Yorkshire and the Humber Kidney Care Conservative Care Forum Tuesday 14th October 2014 1300-1630

Notes

1. Welcome & Introduction

A welcome and introduction was conducted by Dr Lynne Russon, Chair, Consultant in Palliative Medicine.

The group were notified that all presentations are available on request. Please contact Sarah Boul – sarah.boul@nhs.net .

2. Advance Care Planning (ACP) (Pam Davison & Liz Green, Renal Nurse Specialists, York Teaching Hospitals NHS FT)

Pam Davison and Liz Green provided an overview of the Advance Care Planning (ACP) work they are currently undertaking. The work, funded from two NHS Kidney Care projects, is focussed around pre-dialysis patients in York and Pam and Liz explained how the funding has been spent.

The project has a focus on conservative care and empowering patients to engage with ACP to plan their end of life care.

The "York Against Cancer" website (http://www.yacpalliativecare.co.uk/service/renal-service/) have agreed to include a page for Renal. The information is intended to give guidance regarding end of life management of patients with Chronic Kidney Disease including:

- Management of Uremic Symptoms
- Patient and Family/Carer leaflet
- Renal LCP

Please see the presentation notes for further details.

Questions, Answers and Comments:

Comment: In terms of ACP, and a high number not being undertaken, completing a DNAR could be classed as ACP and completion of this could then lead onto other discussions.

Reply to Comment: The focus should be on having the discussion rather than the documentation. It is important to discuss these things but they do not have to be written down, trusts can choose to do ACP or not.

Comment: Your work suggests a change in culture.

Reply to Comment: It is very important to talk to patients for whom dialysis is no longer working. The transition from dialysis to conservative care is the next stage. However, patients are not always receptive to ACP, as they find it depressing and "not for them". These are difficult conversations but a lot of lessons have been learned from them.

Question: Is the Cause for Concern register just for patients on haemodialysis?

Answer: No. Each unit has a register of cause for concern patients.

Question: How often is the Cause for Care register updated and how is it monitored?

Answer: Patients on the register are discussed at MDT meetings. The patients are categorised as stable, deteriorating, EOL. For the deteriorating patients we would look into why they are deteriorating. We would get more involved offer telephone numbers and work with District Nurses.

Question: Are you happy to let the patients go from being direct renal patients, as they sometimes have other co-morbidities?

Answer: Yes. If patients are discharged to the GP then advice and support is offered to primary care.

Question: Do you have involvement with other units i.e. haemodialysis? Who takes the lead for discussions?

Answer: Yes. We do get involved but it depends on staff time on the units, we try to get people to attend sessions to learn about ACP and we also talk to individual staff members. Doing 1-1's on units is very good for engaging staff. Units are getting better at letting us know about deteriorating patients so that the ACP talk can be held before it reaches crisis point. It is very important to ensure that the discussion about ACP has been held in advance of patients reaching a crisis point so that beds in hospices etc. can be secured. Not knowing in advance can mean it is hard to get beds and patients don't end their life in their preferred place.

Comment: Deprivation of Liberty (DOLs) may help to advance the priority of ACP conversations. Having the ACP discussion and plan put in place before patients lose capacity is very important and could assist with issues caused by DOLs after a patient has lost capacity.

3. SAGE & THYME in Leeds (Nicky Lamb, Nurse Educator, LTHT)

Nicky Lamb advised the group how SAGE and THYME has been implemented across Leeds Teaching Hospitals, and the plans for further roll-out.

Please see the presentation notes for further details.

Question: Is SAGE and THYME something that LTHT has considered making mandatory training?

Answer: SAGE and THYME has the support of the matron and the Chief Executive. This has helped to raise the profile of the training but it has not yet been made mandatory.

Question: How have you offered the course and who has it been offered to?

Answer: The training has been offered to everyone who has contact with patients. Training is offered via the LTHT training website and in the staff & training bulletins. Organisational Learning within LTHT has promoted the training, with stands and displays around the Trust, and word of mouth has been really important for example, a consultant in oncology has been promoting the training.

Question: Where are the training teams based within LTHT?

Answer: One is based in Renal, one in Midwifery and then staff within the Organisational Learning.

Question: Is the main method of teaching a 3 hour session?

Answer: Yes. The basic workshops take 3 hours and can be for up to 30 people. However, at LTHT, due to issues with room availability, the sessions are for 20 people maximum but smaller groups has increased active engagement in the sessions.

Comment: It is interesting that basic life support is mandatory training but training on communications is not, particularly given that communications is one of the biggest areas of patient complaints.

Question: Has the Trust paid for the extension of the training license?

Answer: Yes. It has been agreed that it is better having staff in house that can run the course rather than bringing in external facilitators for the 3 day course. LTHT have found that since running the training in midwifery the number of complaints about communications have reduced significantly.

Question: How many doctors in renal have been on the training?

Answer: None. We haven't focussed our full attention on pushing the training with doctors but acknowledge that it is important they have the training.

Comment: It was suggested that doctors would benefit from SAGE and THYME to compliment other training that they receive. It was suggested that the sessions could be held on a Wednesday during regular study time. However, difficulties with using this time were also acknowledged, as SAGE and THYME is a 3 hour session.

4. **The Role of the Cultural & Health Improvement Officer** (Tahira Akhtar, Cultural & Health Improvement Officer, Bradford Teaching Hospitals NHS FT)

Tahira provided an informative presentation regarding the role she holds as Cultural & Health Improvement Officer at Bradford Teaching Hospitals.

Please see the presentation notes for further details.

Questions: How many patients do you deliver services to?

Answer: A lot of patients. The work is varied so it is hard to quantify but it is a highly utilised service within renal and within the community. There is the potential for the role to be used as an interpreting service and so Tahira has to be very specific about the remit.

Question: Is the post full time?

Answer: No, it is 30 hours only and due to demand can sometimes be overwhelming.

Question: Is the post a stand-alone post?

Answer: Yes. Bradford renal unit does not have a social worker and it was decided that the Cultural & Health Improvement Officer was more valuable to the unit than a social worker. The role has value because Tahira is able to spend time working with patients to find out. For example, that they may be non-compliant with their medication because the medication contains gelatine, alternatives can then be explored.

Question: It is often difficult to discuss conservative care with South Asian patients as they perceive conservative care as not doing anything. How do you tackle this?

Answer: Culturally people do think that conservative care is not providing any treatment but the way to counter this is to talk to them and explain the system. Culturally it is believed that hospital treatment is the best treatment and often family members will push for hospital treatment over the wishes of the patient. However, the patient's rights are important and it is important to be the voice of the patient and not be bowed by pressure from older or younger generations of a family group. Following discussions with Tahira about the benefits of conservative care numbers have increased.

Question: Are issues around care more about communication rather than culture?

Answer: Yes. There are cultural issues but often a certain stance is taken because a patient may not understand what is being communicated rather than them objecting from a cultural perspective. Tahira advised the group about masculine culture in Islam and how this can affect the conduct of appointments and communications. Tahira stressed the importance of championing the rights of the patient.

Question: Do you work with PD patients as well as HD? How do they get on with training on PD?

Answer: We do work with PD patients and they generally get on well with the training. The younger generation like PD and female patients like it for the privacy it offers. The PD team train patients and their family and Tahira can go along to training sessions to provide support and explanations in the patients' own language if necessary. However, the majority of patients do opt for HD.

5. Symptom control in end stage renal disease (Dr Lynne Russon, Consultant in Palliative Medicine, Leeds Teaching Hospitals Trust (LTHT))

Dr Lynne Russon presented an educational overview of medicines that could or couldn't be used in end stage renal disease.

Please see the presentation notes for further details.

There were no questions following the presentation.

6. Conclusions, Evaluation & Close of meeting

The meeting was closed by Dr Lynne Russon.

Any further comments should be given to Rebecca Campbell, Quality Improvement Manager, Yorkshire & the Humber Strategic Clinical Network on 0113 8253448 or rebecca.campbell6@nhs.net

Copies of the presentations are available on request. Please contact Sarah Boul: sarah.boul@nhs.net.