



Welcome to the Christmas Edition of the Kidney Health NZ Newsletter, as I write this the sun is shining and the blossom is quite stunning, this has to be my favourite time of the year, especially after a particularly wet winter.

The past four months have been busy including our annual Senior Renal Nurses Conference held in Auckland in September. This conference is held specifically for nurses working within hospitals and satellite dialysis units throughout the country to provide an opportunity for networking and sharing ideas and initiatives around care of the renal patient. The senior renal nursing group meet prior to the conference and report back during the day about the progress they have made in the area of education for nurses and attracting and retaining nursing staff in renal medicine.

This year it was great to hear of the new roles being developed for renal nurses, and the impact this will have on workloads, but in particular the care of renal patients. Such roles as Anaemia Management Coordinator and Chronic Kidney Disease Coordinators are being introduced to ensure renal patients are receiving adequate follow up and education. We are looking forward to hearing about the progress of these roles next year. There is an increasing push to involve primary care more with education sessions for Practice Nurses being encouraged.

The subject of Holiday Dialysis was discussed at length, with many of the units frustrated they are unable to accommodate patients from other parts of the country when they want to have a holiday; this is due to the lack of resources. It was decided one way to manage this current problem is to look at a Patient Exchange Programme. For example; A Christchurch patient looking at going to Auckland for a holiday could swap their dialysis space with an Auckland patient. The dialysis units would liaise with each other to try and accommodate the patients as close to the dates they need as possible. Merete Hipp from the Rotorua Unit has offered to work on this idea.

Professor John Collins talked about the DEFEND study and managing Chronic Kidney Disease in Primary Health Care. The DEFEND study is a study into the management of Chronic Kidney Disease, with a particular focus on blood pressure control. He outlined plans to work with a PHO based in Auckland with a high number of Pacific patients, managing those patients with Chronic Kidney Disease and looking at ways to manage their Kidney Disease. Chrissy and Sandy, both recently appointed as Chronic Kidney

Disease Coordinators will work closely with the patients from the PHO. We look forward to hearing about the project at the next conference.

Yvonne from the National Heart Foundation spoke about the impact Kidney Disease has on the heart and the need to maintain a healthy lifestyle to reduce the risk of heart disease. It was good to know the Heart Foundation and Kidney Health NZ are both singing from the same song book.

Sanja Mirkov, a pharmacist at Middlemore Hospital spoke about medication in kidney disease, with a focus on antihypertensives and the management of the patient with Chronic Kidney Disease.

Tafale and Toa, both Samoan nurses working here in New Zealand, gave a very interesting overview of their time helping out in the reasonably new Haemodialysis Unit in Samoa, following their talk they had several nurses offering their services in Samoa for a week or two!!!

Once again the social side of the conference proved to be a fun night out, with plenty of networking!

Organ Donation

Recently I have been speaking to Year 11 and 12 students (15 – 16 yr olds) from secondary schools in South Canterbury about Organ Donation. This was a prelude to the Organ Donation Forum held in Timaru on October 30th. It was interesting to hear the students' thoughts around organ donation and the knowledge they had regarding this subject.

The Forum in Timaru was well attended with approximately 150 members of the general public attending. It was opened by the local MP Jo Goodhew who talked about the discussion she had with her family that evening around the dinner table about organ donation. Speakers included two families who had donated their family members organs/tissues. These were very emotive presentations from three very brave people. Following these speakers were two recipients of organ donation, one gentleman talked about his experience following a corneal transplant which restored his sight in one eye, while another young man talked about the life changing lung transplant he received 18 months ago which rid him of cystic fibrosis: his wife and children watched on as he described his renewed zest for life and his thoughts for the donor family, whom he does not know but to whom is eternally grateful. Louise Moffat from the Eye Bank in Auckland spoke about her role as coordinator for corneal donations throughout New Zealand. Professor Richard Robson talked about the reasons for organ donation and the growing numbers needing a kidney transplant. Sylvie, an Intensive Care Nurse spoke about Brain Death and how this was determined by a range of tests completed by two specialist doctors separately two hours apart, and the role of the Organ Donor Coordinator in the process of donating organs. I gave a brief overview of Live Kidney Donation in New

Zealand, including the cost of dialysis treatment versus the cost of a kidney transplant. Our Medical Director Kelvin Lynn summed up at the end reiterating the message to discuss your wishes with your family.

Kidney Health Week – 9th – 15th March 2009 and World Kidney Day 12th March.

Plans are already well under way for this week, which incorporates National Just Water week focusing on encouraging water as the drink of choice in the fight against obesity, one of the biggest risk factors in Diabetes. World Kidney Day is on Thursday 12th March, with Lion Nathan coming on board to have their staff screened for signs of Kidney Disease. There are several other activities planned for the week around the country to raise awareness of Kidney Disease. Again the theme for the day is Kidney Disease is common, harmful and treatable, but with a particular focus on Blood Pressure and Kidney Disease with the catch phrase “Keep the Pressure Down” The 2009 campaign highlights the importance of high blood pressure as one of the key symptoms and causes of Chronic Kidney Disease.



Prevention and delay of kidney disease (from the WKD website)

- **FACT:** Screening must be high priority in subjects considered to be at high risk of kidney disease, namely:
 - Patients with diabetes mellitus or hypertension.
 - People who are obese or smoke.
 - People over 50 years of age.
 - People with a family history diabetes mellitus, hypertension and kidney disease.
 - Maori and Pacific people

- **FACT:** Current kidney protective treatments should now be extended to those with early stages of renal failure.

- **FACT:** Key preventative measures have been defined and proven successful in protecting against both kidney and cardiovascular disease, such as:

- ACEs/ARBs for proteinuria and decreased GFR.
- Reduction of high blood pressure -the lower the blood pressure, the lower the GFR decline.
- Control of glucose, blood lipids and anaemia.
- Smoking cessation.
- Increased physical activity.
- Control of body weight.

With the simple testing of Blood Pressure and a simple Urine Test we can detect signs of Kidney Disease, and with more effective treatment available we can slow down the progression of kidney disease.

Once again we hope to head to Parliament to screen the new MPs.

Recently I was asked to speak to the Christchurch Kidney Society monthly interest group about Fatigue, hopefully it might be of interest and I have included it below.

Fatigue in Kidney Failure.

Fatigue: *Mental or Physical tiredness, following prolonged or intense activity*

Persistent fatigue can be one of the most debilitating symptoms of chronic kidney disease. Yet fatigue often goes unreported and untreated, especially in (stage 3 – 4) patients who have not yet begun dialysis.

As a result, as many as 2/3rds of CKD patients reach end stage renal disease in a weakened state, and are at increased risk of serious complications.

The experience of fatigue can, and does have a dramatic effect on the lives of CKD patients. For example it is not uncommon for patients to give up their jobs due to fatigue, before they even start dialysis. Of course with this it may result in lifelong economic hardship as patients struggle to find a job that provides flexibility and an understanding boss!!

Fatigue can also play a major role in reducing the patient's quality of life, this can include the decreased ability to exercise and participate in social activities.

Fatigue can come on slowly and you might not know it is a symptom worth telling your doctor about

Many patients are reluctant to tell their health professionals about their fatigue – even if it is severe – for fear of being considered unmotivated or weak.

What causes fatigue?

Fatigue in CKD is most often caused by anaemia – a shortage of oxygen-carrying red blood cells. Anaemia begins early in kidney disease, and tends to get worse as the kidneys lose function and produce less erythropoietin (EPO).

Other symptoms of anaemia can include:

- Feeling cold all the time
- Shortness of breath
- Pale skin, gums and fingernail beds
- Trouble concentrating
- Dizziness/light-headedness
- Headaches

Anaemia and fatigue can and should be treated early to help you feel better and to prevent heart problems later on.

The most important reason to report your symptoms and get early treatment is that anaemia can cause heart damage called Left Ventricular Hypertrophy. (This is when the heart muscle grows too big, trying to get more oxygen through your body)

Fatigue is one of the most common, but often least reported, symptoms of early chronic kidney disease.

Managing Fatigue

Research shows that if you start dialysis you will do much better if your fatigue and anaemia are under control

Regular assessment, attention to reversible factors, and multidisciplinary approaches to fatigue are essential.

Reporting and managing fatigue and other symptoms will help you maintain your health and lifestyle.

Early Treatment of fatigue can help you to keep doing the things you did before you had kidney disease. Staying active and involved are key to living long and well with any chronic health problem.

Anaemia can be treated. Your nephrologist (kidney doctor) may prescribe EPO to help your body make red blood cells. This treatment will help give you more energy, a better appetite, and greater stamina. You may also be prescribed iron supplements if your iron levels are too low.

Each person's energy levels and sleep needs will vary, but it is important to keep you life as active and normal as you can.

Some people find it helps to sleep later; you may need more sleep, so start your day a bit later.

With changing energy levels take it easy and sleep more when you feel you need to, but keep up some form of exercise. Staying active is key to good health, it is easy to get into the habit of not doing anything.

Walking, if you are able, is a easy way to stay active, it doesn't have to be far, but you can also let yourself sit down and put your feet up if you need to.

Pay attention to how your feeling and don't ignore it, even if you think it could be nothing, report your symptoms. You need to be involved in your care and learn as much as you can about yourself and your disease. As you learn more and talk to others with kidney disease it doesn't seem so scary.

Fatigue among Caregivers

In End Stage Renal Failure often the family is expected to perform at least some supportive functions.

The burden and fatigue experienced by caregivers of these people are often overlooked and have not been well addressed, yet the physical and Psychological status for this group can be important in the recovery or adaptation of patients with chronic renal failure, not to mention the caregivers themselves.

In this era of scarce resources the expectations of the caregiver are increasing, the limited research that has been done in this area suggests that help for this group could be should focus more on rest and respite as opposed for the need for psychological support or counselling.

As health professionals we need to be more aware of the increasing burden that is placed on the caregiver and to encourage them to seek help when they need it.

From The Medical Director

New techniques in kidney transplantation.

The first successful kidney transplant was carried out between identical twins in Boston in 1954. In New Zealand, kidney transplantation began in Auckland in 1965. Kidneys from deceased and living donors were used form the start. The initial deceased donors were usually young and the unfortunate victims of motor vehicle accidents. The living donors were close family members related by blood. The increasing demand for donor kidneys

has resulted in changes in both the type of donors now accepted and the types of transplant procedures that are possible.

Deceased donor kidney transplantation

The first deceased donor kidneys were removed after the cessation of the donor's heart beat but with improved understanding of the concept of brain death there was a change to removal of organs from donors whose hearts were still beating. This resulted in an improvement in the initial function of the kidney after transplantation and a reduction in the need for postoperative dialysis. The reduction in the number of road traffic fatalities has meant that the criteria for the acceptance of donors have been widened to include what has been termed "extended criteria" donors. These donors are older and are more likely to have died from a brain hemorrhage than the younger donors of earlier times. Organ Donation New Zealand is currently developing protocols for accepting organs from non-heart beating donors again and other countries have been able to set up systems to allow for the identification of potential organ donors who have not been admitted to an Intensive Care Unit.

Living donor transplantation

It was considered that the donation of an organ from a donor who was not a blood relative would result in high rates of rejection because of poor tissue matching. Surprisingly, experience in the US in the 1980s showed that spousal donation results in better success than deceased donor transplants, despite poorer tissue matching. This has led to the acceptance of living unrelated kidney donation in New Zealand and recently the acceptance of altruistic, non-directed kidney donation from a stranger to a patient on the deceased donor transplant waiting list. Christchurch Hospital has carried out 10 such transplants since 1998 with excellent results.

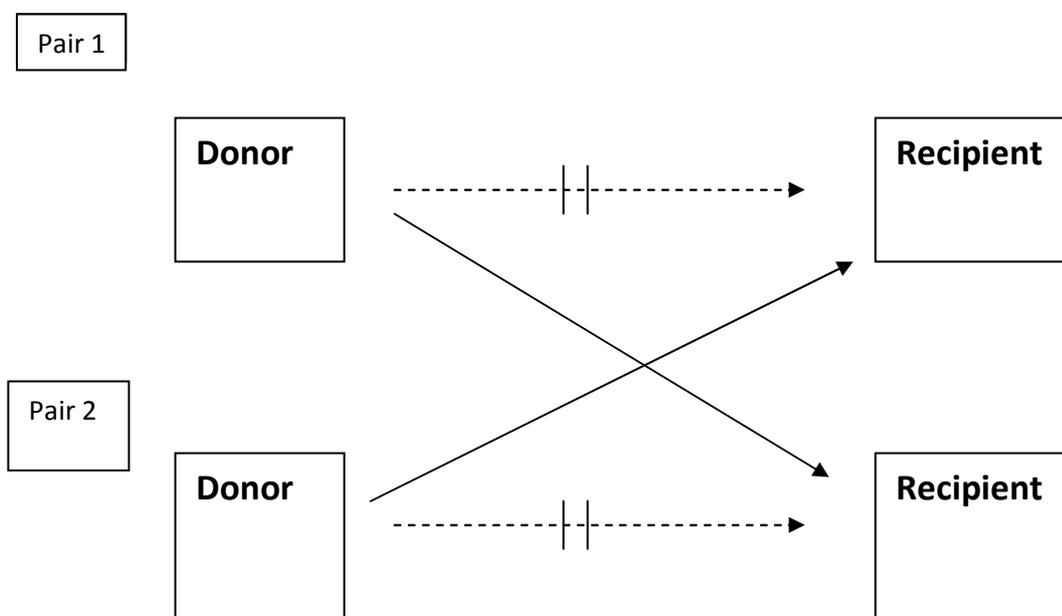
The advent of laparoscopic surgical techniques now makes laparoscopic nephrectomy (kidney removal) a possibility for the majority of kidney donors. This surgical technique is less painful than open nephrectomy and the donor recovers more quickly. Nearly half of the kidney transplants in New Zealand are from a live donor.

What can be done when a person with kidney failure has a donor but he/she has the wrong blood group or the potential recipient has tissue antibodies that result in a positive cross match test?

Successful organ transplantation requires that the donor and the recipient be blood group (ABO) compatible and that the tissue cross match test is negative. If a transplant is carried out when there is ABO incompatibility or a positive tissue cross match the transplant is almost always rejected soon after surgery.

Japanese transplant teams have had considerable experience in carrying out ABO incompatible transplants with good long term success. There are now desensitisation treatment protocols to remove harmful tissue antibodies and enable the cross match test to be negative thus allowing a transplant to go ahead successfully. These operations require the recipient to have pre-transplant treatment to remove the injurious ABO antibodies and then have additional treatment after transplantation to either remove more antibodies or suppress their formation with drugs. The first New Zealand ABO incompatible transplant was carried out in Auckland earlier this year and others are planned. Similar techniques can be used when the tissue cross match test is positive but there is not so much information on the long term results.

If the idea of extra procedures and drug treatment is not acceptable the other option is paired exchange kidney donation as shown in the diagram.



This diagram shows two potential donor recipient pairs who cannot donate to each other but can donate to another pair. In a “conventional” paired exchange the barrier to transplantation is ABO incompatibility and in an “unconventional” exchange a positive tissue cross match test.

These procedures are being carried out in many parts of the world. The Dutch, with seven transplant centres, have the most experience having carried out 143 paired transplants for ABO incompatibility and 133 for a positive cross match. They have an independent computer-supported allocation system and aim to maintain anonymity for the pairs. The operations to remove the donor kidneys are carried out at exactly the same time and usually the donor kidney is transported to the recipient’s hospital. Approximately 40% of incompatible donor-recipient pairs can be found a match in the Netherlands. Theoretically

the number of pairs in an exchange is infinite if the pool is large enough but the logistics of organising more than a single paired exchange are formidable. Concerns have been raised about blood group 0 recipients being disadvantaged by “conventional” paired exchanges as these only involve blood group A and B recipients. Paired exchange transplants are not currently available in New Zealand but they are being done in Australia.

If you want to know more about these new types of transplant operations please contact your local nephrologist or transplant co-ordinator.

For those who want to more read about paired exchanges there is an excellent article by

Mahendran and Veitch. British Journal of Surgery 2007; 94: 657-64 which can be found at www.bjs.co.uk

As at January 31st 2008 there were 606 people on the Waiting List for an Organ Transplant, of these 559 were waiting for a kidney, 31 people were waiting for a liver, 6 were waiting for a heart, 5 for a lung and 5 for a kidney /pancreas transplant.

There were 38 deceased donors in 2007 and 58 living kidney donors.

For further information on Organ Donation call 0800 4DONOR or www.donor.co.nz



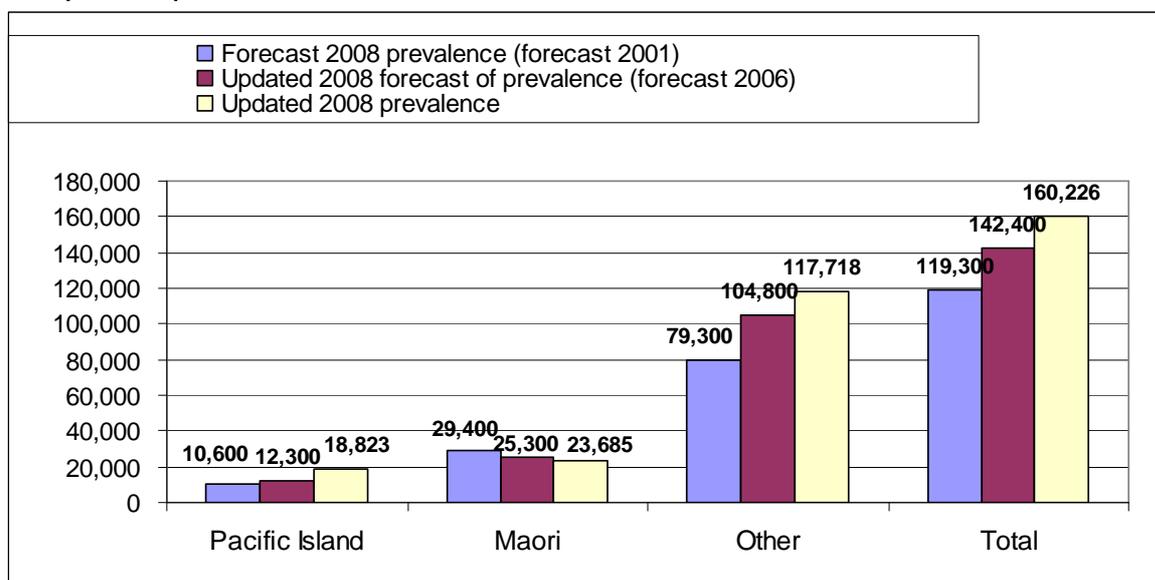
Make a decision

Diabetes and Kidney Disease

The recently released report commissioned by Diabetes New Zealand makes sobering reading.

(see at www.diabetes.org.nz/news/nz_news/2008_type_2_update_report)

The report provides a calculation of the cost of diabetes to the New Zealand community. These costs are derived from the Ministry of Health figures estimating that there are 160,000 people in New Zealand with Type 2 diabetes. Worryingly this figure is much higher than the prediction made in 2001 of the likely 2008 prevalence.



Source: Ministry of Health 2001-2021 Prevalence Projections and Ministry of Health 2006 and 2008 Updated Prevalence Projections.

The Ministry of Health's Diabetes and Cardiovascular disease Quality Improvement Plan (QIP) aims to gradually improve, amongst other things, the services available for people with diabetes. The Diabetes New Zealand report estimates that optimal services for people with diabetes if implemented now would cost \$650 million and \$1,520 million by 2020. The report suggests that if there was an immediate increase in funding of \$60 million for prevention, self management and early detection now, instead of more gradual phased in as proposed, there would be a saving of \$260 million by 2022.

Why should this report be of interest to people concerned about kidney health?

Diabetic kidney disease is responsible for about 45% of the new cases of kidney failure requiring dialysis treatment in New Zealand. People with diabetes and

kidney disease have a very high risk of heart attacks, strokes and amputation of limbs because of blood vessel disease. Diabetic kidney disease places a huge burden on the patient, their family and whanau and the health system. Conservative estimates of the cost of this treatment are about \$36 million annually.

We know who is at most risk of getting kidney failure with diabetes and we know how to detect and treat early kidney disease.

Those most at risk of getting kidney disease are:

- People who have had diabetes for a long period of time (more than ten years)
- Maori and Pacific Island people
- People who smoke cigarettes
- People who have high blood pressure

Early kidney disease can be detected by a simple urine test to check for increased amounts of protein, a simple blood test to estimate kidney function and a blood pressure check. These checks should be done annually by your family doctor as part of a comprehensive diabetes check.

What can be done if you have diabetes and are found to have a sign of kidney disease?

Early treatment with blood pressure lowering drugs called ACE inhibitors can either delay or slow the progression of kidney disease. Excellent control of blood glucose concentrations reduces the risk or slows the progression of both small and large blood vessel complications of diabetes.

Kidney Health New Zealand supports Diabetes New Zealand's call for more investment in the early detection and treatment of diabetes with the aim of preventing important complications, including kidney disease.

Kelvin Lynn

Medical Director

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