

So how can YOU Help?

If you have personal experience of haemodialysis or are a transplanted patient or if you are a carer of someone else who has, we are looking for volunteers to become a member of our **SHAREHD** Patient Group.

This group will advise the **SHAREHD** Programme Board (and its workstreams) on patient and carer related aspects regarding the design, implementation, impact and sustainability of the Programme, by providing personal insights and information.

We are looking for patients who:

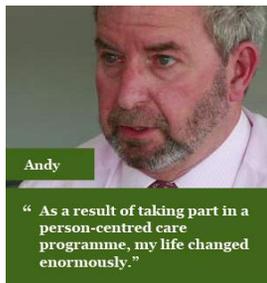
- Are willing to volunteer
- Are willing to attend informal 'Induction' training
- Respect confidentiality
- Are able to use a computer and social media
- Will play an active part in the **SHAREHD** Patient Group
- Can be available for and attend agreed Programme and/or workstream meetings
- Contribute 'patient' views and give advice to the Programme on how to communicate and engage with the patients the **SHAREHD** Programme serves
- Highlight any healthcare issues/priorities or concerns within the renal community that they feel are relevant to the work of the **SHAREHD** Programme
- Use their skills to help in the work of the **SHAREHD** Patient Group and **SHAREHD** Programme for example by using their HD experience to affect change, IT skills to help design a poster etc.

Why not have a look at the Shared Haemodialysis Care (SHC) website;

<https://www.shareddialysis-care.org.uk/>

or Kidney Research UK website;

<http://www.kidneyresearchuk.org/news/shared-haemodialysis-care>



Andy

“As a result of taking part in a person-centred care programme, my life changed enormously.”

Being part of a Team

“Nobody understands what Haemodialysis (HD) patients are going through more than fellow HD patients, who are or have gone through the experience themselves. Being part of this short term practical patient

group will enable you to have a 'patient centered' impact of the future of the delivery of hospital based HD for patients and potentially their families or carers based on common experiences. It is immensely rewarding being a kidney patient who is able to have an impact on the quality of life of other kidney patients”.

Together
Everyone
Achieves
More



Could you help us make this a success? Are you interested in representing the interests of patients participating in the programme? If so, we need you to help us by joining our Patient Group to ensure the patient voice is at the heart of the programme.

For further information, please give Andy Henwood* a call on 07508 890798 or contact Andy via email at patientandy.york@gmail.com. Andy is happy to chat through the Role and Responsibilities and can send further information if required.

*Andy Henwood is the **SHAREHD** Patient Group Lead. Andy spent less than 1 year as a pre-dialysis patient, 4 years as a HD patient and is in his 6th year as a transplanted patient. Andy has been a patient representative for about 7 years, including a Programme Board member for the previous Yorkshire & Humberside Shared Haemodialysis Care Programme.

“This programme **Supports** people to take a greater role in their own care and **Works** within any unit using existing resources”

Version AHv3: 160916 Final



SHAREHD

A Quality Improvement Collaborative to scale up Shared Haemodialysis Care in centre based haemodialysis patients

SHAREHD PATIENT GROUP

“Another NHS programme where Patients and Staff are working together!”

“Patients, we need Your Help!”

Programme supported by



Sheffield Teaching Hospitals **NHS**
NHS Foundation Trust

What is Haemodialysis?

Haemodialysis (HD) is a therapy that filters waste, removes extra fluid and balances electrolytes (sodium, potassium, bicarbonate, chloride, calcium, magnesium and phosphate). It is conducted in a hospital, in a self-care unit or at home. Hospital HD patients generally attend three four hour sessions a week.

What is Shared Haemodialysis Care?

Shared Haemodialysis Care (SHC) is all about supporting hospital based HD patients to become more actively engaged in their dialysis care. The HD process is broken down into 14 tasks such as: preparing equipment, measuring weight and blood pressure and self-cannulation. With the support and supervision of healthcare staff, patients are given the opportunity to take on as many of these tasks as they feel comfortable and able to do, at a pace that suits their individual needs.

HD patient/carer benefits include:

- Gain a better understanding of their condition and treatment
- Become experts in their own care
- Gain both confidence and control
- Feel better in themselves leading to a better Quality of Life

"I can look after myself, feel more in control and can make better health choices. I want to do more."

"It makes me feel that I have self-worth; I am still important"



"The training I received from the 'SHC Trained' Health Care Professional was excellent"

"Once patients understand what Shared Haemodialysis Care is, as the dialysis **nurse** I ask the **patients to choose** which dialysis related tasks they would like to try"

So what is SHAREHD?

SHAREHD is a Health Foundation funded programme, that aims to create, promote and support patients and staff in an environment where hospital based HD patients can be better supported to become more independent and confident, in conducting and managing parts of or all of their own Haemodialysis care.

Together with our partners, including Kidney Research UK, and a collaborative of 12 dialysis units in England, we plan to expand the learning from local initiatives and the *Yorkshire and Humberside Shared Haemodialysis Care programme*, to build provide evidence and practical changes that can support a nationwide change to support HD patients in developing 'Patient Choice' in their own care.

Why we want YOU to be involved?

We believe that meaningful patient involvement is fundamental towards achieving outstanding clinical research and development. By being involved, your help will ensure we will continue to deliver exceptional patient led healthcare now and in the future. You are the expert, and it is from your experiences as a patient or as a carer that we can learn and use this to inform our clinical research and development.

So what is the Aim of SHAREHD?

*The aim of the **SHAREHD** Patient Group is to provide guidance to the Programme Board that the patient and NHS voices are at the heart of patient care, organisational operations, staff and patient education, training and workforce planning processes.*

The secondary aim of the **SHAREHD** Patient Group is to advise individual patients or **SHAREHD** Patient Groups at the 12 sites involved in the forthcoming **SHAREHD** Programme.



"The **SHAREHD** Patient Group will work with programme workstreams, ensuring that decision making is influenced by patients"

Key Shared Haemodialysis Care findings;

- Patients reported greater control of their illness and increased confidence.
- Staff reported increased job satisfaction and greater respect for patients.
- There was more dialogue between patients and nurses.
- Some patients felt frustrated by slow rate of progress, with differing levels of engagement from staff.
- Staff were able to spend more time with more dependent patients.

See more at: www.health.org.uk/programmes/closing-gap-through-changing-relationships/projects/enabling-self-management-and-shared#sthash.YaViyjXN.dpuf

"it's all about caring for yourself according to what you need, it's a step away from being cared for by others who think they know what you need."