Yorkshire and the Humber Kidney Care
Conservative Care Forum
Tuesday 25th February 2014 1300-1630

Notes

1. Welcome & Introduction

Welcome and Introduction by Dr Lynne Russon, Chair, Consultant in Palliative Medicine.

Please note: Presentations are also available on request.

2. National Developments and Yorkshire & the Humber Strategic Clinical Network End of Life Care Work

Dr Fiona Hicks, Consultant in Palliative Medicine, LTHT, provided an overview of national and regional developments.

The National End of Life Care Programme ended in March 2013. Two workstreams have been continued by NHS Improving Quality. These are:

- Transforming end of life care in acute hospitals
- EPaCCs

The other work streams have not continued.

The resources from the National End of Life Care Programme have been archived on the NHS Improving Quality website and are still available, although difficult to find!

The National Clinical Director for End of Life Care within NHS England is Dr Bee Wee.

It was noted that there are plans to refresh the End of Life Care Strategy.

Prior to the 1st April 2013, Strategic Health Authorities had regional End of Life Care Programmes. In some areas this work has transferred to the Strategic Clinical Networks (SCN), for example in the North West. However this is not the case for most SCNs, including Yorkshire and the Humber. Subsequently Dr Wee offered funding to develop Palliative Care Networks. The YH SCN accessed this funding and asked Fiona to act as lead. A GP Lead from South Yorkshire and a GP Lead from East Yorkshire have been funded along with some administrative support. A regional meeting was held recently to discuss the potential.

Health Education Yorkshire and Humber have continued to support End of Life Care education and training initiatives across the Yorkshire and Humber region. An event will be held on 25th March in Leeds and there may be some places remaining.

Health Education Yorkshire and Humber also continue to fund work with consultants not in palliative care. This is currently being evaluated for Leeds and Doncaster, and will be extended to two further Trusts, Sheffield & Harrogate with a training day scheduled for March 2014.

Good links have been established with the dementia and neurology SCNs, alongside those established with renal.

Amongst the list of priorities it was noted that some CCGs have locality groups, whilst others do not. A scoping exercise will be undertaken to identify which areas have locality groups and which do not.

With regards to the future, Fiona reported that the funding was for November 2013 to March 2014, it is not clear whether there will be further funding beyond this or whether the YH SCN will agree to support a YH Network. Although there is clear local interest in developing a Network.

Fiona also took the opportunity to announce details of a Post CCT Fellowship in Palliative Care. This is a one year post. The College will quality badge and accredit for free, but the Trust will need to fund the post. Further details are available on request.

Question: Would the fellowship post be regional, across more than one centre?
Answer: There will be enough to do within one centre. It is written so that it could be a trainee with a CCT in Renal medicine or palliative medicine.

Comment: Also note that the individual will need a mentor/education supervisor and would be expected to produce a brief report.

Question: With regards to the CCG engagement, how difficult has this been across 24 CCGs? Are there dedicated EOLC leads?
Answer: CCGs have engaged and have nominated leads. There are links with CCG priorities such as moving patients into the community, integration and quality.

Comment: EOLC is also of interest for Trusts as it is on the CQC inspection list.

Question: Are CCGs working together? For example LTHT serves the patients of 7 CCGs.
Answer: The three Leeds CCGs are working together, whilst the others are working more independently and these have not been directly engaged as in Leeds 75% of patients come from the Leeds area so the priority has been to work with these CCGs.

3. Liverpool Care Pathway – National Position & Local Plans

Dr Lynne Russon, Consultant in Palliative Medicine, LTHT, presented an update in relation to the Liverpool Care Pathway (LCP).

Following the adverse publicity regarding the LCP and the Neuberger report which followed in the summer of 2013 a National Alliance has been set up to produce nationally agreed standards for end of life care. This is currently an important political issue. It has been reported that non palliative care teams are missing the symptom control guidance particularly in the last few days of life. Although the LCP is not nationally withdrawn until July, most Trusts have already removed the documentation. It has been fed back through all channels nationally that this has resulted in a deterioration of care in the last few days of life.

It is anticipated that there will be no national replacement for care in the last few days of life. Guidelines and standards will be produced locally although these will be shared regionally to ensure a collaborative approach.
End of life care in Trusts is also likely to become more important as it is one of 8 areas to be included in CQC inspections in the future.

An app has been produced by the YH Deanery which includes both renal information and end of life symptom guidelines – **Fiona Hicks will circulate the details.**

Comment: Shareen Siddiqi reported that in Sheffield the LCP was not used, rather the Integrated Care Pathway is used. Consequently this is currently still in use and is also renal specific. There are groups in STH looking at the pathway and it may have to be removed in July.

Question: If the LCP actually addresses the issues and is best practice, should more efforts not be made to look at adapting it rather than stopping use.
Answer: Use continues in Liverpool, although the name has been changed, however most Chief Executives are not prepared to continue use as it is a highly political matter.

Comment: The replacements will not be called a care pathway. The report was entitled 'More care less pathway'. In fact the LCP is not a pathway. The main focus is on reviewing and assessing every four hours. However in future all patients will have an individual end of life plan.

Comment: Communication continues to be a crucial factor. In Sheffield, Shareen explains to patients what the integrated pathway is, and if patients have heard about it also explains what it is not. There needs to be a dialogue with patients and carers.

Question: Will there be a renal variant? This is not currently used in Bradford. Would the regional group agree this?
Answer: This will be discussed in the coming months. It is common for there to be calls asking for advice re renal impairment.

Comment: Charlotte Rock, Chair of the Sub-regional Group, responded that there are local differences, e.g. use of diamorphine versus morphine, but the core themes should be the same. This is an opportunity to look at local guidelines.

4. Do Not Attempt Resuscitation (DNAR) Forms & Dialysis Patients

Charlotte Rock, MacMillan Clinical Nurse Specialist, Bradford Teaching Hospital, gave a verbal update and led a discussion on a couple of regional wide issues.

<u>DNAR forms</u>
The latest draft (v13) was circulated to the group for review. These are not to be used or shared more widely as implementation and launch dates vary across sites. The forms will therefore come via the Trust and not from a central point.

The form will be reviewed in three years.

The regional group are also developing patient information. There has been a good response to the Easy Read version and the plan is to revise this. It is hoped that this will be completed by the end of the year.

<u>Dialysis Patients</u>
A number of queries were raised with regards to renal patients who are not for CPR but make frequent visits to hospital, for example dialysis patients. What happens with the form? Does the patient bring it? How often is it reviewed? Is there consistency in practice? What happens if the patient forgets to bring the form?

Charlotte highlighted three areas for discussion:

i. Current practice re DNAR and frequent attenders
ii. Option for consistent practice
iii. Is it just DNAR CPR or are there other issues to be considered.

The original form has to be in the ambulance each time. This is a legal obligation. It was confirmed that the form does not need to have been printed in colour, but does need to be the original version.

There was a discussion regarding version control as copies are often kept in the notes in the unit. This could be an issue as the form may have been updated. It was not known whether scanned version were legal.

It was noted that the ambulance staff have had training regarding end of life and a learning resource has been produced.

It was agreed that the ambulance staff need to know as the patient gets into the vehicle. This may be easier if there are a small number of patients/ drivers. However, the issue remains that the original form needs to be seen.

Several proposals were made including shrinking the form to credit card size, use of a bracelet or the 'message in the fridge' approach. In York patients carry a passport, this works particularly well for those in nursing homes where the staff can handover to the ambulance staff. The form could be included in a passport for dialysis patients, which could also include other information such as fistula details.

It was not known how many patients in the region currently have a DNAR form, but it was agreed that the number would be increasing.

Pam Davison agreed to share the York Passport.

Lynne & Charlotte will check with the lawyers regarding what is possible legally.

Question: Is the form available in other languages, what provision is made for those for whom English is not the first language?
Answer: It is only produced in English. The form is about the decision made and is to communicate this decision to health professionals. Communication needs to happen with the patient and carers regarding the decision, and where necessary this discussion should take place with interpreters and patient advocates.

Question: There are many dialysis patients who do not want to talk about this. It may also be that the discussion takes place as part of advance care planning but that the patient is not then approaching end of life for several years.
Answer: There is a concern regarding review which should be undertaken regularly, even if only annually for some dialysis patients.

5. Sheffield Service Update

Dr Shareen Siddiqi presented an update on developments in Sheffield since her appointment in October 2013.

Question: Is a decision aid tool used in the conservative care clinic?
Answer: The decision is made in the pre-dialysis clinic and YoDDA is used as part of the decision making process. The decision is reviewed on arrival in the conservative care clinic.

Question: The presentation made reference to plans to develop a Symptom Control Clinic, is this for dialysis patients?
Answer: Yes.

Comment: With regards to tariff, a clinic outcome form is completed and as the clinics are operated jointly with the conservative nurse specialist then they qualify for the MDT tariff. The follow-up MDT tariff is higher.

Question: Since the conservative care clinic has been established, has there been a surge of referrals or greater acceptance of conservative care as an option for patients?
Answer: The number of queries regarding dialysis withdrawal has increased. The changes have allowed for ownership of conservative care and the associated decisions.

Question: What is the difference between the symptom control clinic and the dialysis clinic? Is symptom control not discussed in the dialysis clinic?
Answer: Symptoms are not necessarily discussed or are one of many other things.

Question: Is there an increase in the use of dialysis as symptom control?
Answer: Yes. There have been cases of palliative dialysis for symptom relief.

Question: What provision is there for patients of the satellite units?
Answer: There are no outreach clinics at the satellite units so patients are required to come to Sheffield.

6. The Conservative Diet

Helen Scott, Renal Dietitian, LTHT, gave a presentation on the Conservative Diet. At present there is no evidence base for this area, it is purely based on clinical experience. However a dietician from Wales has contacted Helen and they hope to look at this further.

Question: With regard to phosphate binders, why is Calcichew used locally when NICE guidelines suggest using Calcium acetate?
Answer: There is no reason, except perhaps price.

7. EPaCCs Update and Register Feedback

Dr Lynne Russon gave a brief update on EPaCCs and provided slides showing the new pages on BHLY.

Hull reported that their own 'Cause for concern' pages have been added within the last month but they are not using them in their MDTs yet.
In Leeds the register is known as the Enhanced Care Register and information from the conservative screen will feed in to the register page.

SystmOne is used in Bradford. This allows for good communication between primary and secondary care.

The relevant page will be added to BHLY in the next couple of weeks. It allows for communication within renal regionally (with the exception of Sheffield and Doncaster).

Question: Is it possible to generate a report of patients on the register?
Answer: Yes, in theory. (This has since been discussed with Sara Eastwood and will be possible when the BHLY pages go live).

It was agreed that this will be an agenda item at the next meeting, with an update on register progress from each unit.

8. Conclusions & Close

Dr Lynne Russon thanked everyone for their attendance and contribution.

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