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**35** | Comment | **A matter of choice** *John Bradley*

**36** | Audit | **Renal young adult transition services: a national survey**

*Alexander Hamilton, Rachel Gair, Robert Elias and Constantina Chrysochou*

**40** | Case study | **Acute pancreatitis following thrombectomy of a haemodialysis graft**

*Charlotte K Boughton, Claire C Sharpe, Thoraya Ammar and Sui Phin Kon*

**44** | Service provision | **ACE: a peer educator-based community project**

*Neerja Jain, Mazim Ali, Annette Dodds and Jyoti Baharani*

**51** | Policy matters | **Long-term sustainability of the NHS and social care: we are in trouble** *Donal J O'Donoghue*

**53** | Patient information | **What I tell my patients about shared haemodialysis care**

*Tania Barnes, Andy Henwood, Martin Wilkie and Sonia Lee*

**57** | Research | **Immunosuppression in IgA nephropathy**

*Dharmenaan Palamuthusingam, Clare Castledine and Sarah Lawman*

**Other features** | **43** National Kidney Federation | **47** Kidney Research UK | **48** British Renal Society

**56** Kidney Care UK | **62** The Renal Association | **62** Diary dates

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In recent years, it has become more common for dialysis patients to take an active role in their care. **Tania Barnes** and colleagues explain what shared haemodialysis care involves, the aspects of care that you can participate in, and how it can benefit you.

## What I tell my patients about shared haemodialysis care

**I**t is normal practice for staff to undertake procedures for patients when they attend a hospital or clinic; however, in outpatient haemodialysis units, it is becoming increasingly more common to offer patients the opportunity to participate in aspects of their dialysis. This is called shared haemodialysis care, and it can help to keep you involved in your treatment and more independent. Shared haemodialysis care allows you to choose which aspects of your care that you undertake, from small tasks such as taking your own blood pressure and weight, to any (or all) of the other dialysis tasks. The emphasis is on taking part and engaging at a level that suits you as an individual (see Figure 1).

We know that people who take a greater role in their care do better in many ways. For example, requiring fewer visits to their GP, being less likely to be admitted to hospital and experiencing better mental and physical health. This could be because they are involved in decisions about their own healthcare and people who understand their condition are better able to monitor their diet, fluids and medication. They also know how to reduce the risk of complications and importantly, when to seek help.

Shared haemodialysis care was introduced to create a culture of participation and partnership, in order to improve patients' experiences of dialysis. As a consequence of this work, NHS England's National Service Specification for Haemodialysis now states that shared care should be offered to all centre-based dialysis patients.

### What difference will it make to me?

Being told that you have kidney disease, a serious long-term condition that requires dialysis, can feel overwhelming. It is easy to feel that you have lost control over your life, par-



Programming a prescription on a dialysis machine

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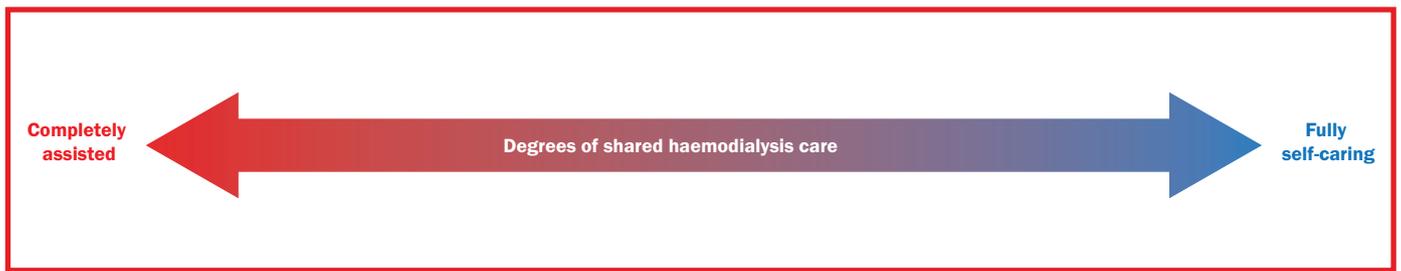


Preparing equipment for dialysis

ticularly as the treatment requires so many changes to day-to-day living.

There is good evidence that people can develop a more positive outlook, feel better and feel more in control, if they understand more about, and involve themselves in their own treatment. Patients who have been involved in shared haemodialysis care tell us that they:

- feel more confident and in control



**Figure 1.** Shared haemodialysis care allows you to choose your level of participation, anywhere between completely assisted to fully self-caring

- feel less dependent on others
- feel they better understand their condition and become experts in their own care
- feel that if needing their own fistula, they experience less discomfort
- feel more positive and have a greater sense of purpose
- feel that they are kept occupied and waiting is less of a problem.

Quotes from patients participating in shared haemodialysis care are shown in Figure 2.

Some patients who participate in shared haemodialysis care gain the confidence and skills to consider going home to dialyse, although this is entirely optional. Others choose to stay within the unit, either sharing their care with staff or undertaking all their tasks themselves (self care).

### How do I get started?

If you would like to become more involved in your care, ask your nursing team about any parts of your treatment that you would like to learn more about. Box 1 presents a list of tasks that you might want to consider; start with a task that you are interested in or would find easiest. You can learn to do as many of the tasks as you wish, and in no particular order. As you learn and become more confident, you and your nursing team will decide when you are experienced enough to safely carry out the procedures unsupervised.

### Shared care in a busy unit

Shared care is a way of working for staff and patients where learning is part of everyday routine. Sometimes, staff may not be able to spend time teaching you, but you can learn from watching others, asking questions and asking staff to explain what they are doing as they work. In this way, you can gain knowledge a little at a time. A list of common questions about shared haemodialysis care is shown in Box 2.

### Step by step

Remember, each journey starts with a single step. For example, if you wish to learn how to prepare your dressing pack for dialysis, you might start with learning where to collect the equipment from. This would be the first small step. The next time you come in for dialysis, you could collect it yourself and a member of staff could show you how to open it. This is another step forward. The next small step might be to practise laying out the equipment; learning how to prepare your pack then becomes an easy and achievable task for you to undertake. You may not be able to learn every time you dialyse, but with each step forward

• **Andy Henwood, York:**

*I feel I have control over my condition, not the other way around. It adds value and self-worth to my treatment. My machine became my friend.*

• **Heather Vance, Altnagelvin, Northern Ireland:**

*The thing I like most about shared care is just that – it is ‘shared’! For example, while I was taking myself off the dialysis machine I suddenly felt unwell. I was glad my nurse was there to take over for me until I felt better again.*

*I now understand all the functions of the machine, which has given me a greater understanding of my dialysis.*

*When I started doing shared haemodialysis care, I thought that some of the tasks would be too difficult for me to learn. However, I now realise I was afraid of the unknown. The things I thought would be very difficult, turned out to be quite easy.*

• **Nargis Khan, Sheffield:**

*I was always too scared to do any of my dialysis care, but now I enjoy having more control over my treatment. I started off getting my dressing pack ready and once I got that right, I wanted to start doing other things. Not everyone is the same, everyone is different. Some people might not feel as confident and might just want to do something like their blood pressure.*

**Figure 2.** Quotes from patients participating in shared haemodialysis care

**Box 1.** Aspects of your care that you may consider taking part in

- Recording your weight
- Recording your blood pressure and pulse
- Recording your temperature
- Setting up your dialysis machine
- Preparing your dressing pack
- Programming your prescription on the dialysis machine
- Putting your needles in or preparing your access line
- Connecting your lines and commencing dialysis
- Responding to alerts from your dialysis machine
- Disconnecting lines and completing your dialysis
- Applying pressure to needle sites after dialysis or locking your own access line
- Administering any of your injections.

you will make steady progress and will become more in control of your dialysis.

**Learning styles**

Everybody has their own way of learning and remembering. Some people like to watch others first, some like to read about it, others make their own lists or reminders. It is your learning, so make sure you do it in a way that suits you. Think about what works and discuss it with the staff who are teaching you. If you use a method that suits you best, then learning will be more productive and easier for both you and the staff.

**Listening to those with experience**

Talking to other patients can be very beneficial, as they have first-hand experience of haemodialysis. Ask your nurse if there is anyone they can introduce you to for a chat, or if you would like to know more about your treatment or shared haemodialysis care. You can also find out more about your condition, shared haemodialysis care or peer support online (see Box 3) ■

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**Box 2.** Common questions about shared haemodialysis care**1. Are the tasks compulsory?**

No, patient choice is central to shared haemodialysis care. You can do as many or as few tasks as you like, or none at all if you wish.

**2. Is it safe for me to do what the trained nurses do?**

Yes, the staff will train you to do the tasks you choose and check that you are competent and confident before you do anything on your own. Even then they will always be around for support and guidance or to carry out the task if you do not want, or are unable, to.

**3. Will I have to go home to dialyse if I learn everything?**

No, you can choose to go home to dialyse if you wish, but you can also choose to stay on the dialysis unit. Ask your dialysis nurse if home haemodialysis is something you wish to consider.

**4. If I can dialyse myself will I be left on my own on the dialysis unit?**

No, you will always be supported by the nursing staff if you choose to stay on the dialysis unit.

**5. Is this a scheme to cut nursing staff?**

No, the nursing staff will always be needed to supervise patients who are learning how to do their tasks. Some patients choose to be looked after, or wish to stop doing tasks, from time to time, and the nursing staff will always be required to support your changing needs and to care for more dependent patients.

**6. Do I still have to do shared care if I arrive feeling unwell?**

No, it is important that you tell staff that you do not feel well so that they can support you.

**7. Can I change my mind?**

Yes, it is entirely your decision. It is important that you explain why, so that the staff understand and can support you in your choice.

**Box 3.** Online sources about your condition, shared haemodialysis care and peer support

- |   |  |
|---|--|
| • <b>Shared Dialysis Care</b><br><a href="http://www.shreddialysis-care.org.uk">www.shreddialysis-care.org.uk</a>                           | • <b>Patientslikeme®</b><br><a href="http://www.patientslikeme.com">www.patientslikeme.com</a> |
| • <b>National Kidney Federation</b><br><a href="http://www.kidney.org.uk">www.kidney.org.uk</a>   | • <b>Think Kidneys</b><br><a href="http://www.thinkkidneys.nhs.uk">www.thinkkidneys.nhs.uk</a> |
| • <b>Kidney Care UK (formerly the British Kidney Patient Association)</b><br><a href="http://www.kidneycareuk.org">www.kidneycareuk.org</a> |  |

**Declaration of interest**

The authors declare that there is no conflict of interest.

**Key points**

- ▶▶ It is becoming increasingly common for outpatient haemodialysis units to offer patients the opportunity to participate in aspects of their dialysis – this is called shared haemodialysis care.
- ▶▶ Shared haemodialysis care can build confidence and independence; patients often say that they feel more in control when they are engaged in their care.
- ▶▶ Shared care allows you to choose what you feel ready and able to participate in. For some, shared haemodialysis care can be a stepping stone to self care or home haemodialysis.
- ▶▶ Shared haemodialysis care can result in better outcomes for patients and it is recommended that shared care is offered in all dialysis centres.