

The service was planned to provide care for up to 72 hours, but this length of time was extended in about a third of cases (60 patients). One patient received care on the service for over a fortnight. Staff described keeping patients on the service because of a lack of alternative care, especially specialist EoLC. Delays in other domiciliary care being able to commence meant that hospices kept providing the service for longer than planned. Sometimes Urgent Care @ Home were able to take on these patients, but at other times the hospices continued to provide care until an alternative was in place. At times, coordinators of the service described having to judge whether to take on a patient if they were not sure that they were going to be able to discharge them within the 72 hours, as it meant that other patients would not be able to benefit from the service.

It is important for patients and families that services work well together. On the whole we found that the service linked well with other services. However, there is scope for improvement in communications between Medvivo and the hospices providing the service.

These are

- Ensuring that there is a clear understanding of when capacity is and is not available on the service to accept new referrals.
- Use of shared computer systems to ensure all staff are up to date on patient status.
- Examination of the referral pathways into the service at night, when there is currently a low referral rate.
- Consistent use of referral pathways, following the correct process each time to ensure flow of patient information and clinical responsibility.

Hospice staff were concerned about how well the service had been advertised to other professionals. They felt that there was capacity for them to take on more patients (when they were not supporting people already), especially to facilitate discharge from hospitals. However, it was difficult to keep advertising the service when its continued existence was in question. Medvivo reported a concern that if professionals try once and find that there is no capacity, this deters them from trying again.

How this fits with other information

What people have told us about this service fits well with other findings about end of life care in Wiltshire. The Patients Association 'Exploring the Experience of End of Life Care' project report for NHS Wiltshire Clinical Commissioning Group (2015) also found that people have mixed experiences of care at the end of life, but there was generally higher ratings for hospice led care. This matches the high level of satisfaction relatives reported with the 72 hour rapid response enhanced end of life service.

Communication and information provision remains a challenge in end of life care. This was also identified locally by the Patients Association, and nationally by the Choice in End of Life Care Programme Board. We have also heard this from members of the public who have taken part in Healthwatch Wiltshire's wider engagement or contacted us with concerns. At times, relatives are reporting that there is good communication, but this is not yet all families' experiences. Wiltshire residents struggle to access information about end of life care and especially about domiciliary care for people at the end of life.

We have also heard accounts from other members of the public and professionals who have contacted us about the challenges in accessing CHC, with concerns being raised with us about referrals not being completed despite requests from families or existing care agencies and more requests being refused as ineligible.

Challenges for health and social care systems

- Providing accessible information about end of life care, including about the service, in a way that people are able to take in at times of great stress.
- Ensuring that all relevant professionals have adequate knowledge of the service and eligibility criteria and referral pathways.
- Managing the use of the service, to take on more patients when the service has spare capacity.
- There is a risk of confusion where different schemes overlap. Coordinating the service alongside other Better Care Fund schemes, such as Homefirst, and other services, such as the existing Urgent Care @ Home will require clear information for professionals and the public.



Next steps

This report will be shared with Wiltshire Council and NHS Wiltshire's Clinical Commissioning Group to inform their future commissioning plans to ensure that the right services are in place for people who are at end of life. It will also be shared with the Wiltshire End of Life Programme Board.

Because people have told us that they would like more information about what to expect when a person is at the end of their life, we will increase the amount of end of life information available on the Your Care Your Support Wiltshire website (www.yourcareyoursupportwiltshire.org.uk). This will be available to patients and families directly and also to professionals and voluntary and community groups.

Thanks

Healthwatch Wiltshire would like to thank everyone who took the time to share their experiences of how the service worked for them, especially the bereaved families who spoke to us. We would also like to thank Dorothy House Hospice Care and Prospect Hospice for sharing information about the project with relevant families, and for facilitating our discussions with their staff. Thanks to Medvivo for providing the statistical information about the service and for taking the time to talk to us.



Why not get involved?

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