End of Life Care
A Single Point of Access

Stakeholder meeting report

Oct 2014

1. Background

End of life care is about caring for people who have an advanced, progressive and incurable illness so they can live as well as possible until they die. It is about providing support that meets the needs of both the person who is dying and the people close to them.

In 2013 a survey was carried out to get the thoughts of patients, relatives and staff about health and care services for people at the end of their life. The survey found that people struggled to get medical support in the evenings and at weekends, and that this can make patients and their relatives feel very isolated and vulnerable.

The NHS Clinical Commissioning Groups (CCG) in Leeds are responsible for commissioning services that meet the needs of people in the city. They are working together to look at ways to improve care for people at the end of their life. They are considering setting up a brand new telephone service, exclusively for patients in the last years of life and their relatives. The aim of the service would be to improve care of patients and their relatives and support people in their own home. The service would be available 24 hours per day, 7 days a week, 365 days per year. If a patient or their relative has any concerns or questions about their condition they can call the telephone line at any time of the day or night. It is proposed that the telephone service will be covered by experienced nurses who can give advice, arrange visits, organise admission to hospital and provide information about other services available.

2. Engagement

In September 2014 the CCG carried out engagement with people at end of life and the people who care for them. We asked people to tell us about their experiences of end of life care and share their thoughts on the new service proposal. People told us that there was a lack of support in the evenings and at weekends for people at the end of life and their carers. They told us they were supportive of a service to address this gap in services. A report from the engagement can be found on the NHS Leeds West CCG website here: http://www.leedswestccg.nhs.uk/get-involved/your-views/

3. Stakeholder Meeting

Following the patient engagement work and various meeting with staff at end of life services, we decided to hold a stakeholder workshop. The aim of the workshop was to bring together stakeholders in the new service to look at good practice and consider what the new service might look like. The meeting was held on Wednesday 8 October at Shine in Leeds and was attended by representatives from the NHS, Adult social Care, Leeds Hospices, Patients and commissions

4. Meeting agenda

a. Introduction

Sarah Follon introduced the SPA and explained the reasons why the service had been proposed. She also outlined the findings from the recent patient and carer engagement.

b. Gold Line

The Gold Line was launched in Airedale, Whafedale and Craven in 2013 after a successful bid to the Health Foundation, and extended to Bradford in 2014. The population served is around 450,000. The service is based at Airedale hospital. Around 876 patients are currently registered. 58% of patients die in their preferred place of death. Between April 2014 and August 2014 62 patients avoided admission and 42 patients avoided transfer to A&E (around 6 patients per week avoid transfer to hospital). In August 2014 nearly 500 calls to the Gold Line were received. 77% of calls received are between 6pm-8am Monday to Friday and at weekends. The calls are answered by experienced (band 6) nurses. Calls are immediately answered by a nurse, there is no triage system. Hub nurses have access to full health care record and EPaCCS template, write into the record and task all services involved to let them know about the call. Feedback from patients/relatives/carers has been very positive.

Outcomes of calls: Telephone advice. Signpost to other services (nurse will contact service on behalf of patients) Refer to outreach team Visit by GP Visit by district nurse Transfer to A&E Admit to hospital Admit to hospice Call an ambulance for immediate assistance. The hub nurse and paramedic will then have a discussion regarding whether the patient can be managed at home or needs admission.

c. PEP project (Partnership for Excellence in Palliative Support)

As part of our work to establish best practice we visited a number of organisations who deliver a similar end of life service. We invited representatives from the PEP service to attend the stakeholder meeting to introduce their project

PEP is delivered by Bedfordshire CCG. This service was launched in 2011. The population served is around 450,000. It is based at Sue Ryder St John's hospice. Around 755 patients are currently registered with PEPS. 65% of patients die in their preferred place of death. A minimum of 2 hospital admissions per week are avoided. About 1500 calls per month are received. It is staffed by experienced palliative care nurses during the day. 11pm until 7am calls are answered by palliative care nurses who work at St John's hospice. There is no triage system, patients have a direct line to the nurses. PEPS also employs a rapid face to face nurse assessment service and health care assistants who undertake home visits to provide additional support and facilitate early discharge. Very positive patient/relative/carer feedback received. Outcomes of calls:

- Telephone advice
- Signpost to local services (nurse will contact on patients behalf)
- Visit by PEPS health care assistant
- Visit by PEPS nurse
- Visit by GP/district nurse
- Refer to outreach team
- Transfer to A&E
- Admit to hospital/hospice

d. Activity one – 'How would an SPA enhance the current service and what gaps would it address?'

We split stakeholders up so that each table had representatives of different sectors and patients. We asked each table to consider the benefits of introducing a 24 hour telephone service for people at the end of life and their carers.

People told us that it would have the following benefits:

- Provide an incentive for professionals to identify patients at the end of life
- Experienced nurses could be rotated into the service so resources are being shared
- Provide continuity
- Liaise between different services
- Support the family to decide on the best course of action
- Support discharge facilitators
- Work with YAS to avoid unnecessary admissions

People told us that it could address the following gaps:

- Reassurance and support 24/7
- Used if the district nurses are not involved
- Prevent patients/carers ringing around for help
- Reduce confusion about who to call in what situation
- Having to repeat the same story with every new contact
- Default tends to be 999
- Speed up access to appropriate care
- Coordination of care
- Signpost to bereavement services

e. Activity two – 'What would a fantastic SPA look like?'

We split stakeholders up so that each table had representatives of different sectors and patients. We asked each table to tell us what they would like the SPA service to provide and how it should be provided. People told us that the service should:

Be run by a professional:

- Nurse coordinates all care so relatives don't have to
- Experienced band 6/7 nurse
- A nurse prescriber, including ability to prescribe anticipatory meds
- A nurse with palliative care experience
- A nurse who can verify death
- Empathetic, kind, polite, professional
- Share information to bridge gaps between services
- Knowledge of local services

Provide a range of options/interventions:

- 24/7 care
- Rapid response
- Access to hospice beds
- Refer to outreach team
- Visit by GP/DN
- Support
- Signposting
- Organise sitters
- Advice

Reassure patients

- Refer to voluntary services
- Symptom management
- Emotional support

Communicate really well:

- Access to translators
- Alternatives for people with sensory impairment e.g. type talk, video conferencing, language link, SKYPE

Develop strong relationships:

- Strong and effective relationship with whole health economy
- For patients and carers/relatives and professionals
- Coordination across all services
- Can get advice from colleagues quickly

Have access to latest technology:

- Capacity for telecare and telehealth
- Develop on app
- Only one number needed
- Smart telecom system
- No triage, direct access to nurse
- Prescriptions could be sent electronically to chemists
- Access to SystemOne/EMIS so knowledge of patient
- Call answered quickly

Provide good governance:

- Appropriate training of staff
- Patient safety is paramount
- Confidentiality respected
- Collect feedback from patients/carers
- Calls audited so service learns and improves

Where based:

- Gateway/SPUR (single point of urgent referral)

Also:

- Be well advertised
- Use a name that is recognised e.g. EPaCCS
- Try to identify patients early

f. Activity three – 'What outcomes would we want it to achieve?"

We split stakeholders up so that each table had representatives of different sectors and patients. We asked each table to tell us how we would know that the SPA had been successful. People told us that the SPA should deliver:

Good patient experience:

- Die in preferred place of death
- High quality service
- Patient satisfaction
- Seamless
- Right first time
- Immediate response to call
- Feeling cared for
- Reduce loneliness/pain/anxiety/breathlessness
- Patient to feel in control/Patient choice
- Confidence in advice given
- One number
- Comprehensive service

Happy and productive staff

- Job satisfaction
- Safety culture
- Efficiency
- Cost effective
- Effective and appropriate signposting
- Reduce inappropriate admissions
- Credible service
- Death in preferred place
- Deliverable
- Partnership with all stakeholders
- Evidence of positive impact
- Part of a coordinated system
- Effective communication across services
- Reduce inefficiency
- Effective use of existing resource
- Seamless

Satisfied commissioners:

- Avoid unnecessary transfer to A&E
- Avoid unnecessary hospital admissions
- Improve patient experience
- Value for money
- Ensure best practice
- Affordable
- Equitable
- Accessible
- For patients and carers and professionals
- Maximise efficiency
- Clinical effectiveness
- Quality assured
- Measurable improvement in outcomes
- Seamless

5. Next steps

Over the next few months a small working group will start developing a service specification which will outline how the service will work.

Early next year we will write a business case to explain how the service will work and why it is important. The business case will be submitted to the CCG in April 2015 and if successful we will begin developing the project.

We have had excellent patient involvement through the process so far and we are delighted that a number of patients have shown an interest in being involved in the project working group. This will help us ensure that the final service meets the needs and preferences of patients and carers in Leeds.

If you would like to follow the progress of this project, please contact Chris Bridle at NHS Leeds West CCG chris.bridle@nhs.net 0113 8435473.