Foreword

For people with end stage kidney disease, a move to home dialysis can literally transform their life. More freedom and flexibility than in-centre dialysis, along with less travel time and fewer dietary restrictions, all lead to a better quality of life. There is evidence too that clinical outcomes can be improved by more frequent dialysis, which is more achievable and manageable when dialysing at home. Last autumn, NHS Kidney Care published *Improving Choice: Listening to Patient Stories*, which featured patients talking about their experiences of home dialysis, and helped to illustrate the positive changes it can bring to life and health.

While preparing that report, it became apparent that living with home dialysis has a significant impact on the patients’ partners and families. Some spoke of the confusing nature of their role as carer, and others struggled with the responsibility of helping someone they love perform a life-saving procedure.

This report is intended to further explore the carer’s role, and to share with healthcare professionals and other patients the realities of life for the family members and partners of those on home dialysis. It contains a series of recommendations for healthcare teams – points to consider when patients are moving onto home dialysis, which may help to improve the experience for those around them.

The situations and experiences of the ten carers interviewed for this study varied considerably, but common themes emerged. The quiet generosity and courage with which they provide ongoing care leaves a lasting impression, and, at the same time, the sense of inadequate recognition of their input was a sore point for some.

Thanks are due to the author of this report, Anthea Duquemin, who interviewed the carers and has done justice to their personal stories by weaving them together into a powerful and captivating narrative.

We are grateful also to the ten interviewees for telling their stories so openly and affectingly, and trust that this report will open debate about how to better meet the needs of those who care for home dialysis patients.
## Contents

**Recommendations** ........................................................................................................... 04

**Background** .................................................................................................................. 06

**‘Carer’ or not** .................................................................................................................... 07
  How do those who live with and/or care for someone who dialyses at home perceive their role?

**Why home dialysis** .......................................................................................................... 09
  What influences the decision to adopt home dialysis?

**Training** .......................................................................................................................... 12
  how do partners train for home dialysis?

**What do they do** ............................................................................................................... 16
  What role does the carer play in home dialysis?

**Technical and clinical support** ...................................................................................... 18
  What support do patients and carers get with the technical and clinical aspects of home dialysis?

**Impact on carer** .............................................................................................................. 24
  How does home dialysis influence the carer’s work and/or use of time?

**Emotional and practical support** .................................................................................. 30
  What support does the carer get with emotional and practical impacts of home dialysis?

**Money** ............................................................................................................................. 36
  Has home dialysis influenced the patient and carer’s financial situation?

**Breaks and holidays** ...................................................................................................... 39
  Do carers want and/or get breaks or holidays?

**Advice** ............................................................................................................................ 47
  What advice would carers give to others considering home dialysis?
Recommendations

Although the experiences of those caring for home dialysis patients are individual and highly personal, this report highlights the common themes faced by some carers. The following recommendations are designed to help the healthcare team ensure that, when a patient decides to pursue home dialysis, appropriate support is offered to everyone involved in caring for the patient outside of the hospital setting.

Ensure patients and their families are given appropriate support to make informed decisions about home dialysis

It can be difficult for patients and carers considering home dialysis to comprehend the reality of how it will impact on their life. The healthcare team should be aware that the person who will become the patient’s carer may have very little knowledge and understanding of dialysis. Some carers might benefit from meeting one or more people who are already providing care for home dialysis, to gain a better insight of how it might impact on them. Carers are keen to see the best outcome for those they care about; they may need active support from a health professional to help them consider their own position, rather than assume that the patient’s needs are paramount.

Recognise the carer’s role

People caring for home dialysis patients are often in an ambiguous position. The combination of being a carer and a partner or close relative leads to close identification with the patient’s needs, yet the carer has their own needs too. As well as the demands on time and the tasks that carers perform, it is the sense of responsibility, and the unending nature of it, that can prove onerous for many carers. The healthcare team should acknowledge the responsibility and demands of the partners and family members of home dialysis patients.

Consider how best to provide effective training for home dialysis

The length of time for which carers train for home dialysis, the extent of input from renal staff, the level of skill and understanding carers are expected to attain, and the input they are expected to have in the dialysis process all vary considerably. Some carers are trained at home while most are trained in a hospital or renal unit. Wherever possible, training should be tailored to suit the needs and capabilities of the patient and carer, rather than be based on the standard practices of the renal unit.

Work with the patient and carer to devise appropriate division of tasks in dialysis

While some patients are trained to dialyse independently, others need active support from their carer throughout the time they dialyse. Independence in dialysis may depend on the patient’s capacity and condition, or the division of tasks might reflect expectations and standard practices of the renal unit where the patient and carer trained. If some patients can dialyse independently, could more do so? Self sufficiency in dialysis may relieve the sense of being trapped that some carers report.
**Help build confidence by offering effective technical support**

Dialysing at home can be nerve-wracking for patients and carers at the outset. Problems that later become manageable may at first feel overwhelming. Carers or patients who are comfortable with technical challenges may adjust more readily, but for others the sense of risk is high and they need reassurance that help is at hand when they need it. Not all carers need the same type or level of support, but it is crucial that carers receive the level and type of support they need to maintain confidence in their ability to cope with the dialysis process.

**Recognise the impact on carer’s time and/or work**

Caring for someone on home dialysis can demand a considerable commitment of time. Carers in paid employment often work to tight schedules to fit in dialysis, and those not in paid work may feel that they have to give up their freedom on dialysis days. In addition, for some carers the sense of responsibility and concern is ever-present. The patient’s needs and hardships are evident, but healthcare professionals should be mindful of the challenges for the carer, and the impact of dialysis on their life.

**Provide channels for the carer to access emotional and practical support**

Although carers establish their own means of gaining emotional support from friends and family, contact with other home dialysis carers to exchange experiences and possibly to give practical support may prove valuable. In addition, some carers would value occasional enquiries from health or social care professionals about how they are coping with home dialysis, along with proactive offers of support initiated via their GP. Carers may need outside help to establish manageable routines and establish reasonable boundaries, avoiding becoming swallowed up in the patient’s needs.

**Ensure information about financial support is readily available**

Financial support is available to help patients and carers with most aspects of home dialysis, but not everyone receives adequate information about their eligibility or how to access it. Access to social worker support for provision of information about financial support should be a specific step in the process of assigning someone to home dialysis.

**Proactively offer breaks for carers**

Holidays with the person they care for may or may not provide a break for the carer. Over time some carers recognise their need for an occasional complete break from dialysis. It can be difficult for carers to acknowledge this need, as they may feel guilt that they can escape the dialysis routine while the person they care for cannot. Proactive invitations to respite - ideally a ‘menu of offers’ - would allow the carer to access a break without having to initiate it.
Background

During 2010 NHS Kidney Care published an account of nine people’s experience of home dialysis, in a report titled *Improving Choice: Listening to Patient Stories*. The report acknowledges the impact of the decision to dialyse at home on the partners of those whose stories were told, but it was glaringly evident that more remained to be explored about the lives of those who are broadly described as carers for home dialysis patients.

This report begins to address that gap. It describes the experiences of ten people who, in some way, care for someone who dialyses at home. As with the patient stories, these ten individuals are not intended to be representative of people in their situation: they are ten people who either responded to an invitation from their renal consultant to participate in the study, or who replied to a request posted on a renal patient support group Facebook page.

The ten individuals (of whom eight were women) were interviewed between April and July 2011, all by the same researcher. Their stories are presented here with their agreement; only their names are changed. Six interviews were conducted in person and four by telephone. Eight of the people were partners of the person who dialyses at home, one was a mother and one a sister. Their ages ranged from 40 to 69. Of the people they care for, all were using haemodialysis. The person who had spent longest on home dialysis (nine years) has now had a kidney transplant. The other nine were still dialysing at home, having done so for periods of time ranging from three months to eight years.

Experiences and views from the ten interviewees are presented in the following pages under ten headings:

1. ‘Carer’ or not: how do those who live with and/or care for someone who dialyses at home perceive their role?
2. Why home dialysis: what influences the decision to adopt home dialysis?
3. Training: how do carers train for home dialysis?
4. What do they do: what role does the carer play in dialysis?
5. Technical and clinical support: what support do patients and carers get with the technical and clinical aspects of home dialysis?
6. Impact on carer: how does home dialysis influence the carer’s work and/or use of time?
7. Emotional and practical support: what support does the carer get with emotional and practical impacts of home dialysis?
8. Money: has home dialysis influenced the patient and carer’s financial situation?
9. Breaks and holidays: do carers want and/or get breaks or holidays?
10. Advice: what advice would carers give to others considering home dialysis?

The report can be found at [www.kidneycare.nhs.uk/Library/ImprovingChoiceListeningtoPatientStoriesFINAL.pdf](http://www.kidneycare.nhs.uk/Library/ImprovingChoiceListeningtoPatientStoriesFINAL.pdf)

For those wishing to find the renal patient support group see [www.facebook.com/home.php?sk=group_187011486194](http://www.facebook.com/home.php?sk=group_187011486194)

The full stories of each of the 10 interviewees are on the NHS Kidney Care website – [www.kidneycare.nhs.uk](http://www.kidneycare.nhs.uk). Type ‘carer’s stories’ into the search box on the homepage.
‘Carer’ or not: how do those who live with and/or care for someone who dialyses at home perceive their role?

During earlier interviews with people who dialyse at home one partner expressed her resistance to being described as a carer, saying that primarily she was a partner of the dialysis patient. Recognising the ambiguity of the position for partners or family members who are also carers, interviewees in this study were asked whether or not they see themselves as carers. In their responses, all emphasised the integrated nature of their roles.

Thomas has been married to Susan for 48 years. He works from home for an engineering education scheme. Susan has suffered from rheumatoid arthritis for some years, then six years ago she unexpectedly developed kidney problems and for the past five years has been on dialysis. She began home dialysis a year ago. Thomas’ response to the question of whether he considered himself to be a carer was typical.

I see myself primarily as Susan’s partner, husband, but I’m also her carer … so I am primarily her partner and then a carer as well.

Norman and Olive are in their 60s and have been married 41 years. Both are retired. Olive knew from the age of 14 that she had only one active kidney and had experienced a number of health issues, so when, in 2010, after three years of hospital dialysis she and Norman decided to adopt home dialysis, her husband was already familiar with playing the caring role. Though not offended by the term carer, he prefers to consider himself a partner, seeing caring as an integral part of his marriage.

Well I prefer to call myself as a partner, because Olive always, she sometimes when she’s having a down - which patients do don’t they - she said you got the rough end of the deal. I said well in the marriage it said in sickness and in health, I said and that’s what we do. …. That’s what you get married for isn’t it?

Vanessa, aged 51, came suddenly to the role of carer when in April 2010, William, her 22 year old son, unexpectedly developed renal failure. In May 2011 William started dialysing in his own flat, with assistance from his mother and his sister Yvonne. While Vanessa, who works full-time, sees herself primarily as William’s mother, she acknowledges that she and his sister are, effectively, also William’s carers.

I just see myself as William’s mum and it’s just something that I have to do. I mean really I am William’s carer because, so is Yvonne because William couldn’t do it without us …

Catherine works three days a week in an administrative position with the NHS. She is the younger sister of Diane, who, eight years ago at the age of 34, suddenly developed renal failure. Two years ago Diane, who lives with her 14 year old daughter, decided to move to home dialysis, and asked her sister to become her carer. Diane was able to access funding that allows her to pay Catherine to assist her with dialysis and with some of her household tasks. Catherine spoke of the confusing and challenging nature of this role.

... because all of a sudden I’m her sister, I’m her employee, I’m her carer, I’m her dogsbody almost … But I have found getting the boundaries of that difficult….. that’s been the difficult thing of being her sister and her employee and her being my employer and my sister…….. the boundaries get really blurred.
Barbara works part time as a pharmacy technician. She is in her late 40s and her husband, Charles, is in his early 50s. Charles had an auto-immune disease from the age of 15 which had been manageable until, at the age of 46, he suffered kidney failure. Charles has dialysed at home since December 2003. Barbara pointed to the hazy concept of what counts as caring, and the contrast between the official classification and the lived experience. She explains how the impact of caring for Charles' dialysis-related needs extends far further than the 19 hours each week he spends on dialysis.

"It’s one of those annoying sort of anomalies really because the government don’t regard you as a carer because you don’t do enough hours but dialysis is something that never goes away. If you’re out shopping for food you’ve got to think right, can they eat this? How much potassium has it got in it? How much salt is in it? … it’s like this afternoon we’re expecting a delivery but it’s an all day thing, because you don’t know when the delivery is going to come. … sometimes we need to take blood samples up to the hospital … So that’s yet another hour … So there are lots of little things … But carer, I mean yes I am his carer …I don’t know that I would sort of strictly regard myself as that’s what I’m doing but I suppose it is.

Gillian is a head teacher, aged 60, married to Harry, who is aged 54. At the age of 42, Harry was found to need dialysis, and, very shortly afterwards, started dialysing at home. After nine years of home dialysis Harry received a kidney transplant. During the years that Harry dialysed at home Gillian viewed her role as a combination of wife and carer. As she described, neither the concept of wife, nor of carer could capture the essence of her role, including as it did, the ongoing nature of the responsibility she holds for his health.

That’s quite an interesting question isn’t it, because I believe I’m a wife. At the time I was a wife, but I was his carer and I needed people to realise that as well as being a wife I was also caring for my husband in terms of a medical sense because it was more than a wife. And there’s no other language that’s available, you needed I’m a wife and carer on top, to give people the perception that you were doing more than or having to do or being part of something that was more than what a wife would do … If you say to somebody, I’m a carer, what comes up in people’s heads is, nursing for somebody and looking after somebody perhaps a stereotype view of whatever. But some people need to know that, because if you say a wife, it’s oh were you dibbing in and dibbing out ….

The sense of responsibility was also stressed by Karen. She is 57 and works full time in a government call centre. Her husband, Laurence, is a computer engineer and also works full time. Laurence has hereditary polycystic kidney disease and was aware that eventually he would need to dialyse, but his move to dialysis came suddenly and unexpectedly in September 2009. He has been dialysing at home since June 2010. In a similar vein to Gillian, Karen identified the inadequacy of the term ‘carer’, but stressed the weight of the responsibility she held, as the partner of someone who dialyses at home.

‘… I do not think I realised at first what a responsibility I was facing with the home dialysis. I do not consider myself as a carer. To me a carer looks after someone who is incapacitated but it is a big responsibility. You are responsible for the patient while they are on the machine … To be a carer I think it’s more, the person possibly ill, you having to do a lot more for them, I’m only sort of doing things for him while he’s on the machine. So I don’t see my role as a carer. Yes I’ve got to be there for him, but I don’t think I class myself as a carer.

Interviewees broadly agreed that there is no satisfactory description of the role played by those who care for someone close to them who dialyses at home, and in the absence of a better term they will be referred to, in this report, as carers. The practical demands on the carer vary between individuals, but some common threads are the weight of responsibility held by the carer, and the way in which, for better or worse, the caring role integrates and blends into other parts of the carer’s time and their relationship with the patient.
Why home dialysis: what influences the decision to adopt home dialysis?

Most carers represented in this report were influenced by very similar considerations when they agreed to support someone to whom they were close to dialyse at home.

Angela and Brian’s decision was typical. They have been married for over 30 years and until five years ago each owned and ran their own small business. Brian has a long history of renal disease, having had his first transplant in 1968, at the age of ten. In total Brian has had five transplants but when his last kidney failed his body was unable to support another one. Realising that he would now be on dialysis for the rest of his life, Angela immediately suggested home dialysis, drawn to the opportunity it offered for Brian to dialyse in his own surroundings.

Angela had no concerns when they made the decision that Brian would dialyse at home and she was unaware of the implications.

But no, I’ve never, even before he was home dialysis, no-one said to me what a commitment it will be, how it will be a tie on your life, nothing, nothing whatsoever. It was kind of just home dialysis, that is it.

She acknowledges that she had not fully thought through the demands it would make on her time, nor how central dialysis would become to her life.

I’ll be honest, I didn’t think about it as much as I should have done. I was just thinking basically that he needed to be more comfortable in his own surroundings really to be fit, because it’s life-long, so you try and make him as comfortable as possible. But I didn’t realise until he came home, what a dramatic change it would make on my life because I’m used to going out every, well more or less every day. I mean we both used to work, have our own businesses and everything, so our life was full on. Then suddenly he’s got to like going on dialysis, he goes home and then suddenly it’s kind of, oh, right, everything now for him everything has got to revolve around his dialysis but for me everything has got to revolve around the dialysis.

Karen and Laurence were influenced by very similar considerations to those that drew Angela to home dialysis. They had already been introduced to the idea of home dialysis two years before Laurence embarked on dialysis. Laurence had been diagnosed with hereditary polycystic kidney disease and knew that eventually he would need to dialyse.

We’d thought about it even before he went on the dialysis and we attended a seminar at the hospital and they told us of the various forms of dialysis. Because at that time I think I didn’t understand what was going to happen and we saw a DVD and they gave us a talk and they gave us a DVD to bring home and that was about two years before he went on dialysis.

When, suddenly, Laurence’s kidneys collapsed and he began dialysing at the hospital at the end of a full day’s work, he and Karen quickly decided that home dialysis was a preferable option.

... we agreed, well it was something that he wanted and I agreed that it would be easier and in some respects it is easier because when he was at hospital on dialysis he was coming in at ten o’clock or nine
thirty possibly and I’d prepared a meal and he didn’t want it. But now he eats while he’s on the dialysis machine so in certain ways it’s a lot easier. Plus you can be more flexible ... I wanted whatever was easier for him and better for him and better for us as a family basically.

Despite having attended a seminar on dialysis and being given a DVD, Karen had little sense of what the reality of home dialysis would involve. She felt no anxiety about the decision to adopt home dialysis.

I don’t think so, I don’t think I realised what it involved. I knew it was better for Laurence ... but I didn’t really know what it involved.

Barbara, having worked in a pharmacy, was familiar with the concept of home dialysis and soon after Charles started hospital dialysis she raised the possibility with a consultant, recognising the health benefits home dialysis could bring Charles, and the normalising effect it could have on their family.

The thought really was just sort of to get him home again ... The risk of infections in hospital and ... because the girls were what ten and eleven when it happened, try and get some normality back into their lives that you know, they’ve at least got two parents around again, even if one of them was tied to a machine several times a week.

Barbara recognised from the start that supporting Charles with home dialysis would limit her freedom, but felt that the benefits outweighed the costs, including the initial anxiety.

I knew because Charles couldn’t do the needles that I was going to be tied more and I think the first year when Charles was on dialysis ... I sat in there with him ... every night I was in there with him and it was like, something might happen if I move out of the room, although Charles is very stable on dialysis ... I knew it was going to tie me but then it was what was best for Charles and what was best for the family, the same as for me sort of ...

Family considerations – being at home when her daughter returned from school, rather than in the dialysis unit - and more flexibility to choose her dialysis times were also key factors influencing Diane’s decision to dialyse at home, and the decision of her sister Catherine to support her.

Catherine had no particular concerns when she agreed to assist Diane with dialysis, having seen only the potential advantages.

To be honest I didn’t think about it, if I’m honest ... Which was really really naïve and that was my biggest falling down point ... I probably had the naive view that I would be doing a little bit of greater good by allowing her to be at home, she’d be at home for her daughter. I mean the improvement in her daughter has been vast ...

Gillian and Harry also readily accepted the option of home dialysis, valuing the opportunity for them both to be engaged in the process.

He was offered it very very early and Harry jumped at the chance because there is one thing about home dialysis that we, not Harry, that we absolutely valued, was that it was something we could do together. And I talk about it as we dialyse him, because that’s how we felt. It was something we could do together. He did not want to be institutionalised in terms of having to go to the hospital.
Gillian acknowledged the potential challenge of fitting home dialysis into her demanding work schedule, but the promise of flexibility to enjoy holidays outweighed the challenges, leaving her with no real concerns.

None at all, absolutely none at all. I was worried about the timing I suppose in terms of how I would manage it with the sort of job that I do, because there’s expectations that I can work until quite late at night. But I suppose that was counterbalanced by the holiday period.

Fiona and Graham were in a different position, with dialysis in a satellite unit being their preferred option. Fiona is aged 42 and has been married to Graham for 21 years. They have a 19 year old daughter. Fiona works in a demanding job with their local authority. Graham has had renal health problems since he was 11 years old and began dialysis in 1989. Since then he has had four kidney transplants, none of which lasted longer than 18 months, and for most of the last 20 years he has been on dialysis.

Until he started home dialysis in 2009 Graham had dialysed for 15 years at a satellite unit only ten minutes drive from his home. Graham was happy to dialyse there and would have continued to do so, had it not been for his need to dialyse for more hours than the unit was able to give him. It was therefore for health reasons that he moved to home dialysis. Graham and Fiona’s daughter was aged 17 when Graham began home dialysis. She was not comfortable with the idea of her father dialysing at home, but Graham and Fiona saw no other option.

I think it affected our daughter worst ... She’s got a needle phobia and the thought of blood was horrifying her. The thought of it all coming home was really quite upsetting for her ... she wasn’t saying no, I don’t want it, but I’m not sure I can cope with it ... And I think ideally probably we would have waited but we weren’t in a position to wait.

The benefits of home dialysis are that it has given Graham the additional dialysis time his body needed. This allows him more freedom with his diet, which creates more opportunities for him and Fiona to enjoy their leisure time.

Being able to be more free with his diet ... it’s more being able to have a bit of cheese when he wants, a bit more calcium, the odd cereal or bit of cereal which he could never have before. It means that we can go out a bit more ... we might go out for a meal whereas before it would be, oh, it’s weekend, I’ve got another two days before I’m on again ... Now because you’re dialysing five times, you’ve got a little bit more freedom to be able to go out

Along with the readiness of carers to accept the restrictions of home dialysis in exchange for benefits to the patient’s health, freedom from hospital regimes and increased flexibility, is a common lack of recognition of the potential impact that home dialysis will have on their lives. Although none of the ten people interviewed for this study said that, had they known what they know now, they would have made a different decision, several acknowledged that they had little idea of what they were agreeing to undertake when they said yes to home dialysis.
Training: how do partners train for home dialysis?

The ten carers’ experience of training for home dialysis differed widely in terms of time required, the extent of their involvement, who taught them, and their place of training. Each of these factors has wider implications, not only on carers’ levels of confidence with dialysis, but also on other parts of their lives.

When Susan decided to move to home dialysis she was trained at her local hospital. The training took only six weeks, and the intention of the training was that she should be able to dialyse independently. Thomas, her husband, was not required to attend every session; he went into the unit just often enough to understand the process.

Susan did six weeks of training at [the local hospital] on the machine. It’s an extremely complicated machine and it does take the six weeks. I also had to be involved in the training but obviously not for the six weeks. I just went in on a few occasions, just to update myself as to what happens. But I haven’t had any training since then ... She was actually trained on the machine that she’s actually got there now.

By contrast, when Brian decided to adopt home dialysis his wife, Angela, was required to attend each of his dialysis sessions until she felt completely familiar with the process, which required three visits a week for a period of about six months. As Brian’s dialysis slot was an early morning one, they both had to be at the hospital by 7am.

Before Angela began her training Brian was trained to line the machine himself. Soon after, Angela started to accompany Brian to the hospital for each of his three weekly sessions. Angela’s role was to connect Brian to the machine, then wait four hours for dialysis to end.

I had to go in, he’d line the machine, I’d put him on and do it all what needed to be done to put him on and then once everything was settled and calmed down, I was kind of surplus to requirements and there wasn’t much room in there really for me to sit down either, so I used to spend most of my time in the gardens ... But the four hours was horrendous and I just kept thinking, I’ve got to learn this quick, I can’t stand this no more! ... it was starting to get a bit tedious ...

During her training much of what Angela learnt came from her own observations.

... it was like a self-train. You kind of, Brian already knew how to do most of it on the machine anyway, so he was showing me and we were kind of helping each other and then I would ask the nurses what if this happened? How do I cope with that? What if? All the problems, but nobody came up and said, oh if you get a blood clot, you’ve got to do this or you’ve got to do that. I had to ask and it was only because he was in a room with other people on dialysis, if they had a problem with their machine, I want to know what that problem is. So I would ask and say, what was the problem with that machine ...

Angela prepared herself by taking notes on how to solve problems that might arise.

I made loads of notes as well for problems ... you don’t get no problems at the hospital strangely enough. It all runs smoothly and as soon as you come home, it’s like, everything goes wrong. So I was preparing myself for all the problems, anything that could happen, made loads and loads of notes, so I knew exactly what to do and how to solve it if that happened. So I was prepared in that way as well.

When Catherine trained to support her sister to dialyse she also had little input from nursing staff, but she made only about six visits to the hospital. Diane was trained to conduct the whole dialysis process herself, though it was emphasised that she should not dialyse alone at home.
she was back at [the main hospital], when she agreed to home dialysing ... so they trained her up how to use the machine, put her on, get her off the machine, but it was then down to her to train me.

Most of Catherine’s training for home dialysis was given by her sister.

... and she said you’re going to have to come in to learn what to do ... but it was Diane who trained me. Now her idea of training is just to say do that, press that. My idea of learning is, ok, why am I pressing that? Why am I doing that? And then I understand it. And she’ll admit herself, she’ll say I’ve no time to teach you, I want to get off the machine, so this is what you do. Whereas a couple of times a nurse maybe had stood by and I said, well why do we do this? And she explained it and then I understood ...

Although the training allowed Catherine to competently deal with the machine, ideally she would have preferred a different approach where she could have asked more questions of the renal staff and gained a better understanding of the process.

... although she wasn’t allowed to come home until her main nurse had seen me do the machine, but I was still a bit like, well I want to know, if I do that, what’s going to happen? Or if I do that, why, and what should I do if that alarm goes off? ... So I think the training possibly, it would be better if the nurses did maybe the initial session or initial couple of sessions, left you alone and then came back for questions ... I’m quite quick at learning and picking things up, but it was Diane’s style of just do it, just do it. And even sometimes she said well I don’t know why you do it that way, but that’s the way I’ve been taught, just do it. So yeah, the training I thought was a little bit lacking ...

Norman’s training took place at the satellite unit where Olive had dialysed for the previous three years. Although his training involved more input from nursing staff than Angela and Catherine’s did, Norman found it difficult to absorb the information, distracted by the noisy environment.
... it don’t sink in, I mean however they train you in the unit, so there’s, well you’ve got seven beds down that side, admittedly around the other end ... if the machines start bleeping, alarming, it’s all noise, distraction and you should be in a place on your own. Well I think, a porta-cabin or something where you can just go into, just you and the patient and the nurse, so you’re on your own. Then you can take things in.

Norman would have preferred a slightly longer training period, with more time spent on potential problems, and with clearly written instructions to take away. At the end of his training of about 12 weeks Norman felt unable to address problems with the machine once Olive starting dialysing at home. He and his wife felt disheartened to the point of almost deciding to return to hospital dialysis.

Somewhere between 11, 12 weeks, which sometimes I think weren’t quite long enough because I’ve learnt a lot more since I’ve been home ... I’ve learnt more on what to do when things don’t go right and what the machine is telling you. Because if you don’t know what the machine is telling you, you’re absolutely lost and that’s where I found it very difficult. We very nearly gave it up.

Fiona’s training was much shorter. While Graham trained for home dialysis over a period of six weeks, Fiona attended eight sessions, spread over four weeks. Graham was trained to conduct the whole process himself and the intended aims for Fiona’s training were extensive.

Yes because it was about putting him on and monitoring as well as learning all the theory side ... so if things do go wrong, you can understand why ... anything that might happen, any alarms that might go off or how he was feeling at some point, what he’ll look like if he starts to become unwell and just signs to look out for and things like that. So all that had to be covered as well, it wasn’t just about putting him on and taking him off ... apart from the needling, I was trained to do everything.

Reflecting on the training she received Fiona feels that it may have been more effective had she been trained at home, in circumstances that reflected reality, rather than with the security she felt in the hospital.

... it shocked me how quickly [the dialysis nurses] dispersed after a few dialysis sessions once he’d come home. It was like we’d done all this training in the hospital with the machines but actually the training would have been better off in the home because you’ve always got the security that A&E is just down another corridor in the hospital if anything goes wrong, so you’re more relaxed, whereas at home it was very different, it was like, oh god, this is it. We’ve to get on with it and actually A&E isn’t down the corridor.

Two of the ten carers interviewed did receive their training at home. Helen is 48, married to Jack who is 56. Jack was diagnosed with renal problems at the age of 15 and started dialysing at the age of 46, initially in hospital and then at a renal unit closer to his home. Jack has diabetes and has difficulties with mobility. He started dialysing at home in August 2010.

... my husband arranged for me to go to [the local renal unit] for two weeks to learn to do the needling and then the home dialysis team from [the hospital further away] actually came to the house to train me.

Helen appreciated being trained at home, and valued not having to travel to the hospital, which is 23 miles from their home.

I found it better that we weren’t having to travel to and from the hospital, but trying to take everything in, it is actually mentally demanding ... they found that people learn a lot better in their own homes rather that at the hospital.

Over a period of six weeks the renal nurses visited three times each week, staying four hours for the whole of Jack’s dialysis session.
Karen and Laurence also trained in their own home. This was the arrangement that suited them best, as they both work full time. Nevertheless, at the end of the training they had used half of their year’s holiday entitlement.

... because we both worked, because we had to take holiday from work to do it, [the dialysis nurse] actually said she would do it in as few a sessions as possible, really good to accommodate us. The nurse is absolutely fantastic ... we had the machine at home about a month before we went onto home dialysis ... I think they came at end of April to do the alterations and the machine came early mid May and then we started in June, last year 2010.

Prior to and during the training Karen experienced high levels of anxiety.

I was just panicky at first, I was a nervous wreck. The night before we were dialysing, I did not sleep. I was in a terrible state, I just kept thinking I was going to do something wrong ... That was basically during the training, the anticipation, am I going to be able to do it? Am I going to do something wrong? Are they going to say no I can’t do it.

The dialysis nurse started training Laurence initially in hospital, then at home, then two weeks later Karen began training. The dialysis nurse was willing to provide as much training as Karen and Laurence felt they needed. Karen felt she would have been better equipped for the training had she been more familiar with the process while Laurence was dialysing in hospital.

I wish I’d been involved more. I had only seen Laurence dialyse twice on the machine when he was taken into hospital when he was rushed in. And because I never went to the hospital with him, I don’t think I realised exactly what was involved. It sounds stupid really but I knew the machine was there and we’d got all the supplies but I didn’t actually realise what actually happens. I think retrospectively, I’d like to have perhaps gone to a couple of sessions at the hospital while he dialysed to see then more things that actually happen to get an idea of what was likely to have to expect.

Finding time for training is a challenge and an additional cost for carers who are employed. Large employers and sympathetic managers are sometimes willing and able to allow staff to train during work hours, and/or to maximise opportunities for flexible working, but this often involves long hours, as when Vanessa trained to support her son William for home dialysis.

I did the training February March April, I did that for three months and that involved me having to be at [the training hospital] at half past six in the morning, I had to get up at half past five, take William up ... stay at [the hospital] ‘til 9 o’clock then once the rush hour was over I’d go back to work. Go in work for three hours then I’d go back for William coming off dialysis. But then there were some days where I had to stay and I didn’t go to work in the morning, so I was up at half past five, going to work then doing all that and then on a Thursday I’d work late to eight o’clock ...

It is natural that some carers will feel more comfortable and confident with the dialysis process than others, but the very different lengths and styles of training suggest room for reassessment of effective and efficient approaches. Most carers acknowledge feelings of anxiety when they first begin dialysis at home with no support from nursing staff, but those who train in a calm environment with an understanding of the process are obviously at an advantage. Training at home supports a sense of reality, and minimises time demands for carers. Another notable difference is the extent to which patients are trained to maximise their self sufficiency in dialysis, while others are trained to share the dialysis tasks with their carer. Allocation of roles is explored in the following section.
Carers vary in the extent to which they are actively involved in the dialysis process. Of the ten carers interviewed for this study, Thomas, was the only one who felt confident to leave his wife, Susan, to dialyse alone completely. Susan dialyses for three and a half hours, five days each week. She was trained to manage the dialysis process herself, and due to having a neckline, no needling is involved. Because her hands are weakened by rheumatoid arthritis, until recently Susan needed help to access the saline, but she can now manage that herself and so can conduct the whole process alone.

Susan does everything herself apart from there are some things that she can’t do ... there’s a saline bag and you have to spike the bag which then feeds into the lines if needed. One of the packs of bags that we had, had a very stiff needle going into the saline bag and she just could not cope with because she’s got very bad rheumatoid arthritis as well. So I had to be on hand to actually spike the bag. However ... we’ve got a new set of neck line spikes which now will go into the bags a lot easier and so she can now do that. So she’s virtually totally independent with the machine. She can set it up, she can make it work and she can get herself off the machine without me now.

Thomas is only required to carry out two weekly tasks: he changes caps that are too difficult for Susan’s hands, and he makes up bags of dialysate. Thomas feels no compulsion to be present while Susan dialyses.

No I don’t, no not at all and in fact there are occasions when I go out and play a game of golf, I have been away for two days of golf, and she has managed to hook herself up all by herself, which is absolutely brilliant. She couldn’t do it before, when she had to spike the bag ... But since we’ve got the new bags she’s had no problems whatsoever. But she’s totally able to do it herself.

Graham was also trained to dialyse independently. He dialyses for three hours, five days a week. During the week, when his wife, Fiona, is working, Graham sets up the machine and aims to be quite independent. At the weekend Fiona is more involved and often sets up the machine.

... we’ve got a bit of a routine going and he’s happy getting up in a morning and setting the machine up during the week so I can just get up and get ready and go to work. But weekends, if it’s later on, I’ll set up or take him off, things like that. On odd occasions during the week I’ve set up in the morning ...

The standard weekday routine is that Graham gets up early enough to set up the machine and already has done almost two hours dialysis by the time Fiona leaves for work.

He’ll put the machine on just so that he’s done the sort of cautious time, the hour and a half up to two hours before I leave for work, so I know he’s ok and I’ve made him a drink and checked blood pressure and he’s had something to eat and I know everything’s fine so that I can go.

Fiona and Graham feel confident that little can go wrong in the final hour of dialysis when he is in the house alone, but they have a plan in place if he were to feel unwell.

His mum is just a few minutes down the road from where we live and we’ve got where the ambulance can get in to him if need be, so he knows if something’s not right, he’ll just call an ambulance.

Diane dialyses three days each week for between three and a half, and four and a half hours, with help from her sister Catherine.

... she sets the machine up, she puts her own needles in ... I get there for her going on because she shouldn’t ever be on the machine without someone being there because if her blood pressure drops and she passes out or if a needle comes out, there would be blood everywhere. So while she’s on the machine I monitor her BP to make sure it is stable...and that her nutritional needs are met, so making sure she has a little cup of tea or water or something to eat. Company as well, trying to be company for her ... Sometimes what I do is I go and do her housework for her or I get quite involved in her paperwork for her ... Then I take her off the machine ... I would then take the needles out, stop the bleeding and then it’s checking her blood pressure when it finishes and then
checking her weight to make sure that we’ve taken off the right amount of fluids ... I put the machine in to disinfect and then strip it down.

Although Diane is capable of conducting the dialysis process herself Catherine feels strongly that Diane should not take herself off the machine, nor should she be alone in the house while dialysing.

_She could but I think taking the needles out would be ... she could bleed out from there, but she shouldn’t do no, because if something happens, if her BP drops or a needle comes out, it could be fatal, so no she shouldn’t do it herself. So they don’t allow that. I mean there’s been the odd time where she’s been a bit naughty, if I’ve been stuck at work or something, I get there and I say where are you? And she’ll say, oh I’m just on and I say, you’re not supposed to do that! ... I don’t want to turn up and she’s passed out or a needle has gone or anything! But now, she generally knows to wait ‘til I get there before she goes on._

Brian dialyses for four hours every other day. He prepares the machine and needles himself. Angela connects and takes him off the machine, and cleans afterwards.

... he does the needles, I don’t do them ... I only do the connecting up to the tubes and any problems with the machine, that’s what I do and I clean the machine, I take it all off when he’s finished and he basically, when he can, he lines the machine and he can put himself on. Because the ideal thing is, when they’re on dialysis they’re supposed to be able to put themselves on and take themselves off and solve any problems in between ... well he can do it all himself but the thing is what I’m saying is, because I’ve been doing it for him now for so long, he’s probably forgotten half of it. So if he had to do it on his own, I think he would be in a bit of tiz woz ...

Although Brian was trained to be self sufficient the hospital would not have let him dialyse at home without Angela’s support, particularly because he has a disability and is unable to move quickly. During the time Brian is dialysing Angela stays in, unless someone else is in the house. Before receiving a transplant Harry dialysed four hours three days each week. Similarly to Brian, he would set up the machine and needle himself and his wife, Gillian, would put him on the machine, stay at home while he dialysed, and clean afterwards. With Gillian’s heavy workload as a head teacher this required well calculated timing, to fit in the four hours of dialysis without ending dialysis too late in the evening.

_Well it was timed, so I would ring when I left [the school] and as I left [the school], he would then set up the machine and then I would walk through the door at home, go up to the room that we had converted and he would be ready to put the needles in. I would then wash up and whatever, and then I would be there as he put the needles in to then hook him up to the machine._

When Harry’s dialysis sessions increased by half an hour the added time became stressful to fit in, creating days that were exhaustingly long for Gillian. Over time, as Harry bled more during needling, Gillian’s role became more essential.

_As time went on, because as he started to needle, he was also bleeding and it could sometimes be quite serious bleeding, he couldn’t do that without me there to support him in terms of stopping any bleeding that was happening, because he didn’t have another working fistula ... And I suppose, we would still manage it, but I think we were lucky to get the transplant when we did._

Two of the ten carers who were interviewed do the needling for dialysis. Charles has a fear of needling, and from the outset his wife, Barbara, has played this role. Charles dialyses four days each week. For three of these days Barbara is at home. Charles sets up the machine and Barbara needles and connects him to the machine. After dialysis she takes him off the machine and cleans. It is feasible for Charles to dialyse on one of Barbara’s work days if she can leave work early.

Jack dialyses for three hours every other day. Helen is responsible for all aspects of the dialysis process.

_Set the machine up, hook him onto the machine, stay within earshot in case any of the alarms go off. Once his therapy has finished, take him off. I do his needling as well because he’s not able to feel the needles ... He’s diabetic, so there’s damage in his fingers._

Although all carers experience a sense of responsibility for the person who dialyses, the routine that they establish - the number of days on dialysis and the extent to which the patient can operate self sufficiently – has a significant impact on the carer’s lifestyle.
The amount of contact that home dialysis patients and their carers have, and want, with visiting renal nurses varies considerably.

Barbara feels well supported by the renal nurse who regularly visits her and Charles, and by the technical staff. When Charles first came home to dialyse in 2003 the renal nurse accompanied their first three dialysis sessions. Since then Barbara and Charles have had occasional difficulties with their machine, but this has never led them to question their decision to dialyse at home.

Because the machines do break down from time to time and have problems. Charles is quite interested in machinery and things and will tap buttons and try and get it to work ... and he’s quite good at talking to [the technicians] and saying, well you know, it’s not doing this and it should be ... But they’re brilliant and the support we get from the engineers as well, we can ring up and they’ll, if it’s something that’s urgent, they’ll be here within a day or two, so that’s fantastic as well.

The renal nurse visits at least monthly, and Barbara feels confident that the renal staff are available and willing to help.

... our renal nurse is fantastic. If there’s the slightest thing, she’s on it and I know it will be sorted out. Having said that, we’re fairly fortunate at the moment really in that there aren’t too many [dialysis] patients at home at the moment in this area ... So whether that might deteriorate a little bit if there were more people and obviously she’s got more people to look after. But all the staff at [the satellite unit], they’re all really helpful and even though they don’t really know us so well now because we’re at home all the time, they’re wonderful. You ring up with a problem and they sort it out.

The combination of Charles’ confidence to tackle potential problems with the machine, along with regular and ready support from nursing staff leaves Barbara feeling secure in the face of challenges that might arise. When Barbara had appendicitis earlier in the year the renal nurse proactively offered Charles a space to dialyse at the hospital where he trained, reinforcing the sense of a system that can step in when needed.

Thomas also feels confident in the system, even though Susan receives no regular visits from renal staff. When Susan first began home dialysis, although renal staff were available by telephone during the day, Thomas felt concerned that there was no technical support available outside working hours if problems arose with the dialysis machine.

... I was a little bit uncomfortable to start with that particularly if she was going to dialyse in an evening, there was no cover, absolutely no cover at all and it worried me that if there was a problem, what would she do ... for the past year there’s been no out of hours help, only during the day.

Due to this concern Susan initially dialysed during day time, but in fact, once they became familiar with the process Susan and Thomas’ confidence grew. Thomas recognises that his background in engineering gives him confidence that he can deal with situations that others may find stressful.
I was quite comfortable with the machine once we’d had the training on it ... there’s lots of in-built safety measures with the machine, you can’t do one thing until you’ve done another, it’s a natural sequence, it tells you how to do the things in sequence. We’ve got two rather large books that if an alarm comes up, we look in the alarm book or in the book and it will tell us what the problem is and if there’s a problem, how to get rid of it. So we’ve got all of the info there that we need ... For me, yes, being an engineer it’s something that I can fairly easily get to grips with.

During the day technical help is available and more recently an out of hour service has begun. Susan receives no regular visits from renal staff, but knows that she can call for help if she needs it.

We’ve had a couple of little problems with the machine when we’ve had to call out the technical people and we’ve had one visit from the nursing staff. But they are there and they will come if we need them.

Similarly, Karen and Laurence receive no regular visits from renal staff and are happy with that arrangement. As people who both work full time home visits can be problematic, often requiring them to take leave. On the occasions when Karen and Laurence have had problems with their machine they have found the renal unit very helpful.

... we’ve had a few problems with the machine. If we’ve had problems, our renal unit at the hospital are brilliant, you can phone them at any time and if we get any message and things that we can’t sort out what they are, any problems, we can phone them and they tell us what to do.

Resolving problems is more challenging when the problem cannot be addressed over the telephone. Arranging times for visits from an engineer can interfere with work schedules.

And we have had a couple of problems where we had to have the engineer out and that is not as practical when you’re working ... Laurence had to take emergency day’s holiday from work to get the machine fixed. It is good to dialyse at home but sometimes the back up you get is not always as good.

Ideally an out of hours repair service would avoid home dialysis patients having to take time off work when the machine breaks down. Laurence does not get regular visits from a renal nurse. He visits the hospital for blood checks and a quarterly check up. Karen sees no need for regular home visits, and would find day time visits an inconvenience.

But because we both work, I mean last year I think we used over half our holiday entitlement in training for the dialysis ...

Although Karen and Laurence have found the support extremely helpful, the system is not well adjusted for people who work full time. Delivery of supplies involves some inconvenience.

... the only thing with home dialysis is the question of supplies. We have supplies from three different sources ... The [hospital] where we dialyse, should deliver every 28 days, but again because they won’t leave outside and they won’t leave with anybody else, Laurence has to go to the hospital to get your supplies which is a bit of a bind really.

Similarly, training updates have to be done in work time.
Another thing … Laurence uses Heparin for the dialysis machine and we had a letter to say they’re changing the procedure … We’ve got to have training on it. So again … that’s going to involve us having to take holiday … things like that are not always easy when you are working.

Although evenings would be ideal for training updates and for visits from a dialysis nurse, Karen recognises that this is unlikely to happen, as the majority of those on home dialysis are not in full time employment.

Fiona feels a need for more support. In 2009, when Graham began to dialyse at home, despite the fact that he had dialysed in hospital and renal units for most of the previous 20 years, Fiona felt anxious and it took her at least a year to gain confidence with dialysis. She emphasised the different levels of understanding between herself, who was new to the process and had other demands on her time and attention, and Graham who, from years of experience, understood it as a system.

… we’ve got everything in a list. Graham had been quite used to it really because … he had to do his own machine up when he went to [the satellite unit]. He was quite familiar whereas it was all so very new to me, so he knew things that pipe goes on that because you have to do that otherwise this won’t come through. And I just knew it as a process and obviously Graham had been doing it for so long, so a bit differently to what I was told … we found that if he tried to sort of interfere and say, oh no, you do it this way first, I wouldn’t get it right and then I’d flap … I had it quite literally listed all the way around the room in stages what I needed to do. To be fair they were on for a good 12 months, them lists, so because I carried on working and with [my daughter] at home and you’ve still got a house to feed, suddenly called in to do it and it’s like, right, what do I do?

Graham and Fiona had some problems with their first machine and often relied on support from technicians to resolve them.

… every now and again we just get an alarm and it’s a mechanic alarm and nobody knows why or what so we just push a few buttons and hope for the best sort of thing … Monday to Friday there’s someone to ring up for, but quite often if it has happened it’s been on the weekend which you’ve got nothing … you leave a message on the answerphone, and presumably it’s somebody who is on call or whatever who will pick the message up and contact you. But that doesn’t help there and then when the alarm is buzzing and you don’t know why.

A nurse visited Graham and Fiona for their first two sessions at home, and now a nurse visits monthly to collect Graham’s blood. Her visits are brief.

… so she might just come in and pick the bloods up. I think she used to at first, when she first came, come down and do a bit of paperwork … but now she’ll just come in, pick up bloods, how are you doing? Alright, lovely, bye, and that’s as much as we see of her. But to be fair on her … so there’s only one [nurse] for the whole of the home dialysis for [the hospital] and she goes all over the place. But also she’s seconded out to short staffed dialysis units as well.

Fiona would like more support than they receive. When she and Graham were both unwell and Graham was in pain when dialysing they had difficulty finding help.

When I came down with this bug … And I could barely stand and then when Graham went downhill badly on the machine, obviously he’d picked it up. We rang the hospital, we rang the unit, we rang our doctor’s and it was like, get on with it basically. It was like what do you want me to do? Our GP went, well what do you want me to do? Well he’s in agony, writhing in pain and what am I going to do exactly? So we had to pull him off
really quickly because obviously he couldn’t dialyse. Now we didn’t know that he could dialyse later on, for all we knew every time he went on dialysis with this he would be in horrendous pain. So I rang the dialysis nurse and she just said call an ambulance ... So we got an ambulance, we took him up to A&E and it was like, alright, fine, after a few hours, go home. ... so then we had to wait while Graham were well enough which was the following day. Luckily everything went alright.

Fiona feels that the support available does not match what she and Graham were promised, due to lack of available dialysis options in hospital.

I feel that the support mechanism needs to be better .... I just felt that what we were promised, because when we went for the training we was told that if I wasn’t well enough or Graham wasn’t well enough, there wouldn’t be an issue, he’d just go into hospital to dialyse and that clearly wasn’t the option.

Angela also feels a lack of support. In 2007 when Brian first started home dialysis a renal nurse visited for their first dialysis session. After that visit and for the following three and a half years, Angela and Brian had no regular visits from the hospital.

No, nothing at all, absolutely nothing, it got to the stage where he came home for dialysis and then it was kind of you was on your own, literally, on your own. ...

During the first year of home dialysis Angela seriously considered giving up with home dialysis, feeling overwhelmed by the responsibility, but eventually resolved to keep going.

I think it was about six months into it, we had a lot of problems at the beginning and it was so stressful because you know ... an air bubble can kill them, you get told and things like that, and you just sort of think, oh god ... it’s a lot of responsibility ... I was having nightmares and everything, and I thought, oh no, I can’t do this ... But I suppose it got to the stage where I persevered and I thought, no, I can do it if I just focus properly and just put my mind to it and just try and get as much information as possible. So I was making the effort to talk to the nurses more, but like I say, nobody was coming, phoning me or coming and seeing me and saying, how’s things? Is everything alright?
Angela knew that she could call the hospital if she needed help with the machine and, over time, gained confidence. Most of the time Angela now feels comfortable with the dialysis process. However, despite having settled into a routine and gained confidence, when, in late 2010, Angela and Brian had a new and serious problem with their machine both felt overwhelmed by the situation and were ready to give up home dialysis.

Last year, this problem was on-going for three weeks and it was constant ... Phoned up the technicians, they came out, didn’t know what the problem was ... And then it got to the stage where Brian refused to use the machine ... I phoned up the technicians ... I was in tears on the phone, saying to him I’ve had enough now, I can’t do this no more. Brian’s refusing to use the machine now, I want something done. Just bring another machine! Brian was starting to think it was him, something was wrong with him. So he’s getting depressed, I’m getting depressed because I’m trying to sort a problem out that I can’t sort out. Anyway, he said give me ten minutes, he phoned me back and he said, alright, we’re going to give you another machine. I thought, about time, you know, two, three weeks I think it went on for. He brought another machine, next thing you know, everything was fine.

Following that episode a renal nurse has begun to visit Angela and Brian every two months.

Yes, last year that was, yeah, that was the last straw for me and I wasn’t going to do it anymore, I said, Brian you can go back to the hospital, it just pushed me too far, literally and the support and everything I didn’t get, I thought no, it’s just not on. And then like I say, and the new dialysis nurse now comes in, every time she comes round, she’s always like, how are you? She comes out, she talks to me, I think because she knew it upset me so much. And it took that, to actually make her put me, do you know what I mean? Give me an importance slot, do you know what I mean?

Helen also spoke of times when she felt so frustrated or daunted by challenges with the machine or with needling that she felt like giving up with home dialysis, but her determination helped her persist.

Believe me there’ve been two or three occasions I’ve thought, I’m not cut out for this. Or that’s it, I’ve had enough. Then afterwards I’ve thought, no, I’m not letting something silly like that beat me ... These occasions where you can’t clear alarms or the needling problems, you just get really frustrated at times and you think that’s it ...

Seven months after starting home dialysis, just as they were gaining confidence with dialysis, Helen had difficulty accessing Jack’s veins. As the problem happened on a Sunday she rang the hospital and Jack was admitted. Helen greatly valued the encouragement and reassurance she received from the renal nurses and appreciated the nurse’s recognition that, at that stage, due to the anxiety she felt around the difficulty of needling her husband, it was she, rather than Jack, who needed support.

As I say, the nurse who trained me, was very good with all those problems. He actually gave me the support rather than Jack at that time. I’m very grateful for it, believe me.

The readiness from the nurse to hear Helen’s concerns and give her reassurance helped restore her confidence.

Norman and Olive also reached a stage of feeling overwhelmed by the challenges of home dialysis. When they first began home dialysis in mid 2010 a nurse accompanied them at home, but Norman feels more support would have been better.
She come about half an hour or three quarter an hour the first session and about half an hour the second session. It’s not enough, because when things go wrong ... and there’s nobody there, I know there’s always somebody there at the end of the phone, but that’s not here. And that’s what I found very difficult. After two or three months of dialysing at home, Norman and Olive were struggling to keep going.... we were having big problems. I mean Olive’s ...weight went up, I don’t know, four or five times we had to put a weight up, so we were constantly getting problems with the machine and I didn’t know how to fix it.

Dialysis was becoming very stressful for both Olive and Norman. They went back to the satellite unit for help.

Because if you don’t know what the machine is telling you, you’re lost, you’re absolutely lost and that’s where I found it very difficult. We very nearly gave it up ... Olive was ... she got in such a state ... I had to take her into the unit. I said we can’t carry on like this. And I think they had us in, they said, well you’d better come back to the unit and have a week’s, give yourself both a rest.

After dialysing at the unit for a week, Norman was ready to come home.

They wanted to keep her there another week, I said no, we need to get back into the saddle, if you fall off a horse you’ve got to get back on it and try. We need to get back home ... but we’re alright now ... it’s gone a lot better

Despite the earlier anxieties, Norman now feels more confident when problems occur with the machine.

Yeah, well I’ve got to secure Olive first, get her off then phone and say, well this is what’s happened, because you can always dialyse the next day, but when you’re first learning, you think, oh messed that up again today. All you worry about is your patient, that’s all you worry about. But they say don’t worry, you take her off, if you’ve done two hours, put her on for two hours the next day, which is common sense. But when you’re home on your own, common sense don’t come into it. Not for a start, it does now.

Norman, Helen and Angela were not alone in experiencing a phase of feeling unable to continue with home dialysis. Others also spoke of times when it seemed too hard, and then they adjusted and settled into a position of acceptance. Feeling alone and unsupported with the technical and clinical aspects of home dialysis is understandably one of the factors that prompts a sense of being overwhelmed by the challenges. Confidence is crucial, and while, for some, this comes from knowing that support is available if they ask for it, others feel a need for regular visits from renal staff to gain a sense of security and of not being abandoned.
Impact on carer: how does home dialysis influence the carer’s work and/or use of time?

Unless patients can dialyse completely independently, inevitably caring for someone who dialyses at home will influence the carer’s use of time. As well as the quantitative number of hours that the patient spends on dialysis, the chosen pattern of dialysis also impacts on the carer. Patients often gain health benefits from more frequent dialysis yet if they or their carers are working, more frequent dialysis creates additional complications for scheduling.

As described earlier, Susan requires minimal help from Thomas with her dialysis. Other than changing caps and filling bags for the dialysis machine, dialysis has little impact on Thomas’s use of time when they are at home.

... she doesn’t need me to be available, apart from as I said earlier, just replacing the little caps ...No, not in the normal sense of time, during the week normal working time, it doesn’t impinge on me very much ... I am very lucky, I really am lucky because she’d not dependent on me, I can go off and play golf and she’s totally independent, which is brilliant!

The key way in which Susan’s dialysis influences Thomas’s use of time is in the limitation it brings for spontaneous holidays.

Yes, I don’t feel trapped in any way. There are times when I think it would be lovely just to be able to jet off to a foreign country like most normal people do. I would love to be able to do that but that’s the only criticism.

Norman and Olive have also found home dialysis quite easy to fit into their routine. Although Norman needs to be at home while Olive dialyses, his time was previously occupied with driving her to the satellite unit.

No, I mean if she was still in the unit, I’ve got to leave here, I’ve got to go to the unit, I’ve got to sit and wait until she goes in, because you can sit there half an hour. I mean when I’m sitting here, I’ll just go upstairs, switch the machine on, line up which takes about ten minutes, come back down, sort everything out then go back up and put Olive on.

Norman acknowledges that staying at home while Olive dialyses absorbs more of his time than when she was dialysing in the unit but, nevertheless, he considers home dialysis a better option.

But I find it a lot better, it’s more time consuming for me, not for Olive. But it’s a lot more, because while she’s on dialysis, I’ve got to be here.

For Barbara, supporting Charles with home dialysis has shaped her working life. Barbara was working part time as a pharmacy technician when Charles became ill. She stopped work during 2003.

I was working bank at the time so I was only going in when their technician was off ... I didn’t work at all in 2003 because obviously with Charles being in hospital, two girls and the first six weeks [that he was ill] my parents came down and stayed with us.

More recently Barbara returned to work and now works two long days on Tuesday and Thursday and a half day on Friday. Charles has adapted his dialysis routine to fit around Barbara’s work hours. Barbara acknowledges that, had it not been for dialysis she would probably have increased her work hours.
I think I would have gone back to fulltime work and be working fulltime had I, or at least four days a week had I not have had Charles on dialysis ... Whilst I would have worked longer hours ... it's not happened and it's unfortunate but you know we've got a nice lifestyle, so it's nice for me now that I am working a little bit more now and earning a bit more money, I've got my own money I can go out and spend ...

When Barbara's daughters were at home she felt able to leave Charles on dialysis for two hours each week while she played netball, which allowed her space for herself.

I used to put him on dialysis and go out and I'd be out for two hours ... so we'd time his dialysis so that I got out, played my netball match, because that was the one thing that I'd done for me and I'd done it from the kids being small ... it was my get-away when I wasn't thinking about them ... a bit of a concern when Charles was on dialysis, I used to play with a phone in my pocket of my netball skirt ... I stopped playing about three or four years ago now, and the girls up to that point there was usually one of them around at home ... So if something happened they could always ring me and I wasn't that far away

Now that their daughters have left home, during the evenings that Charles is dialysing Barbara stays out for shorter periods of time.

I go out and take the dog for a walk, but I'm only down the park for half an hour, so I do pop out but I'd be a bit more wary of doing a couple of hours like I did playing netball.

When Vanessa's son, William, was suddenly taken ill and they agreed to adopt home dialysis Vanessa had no idea of the implications for her work or her use of time.

... Do you know, we didn't know what was involved, we'd no idea what was involved, just said yeah, we'd quite like to do that because we felt that if William, he'd already been [dialysing] in hospital ... six months. ... we didn't want him to become hospitalised, that's just your life going into hospital all the time and we thought that would be better for home dialysis. So what we didn't envisage was the fact that the dialysis would be three nights a week and somebody would have to be there all the time. We were a bit naïve, we didn't realise that would be the case.

Vanessa acknowledges that she was warned that home dialysis involved considerable commitment, but the full reality and extent of the demands was not clear to her until she was actually involved with them.

I mean even if I had known, it wouldn't have made a difference, but they did say it was quite a commitment but we just didn’t appreciate the commitment, because I didn’t appreciate the fact that I’d be coming home, going straight up to William's and then three nights a week I would be like leaving the house at half eight in the morning, getting home at 11 o'clock at night. I didn’t quite realise ...

Initially Vanessa was supporting William with dialysis three days each week after work. More recently his sister, Yvonne, had returned home and was assisting William on Mondays and Fridays.

On a Wednesday I work through my lunch hour so I can leave about 4.15, so if William is on about 5 o'clock then it means he can go off at 9.30 so I’m home for about 10.15 ... Yvonne does it on a Monday and a Friday ... she doesn’t go back to uni until October, so when she gets her hours, then we’ll work out if ... she’ll still do the same. And if not, we’ll swop things around ...
In addition to the five and a half hours required for each dialysis session, Vanessa helps William by collecting medicines and doing heavy shopping. The biggest challenge for Vanessa is coping with the demands made on her time. She is optimistic that, having got through the first year, she is developing a routine that is more manageable.

... I did feel that every day that so many people wanted a piece of me and there’s only one of me and I spend my time with William, with my husband, with Yvonne my daughter, with work and with my mum and dad. Now that Yvonne is home, yes, a Saturday morning is usually a good time for me and I can just go and do whatever … My main priority has been with William for just over a year, but now we are in our own routine and William is much better physically then I have more time for myself.

For Gillian, when Harry’s kidneys failed, accepting home dialysis seemed an obvious decision, despite her demanding work role. She was able to adapt to the dialysis routine only with very significant co-operation from the school of which she was head teacher.

Well in my job, it’s not just a nine to five job. I’m expected to attend various events and things like this. This whole school with 100 staff, was managed around the dialysis, and my governing body also were very supportive … My leadership team managed the school around me and my husband’s dialysis, so meetings that had to take place, I can’t do Mondays, can’t do Wednesdays, can’t do Fridays, and they would shift everything they possibly could, to enable me to be the head teacher of this school, to manage it around dialysis.

Days when Harry was not dialysing Gillian would spend 13 hours at work. After about eight years of home dialysis Harry’s consultant recommended that Harry change his dialysis routine from three days a week to five. Had he done so it would have become impossible for Gillian to continue to juggle work and dialysis demands. Gillian described the indignation she felt at the sole focus on potential benefits to Harry’s health to the exclusion of her own needs, and with no recognition of the sacrifices that she was already making. Both Gillian and Harry accepted that compromises were needed from both of them and, together, they agreed not to adopt this option.

I can remember particularly a few months before Harry was lucky enough to get a transplant, getting really, really angry and just so angry with Harry’s consultant because they wanted him to increase the amount of
dialysis to five dialyses a week with three hours and his consultant seemed to think it would be really good for Harry to do that and I suppose medically it would have been better in terms of blood clearances and things to have done that. But I’m in a full time job and already in a way I was giving up three evenings where I could work, to look after my husband. To give up all of my working time … It was almost saying, is it your husband or your job really? And Harry and I agree afterwards, Harry himself understood that it would give him a better dialysis … but he also felt that it was important that I, because I’ve been in this job 38 years, that it was something that I cared about and values. And he said, and we both agreed, that we would say no to that. And it was a joint decision that we would not go for that option, even possibly at the expense of Harry’s sort of health in a way really.

Gillian emphasised the implicit assumption from the consultant that Harry’s health needs took priority, highlighting a lack of consideration, or a lack of awareness, of the implications for her.

That was because the consultant was looking purely as Harry as a patient and his health, and I understand that, but there was no thought for me in what I was trying to do in my life. I care about Harry but I care about this job, I’ve been in this job now for 38 years and I have done something in this job. There was no consideration in that suggestion at all, that it could have a serious impact upon my life and my work because I walked away from there and I said, what he’s telling me to do, telling me to do, is to give up my job

For Catherine, who took on the role of caring for her sister in a paid capacity, the time challenge took on a different nature. When her sister, Diane, successfully accessed funding from social services to employ Catherine to accompany her during dialysis and support her with household tasks, Catherine was able to reduce her existing four day week with the NHS to three days, and help Diane dialyse during the morning of her two free week days, and directly after work on a Wednesday.

The difficulty for Catherine then, was not finding time for dialysis, but knowing how to limit the time she made available to her sister. The challenge reflected the complex and sometimes contradictory dual roles she found herself in, being both an employee and a sister.

After about a year of supporting Diane with home dialysis Catherine seriously questioned her ability to continue, then recognised the need to draw boundaries to the support she could give.

... but I’ve also seen a couple of dips sometimes where I’ve thought, I can’t do this any more, I need to stop doing it. But touch wood, I haven’t felt like that for about a year now actually. I think we’ve got onto an even playing field really … I think probably after a year, I think Diane was getting poorly but also she was taking advantage but I’d let her take advantage and I was getting to the point where I was thinking, hold on a minute, it’s 24/7 that I’m doing this … but I thought right, hold on a minute, this is affecting me and I’m not sleeping properly and I’m worried. I need to deal with this, there’s no point me being ill because then I’m not actually going to be any use to her or anyone else … I had to back away and say, actually you need to stand on your own two feet and I’ve got a bit better at doing that actually, that’s helped us both..

In some ways Catherine’s role has grown over time, as the support Diane needs has become more evident, but at the same time, Diane has become more ready to acknowledge Catherine’s need for space.
... because I was working four days a week for five years, I’d got used to it, because I did four long days and I had ... three days off, and I initially did feel a little bit begrudgingly I think, this is my day off, but because now I’m better at saying to her, look I’m not going to come at this time of the morning because I want to do xxx, I’ve just taken up yoga for example and I said to her, I still want to do my yoga on a Friday morning ... it finishes at 10.30 I’ll come straight over ... So she is learning to be a bit more flexible I think because she realises, I feel almost I’m on 24 hour duty if I’m honest because if there’s something wrong I know that I’m the first person to be contacted ... if there’s something wrong she will call me. I now also go to most if not all of her consultant’s appointments ... as her memory is now very poor. I think some of it is because she doesn’t want to take in what they’re telling her ... I felt it did get to the point where I just thought I’m exhausted, I feel all I’m doing is working, driving to [the hospital], trying to get the time off, touch wood it’s calmed down at the moment.

Fiona and Graham have established a routine for Graham’s dialysis that minimises the impact on her working week. She recognises however, that although her time is unimpeded, sometimes her ability to function well is affected by her concerns about Graham’s health.

... I delivered some training a few weeks ago and thought, that didn’t go half as well as I wanted it to, why didn’t it go well? I started looking at reasons why, analysing it and I thought maybe I’ve got too much on my mind about Graham or whatever. We had a recent problem where his veins were blowing and we weren’t sure what were happening and was it going to get worse? What’s going to happen if he can’t dialyse? So I’m a bit of a worrier and it does impede both ways.

When Graham dialysed in hospital Fiona was able to believe that his health was taken care of. Since he has been dialysing at home she is far more aware of the responsibility she and her husband hold for his health.

While he was dialysing at hospital they dealt with it, it wasn’t to do with me, it wasn’t my worry as such, he went to work, it was his work sort of thing ... but now we don’t have any contact with anybody really. We have a dialysis nurse that comes once a month to pick the bloods up, five to ten minutes, that’s it. So everything is down to you.

The pressure carers feel on their time is not restricted to people who work in paid employment. When Brian started dialysis and he and Angela agreed to move house, it became untenable for Angela to continue her business. This has led to a big change in lifestyle.

I had my own business, I had a card shop ... So I knew he was going to be doing home dialysis, I knew we was going to move ... I wouldn’t be able to travel from here to that shop, it would be too too far. So I decided, I sold my business, he sold his business and then we moved and then it kind of went from working and having a full life to sort of being at home all the time and him being on the machine.

Angela is very aware of the constraints on her time, and of the ever-present responsibility that dialysis brings.

If I want to make appointments, if I want to go out, if I want to go out for the day, it’s kind of I get sort of three days a week where I can do things and then the rest of the week it’s, you know, you go to the doctor’s and if you’ve got to go back ...

Initially, when Brian started home dialysis, the process could take most of the day, leaving Angela very aware of the freedom that she had lost.
At first ... he would dialyse, that would take nearly all day because his arm might not stop bleeding for hours on end, so he’ll go on at sort of say seven, eight o’clock in the morning, he could still be in there waiting for his arm to stop bleeding or he’s not feeling very well because of the dialysis, he could still be in there at six, seven o’clock in the evening ... then you’ve got to clean the machine, you’ve got to like help him up and everything to get him in the front room or whatever and it’s just, you can’t do nothing on those days, literally you can’t do anything. So you’ve gone from being free to go and do what you want to, now, to like a routine of you can do things only on certain days. Do you know what I mean? And it was such, well I honestly didn’t think it would be the way it was. I mean I’m used to it now, we work round it really well now, but at the time I was starting to think, oh god, for life? This is for life? I’m not going to be able to manage this for the rest of his life!

The sense Angela had of feeling trapped, combined with problems with the machine, led to her feeling badly stressed. Eventually, after about two years, Angela and Brian developed a routine that gave them more freedom and allowed them to spend time outside the house.

Then we had a few problems with the machine and that stressed me really bad and I was saying, I don’t think I can do this anymore and I actually feel a bit of depression might set in because I was indoors too much, wasn’t out and about like I was before. So, but it got to the stage where you have to try and make the best of it and it got to the stage where I said to him, if you get up early on dialysis days, dialyse early, as early as possible ... be off by 12-ish, even if his arm’s still bleeding one, two o’clock in the afternoon that is not too late for me to still go out or do what I want to do. So now, we’ve established a routine where he does it in the morning and that is it. It’s over and done with, if it stops bleeding nice and early and quickly, then we know we can go out, we can just carry on life as normal and now, it’s worked out that we can get out a lot more now rather than spending the whole day indoors ... it’s kind of taken a long time to get there, but we’re there now and it’s sorted, so we can like I say go out and do what we want, especially in the summer.

Helen also recognises the importance of developing a routine that allows her to cope with the loss of freedom during the time that Jack is dialysing, and ensures that she gets out of the house during non-dialysis days.

.. the days I’m not dialysing him, I have a tendency to go into [the local] town centre, probably ... 10.30am and then I come wandering in back about five in the evening. But to me that is what I call ‘my time’ ... but I’m usually doing my shopping that we need as well. I do take time to sit, have a coffee and a little wander round generally in the shops ... I think it is important as a carer if you can try and make a bit of time for you, you’re not stuck in the house all the time and while you’re there you don’t have to worry what’s going off at home. So yes, definitely get some ‘me’ time if you can.

For carers who have other external demands on their time it is evident that the demands of dialysis are just one of the factors that the home dialysis patient and carer must negotiate. For those who are not in paid employment however, the need for time of their own can be equally important. It is easy for health professionals to focus on potential health benefits for the patient to the exclusion of the carer’s needs. Some carers fit more readily than others into the restrictions that home dialysis can bring, but it is reasonable for carers to negotiate and establish patterns that recognise their own needs. Sometimes carers need external support to acknowledge and meet their needs. The following section discusses support for carers.
Emotional and practical support: what support does the carer get with emotional and practical impacts of home dialysis?

Carers often find support from friends and relatives, but in addition, most of those interviewed for this study were interested to meet other patients and carers in a similar position to themselves. Some, though not all, would also like support to be available to them specifically in their role as a carer of a home dialysis patient. This is something that few currently receive.

Norman is an example of someone who, other than wanting more initial support with the technical challenges of dialysis, feels no need for individual support for himself as a carer.

No I don’t see what they can do really .... No I suppose it all depends on the person doesn’t it? I’ve never felt I needed help, at the moment ... No, no, I mean ok, when you first come home and things start to go wrong, you do start to feel a bit, can we cope with this? But it wears off, it soon goes. The next day you suddenly think, well this is what I should have done.

Nevertheless, Norman does value contact with other patients, carers and nursing staff from the renal unit where Olive used to dialyse. He and his wife maintain informal contact when they deliver Olive’s monthly blood tests.

I mean we still go into the unit and have a natter to the nurses, which I find that is important ... once a month, we take the bloods in ... and we just pop into the unit ... and have a word with a lot of the nurses and sometimes I’ll say to the nurses, is it alright if we go into the unit and have a word with some of the patients what we knew when we were there? ... and I find that reassuring ... but it keeps you in contact, and I think you need that anyhow. Because I mean when you visit a unit three times a week ... I used to go in with Olive and sit in the waiting room until they called her in and you could be there three quarters of an hour sometimes, well you’re naturally talking to, and you get to know, that they’re waiting to go in for their dialysis as well and you get to know ‘em. It’s like a continuation of your family after three years, isn’t it? You miss it when you get home.

Recently Olive’s dialysis nurse arranged a meeting for home dialysis patients and their carers. She plans to continue to hold quarterly meetings. Norman values that contact, finding it reassuring.

All the people that had gone home [to dialyse] have a meeting, get together once every three months ... This is new and we went into the ward the first time and the next one ... that’s in a club in [the town] where all the carers and the patients have a get together, a chin-wag ... it’s always good to talk with other people that have been through the same situation because when you talk to ‘em, they’ve all had the same problems I’ve had. And it reassures you, you think, good, it ain’t me then!

Vanessa also sees no need for support from anyone external to her networks. She and her family benefit from the fact that they are well known locally.

I’ve lived and worked in this area since 1981 ... so as a family we’re very well known and we know a lot of people and a lot of people know us and they know obviously of William’s situation
Vanessa has not been offered any external support from health or social care professionals with handling the stress of the situation, but she requires none.

_I don’t get any, I don’t get any support whatsoever. I prefer it that way - I’m quite a private person._

Barbara is very conscious of the support she gains from her friends.

... but then all my friends know everything that happens because to me that’s my way of getting it out and it sort of offloads it a bit ... because one of the things that I think for me has been good is that I do talk about it and all my friends that know me know exactly what my situation is, they know what’s the matter with Charles, they know everything that we’ve been through ...

Barbara is a member of the local carers group and has attended a number of their craft classes, having joined the group when she was working fewer hours than she currently does, but she and Charles have no contact with other people who dialyse at home. Their renal nurse is currently considering developing a list of home dialysis patients, giving them the option of contacting other patients. The idea appeals to Barbara, but may be less attractive to Charles.

So it would be nice to have that contact and if you’ve got other people that can say, oh yes, hello, I’m on dialysis ... Charles, I don’t know how keen, Charles wants to do dialysis, get on with it and forget about it, So whether he would be so keen ...

Helen and Jack have no regular visits from renal staff, nor does Helen have contact with other people caring for home dialysis patients. There are only two other home dialysis patients in the town where she lives.

It would be nice to have ... even just someone to moan to who is in the same boat sort of thing, who you can have a chat to. But unfortunately we haven’t got anything like that here at the moment.

Helen has offered to talk to anyone who is considering home dialysis, knowing how much she would have valued that opportunity.

... because when my husband first started dialysis, there was nobody to talk to. I didn’t know which way to turn, who to talk to or anything. I think it’s nice if you’ve got somebody who is in the same position as you, that you can talk to and as I’ve said to these people, I’ll give you my number, if you want to talk, give us a ring. We know what it’s like.

Brian’s family has been Angela’s main source of support.

Oh his family are very supportive, yeah, they would phone, talk to me or I would say to them, oh Brian is feeling a bit down, because [dialysis patients] do get depressed a fair bit, because obviously they’re tied to the machine and everything ... then you’ve got to try and pick that up, like perk them up as well, and do that as well.

Angela has not met anyone else who cares for someone who dialyses at home, but would like contact with other home dialysis carers.
I actually think that there should be a carers’ support group. I think that all us carers should be able to maybe phone each other and talk to each other if there’s a problem, so that you get then an insight of how someone else is feeling and whether it’s just you feeling the way you are or whether like someone else is the same ... when you talk to each other, you can talk each other through things ...people like myself that have just, that are sort of new to being a carer, ‘cos I mean this is the first time I’ve ever cared for anybody and talking to other carers ... Well I’m talking mainly about carers of dialysis patients, ‘cos we’ve got something in common.

Angela acknowledges that because the hospital where Brian trained for dialysis is far from their home she would be unlikely to travel to meet other carers, but would like a telephone or internet group. Since early 2010, when she faced a crisis with the machine, a nurse has been a regular visitor, coming to see Angela and Brian about every two months. Angela values these visits.

Gillian has only met one other person who cares for someone who dialyses at home. She met this person by chance, through a work connection. While she found meeting the other carer very valuable she recognises that, for her, she would need to find she shared more in common than purely the role of being a carer, to gain benefit from meeting other carers.

Ideally I’d want the opportunity to offload to someone who has an understanding of the issues and who is non-judgemental.

In the eight years that Gillian was supporting Harry with dialysis the only time she was offered advice or support in her own right was when, following her husband’s suggestion, she saw the dietician that treated him and asked advice about her weight-gain. Gillian received no other advice or support from the hospital nor did they suggest she register her status as a carer.

There was never ever anything on offer for the carer to have any, and it wasn’t the hospital that registered me as a carer, it was my own doctor that said, do you realise that you are a carer? .... And I suddenly thought, god, I am a carer!

Q. And once you were a carer, what difference did that make?

Well it gave me access to things like the flu jab! Which isn’t a lot, but it showed that somebody was thinking about me! ...I think at some point in time it would have been nice to have just had a conversation with somebody, perhaps once a year, how are you getting on as a carer? What are you finding stressful? A little bit of guidance in terms of, Harry could get quite angry and frustrated, a little bit about, have you thought of this? Have you thought of that in terms of managing it?

Karen also would value some acknowledgement of her role as a carer. In the 12 months that her husband has been dialysing at home she has only once had an enquiry specifically directed towards her.

I think we’ve had one phone call. Laurence had to phone up ... our dialysis nurse for something, it was a morning before he went to work and she just asked to speak to me and asked how things were going. But I must admit we’d only been home dialysing about six weeks I think when that happened. Since then I’ve not heard anything.
Although Karen recognises that if she needed help she could ask for it, she also would value an occasional proactive enquiry to offer her support.

*I suppose I think if I needed that support, I could ring, but I suppose if there was just periodically just a telephone call to me to say is everything ok? Do you need anything? We do know that they are there if we need them. So yes occasional contact I think would be quite nice.*

Karen later added a corroborative comment:

*I was talking to my son about my conversation with you and he made a comment as an observer. He said he feels that all the focus is on his dad ie. the patient, and I - as the carer - am almost neglected.*

Karen has not met anyone else who cares for someone who dialyses at home, though she can see practical and emotional value from being in contact with other carers.

*... when the engineer came to us about three weeks ago, he said ... there was somebody less than five minutes walk from us who was having her dialysis machine fitted and it’s something I’m actually going to mention to the nurse .. because not necessarily face to face contact, but having somebody so close, if you needed something, if you did run out of something rather than have to go to the hospital for supplies, it would be can we borrow something ‘til our next delivery? But also as well just if you wanted a little bit of moral support, just to have somebody local, it would be quite good.*

Karen values the information and comments she has found on the renal patient support group Facebook page¹, gaining reassurance from realising that her experiences are similar to others.

*I found the renal site on the Facebook... I found it really, really good. Because sometimes you go, I wonder about this, and somebody else has put a comment and you think, oh, I’m not the only one*

¹http://www.facebook.com/home.php?sk=group_187011486194
that goes through that or thinks that. So that renal site on Facebook is very, very good. Laurence sometimes gets very irritable and gets moody and I used to find myself biting my tongue a little bit and again that Facebook site, a lot of people have a mention about having moods and depression and things. So now when I realise that’s possibly part and parcel of his illness, you don’t take as much notice of it when sometimes you think, well he’s been a bit nasty realise that’s part and parcel, it’s not necessarily his fault, it’s something to do with what he has to cope with, with the illness possibly.

Similarly to Karen, in the two years that Catherine has been supporting Diane to dialyse at home, she has only once been actively offered support for her own needs. She commented that while patients have access to a renal counsellor, there is no similar designated support for carers. She suggested the appointment of a home dialysis coordinator who, as well as attending to patients, could also check whether carers are receiving what they need.

The one time I’ve had that is with Diane’s old named nurse and she’d come round to do an assessment and we were in the kitchen, I was making a cup of tea and she said to me, how are you? And that was the first time anyone said to me, how are you finding it? How are you coping? Because I’m sure a lot of people think, oh it’s easy, you just go round and drink cups of tea and just make sure she doesn’t pass out. Some days it is like that and sometimes for months on end it’s not like that. And she was the first person to ask how I was. I think that what ... maybe the area is lacking is having a home dialysis coordinator, so having a person who deals with that and not only for the patients, either getting the patient home, the logistics, but also saying to the carer, do you need access to counselling or access to a group or how can we help with that? So yes, I think there is definitely lacking on that side of it.

Catherine gains support from her family and friends, though she acknowledges that none of them really understand the full extent of the role she plays for Diane.

I think without my friends I would have struggled really. My friends and my family are probably my support network through it. They’re brilliant really, very good. Again they don’t completely comprehend how seriously ill she is and occasionally if I say, I play it down a lot because I admit I don’t want to talk about illness all the time, and occasionally if I say something they’ll say, oh my god, hold on a minute, if you do this, this might happen?

Catherine feels that she can manage her stress and maintain her health by ensuring she takes enough time for herself.

Stress levels, it’s not too bad ... I kind of know I can’t be ill because if I’m ill, who is going to do her dialysis? So unless I had a stomach bug which obviously she doesn’t want to get or I’ve got a really heavy cold, I would still do it regardless. But I think for me, I’ve realised that I need to manage it by seeing my friends or I’ve just started going to the gym and taken up yoga again ...

Catherine would value meeting other people who care for people who dialyse at home. She envisages a group that might meet quarterly for information sharing and mutual support.

I think it would be really good if there was ... something like a carers’ support group for people who administer home dialysis. I’d be willing if I had the names and numbers, I’d be willing to set that up and maybe people could meet, I don’t know, once a quarter and say have a cup and tea and have a chat, but also, say for
example if someone’s got an issue that you can think, oh I know how to answer that … I think there needs to be better care for the carer. Who cares for the carer? … because not only the practical side of things … it would be nice to say to someone else, how do you manage that? Or how do you deal with that? As well as saying, oh, I’m having a really bad day! … even if one or two of us got together every quarter or we all got together or just did something.

Catherine also suggested that carers just beginning home dialysis could be offered support from another carer who had longer experience of dialysis.

And I think a good idea would be to almost set up a buddy system, so anybody thinking of doing home dialysis could maybe ring me and say, how would you feel about meeting this person, going through it with them, maybe being there the first time. I think that would be a really good idea to get you over that first step of thinking, oh my god, what am I doing?!

Finally, Fiona echoed the same sentiment as Catherine, Karen and Gillian, wishing that there were some active enquiry about her needs as a carer.

I think some consideration needs to go on, particularly when you’re working. I just think that they just presume I’m fine. There’s no, are you feeling really shattered, do you want a break? There’s none of that at all … maybe it’s about me going out to find that person, but I wouldn’t know where to start. You see renal patients have counsellors and social workers to talk to. I’ve never been offered anything ever … I do feel that carers do get a bit of a raw deal really that there is support there for patients …

Fiona commented that while people caring for home dialysis patients are often categorised with other carers, in fact the responsibilities and risks for them are greater due to the medical nature of their role. Fiona would like a firm, genuine commitment that respite would be available if needed.

… I think they just put us in line with the carer who might be looking after somebody with dementia or whatever and I’m not pulling that down in no way … but I think because of the medical side of it, because of the physical dialysis side of it, doing the needle, knowing that actually if I do this wrong we’ve got serious consequences here. I feel that perhaps some support should be needed for carers in the way of, I think for me particularly at the moment, I need to know … if I’m not well enough to do it and Graham’s not well enough to do it, he can just go to hospital. And we haven’t got that now

When asked how the situation could be improved Fiona said she would like more personal recognition and consideration, both for Graham as a patient and her as a carer.

Just a thought that actually we are still here and we’re not just money, we’re not just numbers or people, we’re not just a name on a list, that we are here and actually it would be nice to get more information about up to date equipment and instead of just going oh that’s your machine sort of thing, knowing that actually for instance, when the [first machine broke down and was replaced by the] second machine, would there be a machine that actually came out that could have done the job better recently, would they look into that? That’s something that I’m not sure whether [the hospital] do … I think you lose your value then, your sense of value as a patient, particularly home dialysis, I think it’s out of sight, out of mind sort of thing.
Money: has home dialysis influenced the patient and carer’s financial situation?

Carers had quite different experiences relating to the impact of home dialysis on their financial situation. For those who are financially comfortable, money can ease some of the challenges that dialysis brings. People with their own homes and enough space can convert rooms for dialysis, cover additional costs and buy dialysis time overseas without the hardships these might cause other people. Financial support is available, but the experiences of those interviewed showed that information about accessing support is not always readily available or accessible.

Adopting home dialysis had no financial impact on Norman and Olive. They had space in their bedroom to fit the dialysis machine and they are refunded for the additional electricity that the dialysis machine uses.

"No it hasn’t affected us, because like I say, we send the electric bill to [the health authority] and they know how much the machine uses and they just send a cheque back for that amount of money ... Oh yes, it didn’t cost us a penny, nothing at all.

When Laurence started to dialyse at home his dialysis nurse helped him and Karen apply for a disability living allowance, and the hospital cover their additional electricity costs and telephone line, so they have not been financially disadvantaged in any way.

"No I don’t think so, I mean ... the dialysis nurse told us straightaway about DLA. Laurence got a form and I filled it in and [the dialysis nurse] went through with a fine tooth comb and I had to say yes he can do this and no he can’t ... and he’s got the disability allowance care, because he dialyses at home. So they pointed us in the right direction to actually get that. We get the help from the hospital with the electricity and we get help with the phone line as well.

Likewise, Helen and Jack had installation costs covered by their social services and now get ongoing financial support. Due to Jack’s mobility problems, their social services department built Jack a ground level extension to their house which was fitted for dialysis.

"Because I’ve had the extension built, we’ve had a reduction on our council tax and the hospital actually pay so much towards the electric that we use and they pay the line rental for the phone.

Diane was previously living in privately rented accommodation and when she was ready to adopt home dialysis the hospital social worker and renal nurse helped arrange for her to be re-housed in social housing, giving her a permanent home in which she can dialyse.

The local social worker also helped arrange for Diane to claim direct payments, administered through the Independent Living Association (ILA), allowing her to employ her sister Catherine for the time she spends assisting Diane to dialyse and to help her with domestic tasks.

"I think she’s actually one of the first people in [this area], to get this type of funding ... I help her with her shopping and her housework and things like that ... she was really very lucky with this social worker who fought tooth and nail to get her the maximum amount of money, to enable her to come home for dialysis. So what they do is, they pay the agreed amount into the bank account ... and then the ILA do the payroll for her..."
so every four weeks after I ring in and say what my hours are and then they send out a payslip and then she will literally do a bank transfer into my account. So I get a payslip, pay tax on it ... she has to make a payment to the HRMC every month as well...so it’s a properly employed position.

The current arrangement, whereby Catherine works for the NHS three days each week and helps Diane dialyse three times a week, has left her with a similar income to previously, when she worked four days a week for the NHS. In practice, however, she now works longer hours.

... in real terms I’m earning less money because I’m doing more hours, not had a pay rise and I’m doing more hours than I did at my other job ... But no, it covers me with what I lost really.

Catherine was also told, by Diane’s social worker, of the availability of a £1,000 grant, each year, for which they qualify.

... her social worker got us access to money for days out with her daughter ... I twice a year apply for a grant from social services. We’ve already had, every six months £500 to use towards days out, meals out and things like that. So that’s really really helped ... well that’s what it’s there for and it says, enjoying time with the family ...

Not everyone had such immediate access to support. Barbara and Charles, after seven years of dialysis now receive financial support, though it took them some time to discover their entitlements, and they only did so through their own research.

... we get help with the electricity bill, we get I think it’s something like 10%. ... We get the lower rate of Council Tax ... We didn’t know [it was available] until about three or four months ago ... Charles gets the middle band of disability living allowance but that’s the only sort of benefit we get from the government ... again that was something that it was a couple of years before we found that out, it was only that I rang and queried ...to see if we were entitled to a carer’s allowance which we found out we weren’t, but we were entitled to the disability living allowance at the middle band’ ... I think that was the first benefit we got because the first three or four years we didn’t know we were entitled to the money off the electricity bill.

Barbara acknowledged that, because she and Charles both work, financial support for costs associated with home dialysis do not significantly change their situation, but, nevertheless, support of this nature helps address the sense that those who care for home dialysis patients are not recognised.
I mean I do think the government should maybe recognise the fact that people looking after people on dialysis, it’s slightly more than caring really ... I mean we’re well enough off, it’s not particularly that I want to be paid for it or anything, do you know what I mean?

Q. What would it mean to have that recognition?

Difficult to say because like I say, for some people the money probably would make a difference. For us, we’re reasonably well off, we both work, it’s not going to make a huge financial difference but I think it is the recognition that you’ve done that for part of your life. I mean especially towards pensions and things these days which are getting more and more difficult, the fact that if you are looking after somebody at home, it’s difficult. The thing is everybody’s circumstances are so different.

Vanessa and her son William were initially unaware of the funding available to them. When William suddenly developed renal failure in April 2010 he received sickness benefits for six months. At the end of that period the small company he had previously worked for could no longer employ him.

He gave up his job in October, he works for a very small company and they couldn’t really keep him on because his availability for work is so unpredictable, it’s the mornings ...

From that time William received no income, living on his savings supplemented with support from his mother, until they discovered that he was eligible for a disability living allowance.

... it has affected us financially because at first we knew absolutely nothing about benefits or what was available and because William had quite a good job, after that, I think he was on statutory sick pay for six months and we didn’t realise what benefits were available ... However he’s now in receipt of benefit which had we known then ... So the time we applied for him, they wouldn’t back-date them. It wasn’t through lack of asking, if somebody actually said, look this is the situation, you can claim this and you can claim that, then we would have gone down that route, but William went through quite a lot of his savings and I’ve been helping him out quite a lot. But we’re in quite a fortunate position. I can’t imagine what it would be like for somebody who didn’t have parents or family to help them out because at one point William wasn’t getting a penny.

Since dialysing at home Graham receives middle rate disability allowance, and financial support to cover the electricity used for dialysis. Fiona feels strongly, however, that they should also have costs covered for their additional heating bills. Although previously, when Graham dialysed at the satellite unit, they rarely used their central heating, they now need to keep the house much warmer at times when Graham is dialysing.

We do get some reimbursement for electric, we’re not on a water meter, so we don’t get help with water, and we get no help with gas ... when Graham’s dialysing, he just uses a blanket, obviously he can’t sit so cold. So we’ve had to have heating on and that has really hit us financially, our last gas bill over last winter was horrendous. But we get no support at all with gas.

Apart from the fact that additional heating costs are not subsidised, the financial support system does appear to cover costs associated with home dialysis, but knowledge about and access to these funds is not universally readily available. Where home dialysis patients are supported by a proactive dialysis nurse or social worker the process of claiming support can run smoothly. Even for those who do not, essentially, rely on financial support to cover their costs, the availability of funding is often valued for its tangible acknowledgement of a carer’s contribution.
Getting away for a holiday is an important goal for many dialysis patients. Their carers naturally support the patient in this wish and, being close to them, will generally want to share the holiday with the patient. Depending on the holiday dialysis arrangements this may or may not provide a break from dialysis for the carer, and it is reasonable for carers to need a complete break from the ongoing responsibilities of dialysis. The nature of the combined role, as someone who, as well as caring for a dialysis patient is also someone who shares their life with them, leads to complex mixed feelings about the carer’s ‘right’ to a break.

Holidays for people on dialysis always require considerable organisation. Many dialysis patients are waiting and hoping for further developments in portable dialysis machine with the freedom that will bring to travel. Susan already has a NxStage machine that she and Thomas have used for holidays, but as Thomas commented, taking the machine on holiday requires much preparation.

The only slight problem is obviously we can’t have holidays like normal people, we can’t just go off and abroad and that sort of thing, there’s a huge amount of organisation that we have to do to get the machine wherever it is that we want to go.

The potential to travel with the machine was a key factor in Susan and Thomas deciding to opt for the NxStage machine. Thomas described the necessary arrangements prior to a holiday.
Now there are a lot of complications and also implications of taking it away on holiday. The machine is quite heavy, I can’t lift it, we can’t lift it together, so when we do take it, I have to involve a chap next door, because it is heavy. The other thing is, there’s a number of boxes and pieces of equipment that go with it, there’s a heater and there’s a stand like a coat hanger stand from which you hang the bags. So we take that along with us to where we go. We’ve actually only tried it the once so far and we’ve been on holiday to Warner’s hotel. Prior to going on holiday you’ve then got to organise for the bags to be delivered and for every dialysis that she does, she needs four five litre bags which get hung upon this thing ... we took it away with us and the hotel were very good, they actually received all the boxes that we needed because they organised for all the boxes of fluid to be sent, 12 big boxes of fluid to cover the three dialysis days. But we made it ... we had four days over there and she actually dialysed for three of those days, which makes it a little bit more difficult because clearly you can’t go out for a full day.

In the three years that Susan has been dialysing at home she and Thomas have tried several approaches to holidays.

We’ve already done a cruise with the Graham Deilman Cruise Line on the Danube, because they had dialysis on board. It’s the only line that we have discovered that does dialysis on board. But of course it’s hugely expensive. But I’m now looking into sailing from Southampton somewhere with one of the lines and taking the machine with us. I’ve already spoken to the Fred Olsen line and they’re happy for us to take the machine and for them to store the boxes for us and then when we need them they will bring them to the cabin ...

Recently Susan and Thomas holidayed overseas with a holiday company which organised dialysis sessions for Susan. Because Susan can dialyse independently Thomas has no particular need for a break from the routine of dialysis.

In the year since Olive started home dialysis she and Norman have managed weekends away and Norman feels no need for a break from the dialysis routine.

I mean like you say, do I need a rest? If you mean a rest, like go away for a week without Olive, no way, because I shouldn’t rest. I suppose I need to be in control, let’s put it that way, I need to know what she’s doing, and know she’s alright. If I weren’t with her, I should be stressed, oh yeah, I couldn’t cope with that ... Well that’s just the way you are, when you’ve had 41 year together. You’ve done everything together and been everywhere together. No, some people just go away, no I couldn’t do that.

When Fiona and Graham go away on holiday Graham dialyses in hospital, giving them both a break from the responsibility of home dialysis. The freedom from responsibility highlights to Fiona the underlying anxiety she feels much of the time when Graham is dialysing at home.

...we go away with my mum and my sister and their families ... and then Graham will dialyse at hospital so he’s got a break from actually doing it himself. That was good and I think even with Graham doing quite a lot himself I didn’t realise how home dialysis actually affected me emotionally, it was just so nice to not have to worry about that machine for that day. It wasn’t until I was on holiday that I actually realised that my shoulders were more relaxed and you hadn’t to think about anything, you just thought about yourself and having fun or whatever. Being abroad actually made me think just how much I obviously do think about when he’s on dialysis because even when I leave him on a morning I’m obviously thinking is he alright? Is he alright? And I’ve always got my phone by me and I think that emotional drag if you like.
During each of the nine years that Harry dialysed at home he and Gillian made use of the two weeks allocated to them by the hospital to dialyse in a holiday unit. By the third year Harry felt safe to dialyse in the unit without Gillian, giving her a complete break.

... and for the first year I was there with him - the first two years I think - I was there as he needled and then I had to be with him while he was attached to the machine and after the first two times we went, he felt confident enough ... So for two weeks a year, I would not have to dialyse him, although he had to obviously go for dialysis.

For Gillian, the two weeks of respite felt barely enough.

I must admit, for a carer, to have a longer period of respite, would have been wonderful. I think a three week would have been brilliant actually. Two weeks is lovely, but it's not quite long enough ... I need a three week holiday as a minimum in the summer, to re-charge those batteries, because of the depth of the job and the responsibilities of the job ...

In more recent years Harry and Gillian were able to use a hospital caravan, set up for dialysis, for an additional two week holiday.

The hospital Harry was at also invested last couple of years in a caravan type unit which meant that we could have longer, we could have holidays, but I was still dialysing him, so we’d go to the caravan and would set it all up and do it there. So we were away from home on holiday, but I was still doing the dialysis.

During the nine years Gillian only once went away without Harry. Having refused several times, she agreed to take a work trip to China for a week. Rather than contact the hospital their family arranged substitute care for the week.

No never a time when I took a break, except once, I went to China. I was invited to China as part of a team of head teachers ... And I'd been asked for a number of years and it was an opportunity and we had Harry’s sister, we’d sort of trained Harry’s sister to do it. She had to do three dialyses, we didn’t tell the hospital.

Gillian acknowledged that she would have valued the offer of occasional respite from dialysis, even if she had not made use of it. Gillian was aware that she could ask the hospital for Harry to dialyse there, but her husband was very reluctant to do that. From Gillian’s perspective, in recognition of the ongoing contribution she made by supporting Harry to dialyse at home, a choice of some sort of reward, either provision of someone to take over dialysis at home for a few days, or extra holiday dialysis, would have been a valued signal that her role was acknowledged.

They would have said he could go into hospital, never for anybody to come out and dialyse him in the home really. I suppose it’s the cost issue really. But I suppose in a way, I felt that I was saving the hospital a cost and it would have been nice to have been recognised in terms of an offer, a menu that you could or couldn’t take up in terms of some individual support, either extra respite or even an extra dialysis on holiday, which meant you could have stayed an extra couple of days, so that it was recognised that you were saving the hospital or the National Health Service something. Not payment, I’m not suggesting payment ... but something of recognition by way of a reward if you like in terms of the life style that we wanted to lead.
Vanessa suggested a system for taking breaks where carers stood in for each other, or, alternatively, where nursing students provided respite.

I often wonder if there would be a demand for trained dialysis carers to help each other out for instance if I knew of someone nearby who wanted a day off then I could go and help or even if there were any nursing students who could help thus gaining real experience and earning a bit of extra money!

In 2010, towards the end of her first year of home dialysis, Catherine persuaded Diane to take a holiday overseas. Catherine accompanied Diane and her daughter. They are planning another holiday this year.

I said look come on, you can’t spend the rest of your life you’re never going to leave England again. Overseas dialysis and hospitals are supposed to be amazing, so let’s do it. So I actually went away with her last year, so yes I got a break in that we went away but no I didn’t get a break as in obviously when she was dialysing I was looking after her daughter. But the sun was shining and it was lovely. We went to Gran Canaria for a week, so that really bolstered her and we’re actually now going away in three weeks time, going to Spain for two weeks ... So, it’s good, it’s been a really important step.

Catherine had been supporting Diane for some time before she learned, from the dialysis nurse, that she could ask for Diane to dialyse in hospital to allow her a break.

I didn’t realise until her last main nurse came round when she said to me how are you finding it? And I said it’s tough and it is hard ... and I hadn’t known that if I want to take time off, I can ring the renal unit and say, look can she come in for a week or two weeks? And I didn’t know that...
Although she now knows of the option for Diane to dialyse in the renal unit Catherine recognises the difficulty of achieving this, due to Diane’s reluctance to return to hospital.

*But Diane of course hates going to hospital, she hates the psychology of being a patient and going to hospital ... if I say to her, look I want to have some time off, she always says, oh if we do the dialysis that day instead then, because she doesn’t want to go to hospital ...*

Catherine now recognises the importance of taking breaks and does intend to take occasional holidays.

*I will do in the future, definitely ... But now that I know that she can go into hospital, I’m going to have to be firm with Diane and if I want a week off, say I need to have a week off, I’m going to have to book you into [the hospital]. And I know she’ll hate it ... so I know even though she might be annoyed with me and I might feel guilty, at least I know that option is there for me to say, I need to take a week out.*

When discussing potential benefits from meeting other people who care for home dialysis patients Catherine referred to the value of easing the guilt of taking time away from dialysis through mutual recognition of the need for a break.

*Also that respite, getting the respite and realising you’re not the only person who’s doing that as well...*

Barbara was another carer who initially resisted and ignored her needs for a break from dialysis. Soon after Charles started dialysing at home in 2003, he and Barbara organised two holidays together, with Charles dialysing in other hospitals. After a negative experience during one of these holidays, due to the long distance between the holiday accommodation and the hospital and unfamiliar dialysis times, Charles has been reluctant to dialyse in units with which he is unfamiliar.

Initially Barbara had no break from dialysis for several years. Even when she had an operation on her knee they managed dialysis around the operation.

*I think I went for ...maybe four years I didn’t have a holiday and didn’t have a break of any type. In 2004 I had an arthroscopy but we dialysed him on the Sunday, I had my operation on the Monday and we dialysed on the Tuesday at home and that was okay.*

More recently, encouraged by the renal nurses, she has taken breaks while Charles dialysed at the hospital where he trained, or at the nearby satellite unit.

*I’ve had two two-week holidays when I’ve gone abroad and he’s gone into hospital for dialysis ... I think the nurses were the ones that really sort of pushed me the first time and sort of said, look you’ve got to have a break.*

Nevertheless, Barbara still does not take a substantial break each year.

Having been dialysing at home for just under a year Laurence does not yet feel ready to dialyse elsewhere, though he and Karen have been away for weekends. Karen has been offered the option of taking a break while Laurence dialyses in hospital.

*Sometimes you find it tiring, it is tiring but the hospital have said if ever I did need a break they can arrange respite, they can arrange for dialysis at the hospital as long as they’ve got warning. So that back up is there if you actually need it.*
Karen acknowledges that she would be unlikely to make use of the offer of leaving Laurence in hospital.

*No, I wouldn’t do that, because it’s not just the dialysis, no I couldn’t do that. Unless it was an emergency I had to go because somebody was ill or something, that would be the only time. I couldn’t see myself doing that. Again if it’s a long term thing you don’t know what the future holds. Perhaps after being on dialysis a lot longer, I might find I do need a break … Perhaps he would be alright but I just wouldn’t feel comfortable.*

Angela and Brian are limited in the holiday options available to them, partly because, since giving up their own businesses they have less money available and are reliant on holiday dialysis provided through the NHS. Secondly, Brian has Hepatitis B and he has been unable to find self care units in England or Scotland that will take patients with Hepatitis B. The only other options are to book a dialysis slot in another hospital, which, as Angela described, they are reluctant to do, due to the potential waiting time in hospital.

*… but the hospital … it will be when they’re ready to, so there wouldn’t be a timed slot. So say he’s got to dialyse Monday morning … So your day is still controlled by the fact that you’ve got to stay in that hospital waiting for that slot to be free for them to dialyse you so what kind of a holiday would that be? Knowing that you’ve got to spend one day on the beach and one day waiting in a hospital all day.*

Angela and Brian are aware that if they could pay privately for dialysis they would have other options, particularly overseas, but their financial situation does not allow this. They feel strongly that more options should be available to patients suffering from Hepatitis B.

If Angela is unwell she continues to support Brian with his dialysis. While recognising that, in an emergency the city hospital would make space for Brian to dialyse, in less extreme circumstances Angela feels there is no respite. The local hospital will not accept Brian for dialysis because of his Hepatitis B status.

*I’ve been really, really ill and I’ve come down, I’ve put him on and I’ve sat in my kitchen at the table, half dying! Feeling absolutely dreadful, I must admit though, when I’m really ill Brian will cut the hours so he might do, if I’m really ill he’ll do a couple of hours. If I’m not too bad he’ll do three hours and obviously when I’m alright he does four hours.*

Angela suggests that a solution for times when she is unwell would be for a dialysis nurse to take over her role, or, alternatively, for Brian to dialyse at the local hospital, rather than travel to the city hospital.

*… the main issue with me is when I’m not well, it would be nice if … either a dialysis nurse could come out … Or he could go to a local hospital and not have to travel.*

Nevertheless, Angela feels that any illness she feels seems mild in comparison with Brian’s situation, and it would take an emergency before she asked for him to dialyse in hospital.

Similarly, for complete breaks, while Angela ideally would like a nurse who could arrange respite, she feels torn, believing that as a complete break from dialysis is not possible for Brian, she should not want one either.

*I would like a dialysis nurse to come out that was basically assigned to just home patients, be able to sort out for instance going, if I wanted say a break even, not a holiday but I need a break and I just thought, let him go to the hospital for a week. It would be nice that they could yeah, we can do that, we’ll fit him in for a week and you have some time off. But saying that, I don’t feel right really saying that, because he’s on it, he never gets a break, so I don’t feel the right to have to say, I need a break …*
The paradoxical emotion voiced above by Angela captures well the complex situation that carers find themselves in, conducting a role where they feel ongoing responsibility for a process that they recognise as potentially high risk, and yet at the same time feeling that this is a shared experience, and as such that they have no right to escape it when the person they care for has no such opportunity.

Some carers, over time, and sometimes prompted by renal staff, recognise the importance of taking breaks, yet given their complex role, as several carers said, they would much prefer to be proactively offered a menu of options for taking a break, rather than have to request time away from dialysis. Some home dialysis patients would not object to short term hospital dialysis while their carer took a break, while the preferred option among several carers in this study would be for a dialysis nurse to provide respite by visiting the patient’s home. Were these offers to be actively offered to the carer, rather than having to be initiated by them, it may go some way towards providing the recognition or sense of reward that carers understandably feel they are due.
**Advice:** what advice would carers give to others considering home dialysis?

Thomas had no hesitation in recommending home dialysis to others.

*Do it! Because of the experience we’ve had, I would recommend it to anybody, if they’re prepared to accept the time constraints of three days in hospital compared with five days at home and if you can accept that constraint, then I would totally and utterly recommend it, I really would.*

Barbara was similarly enthusiastic in her endorsement of home dialysis.

*Oh I would say, go for it every time, just because it will make such a difference to your life. You’ve got so much more time together. I mean Charles and I sitting there, my sewing machines are in there so if I’m sewing I sit and sew in there ... It’s actually an opportunity to be together in some respects, whereas you might be off doing other things ... the compensation for having time and being able to swap and being able to do the things you want to do and when you want to do them, is just such a huge compensation for all the responsibility that you take ... we really haven’t found anything that’s sort of been that challenging ... there was nothing that I would have said, alright, we can’t possibly do this at home any more, we can’t cope with it, it’s not a going concern any more.*

Despite the challenges she and Harry experienced with dialysis, Gillian has no doubt in recommending home dialysis.

*By far a better option, if you’ve got the confidence enough to do it and I would recommend home dialysis 100% ... I think it was the freedom that it gave us - even though it’s not full freedom - in doing those things together ... So treat it as a joint venture and treat it as not a one person thing but it’s something that two people go into together, eyes open wide and using it as an opportunity to live your life really.*

Karen would advise anyone considering home dialysis to be fully informed before agreeing to adopt it.

*I would recommend that they go to the hospital first of all and find exactly what’s involved. It is a shock, you’re going to dialysis at hospital and coming home and you knew he was there for three and a half hours but you didn’t realise exactly what was involved. It is time consuming and it is hard, the amount of supplies and everything you’ve got. It’s not just the dialysis, as well, it’s keeping your supplies, doing the orders every four weeks and make certain you’ve actually got enough supplies. Plus again the space.*

Had she understood the full extent of home dialysis Karen does not believe she would have made a different decision, but she feels that a better understanding of what she was undertaking may have reduced her anxiety.

Angela also emphasised the importance of patients and carers being very well informed before agreeing to home dialysis. She recommended contact with other carers and patients to get a broad picture of what is involved.

*If it’s long term then I think you need to maybe probably talk to someone else that’s been doing it long term as well and find out more about it because it might all seem all nice to begin with when you go to the unit and you know you’re doing it and everything, but when it’s home and they are home and you are doing it all the time and you’re not getting no support from anyone, it’s hard and it’s not just the machine and problems with the machine, it’s emotional support as well, because they do have up and down days and you’ve got to be there to try and lift them up and do you know what I mean? So there’s just so much more to it that they need to really think about and talk to someone about.*

Angela stressed that people considering home dialysis should be warned about the sense of isolation they might feel, contrasting the sociability of shared dialysis with the isolation of dialysing at home.
I actually think that anyone that's going home dialysis, I think should have some sort of form of talking to, to sort of let them know ... dialysing at home ... you've got the surroundings of your own home and everything, but when ... you're all dialysing, you can talk to each other. Soon as you come home, there's no contact. It's all lost, everything's gone. So basically unless you get a problem, you're not talking to anybody or unless you get visitors you're not talking to anybody.

Helen also would advise anyone considering home dialysis to find out as much as possible about the full impact on their life, having been surprised, herself, when she understood the full extent of the task she had undertaken.

The advice mainly I would give would be to find out as much as you can as to what it entails because although I did have a rough idea, it still came as a bit of a shock to me when I found out exactly how much was entailed with the home haemodialysis. It's not just with the training for your needling and how to line the machine and prime it and connect them up, it's also ordering the stock that you need from the hospital. It's also ordering the dialysis fluid from the company that delivers that. So I would say find out as much as you can first and have a long hard think about it as to whether you still want to do it, before you get onto the actual training programme.

Despite the task being more than she initially recognised, Helen would still, were she making the decision again, agree that home dialysis was the best option, though she, like Angela, referred to the disadvantage for the patient of losing the social aspect of dialysis.

I think so, yes, because I look at it like this, Jack is on it for life, it's saving three trips a week to hospital, he feels a lot better for it. The only minus side for him is, he's not getting out and about much, so he's not really meeting other people. That's the only down-side that he's had basically, because his mobility is not very good.

Fiona and Graham had recently been visited by a woman who was considering home dialysis for herself. Fiona emphasised the importance of considering ways in which the decision would impact on the woman's partner, emotionally as well as practically.

... I think they need to know the good and the bad things about home dialysis, because they need to know how tiring it can be and how emotional it can be and you know talking to [the woman who was considering home dialysis], I think she never really thought about the impact that it would have on her partner. She just thought that it would be me and I said, it's ok that, but when you're not well, your blood pressure is low, and actually to cope with it ...

The advice offered here by Fiona, pointing to the tendency to overlook the impact on the carer, was supported by an observation from the son of Karen, another carer.

... and my son said sometimes his dad does not realise how the dialysis affects all the family and not just the patient.

Finally, Catherine had specific advice to offer, encouraging people adopting home dialysis to think carefully about the location of the dialysis machine, to build a good relationship with the dialysis nurse, and to learn as much as possible from others already doing home dialysis. She also recommends accessing support from other carers, while acknowledging that she has not yet done that herself.

... the practicalities of the geography of the machine, I think is so important ... So I think definitely getting to know the named nurse of the patient that you're doing the dialysis for, I think definitely have that relationship with them. I think the buddy system, if they'd had someone that I could have gone and spoken to, on our own, like we're doing now and said, what is it really like? What do you find and everything? ... So I think maybe if I'd had someone who could say, yes, they are a little bit temperamental and grumpy, apparently it is the kidney thing, 'a renal phenomenon!' ... I think also find the local support ... I think you need to find a way of tapping into what support services there are for you. I haven't particularly done that because I kind of thought I'm ok, I've got my family and friends. But now I think ... maybe it's something that I need to start looking into and say look, we need people to get together and talk about it.
For further copies contact:

Prolog
Prolog House
Sudbury
Suffolk
CO10 2XG

bdm@prolog.uk.com

www.kidneycare.nhs.uk