Experiences of End of Life and Palliative Care Services in Shropshire

Engagement Report

Engagement period:
August – September 2019

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About Healthwatch Shropshire

Healthwatch Shropshire is the independent health and social care champion for local people

We work to make your voice count when it comes to shaping and improving services. We use a variety of methods to find out what people like about services, and what could be improved and we share these views with those with the power to make change happen. Our reports go to:

- the organisations who provide services
- the commissioners who pay for services (e.g. Shropshire Clinical Commissioning Group and Shropshire Council)
- service regulators (the Care Quality Commission, NHS England)
- our national body Healthwatch England to let them know how services are working in Shropshire

We are not experts in health and social care and Hot Topics are just one of the methods we use to put a spotlight on services and ask people to share their views with us. Hot Topics are publicised and promoted through our engagement activities (e.g. talks and stands at events) for 1-2 months. To gather more information we might also do surveys and focus groups.

Please note

Hot Topics are not time limited and so while we have targeted our engagement on end of life and palliative care during August and September 2019 we continue to want to hear from people who are willing to share their experiences with us and we will share them with the providers, commissioners and regulators.

The context

Death and dying can be a very difficult topic to talk about but we wanted to give people the opportunity to share their experiences and feedback on the services they or a loved one has received or is currently receiving.

As a person nears end of life, whether they are in hospital or being supported at home, there is only one chance for the providers of care to get it right.

We wanted to know if people felt that the care their loved one received was what they wanted and expected. For example, if they were treated with dignity, if they felt listened to and if their wishes were respected.

It has been shown that it is really important that those providing care at end of life are open and honest with both the patient and relatives.[1] Being better informed can reduce stress and anxiety and help people understand what to expect. We wanted to know whether the language used by those giving the care was appropriate and if it prepared people for what was going to happen. Were other ways of communicating found if the person's preferences couldn't be expressed verbally, e.g. because of dementia or brain injury?

We wanted to find out whether care for the dying is the same wherever people die in the county and if there is a joined up approach to end of life care between different services including those available overnight and over weekends for those in the community.

According to NHS England:

> 'End of life care includes palliative care. If you have an illness that cannot be cured, palliative care makes you as comfortable as possible, by managing your pain and other distressing symptoms. It also involves psychological, social and spiritual support for you and your family or carers. This is called a holistic approach, because it deals with you as a "whole" person, not just your illness or symptoms.

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[1] https://www.nice.org.uk/news/article/new-guidelines-to-improve-care-for-people-at-the-end-of-life

Palliative care is not just for the end of life – you may receive palliative care earlier in your illness, while you are still receiving other therapies to treat your condition.' https://www.nhs.uk/conditions/end-of-life-care/what-it-involves-and-when-it-starts/ [Accessed November 2019]

Where do people die?

The Public Health Figures for 2017[2] show:

Percentage of people who died	Shropshire Clinical Commissioning Group (%)	National Average (%)
In a Hospital	45.49	49.51
In a Care Home	28.64	22.38
At home	22.42	23.65
In a Hospice	6.34	5.83

Many people prefer to die at home or in the place they call home (including Nursing and Care Homes) and while these figures show that a higher number of people die in Care Homes than the national average, fewer people are dying in their own home and the majority of people continue to die in hospital.

In Shropshire during 2017/18, 34.33% of people who died were identified on GP disease registers as needing palliative care / end of life support, lower than the national average of 45.3%.[3] One impact of not being identified as needing palliative care is that people may not be accessing the services and the support they need in a timely way or have the opportunity to discuss their wishes around their end of life care and treatment.

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[2] Source: Public Health England Palliative and End of Life Care interactive atlas. http://tools.england.nhs.uk/images/EOLCatlas/atlas.html

[3] Public Health England Palliative and End of Life Care interactive atlas. http://tools.england.nhs.uk/images/EOLCatlas/atlas.html

What we did


Do you have experience of local End of Life or Palliative care services?

In order to find out about people’s experiences in Shropshire we decided to focus our engagement for the months of August and September 2019 on end of life and palliative care.

At the end of July we put a call out through our media, stakeholders and community contacts across Shropshire asking people to contact us and share their experiences.

When we approached Shrewsbury and Telford Hospital NHS Trust they told us they carry out their own end of life survey. We explained our independent role and commitment to working sensitively with people who wish to share their experiences with us, including offering anonymity and the Trust agreed to include our flyer in their Swan Packs from the end of September. The lateness of this means that some people will share their comments with us after the publication of this report but their feedback will also be shared with the service providers and commissioners as part of our normal information sharing process.

As we expected, it has been very difficult to achieve a high level of engagement over this very emotional subject. As well as people’s reluctance to speak about their own experiences, particularly if they had been recently bereaved, professionals were protective of the families they were working with. Our requests to speak with specific bereavement groups were generally not accepted with organisers feeling that it would not be appropriate. Our Engagement Officer was able to attend one befriending group in Oswestry and a Living Well session at Severn Hospice in November. Due to timescales the comments received at the Living Well session are not included in the data in the report but our findings are included under Additional Findings (p.18)

We were also able to speak to staff working for a variety of service providers to hear their perspective and experiences of service coordination.

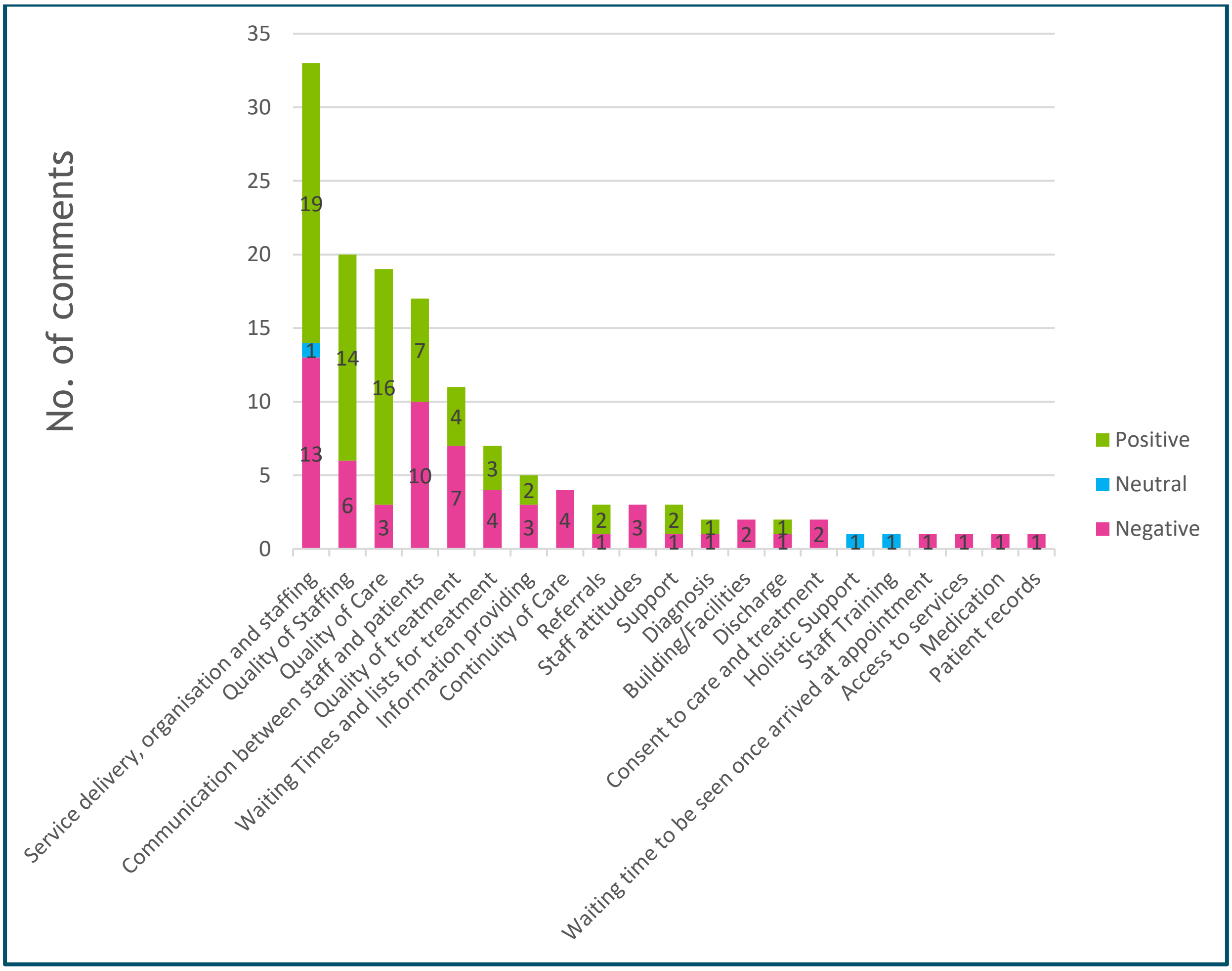
What we found out

We received 33 patient and family experiences of end of life (EofL) care during 2019, the vast majority of which were sent to us during the period of our focused engagement in August to September.

Nearly all of the experiences included comments about a variety of service providers and many covered several aspects of each provider's service.

79% (26) of the experiences shared with us suggest that services could make improvements. It is important to note that not all the feedback we received related to specific end of life services but they do highlight the question - When does end of life care start?

Table 1: Overall themes raised in comments



Important note

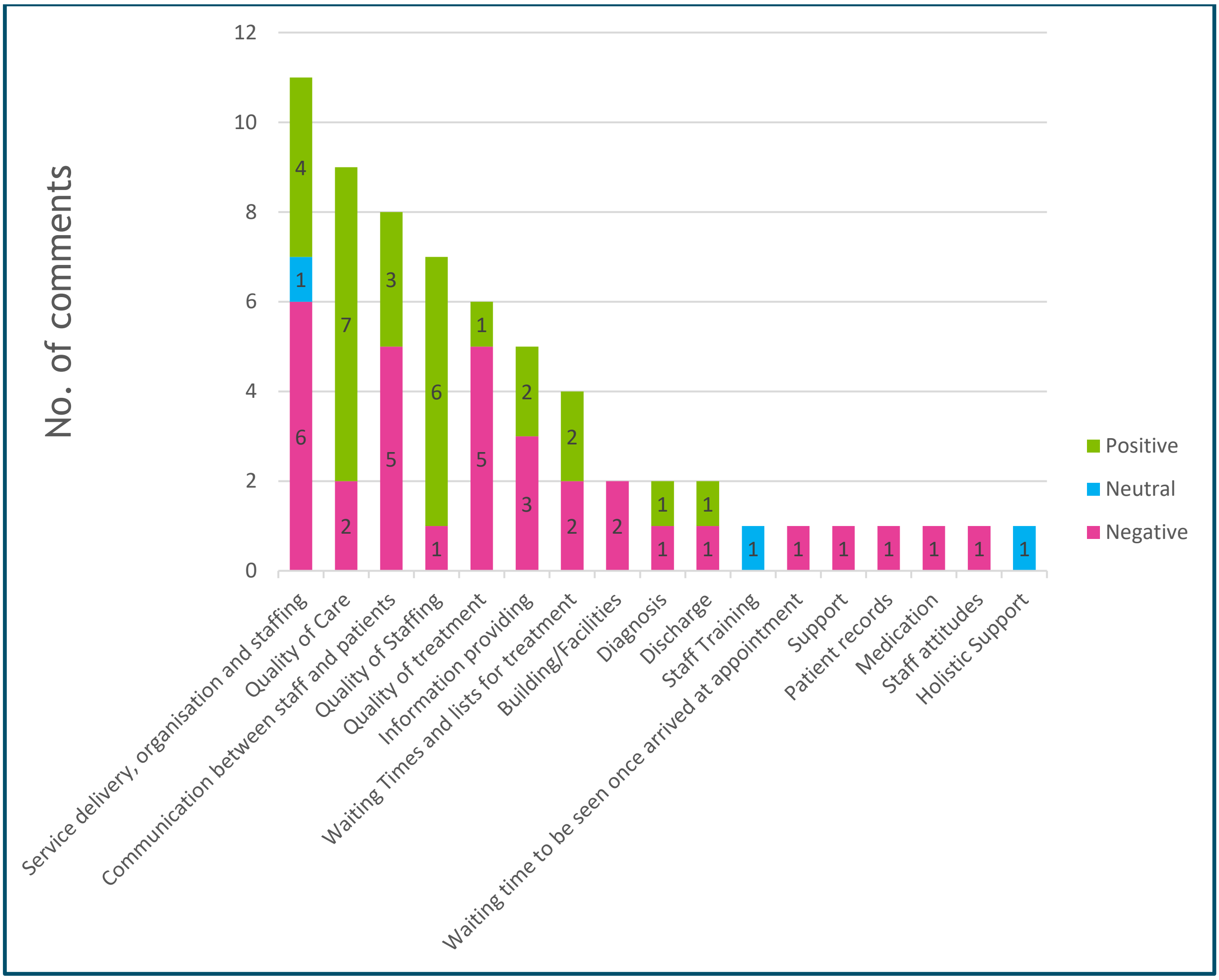
If people share their views with us in writing or via our website it is not possible for us to ask for further information, e.g. name of service, date of experience. Therefore some comments might describe experiences from some time ago and services/practice might have changed.

Individual Service Providers

Hospital experiences

The services provided by Shrewsbury and Telford Hospital NHS Trust (SaTH) received the most comment, 20 experiences (61%) included feedback about services at Royal Shrewsbury Hospital.

Table 2: Themes raised in comments involving SaTH services



The themes receiving the most positive comments were the quality of care, (identified in seven experiences) and quality of staffing (identified in six experiences).

For example:

- “I lost both parents within eight months and can only speak on personal experience. The end of life care that they both received at RSH [Royal Shrewsbury Hospital] was exceptional. The care staff were kind and showed compassion, continued to show them dignity right up to the end. The consultants kept us up to date with information, and everyone kept us supplied with coffee, tea and snacks.”
- “He was admitted to a ward specialising in end of life care where the staff were very kind and the family were treated very well. His wife was shown respect, kept informed and felt that the service exceeded expectations.”
- “[Relative] was diagnosed with COPD, he was referred to RSH specialist who was marvellous, they did everything they could to help.”

The themes receiving the highest number of negative comments were service delivery (identified in six experiences), communication between staff and patients (five experiences) and quality of treatment (five experiences)

For example:

- “Ten days before he died he was taken into RSH A&E (which was full of people on trolleys in the corridor) he was given a cubicle but had to wait from 3.15pm until 11pm to be admitted.”

Hospice experiences

Severn Hospice was mentioned in eight experiences (24%), the feedback was overwhelmingly positive; the quality of care, treatment and staffing were highlighted. For example:

- “The care and compassion at the hospice were tremendous, I cannot praise them enough, the family was involved, respected and cared for. You could literally feel the love. The patient was happy there, he was kept calm and pain free until the end. The family was able to stay with him until the end, even through the night and the provision for it was good.”

The only negative experience arose around continuity of care when a staff member left and their workload was taken up by another member of staff who the family felt already had a full workload.

One person who shared an experience with us suggested:

- “Most of the care [Mum-in-law] received could not have been bettered and the ultimate outcome was never in doubt. However, if we had been able to retain the same Hospice Nurse throughout, I am sure that we would have felt better supported and perhaps her hospital stay could have been avoided.”

Community experiences

District nursing

Five experiences (15%) included feedback about community nursing services provided by Shropshire Community Health Trust. Three negative, one positive and one mixed sentiment. The positive feedback referred to an experience 16 years ago. The mixed experience relates to the experience of services from two members of staff:

- “A Community Nurse came out on the Sat morning and we were so relieved. We asked for a slide sheet so that the carers could move my uncle safely. She hadn’t got one in her car. We asked for mouth swabs, as my uncle was full of fluid, frothing at the mouth and unable to communicate because of the amount of gunk in his mouth. Again, she hadn’t got any. I asked her where she went to get them & she said William Farr House but that she was busy, so I offered to follow her to get them from her, so that she didn’t have to come back. She said ‘no’. She claimed she would come back with everything shortly. We waited three very distressing hours and when she returned she still had none of the items. No apology even. Nothing was done to make him comfortable before she left. Another couple of hours later another Community Nurse came and she was fantastic! She sorted out everything. Cleaned my uncle, propped him up, cleared his mouth, administered pain relief etc. He looked totally different and appeared more peaceful.”

One person described difficulties they had had regarding changing a catheter:

- “I had to fight to get the help I needed. He had a catheter and I couldn’t always get help from the District Nurse, I had to call 111 and ShropDoc to get the catheter cleared.”

We spoke to a member of staff from the community nursing team who highlighted the implementation of the ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) programme across Shropshire from October 2019.

The Resuscitation Council website states:

> 'The ReSPECT process is a new approach to encourage people to have an individual plan to try to ensure that they get the right care and treatment in an anticipated future emergency in which they no longer have the capacity to make or express choices.
>
> The ReSPECT process is intended to respect both patient preferences and clinical judgement.' https://www.resus.org.uk/respect/ [Accessed January 2020]

We received one positive experience about the Trust's respiratory team at Louise House:

- "It was very caring and friendly"

General Practice

Four of the experiences (12%) included feedback about the service received from a GP practice. Three were positive and one was mixed, the mixed experience related to different members of staff.

We spoke to two GP practice care coordinators; neither raised any issues with the services available to patients at the end of life although one reported a case where an end of life patient had not been able to access Continuing Health Care[4] funding in a timely manner.

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[4] NHS Continuing Healthcare (CHC) is a package of support funded by the NHS. It helps care for a patient's physical or mental health needs that have arisen as a result of disability, accident or illness. Individuals assessed as having a certain level of care need may receive NHS Continuing Healthcare. It is not dependent on a particular disease, diagnosis or condition, nor on who provides the care or where that care is provided. If someone's overall care needs show that the primary need is a health need, the person should be eligible for NHS Continuing Healthcare. In Shropshire it is administered by Shropshire Clinical Commissioning Group, https://www.shropshireccg.nhs.uk/local-services/patient-care/continuing-healthcare-chc/

Out of Hours

We didn’t receive any patient or family feedback about the 111 service and only two experiences included feedback about the out of hours primary care service ShropDoc. Both of these described problems with communication, e.g. one family felt that the service did not listen to or respect their wishes by making a “‘Best interests’ decision” to send the person to hospital and in the other there was an issue around contacting the service to get the correct medication:

- “The residential home tried to get hold of the out-of-hours GP the following day for more medication, however the communication was abruptly broken. The relative of the patient travelled to Shrewsbury to collect morphine but upon arrival was told that prescription was incorrect and had to go to RSH for the out-of-hours GP to give a new prescription.”

As part of this project one of our volunteers met with clinical and management staff at one of their local GP practices and discussed the problems relatives of patients who are in end of life can face when they need help out of hours. The practice explained that patients’ records are flagged on the system and when relatives speak to 111 they just need to tell the call operators that the patient is at end of life or receiving palliative care, they should then be put straight through to ShropDoc. The staff agreed that all patients and their carers may not be sure of what to say and said they would make sure that all patients and carers will be advised on what to say when speaking to 111.

Staff we spoke to at a nursing home told us that the call handlers from 111 ask to speak to the patient when staff ring, even when it has been explained that the patient is either unable to talk or unable to understand (e.g. dementia suffers). The call handlers will often then insist that they speak to one of the registered nurses in the home, even if the nurse is not familiar with the patient. However, it was felt that “if a second call is necessary, the handling is much better.”

Care Providers

We received feedback about three care homes and two Domiciliary (Dom) Care providers. This was predominantly positive except for one of the Dom Care providers where there were some issues around communication and changes of staffing.

Examples comments received:

- “She was at home for nine days before she collapsed and was admitted to Isle Court Nursing Home where she died a few days later, a mere three months after the diagnosis. The care she received at Isle Court was exemplary, as was the support provided to us.”
- “The Agape carers did cover some of the hours but not the preferred ones. Evening call should be 9pm but they turned up early. Had 11 people coming in and out of the house to deliver end of life care - no continuity. Last few weeks of life very distressing - husband refused to go to bed before 9pm as he wasn’t ready at that time. This situation was very distressing for him. Husband died in hospice in July.”

One of our volunteers spoke to the managers of two care homes in Oswestry; they both felt well supported by general practice, district nurses and Severn Hospice outreach and ‘Hospice at Home’ services. One however did report that there was an occasion when they had accepted someone who had been discharged from the hospital and they had received very little information about them. It was only when the person arrived at the home that staff realized the patient was in need of end of life care. The community services were also unaware of the patient’s needs.

Patient experience

When does end of life care begin?

From the experiences people shared with us, it seems that they had negative experiences particularly when there was a lack of recognition by professionals that the person was at end of life. A theme running through the negative experiences was that family members could see that their relative was extremely ill but felt that staff were not acknowledging the seriousness of their condition and talking about possible treatments while not discussing end of life care options, for example:

- Mother [aged 95 and admitted to hospital on Sunday morning] had been in heart failure for 10 years and by the Monday was crying out as she was struggling to breathe. Saddlebags of yellow fluid were building up around her body. A Doctor and Sister came and spoke to [woman’s daughter] and told her they were going to treat her mum and get her in to ‘rehab’. Daughter asks why the staff did not seem to know her mum only had hours to live, she was already semi-conscious and delirious…. She died [hours later that Monday] at 3.30pm.'

- "I am still desperately unhappy and angry at the lack of communication from staff at RSH, nobody seemed to know what was going on, and while one team were preparing to send [the patient] home, others were aware that he was in need of End of Life Care. Complete failure of communication led to a very traumatic and stressful time, which I would not want anyone else to go through."
- 'The patient's wife asked one of the doctors whether she should contact her two other children, who were out of the country, and he laughed and joked that there was 'no need for anyone to go buying air tickets'. They were then instructed to go for a coffee as the doctor wanted to get blood from the patient's shinbone and that would be 'alarming' for them to see. "Over an hour after my family first asked for help, a blood test was done. The results meant something 'catastrophic' would occur within two hours." However, the patient was not sent to intensive care. Instead, the patient was sent for a scan. "As my family returned from the cafe, they waited by the bed for him to return but were then sent away as it was meal time and told to return in an hour. Unfortunately, though perhaps predictably, given the earlier blood test reading and heavy internal bleeding, the patient died during the scan."

A theme apparent from the feedback is that once it is acknowledged by staff that the patient is in need of end of life care the patient's and family's experience is more positive, e.g. when they go on to receive hospice services or care from the End of Life Care Team in hospitals.

Communication and information

The lack of good communication or timely, relevant and accessible information was raised in 30% (10) of experiences. For example:

- "At one point [my mother] started to come round [in hospital] and I thought we should have some 'just in case medication' (Sedative and Diamorphine). I realised that she was dying. They didn't explain to us anything about what to expect. They give you information for after the death but not what to expect in the process and they don't check you know how to cope."

- “It may also have been useful to have had someone actually talk through the likely stages [the patient] (and the family) would experience so that they could be more prepared and feel supported. Being given a leaflet about the end of life at that time was ineffective, it needed some compassion and someone to explain and answer any questions. [The patient] too missed out on this opportunity.”
- “I am also keen to get discussions going around staff training for people that support those with Autism around the end-of-life event when a close member of their family dies. In many cases this is likely to be one of their parents who often give support both emotional, practical, monetary or even have the Autistic person’s housing/living arrangements involved in theirs.”

Hospital facilities

Four comments reflected negative experiences around the facilities for patients and their families at the end of life, including:

- “He was admitted onto Ward 15 who put him onto an end of life pathway. Unfortunately, they had no side rooms so basically he died in a six-bedded unit. I have no complaints about Ward 15 they just didn’t have a side ward for him.”
- “The only negative would be that the rooms were a little sterile. Are family expected to stay overnight as we did? If so then a little more thought should go in to comfortable seating. With our father we spent nights draped over his bed as the chairs were so upright and with our mother we took turns on the floor.”
- “Eventually she got into a heart ward. She was put into a bed in a side ward. Dying hasn’t been a pleasant experience. The staff were so busy, if I had not stayed with her she would have been another one that they popped their head round the door to and she would have been found dead. The challenge for this county is that we either have brilliant care or terrible, there doesn’t seem to be anything in between. There are 10 Swan Rooms[5] but really more than 10 people die.”

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[5] ‘The Swan Rooms are a space for patients that are at end of life to use, allowing relatives to spend valuable time with their loved one in a more peaceful and calming environment. They have been made possible by kind donations from various sources. The rooms contain things such as CD players, mood lights, beautiful pictures and reclining chairs. The aim is that each ward will have at least one swan room’. https://www.sath.nhs.uk/patients-visitors/advice-support/end-of-life-care/ We are advised that as of end January 2020 there are ‘there are 23 across the site presently (13 at RSH and 10 at PRH) with more planned.’

Medication in the community

Several experiences raised issues around the administration of medication:

- “ShropDoc was contacted and the GP administered morphine and gave a prescription for more. As no local pharmacies seem to have the correct amount of morphine, the Residential home tried to get hold of the out of hours GP the following day for more medication; however, the communication was abruptly broken. Relative of the patient travelled to Shrewsbury to collect morphine but upon arrival was told that the prescription was incorrect and they had to go to RSH for the out of hours GP to give them a new prescription. Meanwhile a member of the community services came to assess the patient and had to be prompted regarding the management of pain and distress. It was decided to call the District Nurses who could assess regarding a syringe driver. After several delays, a driver was set up but because of protocols a less than effective dose of morphine was administered. All the while, the patient was in pain and distress. They died the following day.”
- “We went to get the prescription filled and were told that there was a shortage of morphine. So we had the syringe driver but no pain relief. We drove around various pharmacies but we kept hearing the same thing. By now my uncle’s breathing was really bad and he had a lot of pain. Boots in Shrewsbury were fantastic and rang their suppliers and associates. After a few hours we had some. Not much, but some to be going on with. The District Nurse came to set the pain relief up but when she read the paperwork, the GP had not given her the written permission to carry this role out, so she couldn’t set it up.”
- “The only negative comment I have though is the meds needed for dad’s final days which were used in a syringe driver. I think they were part of his ‘just in case’ meds. When the time was right for them to be used the hospice asked the GP to prescribe them which they did. However, at a time when we could have done without the stress, we had to drive around many pharmacies to get these meds as they were not stocked. I found one who had the meds in different doses than had been prescribed but I was unable to get the prescription changed as all the surgeries were closed for training. I and two district nurses ended up ringing many pharmacies but eventually finding one who had the meds. This was very stressful as Dad was in an agitated state and needed the meds urgently.”

We shared these experiences with the Shropshire Clinical Commissioning Group Medicines Team, the Director of Primary Care responded:

> “The CCG commissions a ‘just in case’ scheme for end of life care which has been shared with GPs, community pharmacy, out of hours services and our community service provider. This scheme was reviewed and updated in August 2019 in conjunction with our end of life group in order to address some of the problems that we were aware a small number of patients had been experiencing in accessing medicines at end of life.
>
> Full details of the scheme can be found here, including guidance for prescribers, pharmacies and patients:
> https://www.shropshireccg.nhs.uk/professional-resources/medicines-management/clinicalprescribing-guidelines-and-pathways/
>
> There are currently six pharmacies across Shropshire commissioned to hold an extended list of palliative care medicines, which practices, out of hours services and district nurse teams should direct patients to if their local pharmacy does not have items in stock. These are identified on the website.
>
> There have been intermittent issues with the supply of diamorphine throughout the last few years. Therefore the just in case guidance and templates for authorising administration now include an alternative to diamorphine for instances where this is unavailable.
>
> Timely planning in advance for end of life care is key to ensuring patients have access to the medicines they need when they need them at end of life. Our guidance advises GPs to start planning for end of life medicines by issuing ‘just in case’ medicines to patients when they anticipate these are likely to be needed in the next 2-3 months. Patients should then be reviewed regularly to ensure the authorisation to administer documents issued are signed in anticipation of need, and are for doses that are still appropriate to the individual patient’s needs at the time of use.”

Service co-ordination

- A local group told us: “Dudley have … a very good [End of Life Care] forum built up over many years, This means that health/social services/voluntary sector have a good relationship, understand each other’s roles and work together. Shropshire on the other hand is fragmented although parts work very well with the hospice.”
- “No realistic or co-ordinated planning to help him stay at home.”
- “In summary, throughout there was a lack of documentation, communication and inadequate clinical decision-making skills, lack of whole systems planning by commissioners and lack of collaboration between providers and services.”

A plea from a relative

When exactly does ‘End of Life Care come into play?

“For me, it began on Friday 31st May when we were told, quite gently, that J had Stage IV cancer and this was reinforced when I read the words ‘palliative team’ in the discharge letter. At no point had anyone mentioned or said the words ‘palliative care’. However, talking of ‘treatment’ if J was able to eat and get stronger to receive treatment implied to J and other family members that J may get better, they did not understand that the palliative care may prolong his life rather than cure him.

J was not given the opportunity to discuss his end of life fears, concerns or needs with anyone until Thursday 4th July on Ward 22RE, by which time it was too late. J had not wanted to die in a hospice but when the discussion took place there were few options available. There were no beds available at the hospice over the weekend and so the earliest he might have been transferred to the hospice was Monday 8th July. He died on 7th July in a side room on Ward 22RE.

He had a painful and bewildering journey which I feel, could have been less so for him and the family members if only we could have all communicated more with one another. But you are the experts and we, the family, did our best to keep up while struggling with some of the most difficult situations anyone has to cope with.

IT’S ALL ABOUT COMMUNICATING – bearing in mind that we know nothing and need to be helped to understand, accept and feel that everyone is contributing to the same aim – a peaceful and pain free end of life for all of us.”

Additional findings

Late November 2019 our Engagement Officer attended a Living Well session at Severn Hospice and spoke to people attending the session who are currently receiving services. Six people shared comments with us, five of these talked about their own experiences of receiving services. These comments have not been included in the data presented in the first part of this report but will be shared in full with the service providers and their commissioners.

Services commented on included:

- Severn Hospice
- Macmillan nurses
- Services provided at The Lingen Davies Centre[6]
- Services provided at The Hamar Centre[7]
- Royal Shrewsbury Hospital
- GPs
- Shropshire Council

Highlighting the number of organisations involved across health and social care in supporting people receiving palliative care.

As with the previous comments we received, the main themes were:

- Quality of care and treatment, including the attitude of staff
- Communication and access to information

One person commented on how different their recent experience had been compared to when they lost their husband:

> "I lost my husband to cancer 28 years ago. We had a Macmillan nurse who was brilliant and acted as the central point of contact. Anytime we had a question or a problem, we asked her. Since having cancer myself this year, it is much

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[6] The Lingen Davies Cancer Fund raised £3.2m to build a new dedicated centre for patients receiving treatment for cancer and haematological disorders. The unit opened to patients in September 2012 and provides improved facilities for the chemotherapy day unit, oncology clinics and the haematology day unit.

[7] Following a legacy left to The Lingen Davies Cancer Fund by a south Shropshire GP, Dr Linnie Hamar, the charity funded the Help and Support Centre at the Royal Shrewsbury Hospital. The centre offers counselling, therapies and holds support groups for people with cancer and other illnesses.

harder. The system is hard to understand and if you ask one person, they seem to pass you on to next."

This same person described their frustration at the lack of support available to them now they no longer have cancer:

- "[A nurse] just said speak to the oncologist in the clinic. But now that I haven't got cancer I don't have access to the clinic like I did have. I don't go regularly anymore. I think I am due an appointment with the oncologist within six weeks but I have not had anything come through yet. I have tried to chase this appointment but I am worn out by all the chasing. The system seems so fragmented once you are no longer receiving cancer treatment. I come to this hospice group it feels like the only support I now get. The hospital says your first point of call is the GP. However, they will only talk about one thing at a time. Where is the support for someone after cancer when they still have [medical] difficulties? No one seems to know the answer to that question so I keep asking"

One person told us of the difficulties they were experiencing getting a piece of equipment. They have terminal cancer, are partially blind and have a hearing impairment. They were requesting a self-reclining chair to reduce swelling and have had to speak to First Point of Contact at Shropshire Council for a needs assessment who then gave them "some numbers to ring":

- "It seems like you always have to find things out for yourself and it is really complicated. We rang the Macmillan Benefits line because we were not happy and I don't have time to wait for help. They told me I was entitled to income support. Once I had the income support Macmillan were able to give me a grant to buy the chair. [A member of staff] at the Hamar Centre [part of RSH] also deals with Welfare Rights and she helped me through this process. I have a private cleaner because I can't face going through social services. Previously Shropshire Social services did give me a chair and a stool for my bathroom and kitchen. It's crazy that a charity could help me but not social services. I don't like the system."

People shared a number of positive experiences with us highlighting how things can work, particularly when providers work well together:

- "On Monday, I just finished a Pulmonary Rehab programme, for the second time, which teaches you about your oxygen use, gives insight into breathlessness and generally teaches you how to cope. It's two days a week, for six weeks. I attended at the Cambrian Medical Centre although the people who run it are from Louise House in Shrewsbury. It is an excellent course; if I'm around I'll do it again. It was them that recommended this hospice group to me. So M from the Hospice and the lady from the respiratory clinic came together to my home. They said I could come to this coffee morning this morning."

- "I have had Leukaemia since 1987. Now terminally ill the hospice gives us fantastic help. I'm still reasonably fit and able so I don't need much in the way of equipment at home. I have had everything that I needed supplied from here. The staff are very good and very kind. The Lingden Davies Centre we have no complaint about them at all. The kindness of the staff was great. The hospice and the GP (Claremont Bank) work really well together. I have known [my Doctor] for many years. If I need to be seen, I phone at 8am and get in to see someone the same day. I feel supported."

Summary of findings

- Public Health data from 2017 shows that in Shropshire people are most likely to die in hospital (45%).
- Public Health data shows that only 34% of people who died in 2017/18 had been identified by their GP as needing palliative / end of life care. This is reflected in the experiences some people shared with us where they describe a lack of acknowledgement that their relative required palliative care or was at end of life impacting on the type of care and level of support received.
- Overall the people who shared their experiences with us reported slightly more positive aspects (71) about their experiences of palliative / end of life care than negative aspects (65). However 79% of experiences included at least one negative aspect.
- The experiences where the majority of the feedback was positive included comments on general service delivery (e.g. "RSH treated him and they were wonderful, he received great care") and organisation, quality of care and quality of staffing.
- The majority of negative experiences were around communication and information, treatment and continuity of care.

- A theme apparent from the feedback is that once it is acknowledged by staff that the patient is in need of end of life care the patient's and family's experience is more positive, e.g. when they go on to receive hospice services or care from the End of Life Care Team in hospitals.
- Some families found a lack of recognition by professionals that the person was at end of life and did not have the opportunity to prepare for the end of life.
- The lack of good communication or timely, relevant and accessible information was raised in 30% of experiences.
- Three families who were using end of life services in the community reported experiencing problems getting the correct medication for their relative.
- Staff at a GP practice told us that not all patients or families of those at end of life or receiving palliative care might know what to say when calling 111 out of hours to make sure they are put through to ShropDoc.
- Staff at a nursing home told us that when calling 111 to access ShropDoc regarding a resident who is at end of life the call handler often asks to speak to the patient even though it is explained they are unable to talk or understand (e.g. dementia sufferers).
- Four families had negative experiences of the rooms and facilities available in hospital at the end of life.
- Several comments raised the unsettling effect of a lack of regular care staff on patients at the end of life.

Recommendations

In order to improve the experience of people nearing end of life we suggest:

- All staff are supported to feel able to recognise when people are in need of palliative care and/or at end of life so they can have open and honest conversations with them and their family about their wishes and needs (including where they would like to die) in a timely way. This is likely to increase the number of people who are supported to die in their own home and reduce the number of people who die in hospital.
- Staff are trained to have what can be difficult and sensitive conversations with the aim of improving people's quality of life even though time may be short. Staff must also have access to ongoing emotional support.

- Consideration is given to further increasing the number of Swan Rooms and generally improving facilities for people who are at end of life across the hospital.
- Shropshire Clinical Commissioning Group works with community Pharmacies to improve the experience of patients in need of medication (e.g. pain medication) so family members/carers can get what they need when they need it, including at night and over the weekend.
- Work is done to make sure 111 call handlers respond appropriately when people call regarding a patient at end of life.
- Staff across the system make sure families/carers know what to say when calling 111 to request a visit from ShropDoc.
- The content of this report and comments from patients and families is shared with staff so they can see the examples of good practice and impact when things go right.

Service Provider Response

This report was shared with the following organisations for comment:

- Severn Hospice
- Shrewsbury and Telford Hospital NHS Trust
- Shropshire Clinical Commissioning Group
- Shropshire Community Health Trust

At the time of publishing this report we have received the following comments:

Severn Hospice

The Chief Executive at Severn Hospice said:

"I am delighted that palliative and end of life care continues to be high on the agenda and that comments from service users have been sought. It is disappointing that the sample size is so small as this inevitably affects the validity of the report.

The hospice supported around 750 patients during the period. All had palliative and or end of life care needs. Each of those patients would also be supported in the community by their GP and DN teams and most will have accessed care in the hospital. I can't help but feel that this has been a missed opportunity and as the local specialists and leaders in Palliative and End of Life care the hospice could have supported a significant increase in sample size given the opportunity.

As with the Public Health England report on the variation for Palliative and End of Life Care in England (October 2018) the only measure of access to hospice care is the data on place of death showing that in Shropshire access is 0.5% higher than the national average. This is merely access to beds however. What doesn't seem to be understood is that hospices often also provide community services. Severn Hospice for example cares for 4 out of 5 patients to be cared for in their own homes. The section on community care does not differentiate whether patients were supported by hospice/NHS or both services.

On page 4 the report cites a quote from NHS England and an expectation that palliative and end of life care should be holistic and consistent across the organisations. This is of course what we all should expect however we all know that provision is determined by resource and these vary greatly."

The Chief Officer for Healthwatch Shropshire has replied to explain that, as is usual practice, our Community Engagement and Communications Officer contacted a number of people in the organisations involved in the delivery of services, including the hospice, to let them know about the Hot Topic and ask for their help in promoting it to patients and families with the aim to increase the number of responses. We would have welcomed any input to inform the process and increase the sample size.

Shrewsbury and Telford Hospital Trust

The Clinical Lead for End of Life Care said:

"On behalf of the End of Life and Palliative Care team at the Royal Shrewsbury Hospital thank you for this detailed report which provides an excellent overview of the complex care that our patients and their families navigate. It is particularly helpful to have a report that covers all providers as although we work closely with our colleagues in other organisations, our focus is naturally on what happens within the hospital. We have worked very hard with our partners in other organisations, through the Shropshire-wide End of Life Care Group, to join up care as much as possible and to try and care for people in their own homes wherever possible so it is good to see this recognised in the report.

The themes identified in your research are very similar to those that we pick up in our bereavement survey responses, and they guide our ongoing improvement work. The main issue remains identifying patients who are dying at an early enough point to enable good care to be delivered, and then communicating compassionately what this means to patients and their families. We know that we can fall short here, and that the other pressures in an acute hospital sometimes make it difficult to recognise the dying phase of a patient's illness. We are working hard with medical and nursing colleagues through mandatory and supplementary training to improve this and to encourage open and honest conversations with patients and their families.

Your report also mentions the hospital environment - we have made some great improvements, particularly with the introduction of Swan Rooms across the Trust, but there are not enough of these rooms to ensure that all patients who die in our hospitals have access to them. It can be difficult to preserve privacy and dignity - we continue to strive to improve this, and to ensure that it is prioritised in any plans for new buildings. Staffing levels are obviously crucial to good care and we're grateful to you for highlighting this too. It was encouraging, though, to see that negative feedback came from only a minority of people. This reflected in our own survey responses - the vast majority of feedback is positive and makes us feel very proud of, and grateful to, our staff who deliver compassionate care at the end of life."

Shropshire Clinical Commissioning Group

Senior Quality Lead for Care Homes working across Shropshire and Telford & Wrekin CCGs said:

"Thank you for sharing the Healthwatch End of Life Report with us.

It will undoubtedly be a useful resource to use to improve the care of people at the end of life and identify where we can all give better support to families.

Whilst I appreciate the sample size could be considered small, the comments and issues that have been raised clearly identify a concise range of actions that should be addressed.

Please feel free to contact me if I can be on any further assistance, and I will keep you apprised of the actions that we take."

Shropshire Community Health Trust

Jan Ditheridge, Chief Executive said:

"Thank you so much for sharing this and taking the time to conduct this important survey. All patient or carer feedback is valuable and powerful.

Improving end of life care has and continues to be a high priority for Shropcom and while we know we have made improvements we know there is more to do to get it right every time and ensure that patients and families are able to plan for and experience a positive end of life and can die well in the place of choice

We will continue to work with partners to achieve this and hope that Healthwatch will continue to support us in that ambition "

Acknowledgements

Healthwatch Shropshire would like to thank the organisations who helped to promote this Hot Topic and the staff who spoke to us. We particularly thank all those families, carers and people receiving services who have shared their experiences with us.

Get in Touch

Please contact Healthwatch Shropshire to share your views and experiences of this service or any other health and social care service in Shropshire. We gather comments anonymously and share them with service commissioners and providers to highlight areas of good practice and identify areas for improvement.

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