



Home Haemodialysis - A Nurses Guide to Implementing Best Practice in Home Haemodialysis



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Acknowledgements

Dear Reader,

One of the educational objectives during 2017 of the European Dialysis and Transplant Nurses Association/European Renal Care Association (EDTNA/ERCA) is focused on Home Haemodialysis (HHD). The benefits of this modality of renal replacement therapy are clearly demonstrated in the literature and the ability to perform Frequent Home Haemodialysis (FHH) is clearly a key contributing factor to positive outcomes. The aim of this Guide is to reach all renal healthcare professionals caring for Chronic Kidney Disease patients, offering them the chance to learn from experts about caring for patients who choose HHD treatment, focusing on FHH.

This Book and the Application have been brought together thanks to the involvement of several volunteers' who have expertise in this treatment modality. All of them deserve to be acknowledged. The Authors of every chapter have put a lot of time and expertise in the development of their individual sections. We, together with our Reviewers, monitored, assessed and reviewed these chapters, consolidating the content and streamlining formatting. We would also like to thank the EDTNA/ERCA Marketing Director Mrs Anki Davidson and her team for their expertise and design for both the book and the application development.

We are grateful to NxStage Medical who have supported the development of these tools with a cooperation agreement and who also have checked for accurate medical content.

On behalf of the Executive Committee please accept our deepest appreciation. This Project has been achieved thanks to All of You and we are sure that those reading this publication will recognise your commitment to HHD patients and their quality of life.



Debbie Fortnum, Editor
EDTNA/ERCA Brand Ambassador Australia/New Zealand,
Clinical Nurse Manager Dialysis, SCGH Perth, Australia



Maria Cruz Casal Garcia
EDTNA/ERCA Supervisory Board
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Dear Reader,

I joined the dialysis industry in the early 1980's when the pathway to improved care at lower cost was best achieved in freestanding dialysis centers. This has been the logical path to improvements for many decades now. Improving the therapy with better buffers, more physiologic membranes, and machine technology has taken us a long way. Given the state of available technology, we were better served to improve labor and overhead efficiency leading to inflexible therapy frequency and duration. The industry has done a spectacular job of responding to these demands with amazing cost efficiency and impressive clinical improvements.

The exciting opportunity for the future is the availability of technology and tools to bring a new dimension in how we can deliver care. With breakthroughs in technology we now have the ability to turn our approach on its head. We can allow the therapy to move into the patient's home and remove schedule limitations. It's exciting to think how we can put the patient's well being as the primary objective of care. We can explore frequency and duration of therapy that achieves the best individual outcomes. I believe we will all look back in a number of years and say this was the beginning of the trend to individualized patient care and the addition of the virtual clinic. We now need to support the sharing of best practices and clinical experience to expand this option to more patients and their families.

EDTNA/ERCA has been a leader in supporting patients and their families for over 46 years. Their mission; "Achieving the best standards of education, best practise and care and research for our members supporting their patients and families around the world." make them the perfect partner in this effort. With their leadership and reach of 1400 members in more than 70 countries, this Guide can help translate the knowledge held by early adopters into broader practice. I want to thank all of the dedicated people who have taken their precious time to contribute to this project. We at NxStage are honored to be an active part of this exciting revolution in care.



Jeff Burbank
Chief Executive Officer
NxStage Medical

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Purpose of the Guide





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Dialysis is a life supporting treatment, which is very time consuming, requires a certain structure to everyday life and limits the ability to travel. The patient simply enters into an often life-long relationship with the dialysis. For success the relationship with dialysis should be based on acceptance and understanding, instead of constantly fighting it. It takes energy to live in disharmony with this life-sustaining treatment.

The healthcare professional team is responsible to ensure that a patient, in the pre-dialysis phase, chooses the treatment that is best suited by ensuring they are fully informed of the options available to them. However, how should the patient, after receiving information of the different options, choose?

Many start on In-Centre treatment for a while. This is an opportunity for the patient to discover that the entire health care team believes in the patient's ability to manage dialysis treatment at home. Why not, really?

The choices made initially, will not be permanent but experience does show that it is easy to stay on the first choice. It is a big decision to be made by a patient, since it is a life changing choice. Is it our duty to steer the patient toward the choice that we know gives increased health-related quality of life? Possibly, but it is the patients choice. However according to numerous studies, many patients with chronic illness make completely different choices when they receive the right information, in the right way from the beginning. For the future, we think it is important to provide information about HHD and its positive impact.

Many observational studies along with a limited number of randomized clinical trials suggest that frequent HD not only improves outcomes for uremic patients undergoing chronic dialysis but does so with a more favorable cost/benefit ratio compared with conventional HD. Because of this, there has been a rapid increase in interest in HHD.

We hope you are inspired by this Guide to support your patients to do Home Haemodialysis.

Use of the Guide





Anki Davidson, EDTNA/ERCA
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The Guide has been developed to help healthcare professionals to get a greater insight and understanding of what Frequent Home Haemodialysis is and maybe to support by making the choice of this therapy.

The content of this Guide has been written to provide the user with a consistent approach to Home Haemodialysis. The chapters are divided and written for the reader to refer to whatever aspect of Home Haemodialysis interests them and should be easy to follow.

The information published in this Guide is for general and educational purpose only. This Guide will not substitute any existing guidelines or is no way meant to be a substitute. No action or inaction taken should be based solely on the information provided in this Guide.

The aim is to provide practical guidance, and the Guide can complement more traditional training activities such as workshops and lectures.

It is of utmost importance that renal healthcare professionals and patients are provided with adequate information and training as well as appropriate supervision, so that they may safely and efficiently carry out care that is relevant to their role. The EDTNA/ERCA is committed to a standard of excellence in clinical training and long-term educational support.

The EDTNA/ERCA has made all reasonable efforts to ensure that all information provided through this Guide is accurate at the time of inclusion.

This Guide exists in two different formats. A printed Book as well as an Application.

In the Application we have also included the patient perspective of Home Haemodialysis. You will find the Application at HomeHD.edtna-erca.com

The Book can be ordered at the edtna-erca.com



Chapter 1

Introduction

Learning Outcomes

- To understand the importance of nurses being educated about HHD



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Since the initial development of chronic haemodialysis (HD) therapy in 1960 the number of patients treated with HD has increased dramatically. In Europe in 2013, a total of 72,933 patients started Renal Replacement Therapy (RRT) for ESRD according to all the registries reporting to the ERA-EDTA Registry¹.

The decision regarding the choice of the RRT modality is crucial. It impacts all aspects of patients' lives and the lives of their families. Studies demonstrate that many patients, when given the freedom to choose, will select a treatment modality on the basis of their lifestyle². Frequent Home Haemodialysis (FHHD) is a RRT modality that can provide a safe, high quality and flexible treatment schedule. Patients who take responsibility for their dialysis treatments are empowered and this can improve the quality of their life. However most patients are not aware of this treatment option. This means that despite the obvious advantages, clinical and psychological benefits of FHHD, the number of patients who choose this modality remain low³.

Education of the patient and exposing them to the option of FHHD is vital to increase the uptake of this modality. It is also crucial that health care providers are familiar and well educated about the option of FHHD and feel confident being advocates for this treatment option.

One of the main goals of the European Dialysis and Transplant Nurses Association/ European Renal Care Association (EDTNA/ERCA) is to provide educational resources for nurses and other healthcare professionals who care for renal patients, both as printed material and as on-line application tools.

This tool focuses on health professional-patient pathways to support the successful implementation of FHHD. It offers practical guidance for managing a FHHD program with information to enhance effective training of patients to empower them to feel secure performing dialysis at home.

The objectives of this tool are: to increase health care professionals' awareness of the benefits of FHHD, to provide an educational tool which can help them understand the unique needs of home haemodialysis patients, to implement this knowledge into practice and to improve access to FHHD for patients who can benefit from it.

This tool with many chapters has been brought together thanks to the cooperation and collaboration of enthusiastic professionals from various countries.

Chapter 2

The History of Haemodialysis

Learning Outcomes

- To understand how haemodialysis began
- To identify the challenges that doctors and nurses had to overcome in developing haemodialysis as a therapy
- To appreciate the patient perspective and experiences of home dialysis in the 1960's and 1970's



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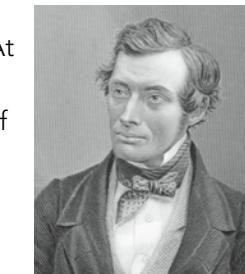
Introduction

The introduction of Haemodialysis (HD) as a life-saving treatment for end-stage kidney disease was not the result of any large-scale research programme, but rather it emerged from the activities of a several pioneering individuals in the USA and later across Europe.

2.1 The beginning of Haemodialysis

Although HD as an accepted treatment for renal failure was not initiated until the 1960's, there had been developments in the previous 100 years. The first time that the term 'dialysis' was used was in 1854 by Thomas Graham, a Scottish chemist¹. In 1913, the first paper on the technique of HD, including the concept of the 'artificial kidney', was reported. At this time, experimental dialysis was performed on animals, by using a variety of compositions of dialysis fluid². The first dialysis treatment performed on a human was carried out by the German physician, Georg Haas, in Giessen, Germany, in the latter half of the 1920's. He performed six treatments in six patients, but unfortunately, he was not supported by either his hospital or his colleagues, so by the late 1920's the work was stopped.

In 1923, Heinrich Necheles experimented with layering of membranes, thus giving an increased surface area without the necessity for multiple dialysers. The membrane that was used was a sheep peritoneum.



Thomas Graham,
Scottish chemist

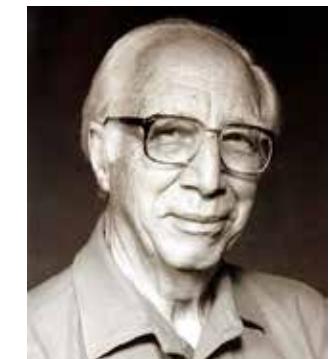


George Haas, Physician, Giessen, Germany

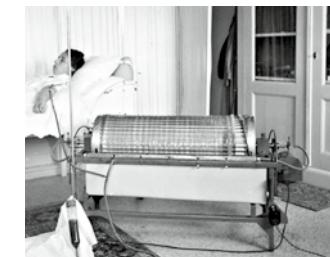
Because the membrane was prone to expansion, support sheets were placed between the layers of membrane, thus allowing a large surface area of membrane to come into contact with dialysis fluid. The 1920's and 1930's saw great advances in synthetic polymer chemistry, resulting in the availability of cellulose acetate which could be used as a membrane for dialysis treatments. William Thalhimer, used cellophane, a form of cellulose acetate, as a potential dialysis membrane³.

Willem Kolff, became aware of the work of a colleague who was concentrating plasma by using cellulose acetate as a membrane immersed in a weak solution of sugar. He built a rotating drum dialyser which provided sufficient surface area for his first attempt at human dialysis⁴. His machine consisted of 30 meters of cellophane tube that was wound around a large cylinder. The cylinder was placed in a tank containing a weak solution of salts (the dialysate). The patient's blood was passed through the cellophane tube. The walls of the cellophane tube acted as a semipermeable membrane. The slats in the construction of the cylinder were of wood. Six hours were required for the treatment. Fluid was removed by increasing the osmotic pressure of the dialysate fluid by the addition of sugar, which increased the pressure on the membrane. This would occasionally result in rupture⁵.

In 1945, after WWII, Kolff's technique was used more widely, particularly in Sweden and the USA. Kolff was invited to take his artificial kidney to New York and the first successful dialysis in Mount Sinai Hospital was in January 1948. Eight hours after the first dialysis using the Kolff machine, the patient passed urine. The treatment had been a success.



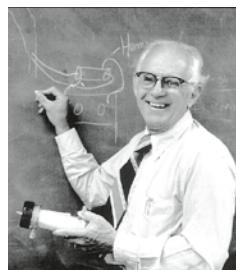
Professor Willem Kolff



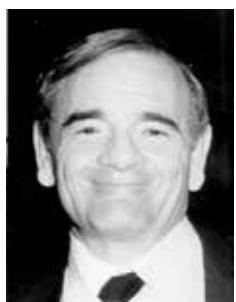
30 meters of cellophane tube that was wound around a large cylinder.



Dr. Fredrik Kiil



Dr. Belding Scribner



Dr. Stanley Shaldon

In later years, the rotating drum was modified to become easier to use. For example, the drum was made of stainless steel and a tensioning device was used on the cellophane membrane as it had a tendency to stretch during use. These improvements paved the way for wider acceptance and use of dialysis treatment⁶.

In October 1956, the Kolff system became commercially available, so the lack of availability of equipment could no longer be used as an excuse for non-treatment of patients. Centres purchased the complete delivery system for around USD 1200 and the disposables necessary for the treatment were around USD 60. The system was still mainly used for reversible acute renal failure, drug overdose, and poisoning.

In the late 1950's Fredrik Kiil of Norway developed a parallel plate dialyser, with a large surface area (1 m^2) requiring a low priming volume. A new cellulose membrane, Cuprophan, was used and this allowed the passage of larger molecules, which until then, had not been previously available. The Kiil dialyser could be used without a pump, as the system used the patients' own arterial pressure. This dialyser was widely used because the disposables were relatively inexpensive compared to other dialysers at that time.

Before the development of the arterio-venous shunt by Dr. Belding Scribner and his colleagues in 1960, repeated dialysis for end-stage kidney disease was not really an option. Moreover, it was Scribner and his team who adapted the Kiil dialyser for use in treatments that were dependent on arterial pressure without the need of a blood pump.

2.1.1 The beginning of Home Haemodialysis

Dr. Stanley Shaldon reported in 1961 that a patient dialysing at the Royal Free Hospital in London was able to self-care by setting up his own machine, initiating and terminating dialysis; so Home HD in the UK became possible.

The shunt was created in the leg for vascular access, to allow the patient to have both hands free for the procedures. Dr. Shaldon reported the results of his first patient to have overnight Home HD in November 1964. With careful patient selection, the venture was a success⁷.

2.2 The story of the pioneers of early Home Dialysis

In February 2017, a group of staff who were involved in the early days of dialysis came together to recall their experiences.

2.2.1 The roles of Staff

Dr. Rosemarie Baillod, who worked alongside with Dr. Shaldon, explained how the machines were developed:

"I had to develop alarm systems and I had to go to a shop called Radio Spares, and I had to buy relays, light bulbs and little alarms we got some monitoring from Cambridge Monitors – if the pressure went too high it would alarm, if it went too low it would alarm, and it was in a box about 2 feet square, it looked very smart. The first time we arrived at the patient's home – everything leaked!"



Dr. Rosemarie Baillod

"We did not originally have flow meters, so when you wanted to know how much dialysate we were running, we were aiming at 500 mls/min, we took a stop watch and a plastic jug and timed it, and then you adjusted pressure valves accordingly. We got Cambridge Instruments to start making machines and we were also in touch with the people in the States, Milton Roy they were called and the machines were beautifully designed. It (the machine) was supposed to look like a television."

Dr. Baillod also explained how patients were selected at the Royal Free Hospital, London.



Sally Taber

"I used to have to go and present 4-6 people every month from different hospitals.....I would get telephone calls and then meet the patient and family.....I would then have to present each case to a selection board....dialysis would never have existed if we did not push the borders as we did at the beginning."

From these beginnings, large home HD programmes developed in the USA and in the UK, thus allowing expansion of the dialysis population without the need to expand hospital facilities. Many patients could now be considered for home treatment, often with surprisingly good results. The dialysis treatments could now be individualized to fit the needs of the patient, rather than the patients conforming to a set regimen.

2.2.2 The Patient focused experience

Often though, it was very difficult for patients, as Sally Taber explains

"The patients had a cooked breakfast, but during the day had to have a whole cup of jam and a whole cup of cream....if they did not eat it, we had to put a tube down."

Ann Eady, a nurse who also cared for her husband on home dialysis, said

"It is hard work...you are constricted, but there are benefits....you can travel, and the well-being of patients was vastly increased."

Joy Foo, explained how the training patients was very satisfying

"We are nurses and we taught people from the street, who knew nothing about medicine and we send them home....that was the most rewarding part."



Ann Eady



Joy Foo

Lesley Pavitt remember it in a similar way and recalls

"...the patients had things (dialysis) done to them for months and years in other hospitals and then they came to us and we were able to give them the skills to take control of their life again....and that is an incredibly empowering thing."

2.2.3 The role of the Nurse and EDTNA/ERCA

Marcelle de Sousa describes how the nurse's role in the renal unit was autonomous.

"If every nurse had the opportunity to work in a renal unit, I tell you, it is the making of them, you feel pride in what you do, and it is the one place that you are autonomous."

The role of EDTNA/ERCA in the development of home dialysis across Europe was also very important, and as Sally Taber recalls taking part in a EDTNA/ERCA Conference in 1975 in a debate 'Home dialysis or not?' which enabled sharing of ideas.

Marcelle de Sousa summarises the role of EDTNA/ERCA by saying

"It was a fantastic forum for us...and you felt you were leading the way....it was a great feeling."



Lesley Pavitt



Marcelle de Sousa



EDTNA/ERCA Conference Programme 1975



Max Sievert dialysis machine invented by Prof. Jonas Berglund in the 60's and a Kiehl dialysis filter.

2.3 Case study: the Stockholm experience

Haemodialysis started in 1964 at St. Eriks Hospital in Stockholm. In 1967 the first patient went home. This relieved pressure on staff and dialysis beds. By 1976 the home population had grown to 40 patients with specially employed technical support. In 1979 the option of using a 'self-dialysis unit' in an apartment became available in Stockholm for those unable to take a machine home.



Drake Willock machine used for HHD in Stockholm. We had around 40 machines.



Dialysis treatment at St Eriks Hospital
1976 with Nycoton autoclavable
machines.

2.4 Further development of dialysis in the 1970's and 1980's

In the early 1970's the overall number of patients on RRT increased as awareness of the availability of treatment increased. Free-standing units for the sole use of kidney dialysis came into being, leading to dialysis becoming a full-time business. Committees for patient selection were disbanded.

However, with the development in the late 1970's and early 1980's, of Continuous Ambulatory Peritoneal Dialysis (CAPD) it became the first choice for Home Dialysis treatment. As a result the use of Home HD steadily declined.

2.5 The 1990's to the present day

In the 1990's, the number of patients on Home Haemodialysis continued to decline. The National Institute for Health and Clinical Excellence (NICE) published guidance in 2002 on home versus hospital haemodialysis⁸ and recommended all suitable patients should be offered the choice between home haemodialysis or haemodialysis in a hospital/satellite unit.

Today there are wide variations in the use of Home HD. The US Renal Data System in 2016⁹ reported that 88.6% of patients in the USA received In-centre HD, and 1.8% had Home HD. the prevalence of Home HD was 18.3% for New Zealand and 9.4% for Australia, with Denmark reporting 5.5%, Finland 6.2%, Sweden 3.6%, Netherlands 3.8% and UK 4.4%. Despite a recent trend to increase HHD penetration in a few countries, this modality is underrepresented worldwide.

NICE National Institute for
Health and Clinical Excellence

Guidance on home compared with hospital haemodialysis for patients with end-stage renal failure

Learning Activity

1. When was the term 'dialysis' first used?
2. What was the name of the doctor who developed the rotating drum dialyser?
3. What did a Kiil dialyser look like?
4. When was 'NICE guidance for Home HD' published?
5. What percentage of patients in the USA today are doing Home Haemodialysis?

Acknowledgements

I would like to thank Gunnar Malmström for the information and photographs provided for the Case Study.

Further reading

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Thomas, N (2014) Chapter One The History of Dialysis and Transplantation in Renal Nursing 4th edition. Oxford: Wiley Blackwell

Cameron, S (2002) History of the treatment of renal failure by dialysis. Oxford: OUP

Photographs of the Kolff drum, Kiil dialyser and other machinery used in the early days of dialysis can be seen here <http://homedialysis.org/home-dialysis-basics/machines-and-supplies/dialysis-museum>

Further reading on Kolff can be found here https://en.wikipedia.org/wiki/Willem_Johan_Kolff

Chapter 3

Home Haemodialysis – The Benefits of Frequent Dialysis

Learning Outcomes

- To understand the clinical benefits of HHD and frequent dialysis
- To understand why patients often describe an improved quality of life with HHD
- To determine the effect of frequent dialysis on blood parameters



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Introduction

There are many perceived benefits of Home Haemodialysis (HHD), and many correlate with significant improvements in health outcomes. The benefits may be due to both clinical and psychosocial effects of HHD:

- In the home environment, patients enjoy the very important benefit of increasing the frequency of dialysis treatments and possibly extending the duration of sessions or at least cumulative hours of dialysis per week.
- The patient manages treatment, so adherence improves; the patient experiences increased self-esteem and regains control of his or her health and life.
- Compared to conventional haemodialysis HHD patients experience increased freedom. The time that previously was put into traveling and waiting to receive dialysis treatment at the clinic can now be devoted to socializing with family and friends, as well as spending time on leisure activities and work, particularly if dialysis occurs overnight¹.

However, the patient must consider that HHD is more than a lifestyle choice and that there might be situations in which risks may outweigh benefits. Dialysis is always a balancing act between benefits and risks, and this form of therapy is not for everyone². In this chapter, we will take you through the benefits. It is important to remember there are also disadvantages to HHD and all patients may not experience all benefits. (see "Benefits and Risks" at the end of this chapter).

3.1 Improved health

Patients who undergo HHD instead of conventional haemodialysis have reported significant improvements in their physical health. These improvements can become more evident over time²⁹.

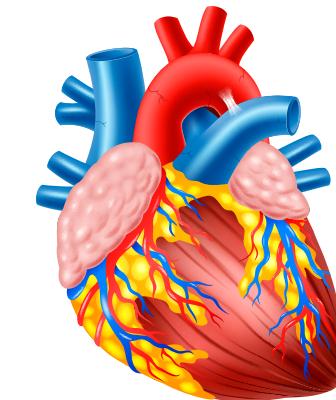
3.1.1 Better control of fluid balance

- Frequent dialysis reduces weight gain between dialysis sessions. Patients report less thirst. Better volume control reduces Left Ventricular Mass (LVM) which is associated with mortality and cardiovascular morbidity^{3,4,5}.
- With less fluid to remove at each session, ultrafiltration can occur more gradually resulting in less cramping and episodes of hypotension during dialysis¹.
- Blood pressure declines. This is one of the most consistent benefits of HHD in randomized and non-randomized studies alike. A reduction in fluid overload seems to be the main mechanism for blood pressure reduction with HHD^{4,5}.

3.1.2 Improved blood biochemistry

The kidney has many functions which means that many different biochemical parameters are adversely affected when the kidneys stop functioning. With dialysis, these improve and with frequent dialysis further improvements are seen. "The more you dialyze, the more you clean"⁶.

- Efficient clearance of urea, creatinine, uric acid and Beta-2-microglobulin.
- Increased removal of phosphorus with more hours of haemodialysis per week^{4,30}.
- Reduction in inflammatory markers³¹.





3.1.3 Improvement in nutritional status

- Reduced need for dietary restrictions^{24,25,30}.
- Improved appetite^{24,25}.

3.1.4 Decreased medication burden

Dialysis patients typically take many prescription medications, many of which are very expensive. The improved physical health associated with more frequent HHD is often accompanied with a reduced need for medications.

- Patients have improved blood pressure control and can decrease or even avoid antihypertensive medications^{26,30}.
- Patients with lower serum phosphorus due to more dialysis may have significantly reduced need for phosphorus binders (especially with nocturnal HD⁷).
- The required dose of erythropoietin may decrease^{8,9}.

3.1.5 Improved pregnancy outcomes

Pregnancy in women with end stage renal disease on renal replacement therapy is uncommon due to the physiologic changes associated with renal failure as well as the complexities and risk involved in managing these patients. For those able to conceive, intensified haemodialysis (HD), through longer and/or more frequent haemodialysis sessions, offers improved maternal and neonatal outcomes¹⁰.

Nocturnal HD (NHD) has been associated with delivery of infants with higher weights born at more advanced gestational ages, as well as fewer maternal and fetal complications. These encouraging results suggest a greater role for much more intensive dialysis in pregnancy¹¹.



3.1.6 Survival

More frequent HHD is associated with improvements in patient survival, compared to Conventional Haemodialysis (CHD)¹². On average, patients on HHD live four years longer than patients on CHD¹³. Several studies have compared survival on Short-Daily Haemodialysis (SDHD), Home Haemodialysis (HHD), Nocturnal Haemodialysis (NHD), and Conventional Haemodialysis (CHD). In general, the survival results have been higher for SDHD, HHD and NHD^{4,12}. Recent data, taken mainly from the Frequent Hemodialysis Network (FHN) Daily Trial provides improved support of higher survival with frequent haemodialysis. In this trial with 245 patients randomly assigned to either 6 or 3 in-centre haemodialysis sessions per week for 12 months, Frequent Haemodialysis (FHD) led to a 40% reduced risk of death or serial increase in Left Ventricular Mass (LVM) index^{5,15}.

Other observational studies report

- A reduction in mortality risk equal to 7% for every 30-min increase in dialysis treatment time¹⁶.
- The long-term survival on frequent HHD is good and has improved over time. More frequent HHD may represent a good alternative to a deceased-donor kidney transplant for certain patients^{13,4}.

3.2 Enhanced Quality of Life

Most patients with end-stage kidney disease experience several physical, mental, and psychosocial problems that have a major impact on quality of life (QoL). They place enormous value on their Health-Related Quality of Life (HRQoL), more so than even survival, and want to know how their HRQoL will be affected by their choice of dialysis modality¹⁷.





KDQoL Survey

3.2.1. Tools to measure Quality of Life

There are a number of tools that can be used to measure quality of life. In the FHN Daily Trial, results showed higher scores for more frequent versus conventional HD using four tools¹⁸:

- Feeling thermometer – a single question that asks patients to rate their own health on a visual analog scale from 0 to 100, where 0 is dead and 100 is perfect health.
- A general health scale – 5 items from the RAND KDQoL SF-36 questionnaire.
- Time to recover from a dialysis session.
- Health Utilities index (The Health Utilities Index Mark 3) – a commonly used and validated survey in which participants rate their health on the following 8 attributes: vision, hearing, speech, ambulation, dexterity, emotion, cognition and pain.

3.2.2 Recovery Time

One of the most striking changes noted with frequent HD is that recovery time or post dialysis fatigue was reduced and that patients could return to normal daily activities shortly after completion of treatment^{17,19}.

3.2.3 Improved vitality and energy

Improvements in patient reported vitality and energy have been seen²⁰. There is improvement in sex-related hormones which can improve the quality of sexual relationships²⁷.

3.2.4 Improved sleep quality

A variety of sleep disturbances are commonly noted in dialysis patients, and may well contribute significantly to fatigue, morbidity, and impairment of QoL. The impact of NHD on sleep patterns is an obvious concern. However, preliminary studies have suggested that NHD results in only a small reduction in total sleep time; however, there is a dramatic improvement in episodes of sleep apnea and hypopnea^{20,19,28}.



3.2.5 Changed mental capacity

Previous data from the FREEDOM study indicated significant improvement in depression scores after initiation of more frequent HHD^{17,19}. This study also reported an improvement in the mental component score and all mental sub-domains of the RAND SF-36²⁰.

There is also an improvement in mental well-being. Patients felt healthier and reported fewer interactions with their physician²¹.



3.2.6 Freedom

Patients experience increased freedom because they control their own times for dialysis. They are able to take responsibility for their own health and can choose how to balance dialysis with work. They experience an improvement in generalized well-being which may be due to increased autonomy¹⁹.





Preparing for dialysis



Family supporting treatment materials monitoring

3.3 Patient experiences and quotes

Improvements in biochemical parameters and observations are less important if there is not a perceived gain in QoL for the patient. The quotes below are positive personal opinions of HHD.

"I can do it on my own and I don't want other people to help me" ²²!

"Really enjoyed the freedom of when I can do my dialysis to fit around my life. It has given me back my independence"!

"The center had too many nurses and traveling techs...the things that I saw! You're locked down four hours three days a week. Your friends are hanging out ...and here I am, 5.00 on Friday, headed to a dialysis unit...at home, you can build it around your schedule...I've got a lot of control back in my life. My energy level is up" ²²!

"I knew I would never survive in-center hemo. I had to sleep for 6, 7 hours afterwards. I could never, ever feel okay...You don't see a hope...I was so very depressed. Even when I took antidepressants, it didn't help...I was so drained. Now...I feel a lot more hope. It has really made a difference in how I view everything. I can enjoy the day. I try to get out and do something every day" ²²!

"After in-center treatments, I'd be really whipped, we could not go out. I saw home-hemo as a new beginning. And we saw benefits early on in doing it at home. I have energy so we can go out on nights after my treatments" ²²!

"No one knows how a person feels except the person themselves. I do it [frequent HHD] how I want within the guidelines of the system" ²³!

3.4. Table 1. Summary of the benefits of HHD

Potential Benefits of More Frequent HHD

Increased clearance of β_2 -microglobulin, possibly lowering risk of dialysis-related amyloidosis ¹
Increased removal of phosphorus, along with significant reduction in phosphate binder dose ^{2,3}
Reduction in inflammatory markers, such as C-reactive protein ⁴
Improvement in erythropoiesis-stimulating agent responsiveness ⁵
Increased weekly standardized Kt/V ^{6,7}
Better control of fluid volume, including less interdialytic weight gain ⁸
Improved control of blood pressure, with reduced need for antihypertensive medications ⁹
Significant reduction in left ventricular mass ^{6,7}
Increased ejection fraction ¹⁰
Less cramping and episodes of hypotension during dialysis ⁹
Minimal "washed out" feelings after dialysis sessions ^{11,12}
Improvement in symptoms of restless leg syndrome ¹³
Improvement in nutritional status, with lesser need for dietary restrictions ¹⁴
Improved sleep quality ¹³
Fewer episodes of sleep apnea per night ¹⁵
Reduction in FGF-23 ¹⁶
Improvement in depressive symptoms ^{11,17}
Improvement in sex hormone levels ¹⁸
Successful pregnancy outcomes ¹⁹
Improvement in vascular smooth muscle cell function ²⁰
Enhanced health-related quality of life ^{6,7,21}
Increased life expectancy ^{22,23}



Dialysis in the comfort of the home

Benefits and risks of frequent Home Haemodialysis (HHD)

Despite the health benefits that more frequent HHD may provide to those with chronic kidney disease, this form of therapy is not for everyone. HHD with the NxStage System One requires a patient and partner who are committed to being trained on and following the guidelines for proper system operation.

The reported benefits of HHD may not be experienced by all patients.

The NxStage System One is a prescription device and, like all medical devices, involves some risks. The risks associated with haemodialysis treatments in any environment include, but are not limited to, high blood pressure, fluid overload, low blood pressure, heart-related issues, and vascular access complications. The medical devices used in haemodialysis therapies may add additional risks including air entering the bloodstream, and blood loss due to clotting or accidental disconnection of the blood tubing set. Patients should consult with their doctor to understand the risks and responsibilities of home and/or more frequent haemodialysis using the NxStage System One.

Certain risks are unique to the home. Treatments at home are done without the presence of medical personnel and on-site technical support. Patients and their partners must be trained on what to do and how to get medical or technical help if needed.

Certain risks associated with haemodialysis treatment are increased when performing nocturnal therapy due to the length of treatment time and because therapy is performed while the patient and care partner are sleeping. These risks include, but are not limited to, blood access disconnects and blood loss during sleep, blood clotting due to slower blood flow or increased treatment time or both, and delayed response to alarms when waking from sleep. Patients should consult with their physician to understand the risks and responsibilities associated with home nocturnal haemodialysis using the NxStage System One.

Learning Activity

1. What is the main mechanism for blood pressure reduction with HHD?
2. Which substances have improved clearance on frequent dialysis?
3. In what way is quality of life affected by HHD?
4. Why is there often a decrease in medications when on HHD?

Acknowledgements

We would like to say Thank You to the patients who provided the quotes and photos of their dialysis at home.

Chapter 4

Basics of Home Haemodialysis

Learning Outcomes

- Identify appropriate patients for HHD
- Understand different options for HHD prescriptions and the benefits of frequent dialysis
- Learn what a Dosing Calculator is and how to use it
- Understand appropriate anti-coagulation use during HHD
- Gain knowledge about optimal vascular access for HHD, benefits and various cannulation techniques
- Understand the technical aspects necessary for successful implementation of HHD
- Understand the steps necessary for successful implementation of HHD



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Introduction

Home Haemodialysis (HHD) is an ideal treatment option for suitable patients requiring renal replacement therapy (RRT). There are challenges involved in the successful implementation of HHD. Appropriate advance planning of the home infrastructure and environment, suitable patient education, finding the appropriate regimen of treatments, home visits schedule and ongoing support to patients and their family members help ensure a smooth start and the continual success of HHD over a long period.

This chapter provides evidence based recommendations for the successful planning of the process, from the identification of suitable patients until the start of independent HHD.

4.1. Target population for Home Haemodialysis:

4.1.1 Capacity to perform HHD skills

Most patients are suitable for HHD. Basic requirements include: adequate manual dexterity and vision, reading and writing skills, home equipment, initiative and motivation¹. Patients lacking in some of these requirements may still be appropriate for HHD with a care partner or paid helper who meets these requirements and will assist during each treatment. Age is not a barrier either, there are many older patients who are capable of learning and undertaking self-care dialysis techniques, though a longer training period may be necessary².

KIHDEy European cohort reported that any access is feasible at home and a wide range of patients may be suitable for HHD regardless of age (from 15 to 84 years), size (BMI from 13.3 to 50.8) and comorbidities (Charlson average score 3.9, up to 11)⁴⁷.

4.1.2 The benefits and indicators for HHD

HHD empowers patients with independence and control over their health care. It reduces the time required traveling to dialysis centers, allows greater flexibility in scheduling, and has the potential to reduce the dietary restraints required of dialysis patients³.

Some populations who may benefit from HHD include:

- Patients upon failure of peritoneal dialysis who need to transfer to HD – these patients are used to performing dialysis at home, already have the set up and storage space, and often prefer to continue with the flexibility and independence of self-care.
- Patients after transplant rejection, who are often younger, healthier and more independent; patients holding jobs or regular activities, who need a flexible schedule and more freedom during daytime work hours^{4,5,6}.
- Complex patients, for example those with severe obstructive sleep apnea, refractory hyperphosphatemia, persistent uremic symptoms, difficult to control hypertension and refractory extracellular fluid overload often benefit from home treatment modalities⁷.
- Special medical requirements as Frequent HHD (FHHD) improves some clinical and quality of life outcomes such as successful deliveries for pregnant patients, bed-side dialysis for untransportable or hospitalised patients, unplanned start recovery, end of life palliative care.
- KDOQI guidelines state: "During pregnancy, women with end-stage kidney disease should receive long frequent hemodialysis either in-center or at home, depending on convenience"⁴⁸.



- Moreover complex patients may specifically benefit from receiving more Frequent Home Haemodialysis (FHHD), e.g. improving blood pressure control and reducing the risk of intradialytic hypotension^{49,50} (see Chapter 3).

Emergency initiation of dialysis treatments is not necessarily a barrier for successful implementation of HHD. Despite the lack of an informed choice at the initiation of the emergency treatment, even a patient with a suboptimal start in HD can be successfully transferred to HHD after appropriate education and training^{8,9,10}.

4.1.3 Maximizing uptake

All target population groups and their caregivers need to be activated and empowered in order to consider home dialysis as a treatment modality. A strong emphasis must be placed on the development of patient-focused educational programs and resources to meet patients' individual needs.

An integral part of shared decision making is development of a programme that meets the health literacy and cultural needs of patients and caregivers. This may enable HHD as a treatment option for most patients^{11,12}. Pre-Dialysis Education Programme (PDEP) should discuss all modalities and involve renal professionals and patients advocates for each. Awareness days or events are usually very successful to inform patients already on dialysis who may want to experience FHHD benefits. In the KIHDNEY European cohort, 61% of HHD patients come from in-centre, 9% from PD, 7% from transplant. Only 17% are incident patients⁴⁷.

Extending the duration of HD sessions can improve clearance of middle sized molecules and larger solutes, normalize serum phosphorus and provide adequate fluid volume control with lower ultrafiltration rates; but an excessive approach can lead to hypophosphatemia and more rapid loss of residual renal function^{14,15,18,19,20,22}.

4.2. Home Haemodialysis therapy options

4.2.1 Schedule and prescription

Home Haemodialysis therapy allow the nephrologist and patient the opportunity to tailor the best self-care therapy for the patient's current health and lifestyle¹³. The principal advantages of dialyzing at home is the flexibility of scheduling treatments, the possibility of more intensive HD and the possibility to incorporate the treatments into the patient's lifestyle; favouring a significant improvement in patient outcomes and quality of life^{13,14,15,16,17,18,19}.

The optimal HHD modality remains unknown, and it is unlikely that any single dialysis prescription will be optimal for all patients^{17,18}. We should try to offer a range of alternative HHD prescriptions that can improve patients clinical and biochemical measures, normalize risk factors, improve health outcomes and best address individual needs.

4.2.2 Benefits and risk of prescriptions

There are risks and benefits to each HHD regimen. More frequent treatments have been shown to improve fluid volume and blood pressure control, with need for less blood pressure-lowering medication, to improve phosphorus removal and serum level control with fewer dietary restrictions, to reduce left ventricular hypertrophy, and to lower mortality, (see Chapter 3).

However, more frequent HHD regimens may also increase some direct costs, there is a higher risk of vascular access complications due to cannulation frequency and failure to follow aseptic technique at home. There can also be burden on caregivers.

Table 1 : Home Haemodialysis therapy options

Modality	Sessions Week	Duration Session (h)	Blood Flow (ml/min)	Dialysate Flow (ml/min)	Potassium (mmol/L)	Calcium (mmol/L)	Base (mmol/L)	Phosphate Added	Principal Benefit	Principal Inconvenient	Important Concerns
Conventional with standard dialysate flow machines	3-4	3-5	300-450	500-800	2	1,25-1,5	Bicarbonate 32-36	No	Since it performs the same pattern as in-center, the only benefit is to be at home.	Long interdialytic break. Interdialytic weight gain. More medication needs to control phosphorus and blood pressure.	Consider this option only, if other more frequent options are not possible. Survival is markedly lower than other options.
Short daily with standard dialysate flow machines	5-7	2,5-3,5	300-450	350-600	2	1,25	Bicarbonate 32-36	No	Maximal fluid control with less medications. Liberal dietary intake.	Increased supplies. Increased risk of vascular access complications.	Most common prescription in HHD in Europe.
Traditional Nocturnal with standard dialysate flow machines	4-6	6-8	250-350	200-300	2-3	1,5-1-75	Bicarbonate 28-35	20-30% need additional Phosphate to the acid concentrate of the dialysate.	Active life is not hampered by intensive regimen. Maximized dietary freedom. Control phosphorus and blood pressure without usage of medication.	Requires blood leak sensor and alarm system. Requires replacement Vit C, group B, folic acid.	Similar survival rate as deceased kidney transplant recipient. Allow improved pregnancy outcomes. Patient with vascular access phobias or problems may not be suitable for nocturnal option.
Alternate- night Nocturnal with standard dialysate flow machines	3-4	6-10	250-350	300-500	2	1,5	Bicarbonate 28-35	Rarely requires addition Phosphate to the acid of the dialysate.	This is the easiest extended-hours regimen to maintain long term. Excellent reported quality of life. May reduce access complications compared with daily regimens.	Requires blood leak sensor and alarm system. Greater loss of water soluble vitamins (require replacement Vit C, group B, folic acid).	Patient with vascular access phobias or problems may be not suitable for nocturnal option.
Short Daily Low-flow dialysate machines	5-7	2,5-3,5	300-400	20-60 L dialysate per treatment	1-2	1,5	Lactate 40-45	No	Liberal dietary intake. Control blood pressure and phosphorus with less or no treatment. Improving quality of life.	It is specially designed for frequent treatment. Increased supplies. Increased risk of vascular access complications. Only one possibility Calcium in dialysate.	Most common prescription in HHD in USA. Designed for patients, easy to train and use. Useful for those who are unable to significantly modify their residence. Portable, freedom to travel.
Nocturnal Low-flow dialysate machines	4-6	6-8	250-350	30-60 L dialysate per treatment	2	1,5	Lactate 40-45	No possibility to add phosphorus in the dialysate bath.	Free time during working hours. Maximized dietary freedom. Control phosphorus and blood pressure without usage of medication.	Requires blood leak sensor and alarm system. Requires replacement Vit C, group B, folic acid. Only one Calcium concentration in dialysate available. No possibility to add phosphorus in the dialysate bath.	Similar survival rate as deceased kidney transplant recipient. Allow improved pregnancy outcomes. Designed for patients, easy to train and use. Useful for those who are unable to significantly modify their residence. Portable, freedom to travel. Patient with vascular access phobias or problems may be unsuitable for nocturnal option.

4.2.3 Choosing the best individualised option

Table 1 (can be found on page 58-59) is an overview of various regimens: different schedules with different equipment, with the main characteristics of each prescription. Adjustments must be made per patient health status, clinical goals and individual lifestyle and preferences.

When it is necessary to increase the dialysis dose, increasing the duration and frequency of sessions is more effective than changing flow rates and/or dialyzer size^{13,16,18,19,20,21}.

There is no single prescription that provides optimal therapy for all patients. Patient health status, clinical goals, lifestyle and preferences all influence the prescription. It is important to be aware of the potential risks and benefits of each option to the patient and care partner, and adapt the prescription when necessary to ensure long-term success.

4.3. Prescriptions for NxStage dialysis

4.3.1 Dosing Calculator

The NxStage Dosing Calculator (<https://dosingcalculator.nxstage.com>) is an online software tool, CE marked, designed to assist in prescribing haemodialysis therapy exclusively with the NxStage System One cycler. With a specified set of algorithms based on formulas documented in scientific literature, it automatically performs calculations to determine a range of appropriate treatment frequencies, treatment durations, and therapy fluid volumes, according to the specific characteristics of an individual patient, to achieve established targets^{23, 24}.

The prescription options provided by this tool can be used as a baseline for the development of a treatment plan, or can be very helpful for modifying the dialysis prescription according to changes in the condition of the patient that may require a change in the patient's prescription over time.

DOSING CALCULATOR

1. PATIENT BODY WATER VOLUME. Using either the Watson calculator or by directly entering the value in liters. To use the Watson body water calculator, we need the patient age, weight, height, and sex. (Patient must be 18 or older to use this formula)	
2. TREATMENT PARAMETERS. In this section we must enter the following data directly related to the treatment	
Target weekly std Kt/V	This value sets the standard Kt/V that will be provided by all choices in the options table. (KDOQI Guidelines suggested a target std Kt/v of 2.3 with a minimum delivered dose of 2.1 for schedules other than thrice weekly) ²⁶
Blood flow rate	This value refers to the flow of blood allowed by the vascular access of the patient.
Hematocrit	This value must be the patient's current hematocrit value; enter the whole number without "%" symbol.
Weekly UF volume	This value refers to the amount of ultrafiltration anticipated to be removed weekly, in liters.
Max UF rate	Establishes the maximum ultrafiltration per hour allowed (UF rates should be below 10 ml/hr/kg to improve mortality) ²⁶
Min hours/week	Establishes the minimum treatment hours per week.
Allow 3 days per week	Yes or No. This setting includes or not, the thrice-weekly schedule choice in the options table.
Round up to nearest SAK	When set to Yes, the calculator will round up the options to 40, 50 and 60 L volumes to match the standard SAK capacities.
Include rinseback in daily UF	When set to Yes, this option adds 280 ml to the UF target for each treatment to account for the rinse-back volume. This improves the accuracy of the treatment time if the rinse-back volume is not included in the Weekly UF volume setting.

4.3.2 Prescribing Frequent HHD (FHHD)

Prescription of Frequent Home Haemodialysis (FHHD) differs from Conventional Haemodialysis (CHD).

Time is not a limit anymore but production of high volume of dialysate is a challenge at home, so came FHHD with low dialysate flow which saturates dialysate and allows multiple time schedules.

Prescription of FHHD with low dialysate volume can be summarised in 2 steps:

Step 1: Calculation of minimal cumulative hours of treatment per week based on weight gain and ultrafiltration limitation. Then time can be divided by the number of sessions per week.

Step 2: Calculation of minimal dialysate volume based on Kt/V target and Total Body Water (TBW).

Observational studies showed that Ultrafiltration Rate (UFR) above 13 mL/kg/h is associated with high cardiovascular morbidity and mortality and suggest UFR should be below 10 mL/kg/h^{25,52}. A recent study showed even better outcomes with UFR below 6.8 mL/kg/h⁵², which is also the average UFR observed in the KIHDEy European cohort of patients in FHHD⁴⁷.

Dosing Calculator²³ is a comprehensive tool on-line, CE marked, to identify a range of prescriptions for a specific patient. Input parameters required are:

- Age, weight, height and gender to calculate TBW.
- Target std Kt/V, blood flow rate, haematocrit, volume to remove per week, UFR limit and minimum hours per week.

4.3.3 How to interpret the results

Once the previous parameters have been entered, the table with treatment options will appear. This “Options table” will show different possible prescription choices, with different frequency, duration and volume of dialysate necessary in each session to meet the target of standard Kt/V based on the patients’ water volume, blood flow rate, hematocrit, and ultrafiltration parameters, complying with the ultrafiltration constraints, minimum frequency, and minimum time selected.

It must be very clear that this is only a tool to help decision making. This tool does not replace the judgment or experience of the physician or licensed healthcare practitioner to make an independent determination of the therapy best suited for an individual patient^{23,24}.

This table of options allows flexible treatment, adjusting the dialysis prescription according to the needs of each patient and allows formulating different options related to the frequency and time of treatment, so that the patient can fit the treatment in his life and not adapting his lifestyle to the treatment. This flexibility in prescribing is an essential characteristic in home treatments, which makes a remarkable improvement in the quality of life of these patients.

4.4. Anticoagulation

4.4.1 Physiology

During HD several mechanisms activate different pathways that alter the coagulation system^{30,32,33}. The coagulation cascade is initiated as soon as the blood is in contact with external surfaces, but also air contact and the presence of turbulent blood flow leads to activation of platelets and leukocytes, resulting in clotting of haemodialysers^{32,33}.

Table 2: Anticoagulation options for Home Haemodialysis

Agent	Advantages	Disadvantages	Loading dose	Maintenance dose	Monitoring	HD Prescription	Important Issue
Heparin free / Saline bolus	Reduced risk of bleeding	Dialyser clotting	Rinsing dialyser and blood lines with 1L 0.9% saline.	Flush dialyser and blood lines with 100–250 mL saline every 15–30 min	Visualization of haemofilter	Short frequent dialysis Conventional Standard HD	Indicated: acute bleeding disorder, high risk of bleeding, recent head injury. Alternative in HIT.
Unfractionated heparin (UFH)	Safety, short half-life Low cost Antidote (protamine sulphate)	Requiring continuous infusion and/or repeated boluses Heparin-induced thrombocytopenia Allergic reactions	1000–1500 IU	1000 IU/h	aPTTr 2.0–2.5	Conventional Standard HD >5–6 hours treatments Long nocturnal dialysis	Anticoagulant of choice in USA. Usual options: bolus and continuous heparin or an initial bolus followed by subsequent intermittent boluses.
Low Molecular Weight Heparin (LMWH)	Single dose, at the start of dialysis. No need for routine monitoring.	Cost Long half-life No antidote Heparin-induced thrombocytopenia Allergic reactions	Enoxaparin 0.8 mg/kg Bemiparin 2500–3500 IU Tinzaparin 2500–4500 IU	None	Anti-Xa 0.4–0.6 IU/ml	Short frequent dialysis Conventional Standard HD with <5 hours treatments. Enoxaparin for long nocturnal HD	Anticoagulant of choice in Europe Administrate in venous injection port of the circuit to prevent loss of effect.
Argatroban	Hepatic metabolism, rapid effect, short half-life (40–60 min) Low cross-reactivity with heparin	Cost Avoid in liver disease. Requires monitoring (prolongs INR)	250 µg/kg or ≤20 mg	2 µg/kg/min 6–15 mg/h	aPTTr 2.0–2.5	Short frequent dialysis Conventional Standard HD with <5 hours treatments.	Alternative in HIT
Fondaparinux	New drug Better to use with patients who need constant anticoagulation	Long half-life Renal metabolism Can accumulate	2.5 mg	None	Pre-HD anti-Xa <0.20 IU/l	Long nocturnal dialysis >5–6 hours treatments	Alternative in HIT Not approved for HD in USA
Danaparoid	Low cross-reactivity with heparin	Long half-life No antidote	3750 IU (2500 UI if <55 kg)	None	Pre-HD anti-Xa <0.20 IU/l	Long nocturnal dialysis >5–6 hours treatments	Alternative in HIT Not available in USA

Note: Even though Regional Citrate and Prostacyclin anticoagulation are valuable options for in-center haemodialysis, their use is not normally employed for home haemodialysis due to its complexity for the patient and risk of adverse events.

Abbreviations: HIT, heparin-induced thrombocytopenia; aPTTr, activated partial thromboplastin time ratio; anti-Xa, anti-factor Xa; INR, international normalized ratio; IU, international unit; HD, haemodialysis.

One more factor directly related to dialyser is the membrane biocompatibility, with a contact area of 1 to 2m², which modifies the capacity to activate thrombotic pathways depending on the type of membrane^{27,30}. Anticoagulation treatment is essential to prevent this phenomenon, and knowledge of basic principles of the clotting cascade^{30,32,33,37} may help to achieve a performance improvement in dialytic therapy, using the lowest possible dose of anticoagulant while also reaching a prudent time of haemostasis of the vascular access.

4.4.2 Determining the dose of anticoagulant

In HHD, the responsibility for anticoagulation is shared between doctors, nurses and an appropriately trained patient³¹. There are some important differences regarding anticoagulation between in-centre HD and HHD. While in-centre there are monitoring methods to adjust the anticoagulation dose, these methods are not available for routine use in the home environment. In HHD, we have to guide through clinical parameters to assess whether a patient is treated with the correct anticoagulation dose.

Signs that the dosing is too high include if the needle sites continue to bleed for more than 15–20 minutes after dialysis; or the dose is inadequate, if there are thrombus or if there is clotting of the circuit^{30,34}.

4.4.3 Determining the type of anticoagulant

Another important difference between home and in-centre HD is treatment duration: as in home the prescription could be short daily or long nocturnal modality, the former would be enough anticoagulation with low-molecular-weight heparins (LMWH) and the latter normally requires unfractionated heparin (UFH), for adequate performance³⁴.

The third aspect in which both therapies differ is: the greater variety of anticoagulants affordable in the hospital setting, where citrate and

prostacyclin are valid options, but are not usually extrapolated to the population on HHD, due to the complexity of the protocol and risk of adverse effects^{30,32,33,35}.

It is important to clarify that systemic anticoagulation and/or antiplatelet therapy is insufficient to prevent clotting during HD^{26,27,29} but increases the risk of bleeding side effects^{29,30} as well as it is remarkable that no differences have been found in anticoagulation regimen between fistula and catheter vascular access²⁷. On the other hand, KIHDEy cohort showed that 40% of patients doing FHHD didn't use any anticoagulation⁴⁷.

In practice, there is no "standard" dosing for anticoagulation; rather there are several choices that can be tailored to meet individual patient needs^{34,35}. Table 2 (can be found on page 64-65) shows a summary of the different types of anticoagulation available and the characteristics of each for home dialysis treatment^{30,32,37}. It is important to update this topic on a regular basis, since prevention of clotting of the extracorporeal circuit with anticoagulation is so important to the safe and effective delivery of HHD therapy^{30,34}.

4.5. Vascular access

Proper vascular access (VA) is essential for successful home haemodialysis. All types of VA: Arteriovenous Fistula (AVF), Arteriovenous Graft (AVG) and Central Venous Catheter (CVC) can be used for HHD^{38,47}. Despite many studies, optimal VA for HHD has yet to be defined. AVF is the preferred vascular access for Renal Replacement Therapy (RRT), as it is associated with lower rates of access-related events, compared to CVC⁴².

There are two common techniques used for self-cannulation with AVF: "buttonhole" and "rope ladder".

CVC is also a possible VA for HHD. Benefits include ease of use and shorter training time. The risk of infection may be higher compared to AVF or AVG, however the correlation with morbidity and mortality have not yet been studied sufficiently for the unique population of HHD patients⁴⁵.

More details about vascular access is available in the chapter on vascular access.

4.6. Setting up the Home Haemodialysis room

4.6.1 Assessing the environment and determining the right space



Many patients will dialyse in an existing room such as the bedroom or the lounge, depending on what time of day they intend to dialyse. Minor changes to power, water or drainage are often sufficient for HHD to occur with small systems designed for home. Installation of a traditional machine would involve more modifications, space and costs. It is strongly recommended that prior to the installation process a technician or home nurse visits the patient's house.

If the patient wishes to develop a new space for dialysis or adapt an existing space it can be helpful to make a drawing and ask the patient to sign the drawing if changes are needed. If there are any structural changes (for plumbing, power or storage space) it is important that the owner of the building is notified and agrees to the changes. Responsibility for costs must be clearly determined and may vary by dialysis unit and region.

4.6.2 Basic requirements

The basic requirements at home include:

- **Electricity:** The dialysis machine should have 240V / 10A fuse for Class 1 equipment. Installation requiring modifications should be carried out by an electrician. Check the current regulations for your country.
- **Tap water:** The water should be drinking water quality according to national standards. Water pressure should be higher than 2 bar. Installation requiring modifications should be carried out by a plumber to avoid the hazard of water leakage.
- **Light:** The room needs good background light. Two 75W bulbs at the ceiling and a lamp with an adjustable arm close to the patient are ideal. It's possible to purchase a LED lamp with a magnifying screen.
- **Dialysis chair:** A comfortable armchair, which can lean back, with a footrest is preferred. If the patient needs a bed, an electric adjustable bed is preferred. However every type of bed may be adapted to the treatment.
- **Table for Connection/Disconnection:** A small table on wheels that can fit next to the dialysis chair to be used during the connection and the disconnection process.
- **Storage of disposables:** Two wardrobes with wire baskets are ideal for storage of concentrates, needles, tubings, dialysis filters, and other disposables that are used during the dialysis treatment. Some people just stack the boxes in a dry area.
- **Water Treatment:** Dialysis always carries a risk of water leaks. If possible it should be installed in a room with a floor drain. Water leakage detectors are an option.





- *Phone:* Always instruct the patient to have a phone close by for emergency calls.
- *Dialysis machine:* Avoid placing the machine on unprotected regular carpet as there is often some leaking water or saline around the machine.
- *Waste:* A waste bin will be needed for consumables after use. A secured box is required for needles.



4.6.3 Checklist for appropriate home environment

A home assessment is done by a team that usually includes a nurse and a technician. The timing of the assessment may vary according to the dialysis units' policy: at the time of dialysis modality selection, before or during the training process. The checklist on page 71 gives some ideas of what should be checked.



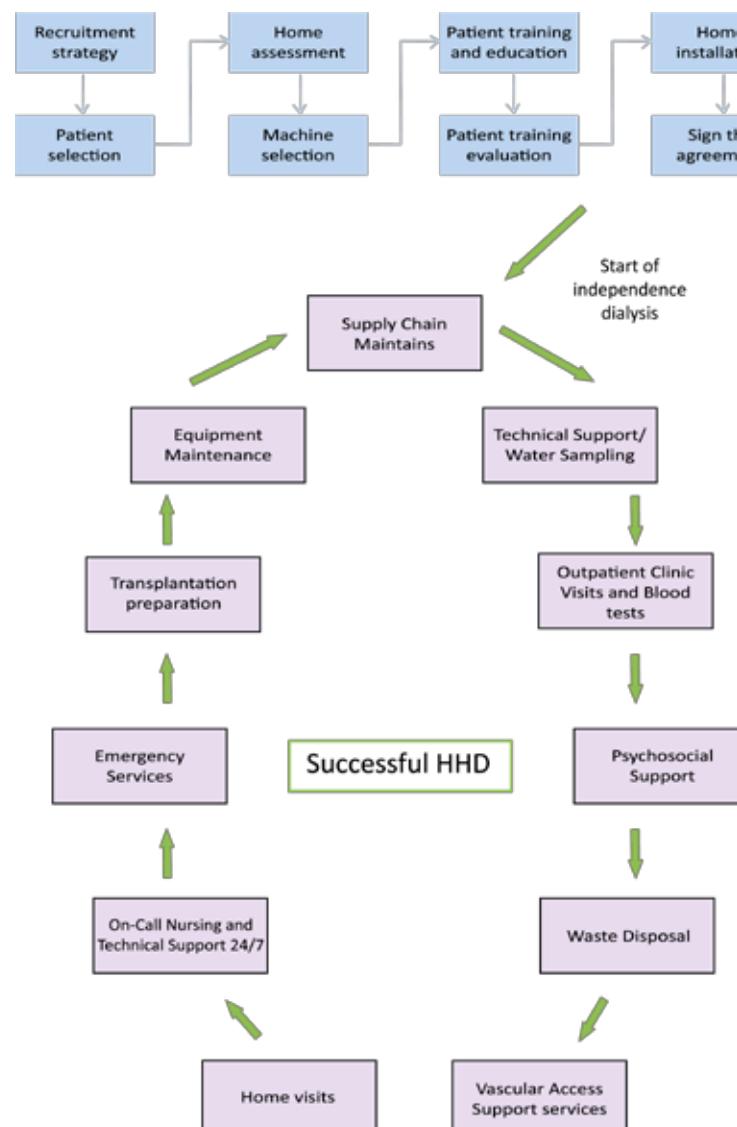
Checklist	Yes	No	Comments
Electric supply available			
Electrician review for safety requirements			
Clean water supply available			
Water quality – standard tests complete			
Water pressure adequate			
Machine preference determined			
Room for dialysis determined			
Space for storage available and clean			
Waste disposal available			
Drainage accessible (Need plumbing assessment or changes)			
Option for reject water use (desirable)			
Appropriate lighting			
Appropriate chair/bed			
Clean environment			
Pet free treatment room			
Access to land line or cellular telephone network			

4.7 Maintenance of HHD

4.7.1. Home visits

The first three months after initiation of HHD are the most crucial, and affect whether the patient will successfully continue this treatment modality. Weekly home visits during the initiation period may be very useful, as well as having the patient call the nurse both before and after completing each dialysis procedure, and having on-call support 24/7⁴⁶. Then home visits may be provided as necessary, most of the units provide on average 3 home visits per year.

Detail on home visits can be found in the chapter on support.



4.7.2 Logistics

Supply delivery: Supply delivery to patient's home most of the time is done by the company that is responsible for dialysis machine equipment. Sometimes a common carrier may be used and supplies will be brought to the door or into the home. The frequency of supply depends of the home storage size, frequency of the treatments and the distance from the warehouse. In some countries deliveries at home may be under the responsibility of a pharmacist to check matching with prescription then delivery route may require a specific organisation.

Waste disposal: HHD produces a large amount of waste products. Most of the waste is considered as biohazardous waste, and requires appropriate storage and pick-up. All sharps waste should be collected in special containers. HHD education programme should include explanations regarding local regulations for biohazard waste disposal. Each country or council will have its own regulations regarding waste management. It is the responsibility of the dialysis unit to know the local regulations and share these with the patient.

(See the Chapter 11 on environment for some handy hints about waste disposal).

4.8. Summary of Process of Home HD

After completing a preparation process that includes installation, patient education and training, the patient is ready to go home for dialysis. Patients' expectations regarding home treatment should be reviewed and communication with a dialysis unit nurse and physician should be a part of the educational process.

An agreement with the patient regarding the HHD process and roles and responsibilities may be used in some units.

All stages of implementation of HHD are shown in the graphic on page 72.

Summary

In this chapter we have discussed the basic issues for successful HHD. This treatment modality is appropriate for many dialysis patients. There are various therapy options for HHD. Patient's health status, lifestyle preferences, place of living and treatment goals play an important role during the planning process of HHD treatment. The Dosing calculator is a very useful tool that can help to plan each treatment. All types of VA can be used for HHD, however it is essential that it works properly and the patient receives appropriate anticoagulation treatment during dialysis. Home installation, required equipment, environmental and logistic processes are important challenges for successful implementation of HHD. Home visits by the nephrology team and professional intervention for home adaptation may be needed.

Learning Activity

1. What patient populations can benefit from HHD?
2. What are the options for prescriptions for HHD?
3. What is the Dosing Calculator and what can it be used for?
4. What differences exist between anticoagulation of in-center haemodialysis versus home haemodialysis?
5. What types of vascular access can be used for HHD?

Chapter 5

Vascular Access for Home Haemodialysis

Learning Outcomes

- To understand how different vascular access types can be used safely for HHD
- To understand how cannulation techniques can be taught to the patient/ carer
- To identify possible complications and know how to limit these



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Introduction

To perform safe and manageable home dialysis, a well-functioning access is vital. Access problems can cause undesirable stress in the home situation and, as a last resort, a transfer back to the hospital might be necessary, thus compromising the quality of life and independence of the patient¹.

There are three types of vascular access, Arterio-Venous Fistula (AVF), Arterio-Venous Graft (AVG), Central Venous Catheter (CVC), and all can be used in the home setting.

5.1 General Information

Many HHD patients dialyse more intensively which may be associated with increased risk of vascular access adverse events^{2,12}. Therefore, educating patients/carers in the care and management of their access, is a very important part of the training programme. At each out-patient clinic or home visit, the vascular access should be inspected. Access flow should be measured during training as a reference point for further follow-up in the home setting.

Ideally the training should start with a permanent vascular access. If this is not possible, training can be done with a CVC and the patient sent home at the end of training. When the permanent access is ready to be used, retraining for cannulation can be scheduled.

Patients on dialysis are prone to have more *Staphylococcus Aureus* on their skin and in their nose than the general population^{3,4}. Therefore, whatever vascular access they may have, patients may need to be screened, and treated depending on unit protocol. Handwashing must be done perfectly.

The use of gloves for the patient in the home setting is debatable.

Gloves may inhibit the patient's ability to maintain aseptic technique (than with bare hands thoroughly disinfected with an alcohol-based rub). Unit policies vary.

Retraining and/or home visit to observe technique is recommended, certainly after an infection episode.

5.2 Arterio-Venous Fistula (AVF)

Although frequent HD is associated with an increased risk of vascular access complications, reported event rates were lower in the AVF group¹². In-centre patients who are on a waiting list for HHD can be trained already to self-cannulate. This might shorten the actual total training time.

The ideal place for an AVF in a HHD patient who self-cannulates, is the non-dominant forearm. Upper arm AVF and AVF on the dominant arm, are more difficult to self-cannulate but it can be learned.

For more general information on AVF, see EDTNA/ERCA publication on 'Vascular Access Cannulation and Care - a Nursing Best Practice Guide for Arteriovenous Fistula'⁴⁸.

"My nurse said that once I had learnt to needle myself, I would never let anyone else do it, and he was absolutely right!" - Stuart

5.2.1 Importance of self-cannulation

- Self-cannulation is a major step towards enabling self-care at home and remains the foremost barrier for its uptake⁵.
- By self-cannulating, patients will feel empowered in their own care, and the benefit of a single cannulator will increase the life of the vascular access⁶. Patients will become experts of their own access.



Picture of an AVF

- In most HHD programmes self-cannulation is promoted, even if the patient has a carer. Indeed, cannulation by the carer can lead to very stressful situations. It should be limited to cases where the patient is not able to self-cannulate i.e. tremor, vision problems, inability to reach puncture sites, needle phobia.

"Self-needling is like the difference between being a passenger and the driver of a car on a twisting mountain road. The passenger may feel uncomfortable or sick. As the driver, though, you are in control and you feel fine."

5.2.2 Practical instructions for self-cannulation

Prepare

- Cannulate in a clean and draught-free **environment** with a **good light source**.
- **Proper hand washing** (with liquid soap) is mandatory before starting to prepare cannulation equipment.
- Materials required: disinfectant, drape, sterile dressing pack, tape, syringes, needles, tourniquet, waste bin, sharps container.
- **Disinfect hands with an alcohol based rub before aseptic preparation** of syringes, prefilling of needles and tape.
- **Washing (scrubbing)** arm before disinfection is extremely important.
- Whatever **skin disinfectant agent** is used, the **contact time** should be respected.
- **Wearing of a mask** is advised but unit policies do vary.

- **Washing/scrubbing of arm** and washing the access arm with liquid soap and water is mandatory in order to remove as many skin bacteria as possible.

Cannulate (standard needle)

- **Assessment of access** must be done at each cannulation. The patient is the expert of his/her own access. They should always look, feel and listen to the access⁷. The patients should be aware of the signs and symptoms of infection, and should never cannulate an infected AVF. They should be taught when to contact the centre for changes in the condition of the access.
- Use a tourniquet for an AVF (optional for button-hole cannulation).
- **Needles with longer tubing lengths** make needle removal easier. Typically the needles used for in-centre dialysis have a length of 15 cm. In order to improve ease of manipulations of needles by patient (especially for upper arm access), tubes of 30 cm are advised.
- The nurse can stabilise the access with thumb and forefinger during the first sessions.
- It is optional for a carer to stabilise the access.
- If self-cannulating, the patient has to hold the wings with thumb and forefinger and at the same time pull the skin towards him/her with the little finger.
- Taping with one tape first (to avoid accidental withdrawal of needle).
- Checking for flashback of blood/flushing.





Withdrawal of needles



The use of marker to indicate the direction of the vessel

- Secure taping prevents infection and needle dislodgement. Taping at the same angle as the insertion is recommended. The Butterfly or Chevron technique is best⁸. Sterile tape should be used for covering the puncture site (or sterile gauze). Bloodlines should be looped loosely to allow movement of patient and to prevent bloodlines pulling on the needles.

Dialyse and disconnect

- Patients doing nocturnal dialysis or sleeping during their sessions should have a **device detecting blood loss** on the venous needle⁸ (see chapter 12).
- Withdrawal of needles** is an important part of the cannulation process. Upon completion of dialysis, withdrawal has to be done at the angle of insertion and mild pressure applied (once needle has been withdrawn) with one finger over the vessel insertion site¹⁰. Experience has shown that using two fingers is not always easy for the patient and that bleeding occurs if fingers are not in the right position.
- When the bleeding has stopped, the cannulation sites have to be disinfected and covered with a dressing according to unit protocol.

Evaluate

- Variations in venous and/or arterial pressure, bleeding along the needle or longer bleeding times after dialysis** should be reported to the centre.

Training hints

- Discuss any concerns or worries and ensure training plan considers these.

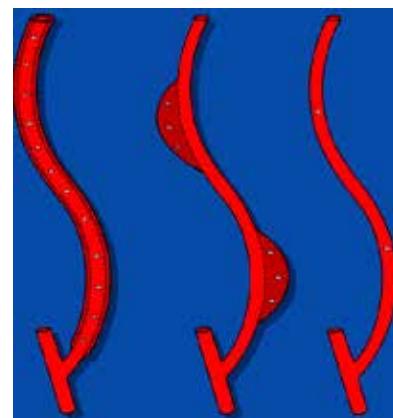
- If training has to be started with newly developed AVF, only qualified staff should carry out first cannulations.
- If ultrasound device is available, it should be used to increase success of cannulation and determine best sites.
- It is much easier for the patient to cannulate both needles antegrade (in direction of flow) and it might be fistula protective¹⁴. Use a marker to indicate the direction of the vessel.
- Removal of the needles is often a good first step in the cannulation training process.
- Practice with an 'artificial arm' such as an orange.
- Patient may benefit from watching others being cannulated.
- Patient should watch himself/herself being cannulated.
- Use a 'Tandem hand' technique, where the hand of the patient is guided by the hand of the cannulator⁹.
- Practice** of cannulation should be **started as soon as possible** during training and whenever successful cannulation seems possible.
- The length of training varies considerably, and is access and patient dependent. Prior to going home the patient has to master the procedure and feel confident.
- Encouraging and praising** the patients in all phases of process is essential.



Plastic cannulae



Possible solution for solo dialysis with cannulae



a. Rope ladder b. Area C. Buttonhole



Rope ladder cannulation



Example of area cannulation

Plastic cannulae

- These are a possible alternative for metal needles in the home setting. Due to their characteristics, they seem to be well suited for restless patients, children, and patients who are allergic to metal¹¹ and nocturnal dialysis. However, a cannulation helper is in most situations needed because it is very difficult during self-cannulation, to withdraw the inner metal needle and to manage the connections because of the absence of attached tubing.

5.2.3 Cannulation techniques (site selection)

Different cannulation techniques

Rope ladder cannulation

The rope ladder technique is a very good cannulation technique. The whole length of the vessel is used with rotation of the puncture sites, leaving a distance of at least 5 mm between the sites. According to the literature there may be less infection risk than in buttonhole cannulation¹³. However, this technique has disadvantages:

- Experience has shown that patients very often don't rotate because of fear of using different sites and length of vessel.
- It is usually done with a sharp needle which carries a risk for haematoma during connection and during nocturnal dialysis.

Area cannulation

Area cannulation has the worst outcome with thinning of the vessel wall, aneurismal formation and stenosis^{15,16} and should be discouraged.

Buttonhole cannulation (BH)

The increased popularity of upper arm AVF which have short and tortuous tracks, the ageing population on HD, the high prevalence of vascular co-morbidities and the rise of frequent HHD have all increased the interest in the BH¹⁷. The BH technique is a cannulation procedure where the AVF is cannulated in the exact same spot, at the same angle and depth of penetration at each dialysis session.

There are many papers reporting an increased infection rate^{18,19,20}. However, many variations in cannulation technique existed among studies, and many descriptions of the procedure were incomplete and unclear. In addition, since the publication of some of the papers, the technique has been evolving. However, to prevent infections it is mandatory to strictly adhere to a clear protocol.

The British Renal Society Vascular Access Special Interest Group recommends screening and selection of patients to undergo buttonhole cannulation:

- All patients undergoing buttonhole cannulation should be screened for MRSA and MSSA including their arteriovenous fistulae site, a minimum of every 3 months.
- Decolonisation can be done for those with MSSA (Methicillin-Sensitive Staphylococcus Aureus).
- Patients should be individually risk assessed by the renal team before initiating buttonhole cannulation²¹.



Buttonhole cannulation

Special attention must be given to patients with a previous access infection since they may be prone to infection recurrence²².



Surgical sponge



"Touch" cannulation performed on a table

Cannulation variation

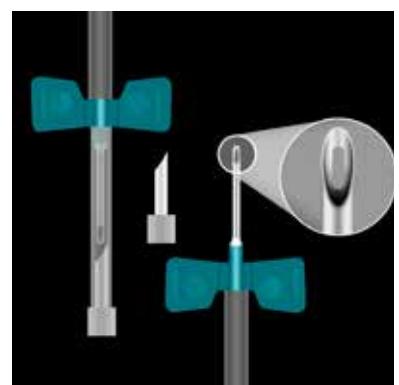
Most aspects of cannulation are identical to standard cannulation but consider these extra aspects:

- Involving the patient during the creation of the tunnel track is not easy, usually training for self-cannulation is started subsequently, when blunt needles can be started.
- If ultrasound device is available, it should be used to increase success and to search for ideal, healthy sites to create buttonholes.
- The sites should be easy to reach by the patient and a distance of at least 4-8 cm in between is recommended.
- It is strongly advised that the procedure is performed by the same cannulator/trainer, until the tunnel track has been created. It takes at least 6 cannulations with a sharp needle before dull needles can be used.
- Some HHD centres create two arterial and two venous puncture sites in case of extensive dialysis.
- Washing/scrubbing of the arm with surgical or exfoliating sponge makes scab removal easier (in some cases scabs are completely being removed during process!) and would have a favourable effect on the infection rate²³.
- Do first disinfection (attention contact time), then complete scab removal with a blunt needle (not cannulation needle) or scab remover (comes with blunt needle) then second disinfection (attention contact time).
- During cannulation it is mandatory to keep the arm in the same position and on the same angle in order to align the needle with the tunnel track. It therefore can be helpful to train the BH cannulation with the arm on a table. The patient can continue the same procedure at home.

- **Touch cannulation** Instead of holding the needle by the wings, it is held by the tubing to prevent cannulator using force and to push the needle in a wrong direction. The needle will follow more easily the direction of the tunnel track, without damaging it. The so called 'trampoline effect', where the needle point bounces against the vessel wall, will be less frequent.
- If resistance is met or the needle bounces back, the patient has to be instructed to gently withdraw the needle in the tunnel until the bevel reaches its entrance and try again (recheck the position of the arm). If the needle has been removed completely outside the tunnel, it should be replaced by a new one.
- If the cannulation is unsuccessful after two attempts (with different needles), the patient should have a rest and retry 15 minutes later. An alternative is to postpone, if possible, the dialysis till the next day.⁶ It is generally recommended not to use a sharp needle if cannulation with a blunt needle is unsuccessful however, it can be allowed if the patient inserts a sharp very gently, using 'touch cannulation' through the tunnel track. Careful use of a sharp needle does not increase complications²⁴.
- Hubbing is when the hub of the needle is pushed into the cannulation site causing the needle to stretch the tunnel entrance. The scab becomes difficult to remove, increasing the infection risk. Therefore, 1 to 2 mm of the metal of the needle should be visible after cannulation²⁵.
- If a tourniquet is used, caution has to be paid not to tear the skin and change the direction of the tunnel track!
- In patients with deep or unstable vessels a subcutaneous vascular needle guide 'VWING' can be surgically implanted on the vessel wall. It guides the needle directly to the vessel through the same pathway every time, rapidly enabling the use of blunt needles and facilitating self-cannulation in these patients²⁶.



Vwing device



Blunt needle with scab remove



Plastic pegs to create BH tunnel track (3 different lengths)



Tunnel track kept open by peg



Moist healing method



Silver coated dressing



Compressive dressing

Developing the buttonhole

An easier way to obtain a straighter tunnel track is the use of a plastic peg. As long as pegs are used, there is no scab formation. When the needle after dialysis has been removed, and bleeding has stopped the puncture site is disinfected and the peg is inserted. It remains in place until the next HD session covered with a compressive dressing. When the peg is removed just before the next session, a sharp needle is gently inserted along the track already formed by the peg. These steps are repeated at least 6 times. The length of the peg can be adapted to the depth of the vessel wall.

Using the pegs, it is not mandatory to have the same cannulator during the whole process. This way the patient can in some cases start self-cannulation earlier. It takes less courage to slide the needle through an open tunnel track (Ideal for patients with needle fear).

Post dialysis care

- When the bleeding has stopped, the cannulations sites have to be disinfected and covered with a dressing. In order to control infections, some centres apply topical 2% Mupirocin ointment to the punctures sites²⁷.
- Two procedures decrease formation of scab and might be infection protective:
 - Moist healing method**²⁸ leads to formation of no scab or a very small scab. When the bleeding is stopped, the site is disinfected with a diluted povidine iodine solution and covered with a sterile plastic dressing for 24h to keep it moist. During the scrubbing procedure, before the next dialysis session, the scab, if any, will be in most cases easily removed.

- Silver coated dressing** has an antibacterial action and decreases the size of the scab.

5.3 Arteriovenous graft (AVG)

- AVG is a good option if creation of an AVF is not possible, although there is an increased risk of complications.
- The ideal place for an AVG in a HHD patient who self-cannulates, is the non-dominant forearm. Upper arm AVG and certainly AVG on the dominant arm, are more difficult to self-cannulate
- The recommended cannulation technique for AVG is the rope ladder technique and there is no evidence supporting the use of BH²⁹. However, some centres apply the buttonhole technique in grafts with good outcomes (based on the experience of the author).



Buttonhole cannulation in AVG

Cannulation variation

- A tourniquet is not required.
- All other recommendations for AVF rope ladder cannulation are appropriate for AVG.
- For more general information on AVG, see EDTNA/ERCA publication on 'Vascular Access Cannulation and Care - A Nursing Best Practice Guide for Arteriovenous Graft'²⁹.

5.4 Central Venous Catheter (CVC)

There are many different catheters available. They should be able to provide a minimum blood flow rate of 300 ml/min consistently in order to maintain adequacy of dialysis¹⁰. However, there is no evidence to guide selection of one type of CVC over another.

- CVC use in patients on HHD is, as well as for patients undergoing in-centre dialysis, associated with higher risk for mortality and hospitalisation^{30,31,12}. Canadian guidelines for the patients treated with intensive HD suggest the use of AVF or AVG over CVC³². However, studies reported good outcomes with use of CVC in intensive HD^{33,34,35,36,37,38}. Also in the KIHDEy European cohort 24% of patients were at home with a CVC⁴⁹.
- In some countries, the use of CVC is not allowed or controversial in the home setting.
- CVC allows a more secure connection to the extra-corporal circuit. It is therefore the preferred access for Nocturnal HD in some HHD programmes³⁹.

5.4.1 Practical instructions for successful CVC handling



CVC handling after proper hand hygiene

- Adherence to **strict aseptic technique** is mandatory when handling CVC and procedures should be consistent with current evidence base¹⁰:
 - Proper hand washing (with liquid soap) is mandatory before starting.
 - Disinfect hands with an alcohol based rub.
 - Wearing mask is advised (patient and carer).
 - Whatever **disinfectant agent** is used, the **contact time** has always to be respected.
- Avoid traction on CVC. During treatment lines have to be secured to prevent trauma.
- Patients doing nocturnal dialysis or sleeping during their sessions may have a **device detecting blood loss** on the venous hub (see Chapter 12 on risk).

5.4.2 "Closed connector" or "closed luer access" devices

Various connectors are currently marketed which create a mechanical and microbiological closed system implicated in decreasing blood stream infections for CVC^{40,21}. The Canadian Society of Nephrology guidelines for Intensive HD, recommend a closed luer device for patients receiving intensive HD¹⁸. However, it is recommended to use the device in all HHD patients with CVC^{41,42}. It protects against accidental disconnection, avoiding bleeding, and last but not least air embolism (negative pressure when patient is not in supine position). In some cases, flushing with 0.9% saline after dialysis is sufficient to keep the CVC patent and avoid injection of an additional lock solution.

However, if not connected properly, the device can also lead to accidental disconnection and related complications, including air embolism and bleeding.

- The devices have to be changed according to unit protocol (aseptic technique).
- At each dialysis session, the patient has to check if connections between the hubs of the CVC and the device are still tight.
- Despite the device, the lines of the CVC always have to be clamped.

5.4.3 Locking of CVC

Traditionally each lumen is flushed with 10–30ml of saline after dialysis prior to locking with heparin/anticoagulation/antimicrobial solution. Each unit has their own protocol. Expert opinion is advocating for increase in volume of flushes (to 30ml) to minimise formation of secondary fibrin membrane and flow issues⁴³. In order to avoid aspiration of blood in CVC, it is mandatory to clamp lumen at each time before removing syringe and leave it closed till next dialysis session⁴⁴.



Complete removing of lock solution/0,9% saline



Checking connection between 'closed connector' and hub of CVC

At each dialysis session the lock solution has to be removed completely and then flushed with 0,9% saline. The centre should be contacted if the lock cannot be removed.

5.4.4 Dressing



Dressing in front of the mirror

- Many types of dressing are available for the exit sites of CVC. They protect against infection and eventual trauma and can, if waterproof, be left on during shower.
- There are different protocols for showering with CVC, with or without protective dressing. The water source can be a source of infection. Also shower and shower head are potential sources of bacteria; therefore, regular cleaning of both is recommended⁴⁶.
- Absence of dressing can be an option for patients with allergic reaction to all kinds of tape (extreme caution) but the catheter should be secured. This procedure is used in some PD programmes⁴⁵.
- Inspecting for signs of infection at each dressing is mandatory⁴³. The HHD unit must be contacted if signs of infection are present.
- Frequency of dressing changes is according to unit protocol, ranging from each session or after shower, to weekly.
- Strictly adhere to prescribed protocol (disinfectant, type of dressing).
- Teaching of dressing change can be done in front of mirror for patients who want to do it themselves.

5.4.5 Complications of CVC

Unfortunately, CVC flow dysfunction occurs regularly and leads to decreased dialysis efficiency. Definitions of catheter dysfunction vary, but in general they relate to the inability to achieve a certain blood pump speed within the venous and arterial pressure limits of 250 and -250 mmHg, respectively, while dialysing⁴⁶. A blood flow change of more than 20% over three consecutive treatments is an indication of a problem⁴⁷, or if inversion of dialysis lines due to flow problems is regular practice¹⁶. Inversion of lines however increases recirculation so is not recommended.

- The patency of the catheter must be checked during training as reference point for follow-up in the home setting.
- The centre has to be contacted if dysfunction, as defined above, is detected.
- Flushing of lumens with 10 to 30 ml of 0,9% saline (push and pull movement) can be effective to clear poor flows.
- Administration of a thrombolytic may be necessary. Some centres allow the patients to administer a thrombolytic at home, others request the patient to come to the unit.

CVC infections occur more frequently than infections of arteriovenous access. They can be local (exit site or tunnel infection) or systemic. Patients must be taught the signs of infection and should check their temperature each treatment or daily. If signs of infection are observed, the patient has to come to the centre for swabbing of pus and or sampling of blood. Topical or systemic treatment has to be started according to centre protocol.

Summary

All types of vascular access can be used in the home setting. A well-functioning vascular access is a key success factor for HHD. Care of the access is a very important part of the training programme. Adherence to the unit protocol is extremely important.

Retraining, observation of the technique during home visits and motivation of the patient, are helpful for infection control and overall survival of the access.

Learning Activity

1. Which vascular access types can be used in the home setting?
2. Give a short description of the different cannulation techniques with advantages and disadvantages.
3. What are the advantages of self-cannulation?
4. What is a "closed connector device"?

Chapter 6

Education and Training in Home Haemodialysis

Learning Outcomes

- To understand the process involved in HHD training
- To highlight the specifics for training on a simple machine designed for HHD
- To provide a practical guide on how to implement a HHD training programme



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Introduction

Training for HHD has historically been a lengthy process, taking up to 3 months in many centres. However, with the development of machines designed specifically for HHD, utilising new and simpler technology, this process has the potential to be much quicker and more accessible to patients. This in turn will enable a growth in the number of patients on HHD.

6.1 Logistics

There are key logistic steps in any training pathway. These should include:

- Referral for HHD training from pre-dialysis/dialysis unit/PD, or shared care to the HHD lead nurse.
- Home assessment performed by lead nurse/technician and arrangement of any engineer/plumbing work.
- Arrange training dates with patient and agree a provisional date for home.
- Order machine/supplies to be delivered to home address one week before training (or one week prior to discharge home).
- Arrange clinical waste removal once commenced at home.
- Organise electric/water payments through hospital/government (if applicable).

6.2 Checklist

6.2.1 Patient suitability

Once a patient has been referred for home training they should be assessed for suitability to perform dialysis at home and they must have agreed to do it. Primarily the patient should be physically and intellectually able and, most importantly, motivated to perform home HD and its related activities¹. The patient and helper must be able to understand and retain information and instructions given. Related to this the patient and helper should be aware of the potential implications for changes in lifestyle.

General Physical Condition: The patient should be assessed for any general physical condition which may prevent him/her from carrying out his/her own treatment, i.e. poor eyesight, arthritis, etc. If so, the helper may be trained to carry out extra procedures. It would be preferable that the first patient has a good functioning fistula and should be physically stable on dialysis to start a programme but KIHDEy cohort reported that any access is feasible at home and a wide range of patients may be suitable for HHD regardless of age, size (BMI) and comorbidities (Charlson score)⁶.

Moreover complex patients may specifically benefit from receiving more Frequent Home Haemodialysis (FHHd), e.g. improving blood pressure control and reducing the risk of intradialytic hypotension^{7,8} (see Chapter 3).

If units offer a shared care option (self-care in the dialysis unit) it will be easier to assess patient suitability. The transition from unit HD, to shared care, to HHD, can be a smooth process and can give staff valuable information on a patient's ability to perform the necessary skills, and the patient valuable insight into self-care.

If shared care isn't promoted it is important to try and spend some time with the patient whilst they attend for their regular dialysis sessions to assess some basic skills and requirements. It may be the carer that is going to perform the dialysis so this needs to be considered when assessing for suitability. The following guide can be used to assess each individual.

6.2.2 Consent

The patient and helper must be given sufficient information to allow them to make an informed decision to train on HHD. The patient should be willing to undertake frequent dialysis, but their treatment regime must be determined with them and taking their lifestyle into consideration. A signed consent may be asked.

6.2.3 Dialysis partner

Patients should be encouraged to manage their treatment at home as they will feel more in control of their life, but a trained care partner is required. Care partners may be a spouse, partner, family member (e.g. parent or sibling), or friend, and have various levels of involvement in the patient's care. Some care partners may take full responsibility for all patient's care, performing all aspects of HHD. Other care partners may only have a limited involvement in the HHD treatment such as cannulating an arterio-venous fistula, and removing the needles post-dialysis, or assisting in case of issue.

6.2.4 Suitability of the home

The patient should have a suitable room which is large enough to house the dialysis machine and other equipment required for haemodialysis.

The location of the machine must be agreed with the patient and helper. Ensure a telephone is accessible in the house.

A home assessment should be performed using these criteria. More information about home suitability is available in chapter 4 "Basics of Home Haemodialysis".

6.3 Training

6.3.1 Cannulation training

If cannulation skills can be achieved prior to training the patients can concentrate on machine skills during HHD training. If a shared care programme is being used this is an ideal environment to prepare patients prior to home training and concentrate on cannulation skills. As part of patient advocacy, promotion of self-care and longevity of access, patients should be encouraged to self cannulate². A cannulation education and competency pack should be used.

It is also possible for patients with tunneled lines to go home, but it would be necessary to train a partner to perform the skills necessary for connection and disconnection.

6.3.2 Training schedule

NxStage has instructions to train on System One with a patient in 10 days. In Wessex Kidney Centre, Portsmouth UK, where 82% of patients are self-cannulating prior starting training on the machine, average training time is 10.5 days, (see Chapter 12).

In the KIHDEy European cohort, overall training time was achieved in 18.9 sessions vs. 27.7 sessions in the FHN Nocturnal Trial on traditional machines⁵.

A training checklist can be agreed with the patient where they attend for up to 5 sessions per week for the two week training period. Ideally the patient has dialysis on the machine in a designated training area.

6.3.3 Training allocation

A member of the home haemodialysis team should be allocated as the trainer. This can be a support worker, or nurse depending on staffing available. There is a worldwide consensus in PD programmes about a maximum ratio of 1 nurse for 20 patients. Wessex Kidney Centre (Portsmouth, UK) experience confirms this maximum 1/20 ratio and recommends a 1/15 ratio for HHD (see Chapter 12). An example of a two week training schedule is attached at the end of this chapter; this schedule is based on training using the NxStage machine.

(Appendix 1)

6.3.4 Training location

Depending on the distance of the patient's home to the hospital, if a designated training area is available in the hospital, and depending on availability of staffing, this can be done at home or in centre. Patients may feel more comfortable and concentrate more in their home environment or they may feel safer initially doing this in the hospital. If patient training happens in the renal unit, a dedicated area is highly recommended but can be just as small as the space to fit 1 home machine and 1 dialysis chair. This to prevent schedule conflicts with routine care or in-centre activity.

6.4 Training tools/curriculum

6.4.1 Adult learning

The principles of adult learning presume that adults are actively involved in the learning process. A training programme can be tailored to allow patients to learn using speeds and styles at which

they feel comfortable¹. One of the most used classifications of learning styles is one proposed by Flemming and Mills, 1992³ the VAK model, this describes 3 main learning styles; visual, auditory and kinaesthetic learning. It is important that a training programme incorporates each of these styles which complement each other and can be adopted by the individuals depending on their own style or mindset with a specific topic to learn.

The trainer should assess the patient and/or carer prior to training to try and understand which their preferred learning style is. It is important to remember there are other learning styles and everyone may adopt their own unique style but memorisation may be limited to only 20% with "receiving" learning styles.

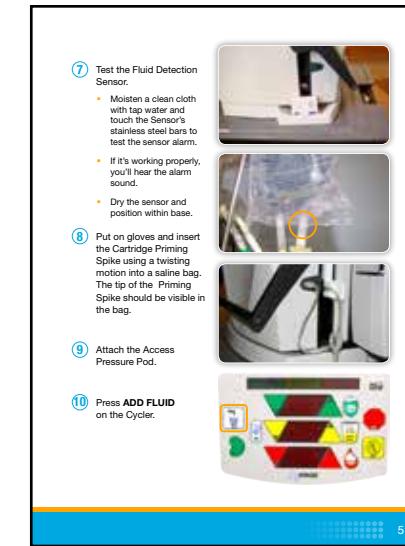
"Participating" teaching that includes demonstration, discussion and exercises may increase memorisation to 75%.

"Doing" teaching with coaching, repetition and verification of skills may allow optimal competence⁹.

6.4.2 Training support materials

A training pack with all written information should be available, with quick guides and pictorial guides. A good start to any programme is the use of training aids that are strong visually, with step by step photography to demonstrate the dialysis procedure with a minimum amount of text¹.

Demonstration videos are also useful for patients to watch on portable devices during their training. These can be accessed from home for reminders of various procedures and machine skills once they are independent at home.



6.4.3 Demonstration machines

During training it is useful to have a demonstration machine which patients/carers can practice on. This enables repetitive training each day on all stages of dialysis. It has been suggested that some sort of patient based simulation training may be helpful to validate patient's readiness to begin HHD¹.

6.4.5 Competencies and follow-up.

During training all competencies for machine and other skills need to be signed off by an allocated nurse and the patient. This is normally done towards the end of week 2. Examples of skills checklist can be found in Appendix 2,3 and 4.

6.5 Going home and follow-up

6.5.1 Transition to home

Follow up is necessary for the first week at home for at least 3-4 dialysis sessions. During these the nurse may be present for the whole session. Once the patient is felt to be safe and confident the patient and carers can be left to undertake the sessions independently. During this initial period it is important to use communication links more frequently such as regular phone calls or Skype calls when performing dialysis. This allows advice and encouragement to be given to increase confidence.

6.5.2 Ongoing follow-up

All patients should then have a routine monthly visit for bloods, QA/ access monitoring, and general checks. Ideally visits should be during a dialysis session to assess cannulation technique and machine skills.

Key follow-up strategies include:

- A formal technique check should be done every 6 months. Retraining and assessments after being at home for a while or if problems are identified are good practice as people develop adaptations to what they have been taught.
- It is important clear guidance is available for patients at home, for them to understand their responsibilities and what the team can provide to assist them at home.
- A guide on who to contact in the event of a technical or medical issue should be readily available.
- A dialysis regime needs to be agreed and this needs to be recorded by the patient at each dialysis session.
- A designated nurse can be assigned to monitor and support each patient before they go home.

More detail on follow-up is provided in Chapter 8 "Ongoing Support".

6.6 Risk reduction

6.6.1 Access

If patients are using a fistula, ideally a buttonhole or rope ladder technique will be taught. The use of 2% mupirocin ointment is recommended for all patients undergoing buttonhole technique⁴. If rope ladder technique is used patients need to ensure that the needle sites are rotated so that even distribution of puncture sites occurs along the length of the access².

If patients are on a tunneled line a 2 person technique should be used to minimise infection risk, an antimicrobial lock solution is recommended⁵.

More information on access and cannulation is provided in the specific Chapter 5 "Vascular Access for Home Haemodialysis".

6.6.2 Blood loss

One of the biggest risks of performing HHD is disconnection within the system or bleeding from fistulas. Reduction of this risk include the use of wetness detectors, good anchoring and secure taping strategies.

It is important for patients to recognise warning signs and take the appropriate response to any problems with their fistula. A safety guide has been developed for patients to use in shared care and at home, to minimise risk of bleeding from fistulas (Appendix 5).

Venous needle dislodgement is also discussed in Chapter 9 "Safety and Risk Management".

Appendix 1 - 2 weeks training schedule (for NxStage Medical)

Week 1	Training topic
Day 1	<p>Patient is introduced to the various parts of the machine ie Pureflow, cycler, PAK, SAK etc</p> <p>Patient is shown how to prepare for treatment, line, prime and programme the machine. Patient is put onto dialysis and shown how to perform observations during dialysis and how to come off the machine.</p> <p>Patient is given a tablet/laptop with training videos and literature and shown how to access these.</p> <p>Patient is given the manuals for the NxStage device and made aware how this is useful for problem solving with their device.</p> <p>Patient is given the helpline number for technical problems once home and explanation given when to use this.</p>
Day 2	<p>Patient prepares their own machine with support and goes onto dialysis.</p> <p>A demonstration is given with the training device, going through the process of lining, priming, connection, highlight key part connections etc.</p> <p>Patient is given tablet/laptop and guided through training videos/literature.</p>
Day 3	<p>Patient prepares their own machine with support and goes onto dialysis.</p> <p>Assessment is made on how the patient is understanding and following instructions from the training book and following demonstration videos.</p>
Day 4	<p>Patient prepares their own machine with support and goes onto dialysis.</p> <p>Introduce some troubleshooting alarms, air 10/11 alarms and pressure pod reset.</p>
Day 5	<p>Patient prepares their own machine with support and goes onto dialysis.</p> <p>Introduce further troubleshooting, including weight loss minimum alarms^{24,25,30,37,38}</p>

Alarms discussed this week

- ALARM 4 BLOOD PUMP OFF
- ALARM 7/8 ALARMS OVERIDDEN / PRESSURE LIMITS OPEN
- ALARM 11 ARTIERAL AIR
- ALARM 10 VENOUS AIR
- ALARM 24 ACCESS PRESSURE LOW
- ALARM 25 ACCESS PRESSURE POD ERROR
- ALARM 30 VENOUS PRESSURE HIGH
- ALARM 37/38 HIGH BALANCE CHAMBER ALARM

Week 2	Training topic
Day 6	Patient performs all machine skills required each day for dialysis. Recap of everything from week 1. Go through alarms 10/11, weight loss minimum, and pressure pod reset. Power failure is simulated on training device to show what to do in a recoverable power failure (none recoverable power failure also discussed)
Day 7	Go through vascular access module and competencies, including fistula safety guide. On tablet/laptop introduce to renal patient view / how to use Skype (a login can be made for patient on this day)
Day 8	With community home dialysis nurse and trainer, install machine at home and demonstrate to the patient how the connections are made. Discuss common alarms and include temporary disconnect. Check bloods/demonstrate blood sampling technique.
Day 9	Discuss alarms 10/11 unless patient is confident with these and temporary disconnect. Perform emergency washback simulation on training device. Sign off all competencies/checklist.
Day 10	Discuss bleaching the waste line and general maintenance of the machine. Ensure the patient is ready to go home / arrange plan for home with community nurse.

Alarms discussed this week

- ALARM 10 VENOUS AIR
- ALARM 11 ARTERAL AIR
- ALARM 40 RECOVERABLE POWER FAILURE
- ALARM 41 NONE RECOVERABLE POWER FAILURE

Appendix 2 - Sample skills checklist

PATIENT NAME	HOSPITAL NUMBER		DATE	
COMPETENCIES				
	INFORMATION PACK GIVEN	PATIENT SIGN OFF	TRAINER SIGN OFF	COMMUNITY SIGN OFF
Set up table/hand hygiene	N/A			
Blood pressure & observations on dialysis/documentation	N/A			
Disposal of equipment/sharps	N/A			
Cannulation pack & Safety information Access care QA & fistula monitoring				
Target weight and assessment				
Giving IV iron				
Giving EPO				
Helpline Support				
Ordering Supplies/ Customer Services				
Blood Sampling/Centrifuge				
Holiday Information				
Renal patient view/Skype				

Appendix 3 - NxStage cycler skills checklist

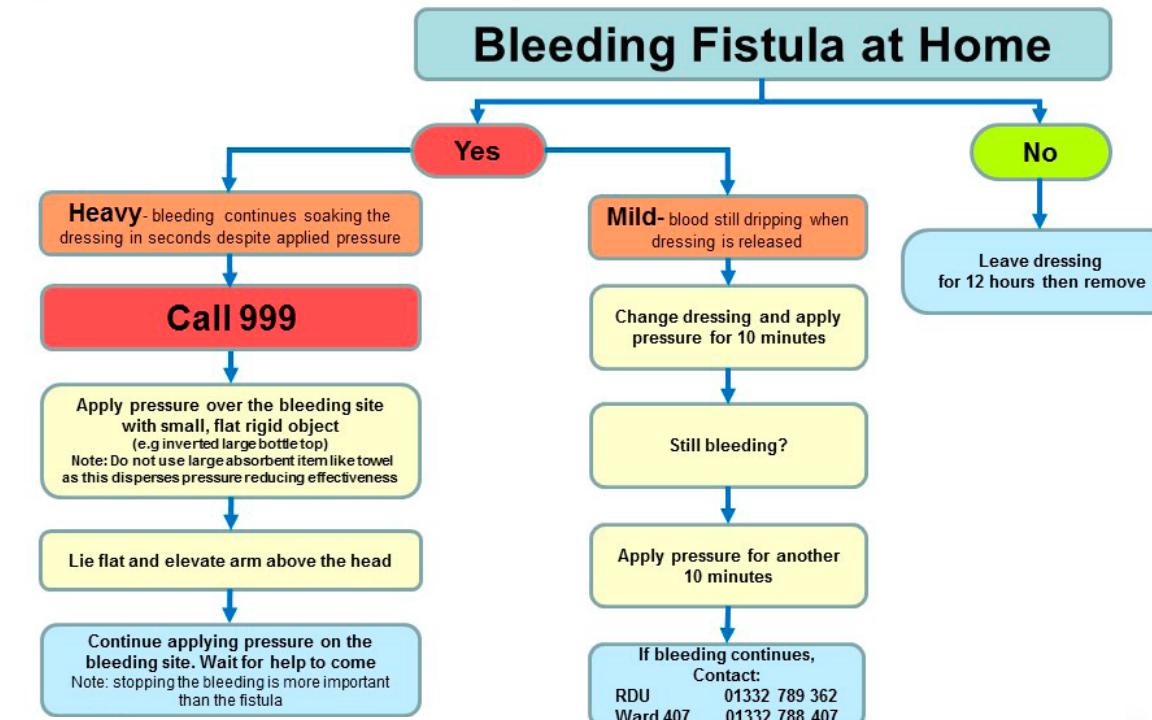
NxStage cycler skills checklist			
Skill	Trainer sign/intial date	Learner acknowledges understanding or demonstrates skill correctly. Learners intials/date	
Initiate Prime and Alarms Test			
Make Cartridge Connections / Prime Machine			
Program Treatment Settings			
Starting and Monitoring Treatment			
Treatment Procedures:			
Reducing the Ultrafiltration Rate Quickly			
Delivering a Fluid Bolus			
Checking for Filter Clotting			
Resetting the Access Pressure Pod			
End Treatment and Return Blood			
Coming off early			
Temporary Disconnection (after Rinseback and with Blood)			
Emergency/straight Disconnect			
Troubleshooting - cycler common alarms			
Equipment cleaning/ cartridge return			
	TRAINER	DATE	LEARNER
			DATE

Appendix 4 - Pureflow skills checklist

Pureflow skills checklist		
Skill	Trainer sign/intial date	Learner demonstrates skill correctly. Learners initials/date
Installing a New PAK /Priming a New PAK		
Installing the Control Unit Adapter (Drain line)		
Loading the SAK /Making the Batch of Dialysate		
Testing for Chloramines		
Using a Batch with the NxStage System One Cycler		
Draining the SAK/ Unloading the SAK		
Adjusting the Heater Setting		
Pausing and Stopping the Pureflow SL		
Removing the PAK		
Draining the SAK from User Maintenance		
Manually Draining the SAK		
Alarms and Troubleshooting		
Cleaning and Disinfecting the Pureflow SL		
Flush the Drain Line		
AT HOME		
Cleaning or Replacing the Air Filter		
Change the Sediment Filter/ Using the CPM-001 Test Kit		
Removing the Control Unit/ Changing the Dialysate SAK Type		
	TRAINER	DATE
	LEARNER	DATE

Appendix 5 - Managing a bleeding fistula at home

The Derby Shared Care in Haemodialysis Safety Guide

Derby Teaching Hospitals 

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Derby Shared Care Unit

Summary

HHD training programmes will vary depending on machine availability and choice, patient uptake, and staffing availability. Training curriculums and strategies to reduce risk are an important part of training.

Learning Activity

1. How do you assess suitability for a patient to undertake HHD training?
2. How do you implement a two week training schedule and what are the training tools required?
3. What ongoing follow-up is required for patients on HHD?

Acknowledgement

Many thanks to Dr. Richard Fluck, Christopher Swan and Janette Cabada for their contribution to the text.

Chapter 7

Living with Home Haemodialysis

Learning Outcomes

- Outline the positive attributes of home haemodialysis when compared to conventional centre-based haemodialysis
- Acknowledge the psychosocial impact of home haemodialysis for both the patient and care partner
- List the three principal intensive home haemodialysis regimens and discuss the relative attributes of each schedule



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Introduction

For individuals with end-stage renal disease (ESRD), a move from centre-based haemodialysis (CHD) to home haemodialysis (HHD) may be life transforming. In addition to promoting self-care, and ultimately independence, HHD is associated with several favorable clinical outcomes in terms of dialysis adequacy, survival, and quality of life^{1,22}. Nonetheless, the decision to dialyse at home is irrefutably the preserve of the patient, based on self-assessment of the advantages and disadvantages of this treatment modality. Such assessment is profoundly influenced by personal beliefs, values, and expectations, which are fundamental to final decision-making. Prior to a definitive decision, the global impact of HHD on the self and potential carers requires scrupulous consideration. The focus of this chapter is to provide an overview of living with HHD, and, in doing so, will address some of the perceived controversies. Issues pertaining to the psychological, sociological, and economic aspects of HHD will be considered, with a view to providing a positive foundation on which to base decision-making.

7.1 Frequency of dialysis

Conventional CHD comprises three dialysis sessions per week, for four hours per session. Whilst this regimen fulfils the function of renal replacement therapy, in that it sustains life, studies indicate that alternative schedules, such as intensive home haemodialysis (IHHD), have the potential to enhance patient outcomes.

IHHD is defined as home haemodialysis with an increase in dialysis frequency (days/week) and/or session length above a standard CHD schedule¹. In accordance with Tennankore et al. (2014)¹, there are three predominant IHHD regimens (Table 1).

Table 1: Principal IHHD regimens¹

Regimen	Dialysis frequency	Session length
Short-daily haemodialysis	5 or more sessions per week	2.5–3 hours
Long haemodialysis	3–4 times per week	≥ 5.5 hours
Long-frequent haemodialysis	5 or more sessions per week	≥ 5.5 hours

Short-daily haemodialysis is characterised by an increase in dialysis frequency and a decrease in session length. Research suggests that, when compared to standard CHD, short-daily haemodialysis may be associated with improved fluid volume management, decreased left ventricular mass index, and reduced inflammatory markers². Long and long-frequent haemodialysis are both typified by session lengths of five-and-a-half hours or more, with the latter, as the term denotes, also involving an increase in dialysis frequency. Both long and long-frequent haemodialysis may be provided overnight while a patient sleeps¹, and are related to improved pregnancy outcomes^{3,4,5}, tighter blood pressure control⁶, and increased survival^{7,26}.

A major advantage of IHHD in general is its flexibility. Patients are no longer subjected to the rigidity of CHD, as evident in the following patient testimonial from Peter, 47 years old, on short-daily haemodialysis for one year:

"I dialysed at the main hospital haemodialysis unit for the first two years after I developed kidney failure. Although the doctors and the nursing staff were great, I found that the schedule was really inflexible. My haemodialysis slots were Tuesdays, Thursdays, and Saturdays at 5.30pm. This meant that if I had a work commitment in the evenings (I work part-time in sales), or a parents' evening at my daughter's school, I had to try and change my dialysis slot, which sometimes was not possible."

Peter obviously values the flexibility that IHHD has afforded, which has, in his own words, enhanced his health-related quality of life:

"As long as I do the required [dialysis] hours, I can fit my dialysis around my life. No more inconvenient, rigid schedules which made me miss things that I wanted to do. I feel that finally, after two years, I have my life back."

Hence, for patients like Peter, IHHD is advantageous over CHD, in that it facilitates continuation in employment or other activities and maintains a semblance of normality.

7.2 Pregnancy

Chronic kidney disease (CKD) is associated with endocrine dysfunction, which has a negative impact on fertility. Decreased kidney function leads to dysregulation of the pituitary-hypothalamic axis¹, resulting in testosterone deficiency, impaired spermatogenesis, and erectile dysfunction in males⁸, and irregularities of the menstrual cycle and amenorrhea in females⁹.

Pregnancy in females with ESRD on dialysis has always been considered a challenge¹⁰. Irrefutably, dialysis is associated with low conception rates and poor pregnancy outcomes, including spontaneous abortion, premature delivery, and low gestational weight¹. Nonetheless, in recent years, pregnancy outcomes have improved¹⁰, which reflects the more intense management of patients with ESRD who become pregnant³.

In addition to the optimisation of nutritional status, and stringent maternal and fetal monitoring, IHHD is associated with favorable pregnancy outcomes. Barua et al. (2008)³ found that conversion from CHD to nocturnal HHD (7–8 hours, 5–7 nights per week) improved conception rate, and resulted in six live births (at a mature gestational age) in a cohort of five patients. More recently, Brahmbhatt et al. (2016)⁴ observed a successful pregnancy in a patient receiving short daily low-volume lactate-based dialysate HHD (10–26 hours of dialysis per week [depending on stage of gestation]) and KIHDEy cohort reported other cases in Europe which are pending publication.

7.3 The psychosocial aspects of Home Haemodialysis

ESRD and its management with dialysis therapy introduces significant psychosocial stressors and adaptive demands¹¹. Nevertheless, the impact of performing haemodialysis at home brings with it specific issues and challenges, which will now be addressed in greater detail.

According to Bennett et al.¹², HHD is far more than a medical treatment: it is, in fact, a lifestyle. Not only does HHD have profound implications for patients, it also influences the lives of those around.

7.3.1 Patient perspectives

Depression is commonly manifested by patients with ESRD¹³, with an estimated prevalence of 20% to 30%¹⁴. This is inevitably a consequence of multifarious factors, such as perceived helplessness, hopelessness, and loss of the self. However, studies denote that patients on HHD experience lower levels of depression when compared to their counterparts on CHD^{15,16}. Although the reasons for this difference are not yet fully understood, Suzuki et al. (2014)¹⁶ propose that the improved sleep quality and energy attributed to HHD may have the potential to reduce depressive symptoms. Irrespective of this difference, Bennett et al. (2015)¹² advocate that patients on HHD should be formally assessed for symptoms of depression. Such assessment should be undertaken on a periodic basis, in order to identify the subtle onset of symptoms and instigate treatment strategies accordingly.

Patients undergoing HHD may experience psychological issues not generally encountered in patients on CHD. One such issue is that of isolation. Tong et al. (2013)¹⁷ investigated the beliefs and expectations of patients and caregivers with respect to HHD. Whilst HHD was generally evaluated positively, isolation from social and peer support emerged as a negative consequence.

In response to this finding, the authors advocate a number of strategies to minimise isolation, including peer group support, Internet-based support, and individual (one-to-one) counselling. The value of peer support is apparent in the following patient testimonial from Anthony, 57 years old, on home haemodialysis for three years:

"The thing that I missed most when I started dialysing at home was the company of the other patients on the unit. I really missed the camaraderie and banter. When I spoke to my nurse about this, she asked if she could put me in touch with a local support group for people who dialysed at home. Although the idea did not appeal to me in the beginning, I agreed and made contact with them. It's been one of the best things that I have ever done. Me and the other patients meet regularly away from the hospital, and are able to support each other through the challenges of home dialysis. I don't feel isolated anymore."

Bennett et al. (2015)¹² also recommend the introduction of "buddy" systems to HHD programmes. Buddy systems enable established patients to be paired with patients new to HHD, as a means by which to provide support through the unique patient-to-patient experience.

7.3.2 Care partner perspectives

Patients should be encouraged to manage their treatment at home as they will feel more in control of their life, but a trained care partner is required. Care partners may be a spouse, partner, family member (e.g. parent or sibling), or friend, and have various levels of involvement in the patient's care. Some care partners may take full responsibility for all patient's care, performing all aspects of HHD. Other care partners may only have a limited involvement in the HHD treatment such as cannulating an arterio-venous fistula, and removing the needles post-dialysis, or assisting in case of issue.

Whatever the degree of participation, care partners are susceptible to a multitude of psychosocial stressors. These include loss of income, social isolation, fatigue, distress, depression, and poor physical

health¹⁸. Combined with an overwhelming sense of responsibility, this may predispose to care partner burnout, with withdrawal from this treatment modality being a potential consequence.

The HHD team are in a unique position to identify the early signs of isolation, poor partner communication, and partner-patient friction, and instigate strategies to minimise care partner burden¹². Such strategies encompass:

- Encouraging the maximum degree of patient independence for self-care
- Providing respite care to relieve care partners
- Developing peer support networks for home dialysis partners

Proactive supervision of patients and care partners is fundamental to the success of HHD programmes, as evident in the following two accounts.

Sylvia, 63 years old, care partner to her husband Michael for 18 months.

"When we [the care partner and her husband] first went home, I was terrified that I was going to do something wrong. I felt quite overwhelmed by the level of responsibility that I had. I'm not a medical person! However, with the help of our dialysis nurse, we soon got into a routine, and I became much more confident at setting up the machine and needling his [her husband's] fistula."

George, 72 years old, care partner to his wife Alice for one year.

"I was fine in the beginning, but after seven months of being a full-time carer and dialysis partner, I began to feel the strain. I started snapping at my wife, but felt really guilty afterwards. We were lucky because our nurse spotted this immediately, and suggested that we access the respite care service."

Carers visited three times every day, and a respite nurse came in to do the dialysis. I was able to take a two-week break, and visit my family in London. I came back feeling refreshed, and resumed my care partner role. I will definitely be doing it again in the future."

7.4 Travel and holidays

The ability to travel and organise holidays are important aspects of many patients' lives, and may strongly influence the choice of treatment modality. Whilst dialysis away from home is associated with an increased risk of infection, anaemia, and inflammatory response¹⁹. Assisting and encouraging HHD patients to enjoy a holiday may provide them with a sense of normality. Moreover, holidays may have a positive impact on health-related quality of life, and keep patients on HHD longer¹².

Kathryn, 53 years old, on home haemodialysis for two years.

"Home haemodialysis has transformed my life as a kidney patient. No more battling with the traffic and the weather to travel to the unit, and no more waiting for the nursing staff to put me on and take me off the machine. I can dialyse in the comfort of my home in the knowledge that help is only a phone call away."



Packing the car for travel



Dialysis away from home

Nurses caring for patients on HHD have the capacity to endorse travel dialysis. Stratagems to facilitate holiday dialysis may comprise:

- Providing patients with detailed information on holiday and required medical documentation.
- Assisting patients to identify suitable dialysis centres at their destinations of choice.
- Encouraging patients to plan their holidays well in advance.
- Ensuring that the required blood test results are readily available (e.g. up-to-date Hepatitis B, C and HIV status).

- Stipulating that patients have appropriate travel insurance.
- Verifying that patients have adequate supplies of medication with suitable storage facilities (e.g. cool bags for erythropoiesis stimulating agents).

7.5 Economical aspects of HHD

From a financial perspective, multiple studies have demonstrated in various countries that HHD is more cost effective than CHD, partly as a consequence of lower staffing and overhead costs as well as minimised transportation and infrastructure expenses^{20,23,24,25}. As population of dialysis patients is growing and the financial burden of ESRD on global health systems steadily increases²¹, health care providers are looking to increase patient uptake to HHD programmes. However, as some costs may transfer from the dialysis centre to the patient, this may be perceived by some patients as a barrier to HHD¹².

Costs in addition to those incurred through the installation of dialysis machines and water purification systems include electricity and water usage, storage of dialysis consumables, room spared to setup dialysis chair, and machine, treatment sets and equipment for health monitoring, such as scales and blood pressure machines²⁰. New portable machines require less utilities to operate at home than traditional machines and reverse osmosis water treatment. Two microcosting studies have shown a cost of € 112 per year for IHHD with these systems vs. € 544 with a traditional machine and € 1 138 for CHD^{24,25}. In some countries private, public or charity allowances or discounts may be available for patients' specific extra costs (e.g. allowance for care assistance, discount on energy bills, travel allocation, tax reduction...). Assistance with these costs through reimbursement schemes may function to minimise financial burden and sustain continued uptake to this modality.

Summary

This chapter has provided an overview of HHD, in terms of the lived experience for both patients and care partners. The flexible nature of HHD shifts away from the rigidity of CHD, and instills a sense of normality into patients' lives. Nonetheless, the continued support of patients and caregivers, through regular nursing contact and peer networks, is fundamental to the success and expansion of HHD as a viable modality.

Learning Activity

1. How might you recognise care partner burnout?
2. What interventions could you employ to address this issue?
3. How could you prevent this from happening in the future?

Acknowledgement

We would like to acknowledge the patients who kindly told us their stories about living with HHD.

Chapter 8

Ongoing Support

Learning Outcomes

- To understand the support required for home dialysis patients and carers
- To understand how to provide the support for patients and carers
- To understand staff and patient responsibilities that ensures adequate and safe governance



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Introduction

Support of patients at home is integral to the success and maintenance of a home programme¹. However, to make certain a home programme is successful we need to ensure that we not only give support to the patients but also their partners, as the impact of home therapies affects everyone who lives in the home¹. In this chapter we will take you through the support mechanisms that should be put into place to provide a successful support network for all involved².

8.1 Dialysis adequacy and well-being

8.1.1 Check ups and general support

All patients at home should be offered regular contact from a member of the home team which can be a home visit, attending a nurse led clinic or telephone and e-mail support. Frequency will depend on the patient and local policy but a minimum of monthly check-ups are common. Consultant clinics are usually attended quarterly³.

8.1.2 Visits to center

If there are robust processes in place to support patients at home the need for visits to the main unit should be negated. A quarterly review by the nephrologist will still be required although this can be done at a local satellite unit if possible therefore reducing travel time. A nurse led clinic can be beneficial as it offers additional support to those patients that need it and can incorporate vascular access, dietetics, anaemia management and dialysis adequacy reviews.

8.1.3 Blood sampling

Patients are usually responsible for taking their own monthly blood tests and sending to pathology via General Practitioner/satellite dialysis units or the home nurse. Some centers advise patients to

attend their local pathology center or clinic so that bloods can be sent in a timely fashion. Most units will follow the unit policy for in center HD patients, typically this will be:

- Pre dialysis renal biochemical profile and post urea (for adequacy calculation) monthly.
- Full blood count monthly.
- Hepatitis B, C and PTH 3-6 monthly.
- Iron studies as requested (often quarterly).
- Patients may also be responsible for taking their transplant bloods.

All blood results should be reviewed by a member of the home team or consultant and acted on accordingly. Prescription changes can then be made as needed.

8.2 Patient empowerment

8.2.1 Expert patient and carer

Patients on a home therapy tend to become an expert patient enabling them more control over their health and treatment options. Involved carers often have the same status. Becoming an expert patient is empowering for patients with chronic conditions and with this comes increased engagement and responsibilities⁴. The patient is responsible for adhering to the prescription and carrying out their therapy as they have been trained. Most units will sign them off as competent to do this. Patients should also report any problems or issues to the home team and in return the home team are responsible for providing feedback or support to solve the problem.

8.2.2 Safety

It is the responsibility of the training nurse to ensure that the patient is competent to perform the home therapy in a safe and supported environment. Training materials will be used to help guide and teach patients about their therapy. The trainer must ascertain the individuals level of knowledge and understanding and gaps in learning, e.g. due to dyslexia, and ensure that the appropriate support tools are available⁵. Learning checklists may be helpful. An informed and educated patient can actively participate in his or her own treatment, improves outcomes and helps to identify errors before they occur^{6,12}.

8.2.3 Community support

It is the joint responsibility of both the home team and the patients to make sure that community services have been informed that home dialysis will be carried out. Letters may need to be supplied to:

- Clinical waste services
- General Practitioners
- Utility providers (electricity/gas/water)

8.3 Procedural support

8.3.1 Machine troubleshooting

Basic trouble shooting will be taught during training. The level of support given by the company in troubleshooting will depend on the equipment chosen for the home therapy. Some centers have dedicated renal technicians who are available to support the patients at home. Some companies will provide a dedicated 24/7 helpline that the patients can access and if necessary a new machine can be sent to the patients' home within 24 hours. With Frequent Home

Haemodialysis (FHHD), in case of unsolved technical issue, it may be possible to rinse back the blood and repeat a session the next day, after the problem is solved.

8.3.2 On call

Some centers will offer a 24 hour on-call service which will offer advice and support for any clinical or technical problems that are encountered. Separate on call may be provided for nursing (clinical) and technical issues. It is important the patient is clear on who to contact, how and when. It is also important that they know that issues that are not dialysis related are managed by their usual community health professionals.

8.3.3 Managing machine alarms

All patients must be confident in the technical aspects of their care and how to rectify and act upon machine alarms competently. This should be incorporated into their initial training package. Simple trouble shooting guides, either paper or online will simplify the process, especially when a rare machine alarm occurs.

8.3.4. Remote monitoring and technology

The use of technology is becoming more popular with the use of specially designed Apps that can record dialysis sessions and problems so that center staff are able to access the data in real time and act upon it. Some centers use Skype to communicate with their patients and having access to an e-mail address is helpful⁹.

Patients in the UK are able to monitor their own bloods with the use of Renal Patient View to manage blood results and if your country has a similar system patients should be encouraged to access this.

8.4 Maintaining competency

8.4.1 Competencies

All patients should be provided with training materials, competency documentation and troubleshooting guides. All competencies should be signed by training nurse, patient and or care partner.

As part of the home visits competencies should be reassessed and retraining given where appropriate. Patients should be made aware that competencies will be reviewed regularly.

8.4.2 Re-training

On routine monthly visits the patients' hand-washing technique can be reassessed. The vascular access should also be checked for signs of infection.

If patients have been hospitalised for a long period of time and may have lost either physical or mental capacity, then retraining should be offered, either in their own homes or within the home training area. Additionally, a visit from a member of the home team should be arranged for the first treatment following discharge to ensure the patient is competent in their home environment and the machine is still functioning properly.

See training chapter for more information on competencies.

8.5 Vascular Access

8.5.1 Vascular access monitoring

Pre-emptive surveillance programme for vascular access should be carried out on a regular basis as this may increase patency rates and decrease the incidence of complications⁷. Vascular access monitoring for flows and potential stenosis should be part of any HD program but will vary by center. For patients on HHD, vascular access monitoring should be carried out as close to usual center policy as possible.

During training patients are taught to recognise and identify the signs of infection, failing access indicators, for example raised venous pressures, prolonged bleeding times and difficulty with cannulation. Trend monitoring of these signs and review of these at check-up are useful in detecting issues with vascular access.

If the equipment is available transonic readings can be performed as part of the monthly home visit. Transonic readings should then be routinely submitted to the appropriate access specialist for review.

8.5.2 Vascular access specialist

To preserve the function of all types of vascular access the involvement of the vascular team or a specialist fulfilling this role is useful. All patients should know who to contact if there are vascular access concerns. It is often the responsibility of the designated vascular access specialist to arrange fistula-grams and any interventional procedures that are required.

The vascular access specialist can also play a role in developing changes in policies and guidelines in relation to infection control and changes in procedures for vascular access.

8.6 Home Visits

8.6.1 Safety at home visits

Prior to commencing training an initial home visit should be performed to assess the suitability of the home. A risk assessment should be carried out at this time and annually thereafter to ensure the safety of the patient, and also for the staff who will be required to visit the patients home. See the risk chapter for more detail.

8.6.2 Frequency of home visits

It has been the experience of the author that following training, home visits should be scheduled weekly for a period of four weeks and then monthly. A risk assessment rating tool should be used to determine if the patient requires extra support, in the form of a phone consultation or additional visits. A risk assessment tool can be found in the risk chapter.

8.6.3 Process of home visits

Home visits should be structured and the use of a checklist is beneficial to make sure that no aspects of care are missed. The home environment should be assessed and a check of the machine carried out from an infection prevention perspective. It is equally important to involve care partners in the home visit to identify any carer burden that may be developing and assess if respite care is required. If signs of dyscopia are evident (such as a neglected house or personal hygiene) it is important to follow up these signs, or just ask the patient what is the biggest concern for you right now?

8.6.4. Home Visit Checklist

To maintain structure it is important to use a checklist for any home visit. A sample checklist for a pre-home dialysis visit is provided in Appendix 1. The home visit should be tailored to each patients' requirements, looking at their physical, social and psychological well-being.

Pre-home visit

It is ideal to conduct a home visit prior to first clinic appointment for those patients who have expressed an interest in HHD. Prior to visit contact patient to arrange convenient time for visit.

You will find the checklist of points to discuss at the pre-home visit on next page.

Document visit on paper or computer system.

Appendix 1 - Checklist for Pre-home dialysis visit

PATIENT NAME	HOSPITAL NUMBER	DATE
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	INFORMATION PACK GIVEN	PATIENT SIGN OFF	TRAINER SIGN OFF	COMMUNITY SIGN OFF
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GENERAL

Introduce yourself and outline the members of the HHD team				
Discuss patient and family expectations of HHD				
Discuss treatment options, short daily and nocturnal. Explain treatment is individualised and can be modified to suit them with the guidance of the team				
Discuss impact on life				
Explain about access and self cannulation				
Explain about machine				

ENVIRONMENTAL ASSESSMENT

Review proposed dialysis area				
Carry out risk assessment				
Discuss plumbing and water				
Water test (as per unit policy)				
Discuss storage and determine suitable option				
Discuss cleanliness and assess environment				
Confirm phone will be available in dialysis area				

ONGOING DIALYSIS ROUTINE

Explain about deliveries				
Discuss council and waste removal				
Discuss travel options				
Discuss monthly bloods				

TRAINING SCHEDULE

Discuss and note any restrictions/needs				
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8.6.5 Water Samples

Water and/or dialysate testing for bacteria, endotoxin and chemistry should be performed according to each individual center guidelines and policies for HHD generally. Adaptations may need to be made to in-center protocols but not compromise patient safety. However, the NxStage therapy handbook does not recommend the need for water testing when dialysis is being performed on a NxStage machine.

8.7 Quality of Life

8.7.1 Quality of life measurement tools

There are a number of quality of life tools available, it is useful to ask the patients to complete one at the beginning of the training and then annually. This helps to obtain general information about the patients physical and psychological well-being at the onset of transitioning home and the benefits that they may identify as a result of performing a home therapy⁷. It also allows identification of a patient who is deteriorating.

For example the Kidney Disease Quality of Life (KDQol) SF-36 questionnaires have become widely used¹⁰. It is apparent that dialysis patients have higher scores on the emotional components of these assessments than controls, indicating, perhaps not surprisingly, that emotional difficulties are present in dialysis patients¹³.

8.7.2 Psychological support

If patients are showing signs that they could be depressed or they voice experiencing psychological issues, referrals should be made to the appropriate agencies. Depending on local availability this could include counselling services, social workers and psychologists.

8.7.3 Support groups

Local support groups may be beneficial for both social and financial support. Charitable organizations may be able to offer grants to help with financial difficulties, the British Kidney Patients Association being one. If there are no organisations offering a support group local to your unit you could facilitate a patient and carer support group for your patients. It can be as simple as a coffee morning.

Many countries have specific carer support agencies who can offer support to carers.

8.7.4 Respite care

If possible there should be the option to offer respite for patients and carers if the need arises. This can be by offering dialysis at the training center, the local dialysis unit or maybe a nurse to provide some dialysis support at home if that service is available. Many countries have private nursing agencies that may be able to help if the patient can pay.

8.7.5 Financial support

Financial stress is common for families using dialysis and many people on dialysis have reduced family income¹¹. However, the flexibility of HHD should facilitate return to work, potentially reducing financial stress. HHD patients should be asked if they have any financial stress and it is important that the home dialysis team or the social worker are aware of benefits or reimbursements that local patients can claim and how to refer to these services.

8.8 Nutrition

8.8.1 Nutritional status

Malnutrition is a predictor of poor outcomes. There are many ways to measure nutritional status and details are provided in the nutrition Chapter 10. For example, the use of a Malnutrition Universal Screening Tool (M.U.S.T) is helpful in determining which patients require extra dietetic input. Utilising this tool also includes management guidelines which can be used to develop a care plan to ensure avoidance of malnutrition at home⁸.

Most units that offer the service encourage regular appointments with a dietitian to individualize diet and fluid intake. More general detail about nutrition is provided in the Chapter 10. Literature also showed that patients on FHHD or Nocturnal HD (NHD) may experience improved appetite and fewer dietary restrictions^{14,15,16,17,18,19,20}.

Summary

Good support at home can extend the time someone stays on HHD and their quality of life on HHD. Each unit must have a structured system to provide support with consideration to individual needs.

Learning Activity

1. How often should patients have contact with the home dialysis nursing team?
2. What are the patient's responsibilities?
3. How can you support a patient to achieve the best quality of life they can?
4. What assessments should occur on a home visit?
5. How can carers be assessed and supported?

Chapter 9

Safety and Risk Management

Learning Outcomes

- To understand the right framework that can improve HHD safety
- To understand the Quality Assurance loop
- To understand some useful risk assessment processes
- To be aware of potential HHD complications and related specific prevention
- To gain an understanding of Venous Needle Dislodgement



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Introduction

Home Haemodialysis today, is generally very safe. This may be because patients are highly selected prior to initiating home therapy and because they initially spend many weeks learning the technical aspect of self-managing the dialysis procedure¹.

There have also been advances in machine technology that have reduced technical complications and longer and more frequent treatments have reduced the risk of hypotension and cardiovascular instability².

Traditional HD patient safety focuses on the care provided by health care professionals. Safety in HHD also involves the patient partnership with their care partner and health care professionals. Patient safety during HHD must also include a proactive stance to minimize patient injury in the event that an error does occur³.

One big important part of safety is to communicate risks to patients. The conversation with patients aims to balance the benefits of HHD with the risks and increased burden of independent HHD. While the risk for HHD will never be zero, patients are reminded that HHD is very safe and that great care has been taken to design resources, policies, and procedures specifically aimed to minimize risks³.

9.1 Quality Assurance

It is relevant to apply a framework of quality assurance to a HHD program so that adverse events can be avoided. Overall event rates for technical complications in HHD are low in most cohorts, the potential for these events to be fatal emphasizes the need for quality assurance by event reporting, and quality improvement¹.

Experienced HHD programs have well established frameworks to minimize the impact for potentially serious adverse events and, if they do occur, to manage them effectively. New HHD programs will benefit from these lessons and must instill a culture of safety – without inciting alarm or undermining assurances – that HHD is a generally safe therapy. A blame free culture is necessary so that safety can be prioritized³.

The treatment environment, the home setting, should be designed with both safety and comfort in mind (See Chapter 4, Basics of HHD)³.

9.1.1 Education

Serious adverse events during HHD are rare and this is due mainly to the use of educating patients in safety procedures. Training is the key element in preventing serious adverse events³.

A successful HHD training program must focus on patient safety. Considerable time should be devoted to troubleshooting machine alarms and responding to emergency situations, including power outage and accidental disconnection¹. Strict routines to prevent serious hemorrhage from needle dislodgment and enable an aseptic cannulation technique are two big focus areas. In addition, vigilance in relation to machine maintenance procedures and attention to water quality are key skills that patients must acquire for optimal outcomes².

Communication plays a key role in the avoidance of error. Training staff should provide clear messages and communication around safe practices and clarify the responsibility between patients and care partners around procedures/protocols, while emphasizing the final objective for training: technically excellent dialysis performed in the home, without compromise to safety³.



However, it is important to be aware that a fear of catastrophic events is a patient-perceived barrier to adoption of HHD⁴. Education about event reporting is also an important undertaking. When an adverse event happens, appropriate identification of the cause and retraining should take place.

Education of care partner - The same attention is required for training and maintaining competence of care partners as it is for the patients themselves³.

9.1.2 Quality assurance loop

Central to any safety framework is an interactive quality assurance loop designed to prevent or minimize the occurrence or recurrence of an adverse event for an individual patient, and for other patients within the same program. The three steps in developing a quality assurance process:

- Identification of the key risks.
- Establishment of robust standard operating procedures for HHD.
- Documentation of process measures related to outcomes and safety. Process measures should include a key performance indicator for near misses. In addition, regular near miss conferences should be held among the clinical staff within the training unit. Where possible, lessons learned from near misses and serious adverse events should be incorporated into the HHD patient teaching curriculum. Existing patients within the program should be made aware of changes in policies and procedures during follow-up visits or by use of periodic communication from the program³.

The principles of a quality assurance loop include early management when risk is identified and interventions for future prevention when an adverse event or near miss occurs (Diagram 1).

Diagram 1. A Quality Assurance loop - patient safety quality assurance framework



9.1.3 Patient risk assessment

Patients using HHD have gone through extensive training and many units ask them to sign a liability form and/or provide certification of competency with HHD. To ensure that the patient maintains their skills and does not take unnecessary risks, an evaluation of their risk should be performed regularly. Below is a suggestion of how that form could be designed.

Basic risk assessment

Support for analysis of individual risk factors for Home Haemodialysis. Highlight which applies to the patient.

	SIGN OFF	COMMENTS
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HYDRATION

Blood pressure stable / unstable		
Tendency to large fluid retention between dialysis or dehydration (diarrhoea /constipation)		
Understanding of the correlation between ultrafiltration rate and blood pressure Yes / No		

PROBLEM SOLVING ABILITY

Systematic / unstructured		
Good / Poor troubleshooting and logical reasoning about ordinary alarms		

PHARMACEUTICALS ADMINISTRATION

Aware / not aware of dosing intervals		
Able to / not able to assess the correct dose at the right time		
Administration Technology – able to / not able to use safely and hygienically		

HYGIENE

Effective / not effective in washing routine and the management of dialysis access when preparing for the start and end of treatment		
Good vision / contamination risk with impaired vision		
Physical impairment / no physical impairment that impedes hygiene		

JUDGEMENT ABILITY

Risk-taker / not risk taker		
Ability to / no ability to report faults and irregularities from mistakes		
Will / won't ask questions when uncertain		

Example assessment of Mr. X:

- In the assessment of the above risk factors for Mr. X it emerges that he has poor understanding of UF velocity impact on blood pressure and that Mr. X's blood pressure is unstable (high risk of low blood pressure).
- Mr. X tends to large weight gains between dialysis which contributes to a high risk of dropped blood pressure during treatment (high risk of low blood pressure).
- Mr. X has a systematic ability to manage the resulting machine alarms and other error with logical reasoning (low risk of machine issues).
- Mr. X is thorough and uses a safe technique when managing pharmaceuticals, both intravenously and orally., and has a safe system for remembering the dosing interval (low risk of drug errors).
- Mr. X has a good understanding of basic hygiene and how infection can occur. Mr. X is thorough and manages the vascular access gently and hygienically. Mr. X has impaired vision and weakness of the hands (high risk of accidental contamination but low risk of infection)
- Mr. X has a good judgment and understanding of the importance of an open dialogue about treatment but has a tendency to smooth over mistakes that have occurred (medium risk of errors).



Patient relaxed during treatment session

It is important that strategies are put in place to minimize areas where Mr. X is at medium or high risk. These may be step-by-step procedures or more training.

9.1.4. Risk assessment matrix

Risk management programs and adverse events systems should utilise a grid that determines the risk of an event occurring against the potential outcomes. This is useful to determine the level of resourcing to be used to prevent a risk. If the risk of an event occurring is high and the outcomes catastrophic then that risk must be addressed. Also, if the risk of an event is high even if the consequences are generally low measure must be put into place i.e. hypotension on dialysis.

Diagram 2 shows an example of a risk matrix⁶.

Diagram 2. Risk assessment matrix

RISK MATRIX - ADAPTED FROM ISO 31000:2009

9.2 Risk management process

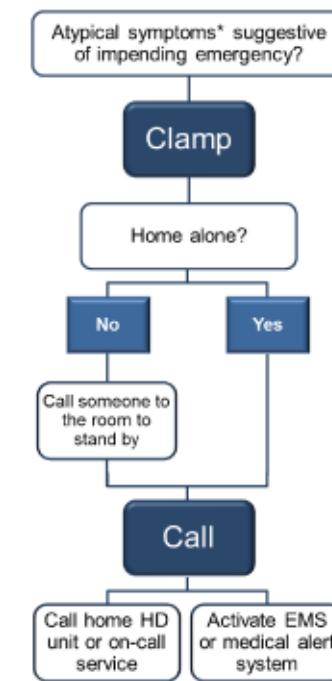
When or if an incident occurs, it is most important that the patient has been trained how to manage this circumstance. One example is a major issue that means dialysis cannot safely continue. The patient is taught to discontinue dialysis and can be provided with a visual reminder "algorithm". All patients can be given a preventive emergency kit with the algorithm and emergency equipment for disconnection directly positioned near their HHD machine.

9.2.1 Emergency algorithm

Significant (potentially life-threatening) adverse dialysis event i.e. major equipment failure, severe hypotension or vascular access bleed requires immediate action and the patient should have a quick reminder available.

A sample “Clamp and Call” emergency management algorithm is provided in Diagram 3.

Diagram 3. Patient algorithm for emergency



9.2.2 Contact accessibility – management of adverse events

Clinical and technical assistance for patients and their care partners should be easily accessible 24 hours/day. Patients should be clear about how to contact emergency medical services and know the location and contact details for their nearest hospital emergency department (See chapter on Basics in HHD)³.

9.2.3 Follow-up after a serious adverse event

Serious adverse events are those that involve hospitalisation or death. Every hospital should have policy and procedure for adverse events, and these apply to HHD programs. Below is an example of steps to consider after a serious adverse event³:

The root cause needs to be determined.

1. If consequences are severe consider if the machine and consumables should be impounded 'as-is' from the patient's home, without being stripped or cleaned, and stored for examination in the home haemodialysis training unit.
2. All documentation resulting from the treatment should be submitted. Copies should be made and the originals stored securely to prevent inadvertent loss of key paperwork.
3. The sequence of events and context of the event should be ascertained as clearly as possible from those present at the scene and through the liberal use of photography of scene and machine.
4. Depending on the nature of the event, the machine should be examined for any stored information (e.g., blood pressure measures, alarms, alarm overrides).

5. Depending on the nature of the event, haemodialysis technical staff (ideally from an external, independent home HD training unit) should ensure that the machine meets standard operational checks.
6. There should be immediate communication of the potential for the specific error in question to the HHD training staff and existing home haemodialysis patients, as necessary.
7. Depending on the nature and severity of the event, there might be an external review of the HHD training program and its resources by the quality improvement team of the parent hospital or another home haemodialysis training unit with more experience. The review may involve root cause analysis or failure mode and effects analysis (i.e., techniques for delineating error that are usually beyond the capabilities of clinical staff).
8. Depending on the nature of the event, there might be communication with the manufacturer of the dialysis machinery to ascertain whether the event has occurred previously, and whether a technical solution is available to prevent similar events.
9. Depending on the nature of the event, consideration might be given to publication in an open-source medical journal, as this is likely the best method of communicating widely with clinicians.
10. Depending on the nature of the event, consideration might be given to communication of the event on a reputable Web-based patient discussion forum, in conjunction with a patient advocacy group.
11. It is recommended that each unit keep a registry of serious adverse events, and communicate these events and near misses to other providers in their region to share experience.

9.2.4 Follow-up after a minor/moderate adverse event

Minor or moderate adverse events include significant hypotensive episodes that are managed without needing hospitalisation, needle dislodgement with minor blood loss and equipment failure.

All adverse events should be logged on a form or in a central database. This database should be reviewed regularly to track trends and patterns in frequency of events. The form should include;

- Details of the event including outcome.
- Potential cause (root cause analysis).
- Actions taken to prevent future occurrence.

Regular policy and procedure review should take place if an adverse event is increasing in frequency. Changes to practice must be communicated to all patients.

9.3 Potential risks/complications of Home Haemodialysis

Performing dialysis in a home setting can generate the same complications as in-centre haemodialysis (ICHD). In addition, there are complications that occur in the home setting because of the absence of professional assistance in machine and water maintenance and in trouble-shooting in the event of problems².

There should be strategies and policy and procedures in place to manage and prevent all of these risks and complications (potential adverse events).

Complications can be divided into three areas:

9.3.1 Technical safety

Home dialysis machine safety requirements do not differ from centre based machines and they must meet international and national safety standards in order to reduce risk. The safety mechanisms include:

- Pre-dialysis safety check.
- Recommended priming procedures (include ways to minimize infection risks).
- Dialysate conductivity alarms.
- Ultrafiltration monitoring.
- Blood flow pressure alarms.
- Blood leak alarms.
- Safety limits that can be pre-determined.
- Air detector mechanisms (to prevent air embolism).
- Disinfection procedures to ensure good water quality.
- Safety cutout mechanisms for electrical risks.

The patient must be taught to follow procedures that maintain this safety and also how to contact technical support if alarms occur related to machine functioning.

Regular servicing of machines and water treatment equipment as per manufacturers recommendations is critical. Servicing can be done at home or by machine swaps to the technical department.

Regular water testing is also a key part of technical safety. National guidelines must be adhered to.

Finally, electricity, water and patients do not mix well. There must be mechanisms in place to prevent accidental electrocution by either macro-shock or micro-shock. Residual current leakage detectors with a power cut out at 10mAmps is recommended, either directly linked to the dialysis electricity provision or the household. Every country will have its own guidelines on medical equipment power supply and each dialysis unit must develop relevant policies.

9.3.2 Medical complications

The medical complications can be similar or can arise from different causes compared to ICHD;

- With Frequent Home Haemodialysis (FHH), there is a higher risk of problem incidence on the vascular access such as infections and access rupture.
- Higher rates of specific non-access-related infections (e.g. pneumonia and sepsis) were observed in HHD patients compared to access-related infections⁵.
- Cardiovascular problems such as hypotensive crisis or overload of fluids can occur but are usually seen less frequently than in ICHD.

Summary of potential risks:

PATIENT NAME	HOSPITAL NUMBER	DATE
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	INFORMATION PACK GIVEN	PATIENT SIGN OFF	TRAINER SIGN OFF	COMMUNITY SIGN OFF
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TECHNICAL PROBLEMS

Machine malfunction				
Water contamination				
Air embolism				
Heparin overdose				
Rate of UF/CV instability				
Dialysate composition				

MEDICAL COMPLICATIONS

Cardiovascular				
Anaemia				
Blood Loss				
Bone/musculoskeletal				
Access				
Infections				
Nutritional status				
Side-effects of drugs				
Gastrointestinal				

PSYCHOSOCIAL

Anxiety and depression				
Maladaptation				
Family /carer fatigue				
Exacerbation of pre-existing psychiatric conditions				
Noncompliance				

- Malnutrition can occur due to "overdialysis" with loss of nutrients (including water-soluble vitamins)^{1,2}.
- Side-effects of drugs and gastrointestinal complications can occur^{1,2}.

Regular check-ups, blood tests and technique checks can reduce the risk of medical complications.

9.3.3 Psychosocial

All patients on dialysis have a high risk of psychosocial complications including; anxiety and depression, maladaptation, family /carer fatigue, exacerbation of pre-existing psychiatric conditions and non-compliance². Regular assessment and communication will detect if a patient has any of these psychosocial complications.

Patient and caregiver burden - FHHD necessarily increases the number of days per week that are accompanied by dialysis treatment. This may increase the burden of dialysis on patients and care partners and lead to reversion to ICHD. Choosing the dialysis routine in close collaboration with the patient is important to minimize this risk.

9.3.4 Life-threatening adverse events

All of the above categories have complications that are potentially life-threatening adverse events. The three most common causes of life-threatening adverse events in HHD are:

- Blood loss - bleeding from the circuit (due to poor connections between tubing and access or dialysers) or bleeding from access dislodgement.

- Human error - patients failed to follow prescribed procedures; e.g. ignoring machine alarms or neglecting to appropriately use wetness detectors (see VND section). This underscores the importance of human error and the observation that patients will find a multitude of unpredictable ways to modify their dialysis that contravene standard operating procedures specifically designed to reduce the risk of accidents.
- Lack of patient awareness - that even small seemingly insignificant change in a procedure may lead to serious consequences^{1,3}.

9.3.5 Venous Needle Dislodgement (VND)

Patients and carers should be aware of VND and the consequences⁷. Two main factors must be taken into consideration to avoid any risk of VND:

Step 1 - Factors affecting how well secured the needles are. These risk factors will make it more likely that a VND incident will occur, either due to a higher risk of tugging on the lines connected to the needles, or to a higher risk of the taping of the needles not being able to hold the needles in place.

- Patients prone to erratic or restless behavior, e.g. intradialytic hypotension, cramping.
- Patients with a history of VND.
- Patients with oozing around venous needle.
- Patients who have a high degree of sweating around the access site.



VND.edtna-erca.com

Step 2 - Factors affecting the ability of patient/carers for a proper monitoring. These risk factors will make it less likely that in the event of a VND event, the carer or the patient will observe the incident and either take suitable remedial action or raise the alarm for somebody else to act.

- Poor lighting in the room.
- Patients covering the access during dialysis.
- Dialyzing in isolation rooms.
- Self-care or minimal care support.
- Tendency to sleep during dialysis.
- Temperature/fever.
- Reduced sensitivity.

The patient who opts for HHD should have appropriate training on procedures for taping needles and bloodlines to be followed at every dialysis treatment:

- An area around the vascular access large enough for taping should be cleaned and air dried before cannulation.
- Bloodlines should be looped loosely to allow movement of the patient and to prevent bloodlines pulling on the needles.
- If it is necessary to reposition a needle, lower the blood flow to 150 ml/min and replace all taping.

- All patients should be assessed for level of risk of VND and, if appropriate, an alarm device intended for monitoring venous needle dislodgement used.
- Vascular access and needles should be visible at all times during haemodialysis.
- When the venous pressure alarm is activated, the vascular access and fixation of needles and bloodlines should always be inspected prior to resetting the alarm limits.
- Patients and carers should be aware that the venous pressure monitoring system of the dialysis machine will often fail to detect VND.
- Additional protection can be provided by devices intended to detect blood loss to the environment.

Staff and patients can also access the Venous Needle Dislodgement App developed by the EDTNA/ERCA⁸.

Summary

Safety and risk management is a critical part of any HHD program. This chapter has highlighted some of the key risks. It is important that all units follow hospital policy and procedure to develop risk management programs.

Learning Activity

1. What are the key elements in preventing serious adverse events?
2. What are the key steps in developing a quality assurance process?
3. What is VND?
4. What is the “Clamp and Call” algorithm about?
5. What are the three most common causes of life-threatening adverse events in HHD?

Chapter 10

Dietary Management in Home Haemodialysis

Learning Outcomes

- To understand the importance of nutrition in patients undergoing HHD
- To identify the nutritional needs of a patient with CKD stage 5
- To identify the differences between the nutritional needs of a patient undergoing more frequent HHD in comparison with the conventional haemodialysis
- To identify how common nutritional problems can be managed in patients undergoing HHD



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Introduction

Dietary intervention is of high importance for patients with Chronic Kidney Disease (CKD), both for disease outcome and for prevention or treatment of malnutrition (over- and under-nutrition), which is quite common in CKD patients. Malnutrition is a general term that indicates a state of nutrition in which a deficiency or excess (or imbalance) of energy, protein, and other nutrients causes measurable adverse effects on tissue/body form (body shape, size and composition) and function, and clinical outcome¹. The first and most important type is Protein-Energy Malnutrition (PEM) or Protein-Energy Wasting (PEW), which is defined as a lack in supply of sufficient energy or protein to meet the body's metabolic demands². The causes for malnutrition are:

- An inadequate food intake secondary to anorexia caused by uremia and altered taste sensation.
- Increased demands due to disease or acute illness.
- Impaired ability to prepare food.
- Unpalatable prescribed diets (low salt, fluid restriction, low potassium, low phosphorus).
- The dialysis procedure itself due to nutrient losses (protein peptides, water soluble vitamins, etc.).
- Hypermetabolism due to chronic inflammation.
- Endocrine disorders due to uremia^{3,4}.

Therefore, a detailed nutritional assessment is of paramount importance in providing optimal care to individuals with CKD of all disease stages. Classically, three major lines of inquiry, i.e. biochemical

measures, dietary intake, and body composition, are used to assess the protein-energy nutritional status.

Protein intake is of major importance, as protein losses occur during HD. Sufficient intake of high biological value proteins should be included. At the same time, phosphate control necessitates the correct use of phosphate binders. Moreover, sodium restriction is necessary to control thirst and fluid intake and facilitate better blood pressure control. Finally, potassium control is of major importance, achieved mainly by the restriction of potassium rich food choices, mainly from the food groups of fruits and vegetables.

The dietary management of patients undergoing Home Haemodialysis (HHD) depends on the type of haemodialysis the patients follow. For the patients following a three-times four hours per week HHD programme, dietary restrictions remain the same as conventional HD. By increasing the frequency and the duration of haemodialysis at home (Short Daily Haemodialysis (SDHD) or Nocturnal Haemodialysis (NHD)) we increase the quantity of waste products removed from the patients' body. Therefore, most of the restrictions existing for conventional HD can be reduced.

10.1 Biochemical control with more frequent haemodialysis

Due to the high prevalence of malnutrition after the initiation of HD a baseline measurement is useful for monitoring of nutritional status. At the beginning of HHD nutritional status may be already negatively influenced by the dietary restrictions of conventional HD or even by the adherence in restrictive dietary plans in earlier stages of CKD.

Unintentional weight loss, which reaches 5% of body weight in 3 months, is considered a significant weight loss and should be an alert for action in order to prevent malnutrition.

Moreover, limited appetite, low phosphorus, cholesterol, and albumin levels should be detected early and patients should be encouraged to increase their energy and protein intake.

According to available research data, after only a few weeks of the initiation of Frequent Home Haemodialysis (FHHd) appetite increases and food intake also improves, resulting in the increase of albumin levels and an improvement of the nutritional status⁵⁻⁸. Nonetheless nutritional status should be monitored closely in patients undergoing as early detection of alterations in nutritional status is important for the early treatment of malnutrition according to Table 10.1.

Guidelines can vary a little and each unit will choose which guidelines to follow. According to KDOQI Guidelines for CKD Care⁹ serum albumin <4 g/dl, pre-albumin <30mg/dl, pre-dialysis creatinine <10 mg/dl and cholesterol <150 mg/dl are clinically useful markers indicating high possibility of protein-energy under-nutrition in CKD patients, whereas the International Society of Renal Nutrition and Metabolism recently included serum albumin <3.8 g/dl as one of three biochemical diagnostic criteria for protein-energy wasting (among transthyretin and cholesterol levels)¹⁰. Moreover, according to EBP Guideline on Nutrition¹¹ BMI should be >23 kg/m² in maintenance haemodialysis patients. These parameters should be monitored regularly, i.e. on a monthly basis, to assess the nutritional outcomes and needs of the patients.

10.2 Nutritional intake – less build up results in more dietary freedom

Due to the increased frequency of dialysis, FHHd can provide a more "physiological" function for the patients, allowing them to excrete waste products of metabolism more efficiently. Consequently, the restrictions applied to patients undergoing conventional HD, mainly for the control of electrolytes, i.e. phosphate and potassium, and the

Table 10.1: Suggested strategies to monitor nutritional status and guide therapy in advanced CKD¹².

Simple (monthly) assessment	Findings	Possible interventions
Body weight / Ideal Body Weight Serum albumin Serum creatinine	Continuous decline or <85% IBW <4.0 g/dl Relative low pre-dialysis values	Suspect PEW and perform detailed nutritional assessment Consider preventive measures
Detailed early assessment	Findings	Possible interventions (simple)
Serum prealbumin Serum transferrin Lean body mass and/or fat mass SGA	<30mg/dl and/or <200mg/dl and/or Unexpected decrease Worsening	Dietary counseling: Protein intake 1.2g/kg/d, energy intake 30-35 Kcal/day Increase dialysis dose to Kt/V>1.4 Use biocompatible membranes Upper GI motility enhancer
Repeat detailed assessment (2-3 months from previous)	Findings	Possible interventions (more complex)
Serum prealbumin Serum transferrin Lean body mass and/or fat mass C-reactive protein	<30mg/dl and/or <200mg/dl and/or Unexpected decrease >10 mg/l	Nutritional support (Oral nutritional supplements, enteral nutrition, IDPN if needed) Anabolic factors Appetite stimulants (experimental) Anti-inflammatory (experimental)

restriction on fluid control may be reduced, according to the patient's serum blood results. Recently FHHd patients in KIHDEy cohort showed stable mineral & bone disorders parameters with fewer dietary restrictions, more patients were in the phosphate target range and had significant improvement in bicarbonate levels from baseline²⁴.

Nutritional intake can be measured in calories for energy or in grammes for proteins, usually expressed per kilogramme of body weight per day (kcal/kg/day or g/kg/day).

10.2.1 Energy intake

Sufficient energy intake is essential in order to achieve a positive nitrogen balance. An energy intake of 35 kcal/kg/day is associated with better nitrogen balance and is recommended in stable CKD patients in the range of ideal body weight $\pm 10\%$ ¹³. The recommended energy intake in a clinically stable chronic HD patient is 30–40 kcal/kg/day, adjusted to age, gender and to the best estimate of physical activity level. For patients >60 years old or obese, energy intake prescription should not exceed 30 kcal/kg/day^{9, 11, 14}.

Overweight or undernourished patients may need adjustments of energy supply, to ensure better coverage of their needs. Energy intake for patients > 60 years old should be 30 kcal/kg/day due to their reduced energy needs if they have a more sedentary life due to ageing⁹. However, regular physical activity should be encouraged as it helps in maintaining the functionality of muscles and improves endurance and cardiovascular health.

10.2.2. Protein intake

Protein needs in patients on maintenance HD exceed the needs of normal healthy people as the dialysis treatment itself induces significant nutrient losses, particularly amino acids, oligopeptides, water soluble vitamins and trace elements. Moreover the dialysis procedure is a catabolic one, inducing catabolic stress and release of proinflammatory cytokines, which raise the protein needs¹⁵.

According to the available guidelines;

- The recommended protein intake is 1.0 -1.5 g/kg/day in clinically stable chronic haemodialysis patients and nPNA at least 1.0 g/ body weight/day.

- The optimum protein intake for a maintenance dialysis patient who is acutely ill is at least 1.2 to 1.3 g/kg/day^{4, 11}.
- More specifically, for patients on HHD, protein requirements are of great importance as the increased frequency of dialysis increases the protein losses.

Therefore, the higher level of recommendations should be applied for patients undergoing FHHD. Generally, it has been reported that protein intake improves after the increase of the frequency of dialysis, with a subsequent increase of phosphate intake, without altering phosphate blood levels, even with potential reduction in phosphate binders use¹⁶. Nonetheless, protein intake is of major importance and should be monitored closely to ensure sufficient coverage of the patients' needs.

Protein intake should be of high biological value, i.e. from animal sources, e.g. poultry, meat, egg whites, soya, cream cheese, etc. On FHHD animal protein high in phosphorus (small fish, dairy products, cheese, meat close to the bones) can usually be more liberally consumed, compared to conventional HD, as the waste products of protein metabolism are excreted more efficiently. In case of poor phosphate control, the consumption of high phosphate protein food items should be limited, and protein should be taken only in the meals when the patient is taking phosphate binders, in order to directly limit phosphorus absorption from the gut.

If alteration in taste of animal protein is reported (metallic taste), alternative sources of high biological value protein should be given. Fortification of food with protein supplements could be a way to provide increased protein.

10.2.3. Fat intake

CKD raises the risk of developing cardiovascular disease¹⁷, due to inflammation, disturbed calcium to phosphorus ratio and pre-existing risk factors such as diabetes mellitus. Therefore, all the nutrition related cardiovascular risk factors should be taken into account^{18,19}. In HD patients, emphasis should be given to the quality of their fat intake;

- Saturated fat should be limited to <10% of total energy intake.
- Cholesterol <250 mg/day.
- Monounsaturated should be 10-20% of Total Energy Intake (TEE).
- Polyunsaturated fat should provide around 10% of TEE.

Therefore, sources of saturated fat, such as full fat dairy, cheese, fatty meat, poultry with skin, fried food, butter and full fat cream should be avoided, while olive oil intake should be one of the main sources of fat. Emphasis should be given in ω -3 fatty acid intake, which could be a part of the dietary plan in patients undergoing HHD with increased frequency or duration, due to better phosphate levels control. Fatty fish intake, such as cod or salmon could be included at least once a week, with the correct use of phosphate binders in patients with poor phosphate control.

10.2.4 Vitamins and trace elements

Dialysis patients are prone to developing vitamin deficiencies due to abnormal renal metabolism, inadequate dietary intake and compliance to strict dietary restrictions, loss of gastrointestinal absorption and dialysis losses. Losses depend on the type of dialysis and its duration, since high-flux and high-efficiency dialysis attenuates losses in water soluble vitamins. Vitamin deficiencies develop slowly but they can affect patients' quality of life. Each patient's vitamin

status should be evaluated on an individual basis, according to the age, gender, dietary intake, dialysis losses, residual renal function and type of dialysis before he is subscribed to any supplemental vitamin therapy¹¹. Blood vitamin levels, alongside with early detection of symptoms of vitamin deficiencies is important to assure the individualization of treatment.

10.2.4.1 Water soluble vitamins

During haemodialysis, a significant amount of vitamins are lost in the dialysate. In conventional HD, due to potassium dietary restrictions in vegetables and fruits, patients are particularly prone to deficiencies in folic acid and vitamin C. Folic acid intake (1mg-5mg) is needed for the prevention of hyperhomocysteinaemia. Vitamin C should also be taken as a supplement (75-90 mg) although this is most important in those restricting their vegetables and fruits¹¹.

Thiamin deficiency is common in haemodialysis patients as it is readily removed by HD and at the same time dietary intake is often inadequate. Dietary sources of thiamin include seeds, legumes and pork. Beriberi is the most known condition caused by thiamin deficiency, while other manifestations include neurological symptoms (Wernicke encephalitis). Currently all the vitamin supplements for renal patients include thiamin¹¹.

Rivoflavin deficiency is not common, even though it is well cleared during a haemodialysis session, as its main sources include lean meat, eggs, food cereals and bread, food items included in end stage CKD patients' diet. B6 needs can be elevated by the accelerated erythropoiesis by erythropoietin use. B12 is necessary for the prevention of pernicious anaemia and for an optimal folic acid metabolism. It is found in sufficient amounts in meat, milk and egg yolk, while supplemental use is safe in renal patients intake is usually close to DRI¹¹.

The recommendations for vitamin intake and supplements for haemodialysis patients are summarized in Table 10.2. There are no specific recommendations for patients undergoing FHHD and further research is needed in order to identify the differences in vitamin needs for HD patients in different types and frequency of treatment.

10.2.4.2 Fat soluble vitamins

Fat soluble vitamins should be treated with caution, as they are stored in the body and the toxicity risk is higher. Vitamin A deficiencies are rare in renal patients as it is not removed by haemodialysis. Therefore, the danger of toxicity is higher and supplemental use is not recommended. Daily needs can be covered by dietary sources which include dairy products, fish oil and carrots. Concerning vitamin K, there is no evidence of deficiencies in CKD patients receiving sufficient dietary intake¹¹.

10.2.5 Electrolytes and minerals

10.2.5.1. Sodium and fluids

Sodium restriction is indicated for all stages of CKD as it is essential for the control of the extracellular volume and for better control of arterial blood pressure. In HD, sodium control is even more important, as it facilitates compliance with fluid restrictions and prevents inter-dialytic weight gain in anuric and oliguric patients, given that it reduces thirst. Salt substitutes containing potassium chloride should be avoided in HD patients. Salt can be substituted by the use of herbs and spices. More specifically, sodium should be restricted to no more than 80-100 mmol (2000-3000 mg) or 5-6 g (75 mg/kg/day).

Fluid intake, is generally more liberal in patients using FHHD at home because more fluids are removed over the week.

Table 10.2. Recommended dietary intake and supplements of vitamins¹¹

Vitamin	Daily recommendations
Water soluble vitamins	
Thiamin (B1)	1.1-1.2 supplement
Riboflavin (B2)	1.1 -1.3 supplement
Niacin (B3)	14-16mg supplement
Pantothenic Acid (B5)	5 mg supplement
Pyridoxine (B6)	10 mg supplement
Biotin (B8)	30 µg supplement
Folic Acid (B9)	1-5 mg supplement
Cobalamine (B12)	2.4 mg supplement
Vitamin C	75-90 mg supplement
Fat Soluble vitamins	
Vitamin A	700 – 900 µg intake – no supplement
Vitamin K	90-120 µg - no supplement
Vitamin E	400 – 800 IU supplement for secondary CVD prevention and cramps

Therefore, many patients can exceed the limit of 500-1000 ml in addition to daily urine output. No strict recommendations exist for fluid intake for patients on FHHD, but the aim is to control interdialytic weight gain¹¹.

In cases of patients who find it difficult to control their fluid intake all foods that are liquid at room temperature (18-20°) should be counted as fluid, except oils. Thirst control can be facilitated by reduction in salt intake, the consumption of chilled liquids, consumption of ice cubes instead of water, addition of lemon in water and the use of chewing gums to hydrate mouth^{20, 21}.

10.2.5.2. Potassium

In healthy subjects, 90% of dietary potassium is excreted by the kidneys. For those on dialysis limiting dietary intake and adequate dialysis can achieve acceptable potassium levels. Potassium exists in almost every food item so severe restrictions should be limited, in order to ensure a balance in patients' diet and quality of life.

In the majority of patients undergoing increased frequency HHD, potassium levels are maintained more easily within normal levels. Therefore, the diet can be more liberal, in terms of fruit and vegetable consumption. Fiber intake is also easier to maintain within the recommended amounts, facilitating the prevention of constipation. In CKD patients, potassium intestinal excretion is increased as a compensatory mechanism and the prevention of constipation also contributes to the prevention of hyperkalemia.

Hyperkalemia causes nausea, weakness, numbness or tingling, slow pulse, irregular heartbeat, and a high risk of heart failure or sudden death. Following any of these signs serum potassium levels should be measured and documented before HD. In patients with pre dialysis potassium >6 mmol/l, daily potassium intake should not exceed 50-70 mmol (1950-2730 mg) or 1 mmol/kg/day¹¹. If potassium levels are repeatedly elevated, patients should be advised to reduce their potassium intake, by avoiding fruits and vegetables rich in potassium (bananas, oranges, potatoes, tomatoes, etc.) and choosing lower potassium ones (apples, pears, lettuce, carrots, boiled vegetables, peeled fruits or boiled and chopped).

Table 10.3. Steps to Calculate the initial binder prescription²².

Step	Example	Example
Phosphate intake	Total dietary P intake	1000 per day or 7000/week
Amount absorbed (50-70% of mixed diet in non-renal) (53% renal vs 77% in non-renal)	Dietary intake multiplied by 50-60% absorbed	600 per day or 4200/week
Average HD/PD clearance HD = 800 per treatment PD=300-315 per day	Amount abs – dialysis clearance = remaining P to be bound by phosphate binder	HD: 4200-2400 = 1800 mg P/wk or 257 mg/day PD: 4200-2205 = 1995 mg P/wk or 285 mg/day
Divided by estimated binding power or the binder of choice	Remaining P/binding power	257/39 (approx. P bound by 1g CaCO ₃) = 6.5 g CaCO ₃ 257/45 (approx. P bound by 1g calcium acetate)= 5.7 g 257/15-30 (approx. P bound by 1 Al(OH) ₃ tablet = 12-17 tablets 257/64 (approx. P bound or 800mg sevelamer HCl) = 4 tablets 257/32 (approx. P bound per 400mg sevelamer HCl) = 8 tablets Note: Calculations for OD would use 285 instead of 257

Note: The above table estimates the initial prescription based on average phosphorus absorption, average dialysis clearance and the approximate binding potential for the binder of choice. The dose should be monitored and adjusted based on response of the individual patient.

10.2.5.3. Phosphate

Hyperphosphataemia is related to hyperparathyroidism, calcification and mineral bone diseases. Therefore, serum phosphate should be closely monitored. In patients undergoing HD, their high needs for protein can lead to phosphorus accumulation, as each HD session only removes 500-700 mg of phosphate. Protein foods provide 12-16 mg of phosphate/g, while dairy products have the highest content¹¹. Selection of protein foods with the lowest content of phosphorus can help in achieving the phosphate goals, without affecting protein intake.

As frequency of HD is increased, phosphate levels can be maintained within the normal levels more easily, and therefore the patients are allowed to follow a more liberal dietary plan. In patients who do not achieve their phosphate levels goals, the appropriate use of phosphate binders - type, dose and time – will increase phosphorus excretion. In Table 10.3 the steps to calculate the initial binder prescription are described for conventional HD and in table 10.4 the main phosphate binding compounds are listed. It is important that phosphate control should not compromise protein intake. According to the existing nutritional guidelines, phosphate intake of 800-1000 mg or <17mg/kg/day is recommended^{4, 11}.

Nocturnal Home Haemodialysis (NHHD) removes about 5638 mg of phosphorus per week, attributed to the increased frequency and long duration of dialysis. This fact liberates the diet of the patients who can control their phosphate levels with minimal or no use of phosphate binders. Short Daily Home Haemodialysis (SDHD) removes somewhat more phosphate than Conventional HD; however, the improved appetite seen in SDHD patients and consequent increased protein and phosphorus intake usually leave patients in a net positive phosphate balance²³. In case of hyperphosphatemia the use of phosphate binders should be considered. In Table 10.4 the main phosphate binding compounds are presented.

Table 10.4. Phosphate binding compounds²².

Compound	Common product names	Estimate of % Ca ²⁺ absorbed	P (mg) bound per mg Ca ²⁺ absorbed	Estimate of potential binding power	Potential Side effects
Calcium Carbonate	TUMS Oscal Calcichew Caltrate Calci-Mix Titralac Chooz Gum	Approximately 20-30% is absorbed	Approximately 1mg P bound per 8mg Calcium absorbed	Approximately 39mg P bound per 1 g Calcium carbonate	Hypercalcaemia, extraskeletal calcification, GI side effects, constipation
Calcium Acetate	PhosLo	With meals 21±1% Between meals 40±4%	Approximately 1.04 mg P bound per 2.3mg Ca abs. 1 mg P bound per 2.9mg Ca absorbed	Approximately 45mg P bound per 1 g Calcium Acetate	Hypercalcaemia, extraskeletal calcification, GI side effects
Calcium Citrate	Citracal	22%	N/A	N/A	Increases aluminium adsorption
Magnesium Carbonate CaCO ₃	MagneBind 200/300	It contains 450/300mg calcium acetate	Approximately 1mg P bound per 2.3mg Ca abs	N/A	Hypermagnesemia
Aluminum Hydroxate	AllernaGEL Alucap Alutab Amphojel Dialume	None	N/A	Liquid: Mean binding 22.3mg P per 5ml Tablet/capsule: mean binding 15.3 mg P per capsule	Constipation/faecal impaction, bone mineral defects, aluminium toxicity, chalky taste, GI distress
Aluminium Carbonate	Basajel	None	N/A	Same as above	Same as above
Sevelamer HCL	Renagel	None	N/A	Unknown	GI side effects, cost

CaCO₃ = 43mg P bound per 1 g elemental Ca

PhosLo = 106 mg P bound per 1 g elemental Ca

Sevelamer = 80mg P bound per 1 g Sevelamer – animal data only

Summary

Nutrition is very important for people on FHHD although more dialysis means less restrictions. Potassium, phosphate, fluid, protein and vitamins are all important elements. Every patient should receive tailor made information based on their daily needs, food preferences and blood results.

Learning Activity

1. What are the main causes of malnutrition in CKD patients?
2. Which biological markers should be monitored for the early detection of malnutrition during haemodialysis?
3. What are the energy needs of patients undergoing HD?
4. What are the protein needs for the patients undergoing frequent HHD?
5. Describe 5 differences to the diet of a patient when they move from conventional to frequent Home Haemodialysis.

Chapter 11

Environmental Home Haemodialysis

Learning Outcomes

- To understand how much dialysis can contributes to the carbon footprint worldwide
- To identify the key dialysis causes of the carbon footprint
- To understand the differences in production of carbon between standard haemodialysis and HHD
- To identify opportunities to reduce the carbon footprint



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Introduction

In this chapter we will address the green side of home dialysis versus traditional haemodialysis in a hospital.

Green dialysis is important because we know that patients diagnosed with end-stage kidney disease are increasing. Prolonged life expectancy and increasing incidence related to diabetes contribute to this increase. It is predicted that in 2020 there will be 3,500,000 patients worldwide in renal replacement therapy¹.

To accompany this rapid advance in medicine, its diagnostics and its treatments, there is high use of energy, water, and raw materials such as plastics, which also leads to a higher production of waste.

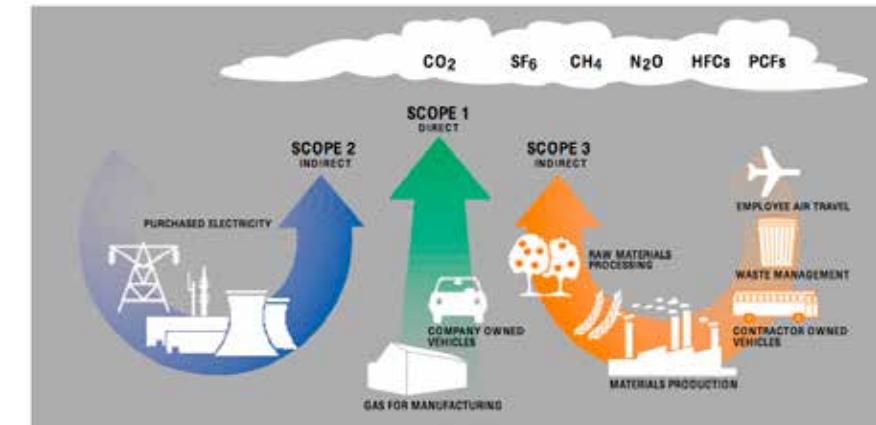
This chapter has the purpose of raising awareness to avoid sparing resources. It discusses resources such as water; electricity; logistics; and waste. Evidence will support this information to facilitate informed decision making regarding green dialysis.

This chapter is just a brief overview and a website entitled Green Dialysis provides more details on this topic². Some countries also have organisations targeting green dialysis. Look for your country on social medias and the internet to see if there are any groups available in your area.

11.1 Basics of environmental HHD

11.1.1 Kyoto Protocol

The Kyoto Protocol on Climate Change is an international agreement that aims to reduce the emissions of six greenhouse gases that cause global warming: carbon dioxide (CO₂), methane gas (CH₄), nitrous oxide (N₂O), and 3 fluorinated industrial gases: perfluorocarbon hydrofluorocarbons (HFCs) and sulfur hexafluoride (SF)⁶.



Source: GHG Protocol

This translates into the Carbon Footprint; "The measure of the impact our activities have on the environment, especially on climate change", that is, the quantification of direct and indirect emissions of greenhouse gases, such as those described above. These are released to the atmosphere as a consequence of the activity of a company, the life cycle of a product, the organization of an event or the activity of a person.

The purpose of this protocol is to contribute to a healthier environment, and support the ability of countries to control the carbon footprint, avoiding its increase with basic measures in our day to day activity.

11.1.2 Measuring carbon footprint

For green dialysis it is important to understand the carbon footprint of each type of haemodialysis:



NxStage System. Home Haemodialysis machine.

- Haemodialysis in a hospital;
- Standard Home Haemodialysis
- Home Haemodialysis with NxStage System³

A key UK report included: energy used, dislocations of both, professionals and patients, medical equipment, water, paper, laundry, construction (facilities, maintenance), sanitary structure, waste management (hospital Incineration; home waste landfill), vascular access surgery, and outpatient visits to determine the carbon footprint of dialysis patients⁹.

The total carbon footprints were:

- For Haemodialysis in a hospital: 3818 kg of CO₂ Eq per patient, per year.
- For standard home haemodialysis: 4346 kg CO₂ Eq per patient, per year.
- For Home Haemodialysis with NxStage system: 1844 kg of CO₂ Eq per patient, per year.

The study concluded that most of the emissions are generated in medical equipment 37%, energy 21% and transport of patients 20%.

The low rate with NxStage system is due to several points where CO₂ emissions, can be saved such as: transportation of nurses and the patient, water, laundry, construction of facilities, sanitary structure and outpatient visits to the hospital.

It is proven that increasing the frequency of dialysis will improve clinical outcomes (see chapter 3). However increased HD frequency is directly related to an increase of CO₂ emissions into the atmosphere.

The carbon footprint of dialysis is influenced more by the frequency of treatments than by their duration.

The incorporation of emerging technologies, such as NxStage equipment, into HD programs might offer a possible solution to this problem. It is also clear that the carbon footprints of other new technologies should be evaluated.

11.2 Water

11.2.1 Water purification process

A patient who is on dialysis three times a week for four hours, has direct blood contact with 360 liters of water. With regard to water consumption, it should be also considered that a water treatment may run continuously even when dialysis machines are idle and production capacity is commonly oversized to ensure higher flows during disinfection of dialysis machines. If this water is not treated and purified morbidity and mortality would be high. Unfortunately water treatment spends a lot of energy to transform drinking water into water meeting international standards for dialysis. There are several general recommendations on how water treatment should reach the quality of ultrapure water once it has been treated: a double stage of osmosis, or a stage with a second element composed of one or a combination of the following: A) UV lamp plus ultrafilter; B) ultrafilter; C) electrode ionizer⁴. European norms describe how to build, certify and maintain the performance of a water treatment for HD as well as the quality required for HD fluids in "Guidance for the preparation and quality management of fluids for haemodialysis and related therapies", ISO 23500:2014 and in "Quality of dialysis fluid for haemodialysis and related therapies", ISO 11663:2014.



Home Haemodialysis machine NxStage System One with a PureFlow SL System⁸

Nevertheless these norms do not consider the green aspect of dialysis fluids production. The ratio of water needed to produce dialysate water in a RO system can be 10:1 (i.e. for each liter of water produced by the RO system, 10 liters of water are required, of which 9 liters are discarded through the drain as waste-water). This entails a significant need for water supply, with the corresponding high cost for water.

The NxStage machine only requires about 30 liters of pure water for each session. Obviously the amount of water required is dependent on session prescription. NxStage either uses dialysate bags ready to use, or can prepare a batch of dialysate with PureFlowSL. It prepares up to 60 liters of ultra-pure dialysate which is fully utilized. With a modern deionisation technology, incoming water is converted into ultrapure product water on a 1:1 basis, so that one liter of product water is prepared with one liter of tap water. The PureFlow SL system prepares batches of 40, 50 or 60 liters of dialysate which, according to the patient's prescription, can be used in up to three treatments.

PureFlow SL minimizes the workload related to the supply, conservation, management and disposal of prepackaged bags of dialysate fluid. Each bag of concentrate (SAK) replaces eight to twelve bags of five liters of premixed dialysate, depending on the patient's prescription⁹.

The value of water consumed for one week in PureFlow SL treatments is, on average, the cost of doing laundry in a normal top-loading washing machine.

Infrastructure wise PureFlow SL requires simple installation compared to standard HD machines. PureFlow SL only requires a simple connection to the water outlet, so it is not necessary to make plumbing modifications to install the system in the home. The connection of the water is made through a simple adapter to the tap, to the socket of the washing machine or to the socket under the sink.

PureFlow SL works with standard domestic electricity. It uses a standard power cord, so it is not necessary for an electrician to install the PureFlow SL system⁸.

11.2.2 Standards for water purification

Europe has standard measures for water quality and design-validation of a water treatment⁴ (Appendix 1). For further details, please read "Guidance for the preparation and quality management of fluids for haemodialysis and related therapies", ISO 23500:2014 and "Quality of dialysis fluid for haemodialysis and related therapies", ISO 11663:2014.

Design of a water treatment plant for haemodialysis: includes different stages that can be defined as: 1. Preparation, 2. Pre-treatment, 3. Treatment and 4. Distribution.

1. The preparation of water consists of removing most of the particles in suspension. This step is usually achieved by filters eliminating particles by sedimentation. To achieve a higher performance, filters in series will be placed, from higher to lower porosity.
2. Pre-treatment should achieve the highest possible elimination of particles, the disappearance of chloramines and other organic matter and the decrease of the amount of cations. This process uses filters such as activated carbon.
3. Treatment: The fundamental element in most water treatments is reverse osmosis (RO), and currently the quality standard is to have two stages of osmosis in series.
4. Distribution of treated water is propelled by a pressure pump, through the distribution circuit, to the haemodialysis machines⁵.

11.2.3 Strategies for recycling water

Other ways to reduce water usage in haemodialysis include recycling of waste RO water (not relevant to the NxStage machine) or the use of waste RO for other functions such as garden watering or washing.

11.3 Electricity

11.3.1 Electricity consumption

In-centre treatment of patients with haemodialysis leaves a large environmental footprint, using high levels of power (approximately 1,000 kilowatt per hours (kWh) which is partly used creating the 80,000 L of water per patient, per year). RO water is energy-expensive to produce⁶.

Approximately 2.5 - 3.5 kWh are used for standard haemodialysis machines. In addition to electricity used for treatment of water, heating and air conditioning. Transporting, extracting and consuming this energy all contribute to the carbon footprint⁹.

Approximately 0.1kWh are used by the NxStage machine during dialysis¹⁰.

11.3.2. Strategies to reduce electricity consumption

The objective is to reduce energy expenditure with measures such as;

- Low energy lighting.
- Structure and orientation of the building reducing heating or air-conditioning needs.
- Decreased volume of water treatment.

- Minimal run-time of machines and any other equipment – use of standby.

Lighting:

Modern LEDs are more energy efficient. This promising technology can save more than 50% (in some situations it can reach 90% compared to traditional technologies) when compared to standard lighting and provide the added advantage of superior lamp life.

Use of motion sensors, daylight sensors, timers and varied options to regulate the level of illumination may also reduce energy use.

Also it may be possible to modulate the level of illumination so that it is adjusted to the requirements of the activities that are being carried out. One example is that the lights in a dialysis room are dim and only increase when medical activities are in demand. Individual modulation: concentrate the lighting only in areas and times when it is necessary.

Heating and cooling:

The requirements of professionals and patients frequently do not match. Patients are often very sensitive to cold air in treatment areas. Normally they sit or lie passively during the treatment so they do not generate energy or body temperature, also dialysis is an exothermic therapy but extracorporeal circulation is cooling down blood temperature. Patients are especially sensitive to cold air currents. The staff is usually moving most of the time, so they cope with slightly cooler air¹.

- Temperature: Ideally set an indoor temperature of 19 to 21°C in winter and 22 to 26°C in summer.
- Orientation of the building: the main façade would have to be facing south and avoid the windows facing west, so as to take advantage of the light and heat of the sun.

- Thermal insulation can reduce the need for heating and cooling considerably.
- Windows: double glazing saves 25% of energy in heating and isolates from outside noise.
- Blinds: help to ventilate the house in summer and block the sun. They retain heat in the winter.
- Adjusting dialysate temperatures (balance with risks of hypotension) and provision of blankets may reduce the need for excessive heating for patients.

Dialysate production:

The PureFlow SL maximum electrical usage is 400W per hour, but usage occurs intermittently when the dialyser heating plates in the PureFlow SL case hub are on. The average electric charge of the PureFlow SL when used at room temperature (18 to 22°C) is equivalent to a single light beam of 100W in continuous operation. This adds up to approximately 70 kilowatt hours (kWh) per month.

The installation and use of the PureFlow SL system does not significantly alter the environment and comfort of the patient's home⁹.

Additional ways to save energy:

If possible we should use medical devices that are efficient for energy saving. All devices must be identified if they can be switched to "stand-by" or "off" after a treatment, at night or on weekends.

11.4 Logistics

11.4.1 The key carbon producing logistics

The logistics involve several factors that are indispensable to the operation of each HD unit. These can be:

- Laundry
- Catering
- Production of consumables such as plastics
- Energy
- Transport (patient and staff)
- Transport (consumables – internal and external)

Connor et al. compared the carbon footprint according to a study for transport³.

	In-centre - kgCO ₂ Eq	NxStage – kgCO ₂ Eq
Patient	747	19
Staff	175	28

11.4.2 Strategies to improve logistic efficiency

Reducing transport of both people and consumables affords the greatest opportunity for reducing energy expenditure. Car-pooling, public transport, transferring patients to dialysis units close to home and of course increased uptake of home dialysis all reduce transport usage.

Simple strategies are often the best. Encourage reuse of blankets, energy efficient cooking methods, recycling of plastics and obtaining supplies from a closer source.



Needle Container

11.5 Waste

11.5.1 Defining waste

Waste is any substance which is discarded after primary use, or it is worthless, defective and of no use. Examples include municipal solid waste (household trash/refuse), hazardous waste, waste water (including sewage and surface run-off) and radioactive waste.

- HHD NxStage equipment dialysis treatments produce waste of 179 kg CO₂ Eq³.
- HHD standard equipment produces 208 kg CO₂ Eq³.

11.5.2 Waste disposal

There are many waste disposal systems:

- Municipal waste includes household waste, commercial waste, and demolition waste.
- Hazardous waste includes industrial waste.
- Biomedical waste includes clinical waste.
- Special hazardous waste includes radioactive waste, explosive waste, and electronic waste (e-waste).
- Recycling of many substances including reusable plastics and paper.

Biomedical waste is any kind of waste containing infectious (or potentially infectious) materials and requires a specific disposal network. Incineration expends high energy levels to reach high temperatures that eliminate all pollutants and harmful to public health.

Domestic waste, which does not constitute a danger to public health can be disposed in a routine disposal process or recycled.

11.5.3 Strategies to reduce waste disposal carbon footprint

It is important to minimise waste going to incineration and maximise disposing of any non-contaminated waste into general waste or recycling. The use of two bins, one for contaminated and one for non-contaminated waste can reduce incineration needs. Also needles have to be disposed in an appropriate secured container.

Assess if the non-contaminated waste can be recycled. Teach patients and check if waste is being disposed correctly.

Both hospitals and community offer recycling and it is important to take advantage of any local recycling opportunities. Recycling is becoming more important and there are many new plastic and crystal materials that can be recycled⁷. Dialysis units can select products that are recyclable; such as bags, some housing, cardboard packaging, plastic wrapping, plastic caps. Taking advantage to separate in dedicated containers, as we do when sorting domestic waste, to recycle.

11.6 Implementing environmental change

To protect our environment it is important to review every step that constitutes logistics, power and water utilisation.

- Appoint an environmental officer to the dialysis unit who considers strategies for both in center and HHD.
- Educate all staff.
- Make environment part of the training program for patients.



NxStage System ready to use



Recycling Icon

- Choose a simple strategy to improve the environment for dialysis patients in your unit.
- Before choosing hardware for your patients, check utilities characteristics: power (kWh), water saving features, disinfection cycles.
- Prefer cleaning and disinfection procedures that limit use of chemicals.

Appendix 1. Water standards

Pollutant	ISO-13959:20141 AAMI-13959:2014	European Pharmacopoeia 4.32	Norma UNE 111-301-903	Parametric value in water for human consumption. R.D. 140/20034
Total Chlorine	0,1	0,1	–	–
Free Chlorine	–	0,5	0,5	1
Combined Chlorine (Chloramines)	–	–	0,1	2
Copper	0,1	0,1	0,1	2
Fluorine	0,2	0,2	0,2	1,5
Lead	0,005	0,005	0,005	0,01
Nitrate as N	2	2	2	50
Sulfates	100	50	100	250
Zinc	0,1	0,1	0,1	–
Electrolytes normally included in L.D. (second group)				
Calcium	2 (0,05 mmol/l)	2	2	–
Magnesium	4 (0,15 mmol/l)	2	4	–
Potassium	8 (0,2 mmol/l)	2	8	–
Sodium	70 (3,0 mmol/l)	50	70	200
Maximum level of other toxic substances (third group)				
Antimony	0,006 (0,005)	0,006	–	0,005
Arsenic	0,005	0,005	0,005	0,01
Barium	0,1	0,1	0,1	–
Beryllium	0,0004	0,0004	–	–
Cadmium	0,001	0,001	0,001	0,005
Chrome	0,014	0,014	0,014	0,05
Mercury	0,0002	0,0001	0,0002	0,001
Selenium	0,09	0,09	0,09	0,001
Silver	0,005	0,005	0,005	–
Thallium	0,002	0,002	–	–
Other substances identified as toxic in dialysis				
Ammonium	–	0,2		0,5
Chlorides		50		250
Heavy Metals	0,1	0,1		–

Summary

Everyone is responsible for the environment. Everyone can contribute to reduce the increasing carbon footprint, each effort is valuable.

It is possible nowadays to measure pollution in Kg CO₂ Eq⁷.

Nurses and patients must be educated so that they can make correct choices about how to reduce the carbon footprint because dialysis care has a serious impact with huge volumes of water, high power and disinfection chemicals usage.

Climate change remains a worldwide concern for governments, businesses and citizens. More information is currently being issued on the emissions produced by certain types of activities, events or even the day-to-day life of a person on foot; and the calculation of the carbon footprint can help us to answer all these questions.

Learning Activity

1. If the patient chooses to perform haemodialysis at home, it will be important to assume the responsibility, normally carried out by the staff of the centre?
2. What strategies do we know to reduce electricity consumption?
3. What factors can increase the carbon footprint in a dialysis centre?
4. What is the best option for haemodialysis technique, to reduce the carbon footprint?
5. What amount of drinking water do we need to transform into pure water in a dialysis centre? And at home, with a deionisation system?

Chapter 12

Home Programme Case Study

Learning Outcomes

- To determine factors that contribute to a successful Home HD programme
- To understand the importance of a designated Home HD (or Home therapies) team
- To learn about the value of education and awareness for all patients and staff
- To identify methods to ensure that patients are always at the centre of the programme



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Introduction

The following chapter will outline the experience of the Wessex Kidney Centre, Portsmouth, UK in establishing and growing a large Home HD programme using the NxStage System One.

12.1. Background

Wessex Kidney Centre (WKC) is located in Portsmouth on the south coast of England. It is a large renal centre with a population catchment area of 2.5 million people spread over a wide geographical area. The regional incidence of end stage renal disease (ESRD) and hence dialysis is growing in line with the rest of the United Kingdom (UK) and Europe¹. WKC has an active and growing renal transplant programme, a large central haemodialysis (HD) unit, eight satellite HD units, and has sustained a large Peritoneal Dialysis (PD) programme even when many others were declining. However, like much of Europe Home Haemodialysis (HHD) declined during the late 1990's² and for a decade WKC had no HHD Programme at all. In 2009 WKC took action to re-established a HHD programme. It has since shown rapid growth and now sustains a large number of patients on HD at home. Figure 1 shows the change in prevalence across dialysis modalities in WKC.

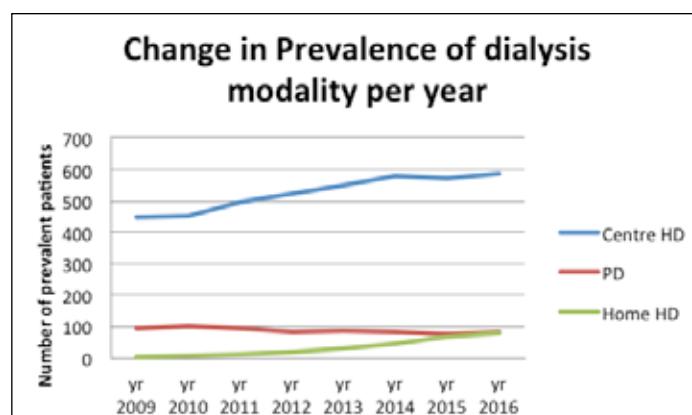


Figure 1: Prevalence of ESRD modalities 2009 to 2016 in WKC

In 2009 the percentage of all HD patients undertaking HHD was just 0.4% (HHD prevalent population). By 2016 this had increased dramatically to 10.4%. The following chapter will outline the successes of this programme and the key learning points.

12.2. Key drivers

The re-establishment of HHD in the WKC in 2009 had several key drivers.

In 2002 the UK National Institute for Clinical Excellence (NICE) concluded that all patients deemed suitable for HHD should be offered HHD. NICE also suggested that 15% of prevalent dialysis patients could be on HHD³.

Patients themselves were a prominent force in driving forward change. Aware of inequitable access to HHD dependent on their base renal unit they challenged WKC to improve the local situation.

The prevalence of patients on HHD in the UK in 2008 varied from 0% to 8% across centres⁴. As a unit without HHD provision prior to 2009, WKC was not meeting NICE recommendations or providing modality 'choice' to patients.

An additional driver was the increasing pressure on dialysis capacity within the UK. Many centres were struggling to meet the demand of a growing dialysis population, for which WKC was no exception. Large capital investment was not available so considering alternative methods to support service expansion was required. In 2008 the National Kidney Foundation released a policy statement that "Dialysis provision must be increased to cope with existing patient numbers and the growth in the number of patients predicted. Patients should be given a choice to receive their dialysis in hospital or at home"⁵.



A patient trained on Home Haemodialysis

Therefore, combining NICE recommendations, patients voicing wishes regarding choice and equality and dialysis capacity issues WKC embarked on a project to address these areas with the view to improve the service provided.

12.3. Establishing a HHD Programme

The initial attempts to re-establish HHD in WKC took place in 2004 when following a small financial investment two patients trained to use traditional machines at home, over a 3-month period. The first patient was transplanted 14 days after starting to dialyse at home, the second patient stopped as they felt it was too much for them, largely due to a lack of in house technical support⁶.

Undeterred by the early difficulties the team set about looking for alternative models. In 2009 the NxStage System One was launched in the UK and WKC viewed this as an option. It was essential that the therapy could be delivered within existing tariff and fit within the current staffing structure. WKC was able to negotiate a tariff price per treatment cost which included technical support and gained agreement to trial the machine in a single patient. Staff already employed within WKC took on the responsibility of managing this in addition to their usual job roles.

The pilot period culminated in data of the experience being presented to the Portsmouth Hospitals National Health Services (NHS) Trust board. Approval was given for a further five patients to join the HHD programme and appointed from a satellite unit to specifically manage this development.

12.4. Growing a HHD Programme

The initial patients enrolled into the programme were considered to be medically stable and highly motivated, with good vascular access.

They would be fully independent without the need for a care partner. By 2011 confidence within the programme allowed for further expansion to include patients with more complex needs. The first patient transferred to nocturnal therapy and the first patient who lived alone was trained for HHD. The lead nurse role became a permanent post and a dialysis assistant was appointed to support her.

The programme continued to grow throughout the next 3 years. During this time an area in the main unit was established as the HHD training area, however this was not a dedicated sole use area and was also set up for bed spaces. Training was interrupted on multiple occasions due to demand on hospital beds. It became clear to the team that to facilitate continued programme growth a dedicated training area away from the inpatient unit was required. An area for this purpose was successfully secured. Despite measuring just 2.4 by 4.7 meters the team were able to rapidly expand their training abilities, training 45 patients during 2014. This area was increased in 2016 to a space 50% larger with the original area still available for use and storage (Figure 2).

HHD staffing numbers have also grown with the programme. There are no current national guidelines on the number of patients a Home HD nurse should support but it became very clear in the WKC programme that once that number exceeded 20 patients per nurse the patients reported feeling unsupported and there was a clear increase in patients stopping therapy for this reason. This evidence supported the successful application for financial support to employ more nurses with the aim to maintain the nurse to patient ratio below this level. This was to ensure adequate support for those established on HHD but also to allow additional staff to continue training. WKC has now set a limit of 15 patients to one nurse; with all Home HD nursing staff also being able to train patients.



Figure 2: A) the 2014 training area measuring 2.4 x 4.7m. B) the 2016 expanded training area.

During 2014 the first patients trained were from pre-dialysis clinic and PD, supported with a tailored training plan. At this point in time all patients expressing an interest in HHD were visited at home by the dialysis assistant. This facilitated providing initial education with a home environment assessment. Home HD was also incorporated into the WKC pre-dialysis DVD which is given to all patients in the pre-dialysis clinic. Educational and awareness events are regularly carried out in all satellite dialysis units to discuss home dialysis with both staff and patients to ensure that patients are aware of this options should they wish to consider it. In 2014 a service tender for HHD services was completed.

Growing the programme also meant thinking outside the box. Renal care overall is complicated by the logistics of living on an island 6km off the coast; the Isle of Wight (IOW). In 2015 a team of enthusiastic nurses working in the IOW satellite unit took on the role of training patients for HHD supported by the main HHD team so patients could remain close to home.

During 2016 the Home HD team set about mapping the patient journey from decision to independence at home. This has enhanced the smooth transition for all patients, streamlined the information given and the subsequent support of a patient once home. All patients were categorised via a traffic light system incorporating their level of medical complexity and support needed (by patients or carers). This has allowed staff to target resources to those who need it the most and highlight changes as patients move through the traffic light categories. In 2016 we took the opportunity to update all standard operating procedures.

As the programme expanded the complexities of patients grew and the team has even gained experience in HHD for patients with terminal diseases.

12.5. Staff training and education

Ensuring staff education and acceptance of HHD has been crucial to the establishment and growth of the programme. The initial set up involved a number of nursing staff from satellite dialysis centres. This meant that dissemination of information across the region occurred by discussion with their colleagues. Many of the nursing staff in the satellite centres were educated and engaged as the programme evolved. The HHD team ensured regular feedback and updates for clinical and managerial staff to maintain their interest and support.

Once the team appointed a lead nurse, liaison roles were formed to link the main HD unit and the other satellite centres. This was vital to ensure efficient communication, support for the patients wishing to do HHD and also to harbour interest from patients on standard HD. Engagement from the satellite units also meant that cannulation training could be provided prior to commencing HHD training reducing the burden and stress for patients.

Regular HHD awareness days take place in all dialysis centres in WKC educating staff and patients about HHD. HHD is now part of the renal course which many of the nursing staff complete and there is an established HHD nurse study day. HHD has been incorporated into the induction programme for both nursing staff and junior doctors, and features in the speciality registrars training days.

In addition to the dedicated HHD nurse team several nurses in the main unit are also trained to use the NxStage System One machine. These staff undergo competency based training for the NxStage system. A regular HHD slot available in the main dialysis centre supports patients for respite and has proven to be a successful initiative.



12.6. Patient education and training

Patient education is essential for programme growth. Following the initial pilot, the HHD team set out to ensure that all existing dialysis patients were now aware of this option, which they would not have been offered in the pre-dialysis setting. This took the shape of patient awareness days in the satellite units. Education of the pre-dialysis nursing teams and the clinicians also played a role in filtering the information to the patients. HHD was incorporated into the pre-dialysis DVD which is given to all patients.



A patient on dialysis in a campervan

The team used media coverage to inform the general public hoping to reach as many individuals as possible. This included the local news, news paper, radio, social media and patient groups.

Existing HHD patients volunteered for peer support events and helped educate others sharing their experience. This has included 'campervan events' where patients have dialysed in a camper van at the hospital and satellite centre sites so others can come, watch how it is done and ask questions.

Patient training has been a great success in this programme and facilitated the rapid growth that has been seen. Where possible the team encourage patients to learn self cannulation prior to commencing HHD training. By undertaking this in a familiar environment with staff they often know well, at a pace they dictate, the stress and anxiety generated over learning this new skill is reduced.

Patients are trained for HHD in a designated area by the HHD nursing team. The HHD team adopt a 'hands-off' approach to training from day one. Patients' being active in their training early on empowers them to take control of their own treatment under watchful supervision whilst highlighting potential concerns / issues promptly. Where possible the team encourage the patient to learn the entire

dialysis procedure rather than relying heavily on a care partner to reduce carer burden. The final two sessions take place in the patient's home so they are comfortable in their home environment. Training times and outcomes are discussed in section 12.7

12.7. Clinical outcomes

Clinical outcomes of the WKC HHD programme have been very good. Data has been analysed of the first 135 patients trained for HHD up to May 2016.

The demographics of this HHD population are mean age 51.4 years (Range 18 to 80 years); 66% male; and mean BMI 27.8 (Range 13.3 to 50.8). The mean Charlson Comorbidity Score⁷ was 4 (Range 2 to 10) and 17.9% had diabetes causing renal failure. The majority of patients (88%) were on in centre HD prior to training, 10.5% were pre-dialysis and 1.5% from Peritoneal Dialysis (PD).

Access type was 73.9% native Arterio-Venous Fistula (AVF), 19.4% Central Venous Catheter (CVC), and 6.7% PTFE Grafts; and the majority of patients use the button hole technique. Of those patients with a fistula 82% were self cannulating prior to commencing HHD training. The mean training time for all patients was 10.5 sessions (Range 6 to 33 sessions) to dialyse independently at home.

Training failure rates have been very low. Only 6% of patients did not complete training and just a further 1.6% dropped within 3 months for any reason other than renal transplantation. Therapy retention has been excellent with 50.8% of patients still on HHD.

Of those who have ceased HHD, 60.7% were for renal transplantation, 9.8% died and 29.5% were for other reasons including therapy burden, change in medical condition or access issues. Average time on HHD prior to dropout for any reason was 15.2 Months (Range 2 to 74 months).

Prescribing is individualised to the patients, their life style and medical needs. The majority of HHD patients at WKC dialyse 5 or 6 days a week with either 25L or 30L of dialysate fluid. There have been a number of patients who have transitioned to nocturnal therapy⁸. These patients dialyse alternate nights using 60L of fluid. We have seen a reduction in the use of anticoagulants with many of those on short frequent therapy not requiring any at all.

There has also been a notable reduction in blood pressure medication.

Data for the nocturnal patients has also been good, data for these patients is shown in Table 2, but the numbers of patients who have reached 1 year of nocturnal therapy are smaller at just 12 patients to date. The additional benefit of reduction in phosphate binders in nocturnal patients has also been noted.

Table 1: Shows the biochemical outcomes of the first 65 patients to complete 1 year on short frequent dialysis at home:

Parameter (Guideline or target)	Baseline Mean (Range)	6 months Mean (Range)	1 year Mean (Range)
Std Kt/V (2.4)	2.56 (1.56-3.72)	2.62 (1.58-3.82)	2.56 (1.79-3.31)
Bicarbonate (18-24mmol/L)	23.7 (16-35.9)	24 (18- 30.7)	23.97 (20-33.8)
Pre-HD K ⁺ (4-6mmol/L)	5 (3.8-6.2)	4.68 (3.2 -6.5)	4.81 (3.4-6.8)
Hb (100-120g/L)	116 (84-156)	113 (79-142)	113.5 (89-150)
Calcium (2.2-2.6mmol/L)	2.34 (1.99-2.7)	2.33 (1.88-2.74)	2.32 (1.78-2.8)
Phosphorus (1.1-1.7mmol/L)	1.77 (0.97-2.69)	1.68 (0.97-2.64)	1.63 (0.88-2.9)
Albumin (35-50mmol/L)	35.7 (25-46)	36.7 (24-40)	36.7 (29-49)

Table 2: HHD biochemical outcomes for nocturnal dialysis at baseline, 6 months and 1 year.

Parameter (Guideline target)	Baseline Mean	6 months Mean	1 year Mean
Std Kt/V (2.4)	2.44	2.64	2.54
Pre-HD K ⁺ (4-6mmol/L)	4.8	4.7	4.7
Hb (100-120g/L)	114	118	121
Calcium (2.2-2.6mmol/L)	2.37	2.37	2.39
Phosphorus (1.1-1.7mmol/L)	1.72	1.7	1.6

12.8. Successes and challenges

The WKC reintroduction of HHD has far exceeded even our own expectations. The programme has grown rapidly achieving short training times, excellent retention rates and good clinical outcomes.

The HHD team feel we have improved the quality of life of our patients by giving them an individualised therapy that fits their needs and allows more freedom. We have supported many of our patients to travel with their HHD machines further enhancing their experience. The WKC can now truly meet the NICE guideline that Home HD should be offered as an option to all patients deemed suitable. The WKC now has an enthusiastic dedicated HHD team providing everything from pre-home visits and education, training and community support.

There have been many challenges along the way especially with sourcing enough staff and training space for an extensive programme. The summary below will share with you the things we feel should be considered when embarking on a project like ours.

Summary

The team at WKC was one of the first European centres to set up an HHD Programme using the NxStage System One, developing a large programme in a short period. There have been learning points along the way that improve programme effectiveness. The key learning points are:

1. A designated training area for Home HD with capacity for respite and review is essential to maintain programme growth.
2. A designated Home HD (or home therapies) team is essential. The data from WKC suggest that no more than 20 patients per nurse but this should be reduced to 15 per nurse if they are also training patients.
3. A clearly set out patient journey from expressing an interest to independent dialysis at home has been extremely helpful in ensuring smooth transition for patients.
4. Education and awareness for all patients and staff, including satellite units, is very important.
5. Early engagement with the Trust and managers is essential to ensure programmes are set up and supported correctly with the appropriate business cases in place.
6. Above all ensuring that patients are always at the centre of all that we do and sharing the learning with them has proved exceptionally valuable to the ongoing development of our service.

Learning Activity

1. How do you think some of these learnings at WKC could be applied to your HHD programme?
2. How can you increase education and awareness in your centre?

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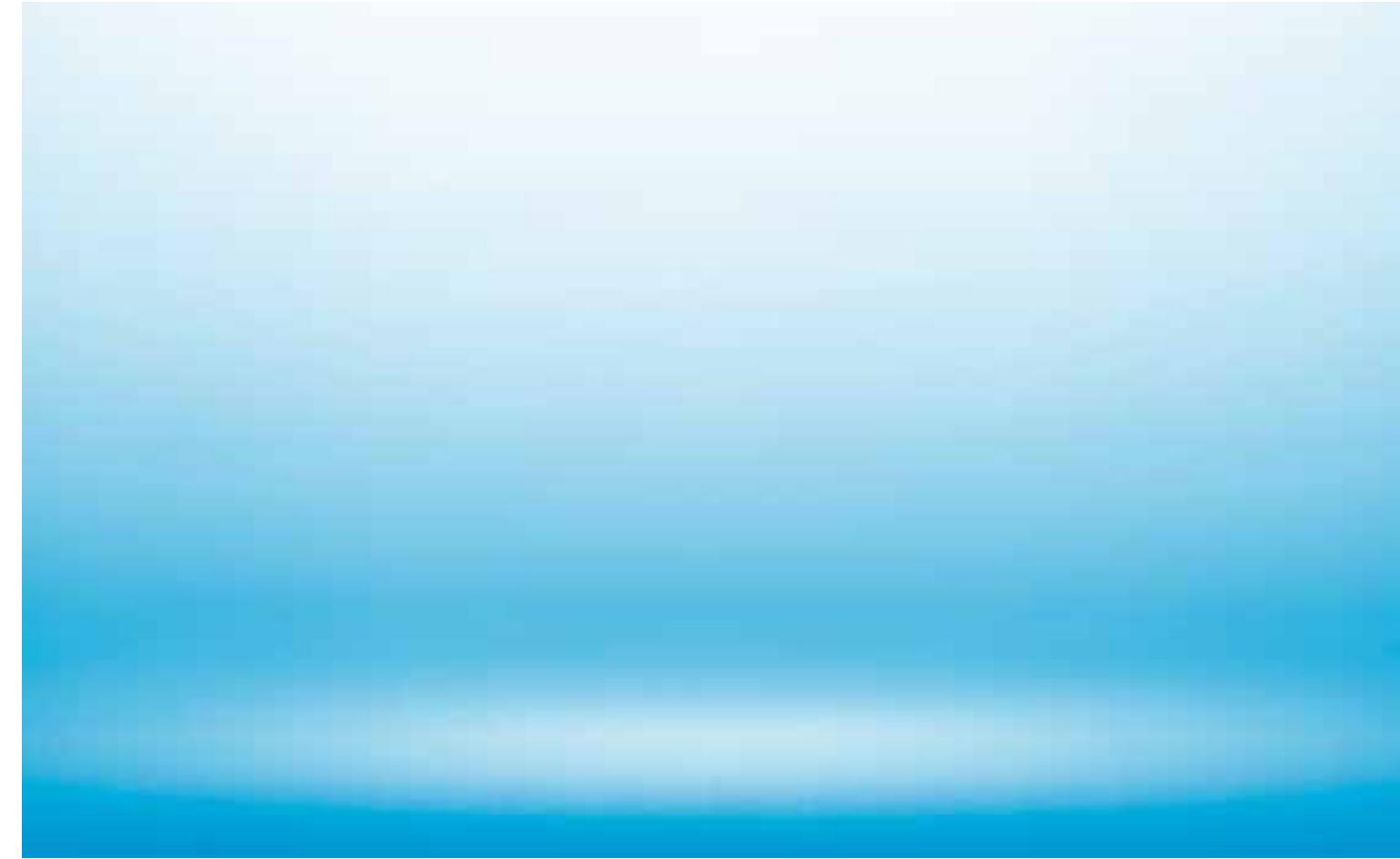
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