Shropshire Telford and Wrekin End of Life Care

Progress report

JHOSC

14th October 2021

Professor Derek Willis – Medical Director Severn Hospice/System End of Life Care Clinical Lead

Alison Massey – Lead Phase 2 End of Life Care Review/ System End of Life Care Commissioning Lead

Purpose of the report

1. To inform JHOSC of the ReSPECT process and the roll out in Shropshire Telford and Wrekin.

2. To inform JHOSC of the developments in Advance Care Planning for the region

3 To inform JHOSC of the progress to date of Phase 2 of the End of Life Care Review

ReSPECT
The Success

ReSPECT Recommended Summary Plan for Emergency Care and Treatment

1. This plan belongs to:

Preferred name

Date completed

Full name

Date of birth

Address

NHS/CHI/Health and care number

The ReSPECT process starts with conversations between a person and a healthcare professional. The ReSPECT form is a clinical record of agreed recommendations. It is not a legally binding document.

2. Shared understanding of my health and current condition

Summary of relevant information for this plan including diagnoses and relevant personal circumstances:

Details of other relevant care planning documents and where to find them (e.g. Advance or Anticipatory Care Plan; Advance Decision to Refuse Treatment or Advance Directive; Emergency plan for the carer):

I have a legal welfare proxy in place (e.g. registered welfare attorney, person with parental responsibility) - if yes provide details in Section 8 ☐ **Yes** ☐ **No**

3. What matters to me in decisions about my treatment and care in an emergency

Living as long as possible matters most to me — **Quality of life and comfort matters most to me**

What I most value:

What I most fear / wish to avoid:

4. Clinical recommendations for emergency care and treatment

Prioritise extending life	or	Balance extending life with comfort and valued outcomes	or	Prioritise comfort
clinician signature		clinician signature		clinician signature

Now provide clinical guidance on specific realistic interventions that may or may not be wanted or clinically appropriate (including being taken or admitted to hospital +/- receiving life support) and your reasoning for this guidance:

CPR attempts recommended Adult or child	For modified CPR **Child only, as detailed above**	CPR attempts **NOT** recommended Adult or child
clinician signature	clinician signature	clinician signature

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ReSPECT

The good

- Same in all organisations
- No duplication for patients
- Easy to spot

The not so good

- Its not an advance care plan
- It’s not complete it’s a summary

Advance Care Planning

Progress

- Written through committee
- Trialed in specific group
- Now rolled out county wide
- Review in a year

Why have an Advance Care Plan?

Reduce Uncertainty

Prevent Unwanted Treatment

Prevent Unwanted Hospital Admission

Determine Future Goals for End of Life

End of Life Care Review
Background

September 2020
End of Life Care identified as a system priority by Shropshire Telford and Wrekin Sustainability and Transformation Partnership.
Aim:- To understand how we can make impactful change on individuals experiences by learning from feedback and working together as a system

October 2020 – March 2021
Phase 1 review
Aims:-
Key Stakeholders reflect on the information held including feedback from people receiving services, their families, the public and staff to identify how care and experience can be improved
People with lived experience listening exercise.

Outcomes
Thematic review
Stakeholder feedback and Identification of 4 key priorities

End of Life Care Review Phase 2

Phase 1 of the review posed 4 priority questions that phase 2 was tasked to answer

1	How do we ensure that everyone knows how to access the information and support that enables individuals to have their symptoms managed at end of life and how can we ensure we are monitoring this is happening and provide support where it is not ?”
2	How do we support staff to better recognise EOL and engage in conversations about this with individuals?
3	How do we ensure that generalists i.e. non palliative care health and social care staff can access the level of information and support they need to deliver an improved experience of care for individuals at end of life?
4	How do we improve our approach to ensuring we are able to proactively identify anticipatory care needs?

Process and Governance

April – May 2021

Three stakeholder workshops arranged with the aims to gain a collective understanding of what the questions meant and what key actions could be progressed in order to answer the questions.

Three Task and Finish Groups established to be;

- Co-productive
- Collaborative
- Action focused

Governance arrangements are now within the Integrated Care System structure; the Task and Finish groups report progress to the System End of Life Steering Group and Shropshire and Telford and Wrekin Integrated Partnership Boards (SHIPP and TWIPP)

Process and Governance

Progress reporting arrangements

System End of Life Care Steering Group

Growing the conversations

Refreshing the pathway

Increasing the confidence and skills to work together to deliver great care

Task and Finish Groups

The questions we are tasked to answer

How do we ensure that everyone knows how to access the information and support that enables individuals to have their symptoms managed at end of life and how can we ensure we are monitoring this is happening and provide support where it is not ?

How do we support staff to better recognise EOL and engage in conversations with about this with individuals?

How do we ensure that generalists i.e. non palliative care health and social care staff can access the level of information and support they need to deliver an improved experience of care for individuals at end of life?

How do we improve our approach to ensuring we are able to proactively identify anticipatory care needs?

Refreshing the Pathway Key actions

1 **Develop standards of care to reflect each step of the pathway to be agreed by the system**

Produce guidance on how these standards can be met

Produce a self assessment framework for organisations/services to measure themselves against the standards

2. **Develop an approach to support better coordination of care**

End of Life Care Coordinator Role Descriptor and responsibilities

End of Life Care Coordinator competencies and skills

3. **24/7 advice line for patients and family/carers**

What is currently available?

Are there gaps?

Recommendations of how these gaps can be closed

4. **Primary Care Survey**

End of Life Care register

Advance Care Planning and ReSPECT

Multidisciplinary Team working

Increasing the confidence and skills to work together to deliver great care
Key actions

1. Develop a standard competency framework for all levels of the health and care workforce (inc volunteers)

2. Develop a standard approach to training that is role specific (inc volunteers)
    - To include a training needs analysis
    - To understand current training availability

Growing the conversation
Key actions

Working towards developing a suite of information and activities with the aim to support more conversations about death and dying

Aiming to have some outputs for

- Grief Awareness week December 2021
- Dying Matters week May 2022

Outputs to date and next steps

Task and Finish Group	Outputs	Next steps
Refreshing the Pathway	System Standards for the care of Adults at the end of life completed Self-assessment framework drafted Role of End of Life Care Coordinator Defined Scoping of 24/7 patient and carer advice and guidance line completed GP survey launched	Consultation and Launch of System Standards GP survey collation of information System recommendations
Increasing the confidence and skills	Competency framework drafted	Consultation and Launch Training needs and gap analysis System recommendations
Growing the Conversation	Plans for Grief awareness week completed Patient/carer related resource pack near competition	Grief awareness week 2 – 7th December 2 pubic facing sessions (virtual) 2 Shropshire radio slots Press releases drafted Learning from this week will inform developments for Dying Matters week in May 2022

Are we answering the questions identified in phase 1 of the review?

Question 1

How do we ensure that everyone knows how to access the information and support that enables individuals to have their symptoms managed at the end of life and how can we monitor this is happening and provide support where it is not?

Answer

The Standards for the Care of Adults at the End of Life make it clear that early identification (people that are in the last year of life), holistic assessment and care planning with regular reviews will ensure that health and care needs are anticipated in advance to enable proactive management of symptoms.

These standards include links to current guidance and information that is available to health and care professionals, people and their carers, to support care needs and access to further information

Key to this question is the role of the End of Life Care Coordinator who will have the responsibility to understand the needs of individuals and their families/carers and to ensure that these needs are met.

We will be making recommendations to the Integrated Care System that an advice and guidance line is made available for people and their carers, building on what is currently available out of hours to make this 24/7.

We have sought for assurance that when care has not been optimised, particularly if a persons symptoms are not managed, that there are processes in place to understand and learn from these cases, we are reassured that this does happen, however, we will make recommendations to the Integrated Care System that organisations/services should assesses themselves against the standards and develop actions plans for improvement if the standards are not met. This will enable a consistent approach to end of life care and support for those areas who are struggling to meet the standards.

We believe that having a competent and confident workforce will safeguard against poor care. A system wide End Of Life Care Competency Framework will make it clear of the level of knowledge and skills that is required in the care of people at the end of their life.

Are we answering the questions identified in phase 1 of the review?

Question 2

How do we support staff to better recognise end of life and engage in conversations about this with individuals

Answer

The End of Life Care Task and Finish groups viewed this question in two ways, firstly the support needed for staff and secondly how we might engage with our public and society to talk more openly about death and dying.

The End of Life Care Competency Framework will make it clear of the knowledge and skills required for the care of people at the end of life, this includes what level of training is required to support sensitive conversations. The framework also supports 'modelling the way' allowing staff or volunteers to work alongside those that have the required knowledge, skills and experience, to gain a better understanding of 'real life' situations and support learning and confidence.

The Standards of the Care of People at the End of Life supports the need to identify those people that may be expected to die within 12 months, the standards signposts professionals to a number of tools that can be used to support this decision making.

The Growing the Conversation Task and Finish Group have worked to develop a suite of information that relate to people having conversations about death and dying either within a more social situation (family and friends) or with health and care professionals. For Grief Awareness week (7th – 12th December) the group have arranged a number of events in support of people that are bereaved, the key messages for this week is how people can support each other when they have lost a person they love and, as a precursor to Dying Matters week in May 2022, how preparing for and talking about an expected death might better prepare people for the grief they will experience.

Are we answering the questions identified in phase 1 of the review?

Question 3

How do we ensure that generalist i.e. non palliative health and social care staff can access the level of information and support they need to deliver an improved experience of care for individuals at the end of life?

Answer

In a workshop prior to arranging the task and finish groups attendees recognised that this question was very closely linked to question 1. Attendees understood that for the majority end of life care is the remit of the generalist workforce who have access to specialist support for more complex situations.

The Standards for the Care of Adults at the End of Life reflects the nationally recognised end of life care pathway, the standards have details of how each step of the pathway can be delivered and the resources available to support this delivery.

The Competency Framework details the knowledge and skills needed for the care of people at the end of life and is intended for the generalist workforce with some additional competencies that are a requirement for professionals in a specialist role

Are we answering the questions identified in phase 1 of the review?

Question 4

How do we improve our approach to ensuring we are able to proactively identify anticipatory care needs?

Answer

Some of the members of the 'Refining the Pathway' Task and Finish group had been involved in the development of the system Advance Care Planning (ACP) Framework who were able to support other members in understanding the focus of advance care planning in recognising and planning anticipatory care needs.

The Standards for the Care of Adults at the End of Life use the principles of the ACP Framework to support earlier identification of people that are predicted to be in the last year of life, regular review of individuals will enable timely reassessment and anticipatory care planning.

In addition, having a system wide competency framework will enable increased and boarder capability of the workforce with the knowledge skills and confidence to complete Advance Care Plans, ReSPECT documents and when a person enters the last phase of life, an end of life care plan.

The End of Life Care Coordinator will have the responsibility of ensuring that individuals' care needs are reviewed and that there is coordination of care delivery.

The End of Life Care review, once the consultation process is completed, will be recommending to the ICS that both the Standards and the Competency Framework is adopted by all health and care organisations.

Learning

- There is a need ensure that information was available from colleagues outside of the Task and Finish groups to ensure that the work did not contradict existing policy and guidance
- Coproduction takes more time than a more traditional quality improvement approach
- Personal stories of group members allows for ‘reality checks’; time and sensitivity is needed for such an emotive subject
- There was a risk of duplication and cross over of the three groups – there was a need for all members to understand and be aware of what each groups was working towards and to keep going back to the original questions to reassure ourselves they were being answered
- A learning session has been arranged for all group members to come together to discuss the work that they have been developing with an aim to understand the experience and learn from it

The End of Life Care review is almost ready to launch a broader consultation process for the output of the work so far.

The first steps for the consultation and as part of the governance arrangements the work first needs to be presented to the End of Life Care Steering Group.

Once this is completed we would be happy to share the work with JHOSC as part of the consultation and for JHOSC to meet with some of the members of the Task and Finish Group who have an extraordinary amount of compassion and motivation to see this work through.