

No. 238 November/December 2023 & January 2024

The Kidney Society

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

Venkateshn's Journey

Ven's journey paints a realistic picture of what some of those living with Kidney Disease may go through.

While everyone's journey is very different, it shows the importance of self-care, sticking to treatment plans, taking care of your wellness, and having strong support systems are all very important.



Read Ven's story inside.

The Kidney Society “Who, what, where.”

P O Box 97 026 Manukau City, Auckland 2241

Phone: 09 278 1321, or FREEPHONE: 0800 235 711

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 is our Community Health Educator 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 February/March/April 2024 News: Thursday 1st February 2024. 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>			



Kia ora, Malo e lelei, Talofa lava, Kia orana, Bula and greetings 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.

It's hard to believe we have almost come to the end of the year, one that will be remembered for many things especially several major weather events that affected so many of us.

I would like to begin by thanking the amazing Kidney Society team for all their hard work over the past 12 months – well done to Gina, Brian, Tracey, Maria, Ashley, Jenny and farewell to Kristin who leaves us after almost 2 years. And thanks to Nora who produces this magazine. I'm also delighted to introduce our new Social Worker, Nuisulu Hellesoe who will be starting with us shortly. Having a Social Worker allows us to provide a broader range of essential support for our clients and to work more closely with regional renal services.

A key feature behind our service expansion is the success we are having with our fundraising and I congratulate all who entered and supported this year's Auckland Marathon and helped us raise over \$11,500.

As 2023 draws to a close, I would like to wish all of you a happy Christmas and a safe summer.

Nga mihi,
Regards

John Loof, Chief Executive Officer

john@kidneysociety.org.nz



Kidney Society Events

Gisborne Advanced Kidney Care Session For people heading towards dialysis (but anyone can attend)

With the Pre-Dialysis Team and Brian
from the Kidney Society

Thursday 23 November, 10 am to 2 pm

Gisborne Presbyterian Church, 176 Cobden Street, Gisborne
Please contact Brian for information and if you would like to
attend: 027 715 3949, email brian@kidneysociety.org.nz

Hawke's Bay Unit and Home Visits

Tuesday 12 and Wednesday 13 December

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

It's been a while, let's catch up!

To all our clients who we have not had contact with during this
year, we have not forgotten about you.

We invite you to give us a call, text, or email just to let us know how
you are managing (good or bad).

If you would like a visit, are currently struggling, or are in need of
some assistance or a listening ear, **PLEASE give us a call.**

We would love to hear from you otherwise we will try to catch up
next year. To all that we have seen or phoned, you are welcome
to call us anytime.

Brian: 027 715 3949

Tracey: 027 378 4544

Call the office on 0800 235 711 and they will put you through to us.



Walking Group in Whangarei

For all our nature and walking enthusiasts in Whangarei, Sport Northland is offering an excellent **Totara Track Loop walking group**, where community members come together for a planned social outing to boost motivation.

Who's it for?

The walk is appropriate for those who are confident and able to walk a distance of 2.7 km without resting. This walk operates along the same basis as a group of friends going for a walk together, with the added bonus, a 'Walk Leader' to encourage participation and safety. Please consider your own safety and the safety of others when participating.

When & where?

The Walking Group meets each week on Wednesdays (weather permitting) on the footpath outside the Totara Café (11 Wairau Drive, Totara Parklands, Tikipunga) ready to depart on the walk at 10.00am.

Want to join?

Get in touch with event lead, Mark Burkill on 021 0268 0985 for more info.



Switching To Digital! Kidney Society Magazine Is Online

We want to say thank you to everyone who has now made the switch to digital, helping us be eco-friendlier and more cost-effective. For those who'd still like to make the switch, you can still do so and gain instant access to our November magazine. All you have to do is email us at contact@kidneysociety.org.nz and let us know. Additionally, we'd like to remind anyone who is visually impaired that our online magazine allows for zooming so you can make the text larger, and there are online options available for listening to the magazine as well. And... big congratulations to **Phillipa Crocker**, who is the winner of a \$50 Prezzie card for switching to the digital version of the Magazine!

Diabetes Action Month

November 1st to 30th, 2023

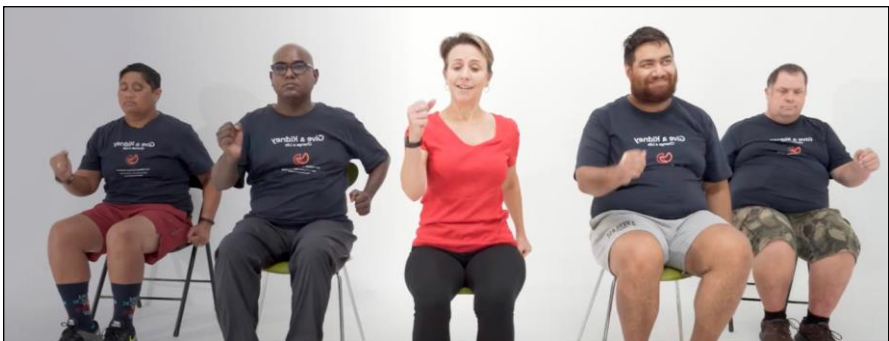
Diabetes New Zealand is on a mission this November during Diabetes Action Month, and it's all about safeguarding the vision of those affected by diabetes.

With their theme, "Eyes on Diabetes," the focus is clear: raising awareness about the importance of diabetes prevention and management. Diabetes Action Month is New Zealand's most significant awareness campaign, rallying the nation to tackle its fastest-growing health condition.

There are several ways you can get involved. You can check out Diabetes NZ's eye health resources and facebook live sessions to get more information. You can also join Sneaker Friday (November 17th) a day when you simply wear sneakers on this day and help raise awareness.

Find out more here on: <https://www.diabetesactionmonth.org.nz>

4-Week Wellness Challenge COMPLETE!



Congratulations to all the participants of our 4-Week Wellness Video Challenge! We are incredibly proud of your dedication and commitment to your wellbeing throughout this journey. We really hope you enjoyed this, and it was valuable.

For those who may not be familiar with the challenge, it was a 4-week challenge where we sent out weekly wellness challenges to those who signed up. These challenges had a variety of exercises

and goal-setting activities, all with the goal of helping clients embed wellness into their lives in a way that felt right for them.

As we move forward, we are eager to continue providing resources that are both relevant and valuable to you. Your feedback is very important to us so please do share your thoughts and let us know what tools and resources would best support your wellness journey. Once again, thank you for being a part of the Kidney Society Wellness Video Challenge! Please don't forget we have a Wellness Challenge so do like and subscribe so you can easily find the videos and use them as you wish.

<https://www.youtube.com/@kidneysocietyadks>



Renal Diabetes Study Day in Hamilton

Our amazing educators, Brian and Tracey, attended and participated in a Renal Diabetes Study Day in Hamilton. It was great to have the opportunity to provide valuable information about the Kidney Society to healthcare professionals who are actively involved in the care of those with chronic kidney disease (CKD) and diabetes control.

We had some great feedback from Pinnacle Health:

“We would like to extend our heartfelt thanks to you all for giving us your time, not only yesterday but the time you spent preparing such amazing presentations for our group of nurses, pharmacists, and one dietitian.... It was a great day of learning, and everyone took something positive away with them that they can put into practice with their patients.”



Does everyone with kidney disease need to follow a kidney diet?

There is no specific kidney diet.

Dietary advice will be different for everyone. It is important that you do not change your diet just because someone else has or because you have read something on the internet. Everyone has different needs depending on their stage of kidney disease and the treatment they are having, so it is important that you only follow advice which has been given to you personally.

If you do need to make some changes to your diet for your kidney disease, you will be referred to a kidney dietitian.

What does a kidney dietitian do, and how they can help me?

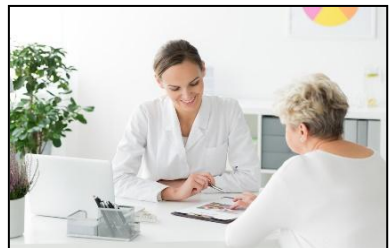
A kidney dietitian (also known as a renal dietitian) is a health care professional who helps support you to make the best choices for your health by giving you advice on your food and drink choices that suits your individual lifestyle. They are there to make it easier for you to know what to eat when you have kidney disease.

You may think a dietitian will tell you to cut out lots of foods, however often this is not the case. Their goal is to help you include foods in your diet that will be beneficial to your health and kidneys, and that you enjoy.

What will happen if I see a kidney dietitian?

They will ask you questions about your current medical conditions, medications, and about the types and amounts of food and drinks you have.

They will also look at your blood test results to see what changes will be most important for you.



You are also welcome to ask questions, so come prepared with any questions about food and drinks when you attend your appointment if you would like. Together, you and the dietitian can make a plan and discuss any changes with food and drinks that will be best for you.

What kind of dietary advice may be helpful for people with kidney disease?

- Eat regularly over the day and include a variety of foods.
- Try to eat mostly fresh foods rather than takeaways or foods in packets.
- Limit your salt intake - try to flavour meals with herbs and spices instead.
- Reduce alcohol.
- Water is the best choice of fluid.



How can I see a kidney dietitian for more advice?

You can ask your doctor, nurse, or other health care professional to refer you to a kidney dietitian.

Kidney Dietitian Team from Te Whatu Ora, Waitemata

An important quote to remember.....

“Often the people who do the best, are the people who eat well”

Blueberry Lemon Ice blocks

(makes 6 delicious ice blocks)

Ingredients:

Blueberry Layer

- 2 cups blueberries
- 5 tablespoons fresh lemon juice
- 2 teaspoons honey
- 1/3 cup water

Lemon Layer

- 1 cup lemon flesh (pith removed)
- 1 cup water
- 3 teaspoons honey



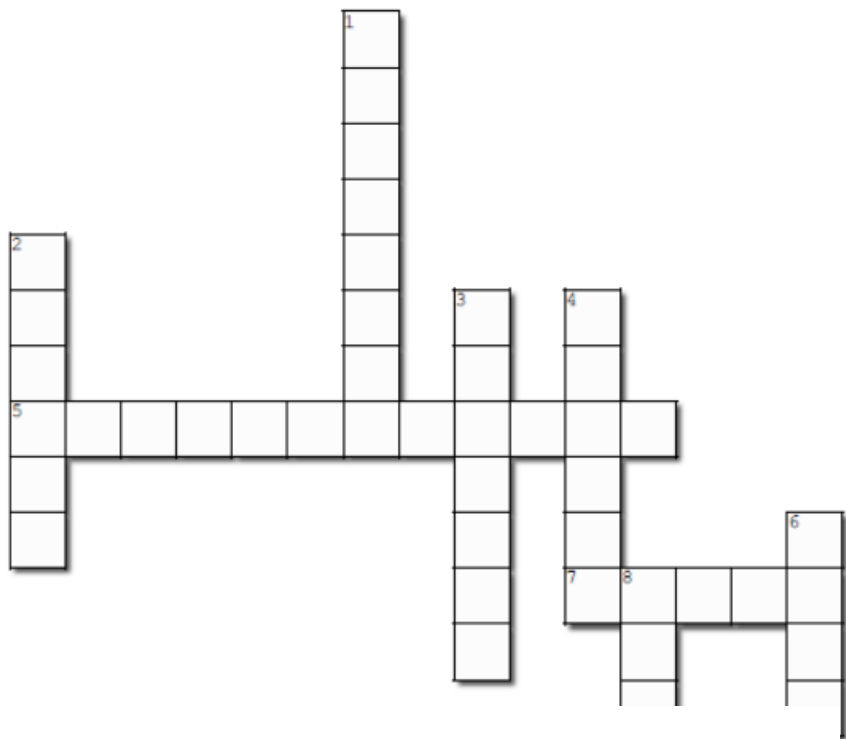
Method:

1. Place blueberries, lemon juice, honey and water in a blender and blend until very smooth.
2. Pour through a fine mesh sieve, pressing on the mixture with the back of the spoon to get as much of the goodness through.
3. Pour the sieved blueberry mixture into the ice block moulds to ¾ full.
4. Place in the freezer for approximately 30 minutes.
5. Place the lemon flesh, water and honey in the blender and blend until smooth.
6. Pour through a fine mesh sieve, pressing on the mixture with the back of the spoon to get as much of the goodness through.
7. Take the partially frozen blueberry layer out of the freezer and fill each mould to the top.
8. Insert wooden ice block sticks and freeze until firm, around 4-5 hours.
9. Enjoy!

Recipe adapted from:

<https://www.nzwomansweeklyfood.co.nz/recipes/blueberry-lemon-ice-blocks-2038>

Complete the crossword puzzle below to find the lower potassium fruits



Down

1. What is a small citrus fruit?
2. A fruit used to make a common alcoholic beverage.
3. A large variety of small, red, pink and purple fruits, which are great in smoothies, porridge and dessert.
4. Green fruit grown on a tree from March to June.
6. Packham, bosc, nashi, winter nelis are all types of what?
8. In the nursery rhyme 'Little Jack Horner', what fruit did Jack pull out of the Christmas pie?

Across

5. The fruit has a shrivelled purple outside which doesn't get eaten.
7. An _____ a day keeps the doctor away.



This article was written by Stephanie Rozbicki and Rose Stirling on behalf of the Counties Manukau renal dietitians.

A big thank you to **Counties Manukau Dietitians** for this great content!

Colin's Story

Colin's dedication to deep-water aqua walking is truly inspiring. Despite the challenges of being on dialysis, he makes it a point to visit Westwave three times a week. What drives him is not just weight management but also a quest for better fitness and health.

Colin finds solace in the pool during quiet lunch hours, relishing the freedom of movement that water provides. It's more than just a routine for him; it's a lifestyle. Through his unwavering commitment, he has not only shed weight but also significantly improved his overall fitness and health. Colin's journey is an inspiration for anyone looking to start their own wellness journey.



If you're ready to take the plunge and follow in Colin's footsteps, our Wellness Educator, Tracey, is here to guide you. You can reach her at 027 378 4544 or email her at tracey@kidneysociety.org.nz

Easy SpinPoi for Beginners



A big thank you to SpinPoi and Kate Reigle-Van West for sharing their SpinPoi videos with us and allowing us to introduce them to our clients.

As many of you probably already know, Poi is a traditional performing art deeply rooted in the culture of the Māori and Pasifika people. For those of you who may not have heard of it, a poi is a weighted ball attached to a flexible cord that is used to spin and swirl around your body. Kate and the SpinPoi team have scientifically proven that these movements are a great way to boost both your mind and body's happiness. Poi involves the ideal blend of physical movement and mental engagement, keeping your brain and body in sync.

We want to share this video with you – including poi, a cultural treasure, which has shown substantial improvements in grip strength, balance, and sustained attention.

Ready to see it in action? Check out the beginners' seated poi video below on our Wellness Channel:

<https://www.youtube.com/@kidneysocietyadks>

And... we also have some exciting news! We're working on a tailored SpinPoi video for you! The video is being designed for our clients with Kidney Disease and will even feature a few of you. Keep an eye out for updates for this project.

Auckland Marathon - We Did It!



We're SO proud of our absolutely incredible Kidney Crew: **Tony, Denise, Tracey, Claudia, and John** who not only trained hard but fundraised hard.

We want to do a bit of a shoutout to this team - your support has been nothing short of amazing, and we can't express enough gratitude for your contributions.

This has been the first year that the Kidney Society has been involved in the Auckland Marathon and peer-to-peer fundraising of this sort so

the support we've received has been truly inspiring, and it's been so great to see our success.

We're already excited about the next marathon! Who's in?

Venkateshn's Journey

We recently spoke to one of our very resilient clients, Venkateshn (Ven) Asiriah, who shared his journey of being diagnosed and living with Kidney Disease.



It all started in June 2014 when he found out he had Kidney Disease. Ven was shocked, sad, extremely angry, and confused because the decline of his kidneys over time was not raised as a concern as it should have been. He had always led a healthy lifestyle so the diagnosis was a shock. In 2015, Ven had a stroke and became paralysed. He had to recover

from this while living with kidney disease at the same time.

Over the years, he's been on different treatments like haemodialysis and peritoneal dialysis as well as trying alternative therapies like ayurvedic treatments and acupuncture. Being on dialysis has been a real challenge and having to commit to 3 times a week and in total 15 hours of being connected to a machine per week.

Ven's strong spirit helped him find support from other people and other places. Ven is thankful for the Kidney Society and in particular for Wellness Educator, Tracey Drinkwater.

"She has been very supportive from the very beginning.

The amazing thing about Tracey if she can't give you an answer, she will direct me to the necessary person. She is very resourceful."

When there is no way out, the only way is to roll with it. Once again during those difficult times, Tracey would just talk to me."

Ven stayed resourceful and reached out to people who were on dialysis or had received a kidney transplant because they understood what he was going through.

Kidney disease changed many things in Ven's life. He doesn't enjoy food as much as he used to, has a lot less energy and tasks like travelling or working have become difficult. Some relationships suffered as people didn't quite understand the impact of Kidney Disease.

Ven has had to make significant changes in his life, like watching how much water he drinks and being very careful about his diet. His family, especially his parents, have been a big source of emotional support.

Managing emotional and mental well-being is definitely not an easy task while living with Kidney Disease. The treatments and surgeries took a toll on Ven, but the support he received from psychologists like Kat Skinner who stepped outside the box to find solutions, proved invaluable. He also expressed gratitude to Rita and her team at Tamaki Health's Self-Management Team, a part of the Self-Management Chronic Team, for their helpful assistance.

Despite all the challenges, Ven has been achieving a lot. It's been truly inspiring to see that Ven started work last year which he said really helped increase his confidence. Ven started a degree in psychology, even became a homeowner and he also supported his mother during her open-heart surgery.

His advice to others facing similar challenges is not to blindly trust doctors and GPs and to be vigilant and get second opinions if you are unsure. Ven says one must take care of oneself, attend dialysis as you need to take care of your exercise, diet, and medications and their side effects, and be aware of your energy levels".

"Having a relationship with the Kidney Society is a must as it gives you a sense of belonging, provides support and care - as sometimes support from the hospitals can be rather limited due to resourcing."

Ven's journey paints a realistic picture of what some of those living with Kidney Disease may go through, while everyone's journey is very different, it shows the importance of self-care, sticking to treatment plans, taking care of your wellness, and having strong support system are all very important.

Ven, we are truly inspired by you, your positivity, strength, and resilience and we thank you for sharing your story with us.

Renal Health Psychologists

Counties Manukau District

Kia ora, Talofa, Mālō e lelei, Kia orana

Living with kidney disease can be challenging for the person diagnosed, their whanau, and their community. Not only can it impact physical health, but it can also impact other areas of your health such as your emotions, wairua/spiritual connections, and the relationships you have with your whanau/friends/community.

One of the reasons a diagnosis of kidney disease can be so challenging is because it comes with a lot of change. Amongst other things, there may be changes to your diet, treatment/medications, and daily routines.



On top of this, a huge amount of information comes with a diagnosis of kidney disease, which at times can feel like learning a whole new language!

With so much change, it is normal for people to feel overwhelmed, worried, anxious, frustrated, angry, low, or depressed at points in their journey. Research tells us that experiences of anger, anxiety and depression are common for people with kidney disease (Gadia et al., 2020; Kunwar et al., 2020). Just like it is important to care for your physical health, it is also important to care for other aspects of your health.

People that come to see us often have good ideas on how to look after their emotional/spiritual and relational health, such as connecting with whanau, enjoyable activities, or community events. However, sometimes these ideas don't come easily, you may feel a bit flat, or it may seem as though there are lots of barriers in your way.

Renal health psychologists help by working with you to navigate and manage challenges that can arise with kidney disease and its

treatment. We are trained to understand kidney disease, dialysis, and transplants, and how this relates to behaviours, thoughts, and feelings. In our kete are a range of proven therapies that can support a variety of challenges you may face. Areas we often work with include: anxiety and stress, grief, sadness, depression, anger, symptom management e.g. pain, lifestyle changes, sleep challenges, difficulty taking medication, fear of needles or medical procedures, and adjusting to life with a long term condition.

How can I see a renal health psychologist?

At Counties Manukau, we work across inpatient settings and dialysis units, and we have outpatient clinics (offering face-to-face, tele-health, and Zoom sessions). We are far less scary than what you may have seen on TV – we don't wear white coats nor do we hover over you as you lay on a couch!

Whether you are under Counties Manukau or another region you can ask staff from the Kidney Society, your nurse, doctor, or other health professionals for a referral to the renal health psychology service for free, confidential support.

Counties Manukau Renal Health Psychologist



**If you get stuck...
our team is here to help!**

You can call the Kidney Society for free: 0800 235 711.

- ❖ If you can't get the answers, the information or help you need:
 - from a doctor, nurse, or other health professional.
 - from Work and Income (WINZ), ACC, Needs Assessment (NASC) or another Government department.
- ❖ If you do not understand what they are saying.
- ❖ If you don't know what to do next.
- ❖ If you have a letter, you do not understand.

CALL US!

Sometimes you just need help finding ‘the words’ to use’ or ‘the questions’ to ask, our staff can help by pointing you in the right direction.

A Medical Alarm for Peace of Mind

For people who have a health condition or disability a medical alarm can give peace of mind in the event of a medical emergency, whether you are at home or out and about.

Medical alarms generally come as small, wearable pendants that are connected to emergency medical teams, so that assistance can be despatched right away. In New Zealand, there is a cost to rent and monitor a medical alarm.

There is a cost to rent and monitor a medical alarm and the weekly charge to monitor a medical alarm varies between suppliers.

Provided you are eligible for the special Disability Allowance the cost of renting a medical alarm may be fully funded.

You must have a health condition or disability that is likely to last at least 6 months from when you were diagnosed.

You don't have to be on a benefit to qualify for a Disability Allowance.

If you already have an 'in-home' medical alarm (that only works inside your home) and, would like an 'anywhere' medical alarm (that works outside of your home as well), you'll need to:

- see a medical practitioner to see whether you qualify.
- apply to change it.

<https://www.workandincome.govt.nz/eligibility/health-and-disability/medical-alarms.html>

Zero Data

For some New Zealanders, the cost of mobile data can be a barrier to accessing essential health and wellbeing information and digital health services. Those who cannot access information and services often have the highest needs.

Zero Data removes this barrier by providing free access to key health sector and other government websites accessed through the www.zero.govt.nz website for anyone using the Spark, Skinny, One NZ, 2degrees, Warehouse Mobile, Slingshot or Orcon mobile networks.

The purpose of Zero Data is to ensure all New Zealanders can access essential information and digital services.

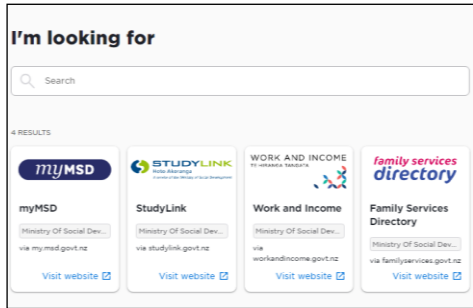
<https://portal.zero.govt.nz/0ecf2ab113c023c8de862f3822ad4687/>

If you're running low or have no data you can now access the websites of health, social services, education, housing and more for free from your smart phone. Just make sure data is turned on and visit **zero.govt.nz**. From there you can access the government department you need as shown below, with some agencies showing as an

example
(but there are more to choose from).

AGENCY ▾

- Health
- Education
- Ministry Of Social Development
- ACC
- Ministry Of Justice
- Kāinga Ora Homes And Communities



Does everyone choose to have dialysis treatment?

You have the right to make your own choices about how you are treated for kidney failure. That means you can choose not to start dialysis. It is important for you to have all the information you need to make this decision.

People with complete kidney failure will die as a consequence of this if they don't have treatment with dialysis or a kidney transplant.

- Dialysis treatment can greatly improve the quality of life of many people with kidney failure.

- However, dialysis treatment is demanding and time-consuming and requires lasting changes to lifestyle.
- Many people on dialysis are able to make these adjustments and still lead a fulfilling life, but dialysis is not a cure-all.
- Dialysis may not improve the quality of life for some people, particularly if they have other serious health problems such as heart disease or cancer.

Some people decide to have 'conservative' treatment (also called, palliative or supportive care) rather than have dialysis or a transplant.

What is conservative treatment?

The aim of conservative treatment is to manage the symptoms of kidney failure without using dialysis or transplantation.

Conservative treatment includes medical, emotional, social, spiritual, and practical care for both the person with kidney failure and their family/whanau.

Although many people who choose conservative treatment are elderly, old age is not the only reason to choose this option.

If you choose to have conservative treatment, your kidney unit will continue to look after you for as long as you wish. You may also wish to be cared for by another service such as Hospice/Palliative Care in collaboration with your family doctor.

Why might somebody decide not to have dialysis treatment?

There are a number of reasons why somebody might decide to have conservative treatment for their kidney failure.

- They have been advised that they have other serious illnesses that will shorten their life, and that the burden of dialysis treatment would be greater than any likely benefits.
- They consider the dialysis treatment so demanding and time consuming that it will change their lifestyle so that they will have a very poor quality of life. They are being treated with dialysis, but now have another serious physical illness such as severe or worsening heart failure that will shorten their life.
- They are being treated with dialysis but consider that their quality of life has become very poor.

Can I decide not to have dialysis treatment?

Yes. You have the right to decide not to start dialysis if you feel that the burden would outweigh the benefits and reduce your quality of life. You also have the right to stop dialysis at any time after starting dialysis. Only you know what it is like for you to live with kidney failure.

It is very important that you have plenty of time to discuss the issue thoroughly with those close to you and with members of the renal team looking after you.

The kidney care team will ensure that you receive the necessary information to make a good decision and will support you.

What does conservative treatment involve?

This treatment involves a team of people from the hospital, the community, and your home. Your medical care will normally be managed by your kidney doctors together with your family doctor.

Doctors, nurses, and other people in the kidney care team will make sure that you have:

- Medicines to protect your remaining kidney function for as long as is possible and appropriate. This will include advice on preventing further kidney damage by avoiding drugs such as Brufen, Neurofen and Voltaren.
- Advice on the right diet. But, as your kidney failure worsens and your appetite deteriorates, sticking to a rigid diet will become progressively less important and feasible.
- Advice on how to avoid dehydration which may worsen your kidney failure. Dehydration can develop during illnesses that cause diarrhoea and/or vomiting.
- Remember to have your annual 'flu jab. If you know that your time is limited, however, this may not be appropriate.
- Medicines to treat other symptoms of kidney failure, such as feeling short of breath, nausea, anaemia (low blood count), poor appetite or itchy skin.
- Adequate community support, such as home help and district nursing.
- Referral to a local Palliative Care service. The aim of palliative care is to keep you active and independent for as long as possible as well as supporting you in the final stages. Palliative

Care focuses on support and comfort and works alongside your family doctor.

- Adequate information on where to get financial support, assistance with making a will and, if necessary, the completion of an Advance Directive if you have particular wishes about end of life care that you want to be respected.
- Adequate support for your family/whanau. Counselling for family members is sometimes needed to cope with the prospect of losing a loved one. You may also help to inform and support your family about your decision.
- Ultimately once you have died, your family may wish to receive bereavement support. Your family doctor and/or Palliative Care Service can coordinate this if need be.

What if I cannot decide?

Sometimes it is difficult to decide whether dialysis will be worthwhile.

In this case, your kidney doctor may suggest you have a trial period of dialysis; usually a few weeks. Embarking on such a trial is very arduous so ensure that you discuss it fully. During this time you, your family and the kidney care team will see how dialysis is affecting you, both medically and psychologically. The doctor and other members of the team will then be able to talk with you and decide together whether it is in your best interests for dialysis to continue.

Talking to a trusted family doctor might help you come to the right decision for you.

How long will I live if I don't have dialysis?

This varies from person to person and depends on many factors. An accurate prediction is very difficult to make as each situation is different.

Important factors are:

- How much kidney function remains.
- How sick you are from other serious illnesses.
- How determined you are to reach milestones or special events.

Chronic ill health affects both your physical and emotional strength – sometimes it is just too hard to fight anymore. If this is the case, then it may mean that you deteriorate more quickly than anticipated.

It is reassuring to know that most people who die of kidney failure are able to be kept very comfortable and pain free. Other troublesome

symptoms during this time will also be managed and your family/whanau will receive specific support to help them cope.

You have the right to re-visit your decision about dialysis at any time. Any concerns that you have will be addressed promptly by your kidney care team.

This is a sensitive and emotional issue. If you are worried about how you will cope, you can talk it through with a member of the team that you trust.

Will I have a choice of where I die?

Many people would prefer to die at home, where they feel more comfortable and can be in familiar surroundings. This is especially so when there is help from family, friends, or carers. Support from community services and your family doctor will be arranged before discharge.

In many areas, Hospice Care or Palliative Care is available and in this case, you may wish to receive such support. Hospices are not just for cancer patients, and it may be possible for you to receive such care if you wish.

A hospital admission may be another option for some people.

You should discuss these issues with the kidney team. The priority is to support you and your family as much as we can.

Is deciding not to have dialysis the same thing as taking my own life?

No. No one should feel obliged to receive treatments that are not right for them and ethically you do not have to have life-prolonging treatments if that is not your wish. Each person should be encouraged to make their own decisions regarding their health, and this should be respected.

Most religions believe that people have the right to decline medical treatment, including dialysis, if they feel it will not help them.

You may wish to speak with your religious advisor if you have any concerns about this.

If you have other questions or concerns, feel free to ask your kidney team or your family doctor.

<https://www.kidney.health.nz/resources/files/links/conservative-treatment-1.pdf>

Talking to Children About Kidney Disease



Having a chronic disease changes the lives of everyone in a family. When you are diagnosed with kidney disease, your children or grandchildren may come to you with many questions. Even the youngest kids can be aware of a change in the family, although they may not be able to verbalise their feelings.

Your first instinct may be to protect your child or grandchild by withholding information. Usually, this idea isn't the best. Children may already sense something is going on in the family, sometimes because of overhearing bits of conversation or seeing the worried expressions on a parent's or grandparent's face.

Talking to your kids about your chronic kidney disease (CKD) can help them in several ways, including:

- Feeling less alone.
- Learning to trust their own perceptions.
- Appreciating the fact that you're sharing this information with them.
- Being reassured that they are important to you.

Difficult questions children ask about kidney disease

Sometimes it's hard to answer a child or teenager who asks a difficult question. Prepare yourself for questions such as:

- Why are you sick?
- Will I get sick too?
- When will you be well again?
- What is dialysis?
- What is a kidney transplant?
- Who will take care of me if you're too sick to do it?
- Are you going to die?

Sometimes a child will have a question but not voice it. However, if your child does ask you a question outright, be as open as you can.

Explain why your kidneys are not functioning the way they should and reassure the child that you are getting the finest care possible. Explain dialysis and transplantation so they have a better understanding of your current or future treatment. Talk about other family members or friends who will be helping the family. Admit that you get worried sometimes too, but by supporting each other, you know your family can get through this tough time.

Death is a difficult topic to discuss, but you can reassure children by saying that you are getting the best care possible and don't think you are going to pass away tomorrow or anytime soon.

Also, tell them what you can and can't do. For instance, you might not be able to participate in the 5K run sponsored by your child's school, but perhaps you can still bake treats to share at the event.

Talking to young children about kidney disease

Although it is a good idea to be clear when explaining kidney disease to kids, you should also take into account their age and how much information they can handle.

If you have a very young child in the family who is not able to fully comprehend your disease, it's important that you convey your love and concern with some extra attention. Giving extra hugs and comfort can go a long way toward making your young child or grandchild feel reassured. Maintaining their routine as much as possible will also help a child feel protected, as will being surrounded by familiar people and things.

A child who is 3-5 years old is in a stage of development where they may experience feelings of guilt. They may think that somehow your being sick is their fault. However, they aren't old enough to understand death or worry about you leaving.

Answer their questions as clearly as you can without overwhelming them with too much information.

Sometimes kids in this age group will idolize the family member who is sick; other times, they will transfer their feelings to another adult, such as a teacher or family friend. Realize that these behaviours are normal and reflect the child's desire to cope with a complex situation.

Talking to school-aged children about kidney disease

Children who are between the ages of 6 and 9 are more likely to worry. Ease their mind by explaining your treatment and what is involved. Children this age can understand the basics of dialysis. Some children even go to the dialysis centre with their parents or grandparents.

Children 9-12 years old have a better understanding of how the human body functions. They can grasp what kidney disease is and its possible long-term effects. Help them understand what you are doing to slow the progression of CKD; or if you have end stage renal disease (ESRD), that you need dialysis to replace lost kidney function.

Talking to teenagers about kidney disease

Teenagers are coping with double the emotions: they're trying to learn how to transition into adulthood, and at the same time they are coping with a loved one's illness. The stress a teen can feel may be displayed as acting out, trouble sleeping, sullenness and mood swings. They may even express their feelings as anger, when in fact they are experiencing sorrow and fear.

Because they have more experience than younger children, teens should be talked to on a more adult level. A teenager may be able to handle more information and ask you more questions about your condition.

In order to answer a teen's inquiries, offer to explore the education articles on DaVita.com together, as well as other trustworthy resources such as the National Kidney Foundation or the Centre for Disease Control and Prevention (CDC).

When teenagers know more of what you're going through, they may be more inclined to help around the house or take on more chores. A mature discussion about kidney disease may help them feel less overwhelmed so that they can still concentrate on schoolwork, after-school activities and a normal teenage social life.

Summary

Rather than hiding your health condition from your kids, **have a conversation with them about kidney disease**. Explain as much about CKD and its treatments as they can understand based on their age. Give them a chance to ask questions, reassure them that you are getting good treatment and keep them informed about any changes along the way. By starting a conversation and answering their questions, you and your children can feel more at ease.

<https://www.davita.com/education/ckd-life/support/talking-to-children-about-kidney-disease>

There are many more great resources available on the Davita site.

Accessing dialysis while on holiday

Dialysis 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.

<https://www.tewhatauora.govt.nz/our-health-system/claims-provider-payments-and-entitlements/accessing-dialysis-while-on-holiday/>

HOLIDAY DIALYSIS INFORMATION

Private Holiday Dialysis

For people looking for **private dialysis treatment while visiting New Zealand**, the only available facility is based in Auckland.

Contact Chris at: dialysis@kidneykare.co.nz

(see KHNZ website to download: [Dialysis Information Request.pdf](#))

Mobile Dialysis Units

Waikato: Freedom Dialysis Project - Camper Van

The van is available for hire, pick up from Waikato Hospital, Hamilton. \$50 per night, \$200 bond (refundable) and \$60-80 for cleaning. It has a warm heater system so it can be used all year round. It has a Fresenius 4008b machine in it.

Bookings available by contacting Home Haemodialysis Unit, Waikato Hospital, Contact: Lynne Bester Phone 0800 77 22 99 and push 5 for reception. Email: Lynne.Bester@waikatodhb.health.nz

Christchurch Mobile Dialysis Unit

Conditions of use apply, bond and hire fees must be paid in full by either cash or cheque at least two weeks prior to picking up the vehicle. Take off on your long awaited (aren't they always) holiday weekend or plan a spring break. Our mobile Dialysis Unit is fully equipped for all dialysis needs.

Bookings available by contacting Dialysis Services, Christchurch Hospital, Phone: (03) 364-0614, Email: dialysis.workshops@cdhb.health.nz Address: Private Bag 4710, Christchurch 8140. New Zealand.

Hire Charges:

The current fees are as follows: (all include GST, insurance, and road user charges): NZ dialysis patients: @200 bond plus \$50/day. Overseas dialysis patients: \$500 bond plus \$125/day (\$NZD).

Conditions of use:

Bond and hire fees must be paid in full by either cash or cheque at least 2 weeks prior to picking up the vehicle.

Getting Motivated Again

Well we've nearly made it!.. We just about got through 2023.

Over the holiday season no matter how you celebrate it, many of us will hit the OFF switch and just exhale. But then, at the beginning of the New Year, it is good to focus on moving forward and being motivated!



For example, once you have got out of your usual routine of going for a walk, you start losing fitness (it only takes 2 weeks for this to happen), you feel more tired than usual, you don't have the energy to go for a walk, your fitness reduces further, it starts affecting your blood pressure, circulation, sleep pattern etc etc....



You CAN reverse the flow of the negative cycle back to a positive one!

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 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:

- | | |
|----------------------------------------------|-----------------|
| • Maurice Paykel Charitable Trust | \$5,000 |
| • Trust Tairawhiti | \$10,000 |
| • Foundation North | \$20,000 |
| • Eastern and Central Community Trust | \$10,000 |
| • The Trusts Community Foundation | \$7,597 |
| • Bay Trust | \$25,000 |
| • Milestone Foundation Limited | \$7,000 |
| • Four Winds Foundation | \$15,000 |
| • Page Charitable Trust | \$7,000 |
| • Dragon Community Trust | \$5,579 |

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 **John Andrew Spence**. We offer our thoughts to family and friends and thank them for their support.

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
- Bank account number: **12-3032-0705009-00**

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

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.