

HOME HAEMODIALYSIS:

Tackling unequal access in the UK





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EXECUTIVE SUMMARY

Haemodialysis is a treatment for those living with end-stage renal failure, where a patient uses a dialysis machine, passing his/her blood through a filter and cleansing it in the process. Home haemodialysis is a form of this life-sustaining treatment that allows a kidney patient to perform treatment from the comfort of his/her own home.

Home haemodialysis makes it simpler and more practical for patients to treat more frequently, compared to those that treat at in-centre clinics. Kidney patients treated more frequently can benefit from improvements to their health, a better quality of life,¹ and an increased chance of survival.²

In addition, home haemodialysis presents the most practical setting for dialysis. Unlike in-center haemodialysis patients, who are restricted to treatment schedules constrained by staffing and time slot availability, home

haemodialysis patients benefit from dialysing as often and for as long as they need.

In the UK, we face a postcode lottery that sees huge discrepancies in which kidney patients are offered home haemodialysis as a treatment option. Despite the National Institute for Health and Clinical Excellence (NICE) recommending that all patients who are suitable for home haemodialysis should be offered the choice,³ this is far from the case. There are more than 28,000 patients on dialysis in the UK, yet just 4.4% of these are on home haemodialysis.⁴

Independent polling of kidney haemodialysis patients found that 27% were not educated on all types of dialysis that would be beneficial to them, and 31% of in-centre patients cite never being offered home haemodialysis as a treatment option.⁵

Using insight from kidney patients, renal health

¹ Heidenheim PA, Muirhead N, Moist L, Lindsay RM. Patient quality of life on quotidian hemodialysis. *Am J Kidney Dis*. 2003;42(1)(suppl 1):S36-S41.

² Weinhandl, E., Liu, J., Gilbertson, D., Arneson, T. and Collins, A. (2012). Survival in Daily Home Hemodialysis and Matched Thrice-Weekly In-Center Hemodialysis Patients. [online] Available at: <http://jasn.asnjournals.org/content/23/5/895.full.pdf+html> [Accessed 31 Jul. 2018].

³ nice.org.uk. (2002). Guidance on home compared with hospital haemodialysis for patients with end-stage renal failure. [online] Available at: <https://www.nice.org.uk/guidance/ta48/chapter/6-resource-impact-for-the-nhs> Accessed 2 Feb. 2018.

⁴ MacNeill S, Ford D, Evans K, Medcalf J. (2018). K Renal Registry 20th Annual Report: Chapter 2 UK Renal Replacement Therapy Adult Prevalence in 2016: National and Centre-specific Analyses. [online] Renalreg.org. Available at: <https://www.renalreg.org/wp-content/uploads/2018/06/02-Chap02.pdf> Accessed 4 Jul. 2018.

⁵ Commissioned by NxStage, hosted by Censuwide. (102 participants who are/have been treated for kidney failure and have been treated with either Centre Haemodialysis, Home Haemodialysis or Peritoneal dialysis, December 2017)



professionals, and patient charity groups, this report shines a light on the disparities over patients' experience of home haemodialysis across NHS trusts and looks at why the uptake stalls at less than 5%. It also highlights the importance of home haemodialysis being offered as a viable treatment option, the potential health benefits for patients, and the opportunities it offers for the NHS to save on money and resources.

Kidney failure services are costly—1.3% of the NHS budget is spent on Chronic Kidney Disease, which is approximately £1.45 billion a year.⁶

By 2030, the number of people requiring renal replacement therapy, including dialysis, and the amount it costs to treat these people, is expected to double globally.⁷ It is vital that attitudes towards home haemodialysis shift before we reach this point.

This important issue is one that has not been

given its deserved attention since 2013, when the All-Party Parliamentary Group for Kidney Health published its Home Dialysis Manifesto recommending ways for the NHS and government to increase the uptake of home haemodialysis.⁸ Since then, not enough has been done.

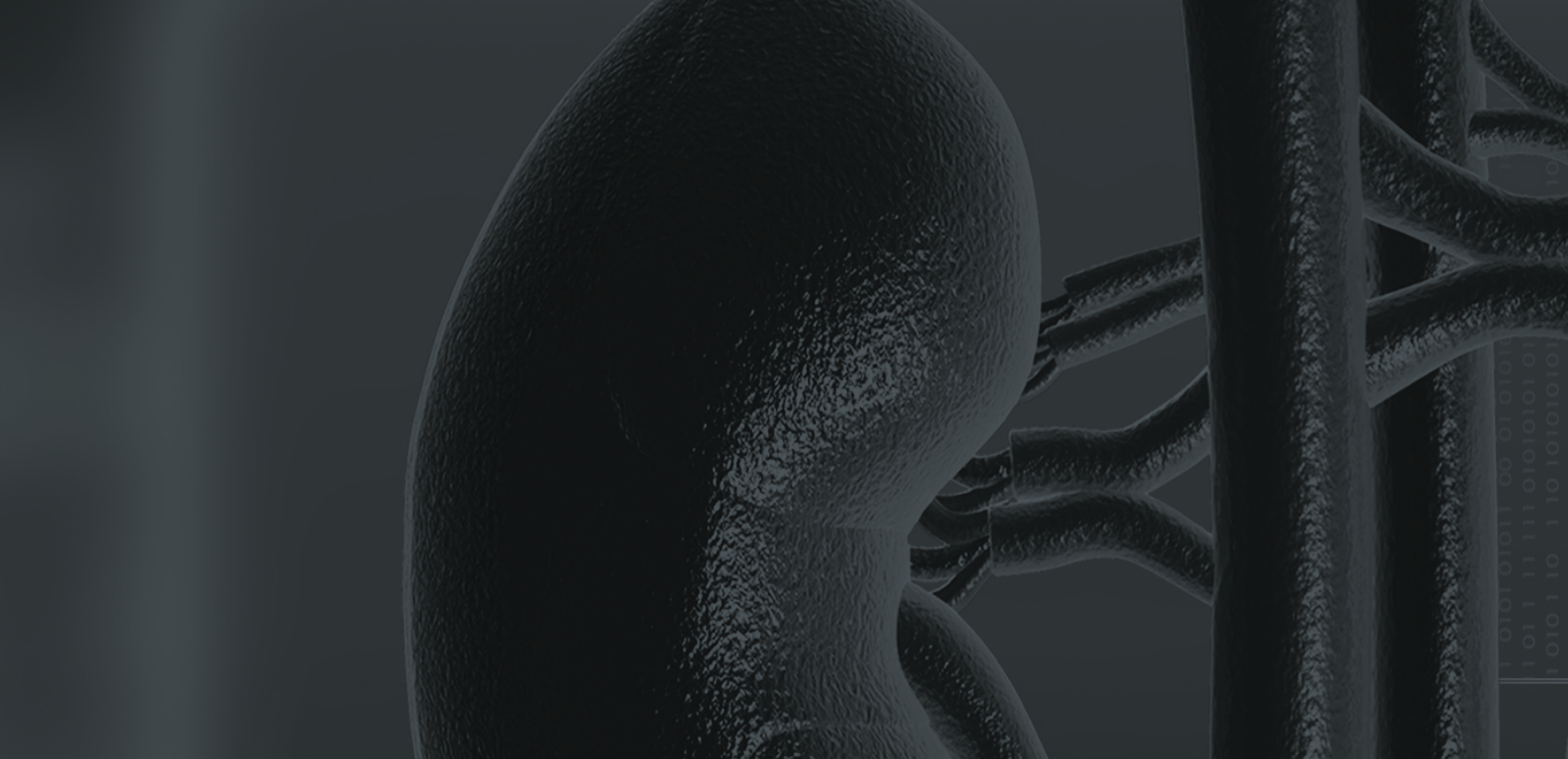
Five years on, this report calls on a coalition of influencers to refocus on the issue of home haemodialysis and continue to drive change. It draws on the support of NHS staff at all levels—from doctors and nurses to business managers, government policy makers, and kidney organisations, asking that all commit to patient choice through encouraging the uptake of home haemodialysis and offering education programs to patients and providers.

Ultimately, this report looks at patient choice and the right for every haemodialysis patient to have access to the treatment that is right for them.

⁶ England.nhs.uk. (2017). Chronic Kidney Disease in England: The Human and Financial Cost. [online] Available at: <https://www.england.nhs.uk/improvement-hub/wp-content/uploads/sites/44/2017/11/Chronic-Kidney-Disease-in-England-The-Human-and-Financial-Cost.pdf> Accessed 6 Apr. 2018.

⁷ Liyanage T, Ninomiya T, Jha V, et al. Worldwide access to treatment for end-stage kidney disease: a systematic review. *Lancet*. 2015;385(9981):1975-1982.

⁸ All-Party Parliamentary Kidney Group A HOME DIALYSIS MANIFESTO. (2013). [pdf] kidney.org.uk. Available at: https://www.kidney.org.uk/documentlibrary/Home_Dialysis_Report.pdf Accessed 2 Feb. 2018.



GLOSSARY OF TERMS

Renal replacement therapy (RRT)

A renal replacement therapy is a treatment that takes on the role of the kidneys when they are not working correctly due to renal failure such as acute kidney injury or chronic kidney disease. RRT filters the blood through therapies such as dialysis, haemofiltration, haemodiafiltration, or with transplantation.

Haemodialysis (HD)

Haemodialysis is a form of RRT where a kidney patient uses a dialysis machine, passing his/her blood through a filter and cleansing it in the process. The majority of patients on this form of dialysis receive it at haemodialysis centres. It is also possible for patients to perform haemodialysis at home.

In-centre haemodialysis (ICHHD)

Where a haemodialysis patient travels to a dialysis centre for treatments, usually three times a week. Many centres are only open Monday-Saturday, closing on Sundays.

Home haemodialysis (HHD)

Where a haemodialysis patient conducts the haemodialysis treatment at home.

Peritoneal dialysis (PD)

An alternative form of dialysis, most commonly in the form of continuous ambulatory peritoneal dialysis (CAPD). With this modality, dialysis fluid is inserted into the patient's stomach in the peritoneal membrane for around six hours, helping to cleanse the blood. It is then removed and replaced.



Transplant First

A national project of the Kidney Quality Improvement Partnership (KQIP) run by the NHS. Its aim is to improve nationwide access to kidney transplantation. This report wholeheartedly supports the policy of Transplant First but recognises that, while there is a shortage of kidney donations, not all those who need one will be able to have a transplant immediately.

Kidney Quality Improvement Partnership (KQIP)

KQIP is a dynamic network of kidney health professionals, patients, and carers who are committed to developing, supporting and sharing quality improvement in kidney services in order to enhance outcomes and quality of life for patients with kidney disease.



KEY CONTRIBUTORS AND SUPPORTERS



NxStage Medical, Inc. is a medical device company that develops, manufactures, and markets home haemodialysis systems to patients across the UK, US, and more than 20 other countries. Its inventions and ground-breaking technology are helping to improve the lives of patients living with end-stage renal disease. NxStage is committed to providing education, advocacy, and social responsibility to change the face of renal care across healthcare settings and ultimately ensure a patient's quality of life is put first.

NxStage has commissioned this report to highlight the clinical and quality of life benefits of more frequent home haemodialysis, and the need for it to be offered as a viable treatment option consistently across the UK.

NxStage would like to thank the following NxStage advocates who have helped shape this report with their personal and clinical insights.



Member of NxStage's US Medical Advisory Board, Dr.

Richard Fluck – Consultant Renal Physician at Royal Derby Hospital and previously National Clinical Director for Renal Disease for NHS England. Royal Derby Hospital uses NxStage home haemodialysis machines for over 50 of its kidney failure patients.

“Dialysis is an important life sustaining treatment but can be a burden for many individuals. Home haemodialysis, which makes frequent dialysis more accessible, offers improved physical outcomes but, most importantly, it can allow people to live their lives to a far greater extent than those on in-hospital treatment.”



Member of NxStage's EU Medical Advisory Board, Dr. Natalie

Borman – Care Group Director for Renal and Transplantation, Wessex Kidney Centre, Portsmouth. QA Hospital is one of the largest home haemodialysis departments, currently with over 88 patients using the NxStage System One™ for home haemodialysis.

“Our home haemodialysis programme was re-established in the Wessex Kidney Centre in QA in 2009 in response to increasing evidence that more frequent haemodialysis is associated with improved survival, better patient outcomes, and improved quality of life. It's so important for patients to have the right to choose which treatment is best for them and their life.”



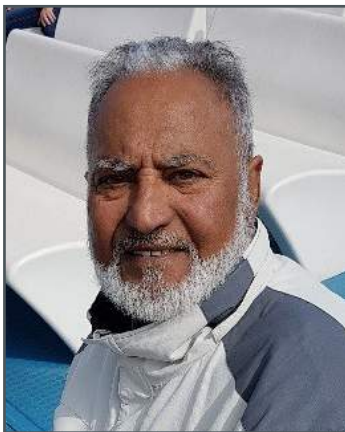
Sister Carol Rhodes, Senior Sister and Home Haemodialysis Lead of the Renal Unit at Royal Derby Hospital.

"In the last six years, awareness and funding for home dialysis in Derby has grown massively and, since then, this has been a viable treatment option to our patients at Royal Derby Hospital. We now have over 50 of our haemodialysis patients on home haemodialysis, which equates to more than 35%, benefiting from the life transforming effects of home haemodialysis."



Home haemodialysis patient, Giuletta Whitmore, 35

"When I was 32, my life changed within a few days, I was pregnant with my second child and diagnosed with eclampsia, which caused my kidneys to fail and my baby to be stillborn. I spent 18 months on in-centre haemodialysis before I found a leaflet on home haemodialysis and pushed to be moved onto it. I was transferred onto the home haemodialysis program and now have so much more freedom to dialyse when and where I like. I dialyse five times a week and I've even been able to travel abroad with my machine too, which was such an amazing moment for me."



Home haemodialysis patient, Afzal Moghal, 64

"My intention was always to move to home haemodialysis, but my wife had her reservations. She had convinced herself that the machines would be too big and too risky to use at home by ourselves, but in 2016, my wife and I were invited to an event designed to educate home haemodialysis patients. The event dispelled any myths or concerns and reassured my wife that my health and quality of life may improve massively if I dialysed more frequently at home. Within a week of dialysing from home, she'd become the biggest ambassador for it."



Home haemodialysis patient, Matt Herbert, 38

"I've had kidney failure for the past 20 years. In my early twenties a transplant failed, and I was on in-centre haemodialysis for a long time. It was three years ago that I made the move to home haemodialysis, and being able to dialyse more frequently, it feels much closer to having your own kidneys. My son was born in 2016, so I've been able to enjoy more time with my newly-expanded family rather than in hospital. I no longer have to get up at 5:30am, three times a week to travel to the dialysis unit which means I arrive at work on time. Because I can dialyse more regularly, I feel a lot healthier."



Home haemodialysis patient, Kim Richards, 43

"When I first went onto dialysis, I was dialysing in-centre after work three times a week. I was finding myself going to bed at 1am before getting up the next day at 7am to return to work. I then transferred onto peritoneal haemodialysis and stayed on it for seven years, before finally moving to home haemodialysis where I could dialyse five times a week. I was only on it for eight months before I was lucky enough to get a kidney transplant, but if I was ever required to go back to dialysis I would 100% choose home haemodialysis. I had control over my life and more freedom."



Home haemodialysis patient, Roxy Parkinson, 31

"I've had trouble with my kidneys since I was 21 and, after a failed kidney transplant and other health complications, now need regular haemodialysis. I dialysed in-centre on and off for seven years but found it really damaging to my mental health. I was depressed, suffering bad mood swings, and was fed up with my life revolving around dialysis. It was like a job I hated, but had to go to. I researched home haemodialysis and asked my doctors to look into NxStage machines. Since switching to frequently dialysing at home, I feel healthier and so much happier. I dialyse four times a week and I love the flexibility it gives me to take back control of my life."



AMBASSADORS OF EQUAL ACCESS TO HOME HAEMODIALYSIS IN THE UK



“We believe in choice for people with kidney failure; no matter who you are, or where you live, you should be able to choose the treatment that suits you. Whilst home therapies won’t work for everyone, research shows that only a quarter of the patients who could receive and benefit from home dialysis are currently receiving this treatment. It is vital that patients have the opportunity to explore all the options available to them and can make an informed decision about the treatment that will work best for them.”

FIONA LOUD
Policy Director at Kidney Care UK



NKF is the voice of renal patients, having been formed by patients 40 years ago and run by kidney patients ever since. The benefits of home haemodialysis for some patients has been obvious for many years and this benefit was targeted by NICE for greater take up and expansion nearly 10 years ago. It was because little changed following the NICE recommendations that NKF enlisted the help of 176 MPs (the All Party Parliamentary Kidney Group) and gathered them together for a Home Dialysis Summit within the House of Commons. The resulting Manifesto, published in 2013, was received with acclaim but the take up around the country remains desperately slow. NKF welcomes this latest report by NxStage and looks forward to the day when home haemodialysis is offered to every suitable patient wherever they live in the UK.

WHY EQUAL ACCESS TO HOME HAEMODIALYSIS MATTERS: PATIENT HEALTH AND WELLBEING

IMPROVED PHYSICAL HEALTH

- » **Increased survival rates:** Frequent home haemodialysis patients have up to 13% lower risk of death, compared to in-centre haemodialysis patients.²
- » **Reduced reliance on additional medicine:** One study found 42% of home haemodialysis patients did not require blood pressure medication 12 months after switching from in-centre to more frequent home haemodialysis.⁹ 26% of frequent home haemodialysis patients rely less on medication overall.²
- » **Reduced recovery times:** Patients on frequent home haemodialysis report an average of one hour recovery time post haemodialysis sessions, compared to eight hours for in-centre.¹⁰
- » **More likely to receive a transplant:** Enabling the 'transplant first' agenda, patients on frequent home haemodialysis have an increased chance of receiving a kidney transplant due to better health levels.²

42%

of home haemodialysis patients did not require any blood pressure medication after 12 months after switching from in-centre to more frequent home haemodialysis

- » **Less risk from 'two-day break' from haemodialysis:** The 'two-day break' imposed by weekend closure of centres puts in-centre haemodialysis patients at a higher risk of mortality caused by an accumulation of fluids from the blood.¹¹

Frequent home haemodialysis patients have the potential to see vast improvements to their physical health from dialysing more often, with 77% of kidney patients saying they had seen an improvement in their health dialysing at home.⁵ Sister Carol Rhodes says *"In my experience, every patient dialysing more frequently on home haemodialysis has a better quality of life. They're*

ultimately able to lead much more independent, normal lives again."

A normal kidney functions 24 hours a day, seven days a week, but patients on in-centre haemodialysis only tend to receive around 12 hours of haemodialysis per week. The more frequent haemodialysis a patient receives, the more fluid and toxins that are removed, which more closely mimics the function of a normal kidney, and therefore makes the patient feel better. The majority of home haemodialysis



26% of frequent home haemodialysis patients rely less on medication overall²

⁹ Nair S. New European Evidence with Home HD Patients: 12 Months Follow-up in KIHdNEY Cohort. Presentation given at 2017 EDTA Congress. Madrid, Spain.

¹⁰ Rayner HC, Zepel L, Fuller DS, et al. Recovery time, quality of life, and mortality in hemodialysis patients: the Dialysis Outcomes and Practice Patterns Study (DOPPS). *Am J Kidney Dis*. 2014;64(1):86-94.

¹¹ Benefits case study summary – Release of Hospital Episode Statistics data to UK Renal Registry (UKRR) and Sheffield Kidney Institute. (2016). [ebook] Health & Social Care Information Centre. Available at: http://webarchive.nationalarchives.gov.uk/20180328130852tf_/http://content.digital.nhs.uk/media/20935/Benefits-Case-Study-Summary---UKRR---linkage-of-HES-data-with-UKRR-and-ONS-mortality-v10/pdf/Benefits_Case_Study_Summary_-_UKRR_-_linkage_of_HES_data_with_UKRR_and_ONS_mortality_v1.0.pdf

patients dialyse four times or more a week⁵ for two to three hours, or eight hours if dialysing overnight, compared to the standard three times for around four hours each time for in-centre haemodialysis patients.¹²

Patients on frequent home haemodialysis see an **increased chance of survival** compared to patients dialysing three times per week in-centre, with one study showing up to 13% lower risk of death.² *Dr. Natalie Borman reports that feedback from patients on home haemodialysis has been very positive, saying, "Our patients report feeling better when dialysing more frequently at home."*

Some patients also see a **reduced reliance** on additional **medication** when dialysing more frequently at home. One study showed that 42% of more frequent home haemodialysis patients did not require

any blood pressure medication after twelve months⁹ treating at home and, according to a poll of home haemodialysis patients, 26% relied less on additional medication overall.⁵

Haemodialysis patient Afzal Moghal said "I get a better quality of dialysis with home haemodialysis; in hospital, you usually dialyse for four hours a day, three days a week, but at home I dialyse three hours a day, five days a week. Because I dialyse for longer over the week, I feel so much better than when I was in-centre."

Frequent home haemodialysis also offers reduced **recovery times** post sessions compared to in-centre haemodialysis, with 48% of frequent home haemodialysis patients reporting this to be the case.⁵ One study shows that patients on in-centre haemodialysis report an average of eight hours of recovery time post haemodialysis session, whilst those on frequent home haemodialysis report an average of just one hour.¹⁰

Haemodialysis patient Kim Richards says, "On in-centre haemodialysis, it's often the day after that it really hits you. You can feel ill up until the day after a session. When I was dialysing more often at home this didn't happen."

Haemodialysis patient Giulietta Whitmore says "I would go in to the centre for dialysis in the afternoon, but I would feel really awful right up until the next morning. I often used to black out after treatment in-centre and

would have to leave in a wheelchair, but after a few weeks dialysing more frequently at home this stopped happening."

Dr. Natalie Borman reports patients having a much faster recovery time after dialysing at home, "Many patients are able to do whatever they want within 30 minutes of finishing home haemodialysis dialysis. This is predominantly the result of being able to dialyse more frequently."

The KQuIP policy of **'Transplant First'** sets out the notion that a transplant is the preferred and

48%

of frequent home haemodialysis patients report reduced recovery times post sessions

Average of one hour recovery time, compared to eight hours for in-centre

¹² nhs.uk. (2018). Dialysis. [online] Available at: <https://www.nhs.uk/conditions/dialysis/> Accessed 2 Feb. 2018.

best option for someone with end-stage kidney failure to return to near-normal kidney function independent of haemodialysis support. However, there aren't enough organs for all those in need, and the waiting time for a kidney transplant in the UK is two to three years.¹³ Home haemodialysis can first, improve patients' quality of life during this waiting time, and second, improve their health levels and subsequent chances of receiving a kidney transplant.¹⁴

As haemodialysis is not a constant treatment, fluids have long periods of time to build up in a patient's body before they are removed. This is especially dangerous for in-centre patients that have to take a two-day break from treatment during the weekend, over either Saturday and Sunday, or Sunday and Monday.

The consequences of this are significant; in-centre haemodialysis patients are more likely to die after the 'two-day break' from haemodialysis. One study found a **22%** increase in deaths on the first day after the two-day break, when compared to the rest of the week,¹⁵ a fact that 24% of in-centre haemodialysis patients report is a concern to them.⁵ *Dr. Richard Fluck reiterates, "There is data showing that a long gap between dialysis is damaging. There is a greater risk of dying after a two day gap in dialysis compared to one day."*

IMPROVED MENTAL HEALTH

- » **Decreased levels of depression and anxiety:** Since beginning home haemodialysis, 58% of patients report being happier, and 52% experienced decreased anxiety levels.⁵
- » **Quality of life:** 71% of home haemodialysis patients have more time for hobbies and leisure, 61% are able to spend more time with friends and family, and 29% report a better quality of sleep.⁵

Studies show that long-term physical health conditions can lead to mental health issues¹⁶ and, according to Kidney Care UK, up to one in three patients with kidney disease will experience depression at some point,¹⁷ compared to approximately three in 100 of the general population.¹⁸

The benefits of switching to frequent home haemodialysis from in-centre haemodialysis are significant on mental health; polling reveals that 58% of patients report increased happiness, 52% feel reduced anxiety,⁵ and another report cites overall **lower levels of depression.**¹⁹

58%

of patients report being happier and

52%

witness decreased anxiety levels since switching from in-centre haemodialysis to home

¹³ nhs.uk. (2018). Kidney transplant waiting list. [online] Available at: <https://www.nhs.uk/conditions/kidney-transplant/waiting-list/> Accessed 2 Feb. 2018.

¹⁴ Weinhandl E, Liu J, Gilbertson D, Arneson T, Collins A. Transplant incidence in frequent hemodialysis and matched thrice-weekly hemodialysis patients. Poster presented at National Kidney Foundation Spring Clinical Meeting, 2012.

¹⁵ Benefits case study summary – Release of Hospital Episode Statistics data to UK Renal Registry (UKRR) and Sheffield Kidney Institute. (2016).

¹⁶ Naylor, C. (2012). Long-term conditions and mental health. [ebook] The King's Fund. Available at: https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/long-term-conditions-mental-health-cost-comorbidities-naylor-feb12.pdf Accessed 2 Feb. 2018.

¹⁷ Kidney Care UK. (2018). Mental health. [online] Available at: <https://www.kidneycareuk.org/about-kidney-health/living-kidney-disease/mental-health/> Accessed 2 Feb. 2018.

¹⁸ Mind.org.uk. (2017). How common are mental health problems? | Mind, the mental health charity - help for mental health problems. [online] Available at: <https://www.mind.org.uk/information-support/types-of-mental-health-problems/statistics-and-facts-about-mental-health/how-common-are-mental-health-problems/#.Wl8s865lIU> Accessed 2 Feb. 2018.

¹⁹ Jaber BL, Collins AJ, Finkelstein FO, et al. Daily hemodialysis (DHD) reduces the need for antihypertensive medications. Abstract presented at American Society of Nephrology Conference, October 29, 2009. (AMP1732:5 Mountains of Evidence. 2003: 21). And Finkelstein FO, Wuerth D, Troitle LK, Finkelstein SH. Depression and end-stage renal disease: a therapeutic challenge. *Kidney Int.* 2008;74(7):843-845.

Contributing factors could stem from improvements around quality of life and overall health; for example, 71% of patients on home haemodialysis have more time for hobbies and leisure, 61% are able to spend more time with friends and family, and 29% report better quality of sleep.⁵

Haemodialysis patient Matt Herbert says, "Mentally, I found having to rely on hospital visits really difficult. It was really tricky to juggle all aspects of my life—my dialysis appointments, my job and my family. Moving to home haemodialysis has really helped me to have the freedom to choose when and where I dialyse."

REGAINING CONTROL OVER LIFE

- » **Patients decide when they dialyse:** Home haemodialysis patients have more freedom than in-centre patients to choose their own dialysis schedule. 49% of in-centre patients claim a lack of independence and 62% want more flexibility on how often they dialyse.⁵
- » **Gain back time:** Home haemodialysis patients can save up to 52 days a year*, with less dialysis recovery time¹⁰, time spent travelling to the centre, and waiting for appointments.
- » **Employment opportunities:** 29% of frequent home haemodialysis patients are able to either work more often or to return to work.⁵
- » **Holidays:** In-centre haemodialysis stops 52% of patients from having the freedom to go on holidays.⁵
- » **Understanding treatment:** A patient's ability to understand his/her condition and treatment allows a greater sense of freedom and control over his/her illness.

For a patient on in-centre haemodialysis, inflexibility around the timings of sessions can be a strain. 49% of in-centre haemodialysis patients say they have experienced a loss of independence since needing to dialyse, with 62% seeking more flexibility on how often they dialyse and 60% wanting flexibility on what time of day they dialyse.⁵

Compared to in-centre haemodialysis patients, **71%** of patients on more frequent home haemodialysis have more time for hobbies and leisure, **61%** are able to spend more time with friends and family, and **29%** report better quality of sleep

Including recovery time, travel, and waiting times, in-centre haemodialysis patients spend **52 days** per year more than home haemodialysis patients on the process

*NxStage Data On File, NxStage Polling. 23/11/2017. Travel time: According to NxStage polling (2017), on average, ICHD patients have to travel 59 minutes to get to and from each dialysis session. 1 hour x 3 = 3 hours, 3 hours x 52 weeks = 156 hours / 6.5 days. Waiting time: According to NxStage polling (2017), on average On average, ICHD patients wait 20 minutes for their dialysis appointment to begin 20min x 3 = 60 min. 1 hour x x 52 = 52 hours / 2.2 days. Recovery time: A study by Rayner HC, Zepel L, Fuller DS, et al. reported that the average recovery time for a ICHD patient is eight hours per session. 8 hours x 3 times a week = 24 hours a week. 24 x 52 = 1248 hours a year / 52 days. MFHD patients report one hour recovery. 1 hour x 4 times a week = 4 hours a week. 4 x 52 = 206 hours a year / 8.6 days. 52-9 = 43 days. 43 + 2.2 + 6.5 = 52 days per year

On average, in-centre haemodialysis patients have to travel for one hour for each session, with 5% travelling more than two hours each time.⁵ Average waiting time once at the centre is then 20 minutes. For a patient dialysing three times a week, that's seven days a year spent travelling, and two days waiting for appointments. Combined with additional recovery time, and not including actual time spent dialysing, **in-centre haemodialysis patients spend 52 days per year more than home haemodialysis patients on the process.**

On home haemodialysis, patients can dialyse when they like — overnight or during the day. This flexibility can increase quality of life and feelings of autonomy, with 90% of patients saying home haemodialysis gives them more freedom and 87% claiming they have more independence.

Matt Herbert said “I choose to dialyse overnight in my own bed, which means I can spend much more quality time with my family. I would have missed out on special family moments had I been dialysing in-centre.”

Also limiting choice is the fact patients on in-centre haemodialysis often have **restricted diets**.²⁰ According to Dr. Natalie Borman, “Frequent home haemodialysis patients have the ability to be more liberal with their diet and fluid intake. This is hugely important for patients trying to live life as normally as possible.”

Compared to dialysing in-centre

90%

of home haemodialysis patients say they have more freedom and **87%** have more independence

Matt Herbert says, “When I was on in-centre haemodialysis I had a very restricted diet, but now it’s much more relaxed and I don’t have to worry so much.”

With in-centre haemodialysis patients spending days of the working week in hospital dialysing, many patients find themselves with no option but to give up their jobs or reduce their hours at work — an issue reported by 37% of in-centre haemodialysis patients polled.⁵ This loss of income can cause further stress to both patients and families, with studies linking unemployment to an increased risk of mortality, lower self-esteem, depression, and damaged family and social life.²¹

By comparison, quicker recovery time and the increased flexibility with frequent home haemodialysis means **regular employment becomes more of an option.**

Dr. Natalie Borman says: “We’ve seen an increase in people returning to work or increasing their hours at work. Our patients also report being able to take part in more social events which they were otherwise having to turn down because of their rigid dialysis regime.”

Giulietta Whitmore said “Flexible treatment has transformed my life. Since being on home haemodialysis, I’ve been able to go back to work, knowing I can come home and be on my machine around 8pm.”

²⁰ Spanner E, Suri R, Heidenheim AP, Lindsay RM. The impact of quotidian hemodialysis on nutrition. *Am J Kidney Dis.* 2003;42(1 suppl):30-35. And Galland R, Traeger J, Arkouche W, Cleaud C, Delawari E, Fouque D. Short daily hemodialysis rapidly improves nutritional status in haemodialysis patients. *Kidney Int.* 2001;60(4):1555-1560

²¹ Leahy, R. (2013). Unemployment Is Bad for Your Health. [online] HuffPost. Available at: https://www.huffingtonpost.com/robert-leahy-phd/unemployment-health_b_2616430.html?guccounter=1 Accessed 5 Jul. 2018.

Morris J, Cook D, Shaper A. (1994). Loss of employment and mortality. *BMJ*, 1994;308(6937):1135-1139.

Griffin, J. (1993). The Impact of Unemployment on Health | OHE. [online] Ohe.org. Available at: <https://www.ohe.org/publications/impact-unemployment-health#> Accessed 2 Feb. 2018.

Matt Herbert said, “I did still work as a chef when I was dialysing in-centre but juggling work with my dialysis appointments was a real struggle. I had to get up at 5:30am three times a week to travel 25 miles to the dialysis unit. I was always late for work and, once I was there, I wasn’t fully recovered from the dialysis session, so I felt unwell.”

52% of in-centre haemodialysis patients say they have not been able to go on holiday because of their treatment.⁵ While it is possible, patients must ensure destinations are close to dialysis centres, and plan months in advance to ensure there is space for them to attend. Haemodialysis across the EU/EEA is currently provided for free, or at a reduced cost if you travel with a valid EHIC card²²; however, once Britain has left the EU, this is no longer guaranteed.²³

With home haemodialysis, travelling within the UK and abroad becomes a great deal easier as machines are portable and can often be checked with baggage on airplanes for free when prearranged.²⁴

Afzal Moghal, who recently travelled for the first time in a while, said “My wife and I went on holiday to Barcelona with our two daughters. If I had been dialysing in a Spanish dialysis unit, I would’ve lost four days in a hospital and then recovering in the afternoon. Taking my home haemodialysis machine meant I could dialyse in my hotel room at night without losing a day of my holiday.”

Also adding to the value of home haemodialysis is a patient’s opportunity to gain a **deeper understanding of their condition and treatment.**¹⁹

According to Dr. Natalie Borman “Self-engagement helps a patient learn and control their personal diagnosis and ultimately improve their overall wellbeing. Taking control of their diagnosis and having a sense of self-awareness certainly helps to empower patients”.

Afzal Moghal agrees: “When you do your own treatment, you understand far more about your condition. When you go in-centre, you just sit in your chair and have dialysis. Now I actually understand the process.”

²² Brexit Health Alliance, Maintaining reciprocal healthcare for patients after Brexit. (2017). [ebook] Brexit Health Alliance. Available at: <http://www.nhsconfed.org/~media/Confederation/Files/Publications/Maintaining-reciprocal-healthcare-for-patients-after-Brexit.pdf> Accessed 2 Feb. 2018.

²³ Kidney Care UK. (2018). Future of European Health Insurance Cards (EHIC) for kidney patients. [online] Available at: <https://www.kidneycareuk.org/news-and-campaigns/news/kidney-care-uk-calls-uk-government-ensure-thousands-people-dialysis-can-continue-travel-europe-after-uk-has-left-european-union/> Accessed 26 Jun. 2018.

²⁴ Caa.co.uk. (2018). What items can I travel with | UK Civil Aviation Authority. [online] Available at: <https://www.caa.co.uk/Passengers/Before-you-fly/Baggage/What-items-can-I-travel-with/> Accessed 26 Jun. 2018.

WHY EQUAL ACCESS TO HAEMODIALYSIS MATTERS: COST SAVINGS FOR THE NHS

- » 1.3% of the NHS budget is spent on kidney failure treatment.²⁵
- » By 2030, the number of people requiring haemodialysis globally may double.⁷
- » 50% of England's dialysis hospitals' transport costs are accounted for by haemodialysis.²⁶

Any opportunity to save the NHS money whilst offering the opportunity for better patient outcomes should be explored fully, especially in light of rising healthcare costs, reduced funding, lifestyle changes, and an increased demand on services.

Kidney failure services are costly—1.3% of the NHS budget is spent on this area of treatment, approximately £1.45 billion a year.²⁵ Only 0.1% of the UK population receives renal replacement therapy, yet their treatment takes up 1.3% of the overall budget.²⁷ Home haemodialysis can provide an important opportunity for the NHS to save resources. This is significant when considering that the need for haemodialysis may double across the world by 2030.⁷

A large cost of in-centre haemodialysis is transport, as patients travelling to hospital three times a week for dialysis travel to and from their sessions. According to the National Kidney

Federation (NKF), in England's 52 hospitals offering dialysis, 50% of their patient transport costs are accounted for by dialysis.²⁸

Dr. Natalie Borman says, "One significant area where home haemodialysis saves the NHS money is the reduction of water and electricity use. Standard in-centre machines need expensive water tests to run. With NxStage home haemodialysis machines, provided the home's water supply reaches certain standards, just an initial one-off test is required."



50%

of England's dialysis hospitals' transport costs are accounted for by haemodialysis

²⁵ England.nhs.uk. (2017). [online] Available at: <https://www.england.nhs.uk/improvement-hub/wp-content/uploads/sites/44/2017/11/Chronic-Kidney-Disease-in-England-The-Human-and-Financial-Cost.pdf> Accessed 28 Jun. 2018.

²⁶ kidney.org.uk. (2017). Home Haemodialysis the advantages for suitable patients. [online] Available at: <https://www.kidney.org.uk/help-and-info/medical-information-from-the-nkf-/medical-info-haemodialysis-why-home-dialysis/> Accessed 2 Feb. 2018.

²⁷ Number of patients on RRT: MacNeill, S et al (2018). UK Renal Registry 20th Annual Report: Chapter 2

UK population: Population estimates for UK, England and Wales, Scotland and Northern Ireland - Office for National Statistics. (2018). Ons.gov.uk. <<https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/bulletins/annualmidyearpopulationestimates/mid2017>> <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/bulletins/annualmidyearpopulationestimates/mid2015#main-points>

²⁸ kidney.org.uk. (2017). Home Haemodialysis the advantages for suitable patients, Accessed 4 July 2018.

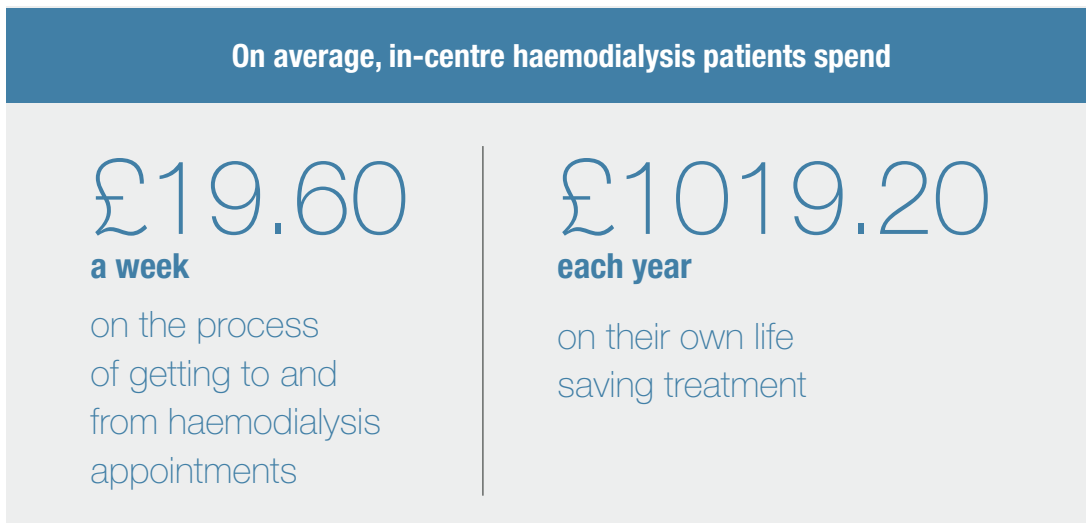
WHY IT MATTERS: COST SAVINGS FOR THE PATIENT

» In-centre haemodialysis patients spend, on average, £1019 each year on haemodialysis appointments.⁵

On average, an in-centre haemodialysis patient spends £19.60 a week on the process of getting to and from haemodialysis appointments.⁵ This takes into account costs that wouldn't otherwise have to be spent, including travel costs not paid for by the NHS, parking, food, and childminding. That is **£1019.20 each year that a patient has to pay for their own life saving treatment.**⁵

According to MP Robert Halfon, considering the minimum appointment time and average parking costs, the average in-centre patient spends approximately **£511.68 a year on car parking charges.**²⁹

These costs are in addition to the likelihood that many in-centre haemodialysis patients find themselves with no option but to give up their jobs or reduce their hours at work.



²⁹ UK Parliament. (2018). Early day motion 889 - HOSPITAL CAR PARKING AND DIALYSIS PATIENTS. [online] Available at: <http://www.parliament.uk/edm/2017-19/889> Accessed 2 Feb. 2018.

ACCESS TO HOME HAEMODIALYSIS: A POSTCODE LOTTERY

- » 4.4% of patients on dialysis in the UK are on home haemodialysis.⁴
- » NICE suggests that 10–15% of dialysis patients would opt for home dialysis, if given the choice.³

Independent Polling of kidney haemodialysis patients found:

- » 27% of patients were not educated on all types of dialysis that would be beneficial for them.⁵
- » 36% of patients rate their knowledge of home haemodialysis as not good.⁵
- » 8% of patients were given no information about home haemodialysis at all.⁵
- » 32% of patients on home haemodialysis found relevant information independently.⁵

NICE recommends that 10–15% of dialysis patients, if given the choice, would opt for home haemodialysis, but the reality is much different and the regional variation in uptake is huge.³

Just 4.4% of dialysis patients in the UK are currently on home haemodialysis. In England, this figure is 4.5%, Northern Ireland 2.4%, Scotland 2.5%, and Wales 6.8%.

City to city, it is a postcode lottery as the range of dialysis patients on home haemodialysis varies a great deal from 0% of patients to 13.2%. Derby is the centre with the highest uptake (13.2% – three times higher than the national average).⁴

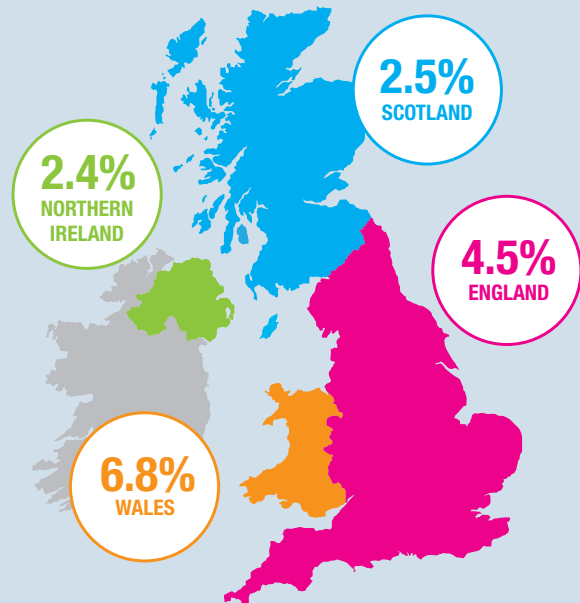
As a global comparison, New Zealand currently has more than 17% of its haemodialysis patients dialysing at home, with Australia having around 9%.³⁰

Just **4.4%** of dialysis patients in the UK dialyse at home,

10% lower than the upper boundary of the NICE recommendation

New Zealand has more than **17%**, and Australia has around **9%**

Percent of dialysis patients in the UK that are currently on home haemodialysis



³⁰ Anzdata.org.au. (2017). Highlights key for 2016: ANZDATA Australia and New Zealand Dialysis and Transplant Registry. [online] Available at: http://www.anzdata.org.au/brochures/brochure_2016v1.0_20180417.pdf [Accessed 2 Aug. 2018].

According to Dr. Richard Fluck, “There are pockets of the UK that are doing well with uptake of home haemodialysis, but rates are shockingly varied and there’s no clear pattern such as rural vs. urban. It’s the culture and leadership of the team that is key, not the location. There should be equity for patients across the country, but at the moment there really isn’t.”

Highlighting the lack of choice around home haemodialysis: 27% of patients were not educated on the types of dialysis that could be beneficial for them, 8% reported receiving no information about home haemodialysis at all, and 31% of in-centre patients say home haemodialysis was never discussed by their health professional.⁵

Of those who are now on home haemodialysis, 32% resorted to finding the relevant information independently.⁵

It’s therefore of little surprise that 36% of all haemodialysis patients rate their knowledge of home haemodialysis as not good.⁵

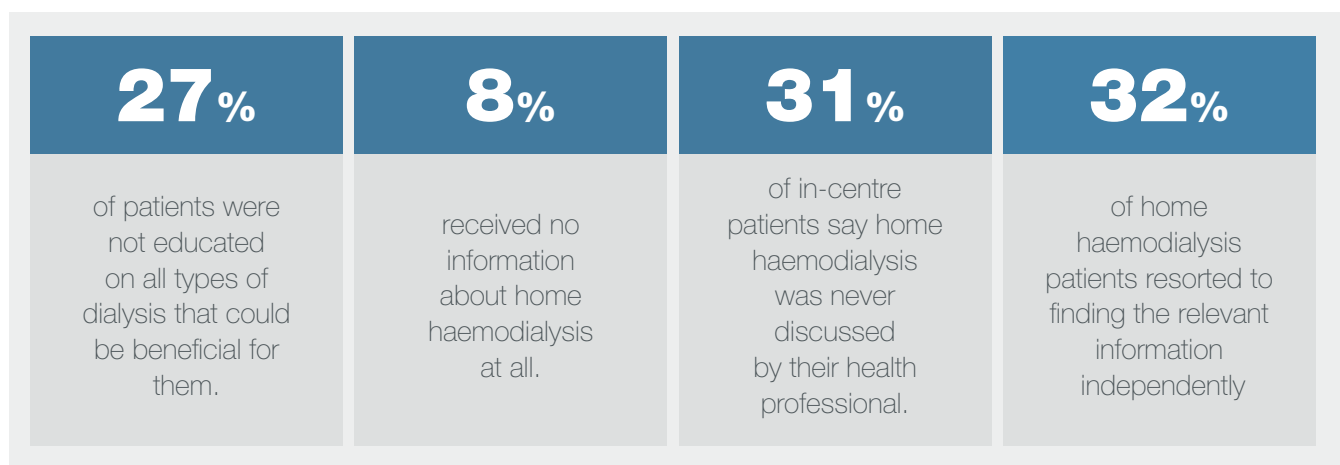
Giulietta Whitmore says, “I wasn’t offered the choice of home haemodialysis by my centre as it was a new programme. I found a leaflet on home haemodialysis at my satellite renal unit and enquired about it myself. Once I asked they were quick to transfer me and really

supportive of my decision, but I had to push for it in the first instance.”

Kim Richards said, “The only reason I knew about home haemodialysis was because my mum works at QA hospital in Portsmouth where they offer it to a lot of kidney failure patients. My hospital only offers home haemodialysis if you ask for it, they don’t suggest it to you even if it might be the best treatment for you. Once I was on the programme, the nurse was brilliant.”

Afzal Moghal found the process more straight forward, saying, “I was invited to a Home Haemodialysis Tea Party by my hospital, where patients spoke to my wife and I and helped to convince her that home haemodialysis would be beneficial for me. The hospital then showed us the device that would be put in our house, and we made the decision to go for it. They were really helpful.”

Where you live in the country should not significantly impact whether or not you even hear about home haemodialysis as an option. Whilst some trusts are working hard to increase uptake, all centres fall below the recommended NICE guidelines.



BARRIERS TO HOME HAEMODIALYSIS: CLINICIAN-LED CHANGE, EDUCATION, AND MYTHS

There are a number of barriers that stand in the way of greater uptake of home haemodialysis. These range from cultural barriers within the healthcare sector, to myths that can be tackled through education of both professionals and patients.

Key learnings emerging from conversations with clinicians and patients are:

Change has to be clinician led

Without the support of clinicians, patients may find it hard to push for a different treatment modality themselves. Not everyone will research it independently, so it is important that a meaningful discussion about home haemodialysis is had as soon as possible, and that the infrastructure is in place to make it easy as possible for patients to access.

Dr. Richard Fluck says that “Patients need to be involved in discussions about their treatment, but if home haemodialysis isn’t part of the conversation at the start, patients will rarely bring it up themselves. They need the encouragement from their renal team to have the confidence to go for it.”

Sister Carol Rhodes says “The postcode lottery of patients receiving or being offered home haemodialysis is largely down to the decisions made by business managers and non-clinical staff. But, as clinicians, it is our job to educate

on the many benefits and justify through a focus on cost savings over time.”

Lack of patient education

It is absolutely vital that all patients are given full information on all types of dialysis to inform their choice before starting treatment. 55% of patients who are educated on their options, before they start treatment for kidney failure, select self-care options, including home haemodialysis, suggesting that those that aren’t fully informed may be missing out.³¹

9% of haemodialysis patients said that they didn’t opt for home haemodialysis because they didn’t receive enough training or education on it, with 9% dismissing it as too complicated.⁵

Sister Carol Rhodes says, “Having a dedicated team promoting home haemodialysis to patients and encouraging safe training environments is key to increasing the uptake. Derby’s success has been down to a solid team that educates patients, and gives them the chance to meet with patients already on dialysis at home.”

³¹ Goovaerts T, Jadoul M, Goffin E. Influence of a Pre-Dialysis Education Programme (PDEP) on the mode of renal replacement therapy. *Nephrol Dial Transplant.* 2005;20(9):1842-1847.

Myths around home haemodialysis

A number of myths around home haemodialysis remain:

- » **45% of in-centre haemodialysis patients believe you need a lot of training to do home haemodialysis.**⁵

This is incorrect; training can be done in just two weeks. For kidney patient Matt Herbert, who had been needling himself in-centre for about five or six years, learning how to work his home haemodialysis machine only took four days. **17% of in-centre haemodialysis patients make the assumption that the majority of kidney failure patients are not suited to home treatment.**⁵

Dr. Natalie Borman says, “We find ourselves selecting patients with more complex needs for home haemodialysis as they often have the most to gain from being at home. Of course, home haemodialysis is not right for everyone, but patients should not be excluded based on their medical conditions alone.”

- » **36% of home haemodialysis patients wrongly believe that all home dialysis machines are big and bulky; 35% believe there are complicated plumbing issues to install in the home.**⁵

In reality, new technology means that this is no longer the case. There are machines that are no bigger than a desktop printer, and the plumbing needed is very minimal.

RECOMMENDATIONS FOR CHANGE WITHIN THE NHS

NxStage and leading home haemodialysis health professionals have the following advice for other professionals looking to increase the uptake of home haemodialysis within their trusts.

Think can, not cannot

While home treatment will not be right for everyone, consider whether a patient can do the treatment at home, rather than whether they cannot. Older people are often unfairly written off from home therapies and, sometimes, it is the people with the most serious cases who have the most to gain.

It is important that all patients are informed of the potential benefits that home haemodialysis can offer and have positive conversations about their options.

Dedicated and efficiently trained staff/ home haemodialysis team

Having a cohesive team that is on the same page in speaking about home haemodialysis positively can help increase the uptake. It's wise to invest in a training programme for home haemodialysis to ensure that all staff are fully informed about all aspects of the treatment; including the treatment process itself, the technology, and the pros and the cons for different patients.

Provide solutions, not barriers

Be positive in conversations around home haemodialysis and have an open mind. If patients have questions, it's often effective to introduce them to other patients that are already dialysing at home so they can speak to someone first-hand about the treatment.

Patient outcomes are key

In the case of home haemodialysis, the cost savings tend to be easiest to quantify for the overall health system rather than for individual units. With the majority of trusts focusing on their own output, rather than the systems', focusing on how more frequent home haemodialysis can improve patient outcomes, rather than cost savings, might result in better success.

A GUIDE FOR HAEMODIALYSIS PATIENTS, BY HAEMODIALYSIS PATIENTS

The following recommendations have been made by kidney patients that have benefitted from home haemodialysis, for those who are considering switching from in-centre dialysis to home haemodialysis.

1. Ask your consultant or dialysis nurses if your centre has a home haemodialysis team.
2. If your renal team does not have a home haemodialysis team, discuss your wish to start home haemodialysis with your consultant as there may be something he/she could do. If not, think about getting in contact with Kidney Care UK or a similar charity as they may be able to provide support with treatment options.
3. If your renal team does have a dedicated home treatment team, discuss moving onto home haemodialysis with your consultant; healthcare decisions should always be made in partnership with your doctors and nurses.
4. Consult with your family. Dialysing at home will impact them as well so it's important to involve them in the decision.
5. Ask your renal team about the possibility of moving on to self-care treatment in-centre first. This can be a brilliant way to prepare yourself to dialyse at home as you learn how to set up the machines, needle yourself, and then remove yourself and clean up in the safety of the hospital before you move home.
6. After consulting with your doctor and family, decide whether you think home haemodialysis might be for you.

CONCLUSION

This report demonstrates the significant benefits of frequent home haemodialysis for patients in terms of health outcomes, quality of life, and overall wellbeing.

Home dialysis won't be right for every patient, but the injustice in the system is the denial of choice and blocking of better treatment options for so many kidney patients.

Healthcare professionals have a professional obligation to discuss options in a meaningful way. The independent research conducted for this report shows that, at the moment, this is not happening.

Instead, access to what is often a transformative alternative to in-centre dialysis is blocked by patchy delivery of information and service. The result is that, while some progressive centres have five times the national uptake average, the vast majority of kidney patients are given no real choice when it comes to dialysis options.

Systemic denial of access to the benefits of more frequent home haemodialysis, including greater chance of transplant and lower risk of death, represents a shocking unfairness for patients. It also blocks the opportunity for financial savings for the NHS when it comes to dialysis care, transport costs, and additional medication. The loss of independence, freedom, and flexibility also impacts patients' wellbeing and mental health, further draining NHS resources.

It's time for policy makers, healthcare professionals, and NHS management to take note of home haemodialysis as a solid and viable alternative for costly, time-consuming, and, for many, physically and emotionally draining in-centre dialysis treatment. Particularly at a time when the health service is being stretched and demand for dialysis is set to increase dramatically.

This is not the first time this issue has been looked at, and this report ends with a call for urgent action. Ultimately, it's a matter of patient choice; each of us should be granted access to the best possible treatment available — irrelevant of our postcode.

APPENDIX

Table 1: Percentage of prevalent dialysis patients by dialysis modality and centre on 31/12/2016, from 2017 UKRR report.⁴

Centre	Prevalence of HHD as a proportion of all dialysis patients	Centre	Prevalence of HHD as a proportion of all dialysis patients
Aberdeen		London Guys	6.6
Airdrie	0	London Kings	2.7
Antrim		London Royal Free	2.3
Birmingham Heart	3.9	London St. George	
Birmingham QEH	4.9	London West	1
Bangor	11	Leeds	3
Basildon		Leicester	6.9
Belfast	4.1	Liverpool Aintree	6.1
Bradford		Liverpool Roy	8.9
Brighton	7.1	Manchester Royal Infirmary	10.2
Bristol	3.4	Middlesbrough	3.1
Cardiff	5.2	Newcastle	
Carlisle		Newry	
Carsh	3.0	Norwich	4.2
Chelmsford		Nottingham	6.1
Clwyd		Oxford	3.5
Colchester		Plymouth	4.4
Coventry	2.7	Portsmouth	10.6
D& Gall		Preston	6.8
Derby	13.2	Reading	2.2
Doncaster	4.1	Salford	5.5
Dorset	2.8	Sheffield	7.9
Dudley	5.5	Shrewsbury	7.8
Dundee		Stevenage	4.7
Edinburgh		Southend	
Exeter	1.7	Stoke	8
Glasgow	3.6	Sunderland	2.2
Gloucester		Swansea	9.1
Hull		Truro	4.8
Inverness	6.7	Ulster	
Ipswich	0	West NI	
Kent	4.5	Wirral	4.5
Kilmarnock		Wolverhampton	7.8
Kirkcaldy		Wrexham	
London Barts	1.9	York	6.1

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RISKS AND RESPONSIBILITIES

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

Despite the health benefits that home and more frequent hemodialysis may provide to those with chronic kidney disease, these forms of therapy are not for everyone. Please review this information carefully and discuss it with your doctor as you evaluate your therapy options.

Personal and Partner Responsibility

Home hemodialysis with the NxStage System requires a patient and partner who are committed to being trained on and following the guidelines for proper system operation. If you choose to do more frequent home hemodialysis, you will be responsible for complying with your dialysis prescription, which may require treatments up to six days per week.

If you choose to do home hemodialysis, you and your partner will need to take on the responsibility for tasks that would normally be taken care of by staff when in-center. You will need to perform all aspects of dialysis treatment from start to finish, including equipment setup, needle insertions, responding to and resolving system alarms, and system tear-down after treatment. In addition, you must monitor your blood pressure, ensure proper aseptic technique is followed, and follow all the training material and instructions given to you by your training nurses. You and your partner will also be trained on and need to know how to respond to health emergencies that might happen during treatment at home, including dizziness, nausea, low blood pressure, and fluid or blood leaks.

Treatment Environment

You must ensure that you have a clean and safe environment for your treatments. You also need to set aside space in your home for the needed supplies.

Risks Associated with All Forms of Hemodialysis

All forms of hemodialysis involve some risks. These may include high blood pressure, fluid overload, low blood pressure, heart-related issues, vascular access complications, cramps, backache, headache, dizziness, nausea, an “off”

taste in the mouth, fatigue, fever, chills, joint pain, itching, seizures or sinusitis.

All hemodialysis therapies also involve the use of medical devices that introduce the potential for additional risks including air entering the bloodstream, damage of red blood cells, inflammatory reactions, blood chemistry imbalances, blood loss due to clotting of the blood tubing set or accidental blood line disconnection or other leak, allergic reactions, and excess warming or cooling of the dialysate. In addition, dialysis patients may have other underlying diseases that may, in some cases, make it more difficult for them to manage their hemodialysis treatments.

Risks associated with More Frequent Home Hemodialysis

Studies suggest that patients performing more frequent home hemodialysis may experience slightly fewer complications associated with their treatments and may experience improved clinical outcomes. However, there are certain risks unique to treatment in the home environment. 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. When vascular access is exposed to more frequent use, infection of the site, and other access related complications may also be potential risks.

Increased Risks Associated with Home Nocturnal Hemodialysis Therapy

The NxStage System may be used at night while the patient and care partner are sleeping. Certain risks associated with hemodialysis 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. Treatment with nocturnal therapy may require adjustments

to medications, including but not limited to iron, Erythropoiesis-Stimulating Agents (ESA), insulin/oral hypoglycemics, anticoagulants, and phosphate binders.