

**Yorkshire and the Humber Kidney Care
Home Therapies Forum**

Wednesday 25th March 2015

1400-1700

Medical Education Centre, Hull Royal Infirmary

Notes

1. Introduction and Welcome

A welcome and introduction were conducted by Dr Helen Collinson, Consultant Nephrologist, at Hull Royal Infirmary. Dr Collinson advised the group that this was the 14th Home Therapies Forum and that this was the third time the forum had been held in Hull.

Dr Collinson thanked everyone for attending the forum and highlighted that there was a good skill mix at the forum. Dr Collinson gave especial thanks to Amgen, for generously providing refreshments, and to all speakers and those who had assisted in the organisation of the forum.

Dr Collinson reminded everyone to complete the evaluation forms and advised that presentations were available on request via mail to sarah.boul@nhs.net.

2. Home Dialysis – Patient Perspectives

Marius Ndofor & John King

Marius and John presented to the group on their personal experiences of home haemodialysis. The first presentation was conducted by Marius and the second presentation by John.

Please see the presentation slides for further information.

Questions, Answers and Comments:

Question: Reflecting on your experiences it seems that a lot of patient education takes place but there is less focus on educating family or children. Would it be helpful if nurses and other professionals talked to children and explained what happens on dialysis?

Answer: Yes it would be very helpful.

Comment: Dave Border advised the forum that York hospital is developing a set of materials to help to children understand dialysis and its impact better. Dave Border advised that he would share the booklet once complete.

Comment: Helen Collinson suggested that paediatric materials should be

shared with families due to the “ripple effect” of impact on the wider family circle when a patient starts on dialysis.

3. Start-up Regime for New PD Patients in Hull

Phil Ward, C/N Home Dialysis Service, Hull & East Yorkshire Hospitals

Phil presented to the group on his experiences of implementing a new regime for patients on PD in Hull.

Please see the presentation slides for further information.

Questions, Answers and Comments:

Question: Have your patients reported any issues with drain pain?

Answer: Pain seems to be irrespective of the new regime but it should be noted that patients generally start on CAPD.

Question: Could I ask Marius how many bags he started on?

Answer: Two

Question: How cost effective is the new regime?

Answer: We have not yet analysed the cost per bag versus cost per session.

Question: How many patients do you have on PD?

Answer: The number fluctuates but there is increasing popularity. There are approximately 80 patients on PD, but over the last couple of years it has been up to 100.

4. Update on Reimbursement for Home Dialysis Patients

Linda Pickering, NKF

Linda Pickering advised the forum that patient Paul Taylor had raised the issue of reimbursement with her. Linda advised that she had written, on behalf of patients, to a number of health care organisations highlighting the issues associated to reimbursement for home dialysis patients.

Linda received a number of replies from hospitals in Yorkshire and the Humber and the North East regarding reimbursement and shared this with Kirit Modi, Chair of the NKF. Kirit discussed the information received from Linda with Richard Fluck who agreed to ask the BRS to investigate. Karen Jenkins, Nurse Consultant, at the BRS is now conducting a nationwide investigation into reimbursement rates.

Linda advised that the NKF had asked Karen to investigate two issues: the first being the amount paid to patients for heat, light, use of a television etc. and the second the way in which payments are made, as some payments are made by cheque and synchronised bank payments would be preferable.

Karen has advised Linda that she will not be considering patients on APD

during this review of reimbursement. However, Linda has been keen to champion the rights of APD patients to be considered also as she has been contacted by a number of APD patients who are struggling to pay their electricity bills.

Linda advised that Karen is due to feedback her findings at the end of March 2015 and these would be shared more widely as soon as possible.

Questions, Answers and Comments:

Comment: John King advised the forum that he receives reimbursement but since he has been with Fresenius his consumption has increased as the machine stays on for longer than it used to.

Question: Linda Pickering enquired if John's reimbursement was reviewed annually?

Answer: John advised no.

Comment: Helen Collinson advised that the hospital trust is considering an annual review but has not put anything in place yet. Helen stated that a national consensus is required to assist trusts.

Comment: Paul Taylor advised the group that he dialyses at home and does receive reimbursement but he feels that this needs pursuing for other patients who are in receipt of benefits and are unable, or struggle, to afford their energy payments. Paul also advised the forum that patients have reported issues with energy providers upping the tariff for patients making their bills unaffordable. It was suggested that a letter be sent to energy providers outlining this issue and that information regarding energy consumption costs should be included in patient information provided by hospital trusts.

Comment: Dave Border advised the forum that York is sensitive to these issues but also advised that the billing for energy consumption is very complicated due to tariffs repeatedly changing. Paul Taylor advised that Manchester had developed an algorithm to calculate payments. Dave advised that York uses this but due to constant tariff changes it is still a complicated process.

Question: An enquiry was made about the possibilities of linking in with other home services i.e. home oxygen services to find out how they reimburse patients?

Answer: Linda Pickering suggested it was worth investigating and would take the idea back to the NKF.

5. Baxter – Delivery Issues

Paul Taylor, West Riding KPA + Clare Granger, Regional Manager, Baxter

Paul Taylor addressed the forum and relayed his experiences of home haemodialysis. Paul advised that he had previously had dialysis on the unit but as he required more hours of dialysis he opted to try dialysing at home.

Paul then relayed to the forum his experiences of ordering stock from Baxter. Paul advised that he had experienced many issues with telephone ordering. He found that frequently after ordering via telephone items of stock were either missing or incorrect on the delivery.

Paul advised that he had requested the ability to order stock electronically and return via email. This was arranged by Baxter and was successful until the representative who processed Paul's orders went on maternity leave and Paul was subsequently advised to email two other Baxter representatives. Paul found that his emails were not responded to and incorrect items were again delivered. Paul stated that it would be appreciated if a reply email could be sent within 48 hours.

Paul also expressed issues regarding being informed about back orders by Baxter. Paul advised the forum that often, if an item was not available, this was simply stated on the delivery slip when stock arrived. Paul expressed concern that the item not delivered may have been required to allow him to dialyse that day and felt that patients needed to be notified in advance if items were not available to allow patients the opportunity to source necessary items from another source, such as the dialysis unit. Paul stated that it would be appreciated if Baxter could be advised within 48 hours of an order being submitted if they do not have relevant stock.

Paul also advised the forum that he had experienced issues with button hole needle stock. Paul stated that he has been ordering button hole needles but these have not been delivered and have instead been replaced with an unsuitable substitute. Paul advised that he has written to Baxter several times to express his concerns about why the stock of button hole needles is so low. Paul advised that, following his letters, Janet Wild from Baxter contacted him and advised that she would be allocating a key worker to process Paul's orders. Additionally, Janet Wild stated that she would ensure staff in the sales and supply departments were educated about different needle types, to ensure suitable alternatives are sent if button hole stock is low.

Clare Granger from Baxter then addressed the forum.

Clare apologised to Paul and to other patients who had experienced issues and stated that Baxter was genuinely committed to getting deliveries right for every patient. Clare stated that the supply issues do need to be addressed and provided further apologies regarding this.

Clare advised the group that Baxter had recently hired more representatives to process customer calls and advised that a programme of education was being put in place to increase expertise in the sales and supply team. Clare advised the forum that she was keen to pursue all individual concerns and was happy to take away any issues and complete a root cause analysis on these.

Questions, Answers and Comments:

Comment: Paul Taylor stated that from Baxter he would like to be informed if stock is unavailable and be informed when his deliveries are coming.

Comment: Dave Border stated that patients at York were experienced many issues, especially PD patients. Specifically deliveries have been arriving late with the wrong quantities of stock and patients have not been able to dialyse, which is very high risk. Dave stated that Baxter have been interactive on this issue but it has still not yet been resolved and more work needs to be done.

Comment: It was stated that Leeds are also experiencing issues with Baxter deliveries.

Comment: Clare Granger advised that Baxter want to be made aware of all the issues people are experiencing and stated that, if people are having issues, they need to contact the customer services department so this can be investigated and resolved.

6. Harrogate Self-Care and York Home Haemodialysis Service

Dr Dave Border, Clinical Lead, York Hospital

Dave Border provided the forum with a review of the York Home Haemodialysis service and provided information on the Harrogate Self-Care unit.

Dave invited all attendees at the forum to the opening of the Harrogate Self-Care unit on Friday 10th April 2015, 11am-12pm.

Questions, Answers and Comments:

Question: You have advised that it takes on average 43 days to train a patient for home haemodialysis. Is this 43 days of training whilst a patient is in dialysing or 43 consecutive days?

Answer: It is 43 days consecutively.

Question: For your cohort are most patients previous PD or Home Haemodialysis?

Answer: We have a mixture. We have had patients who used to be on home haemodialysis, got transplanted and then returned after their transplant failed. We have also had PD patients who then move to HHD.

Question: What is the average age of your home haemodialysis patients?

Answer: Patients tend to be young and tend to be men.

Question: How many patients do you have dialysing in the self care unit?

Answer: We have one in Harrogate and two currently in training. In Selby we had four but two have now been transplanted.

Question: Is your main unit NHS run?

Answer: Yes.

Question: Do patients have to sign a disclaimer to undertake self-care?

Answer: Yes and occasionally it can be a disincentive but we have received legal advice stating that we must ensure patients sign a disclaimer.

Question: Do patients bring their own drugs to the unit?

Answer: In Harrogate patients drugs are delivered to the unit.

Question: Are patients allowed flexible times for their dialysis?

Answer: Yes, to a point. The unit is open 7am to 11pm and so patients can use it during those times.

Question: Can patients use the unit to dialyse daily?

Answer: Yes.

Question: How much contact do HHD patients have with the nurse?

Answer: Patients can have as much or as little as they want we aim to be flexible.

7. Audit on Eating on Dialysis Days & BRS Role

Louise Wells, Dietitian, York Hospital

Dr Collinson introduced Louise Wells to the group.

Louise provided the group with a presentation on a hospital based audit conducted at York. Louise stated that listening to the patient presentations earlier had already highlighted the dietary restrictions of dialysis and the audit provided further learning for the group.

Louise advised the group that if anyone had any questions with regards to her presentation she could be contacted via email at Louise.Wells@York.NHS.UK.

Louise advised the group that she is also a Vice-President for the BRS, working on quality improvement. Louise also advised that she is working alongside Karen Jenkins, who is undertaking the reimbursement project. Louise stated that the BRS is a key association for professionals and patients. It is multi-professional and brings everyone together.

Please see the presentation slides for further information.

Questions, Answers and Comments:

Question: Currently for patients on the afternoon session of dialysis we provide them with a sandwich and a cup of tea. Reflecting on your audit findings should we be providing more refreshments?

Answer: A recent journal article has touched on this and it is clear that provision of refreshments is varied depending on individual unit policy as to whether patients should be eating when on dialysis. There is a clear link between time of dialysis and poor nutrition and we should be finding more creative solutions for people to eat and food to be provided when on dialysis.

8. Renal Patient View for Home Dialysis Patients

Dr Adil Hazara, Research Fellow, Hull & East Yorkshire Hospitals

Dr Collinson Dr Hazara to the attendees and advised that Dr Hazara was both a Research Fellow and Renal Registrar at Hull & East Yorkshire hospitals.

Dr Hazara presented to the group an overview of Renal Patient View. Please see the presentation slides for further information.

Questions, Answers and Comments:

Question: Many websites now allow users to create a login and password on the site itself. Can Renal Patient View offer this?

Answer: Yes. The ability to set up a login is available on the website.

Comment: Linda Pickering advised the group that a letter has been sent to the 10% of patients who do not currently use renal Patient View encouraging them to open an account.

Comment: Michael May advised the group that the best new feature of Renal Patient View was that it provided an email alert service when new results come in to the system.

9. Closing Remarks

Dr Collinson thanked everyone for attending the Forum. Dr Collinson gave especial thanks to the speakers and to those who assisted in organising the Forum.

Any further comments about the Forum should be given to Rebecca Campbell on 07825 256356 or Rebecca.campbell6@nhs.net .

Copies of the presentations are also available on request from sarah.boul@nhs.net.

10. Next Meeting

Please note that the next Forum will take place on 22nd September at 14:00 - 17:00 (lunch from 13:00) in Harrogate.

In addition please note the next Shared Haemodialysis Care Learning Event will be taking place on 10th June 2015, at the Marriott Hotel, Leeds.

The Shared Care event is for both patients and staff and if you would like to attend you can register for a ticket at the following link:
<https://www.eventbrite.co.uk/e/shared-haemodialysis-care-4th-learning-event-tickets-15217116806>

Please note the ticket booking site only works in Internet Explorer 9 and above, Google Chrome or Firefox. If you experience issues accessing the

ticket booking site please email sarah.boul@nhs.net for a manual booking form.