



Thank you for coming to this event

Please let everyone know you are here by posting on social media using

#HWSOneChance





One chance

Conversations and information about
death and dying

healthwatch
Shropshire



Welcome

Lynn Cawley - Chief Officer

healthwatch
Shropshire

Today

Time	
1.30pm	Introduction – The work of Healthwatch Shropshire
1.40pm	Short Film – ‘Dying is not as bad as you think’
1.45pm	Panel discussion
2.35pm	Presentation 1: Advance Care Planning
2.50pm	<i>Refreshment break and marketplace</i>
3.20pm	Presentation 2: Considering faith and culture
3.35pm	Presentation 3: The End of Life Strategy
3.50pm	<i>Marketplace</i>
4.15pm	Panel Q&A
4.25pm	Closing remarks
4.30pm	Close



Experiences of End of Life and
Palliative Care Services in
Shropshire
Engagement Report

Publication date:
14th January 2021



Experiences of out of hours
Palliative Care in Shropshire,
Telford & Wrekin
Survey Report

Engagement period:
July - November 2020

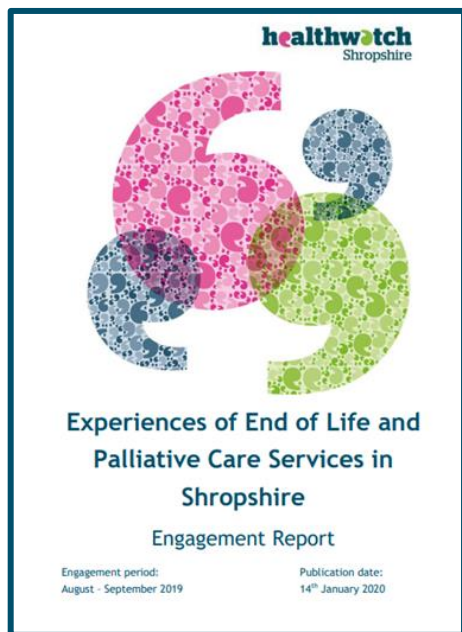
Publication date:
21 January 2021

Introduction

The work of Healthwatch Shropshire to gather people's experiences of end of life care

healthwatch
Shropshire

Why end of life?



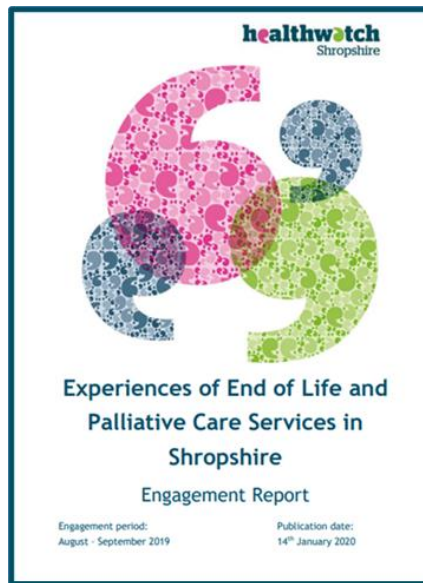
Many people prefer to die at home or in the place they call home (including Nursing and Care Homes) and while Public Health Figures for 2017 showed that a higher number of people died in Care Homes than the national average, fewer people were dying in their own home and the majority of people continued 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%.

We were concerned that the impact of not being identified as needing palliative care or end of life support would be that people may not have access to the services and the support they needed in a timely way or have the opportunity to discuss their wishes around their end of life care and treatment.

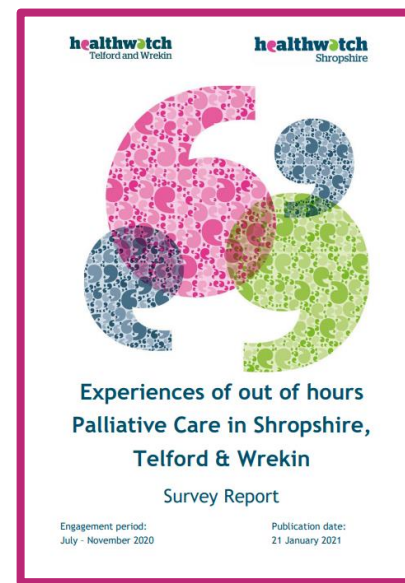
Our work

When? August – November 2019



33 patient and family experiences of care

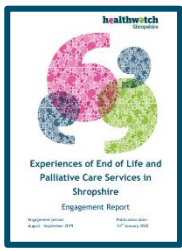
When? July – November 2020



27 people, including 10 people receiving services or their friends/family, shared a total of 51 experiences

[Healthwatch Shropshire End of Life Report 2019 \(Updated 20190129\).pdf](#)

[HWS & HWTW OoHPC survey report.pdf \(healthwatchshropshire.co.uk\)](#)




Key findings

Importance of identification


- Some people described a lack of acknowledgement that their relative required palliative care/was at end of life impacting on the type of care and level of support received.
- A theme apparent from the feedback was that once it was acknowledged by staff that the patient was in need of end of life care the patient's/family's experience was 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.

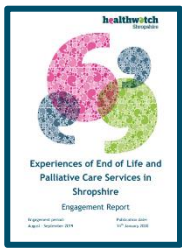
Our recommendation

- *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.*



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. [Staff] told her [daughter] 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]





Key findings

Communication

- The majority of negative experiences were around communication and information, treatment and continuity of care.
- The lack of good communication or timely, relevant and accessible information was raised in 30% of experiences.

Quality of services

- The experiences where the majority of the feedback were 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.

Our recommendations

- *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.*

6

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.

Member of the public whose parents died within 8 months of each other at the Royal Shrewsbury Hospital

9

6

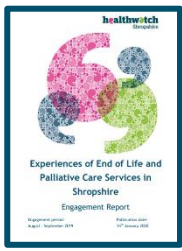
The care and compassion at the hospice were tremendous, I cannot praise them enough, the family was involved, respected and cared for. You could literally feel the love. The patient was happy there, he was kept calm and pain free until the end.



6

She was at home for nine days before she collapsed and was admitted to [a] nursing home where she died a few days later, a mere three months after the diagnosis. The care she received at [the home] was exemplary, as was the support provided to us.

9



Key findings

Medication

- Three families who were using end of life services in the community reported experiencing problems getting the correct medication for their relative.

Environment

- Four families had negative experiences of the rooms and facilities available in hospital at the end of life.

Continuity of staff

- Several comments raised the unsettling effect of a lack of regular care staff on patients at the end of life.

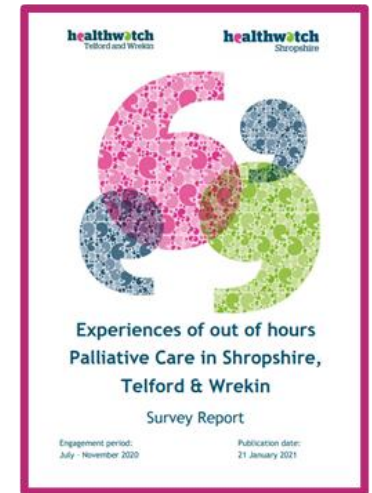
Our recommendations

- *Work be done with pharmacies to improve the experience of patients in need of medication so family members /carers can get what they need when they need it, including at night and over the weekend.*
- *Consideration be given to further increasing the number of Swan Rooms and generally improving facilities for people who are at end of life across the hospital (SaTH).*

What did we do next?

We:

- Conducted a follow-up piece of work with Healthwatch Telford & Wrekin to find out people's experience of accessing support out-of-hours provided by the ShropDoc Palliative Care Helpline and NHS 111
- 100% of Patients, carers and professionals rated their experience of contacting ShropDoc as 'excellent' or 'good'
- Shared the findings and recommendations of both reports with ST&W CCG so that the voices of patients, families and carers could be included in their End of Life Care Review and inform the End of Life Strategy
- Attended the three working groups set up as part of the Review to continue to represent the patient voice, including 'Growing the conversation'





Let's start the
conversation

healthwatch
Shropshire

'Dying is not as bad as you think' | BBC Ideas



Panel Chair: Professor Derek Willis

The panel	Position
Dr Ian Chan	Medical Director, TELDOC and Place Based Care Clinical Lead for Shropshire Telford & Wrekin Clinical Commissioning Group
Claire Childs	Manager, Innage Grange (Coverage Care)
Dr Julia Head	Senior Clinical Fellow, Severn Hospice
Dr Gail Nandhra	Specialty Doctor in Advance Care Planning ACP in Care Homes Team/ Royal Shrewsbury Hospital
Bishop Les Pointer	Representative from The Church of Jesus Christ of Latter-day Saints , and member of the Telford and Wrekin Interfaith Council
Dr Karen Stringer	GP and Associate Medical Director (Strategy), Shropshire Community Health NHS Trust
Professor Derek Willis	Medical Director, Severn Hospice

Advance Care Planning

**Dr Gail Nandhra – Specialty Doctor in Advance Care Planning
(Shrewsbury & Telford Hospital Trust)**

**Sarah Venn – Clinical Lead Advance Care Planning in Care Home
Team (Shropshire Community Health Trust)**

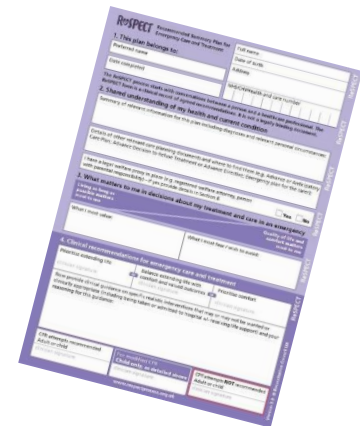
What is 'Advance Care Planning'?

In life we prepare for many things – birth, education, marriage and retirement.

Advance care planning is an opportunity to plan for future care and support, including medical treatment, while that person has the capacity to do so.

It sets out their values, wishes, beliefs and preferences about their future care, including medical treatment, and where they would like to be cared for should they become unwell.

It includes a **ReSPECT** document which is a Recommended Summary Plan for Emergency Care and Treatment. This document lets health professionals know, in an emergency, their wishes such as whether they would wish to be taken to hospital, and decisions regarding resuscitation.



Why is it important?

Planning for future care is an empowering act that allows that person to feel confident that their wishes will be considered if they are ever unable to fully participate in decision making.

Make it more likely that someone's wishes are known and carried out – for example, they may be more likely to die in their preferred place of death and improve the quality of end-of-life care that someone receives.

By having good quality conversations about future treatment, that person will have a greater sense of control over their ability to live and die well.

It can help us, as health care professionals caring for that person, and to meet their wishes and preferences. **Advance Care Planning is for everyone.**



What difference does it make?

Having these conversations with health professionals and loved ones early and having them documented in the form of a care plan ensures that everyone who has been part of the discussions know what kind of care you would like to receive if you become unwell.

It can benefit you by strengthening personal relationships and relieving anxiety and the burden of decision making that loved ones may experience.

Overall, this can result in people feeling more hopeful that they can live well and die well.



6 Violet's Story



- Violet is 95 years old
- Lives in a Residential care home
- Has a history of advanced Dementia and Heart Failure
- Attended A&E for a chest infection and reduced appetite
- Being in the busy A&E environment caused Violet Anxiety and further confusion
- Violet and her family became distressed
- Discussed with A&E doctors and nurses, Violet to return home with antibiotics
- Arranged to meet with Violet and her family the following day at the care home
- Respect and Advance care plan completed
- Violet's preferences and wishes were shared with her GP and the care home
- Violet recovered from her chest infection



A woman with long red hair and black-rimmed glasses is looking towards the camera. She is wearing a maroon top and a pink lanyard with a white logo. In the background, a man with dark hair and glasses is seen from the side, wearing a dark blue jacket. The setting appears to be an indoor event with purple and blue lighting.

Refreshments and Market Place

#HWSOneChance

Back for 3.20pm

Today

Time	
1.30pm	Introduction – The work of Healthwatch Shropshire
1.40pm	Short Film – ‘Dying is not as bad as you think’
1.45pm	Panel discussion
2.35pm	Presentation 1: Advance Care Planning
2.50pm	<i>Refreshment break and marketplace</i>
3.20pm	Presentation 2: Considering faith and culture
3.35pm	Presentation 3: The End of Life Strategy
3.50pm	Marketplace
4.15pm	Panel Q&A
4.25pm	Closing remarks
4.30pm	Close

Faith and culture

Bishop Les Pointer (The Church of Jesus Christ of Latter-day Saints -
Telford Ward and The Interfaith Forum)

Why it is important to consider people's faith and culture at end of life

A person's cultural, spiritual, or religious beliefs are often integral in how they and their family understand death and cope with it. People who have a strong religious faith are often comforted by the idea that a higher power is present in their lives. This faith can help them cope with loss and suffering.

2019 ONS Statistics:

- 84.8% of the population identify as White, the remaining 15.2% identified as Black, Asian, Mixed, or Other Ethnicity. Those identifying as White will also include many people and families from Europe and further afield.
- 51% of the population identify as Christian, Muslim (5.7%), Hindu (1.7%), Sikh, Jewish, Buddhist, "Other religions not identified" (3.2%). With 38.4% stating that they have no religion.
- Faith affiliation is greatest in those over 60 years old (over 65%)

Everyone deserves a high level of respect, dignity, and empathy during the last days/weeks/months of their lives. Gaining an understanding of a person's culture or faith goes a long way in showing the above attributes to the patient.

The impact of people's faith and culture on their experience at end of life

There are many cultural and religious traditions during end of life care for any given person.

These traditions even vary within the main religious groups (Judaism, Christianity, Islam, Hinduism, Sikhism, and Buddhism)

Cultural traditions can include dress, privacy requirements, decision making, visiting.

Faith traditions can include, prayers, scripture reading, dress, privacy, and face/body coverings.

To many, these traditions are a way for them to prepare for the afterlife (or the next stage in their existence). These traditions calm them, help them be at peace.

We all want the End of Life experience to be as peaceful as possible for the individual, and that doesn't just mean "pain free".

Being away from the home for many can also hinder some of these traditions and beliefs due to restrictions within Hospices and Hospitals (e.g. number of visitors, being in mixed wards, privacy/modesty for women).



Case study

During the Covid restrictions at the beginning of 2021 an elderly Female patient (86 years old) was placed in a care home for palliative care. As part of her religion she wore religious clothing, which were classed as sacred within her faith.

The care home in question allowed a family member to collect said clothing to wash at home rather than being washed with other residents clothes. The care home also allowed other religious practices to be carried out, including prayers and religious blessings. This was difficult due to the Covid restrictions in place, but the staff in question went above and beyond to get permission (with safety conditions in place) so that the patient could observe her religious beliefs.

She died within 8 days of being in the care home.





Case study

A minister of religion was refused access to a Ward to give 'Last Rites' as part of their own religious beliefs to a female member of their congregation, who was blind and did not have long to live.

Thankfully the minister stood their ground and escalated the issue as high up the chain as they could within the hospital and was able to minister to the lady in question.

This caused distress for the minister, the family, and the individual in question as it was unclear how long the patient would be conscious and able to understand.

The lady died the next day.





Case study

A relatively common occurrence within the Muslim community is that females who have observed religious modesty their entire lives (including the wearing of the hijab) find it difficult to be able to continue this practice in hospital during end of life care.



Shropshire Telford and Wrekin Palliative and End of Life Care Strategy (Adults) 2022 - 2025

**Alison Massey - Interim Transformation and System Commissioning
Partner – Community (Shropshire, Telford and Wrekin CCG)**

Why did we develop this strategy?

- The new Integrated Care System gave the opportunity for health and care organisations to work collaboratively with people with lived experience and other organisations including Healthwatch, to develop a model of care to ensure that people, their family and carers have access to the right care at the right time in the care setting that meets their needs.
- As a response to the concerns that were raised by people with lived experience and following reports such as those from Healthwatch Shropshire
- To ensure that the recommendations following the review of End of Life care are implemented to include;
 - An End of Life Care Coordinator as a key role
 - 24/7 access to advice and guidance for people and their families/carers
 - To have a workforce with the knowledge skills and confidence to care for people in the last year of life
 - To work with communities to encourage more conversations about death and dying

National Palliative and End of Life Care Framework

Foundations

Personalised care planning	Shared records
Education and training	24/7 access
Evidence and information	Involving, supporting and caring for those important to the dying person
Co-design	Leadership

Ambitions

- 01 Each person is seen as an individual
- 02 Each person gets fair access to care
- 03 Maximising comfort and wellbeing
- 04 Care is coordinated
- 05 All staff are prepared to care
- 06 Each community is prepared to help

Shropshire Telford and Wrekin Model for Palliative and End of Life Care

Working with the person their families, loved ones and health and care workers to offer holistic assessment and specialist advice, comfort and support

Specialist Palliative Care

Wrapped around localities to offer an enhanced level of support for those with more complex needs or circumstances

Enhanced Support Services

Health and care services work with local communities to enable care needs to be met. One assessment, one care plan, one identified care coordinator

Localities

The person at the centre, supported to stay as well as possible as long as possible and to die with dignity in a place of their choosing

Person
Their family
and loved ones

How will the strategy improve people's experiences at end of life?

Our Aims:


To build on what we have to improve the experience and care for people that are in the last year of life, their families and loved ones.

To enable:

- People in the last year of life to be systematically identified and offered an assessment and advance care plan
- All people on an End of Life care register will have an identified coordinator
- Everyone will have access to the care they need at any time of the day
- People their families and loved ones will have access to 24/7 advice and guidance

How will the strategy improve people's experiences at end of life?

- A workforce with the knowledge skills and confidence to deliver compassionate care
- Address inequalities to ensure that access to care is available to all
- Localities working together for people, their families and loved ones
- An enhanced service to provide an additional level of care for those with more complex needs
- Digital enhancement to support electronic shared care records, centralised information to support care delivery and monitor progress
- Palliative and end of life care is seen as everyone's responsibility
- Offer support for families and loved ones in the care of someone that is dying and after their death




Working on the End of Life strategy has been incredibly rewarding. As an expert by experience I have been listened to, involved and I have contributed to the new Standards for End Of Life care.

I just hope my small involvement will have helped towards a move of openness in the conversations about End-of-Life choices; this should be integral and very natural to all our thoughts as a society.

Throughout the project I felt comfortable in putting forward comments and suggestions and was happy to get involved with tasks.

I volunteered to participate in this project not really sure how, as a member of the public, I could make a difference. I was quickly welcomed into the group which consisted of people with a great deal of experience of End of Life services.



6

Any questions?





A Nurse's Reflections

"How do you do the job that you do?
Don't you get strung out and stressed?
Surely caring for folk who are critically ill
Must make you so very depressed."

"Oh no!" I reply, "it's a wonderful chance
To make someone's last wishes come true.
If all that's required to make staying at home
A real proposition is YOU!"

To watch someone nursed with genuine love,
To enable a family to care,
To be able to help with hands-on support
Is a privilege only too rare.

Fran Robinson (2002)
Healthwatch Shropshire Volunteer

Market Place
Back for 4.15pm

Today

Time	
1.30pm	Introduction – The work of Healthwatch Shropshire
1.40pm	Short Film – ‘Dying is not as bad as you think’
1.45pm	Panel discussion
2.35pm	Presentation 1: Advance Care Planning
2.50pm	<i>Refreshment break and marketplace</i>
3.20pm	Presentation 2: Considering faith and culture
3.35pm	Presentation 3: The End of Life Strategy
3.50pm	<i>Marketplace</i>
4.15pm	Panel Q&A
4.25pm	Closing remarks
4.30pm	Close

Final questions for the panel

The panel	Position
Dr Ian Chan	Medical Director, TELDOC and Place Based Care Clinical Lead for Shropshire Telford & Wrekin Clinical Commissioning Group
Claire Childs	Manager, Innage Grange (Coverage Care)
Dr Julia Head	Senior Clinical Fellow, Severn Hospice
Dr Gail Nandhra	Specialty Doctor in Advance Care Planning ACP in Care Homes Team/ Royal Shrewsbury Hospital
Bishop Les Pointer	Representative of Interfaith Forum
Dr Karen Stringer	GP and Associate Medical Director (Strategy), Shropshire Community Health NHS Trust
Professor Derek Willis	Medical Director, Severn Hospice



Experiences of End of Life and
Palliative Care Services in
Shropshire
Engagement Report

Publication date:
14th January 2021



Experiences of out of hours
Palliative Care in Shropshire,
Telford & Wrekin
Survey Report

Engagement period:
July - November 2020

Publication date:
21 January 2021

Closing remarks

Vanessa Barrett – Chair of Healthwatch
Shropshire

healthwatch
Shropshire

For more information

Healthwatch Shropshire

4 The Creative Quarter

Shrewsbury Business Park

Shrewsbury

Shropshire, SY2 6LG

www.healthwatchshropshire.co.uk

t: 01743 237884

e: enquiries@healthwatchshropshire.co.uk

 [@HWSShropshire](https://twitter.com/HWSShropshire)

 facebook.com/HealthwatchShropshire

**Thank you for joining us today, please
share your feedback**

healthwatch