

## **NORTH YORKSHIRE HEALTH AND WELLBEING BOARD – 23 JANUARY 2019**

### **Report of the Executive Nurse, Hambleton, Richmondshire and Whitby CCG**

#### **Multi-Agency Forum on End of Life Care – Concluding Report**

#### **1. Purpose of Report**

- 1.1 To update the Board on the work of the Multi-Agency Forum on End of Life Care.
- 1.2 To seek its support on work in connection with Dying Matters Awareness Week 2019.

#### **2. Background**

- 2.1 The Scrutiny of Health Committee Report on End of Life Care was presented to the Health and Wellbeing Board in March 2017.
- 2.2 The recommendations followed an extended piece of scrutiny undertaken into the commissioning and provision of end of life services in the county.
- 2.3 The Board resolved that the North Yorkshire Commissioner Forum and Executive Nurses respond to the recommendations in the report and come back to a future meeting with a progress update.
- 2.4 The main recommendation was that a Multi-Agency Forum for commissioners and providers of end of life care in the county be established.

#### **3. What has happened so far?**

- 3.1 Terms of Reference for the Multi-Agency Forum (“the Forum”) were drawn up. Its principal aim is to share best practice and add value.
- 3.2 The Forum, which I was asked to Chair, comprises representatives from, among others:-
  - Clinical Commissioning Groups
  - Hospices
  - The County Council (Health and Adult Services, Children and Young People’s Services; and Public Health)
  - Yorkshire Ambulance Service
  - Independent Care Group
  - Marie Curie

- 3.3 It has met on five occasions, including a Leaning Event in September 2018, at which Hambleton, Richmondshire and Whitby CCG shared its End of Life Pathway and Vale of York CCG reported back on their End of Life Care engagement.
- 3.4 Other subjects covered include:
- What does good/success look like?
  - Clinical Networks Briefing
  - End of Life Care Services Mapping
  - Indicators to measure progress
  - Consideration of the value of having an End of Life Charter
  - How can we be involved in Dying Matters Week
- 3.5 The Forum has also acted as a network for the sharing and exchange of information.
- 3.6 It has decided that it the best way forward is to concentrate its efforts on things that will make a practical difference to people who are coming towards the end of their life and their family and carers. For instance, one of the subjects referred to above, is considering the value of having some form of End of Life Charter. The Forum feel that there is no point in producing a Charter unless it can be sure it would add value. It would be more beneficial to think about what needs to be done to enable families to prepare, as best they can, for the death of a loved one. For example, having Lasting Power of Attorney arrangements in place may, practically, be more beneficial to people than the existence of a Charter.
- 3.6 Following on from this, the Forum feels that a great opportunity to contribute to something that will make a real difference, would be to get involved in Dying Matters Awareness Week 2019.
- 3.7 *Dying Matters is a coalition of individual and organisational members across England and Wales, which aims to help people talk more openly about dying, death and bereavement, and to make plans for the end of life. (Source: Dying Matters Website).*
- 3.8 The organisation run an annual Awareness Week which seeks to help individuals, families and communities face up to death and bereavement.
- 3.9 In 2019 the Awareness Week will be from 13<sup>th</sup> to 19<sup>th</sup> May.
- 3.10 The Theme for 2019 is *Are we ready?* For instance:-
- *Are We Ready to help others get their affairs in order?*
  - *Are We Ready to help people we know who are caring for someone who is dying?*
  - *Are We Ready to support someone who is grieving?*
  - *Or even something as simple as “Are We Ready to talk about it?”*

- 3.11 When the Forum met on 14<sup>th</sup> November and had an initial discussion about the Awareness Week, it was clear from representatives present that several activities are planned across North Yorkshire. The Forum acknowledged this and does not want to interfere in these in any way. It does feel, however, that it would be beneficial to co-ordinate activities, where possible, and to agree a minimum approach across the county. If, say, there was one Communications Strategy with a single link for people to access, this is likely to increase awareness of the activities taking place during the week.
- 3.12 The Forum agreed to set up a Co-ordinating Group to oversee the contribution to the Awareness Week across North Yorkshire. Some examples as to the sort of things that could be done across the county are set out below:-

Events e.g. Free will writing sessions in libraries or other venues; setting up “death cafes”.

Press release with key messages to raise awareness of talking about death and dying, and encouraging people to plan by writing a will, etc. Devise a quiz with statistics around planning e.g. 35% of adults have made a will, 30% of adults had let someone know their funeral wishes.

Promote any events that week this could be via:

- Joint Press Release with partners
- CCGs Newsletters
- Local Forums e.g. Learning Disabilities Groups, Older People’s Forums
- Newspapers, Social Media
- Space in the Johnson Press
- Stray FM interview
- Internal Communications e.g. Key Messages Bulletin, Stronger Communities, etc.
- Website
- The County Council’s 72 Councillors (in their role as Community Leaders)

Disseminate dying matters materials through:

- Libraries
- Residential Homes
- NYCC Offices
- CCG Offices
- GP Surgeries
- Pharmacies
- Carers Resource Centres

Encouraging people to make a pledge.

*For example, I am going to make a Will in the next x months; I am going to discuss with loved ones where I wish to end my days...*

*Looking particularly at Internal Communications, the County Council could utilise its weekly Key Messages Bulletin 4 or 5 weeks beforehand to get Dying Matters Week on people’s radar and then, each following week, highlight a particular area, such as Will Making, culminating in the message the week beforehand saying what events are being held in North Yorkshire.*

- 3.13 The Co-ordinating Group will hold a mapping/planning session on 16<sup>th</sup> January. That is the day after this report needs to be sent out with the papers for Health and Wellbeing Board. Therefore, I will update you verbally on the outcomes of these discussions when I present this report.
- 3.14 A number of partner organisations represented on the Board are already contributing to this work. It would be appreciated if partner organisations could *spread the word* about Dying Matters Week and support local initiatives, where appropriate.
- 3.15 An example of work undertaken elsewhere is provided in the link below, which relates to Leeds:-

<http://dyingmattersleeds.org/>

#### **4. Conclusion**

- 4.1 Good work on end of life care across the county is continuing. However, on occasions, that work could benefit from being better co-ordinated, as with Dying Matters Awareness Week. The establishment of the Co-ordinating Group will help raise awareness of the events planned across North Yorkshire and give greater consistency across areas.
- 4.2 The current Chair of the Forum is retiring at the end of March 2019 and, therefore, consideration needs to be given as to whether the Forum should continue beyond Dying Matters Week.

#### **5. Recommendations**

- 5.1 That the work of the Forum be noted.
- 5.2 That the Board give its support to the work being undertaken in respect of Dying Matters Week 2019 in the form of raising awareness of the Week in its own organisations by, for example, encouraging people to sign a pledge and supporting local initiatives where appropriate.
- 5.3 That the question of whether the Forum continue beyond Dying Matters Week be considered.

Gill Collinson, Executive Nurse, Hambleton, Richmondshire and Whitby CCG

January 2019

#### **Background papers relied upon in the preparation of this report:-**

Information from the Dying Matters Website