

## **North Tyneside CCG Patient Forum End of Life Working Group Notes**

Tuesday 7 August 2018  
9.30am – 11.00am  
205 Park Road  
Wallsend  
NE28 7NL

### **Attendees**

Hazel Parrack	49 Marine Avenue
Dr Kathryn Hall	Chair
Donna Sample	Clinical Commissioning Group (CCG)
Pam Ransom	CCG
Carole Reed	Community and Health Care Forum (CHCF)

### **Apologies**

David Hall	Northumberland Park
Val Telfer	Wellspring Practice
Gillian Bennett	Wellspring Practice
Chris Walker	
Michele Spencer	CHCF

### **Welcome and Introductions**

#### **Notes of last meeting Tuesday 1 May 2018**

Agreed as a true record

### **Matters Arising**

Hazel made some comments about the Palliative Care Factsheet. On page 2 (Palliative Care at Home) paragraph 3 would sound less confusing if the sentence read 'Our Care Home team support and train staff in care homes in North Tyneside'. Also she noticed that the Rapid Response Team telephone number was missing and Care Navigators weren't listed on the Primary Care Team. Dr Hall wasn't sure if Northumberland have Care Navigators but agreed Primary care services should be added which would cover this. Hazel also expressed a dislike for the term 'toolkit' which is shown in Dr Hall's presentation on the National Drivers page (4<sup>th</sup> bullet point) all agreed that 'framework' would sound better. She also asked if there was any communication with Complimentary Therapists and Dr Hall confirmed they are involved in day hospices. It was suggested we added this to the factsheet.

### **Dr Kathryn Hall**

Firstly Dr Hall acknowledged the input from working group members as their feedback has always been very useful.

This was followed by the Palliative Care and End of Life presentation (copy attached). GP Registers have been looking at non-cancer disease groups and how many people there are, who die on the Palliative Care Register, 60 to 80% of deaths could in theory be predicted. The idea is have patients on the register to capture people's preferences on where they would like to die. The national figure regarding deaths in usual place of residence for North Tyneside is currently at 53.7%. This compares to the national average of 46.7% dying in their usual place of residence.

There are 15 nursing homes and these and 20 of the 40 residential homes in North Tyneside receive regular support from the Palliative care care home team.

In Nursing Homes, 86% of patients have died in their homes on average in the last 6ms. There is a home deaths register colour coding chart; red and yellow statistics stand for people who will die within days or weeks. The green and blue represent the less urgent cases. The chart shows DNARs and EHCP figures and percentages as of June 2018 according to their register colour.

The service has an individualist approach tailored to the patient's needs and obtaining GPs continuing engagement. Dr Hall explained that residential and nursing homes are now feeling more supported.

The Rapid Response Team which work seven days a week 9am to 10pm has made a massive difference to reduce hospital admissions; the data shows the number of referrals and phone call advice. The number of GP referrals is down, most come from carers and families who ring the Rapid Response Team to access help, they are responded to within an hour therefore cutting the need to ring 999. For example in January out of 220 referrals only 5 were admitted to hospital. The families of Palliative Care patients are given a leaflet with relevant telephone numbers and other information.

The number of deaths in hospital is shown on a graph starting in September 2015 when the staff numbers were down, by January 2017 the service was fully staffed and the figures are significantly reduced. Terminal admissions have been lowered and the number of A & E attendances are down dramatically especially from January 2018 to March 2018 even though deaths caused by flu were up at this time.

Even though a patient's care package may be in place sometimes people will change their minds and want to go to hospital these decisions made by families are to be respected but it can be disheartening for the staff. They will always ensure there is a smooth handover.

End of Life services were looked at in 2012 and now seven years later things are substantially ahead in North Tyneside. However there is an identified need to consider minority groups and their requirements for end of life care.

Inequalities in the borough include ethnic minorities, religion, LBGT, homelessness and people with learning disabilities; the average age of a homeless person to die is 42. It would also be necessary to employ translators, advocates or interpreters. It was agreed that the draft Palliative Care sheet should be available to be printed in different languages. Dr Hall hasn't engaged with any of the community leaders of these groups to date but have

discussed with the trust the need to do so and look at the areas of inequitable access for patients groups that there may be. This issue is included in the strategy going forward for North Tyneside.

All of the figures in the presentation are pertaining to adults no young person is included. It is however noted that approximately two children die a year from North Tyneside. Palliative Care for young people is at a tertiary level throughout North and South Tyneside. Dr Hall hasn't been involved personally but is aware of the issues of commissioning these services to support families. The Great North Children's hospital on the Victoria Wing of the RVI and St Oswald's Hospice in Gosforth are heavily involved and provide a fantastic service. The RVI do an outreach provision but it is not easy to access on occasion.

Dr Hall went through the Ambitions for Palliative Care and Key Points and everyone agreed there is a lot of great work being done throughout the service and although challenging the results are encouraging.

The EPaCCS or Palliative Care Plan project is seeking to ensure that all services caring for a patient on the Palliative Care Register can access current and key information so the best treatment can be given.

### **Any Other Business**

Hazel showed concern about a recent newspaper article introducing a green light to let patients die without consulting a judge. Dr Hall said all cases are different and the circumstances are notoriously difficult and challenging. There has been a national debate on assisted dying since the eighties and this still goes on today. Cases are very rare and usually happen when people go into an Intensive Therapy Unit (ITU).

### **Date of Next Meeting-*\*Please note date change***

The next meeting date was 9 October 2018 but Dr Hall is on holiday then. The date was then changed to:

Tuesday 30 October 2018

9.30am to 11.30am

205 Park Road, Wallsend

### **Actions**

1. Dr Hall to send out Care of the Dying Audit Report results once available and we can discuss the slides further as necessary at the next meeting.
2. Michele to extend an ongoing invitation to members of the Patient Forum to this meeting. **Don't know if this action was completed can't see anything in the last forum notes.**