

Renal Services : A Patients' Perspective.

Introduction.

I am grateful to the Scrutiny Board for being given this opportunity to make representations on behalf of renal patients in Leeds.

I shall begin by providing some background information, go on to examine, in broad terms, some of the main issues of importance to such patients, and finish by addressing the specific issue of transport provision for patients undergoing haemodialysis treatment in hospital.

Patient Priorities.

As is the case with many patients with long term, chronic conditions, renal patients tend to be extremely knowledgeable about their own disease, the range of possible treatments, national standards, and how services are delivered in other parts of the country.

Not unreasonably, they expect to receive equity of access to high quality services regardless of where they live or are treated.

Furthermore, they require a holistic approach to their condition, given that it affects not only their physical well being, but also impacts on other aspects of their lives, (e.g., employment, financial circumstances, etc), and the lives of those closest to them.

There are a number of issues about which all renal patients are concerned, and which can, broadly speaking, be categorised under the following headings. Some examples are given in each category, but do not comprise an exhaustive list.

Choice – Clinical considerations as to the appropriateness of treatments for individual patients must be paramount. Once that is determined, the venue and timing of treatment, (i.e. hospital or home based in the case of haemodialysis, and at a time that fits in with other commitments, e.g., employment), should be the choice of the patient, but that is not always possible, owing to capacity, staffing, and other issues.

Consistency – Avoidance of the so called 'postcode lottery' whereby patients with the same need are treated differently according to their place of residence is particularly important for this group of patients, most of whom are well aware of minimum standards, such as those laid down in the national service framework for renal services, (renal NSF).

Communication – All patients are meant to have an individual care plan, (standard 1 of the renal NSF). These should be monitored on a regular basis, and patients should play an active role in them. Such written plans help to avoid confusion as to what was agreed between the doctor and patient at a clinic appointment, and give patients a share in the responsibility for their own well being. In many cases, such plans do not exist.

Continuity of Care – As patients progress through the 5 stages of chronic kidney disease, (CKD), it is important that appropriate and timely measures and protocols are in place to ensure they are referred from primary to secondary care, (and that other agencies are involved also, where required, e.g., social services). Given the long term nature and complexity of their condition and treatment, wherever it is practicable patients should have access to the same staff within the multi disciplinary team who are conversant with their medical history and individual social and other circumstances.

Service Development and Monitoring – The forum in which this takes place is the North, East, West Yorkshire & North Lincolnshire renal strategy group, (NEWNYL RSG). Membership of the RSG includes clinical and managerial representation from Leeds Teaching Hospitals Trust, the 3 other main renal centres in the region, (Bradford, Hull and York), a local GP, PCT commissioners, and patient representation through the author of this report. Arrangements for meetings lie with Leeds PCT.

It is a matter of great concern that this group has only met once in 2008, and that, by the time of its next meeting on 26 September, virtually 8 months will have elapsed since it last met.

Transport Provision for Hospital Based Haemodialysis Patients.

I must begin this section of my report by apologising for my non-attendance at the Scrutiny Committee meeting as, ironically, I have to be at a renal transport meeting in the North West of England at the same time.

I shall leave it to others who will be present at the meeting to deal with specific local issues, as they are much more knowledgeable about, and directly affected by, the current concerns.

Transport is an essential part of a hospital based haemodialysis patient's care; without access to the treatment, they will die.

The renal patient population is composed increasingly of more elderly and frail individuals, many of whom have co-morbid conditions. Those factors, together with the distance many patients have to travel to receive their treatment, even in an urban conurbation such as Leeds, make the provision of an effective and efficient transport system vital.

Failure so to do not only affects patients in terms of increased stress, long delays, and, on occasions, reduced treatment hours, but also creates difficulties for the staff in units when the late arrival of patients can cause a 'knock on' effect for other patients later in the day, and extend staff working hours.

It can lead to vulnerable patients returning home late at night, having spent up to 10 hours away from home for a 4 hour treatment session.

There are occasions also when patients have to be kept in hospital overnight as no transport is available, or it is too late for them to return home safely, and this is not a cost effective use of scarce hospital in-patient beds.

Other problems include staff time being wasted in ringing transport providers to ascertain why patients have not arrived on time for their treatment; transport providers making aborted journeys because they have not been informed patients have been admitted to hospital or are on holiday, and generally increased and unnecessary levels of stress caused to patients.

This is a national problem; not one only for patients treated at the various units in the Leeds area. As a result, the Department of Health set up 2 action learning sets to make recommendations as to how the service might be improved.

The author of this report was a member of the Cheshire & Merseyside action learning set, which reported with a list of recommendations for improvement early in 2007.

At the present time, a pilot scheme to implement the recommendations is in place, and the findings from that pilot will be shared widely within the renal community when it finishes in May 2009, and have been evaluated externally.

I should like to end this report by using an analogy which, I hope, encapsulates the points I have made above, and makes them meaningful to individual members of the Scrutiny Committee.

Imagine you have booked a taxi to take you to the airport at the start of your annual, and much looked forward to, Summer holiday.

5 minutes before the time the taxi is due to arrive, you start looking for it approaching. It fails to appear on time, and, despite the fact you have allowed plenty of time for a late arrival, you start to feel concerned.

After another 5 minutes with no vehicle in sight, you phone the company concerned, only to be told, 'it's on the way'. Eventually, some 10 minutes later it turns up. By then your relaxed mood at the prospect of a well earned break has disappeared.

Now, imagine that situation being replicated 3 times a week, week in, week out, over a long period of time, and where your end destination is not a warm and welcoming holiday resort but an aggressive, invasive and tiring form of hospital treatment.

Wouldn't you feel aggrieved and expect something better?

Conclusion.

This report is presented for the information of the Scrutiny Board.

Dennis Crane, North Region Advocacy Officer National Kidney Federation.

Author's Note.

Dennis Crane has been an identified renal patient for more than 40 years. He has first hand experience of all forms of renal replacement therapy; home and hospital based haemodialysis, peritoneal dialysis, and failed and successful transplantation.

A founder member of the North West Region Kidney Patients' Association in 1983, he worked on a voluntary basis with and on behalf of patients both regionally and nationally on a range of renal and transplant related issues for more than 20 years.

He was awarded the MBE for his services to people with renal disease in 2002, and was appointed to his present part time salaried post in April 2004.

Prior to that, he worked for almost 36 years in the Education Department of Manchester City Council, retiring from his post as Head of School Governor Support and Training in September 2002.