

The **Kidney** Society **news**

No. 235 February/March/April 2023

The Kidney Society

'Helping people with kidney disease get on with life'.

You can watch videos for a look inside one of our Kidney Society Dialysis Houses and listen to what people who dialyse there think about them!



The Kidney Society “Who, what, where”

P O Box 97 026 Manukau City, Auckland 2241

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E-mail: contact@kidneysociety.org.nz

Website: www.kidneysociety.org.nz

Facebook: <https://www.facebook.com/kidneysocietyadks>

Kidney Society Centre, Auckland: 5 Swaffield Road, Papatoetoe, Auckland 2025. Office hours: generally, 9 - 5 Monday to Friday, Answerphone a/hrs

<p>Contributions to the Kidney Society News are always welcome. Why not write us a story or send us a photo!</p>		<p>John our Chief Executive Officer is responsible for managing the Society overall. John leads the staff as they go about supporting Kidney Society clients.</p>		
	<p>Gina our Office Manager is in charge of running the office, the community houses, raffles, events organising and general administration.</p>		<p>Tracey our Wellness Educator can help you keep mobile and feel good “the gentle” or “the active” way. She can find you a gym or give you exercises for at home.</p>	
		<p>Brian and Kristin are our Community Health Educators who can help you understand kidney disease and treatments and how these things affect you and your family.</p>		<p>Nora writes the News. Send in a story for the next magazine!!</p>
	<p>Jenny keeps an eye on things at the dialysis houses, shows new people how things work and helps them settle in.</p>		<p>Maria our Office Assistant works with Gina to keep everything in the office ticking over, leaflets printed, the News mailed out and more.</p>	
<p>Deadline for the May/June/July News: Wednesday 26th April Contributions are very welcome!</p>				
<p>Contact us for information or a chat, weekdays 9-5, phone 0800 235 711, email contact@kidneysociety.org.nz Facebook https://www.facebook.com/kidneysocietyadks or just come to the Kidney Society Centre, 5 Swaffield Road, Papatoetoe, Auckland</p>				
<p style="text-align: center;">0800 235 711</p>				



Kia ora, Malo e lelei, Talofa lava, Kia orana, Bula and happy new year to all those in the Kidney Society extended family.

Kia ora, Mālō e lelei, Talofa lava, Kia orana, Bula and greetings to all those in the Kidney Society extended family.

This summer will be one to remember for all the wrong reasons with flooding, strong winds, power outages and road closures - these are all worrying factors for people on dialysis. We extend our thoughts to any readers affected by the recent significant weather events.

At the start of 2023 I am pleased to announce an important change with Brian Murphy, our highly experienced Community Health Educator, has relocated to the Coromandel Peninsula. The good news is that Brian remains on staff and the move gives him more time to focus directly on our clients living south of Auckland. Meanwhile Kristin Leslie takes responsibility for Northland and Auckland. Both Brian and Kristin will continue to work closely with the Society's Wellness Educator Tracey Drinkwater. Brian retains the same contact details as before.

Last year ended well for the Kidney Society and I would especially like to thank all those wonderful people who supported our Xmas appeal. Over \$3500 was raised to fund client services in a matter of weeks – thanks again for your kind support.

Another exciting development is the launch of our new website which can be found at www.kidneysociety.org.nz. The new site is packed with information and inspiring client stories, we hope you find the new site easy to navigate and that you can get the information you want. As with any new website, your feedback will help us make it even better so please tell us what you think.

This year we are celebrating World Kidney Day on the 9th of March. It's an important day when we highlight kidney disease in New Zealand and the important stories of people with this condition. Look for the piece in this edition of the Kidney Society news.

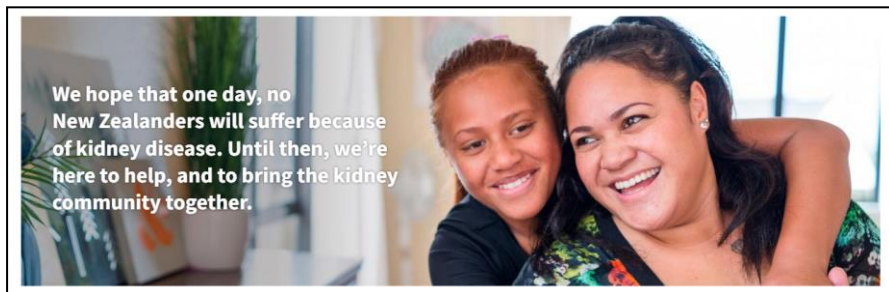
Have you joined our Facebook community yet? If you haven't, do follow our Facebook page **Kidney Society - ADKS**. It's a place where we share stories, what we've been up to as well as our upcoming plans and events, information, statistics, and resources. It's a place for us to be able to create a two-way conversation about how we can continue making a positive impact on you and others living with Kidney Disease together.

Nga mihi, Regards

John Loof, Chief Executive Officer

Check out our new website:

<https://www.kidneysociety.org.nz/>



Looking after your fistula or graft with a fistula cover: you can order many different ones online:

https://www.etsy.com/nz/market/fistula_cover

The photo shows the first option, but you can also find longer; plain fistula covers on Amazon:

<https://www.amazon.com/gardening-leeves/s?k=gardening+sleeves>



Kidney Society Events

Home visits in cyclone affected areas may or may not be possible. If you would like a visit, make sure to phone and ask!

Coming up: Northland Wellness Day, Whangarei

We are currently organising a Whangarei Wellness Day for mid-March to coincide with World Kidney Awareness Month.

Dates & location are yet to be confirmed.

We will have:

- **information on safe and suitable exercise for people with Chronic Kidney conditions.**
- **Exercise demonstrations and some wellness equipment give-aways.**
- **Guest speakers from Green Prescription and Sport Northland on community support and programs.**

We will have updates on our Facebook page closer to the date.

You can contact Tracey at the wellness program – Email:

tracey@kidneysociety.org.nz or **0800 235 711** to have your name added to the contact list for the event.

Home visits in Te Kuiti, Taumaranui and Te Awamutu:

Wednesday 7th and Thursday 8th March

Brian will be visiting in your area, if you would like to see him, call **0800 235 711** or **027 715 3949** or email brian@kidneysociety.org.nz

Home visits in Hamilton:

Monday 13th March

Brian will be visiting in your area, if you would like to see him, call **0800 235 711** or **027 715 3949** or email brian@kidneysociety.org.nz

Home visits in Hawke's Bay

Tuesday 21st and Wednesday 22nd March

Brian will be visiting in your area, if you would like to see him, call **0800 235 711** or **027 715 3949** or email brian@kidneysociety.org.nz

Home visits in Gisborne

Tuesday 18th, Wednesday 19th and Thursday 20th April

Brian will be visiting in your area, if you would like to see him, call **0800 235 711** or **027 715 3949** or email brian@kidneysociety.org.nz



Connecting Kidney Society clients with each other

Brian our health educator helps clients get hands on information about the treatments that they are likely to experience on their 'kidney' journey by connecting them with each other. Below is an example of how that works. This is a real story, but without using people's real names.

Email from Brian to 'John and Susan':

Hi 'John and Susan, It was a pleasure to meet you both and I am pleased you both got some benefit from our chat. As promised here are the details of a local person on the bag treatment who is doing very well. Her name is Marion and you can contact her on her mobile.

Brian

Email from 'Marion to John:

Hi John,

My name is Marion. My husband and I are locals here. I wish I could say welcome to the club... but it is not the kind of grouping anyone intends to be a part of, but here we are. I completely understand living without kidneys.

I am happy to talk with you about peritoneal dialysis. I certainly would have liked that when I had my acute kidney failure some 2 years ago. My nurse has been wonderful, full of information and basically leaves me to it and I can text message her whenever I need help.

It is a journey; you learn a lot about yourself and what you are made of. Fear of the unknown is always there, but mostly everything now is done with purpose, my motto is to "just carry on" and I do.

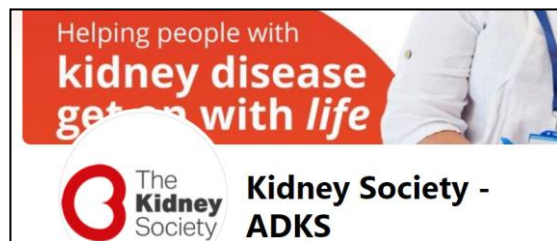
Certainly, it helps if your significant other is in full support of you as they are very important people to us.

You and Susan are welcome to come visit me and my hubby at my home. Or we can meet in town at a café if you prefer, whatever suits you.

Until then, I look forward to meeting you both.

Regards, *Marion*

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information, statistics, and resources. It's a place for us to be able to create a two-way conversation about how we can continue making a positive impact on you and others living with Kidney Disease together.

Accessing dialysis while on holiday

Te Whatu Ora
Health New Zealand

Dialysis for eligible patients within New Zealand while on holiday is available free of charge for eligible patients within New Zealand while on holiday is available free of charge.

How to arrange dialysis

A patient's current doctor needs to arrange dialysis treatment dates with the relevant unit where the patient is visiting. They will need to forward the patient's clinical background and any notes. They should do this with as much notice in advance as possible.

Arranging dialysis treatment is informal

The renal unit where the patient is visiting will assess whether or not they can provide the service at that time. Their decision will be based on the needs of their existing patients and the capacity of the existing service.

It may also be more difficult to arrange dialysis if the patient also needs additional, hospital-based care as it may not be available.

Dialysis over holiday periods

It may be necessary to be flexible over holiday periods. For example, a small unit in a provincial hospital may not be able to take several holiday patients at one time, such as over the Christmas and New Year break.

Dialysis during sudden events

For a sudden event like a bereavement, a visiting patient will almost always be accommodated at short notice.

For more info go to <https://www.tewhatauora.govt.nz/our-health-system> then search for *Accessing dialysis while on holiday*

Herbal medicine and kidney disease



Herbal medicines have been used by humans for over 5,000 years. If you have chronic kidney disease (CKD) however, there are good reasons to be cautious about taking herbal medicines. Herbal supplements are made from plants, fungi or algae, and are usually sold as extracts, teas,

powders or tablets, or capsules. The fact that they are marketed as "natural" is appealing to people who want to shy away from drugs.

Unlike prescription or over the counter drugs, herbal supplements are not regulated so their manufacturers can put in whatever ingredient they want. Some herbal medicines are high in glucose, phosphate and/ or potassium. When you are seeing your doctor, renal dietitian and or pharmacist it is very important to discuss herbal medicine with them, so that it won't negatively interact with your prescribed treatments.

Source: Kidney Health NZ website <https://www.kidney.health.nz/>

Healthy, Cheap Eats

Maia Lingman Waitematā District Renal Dietitians

My grocery bill is through the roof! How can I eat well for less?



Saving money at the grocery store can be tough. Here are our top tips to saving money on your grocery bill. Note: The information contained in this article is designed to provide helpful information to most people. Please also consider your own individual dietary requirements.

Shop in season - Its Autumn - Whats in season?

Fruit: apple, banana, feijoa, pears, berries, avocado, kiwifruit.

Vegetables: beans, beetroot, broccoli, buttercup squash, pumpkin, cabbage, capsicum, carrot, cauliflower, celery, courgette, cucumber, kūmara, leek, lettuce, mushroom, onion, parsnip, potato, silverbeet, spinach, tomato, watercress.



Frozen produce = good produce

- Frozen vegetables and fruit are good quality, reasonably priced and help you cut down on food waste.
- Pre-cut fruit and vegetables are easy to add to meals.

Plan your meals, make a list and stick to it!

- This makes sure you are using everything you buy and reduces food waste.



- Shopping lists stop you from buying food you do not need.

Buy the house brand products

- House brands make great quality, cheaper products.

Use sales to your advantage

- Buy products that are on sale instead of the brand name products.

Buy in bulk

- Buying in bulk is often better value for money.

Canned food

- Canned fruit and vegetables are long lasting.
- Be sure to buy foods canned in water rather than brine or syrups, and drain before use.

Add “fillers” to stretch meals further

- Add grated vegetables, rice or cans of drained and rinsed lentils, beans, chickpeas to meals.
- E.g. Add a can of lentils to a mince dish.

Try grocery shopping online/click and collect

- Ordering groceries online can save money because you only search for the things you want to buy and don't have the temptation of food displays in a grocery store.
- You can also more easily shop the specials.

Beef and Lentil Burgers – Serves 6



Ingredients	Method
250g lean beef mince 400g can lentils, drained and rinsed 2 Tbsp tomato sauce 1 egg 1/3 cup parsley, chopped (optional) 1/2 medium onion, finely chopped 1 cup dried breadcrumbs 1 carrot, grated Pinch ground pepper	1. Combine all ingredients. 2. Knead mixture until well combined and sticking together. 3. Divide mixture into six portions, then roll into a ball and flatten. 4. Heat oven on grill. 5. Place the burger patties on a baking tray and grill until well browned on each side. 6. Serve with salad vegetables and a wholegrain burger bun.

Recipe courtesy of Heart Foundation New Zealand.

Cauliflower and Chickpea Curry – Serves 6



Ingredients	Method
<p>1 tsp oil ½ medium onion, diced 2 cloves garlic, crushed 2 Tbsp curry powder 240 ml can lite evaporated milk 3 medium carrots, sliced ½ head cauliflower florets 2 cups frozen peas 1 can chickpeas, drained and rinsed Juice of 1 lemon ¼ cup fresh coriander, chopped (optional)</p>	<ol style="list-style-type: none">1. Sauté onion in oil until soft and lightly browned.2. Add garlic, curry powder, 1 cup water and evaporated milk.3. Bring to the boil, then reduce to simmer.4. Add carrot and cauliflower. Cook until almost tender.5. Add peas and chickpeas. Cook for 5 minutes then remove from heat.6. Add lemon juice and coriander. Serve with brown rice.

Recipe adapted from Heart Foundation New Zealand.

MEDIFIT

Hamilton UNIREC Exercise Programme

If you live in the Hamilton area and are interested in a supported community exercise programme designed for people with health conditions, then the UNIREC Medifit Programme may be a suitable option for you.

Below is the information about the programme, you can also call Tracey at the Kidney Society for more information on 0800 235 711.

Individuals participating in the programme complete a personalised programme and then work out within a social, group environment.

The sessions are designed to be interactive with individuals choosing to work independently or within the group.

Support and motivation are readily provided by supervising staff who oversee individuals' progress and this includes feedback on technique and appropriate training intensity.

MediFit is especially helpful for those who may have reservations or specific considerations regarding training on their own.

THE PROGRAMME INCLUDES

- Initial consultation and programme prescription (1 hour)
- Two weekly supervised sessions, Tuesday & Thursday 10am – 11.30am

The program is run by Dr Glynis Longhurst, an Exercise Specialist (REPs) and an Accredited Exercise Physiologist (SESNZ).

12 Week Program

UNIREC Member	\$20.20 pw or \$120 upfront
Non-Member	\$31 pw or \$250 upfront

(If you are currently receiving support through WINZ Disability Allowance, you may be able to apply for financial support for the program.)

To make an appointment to get started contact Dr Glynis Longhurst on 020 458 7700 or email urmedifit@waikato.ac.nz



Thinking About Joining a Gym?

Joining a gym can be a great option for regular exercise.

Gyms have a wide selection of equipment, going to a gym gets you out of the house and it can also be a way to socialise and meet other people.

If you get a paying a membership this can motivate you to attend too – but you want to avoid becoming what gym's call DONATORS, which are people who join and pay but never attend.

If someone is wanting to join a gym, I usually ask them a few questions to see if a gym membership is suitable for them:

1. Is a gym membership suitable for you (MEDICAL CLEARANCE)?
2. What are your fitness goals and will the gym be suitable for these goals?
3. Where is a suitable gym near you?
4. What is your budget for a membership?
5. Are you able to attend at least 2-3 times per week for best value for money?

With so many gyms to choose from it can be a bit overwhelming. If you are new to using a gym the gym equipment can also seem daunting and having the right support to ensure you can use it safely is essential.

There are also many gyms that may not have suitably qualified staff to safely support you without paying extra.

Council run gyms in most areas are, in my opinion, one of the best gym options around. Staff are well trained and are available to support you safely in the gym.

These gyms are well equipped and often have classes and pools if it is suitable for you to use them. And the prices are often more affordable than many of the other gyms.

The Kidney Society & Green Prescription work closely with Council facilities to ensure that people with Chronic Kidney Conditions are well supported.

What is a Green Prescription?

Green Prescription programmes offer community exercise classes, walking groups, health education and discounted gym memberships and programmes.



How to get a Green Prescription:

Ask your GP or practice nurse about a Green Prescription. Or You can do a self-referral online, depending on which area you are in. Once you receive your Green Prescription, a trained support person will get in touch and support you to find a suitable physical activity programme in your area. You will get help with planning regular physical activity to help you stay active.

There's also the chance to meet and join other people in your community who are choosing to be more active just like you.

Many of the green prescription programmes also have online classes and programmes.

And remember I am available to support you with joining a gym, getting a Green Prescription, a suitable programme and ensuring your gym journey is a safe and successful one.

I can also work with gym staff and personal trainers to provide them with information on suitable exercise education for people with Chronic Kidney Conditions.

If the cost is a barrier and you are currently receiving a Disability Allowance you may be able to apply for funding for your gym membership which I am also able to assist you with.

Tracey Drinkwater

Wellness Educator Kidney Society

0800 235 711, 027 378 4544 or tracey@kidneysociety.org.nz



Kidney Society YouTube Wellness Channel

All you need to do to find our YouTube channel is use the link below or, once in YouTube, search 'Kidney Society'.

<https://youtube.com/channel/UC1uP59-O1pCnuS97IY91Grg>

REMEMBER to CLICK SUBSCRIBE & LIKE!!

Tracey Drinkwater, Wellness Educator

027 378 4544, freephone 0800 2345 711 or

email tracey@kidneysociety.org.nz

For personal advice you can contact Tracey by phone, email or text.



World Kidney Day is around the corner



**KIDNEY
HEALTH
FOR ALL**
PREPARING FOR
THE UNEXPECTED,
SUPPORTING
THE VULNERABLE!



World Kidney Day (9 March, 2023) is a global awareness campaign that aims to educate people about the importance of kidney health and the steps they can take to protect their kidneys.

Many people don't know what exactly their kidneys do for them and they know even less about kidney disease; so events like World Kidney Day are important opportunities for us to put the focus on this important health issue.

Kidney disease is a serious and growing health problem that affects over 5000 people in New Zealand each year. We know that our kidneys are vital organs that filter waste products from the blood and help regulate fluid balance in the body. When the kidneys are damaged, they are unable to perform these important functions properly, which can lead to a variety of health complications.

World Kidney Day is a reminder to all of us to raise awareness of an issue that we think can sometimes go under the radar in New Zealand and around the world. Raising awareness is important because it is a significant health issue in the country. According to Kidney Health New Zealand, 1 in 10 New Zealanders have some form of kidney disease... yet it's not something we hear enough about.

So how can you help raise awareness?

- Use and share the range of resources provided by World Kidney Day on <https://www.worldkidneyday.org/>
- Share your journey and anything that helped you along the way.
- Connect with those you know who have Kidney Disease or their families to help them cope with the diagnosis and treatment.
- Educate people and talk about it: share with people any signs and symptoms of kidney disease, as well as the risk factors and ways to prevent it.
- <https://www.worldkidneyday.org/2023-campaign/2023-wkd-theme/>

Take a video tour with us around our Community Dialysis House



Last year, we decided we needed to show what a difference our community dialysis houses make to our clients so we can help anyone else who needs this support... So we decided to take you on a tour through video around Ripley House.

Our Community Dialysis House is an alternative option to dialysing at the hospital. It can be a home away from home, where you can meet others on the dialysis journey. We have more than 3 dialysis houses in South Auckland, all conveniently located near the Middlemore Hospital.

In our new video, you hear from our staff about our mission, and hear from our clients about their journey, and what they like about dialysing at the community house. A special thank you to Kevin, Sandra, William, and Tainui for sharing your stories with us.

We wanted people to know there's no complicated process or waitlist to start community dialysis at one of these houses, but you need to be a Counties Manukau dialysis patient. We work with Middlemore hospital to make sure new clients are fully trained and are comfortable to start their own treatment.



To see our video, simply go to YouTube and type 'community dialysis house' or scan the QR code above.

Or, go to our new website using the link below:

<https://www.kidneysociety.org.nz>

You can also quickly find the videos here:

<https://www.kidneysociety.org.nz/client-stories>



The Kidney Project successfully tests a prototype bioartificial kidney. Read the full story here:

<https://pharmacy.ucsf.edu/news/2021/09/kidney-project-successfully-tests-prototype-bioartificial-kidney>

‘Advance’ is awarded KidneyX’s Artificial Kidney Prize Thursday Sep 9th, 2021

The Kidney Project’s implantable bioartificial kidney, one that promises to free kidney disease patients from dialysis machines and transplant waiting lists, took another big step toward becoming reality, earning a \$650,000 prize from KidneyX for its first-ever demonstration of a functional prototype of its implantable artificial kidney.

KidneyX is a public–private partnership between the U.S. Department of Health and Human Services (HHS) and the American Society of Nephrology (ASN) founded to “accelerate innovation in the prevention, diagnosis, and treatment of kidney diseases.”

The Kidney Project, a nationwide collaboration led by Shuvo Roy, PhD of UC San Francisco and William Fissell, MD of Vanderbilt University Medical Center (VUMC), combined the two essential parts

of its artificial kidney, the hemofilter and the bioreactor, and successfully implanted the smartphone-sized device for preclinical evaluation.

For this advance, the team was awarded KidneyX's Phase 1 Artificial Kidney Prize and was one of six winning teams selected out of an international field.

In the last few years, The Kidney Project successfully tested the hemofilter, which removes waste products and toxins from blood, and the bioreactor, which replicates other kidney functions, like the balance of electrolytes in blood, in separate experiments.

For the Artificial Kidney Prize, the team married the two units into a scaled-down version of the artificial kidney and evaluated its performance in a preclinical model. The units worked in tandem, powered by blood pressure alone, and without the need for blood thinning or immunosuppressant drugs.

"The vision for the artificial kidney is to provide patients with complete mobility and better physiological outcomes than dialysis," said Roy, who is a faculty member in the Department of Bioengineering and Therapeutic Sciences, a joint department of the UCSF Schools of Pharmacy and Medicine. "It promises a much higher quality of life for millions worldwide with kidney disease."

Chronic kidney failure, also known as end-stage renal disease, leads to the progressive and dangerous loss of kidney function. Most patients with kidney disease must visit dialysis clinics multiple times every week to have their blood filtered, a process that is time-consuming, uncomfortable, and risky.

A minority of patients live with transplanted kidneys, thanks to a pool of donated kidneys that are constantly in high demand. But even these patients must contend with a lifetime on immunosuppressant drugs that can have severe side effects.

The Kidney Project's artificial kidney will not only replicate the high quality of life seen in kidney transplant recipients—the "gold standard" of kidney disease treatment, according to Roy—but also spare them from needing to take immunosuppressants.

"Our team engineered the artificial kidney to sustainably support a culture of human kidney cells without provoking an immune response," said Roy. "Now that we have demonstrated the feasibility of combining the hemofilter and bioreactor, we can focus on up-

scaling the technology for more rigorous preclinical testing, and ultimately, clinical trials.”

The KidneyX Artificial Kidney Prize called on scientists and engineers to submit “continuous kidney replacement therapies that provide transformational treatment options beyond current dialysis methods,” a high bar that UCSF's artificial kidney is poised to clear in the coming years.

“This award is a testament to The Kidney Project's bold vision and execution of a viable solution for millions of patients with kidney disease,” said UCSF School of Pharmacy Dean B. Joseph Guglielmo, PharmD.

Bioartificial kidney aims to mimic natural kidney function with \$1 million grant from the John and Marcia Goldman Foundation

The Kidney Project wins KidneyX Award to enable simpler, safer at-home dialysis and to make home dialysis better for patients.

Maybe one day they will be ready to use and available in New Zealand...



The Kidney Society

WITH THE HELP OF NEW ZEALAND

WE CAN IMPROVE THE LIVES OF MORE PEOPLE LIVING WITH KIDNEY DISEASE

We need to come together as a community to ensure those with Kidney Disease are not forgotten.

kidneysociety.co.nz  **Kidney Society - ADKS**

1 IN 10 PEOPLE ARE LIVING WITH KIDNEY DISEASE

WE WANT TO SUPPORT AS MANY OF THESE PEOPLE AS WE CAN, TO HAVE A QUALITY OF LIFE THEY'RE HAPPY WITH, THROUGH OUR SERVICES.

If you're one of our clients, you already know exactly what's like to be diagnosed and to live with the impact of kidney disease so we want to ask your help. Not for a donation but for you to help us reach those who're in the position to donate and make a difference to the community.

This World Kidney Day (9 March, 2023) if you know someone who wants to donate, please ask them to do so in one of the following ways:



DONATE ON OUR WEBSITE

You can amount any amount on our website at: kidneysociety.co.nz



DONATE VIA INTERNET BANKING

Our banking details are: **12-3032-0705009-00**. Please add a reference of World Kidney Day



DONATE VIA PHONE

Please call us on **0800 235 711** if you'd like us to process a credit or debit card payment for you.

What Happens If Someone Stops Dialysis?

For many people with kidney failure, dialysis or a kidney transplant enables them to live longer and enjoy their quality of life. However, this may not be the case for everyone and each person has the right to choose how - or if - they want to receive treatment for chronic kidney disease. Without life-sustaining dialysis or a kidney transplant, once a person with kidney disease reaches stage 5 (end stage renal disease or ESRD), toxins build up in the body and death usually comes within a few weeks.



The decision to stop treatment should be an informed and voluntary choice. Experts recommend patients talk with their physicians and a social worker or therapist to understand their choices and know what to expect.

Talking to family members about stopping dialysis

It's the patient's right to make the decision to stop dialysis. Sometimes, knowing that death can be pain-free and peaceful for the person with ESRD helps ease family members' fears.

There are many reasons why someone with ESRD may not want to continue or start dialysis.

Some people feel they've lived a full life and don't want to bother with additional surgery and treatments.

Studies have shown that people most likely to withdraw from dialysis are older and living in nursing homes. They often have health problems in addition to kidney disease and suffer more severe pain. They usually have physical limitations that restrict normal daily activities.

If a loved one decides to stop dialysis, it's important that family members try to understand and respect that decision. The patient's treatment team should be available to make sure the patient and family members understand the effects of the decision.

Preparing for stopping dialysis—advance directives and hospice

While talking about death and dying can be difficult, most families find it's a relief to have a plan in place for when the time comes.

Planning for care and respecting the wishes of the patient makes end-of-life decisions easier. An advance directive can help family members know what the patient wants regarding end-of-life care so the family doesn't have to make those decisions for the patient.

An advance directive is a legal document that spells out a person's wishes regarding future crisis care.

All adults should have an advanced directive. Having an advance directive lets everyone know what to do if you become unable to communicate those wishes. If you have questions about an advance directive, please talk with your physician or an attorney.

Patients who stop dialysis receive what's called palliative care, also called comfort care, which focuses on helping patients stay as comfortable as possible during the time remaining. When someone has made the decision to stop dialysis, hospice can be referred by their physician. Hospice, a form of palliative care, provides pain relief and symptom control and can take place in the patient's home, at a hospice facility or in the hospital. For more information on hospice, talk to your physician.

What to expect once dialysis is stopped

Without dialysis, toxins build up in the blood, causing a condition called uremia. The patient will receive whatever medicines are necessary to manage symptoms of uremia and other medical conditions. Depending on how quickly the toxins build up, death usually follows anywhere from a few days to several weeks.

As the toxins build up, a person may experience certain physical and emotional changes. In the final days, the body starts to shut down. In most instances, the shut-down is an orderly series of physical changes which may include:

- Loss of appetite and fluid overload.
- Sleeping most of the day.
- Restlessness.
- Visions of people who don't exist.
- Disorientation, confusion and failure to recognize familiar faces.
- Changes in breathing Congestion Changes in colour and skin temperature.

Patients who choose to stop or not start dialysis are not required to eat or take in fluids. In most cases, a patient is allowed to eat or drink if they want to, but forcing fluids or nutrition is not recommended.

Medicines can be given for pain, anxiety, agitation or congestion. As the body's systems shut down, a person slips into unconsciousness and the heart stops beating.

Most people who pass away from kidney disease have what family members and caregivers describe as a “good death.”

A study reported that patients who discontinued dialysis described a good death as pain-free, peaceful, and brief. The patients' families echoed this sentiment, adding a good death included having loved ones present at the end.

Treasure the time you have

When the dialysis patient and their loved ones are prepared for the final days, the time remaining can be spent in companionship, reminiscing, laughing and crying. Many people never have the opportunity for closure. Many kidney failure patients and their loved ones say they're grateful for the opportunity to express affection and say goodbye.

<https://www.davita.com/treatment-services/dialysis/what-happens-if-someone-stops-dialysis>

National Renal Transplant Services papers and reports produced by the National Renal Transplant Service can be found here:

<https://www.health.govt.nz/about-ministry/leadership-ministry/expert-groups/national-renal-transplant-service/nrts-papers-and-reports>

Included are topics such as:

- Australian and New Zealand Paired Kidney Exchange Program (ANZKX).
- Guidelines for the Evaluation of Living Kidney Donors in NZ.
- National Kidney Allocation Scheme.
- National Review Policy for Patients Declined Access to Deceased Donor List.
- Receiving a deceased donor's kidney.
- Transplant Activity Report.

DOES HOT WEATHER AFFECT CHRONIC KIDNEY DISEASE PATIENTS?

We share **crucial precautions** that every **CKD and Dialysis patient** should take during the **sunny and warm summer months** to protect their kidney health.



Summer often brings sunny skies, warm weather, and good times for many Chronic Kidney Disease and Dialysis patients.

It also brings challenging times for workers exposed to chronic heat stress and recurrent dehydration, increasing their risk for CKD and, ultimately, kidney failure.

There are crucial precautions that every Chronic Kidney Disease and Dialysis patient should take during the sunny and warm summer months to protect their health gains and improve their quality of life.

The summer season can have very high temperatures and high humidity. As a result, heat illness could affect many people. Heat illness occurs when the body temperature exceeds the individual's ability to dissipate that heat. The clinical characteristics of heat illness are when the body temperature approaches 104 degrees Fahrenheit and when humidity is greater than 70%. Once the humidity is high, sweating becomes less effective at dissipating body heat, and the core body temperature begins to rise.

What Happens to the Kidneys When Someone Has Heat Illness?

Body temperatures above 104 degrees Fahrenheit (40 degrees Celsius) will cause significant problems for the kidneys. Dehydration will lead to low blood pressure and decreased kidney function.

Many metabolic systems start to shut down in response to heat illness, and a decline in kidney function is part of that abnormality in metabolic systems. There is a breakdown of muscle tissue that results in kidney failure. Finally, heart failure and shock can lead to kidney failure during episodes of severe heatstroke. Avoid using non-steroidal anti-inflammatory drugs (NSAIDs) such as Ibuprofen during exposure to heated environments, as this could lead to acute kidney failure.

What if I Suspect Heat Illness?

If you have someone who is warm and confused or delirious, not making any urine, and breathing rapidly, you must get this person to a cooler environment. You should activate emergency services to have them transported to an emergency facility.

If you have access to a fan, ice, or cooling mist, you should place the patient in a cooler environment. If they are unconscious or poorly responsive, do not offer them oral liquids for the risk of inducing aspiration and pneumonia. External cooling such as mists plus fan, ice packs to the head and neck, removing clothing, and applying cool compresses can all be effective. Getting the patient to emergency services is the most important thing.

1. Protect your access if you go swimming:

Dialysis patients should always remember to cover their Dialysis Access with a protective dressing when going swimming. Talk to your nephrologist or nurse, to find out which holds up best in water. Your Healthcare Team will show you how to clamp your Peritoneal Dialysis catheter shut adequately for people on Peritoneal Dialysis.

You should immobilize the Peritoneal catheter to avoid trauma or tension on the catheter while swimming. Ideally, you should change the dressing as soon as you finish swimming. When going for a swim, do so in the ocean or a chlorinated pool. Patients must be careful to avoid lakes or polluted areas of the sea, as they increase the danger of contracting an infection.

2. Fluid balance:

It is hard for Dialysis patients to maintain their fluid restrictions during the warm months of summer. Although patients do not want to become dehydrated, they also do not want to experience fluid overload, short-term and long-term health complications.

Be careful of icy beverages, which can cause stomach cramps. It's best to avoid drinking caffeine or alcohol or ingesting large amounts of sugar, as these can cause your body to lose more fluid. Try to stay cool by wearing a hat or a wet bandana around your neck to help control your thirst. You might also want to carry a small spray bottle filled with lemon water or mouthwash to spray your mouth when you feel excessively thirsty.

Check with your nephrologist for guidance about your fluid intake during hot summer days and whether it should be adjusted to account for the rising temperatures.

3. Wear sunglasses:

Sunglasses protect your eyes in the same way that sunscreen protects your skin from harmful sun damage. Your sunglasses should block at least 99% of UVB rays and 50% of UVA rays. Wraparound sunglasses and other styles that completely cover the eyes are best to avoid sun damage. The last thing patients need is another health complication.

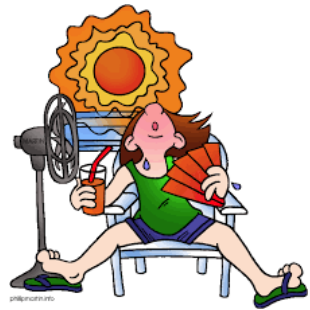
4. Save your skin from sun exposure:

Every Chronic Kidney Disease, Dialysis, and Kidney Transplant patient should wear sunscreen and apply it liberally. Unprotected sun exposure can cause skin damage and, in some cases, may even lead to skin cancers. Use sunscreen with an SPF of at least 15.

Remember to reapply your sunscreen every two hours and also right after swimming or exercising. A water-resistant sunscreen will be less likely to come off if you swim or perspire. You can also protect your skin by covering up with a shirt, wearing a hat, or sitting in the shade.

5. Go outside. Get moving:

Many Chronic Kidney Disease and Dialysis patients avoid going outside on summer days because they fear the impact that it may have on their health. Morning or late afternoon sunny days of summer are great times to walk or enjoy a light exercise routine. Even if you feel tired at times, easy exercises may help you feel better. Please, check with your nephrologist before starting a summertime exercise routine.



Whether you're spending time outdoors with your family, caring for a loved one with a chronic condition, or working outdoors, it's essential to keep cool, keep a good fluid balance, and know the warning signs of heat-related illnesses.

Be sure to talk with your nephrologist before the summer season about other ways you can stay safe during the warm summer months.

Are you ruining my Life?

A timeless story in "Kidney Life" magazine of the National Kidney Federation, UK, Autumn 1998

The last time my husband was in hospital for haemodialysis, a young man in the next bed was out of harmony with his wife. Suddenly she shouted .. "You don't realise you are ruining my life". This made me think - has my life as a carer for 20 years been ruined?

Peter's polycystic kidneys were diagnosed in 1977 when he was 46. There were many anxious and tearful moments as dialysis became part of a different life.

I left my teaching job to become a home tutor to sick children in the mornings. I became a clock- watcher - any delay getting Peter 'on' the machine meant a later time getting him 'off' after 8 hours.

I became a keen gardener - a shout from the bedroom window was enough to bring me running! I went to a weekly art class, a hobby I could practice confined to the house.

We got hardened to explaining to wine waiters that Peter shouldn't drink wine and my mother never could accept that he didn't want a full cup of tea.

It's not all sweetness and light being a carer. Tempers become frayed by both partners. One has to put up with irritability and unfair criticism, but if the partner says 'sorry', then it alleviates hurt feelings.

One can only be ill on non-dialysis days and 36 hours in bed with 'flu is the maximum. Even with a streaming cold, needles have to be put in - and you stand on one leg if you have sprained your ankle!

The mental and physical strain is tiring. My husband had a breakdown and took early retirement. A transplant in 1995 failed after 7 months and he was back on dialysis, very anaemic, lethargic and apathetic. It was hard not to give in to despair. It was ack to manoeuvring a very heavy machine and, being 20 years older, I don't find it easy. But, Peter now dialyses for 4 hours; he is feeling better mentally and physically and I am happier to see improvements in his condition.

It is best to accept one's lot, to be content and not hanker after the

unobtainable. Yes, my life has been restricted to an extent, but not entirely. It certainly has not been ruined.

Sybil Humphreys

in "Kidney Life" magazine of the National Kidney Federation, UK, Autumn 1998

Has your address or phone number changed?

It is important that we have your current details so you can continue to receive this magazine and we are still able to support you. If any of your details have changed or you would like to join our mailing list – please contact us on 0800 235 711 or at kidneysociety.org.nz

The Kidney Society News in 2023

In 2023 look out for the Kidney Society News coming to you in **May, August and November**. Contributions are always very welcome, send to gina@kidneysociety.org.nz, Deadline for contributions: Wednesday 26th April 2023. More frequent News on the website or Facebook!

Kidney Society YouTube Wellness Channel

All you need to do to find our YouTube channel is use the link below or, once in YouTube, search 'Kidney Society'.

<https://youtube.com/channel/UC1uP59-O1pCnuS97IY91Grg>

REMEMBER to CLICK SUBSCRIBE & LIKE!!

**Tracey Drinkwater,
Wellness Educator**

027 378 4544, freephone

0800 2345 711 or email

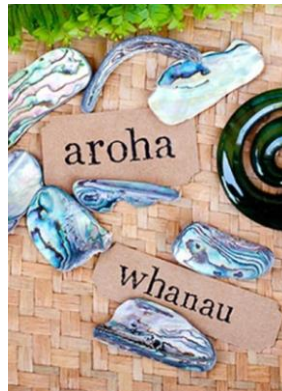
tracey@kidneysociety.org.nz



For personal advice you can contact Tracey by phone, email or text.

NEW! Paying family is now a permanent option.

More flexible approach for paying family members to provide support is made permanent.



Whaikaha is pleased to confirm that its more flexible approach for disabled people to engage family, whanau and aiga to provide supports is here to stay.

The expanded flexibility was put in place as part of the Government's response to the COVID-19 pandemic.

It gave disabled people, tangata whaikaha, Maori, families and whanau more options about who could be paid to provide support.

Whaikaha has listened to feedback from whanau and carers, disabled people, and tagata whaikaha Maori, who have told us they value this more flexible approach.

"After extending this approach several times, I am really pleased to be able to give the community the certainty that flexibility has become a permanent feature of our approach", says Amanda Bleckmann, Deputy Chief Executive – Operational Design and Delivery.

When other household whanau, family members can provide support for disabled people, it financially recognises their mahi aroha, work performed out of love, and makes it easier to ensure needed support is available. Most importantly, decisions about who is being paid to provide support and when are made directly by disabled people and their families, whanau and aiga. Last year permanent changes were also made so family members providing support for disabled people could more flexibly use Carer Support and Individualised Funding. Purchasing guidelines for Carer Support and Individualised Funding were adapted so disabled people and families had more choices about how to use their funding, including being able to purchase items such as books, technology and exercise equipment.

These changes align with the **Enabling Good Lives approach** and the **Mahi Aroha Carers' Strategy Action Plan 2019-2023**.

Budget 2022 funding (over four years) of \$39 million for Whaikaha for paid whanau support in disability services, is supporting this initiative. If you have any questions, please contact your NASC.



Facts And Figures



KIDNEY FACTS

- The kidneys have a higher blood flow than even the brain, liver or heart.
- The kidneys reabsorb and redistribute 99% of the blood volume and only 0.1% of the blood filtered becomes urine.
- Each kidney is about 4½ inches (11.4 cm) long.
- Each kidney weighs approximately 170gms and is the size of your fist.
- The kidneys of a newborn baby are about 3X larger in proportion to body weight as in the adult.
- The volume of urine excreted daily varies from 1000 to 2000 ml (averaging 1500 ml).
- What year was the first successful kidney transplant? (1954 with identical twins in the US).
- Your kidneys represent about 0.5% of the total weight of the body, but receive 20–25% of the total arterial blood pumped by the heart.
- Your kidneys receive about 5.6 litres of blood per hour.
- Each kidney contains approximately one million nephrons.
- Placed end to end, the nephrons of one kidney would stretch about 8 km.

RENAL STATISTICS

The 45th Annual ANZDATA Report (2022) includes analyses of data to 31st December 2021.

For the survey period ending 31-December-2021, all renal units across Australia and New Zealand contributed data to the Registry.

This report produces a wide range of statistics relating to incidence, prevalence and outcomes of treatment, of those with end stage kidney failure.

For more info click : <https://www.anzdata.org.au/report/anzdata-45th-annual-report-2022-data-to-2021/>

With Thanks

The Kidney Society is a well-respected charity that relies on public donations, bequests, sponsorships, and other forms of financial support from the community in order to be able to meet the needs of those with a serious kidney condition. The Society's services are provided to you free of charge because we firmly believe that everyone with a kidney condition should have access to good quality support and information.

We offer our sincere thanks to the following Trusts and Foundations who have recently provided grants to help fund our client services:

- | | |
|--|----------|
| • Bay Trust | \$20,000 |
| • Trust Waikato | \$8,000 |
| • Ernest Hyam Davis & Ted and Mollie Carr Legacies | \$10,000 |
| • MSD Care in the Community Disability Welfare Fun | \$40,000 |
| • North and South Trust | \$7,000 |
| • Frimley Foundation | \$9,000 |
| • DV Bryant Trust | \$5,000 |
| • Oxford Trust | \$5,000 |

We acknowledge, and are grateful for, the generous support received from all of the organisations listed above.

In Memoriam:

Donations have been received in memory of:

Zelma Forster
K J Tailor
John Spence

Val Mortensen
Marie Gock
Gordon Tang

We offer our thoughts to family and friends and thank them for their support.

Xmas appeal

Special thanks to all those who contributed to our Christmas appeal. With your generous support close to \$4,000 was raised for client services – an amazing effort!

Donations:

The Kidney Society welcomes public donations, and these are tax deductible. Donations can be made via the Society's website or directly into our secure bank account. Details below:

- Website address is: www.kidneysociety.org.nz
- Account number: 12-3032-0705009-00

Please include your details so we can send you a receipt for tax purposes.

We would also like to offer our sincere thanks to Dr Hari Talreja and the rest of the renal team at Middlemore for an extremely generous Christmas donation of \$950! It is so humbling to receive this kind of support from our great friends 'just up the road' – many thanks again.

If you would like to talk to us about a donation, sponsorship or fundraising event, please contact John Loof on mobile: 021 663 435 or email: john@kidneysociety.org.nz

- * A **\$20 donation** supports a client to receive this magazine for a whole year!
 - * A **\$96 donation** funds the purchase of 20 Wellness packs for clients.
 - * A **\$240 donation** funds a series of home visits to clients
-

[Contributions to the Kidney Society News](#)

Do you have a travel or holiday story to share?

Do you want to write about how you survived the February disasters?

Do you have some tips for others who have, or are planning to work as well as dialysis?

Please send to: nora@kidneysociety.org.nz