

SHARED HAEMODIALYSIS CARE NEWSLETTER



The Health Foundation
Inspiring Improvement

Closing the Gap



Yorkshire and The Humber
Sharing Haemodialysis Care
Improving Outcomes

Winter 2013

ISSUE 5



Introduction

By **Adrian Seiff**,
The Health Foundation

Shared decision making and self-management support can sound a bit woolly – nice, but not really medicine. Haemodialysis is hardcore medicine – it takes place in high tech hospitals and saves lives with a clinical team doing things to you.

With funding from **The Health Foundation** as part of our **Closing the Gap through Changing Relationships** programme, the **Shared Haemodialysis Care** team are transforming hospital based haemodialysis from a staff-led service to a patient-staff shared self-management programme. On a visit last Autumn I saw how inspirational their work is.

The team has thought through how to embed change, whether through peer-to-peer engagement of senior staff, frontline staff who are trained and then cascade their learning to their peers; or changes to the competency framework. Training for patients takes account of their ability and expectations are flexible in recognition that people living with a chronic condition will have the ability to do more or less at different times depending upon a host of factors.

I was impressed with the impact the team is having. Nurses are now problem solvers and 'care facilitators rather than care doers.' As one nurse put it, 'it's a move away from a conveyor belt system and it has increased staff satisfaction ... it doesn't feel like groundhog day anymore'.

Responding to patients, the Sheffield unit opens half-an-hour earlier and has changed from dialysis chairs to beds (which are also more cost effective). With more control, patients spend less time on dialysis.

I also learnt about the team's efforts to overcome challenges, whether patient and staff resistance accountability concerns, or financial disincentives built into the tariff.

The Health Foundation wants to spread our learning on how to equip patients and professionals to work in partnership. The York and Humber team's enabling self-management and shared haemodialysis care in hospital based dialysis is certainly showing us how to do it. When I asked one 74 year man who now shares his renal dialysis care what difference has shared care made to him he said simply, **'Everything about it is better.'**



by **Jackie Parr**,
Commissioning Lead

Sustainability

From 1st April 2013, the **NHS Commissioning Board (NHS CB)** will be established, with an overarching role to ensure the NHS delivers better outcomes for patients, within its available resources, and to uphold and promote the **NHS Constitution**. The Department of Health will hold the NHS CB to account, and set its objectives.

Specialised services have a key role to play and are provided in relatively few specialist centres. These services treat either rare conditions or those that need a specialised team working together at a centre, and include renal replacement therapy (dialysis and transplant).

The ambition of the NHS CB is to help achieve equity and excellence in the provision of specialised care and treatment through ensuring excellent commissioning, which:

- * Is patient centred and outcomes based. The patient must be placed at the centre of planning and delivery and commissioners, working with providers, must deliver improved outcomes for them across each of the five domains of the 2013/14 NHS Outcomes Framework:

1. Preventing people from dying prematurely.
2. Enhancing quality of life for people with long term conditions.
3. Helping people to recover, following episodes of ill health or following injury.
4. Ensuring that people have a positive experience of care.
5. Treating and caring for people in a safe environment and protecting them from avoidable harm.

- * Is fair and consistent throughout the country, and ensures that patients have equal access to services, regardless of their location.

- * Improves productivity and efficiency.

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FIND OUT MORE

Sharing Haemodialysis Care : <http://www.yhscg.nhs.uk/Networks/sharing-haemodialysis-care.htm>

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Sustainability

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The NHS CB will be responsible for the needs assessment, strategic planning, procurement (contracting), monitoring and evaluation of the performance of specialised services delivered by providers of specialised healthcare.

***Planning** – Setting priorities and a strategic direction for services based on an assessment of the health needs of our populations, developing plans for services which meet national standards and local ambitions, ensuring that patients, carers and the public are involved in the process, alongside other key stakeholders. This will include the design of pathways, involving patients and carers to improve services.

***Specify and Procure** – The method by which services are secured and agreed with providers, using a contract that puts the strategic plans into action locally.

***Deliver and Improve** – The way in which the performance of the contract is monitored and, where necessary, challenged. To use this process to gather intelligence to design and plan and continuously improve services for the future.

Clinical engagement is vital to successful commissioning. Clinical advice to specialised commissioning needs to be service specific. During the transition to the new commissioning arrangements for the NHS, **Clinical Reference Groups** were established,

which brought together a range of service speciality experts, patients, clinicians, public health experts and commissioners. **The Clinical Reference Group for Dialysis** is chaired by our Shared Haemodialysis Care Programme Chair, Dr. Chas. Newstead. These Clinical Reference Groups have produced the first ever **national service specifications and commissioning policies** for a number of different clinical areas, including dialysis and transplant. The national service specification for hospital/satellite haemodialysis includes this important narrative: *“Providers should be able to demonstrate that they have processes in place for promoting shared as well as self-care*”

A core function of the NHS CB is to **champion the effective involvement of patients and carers**, especially in making decisions about, and managing their own care. This includes shared decision making about treatment, and choice of provider, where possible.

Clinical Commissioning Groups (CCGs) – (groups of GP practices) will be responsible for the commissioning of health services to meet all reasonable requirements for their patients, with the exception of services directly commissioned by the NHS CB (primary care, specialised services, offender health and military health). Improving patient care means providing a seamless service, with planning across the whole patient pathway and across

commissioners. It will be vitally important for the NHS CB to engage locally with CCGs, to manage the interface between services for patients – GPs – local hospital services – specialist centres.

The NHS CB has also set out its plans for a small number of national networks to improve health services for specific patient groups or conditions. **Strategic Clinical Networks** (hosted and funded by the NHS CB) will be condition specific and include patient groups where improvements can be made through an integrated, whole system approach. These networks will help local commissioners of NHS care to reduce unwarranted variation in services, and encourage innovation. The areas chosen for the first Strategic Clinical Networks are:

- *Cancer
- *Cardiovascular Disease (including cardiac, stroke, diabetes and renal disease)
- *Maternity and Children’s Services
- *Mental Health, (including dementia and neurological conditions)

Specialised commissioning has traditionally harnessed the strength of networks to achieve improvements to the patient pathway across geographical boundaries, and our Shared Haemodialysis Care Programme certainly provides evidence of this! The new strategic networks should continue to provide vital support activity to embed change and innovation.

Delivering the ambitions of the NHS CB will continue to challenge to us all!

SHC updates from around the region

The last few months have been a time for consolidation of the SHC programme as it extends across the Yorkshire and the Humber region and beyond. Clinical leads have joined the Programme from Hull, Leeds, Doncaster and Bradford supporting as it develops in those areas.

Bradford Update



by **Tahira Akhtar**,
Cultural and Health
Improvement Officer

As the Cultural and Health Improvement Officer for the Renal Team at Bradford Teaching Hospitals, NHS Foundation Trust, I was asked to become involved in the Shared Haemodialysis Care Programme, to facilitate communication

with and educate our South Asian patients on Shared Haemodialysis Care.

The team agreed that it is essential to provide the South Asian patients with literature in their first language, in order to ensure that the patients, who cannot read English, understand the SHC programme, engage in the programme and feel included in their care.

I arranged for the SHC patient Handbook and the ‘An Introduction to Shared Haemodialysis Care’ leaflet to be translated into Urdu.

I have also arranged for an audio CD for the

patient handbook and leaflet in Urdu to be produced, in order to enable the patients who cannot read English or Urdu to become involved in the programme.

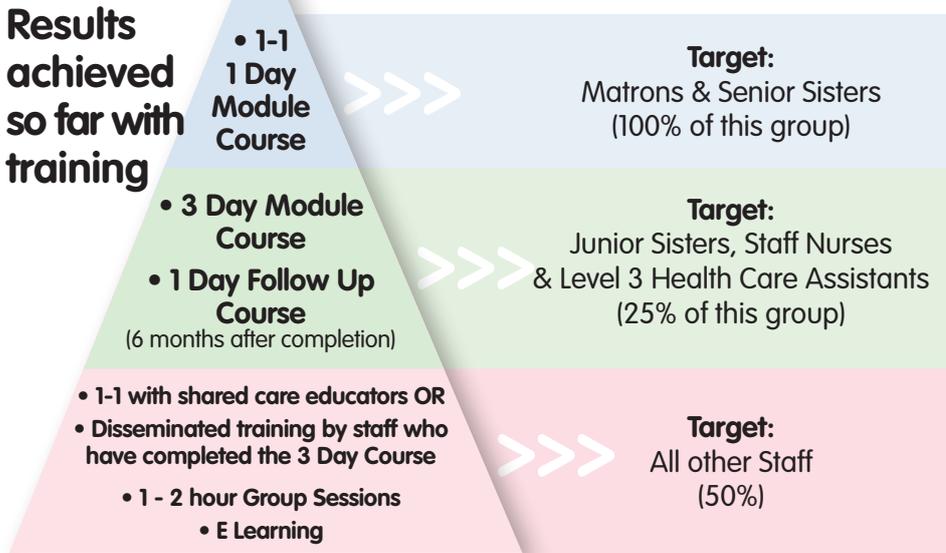
I think it is important to involve the patient’s family members in the programme to help us encourage patient involvement; therefore all the above resources are also available to patient’s family members.

The above resources have in addition to the above, been formatted into MP3 format which will allow us to put the handbook and leaflet on our relevant websites.



Update on 3 day Shared Haemodialysis Care course

Results achieved so far with training



Comments from the evaluations of Course 8 held in December 2012:

"Excellent course"

"Really enjoyed the course as a whole and feel I've gained confidence"

"Thanks for all the information you all share....will continue sharing this care"

"I feel that I have more confidence with my teaching and assessing skills. I'm motivated and eager to continue to use my skills"

Six Month Review Study Day

We have now run our **Six Month Review Study Day** for six courses and have completed the full training package for our pilot sites. The study day has been evaluated each time and its content adjusted to suit each group's needs, taking into account what was delivered to each cohort during the three day course.

The **Six Month Review Study Day** focuses on the positive changes made in the units and delegates are encouraged to

share the contributions they have made and the effect this has had on both patients and staff. Through discussion, delegates begin to recognise their achievements, however small, that demonstrate their steady progress. Delegates report back on barriers to Shared Care that are no longer a problem and share with the group a "can do" attitude and a "more relaxed feel" to the haemodialysis routine which demonstrates a real shift in behaviour on their units.

Cultural changes, for example, "It's normal for patients to do their observations and wash their hands", encourage other delegates in their mission to drive Shared Care forwards.

Bringing the cohort back together at the **Six Month Review Study Day** provides an opportunity to celebrate achievements, provide support and encouragement and discuss expectations of cascade training.

Evaluations of the Six Month Review Study Day report that delegates have:

- Recognised their achievements
- Strengthened their links with other staff
- Shared useful ideas
- Felt part of a bigger haemodialysis community
- Renewed their enthusiasm for Shared Care

The content and experience of the **Six Month Review Study Day** completes the full training package by ensuring that delegates receive the education and support they need not only to continue Shared Care but to disseminate their experience and knowledge to other staff within their units.

Cascading SHC training to other staff

Staff who have attended the course are expected to complete their own shared haemodialysis care competencies and send evidence of this to the Shared Care Educators. When they attend their cohort's 6 month review study day we then talk to them about how they can cascade training to staff who have not had the opportunity to access the course themselves. Managers from all units have been sent a record sheet on which to record this information so that we can monitor progress with the cascading of training. We would encourage all units to look at integrating the 'shared care competency' into the regular professional development of all staff as part of the Review process. This has already been successfully implemented within one of the first pilot units – Peter Moorhead unit.

Future Course Dates

FOR COURSES 11 & 12 - THESE ARE 'PROVISIONALLY' FULLY BOOKED BUT WE HAVE A RESERVE LIST. PLEASE SPEAK TO YOUR UNIT MANAGERS DIRECTLY AS YOU MAY HAVE BEEN GIVEN A PROVISIONAL PLACE ON THE COURSE.

Course 10	Day 1:	28/03/13
	Day 2:	13/03/13
	Day 3:	28/03/13
Course 11	Day 1:	30/04/13
	Day 2:	08/05/13
	Day 3:	22/05/13
Course 12	Day 1:	19/06/13
	Day 2:	03/07/13
	Day 3:	17/07/13

Patient Perspective

Mike's Story ...Final Part



By **Mike May**
(Patient from Hull)

...continued from
Autumn Issue.....

So I had been on dialysis for about 6 months and I was starting to take an interest in my treatment. I was coming in and doing my observations, after talking to nurses more they were saying 'why don't you needle yourself?' My first answer was 'no thank's' but after a few weeks of being talked around and being told I could do it I finally gave it a go and started needling just the bottom of my fistula with the nurse coaching me along. Eventually I started to do both needles and I have never looked back.

By then a shared care training programme had been developed for patients who wanted to take control of their treatment and learn in a structured programme working through with a named nurse training you and helping you understand. The programme was great to work through and easy to follow. The great thing about the programme is there are about fourteen different competencies to work through but you don't have to do them all. You can choose what you are comfortable doing where you start with the basics with infection control i.e. learning to wash your hands and fistula properly and prepare your table. You learn to line the machine and prime it but it's again at your pace as there's no rush and help is always on hand. For me I have found it has really helped me understand my treatment and feel like I'm helping myself. The programme is very comprehensive and explains all aspects of dialysis including understanding

your bloods and problem solving; it has definitely made me feel more confident about doing my own treatment.

For me in the future I would like to see more for this programme going further with the introduction of minimal care leading to self-care giving patients even more freedom and choices and a bigger say in their treatment.

On A final note I would just like to thank the nurses in Hull for all their help and patience in my training. I think this programme has helped me personally and kept me feeling positive about the outcome in the future, knowing there are so many people in the background working for dialysis patients.



The 2nd Regional Shared Haemodialysis Care Learning Event 2013

Please can you help?

Renal Patient involvement and interaction in last years learning event played a vital part in it's success!

We would again like to invite patients to join us in sharing your experiences of Shared Haemodialysis Care, with other patients and staff from across the region and other parts of the UK. Your participation would be valued in small, informal discussion groups. During the event you will be able to view posters and presentations, all of which we hope will be of interest to you as an active participant in your own haemodialysis care.

"As patients we have a valuable contribution to make."

Andy Henwood - York patient representative

The day is **FREE** and includes lunch and afternoon tea:

Date: Tuesday 4th June, 2013 | 10:30 – 16:30

Venue: Marriott Hotel, Leeds, LS1 6ET.

For a booking form, please email debbie.rae@barnsleypct.nhs.uk or call **01226 433 776**.



Kidney Care



Competition Winners

Jane's Story

The first time I was approached about Shared Care, I was very much no way. I'll blow something up or make the sinking of the Titanic take place on dry land, but my interest had been raised. I started small with getting my table ready. No disasters – so I moved up to filling my sheet in. This was making me feel good and I was part of my treatment not just a patient. Confidence built up and I said I would programme my machine from the data I had put on my sheet. When I was approached about my needles I surprised myself by saying yes. Taking them out for the first time was a mixture of trepidation and joy that I had actually done it. This has given me so much confidence that I find myself more confident in life with a self assurance that has now replaced the feeling of I'll never manage that.

By **Jane Evans** - Patient, York.

Liz's Story

I am a renal dialysis nurse at Skipton dialysis unit in North Yorkshire, a satellite unit of Bradford Hospital.

My experience of "kidneys" dates back to 1970 when my father had kidney failure. He was probably one of the first people to have a machine at home, which was donated to him from his place of work. I remember helping my mother to build this huge "kidney" whilst my father was at work. So there was no playing out for me after school with my friends, as it was straight home to help mum.

He needled himself I remember, first in his leg and then in time, in his arm. We had a room specially made into the "kidney room". I had to share my brother's tiny box room which was in the attic.

My memories are of my dad being sick all the time and helping him with the care he needed. I used to do my homework and chat to him while he was on dialysis. He was on the machine for ten hours every alternate day through the evening and into the early hours of the morning.

In 1975 my dad passed away quite suddenly from renal dementia. Thankfully due to improved standards and medical advances this is no longer a problem.

Helping me care for my dad inspired me to become a nurse. I later married and had two children.

My son at the age of 15 years suffered a huge nose bleed which required hospital treatment. Routine blood tests revealed he had ESRF (end stage

renal failure). I was devastated. He commenced hospital haemodialysis initially and progressed to APD (automated peritoneal dialysis) at home. He was very poorly and I looked after him learning about the machine. As a partnership we cared for his kidney failure with lots of help from the Doctors and Nursing team from the Hospital. Eight months later he was given a kidney transplant, and to this day is still doing well. He is fourteen year post transplant. He missed a lot of schooling whilst he was poorly but has successfully completed a college course and is now building a career working full time for a huge international firm.

I am so proud of him.

I look back on my life and today my care is very much shared with love for my job and my past experience.

Throughout my life I have been a carer. Caring with my mother, for my father and also for my son.

The love of my job and past experiences have influenced me to look after our patients at Skipton. I enjoy sharing my knowledge and skills in order for them to become more independent and hopefully will promote a "normal" way of life and life on dialysis more tolerable.

Shared care is not a new concept to me I have experienced it both as a "loved one" and as a "professional". We should embrace it.

By **Elizabeth Burns**
Nurse, Bradford

Qualitative Research



By Dr. Liz Glidewell, Research & Evaluation Lead.

We do not understand why interventions to support self-management in other conditions have variable effects or how to optimise the delivery of shared haemodialysis care. The purpose of this study was to identify perceived patient and professional (nurses and health care assistants) barriers to the uptake of Shared Haemodialysis Care, and to use these data to identify intervention components to optimise care.

Individual semi-structured interviews with patients and professionals were conducted to identify barriers and facilitators. Data were coded to behavioural theory to identify solutions. A national UK learning event with multiple stakeholders (patients, carers, commissioners and professionals) explored the salience of these barriers and the acceptability of solutions.

“...Data were coded to behavioural theory to identify solutions.”

A complex intervention strategy was designed to optimise shared care for patients and professionals. Interviews were conducted with patients (n=15) and professionals (n=7) in two centres

and their three satellite units piloting shared care. Data from patient and professional interviews could be coded to behavioural theory.

Analyses identified key barriers (knowledge, beliefs about capabilities, skills and environmental context and resources - see Table). An intervention strategy that focuses on providing a) patients with information about the shared nature of care, how to read prescriptions and use machines; and b) professionals with skills and protected time to teach both professionals/patients and provide ongoing review is most likely to improve the implementation of shared care and be acceptable to stakeholders.

Facilitators		Barriers
<p>Patients had more knowledge of the dialysis procedure, their condition, dietary and fluid recommendations and blood pressure.</p> <p>Professionals learnt more about the patient and how they managed their condition; they could see improved outcomes (e.g. Hb, potassium and phosphates); there was a reduction in time to train for home haemodialysis; increased team working and benefits for patients who may have been excluded from home dialysis (e.g. elderly and learning disabilities)</p>	KNOWLEDGE	Some patients have none or limited knowledge of their condition and haemodialysis before starting.
<p>Patients could (and sometimes did) rely on professionals to take over in periods of ill health</p> <p>“it makes me feel I’m in command, more responsibility (Beliefs about capabilitiesYork12patient</p>	BELIEFS ABOUT CAPABILITIES	Those who opt out are thought to vary in the amount of information that they can process, their willingness to get more involved (co-morbidities, impact of their diagnosis).
<p>Professionals provided incremental skills training that assessed willingness and competency to perform goals set in collaboration with patients who expressed a desire to be involved in their own care</p>	SKILLS	Some patients are focusing on a kidney transplant in the short-term and don’t want to spend time learning new skills.
<p>Settings that protected areas for those participating in shared care increased communication and support between patients.</p>	ENVIRONMENTAL CONTEXT AND RESOURCES	Misunderstandings that shared care meant independent self-care or having to do all of the competencies in preparation for a transfer to home haemodialysis or an unsupported unit staffed by limited numbers of professionals.

We have developed an intervention strategy to improve the implementation of shared haemodialysis care for patients and professionals. Whilst this

intervention strategy has been systematically developed using behavioural theory it should be rigorously tested in a subsequent

effectiveness evaluation study to ensure that haemodialysis care can be delivered equitably, efficiently and safely for all patients.



Forthcoming Events



The 2nd Shared Haemodialysis Care Learning Event 2013

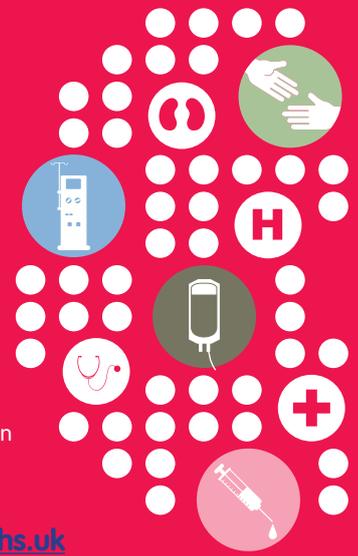
Date: Tuesday 4th June, 2013 | 10:30 – 16:30

Venue: Marriott Hotel, Leeds, LS1 6ET.

Learning Objectives:

- Understanding of what Shared Haemodialysis Care is
- Recognising the impact of patient involvement in their care
- Exploration of barriers and drivers to Shared Haemodialysis Care
- Share your experiences and learn from each other - presentations from self-care units in the UK and Sweden
- Examine whether Shared Haemodialysis Care is patient centred, safe, efficient and effective
- Report on Results from the Yorkshire & the Humber Shared Haemodialysis Care Programme

For more details and to book your place, please email debbie.rae@barnsleypct.nhs.uk



Sponsored by:



Kidney Care

If you would like to present your experience of Shared Haemodialysis Care as a poster at the learning day, please send an A4 abstract to Shamila Gill at Shamila.gill@barnsleypct.nhs.uk by 30th of April.

BRS Conference 2013 Manchester

Tuesday 14th – Thursday 16th May
Manchester Central, Manchester, M2 3GX

“Improving Patient Experience”

For any further information please contact:
The BRS Secretariat: 01483 764114

Email: brs@britishrenal.org • Website: www.britishrenal.org

The Shared Haemodialysis Programme are presenting at one of the BRS sessions:

Evidence for the benefits of greater patient involvement in their own care in long-term conditions.

Martin Wilkie - Consultant Nephrologist, Northern General Hospital, Sheffield.

Shared Care Haemodialysis - A patient's experience.

Patient

Challenging the Culture and training the trainers

Marissa Dainton & Collette Devlin - Shared Nurse Educator, York Hospital

A qualitative evaluation of the impact of Shared Haemodialysis Care

Kelvin Pine - Patient/Carer Volunteer, York's & Humber-side Shared Care

Haemodialysis Project.

International Forum on
**QUALITY &
SAFETY in
HEALTHCARE**

London, 16-19 April, 2013

The Shared Haemodialysis Care Programme has been accepted to do 2 poster presentations on “Sharing the care in haemodialysis care, improving outcomes” at this forum.

Co-sponsored by IHI and the BMJ Publishing Group

FIND OUT MORE

Sharing Haemodialysis Care : <http://www.yhscg.nhs.uk/Networks/sharing-haemodialysis-care.htm>



Contacts

Dr. Chas Newstead

Chair of Programme Board
chas.newstead@leedsth.nhs.uk

Shamila Gill

Y&H Sharing Haemodialysis Care
Programme Manager
shamila.gill@barnsleypct.nhs.uk

Stephen Boocock & Andy Henwood

Patient Leads
stevejb@talk21.com
andy.henwood@york.ac.uk

Tania Barnes, Collette Devlin & Katy Hancock

Nurse Educators
tania.barnes@sth.nhs.uk
collette.devlin@york.nhs.uk
katy.hancock@sth.nhs.uk

Dr. Liz Glidewell

Research & Evaluation Lead
l.glidewell@leeds.ac.uk

Jackie Parr

Commissioning Lead
jackie.parr@barnsleypct.nhs.uk

Rebecca Campbell

Y&H Renal Network Manager
rebecca.campbell@barnsleypct.nhs.uk

Clinical and Nurse Leads from Hull, Leeds, Doncaster and Bradford

Bradford

Tracey Harrison

Nurse Lead - Bradford
tracey.harrison@bthft.nhs.uk

Doncaster

Dr. Mohsen El-Kossi

mohsen.elkossi@dbh.nhs.uk

Mercy Ofori Dartey

Nurse Educator -
Doncaster
mercy.dartey@dbh.nhs.uk

Hull

Dr. Martin Chanayireh

martin.chanayireh@hey.nhs.uk

Sharon Appleby

Nurse Educator - Hull
sharon.appleby@hey.nhs.uk

Leeds

Dr. Elizabeth Garthwaite

elizabeth.garthwaite@leedsth.nhs.uk

Diana Swales

Nurse Educator - Leeds
diana.swales@cht.nhs.uk

Karen Baharvand

Nurse Educator - Leeds
karen.baharvand@midyorks.nhs.uk

Sheffield

Dr. Martin Wilkie

Programme Director

martin.wilkie@sth.nhs.uk

Christine Stubbs

Nurse Lead - Sheffield

christine.stubbs@sth.nhs.uk

York

Dr. David Border

david.border@york.nhs.uk

Melinda Howard

Nurse Leads, York

Dr. Paul Laboi

paul.laboi@york.nhs.uk

melinda.howard@york.nhs.uk

Further Information



Yorkshire and The Humber
Sharing Haemodialysis Care
Improving Outcomes

For Further Information on the
Y&H Shared Haemodialysis Care Programme please contact:
Shamila Gill - Y&H Sharing Haemodialysis Care Programme Manager

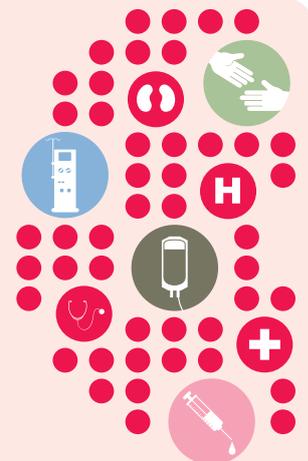
NHS Barnsley, Hillder House, 49-51 Gawber Road, Barnsley, S75 2PY.

Phone: 01226 4633711

Mobile: 07825 385661

Email: shamila.gill@barnsleypct.nhs.uk

Website: <http://www.yhscg.nhs.uk/Networks/sharing-haemodialysis-care.htm>



Acknowledgements

The Sharing Haemodialysis Care Programme is being funded by the Health Foundation through the Closing the Gap through Changing Relationships programme.



Closing
the Gap

The programme is in partnership with the Yorkshire and the Humber Renal Network, NHS Kidney Care and the Leeds Institute of Health Sciences. It is being led by Dr. Martin Wilkie, Consultant Nephrologist at Sheffield Teaching Hospitals NHS Foundation Trust.

FIND OUT MORE

Sharing Haemodialysis Care : <http://www.yhscg.nhs.uk/Networks/sharing-haemodialysis-care.htm>