ESSEX PALLIATIVE, SUPPORTIVE AND END OF LIFE CARE GROUP

Thursday 19th July 2012
at
2.00pm-4.00pm
Kestrel House, Board Room
Chelmsford, CM2 5PF

MINUTES

Present:

Catherine O’Doherty (Chair) COD Palliative Care Consultant, BTUHFT
Aqdas Kazi AK Speciality Registrar Palliative Medicine, Farleigh Hospice
Ann Smits AS Head of Patient Care, Farleigh Hospice
Carolyn Doyle CD Lead Nurse for End of Life Care, SW Essex Community Services
Carol O’Leary COL Nurse Director, ECN
Debbie Sevant DS Head of Community Services, Havens Hospices
Ken Aldred KA Chair, ECN Partnership Group
Kate Patience KP Macmillan AHP and Survivorship Lead, ECN
Lynda Hampel LH Commissioning Officer, Essex County Council
Matt Gillam MG Commissioning Manager, SE Cluster PCT NHS SEE/Castle Point and Rochford CCG
Michael Scanes MS User Involvement Facilitator ECN
Nicky Goodwin NG End of Life Care Facilitator, CHUFT
Stella Fletcher SF Inpatient Services Director, St. Helena Hospice
Sirupa Gupta SG Consultant in Palliative Medicine, Farleigh Hospital/MEHT
Sharon Quinn SQ Community Services and Development Manager, St. Luke’s Hospice

In attendance

Jill Butten - for minutes

1. Apologies

Shamsul Shah, Debbie Hickey, Eileen Marshall, Janine Tickner-Phillips, Bridget Moss, Pat Ahlquist, Linda Mahon-Daly, Lucy Archer, Melanie Lodge, Suzanne Sinclair, Alan Lamont, Karen Spurgeon, Karen Munro, Matt Riddleston, Janet Doghan

2. Previous Minutes - 24th May 2012

The minutes were recorded as a true record of proceedings.

Following the presentation by Sarah Bradley at the previous meeting, AS mentioned a problem whereby ambulance crews are refusing to take patients until they have physical evidence of the DNACPR form. It was revealed that there are a small number of instances where discussions as to the use of the form between 'hospice' and patient are felt not to be appropriate resulting in the patient going home without said form which in turn affects any subsequent calls to the service and might lead to unwanted intervention.

Following discussion it was decided that this issue was more to do with the “process” rather than the policy itself.
A further Essex-wide problem was highlighted whereby there appeared to be some misunderstanding as to the exact circumstances when the form should actually be used, along with concerns as to the legality of the form. It was felt that perhaps further training would help. CD advised she had a meeting planned with the ambulance service next week and would discuss further.

Action: CD

3. Patient and Carer Issues

MS explained the reasoning why this item now appeared earlier on the agenda whereby it had been raised at the User Partnership Meeting that this matter warranted earlier discussion during meetings rather than appearing towards the end when time was more limited.

KA reported that he had been unable to meet with colleagues from the Cardiac and Stroke Network (CSN) in order to discuss and identify a patient representative from that speciality for this Group. MS agreed to speak with the Network Director of the CSN whilst he is at Colchester.

Action: MS

Initial discussions had taken place in the North East as to an additional service of a Registrar on site at CHUFT in order that deaths, as well as births, could be registered to avoid further distress and delays. Discussions with Essex County appeared to be positive but User Group members will be asked for their opinions. It was noted that the hospice user group had suggested there were advantages, on occasions, of taking a few days to come to terms with a bereavement before registering the death at a later date.

4. Matters Arising

4.1 Membership/ Terms of Reference

Already discussed under item 3.

In addition it was noted that the Lead Clinician, or their representative, of each MDT should attend this meeting. There was some ambiguity around this wording which COD and COL would investigate further. SG advised that if appropriate, she would represent Claire Plunkett on this group.

Action: COD/ COL

4.2 Update: NICE Guidance - Supportive and Palliative Care

Specialist Palliative Care Peer Review Measures

COL advised that the Palliative Care Directory and Constitution had been circulated prior to the meeting, to allow members time to consider amendments. The Constitution was studied with minor amendments suggested and applied during the meeting.

Specific action points were as follows:

Contact numbers for the 24 hour on-call out of hours service at Mid should be forwarded to COL.

Action: AS

Contact numbers for the 7 day visiting service for direct assessment at Mid, Farleigh and the South East should also be forwarded to COL.

Action: SG/ AS/ DS/ MG
Network Audit: COD reported that the Mouth Care Audit had been completed, although the raw data was still awaited from North Essex. SF advised that she had been unaware of the Audit having taken place but would speak with Jane Elliott and forward data to COD.

Action: SF

The results would be discussed at the September meeting.

Proposals for Service Development: COL had met with management trainee, Sasha Hewitt, earlier in the day and they had agreed that she would begin work on this project on her return from maternity leave in August.

Draft Directory of Specialist Palliative Care Services: Any further alterations/additions should be sent to COL by the beginning of September, in time for the next meeting of this Group, in order that the directory can be cascaded to organisations that might use our services.

Action: ALL

Functions of the Specialist Palliative Care Provider Organisation Measure - Operational Policy: COD offered to circulate a copy of the BTUHFT policy which individual provider organisations could adapt as necessary.

Action: COD

Claire Langslow, from the Peer Review Team, had contacted COL to clarify which organisations, who provide specialist palliative care, should be added to CQUINS. Discussions took place and it was decided that only the “host” provider organisation, who would be up-loading documents, should be added. DS agreed to investigate further with regard to SE and advise COL

Action: DS

4.3 Work Programme

Network Audit

This had been briefly discussed above under item 4.2, but further discussions took place with regard to future yearly audit presentations, including identifying a lead and perhaps an Audit Group. It was decided that this would be discussed in more depth at the September meeting, and agreed that any audit outcome should “direct” the service. Suggestions for possible Audit presentations were:

- Network wide Patient Satisfaction Survey
- Rehab Audit

4.4 Locality Updates -

North Essex: Advanced Care Plan has now been printed and circulated. Work is still on-going on Marie Curie Delivering Choices Programme.

Mid: Work still on-going

South East: Macmillan Nurse re-organisation is on-going.

South West: Work on-going with the electronic register. Second Macmillan GSF Facilitator Post will be going out to advert fairly soon.

SQ advised of a new development of a Physio Team at the hospice.
4.5 End of Life Care

Education Facilitators ABC and GP Education

CD reported that in conjunction with the SHA a Train the Trainer Programme is being explored with three of the biggest home consortium, this would be a six month project with evaluation by one of the universities training will be aligned to skills for care with accreditation attached. East of England care home targets are going well but need to measure impact of the training.

GP Education Programme is continuing but there are still some issues with GP’s identifying End of Life Care Training needs, it is hoped to acquire some extra capacity in East and West for Karen Spurgeon (KS). Additional resource has been identified in the North to work with (KS) in order to facilitate appointments with GP surgeries. SG asked that a meeting be arranged with KS.

Action: KS/ SG

Quality Marker Measures are still on-going and further information is awaited.

4.6 Palliative Care Funding Review

This is still on-going with data from the pilots awaited.

4.7 Research

COL has spoken with Ashley Solieri, ERCN Manager, who had provided copies of Palliative Care Cancer Research, some of which were not within the remit of this group. It was generally felt there was interest in certain trials but no suitable patients had been identified.

COD advised that there were some NCRN Studies which were open and she could supply further details if required. Of particular interest was the RECC study, which KP agreed to investigate further and report back.

Action: KP

5. Any Other Business

5.1 Route to Success in End of Life Care - achieving quality for lesbian, gay, bisexual and transgender people

This document had been provided for information by Bridget Moss. She had been extensively involved in the compilation and publication and had asked that it be circulated to members of this group.

5.2 KA advised that the first national survey of bereaved individuals had been published, which looks at care in different settings with some significant differences between North and South Essex. He offered to circulate the survey and asked if this could go on the September agenda to explore the matter further. This was agreed.

Action: KA/ COD/ COL

Following further discussion it was agreed that more thought might be given to a local survey for issues which have more relevance to this group, and could also form a Network audit.

5.3 KP discussed a Rehab Audit of Equipment at End of Life, as there are still individuals struggling to justify provision of equipment due to cost.

5.4 Survivorship Group are looking at work in Acute Trusts around low risk patients and health and wellbeing, she will bring to the next meeting the workstream looking at active and advanced disease and where Survivorship fits into the Palliative Care agenda.

Action: KP
5.5 SQ reported on the Help to Overcome Problems Effectively (HOPE) Programme certain individuals from South West and Mid had undertaken training with Coventry University, looking at delivering a carers programme at the end of 2012 early 2013, which is fully supported by Macmillan. Information will be disseminated.

5.6 AS advised of two programmes set up. KP also advised of programmes running in North East for any patients at whatever stage in their recovery and unable to come to terms with their diagnosis.

5.7 COD and CD discussed the NICE Guidelines use of Opioids in Palliative Care. Most of the requirements are met in the Network Guidelines in terms of the general use Opioids, where there are issues is with written information for patients when commenced on step 3 Opioids.

COD asked if anyone in the Network already have existing information or perhaps this area is something to look at as a Network project. CD and COD agreed to draft a paper.

Action: CD/COD

5.8 KP had noticed that the subject of Palliative Care was not mentioned in the majority of the NSSG Guidelines, she had therefore been adding a standard paragraph, which she agreed to forward to COD to ensure accuracy.

Action: KP

6. Date of Next Meeting and for 2012

All 2.00 pm - 4.00pm - Kestrel House, Board Room

Thursday 27th September
Thursday 15th November

Dates of Meetings for 2013

All 2.00pm - 4.00pm, Middle and Annexe, Swift House

Thursday 31st January
Thursday 7th March
Thursday 9th May
Thursday 4th July
Thursday 26th September
Thursday 14th November