Yorkshire and the Humber Kidney Care Conservative Care Forum
Tuesday 24th June 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. Contact *Rebecca.Campbell6@nhs.net*

2. 'End of the road and new beginnings' - Replacing the Liverpool Care Pathway

Dr Jeena Ackroyd, Consultant in Palliative Medicine at Calderdale & Huddersfield NHS Foundation Trust provided an update on plans to replace the Liverpool Care Pathway.

NHS England has highlighted that when it is thought that a person may day within the next few days or hours, the Priorities for Care are …

i. that this possibility is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.
ii. Sensitive communication takes place between staff and the dying person, and those identified as important to them.
iii. the dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
iv. the needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
v. an individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

Calderdale & Huddersfield NHS Foundation Trust have developed a document, iCODD (Individualised Care of the Dying Document) which is being piloted in wards and Hospices. The iCODD includes prompts to remind staff of the five priorities of care.

Question: Has there been any opposition to producing a booklet?
Answer: The document has been produced by a working group which included other professionals. It has been made to look like existing care plans.

Comment: All Trusts are trying different approaches. There will not be a single document and this is the intention. For example, in Bradford there are separate medical and nursing documents.

Comment: Only Leeds is ready with a new document. The rest are piloting and it will not all change by 14th July. There will be interim arrangements.

Question: The presentation made reference to an embargo on AMBER, what has prompted this?
Answer: In light of the issues with the LCP, the national team has been very cautious. The focus is on evidence and research using those already participating in the AMBER Care Network. New hospitals are not currently able to join.

Comment: Reference was made to a recent DNACPR breach.

Comment: Consideration should be given to including questions about communication and language spoken in the iCODD.

Comment: The symptom control guidance of the LCP is being missed by many and there is a push to develop this guidance and create an app.

Comment: In relation to communication skills training, it is not yet clear whether training will be mandatory. There may be a push from the CQC.

3. EPaCCS – Leeds development of the electronic record for palliative care patients and how it will integrate with the renal registers

Karen Henry, CNS Team Leader at LTHT provided a summary of development of EPaCCs in Leeds.

Electronic Palliative Care Co-ordination System (EPaCCs) is an electronic summary of up-to-date patient information to inform end-of-life decision-making and care delivery at the point of care across service boundaries, for patients in the last months/years of life who have consented to have their data shared. It is an 'electronic out-of-hours form' accessible in all care settings – including out of hours (OOH) and ambulances.

This work commenced in 2009 with Department of Health funding, however there was a delay in enabling the electronic systems to talk to each other. A pilot phase with 4 practices was undertaken between November 2011 and March 2012. All but three SystmOne Practices are now live and all of the community nurses are now using EPaCCS, along with both hospices. The acute Trust has an EOLC tab in PPM and a view in PPMP, and the out of hours service has access to a view. Four EMIS practices are piloting EPaCCS and the plan is to roll-out to the remaining SystmOne GPs and develop interoperability between all IT clinical systems across Leeds.

The impact to date has been an increased number of patients on EPaCCS and identified as palliative. GP practices are thinking about increasing the frequency of Gold Standard Framework (GSF) meetings and GSF meetings more structured and thorough. More patients have OOH and DNACPR forms completed.

It is expected that implementation of EPaCCS will result in:

- More patients dying in their preferred place of death
- Fewer unplanned hospital admissions
- Greater co-ordination of care between all services
- Starting to get quarterly data from July 2014

4. SAGE & THYME in Sheffield

Shirley Thompson, Manager of South Yorkshire Education in Cancer & Long Term Conditions at Sheffield Teaching Hospitals, presented an overview of the implementation of the SAGE & THYME within the Trust.

'SAGE & THYME' is a mnemonic which guides healthcare professional/care workers into and out of a conversation with someone who is distressed or concerned. It aims to provide

structure to psychological support by encouraging the health worker to hold back with advice and prompting the concerned person to consider their own solutions.

SAGE & THYME is designed for foundation level communication, suitable for any member of staff (e.g. medical secretary, outpatient clerk, nurse, physiotherapist, doctor, social worker, student) and for any specialty. It is suitable to be used with patients and carers, students, colleagues and children – anyone who is distressed or concerned – inside and outside of health and social care.

SAGE & THYME is taught in a 3 hour 'SAGE & THYME foundation level' workshop for up to 30 participants using three facilitators.

There have been twelve workshops in Sheffield since June 2013 with 215 attendees. There are five facilitators and workshops are currently delivered one per month. The intention is to increase the number of facilitators to seven and deliver more sessions per month.

Shirley reported that it can be a challenge to find training dates which suit three facilitators, to book venues and to enrol 30 delegates. There is an average of 22 attendees at the workshops. Delegates are also required to arrive on time and this has caused some problems.

To overcome some of these challenges, workshops are attended by mixed groups of staff to enable better attendance. This has also resulted in improved dynamics in the workshops, as staff feel more able to speak openly. Continual advertising and liaison with department leads and managers is required to ensure that staff remain aware of the workshops. Advance planning is also essential to ensure facilitator and room availability.

Question: Is the training voluntary or mandatory?
Answer: It is voluntary but management are encouraging staff.

Comment: Leeds are planning to make SAGE & THYME mandatory and there is an ambition to have 36 facilitators.

Question: How is the impact of the course being evaluated?
Answer: The developers of SAGE & THYME have undertaken research into its impact. STHT has been approached to do some pre & post evaluation.

Comment: One method of evaluating the impact may be to look at the number of complaints. Comparisons could be made between the number and type of complaints before and after implementation of the training. Communication is one of the top reasons for a complaint.

Comment: Shirley noted that all attendees complete an evaluation form. The most common feedback received is that it has given the staff member the confidence to approach patients.

5. Sheffield Update: Register Development & Communication Skills

Dr Shareen Siddiqi, Consultant Nephrologist, gave a verbal update on developments in Sheffield.

The update included details of plans for one of the satellite units to launch a Supported Care

Register in September. Staff at this unit will be undertaking the ACP training. The intention is to then roll-out across the other sites. There have been some issues regarding the name and ensuring that the advanced communication training has been completed prior to the launch.

Shareen also reported that a talk is planned about DNACPR and work is underway in relation to GP communication. Shareen also highlighted that staff are still nervous about advance care planning.

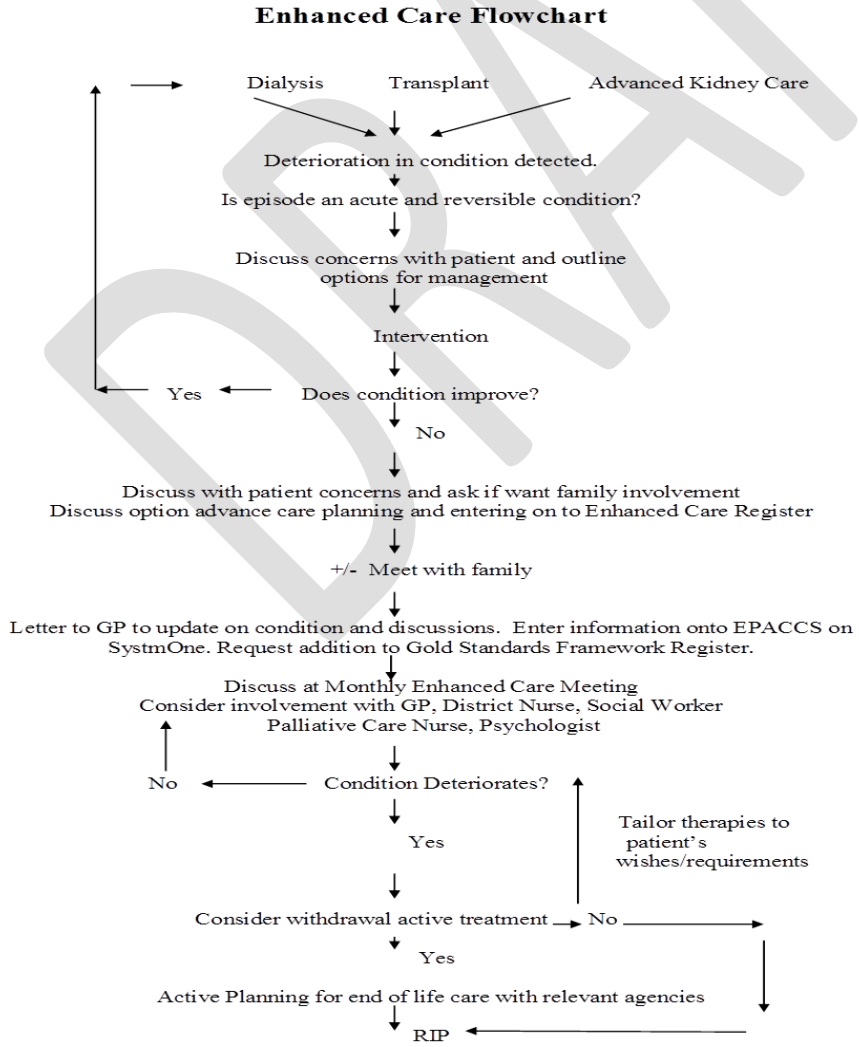
Comment: There is some sensitivity regarding naming. For example, NHS IQ has removed all reference to 'pathway', 'register' and 'list'.

There was some discussion regarding seeking consent for inclusion on EPaCCS. Karen noted that it can be considered as adding to the existing record, if confident that the patient has already given consent.

6. Bradford Update

Vicki Hipkiss, Pre dialysis nurse at Bradford Teaching Hospitals NHS FT, gave a presentation on the development of the Enhanced Care register in Bradford.

The following flowchart has been developed:



Question: What is Gold Line?
Answer: Airedale NHS Foundation Trust received £500k to improve End of Life Care. This resulted in the development of the Gold Line. This is a new dedicated service for people who are being cared for on the Gold Standards Framework. It is a single point of contact for patients and carers and provides access, help and advice 24 hours a day, 7 days a week.

It is an alternative to 111, and the senior nurse who answers the call is able to access the palliative care record. Feedback has been good.

Question: What happens to patients who do not engage and are therefore not added to the register?
Answer: Generally the aim is to obtain permission first, and patients would not be added to the Enhanced Care Register if they say no. However, these patients would be added to the pre-registration section to ensure that they are not lost.

Comment: 300 patients have been identified on EPaCCS and 75-80% are achieving their preferred place of death.

Comment: Feedback from GPs is that being able to access patients on SystmOne is very much valued.

7. Leeds Update

Dr Lynne Russon provided an update on the development of the Enhanced Care Plan in Leeds. There have been significant delays due to IT issues. The plan now is to have a renal register page in BHLY and request a paragraph in GP letters asking them to add the patient to EPaCCs following a clinic or MDT until direct access to EPaCCs or PPM is possible.

There will be a presentation at the next renal morbidity and mortality meeting in September, Karen will also be attending, when the renal register will be officially introduced to the department.

It was noted that it is useful that clinic letters, containing wishes and preferences, are now available to view across the Trust, for example when a patient presents to A and E.

8. York

Liz Green, Renal Specialist Nurse, was asked to give a brief update from York. Liz reported that IT systems do not communicate, however there is a Cancer website which hosts Renal information. Use of BHLY is still under development.

There were difficulties implementing SAGE & THYME as this was limited to renal and there were problems with facilitator availability.

9. 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.