**Walsall End of Life Patient Experience**

**Patient, Carer, and Family Engagement (others identified as important to you)**

**“How we care for the dying is an indicator of how we care for all sick and vulnerable people***”*

(National End of Life Care Strategy 2008)

Death and dying are inevitable. The quality and accessibility of this care will

affect all of us and it must be made consistently better for all of us.

Walsall has a developed End of Life Strategy 2018 – 2023. Underpinning principles for the Strategic Goals identified within the Strategy are:

* It applies to wherever the patient and carer are receiving care.
* Unless otherwise stated all references are to people who are in the last year of life.
* The actions apply to all people regardless of diagnosis and cultural background.
* The strategy applies to all partnership organisations in Walsall and is inclusive of the broad Voluntary and Community Sector that exist as means of support.
* Responsibilities in all actions apply to both patients and carers.

Progress has been made in the last five years with Palliative and End of Life Care within the Borough. The principle for this strategy is that we continue to focus on previous priorities but now identify key strategic objectives which will deliver greater continuity, response and improved communication for patients, carers and professionals.

The emphasis of the Walsall End of Life Strategy is on local decision-making and delivery, core to its centre is the needs of people of all ages who are living with dying, death and bereavement, their families, carers and communities which must be addressed, taking into account their priorities, preferences and wishes.

Taking this into account as part of the end-of-life strategy engagement with patients and those identified as important to them is an essential part of the end-of-life strategy.

**Walsall Together**

Healthwatch Walsall have been commissioned through Walsall Together to capture experiences of care pathways around 6 key Lines of Enquiry:

* Diabetes
* Respiratory Illness
* Cardiology
* Mental Health
* End of Life & Palliative Care
* The best start in life, early child.

As part of this engagement work it has been agreed that Healthwatch Walsall under the commissioned programme will work in conjunction with Walsall CCG to plan and deliver the patient and (those close to them) engagement work.

**End of Life Strategy Key Priorities**

There are 5 key priorities identified within the end-of-life strategy. These priorities are to be used as part of the engagement with those who are important to the patient.

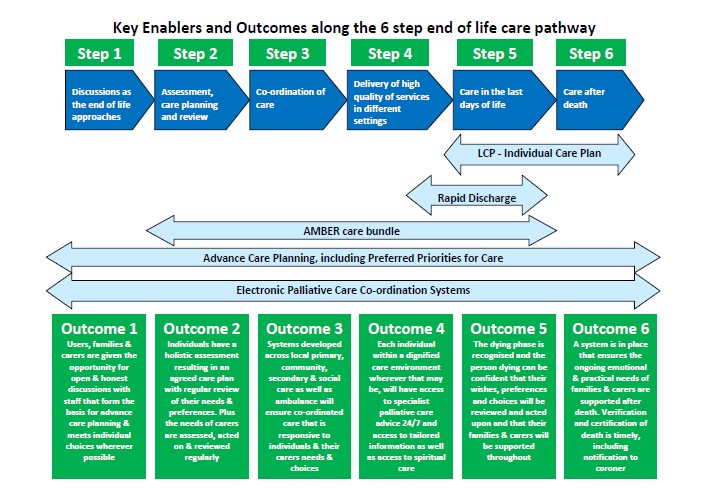
1. **Recognise**  
   The possibility that a person may die within the next few months, days, hours are recognised and communicated clearly, decisions make, and actions taken in accordance with the persons needs and wishes, these are reviewed regularly, and decisions revised accordingly.
2. **Communicate**Clear and sensitive communication needs to take place between the person who is dying and those identified as important to them.

This includes identifying the extent of the persons need for information and allowing them to decline discussion regarding that possibility that they may be dying.

1. **Involve**The dying person and those identifying as important to them are involved in decisions about treatment and care to the extent that they dying person wishes.
2. **Support**The needs of family and others identified as important to the dying person are actively explored, respected and met as far as possible.
3. **Plan & Do**An individual’s plan of care is agreed, coordinated and delivered with compassion (including food and drink, symptom control, psychological, social and spiritual support.

**Stages of the Care Pathway**

These aspects detailed below should guide the patient care pathway.



**Voices Questionnaire**

There is a national and abbreviated local question capturing the views from those who are important to the patient in relation to their end-of-life care pathway. This is a more in-depth tool used to capture experiences. Whilst it is recognised that the Voices questionnaire is used and recognised nationally and locally as an important element within the end-of-life strategy, in relation to engagement, we are looking at widening the engagement through:

An agreed approach to engage with patients / those important to them through:

* One to one telephone conversations
* Focus Groups
* Surveys

Through these mechanisms our aim is to capture qualitative data from participants.

**Target Audiences**

We will as part of the engagement define our target audiences:

Carers  
Family Members  
Those who are important to the patient.

As part of our engagement, we must also recognise the demographics of Walsall in relation to ethnicity. We will be working with local communities and voluntary groups, community leaders and member within BAME communities in relation to engagement around end of life.

**For Consideration**There are current mechanism for feedback on experiences such as through:

* Walsall Healthcare NHS Trust PALS, Patient Relations Team.
* Staff, patients and loved ones through Goscote Palliative Care Centre.
* St Giles Hospice.
* Walsall Healthcare NHS Trust Bereavement Team.

**Next Steps**

We endeavor to be clear with participants on the rationale for capturing experiences, but most importantly that the aim of the intelligence is to improve patient experience.

We will need to consider whether the intelligence around care experiences from other sources will be incorporated into this engagement work as part of the wider end of life strategy.

We would anticipate that providers at acute, community, primary care levels, hospice, would support us with the promotion of engagement opportunities. The support from the community and voluntary sector is also recognised as a crucial part of this engagement.

Rationale – This Questionnaire has been intentionally kept short due to the sensitive nature of the subject with open text boxes for the participant or engagement person to free type experiences.

**Draft - End of Life Experience Questionnaire**

***Context – Narrative Front Page to be agreed (webpage / newsletter)***

**Note: summary headings and monitoring questions to be fully completed on Survey Monkey / SNAP (other virtual system).**

We would very much like to learn about your experiences of End of Life or palliative care services. Our aim is for all Adults**,** Children and Young People at End of Life to be supported to achieve their ambitions as identified through the care planning process**.**

This questionnaire relates to any experiences in the last 18 months both before and during the Coronavirus pandemic.

This listening exercise will run for (fill in dates/weeks) and close on …….. 21.

We greatly appreciate you taking time to help us monitor and improve our care for End-of-Life services in Walsall.

**1.About you:**

Are you a carer / family member / other relationship to patient [multiple choice question]?

Other (please advise) – [Free text box]

**2. About the Care Received**

**2a**.

Was the care of the patient received at   
home  
hospital   
hospice   
Other location? Please advise [free text box]   
Please advise name of hospital or hospice. [free text box]

**2b.**

**Where did your loved one (close to you) pass away?**

At individual home  
Residential or Care Home  
Hospice  
Hospital

**3. Care Plans for Patients**

Were you or your family advised by medical staff that the patient was dying, given the opportunity to talk about a Care Plan with the patient and what were their wishes?

Yes / No

Can you please explain why you have answered Yes or No to the previous question? [free text box]

**What is an End-of-Life Care Plan?**

An individual’s plan of care is agreed with the patient / those close to the patient, coordinated and delivered with compassion (including food and drink, symptom control, psychological, social and spiritual support).

**End of life care** aims to support someone in the later stages of a life- limiting condition to live as well as possible until they die. It also aims to support family and carers during this time and after the person dies.

**4. What worked well / Could have been better?**

What went well or not so well? E.g., Medication / pain management, staff care, communication, between organisations, access to timely equipment etc.

[free text box]

1. **Additional Feedback**

Do you have any comments to help improve End of Life care or services in future? [free text box]

**Ethnicity Monitoring Questions**

Please could you advise the first 3 characters of your post code e.g., WS2?

Male / Female / Prefer not to say.

Age

Ethnic Origin

Religion

**For Discussion**

**Data Protection**

We would hope through numerous engagement mechanisms that we will capture in depth qualitative data. Whist we will not be sharing individual stories without permission it important that we protect the anonymity of participants. We would therefore be due to the sensitivity of the data that a GDPR and DPAI statement and control system for data.

**Timescales for Engagement**

The Walsall Together EOL Strategic Delivery Group to advise timescales for the engagement process. These will need to be considered in order to capture meaningful data and intelligence.

**Additional Resources**

We recognise that end of life is an emotive subject. Whilst capturing the views from participants we will need to be able to signpost to other professional with experiences in areas such as children, babies, as the participants may become distressed reliving their experience. Therefore, we would hope that in such circumstance professionals will support this work.