North Tyneside CCG Patient Forum
End of Life Working Group Notes

Tuesday 4 February 2020
10.00am to 12-noon
Linskill Centre
Linskill Terrace
North Shields
NE30 2AY

Attendees

Dr Kathryn Hall	Chair
Pam Ransom	Northumbria Health Care Trust
Karen Robinson	Community Macmillan Nurse
Rachel Spratt	Specialist Macmillan Nurse
Hazel Parrack	49 Marine Avenue
Val Telfer	Wellspring Health Centre
Gillian Bennett	Wellspring Health Centre
David Hall	Northumberland Park
Ray Calboutin	Park Parade Surgery
Carole Reed	Community and Health Care Forum (CHCF)

Apologies

Michele Spencer	Community and Health Care Forum (CHCF)
Donna Sample	Clinical Commissioning Group (CCG)
Patrick Mayne	Collingwood Health Group

Welcome and Introductions

Notes of last meeting Tuesday 3 September 2019
Agreed as a true record.

Matters Arising
Kathryn thanked Val for her input about the bereavement which she is now co-working on with Karen and Rachel. They have had an initial meeting and were scheduled to meet again in January. Unfortunately, this was cancelled due to Kathryn being off sick. The Macmillan nurses are keen to have a fusion about the work they're doing with bereavement across community, primary and secondary care. The aim of the bereavement policy is to make sure services are kept up to standard and gathering information from national and local documents. Basic outlines will be discussed at the next meeting on 18 February. The work plan is ongoing, and Kathryn would appreciate any feedback from members.

Kathryn met Pam met years ago and this inspired her in her Palliative Care work and to be driven by patient centredness. A lot of work has been done to manage the grieving process; there should be a constructive relationship with the family before death identifying specific and appropriate needs of the patient and their carers and family. If children are involved it is slightly different, they can be very distressed and act accordingly making the situation very difficult. Evidence shows that engaging with people at around three months before death to prepare them for the inevitable is so helpful; then contact after death and around 3months after death is helpful or in some cases up to a year depending on the circumstances. It can be more frequent and sooner depending on the needs of the family and carers. Referrals can be also arranged to different organisations such as Talking Therapies. Sometimes it is all too much for bereaved person or family and things can become very complex.

The aim is to produce a strategy within a standardised policy to underpin ideals and make sure everything is done to the same standard across services. There can be a gap in primary care when a bereft persons loved one dies in hospital and they have no contact from their GP. This may be because there has been a lack of communication and the GP is unaware of the situation. GPs will welcome the chance to have the necessary guidance and information, in order to help the patient. Being realistic, if they don't know what has happened, they can't give the guidance. A survey was produced two years ago, and every single surgery got involved; it saw big gaps in the service and proved really helpful. This triggered clinicians into having meetings with each other to remedy this. Kathryn is hoping to complete the Bereavement work by the end of Summer.

Karen Robinson

Karen has two files showing some areas of work that is currently done elsewhere and locally; she handed out guidelines to the members, one of which was adapted from the health service in Cheshire.

Locally when a patient dies the standard procedure in place there means the family will be contacted within 2 working days by the Macmillan team. They will decide if it is appropriate to send certain information out depending on the circumstances.

The Macmillan nurses currently don't send out leaflets as they may contain inappropriate information and they are not personalised. Macmillan will seek permission to arrange further contact within five working days. They will also send a condolence card from either Macmillan or Marie Curie and a further two weeks later they will offer a face to face meeting. It is different for everybody.

Bereavement can be a forgotten symptom and it is important to embed something similar with all clinicians where initial information comes from really important contact and no disparity with the service received. It is important to vary the cards when sending to bereaved families this makes it personal to them. Always address the bereft recipient by their name. Sometimes it is obvious what the needs are but sometimes not. In complex cases the GP would get involved and visit the person together with the Macmillan nurses.

The bereavement support will depend on where the person was when they died and in what circumstances. Whatever the case the same level of contact support and care should be given in every case. The bereavement care starts before the person dies.
If they died of frailty the care and discussions may start well ahead to prepare the family.
In the event of a sudden death the GP would respond in exactly the same way as in a palliative death. After every death a notification email is sent to all GPs informing how, when and where the patient had died. Obviously, confidentiality is standard practice.

Specific bereavement care is extended to mums who have had a still born baby. In this case the Health Visitors nurses would liaise with the midwife. When a woman has a miscarriage, she can often feel abandoned and can suffer from post-traumatic stress disorder. Not all clinicians class a miscarriage as a case of bereavement. In the case of a sudden or suicide death there will be specialist care available and the Mental Health Team are often involved; they carry out their own procedures in these circumstances.

It is important to keep up really good practices, policies and signposting, the majority of practices are doing this. Health professionals learn so much from bereaved families they gain intelligence and bring useful information back to the surgeries.

Another aspect of the bereavement care is the dying person worrying about what's going to happen to their cat or dog; Macmillan has a classified list of animal welfare organisations which can reassure the patient. Regarding bereavement care the system could work more cohesively and there are opportunities for PCNs to link with Primary care Navigators, Talking Therapies and Social Prescribers to a get a sense of their working together.

In most surgeries the IT system elements are standardised, the most common is System One which is a centrally hosted clinical computer system development.

At this time there are a lot of new nurses coming into the bereavement service and developing skills around it. Twice a year Kathryn meets up with new and junior clinicians to discuss support, communication and education built around palliative care including bereavement.
Kathryn invited the Macmillan nurses to come back to group meeting in October to give feedback but will also keep them updated in between.

Update on Rapid Response
Pam explained to members that the Rapid Response Service is commissioned for seven days a week 9am to 10pm but recent measures plan to cut this by three hours. This is partly because Marie Curie are short of band 5 nurses and there are lots of other staff off sick; this has put extra pressure on the Palliative Care Team. There will however be a 24-hour hospice advice line telephone service. Recruiting staff takes longer than six weeks, this is because some of the candidates interviewed are unsuitable and HR requirements can lead to delay.

When patients are referred it is important to generate feedback to find out the exact impact put on the service and this will be observed closely. A lot of the time when people have problems they happen in the evening and therefore certain cases may end up with a hospital admission. Although this is the case general admissions have plummeted. We need to be mindful of any impact on the District Nurses and there has an influx of new District Nurses coming through the service.

Presentation by Dr Hall
Kathryn gave a presentation on End of Life statistics and how many patients the Macmillan Nurses have on their registers compared to the GP surgery records
and whether patients are on both systems registered as palliative. Kathryn gave specific numbers of the palliative care patients and it has proved that since 2015 the number of duel registrations was 117; in four years this has gone up to 968. This is an indication of how much better services are aligned.

Care of the Dying Audit
There were no updates.

Work plan
The Palliative Care and End of Life Work Plan will run from 2019 to 2025. Kathryn has sent a copy of the work plan out with the last set of notes. This is a very early draft produced by the CCG which will document and capture the work done in the next five years. Within the work plan the service will be streamed to find out the principles and what the objectives are. The actions will be shared with colleagues including consultant and management level. It is a work in progress. Kathryn will have further discussions with members at the next meeting. It is early days and there is a lot of work to be done.

- Ambition 1 is aiming to treat each person as an individual and make sure they have honest, informed and timely conversions about dying. Asking what matters most to them and their carers.
- Ambition 2 is to see each person gets fair access to end of life care regardless of who they are, where they live or whatever the circumstances.
- Ambition 3 is to maximise comfort and wellbeing and make sure the care is regularly reviewed and every effort made to have the support and treatment that might be needed to keep the person free from distress.
- Ambition 4 is to make sure the care is co-ordinated at the right time from the right people and having a team around who will listen and respond at any time.
- Ambition 5 requires all staff to be prepared to bring empathy and give competent, confident and compassionate care.

Kathryn respectfully asked the members to keep this information within the End of Life members group and not to share with anyone else at this stage.

Data shows that more patients (63.7%) are dying in their own homes and care homes which is their place of choice. Apart from cancer other causes of death are COPD, heart failure and dementia; on the whole people are living longer. Records in North Tyneside show that there were higher palliative care numbers admitted to hospital in August, it is not known why but maybe it is when carers and families go away on holiday.

Paul Maitland from the CCG has done a clever piece of work showing all the work the Rapid Response service has done in reducing terminal admissions and not keeping patients in hospital a long time before dying. Although emergency admissions have gone up, patients are not staying long as they are admitted, treated then discharged.

The Palliative Care Unit at Redesdale Court is moving to Ward 5 at Rake Lane Hospital, Kathryn is hoping to get an invite to look around before it opens. Work on it will be underway by 1 May 2020. The ground floor has its own entrance and there is a lovely garden and car park.

Kathryn concluded that everything on the whole is going well with some exciting things coming up this year. She also offered to go and do a talk with the Macmillan Nurses to keep them updated.

Any Other Business
There is a piece of work coming up with the coroner to restructure and input new changes in the system. Kathryn will give members an update at the next End of Life meeting in June.

Kathryn confirmed that the Electronic Palliative Care Co-ordination System (EPaCCS) is going well.
David asked what preliminary provisions would be provided by the current government as they have promised to put more money into the NHS. It will be interesting to see what is ahead The entry level to be a GP could be made easier, at present they have to go through a standard Vocational Training Scheme which is very stringent, they are well supported but there are still applicants who don't pass.

Actions

1. Katheryn and Michele to cascade the leaflet.

2. Kathryn to invite Tom Dunkerton from the CCG to the next meeting.

3. Kathryn to add other items to the next agenda.

Note: Date of Next Meeting has been changed to
Tuesday, 9 June 2020
10.00am to 12.00-noon
Linskill Centre, Linskill Terrace
North Shields NE30 2AY