

From Ann Keen MP
Parliamentary Under Secretary of State



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31 MAR 2010

Dear John,

Thank you for your letter of 11 February to Mike O'Brien on behalf of your constituent Mr Paul Brazier of 35 Grosvenor Road, Doncaster DN11 8EY about dialysis and transplants. I apologise for the delay in replying.

In April 2008, the Department of Health established a new team, NHS Kidney Care, to support frontline staff in delivering care that meets the standards set out in the *National Service Framework (NSF) for Renal Services*. NHS Kidney Care has been working closely with specialised commissioning groups to review dialysis capacity. This included ensuring that expansion plans are based on sound assessment of local need and comprise a balanced portfolio of treatment options, including options for care at home. To help with planning dialysis provision, the Department has developed a tool to predict the cost and volume of renal replacement therapy (RRT) (dialysis or transplantation) at both a national and a local level, over a ten-year time period.

The NSF covers the whole patient pathway from the identification of risk to end-of-life care. It was published in two parts in 2004 and 2005. Part One, published in January 2004, sets five standards and identifies 30 markers of good practice in the areas of dialysis and transplantation, aimed at improving fairness of access, patient choice about the type of treatment they receive and reduced variation in the quality of dialysis and kidney transplant services.

We are also revising the content of the NHS Choices website to improve the availability of information for patients, including through the Department of Health's Information Prescriptions initiative.

The introduction of eGFR (estimated glomerular filtration rate) in April 2006 as the standard measure of kidney function has meant that chronic kidney disease (CKD) is being identified earlier within the primary care system and in many cases enabling preventative work to take place to slow down progression of the disease. In addition, inclusion of CKD since April 2006 in the Quality and Outcomes Framework has helped raise the profile of kidney disease in primary care, enabling earlier interventions.

In January 2008, the Prime Minister announced the Government's intention to shift the focus of the NHS in England towards empowering patients and preventing illness. As part of this, he set out his ambitions to dramatically extend the availability of 'predict and prevent' checks to give people information about their health, support lifestyle changes and, in some cases, offer earlier interventions. The NHS Health Check programme is a universal and systematic programme for everyone between the ages of 40-74 that will assess people's risk of heart disease, stroke, kidney disease and diabetes and will support people to reduce or manage that risk through individually tailored advice. The Health Check programme is designed to target common modifiable risk factors for vascular disease (such as high blood pressure and smoking status). All four diseases share the same risk factors, and having one vascular condition increases the likelihood of suffering from others.

Part One of the NSF includes a marker of good practice that identifies pre-emptive transplantation and specifically asks that patients be placed on the national transplant list, if clinically appropriate, within the six months before they need to go on dialysis. Information provided by UK Transplant – part of NHS Blood and Transplant – indicates that between 10 and 40 per cent of each transplant centre's list is made up of pre-emptive patients, a good indication that all centres are giving access to transplant to such patients. In 2008/09, 17 per cent of adult transplants and 25 per cent of all paediatric transplants were carried out in pre-dialysis patients.

Part One of the NSF (Standard 3) aims to improve the outcomes of permanent vascular or peritoneal dialysis access surgery, minimise complications and maximise the longevity of the access, and requires that all patients with established renal failure have timely and appropriate surgery. Current best practice suggests that permanent vascular access should be established six months before dialysis (and peritoneal access four weeks before starting peritoneal dialysis). We are also looking into the development of a 'best practice tariff' for dialysis, under Payment by Results (PbR), which should encourage timely permanent vascular access and improve patient care, including reducing the infection rate, which is high with temporary lines.

The NSF identified the need for an agreed care plan that supports people in managing their condition. NHS Kidney Care, which was set up in 2008 to help the NHS implement the Renal NSF, has developed a template for care plans for people with kidney failure being looked after by specialist teams to ensure that effective care planning is in place in all 52 kidney care units across England by the end of this year.

The UK Renal Registry was established by the Renal Association with support from the Department of Health, the British Association of Paediatric Nephrologists and the British Transplant Society as a resource for the development of patient care. The Registry provides independent, professionally led audit and analysis of RRT in the UK and is funded directly by participating renal centres through an annual capitation fee. The Registry receives quarterly electronic data extracts from information systems used for clinical and administrative purposes within each renal centre. Once submitted, the data undergo an extensive period of validation before analysis is

carried out and published. The report on the 2008 data, the latest published data, covers every renal centre in the UK. The Renal Registry data are used throughout the NHS to plan and audit dialysis services and by the Department of Health.

As well as measures to encourage increased dialysis capacity, the Department set up a working group specifically to look at ways of improving patients' experience of dialysis away from their home units (dialysis away from base, or DAFB). This group has reported to the Department and an action plan has been produced in consultation with specialised commissioners. The Department has also set up a group to clarify isolation protocols for blood-borne viruses and worked to ensure adequate DAFB provision is made for peritoneal dialysis patients in the negotiation of new contracts. In addition, movement towards a tariff for dialysis under the PbR initiative may provide better national consistency in pricing arrangements and reimbursements for DAFB.

We have recently consulted on fairer NHS parking charges. Details can be found on the Department of Health website at www.dh.gov.uk.

We have no plans to change the status of dialysis services from their current status as specialised services.

There is growing evidence that dialysis at home has benefits for kidney patients. It can improve blood pressure control, reduce medication and enable patients to live a more normal life. We want to see this increasingly offered as a realistic choice for dialysis patients when considering how and where they wish to receive their treatment. The package of measures that the Secretary of State, Andy Burnham, announced on 18 February will help services to be more innovative, deliver better quality for patients, control costs, and give patients more choice and control over how they manage their condition. The Department of Health and NHS Kidney Care will be working closely with the NHS to improve the provision of home therapies, including home haemodialysis in line with NICE recommendations.

The measures include the following, available via the NHS Kidney Care website (www.kidneycare.nhs.uk):

- information for patients and carers including dialysis patients' stories, videos showing what to expect, and on the benefits of dialysing at home;
- a report, *Improving Choice for Kidney Patients: Home Dialysis*, identifying the key barriers with potential solutions and examples of 'what works'; and
- a 'toolkit' for commissioners and providers including access to model business cases.

The National Clinical Director for Kidney Care, Dr Donal O'Donoghue, will lead workshops in each region to begin to change the culture needed to make the shift from hospital to home dialysis.

A dedicated section has been created on the NHS Evidence website containing a comprehensive list of papers and articles on home dialysis.

The Centre for Evidence-Based Purchasing will, by the end of March, publish a service provision guide giving information about how to set up a home haemodialysis service, and a market review comparing products available to the UK market to assist patients and carers in the selection of the most appropriate home haemodialysis machines.

In addition, the National Institute for Health and Clinical Excellence will work during 2010/11 on producing a guideline on peritoneal dialysis.

You also ask for a progress report in respect of increasing transplantation rates. As you will be aware, organ transplantation is one of medicine's great success stories, transforming thousands of lives each year. You will also know that despite being a pioneer of transplantation, the UK has one of the lowest organ donor rates in Western Europe and, tragically, hundreds of people die each year in the UK because the organs they require are not available.

It was for this reason that we established the Organ Donation Taskforce in 2006 to identify the barriers to donation in the UK and to make recommendations on the action to be taken. Its report, *Organs for Transplant*, with 14 specific recommendations, was published in January 2008. The Taskforce was greatly encouraged by the evidence it considered from across the world, particularly from Spain, and the success achieved in other countries to turn around poor donor rates by investment in the donation infrastructure. The Taskforce therefore believed that at least a 50 per cent increase in organ donation was both a possible and an achievable outcome in the UK within five years.

The Government is committed to implementing the Taskforce recommendations and realising (and hopefully exceeding) its aspiration. Additional funding amounting to £16.4million for 2008/09 and £26.4million for 2009/10 has been agreed, with by far the greatest part of this funding allocated directly to the NHS to enable local implementation.

I am encouraged by the progress made. Since the publication of the Taskforce report, we have significantly strengthened the donation infrastructure with the aim of increasing organ donation by at least 50 per cent by 2013. 2008/09 saw a record 11 per cent increase in donation over the baseline year of 2007/08, and donor rates continue to rise.

You may be interested in some of the key achievements so far:

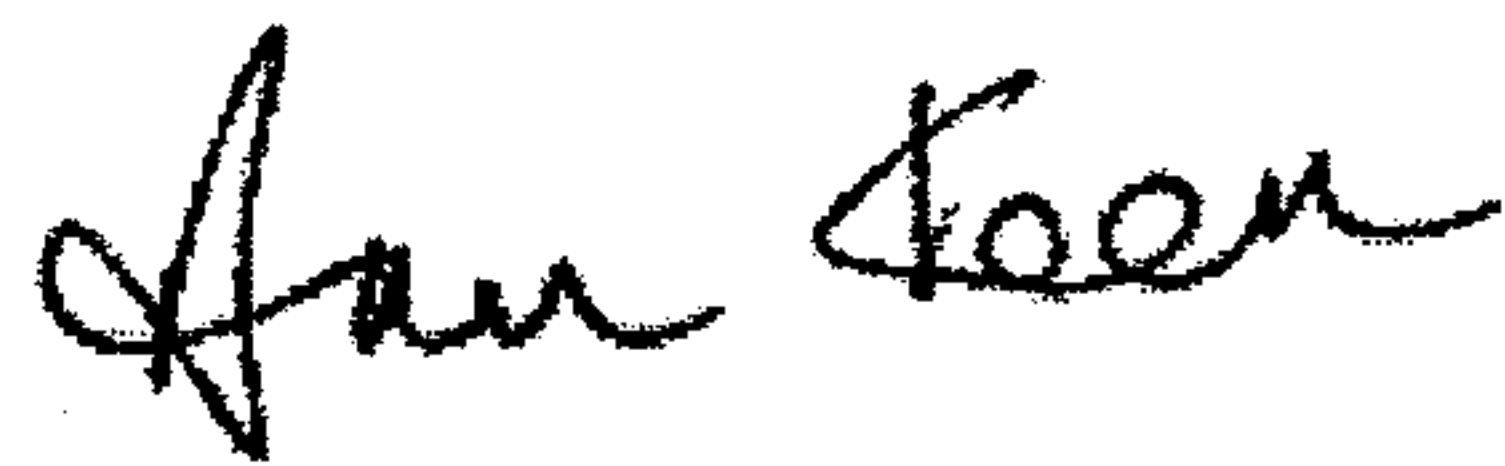
- Chris Rudge has been appointed as the first ever National Clinical Director for Transplantation and is responsible for leading the work to implement the Taskforce's recommendations;
- an independent UK-wide Donation Ethics Committee has been established within the Academy of Medical Royal Colleges to help resolve outstanding ethical issues such as those around non-heart-beating donation (NHBD);
- a series of successful roadshows around the UK has helped establish the implementation programme in each region, identify issues and drive the programme at a local level;
- the establishment of a research consortium has helped identify and address gaps in knowledge;
- engaging with the public and other stakeholders has helped to identify the best methods of personally and publicly recognising the gift of organ donation;
- last November we published guidelines for NHBD to help more hospitals develop NHBD programmes and increase donor rates. This year has seen NHBD rates continue to rise; and
- we have commissioned a range of work to engage with national and local faith and community leaders to encourage greater donation from all faith groups.

Leadership within frontline NHS services was also identified as a major driver to make organ donation a usual part of healthcare and increase donor rates. The Department has therefore provided funding to support:

- a doubling of donor transplant coordinators – 135 out of 266 hospitals now have a functioning embedded donor transplant coordinator with appointments to be made in all Acute Trusts by June this year;
- the appointment of clinical leads in acute hospitals – 166 out of 194 such leads are now appointed;
- the establishment of Trust donation committees and non-clinical donation champions – 90 out of 180 non-clinical donation champions have been appointed and 95 donation committees are up and running, with the remaining ones due to be appointed by June 2010;
- the dissemination of donation data – now shared six-monthly with all Trusts nationally so that everyone involved in organ donation is able to see the results of their actions and opportunities for improvement;
- a strengthened framework for a coordinated UK-wide system of organ retrieval;
- reimbursement of Trusts for donation activity; and
- a major national media campaign between last November and this March coordinated by NHS Blood and Transplant, with planned roadshows in 20 locations around England, Wales and Northern Ireland and TV advertising during February and March.

I appreciate that there is still a long way to go if we are to bring the UK donor rates in line with the rest of Europe. Much of our work relies on cultural changes in the UK and the NHS and these inevitably take time to have an effect. We must also ensure that transplant units have the capacity to undertake the predicted rise in transplantation, and Chris Rudge is overseeing this as a separate piece of work. However, I believe that we have made a very positive start and I remain committed to increasing the organ donor rates so that many more people can have their lives saved or transformed by the miracle of organ donation.

I hope this reply is helpful.

A handwritten signature in black ink, appearing to read "Ann Keen". The signature is written in a cursive, flowing style.

ANN KEEN

Approved by the Minister and signed electronically in her absence.