Use of The Information Standard's Member Logos

Choosing your logo
The Information Standard has four logo versions for its members. They are designed to fit neatly on your printed and online information material according to available space and usage.

V2.0 logos

What about the previous logos?
The previous member logos are still valid while they remain in circulation. We are looking to phase them out. When producing new information products, or reviewing and updating products please use the logos shown above.

Previous logos

Working together for better patient information
Being diagnosed with chronic kidney disease (CKD) can feel overwhelming. You may feel that you have lost control over your life, particularly as treatments such as haemodialysis require so many changes to your day to day living. This leaflet explains how you can get more involved in your own haemodialysis care and the benefits this may bring to you.
What is shared haemodialysis care?

Shared haemodialysis care gives you the opportunity to participate in any aspect of your dialysis treatment, with guidance and support from nursing staff. It allows you to choose which aspects of your care that you would like to 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 feeling involved at a level that suits you as an individual.

You choose your level of participation, anywhere between complete assistance to fully self-caring.

How can shared haemodialysis care help me?

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

- I feel more confident and in control
- I experience less discomfort if needling my own fistula
- I am less dependent on others
- I am occupied so that waiting to start dialysis is less of a problem
- I feel more positive, have a greater sense of purpose and an improved quality of life
- I better understand my condition and became an expert in my own care
Is shared haemodialysis care 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.

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 to, or are unable to complete it.

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. Talk to your dialysis nurse for more details if home haemodialysis is something you may wish to consider.

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.

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. The nursing staff will always be required to support your changing needs and to care for people who want or need more help.
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.

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.

Gerry at Altnagelvin Renal Unit – Northern Ireland

“Shared care and the learning involved in doing this has given me a better understanding of dialysis and allows me to have overall control of my condition. I actually feel that I can control it rather that it controlling me. I would encourage dialysis patients to give shared care a go as this better understanding and control has improved my overall well-being.”
What aspects of my care can I take part in?

This can vary depending on your treatment and where you want to start, but can include:

<table>
<thead>
<tr>
<th>Activity</th>
<th>Description</th>
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<tbody>
<tr>
<td>Recording your weight</td>
<td>Recording your blood pressure and pulse</td>
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<tr>
<td>Setting up your dialysis machine</td>
<td>Preparing your dressing pack</td>
</tr>
<tr>
<td>Putting your needles in or preparing your dialysis access line</td>
<td>Connecting your lines and starting dialysis</td>
</tr>
<tr>
<td>Disconnecting lines and completing your dialysis</td>
<td>Applying pressure to needle sites after dialysis or “locking” your own dialysis access line</td>
</tr>
</tbody>
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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. 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.

Sometimes, staff may not be able to spend time teaching you, but you can learn from watching others, including patients, or 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.

Remember, each journey starts with a first step. For example, if you wish to learn how to prepare your dressing pack for dialysis, you might start with asking 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 you will make steady progress and will become more in control of your dialysis.
Where can I find out more information?

- Kidney Care UK - www.kidneycareuk.org
- Shared haemodialysis care - www.shareddialysis-care.org.uk
- Renal Association: Patient Information – www.renal.org/information-resources/patient-leaflets
  - includes leaflets on chronic kidney disease and haemodialysis
- The National Institute of Health and Care Excellence (NICE) guidance on Renal Replacement Therapy and Conservative Care Management places shared decision making at the heart of treatment choices www.nice.org.uk/guidance/ng107