



**End of Life and Palliative Care  
Services Report  
2019**

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## Glossary of Terms

Abbreviation	Full Abbreviation
A&E	Accident and Emergency
EOL	End-of-Life
HOSC	Health and Adult Social Care Oversight and Scrutiny Committee
HWT&W	Healthwatch Telford and Wrekin
HWS	Healthwatch Shropshire
LCP	Liverpool Care Pathway
T&W	Telford and Wrekin
SaTH	Shrewsbury and Telford Hospital
SCHT	Shropshire Community Health Trust
WHO	World Health Organisation
WMAS	West Midlands Ambulance Service



## Executive Summary

Healthwatch Shropshire (HWS) were asked to speak to people regarding their experiences of End-of-Life (EOL) Care within Shropshire and to identify whether there were any issues, particularly within the out-of-hours services. Additionally, it was suggested that Healthwatch Telford and Wrekin (HWT&W) could be involved in order to provide a comparison across the county. Therefore, following a 6-month review HWT&W were asked by Shropshire Doctors Co-Operative Ltd to explore people's views of EOL/Palliative Care services with a focus on out of hours services in Telford & Wrekin (T&W). Due to the sensitive nature of this piece of work, difficulties were to be expected. However, Healthwatch Telford and Wrekin's staff and volunteers dedicated their time and continued to engage with members of the public.

The purpose of this study was to reflect the views and experiences of the resident of T&W who have used EOL/Palliative Care services, with a focus on out-of-hours services. This would highlight what was working well and address any key issues in order to improve the service.

## Summary of Findings

This study demonstrated that while EOL care services were generally running well, some improvements could be made to the service. Feedback from respondents heavily centred around Communication and Staff Attitude, they felt that how professionals communicated with them was very important and how they were treated by staff impacted on the delivery of care and their overall experience. Out-of-hours services was one of the main areas we wished to explore; unfortunately, however, this was restricted by the limited amount of feedback received on this topic.

To summarise our main findings:

- There were breakdowns in communication between services and professionals, resulting in some patients/relatives not receiving appropriate information/guidance. Others were not fully supported with adequate care or equipment, including the failure to organise the provision of necessary medication.
- Some homeless people feel that they do not want to visit their Doctor because of the way they have been treated. Also, due to not having access to technology (phones, internet) they are unable to make appointments
- Communication between professionals and patients/relatives was good, they used appropriate language that was easily understood, and patients/relatives felt well informed.
- People's wishes were listened to and fulfilled.
- Nurse Co-ordinators, Health Visitors, Nurses and Carers made the biggest impact, with most people stating they had positive experiences with these staff.
- Some respondents felt specific staff attitudes in GP Practices made access to Doctors and prescriptions more difficult.
- Language barriers were identified which impacted not only the patient but also their relatives.
- Difficulties were identified in acute care, whereby staff shortages affected patients' quality of care and their experiences of A&E.
- West Midlands Ambulance Service provide good care; however, their waiting times had on numerous occasions left people stranded for hours.

## What is Healthwatch Telford and Wrekin?

HWT&W is an independent consumer champion/patient voice, created to gather the views of people who live in T&W. Nationally, Healthwatch England, supports 152 local Healthwatch that cover local Clinical Commissioning Groups and local authorities. We are a small team, consisting of a General Manager; an Information Analyst, Business Support Manager and an Engagement Officer. We are supported by a Board of Directors and a team of volunteers.

Our aim is to provide our communities with a stronger voice, to influence and challenge how health and social care services are provided in T&W. HWT&W routinely gathers the views of residents who use or have access to health and social care services. Their feedback is analysed to allow HWT&W to provide evidence-based comments to inform the key groups who plan, manage and regulate the service. HWT&W engages with many statutory/voluntary organisations including the Local Authority, Care Quality Commission, Clinical Commissioning Groups, providers, individuals and groups, to ensure that services are designed and structured to meet the needs of local people. In addition, HWT&W have a responsibility to carry out Enter and View visits to provider services offering health or social care activities.

## Introduction

Through the years understanding what good EOL care should look like has changed (Ellershaw et al., 1997). The World Health Organisation (WHO, 2007) states that palliative care is defined as aiding to improve the quality of life a patient has who is facing a life-threatening illness, by prevention and relief of suffering by means of early assessment and correct pain management. This is to ensure the patient is free from physical, psychosocial and spiritual suffering.

In the 1990s The Liverpool Care Pathway (LCP) was developed in England as a guide for health professionals to provide the best possible quality care for dying patients. It was suggested that in order to offer best practice to support the dying individual health professionals needed to follow certain steps and the LCP provided that platform, however, this approach was heavily criticised. People were labelled as 'dying' and diagnosed inaccurately, causing distress for the individual and their loved ones and many felt that the LCP accelerated people's deaths due to poor planning and decision making. As a result, an independent review of the LCP was conducted and ultimately led to the approach being phased out. Following this, The Leadership Alliance for the Care of Dying people produced a document; 'One Chance To Get It Right' (2014). The findings of this review played a huge part in recognising what changes needed to be made in EOL care, creating the 'five priorities of care'. These priorities enable professionals to care for those who are dying and be responsive to the overall needs and wishes of the individual and loved ones, finally changing how EOL care is delivered.

Shropshire's response to the LCP being phased out led to the development of 'Shropshire End of Life Plan for Adults. Implemented by the Shropshire Community Health Trust (SCHT), who provide palliative and EOL care to all residents of Shropshire (310, 278) and Telford (170, 2000) which includes both rural and urban areas.

*Their vision:*

*"Every adult in Shropshire, Telford and Wrekin is supported by high-quality person-centred care, which is recognised and delivered early and collaboratively. Meeting the individual wishes and preferences of those in the last year(s) of life and those who are important to them."*

(C, Molineux. Palliative and End of Life Care in the Last Years of Life. A Strategy for Adults, 2017-2020. Pg.9)



This plan is supported by the specialist palliative care team at Severn Hospice and Shrewsbury and Telford Hospital (SaTH). (Molineux., 2017-20) In T&W 43.3% of deaths were in hospital (which is lower than the national average), 22.5% of deaths occurred at home, 23% of deaths occur at care homes, followed by hospice deaths at 9.7%. This demonstrates that fewer people are dying in hospice and there is an increase in the amount of people dying in care homes. An indicator for this could be due to the rurality of T&W (and Shropshire), that there are fewer health and social care resources within the community.

Following a 6 month review meeting with Health and Adult Social Care Oversight and Scrutiny Committee (HOSC) & Shropshire Community Health Trust (SCHT), that due to feedback received regarding EOL care services it was suggested that a patient survey should be conducted to identify what the service is doing well on and highlight what requires improvements. This is to ensure that residents of Shropshire, T&W receive the best EOL care and the service is performing to the highest standard.

We were asked by Shropshire Doctors Co-Operative Ltd to explore people's views of EOL/Palliative Care services with a particular focus on out of hours services in T&W. The purpose of this study was to reflect the residents of T&W views and experiences of EOL care and to highlight issues in order to improve the service.

## What we did

Altogether we engaged with 14 people seeking their views and experiences. We gathered feedback between August - October 2019 by hosting informal 1:1 discussion, attending coffee mornings at the Severn Hospice, Maninplace (Telford) and visited people in their own homes. Other forms of engagement were conducted through social media, local press, telephone and email.

Questions were designed by Healthwatch T&W to help capture people’s experiences from different approaches within EOL care. These were used during our analysis for our overall themes; Communication, Staff attitude, Out-of-Hours Service and Overall Satisfaction. All responses were anonymous, and no demographics were obtained.



The table below is a breakdown of the 14 people we engaged with:

Summary of Engagement

Activity summary	Total
Number of interviews with staff	1
Number of interviews 1:1	9
Number of feedback received by email	4
<b>Total number of people spoken to</b>	<b>14</b>

Due to this being a sensitive subject we did not manage to engage with as many people as we hoped, however, we still managed to bring to light key points regarding the overall delivery of EOL care in T&W. Feedback was collected based on people’s experiences of using; local GP Surgery, ShropDoc, charities/support groups, Severn Hospice Shrewsbury and Telford Hospital (SaTH) and West Midlands Ambulance Service (WMAS).

## What we found

### Themes:

Feedback from this survey was analysed quantitatively and themes have already been identified (Communication, Staff attitude, Out of Hours Service, Overall Satisfaction). We have also included 3 case studies which demonstrate how EOL care has impacted people's experiences from 3 alternative perspectives. Therefore, bringing this together we were able to identify key issues and to discuss what has been working well within the service.

### Communication

We asked people to comment on the communication between the staff/professionals involved in the care of their relative. We found that most of the respondents stated they had a positive experience in terms of communication with professionals (Doctors, Nurses and District Nurses), charities/groups, Domiciliary Care and volunteers (Severn Hospice, Helping Hands and Age UK). It was highlighted that support given by charities/groups, Domiciliary Care and volunteers such as; Severn Hospice, District Nurses, Helping Hands and Age UK was really good. We were told that language used by professionals was easy to understand because it was not technical. Respondents had spoken to Doctors and Nurses, made particular comment on how supportive they were. This was because they took time to explain the procedures, which allowed them to come to terms with the process and know what to expect. This also allows people to put plans in place, in accordance with their needs and wishes. Access to these professionals was good and the reception staff were kind and approachable. Additionally, some respondents had stated how care homes and their staff (including management) were kind and supportive. Support was provided by having arranging discussions with the patient/relative(s), documenting and adhering to peoples wishes regarding medication and dietary needs.

### Respondents' comments:

- *"Language was tailored where it was easy to understand and explained in a good way."*
- *"People were patient and took time to explain things."*
- *"Both Doctors and Nurses without being too technical."*
- *"I was unable to grasp the fact that I could not cope, and that professional help was needed, when in the end I had to agree to allow them to move my wife to hospice."*
- *"My wife comes here for the social aspect because she can access support and information... and it is only once a week, it gets me out of the house."*
- *"Communication between staff at the Hospice is really good, you get excellent support from staff and others who attend the coffee mornings."*
- *"The nurse co-ordinator came to see father regarding care at home...they came one month later to check how he was. We had a really good service."*
- *"Professionals allowed my mom time to understand what was happening."*
- *"Access from our local GP's, nurses, receptionists were all professional and kind."*
- *"The NHS nurses called every day, the advice I received from them was priceless and they are a credit to their calling"*
- *"The health visitor and nurse co-ordinator communicated well with me."*



- *“I was supported by the Severn Hospice, District Nurse and Helping Hands care workers.”*
- *“Had oral morphine prescribed and given recommendations on when to take it.”*
- *“I did not know what to expect but it was explained by the Doctor what was going to happen.”*
- *“He said he wanted to die at home which was adhered to.”*
- *“If dad didn’t want to eat, they accepted that...he refused medication, swallowing became difficult, again we had a discussion with the home and medication was stopped.”*
- *“When diagnosed with cancer, mom attended all meetings with the consultant and agreed to radiotherapy until the point she did not want anymore.”*
- *“Once I understood what they offered I have been able to plan what I want.”*
- *“We also had support from the local hospice team and Age UK who were excellent, kind and considerate.”*
- *“My father many years ago said that if there came a time that nothing further could be done for him, he didn’t want to be resuscitated but to be made comfortable to accept death...when dad first entered the home the manager went through and logged all his wishes, sharing with all members of staff.”*

Unfortunately, not everyone experienced good communication from professionals, specifically from some Doctors. It has been suggested that seeing the same Doctor would be beneficial in terms of continuity of care and it eliminates the stress brought on when having to explain your situation every time patients (in particular) see a different Doctor. Moreover, some have had trouble accessing their Doctor and experienced lengthy waiting times. This can be particularly difficult for people who are homeless who do not have any modern-day communication devices. Furthermore, people who are homeless do not manage to easily access their Doctor, they feel they are not treated fairly, and this deters them from going back (Maninplace, 2019). Additionally, we found that some services are not communicating with each other very well and as a result people are being forgotten about and not receiving extra support when reaching crisis point. Additionally, at times homeless people may not be supported upon discharge from hospital, this includes aftercare and social support (Maninplace, 2019). Also, due to services not communicating with relatives, people are unable to obtain equipment enabling them to deliver care properly. This leaves relatives without the correct equipment to provide effective care which then impacts patient’s health.

#### Respondents’ comments:

- *“We reached an exhaustion point and asked social services for help...we never got any more care, no one ever arrived.”*
- *“As a result of this mom developed a pressure area, something mom had never had in all her life...we required simple help such as pressure area mattress, lifting aids, slide sheets!”*
- *“They don’t talk to each other, there is a lack of communication between services.”*
- *“The Hospice need to show a clearer understanding of what they do - clear roles and responsibilities, but they did offer good support.”*
- *“Communication between services is lacking, they don’t talk to each other and I have to give an update to my Macmillan nurse.”*

- *“Doctors and Nurses need to get to the point and make it clear so relatives know exactly what’s going on.”*
- *“Access to my local GP was not good at all, having to explain things to different Doctors didn’t help and had to travel to different practices.”*
- *“Not a good experience over waiting times, long wait to get appointments...I had no follow up calls.”*
- *“I should have been a priority, I need to see the same Doctor they know my conditions, if I see a different Doctor I have to explain everything...Constantly chasing things up is not good at all.”*
- *“The Memory Service was a bit task focused, it was like, here is your result, this is what we found, here’s some leaflets, any questions? - bye”*

Overall, the feedback shows that communication is lacking within particular areas and this suggests that depending on which GP Practice you are with, can affect; access and support offered by professionals, including getting equipment. However, language used is suitable and easy to understand and majority of respondents felt they were communicated with well.

### **Staff Attitude**

We asked people to comment on the support and treatment that was delivered by professional staff and whether the attitude of staff impacted the delivery of care they received. Feedback showed that most respondents stated that the attitude of professional staff was good, especially Health Visitors, Nurses and Nurse Co-ordinators. This was because they had a greater effect on the delivery of care in terms of organising care packages when patients were discharged from hospital and organising medication such as home oxygen and syringe drivers to be prescribed. Also, Carers were supportive from places such as Helping Hands and the Severn Hospice, with one respondent describing them as a “God send.” People were treated with dignity and respect and could ask for advice when required at any time which demonstrated professionalism and attentiveness attitude towards patients/relatives. Also, it is important to involve patients/relatives in any changes made in order to provide comfort or safety for the individual. We found that within a care home setting, staff provided equipment to adapt to the patient’s unsettled behaviour in order to keep the patient safe.

Respondents’ comments:

- *“I had no worries with staff, I know she was well looked after.”*
- *“The carers from Helping Hands were excellent.”*
- *“I have nothing but praise for all they did for my lovely wife and myself.”*
- *“Carers at the Hospice are brilliant cannot fault them.”*
- *“Staff were very compassionate, making sure that there was everything dad and mum needed for this final journey.”*
- *“Yes, I felt like they treated me with dignity and respect.”*
- *Health visitors came in the last few weeks before father passed, and they came every day and did skin checks.”*
- *“Dad kept trying to get out of bed so crash mats were put down after an agreement with ourselves and the home.”*

- *“I received a call to say that dad was struggling with his breathing, the call was very sympathetic and there was someone when I arrived.”*
- *“Nurse Co-ordinator and carers were a God-send, they made a big impact on the delivery of care.”*
- *“We could seek advice and guidance as required and never felt a burden to them. Nurses also very supportive to mom and family.”*
- *“Staff kept us refreshed and throughout the morning as the shift changed different members of staff asked us if they could say goodbye.”*
- *“Whenever staff came into the room, they spoke to my dad and had a little chat with him.”*
- *“The co-ordinator came to see father while in hospital and made sure he was not released until the home oxygen had been put in place, this was done within 2 hours... they organised a care package and health visitors brought a syringe driver to make my father more comfortable.”*
- *“The hospital bed was placed in the same room as his wife, which I was very grateful for.”*
- *“I had a difficult day and night care was provided and they even stayed for longer than what was originally planned, they stayed over for 4 days and they waited for me to arrive at my father’s home until they left.”*
- *“They made dad very comfortable on the floor on a mattress with his pillow and quilt, mum liked this as she could lye by his side and stroke his hair which he loved.”*

We only received a few negative comments, however, the feedback reflected the attitude of particular staff such as GP Practice Receptionists and Doctors. According to our feedback, respondents felt Reception staff were not very compassionate and communication was poor. Resulting in people feeling upset, having to push for appointments to be made and prescriptions processed. Additionally, some felt Doctors did not review EOL patients appropriately and perhaps Doctors need to address these types of patients differently in terms of treatment plans. Also, we were informed that while Medical Practices/Surgeries have a zero tolerance to people who challenge the service (physical/verbal aggressiveness), in particular - this may impact upon people who are homeless accessing treatment as required. Therefore, it is important to have more specialist services/professionals who can support people who may challenge this service (Maninplace, 2019).

Respondents’ comments:

- *“We just wanted an hour to get a cup of coffee...just a tiny break, anything really.”*
- *“I rang the GP again on the Wednesday and the secretary advised that the referral had been made. No one ever got back to us!”*
- *“We attended A&E...we did on one occasion have a Doctor who didn’t look at mom holistically. Yes, medical issues had been treated with medication, but mom was not weight bearing and he was ready to discharge.”*
- *“I required a home visit and was told to ring back the next day, I was astonished and upset but fortunately I know the system and as I believed mom had only a few days/weeks I advised that was an inappropriate request to the receptionist.”*

- *The Doctors came to see father but they were not sure what to do with him and it was 5 days before he died, they kept wanting to pursue treatment and they didn't even review his medication.”*
- *“I went to the GP to get some medication and the receptionist said the prescription had not arrived but may be upstairs on the fax machine, they did not go and check and was unhelpful...I go to Macmillan Nurse to process my prescriptions as its faster.”*

Overall, the feedback shows that the attitude of staff is very positive and effected the overall delivery of care. The feedback showed how well certain staff impacted to patients/relatives EOL care, with some comments reflecting input of medication and organising correct care when discharged from hospital. Alternatively, some respondents felt specific staff attitude in GP Practices contributed to making access to Doctors and prescriptions difficult.

### Out-of-Hours Service

We asked people to comment on their experience of using out-of-hours services. This service operates out of normal working hours and delivers care/support to those who require urgent assistance. Unfortunately, we did not receive much feedback in this area with mixed comments reflecting WMAS, NHS 111, Paramedics and Nurse Co-ordinators efforts. It was highlighted that respondents commented on how WMAS Paramedic staff were very good, however, there could be long waiting times due to the time of day. This suggests that WMAS have ‘peak hours’ where they are busy and people are therefore left waiting for ambulances for too long. Alternatively, we found that patients who are terminally ill are considered a ‘priority’ when relatives contact services for support at night and therefore receive help rapidly.

Respondents’ comments:

- *“West Midlands Ambulance Service (WMAS) attended to mom 3 times due to acute medical emergency, but depending on the time of day the out of hours meant long waits for ambulances to arrive, however all paramedics were very good, we felt involved in the care provided.”*
- *“Father took a turn for the worse, we phoned the out of hours service 6/7pm and they came out within the hour, there was a list and he was one of the priority people because he was terminally ill.”*
- *“The Nurse Co-ordinator was very proactive and kept to her word with no false promises made.”*
- *“NHS 111 I used once and it was very good, I had a nurse come out the next day.”*
- *“I speak to Macmillan once a week and was referred to the Community nurses.”*

Some respondents felt unsupported due to the limitations of certain services. We found that services did not communicate effectively, and carers were ill informed regarding a patient passing. Additionally, when carers tried to seek extra support during night they were refused and this led to the patient becoming distressed. This demonstrated poor communication and support from services to carers and relatives. We were informed that those without transport and means of communicating (telephone, internet etc...) with medical professionals, require

local services that include out-of-hours and acute services based locally and are easily accessible (Maninplace, 2019).

Respondents' comments:

- *"I had the luxury that other people don't get and called Shropdoc to expedite matters and they were sympathetic and accommodating given how upset I was...the general population don't have this luxury."*
- *"The carer phoned out of hours service one night for extra help but because they were there nobody came and my father became distressed."*
- *"Communication between staff wasn't good because carers turned up when he had already passed away, it didn't bother me but if it was someone else that could have upset them."*
- *"I called 111 to ask for a visit to verify death and was told that Shropdoc would call within the next 5-6 hours, I was horrified."*

Overall, the feedback has evidenced mixed responses showing both positive and negative experiences of using some, if not the same, services. It was highlighted how well certain services run outside of normal working hours by being proactive in terms of providing professional assistance within a timely manner for some. However, for others who have used the same service their experience/support has been completely different. Also, it was recognised that some were able to escalate issues/matters more easily than others.

### **Overall Satisfaction**

Altogether, we wanted to know if people's experiences of using EOL care was made easier with the support provided and whether people were signposted to different services. The feedback was mainly positive and negative feedback mostly related to specific services and professionals. Respondents who had a positive experience did not offer much detail other than stating how happy they were with the service. Additionally, some respondents stated how helpful carers were when looking after their relative at home and others explained how being signposted to services helped them access benefits their relative was entitled to.

Respondents' comments:

- *"Was I happy with her end of care treatment, the answer is a resounding yes."*
- *"100% happy."*
- *"Yes."*
- *"I could not have wished for a more perfect end of life care for my father, and I know that he would have agreed."*
- *"Really satisfied."*
- *"We mainly cared for him at home, but the support from carers helped and was really good."*
- *"We were signposted to Asbestos West Midlands, they sorted benefits/compensation from the Navy because he was in the Navy and was entitled to industrial injury benefit. Organisation was very helpful."*

Respondents overall experiences were affected negatively either because of one significant event involving a specific service or professional or they were not fully supported throughout their journey. Furthermore, respondents felt whilst in A&E they were not supported appropriately because of the environment, lack of staff and poor communication. They were placed within a corridor for a considerable amount of time, information communicated between staff was not passed onto the relatives correctly and left patient/relative(s) misinformed. Also, some respondents were not signposted to services by professionals and had to self-refer. Additionally, one respondent stated how considerate it would have been to receive a call from a competent person. This demonstrates that for some, people feel supported and not forgotten about when they are contacted by someone who checks in on their welfare occasionally, this could be vital to those who do not have support available close by.

Respondents' comment:

- *“The worst months of my life through sheer frustration...we had no support, no help, not even an hours break and my mom deserved more.”*
- *“We did make a complaint with the hospital and WMAS because; Hospital staff were under pressure due to demand, so care was good but it could have been better...we were placed in the corridor for a long time, test results differed from hospital compared to what the GP told us, information on discharge was discussed with the GP and not mom and family, a risk assessment was done by agency staff but we were not informed and whilst waiting for an ambulance on two separate occasions - both took a long time to arrive, therefore more staff need to be on duty so they could spend more time with us and more ambulances need to be available.”*
- *“Only signposted to Macmillan but I was aware of some support groups now after I went online to find out myself. If there is information, I wasn't given it.”*
- *“It would have been nice to have a fortnightly call, it doesn't have to be from a Doctor as long as they are clinically competent.”*

Overall, the feedback has been positive and shows how effective signposting can assist people to access benefits and services. However, it was recognised that due to the pressures in hospital this will affect the quality of service you receive. There are information and communication failures from services and professionals.

To conclude, looking at the emerging themes (Communication, Staff Attitude, Out-Of-Hours Service, Overall Experience) most of the feedback we received was from Communication and Staff Attitude. Whilst we received a huge amount of positive comments from respondents, improvements were still identified regarding GP Practices and their staff. Mixed responses regarding Out-Of-Hours Service have highlighted areas of improvement from certain services in terms of offering support for both patients/relatives and professionals and implementing better communication from services to front line staff. Finally, mixed responses for Overall Experience has shown that whilst many respondents are happy with the service and support they have been provided with, there are still areas that require improvements. Therefore, the feedback has captured the views and experiences of residents within T&W who have used EOL care services, and highlighted issues that require improvements.

## Case Studies:

Professionals play a vital role in the delivery of EOL care and providing effective support to patients and relatives at this crucial time. We spoke to one professional and asked them questions regarding how well communication is between staff, volunteers and patients/relatives. We also wanted to know whether they provided information and signposting and how well they collaborate with Shropdoc, Doctors and Outreach Teams. They discussed and highlighted the importance of communication between staff and volunteers in ensuring patients/relatives remained well informed. Additionally, the working relationship between staff and volunteers is vital to everything they do and what they want to achieve in delivering effective care. Language is tailored to the individual with a sensitive approach, offering the opportunity for patients/relatives to reflect and clarify what has been discussed. Overall, this is a very person-centred approach to EOL care.

### Case Study 1;

*“To communicate with patients we use different methods, this includes boards, writing and speaking with the family, they are very important and are usually present at the first visit for the Assessment Programme. We always make sure relatives and the patient understand what we have discussed. The language used is ‘reflective’ so relatives reflect back to us what has been said and we can clarify any queries. Our staff are brilliant and work well together with the volunteers. The volunteers are diamonds.*

*We only operate Monday-Friday 9am-5pm and therefore we have to signpost people to the out of hours service. This includes GP’s, Shropdoc, outreach Nurses who provide support on a weekend but must be put in place on a Friday. We also have ‘Hospice at Home’ but this is for patients who are terminally ill and this provides cover for bank holidays. Age UK also offer advice and come to us with a stall.”*



Language barriers can affect people accessing services, making it particularly difficult if English is not their first language. We spoke to one respondent who encountered issues with communication and staff attitude, as well as language problems, whilst supporting an individual and their family. Not only did this impact the patient's experience whilst in acute care, this also influenced relatives' views on community-based care; making the overall EOL care experience incredibly hard.

### Case Study 2;

*"The communication was the biggest let down during the whole EOL experience. Their wishes in regards to wanting to die out of hospital was listened to. For me, I am aware of language barriers but I wasn't expecting the process to be as difficult as it was. For the person/family, luckily I was around during the EOL time so I could translate a lot and explain to the person and their family; if it wasn't for me this would have been difficult. Whilst staying in the hospital, the person felt they weren't supported (by Nurses) as they would just stand and watch him be sick, he wouldn't be able to know if they were compassionate as he couldn't speak their language - physically I don't think he thought they were sympathetic.*

*Once he passed the family contacted me and asked if I could call Shropdoc to confirm his death. The process to ask for a clinician was ever so difficult, they wanted to speak to the family not me although they couldn't speak English which caused a delay when finding an interpreter on their end. Then it was a further 1 hour wait for a clinician to come out. Again, luckily I was there (voluntarily) to be able to translate to the family what the coroner was doing...A further 3 hour wait then for the coroner. During his terminal diagnosis he became homeless, this was a difficult time as there was very little support out there from Wrekin Housing. He needed supporting to find a place to live whilst going through treatment.*

*The overall experience could have been made easier if the language barrier was not there. District Nurses were brilliant, however there was no polish nurses, I felt lots of pressure was on me throughout this poor man's EOL care. What are people experiences like if they don't have a 'me'?"*





Finally, we received feedback demonstrating failures in specific areas during one respondent's EOL journey with their relative. The main issue highlighted was the amount of time they spent waiting for services to provide support; hospital transfer, prescriptions and medication. The delay not only affected the patient but caused distress for relatives who had to chase professionals in order to obtain what should have already been provided at such a crucial time.

### Case Study 3;

*"The doctor said that dad would be looking to be transferred to Stoke and he was waiting on a neurologist to contact him. He did not tell us the reason for the transfer, my dad's wishes were to be at home which was recorded with the Hospice and we explained this to the Doctor but said we had to wait. Hours later we were still waiting, the Nurse said she would make enquiries to discharge dad (on discharge he was given anti sickness injection). My brother could not read the handwriting on the prescription so they refused to hand it over. The Hospice organised a prescription for slow release morphine tablets to be collected to which they had no record. In the end my brother went back to A&E and got it re-prescribed.*

*The hospice arranged for a Healthcare Assistant to stay overnight with us and dad was shouting 'help me' as he was in so much pain as he wasn't given anything other than IV paracetamol. She called Shropdoc who arrived nearly 3 hours later and gave dad injections of diamorphine, anti-sickness and water. She then called the Shropdoc back and gave dad injections of diamorphine, anti-sickness and anxiety. He then wrote a referral for the District Nurse to set up a syringe driver which they did the following day but there was such a long period where dad had no pain relief. A District Nurse calls for prescription and we were told to collect it at 5pm. Numerous times medication was missing from the pharmacy.*

*I just want to put this forward as feedback as I feel in the short few weeks we had dealings that there was a number of errors/mishaps that made a difficult and traumatic time even worse and that sometimes advice was not given readily. We had not experienced this before and everything moved so quickly."*



To conclude, looking at these case studies they provided an insight into individuals' experiences and perspectives on EOL care. They highlighted where the service was doing well, whilst emphasising the vital role professionals played in delivering EOL care; by implementing effective communicating and having a person-centred approach. Additionally, we identified recommended improvements; an awareness of language barriers and the importance of effective time management, which could jointly affect patients' and relatives overall outlook on EOL care.



## Future Considerations

After evaluating our feedback, it is clear to see that there are certain areas which could be improved within the service. Therefore, we have provided future recommendations based on what people have told us:



- Services need to communicate with each other better, so people do not get forgotten about and to ensure they are provided with the correct support, this includes medication, personal care and equipment.
- For patient/relative(s) who experience language barriers, it would be good if (within Acute Care as well) access to an interpreter/translator was made easier and more readily available. This would reduce stress for everyone involved and people would be able to communicate effectively and be able to obtain support/care.
- Doctors need to provide continuity of care with EOL patients and relatives to eliminate stress/upset. Being able to access the same Doctor benefits patients/relatives mentally and emotionally because they do not have to keep explaining their situation to someone new every time and this can be draining and upsetting for them.
- When patients/relatives come to professionals they expect to be supported and spoken to politely, therefore, staff need to be mindful of their approach and attitude towards patients/relatives.
- Doctors assessing/treating EOL patients need to consider their approach, by looking at them holistically they can act in the patients' best interests whilst giving due consideration to their current circumstances.
- A significant increase in ambulance availability is required, in order to address rising levels of need and regular lengthy delays; in the provision of patient transportation within the T&W community.
- More front-line staff are required within acute care, particularly within A&E.
- A weekly/fortnightly welfare check by telephone would benefit patients to help with social isolation and their wellbeing. This would assist in their continuity of care (particularly for those who do not have family support).
- Services and professionals need to ensure they provide patients and relatives with information from the beginning and throughout their EOL care, including signposting people to charities/organisations.

## Acknowledgments

Healthwatch Telford and Wrekin would like to thank the following people and organisations, without whom this survey would not have been possible;

- ❖ Healthwatch Telford and Wrekin staff & volunteers
- ❖ Maninplace
- ❖ Severn Hospice (Telford)
- ❖ Individuals who provided us with case studies

This research showed that people who have used EOL services within T&W experienced a lack of effective communication in all areas between professionals, services and patients/relatives.

This provided the indicator that 'communication' is a key enabler for this service to function. It also identified that the professionals who made the biggest impact in terms of care/treatment were; Health Visitors, Nurse Co-ordinators, Carers and Nurses.

Total Summary of Engagement

Engagement	Type of activity	Number of people
Severn Hospice (Telford)	Coffee morning	2
1:1	Email	4
1:1	Home/organisation visit	3
1:1	Office based	5
		<b>Total: 14</b>

## References

- Ellershaw, J., Foster, A., Murphy, D., Shea, T., & Overill, S. (1997). *Developing an Integrated Care Pathway for the Dying Patient*. *European Journal of Palliative Care*, 4: 203-207.
- Shropshirecommunityhealth.nhs.uk (2017). Accessed on 14/10/19 <http://www.shropscommunityhealth.nhs.uk/content/doclib/12917.pdf>
- Leadership Alliance for the Care of Dying People: One Chance to Get it Right (2014). Accessed on 08/10/19 [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/323188/One\\_chance\\_to\\_get\\_it\\_right.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf)
- Molineux, C. (2017-2020). *Palliative and End of Life Care in the Last Years of Life*. A Strategy for Adults. Pg.9.
- Williams, L. (2013). *More Care, Less Pathway A Review of The Liverpool Care Pathway*. Independent Review of the Liverpool Care Pathway.
- WHO, (2007). WHO Definition of Palliative Care. World Health Organisation. Accessed on 14/10/19 <http://www.who.int/cancer/palliative/definition/en>

## Service Provider Responses

This report was shared with the following organisations for comment:

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

### Shrewsbury and Telford Hospital NHS Trust

The Clinical Lead for End of Life Care stated:

“On behalf of the End of Life and Palliative Care team at the Shrewsbury and Telford Hospitals NHS Trust 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.

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. Communication remains absolutely key - not just between patients, families and professionals, but also inter-professional communication which is made more difficult by the lack of shared records.

Your report also mentions the hospital environment - patients and families do have to wait longer than we would like on corridors and in assessment areas and this is particularly distressing towards the end of life. We have made some great improvements, particularly with the introduction of Swan Rooms across the Trust - we now have 23 in total, but not enough to ensure that all patients who die in our hospitals have access to them. These pressures are reflected in our own survey responses, but the vast majority of feedback is positive. We are proud of, and grateful to, our frontline staff who deliver compassionate end of life care every day under challenging conditions.”

### Telford and Wrekin Clinical Commissioning Group

Senior Quality Lead for Care Homes working across NHS Shropshire and NHS Telford and Wrekin CCGs stated:

“Thank you for sharing the Healthwatch End of Life and Palliative Care Services Report with us. This is really useful feedback for us to use to improve the care of people at the end of life and in receipt of palliative care.

The comments and issues that have been raised in the report clearly identify a concise range of actions that should be addressed. Although looking at some different services, the report concurs well with content from the Shropshire Healthwatch end of life report, and together they will inform where action needs to be applied.

We have already made contact with NHS111 and WMAS to discuss the difficulties ensuring that the correct information is communicated and received by services.

I will share this draft report with colleagues, and we will start to identify local targeted action to address the issues you identify.”

Shropshire Community Health Trust  
Jan Ditheridge, Chief Executive stated:

“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.”

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