CHESHIRE AND MERSEYSIDE KIDNEY CARE NETWORK

Provision of Home Therapy Treatments for Kidney Patients in Cheshire and Merseyside

September 2009

APPROVED: 24.09.09
FOR REVIEW OF RECOMMENDATIONS: SEPTEMBER 2010
PURPOSE

1. The purpose of this report is to develop a clear patient pathway of choice for patients requiring renal replacement therapy, and to consider methods to achieve the planning assumptions for 2013 for patients accessing home therapy treatments.

BACKGROUND

2. In September 2008, the Strategic Framework for Kidney Care in Cheshire and Merseyside for 2008-2013\(^1\) was approved.

3. The Framework highlighted that the percentage of patients receiving home haemodialysis in Cheshire and Merseyside was low. The National Institute for Health and Clinical Excellence (NICE) produced technical guidance (TA48) on Home verses Hospital Haemodialysis\(^2\) which recommended that all clinically suitable haemodialysis patients should be offered home haemodialysis as an option. It is recognised, however, that the number of patients will remain relatively low, due to the predominately older nature of the population with kidney failure.

4. In September 2008, the Kidney Care Network agreed that 8% of the haemodialysis population will receive home haemodialysis by 2013.

5. The assumptions, taken from the Framework, are illustrated in the table below.

<table>
<thead>
<tr>
<th>Planning assumption</th>
<th>By March 2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total patient numbers on dialysis</td>
<td>1,145</td>
</tr>
<tr>
<td>New patients</td>
<td>307</td>
</tr>
<tr>
<td>Prevalence rate</td>
<td>538 pmp</td>
</tr>
<tr>
<td>20% new PD patients</td>
<td>61 new PD patients</td>
</tr>
<tr>
<td>80% new HD patients</td>
<td>246 new HD patients</td>
</tr>
<tr>
<td>(of which 8% will be home HD)</td>
<td>(of which 20 will be new home HD patients)</td>
</tr>
</tbody>
</table>

6. As the patient numbers for home haemodialysis within Cheshire and Merseyside are considerably low, the Task and Finish Group agreed that this report will focus on this cohort of patients. The number of patients receiving peritoneal dialysis will continue to be monitored by the Network.

7. At the end of July 2009, the Network had a total of 14 patients receiving home haemodialysis.

8. The numbers of patients receiving home haemodialysis from 2007 to July 2009 are detailed in the following table.

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\(^1\) Strategic Framework for Kidney Care Services in Cheshire and Merseyside: 2008-2013
<table>
<thead>
<tr>
<th>Lead Centre</th>
<th>Home Haemodialysis</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2007</td>
</tr>
<tr>
<td>Aintree</td>
<td>3</td>
</tr>
<tr>
<td>Arrowe Park</td>
<td>2</td>
</tr>
<tr>
<td>Royal Liverpool</td>
<td>5</td>
</tr>
<tr>
<td>Total</td>
<td>10</td>
</tr>
<tr>
<td>Total number of patients on haemodialysis</td>
<td>714 **</td>
</tr>
<tr>
<td>% of Patients on Home haemodialysis</td>
<td>1.4% **</td>
</tr>
</tbody>
</table>

*Figures for 2009 are from July
**Accurate data for 2008 not available

9. Based on these figures, as a Network, we will not achieve our target of 8% by 2013.

OUTCOMES FROM THE TASK AND FINISH GROUP

10. Whilst it is recognised that not all patients with kidney failure want to dialyse at home, we need to ensure as a Network that we have provided as much information for patients and their carers to make a fully informed choice about the options for renal replacement therapy are available to them.

11. The following highlights some of the achievements made within the life time of the Task and Finish Group, and also detail matters which the Network will need to consider further in order to achieve the 8% target.

Dedicated Training Facilities

12. All home therapy training for patients is carried out onsite at the three Lead Centres.

13. The Task and Finish Group identified that there is an inconsistent provision of training facilities across the Network:

   a. The Royal Liverpool Hospital has a dedicated training suite located on Ward 11C, with 2 beds;

   b. Aintree Hospital has a single-bedded side room off Ward 20 (nephrology inpatient ward) to train both home haemodialysis and peritoneal dialysis. This room is not for exclusive use for the home therapy team, and is also used by dialysis/non-dialysis infected inpatients, when the room is available;

   c. Arrowe Park Hospital train home haemodialysis patients at their regular dialysis station located on the maintenance dialysis unit. The home therapy team do have access to a side room to provide a degree of privacy for the patient during training; however this is often used for bacteremia patients requiring maintenance dialysis. During the patients first week at home, there is a small amount of training provided during the supervised week.

   For patients who live in Chester and are dialysing in the satellite unit at Chester, training is provided by the Arrowe Park team, at Chester.
14. The Home Therapy teams reported that training is often very difficult, especially when the patients are located within the main maintenance dialysis unit setting. It can often lead to patients becoming incompliant with the training programme.

15. Nurse trainers for home haemodialysis can often get distracted during a training session with other maintenance patients, whilst on the ward.

16. The provision of “ad-hoc” side rooms also impacts on the training programme. Patients need consistent privacy whilst undergoing the home training programmes.

17. The Task and Finish Group did discuss the option of having a central home therapy training facility for Cheshire and Merseyside. However, it was felt that this would not be viable due to:

   a. Patients may have to travel further to the Central Training Facility than they would to their local unit, and therefore may defer from the home haemodialysis training programme;

   b. Due to the geographical spread of the Network, it would be impossible to have a geographically “central” unit.

   c. Central Training Facility could provide complications over governance arrangements.

Audit of Patients Receiving Home Therapy (Home Haemodialysis and Peritoneal Dialysis)

18. The Task and Finish Group carried out an audit of existing home therapy patients and 78 responses were received out of 144. A response rate of 54%. The Group agreed to only audit this cohort of patients, rather than patients who dialyse in centres or satellite units, as they have recently been regularly audited on a number of issues, such as transport.

19. A questionnaire was devised (see Appendix 1) which provided tick box answers and a free text section at the end of the questionnaire giving an opportunity for patients to provide their own comments and suggestions. A covering letter explaining the reason for the audit also accompanied the questionnaire.

20. The method of data collection varied across the three Lead Centres.

   a. Aintree Hospital: Patients were personally given the questionnaire by the Home Therapy Team with an outline as to its purpose. Patients were then left to complete the form on their own and in their own time.

   b. Arrowe Park Hospital: Patients were personally given the questionnaire by the Home Therapy Manager, who guided each patient through the questions and explained the questions in detail.
c. Royal Liverpool Hospital: Because of the large number of patients receiving home therapy, the questionnaires were posted out to each patient, with a self addressed envelope to return their completed form.

21. The results of the audit highlighted:

a. Pre-emptive / live / Cadaveric transplants are not widely offered as a treatment choice;

b. Consultants provide the majority of information on dialysis choices available;

c. Patients receive their information on dialysis choice mainly in the clinic setting. Some patients also recorded they also receive information within the renal unit.

22. Patients were invited to provide any comments as to how improvements can be made in giving information to patients. A number of suggestions were made:

a. Talk with other patients;

b. Visit other patients already on peritoneal / home dialysis;

c. Home Therapy Nurses to visit satellite units to raise the profile of home therapies;

d. Ensure patients are fully aware of the commitment needed, ie, its more than 4 hours, 3 times a week;
23. In summary, patients receive information regarding renal replacement therapy options within the clinic setting from their consultant. It is therefore essential that documents that are given to patients clearly outlines the options available to them.

**Patient Leaflet**

24. Current literature available to patients either in the pre-dialysis stage or with kidney failure was reviewed. A lot of the literature used is provided by the pharmaceutical companies, all of which placed transplantation as the last option within their booklets. Hospital Trust leaflets, designed and printed internally, cover a range of subjects associated with kidney disease, are available.

25. In order to provide a consistent message across Cheshire and Merseyside in informing patients of the different modalities of renal replacement therapy available, the Task and Finish Group produced a Network Patient Leaflet (Appendix 2). This leaflet sets out the options in the correct “best clinical” order, ie, transplant should be offered first as this is the best form of treatment, (to those who are clinically appropriate); with hospital haemodialysis last as the option.

26. The leaflet is intended to provide a summary of the advantages and disadvantages of the treatment options available, in order to stimulate more open discussions for patients and their carers/family with the clinical teams.

27. Any documentation provided by pharmaceutical companies, should be provided as additional information and/or by request from patients.

**Review of Patient Modality**

28. There is no documented evidence to state that all existing patients receiving any form of dialysis treatment, has their modality of treatment reviewed on an annual basis. The Task and Finish Group agreed that discussion should take place with the clinical team, the patient and their carer/family about alternative treatment options available annually. These discussions should be documented by the clinical team in order to provide valuable information for audit purposes.

**Home Haemodialysis Poster**

29. Inspired by two members of the Task and Finish Group, is a marketing exercise to encourage pre-dialysis and existing dialysis patients to join the Home Haemodialysis Programme. The poster (Appendix 3) is intended to be eye catching and provide thought provoking questions to these two groups of patients. To provide a consistent message, this poster will be displayed in the patient waiting areas in all Lead and Satellite Units, and in areas where any nephrology outpatient clinics may take place.
Dialysis Administration Officer

30. All patients who receive home haemodialysis are supported, not only by a specialist nursing team from each Lead Centre, but also from the Dialysis Administration Officer based at the Royal Liverpool Hospital. The Administration Officer also provides administrative support for Aintree Hospital and Arrowe Park Hospital for patients on their home haemodialysis programmes. An outline of the duties carried out by the Administration Officer can be found in Appendix 4.

31. As the Administration Officer is based in the Royal Liverpool, it can often cause delay and confusion when dealing with either Aintree or Arrowe Park when trying to deal with finance departments, or speak with a member of staff from the home therapies team etc.

32. When patients are near to completing their home haemodialysis training programme at the Royal Liverpool Hospital, the Administration Officer would often meet the patient and discuss issues relating to reimbursement for electricity and water usage, and other issues related to home haemodialysis. The Administration Officer is unable to provide this face-to-face support with patients preparing to go home from either Aintree Hospital or Arrowe Park Hospital.

33. The Task and Finish Group have worked with Arrowe Park Hospital and Aintree Hospital to incorporate the duties of the Administration Officer into the existing role of the Dialysis Away from Home Co-ordinator at Aintree Hospital, and into the existing role of a nephrology medical secretary at Arrowe Park Hospital. This will now provide Aintree Hospital and Arrowe Park Hospital with a dedicated Administration Officer to support the nursing team and the patients receiving home haemodialysis.

Nursing Support in Satellite Units

34. More often than not, patients who dialyse in satellite units are generally fitter than those who dialyse in a hospital unit.

35. Nursing staff based in satellite units who have a contact to the home therapy teams, could also identify patients who have either expressed a wish to have dialysis at home, or would like more information about this option.

Lone Patients

36. There is a requirement for patients who wish to dialyse at home, to have a carer or family member present in the house during their dialysis session.

37. The Task and Finish Group highlighted that there are more patients who could dialyse at home, but because they are the sole occupier of their house, they are unable to join the home haemodialysis programme.
38. However, in other parts of the North West, it is common for lone patients to dialyse at home. The Task and Finish Group felt that this does pose a clinical governance risk and it was discussed in some detail. Concern was raised as to who would be ultimately responsible, should anything happen to a patient in their own home, and they were unable to raise an alarm.

**Dialysis Tariffs**

39. NHS organisations facing lean times ahead, are looking at steps to reduce their financial overspend without reducing the quality of care for patients.

40. There is clinical evidence to state that patients receiving home haemodialysis have a better quality of life to those patients who receive satellite or centre dialysis.

41. It is also well known that the current tariff which the hospitals receive for home haemodialysis is a lot less than the tariff for satellite or centre dialysis. This is mainly due to the fact that there are no overheads (ie staffing costs) to pay.

42. It is currently planned that dialysis will become part of payment by results in April 2011. In preparation for this from April 2010 there will be a non-mandatory tariff for dialysis in preparation for the mandatory tariff. Current indication is that incentives will be given to Trusts in order to increase the proportion of dialysis patients receiving dialysis at home.

43. The current haemodialysis tariffs (regardless of it being home, satellite or centre) are based on patients dialysing three times a week. It is recognised that all patients who dialyse at home, dialyse to fit around their lifestyle, and could be dialysing up to 6 times a week (but for shorter times).

44. Specialised commissioners are negotiating with Trusts to pay them per dialysis session, instead of based on three times a week. As they are keen to ensure that Trusts are remunerated for the correct amount of session’s patients dialyse at home, commissioners will require this information on a monthly basis. At present, the renal technicians, visit home haemodialysis patients to download data from their machines every 2-3 months.

**Dialysis Expansion Scheme**

45. Cheshire and Merseyside Network are part of a national dialysis expansion scheme. By the end of 2010, there will be an additional 47 dialysis stations enabling over 240 patients to have more local dialysis in a high quality facilities.

46. As new and refurbished units are opening, existing dialysis patients are invited to repatriate to their local satellite unit. This is impacting on the Home Haemodialysis Programmes in all the Lead Centres. Some patients who have been highlighted to join the Home Haemodialysis training programme, and even some who are due to start their training, have at the last minute, re-considered
their position, as a local facility where everything is provided for them, is more appealing.

47. With new dialysis capacity being available, the perception is that dialysis slots need to be filled, regardless of whether the patient is suitable for peritoneal dialysis or even home dialysis.

New Technology

48. Kimal Healthcare recently launched their new home haemodialysis machine, ‘NxStage System One’. They have reduced the dialysis machine to the size of a portable TV, with the box that it stands on converting ordinary tap water into essential liquid dialysate needed to carry out the essential treatment. This machine has significantly reduced the storage requirement, thus making it much more user friendly.

49. In July, the Lister Hospital in Stevenage, was the first hospital to take delivery of the NxStage home haemodialysis machine. Their experience is detailed below:

a. Following the outcome of the trial, Lister Hospital now have 2 patients trained and using the NX Stage machine at home. They have 1 patient in training, and they are awaiting delivery from Kimal for the 4th machine, with a patient identified for training.

b. The staff at the Trust are pleased with machine, and they have commented that it is "very different from traditional machines". The training time for patients is approximately 3-4 weeks. Staff were also training at same time, so the Trust envisage a quicker training time once experience has been gained.

c. Patients using the NxStage machine report they feel "better than they have done in a long while". The dialysis regime using NxStage ranges from 2hrs 15 min to 3hrs, 6 times per week, based on body volume.

d. The 60L batch of dialysate lasts 2-3 treatments, and are patients happy enough setting up for next batch and leaving it to prepare overnight. No significant interference in their regime has been reported.

e. Home conversion issues: The Trust use a local plumber and have appropriate flooring in place. The costs were not available for this report, but it was highlighted that the plumbing is far less intrusive, and the assumption is that the costs reflect this.

f. Home deliveries: The Trust are currently in negotiations with Kimal and a local company to provide all ancillaries to patient's home.

g. The outcome of the trial was that the Trust were going to use a mix of NX Stage as well as their previous provider (Fresenius 40008s) to ensure patients are given the widest choice available to them and to suit their clinical circumstances. If a patient is thought to require more than 18hrs
dialysis per week, NX would not be a feasible option, however, the majority who can manage 2-3 hrs x 6 per week, would be offered NX Stage.

50. It has been reported that the cost of this machine alone is approximately £25k. This does not include the cost of the consumables. The average cost of the current home dialysis machines being used in Cheshire and Merseyside range from £9k - £18k.

51. With the power of the internet and patient groups, Trusts may feel the pressure from patients to dialyse at home using the Nx Stage machine.

RECOMMENDATIONS

52. The Kidney Care Network is asked to approve the following recommendations in order to help achieve the planning assumptions for 2013 for patients to access home therapy treatments:

a) Dedicated Training Facilities: To ensure patients are compliant and complete the home haemodialysis training programmes, dedicated training rooms, located away from the maintenance dialysis units are needed.

b) Patient Audit: Roll out the patient audit to those receiving maintenance dialysis treatment to gather information on what choice of options were given to this cohort of patients.

c) Develop a patient buddy system to encourage existing home haemodialysis patients to visit maintenance dialysis patients to talk about dialysing at home. This can provide a patient-to-patient experience which can be extremely powerful.

d) Patient Leaflet: Agree the contents and production of the Network patient leaflet and agree to use it widely, within clinics and dialysis units.

e) Review of Modalities: Review and document all existing patients modality of treatment on an annual basis.

f) Home Haemodialysis Poster: Agree the contents and production of the home haemodialysis poster and to display it in patient waiting areas at Lead and Satellite Units, and in nephrology clinic settings.

g) Dialysis Administration Officer: Support the role of the Dialysis Administration Officers within each Lead Centre.

h) Nursing support: Each of the home therapy teams from the Lead Centres to liaise with the Unit Manager at each Satellite Unit to provide a “Link Nurse” role for identifying any potential patients who wish to dialyse at home.
i) **Lone patients:** Develop a “consent form” for patients who wish to dialyse at home on their own, outlining the risks of lone dialysis, and patients taking full responsibility.

j) **Dialysis Tariffs:** In 2010, there will be a non-mandatory best practice tariff. Trusts do not have to take part in this exercise, but it is good practice to do so in preparation for the mandatory tariff. Incentives will be given to Trusts for increasing patients on their home haemodialysis programme.

k) Trusts will need to ensure renal technicians can access patients’ homes on a monthly basis to down load data relating to the number of dialysis sessions carried out.

l) **Dialysis Expansion Scheme:** Clinical teams within each Unit to ensure patients who require dialysis and are clinically suitable, are given the option to consider home haemodialysis first, avoiding any dialysis slots that become available through the expansion scheme being filled unnecessarily.

m) **New Technology:** As the decision of purchasing of equipment ultimately lies with the Lead Centres, it is for them to consider the purchase of the Kimal NxStage machine, or any other models that come onto the market.

n) **Other:** Agree to continue to raise the profile of the home haemodialysis programmes and agree to the ongoing monitoring of the patient numbers across the Network.

o) Review the progress of these recommendations in 12 months time.

IN CONCLUSION

53. The Network is asked to:

    a) Note the contents of this report.

    b) Approve the Recommendations.

Hannah Pulley
Network Lead

September 2009
APPENDIX 1

Needs to go on Trust headed paper

Provision of Home Therapies for Dialysis Patients
May-June 2009

Dear Patient

The insert hospital name has a clear vision for kidney care. A fundamental aspect of this is the commitment to place the patient and their carers at the centre of all service planning, in order that the quality of care will be focussed on patient outcome.

Whilst a significant proportion of dialysis patients receive hospital haemodialysis, it is recognised that there is a need to increase patient choice for dialysis through expanding home therapy provision, i.e., home haemodialysis and peritoneal dialysis.

We want to ensure that all dialysis patients have equal access and a full understanding of all the different types of dialysis treatments available to them in order to make an informed choice. As you are currently receiving home therapy dialysis treatment, it would be helpful to understand why you chose this option, so we can learn from your experiences to help improve the experiences of future dialysis patients.

Please complete the attached questionnaire as fully as possible, and return it to Dawn Westhead / Andy McGlashan / Angela Cooper* at the address below no later than Friday 26 June 2009. If you have any queries about this questionnaire, please telephone: insert telephone number

You do not need to include your name on the questionnaire.

Thank you for your assistance.

Home Therapies Team
Insert trust
Insert trust address
Home Therapies Questionnaire
April 2009

What type of dialysis are you currently on?
- CAPD □
- APD □
- Home HD □
(please specify number of sessions per week) …………………

What type of dialysis, if any have you previously had? Please tick all that apply:
- CAPD □
- APD □
- Home HD □
- Unit HD □
- No other type □

How long before you started dialysis did you know you had kidney disease?
- Less than 3 months □
- 3-12 months □
- 1-2 years □
- 2-5 years □
- More than 5 years □

Kidney disease can be treated in different ways. Did you have a choice in the way your kidney disease was treated?
- No choice □
- As much as I wanted □
- It as much choice as I wanted □

Please tick all types of treatment choices you were offered, or were discussed with you BEFORE you started dialysis:
- a) Pre-emptive transplant (transplant before you need dialysis)
- b) Live related transplant
- c) Cadavar transplant (transplant list)
- d) CAPD
- e) APD
- f) Assisted APD
- g) Home Haemodialysis
- h) Satellite Haemodialysis
- i) Active Supportive Care
  (no dialysis at all: sometimes called Conservative Management, Renal Supportive Care or Medical Management)

Who gave you the information on your dialysis choices?
- Kidney Consultant □
- Other Doctor at Clinic □
- Specialist Nurse □
- PD Nurse Specialist □
- GP □
- Haemodialysis Staff □
<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>Where did you receive the information on your dialysis choices?</td>
<td>Clinic</td>
</tr>
<tr>
<td>How much information about your condition were you given?</td>
<td>Not enough</td>
</tr>
<tr>
<td>How much information about your treatment choice were you given?</td>
<td>Not enough</td>
</tr>
<tr>
<td>Where do you think would be the best place to receive information on your dialysis choices? Please tick all that apply:</td>
<td>Kidney Clinic</td>
</tr>
<tr>
<td>Who do you feel would be best to give you the information on dialysis choices? Please tick all that apply:</td>
<td>Consultant</td>
</tr>
<tr>
<td>Overall, were you satisfied with the information given to you to make the decision to choose the dialysis type you have chosen?</td>
<td>Yes, completely satisfied</td>
</tr>
<tr>
<td>At what stage would you prefer to receive the information needed to make a decision on what treatment choice you would like?</td>
<td>1 – 2 years before needing dialysis</td>
</tr>
</tbody>
</table>
Finally, if you could suggest ways in which we could improve how we give information to patients before they choose their dialysis treatment, please state below:

Thank you for completing this questionnaire. We aim to use the responses to improve the care we give to our patients, and we value your opinion and suggestions.
APPENDIX 2

Please see attached leaflet “Renal Replacement Therapy Options for Kidney Patients with CKD 5” (pdf format).
APPENDIX 3

Please see attached “Home Sweet Home” poster (pdf format).

NB: This poster will be printed in A3 format.
APPENDIX 4

**Dialysis Administration Officer - Home HD**

**Initial Set up:-**

Create Home HD file for patient

Fax details to Steve Thomason to do Home assessment.

Order Dialysis Chair or arrange to pay for bed if chair not required.

Fax patient advice to Gambro. (Liverpool Patients only)

Arrange for prescription to be authorised by consultant and fax to Gambro to arrange deliveries. (Liverpool Patients only)

Identify and contact the local Fire and Rescue Service and water authority to advise there will be a patient dialysing at the address.

Obtain details of telephone and electricity suppliers, names on the bills and account numbers from patient. (Suppliers will only speak to me with all this information)

Contact BT or advise patient if with different telephone company to arrange for priority repair service to be added to account.

Contact the Electricity company to arrange priority repair service or advise patient if company will not take request from me.

Set up clinical waste collections for patient to include yellow bag and sharps box exchange/

Send letter to patient regarding clinical waste collection, explaining expenses procedure and enclosing any forms required. i.e. to claim Water allowance if have a water meter.

Send the patient the Home HD Patient Information Booklet.

Raise requisitions, provide order numbers and process invoices for suppliers in relation to all conversion work done. E.g. Plumber, electrician, flooring, building services, cabin where applicable. (Set up costs cross charged to specialized commissioning)

**Ongoing:-**

Deal with any queries home patient may have. Problems with clinical waste, expenses etc.

Deal with suppliers in event of emergency. E.g. Burst water main, delivery problems with orders.

Calculate and prepare patient expenses every six months, for Water, Electricity and heating, provide ongoing forms to be completed and deal with any queries around expenses.

Deal with any maintenance issues with room / cabin and provide order numbers pay invoices. (Liverpool Patients only)