

Y&H Shared Haemodialysis Care Learning Event

SPECIAL EDITION NEWSLETTER

Tuesday 26th June, 2012.



The Health Foundation Inspiring Improvement **Closing the Gap**

Yorkshire and The Humber **Sharing Haemodialysis Care** Improving Outcomes

Thankyou!



By Dr. Chas Newstead, Programme Chairman

I have been very fortunate in my career to have had the chance to work with a large

number of extremely committed colleagues. I have always regarded it a privilege to be able contribute to the care of patients with kidney disease. The shared learning event that is summarised in this newsletter brought together these two elements as powerfully as I have ever seen. None of this would have happened without effort well beyond the "call of duty" by people some of whose contributions feature in this newsletter and some who do not. Many of those featured have been involved with the project from the beginning others have volunteered as the project has evolved. I was very pleased to see colleagues from other parts of the UK who came to share their experiences as there is more than one way to work towards better kidney care, which is of course what it is all about. Many thanks to all, not just the presenters and project team but to the delegates for their part in this event.

Market Place – what was displayed?



The SHC team displayed various posters describing the different areas of development of the programme and support the development of greater self-efficacy among centre based dialysis haemodialysis patients in our region through a "training the trainers" course for nurses. Patient partners have been involved at every stage of the work, including working at a board level to advice on course development and the conduct of qualitative research. Early results, barriers and enablers are discussed on the posters.

Teams from around the country also displayed their posters providing examples of similar experiences to ours and describing greater patient involvement in HD using a range of approaches.



From the **Nursing Perspective** the SHC team displayed a wide range of materials designed and developed for delivering the nursing course at all levels as well sharing the experience of the course from delegates who have completed the course.



From the **Patient Perspective** the SHC team again displayed a wide range of materials developed such as the patient awareness leaflet on SHC, the patient handbook and showcased a montage of photographs of patients participating in their own care.

NHS Kidney Care shared a wide range of publications including an electronic information kiosk which contained information on what patients can do to manage their condition.



The **Health Foundation** provided a selection of publications on who they are, what they do and on their approach for improving the quality of healthcare.

Hull and East Yorkshire Hospitals NHS Trust Staff displayed their interactive Haemodialysis DVD Resource which has been developed in partnership with patients. The resource included patient interviews, a video of treatment, 360° interactive images, and supporting information from across the multi-disciplinary team working in haemodialysis.



Inside this issue	Page
Market Place - Displays	1
What the presenters had to say	2
Workshop themes & outcomes	4
Questions & comments	6
Contact information	6

FIND OUT MORE

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

What the presenters had to say

Angela Coulter

Specialist in healthcare patient and clinician engagement

Angela Coulter presented the evidence for the benefits of greater patient involvement in the management of long

term conditions, and these are summarised on this slide.

She also reviewed "what works" to change the relationship between patients and health providers including giving patients the resources they need to have greater control over their condition, developing a culture of shared decision making, supporting self-management and promoting health education.

Delegates feedback:

" Helpful summary of the wider academic & political context "

Informed, Empowered Patients

Have the knowledge, skills and confidence to manage their own health and healthcare, And they.....

- Make healthy lifestyle choices
- Make informed and personally relevant decisions about their treatment and care
- Adhere to treatment regimes
- Experience fewer adverse events
- Use less healthcare



Delegates feedback:

" Excellent background will get book! "



Martin Wilkie

Programme Director

This slide summarises the benefits for patients that we expect to see with Shared Haemodialysis Care. This approach is clearly patient centred and enhances the effectiveness of therapy as patients understand their treatment better and can take a greater role in it. Nursing staff work more efficiently as problem solvers and trainers rather than performing repetitive tasks. Patient safety is enhanced with patients taking a key role in risk reduction for example through understanding and participating in infection control procedures. There are also benefits in terms of timeliness and equity of access to care.

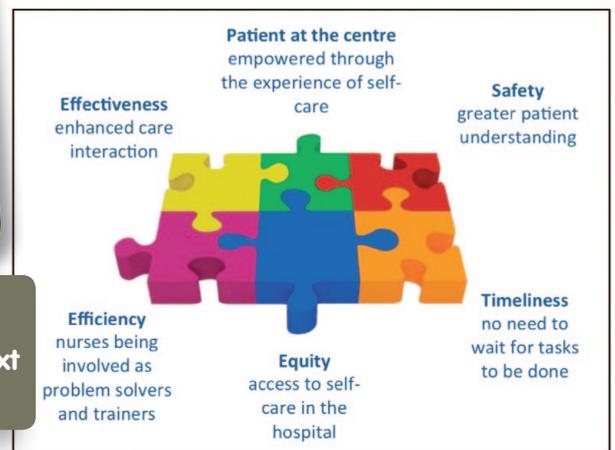


Delegates feedback:

" Grounded me well in the focus & context of the day "

Delegates feedback:

" Very similar model to that used in my area but wish I'd come up with 'shared' rather than 'self' care "



David Pargeter

Patient Partner

David Pargeter, a patient, gave a patient perspective on Shared HD Care.

He gave a passionate and powerful presentation about his personal experience with the programme.

He said, *"this programme has given me my life back"*.

Delegates feedback:

" Good perspective put across in a simple effective manner "

Delegates feedback:

" Massively engaging to hear a real vivid personal story not simply a 'list' of experience "



What the presenters had to say....continued

Katy Hancock

Shared Haemodialysis Care
 Nursing Team

As part of the spread and sustainability of the Sharing the Haemodialysis Care Programme we have put together a definitive portfolio of support materials including a Patient Information Leaflet, Patient Handbook and promotional posters. In addition, we have developed "The Sharing the Haemodialysis Care Course" for nurses to further support spread and sustainability.

The slide demonstrates the positive feedback from recent course delegates and goes in some way to validate its success.



Some of the course delegate comments....

"I have learnt some valuable things about myself as well as patient needs"

"The programme has acted as a springboard for development within our unit. I believe this will have a positive benefit for patients"

"No more groundhog day!"

"I have enjoyed the three sessions and will go back to share and encourage staff/patients with a much greater understanding"

"Renewed the existing relationship with my patients & has made it a more positive one"

Delegates feedback:

"Useful presentation to help frame the project from a nursing perspective"
" Good to hear some of the details of the Y&H programme "

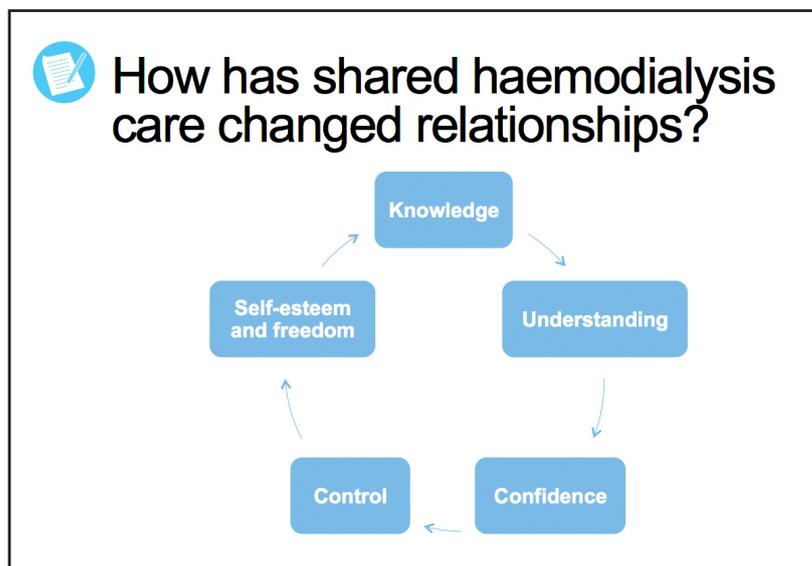
Liz Glidewell & Kelvin Pine

Researcher / Patient Involvement

We conducted semi-structured interviews with patients (15) and staff (7) who were involved or not in Shared Haemodialysis Care (SHC) to understand their unique experience. SHC has increased patient

knowledge of dialysis and their condition. Staff know more about the individual and work more closely with others in the ward and other specialists. This has increased shared understanding, confidence,

self-esteem and control over the process that was previously lacking. Together these factors allow patients and staff to participate in SHC at a level that is appropriate for them.



Delegates feedback:

" Good collaboration, but could have done with more time! "

Workshop Theme & Outcomes

Workshop 1

Facilitated by:



Beverley
Matthews



Dr Donal
O' Donoghue

How would you make this a sustainable and a valuable resource for the NHS?

- * Creating a culture change of patients and staff through education, motivation, encouragement and don't be afraid, learn from failure & success.
- * Create incentives for self-care
 - Tariff
 - Access to care drivers to get their lives back
 - Job satisfaction
- * Opportunities to share at local and national level (virtual and face-to-face) to prevent reinvention of the wheel
- * Understand where we are and where we want to go
- * Measure – what have you achieved



Workshop 2

Facilitated by:



Dr Angela
Coulter



Dr Mohsen
El Kossi

Are you convinced by the evidence for benefit of greater involvement and care in Long Term Conditions?

- * No robust evidence but a lot of enthusiasm and obvious benefits based on patient voices
- * More evidence needed:
 - Measures
 - Cost effectiveness
 - Impact on disadvantaged groups
 - Litigation
- * Patient evidence is the most robust and what to do with the evidence to influence care and policy making
- * Evidence for long term conditions is available (e.g. DM)
- * Need good quality evidence for HD
- * How would you measure the outcome?
 - Self-efficacy
 - Clinical outcomes measures
 - Centre vs. cluster

Workshop 3

Facilitated by:



Paul
Taylor



Andy
Henwood

What is the challenge of changing relationships from the patient perspective?

- * Has to be culture change from both staff and patients
 - Patients to learn staff not just there to put them on and take them off the dialysis machine – take ownership of their treatment
 - and likewise staff need to spend more time to understand the patient by discussing bloods, medication, diet and allow patient time to learn more about their treatment
- * Patient education – educate patients at early stages such as pre-dialysis stage
 - Advertise more in units
 - Time Restraints – allowing a dedicated nurse to a certain point in training patients such as button holing to keep the patient interested and the training consistent
- * Fear of unknown
 - Medical
 - Technical
 - Information (well, informed)
- * Confidence
 - Loss of 'comfort' zone
 - Having to take responsibility
- * Staff
 - It's your job or
 - Don't want Health Care Professionals to lose job
 - Staff not wanting to let go

Workshop 4

Facilitated by:



Jane McDonald



Rebecca Bieraugel

What is the challenge of changing relationships from the staff perspective?

- * Understand (listen to) what the patient wants
- * Invest time and benefits will be realised
- * Risk aversion - changing the professional role and responsibility
- * Staff - feeling threatened / service reorganisation/ role changes / job cuts
- * Staff & Patients – sustaining motivation
 - Communication
 - Involvement
 - Why (outcomes)
- * Patients – promoting / cultural change / patient empowerment 'letting go'



Workshop 5

Facilitated by:



Dr Sandip Mitra



Sue Flintham

How can we overcome the challenges of implementation to SHC in a range of dialysis settings?

- * Normalising SHC as part of standard care
 - Early patient engagement
 - Recognising patient variability and therefore being flexible
- * Service redesign
 - Top down support
 - Flexibility of resources
 - Patient centeredness
 - Safe systems – ongoing training / assessment
 - Appropriate response to negative events
- * Patient interactions
 - Trust
 - Understanding
 - Peer groups / expert patients (doctors don't how it feels)
- * Terminology – is it self-vs. shared care / language / cultural
- * Consistency –
 - Of staffing,
 - Of infrastructure
 - of delivery of training
 - of staff time
 - facilities / equipment / consumables
- * Incentives / Benefits
 - Sell sense of achievement
 - Change of prescription
 - Consenting to swapping patient shifts
 - Not just meeting targets

Workshop 6

Facilitated by:



Sue Cox



Dr Sarah Jenkins

How can we sustain the culture of patient involvement?

- * Culture flows through the whole pathway not just at renal replacement therapy, all types of management
- * Encouraging patients to use self-management tools and resources (home therapies)/patient peer support
- * staff courses and patient experts educating staff
- * physical environment – difficult if 100% occupancy
 - dedicated area, led by example
- * Political involvement – landscape in agreement
- * Preservation of independence – eg. own observations in CKD clinics / home

Workshop 7

Facilitated by:



Dr Chas Newstead



Dr Martin Wilkie

What has been your personal learning from being involved in the SHC Programme?

- * Seeing through the patients eyes made us better health care professionals, allowed more flexibility, opened minds and gained staff satisfaction
- * Change management has been lived through pilots, one step at a time and PDSA cycles
- * Skills stretched working with multi-disciplinary team, strengthened project management skills at local and regional level
- * The value of sharing experience – eg. learning from each other, centres collaborating and patients collaborating
- * The importance of explaining and revisiting options – concepts originally rejected can be revisited with growing confidence

Your questions and comments

Q. How do we sustain SHC in our individual units?

A. The 3-tiered model is the best way to ensure staff are engaged at all levels in the nursing hierarchy and that training is targeted towards individual groups based on seniority – start training with the individuals who are enthusiastic first to champion the positive change back at their units.

Comment: One of our participants mentioned made a comment on the availability of SHC in other countries. We know that SHC is developing internationally.

Q. What is huddle and how do we use it?

A. **An interactive online forum for sharing of information and discussion.**



We use the Huddle workspace to store all working and under development materials and file minutes and notes from our Programme Board right through to individual Workstream meetings. We also have a separate Huddle workspace for HCPs and Patients for updates and information on the programme and our published materials.

Q. How can we maintain quality as the programme is rolled out?

A. A training course, excellent supporting materials and patient involvement. Also reporting on measures coupled with research to determine the most appropriate long term outcome measure of quality.

Q. How can we access the Y&H SHC materials in Microsoft word?

A. We are working towards making the materials available so that other units/regions can adapt and localise them. Guidance on this will be out soon through our Huddle workspace.

Q. How can we share the learning across other disciplines such as Peritoneal Dialysis and Dietetics?

A. With PD we could share the learning materials for example the patient hand book. Also a validated course with a clear curriculum and training materials for nurses who are going to be training patients.

For the dieticians the motivational interviewing and working on shared goals with patients, these are the co-creating health objectives that were highlighted by Angela Coulter in her presentation.

The presentation slides and a full evaluation of the event is available on the Yorkshire & the Humber Renal Network website:
<http://www.yhscg.nhs.uk/Networks/sharing-haemodialysis-care.htm>

Further Information



Yorkshire and The Humber
Sharing Haemodialysis Care
 Improving Outcomes

For Further Information on the Y&H Shared Haemodialysis Care Programme please contact:
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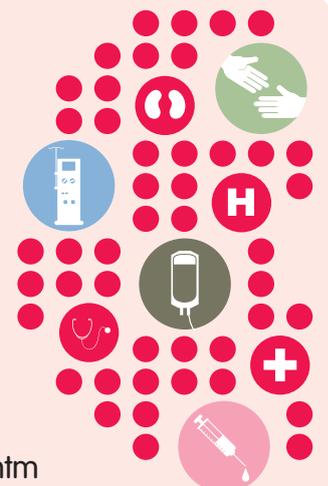
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