IMPROVING CHOICE: LISTENING TO PATIENT STORIES
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Patients are at the heart of everything we do in the NHS. In order to uphold the high quality service during these lean times, the government has pledged to create a patient-led NHS, with a focus on outcomes rather than numbers. The services provided will be underpinned by patient experience and safety.

The patient experience of those with end stage renal disease depends very much on their type of treatment. Access to home dialysis can literally transform a person’s life. More freedom and flexibility, less travel time and fewer dietary restrictions all lead to a better quality of life. One home dialysis patient reports that she now “dialyses to live, rather than lives to dialyse.”

Shared decision making is key to ensure patients can access the most suitable type of treatment, by equipping them with relevant information to make an informed choice. Equity and Excellence: Liberating the NHS makes clear the government’s commitment to shared decision making, with the patient pledge: ‘no decision about me without me’.

Home dialysis may not suit everyone, but NICE guidelines recommend that all patients are given the choice to dialyse at home, with evidence suggesting home dialysis patients have better clinical outcomes. However, although the overall number of people needing dialysis continues to rise, the number of patients on home haemodialysis and peritoneal dialysis has fallen in recent years, which suggests barriers exist to prevent the uptake of home dialysis. There also appears to be wide variation between units offering home dialysis as a treatment option.

Geography, and indeed any other factor, should have no bearing on access to home dialysis. There is no typical home dialysis patient. I have met people of all ages, men and women from every ethnic and socio-economic background, most with other underlying health problems. On a recent visit to a renal unit in the Midlands I met a lady in her 80s who, with the support and care of her husband, successfully manages home dialysis. I have also heard about a student in her 20s whose university adapted her accommodation to allow her to dialyse whilst continuing her studies. All too often, the barriers that prevent dialysis in the preferred place of care are perceived barriers, which can be overcome with a team approach and an open mind.

Even for those who already successfully dialyse at home, there is still work to do. Many home haemodialysis patients struggle to take holidays as their machines are either too bulky or too costly to take abroad. One person in this report describes how a return to hospital dialysis while on holiday makes him feel quite unwell – surely the opposite effect that a holiday should have. There is also a greater level of support required for the partners and family members of home dialysis patients, who often take on the role of carer. Recognition by the local care team of the impact on patients’ partners is hugely important along with the need to consider respite care within the care plan. Providing access to peer support for both patients and carers also requires consideration at a local level – nationally, the online home dialysis discussion forum that has recently launched on Renal Patient View will, I’m sure, prove to be a very useful resource.

Throughout summer 2010, NHS Kidney Care hosted ten roadshows, one in each Specialised Commissioning Group patch, to help improve patient choice and open up access to home therapies. I was lucky enough to meet a number of fascinating, focused and determined people, from all different ages and backgrounds, but all with one thing in common – they are people who dialyse at home. Some of their stories are summarised in this report, which provides a very personal, yet powerful, insight into home dialysis.
I would like to thank all the patients and partners who gave their time so willingly and spoke so openly and honestly about their experiences on home dialysis. Not only will this report be useful to those considering dialysis options, it will also provide a tool for commissioners, providers and clinicians in helping to overcome the barriers that exist in offering home therapies, and in ensuring that all kidney patients have genuine choice over their treatment.

I would also like to thank the author of this report, Anthea Duquemin, for her sensitivity and skill in bringing together the individual accounts into one compelling story; also Mark Brady and Helen Hoyland, for their invaluable help and advice.

Beverley Matthews
Director
NHS Kidney Care

1. Equity and Excellence: Liberating the NHS
Between April and September 2010 NHS Kidney Care hosted ten Improving Choice: Home Therapies Roadshow events across England, describing and discussing in each region local approaches towards home dialysis. Presentations demonstrated national and local trends in renal replacement therapies; clinicians and commissioners presented facts and views about home dialysis; and small group discussions devised potential strategies for increasing opportunities for choice in their region, particularly for those who wish to dialyse at home.

Valuable as these presentations and discussions were, one of the most powerful parts of each of the ten events was the personal story told by a resident local to each region of his or her experience of home dialysis. In some cases the partner of the person who dialyses at home also spoke about the impact home dialysis has on their life.

With permission from the people who described their experience, nine of the home dialysis patient stories have been captured, either by recording them at the event, and/or by interviewing the person shortly afterwards. Information from these stories paints a powerful and personal account of the situations, options and implications relating to home dialysis, for those who dialyse and for those closest to them.

Of the nine people whose stories inform this report eight, by chance, are men. Eight are on home haemodialysis and one on Continuous Ambulatory Peritoneal Dialysis (CAPD). The ages of the nine range from early 20s to early 60s. Some have been on dialysis for a long time, others not; some grew up knowing that they were likely to have renal problems, for others kidney failure came as a complete surprise. These people are not chosen as a representative sample of people who dialyse at home, they are nine people who were known to the regional organisers of the roadshows and who were willing to tell their stories. We are very grateful for their generosity in sharing their experiences so openly.

The following pages of this report highlight some of the experiences of home dialysis under the following headings:

- How do people discover home dialysis?
- What factors influence the decision to dialyse at home?
- What training is required for home dialysis?
- What adaptation is required for home dialysis?
- What are the advantages of dialysing at home?
- What are the costs and challenges of dialysing at home?
- What improvements are yet to be made?
- What advice would those using home dialysis give to those considering it?

The summary at the end of this report highlights key points, but the words of the home dialysis patients themselves in the body of this report and in their individual stories express the issues far more eloquently and powerfully.
How do people discover home dialysis?

The varied ways in which people represented in this report learned about the option to dialyse at home illustrate the different approaches to home dialysis across different regions, and across time.

Paul, who is in his early 40s, recalled being given little choice, in the late 1980s, other than home dialysis.

I can vividly still remember the actual, the conversation that we had and what actually happened. I was sat down dialysing and because at that time we’d had quite a big predominant home dialysis programme and they couldn’t keep me in hospital, they didn’t have, well they may have had a satellite somewhere, but they didn’t have anywhere for me, and I couldn’t keep going to St James’s, I was told that I would have to go upstairs to start training to do my own needling and things like that, for home dialysis. .... But at that time I didn’t want to do it and that’s when the CAPD nurse came up to me and started talking about the CAPD side of things which was the way that I went.

More recently, in the past four years, a further four of the people represented here who were dialysing in hospital or satellite units were invited by staff to consider dialysing at home.

By contrast, in the same four years people from other regions made their own discoveries about the option of home dialysis, and achieved it only through their own motivation and persistence. Nick, 41, had been dialysing in hospital for four years, after his long-standing kidney transplant failed.

... my wife & I knew about the NICE guidelines and we started bombarding the matron of the local hospital with letters saying the NICE guidelines say we should have access to home haemo. ... After a sustained campaign of letters, [the matron] came and started talking about this NXStage machine ...

William, in his mid 30s, had been on CAPD for five years, then satellite haemodialysis for two years, before learning of home dialysis when dialysing in a Danish hospital while visiting his grandparents.

So for that year, after I first heard about home dialysis, I did a lot of research on the web about it and I thought, this sounds really good. It sounds like something that I could do if I could get over my needle phobia. So I started, I hadn’t spoken to any consultants or anybody at this point, so I just started at the dialysis unit, learning the machine as much as I could and taking my own needles out ...

With determination he overcame his needle phobia and began to self-care at the satellite unit.

It was at that point that I then thought, well I probably need to do home dialysis now. Unfortunately there wasn’t anything, there was no training available at the time, to do home dialysis ... So I had to carry on with what I was doing. I think I probably waited about six or seven months for them to recruit somebody and get the training programme going again.
What factors influence the decision to dialyse at home?

For some people home dialysis is self-evidently the optimal choice. Those who fought for the right to dialyse at home saw the benefits as overwhelmingly outweighing any challenges involved.

For others their circumstances and concerns made the decision less clear cut. Paul who, in the late 1980s resisted the invitation to dialyse at home, illustrates some of the factors that influenced this decision. At that stage he was in his early 30s and had just begun dialysis.

But at that point, in my life, I mean I was just starting and the thought of doing all that and everything was quite daunting to me ... my parents had actually moved house to somewhere that actually had land at the side of the house ready to put a portable porta-cabin in and things like that .... But at that time I didn’t want to do it ...

Again, after failed transplants he chose to continue with haemodialysis at the satellite unit to avoid dialysis being a presence at home.

I didn’t want my house, everything in my house to sort of look like a hospital ... with the machine and the stores and the needles and things like this, especially having a young daughter as well at the time.

In October 2009 Paul reluctantly acknowledged that home dialysis was the only way to access the additional dialysis time that was crucial for his health. His home circumstances had changed, making the decision more palatable than had previously been the case.

And my daughter was older ... she was 18, so she was at that stage in her life where it didn’t matter as much for her to ... have everything around the house ...

At that stage he was dialysing three times a week at a satellite unit.

... I was quite happy to go three times a week up to the satellite unit, which is only ten minutes away from where I live, to go up there and it was sort of like a socialising side of it as well. So I was seeing the nurses, I was seeing you know, the usual staff and patients, having a bit of banter and a chat and things like that.
The combination of proximity to home, sociability, and the freedom it gave him to leave it all behind made dialysis at the satellite unit the most attractive option for Paul.

... the defining thing was for me to go home was that they just could not give me any extra hours on the machine. I would have been quite happy to be going up [to the satellite unit] three times a week if they could have given me four or five hours, because it was only ten minutes away from where I lived. If I had to do 40 minutes in an ambulance, then that would have been a different matter, you know, I would’ve probably gone [to home dialysis] that little bit earlier. But because I drove myself in and drove myself home as well, and did everything for myself while I was there, it was sort of like home dialysis but in a hospital setting, which kind of suited me.

The strength of social ties built over years of dialysing together was evident.

... when I did leave ... I kept the leaving to myself until a couple of sessions before I actually left because I knew how one or two of the people that I’d dialysed with there for the last ten years ... I knew how they’d sort of take it. They got quite upset and I think it was a bit of an upheaval for them as well. I still go to the satellite unit ...

Yeah, I go up and see them once a month, once a couple of months, something like that, just keep in touch.

Stuart, in his late 50s, who was offered home dialysis after about a year of hospital haemodialysis was happy with the idea, but his wife was less sure.

... then I was approached to see whether in fact I might be interested in doing home dialysis. ... I had the space to put a dialysis machine in a room and there was no difficulty with it there. My wife ... wasn’t particularly keen to take the responsibility of it, but as time has gone on, she’s got more comfortable with it, I’m not saying it’s ideal and perfect.

Stuart’s wife Jean feels strongly that more attention should be paid at the outset, when home dialysis is first considered, to ensure that the home dialysis patient’s partner is fully informed about the requirements and implications.

I was never told at the beginning that I would be responsible for life, you know? ... it was suggested, the dialysis at home, and we thought, oh that will be fine, that will be so much easier, and I just assumed somebody came and sorted it. Nobody told me ...

I thought what should have happened is that somebody should have got me in, without the patient, without my husband and said, look, this is what you’re going to have to do.

Another wife experienced a similar lack of recognition of the impact that the decision to dialyse at home would have on her as a partner.

... kidney patients do have wives and husbands and families and whatever type of dialysis is chosen as being the best one for them, obviously their family will wholeheartedly support that, because we want them to be as well as they possibly can, but you know, we are husbands, wives and families and the choice is going to impact on our lives to some greater or lesser extent. And I’m not sure that that is always considered.

... I think just an acknowledgement that there is an impact on my life too.
What training is required for home dialysis?

For people who were already self-caring in their regular dialysis at the hospital or satellite unit, training for home dialysis involved minimal adaptation.

Paul, who had been on haemodialysis since the 1980s had been taught to self-care from the start.

I've always been able to do everything for myself, for the last sort of 10-15 years ... to needle myself and prime my machine and everything, because that's the way that I was taught, in the early days ... I didn’t have any problems. Because I’d been doing everything for myself for so long, the only thing that I had to do was ... learn how another machine works and what button does what and how you line it, set it up and strip it down and things like that, because for some reason, they went with another provider for the home dialysis service ... But I mean after two days, after a couple of sessions doing it, getting used to it and things, I was away really in the hospital where the home dialysis takes place.

More recently, about four years ago, William, who had a needle-phobia, taught himself to self-care over a period of about three months, in the satellite unit where he dialysed.

I got used to the feel of the needle and because I’m right handed and my fistula is in my right arm, I had to get used to doing it with my left hand as well. And it was probably about two or three months after that that I actually plucked up the courage to push a needle in and I started doing one out of the two. And I had a few bad times with it but it got a little bit easier after a while, until I was completely self caring at the unit. I used to come in, set the machine up, put myself on, put the needles in, dialyse, take them out and go home again ... But when you consider how long I’ve been on dialysis, I really had a real problem with just the thought of putting them in. But I'd had a lot of time prior to that thinking about it and why it would be good for me to be able to do it. So basically I was ... doing dialysis in a self-caring situation, without any help from the nursing staff.

William emphasised the value of learning to self-care as an intrinsic part of dialysis, rather than in a hurried training programme.

... what’s important is to do it at your own pace in your own time. That’s the comfortable way to learn, not in a crash course. It’s much better to become self-caring at the unit, where you can learn at your own pace.

He also stressed the importance of home dialysis patients being able to select the machine best suited to their situation.

I also wanted the same machine that I had at the unit, which was another issue because ... they only did Gambro machines for home dialysis, which are smaller and more portable but arguably not as good. So I had to push quite hard for them to give me a Fresenius machine. And the reason, as well as me already knowing the machine, so I was comfortable with it, I actually wanted to do single needle dialysis rather than two needles. The reason why I wanted to do that is (a), because I still hated pushing needles in, ... But I didn’t want to increase the number of needle punctures to my fistula because there’s obviously an infection risk and a risk of damage to the fistula, the more that you needle it. So I was quite insistent that I needed a machine that could do single needle ...
Nick, who was motivated enough to lobby for home dialysis, also learned to self-care while dialysing at a satellite unit.

It was all predicated on starting needling fairly early ... so I’d been needling for about a year before the NXStage machine came along.

Nick was very conscious of the role individual dialysis units play in shaping the experience and expectations of those using them, and how readily self-responsibility can be eroded.

... a lot of health systems are geared around acute care, not around us taking responsibility for things. You wander into your unit, you plonk yourself down on the scale, where you can’t see the weight reading because it’s behind you, wait for someone to come along behind you, note down your weight on a bit of paper that you never see and then wander on and stick your arm out and wait to be needled. That was the kind of the standard practice. Of course our systems are enabling the patients to abdicate responsibility ... the culture is, if you see this happening then you just assume that’s how it works.

For most who had already become self-caring during dialysis, training itself was shortened to about two weeks. Two other people took, respectively, about three and six months to train, as part of deliberate preparation for home dialysis.

... they don’t train on the ward now ... they have a room where you go and do your training, which is a lot better, because there’s only the two of you and the dialysis nurse, so it’s a lot quieter, whereas when I was training it was in the unit and there was lots of things going on, lots of noise and everything ..., there was like twenty-two beds and it was just huge and horrible ... But it took about three months

... initially when I went to start home dialysis, I wasn’t as well as I should have been and I didn’t maybe concentrate as well with my dialysis nurse but he always said that there’s no rush, you know, you’ll take your time and when you’re happy you’re happy, and so initially I think it took me six months.

Roger, 59, is the one person represented here who is on Continuous Ambulatory Peritoneal Dialysis (CAPD). He demonstrated a similar pragmatic approach to training, illustrating the key role of motivation and positive attitude.

... the system is straightforward. Mind you I’m quite a practical person, I mean my philosophy on it is, you listen to what you’re told to do and you do that and it’s worked so far. I haven’t had any peritonitis or anything, so I try and follow the rules as best I can really. ... it’s very difficult to explain it, you just have to get your head round the fact that you’ve got to do this, you might as well get on with it. There’s no point in trying to fight it because you know, it’s making you better, or as well as you’re going to get.

William spoke of the difficulty for him and his partner in getting to the training. Both of them are employed and the training takes place in working hours.

The other problem with the training programme was that it only ran Monday, Wednesday, Friday during work hours. Also they wanted my partner there as well, and obviously she also works as well.

The extent to which partners or those close to the person training for home dialysis were involved in the training, and to which they are relied on for support with dialysis varies. Several of the people whose stories are represented here are completely self-reliant, while others need or accept help in different ways.
Ian is in his late 30s and started haemodialysis in 2009. Having done peritoneal dialysis for the previous five years he was seen by hospital staff as a good candidate for home haemodialysis.

They fast tracked me to be honest. My room was converted virtually as soon as I started dialysing in the unit.

When Ian started training he found he was not able to needle himself.

The only problem that I had really from the training point of view was, I’m incapable of needling myself ... it’s a phobia that I have. As soon as I attempt to do a needle in my arm, ... I feel I’m going to vomit, so I had to twist my wife’s arm and she came and learnt how to do the needling and she does that to this day ...

Ian’s wife attended training one day a week and has been helping her husband dialyse at home for the past four months, but still she feels uncertain about the process.

... she would probably have liked to have had more guidance and she still says to me now, she doesn’t feel like she really knows what she’s doing ... she still feels like it’s almost a guess when she puts the needle ...

As noted above, partners who commented at the roadshow events felt strongly that more attention should have been paid at early and later stages to the implications for them, giving them information and support, alerting and preparing them for inevitable changes.

When .. they said he needed to go on dialysis, we went to see somebody who was, he was actually doing the machine, and to have a look at it all, but it perhaps would have been good if somebody had actually had the opportunity to talk to me and say, this is what will happen with your life, you know, you need to actually perhaps take control of your home and say, right this is the area for dialysis, don’t sort of let bits creep there and everywhere and you know, just be aware that this is what it can be like.

... you don’t always know what questions you want to ask, you’re so in shock I think, at the time, that this has happened ... and suddenly your life is changing, you know, however much you plan to keep on in a sort of normal way, you can’t ... that does come as a bit of a shock and you can’t quite visualise how your life is going to be or how much impact it is going to have on you.

Another woman spoke of her perception that the hospital has never recognised or acknowledged the role and responsibility that she has to bear, as the partner of a person who dialyses at home.

And they don’t seem to get it, you know, they don’t seem to understand that, that the home environment where the patient is, with the carer, is just as important as the actual patient. And they said, well, you know you shouldn’t be having to worry about it, you shouldn’t be stressed, because it’s the patient’s responsibility. Well that’s ok in theory, but in practical terms, it’s not, it’s just as much my responsibility, I have to be here.
Once the training was complete and patients were considered ready to start dialysing at home, those who had learned to self-care some time earlier adapted very quickly.

Andrew, in his early 20s, had also become self-caring at the unit and, for him, training chiefly involved becoming familiar with the machine. His partner accompanied him to some of the training sessions. Once at home with the machine a nurse visited for the first session, but since then he has dialysed alone, though his partner stays in the house.

Paul generally needs no help from his partner.
William can dialyse alone without help from his partner, but with her help the process is faster, and he prefers to dialyse with her there in case of difficulties. 

... in Denmark they don’t allow you to do home dialysis unless you can do it by yourself ... and to be honest, that was something that I thought was quite important, I wouldn’t want to have done it unless I could do it myself ... So no, I do, if my partner’s here, then I ask her to help, only to get things done quicker, but I don’t need her help ... I try to have my nights off when she’s away, just in case I did have a problem and needed help, it would be better if she was there.

For others adapting to dialysing at home without medical support was initially a challenge.

... it took about three months to train and then we did it at home with nursing support for a couple of weeks. But I think the scariest bit was the first time we did it at home when the dialysis nurse that looked after the home patients wasn’t there. But we did it and you know, you get a real sense of achievement.

Jean helps her husband at the start and end of dialysis sessions.

I need to be there to put him on because he can’t put him on himself and I have to be there to take him off, but I pop in to see him when he’s on and give him a cup of tea ... it does take over your life, there’s no denying it ...

Nevertheless, the fact that her husband now dialyses for two and half hours at home, rather than four hours at the hospital, allows them to more easily fit dialysis into their routine, both being employed full time.

Stuart felt that it took him six months to fully adjust to home dialysis, though he maintains a calm and positive attitude towards any challenges.

... even after a year I still make, if I don’t concentrate, I can make stupid mistakes setting up the machine. Or if I’m feeling, if sometimes I don’t feel as well or my blood pressure is particularly down, I make stupid mistakes. But they’re all correctable, you know, you learn after a while, you know, to carry on and it really is no big deal ... if something goes wrong for instance if I stupidly clamp something wrong when I’m coming off, clamp the wrong needle and there’s blood pouring all over the place. I wouldn’t say it’s frightening but you know, blood pressure is probably affected. But you just clean up and start again and you know not to make that error again ...

Although Stuart felt no concerns about dialysing at home, Jean felt anxious and would have preferred a longer period with a home dialysis nurse at the outset.

... my wife did have training in the hospital with me, but all fine and dandy while there’s a nurse if you like, standing next to you, but you know, we did have a nurse for a week I think, when we came home, but it was just a great shock to my wife ...

Jean felt that, were it not for the flexibility of self-employment she would have been unable to continue her paid work. As a self employed worker, and now the main breadwinner, fitting in dialysis has been stressful for her.
... undoubtedly it’s better for [my husband] because … we do two hours every day, but that has to fit in with me as well … I mean clients aren’t interested if I phone them and say, I’m going to be an hour late because I’ve got a problem with the dialysis machine. It’s not their problem, they’re paying me to do a job … So I find it very very stressful. Really do, and as I say I’m on anti depressants …

For Ian’s wife, who helps her husband by needling him, fitting in dialysis alongside work is also a challenge.

… because my wife works full time and she’s got a job where sometimes she’s just not able to walk out at the end of the night … so if there’s a crisis [at work] that she’s involved with she can’t just … leave everything and walk out. So it’s placed quite a bit of stress on her really …

Reflecting on the issues that had concerned them prior to making the transition to dialysing at home, for most, the potential problems were less significant in reality than they had feared.

Initial concerns Nick had about reliability and maintenance of the dialysis machine proved unfounded.

… I thought we might have a bit of reliability problems … but we’ve had no problems at all … The servicing I have to do is all very simple: bleaching the lines, cleaning fairly regularly, and the programme maintenance has gone fine. In terms of reliability and ease of use it really hasn’t been any problem, it’s all gone fine.

Paul, who initially refused home dialysis for fear of it taking over his home has found it easier to contain that he anticipated, though he acknowledges the ongoing importance to him of being able to hide away the signs of dialysis.

To be honest it hasn’t taken over the house as much as what I thought it would … I’ve got a back garden where I’ve been able to have some sort of storage. The hospital provided the wooden hut and all the stores go in there and my machine is actually in an upstairs front bedroom, the small front bedroom. Now if I didn’t have that … I probably wouldn’t have gone onto the home dialysis as quick as I actually did …

Stephanie had been concerned about potential loneliness, missing the dialysis community.

My biggest concern … was loneliness, being alone. Because for … 17 years I’d been in a hospital environment, dialysing, seeing the same people three times a week, it’s almost like another family. You see the same people, the same patients, the same doctors and nurses, every other day in a unit.

In fact, the added freedom to socialise that the flexibility of home dialysis brought Stephanie has compensated for the sociability of the dialysis unit.
What are the advantages of dialysing at home?

For Roger, who is on CAPD, the benefits he values most are the flexibility to dialyse almost anywhere and the freedom that accompanies that flexibility. He also notes that CAPD avoids peaks and troughs.

So the benefits of CAPD for me are the great flexibility, you can do it almost anywhere, it's easy to transport. You feel well, you don’t have peaks and troughs as you do with haemodialysis.

The other people represented here, all on home haemodialysis, unanimously voiced appreciation of two main benefits: improved health, and increased flexibility in their dialysis regime. Some, depending on their circumstances, had more time to themselves. Several commented on relaxed fluid and dietary restrictions and others on an increased sense of control over their health.

All home haemodialysis patients commented on the health benefits from more frequent dialysis.

Nick, who remembers dialysing twice a week in the 1980s, contrasted how he felt then with his more recent regime of three times a week, and now, dialysing at home six times a week.

... in the late 80’s I had haemo twice a week ... The transport to and from was tricky, recovery times were difficult. After seven hours you were very wiped for the next day, had one good day, and the day after that back on it again. There was very little recovered time ... On the three times a week dialysis the rest of that day was wiped out, I used to go to sleep and feel better in the morning. Now [on six days a week] for an hour or so, slightly wobbly blood pressure, then when things settle down I can actually function. ... So, big changes in post-dialysis function - much better!

Stephanie has significantly increased her dialysis time since dialysing at home.

... when I'm at home, I dialyse more. In the unit you do it three times a week for four hours each time. At home you try and do it four or five, maybe even six times a week, still trying to do four hours each time, but then you've got more of an equal function to a working kidney as it were ... my health has improved a lot ...

Ian dialyses at home four days each week: two days for four hours and two for three and a half hours. While less frequent than the recommended home dialysis regime of five days for three hours, he still achieves notably better outcomes than when dialysing at the unit.

... the problem that I used to have as an in-centre patient was the gap over the weekend, so I’d dialyse on a Saturday night and then I wouldn’t go back until Tuesday and I was getting to maybe Tuesday lunchtime and I’d reached the limit of the fluid that I know I can take off comfortably .... Obviously I don’t have that problem any more, because we’re doing it four times a week. So the biggest gap we allow is one day without dialysis. And that works very well actually.

Jean described how dialysing at home had helped her husband’s health, partly because he was more relaxed at home than in hospital, making access easier, and partly because of the increased frequency.
It’s easier, because I understand how his lines work. When you’re at the hospital, what happens is that you quite often get a different nurse every time and some of the nurses ... used to find problems with his access ... But when you get stressed, all those veins and arteries contract and it stops the blood flow ... whereas at home he’s a lot more relaxed and a lot of the problems that he had was caused by the fact he used to get so stressed about being in hospital. ... Every now and again he does have problems with the access because the lines clot and things, but we now do it every day, six days a week ... two and a half hours ... and because of that, we get a lot fewer problems than we used to have when he did it every other day.

William valued the fact that he could free himself from medication.

The first thing I noticed was that I got rid of all of my phosphate binders, I used to take three big torpedo-sized tablets with every meal. They stopped straight away ... over the coming months I actually stopped all of my blood pressure tablets. I was on four different types at the time and I had very bad poorly controlled blood pressure ... but when I moved to home dialysis, all my tablets went and I’ve got perfect normal blood pressure now.

Most found that with more frequent dialysis they were able to be somewhat more relaxed with their dietary and fluid restrictions.

All nine home dialysis patients valued the freedom to fit dialysis around their lives, rather than their lives around dialysis.

The biggest positive that I’ve had from doing it at home is that I’ve been able to do it when I want. Hospital dialysis is regimented, you go on three days a week, two days a week, and it’s very set days. If you want to arrange any holiday at some point, when you’re in hospital, it’s fine if you can just go away on those days, but if the place you’re going to needs you to dialyse on other days, it means then you’ve got to try and swop with somebody else to get into sync on those days, whereas at home, I can do it when I want, how long I want, as long as I get my prescription in.

Nick has valued the freedom to attend conferences without having to fit around dialysis regimes. Home dialysis has increased his work potential and allows him to spend dialysis time at home, rather than in a hospital unit.

I don’t have to spend time in [the hospital], finest of wards, it’s a great unit but I’d rather not spend time there, I’d rather spend time at home. They were also very very flexible. When I’d go to London they’d allow me to come back a bit later or start a little bit later or do a three hour dialysis, but it’s not the same as being able to pick the night I don’t have to dialyse or dialyse late. So the work that I do when I have to work away is much enhanced, much improved, and the opportunities I can exploit are greater, I can go on more conferences without thinking about whether I have to fit in with a NHS regime.

Stephanie appreciates the flexibility to fit dialysis around social events in a way that she previously could not.

Socialising ... like on Friday, I’m going out with some girlfriends, so I know I won’t dialyse tomorrow, I’ll dialyse on Saturday, so I can chop and change, whereas you can’t in a unit because obviously there’s too many people to be juggling about. So I can make events and things now, weddings or whatever, which I might not have been able to do before. So it actually works well around me.
The extent to which people represented here felt they had gained extra time by dialysing at home depended largely on their dialysis arrangements prior to home dialysis.

Stuart, who said he valued the extra time gained since moving to home dialysis, described his routine while still dialysing in hospital:

... I was on a twilight slot, for ... eighteen months ... I had to go into the hospital for six o’clock and I’d be on hopefully by seven, coming off at say 11 and by the time one thing and the other, I’d get out of the hospital for 20 past 11, down and get into the car and drive home. ... But by the time you park up and you walk into the hospital ... if the people who were on it before are late or they’ve had a problem, you’ve got to wait around until the machine is ready for use again, until it’s been cleaned etc ...

William described his experience of dialysis up to 2007.

... during that time I was doing a 70 mile round trip backwards and forwards to dialysis three times a week. Getting in after midnight Tuesday, Thursday and Saturday. And I really was quite worn out. ... I used to leave work at half past three in the afternoon ... I used to dialyse for five hours ... and I used to get home just after midnight ...

Once he moved to home dialysis, though William appreciated freedom from the dialysis unit, he still regretted the limitations on time that home dialysis imposed.

The only problem I had was that I didn’t really get a lot of time to myself, as I was at work and then I came home and dialysed, so although I could sit on my bed in the evening, I couldn’t get up and go anywhere, because I was tied to the machine.

Having heard about nocturnal dialysis in Denmark, William decided to try it.

... I had all the equipment at home to do it, so I decided to give it a try, without the knowledge of my consultant, basically because when I first asked about home dialysis, and I asked about nocturnal, they said ... we don’t do it here ... So I spent a lot of time talking to my other consultant, in Denmark, and I also struck up a conversation with a consultant in Australia who is a very big advocate of nocturnal dialysis. And between those two I got myself ready and set up to do nocturnal dialysis at home. I got a moisture blood monitoring cuff to put over my arm in case of leaks, that would alarm and stop the machine and that’s about the only difference there is really. The rest of the dialysis is exactly the same.

Immediately I noticed more of an improvement over how I felt doing short daily dialysis. Plus the bonus that I actually had probably three, four or five hours in the evening that I hadn’t had before. It was really good and I started to enjoy just doing ordinary things like cooking and cleaning and things that I hadn’t really had energy or the time to do before.

Another two of the home haemodialysis patients were keen to move on to nocturnal dialysis, for the same reasons: to free up time and for the health benefits.

... hopefully I’m about to commence a trial of nocturnal haemodialysis ... if that works, then obviously that will relieve that time pressure from us, because in theory I’ll be asleep while it’s happening ... it’ll just be the set up time and the clean up time when you come off. ... there are another huge list of benefits that will come out of it, if it does work, because you’re dialysing virtually every night and ... obviously over such a long period of time, the research that we’ve read ... says that your fluid and your diet restrictions almost disappear.
Andrew had briefly tried and was keen to try again.

I did try doing the nocturnal dialysis at one point, but the anti-coagulant, tinzaparin, wasn’t lasting long enough and my platelets and haemoglobin dropped but I’ve heard that that’s something that we can sort out at a later date. And that’s something that I do want to do mainly because of the phosphate, I’ve heard that it’s better to do a longer session, because you get better clearance with the phosphate.

Finally, comments were made by some about the satisfaction they gained from the added sense of self-responsibility that accompanied dialysing at home.

Andrew was relieved to be able to make his own choices.

It’s very comforting to have my healthcare in my hands and I can do my dialysis when I feel ready to do it.

Nick described how self-responsibility spreads from one behavioural area to another.

... the responsibility that I take for my health. Because it’s been handed to me, because I’m not abdicating responsibility, I take responsibility for other things. So it started with needling, I notice that I pay much more attention to fluid intake, and also diet. My two big things were potassium and phosphates. Potassium is kind of under control, phosphates perhaps not quite so much ... But what I really take notice of is when I’m just given the figures - see there you are, look at the figures you see your phosphates are high, now try to think back to what you’ve been eating, what is it you’ve been doing.

So when you start to get people to take responsibility for some of the big things, they start to take responsibility for other smaller things because their belief has changed from, ‘Well that’s their responsibility’, and the reason I might make changes are extrinsic to them, their belief has now changed to, ‘Now I’m responsible for the whole process’, when it’s at home, so therefore I get to be responsible for a lot of the restrictions around diet and fluid intake ...
What are the costs and challenges of dialysing at home?

Amongst those who dialyse and those who support them the biggest costs were commonly agreed to be the time involved in home dialysis. Another cost already mentioned was the loss of companionship from the dialysis unit. Challenges, for some, were uncertainty that they could get fast access to technical support if they need it; issues of space; concern about the quantities of non-recyclable materials; and restrictions on water use while dialysing.

Although everyone welcomed the flexibility of home dialysis, the time it takes is an inevitable limitation on people’s lives. Several people said that though the actual hours spent were the same as when dialysing at a unit, the fact of dialysing most days could feel that ‘all you do is dialysis’.

There are costs in time. I’m going from three times a week to six times a week. The number of days has increased but the [total] number of hours is about the same. It’s about 18 hours in all ...

The partners of those who dialyse are inevitably influenced by the dialysis regime. As one wife said:

The one thing I would say is that if we want to go out in the evening, occasionally, it’s fine, but if you want to go out at the weekend and in the evening, with doing it every day, it can get a bit problematical to find the time to do it.

The pressure felt by two other wives, fitting together their working lives and their husbands’ dialysis, has already been noted.

As well as the time spent dialysing, as Paul described, home dialysis brings other time demands.

When you go to hospital nine times out of ten these days, the machine and everything is done for you and things like that. Although you do your two hours, three hours, whatever treatment it is at home, you’ve got sort of an hour beforehand and ... half an hour afterwards, in preparation and stripping down and cleaning and things like this. So although you only do two hours, three hours, the treatment could actually be four hours ... depending on how good you are at setting it up ... there’s another side to it ... at the hospital you didn’t have to keep things meticulously clean ... you could just walk in and walk out, the cleaning side of it was done by the hospital. Whilst you’re at home you see you’ve got that side of it to do as well ...

... you’ve got your stores to order as well ... all the consumables and things like that ... and you’ve got stock rotation ... and what you’re running out of and what you need ... not just the actual time that it takes to do [the dialysis].

Ian felt that he and his wife were not fully informed at the outset of the total time commitment involved in home dialysis.
... one of the things that they probably don’t necessarily tell you about when you choose to start the home dialysis is obviously, it's not just the four hours worth of dialysis that you do, you’ve also got to set up and prepare the machine. And then after you’ve finished your session, you’ve got to clean it up, disinfect the machine and so on and so forth.

So hours really, an hour onto each side, so a four hour session turns into a six hour session ...

Another unexpected limitation for Ian was the restriction on water use while he is dialysing.

... you can’t use any water while you’re using the machine, because the machine obviously needs quite a lot of water pressure, so for instance if you flush your toilet, the machine trips out. Can’t use your washing machine or run any other water ... We’ve got a three and a half year old child, and you can imagine, he needs a bath at night ... so it just creates little issues. It’s not unmanageable but it’s just been, you don’t necessarily think about it until you’re in the situation really ...

When he first started home dialysis Ian dialysed six days a week for two or three hours, but this regime proved too demanding on his and his family’s life.

... we just found all we were doing was going to work and dialysing. So initially you get up, go to work, come home, I’d set the machine up, do whatever I needed to do round the house, load of washing or anything else that involved water, and then be on the dialysis, probably finish about half nine quarter to ten at night, by the time I’d finished cleaning up it’s half past ten and it’s time to go to bed. So you see it goes from being something that just happens three times a week and ok, you’ve got to travel to where you’re going, but you get there, you get connected up, you do your session, you get disconnected and you’re sent on your way.

... you also lose the separation between dialysis and your home life ... obviously before, I walked out of the door at six o’clock three nights a week and that was it. And I had no involvement in anything at all from there.
Despite all the constraints for Ian and his wife, the long term health benefits still make home dialysis the best option.

I could choose to go back and do the in-centre dialysis but obviously the long term outcome - the more dialysis I do, and the more frequently I do it, the better for me, so you know, I'll persevere with this unless it becomes a major problem.

Space in the house has been mentioned already. Roger’s wife spoke of her need to restrict where dialysis stock is stored, because of the tendency for dialysis to make its presence felt everywhere.

... the other downside of course, is the amount of stuff in the house. I’ve got a shed full of boxes and I have actually now, I have kind of insisted that he doesn’t spread into every single room in the house, because he did have stuff in the spare room, stuff in the study room, stuff in our bedroom, ... you’ve got to have some space where dialysis doesn’t actually make itself felt, it’s about sanity there I think. So it’s about keeping it under control I think.

Andrew expressed concern about the environmental costs of home dialysis.

I’m quite eco friendly, if you like. To start off, I mean I’ve had additional equipment added to my machine to make the purification packs last longer and they are now lasting around 12 weeks, which is good. But just recycling and kind of the pain that I felt having to put one of those massive packs in the rubbish every four weeks, I just thought surely is there not any way that I can recycle this or do something with it. The other thing is the rubbish from opening all the packets. At the unit I did have one pack that I opened that had pretty much everything in it that I needed, so to have the same sort of thing at home would be very good.

Andrew, like several others, missed the opportunity to be with other dialysis patients.

... it’s great being at home and having my own space and actually being able to do it in my own room, but actually I miss not having the community that you have at the unit and meeting other people that are in the same situation as you.

For some, the biggest concern was lack of instant access to technical support, leading to stressful time spent waiting if problems occur. Stuart Segal spoke of the tension that builds when support is not instantly available.

... there is a telephone line we can ring whenever we’re in difficulties, which sometimes, when I say didn’t work, would mean the hospital and if you have something major like a clot in the machine or something, while we were taught what to do, we still need reassurance and by the time you get through to the ward and the ward clerk gets a nurse and we’re talked through it, it seems more serious really than it is.

For Jean these situations are frightening.

... when it goes ok it’s alright; when things go wrong with the machine, I just freak out because I don’t know what to do.
Jean spoke of the risk of her husband having blood clots, cramps or fainting and the stress she sometimes feels.

... there’s been a couple of times when he’s sort of passed out when he was on dialysis and I was thinking, I was dealing with it on my own and that was scary, but I got through it and he came round and he was alright. On the unit there is always help at hand for the nurses in that situation which is not available at home.

Jean did, however, comment that since dialysing at home difficult events occur less often.

Occasions when technical support is needed are especially challenging for people who dialyse in the evening in areas with no instant access to technical support outside business hours.

... we only have a service ... half past seven to five o’clock. Outside of those hours, it’s leave a message on an answer phone and then you’re on tenterhooks waiting for the phone to go for a technician to tell you when they can come over to fix your machine ...

Others have a more relaxed attitude towards non-emergency technical problems.

Any problems that I’ve had with the machine – it’s very good doing it every day, because if I have a problem with the machine, it means that I can just take myself off and I can leave it for the day. I can then ring ... somebody at the unit the next day to sort out the problem. The day that I don’t do dialysis I just take that as my day off and then dialyse the next day, so it is very flexible and easy to work round actually.
What improvements are yet to be made?

From the comments above there appears to be a need, at least in some areas, for a faster response when home dialysis patients need help, particularly after hours, and/or there is a need to build more confidence with the technical aspects of dialysis and provide reassurance that the help that is available is effective and adequate.

... when you phone up after ... business hours, it can be difficult to get hold of somebody ... sometimes when we’ve got through to the ward when we’ve had a problem, when we’ve had a blood clot or the machine has just done something weird, you know, you phone up and they say, ok, what is your date of birth? Who are you? I think there should be a hot-line, you know ... Home HD, we need help now! ... you know: Who are you? Yes we know who you are. This is what you do next.

Paul observed that while, in his experience, the process of supporting people to establish themselves on home dialysis was efficient, the broader system in his area appeared not to have kept up with developments, resulting in clumsy or unnecessary processes. He gave several examples:

... it grates against everything that you hear on the TV where the NHS is saying, well we want to treat people nearer home. I’ve got a consultant ten minutes away but I can’t see her ... when I used to go to the satellite unit, I was seen ... at the local hospital which is only ten minutes away, by the consultant, but now because I’m on home dialysis I had to change my consultant and now I have to trail over to Leeds which is a fifty mile round trip, just to sit down with a doctor in a room to say yes no yes no yes and then I’ll see you in four months. ... my consultant ... was happy for me to see her ... I couldn’t, I had to go onto the home dialysis side of things.

Aware of the shortage of home dialysis nurses in his area, Paul noted ways in which the system appeared not be making best use of the skills and facilities available to home dialysis patients.
... your monthly bloods which every patient does. Now the home dialysis nurse comes and takes those bloods, whereas to me, it’s like I’ve said to them, I’ve got a satellite unit within ten minutes ... which has a collection delivery, why can’t I just take them and deliver them to there? ... And because I’ve got Renal Patient View, I’m able to check my bloods as soon as they’ve done them ... But for some reason they want the home nurse to come along and take them ...

Similarly, Paul observed that while in some areas home dialysis patients can give their own iron injections, in his area he has to go to the satellite unit for the injection.

Nick, as noted above, commented on the tendency in some units to foster a sense of reliance, rather than self-responsibility. He observed that by increasing the role dialysis patients play in their own care while in the unit, people’s expectations can be changed and they can be encouraged to adopt a broader sense of ownership of their health.

... if we change some of the structural components, the kind of systemic components, and we change the expectations of patients. So the motivation to make changes in things like diet and fluid and cleanliness and hygiene become intrinsic, I take them on, I’m not doing it because I’ve been told to, I’m doing it because I get benefits and the benefits are very tangible. You start taking responsibility for your own care, you start with needles, then with taking your own blood pressure and you start writing on little charts that you never even saw before ...

A potential improvement mentioned by several home haemodialysis patients was access to a portable dialysis machine.

... there are now ... portable dialysis machines, ... about the size of a portable television. Now they don’t give a great clearance at the moment, but if each hospital had one machine for argument’s sake, and when somebody wanted to go on holiday ... they could if you like, rent it, borrow it, whatever, take it with them, and while you’re in your hotel room or whatever, you dialyse, bring it back after the holiday.

Other people spoke of how challenging it can be, while on holiday, to go back to hospital dialysis having become used to home dialysis.

There is one final thing that makes me remember that I’m still on dialysis and that’s when I go on holiday, because I have to go back to doing four hours three times a week and the first time I did that I really felt it, it was a horrible experience and I was supposed to be on holiday. It really kicked me. So I think some thought into providing home dialysis patients with the portable dialysis options which are available, is kind of my last thing on my wish-list, if you like.

The benefits of nocturnal dialysis were much appreciated by the one person who was already doing it; others were waiting for the opportunity to access it.

Several mentions were made of the value that dialysis patients gain from meeting each other. Online communication may replace some of the sense of community that home dialysis patients miss, and/or occasional events could be held when people on home dialysis (possibly with people on unit dialysis) could meet together.

[an online home dialysis forum] can be a sort of community where we can all sort of talk together and support each other, doing the same sort of thing. ... I think it would be good to have somewhere where everybody can come together and support each other.
The most significant area for improvement that emerged from these stories is the need for greater recognition of the role played by partners of those who dialyse at home and/or those who support them. It is important that their contribution is valued and their needs identified and met.

Roger’s wife spoke of her preference not to be called a carer, but to be recognised as the wife or partner of the home dialysis patient, with the implications that brings for her life.

I think it’s important that the people who live with the patient, are known as their husbands or wives or partners and not carers, because I’m not [my husband]’s carer, he’s perfectly able to look after himself and I’m his wife and I think it puts a whole different perspective on things if you’re simply known as a carer. But as a wife or a partner, it just gives a very different sort of status and I think it makes people think differently about how things might affect you. I think the term carer implies that everything I do is going towards looking after [my husband] and of course, you know, we are a sort of partnership in this, and I would much prefer to be known as his wife or his partner.

She spoke of the lack of support she felt from the hospital, and how strongly that contrasted with the support available for her husband.

... just to be told that when you know, if I had got questions, I can go and talk to somebody. That would have been helpful at the start and I might not have had any, but it would have been nice to know that somebody would have been there if I had had questions.

... [my husband] has a fantastic team of support helping him and X, his home care nurse is lovely, but I have absolutely nobody I can talk to ... it’s a bit sad really that we are all here, we’re all part of the process because we have to be, and yet I don’t have anyone ...

I’ve got questions that I want to ask people, [my husband] doesn’t. He is unusual in that he will do exactly what he is told and he doesn’t want to know why, he doesn’t want to know what the side effects might be and he doesn’t want to know how the mechanics are of what he’s doing or what the effects might be. But I do, because I can see, I always look ahead and I do want to know how long can he go on doing this sort of dialysis. If he doesn’t get a new kidney, what will happen? He doesn’t want to know those sort of things, but I can’t ask those questions, because I don’t have anyone I can ask them.

... just having someone that I can go and talk to in confidence and you know, just if things are a bit frustrating sometimes, just say, perhaps a chance just to say, just listen to me for a minute. Nobody can change anything, but sometimes it’s just nice to go and sort of, I don’t know, let off a bit of steam and sort of scream and maybe that’s it really.

She also suggested that, at the least, time could be offered to partners or those close to home dialysis patients when the patient has a regular hospital check-up.

... what would help me even now, when [my husband] goes [to the hospital] you know he goes and has sort of the full service, he sees the dietician and the pharmacist and his consultant, that might be a good time, someone to say, you know, if your wife wants to come too, there’s someone there she can have a chat with and we’ll catch up with her and see how things are going for her ... I could have my ten minutes then with someone.
Jean spoke powerfully of her sense of not being acknowledged by the hospital. Although she was aware that she could request help if she needed it, she felt a need for active engagement from the hospital.

And the occasional contact from somebody at the hospital phoning me, not phoning [my husband] and asking me, via [my husband] - phoning me and saying, how are you? How are things going? Have you had any problems? How are you getting on? Just a five minute phone call ... just a communication from the hospital and knowing there's help there if I need it ...

... I get no support whatsoever from the hospital and I've voiced this on numerous occasions to people at the hospital and I've said to them, why can't somebody phone me up, say once a month, and say, how are you getting on? How are you feeling? How did it go this month? ... Nobody ever has ...

Everything with the hospital is reactive and not proactive, they're not interested in the carers' point of view, I mean they're not really interested in the home situation of the patient, which I think they should have been ...

Similarly, although respite can be made available, Jean would like respite to be offered to her as a matter of course, so that she did not need to wait until she felt desperate enough to ask for it.

I feel guilty, if I'm going away, I feel really guilty, it's as I say, it's coming from me: 'I need a break, you've got to sort it out.' It's all re-active not pro-active. And they say, well whenever you want to go away, just let us know!

Jean also spoke of the need for respite care for her husband. Ideally respite would be provided by familiar staff.

The one thing that I think would make it better for me is, occasionally I need to go away for work or I would like to sort of go out, go away for two or three days and my husband hates going into hospital to do the dialysis and what would be nice if they had resources for somebody to come and do it with him at home.

... when you get to know the nurses in a sort of closer relationship, which you get a closer relationship with the home dialysis staff because they have a limited number of patients and they see you all the time, then you do become more comfortable with them ... if they got somebody like a bank nurse in to do it, I don’t think that would work as easily as if they got, they had somebody that would come and do it every time that he needed it ...

Jean was interested to meet other partners of home dialysis patients, in person or by email.

All you need is email addresses of other people and that would give a lead, you could just email around and say, do you just want to contribute or here's my email address, you know, here's the group address ...

A salutary comment from Ian effectively summarises some of the areas for improvement.

I think one of the things that maybe all of the renal units suffer from is that they sometimes lose focus of the fact that it's more than just a technical process, because obviously the psychological side of it as well ... there's often not enough support around that side of things.
Those speaking of their experiences were unanimous in encouraging anyone considering home dialysis to explore it further. There was general agreement that it is helpful to speak to others who are already doing it, to become fully aware of the advantages and disadvantages, as the following two people describe.

... you need to consider the amount of time that you need to spend in doing it and I think if you were somebody that didn’t work, then it’s obviously the definite way to go, because it makes things much easier on you, but when you’ve got a young family like I have and when you both work, I think you need to make a very careful decision and you need to decide whether or not it’s going to fit in with your life really.

... if somebody was thinking about home dialysis I would sort of ask them before they do anything, is to go and see somebody that actually does it ... listen to the doctors, listen to the home dialysis nurse and everything like that. I mean they obviously are going to give you the benefits of it and everything like that, but there’s always a down side to it and I think that if you can speak to a patient that’s ... already doing dialysis at home, CAPD, or haemodialysis, then they can tell you the benefits of that ... but they can also give you an insight into the sacrifices that you have to make as well ...

Jane wished more people could be encouraged to consider home dialysis. She recalled how her views had changed over time.

... when [my husband] first started, I wouldn’t even go into the dialysis ward with him, he used to say, come and help me along and I used to dump him in the waiting room and I just couldn’t go near the place.

It wasn’t until she saw dialysis at close quarters that she realised it was less frightening than she imagined.

... the whole thought of it made it seem really, you know, I thought it was awful ... what made me start to think about whether I could actually do it was, my husband had a failed transplant ... they had to give him some dialysis whilst he was on the ward because the kidney wasn’t working properly and then when they took it out afterwards, and it made me realise that at that point that it wasn’t as scary as I thought it was, even despite all the horrible things that could happen, it’s still not as scary as you think it is.

Finally, words from William, one of the most enthusiastic home dialysis patients.

Stop wasting your life, because you don’t have a life. Dialysis is not a life but the trouble is you don’t realise you’re so poorly. For a lot of people it’s a gradual thing, for some it’s a bit more quicker, but you don’t realise how ill you are until it’s too late. ... I try and tell anybody I come into contact with, you know, you need to think about it at least.
A wide range of people dialyse at home; there is no typical age or health history for home dialysis. Despite these differences there was much commonality in the views and experiences of the nine people on whom this report is based.

**How do people discover home dialysis?**
Different hospitals take very different approaches to home dialysis. In some areas hospitals proactively offer home dialysis to patients while in other areas dialysis patients who are interested in home dialysis have to request, demand or push for it.

**What factors influence the decision to dialyse at home?**
A range of considerations influence a dialysis patient’s decision whether or not to dialyse at home. People sometimes change their mind about the significance of the factors over time, and/or their circumstances may change. Influential factors include:

- feeling daunted if new to dialysis
- wanting to keep dialysis separate from home life
- not wanting to lose the sociability of dialysing with others at a unit
- the convenience or inconvenience of their current dialysis arrangements
- the views and concerns of their partner.

**What training and adaptation is required for home dialysis?**
The experience of training for dialysis highlighted areas for comment and/or improvement. People who learn to self-care as part of their regular dialysis practice tend to make the transition to home dialysis most smoothly. Training is most effective when it takes place in a calm and relatively quiet environment, at a speed at which people feel comfortable and unhurried. Training that is only available in working hours creates a significant challenge to people who are working, and/or for their partners who may be working. More time and attention is needed during the early decision and training stages for partners of those who dialyse at home and/or for those who support home dialysis patients to ensure that they are aware of the implications for their lives and that they are well supported to address concerns. Some home dialysis patients depend on their partners for the process of dialysis and their partners are involved in the training; others are completely self-caring. Even partners not directly involved in the process of dialysis should be offered the opportunity to consider and discuss the implications of home dialysis for their life. If partners are involved in the dialysis process it is essential that they receive enough information, training and support to feel confident in what they are doing.

**What are the advantages of dialysing at home?**
The following advantages were mentioned by people who dialyse at home:

- improved health from more frequent dialysis in both short and longer term
- flexibility of choosing when to dialyse and the freedom that brings
- for those who previously lived a long distance from their dialysis unit, less time spent
- more relaxed fluid and dietary restrictions
- the satisfaction of taking personal responsibility for their own health.
Nocturnal dialysis brings added benefits of freeing up more time and even greater health improvements.

**What are the costs and challenges of dialysing at home?**
Costs and challenges of home dialysis are the extra time involved, not only through more frequent dialysis but also time spent on cleaning and maintenance. Space is needed for equipment and storage; confining and containing dialysis to avoid it being too constant a presence can be a challenge. Constraints on water use in the house while dialysis is in process can create difficulties for the household. Home dialysis creates large amounts of non-recyclable waste. Some people experience considerable anxiety when unable to quickly access technical support, especially outside business hours. Home dialysis inevitably places additional pressure on partners of those who dialyse, especially if they play a crucial role in the dialysis process.

**What improvements are yet to be made?**
Improvements suggested for home dialysis include ensuring a fast response when technical support is needed, even if after hours, and ensuring that home dialysis patients and those who support them feel confident in their ability to cope with technical difficulties, and better able to believe that adequate support will be available when they need it. In some areas home dialysis and the skills of those who dialyse at home could be more efficiently integrated into the rest of the health system. There are missed opportunities in some dialysis units where, instead of fostering self reliance, processes appear to support dependence. Opportunities could be developed to enable those on home dialysis to communicate with each other electronically and/or at occasional meetings. People want access to mobile dialysis units. Nocturnal dialysis offers better health outcomes and creates more free time; some people see access to nocturnal dialysis as their best solution. Ongoing attention should be paid to partners and those who support people who dialyse at home, ensuring they are given adequate information and support at the outset and in an ongoing way, offering opportunities to ask questions, express emotions, increase understanding and access support. It was suggested that a proactive service should offer support and respite as a matter of course, rather than in response to requests.

**What advice would those using home dialysis give to those considering it?**
Advice to those considering home dialysis from those already doing it was to seriously consider the potential benefits and to talk to people who are doing it to hear the advantages and disadvantages.