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IMPROVING CHOICE FOR KIDNEY PATIENTS: Home Haemodialysis

February 2010

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Foreword

Care at home, and other forms of self-care, offer real benefits for kidney patients and link closely to the vision of an NHS that is organised around patients, giving them more choice, convenience and control over their care.

Building on the achievements of the kidney care community outlined in the report *“Achieving Excellence in Kidney Care: Delivering the National Service Framework for Renal Services”*,¹ we are now working with the system to focus on improving quality and efficiency simultaneously as we prepare for a harsher financial climate.

Dialysis capacity has expanded as more facilities, including satellite units closer to patients, have come on stream. Against this backdrop, the number of people with kidney disease continues to rise year on year. The challenge now is to make innovative changes and improvements to accomplish our mission of moving services from good to great.

As this Report demonstrates, there is a robust case – on both clinical and financial grounds – for improving choice for patients who wish to opt for care at home, and in particular home haemodialysis. From an historic low in recent years, there are growing signs of an upturn in interest in this treatment modality with pockets of success and good practice around the country.

This Report, and the associated Toolkit and information resources produced by NHS Kidney Care, aim to make informed choice of haemodialysis at home a realistic option for all patients who can benefit from this modality as part of a full range of options including peritoneal dialysis and conservative management. This aim has the clear support of professionals and patients’ representatives and is closely aligned with the direction of travel set out by Ministers in the strategy paper *“NHS 2010-2015: from Good to Great, Preventative, People-centred, Productive”*.²

Sir David Nicholson has written to the NHS to emphasise that quality, innovation, productivity and prevention must become the focus, and all staff have the responsibility to share their skills and collaborate to develop local solutions. This is an exciting time for local kidney services, with clear opportunities to drive up quality and productivity for the benefit of patients at scale and pace.

I look forward to working with you to make this key change for improving kidney care a reality.



A handwritten signature in black ink that reads "Donal J. O'Donoghue". The signature is written in a cursive style.

Dr Donal O'Donoghue
National Clinical Director for Kidney Care
Department of Health

¹ http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_109978

² http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_109876

Introduction

Building on the publication of the Specification for the *Commissioning of Peritoneal Dialysis Pathway*³ and the *End of Life Care in Advanced Kidney Disease: A Framework for Implementation*⁴ NHS Kidney Care continues to prioritise improving choice for people with kidney disease. This report makes recommendations to ensure Home Haemodialysis is increasingly offered as a realistic choice for dialysis patients when considering how and where they wish to receive their treatment as set out in the National Service Framework for Renal Services (2004) Standard four:

Renal Services are to ensure the delivery of high quality clinically appropriate forms of dialysis which are designed around individual needs and preferences and are available to patients of all ages throughout their lives

Patient choice should be available from diagnosis to end of life care, and this is particularly important during the time before dialysis. Patients approaching established renal failure, or changing therapies, should feel empowered with knowledge and information to enable them to choose the type of renal replacement therapy that is best for their own personal circumstances. The role of healthcare professionals is key to achieving this and they should, whilst recognising their own clinical preference, be able to explore with every patient the full range of opportunities available to meet their individual needs, identifying solutions to what previously may have been seen as barriers. Each patient should have a care plan that reflects this shared decision making.

The case histories at the end of this report show compelling evidence that those who currently dialyse at home, though relatively small in number, describe improved physical and mental health. The ability to control one's treatment, to arrange dialysis around your life, rather than having your life dominated by pre-determined visits to the hospital for months or years, is a powerful incentive to enabling self-care for patients.

I am indebted to the patients and staff who contributed to this report and to Dr Mark Brady, Clinical Advisor to National Clinical Director for Kidney Care, Department of Health and Francesca Taylor, Project Officer, NHS Kidney Care for their detailed and sensitive approach to this project.



Bev Matthews

Bev Matthews
Director – NHS Kidney Care

³ & ⁴ www.kidneycare.nhs.uk

1. Executive Summary

There is growing evidence that haemodialysis at home has benefits for kidney patients. Patients able to dialyse more frequently, than is realistically possible in hospitals or satellite units, show beneficial clinical outcomes including improved blood pressure control, reduced medication and the ability to live a more normal life. The qualitative research element of this project suggests that patients on home haemodialysis themselves perceive significant benefits in dialysing at home, in particular flexibility in terms of when and how often to dialyse, greater freedom to work, a more enjoyable diet and feeling better emotionally and physically.

It is clear from this work that currently there are considerable perceived barriers which inhibit a widespread increase in the number of patients on home haemodialysis. These barriers are cultural, emotional and institutional, as well as financial. This report proposes solutions by outlining key learning in relation to 'what works' in renal units; discussing the patient perspective, and outlining costs and tariffs.

This report concludes with key recommendations for commissioners and providers of kidney services to support improving uptake of home haemodialysis:

1. To work with kidney care networks to undertake a local evaluation of current provision and consider opportunities for improving uptake
2. To review the package of measures available on the NHS Kidney Care website (www.kidneycare.nhs.uk) to help find solutions to local identified perceived barriers:
 - o Five Steps to Home Haemodialysis Toolkit
 - o Stories on DVD showing what patients and carers can expect and the benefits of dialysing at home
 - o Template business case and examples of 'what works'
3. Develop a network-wide Action Plan, taking into consideration the Problem Solving Fund available from NHS Kidney Care

These recommendations are key steps for supporting providers of kidney services to be more innovative, deliver better quality for patients, manage costs and give patients more choice and control over how they manage their condition. Clinical leadership with effective care planning are the main drivers that will embed this change locally.

2. Background

NHS Kidney Care and the Department of Health undertook a focused project to understand the barriers, incentives and issues that would support wider uptake of Home Haemodialysis (HHD). The project undertaken between September 2009 and February 2010 includes:

- A literature review to identify existing publications on key themes linked to the uptake of self-care dialysis therapies (Appendix A)
- Information gathering visits to six renal units with a relatively high proportion of patients on home haemodialysis or with emerging programmes
- A workshop involving attendees at the Symposium on Home Dialysis, Manchester, October 2009 (Appendix B)
- A series of in depth qualitative interviews involving patients on home haemodialysis to find out about their experiences (Appendix C)

2.1. Provision of home haemodialysis

Until the 1980s HHD was the predominant form of renal replacement therapy (RRT). Since then the emergence of continuous ambulatory peritoneal dialysis, increased transplantation rates and a sharp rise in the number of patients with established renal failure (7,000 to 45,000 between 1982 and present⁵), and an associated significant increase in the median age of the dialysis population, led to a move away from home haemodialysis with treatment in hospital and satellite units being the fastest growing dialysis modality.

The National Institute for Health and Clinical Excellence (NICE) guideline produced in 2002 suggests 10-15% of dialysis patients might opt for haemodialysis treatment at home with appropriate education⁶. Despite this, there has been no overall increase in the proportion of people undertaking HHD and currently only 2% of the total number of dialysis patients in England receive home haemodialysis⁵. These rates compare favourably with other European countries and are in excess of those recorded in the United States, with 0.7% of dialysis patients on HHD in 2006⁷. However, New Zealand and Australia lead the way with 15.6% and 9.4% of dialysis patients undertaking HHD respectively⁸.

Nonetheless, whilst the current number of patients choosing home haemodialysis is relatively low there have been signs of positive progress emerging within some renal units. See table 1.

⁵ Byrne C, Steenkamp R, Castledine C, Ansell D, Feehally J. UK Renal Registry 12th Annual Report (December 2009): Chapter 4. ESRD Prevalent Rates in 2008: national and centre-specific analyses. *Nephron Clinical Practice* 2010, in press: available from www.renalreg.org

⁶ National Institute for Health and Clinical Excellence (NICE) Technology Appraisal Guidance – no 48 (TA48) *Guidance on home compared with hospital haemodialysis for patients with end stage renal failure* 2002

⁷ USRDS 2008 US Renal Data System Annual Data Report: *Atlas of Chronic Kidney Disease and End-Stage Renal Disease in the United States*, National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, 2008

⁸ ANZDATA ANZDATA 32nd Annual Report 2009 (Australian and New Zealand Dialysis and Transplant Registry, 2008 Data)

Table 1. Renal Units with highest percentage of prevalent dialysis patients on Home Haemodialysis (UK Renal Registry, 11th & 12th Annual Reports, 2008⁹ & 2009⁵ respectively)

Renal Unit	% of prevalent dialysis patients on home HD on 31/12/2007	% of prevalent dialysis patients on home HD on 31/12/2008
Manchester	8.6	11.4
Brighton	5.5	5.7
Sheffield	5.2	5.7
Guys	5.1	5.1
Bristol	5.5	5.0
Preston	3.6	4.6
Derby	3.6	3.8
Birmingham Heartlands	3.6	3.2
Oxford	4.1	3.5
Hull	2.8	3.3
Newcastle	2.6	3.1
Liverpool Aintree	1.7	3.1

2.2. A Summary of the clinical evidence and cost effectiveness

The literature review (appendix A) focused on publications from 1997 to 2009 in the UK and internationally, and was based on three key themes linked to the uptake of self-care dialysis therapies:

- Clinical evidence for home haemodialysis being preferable to or equivalent to hospital based dialysis
- Benefits of home haemodialysis on quality of life, morbidity and mortality, and whether this reflects healthier patients at the outset
- The true cost benefits of self-care dialysis therapies, including contribution to the economy through patients continuing continuing or returning to work.

Findings from the literature review demonstrate that the opportunities for longer and/or more frequent haemodialysis sessions in the home is the main clinical argument for home haemodialysis being preferable or equivalent to, unit based dialysis. There is evidence to support the superior clinical effectiveness of more frequent and/or longer haemodialysis, in particular nocturnal daily haemodialysis, as compared with conventional three times weekly haemodialysis available in the majority of hospital and satellite dialysis units.

There is robust evidence to demonstrate better blood pressure control, with fewer or no antihypertensive medications required. Although reported studies are often limited by small patient numbers and weak study design, the weight of evidence also suggests there are lower rates of cardiovascular disease, better measures of anaemia, higher levels of dialysis control, fewer hospitalisations, better nutritional status and fewer adverse effects overall during home haemodialysis when compared with standard therapy.

There is also strong evidence that more frequent daily haemodialysis, especially nocturnal haemodialysis, offers better quality of life, morbidity and mortality benefits versus three times weekly haemodialysis.

In relation to cost effectiveness, the literature review findings indicate that home haemodialysis is more cost effective than haemodialysis carried out in a hospital or satellite unit because of the relatively lower staffing requirements of home haemodialysis. Several of the included studies highlight the initial high costs of home haemodialysis as a result of set-up and training expenses with the calculated payback period for these start-up costs varying between 12 and 36 months, with an often accepted average of 14 months based on UK data.

There are few papers that examine the broader economic benefits of home haemodialysis. However those that do suggest that patients on home haemodialysis are more likely to be employed full-time than those undertaking hospital or satellite unit haemodialysis, with the associated benefit of decreased social security dependence.

Self-care is an increasingly important theme. There is evidence showing self-care interventions benefit patients and improve health outcomes and whilst only a limited number of research studies focus on the overall cost effectiveness and/or benefit cost ratios of self-care, those available indicate there can be significant cost benefits involved.

⁹ UK Renal Registry *UK Renal Registry 11th Annual Report 2008*. Bristol: UK Renal Registry

3. Perceived barriers to improving choice for kidney patients

A workshop was held at The Home Therapies Symposium, Manchester in October 2009 with over 70 people attempting to identify perceived barriers to improving choice for kidney patients (appendix B). The responses from workshop participants highlighted a number of factors in relation to increasing the uptake of home haemodialysis. This workshop was complemented by a series of visits to six renal units across England with established or emerging home haemodialysis programmes.

Healthcare professionals were aware of specific barriers inhibiting the uptake of home haemodialysis. The key barriers appear to be:

- Selecting individual patients for self-care rather than offering realistic patient choice
- Lack of proactive clinical leadership
- Lack of knowledge as to the benefits of home haemodialysis
- Perceived high initial set up and training costs with an uncertain financial payback period in comparison to other treatment options
- Lack of clarity around cost and implementation models, sources of funding and current tariffs
- Lack of experience and expertise in home haemodialysis
- Pre-conceptions from healthcare professionals about the ability of patient/carer to cope
- Limited facilities or funding to create training capacity
- Negative impact of patients receiving dialysis in-centre, becoming indoctrinated, passive and less likely to consider home haemodialysis
- Patient concerns regarding risks of suffering harm at home
- Patient worries about inserting needles into their own fistula

3.1 Overcoming the perceived barriers - 'what works' in renal units

Visits to six renal units identified significant pockets of enthusiasm and good practice in relation to improving choice for kidney patients. 'What works' in terms of practices and processes along the patient pathway include:

Self-care for all

- Open and early patient choice as a key first step on the pathway allows wider choice to all those who might benefit from Home haemodialysis rather than exclusive selection of individual patients that might be suitable e.g. Manchester Renal Unit
- Provision of a 'choice room', a stand alone private room with access to operational machines and equipment for all therapies, where the patient and their family can discuss their therapy choices and care pathway in confidence with a health professional e.g. Lister Hospital Renal Unit
- Engagement in ongoing dialogue with patients about their choices as they may change over time, and establishment of fixed review points e.g. Guys Hospital Renal Unit

Clinical champions

- Adopting a proactive approach towards home haemodialysis in consultant clinics, regardless of personal clinical preference, and providing clear evidence to patients of the relative clinical effectiveness of home haemodialysis e.g. Northampton Renal Unit
- Attempting to break down perceived local clinical barriers, such as changing policy so that all patients are offered choice of HHD with the exception of those patients with a realistic likelihood of pre-emptive live donor transplantation e.g. Northampton Renal Unit
- Encouraging clinicians or other health care professionals when initially discussing dialysis options with patients, to first ask whether they would like to receive their treatment at home or in centre e.g. Derby Renal Unit

Patient education programmes

- Adaptation of education programmes to improve patients understanding of home haemodialysis as a genuine dialysis choice e.g. Guys Renal Unit; Derby Renal Unit and Sussex Kidney Unit.
- In one renal unit this includes a programme run by specialist nursing staff with the initial assessment led by a nurse rather than a consultant. The patient consequently has more time to consider the different dialysis options in detail and to ask questions. The patient is then allowed further time for reflection, given additional access to health professionals, materials (decision aids such as leaflets and DVDs) and most importantly other patients before making a decision.

Peer support network

- Provision of a peer support network to assist patient choice e.g. Guys Renal Unit. Selected patients receive specific training to become peer supporters for other patients. Peer supporters are patients and carers who have had first hand experience of living with dialysis. Support is offered to patients on an individual basis by phone or face-to-face, or in group sessions. This is dependent on patient and peer supporter preferences and provides the patient with the opportunity to ask questions and to find out what the different types of dialysis are really like.

Self-care training

- Provision of training that offers incremental increases in self-care for all e.g. Guys Renal Unit and Sussex Kidney Unit. From the first day of training, patients start on self-care training irrespective of their chosen haemodialysis location.
- Training stations near but separate from the main unit, to encourage independence from the outset e.g. Manchester Renal Unit, Sussex Kidney Unit.
- Increasing the opportunities for all patients to observe the existence and practice of self-care, to stimulate discussion and encourage interaction primarily between individual patients but with staff members too. This can be achieved by having the training stations visible to all those entering the main dialysis unit (Derby Renal Unit)

Dialysis machine installation and monitoring

- Establishment of a relationship between one technical team and one contractor who perform all dialysis machine installation steps including assessment of space for dialysis and storage, assessment of the water supply, electricity provision and telephone access e.g. Manchester Renal Unit and Leicester Renal Unit
- Technicians maintain equipment and deliver products and upgrades to equipment e.g. Manchester Renal Unit, Leicester Renal Unit
- Technical assistance available when required, including 24 hr telephone contact e.g. Guys Renal Unit

Supporting environment

- Monitoring activity including vascular access, blood samples posted securely on a monthly basis by patients, planned formal follow up, and regular review of patient satisfaction with chosen therapy e.g. Guys Renal Unit
- 24hr clinical support telephone contact (home therapies team 9-5 and renal unit thereafter) e.g. Manchester Renal Unit

3.2 Overcoming perceived barriers - the patient perspective

A series of qualitative interviews were undertaken focusing on the patient perspective of HHD (Appendix C). The study was designed to explore the views of current home haemodialysis patients in order to understand what works well in terms of the advice, information and training they received, what they consider to be the impact of home haemodialysis, and their experiences of undertaking the treatment at home.

Twelve semi-structured interviews were conducted with home haemodialysis patients. Patients were identified as suitable to be interviewees following suggestions from individual renal units across England. Interviews of an hour in length were conducted in the patients' homes between December 2009 and February 2010. Interviews were recorded and transcribed in full, and all interviews were conducted and analysed by the same researcher.

Key findings from the research study were:

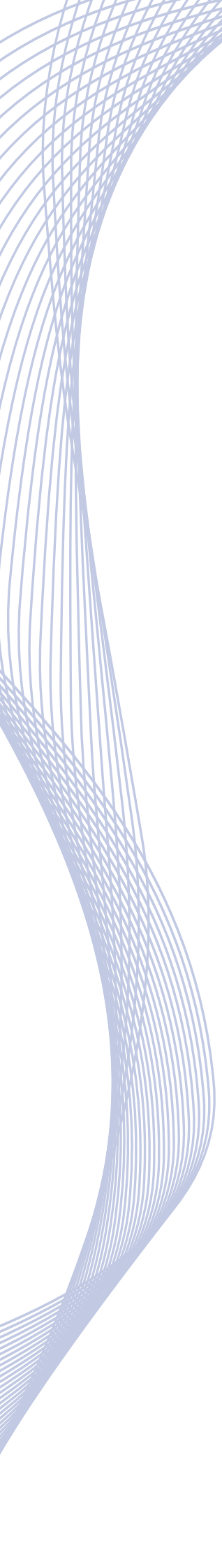
- Whilst patients appreciate the information provided by nurses and consultants, they find listening and talking to patients already on home haemodialysis most helpful and informative, as well as giving them more confidence.
- The more involved patients have been in self-caring when moving from unit to home haemodialysis, the less worried they are about training and the easier they find treatment at home.
- The main benefits of dialysing at home are felt to be flexibility in terms of when and how often to dialyse, greater freedom to work and a more enjoyable diet, in addition to feeling better emotionally and physically. However, some patients can also experience feelings of isolation despite enjoying these benefits.
- There was a positive impact on the patients' relationships at home, particularly with partners or carers and a significant impact on self image and esteem
- Finally and very significantly, patients are unanimous in their strong desire to only return to unit haemodialysis when absolutely necessary.

3.3 Overcoming perceived barriers - costs and tariffs

Throughout the visits and when reviewing published literature, it was clear that no uniform analysis incorporates all potential costs. Many units use different funding sources and published data consider different cost variables.

The report on the main findings of the Payment by Results (PbR) for Kidney Dialysis Project Group¹⁰ underlined that costing for home haemodialysis should be based on the assumption that it is more than a three times weekly therapy, and the cost of additional home haemodialysis sessions is not linear. The Kidney Dialysis Project Group average cost for home haemodialysis showed a significant variation from £28 to £133 per dialysis with differences in estimated numbers of dialysis sessions (three to seven) undertaken each week although the difference was more likely reflecting the need for more accurate data collection, coding and financial analysis. The cost range was significantly lower than that for satellite unit haemodialysis or hospital

¹⁰ www.kidneycare.nh.uk



haemodialysis. Similarly, the average unit cost for home haemodialysis of £83 per session was markedly lower than that for satellite unit haemodialysis (£142) and hospital haemodialysis (£185) without including the associated impact on hospitalisations and requirement for patient transport.

As a result of learning from the programme of work covered in this report, NHS Kidney Care is working closely with the Department of Health through an established kidney services expert reference group to ensure there are incentives to provide home haemodialysis and payment for evidence based practice (i.e. more frequent dialysis sessions than conventional three times weekly haemodialysis). At the same time it is recognised that there is a need for some flexibility, especially under a non-mandatory tariff, in order that commissioners can reach workable arrangements where the number of dialysis sessions is high, and with no arbitrary cap on home haemodialysis sessions or numbers of patients able to choose this therapy.

4. Recommendations to Commissioners and Providers of Kidney Services:

As result of the findings presented in this report, the following actions are recommended:

1. To work with kidney care networks to undertake a local evaluation of current provision and consider opportunities for improving uptake
2. To review the package of measures available on NHS Kidney Care website (www.kidneycare.nhs.uk) to help find solutions to locally identified perceived barriers:
 - a. Five Steps to Home Haemodialysis Toolkit
 - b. Patient Stories on DVD showing what patients and carers can expect and the benefits of dialysing at home
 - c. Examples of 'what works'
3. Develop a network-wide Action Plan, taking into consideration the Problem Solving Fund available from NHS Kidney Care

5. Conclusion

This report shows that there is now an opportunity for healthcare professionals, commissioners and patients to work collaboratively to break down the perceived barriers to offering genuine choice to all patients requiring renal replacement therapy. Staff in kidney services are uniquely placed to work across local health economies and SHA patches to share their skills and expertise, working collaboratively to identify 'what works' and creating local solutions to this national challenge.

6. Acknowledgments

We would like to express our thanks to the following people for giving up their time, providing access to their units and resources but in particular for their invaluable insights, openness, ongoing communication and willingness to assist towards improving the uptake of home haemodialysis.

Dr. Mark Brady, Clinical Advisor to the National Clinical Director for Kidney Care, Department of Health

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Guy's and St. Thomas' Charity

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APPENDIX A

Increasing Choice and Uptake of Self-care Therapies Literature Review

1. Aim

The literature review identified existing literature on the following three themes linked to the uptake of self-care dialysis therapies:

- A. Clinical evidence for home haemodialysis being preferable to or equivalent to hospital based dialysis.
- B. Benefits of home haemodialysis on quality of life, morbidity and mortality, and whether this reflects healthier patients at the outset.
- C. The true cost benefits of self-care dialysis therapies, including contribution to the economy through patients continuing to work.

2. Methodology

The descriptive literature review focused on literature from 1997 to 2009 published in the UK and internationally. A database search of published material was used as a basis for the review. As well as published articles, a number of papers were accepted from central government including two from the Department of Health.

Initially abstracts were used as a basis for inclusion or exclusion as appropriate to the aims of the literature review. Those studies identified for inclusion in the review were then read and analysed in full.

The main reasons for excluding papers were that the study did not relate to haemodialysis or include clinical findings. The review did not attempt to evaluate in detail the methodology of the included studies. However, methodology was taken into account when deciding which papers were included. 88 papers were identified for inclusion in the review.

3. Search terms used

home haemodialysis	hemodialysis	daily dialysis	nocturnal dialysis
home dialysis	self-care	self-treatment	home therapies

4. Databases

Medline, Cochrane, Embase, HMC, Centre for Reviews and Dissemination, NHS Evidence, Cinahl, PubMed

5. Summary of Findings

- The opportunity for longer and more frequent haemodialysis sessions in the home than is generally possible to undertake in hospital or satellite units, is the main clinical argument for home haemodialysis being preferable. This is because there is strong evidence to support the superior clinical effectiveness of more frequent and longer haemodialysis, in particular nocturnal daily haemodialysis, as compared with conventional three times weekly in-centre haemodialysis.

- People who are able to dialyse more frequently and/or longer clearly benefit from improved clinical outcomes. In this respect, there is most substantive evidence available to demonstrate better blood pressure control, with fewer or no antihypertensive medications required. Although often limited by small patient numbers and study design the weight of evidence also suggests there are lower rates of cardiovascular disease, better management of anaemia, higher levels of dialysis control, fewer hospitalisations, better nutritional status and fewer adverse effects overall during haemodialysis.
- The evidence that exists strongly suggests more frequent daily haemodialysis, especially nocturnally, offers better quality of life, morbidity and mortality benefits over more conventional three times weekly haemodialysis. Since there are greater opportunities to undertake short daily or longer daily nocturnal haemodialysis in the home than hospital or satellite units, it is reasonable to argue that the benefits of these dialysis modalities can be ascribed to home haemodialysis.
- On the basis there is a fairly robust support for the superior benefits of home haemodialysis in relation to morbidity and mortality. However in terms of quality of life, study design limitations make it harder to argue that reported benefits are not reflective to some degree of emotionally and psychosocially 'healthier' patients from the outset.
- Available evidence indicates that home haemodialysis is more cost effective than haemodialysis carried out in a hospital or satellite unit for patients with end-stage renal failure. The principal reason for this generalised finding is the relatively lower staffing requirements of home haemodialysis.
- Several of the included studies highlight the initial high costs of home haemodialysis as a result of set-up and training expenditure. There are quite marked differences of between 12 and 36 months in the published calculated payback period for these start-up costs, with an average of 14 months based on UK data.
- Many of the economic evaluations favourably compare more frequent self-care dialysis regimens in the home to hospital or satellite units. Despite this difference, the evidence shows home haemodialysis to have a relative cost benefit.
- There are few papers that examine the broader economic benefits of home haemodialysis. However those that do suggest that patients on home haemodialysis are more likely to be employed full-time than those undertaking hospital or satellite centre haemodialysis, with the concomitant benefit of decreased social security dependence.
- There is evidence showing self-care interventions benefit patients and improve health outcomes. Whilst only a limited number of research studies focus on the overall cost effectiveness and/or benefit cost ratios of self-care, those available indicate there can be significant cost benefits involved.

6. Evidence for home haemodialysis being preferable to or equivalent to hospital based dialysis.

6.1. There is evidence that home haemodialysis is more clinically effective than hospital based dialysis

It is the opportunities for longer and more frequent haemodialysis sessions in the home than is generally possible to undertake in hospital or satellite units, which is the main clinical argument for home haemodialysis being preferable. This is because there is strong evidence to support the superior clinical effectiveness of more frequent and longer haemodialysis, in particular nocturnal daily haemodialysis, as compared with to the average three times weekly haemodialysis available in most hospital and satellite dialysis units.

People who are able to dialyse more frequently and longer clearly benefit from improved clinical outcomes. In this respect, there is substantive evidence available to demonstrate better blood pressure control, with fewer or no antihypertensive medications required. Although often limited by small patient numbers and study design the weight of evidence also suggests there are lower rates of cardiovascular disease, better management of anaemia, higher levels of dialysis control, fewer hospitalisations, better nutritional status and fewer adverse effects overall during haemodialysis.

6.2. Better blood pressure control

Increasing the frequency of haemodialysis appears to have a substantially positive effect on blood pressure control. Kooistra et al (1998) showed that there was an improvement in haemodynamic control amongst the 13 patients they monitored after increasing haemodialysis frequency from three to six times a week, without changing the dialysis dosage. Long, slow home haemodialysis provided good daytime blood pressure control amongst most of the 24 patients monitored by McGregor, Buttimore, Nicholls and Lynn (1999), without the need for antihypertensive drugs. The patients were dialysing on average for seven hours three times a week. However, abnormal circadian blood pressure rhythm and left ventricular hypertrophy remained common. Similarly, significant blood pressure and left ventricular mass index decreases were noted amongst patients in a French study who had moved from standard to daily haemodialysis (Traeger, Sibai-Galland, Delawari, and Arkouche, 1998). A short-term crossover study in Japan (Koshikawa et al, 2003) further demonstrated significant improvements in blood pressure amongst patients who had moved from conventional to short daily haemodialysis. Chan (2002) also noted a reduction in left ventricular mass index and improvement in left ventricular function amongst patients moving from three times weekly haemodialysis to nocturnal daily haemodialysis.

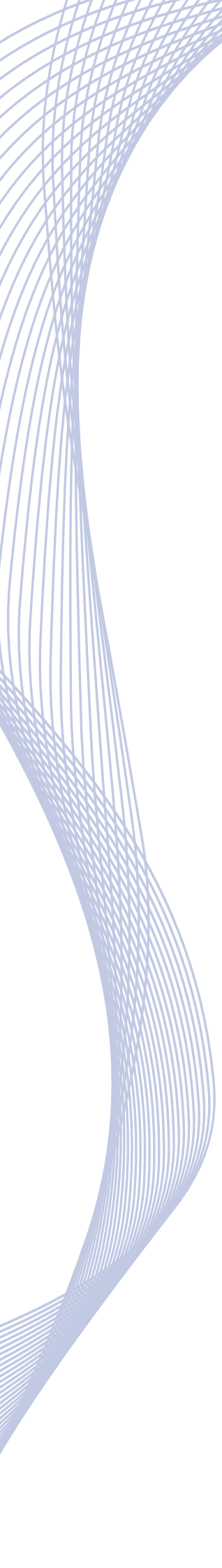
A systematic review of available literature on daily haemodialysis by Suri et al (2006) noted that 10 of the 11 studies included in their review suggested improvement in blood pressure as a consequence of patients moving to daily haemodialysis from the more conventional three times a week.

In a randomised crossover trial involving nine patients, McGregor et al (2001) reported better blood pressure control in the home dialysis group relative to the hospital based group. They recorded 16 episodes of hypotension in 216 treatments for the home dialysis group, five of which required saline to restore blood pressure as compared with 31 episodes in 216 treatments for the hospital based group, eight of which required saline to restore blood pressure. Similarly, a randomised two-period crossover study undertaken in Italy by Fagugli et al (2001) concluded that short daily haemodialysis allows optimal control of blood pressure. 12 hypertensive patients that had been stable on standard three times weekly dialysis for over six months were placed on six months of short daily haemodialysis. A significant reduction in 24-hour blood pressure during short daily haemodialysis was reported. This decrease in blood pressure was accompanied by withdrawal of antihypertensive therapy in seven of eight patients completing the study.

A more rigorously controlled crossover study of short daily haemodialysis in the US (Goldfarb-Rumyantzev et al, 2006) observed decreases in blood pressure, but only 12 patients were involved. The study design involved the patients being firstly on a four-week phase of three to four hours haemodialysis three times weekly, a second eight-week phase of one and a half to two hours haemodialysis six times weekly, and a final four-week repeat of the first phase. Average blood pressure was found to be lower during the short daily haemodialysis compared to the initial and last conventional three times per week haemodialysis.

Reductions in blood pressure and antihypertensive medications were also noted by Kraus et al (2007). The authors conducted a prospective, two-treatment, two-period crossover study of in-centre haemodialysis compared with home haemodialysis in 26 patients treated at six US centres.

Nocturnal haemodialysis is reported to have particularly significant benefits for blood pressure control. Chan (2002) reported that nocturnal daily haemodialysis provides better blood pressure control with a reduction in blood pressure medications and furthermore this was not related to a



reduction in extracellular fluid volume. Chan et al (2003) also tested the hypothesis that short-term nocturnal haemodialysis would reduce ambulatory blood pressure. They studied 18 consecutive patients in Toronto, Canada before and after conversion from conventional three four-hour haemodialysis sessions per week to six eight-hour nocturnal haemodialysis sessions per week. As the dialysis dose per session increased after two months, symptomatic hypotension developed and most antihypertensive medications were withdrawn. Accordingly nocturnal haemodialysis lowered 24-hour mean arterial pressure, total peripheral resistance and plasma norepinephrine.

Pierratos et al (1998) provided evidence that nocturnal haemodialysis achieved satisfactory blood pressure control with fewer medications. The study involved monitoring 12 patients in Canada who had completed training and successfully performed nocturnal haemodialysis for up to 34 months.

All 14 nocturnal haemodialysis studies included in a systematic review undertaken by Walsh, Culeton, Tonelli and Manns (2005) demonstrated improved blood pressure control after conversion to nocturnal haemodialysis.

6.3. Better measures of anaemia

Anaemia is an established cardiovascular risk factor in patients with established renal failure. Covic (1998) reported statistically significant outcomes in favour of home haemodialysis on measures of anaemia. The study compared eight-hour home haemodialysis with four-hour standard dialysis and identified that mean haemoglobin for the home group was higher.

Increases in frequency or duration of haemodialysis are reported to offer improved clearance of uraemic solutes resulting in better anaemia management. Eloot et al (2009) identified that increasing dialysis duration reduces uraemic solute concentration levels, especially those distributed in larger volume. Schwartz et al (2005) demonstrated that increased frequency of haemodialysis results in better uraemic solute clearance through a retrospective cohort study amongst 63 patients in Canada receiving nocturnal haemodialysis compared with 32 established renal failure patients who remained on self-care conventional haemodialysis.

McGregor et al (2001) in a randomised crossover trial reported a mean haematocrit (%) of 33 for longer home dialysis sessions of six to eight hours compared with 31 for shorter in-centre haemodialysis sessions of three and a half to four and a half hours.

Significant increases in haemoglobin were noted amongst patients who converted from in-centre conventional to intensified nocturnal haemodialysis in Germany (David et al, 2009). 13 haemodialysis patients were converted from conventional three four-hour dialysis sessions a week to nocturnal three eight-hour dialysis sessions per week and longitudinally monitored over 12 months. In association with a reduction in erythropoiesis-stimulating agents there was a substantial rise amongst patients in haemoglobin levels.

6.4. Higher clearance of beta-2-microglobulin

Evidence of nocturnal haemodialysis resulting in much higher clearance of beta-2- microglobulin is provided by Raj et al (2000). They studied 10 end-stage renal disease patients over two consecutive weeks of three conventional 4-hour sessions and six 8-hour nocturnal haemodialysis sessions. Nocturnal haemodialysis provided much higher clearance of beta-2-microglobulin than conventional haemodialysis.

Pierratos et al (1998) reported clearance of beta-2-microglobulin to be four times higher amongst patients undergoing nocturnal haemodialysis than for conventional haemodialysis. Better clearance of beta-2-microglobulin was also observed by Goldfarb-Rumyantzev et al (2006) amongst patients during short daily haemodialysis in contrast to conventional haemodialysis.

6.5. Higher levels of dialysis adequacy

Most studies compare small solute clearance in dialysis modalities of different frequency and duration by calculating the standard Kt/V (a measure of adequacy of dialysis treatment). Covic

(1998) found that the mean Kt/V for the home dialysis group was higher than the hospital based group on comparing 8-hour home haemodialysis with four-hour standard dialysis (1.72 versus 1.23). No information was provided on frequency of dialysis.

McGregor et al (2001) reported an equilibrated Kt/V of 1.19 for longer home haemodialysis of six to eight hours three times per week, as compared with 1.17 for shorter in-centre haemodialysis of three and a half to four and a half hours three times per week.

Studies of more frequent and longer, nocturnal home haemodialysis, show urea levels fluctuate within the normal range (Pierratos et al 1998; Chan et al 2002).

Although dialysis adequacy is still considered appropriately monitored by either Kt/V or urea reduction ratios, more recent studies suggest Kt/V has deficiencies as a measure of adequacy. For example, Agar (2005) argues that dialysis adequacy is more complex than just small solute clearance and puts emphasis on the importance of phosphate controls, and dietary and fluid freedoms (see section 4.8).

6.6. Fewer hospitalisations

Three studies provided information on hospitalisation rates. Mohr et al (2001) in a review comparing short daily or nocturnal haemodialysis with conventional three times a week in-centre haemodialysis, found an average 43% reduction in unplanned hospital days associated with daily or nocturnal haemodialysis.

A study of 12 daily home haemodialysis patients carried out over 234 months in the USA by Kumar, Ledezma and Rasgon (2007) demonstrated decreased unplanned hospital admissions. Over the study period there were 0.56 admissions per patient per year with a mean length stay of 3.7 days. Ting et al (2003) evaluated hospitalisation rates and length of stay and found that these decreased for patients up to six years on daily haemodialysis compared with their year on conventional haemodialysis prior to starting daily haemodialysis.

6.7. Improvements in sleep apnoea

Sleep apnoea is common in patients with chronic kidney disease and established renal failure. Conventional haemodialysis has not been found to improve sleep apnoea whereas nocturnal haemodialysis is reported to correct sleep apnoea. Hanly and Pierratos (2001) carried out a study in Canada amongst 14 patients undergoing conventional haemodialysis for four hours on three days a week, who were then switched to nocturnal haemodialysis for eight hours on each of six or seven nights a week. Conversion from conventional to nocturnal haemodialysis was associated with a reduction in the frequency of apnoea and hypopnoea, predominantly in seven patients with sleep apnoea. These patients also experienced increases in the minimal oxygen saturation, transcutaneous partial pressure of carbon dioxide and serum bicarbonate concentration.

6.8. Better nutritional status

Serum phosphate level appears to be most consistently controlled amongst patients who convert to nocturnal daily haemodialysis, with liberalisation of the diet and elimination of phosphate binders being recorded in some patients. Pierratos et al (1998) found that weekly removal of phosphate was twice as high amongst patients on nocturnal haemodialysis compared to removal when they were on conventional haemodialysis. All their study patients on nocturnal haemodialysis were reported to have discontinued use of phosphate binders and to have increased dietary phosphate and protein intake. The reported results from Pierratos et al have been validated by Lockridge et al (2001), Kooistra (2003) and Agar (2005). The results from the London Daily/Nocturnal Hemodialysis Study (Lindsay, Alhejaili et al, 2003) also show the superior control of serum phosphate levels in nocturnal haemodialysis patients compared with daily haemodialysis or conventional haemodialysis patients. Additionally the authors identified significantly reduced phosphate-binder use amongst nocturnal haemodialysis patients.

Improved nutritional status was further demonstrated by David et al (2009) amongst patients converting from in-centre conventional dialysis to nocturnal haemodialysis. The nutritional status was assessed by body weight and bioelectrical impedance analysis with both measures showing improvement after the conversion to nocturnal haemodialysis. The calcium-phosphate product slightly declined, without changes in the dose of any phosphate binders.

In contrast, the systematic review undertaken by Suri et al (2006) found little evidence of phosphate level improvements with daily haemodialysis. Six out of the eight studies that monitored phosphate levels included in their review, recorded no significant changes in phosphate or phosphate binder dose with daily haemodialysis. However, McGregor et al (2001) reported lower mean values for phosphate for longer home haemodialysis compared with shorter in-centre dialysis.

Additionally, Kumar, Ledezma and Rasgon (2007) demonstrated improved nutritional status for daily home haemodialysis patients in the USA, including increases in mean dry weight and mean albumin levels. An increase in dry weight was also observed amongst study patients in France undergoing daily versus standard haemodialysis (Traeger, Sibai-Galland, Delawari and Arkouche, 1998) along with a significant increase in the normalised protein carbolic rate and a rise in calorific intake.

6.9. Vascular access risks

Vascular access failure as a result of more frequent cannulation is considered a potential risk of daily haemodialysis, yet there is little evidence to support this. Woods et al (1999) provide evidence that no harm results from increased cannulation, having examined 72 patients treated at nine centres between 1972 to 1996, who switched from thrice weekly haemodialysis to six times weekly. Two years after commencing six times weekly therapy, fistula patency was recorded at 92%, above conventional rates. Having one operator repeatedly perform cannulation is likely to contribute to this observed success rate.

Another study reported decreased permanent access failures for arteriovenous fistulae compared with patients on conventional haemodialysis (Quintaliani et al, 2000). Whilst Piccoli et al (2004) argued that the setting of vascular access creation may influence its success but found no evidence that daily cannulation lead to increased rates of vascular access failure or procedures to restore optimal vascular access.

6.10. Evidence of the effectiveness of self-care in general

There is a fairly substantive body of evidence showing self-care interventions benefit patients and improve health outcomes. The reported findings to date from an extensive review of self-care support, still in progress (Department of Health, December 2007), indicated that self-care support interventions have definite potential to benefit patients. The evidence examined in this report encompassed a large number of systematic reviews, primary research studies and surveys covering a range of different health problems, conditions and issues. Overall the review found clear evidence suggesting that self-care support can result in beneficial health outcomes for people and with more appropriate use of health and social care services.

Examples of research studies that support this conclusion include a review of 25 random controlled arthritis self-care trials undertaken by Astin (2002). The review found that different self-care interventions significantly improved pain, functional disability and self-efficacy post-intervention; and, tender joints, psychological status and coping both post-intervention and follow-up. Although the findings suggested that self-care support may be more effective for patients that had been ill for a shorter time period.

A Cochrane review conducted by Riemsma et al (2004) also found some evidence of the effectiveness of self-care interventions for arthritis patients. The review covered 50 randomised controlled trials on interventions involving patient education and self-care skills training amongst patients with rheumatoid arthritis. The findings showed that self-care interventions had a significant positive effect on disability, patient global assessment, depression and pain. There were however no significant effects for psychological status or anxiety.

Gibson (2004) carried out a Cochrane review of 36 random controlled trials of asthma self-care interventions including asthma education, self-monitoring and written action plans. There were recorded improvements in health outcomes and quality of life, and reductions in hospitalisations and Accident and Emergency department visits, days off work or school and in nocturnal asthma.

A systematic review by Bower, Richards and Lovell (2001) of the clinical effectiveness of self-help treatments for anxiety and depression in primary care also offers evidence of the benefits of self-care. Eight randomised controlled trials with a total of 636 participants were included in the review. All the research studies reporting on between-group comparisons found significant advantages associated with self-help on at least one clinical effectiveness measure although most studies reported on multiple comparisons. The authors concluded that the review offered some evidence that self-help treatments might offer some clinical advantages over routine primary care. However, they highlighted that the studies on which they based their findings were limited in number and relatively low in quality.

A randomised controlled trial to assess the effectiveness of a patient orientated self-management approach to chronic inflammatory bowel disease was reported on by Kennedy et al (2004). 700 patients with established inflammatory bowel disease were recruited to the study, carried out in 19 English hospitals, split equally between control and intervention sites. One year following the self-care intervention, self-managing patients had made fewer hospital visits without any corresponding increase in primary care visits and that quality of life had been maintained without any evidence of anxiety about the programme. The two patient groups recorded similar findings in relation to satisfaction with consultations.

More recently, a randomised controlled trial has been undertaken by Kennedy et al (2007) examining the effectiveness of national lay-led self-care support for patients with long-term conditions, developed through the Expert Patients Programme. A two-arm pragmatic randomised controlled trial design was used amongst 629 patients with a wide range of self-defined long-term health conditions. The lay-led self-care support group involved six-weekly sessions to teach self-care skills. The self-care support groups were effective in improving patients' self-efficacy and energy after six months but there were no statistically significant reductions in the use of routine health services.

A number of research studies have examined which methods of motivating and engaging people in self-care achieve better clinical outcomes. Simply providing information has been found insufficient to ensure people feel informed, educated and able to manage their own conditions. Information needs to be presented in easily accessible ways that invites and encourages people to apply it in practice (Hibbard and Peters, 2003). Department of Health (December 2007) discussed the idea that self-care interventions may work through their potential to help build 'primary groups': for example, community networks, peer groups, and social support, that in turn result in varied beneficial effects for individuals such as self-care skills, training courses and education programmes.

Educational sessions that help people learn how to undertake self-care activities or manage their condition more effectively, have proved particularly effective. For example, a randomised trial in six United States (US) hospitals examined the effects of self-management rehabilitation education for older women with heart disease and found unplanned days in hospital reduced by 46% (Osman et al, 2002). Similarly Singh (2005), after undertaking a systematic review of evidence on self-management education, concluded that self-management education programmes improve how patients feel about their condition and their ability to cope on a daily basis.

Groessl and Cronan (2000) argue that the efficacy of self-management for chronic illness is most effective when combined with a support group. Virtual support also appears to enhance effectiveness. A randomised trial by Lorig et al (2002) found that an e-mail discussion group for back pain led to significant improvements in pain, disability and distress as well as a 46% decline in visits to the doctor.

7. Benefits of home haemodialysis on quality of life, morbidity and mortality, and whether this reflects healthier patients at the outset

The evidence that exists strongly suggests more frequent daily haemodialysis, especially daily nocturnal haemodialysis, offers quality of life, morbidity and mortality benefits over conventional three times weekly haemodialysis. Since there are greater opportunities to undertake short daily or longer daily nocturnal haemodialysis in the home than hospital or satellite units, it is reasonable to argue that the benefits of these dialysis modalities can be ascribed to home haemodialysis. On this basis there is fairly robust support for the superior benefits of home haemodialysis in relation to morbidity and mortality. However in terms of quality of life, study design limitations make it harder to argue that reported benefits are not reflective to some degree of emotionally and psychosocially 'healthier' patients from the outset.

7.1. Morbidity and mortality

Bleyer, Russell and Satko (1999) first raised concerns about the effect of the intermittent nature of conventional three times a week haemodialysis on mortality rates. Their study of 1977-1997 data from the US Renal Data System (USRDS) on the day of death for US haemodialysis found that for all haemodialysis patients, Monday and Tuesday were the most common days of sudden and cardiac death. The authors concluded that this finding may be a consequence of the intermittent pattern of haemodialysis sessions.

Several studies report improved survival for patients receiving more frequent haemodialysis sessions compared to conventional three times a week haemodialysis.

However, these studies do not compare the outcomes of short daily or nocturnal haemodialysis users with a matched comparison cohort and therefore it can be argued that the positive results might reflect healthier patients from the outset. Saner et al (2005) tried to minimise selection bias by comparing outcomes of home haemodialysis and in-centre haemodialysis patients with a nested case-cohort study. For each patient trained for home haemodialysis between 1970-1995, a corresponding matching conventional haemodialysis patient was identified by retrospective analysis. Pairs were matched for gender, age, time of dialysis onset and renal disease category. 58 of the 103 home haemodialysis cohort were matched. Results showed that survival was significantly longer on home haemodialysis compared with in-centre haemodialysis. Five, ten and twenty-year survival rates were 93%, 72% and 34% with home haemodialysis and 64%, 48% and 23% with in-centre haemodialysis respectively.

Accepting that the survival of any group of patients is influenced by the selection process, Kjellstrand et al (2008) ensured that one-third of their study population had serious complications or co-morbidities, with accompanying poor prognosis, when examining survival amongst short daily haemodialysis patients. They also argued that the increasing age and numbers of patients with secondary renal disease over time, amongst these daily haemodialysis patients, paralleled that of all dialysis patients. Consequently they viewed the sample of 415 study patients as representative of a wide spectrum of chronic dialysis patients and a suitable group for survival comparisons. They showed that the survival of patients on short daily haemodialysis was two to three times higher and the predicted 50% survival time 2.3 to 10.9 years longer than that of matched conventional haemodialysis patients reported by the USRDS 2005 Data Report.

Johansen et al (2009) acknowledged that patients starting nocturnal haemodialysis or short daily haemodialysis identified for their study were younger and less likely to be lower income or have established renal failure secondary to diabetes than the overall haemodialysis population in the US. However, they also argue that the matching strategy employed resulted in control groups with a similar demographic profile and early hospitalisation rate. Their findings showed a survival and morbidity benefit of nocturnal haemodialysis compared with conventional haemodialysis in a relatively modern cohort assembled from multiple centres in the US, in which patients received nocturnal haemodialysis five or six nights per week. A reduced but not significant risk of death for patients using short daily haemodialysis was also recorded compared to controls.

Interestingly Pauly et al (2009) have recently reported comparable survival rates amongst patients on nocturnal haemodialysis and randomly matched deceased donor renal transplant recipients. Their study compared 177 nocturnal haemodialysis patients on two regional Canadian nocturnal haemodialysis programmes, matched to 1,239 deceased and living donor kidney transplant patients using the USRDS data, 1994-2006, followed for a maximum of 12.4 years. During the follow-up period, the proportion of deaths among nocturnal haemodialysis patients was 14.7%, as compared with 14.3% amongst deceased donor kidney transplant patients and 8.5% amongst living donor kidney transplant patients. The authors conclude that given these survival rates, nocturnal haemodialysis may be used as a 'bridge' to transplantation or even a suitable alternative in the absence of a living donor kidney transplant.

7.2. Quality of life

The available evidence provides clear indications that the quality of life, both psychosocial and emotional, is better amongst patients undertaking more frequent haemodialysis, especially nocturnal dialysis. The studies described suffer from small sample sizes and limited duration of assessment follow-up. Additionally, whilst quality of life differences are evident between more frequent haemodialysis treatments and conventional haemodialysis, the types of patient may differ significantly in terms of case-mix variables relevant to psychosocial well-being and emotional measures. Therefore it is difficult to argue with confidence that the quality of life benefits that might be attributed to home haemodialysis, do not in some way reflect 'healthier' patients.

Studies specifically relating to home haemodialysis support there being better quality of life for home haemodialysis patients over hospital haemodialysis patients. A small study by Courts and Boyette (1998) reported that patients on home haemodialysis achieved better scores than patients on hospital haemodialysis in relation to the Haemodialysis Stressor Scale which assessed the type and extent of stress factors perceived by people on haemodialysis. They also achieved better scores on the Clinical Anxiety Scale, Generalised Contentment Scale and the Psychosocial Adjustment to Illness Scale Self Report. Cameron et al (2000) found that home haemodialysis was associated with less emotional distress than hospital haemodialysis.

Other studies provide evidence that short daily haemodialysis offers many quality of life benefits compared to three times weekly dialysis. Bremer et al (1989) demonstrated that patients on home haemodialysis achieve better outcomes for both objective and subjective quality of life measures when compared with patients on satellite unit or hospital dialysis. Home dialysis patients also generally scored higher than satellite unit or hospital dialysis patients on a range of satisfaction measures including standard of living, friends, sex life, health, religion, marriage and children.

Patients in the London Daily/Nocturnal Hemodialysis Study (Heidenheim, Muirhead, Moist and Lindsay, 2003) completed three sets of quality of life assessment tools and a sub-set of patients completed a Time Trade-Off assessment. Results showed that given the choice, all patients preferred to remain on daily haemodialysis after switching from conventional haemodialysis. The Time Trade-Off analysis indicated that patients were willing to trade far less time on daily haemodialysis and much more time on conventional haemodialysis in exchange for 'perfect' health. Whilst short daily haemodialysis was found by Vos et al (2006) to improve health-related quality of life, there was seen to be no effect on cognitive functioning and electroencephalograms.

Nocturnal haemodialysis has been found to have particularly good comparative quality of life outcomes. In 1994 Uldall and Pierratos initiated a programme of more frequent nocturnal haemodialysis in the home involving six to seven dialysis treatment sessions a week. The three-year experience with 13 patients demonstrated significant improvements in quality of life measures (Pierratos et al, 1998). Since then several studies have examined quality of life of nocturnal haemodialysis using a variety of assessment measures.

The Nightly Home Haemodialysis Program reported on by McPhatter et al (1999) suggested that patients have improved overall quality of life as measured by the CHOICE Health Experience Questionnaire. Whilst a two-group, parallel and randomised controlled trial at two Canadian university centres by Bruce et al (2007) revealed that frequent nocturnal haemodialysis as compared

with three times weekly haemodialysis was associated with clinically and statistically significant improvements in selected kidney-specific quality of life measures (effects of kidney disease and burden of kidney disease). However there was no overall significant improvement in quality of life recorded (difference of change in EuroQoL index from baseline), whereas Finkelstein et al (2007) summarised that nocturnal haemodialysis consistently improves quality of life measures.

Mohr et al (2001) concluded that there was convincing evidence of improved quality of life with nocturnal or short daily haemodialysis. The researchers had compared the effect of being on nocturnal or short daily haemodialysis with being on conventional three times per week hospital haemodialysis in relation to quality of life. Statistically significant findings were collated from four studies in which a variety of quality of life instruments were used (SF-36, Nottingham Health profile, SIP, Beck Depression Inventory, KDQOL ESRF-targeted areas and Dialysis-Related Symptoms).

Cognitive function has also been demonstrated to respond positively to nocturnal haemodialysis. Jassal et al (2006) measured clinical subjective symptoms for cognitive functioning and depression using the Patient Assessment Own Functioning inventory and the Beck Depression index. 12 patients were measured over a six-month period after converting from three times weekly to daily nocturnal haemodialysis. The results suggested that nocturnal haemodialysis may be associated with improved general cognitive efficiency, attention and working memory.

8. The true cost benefits of self-care dialysis therapies, including contribution to the economy through patients continuing to work

8.1. Home haemodialysis is the more cost effective therapy compared with hospital or satellite unit based haemodialysis

The available evidence indicates that home haemodialysis is more cost effective than haemodialysis carried out in a hospital or satellite unit for patients with established renal failure. The principal reason for this generalised finding is the relatively lower staffing requirements of home haemodialysis. Many of the included studies highlight the initial high costs of home haemodialysis resulting from set-up and training costs, with the calculated payback period varying considerably.

It is also important to note that many of the economic evaluations compare the increased frequency of dialysis sessions in the home versus only three sessions in hospital and satellite units. Despite this difference, the evidence shows home haemodialysis to have a relative cost benefit.

Whilst some studies included in this review involve only small patient numbers or short observation periods, in general the evidence from these studies suggests home haemodialysis is less costly than in-centre dialysis. De Wit (1998) conducted an economic evaluation in the Netherlands using a five-year Markov modelling approach and provided an analysis of costs by age and first versus subsequent treatment years. The models showed that home haemodialysis had the lowest annual treatment costs, followed by satellite unit haemodialysis and then hospital haemodialysis. However, the models included data for only five patients receiving home haemodialysis and treatment-associated hospitalisation costs varied substantially by age.

A study based in the USA undertaken by Ting et al (1999) analysed data from 22 patients to determine the cost differentials between short daily home haemodialysis and hospital haemodialysis three times a week. Patients were prospectively selected and each served as their own control. The cost benefits of patients being able to work or not requiring travel were excluded. The results showed a reduction in costs of US\$4,241 per patient, for the year after switching treatment compared with the year prior. However, this cost reduction was not significant, probably because of the small sample size.

Arkouche et al (1999) compared out-centre haemodialysis in France (defined as home haemodialysis and self-care/satellite haemodialysis) with hospital haemodialysis. Using one year of treatment data they estimated expenditure of US\$42,000 per patient for home haemodialysis,

US\$42,000 for Continuous Ambulatory Peritoneal Dialysis, US\$50,000 for self-care/satellite haemodialysis and US\$80,000 for hospital haemodialysis.

Results from a UK based study reflect a similar economic picture for home versus hospital based haemodialysis. Baboolal and his colleagues (2008) estimated the cost of different dialysis modalities in the Cardiff and Vale NHS Trust and six other hospitals in the UK. Using semi-structured interviews with nephrologists, head nurses and business managers the researchers identified the steps involved in delivering the different dialysis modalities and then assigned costs to these using published figures or supplier's published price lists. Dialysis costs themselves were estimated by a combination of micro-costing and a top-down approach. The study findings revealed home based haemodialysis to cost £20,764 per annum, markedly less than hospital based haemodialysis (£35,023) or satellite unit-based haemodialysis (£32,669). However, the home based haemodialysis costs were based on results from only one centre, which outsourced home haemodialysis delivery to a commercial organisation using locally negotiated prices.

A more reliable systematic review of economic evaluations of haemodialysis in Western European countries examined service costs as well as costs of treating morbidity associated with dialysis treatment (Peeters et al, 2000). Where costs were provided per session, the analysis considered three sessions per week for hospital dialysis and daily sessions for home haemodialysis. All the studies involved in the review showed that average annual treatment costs of home dialysis were lower than those of hospital dialysis, including treatment for complications or morbidity related to treatment. The main reason for this cost differential was shown to be lower staff use.

Similarly, a systematic review designed to assess the cost effectiveness as well as the overall effectiveness of home haemodialysis compared with haemodialysis carried out in a hospital or satellite unit concluded that "the evidence is overwhelmingly in favour of lower total costs for home haemodialysis compared with hospital haemodialysis" (Morratt et al, 2003). A total of 27 studies undertaken between 1978 and 2001 were included in the review, 18 of which considered cost effectiveness.

The authors' analysis showed that despite the initial high costs of home haemodialysis relative to hospital haemodialysis, linked to set-up and training costs, the payback period for these higher costs is about 14 months (it should be noted that this estimate is based on data from the early 1990s). There were some notable variations in the cost of satellite units, linked primarily to different staffing levels and variations in the ability to maximise use of the haemodialysis machines. Overall though, satellite haemodialysis units were found to be less costly per dialysis session than hospital haemodialysis, and in turn home haemodialysis less costly than satellite haemodialysis units. The principal reason for these variations was the lower staffing requirements of home and satellite haemodialysis. However, the authors caution that these figures should be assumed for 'low risk adults' since historically people undergoing home haemodialysis are a highly selected group tending to be younger and having fewer co-morbidities than those being dialysed in hospital or satellite units.

In the UK, evidence referenced by the National Institute for Health and Clinical Excellence (NICE), suggested that once initial set-up costs of home haemodialysis are recovered – after around 14 months - treatment at home is cheaper than hospital treatment largely due to lower staffing and transport costs (2002). Work by NHS Kidney Care analysed dialysis costs from 16 renal units (2009). This demonstrated annual costs of £17, 264 for home haemodialysis versus £23,868 for unit based dialysis (hospital and satellite units) per patient. Costs assumed 4 dialysis sessions per week for home haemodialysis versus standard thrice weekly treatment for unit based dialysis. This analysis incorporated the additional training costs but did not take into account home conversion costs, the benefits of reduced travel from home to unit for dialysis, predicted reductions in medications or hospitalisations or the ability to return to work or manage child care. It also did not take into account the capital costs required to provide sufficient hospital or satellite dialysis stations in the future to meet rising demand.

United States Government Accountability Office data (GAO, 2009) provides evidence of lower costs per dialysis session when undertaken in the home when compared with dialysis in a medical facility.

The GAO based their analysis on self-reported cost information from six dialysis providers, which showed that average costs per treatment for home dialysis were 17-50% lower. Some costs were higher for home dialysis, in particular supply costs, since certain supplies can be reused for patients receiving dialysis in a facility. The main cost savings linked to home dialysis came from drugs and staff. After training, home dialysis patients required significantly less staffing resource. However, several providers indicated that the costs of training can be significant and these were not included in the average costs per treatment.

The potential for cost savings by moving from hospital to home based haemodialysis were also highlighted in a recent Australian research study (Kirsten et al, 2009). A multiple cohort Markov model was used to assess cost outcomes of different renal replacement therapies for new established renal failure patients from a health-care funder perspective, over the period 2005-2010. Patient characteristics and current practice patterns were based on the Australia and New Zealand DATA Registry. Under one scenario of switching new patients from hospital to home haemodialysis, cost savings of A\$46.6 million by 2010 were predicted. The authors concluded that encouraging home-based over hospital-based dialysis would help optimise cost effectiveness in renal replacement therapies.

Interestingly, one small-scale study undertaken in Finland (Malmstrom, 2008) suggests that self-care haemodialysis in a satellite unit can be as cost effective as home based haemodialysis. The study involved collection of cost data from patients on self-care dialysis treatment during 2004 in Helsinki. 33 of the patients participating in the study were on home haemodialysis, and 32 on self-care satellite dialysis. No significant differences in total costs between home haemodialysis and self-care satellite haemodialysis were evident, although there were significant variations in the distribution of costs between the two approaches. In particular, the direct medical costs of dialysis and hospital treatment were higher in home haemodialysis than in self-care satellite dialysis, and travel costs were much lower for home haemodialysis. Nonetheless despite there being no cost differential between the two study groups, in the home haemodialysis setting patients had on average more and longer dialysis sessions.

8.2. More frequent and longer-duration home-based haemodialysis produces cost benefits relative to in-centre dialysis

As a result of increasing interest in daily forms of haemodialysis such as nocturnal haemodialysis and short daily haemodialysis, several studies have focused on the relative costs of these different modalities, undertaken at home or in-centre. Most studies indicate that annual and/or per dialysis session direct health care costs are substantially lower for patients undergoing more frequent haemodialysis in the home, as compared with more conventional in-centre haemodialysis.

In this context, Mohr and his colleagues (2001) conducted a comprehensive economic evaluation of short daily haemodialysis (at home or in hospital) or nocturnal haemodialysis versus hospital dialysis three times a week. Cost data were sourced primarily from the US Renal Data System, Centers for Disease Control and Medicare Payment Advisory Commission. Resource use during daily haemodialysis was modelled on two ongoing US programmes from a single year. The economic modelling, using a clinical decision analysis framework, showed that simulated costs were lower with all three modalities of treatment involving daily treatment versus haemodialysis three times a week. Estimated annual costs (1998) were US\$68,400 for conventional hospital haemodialysis, US\$60,800 for short daily hospital haemodialysis, and US\$57,700 for nocturnal home haemodialysis. The cost benefits resulted primarily from reductions in unplanned hospital days.

However, whilst the Mohr et al study provides a favourable analysis of nocturnal home haemodialysis costs, the projections involved were performed without prospective patient-level data, and sensitivity analysis linked to expected costs showed some uncertainty in the estimates. Such a prospective one-year descriptive costing study was undertaken in Canada and this revealed considerable cost savings for home nocturnal dialysis as compared with conventional in-centre haemodialysis (Mcfarlane, Pierratos and Reselmeier, 2002). The study was carried out at two centres

in Canada involving 33 patients from a home nocturnal haemodialysis programme and a matched cohort of 23 patients from a conventional in-centre haemodialysis programme. The two patient groups had similar demographic features. Despite the fact patients undertaking home nocturnal haemodialysis had almost twice as many dialysis treatments and triple the number of dialysis hours over the study period, than those undertaking conventional in-centre haemodialysis, the projected annual total cost for health care was Can\$10,000 lower for the home dialysis patient group. Cost savings in terms of staffing, overheads, support, unplanned admissions and procedures were higher than the cost increases for direct haemodialysis materials and the cost of depreciable items. Staffing costs reductions being predominantly driven by the lower requirement for nursing staff. It should be noted though that whilst home nocturnal haemodialysis was found to be the less costly therapy option, a sensitivity analysis conducted by the authors showed that the cost savings were only statistically significant if the patient remains on the modality for at least three years.

Agar et al (2005) compared the expenditure of two haemodialysis programmes in the same Australian renal service during the financial year 2003-2004. One was a conventional satellite haemodialysis unit offering four-hour long treatment three times a week and the other a nocturnal home haemodialysis programme of eight-hour long treatment six nights a week. All wage costs, recurrent expenditure, fixed costs and the estimated costs of building and infrastructure were included for 30 'notionalised' patients in each programme. The findings revealed the total nocturnal home haemodialysis programme expenditure to be A\$33,392 per patient a year, as compared with A\$36,284 per patient a year under the conventional satellite haemodialysis programme. The authors calculated that this represented an annual A\$116,750 nocturnal home haemodialysis programme saving for a 30-patient cohort with other potential additional savings in erythropoietin use, hospitalisation and social security dependence.

A beneficial operating cost comparison for daily home haemodialysis as compared with more conventional three times weekly haemodialysis was also revealed by the London Daily/Nocturnal Hemodialysis Study (Kroeker et al, 2003). The study undertaken in Canada compared the economics of short daily haemodialysis with long nocturnal haemodialysis and conventional three times weekly haemodialysis. A retrospective analysis of patients' conventional haemodialysis costs during the 12 months prior to the study was conducted to measure changes in cost after switching to daily haemodialysis. Although the patient numbers involved were only small – short daily HD (10), long nocturnal HD (12) and conventional HD (22) - the resulting data suggested a clear economic advantage for daily home haemodialysis over both nocturnal haemodialysis and conventional haemodialysis groups. The increase in number of treatments for the daily and nocturnal haemodialysis led to treatment supply costs per patient being approximately twice those for conventional haemodialysis patients. However, average costs for consultations, hospitalisation days, emergency room visits and laboratory tests for daily haemodialysis patients tended to decline after patient entry to the study. The major cost saving in home daily haemodialysis resulted from the reduction in direct nursing time, but notably excluded patient training costs.

Nonetheless, McFarlane (2004) found that whilst daily home haemodialysis remains less expensive than in-centre haemodialysis, much of the savings between home conventional haemodialysis and in-centre haemodialysis are lost. He identified and reviewed four descriptive Canadian costing studies linked to these modalities. Two were whole-programme comparisons of home conventional haemodialysis and unmatched in-centre haemodialysis patients, and two compared daily home haemodialysis and matched in-centre haemodialysis patients. In the two whole-programme analyses, conventional home haemodialysis was less expensive than in-centre haemodialysis, based on 2003 (US\$36,840 v. US\$100,198 and US\$34,466 v. US\$58,959). McFarlane argued that reductions in staffing and overhead costs were likely to be due to the modality, whilst reductions in medication and hospital admission costs may be due to differences in the patient mix. However, the savings for daily home haemodialysis, whilst significant, were less striking. In the two matched analyses, nocturnal haemodialysis cost less than in-centre haemodialysis (US\$48,656 v US\$59,476) and costs decreased by US\$8,046 in those converted to short daily haemodialysis, and by US\$14,341 in those converted to nocturnal haemodialysis, but increased by US\$2,521 amongst those remaining on in-centre haemodialysis.

8.3. Broader economic benefits of home haemodialysis

The only studies that consider the broader economic benefits of home haemodialysis do so in relation to employment status. The limited evidence available indicates that patients on home haemodialysis, in particular nocturnal haemodialysis, are more likely to be employed full-time than those undertaking hospital or satellite unit haemodialysis. Therefore they are more likely to be making a greater contribution to the economy.

A systematic review by Parsons and Harris (1997) provided comparative information taken from four research sources on the employment status of people being dialysed at home, in satellite units or in hospital. All of these reported that a higher percentage of people undergoing haemodialysis at home were employed full-time, than those being dialysed in hospital or satellite unit. Agar et al (2003) and Agar (2005) demonstrated that in Australia, patients moving from conventional haemodialysis to nocturnal haemodialysis have frequently rejoined the workforce. In combination the return to daytime freedom, improved well-being and the capacity and desire to return to work, have acted as a driver to encourage re-employment amongst nocturnal haemodialysis patients. In parallel, there has been a decrease in social security dependence.

8.4. Evidence of the cost benefits linked to self-care interventions in general

There are a limited number of research studies that focus on the overall cost effectiveness of self-care, but those available tend to suggest there can be significant cost benefits involved through employing self-care strategies. The Wanless review (2002) argued that a fully engaged public who self-care appropriately would reduce the financial costs for a health service. It was estimated that for every £100 spent on encouraging self-care, £150 worth of benefits could be expected in return. Richardson et al (2005) undertook a systematic review of the cost effectiveness of information to support patient self-care of their condition. 39 economic evaluations were assessed with the majority of the studies concluding that self-care support interventions were cost effective or cost-saving. However, the authors cautioned that the overall quality of economic evaluation was poor because of methodological flaws.

The work in progress study by the Department of Health (July 2007) of research evidence on the effectiveness of self-care support, estimated a weighted cost per self-care user of £100, and a corresponding benefit of £200 through savings from the reduction in use of health care services. However, although the Department of Health explored a large number of systematic reviews, primary research studies and surveys covering the different types of self-care support interventions, they found only a few studies highlighting cost effectiveness on which to base their cost estimates.

There is some evidence of cost effectiveness from a number of specific public health self-care initiatives in the UK and internationally. These include a cost analysis of self-management programmes amongst older people, 60 years and over, with osteoarthritis conducted by Groessel and Cronan (2000). 363 study participants were randomly assigned to one of three intervention groups – self-support, education, a combination of both or to a control group. It was found that along with improving health and increasing feelings of control amongst patients, health care costs increased less in the intervention groups than in the control group. Cost analysis was used to demonstrate that the monetary savings from self-care interventions greatly outweighed the cost of conducting the interventions.

Richardson et al (2006) undertook a randomised trial amongst 651 patients in 19 English hospitals, to determine whether a whole-system approach to self-management in inflammatory bowel disease results in cost effective use of health system resources. Using a cost effectiveness analysis over one year, the researchers found that the whole system self-management approach resulted in a mean reduction in costs of £148 per patient per year and a small reduction in quality adjusted life years (QALY), in contrast to the conventional treatment. An economic evaluation was also conducted relating differential health service costs from a UK NHS perspective to differences in QALY. This suggested a probability of around 63% that the self-care approach is cost effective, assuming a willingness to pay up to £30,000 for an additional QALY.

A cost effectiveness analysis undertaken as part of the randomised controlled trial of the Expert Patients Programme, reported on by Kennedy et al (2007) and then Richardson et al (2008), revealed that those patients receiving immediate access to training in self-care skills evidenced better patient outcomes at a slightly lower cost of around £27 per patient, and considerably greater health related quality of life. Valuing a QALY at £20,000 the researchers determined there was a 94% probability that the self-care intervention was cost effective and concluded that lay-led self-care support groups were likely to be cost effective over six months at conventional values of a decision-makers willingness to pay.

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APPENDIX B

NHS Kidney Care Workshop on Home Dialysis Therapies

A Symposium on Home Dialysis took place in Manchester during October 2009. On the second day of the meeting, NHS Kidney Care organised a workshop to promote discussion and gather the thoughts of the assembled home dialysis experts and enthusiasts. Over 70 people participated and attempted to answer the following three questions:

- 1. What prevents units from having successful home dialysis programmes?**
- 2. What are the key elements required for a successful unit?**
- 3. How will YOU contribute from here?**

1. What prevents units from having successful home dialysis programmes?

• Clinical Team

Lack of leadership, limited promotion of availability or benefits
Lack of knowledge or education regarding benefits particularly for junior staff
Inertia, lack of enthusiasm, historical practice limits
Physician bias – traditionally decided on which modality for which patient.
Preconceptions about ability of patient/carer to cope (medical & nursing staff)
Perceived or real lack of demand
Prohibitive policies – such as no lone home dialysis
Difficulties identifying suitable patients

• Patients

Lack of genuine choice, especially if English not first language
Lack of knowledge or awareness of benefits/potential
Lack of suitable role models or advocates locally
Fear of technology
Fear of needling
Concerns regarding risks in event of adverse events at home
Negative impact of in-centre exposure
Those without 'suitable' homes or 'carers'

• Resources

Perceived high capital costs; especially for units with no or limited HHD programme
Perceived need for carer at home, lack of support for carers (financial/emotional)
Perceived insurmountable lack of resources
Limited training capacity
Potential negative impact of new satellite units
Uncertain demand
Existing need for home conversions/installations and uncertain true cost
Availability of new technologies
Monitoring and support of home therapy

2. What are the key elements required for a successful unit?

• Clinical Team

Clinical leadership, courage and vision
Change culture to 'can do', wider enthusiasm and advocacy for HD
Increased education for all staff; incorporate home therapies into curricula
Earlier interventions
Creating right team and environment in evolving process, reviewed regularly
Dedicated HHD teams, greater creativity in meeting patient choice
Trusting patients, transfer risk to patients as appropriate
Sharing of best practice

• Patients

Creating environment for genuine choice e.g. choice rooms
Listening to patients' views
Patient support network
Empowerment of all patients, encouraging self-care for all, not a select few
Review choices across modalities regularly
More high profile publicising of strong patient examples
Increased training flexibility; shift training to home early

• Resources

National directives, clear protocols and streamlined pathways
Use of uniform tariff to incentivise self-care
Involvement of commissioners from outset
Identify and reach all stakeholders
Incorporate private providers as appropriate for training/machine service etc
Dedicated HHD training units/self-care units if home not available
Sharing of best practice, funding training of existing or employment of new staff
Examine feasibility and long-term cost/benefits of new technology
Standardise installation process

3. How will YOU contribute from here?

• Clinical Team

Push for clinical leadership on HHD, support development of champions
Recognise no single or simple solution to improve access to HHD
Channel existing enthusiasm into building partnerships and networks that better enable and support local implementation
Change culture amongst staff at all levels
Communicate benefits of HHD to nephrologists
Share best practice and audit information

• Patients

Create environment that enables patients to shape their own treatment
Be more creative about promoting HHD to patients
Provide online local and national forums for patient support groups
Mobilise local patient groups to press local renal units to increase access to HHD
Collect and share patient stories
Push for patients to have control of their own budget

• Resources

Encourage private companies to produce newer, smaller dialysis machines
Ensure no financial disincentive to patients or carers with respect to utilities etc
Recognise and support those with and without carers appropriately
Invite champions to educate and raise awareness of HHD across networks, PCTs, patient groups etc

Appendix C

Home Haemodialysis Patient Stories

Patient A

Patient A is aged 64 years and married with grown up children who have left home. Being on home haemodialysis, which he started two years ago, has enabled him to continue working, but he retires in a month's time. He enjoys fishing, gardening, and doing DIY around the house.

The first appointment he had in the dialysis unit was with a nurse who told him about the different dialysis options and gave him some DVDs which he watched. At first peritoneal dialysis appealed as he thought it was the best way to carry on working. Although there was the problem of hanging bags on the back of your door all day at work, it seemed the easier route to go. An appointment was made for the consultant to look at his veins. The consultant explained that peritoneal dialysis may fail after 2 years, and it was likely that the wait for a new kidney would be much longer, depending on multiple factors. The consultant also said haemodialysis would suit him better, being an active man, than peritoneal dialysis. The other thing he remembers is the consultant telling him haemodialysis would make him feel better. It was a long conversation, about three-quarters of an hour. He was persuaded and has not thought about peritoneal dialysis since.

He then went on a course where different people talked about being on home haemodialysis, hospital dialysis and peritoneal dialysis. This was very interesting. What influenced him to choose home haemodialysis is that it takes less time than hospital dialysis. He felt that since dialysis was going to take over his life anyway, the minimum time he spent on it the better. He is not a person for sitting on a big ward and waiting for things to happen which is what he would have to do in a dialysis unit. He would have to wait around until it was his turn and he is not very good at that, basically he wanted to get on with it, get it over, and carry on with his life.

His main concern was about sticking needles in himself, having had no experience of that. He hated needles and still does. The other worry he had is what happens if something goes wrong with the machine.

There was a waiting list to start the training for home haemodialysis which he found frustrating. He had to start dialysing on the self-care unit. It was 2 months before he could go into the home haemodialysis training unit. He thought the training was excellent. Within 5 weeks he could do more or less what he can now. He had a few problem to start, but after a couple of weeks things worked out and the nurse was able to take a backseat. He felt he was being prepared to go home from day one. Every time something went wrong with the machine, such as an alarm going off, a nurse would come over, re-set the machine, explain what had happened, and then show him what to do. He was also given a book to read each day whilst he was dialysing, with questions and answers on all the things you should know about home haemodialysis. The first week the questions were easy and then they got more challenging. Finally they took the book away and he was just asked questions by a nurse, if he did not know the answer he was told he should by now.

He was ready to go home after 3 months of training, but had to wait for a further 3 months. The delay was due to the hospital's builder being too busy to start the alterations needed to his house. The machine was installed in the room he wanted, a small downstairs room. It is about the same size as a dialysis bay at the hospital so he knew the machine and tray would take up most of the space. It took about 5 days to complete the work. He felt euphoric when it was finally done and he could come home to dialyse.

The installation was fully paid for and he had to make no contribution to the cost. He is also able to get the dialysis room delisted from his council tax. Although he is sent £70 by the hospital every 3 months, in his view this nowhere near meets the extra electricity and water costs involved, especially since he has to do a deep clean of the Reverse Osmosis for 1 1/2 hours, three times a week.

When he first went home he was quite apprehensive, although he had been trained he was very conscious of being on his own. Having a nurse with him during the first week gave him more confidence. He had several problems with the machine in the early weeks, but he phoned the technicians and they talked him through what needed to be done and he was able to sort things out. He finds the technicians easy to deal with and very competent. It gives him tremendous confidence to know there are always people there to help. He knows he can always call a nurse or technician, depending on the problem, at any time.

As soon as he started dialysing at home he felt better and inconveniences like not being able to drink and having to think about potassium levels diminished. He could dialyse as often as he wanted and did not have to worry about restricting his liquid intake and so he could drink more at weekends. He usually dialyses for 5 hours, every other day. He tends to do everything himself because his wife, although very helpful, can panic if something goes wrong and she does not like the sight of blood.

He feels the main benefit of home haemodialysis is the choice it offers him. His working hours are 7.30am to 4.30pm so he can dialyse when he gets home. At the weekend if he is going shopping with his wife in the morning, he can dialyse in the afternoon. If they are not going shopping he can get up at 5.00am and by 11.00am be finished and have the rest of the day. If they want to go away for a long weekend, he can miss out a day of dialysis and dialyse as soon as he gets back. He also likes being able to talk more to his wife than he can when dialysing at the hospital. He is able to have all his home comforts around him, TV, phones, computer, which is a lot more convenient. He is far more comfortable and can choose whether to have the heating on or off.

Unfortunately he is currently dialysing back in the unit, 3 days a week for 4 hours at a time, because his fistula stopped working. He had neck access for a while and is now training to use a new fistula. Dialysing less often he feels more tired and cannot drink as much, especially at weekends, which he finds annoying. It has also put his blood pressure and pulse rate up. He cannot keep them as constant as when dialysing every other day. It has been very difficult to maintain his job and so he is on leave now until he retires. He wants to come home to dialyse as soon as he can.

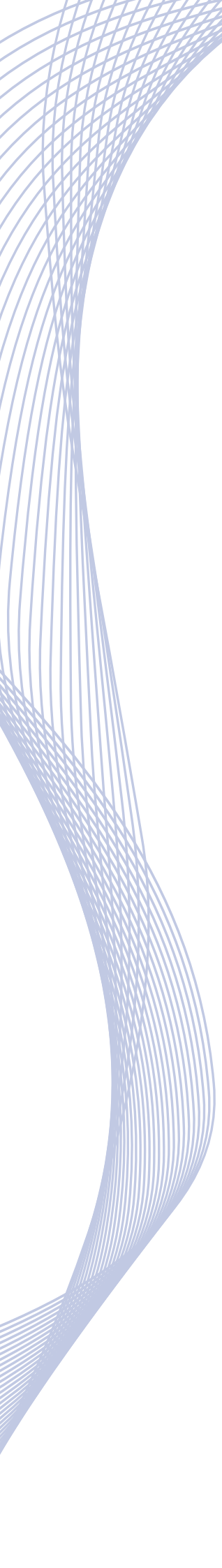
Patient B

Patient B is aged 40 years and lives with her husband of 12 years. They have no children. Since starting home haemodialysis she has been able to work part-time running children's workshops. Going out to work is very important to her quality of life. When hospital dialysis prevented her working, she felt her life was just about dialysis. She also enjoys long walks with her husband, socialising, going to the cinema and theatre, and playing the guitar.

She was on hospital haemodialysis for 15 years and had three failed kidney transplants before starting on home haemodialysis 5 years ago. She recalls the years of hospital haemodialysis with considerable negativity. She generally felt poorly and was often sick. Dialysing three days a week meant going from Friday to Monday without dialysis which left her feeling very ill on the Sunday and Monday. She had to completely 'write off' these two days. Most Sunday nights the nausea would reach a point where she felt she was going into kidney failure, being unable to breathe or see very well. Often she had to sleep sitting up which was very depressing. Monday's dialysis would result in cramp and nausea and she felt completely flattened. She did not recover till the Tuesday.

She first heard about home haemodialysis 8 years ago from her consultant. She was told it was a treatment option that would be gentler on her heart and so potentially offer her a longer life. There would be more of a gentle wave as opposed to massive peaks and troughs in her blood pressure, and uremic and creatinine levels. Her consultant also said the nausea, restless legs and fluid gain she suffered from should lessen.

She remembers very quickly deciding she would like to move to home haemodialysis. She felt overjoyed that after all the years of treatment there seemed a way of living life differently and with hope of longevity. She thought it might give her more freedom, and a bit more say in her treatment. What she calls 'hospital politics' was also important to her decision. She used to be given toast and a cup of tea, and then after a couple of hours on dialysis, crackers or maybe a sandwich. Then they



introduced new arrangements and she only got a cup of tea and a biscuit which she thought really poor since she was often in the hospital up to 6 hours. The hospital became more about rules and regulations than personal care, making her feel pushed into a corner as 'patient 4324' rather than a person.

However she had to wait a further 3 years to start home haemodialysis. Initially it was not available through her hospital trust and then when it was possible, her cottage was considered too small for a dialysis machine and all the stores. Therefore she and her husband moved to a slightly larger home specifically to be able to get a dialysis machine.

Although determined to go onto home haemodialysis, she worried how it might affect her marriage. Hospital haemodialysis was time consuming and restricting, but once she came home she was free and did not have to think about dialysis. She and her husband were able to go out many evenings. Knowing the dialysis was going to come home with the machine in the house, that her husband would have to watch her put needles in and be the one to give her saline, made her concerned about how he would handle the change and responsibility. However nurses at the hospital discussed what it would be like with both her and her husband, and the two of them had long conversations together. She also listened to his view that no matter what he would sooner have her at home than the horrible Sunday nights with a dreadfully poorly wife which he dreaded each week.

She thought the home haemodialysis training very good. It lasted about 7 or 8 weeks. She found it fairly easy since in the satellite unit where she was beforehand, she had lined her own machine and done a lot of self-care.

She is very pleased she moved to home haemodialysis. She now feels in control of her treatment. She has the 'say so' if she dialyses, when she dialyses, for how long, and how much fluid she takes off. Having choice and not being restricted by hospital rules is a hugely positive aspect. She does not have to get up early or hang around waiting for hospital transport. She has a more normal and everyday life. No where near as good as having a kidney, but the best of the treatments she has had.

Very importantly for her, she can now eat healthily including things like tomatoes, spinach and tofu which she could never do before. She particularly remembers having her first pasta meal with lots of tomatoes, chillies and mushrooms. Before would have a little taste, never a whole dish. It felt daunting and she thought she might have a heart attack. But no, it was fabulous. It was like being reintroduced to food again after the restrictive renal diet. She started cooking and became fascinated by all the food she had stopped eating, making lots of Thai and Chinese meals and her own soups.

To start with she dialysed 6 days a week, 2 hours a day. Her phosphate and potassium readings came down very quickly, her blood results became normal. She felt much better, did not have restless legs, ate more and was nutritionally better off. She was able to go out to work and she and her husband did more together. Then life became too busy not to dialyse and she has ended up doing 7 days a week.

Being on home haemodialysis has changed the relationship with her husband. On the positive side, she thinks he sees her less as a patient because she can go out to work, bring a bit of money into the home and talk about normal things. They spend more time together and she feels they are closer. If she is on the machine he will bring her tea, toast, a hot water bottle, whatever she likes and come to sit with her. They may watch a film together or go on the Internet. However, she is also aware of being more reliant on him for care and support. They both work during the day so their evenings are now dialysis. She ends up in her pyjamas and they become more carer/patient than husband/wife.

Another difficulty is she can sometimes feel quite isolated. On the unit she could just say to another patient, 'I'm having a bad day, how's your day?' She feels there should be some sort of home dialysis chat line. She can phone the home dialysis nurse, but it is not the same as talking with other patients, and the nurse only works part-time. She also thinks the technical support is not very good. She can only contact the technicians between 7.00am and 5.00pm. At other times she can phone the main hospital dialysis unit, but they are not always able to help. She feels she does not have enough back-up. Despite these difficulties she would never want to go back to hospital haemodialysis.

Patient C

Patient C is 59 years old. She lives with her husband who has recently retired. They have no children. She is limited in what she can do because she has had quite severe ME for 20 years. She needs her husband's assistance whenever she goes out. Any trips require a lot of planning. She is able to read and watch TV a little, but her eyesight is poor. The one thing she can still really enjoy is her dog and she gets a lot of pleasure from having him around. Being on home haemodialysis made it possible for her to get a dog because dialysing at the hospital would have meant leaving it for too long on its own.

At her first pre-dialysis clinic appointment she asked the nurse straight away if she could go onto home haemodialysis. She did not need any persuasion. She had heard about home haemodialysis through reading newspaper reports and magazine articles. The main appeal of home haemodialysis was that she would not have to travel to the hospital three times a week. She knew because of her ME she would not manage the journeys. She also wanted to dialyse at times that suited her whereas she would have to go on certain days to the hospital and fit into their slots. She and her husband had no worries about managing the dialysis themselves. Since she knew there were lots of other people doing it, she thought they must be able to too since they cannot be more stupid than average.

She was extremely relieved when told she could go on to home haemodialysis. She had worried it might be a matter of cost and the hospital would have a limit as to how many people could do home haemodialysis. It was such a relief she just thought 'thank god' I can have it at home. She would not have to be bussed in on the 'biddy wagon' 3 times a week, which she just knew she could not cope with, physically or mentally.

Whilst waiting for various hospital appointments she sat and talked to other patients. On one occasion she mentioned to a couple of patients that she was going to do home haemodialysis and they said 'oh you're so brave'. She thinks some patients would be perfectly capable of doing home haemodialysis, but they are scared. She suggests instead of the hospital just saying to patients would you like to go onto home haemodialysis and them being scared and saying no, patients should be able to talk to a couple of people already on home haemodialysis as this might remove the fear factor.

Even though she really wanted to do home haemodialysis she would have liked the chance to talk to patients who were already at home dialysing. She would have asked how they found the training, if it was daunting when they first started, and how they remembered things they were taught. She thinks it would also have been nice to know how the dialysis actually affects you when you first start. She got a DVD from the nurses of various patients on home haemodialysis, but believes you really need to speak to someone who is physically going through it themselves in order to give you confidence.

The training was rather stressful to begin with because the nurses could not needle the fistula. She had to go through two procedures to try to rectify the problem, but it still did not work. Therefore she had to have a line fitted, which after two days fell out. She does not know why this happened, it was nobody's fault, but that was the worst part for her. It just about 'finished her off'. She screamed at her husband and spent a morning weeping and worrying. However, the second line she had put in has stayed in place. It took some time to adjust to having the thing hanging out of her, but she is used to it now.

Although she and her husband picked up the training quickly, after the 3-4 months it lasted, they were worn out. They had to leave at 6.30am in the morning and were not getting home till 2.00pm. The last month of training they felt absolutely shattered. She was so relieved they did not have to do that travelling to the hospital permanently.

What she liked about the training was being with other home haemodialysis patients. It gave her a sense of all being in it together. There was another woman who also had problems with her fistula which made her think at least she was not the only one with difficulties. They all got on well and it was like a little friendly social group.

The installation process went fairly smoothly. First the technical manager came to the house to make sure the machine could go where she and her husband wanted it, in the back bedroom, and then the

builder arrived. It all felt a bit rushed though and she would have liked more time to ask questions. There are things she might have done differently in the room if she had been given more time to think it through. She would particularly have liked more idea about the size of the tray.

The dialysis machine they delivered was a brand new one, but it kept breaking down and in the end had to be taken back to the manufacturers. That made things a bit fraught because having just come home she thought she the problems were due to her. However, she cannot fault the technicians. She thinks they are brilliant. They are always on-call so she can get through straight away even evenings and weekends. They will come out the same day and are always very pleasant. Whilst there have been problems with the machine, she herself has experienced no adverse events.

After starting home haemodialysis a year ago, she immediately felt better. It was such a relief not having to make the journey to the hospital anymore. She feels more in control of her life. She has not got the rigidity she had when going to the hospital. She has got more of her life back as she can now do the dialysis to suit her. In the morning she gets up and just goes into the back bedroom and her husband connects her up and then brings her breakfast. The time does not drag like it did when at hospital because she can watch TV, listen to the radio or read bits and pieces. She worries she might be a bit of a burden on her husband, but the advantage of dialysing at home is that he can do things around the house whilst she dialyses, he does not have to sit with her, and since she finishes dialysing by 2.00pm he has the afternoon free to do as he wishes.

She dialyses every other day for 4 1/2 hours. She feels better for doing the extra time compared to being at the hospital. She thinks there is probably a psychological benefit too because although she cannot see it, she knows there are probably more toxins coming out. She also finds her head is clearer and she does not get so 'fogged up' all the time. Neither does she feel the cold as much as she used to. She still has to be very careful about what she drinks because of her phosphate levels, but fortunately she is allowed coffee.

Patient D

Patient D is aged 61 years and has lived with his partner for 14 years. His partner's children have now left home, but are regular visitors. Since taking early retirement he loves to visit different towns and explore the nearby countryside. Other hobbies include reading, walking and doing Wii keep-fit. He is also a keen supporter of the local football team.

He was told 3 years ago that he would need to start dialysing as a result of having half a kidney sliced off to remove the cancer that had been found there. After referral to the dialysis unit he and his partner attended six education sessions. There was a session on each type of dialysis and one on emotional well-being. He found them very helpful. What sticks in his mind as especially useful were the talks from people actually on the different types of dialysis. He liked the fact they told it as it was, as they saw it. The doctors and nurses explained what happens and gave him some leaflets, but he feels it was no substitute for hearing someone say, 'I do it and this is what happens to me, this is how I feel when I finish, this is what I experience'.

There seemed a lot of dialysis choices, but home haemodialysis appealed most because of its flexibility. It might be a 4-hour session, but then it is done and he would have the rest of the day for his activities and interests, whereas he was unsure how he could juggle peritoneal dialysis to enable him to still get out for the bulk of the day. He did not fancy signing on for a dialysis ward because it would take too long to travel there and back, and with 4 hours on the machine, make it a 7-hour time slot in total. The nurses thought he was suitable for home haemodialysis and he was fairly confident he could do it. So it seemed the best option. He only had one real concern and that was whether he would be able to needle himself. His partner was also happy with the choice even though it meant alterations to the house which she owned.

Before the training started he was given the opportunity to visit a home haemodialysis patient to see the set up in her home which he found really helpful. He could talk about how she did the dialysis as well as seeing how much space the machine took up, how it fitted into what was a study for her, and where she stored her supplies. It was not as intrusive as he thought it would be with the machine just part of a room, not taking over the whole place.

His first training session was very disappointing because the nurses could not get the needle into a vein, even though he had a good working fistula at the time. It was upsetting because he thought, if nurses who have been doing it for years cannot needle him, how he would ever cope. However, he went back a week later, they started again and it worked. He feels he cannot sing the praises enough of the nurses who trained him. They were so encouraging, very down to earth and would not let him 'wimp out'.

He was training quite a long time from November through to March. He could have come home earlier, but was waiting for alterations to be made to the house. The technician and builder had come to the house to look at the options for where to install the machine. There was a possibility of using the spare bedroom, but he and his partner decided against that as they wanted to keep it for when the grandchildren visited. Therefore they chose to pay for an extension. The hospital's technician and builder liaised extremely well with his builder, and when it came to the work needed to install the machine, he thought it was first class. He did not get any grants for the extension, but the hospital paid for installation of the dialysis machine. He gets a cheque every 3 months for about £70 which he thinks is for water. He did not expect to get that.

When the machine was delivered the technician took him and his partner through changing the filters, doing the RO and generally keeping an eye on the machine. For his first dialysing sessions at home, the home haemodialysis nurse was with him to make sure he was confident enough to do things. It was obviously different from doing it in the hospital where he would turn up and the stuff is set out ready for him. Instead he had to get everything ready himself, but it worked fine.

He is able to dialyse himself, without assistance. However, since having a stroke earlier in the year he always tells his partner when he starts and finishes dialysis sessions. He now also wears a phone link around his neck which goes direct to the council. If he rings that and does not talk, they would immediately call an ambulance.

He tends to dialyse first thing in the morning Monday, Wednesday and Friday, from 8am or 9am for 4 hours so that he is free for the rest of the day. The hospital would like him to dialyse every other day, but having the weekend off is very precious to him because he likes to go on journeys away from home and then walk for a while.

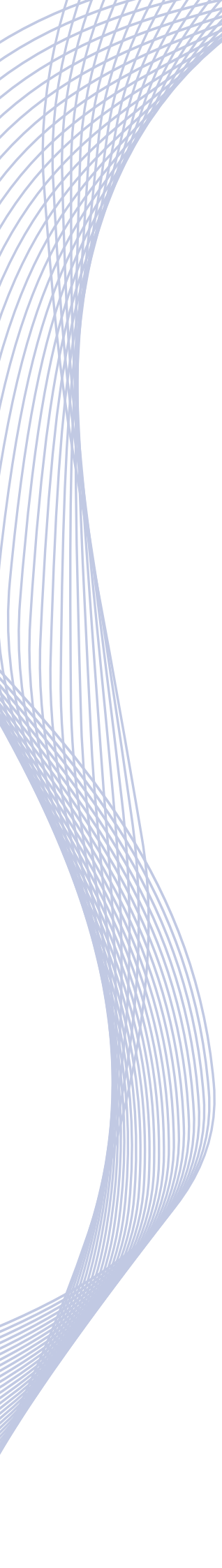
He has experienced a few problems. His first fistula lasted only 4 months. He then had a neck line fitted before another fistula was built for him. Just last week as he was coming off the machine he got blood all over the place having not done a clamp properly. He gets up tight when things go wrong, but speaking to the home haemodialysis nurse on the phone calms him down. She makes him go back to the beginning and work out what he needs to do. He thinks the nurses who help on the phone are brilliant. He also praises the technicians because he can phone them at any time about a problem with the machine and they will come to sort it out.

He is very happy having chosen home haemodialysis because of the flexibility it offers. He has been given back a degree of life he did not think he would have. Although it is not a large part of his life, he has more control over what he is doing with it. If he and his partner want to go away for the weekend, he might dialyse on Monday afternoon rather than in the morning. Or if he wants to be away on the Friday he will simply put in an extra dialysis session on the Thursday. He sometimes has difficulty keeping within his drink restrictions and if this happens he will simply do a 5-hour dialysis session instead of 4 hours. The other important advantage is that when dialysing at home he can enjoy all the facilities he has like TV and digital radio. He tends to record lots of football matches which he can watch whilst dialysing. It is much more pleasant than at the hospital because he has everything he wants in the room.

Patient E

Patient E is 43 years old, married with two children aged 6 years and 8 years. He does the majority of the childcare as his wife works full-time. Since starting on home haemodialysis he has been able to do voluntary work 3 days a week.

He was on peritoneal dialysis for 2 years before his health declined and he had to start hospital haemodialysis. It was a tremendous life change. He had to give up a good full-time job as an



accountant because he needed to be at the hospital 3 days a week, Monday, Wednesday and Friday. He hated being on the unit as it meant being far more 'medicalised'. He found the 3-day period of not dialysing over the weekend particularly hard. The fluid restrictions were very difficult to cope with and made him depressed. As a result he was not a very nice person to be around at the weekend.

It was his consultant that first mentioned home haemodialysis, soon after he started at the unit. He did not think about it deeply at the time. Moving from peritoneal dialysis had been such a big change he backed away from considering another one. He also wanted to get his health sorted first. However the restrictions doing hospital haemodialysis were so much worse, it was good to think that if he overcame his health problems and got back on an even keel, he had the option of home haemodialysis. The nurses and consultants were certainly keen to get him home and were always encouraging him. He finally made up his mind that he wanted to go home after about 6 months on the unit. The main reasons being to get away from the unit and to dialyse more often so he could have his weekends back

He thought the training was fine and the nurses doing it very good. Needling was the hardest part. He had slight needle phobia and had to overcome this fear. He worried that he would never be able to put a needle in his own arm. What finally made him do it was seeing a girl of 21 years needling on the unit. He thought if she can fearlessly put a needle in her own arm, he could, he just needed to be a bit tougher, and so he did.

The training probably went on a bit longer than he required because there was a hold up waiting for the builders doing the installation. They converted his younger son's room who now shares a bunk bed in a room with his brother. The amount of space taken up by the machine and tray and other things in the room is what he expected. Having been on peritoneal dialysis before, he was used to having a lot of supplies, although there are probably more now. He gets annoyed at the stock levels being so over the top. He thinks it wasteful because he is over supplied and then the stocks go past their use by date.

When he started home haemodialysis, he expected to be able to do the whole process by himself, but unfortunately he cannot. He has a very high access point and a long arm so cannot reach with his right arm, the one the needles are in, to unscrew the various bits. Therefore his wife has to do that for him. In an emergency he can do it with his teeth, which has happened a couple of times.

The home haemodialysis nurse came to his house for the first three sessions and sat with him. He feels it was very important to have had her there at the start because he would have found it very difficult to just go straight home on his own.

Unfortunately he has had a lot of problems with his fistula and has needed six operations. He has also got infections. On one occasion the fistula burst which was very scary. Luckily he managed to stop as much of the blood as possible and the ambulance came very quickly. Since then he makes sure he gets any possible sign of an infection checked out straight away. He finds all the back up support at the hospital very good.

He has now been on home haemodialysis for 4 years. He dialyses four times a week, generally for 4 1/4 hours, so he does a total of about 17 hours a week. As soon as he started dialysing this way he felt much better. He had a lot more energy. When he was on the unit, after the Monday dialysis session he felt so tired he would go to sleep. He never feels like that now. He cycles everywhere and goes running. Everything feels less stressful. Being able to drink at weekends is a huge relief and enjoyment. His social life has improved. He can go to parties and not feel anxious and in a bad mood all the time. He can enjoy treats like drinking a very good cider they have at the country fair held occasionally in the park opposite his home. He can have a couple of pints and come straight back and dialyse. He would never have been able to do that when on the unit.

Also he cannot emphasise enough how home haemodialysis has helped him psychologically. He now feels back in control. He has flexibility in his life knowing he can dialyse to suit himself. It is an enormously positive change. He can swap the dialysis around to suit his plans. This Friday for example, his wife has an office party which they will both go to. Therefore he will probably do an extra 1 1/2 hour session on the Saturday morning so he still gets his Saturday freedom to eat and

drink. Earlier this year he went to Australia for 3 weeks to visit his wife's relatives. He was nervous going all that way, but being able to dialyse right up to the last minute before he went and as soon as he got home made a real difference.

Looking back he feels going onto home haemodialysis has hugely improved the relationship with his wife. There is no doubt he is a much happier person, and a much nicer person, especially at weekends. He realises that as the patient there are many tangible benefits for him whereas his wife now helping with the dialysis has more stress, but he feels sure she prefers him as a person and a husband. He can also spend more time with his wife and children. He feels part of the family again rather than always going off to the hospital. He dialyses in the evening and his children will come and talk to him. His youngest son sometimes helps him set up and then sits chatting on the arm of the chair. He is aware there is an element of showing the children that he is ill, but he does not think it too much of a problem because they can see how much happier he is.

The dialysis itself is more comfortable and enjoyable. He has all his stuff around and spends a lot of time on the Internet. Sometimes he finds it quite pleasant just sitting which it never was at the unit. It is also a good feeling knowing the prognosis for his health over the longer term is better because he is doing more dialysis in a week. He doubts anyone who has done home haemodialysis would dream of going back to a unit unless they had to.

Patient F

Patient F is aged 49 years, has been married for 22 years and has a 14-year old daughter. He is an athletics coach for young people with learning disabilities. He enjoys watching golf and cricket, and plays golf himself most Sundays. He also likes to spend time with friends and family at horse races.

He started on CAPD in 1985 and in 1987 had a kidney transplant that lasted 14 months. He then went onto hospital haemodialysis, but was able to have another transplant which functioned well for 7 years. After that he went back onto hospital haemodialysis. He has been on home haemodialysis for the last 14 years.

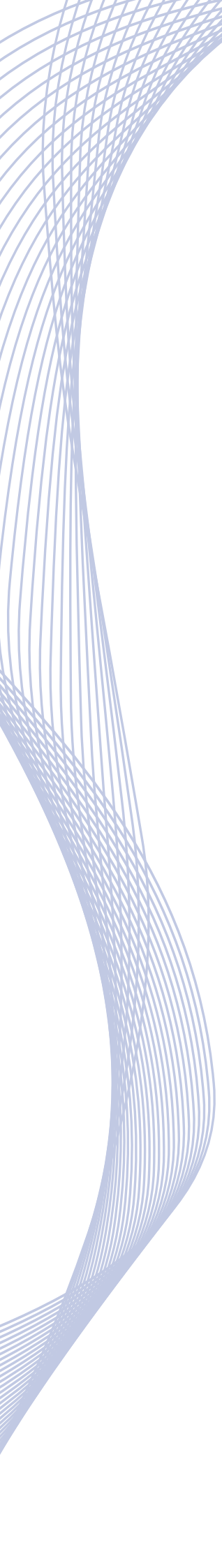
He hated the structure and routine of hospital haemodialysis. He got very frustrated having to wait sometimes up to 2 hours at the hospital to get on a machine. He was doing shift work at the time and was often coming off the machine at 10.00pm and getting home at 11.30pm which was doing him in. His love of sports deteriorated because he was not fit enough to compete and this led to him not even wanting to watch any of the sports he normally likes. As a result he became very depressed.

He was also getting aggressive and did not like the way he was behaving. He was abusive on the unit and even threw a bag of saline at one nurse. He was not a compliant patient. It was due to sheer frustration. He was desperate to get out of the unit. He felt he had to get out or he would refuse treatment despite his young age.

Even before home haemodialysis was mentioned he was lining his machine and actually putting himself on it which caused a lot of friction. He thought he could just go into the unit and look after himself which he did do. He was told he needed to ask the nurses, but he just got on with it.

He cannot remember how he first heard about home haemodialysis. He thinks it was probably the nurses on the unit who discussed the option with him. He just wanted to get away from the unit. He was desperate to get out. The nurses' main worry was the fact he was not a compliant patient. He also had to convince his wife about it. She was not very happy about him going on dialysis at home because of him being noncompliant. She worried about fluid overload and him cheating. She was also concerned about the responsibility she would have. They talked and he said it was what he wanted to do. She also had plenty of opportunity to talk to the nurses and other people at the unit on her own without him there and go through what she was concerned about. He thinks this was very important and helped them work it all out. He thinks the fact his wife is a nurse helped as well.

The training did not take very long, about 6 weeks. He had been doing so much himself on the unit and was so keen to leave that he quickly picked up what he needed to do. After the first couple of sessions he was needling himself. The main thing he had to do is convince the nurses he would be compliant. There was a short delay waiting for them to get the installation work done on his house.



He had wanted to use a little back room, but they decided on a larger room in the middle of the house. It took a bit longer doing the installation than he expected, about two weeks, as it was quite a lot of work. He gets about £30 to £50 a quarter for the water and electricity. As the water board know he is on dialysis they will always ring him if there is going to be a drop in pressure to find out when he is going to do his treatment.

At first he was a bit nervous, worried if something would go wrong. There was a lot of pressure because he started at home only two weeks after his daughter was born. He was so pleased to be out of the unit though that he did not mind it being that way. Mentally he started to feel so much better because he could just finish work and come home. He did not have to travel to the hospital. He could also help out with the little baby, be more of a family man, by having her in the room while he dialysed so giving his wife time to do things around the house. Work became better because he could concentrate more. He was able to relax and be more sociable. He could enjoy time socialising with his work colleagues, as well as with other friends, because he did not have to rush off to the hospital. He had more energy and started playing and watching sports again which made him far less depressed.

Another very important benefit for him of being on home haemodialysis, is there is less routine and structure. He dialyses on 4 days a week for 5 1/2 hours, but because of his dislike of routine he prefers to change around the days he dialyses. Now he can fit the dialysis around his own life. The thought of going back to the unit 3 or 4 times a week is horrible. If anything happened where he could not dialyse at home he feels he would stop treatment, full stop.

Sometimes he can feel a bit isolated, but he knows he is not alone because there is always someone at the end of the phone. He thinks you have to be quite open when you are feeling low and get on the phone. He speaks to the home dialysis nurse who is very helpful. There is other support available as well, a counsellor and psychiatrist, and a dietician, which he thinks is very good.

He recognises that dialysis puts a lot of pressure on the marriage. He thinks it is hard enough having a marriage, but then with one person being ill and having dialysis at home, it is definitely more pressure. He knows that his wife takes a lot of flak from him. He can be very moody at times. He has mood swings that can last for a couple of days when he does not want to talk. However he gets far less depressed than when he was on the unit, which he feels makes things a bit easier for his wife. He is a better family man being around at home more. He and his wife do try to talk as much as possible. She can come up and have discussions while he is on the dialysis machine which he thinks is important. They are also able to do more things together than when he was on the unit. The days he is not dialysing he likes to shut the door and forget about it.

He has not experienced any adverse events since being on home haemodialysis. There have been the odd occasions when something has gone wrong with the machine, but there is always a technician available on the phone. The technician will tell him what to do or will come to the house to look at the machine and sort the problem out.



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