APPENDIX 6

Renal Services : A submission on behalf of the National Kidney Federation

I apologise for not being able to be present at the Scrutiny Board meeting on 28 July 2009. I hope this written submission will be helpful to members in their deliberations on this agenda item.

I am sure representatives of the Leeds General Infirmary and St. James's kidney patients' associations will make their own case for the respective capital works programmes.

They have much more detailed knowledge than I do, and it is, of course, their members who are directly affected by the decisions taken.

What I shall endeavour to do in this report is to provide an external and neutral renal patient view of each proposal.

Can I begin by stating that I recognise fully the very real financial pressures facing the health service, especially at the present time, the many competing demands on available monies, and the need to ensure the most effective use of scarce resources.

I appreciate also that changing financial circumstances may necessitate a review of decisions previously agreed, but any such review should, in my view, take into account primarily whether the clinical circumstances that led to the original decision have changed any way.

I do not intend to repeat here the background history to these matters, but will set out, as I see it, the respective need for both two schemes.

Leeds General Infirmary Scheme.

It seems to me that there are at least three reasons why this scheme should go ahead.

(a) It would make more efficient use of the nursing staff already working at the LGI site who are providing specialist renal support to patients who have been admitted for other conditions.

(b) A number of patients who are dialysing at the Seacroft unit and who live closer to the LGI site would have a shorter journey, and less time spent in travelling to and from their thrice weekly sessions, with the transport and environmental costs benefits that would be achieved

(c) Enabling the patients identified at (b) above to dialyse at the LGI would also be in line with best practice of ensuring that patients who are clinically suitable undergo their dialysis as close to home as possible.

The one caveat I would add about b). and c). above is that I have no way of knowing whether the number of patients to whom those points apply is greater than the number for whom Seacroft is the nearer unit.

APPENDIX 6

St. James's Hospital Scheme.

Quite by coincidence, I can see three reasons also for supporting this scheme.

(a) A continuous supply of specially treated water is essential to the haemodialysis process.

(b) Any temporary disruption to the supply itself, and/or to the required standards of purity owing to water treatment plant breakdown, can lead to delays in patients accessing their treatment, with a knock on effect for patients dialysing later on the same day, which can, in turn, cause transport difficulties for patients, and, in extremis, a shortening of their prescribed treatment session.

If such problems occur continually, the overall cost of putting in place essential repairs would need to be weighed against the cost of a full replacement service.

(c) Longer term failure of the water treatment plant would lead to patients having to be transferred to other units to undergo their treatment, with all the potential difficulties that would create in terms of additional travel costs and journey times.

The possibility of patients having their dialysis delayed, or having to dialyse at different times of day or days of the week at a different unit to the norm could well arise, which in turn would impact on other aspects of their lives. Such effects would not necessarily be ones of 'minor' social inconvenience.

For example, a patient who is a resident in a care home could miss a meal that is provided at a set time, or an elderly person living alone might not arrive home until after dark, rather than in daylight hours.

The disruptive effect on staff also should not be forgotten.

Haemodialysis Capacity

I mention this issue only because I know it is referred to elsewhere in the papers that members have received for this agenda item.

The national body that sets standards for renal care in the UK, the Renal Association, states unequivocally that failure to provide thrice weekly dialysis for patients with a clinical need for it, on financial grounds alone, is totally unacceptable.

There may, of course, be reasons other than lack of capacity that prevent such frequency of treatment being available at any given time; for example, relating to staff recruitment, retention and absence levels.

Forecasting future treatment demand can never be an exact science. However, the modelling tool used in the region in recent years has proved to be remarkably accurate.

It is anticipated nationally that numbers of patients requiring all forms of renal replacement therapy will continue to grow for the foreseeable future, with the greatest demand coming in the hospital based haemodialysis sector, (forecast to rise by up to 8% per annum).

Not all patients are suitable for alternative forms of treatment, (home haemodialysis, peritoneal dialysis and transplantation). Even if the numbers of patients on such therapies were to increase significantly, there would be a proportionate increase over time in the number of them needing hospital based haemodialysis because of their transplants failing, home patients becoming too old or frail to dialyse themselves, or being in need of 'respite care' 'should their home carers become unwell.

On current evidence from elsewhere, there is a timescale of anything up to 2 years between the need for additional facilities being identified and the actual opening of the new unit.

In certain circumstances, there could be a need to bring what is currently deemed as 'spare' capacity into use quickly.

Examples might include the need to transfer patients from an existing unit in the event of a serious incident, (e.g. water treatment plant failure or major fire), or, should a 'flu pandemic arise, there being a need to accept patients for treatment in Leeds from the wider region owing to staff absences at units where patients would dialyse usually, (although I accept this could apply equally in respect of the effect on units in Leeds).

Finally, and importantly, there is much evidence now to suggest that patient outcomes, both clinically and in terms of overall quality of life, are enhanced by more frequent and longer hours sessions of dialysis. Inevitably, this improvement in patient care will have implications for the number of hospital based dialysis facilities required.

Conclusion

On the basis of the above, it is my view that there is a need for both the new LGI unit and the replacement water treatment plant at the St. James's site to be priorities for capital investment by the Trust board.

Dennis Crane, MBE, North Region Advocacy Officer, National Kidney Federation.

20 July 2009

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.