Yorkshire and the Humber Kidney Care
Conservative Care Forum
Tuesday 3rd March 2015 13:30-16:00

Notes

1. Welcome & Introduction

A welcome and introduction was conducted by Dr Lynne Russon, Chair, Consultant in Palliative Medicine at Leeds Teaching Hospitals NHS Trust.

Dr Russon welcomed Gwyneth Whitehead, Palliative Care Community CNS, from Wheatfields Hospice to the forum and advised that Gwyneth would be providing the forum with information and experiences from a community setting.

Dr Russon advised the forum that the agenda was mainly focussed on case discussions and what we could learn from these experiences.

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

2. Advance Treatment Options- whose choice is it anyway? (Vicki Hipkiss, Pre dialysis nurse, & Tahira Akhtar, Cultural & Health Improvement Officer Bradford Teaching Hospitals NHS FT)

Vicki and Tahira introduced a case study to the group, which charted their difficult experiences with a patient and her family throughout the renal pathway, how they managed this experience and what they learned from it.

Please see the presentation notes for further details.

Questions, Answers and Comments:

Question: Did the patient state that she did not want dialysis?

Answer: Not initially. However, she then changed her mind on return from a trip abroad. The patient saw two Consultants for PD and the Consultants were asked to ensure that this was what the patient really wanted. In the end it appeared that the patient had treatment options desired by her family not the treatment options she wanted.

Comment: We had a similar patient and due to their cultural background they were unable to independently decide on their treatment of choice.

Comment: The patient in our case study was different, in the sense that she was very independent and had the ability to make her own decisions. However, as she became frail the decision was taken out of her hands.

Comment: We have had issues with young people of different cultures also not just frail and elderly patients. Some young patients have refused transplants and been non-compliant with dialysis due to being needed at home to look after children. However, we have given such patients as much support as we can on the unit and have referred a few to safeguarding.

Question: You have indicated that you were concerned that your patient was not managed how she wanted to be. How would you have altered the outcome?

Answer: We would not have wanted our patient to go through what she went through. She wasn't strong enough and we wish she hadn't had to go through the experience she did. Conservative care might have meant she had a longer life.

Comment: The treatment decision was made by a family that sees dialysis as treatment but did not see Conservative Care as an option.

Comment: The family were very educated and wanted their mother to have dialysis treatment and unfortunately Tahira was not involved in the latter part of the patients care and so could not provide supportive assistance.

Comment: The patient's views were documented but in the end she went with her families wishes.

Question: Was there an opportunity to speak to the patient alone?

Answer: Unfortunately there wasn't an opportunity to do that. If she had lived alone we could have taken the opportunity to speak to her but as soon as she moved to her son's house she could not be seen alone. The weaker she got the more influence her family had. In the future though we would want to aim to talk to patients alone.

Comment: I once asked an interpreter to come to an appointment to try and ascertain what a patients real wishes were as it had become clear that their family was not interpreting their wishes honestly.

Comment: Tahira also does this as, on occasion, some family members do not allow the patient to speak.

Comment: As patients' get frailer often family opinion takes over.

3. **Community Palliative Care Services and their Integration into Wider Community Services** (Gwyneth Whitehead, Palliative Care Community CNS, Wheatfields Hospice)

Dr Russon introduced Gwyneth, a palliative care community nurse from Wheatfields Hospice and advised the group that Gwyneth was also a nurse prescriber. Dr Russon advised that the hospice has funding to provide a 7 day service for palliative care and being able to provide this 7 day service has made a huge difference for patients in Leeds. An independent audit has confirmed the effectiveness of this service and provides evidence for better integration of services.

Gwyneth advised the forum of her job role and presented a case study.

Please see the presentation notes for further details.

Questions, Answers and Comments:

Questions: What is the gold standard framework (GSF)?

Answer: The GSF is essentially a register for people who are deemed to have less than a year to live. Each surgery runs them differently but it generally entails a monthly meeting per practice to discuss who is on the GSF and to make sure people who are actively involved in the patients care are aware of the people on the register and that they are getting the right treatment. Access to the register for patients differs between surgeries. The framework intends to support people at home and to keep professionals informed of their care.

Question: How many patients might be on the GSF?

Answer: Approximately 7-8 at each GP surgery but for surgeries that cover nursing homes it can be up to 20 patients.

Question: How many GP surgeries do you cover?

Answer: Around 8 surgeries

Question: Do you see all their palliative care patients?

Answer: I see the ones referred to me and any that the GP asks me to review.

Question: Do you see patients for a set period of time and then discharge or do they stay on your books?

Answer: Generally they stay on the books for visits. However, if they are doing okay then I maintain just phone contact. It is important not to restrict people they need plenty of options for getting in touch.

Question: Is 3 months the minimum amount of time for the GSF?

Answer: It is QOF point for 3 months but amount of time on the register is variable.

Comment: In Calderdale there is a lot of variation in levels of accessibility and service.

Comment: A GP should know about a patient in the last three months of life

Question: Can I, as a Consultant, put a patient on GSF?

Answer: Yes and Consultants should. On SystmOne it can be highlighted and this works well in Bradford.

Question: Is the care varied?

Answer: It is varied but all surgeries should know how to operate the GSF correctly. It is important to work with people and build up relationships and ensure everyone is working to the same standard.

Comment: We as Consultants need to be more generous with our information. GPs have said they need more information about timescales and prognostic markers from Consultants and we should include in our letters when it is appropriate to patients to the GSF register.

Comment: In Bradford on SystmOne we are able to put contact points with telephone numbers so GPs can call to be certain of what needs to happen with a patients care.

Comment: GSF is being highlighted on the palliative care commissioning agenda. The intention is to set up a single point of access and, for patients on GSF, or on the palliative care register, they will be given a direct number to ring and be triaged faster. In Bradford and Airedale this is already working and it is called the Gold Line.

Question: Is the service 24/7

Answer: Yes

Question: Is it run by generalists?

Answer: Yes it is and they then refer on to specialities as necessary.

4. **A Challenging Case** (Dr Shareen Siddiqi, Consultant Nephrologist, STHT)

Dr Russon introduced Dr Shareen Siddiqi who is the Conservative Lead for Sheffield Teaching Hospitals.

Dr Siddiqi presented a case study in the difficulties of establishing and maintaining patient choice.

Please see the presentation notes for further details.

Questions, Answers and Comments:

Question: Do we do Advance Decisions to Refuse Treatment (ADRT)?

Answer: Yes but even after completing an ADRT patients can change their mind.

Question: Is ADRT legally binding?

Answer: Yes.

Comment: There are issues around choice dependent on a patient's culture. Also if other family members are having treatment they can influence choice of the patient wishing to undertake Conservative Care.

Question: Can it be a medical decision to decide not to dialyse a patient?

Answer: Yes it can be but generally you can only say no to dialysis when they are absolutely not medically fit.

Comment: We had a patient that ended up at A&E confused and non responsive and dialysis was started against wishes he had previously made. When he was fully conscious he was very angry at having been put on dialysis, came off dialysis and then died.

Question: Do other people find that patients state that they would like conservative care reputedly but then eventually choose to go onto dialysis?

Answer: Yes it does happen.

5. **Do Not Attempt Resuscitation (DNAR) Update** (Dr Lynne Russon, Consultant in Palliative Medicine, Leeds Teaching Hospitals Trust (LTHT))

Dr Russon provided an update to the forum on rules regarding resuscitation and the completion of DNAR forms.

Dr Russon advised the group that the latest version of the DNAR form (Version 13) had an additional section for commentary on the form being reviewed and now included a signature box. Dr Russon advised that there are four options on the form and Option D, stating resuscitation is of no clinical benefit and has not been discussed with the patient, is the box most often ticked by doctors in a previous audit at St James s hospital Leeds.

Dr Russon advised the forum to read the document "Decisions relating to Cardiopulmonary Resuscitation (3rd edition)", which can be accessed here:

http://www.resus.org.uk/pages/DecisionsRelatingToCPR.pdf

Dr Russon then presented the recent legal case of Mrs J Tracy and Addenbrooks hospital which was heard by the court of appeal in 2014. As a result of this ruling we now have a duty to discuss with patients and/or their families when the decision is made to make them

not for resuscitation. ‘Causing distress’ is no longer acceptable as a reason not to discuss only ‘significant psychological harm’

Please see the presentation notes for further details.

Questions, Answers and Comments:

Question: If a patient had a DNAR tattoo would you resuscitate?

Answer: Yes, unless they have a DNAR form.

Question: What if an ADRT is in place?

Answer: You still need the DNAR form too.

Comment: I would recommend that the best indicator for resuscitation is performance status. Make use of the WHO performance status and make your judgement based on this. If anyone has performance status of 2 and above in several large American studies nobody survived resuscitation to discharge from hospital.

Question: Do you make resuscitation a medical decision?

Answer: Yes we tell patients what our judgement is and why. We do not have an obligation to provide a treatment that will not work but we are obligated to discuss our reasoning with patients.

Comment: I had a dying patient and due to their culture I was unable to discuss dying with them.

Question: Could you recommend a way of wording to a patient to explain when resuscitation is not the right choice for them?

Answer: It is hard to know what to say and you have to judge individually how a patient will take things. We sometimes say this is the DNAR form and legally we have to complete it. We have decided not to resuscitate you, as it would not be successful and the procedure of resuscitation would be brutal for you. It is very important to reassure patients that they would receive all other treatment ie, resuscitation in its wider sense eg. fluids, antibiotics etc just not CPR.

Comment: As a non-medical person I believe that patients should have a choice. I agree that reasons for no attempt at resuscitation need explaining but patients should be offered a choice.

Question: Are there any cases where you have said we are not going to resuscitate and then a family has tried to sue the Trust?

Answer: No, patients cannot demand inappropriate treatment and that was tested in the courts several years ago. For DNAR discussions good communication is essential. The Tracy family did not question the decision just the fact that it had not been discussed.

Comment: Always make sure you document everything and remember that you do not have to provide resuscitation if medically it is not the right decision.

6. Conclusions, Evaluation & Close of meeting

Dr Russon asked the attendees to complete their evaluation forms, thanked the attendees and presenters and closed the meeting.

ACTION: If anyone has any topics for discussion or would like to present to the forum please contact rebecca.campbell6@nhs.net or sarah.boul@nhs.net.

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.