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Hard to believe we are already into 2018, and what a summer it has been so far, with record temperatures in some parts of the country and record rainfall in other parts! We have all returned to the office rested and preparing for a busy year ahead. The Consumer Council meet at the end of February to help the Board with their Strategic Planning, there will be an update of this in the next newsletter.

World Kidney Day falls on Thursday March 8th; this year's theme is Kidneys and Women's Health, we are taking a different approach this year so keep an eye out! As part of the day we will focus on Chronic Kidney Disease, risk factors and how to look after your kidneys.



KHNZ chief executive Max Reid speaking at the Ministry of Health's launch of the new compensation regime for live organ donors

From the CEO

Welcome to 2018! Already it promises to be a full and interesting one for Kidney Health New Zealand – and it's great to have your support as we venture into it.

A new Year. A new Government. A new Minister of Health. And, for Kidney Health New Zealand, the development of a new Strategic Plan.

Our current Strategic Plan was signed off by the KHNZ Board in late 2014, and has guided our work for the past three years. Only intended to last that long – so much change in health in such a short time – the Board reviewed the organisation's progress against the plan at its AGM in November, and was pleased with how much had been

achieved in that three years. Now, as we enter 2018, we have the opportunity to look at a further three years. What work is still left to be done? What new priorities can we identify? What has changed in terms of kidney health in New Zealand, and what can this organisation do to address that?

A number of our priorities are contained in a briefing document currently being drafted for the new Minister of Health, the Hon. Dr David Clark. These include:

1. Ensuring the full implementation of the Deceased Organ Donation Strategy – including appropriate input from the kidney health sector – in order to both co-ordinate and actively promote deceased organ donation.



2. Ensuring timely, equitable and nationally consistent delivery of dialysis treatment. This includes:
 - a. Identifying the causes of and addressing the significant disparities in access to appropriate RRT treatment amongst Māori and Pacific patients, and younger patients.
 - b. Improving rates of Home Dialysis and ensuring adequate support for home dialysis patients.
 - c. Increasing permanent vascular access rates for haemodialysis patients.
3. Ensuring ongoing oversight, support and evaluation of the Ministry of Health's CKD in primary health initiative, launched in early 2015.

We will continue to work closely with the Ministry of Health on various projects – including, as mentioned in the last newsletter, the development of a suite of indicators that will enable the Ministry to measure appropriate outcomes for patients across the spectrum of Chronic Kidney Disease. I have also agreed to meet with Ministry staff on a quarterly basis to discuss progress against the various projects they are involved with in the area of Kidney Health.

Our Consumer Council will again meet in Wellington in late February. That meeting, too, will have the opportunity to help shape the next Strategic Plan, ensuring that the priorities they identify as consumers of Kidney Health services guide our own priorities and health advocacy.

Another major opportunity that KHNZ has been made aware of is the intention of the NZ Transport Authority's intention to review the current driver licensing system with a view to making new driver licensing and licence renewal available online. Should such an online option become available, it would potentially make registering your intent to be an organ donor – and accessing the information required to guide such a decision – so much easier than is currently the case.

The other major change on the horizon – again as briefly mentioned in the last newsletter – is the KHNZ Board's adoption of a comprehensive fundraising strategy. As a result, we are currently in the process of appointing a part-time Fundraising Coordinator, whose responsibility it will be to oversee the implementation of that strategy. At the moment, the work that KHNZ undertakes is only limited by the income we receive. If we are able to increase our sustainable income by various fundraising activities – trust and grant applications, growing our donor database, corporate sponsorship, etc. – there is so much more we could be doing to support kidney patients and their families. Watch this space!

Warm regards,

Max Reid

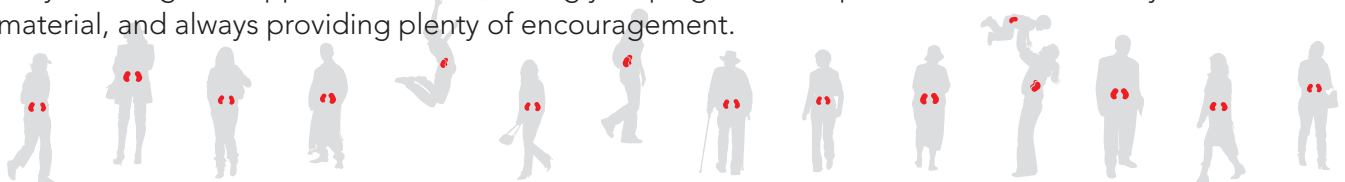
Remembering Dr Tonya Kara

Recently we all sadly lost a true friend, colleague and amazing person with the death of Dr Tonya Kara. She passed away peacefully in the company of her sister and friends on Monday evening 22 January 2018 after a diagnosis of cancer just a few short months ago.

Tonya was a highly respected Paediatric Nephrologist at the Starship Childrens' Hospital in Auckland. She absolutely loved all those she cared for and her patients and their families are devastated with this loss. She was also an excellent teacher and friend to all those who had the privilege to work with her. She was a highly productive member of the paediatric nephrology community, the New Zealand Nephrology Group and ANZSN working on many committees advocating for better patient care and outcomes. She will be sorely missed by many.

Tonya was adamant that she not be referred to as brave but she certainly faced her illness with strength, stoicism, grace and dignity.

Tonya was a great supporter of KHNZ, willingly helping to develop resources and a variety of educational material, and always providing plenty of encouragement.





Every year World Kidney Day acts as a rally cry for Kidney teams around the globe to stand together with the patients we care for in attempt to raise awareness of Kidney Disease in the communities we serve.

Unlike other major diseases such as Heart Disease, Cancer and Diabetes, which have high profiles both in the media and the hearts and minds of many people, Kidney Disease is often a condition that rarely features in the media and most people have little insight into how common it is and just how serious a condition it is. World Kidney Day provides a wonderful opportunity to raise awareness in New Zealand about how important Kidney Disease is to our communities.

Worldwide it is estimated that 1 in 10 people have Chronic Kidney Disease, chronic means a form of Kidney Disease that is permanent or lifelong. That equates to over 400,000 people in New Zealand.

Kidney Disease is often described as the “silent” killer. The reason for this is that until Kidney Disease is very advanced there are almost no symptoms. It is therefore not uncommon that the first time an individual is aware they have a kidney problem is when they have had a blood test and it is an incidental finding. Individuals kidney function can fall from 100% to less than 30% with no symptoms and sometimes as low as 15% before symptoms start.

The tragedy currently surrounding Kidney Disease in New Zealand is that over 50% of severe cases are secondary to preventable causes which if picked up early and managed well the kidney outcomes could be greatly improved.

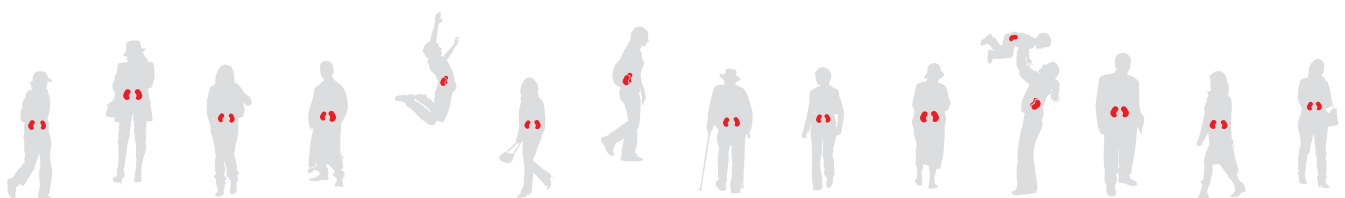
Therefore, in 2018, Kidney Health New Zealand will continue our work to raise the profile of Kidney Disease both to communities here in New Zealand, the primary care teams who care for them, the specialist teams at the District Health Boards and the Ministry of Health itself. Our focus and challenge to all of these groups is that as Health Care communities in New Zealand we need to focus on “doing the simple things well” to prevent preventable Kidney Disease.

Our challenge to health care teams is that they have systematic approaches to ensuring:

- Screening for early Kidney Disease occurs in targeted populations
- Recall and management of patients with Kidney Disease is systematically co-ordinated at a practice level and is not left to individuals to remember
- Timely referral to specialist services occurs in a systematic manner
- Patients receive the same care whichever part of New Zealand they live in

In 2017 we started discussions with the Ministry of Health about introducing mechanisms to monitor the performance of Health Care Teams, as they look after patients at risk of or diagnosed with Kidney Disease. In 2018 we will continue to work with the Ministry to maintain some momentum in this area.

Unfortunately when the “simple things” are not done well then individuals with preventable Kidney Disease progress to severe Kidney Disease and this is associated with a greatly reduced life span and quality of life. It has been well described that individuals with advanced Kidney Disease have worse outcomes than nearly all cancers.



Chronic Kidney Disease in New Zealand



What is Chronic Kidney Disease (CKD)?

CKD is a progressive loss in kidney function over a period of months or years. Each of your kidneys has about a million tiny filters, called nephrons. If nephrons are damaged, they stop working. For a while, healthy nephrons can take on the extra work. But if the damage continues, more and more nephrons shut down. After a certain point, the nephrons that are left cannot filter your blood well enough to keep you healthy.

When kidney function falls below a certain point, it is called kidney failure. Kidney failure affects your whole body, and can make you feel very ill. Untreated kidney failure can be life-threatening.

The number of people in New Zealand with CKD is currently unknown, although based on overseas populations an estimate of 7–10% of the population would seem reasonable. It has also been estimated that one in three people in the general population are at risk of developing CKD.

The burden of CKD on New Zealand communities is increasing and the number of people requiring dialysis has almost doubled since 2000; in 2016 there were reported to be 2678 people undergoing dialysis and 1694 people who had a successful kidney transplant.

Approximately half of all people in New Zealand requiring dialysis have diabetes as a primary cause of their condition.

Most patients with stable CKD can be fully managed in primary care, particularly patients with stable stage 3 CKD or those patients aged over 75 years with early and stable stage 4 CKD. The most important aspects of CKD management are:

- Controlling blood pressure; and if the patient has diabetes,
- Controlling blood glucose

Patients with stable CKD (stage 3 – 4) have a five-year cardiovascular risk > 15%, if they do not have diabetes, which increases to > 20% if diabetes is also present. These patients need appropriate cardiovascular disease management and it is important that additional medicines, e.g. statins and aspirin, are initiated according to cardiovascular guidelines to reduce cardiovascular risk.

Complementary community-based care strategies involving nurse-led teams have been shown to improve outcomes in patients with moderate CKD who are at high-risk of progressing to kidney failure.

People with end-stage renal disease commonly have a progressive fall in eGFR, marked proteinuria and hypertension. Early recognition and management, and appropriate referral can prevent end-stage renal disease in some cases and greatly improve the outcome for others.

Being able to detect CKD early allows:

- Early protective intervention to reduce progression towards end-stage renal disease (CKD stage 5)
- Monitoring and treatment of cardiovascular risk factors to reduce cardiovascular disease
- Monitoring and treatment of complications

Who is at risk of CKD?

- Aged over 60 years
- Cardiovascular disease
- Smoking
- Māori, Pacific, South Asian origin
- Obese
- Hypertension
- Diabetes
- Family history of Kidney Disease
- History of Acute Kidney Injury



What you should not forget:

Early Chronic Kidney Disease has no signs or symptoms.

Chronic Kidney Disease usually does not go away.

Kidney Disease can be treated. The earlier you know you have it, the better your chances of receiving effective treatment.

Blood and urine tests are used to check for Kidney Disease.

Kidney Disease can progress to kidney failure.



Important Medicine Sick Day Rules

When you are unwell with any of the following;

- Vomiting or diarrhoea (unless only minor)
- Fevers, sweats and shaking

Then **STOP** taking the medicines listed below.

Restart when you are feeling well (after 24-48 hours of eating and drinking normally)

If you are not sure contact your pharmacist, GP or nurse.

Medicines to stop on sick days

- Blood pressure tablets which include:
ACE inhibitors: e.g. those ending in "pril" such as cilazipril, lisinopril
ARBs: e.g. those ending in "sartan" such as candesartan, losartan
- Diuretics (water tablets) e.g. frusemide, spironolactone
- NSAIDs: anti-inflammatory painkillers e.g. diclofenac (voltaren), ibuprofen
- Metformin: a medicine for diabetes

Exciting Announcement from Caring for the Carers



Caring for Carers has been a huge resource in our community for over 20 years. At the end of last year, Caring for Carers had to close its doors due to financial restraints. When I heard the news, I was determined that such a valuable resource needed to continue. Being so passionate about Carers in our community I am delighted to introduce my new venture Caring for the Carers which is aimed at giving back to the care community.

Caring for the Carers is:

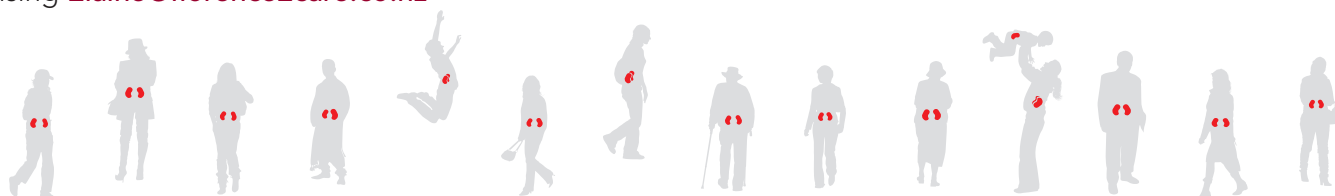
- A voluntary group
- Ideally seen as a supporter of family members looking after a loved one who requires special care
- Privately funded by the **Florence Nightingale Agency**

I am delighted to announce that both Alecia and Elaine, who you will remember well from Caring for Carers, will help me ensure the good work continues under **Caring for the Carers**. In addition my Agency has just celebrated 20 years in business which has evolved over the years to be able to offer a wide range of resources and knowledge which I feel can benefit all Carers, whether in the form of volunteer visits from my team, provision of support from a social worker or advice. Sometimes, just being able to meet at gatherings of other Carers facing similar issues is all Carers are looking for.

The support we are able to offer includes:

- Monthly coffee and support groups
- Information and resources
- A listening ear
- Social outings
- Introducing "My Advanced Care Plan"
- Social worker/office or home visits
- Advocacy
- Telephone support
- Guest speakers
- Peer Support

We welcome any new family members whom you feel would be suited to our service. Please feel free to pass on our contact details or email me personally heather@florence2care.co.nz or you can contact Elaine using Elaine@florence2care.co.nz



Much has been happening in the organ donation space over the past year. In July, the then Minister of health Hon. Dr Jonathan Coleman launched a national Deceased Organ Donation Strategy, the result of some two years of work involving Ministry of Health staff and broad renal sector representation. In November of last year the new compensation regime providing full reimbursement of lost income for live organ donors was launched by the Ministry, replacing the previous WINZ financial support package that provided no more than the sickness benefit. Again, the work required to develop this compensation regime and transfer responsibility from WINZ to the Ministry of Health was the result of a significant amount of work on the part of an Advisory Group that drew together staff from the Ministries of Health and Social Development, ACC and Inland Revenue, together with sector representatives and past live organ donors. Full compensation is available retrospectively to anyone in New Zealand who donated a live organ after 7 December 2016.

Recently the Ministry of Health published a Bulletin updating the sector on both of these projects. The following are excerpts from that Bulletin:

Implementing the [Compensation for Live Organ Donors] Act required a cross-sector approach to development of processes, systems and communications. The Ministry received excellent guidance and advice from a range of sector stakeholders via an Advisory Group, with strong co-design collaboration from a Donor Advisory Group (comprising past donors) and the Donor Liaison Coordinators within DHBs. We are proud to advise that, as at mid-January 2018, more than 50 people have been supported with a Compensation claim.

Increasing Deceased Organ Donation and Transplantation: A National Strategy was published in July 2017. The strategy aims to increase deceased organ donation. The focus of the strategy is to make it easier for families to know what their family member wanted, and to make sure the possibility of donation is discussed with families of all potential donors in intensive care units at the time a decision must be made, and those conversations are conducted in the most sensitive way. The strategy sets out actions to improve:

- a. *public awareness and media engagement about organ donation and transplantation*
- b. *systems of registering and sharing donation intent for individuals, families and clinicians*
- c. *capability and consistency through improved training*
- d. *hospital-based capacity for deceased organ donation, and*
- e. *measurement of progress.*

The Strategy also recommended that a national agency be established to lead action on deceased organ donation, operationally separate from District Health Boards. The need for, and characteristics of, a national agency were identified from the experience of similar countries that have increased donation rates, where a single organisation has a clear mandate to increase donation and organise public awareness and promotional activity.

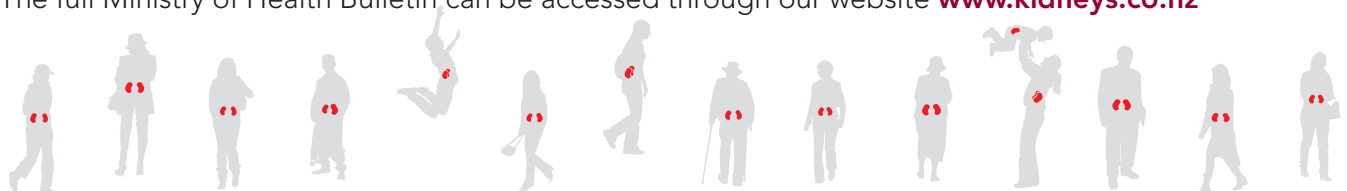
With the recent change of government, the Ministry sought confirmation prior to Christmas from the new Minister of Health, Hon. Dr David Clark, on the Strategy, and in particular the timing and form of implementing the Strategy's recommendations.

The Minister confirmed his preference to establish a new national deceased organ donation agency to implement the Strategy. This means assigning implementation of the Strategy to an agency independent of DHBs and the Ministry, such as an existing (non-DHB) health Crown entity.

In February 2018, the Ministry will provide fuller advice to the new Minister of Health on the most suitable Crown entity to implement the Strategy. To transition existing, and incorporate new functions into a Crown entity requires Cabinet decisions and legislative change. At this time, the indicative 'go live' date is proposed for mid-2019, allowing time for these processes to be completed.

The Ministry will engage with sector stakeholders as it progresses development work to establish the national agency. Further progress updates will be provided as new information becomes available.

The full Ministry of Health Bulletin can be accessed through our website www.kidneys.co.nz



Nick Cross – Clinical Director National Transplant Service



Three years ago the Government invested \$4 million to improve live donor rates in New Zealand. Some of this money was directed into the establishment of the National Renal Transplant Service, of which Dr Nick Cross is the Clinical Director. Nick very kindly gave his time to explain the role and how the funding is being used.

Nick is contracted two days a week in the Clinical Director role. Donor Liaison Coordinator positions were created, these are senior nurse positions. Spread across the 11 District Health Boards (DHBs) with nephrology services, three of these are full time positions in the transplanting centres, with 8 part time positions being funded for the non-transplanting renal units. Donor Liaison Coordinators are funded by MOH separate from the NRTS, Nick works in an advisory role to ensure these DLCs work better. These are reported back to the DHBs.

Already these roles are making a difference, especially in the non-transplant centres, where they are more accessible to potential donors, raising awareness & increasing the number of potential donors coming forward.

Another of Nick's roles is to lead the National Renal Transplant Leadership Team (NRTLTL); this team consists of clinicians from transplant centres, clinicians from non-transplant centres, nurse coordinators, and managers from the DHBs doing transplants, ODNZ and Science representatives from NZ Blood Services and two patient representatives. This ensures both the clinical aspects and the managerial aspects of transplant services are represented.

This team meets six times a year. The aim is to work together to try and increase the number of live donor transplants and improve the quality of care for those receiving transplants, and live donor's experiences.

A separately funded group "Living Kidney Aotearoa" have produced some useful resources such as the booklets, which are utilised by the DLC's.

Currently Nick and the team are working on five identified metrics that will be measured and reported back to the DHB's. It is hoped that areas requiring further improvement will be identified and fed back. DHBs need visibility of data to enable provision of resources.

The metrics are;

1. ***Time between when a live donor recipient pair is ready for surgery and when the actual transplant surgery goes ahead.***

The current target is within four months. The transplanting DHBs have used this information to feedback via their management to allocate more resources to their operating theatres, and as a result patients are getting their operations in a more timely manner i.e. Auckland and Wellington units medium time is 1 month, it's a bit longer in the South Island which is around 2 months, so this is something the DHB might want to look at. The beauty of this is it provides some visibility of how services are performing. It also means that referring DHBs can see that their patients are getting access to the transplant services in a timely way.

2. ***What proportion of transplants occurs pre-emptively?***

This is difficult to monitor as there are a number of factors that influence this. It depends on how soon a recipient presents to the nephrology department, or how they are referred in primary care etc.

Current information has shown that everywhere there is a live donor programme around 40% of live donor transplants are occurring pre-emptively. It's pretty even across the country. It's encouraging to know that most people are accessing live donor transplantation.

3. ***Every patient that is reaching End Stage Kidney Failure should be assessed by a nephrologist as to whether or not they are suitable for a kidney transplant.***

By the time they reach the predialysis educator (PDE) the PDE knows whether or not the patient will be assessed for a kidney transplant. This ensures that every patient has that question answered for them. It's important that no patient is missed out. Around 6.5 patients per 100 patients received a kidney transplant last year.

4. ***How long does it take for a recipient to complete the transplant assessment?***

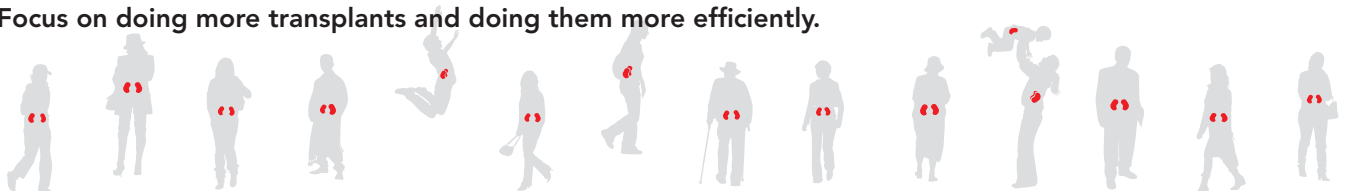
The length of time can be quite long, that's because the process can stop and start depending on the length of time it takes to get to the point their kidney function has deteriorated enough!

5. ***How long does it take for a donor to complete an assessment?***

As with the recipient it can be a stop start process as the recipient isn't progressing (heading towards ESRF) so the assessment is paused. To get an accurate picture, the pauses need to be taken into consideration when measuring length of time.

Data is being collected from all the DHBs so the metrics can be produced for the MOH and fed back to the DHBs.

Focus on doing more transplants and doing them more efficiently.



Walking for Kidney Health



"Not a Race Your Pace"

Harbourside Walkway – starting at the Dunedin Yacht Club

PROMOTED BY OTAGO KIDNEY SOCIETY

Sunday 4th March

Anytime between 11:00am – 2:00pm

- Spot Prizes
- Raffles
- Free Blood Pressure Tests
- Donations Welcome
- Walk for yourself, Walk for a loved one!!

Currently, only 30% of the approximate 450 people on the kidney transplant waiting list will receive a kidney transplant. By becoming a live kidney donor or by having "that conversation" about donating your organs with family/whanau/friends, could significantly improve a recipient's quality of life and reduce the numbers on the waiting list.

Please have "that conversation": give a kidney: improve a life.

For more information contact:

Anita: 027 489 8843, Fiona: 021 0246 2212, Cath: 027 293 5056

Are Your Kidneys OK? Cycle Challenge



Biking the length of NZ
for Kidney Health NZ



Helen Kettles is dedicating her ride to her late Father, who died as a result of Kidney Disease just over two years ago, while raising awareness of Kidney Disease as she cycles the length of the country.

Kidney Health New Zealand is very grateful for Helens support of our work.

You can follow Helens journey on the link below:

<https://givealittle.co.nz/fundraiser/tour-aotearoa-cycle-challenge-are-your-kidneys-ok>

Wishing you safe travels Helen, keep an eye out for updates of Helen's progress on our Facebook Page:

<https://www.facebook.com/Kidney-Health-New-Zealand-206096806091572/>

Yes, I want to help in the fight against Kidney Disease and support Kidney Health New Zealand!

I/we would like to donate: \$100 \$50 \$30 Other: _____

Payment type: Cheque (made payable to Kidney Health NZ) Mastercard Visa

Card number:

Card expiry date: / / Name on card: _____

I would like: A receipt for my donation Information about gifting to Kidney Health in my will

Information about kidney donation/transplants To become a member of Kidney Health NZ

Name: _____

Address: _____

Please return this form to Kidney Health New Zealand, PO Box 20072, Bishopdale, Christchurch.