CHESHIRE EAST COUNCIL

Health and Wellbeing Board

Date of Meeting: 29th July 2014
Report of: The End of Life Partnership
Subject/Title: Introduction to the Care Plan for End of Life

1.0 Report Summary

1.1 In June 2014 the Leadership Alliance for the Care of the Dying person (LACD) produced **Five Priorities for the Care of the Dying Person**:

1. The possibility that the person may die within the next few days or hours is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.
2. Sensitive communication takes place between staff and the dying person, and those identified as important to them.
3. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
5. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion

The above priorities are intended to guide a more personalised approach to the care of the dying in contrast to more traditional approaches such as 'The Liverpool Care Pathway' which has received widespread media attention and criticism over the last few years largely due to its 'tick box' approach.

Individualised care planning during the last days and hours of life is of fundamental importance in order to meet the needs and preferences of a wide variety of people dying from a range of different conditions, and within a number of different care settings. These include people with conditions such as heart and respiratory diseases, dementia, cancer, neurological conditions and the frail elderly, who are being cared for in hospital, at home, within a hospice, or in a care home.

The Care Plan for End of Life, which is attached within **Appendix One,** is therefore presented as an example of an individualised care plan for end of life for use across the Cheshire East locality.

2.0 Recommendation

2.1 That the Health and Wellbeing Board consider the approach taken by the End of Life Partnership in developing, and implementing the Care Plan for End of Life as well as the plans being made to evaluate its effect in practice. That this approach is then endorsed as being supportive of the delivery of high quality and individualised care of the dying person and their family.

3.0 Reasons for Recommendations

3.1 To ensure local approaches to last days of life care are closely aligned to the **Five Priorities for the Care of the Dying Person** and that processes followed demonstrate appropriate levels of inclusivity and transparency.

4. Development of the Care Plan for End of Life

4.1 One of the key objectives of the End of Life Partnership is to coordinate a whole system approach to end of life care across Cheshire through promoting high quality care for the dying; regardless of disease type or place of care. In August 2013 a local group was formed to coordinate a locality response to the recommendations made within the Liverpool Care Pathway review with professional representation from organisations within the Eastern, South, and Vale Royal areas of Cheshire.

The group which was made up of 22 professionals and 1 member of the public, met between August and December 2013 to develop and to coordinate an action plan, and to agree a way forward in terms of supporting a more individualised approach to care of the dying across local organisations. In February 2014 a few of these group members were nominated to progress two key areas of work, this work resulted in:

1. The development of an Individualised Care Plan for End of Life
2. The development of Education and Training programmes and resources to support the use of the new care plan

A draft care plan was subsequently developed and informed by the recommendations made within the LCP review, alongside interim guidance provided by the LACD. This draft care plan was then made available for a consultation period of 3 weeks (1st April – 23rd April 2014) to local professionals, carers, members of the public, faith groups, and other community groups, with feedback facilitated via a survey monkey questionnaire.

The expertise and networks of the various patient engagement and communication leads from participating organisations were utilised in an attempt to gain feedback from a wide representation of local people. Media such as twitter, local press and patient user forums were therefore used to raise awareness of the consultation period and its purpose. Feedback was collated via a survey monkey questionnaire.

4.2 Emerging Themes

The survey monkey questionnaire was designed to facilitated constructive feedback that could then be used to inform the final version of the local care plan. Space was also provided for respondents' to feedback any qualitative comments that they had.

The main themes that emerged within the feedback received were as follows:

- A need for more explicit patient and family involvement at an early stage
- Named professionals involved in the decision making process needs to be clear
- The language used needs to be understood by patients and their loved ones
- Dislike of the term 'potential' to die- needs to be less ambiguous
- Details of the Lasting Power of Attorney for Health & Welfare (where relevant)
- More detailed and supportive information for both members of staff and for patients and their loved ones is needed
- Concern that elements of the care plan are duplicating information that is already recorded elsewhere within medical/nursing notes-
- Some suggestions that we do not need a care plan at all
- Too lengthy, needs less writing and more tick boxes/prompts
- General dislike of the daily assessment format
- Training was felt to be essential to ensure the care plan is used appropriately

4.3 Response to these emerging themes

- Names and roles of all professionals now detailed within initial assessment
- Term 'has the potential to die' replaced by 'the person's condition signifies that they are likely to die within hours or a small number of days'.
- Initial assessment requests specific information concerning the involvement of the patient and the family/significant others on initiation of the care plan.
- Where possible language has been simplified. Separate guidance notes and supportive information to be developed to assist understanding.
- Dedicated area included to record the contact details of the LPA
- It is believed that there are added advantages to having all the relevant information available in one place for quick reference, particularly if there is a need or desire for the person to change care settings during their final days e.g. Rapid Discharge.
- Unfortunately suggestions that we do not need a care plan are unfounded and go against recommendations made at a national level. Repeated clinical audits have demonstrated that without a framework used to guide the delivery and documentation of end of life care, many important elements can get unintentionally missed.

- One of the major criticisms of the Liverpool Care Pathway was the reliance upon tick boxes and therefore the inability to hold professionals accountable for precise elements of their decision making and care provision. The new care plan will therefore place an onus upon the individual who is providing the care and/or making the decisions to provide explicit documentation which will reduce the risk of misinterpretation of the plan of care. Inevitably this makes the care plan appear longer but the documentation within it becomes individualised to the person and their family/significant others. The complexity of the situation will inevitably dictate the amount of writing needed.
- The format of the ongoing assessment has completely changed in response to feedback. Now more in-keeping with familiar care planning documents.
- A comprehensive training programme is currently being planned and led by the End of Life Partnership. This includes the use of core training materials and resources to facilitate the consistent exchange of high quality information and advice concerning use of the care plan in practice.

4.4 Next Steps

June/July 2014 –The Care Plan for End of Life will go for formal ratification to various executive boards across the locality.

June-Dec 2014- Implementation of a comprehensive training strategy will begin across the locality. Extensive training will continue for the duration of 2014 and planning will take place for ongoing training into 2015 and beyond

September 2014- Reconvening of the group that has led the development of the care plan to begin the development of other supporting resources i.e. additional guidance notes for professionals/patients/carers, specialist one page inserts to the care plan for complex areas such as Intensive Care, Learning Disabilities etc Experts within these fields will be co-opted to guide this work.

January 2015- Spot audits of the care plan to take place across all care settings

June 2015- A comprehensive and robust evaluation of the care plan will take place, informed by the views of family/significant others, professionals and members of the public. The End of Life Partnership will be leading this evaluation and will begin planning how this will occur over coming months.

5.0 Access to Information

The background papers relating to this report can be inspected by contacting the report writer:

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