

Pre-dialysis Points

News from the first Pre-dialysis Forum Seminar

June 2001

Inside

Planned care is paramount	2
Patients need better advice	2
More pre-dialysis nurses needed	3
GPs need to refer earlier	3
Workshop Feedback	3
Steering Group's plans	4
Facilitating Choice scoops prize	4
Who's who on the Steering Panel	4
Pre-Dialysis Forum: the way forward	4
Become a networking Pre-Dialysis professional	4

FORUM TO FIGHT FOR BETTER PATIENT CARE

Delegates to the First Pre-Dialysis Forum Seminar have called for a strategy to improve patient care before end-stage renal failure (ESRF), with specialist nursing posts playing a vital role.

Nurses have launched a Forum to give kidney patients better care during the pre-dialysis stage.

At the inaugural seminar of the Pre-Dialysis Forum, called *Pre-Dialysis: sharing a vision*, delegates agreed a mission statement, which says: "This Forum is devoted to improving renal patient outcomes through optimal care and management during the pre-dialysis phase."

The Forum plans to set up a directory of nurses with an interest in the field, who can share resources, materials and information for patients.

The aims of the Forum are to:

- enhance patient and carer insight and well-being;
- improve the standards of pre-dialysis management and standardise information;



Debi Kendray Pre-dialysis Clinical Nurse Specialist at Northern General Hospital, Sheffield

- educate other healthcare professionals through sharing good practice;
- measure the effects of pre-dialysis management; and
- stress the importance of having designated nursing posts in the specialty.

Delegates highlighted the provision of nurses with a designated interest in pre-dialysis as vital to the Forum's aims being achieved. They believe such posts are key to improving the quality of life for patients with renal failure.

"Pre-dialysis care is an integral part of the care of dialysis patients," Debi Kendray, Pre-dialysis Clinical Nurse Specialist at Sheffield's Northern General Hospital and a member of the Forum's steering group, told delegates.

"Renal patients need the support of a nurse specialist in this area.

"The consistent promotion of pre-dialysis care is essential," she stressed.

FORUM GETS MASSIVE THUMBS UP

The First Pre-dialysis Forum seems to have been a massive hit.

All delegates who completed their feedback forms gave the presentations a 100 percent thumbs up for their length and the time available afterwards for questions.

Risk Groups: horses for courses, the presentation by Dr Roger Greenwood which discussed the importance of planned care for pre-dialysis patients, was voted the most useful presentation, because it was relevant, clear and informative, delegates said.

And none of the presentations could be accurately described as fitting into a category of "least useful", they added.

Delegates also said that they would be putting three key points into practice in their units:

- gathering more patient information;
- setting up information evenings for patients and carers; and
- using the criteria for early start to pre-dialysis.

Delegates agreed that multi-disciplinary involvement among the various members of the healthcare team was essential to good pre-dialysis care.

"Would like to see the Forum expand to all team members (Drs etc) and to ward staff with an interest in anaemia to help disseminate information," one delegate suggested.

Another concurred: "I think the Forum is an excellent idea which will help to influence changes in pre-dialysis management and hopefully will encourage standard setting."

Another said: "I am keen to continue as a member of this Forum. I think it has the potential to help us develop a supportive pathway for those patients who opt out of renal replacement therapy."

Following the seminar, nearly two-thirds of nurses known to be interested in pre-dialysis have already agreed to be listed in the National Pre-dialysis Directory.

Setting up such a Directory is one of the main aims of the Forum.

Requested topics for Seminars

- Care pathways
- Latest research into anaemia and bone management
- Hepatitis immunisation in pre-dialysis patients
- Setting standard protocols
- Anaemia management
- Transition from adolescent to adult
- Patient and carer psychological care
- Standards of pre-dialysis care

The
Pre-dialysis
Forum

PLANNED CARE IS PARAMOUNT



**Dr. Roger Greenwood, Clinical Director
Lister Hospital in Stevenage**

Dialysis patients needed planned care to have the best chance of survival but not all people with renal failure were suitable candidates for such treatment, delegates heard.

Renal patients benefit markedly from planned care, the seminar heard. Clinical director at Lister Hospital in Stevenage Dr Roger Greenwood told delegates that planned care of renal patients was paramount because without pre-dialysis care, patients with renal failure were at a serious disadvantage.

“People who come in, in a planned fashion for dialysis do very, very well.

But unplanned patients – these are the acute, the last minute, elderly patients who are flat out – do extremely badly, particularly in the first year,” he said.

But Roger Greenwood stressed that dialysis was inappropriate for some patients with renal failure, something dialysis specialists needed to understand.

Research at his hospital had demonstrated that dialysis therapy for high-risk patients often simply meant that the patient died in hospital. Conservatively managed patients would usually die in the home with the families or in a hospice in a managed environment.

“I now think that non-dialytic therapy for end-stage renal failure in high-risk groups is a viable option. You’ve got to be careful dialysing these patients because you are in danger of medicalising their death,” Roger Greenwood said.

He also warned delegates to be on the look out for patients who agreed to undergo dialysis just to “please” the health professionals caring for them.

“There is even a fear among some patients that they will be labelled as in danger of committing suicide if they turn down the option of dialysis,” he said.

“We must tell them that is not the case.”

*“People who come in, in a planned fashion for dialysis do very, very well.
Patients without a plan do very badly”*

PATIENTS NEED BETTER ADVICE

Kidney patients need to be given better information about their disease, the seminar was told. And this was better coming from hospital nurses or hospital doctors than GPs, a patient-group leader said.

This was one of the findings of a large patient survey conducted by the National Kidney Federation (NKF) in November of last year of 17,000 kidney patients which generated nearly 3000 replies.

From the patient’s point of view “it’s absolutely no good going to a GP for information about renal disease,” NKF general manager Tim Statham said.

“And that’s not surprising, and not a criticism. A GP is unlikely to see a renal patient in his entire career. It is that rare for a GP.

“So clearly a GP is not always the best source of information for a patient.”

The problem was that this lack of information meant patients often had little idea of the seriousness of their condition, Tim Statham continued.

“One patient who contacted us had known for six weeks that he was heading for renal failure,” he said.

“He turned up at one of our meetings and expected to be told what pills would make him better. He had no idea what he was facing.”



**Tim Statham OBE
NKF General Manager**

“As dialysis numbers increase, so staffing levels will have to rise”

MORE PRE-DIALYSIS NURSES NEEDED

Pre-dialysis management has proven value in the care of kidney patients but needs a boost in specialist nursing posts to make it as widely available as it should be to meet predicted demand, delegates to the First Pre-Dialysis Forum Seminar were told.

Frances Coldstream, Steering Panelist and Renal Nurse Consultant at Guys' and St Thomas' Hospital NHS Trust, London



Effective pre-dialysis management was crucial to ensure appropriate, high-quality care for people who were referred with a diagnosis of chronic renal failure, a nurse consultant in pre-dialysis management told the seminar.

But, added Frances Coldstream, Renal Nurse Consultant at London's Guys' and St Thomas' Hospital NHS Trust, while a designated nurse specialist in pre-dialysis care was the key to improving quality of care for patients with chronic renal failure, predicted increased demand would necessitate an increase in the number of nurse specialists.

"As the number of patients needing dialysis increases, so staffing levels will have to rise," Frances Coldstream said.

"As pre-dialysis nurses, we can help to set the standards for quality of care for our patients and assist them in making realistic choices for the future."

The annual incidence of new patients who could benefit from renal replacement therapy (RRT) was at least 80 in one million of the UK's population, Frances Coldstream continued.

The figure was higher in certain areas because of local-population age composition, but age itself was not a contraindication to dialysis therapy, according to the Renal Association, she explained.

The most common cause of end-stage renal failure (ESRF) was diabetic nephropathy, she told delegates.

And she cited research by Khan, which showed that late referrals have an adverse effect on survival rates in RRT.

"Patients who are referred with advanced renal failure for the first time often require temporary vascular access, with its attendant risks and complications," she said.

"Such patients are not psychologically prepared for life on RRT and are often malnourished, elderly or suffer from co-morbid illness."

The implications of late referral were "legion", Frances Coldstream concluded.

WORKSHOP FEEDBACK

During the afternoon, the Forum split into four workshops. Delegates were asked to discuss and report back on four key topics.

- Management of Anaemia
- Facilitating Choice
- When to Begin Dialysis
- Patient/Carer Information.

No-cost provision of erythropoietin (EPO) was top of the **Anaemia Management** workshop's wish-list, the Forum heard. This group also wanted a non-injection form of the hormone. Other wishes by this group were:

- a designated pre-dialysis nurse;
- holistic care provided by all renal care nurses;
- an effective oral iron preparation; and
- more research.

More research also featured in the wish-list of the workshop tasked with discussing **Facilitating Choice**. They also wanted to see:

- a more consistent approach;
- national standards; and
- evidence-based practice.



No-cost provision of erythropoietin (EPO) was top of the Anaemia Management workshop's wish-list

The wish-list of the workshop on **When to Begin Dialysis** included: better communication between medical staff and earlier referrals.

The final workshop looked at **Patient/Carer Information** and wanted to see:

- finance for producing information for diverse cultures;
- administrative support; and
- greater attention on young dialysis patients transferring to adult units.

GPs NEED TO REFER EARLIER

Late referrals are jeopardising patient care and wasting money, the Forum was told. According to the UK Renal Registry published in December 1999, 30 percent of patients with chronic renal insufficiency were referred at a late stage in their disease and, as a result, often received less-than-best care, it heard.

Other research, by Jungers *et al.* in 1993, (Late referral to maintenance dialysis: detrimental consequences. *Nephrol Dial Transplantation* 8: 1089-10930) had highlighted the risks of late referrals. It had shown that delayed referrals could cause clinical complications and increase NHS costs, anaemia nurse specialist at London's St George's Hospital Andrea Whitmore told the meeting.

"Primary-care professionals should be better informed about the benefits of early intervention," she said.



Anaemia Nurse Specialist at London's St George's Hospital, Andrea Whitmore

STEERING GROUP'S PLANS

Following the success of the first Pre-Dialysis Forum, the Steering Group met to discuss the feedback it had received from delegates and to plan both future events and initiatives.

The next Forum seminar will be held on the 23rd November 2001 at a location in London.

Plans are afoot to make this an even more interactive event than the York event. Among many new ideas for this Forum, delegates are likely to get the chance to put questions to a panel of experts and debate issues with them.

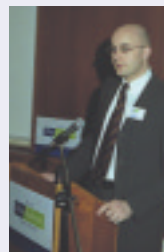
To take the Forum forward in general, the Steering Group agreed to open up the next Forum to nurses who are not currently active in the pre-dialysis field but who wish to become involved. This, the Steering Group agreed, was a vitally important step in ensuring that the overall aims of the Forum were met. Chief among those being stimulating increased interest in pre-dialysis care and the creation of more dedicated pre-dialysis nursing posts.

The Steering Group also agreed that the Directory should be put on the nephronline.org Website. This would allow easier access by interested parties to fellow professionals interested in this field of care. The Directory, itself, should be updated at least yearly, too.

Other initiatives the Steering Group plans to advance at the earliest opportunity include the setting up a Discussion Board on this Website within a special section dedicated to the Pre-Dialysis Forum; and creating a database of education materials which Forum members can use both to teach fellow health professionals and patients.

The Pre-Dialysis Forum is also interested in research and the Steering Group invites UK and Ireland readers to write in to tell colleagues about imminent or underway research projects with which they may wish to collaborate

FACILITATING CHOICE SCOOP PRIZE



Members of the workshop group discussing **Facilitating Choice** scooped the prize of a bottle of bubbly for the quality of their presentation acetates.

Dave Allmond, (pictured above) Senior Product Manager for AMGEN Nephrology, presented the bottle of champagne and praised all delegates for sowing the seeds of a vital initiative in pre-dialysis care.

THE PRE-DIALYSIS FORUM: THE WAY FORWARD

Forty-one delegates attended the 6th April Forum seminar and already the network has established over 60 contacts in the Pre-dialysis field, all eager to share resources and information useful to patients.

Delegates called for a network of Pre-dialysis colleagues from around the country to facilitate the sharing of ideas and practice. One of the first tasks of the Pre-dialysis Forum will be to

set up a UK and Ireland directory of health professionals with an interest in this fast-growing renal specialty.

Delegate comments about the seminar were encouraging, with support and ideas for future Pre-dialysis Forum meetings including the issues of sexual dysfunction, the education of patients and the transfer of adolescents to adult units.



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THE PRE-DIALYSIS FORUM: MAKING A DIFFERENCE FROM THE OUTSET

Nominate a colleague who would like to join a new renal group devoted to improving renal patient outcomes through optimal care and management during the pre-dialysis phase.

Name	<input type="text"/>	Post	<input type="text"/>
Department	<input type="text"/>	Hospital	<input type="text"/>
Address	<input type="text"/>		
	<input type="text"/>		
Town	<input type="text"/>	Post Code	<input type="text"/>
Tel Number	<input type="text"/>	E-mail	<input type="text"/>

WHO'S WHO ON THE PRE-DIALYSIS FORUM STEERING PANEL

The Forum's steering panel comprises seven members.



FRANCES COLDSTREAM

Panel Co-ordinator, Renal Nurse Consultant at Guys' and St Thomas' Hospital NHS Trust, London.



CORAL GRAHAM

Renal Homecare Team Leader, Leicester General Hospital.



VALERIE HEANEY

Anaemia Co-ordinator at Adelaide and Meath Hospital, Dublin.



DEBI KENDRAY

Pre-Dialysis Clinical Nurse Specialist at Northern General Hospital, Sheffield.



GERALDINE MCGEE

Anaemia Nurse Specialist at St Helier Hospital, Carshalton.



ANNI SCHNEIDER

CAPD Staff Nurse at Western Infirmary, Glasgow.



ROSAMUND TIBBLES

Senior Nurse Pre-Dialysis/PD, Bart's and The London NHS Trust, London.

BECOME A NETWORKING PRE-DIALYSIS HEALTH PROFESSIONAL

To register on the Pre-dialysis directory free of charge or if you have something to include in the next issue, contact the co-ordinators:

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