COMMUNITY PARTNERSHIP FORUM

26 March 2015

Attendance

Name	Organisation/role
Peter Haley (Chair)	Chief Executive, People to Places
Ally Green	Associate Director of Communications and Engagement, East Berkshire CCGs
Pip Collings	Public Health, Slough Borough Council
Chris Taylor	Healthwatch Bracknell Forest
Ramesh Kukar	Slough CVS
Dr William Tong	Clinical Chair Bracknell and Ascot CCG
Geraldine Richardson	Healthwatch WAM
Roger Battye	Healthwatch WAM
Marjorie Clasper	Older people's Advisory Forum
Pam Curry	Older people's Advisory Forum
Lilly Evans	Sunningwell Parish Council
Cllr Lynda Yong	Royal Borough of Windsor and Maidenhead
Robert Cooper	PPI Governing Body member, Windsor, Ascot and Maidenhead CCG
Andrew Battye	South Central Ambulance Service
Tony Virgo	Bracknell Health Panel
Cllr Martin Carter	Slough Borough Council
Debbie Raven	Thames Hospice
Rosemary Martin	Berkshire Healthcare NHS Foundation Trust
Apologies	
Cllr Dale Birch	Bracknell Forest Council
Sonya Lippold	Health Advisory Group
Pat Rodgers	Berkshire Healthcare Foundation Trust
Philip Cook	BF Involve
Dr Adrian Hayter	Clinical Chair, WAM CCG
Karen Maskell	PPI Governing Body member Bracknell and Ascot CCG
Cllr Sabia Hussain	Slough Borough Council
Mike Connolly	PPI Governing Body member, Slough CCG
Madeline Diver	Bracknell Forest Voluntary Action
Cllr David Coppinger	Royal Borough of Windsor and Maidenhead

Conflict of interests

There was no declaration of a conflict of interest.

Notes of meeting on 26 February 2015.

The notes were agreed with the following corrections:

- Cllr Lynda Yong should have been listed as attending.
- The Urgent Care Centre has no 4 hour target.

End of Life Care

Debbie Raven, Chief Executive at Thames Hospice introduced the session with a film clip giving Walter's story.

The hospice is based in Windsor with 17 beds and a community unit is based in Ascot. The hospice at home service provides outreach to people's home with a range of specialist care available 24/7. Complimentary therapy is provided as needed. Lymphodema therapy is provided including a bespoke massage service. Counselling, spiritual care, physiotherapy, occupational therapy, social worker and consultant care are all available from the hospice or in the community.

Facts for last year:

- 410 new admissions in the year
- 83% occupancy rate
- 54% of inpatients are discharged home
- 142 people were supported through hospice at home
- 1,438 complimentary therapy treatments were provided
- 2,142 counselling sessions provided
- 2 complaints were received
- 1:2 ratio for nurses to patients
- £5.5m was spent on the service
- 78% of funding came from charitable donations through shops, other fundraising initiatives and from legacies.

Strategic aims were set out that included being the preferred provider of specialist palliative care in East Berkshire.

Highlights from 2014/15 include:

- The 'Sanctuary'
- Strong, good relationship with Frimley and Wexham Park hospitals.
- Expansion and integration of Hospice at Home with Berkshire Healthcare Foundation Trust
- In-patient unit occupancy levels sustained at 80-85%
- Focus on infrastructure to ensure fit for the future
- New build project and service development
- Palliative care funding review that is changing the way palliative care is funded nationally.
- Project 25 expansion plans.

Thames Hospice is the only hospice in East Berkshire.

The presentation was followed by a wide ranging discussion. The following are some of the questions and answers given:

Q: Where the patient is a parent of young children, the child/ren is not able to stay overnight. This has caused some difficulties. Why would this be the case?
A: Hospices are not good places for young children to be for a long period of time. There is support offered to the patient and the family but this does not extend to children staying overnight.

Q: A young man (aged 27) with terminal brain cancer wants to meet others of his age with similar condition. The hospice seems to be more for older people and he is not keen to go there. Is there a gap for the younger age adults?
A: There are demographic changes week by week and although we might be predominantly for older people, there are many younger people who come and stay. We are looking at having more single rooms to allow more privacy and for family and friends to come.

Q: What is the relationship like with the acute hospitals in the area? Are there problems of people bed blocking who could come to hospice earlier? What could councillors do to support?
A: There are times when we think someone could have come to the hospice earlier but on the whole this is not because of what is happening in hospitals. Councillors could help to raise the profile of end of life care and to encourage conversations. We need to dispel the myth of hospices being the last place someone goes which means they are fearful. The hospice is more than just the in-patient facility and a patient whose first contact is being supported through the community service will have an easier transition to being an in-patient.

Q: How do you increase the funding and how do we compete with other national charities all looking for funding from the same pot?
A: The palliative care funding review will change the way funding will come from NHS. Our beds cost less than an acute bed. We don't have the capacity currently to respond to increased demand. Our supporters are very loyal and will support us for many years, more than 60% have had direct experience of using the service. We need to consider what our community would be willing to support. We know what our doctor and nursing ratio is and so can estimate costs of expanding.

Q: When the ambulance service gets involved in an emergency, what is the likelihood of patients who are known to you coming to you direct rather than them being taken them to an acute hospital?
A: Where you are confident that there is not a reversible condition the patient can come straight to us. However, family can be particularly upset and may want hospital. We can support with domiciliary care and if the community service is involved, they can ensure the patients get the right service.

Rosemary Martin, Slough Community Nurse Manager at Berkshire Healthcare NHS Foundation Trust (BHFT) gave a presentation on the community end of life care.

Specialist palliative care:

- Community team includes:
    - Clinical nurse specialists
    - Social worker for children and families
    - Psychologist working closely with counselling team

    - Telephone support worker to provide ongoing support
    - GP with specialist interest working one session a week, liaising with consultant
    - End of Life Care Educator
- Hospital:
    - Clinical nurse specialist
    - End of Life Care Educator

BHFT support patients and families in the community. They spend time talking to families about what they want to happen and try to facilitate the conversation for the whole family whilst recognizing that the patient needs to be heard.

They provide support for difficult conversations to aid communications.

The service is available 7 days per week between 8.30 – 16.30.

The service was reorganised in April 2014. There is now a single point of access based in Windsor which can manage referrals and help to support the liaison with the hospice and hospice at home.

Last year they received over 1,000 referrals. The average length of stay on caseload is 3 months. 75% of patients died out of hospital, in the community.

The presentation was followed by a wide ranging discussion. The following are some of the questions and answers given:

Q: Do you have an out of hours service?
A: No. There is a 24/7 district nursing service and the hospice is available 24/7.

Q: Do you have enough resource from the NHS?
A: It is very tight and we could do more to integrate but we do have more people living longer in a poorly state. For cancer patients it might be easier to estimate what is ahead and what might be needed. For frail older people with long term conditions, this is less easy.

Q: Do patients stay longer in hospital if they need palliative care and no-one asks for it? Is there a need for a main ward, for intensive nursing until the family recognize that what their loved one needs is a different level of care.
A: The palliative care teams spend a lot of time educating colleagues to be able to recognize the end of life state so that it becomes everybody's responsibility. New doctors have that training built in. At Wexham Park Hospital, there is a good process with conversations happening to allow people to go home or to a hospice. There is also a facility in the hospital for patients at the end of life. It is difficult for someone who isn't a palliative specialist to say 'I'm sorry, there's nothing more we can do..'

Awareness is being raised through various public discussions including the topic cropping up in soaps on TV and debates in House of Lords. This all helps to raise awareness.

Comment: We have a system with many contact points with patients and families. As a GP, I see this failing when communication is poor. Cancer patients are being looked after at home and often the correspondence I receive doesn't reflect the training coming through so that the terminal nature of the condition and/or the conversations about end of life is often not recorded. We need to skill up GPs as generalists so they have the skills for these difficult conversations.

Q: Do consultant letters get copied to patients?
A: Yes. The quality of letters varies and language could be frightening if no conversation has taken place.

Comment: This year's BBC Reith Lectures focused on end of life. They are available on the website.

Q: Is there a moral dilemma for clinicians who will want to do anything to try and save their patient?
A: No. Morally we all have a duty to treat people in the way they want at that time of their lives. It's a cultural shift that's needed.

Q: Research has suggested that a huge majority of people want to die at home. However, people are usually asked this question when they are fit and well and this might be their view at that time. Further research, asking people who have been in a hospice the same question, say they would like to die in hospice.

Q: Is there a dilemma regarding 'do not resuscitate' (DNA) requests? Ambulance staff will want to do something because they have been called.

A: The DNA for Cardiopulmonary resuscitation (CPR) is recorded on a lilac form. The fact that a patient may have made this choice still means other treatments could and should be provided but if their heart has stopped they will not be resuscitated.

There are times when this is not a difficult conversation. It depends on where the individual is in their thinking and in their treatment.

The conversations are difficult but should include more about what to expect and to acknowledge that they can change their minds.

Q: We need to think about how to engage the faith leaders in our communities who will have a role to play.
A: The hospice has engaged with faith leaders and they have become more aware of how we provide our service to people from different faiths. We now have 12% of people using the hospice coming from ethnic minority groups.

Open Forum

NHS 111 re-procurement: The contract expires at the end of March 2016 and plans are being made to re-procure this service. Patient engagement is going to take place. The process includes the ten CCGs across Thames Valley. Currently the CCGs are looking at the specification to ensure it reflects the different need for each

area. The three CCGs in East Berkshire are considering the potential benefits of integrating NHS 111 with GP Out of Hours service.

Healthwatch WAM reported that they are asking questions about NHS 111 in their mail-out. There is an opportunity to amend the questions to help this effort. Links will be made with William Tong.

Mental Health: Recent changes to mental health funding for children's mental health was noted and the profile given to this service by the CPF.

Specialist commissioning
It was noted that responsibility for commissioning wheelchairs is transferring from NHS England to CCGs.

Future meetings

Next meeting: Thursday 28 May 2015
6.30pm – 8.30pm

Suggested topics for future meetings:

- Patient engagement
- Mental Health and wellbeing
- Collaborative Care for Older Citizens
- HealthMakers feedback
- CAMHs update
- Car parks and transport
- Pharmacy – role of the pharmacist and opportunity for patients