

The Kidney Society

'Helping people with kidney disease get on with life'



Thanks to our amazing team of volunteer knitting ladies our community health educators Brian and Kristin recently dropped off some warm winter woollies to grateful clients in Kaitiaia.

The Kidney Society News is proudly supported by our printers

The Kidney Society “who, what, where”

P O Box 97026 Manukau City, Auckland 2241

Phone 09 278 1321, or FREEPHONE 0800 235 711

e-mail: kidneysociety@adks.co.nz website www.kidneysociety.co.nz

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>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 November/December News: Wednesday 12 October. Contributions are very welcome!</p>			
<p>Contact us for information or a chat, weekdays 9-5, phone 0800 235 711, email kidneysociety@adks.co.nz or just come to the Kidney Society Centre, 5 Swaffield Road, Papatoetoe, Auckland</p>			
<p>0800 235 711</p>			



Kia ora, Mālō e lelei, Talofa lava, Kia orana, Bula and warm winter greetings to you all

It has been a busy time here at the Kidney Society as we have grown our team, started work on a new website and finished our

financial year.

Recently it was also pleasing to hold our first pre-dialysis patient orientation session in many months. These valuable gatherings, which had been stopped because of Covid restrictions, are a great way of sharing important information to newly diagnosed clients / patients who are looking at starting kidney replacement therapy (transplant or dialysis). Of real value is the input from existing clients who have 'been there done that' and we thank them for sharing their personal stories on the day. Look out for a session happening in your area.

The end of the financial year sees the closing of our accounts and the annual audit. Closer to Xmas we will be holding the Society's Annual General Meeting. This is an important occasion for the Kidney Society, its members and clients. In the next issue I will share details about the AGM in the hope that many of you can join us on the day, or on-line, as we share information about our highlights from the past year as well as our plans for the future.

Nora Van der Schrieck Scholarship Winner Announced

We are delighted to announce that the winner of the inaugural Nora Van der Schrieck Scholarship is

**Rajeev Kumar, a renal physiologist
from Auckland City hospital.**

Recently the Kidney Society Board decided to create a series of scholarships designed to support the development of renal health professionals working in our field and



also to acknowledge and mark the legacy of Nora's amazing contribution to the Kidney Society.

Applications came from across our region and Rajeev was deemed a worthy winner of the \$4,000 Scholarship which he will use towards his Master's degree.

Kidney Society CEO John Loof says, 'Congratulations Rajeev, we look forward to hearing how you progress with your studies'.

Please keep an eye out for the next round of scholarship applications that will open later in the year.

Introducing our new Community Health Educator Kristin Leslie

One of the realities of kidney health in New Zealand is that patient numbers continue to grow and this puts pressure on already stretched services. In response to this increased demand, we are



thrilled that a new team member has joined the Kidney Society.

Kristin Leslie has been appointed as the Society's new Community Health Educator and will be working closely with Brian. Kristin describes herself as a passionate and conscientious health care professional with over 20 years' involvement in primary and secondary health care roles. She has worked as a Clinical Educator for Aged Care, Disability, Community Care and Health Service Assistant (Theatre and Acute Care) and

has experience as an assessor for a community health care provider. Kristin trained as a nurse in Auckland and worked in New Zealand for a number of years before furthering her career in Australia. She has recently returned home and has quickly established herself as a valuable member of our small team.

When not at work Kristin likes nothing better than to spend time with her grandchildren, here in Auckland and "on the farm" in Te Awamutu.

No doubt many of you will get the chance to say "welcome Kristin" in the near future!

Magazine Survey Results

Many thanks to all of you who participated in our annual magazine survey. Your responses give us valuable insights into how we can make the magazine even better for our readers! And special thanks to all those who told us they would like to receive the on-line version of the magazine. Not only is this more convenient but it also saves money for the Society on printing and postage during these difficult times. Your feedback on any subject is always welcome.

ADKS Board Update

A vacancy exists on the Kidney Society Board. The Society is looking for new board members who are willing to help grow the organisation and its services.

Previous governance experience and knowledge of community health services is desirable but not essential. Strong community connections and the ability to influence are seen as being important. This is a wonderful opportunity for someone wanting to make a difference in the community healthcare space.

We particularly encourage applications from women, Tangata Whenua, Pasifika, younger members of the community, individuals with a disability.

Please direct all enquiries to Board Chair, Tony Miller via email - Tony.Miller@carters.co.nz

Ngā mihi, Regards,
John Loof, Chief Executive Officer

Kia orana and Talofa Lava,

Kia orana and Talofa Lava,

I am a Pacific Island student completing my Bachelor of Health Sciences degree at the University of Auckland.

My roots lay across the Pacific, my home is within the Cook Islands – *Tupapa Maraerenga, and Purapoto*, and Samoa – *Mata'utu-uta*. Being raised in South Auckland has grown my love for the Pacific, my culture is important to



my identity and how I want to carry myself in this world.

Giving back to my community has always been very important to me. Growing up I've been taught a Samoan proverb, "O le ala ile pule o le tautua" – the pathway to leadership is through service. This value shaped my decision to pursue this degree and bring positive changes to health. Although my degree can lead to different jobs, I'm drawn to the Health Promotion field. Ultimately, I'd like to support Māori, Pasifika, and South Auckland communities through empowerment.

I'm gaining a lot of rich experiences by working with the Society – I can see how they empower and support those living with challenging health conditions. Thank you to the team for supporting my education and teaching me how to support everyone through acknowledging each person's culture, histories, worldviews, and aspirations.

Fa'afetai lava, ia manuia

Lauryn Mehau

Kidney Society YouTube Wellness Channel

Use the link below,

<https://youtube.com/channel/UC1uP59-O1pCnuS97Y91Grg>

or put 'Kidney Society NZ' in the YouTube search field.



The channel has been developed for our clients so we can reach and support as many of you as possible, no matter where you are or what is happening.

We have started with some basic exercises and information to support people with CKD to improve and maintain their general wellness with safe and suitable exercises.

The first series of videos covers:

- How to improve your posture
- Exercise and ideas to improve your circulation in your hands and feet.
- Basic lower and upper body strength exercise to help with your mobility.
- 3 short chair-based exercise programmes to help you get started.

We would love your feedback on what YOU would like to see on the channel too.

All you need to do to find our YouTube channel is use the link <https://youtube.com/channel/UC1uP59-O1pCnuS97Y91Grg> or, once in YouTube, search 'Kidney Society'.

REMEMBER to CLICK SUBSCRIBE & LIKE!!

Tracey Drinkwater, Wellness Educator

027 378 4544, freephone 0800 2345 711 or email tracey@adks.co.nz

As the wellness educator for the Kidney Society I am known around the office as the "posture police" with the staff sitting up tall whenever I walk past. This is because posture plays a much more important role in our wellness than just making us look better.



An article published in the New Zealand Mental Health Association: ***"New research suggests an increased awareness of our posture can also bring great benefits to our mood. But it seems that by raising our head up and being aware of maintaining an upright posture, we may be able to boost our energy levels and mood"***.



Erik Peper is an internationally recognised authority on biofeedback, self-regulation and stress management. He suggests that our modern lifestyle has resulted in poor posture with many slouching while walking, sitting for hours collapsed in front of the computer or TV, or slouched forward while texting or working on smart phones. The findings suggest that for people with a history of depression, energy levels may covertly increase or decrease depending upon posture. When you have less

energy, you feel you can achieve less, and this feeling tends to increase depressive thinking." Good posture also makes you look better! I like to call it the "before and after photos" like the ones you often see in the weight loss pictures. Look at the difference in the

photos of the woman on the previous page and see how her entire body shape changes with better posture.

Yes, it is the same woman!

Poor posture can also have a physical effect on our body. Our heads are very heavy weighing between 3 & 5 kg as an adult. For many people who have poor posture their neck and shoulder muscles are not happy about holding up this weight which is actually the job of your “core muscles” - the muscles in your torso. Try holding a 3-5kg bag of potatoes up for any length of time and you will know how your neck and shoulders are feeling on a daily basis. Poor posture is literally **a pain in the neck!**

For many dialysis patients who spend many hours per week in a sitting position with their head forward and shoulders hunched they can feel a lot of discomfort and even pain in the upper back, shoulder and neck area. Add to that low energy and muscle loss and their posture can be the reason for a lot of extra aches, pains and general discomfort.

Poor posture also puts pressure on our lung capacity and abdominal area by reducing the area and compressing and restricting movement. This can make you feel tired and sluggish, restricting the breathing into your chest and diaphragm and even cause problems with your bowels & digestion.

Try this basic posture awareness exercise whenever you start feeling those shoulder and neck aches and pains or even if you are feeling low...

- Sit up tall in your chair as though your spine is being stretched by a rope from the top of your head through the ceiling.
- Roll your shoulders back and push them down.
- Feel your neck relax and imagine your head being weightless.
- Pull your chin back as though you are holding a grapefruit between your chin and your neck.
- Feel you back and tummy muscles tense very gently to support your spine.
- Hold this position and breathe comfortably.

For those of you who spend hours dialysing be aware of your posture during this time.

If you tend to read, are on a device or doing a puzzle try and set yourself up so your head, neck and shoulder posture is not dropped

forward. Using a tray table, holder or book cushion as pictured below can be very helpful.



Stop and lift your head regularly. Try doing some gentle neck and shoulder stretches to reduce the tightness building up in your neck and upper back area.

If you get that "BURNING" sensation in your neck or upper back area that is a signal from your body that your posture is poor, and you need to change your position.

We have a great video on Posture on our Kidney Society Wellness YouTube channel to help you improve your posture.

Use the link below or search Kidney Society NZ in the YouTube search bar.

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



Kidney Society Events

EVENING Pre-Dialysis Education, Mangere

with the Counties Manukau Pre-Dialysis Nurses
and Brian from the Kidney Society

Wednesday 14 September, 6.00 – 8.30 pm

Selwyn Anglican Church, 330 Massey Road, Mangere East
(corner Massey Rd & Hain Ave)

For information phone the Pre-Dialysis Nurse Specialist on
09 276 9944 Ext 2246

or contact Brian at the Kidney Society

Phone: 0800 235 711 or Email: brian@adks.co.nz

EVENING Pre-Dialysis Education, Papakura

with the Counties Manukau Pre-Dialysis Nurses
and Brian from the Kidney Society

Wednesday 2 November, 6.00 – 8.30 pm

Papakura Anglican Church, 40 Coles Crescent, Papakura

For information phone the Pre-Dialysis Nurse Specialist on

09 276 9944 Ext 2246

or contact Brian at the Kidney Society

Phone: 0800 235 711 or Email: brian@adks.co.nz

Travel throughout the regions for home visits has started again after a long 'Covid'-break. Our usual notices in the News should resume from the next News - meanwhile, call Brian at the Kidney Society, 0800 235 711 or email brian@adks.co.nz if you would like a chat.

Spring into spring with Seasonal Vegetables!

The benefits of vegetables:

The Ministry of Health recommends that New Zealanders should eat five or more servings of fruit or vegetables every day.

Fresh vegetables are naturally low in fat, salt and sugar, making them an excellent food choice. Vegetables provide energy, vitamins, minerals and fibre and there is growing evidence of additional health benefits from a range of antioxidants. Adequate fibre from vegetables is an important component of diabetes management, resulting in improvements in measures of blood sugar control.

Fibre keeps the digestive system healthy, helps keep a healthy body weight and decreases the risk of heart disease and cancer. Fibre has also been found to lower cholesterol levels by reducing the reabsorption of cholesterol produced by the body to help with the digestion of fat. It also helps you to feel fuller for longer.

Aim to make half your dinner vegetables and choose a range of different coloured vegetables. About one-quarter of the plate should be starchy foods for energy.

Starting your own vegetable garden

We're all looking forward to the delights of the upcoming spring season after a long, wet, windy and illness filled winter. Spring is a great time of year to make the most of your garden coming alive again and plan for a bountiful summer ahead. In fact, even not having a garden shouldn't be a barrier to being able to grow your own fresh produce and experiment with those green fingers! Read on for some tips & ideas to utilise outdoor space and delight in seeing your plants come to life.

Try growing your vegetables in a dug-in veggie patch, a raised bed/planter or in large pots and containers – even a bucket. Always ensure your plants have enough room for their roots before you start planting. Think about the outside space available to you – deck, windowsill and how much light will be available to make your plants thrive – most plants require a good deal of sunlight to encourage growth. Some plants are better sown in seedling trays to get started, or you can also buy seedlings from many shops, markets & supermarkets. The time of year & location within NZ will also

determine what you can sow & when, so always check before sowing or planting (this is usually stated on the back of seed packets).

CHECKLIST

- Suitable area/container for planting
- Good quality soil/compost
- Seeds or seedlings suitable for time of year
- Water & sunlight

What vegetables should I plant in the springtime?

Have a look at what vegetables will be most likely to thrive when planted in the springtime. Also look at choosing those that will be most appropriate for you, your whanau, your dietary needs and what resources you have available to plant. There are so many delicious vegetables you can plant in Spring. Some will be ready to eat within weeks, while others might be ready for your Christmas dinner (*depending on whether you plant seedlings or seeds*). Feed vegetables already planted with fertiliser to give them the nutrients they need to grow & remember to water them regularly.

Here are some good examples of vegetables to try:

LOWER IN POTASSIUM:

Broccoli	Carrots	Celery	Lettuce	Peas
				

Beans	Spring Onions	Cabbage	Cauliflower	Okra
				

HIGHER IN POTASSIUM:

Courgette	Spinach	Silver beet	Tomato	Potato
				

*For those on a potassium restriction, keep in mind that for those starchy high potassium vegetables (such as potatoes) cutting, boiling and draining water assists with reducing the potassium content.

Recipe idea: Smashed Cucumber Salad - serves 6

INGREDIENTS:

- 1 telegraph cucumber
- 1 punnet cherry tomatoes, halved
- 1 orange capsicum, deseeded, chopped
- 1 yellow capsicum, deseeded, chopped
- 1 shallot or small red onion, finely sliced in rings
- ½ tablespoon toasted sesame seeds



DRESSING:

- 1 teaspoon runny honey
- 1 tablespoon grated ginger
- 1 teaspoon sesame oil
- 1 tablespoon rice wine vinegar

For further inspiration head to <https://www.vegetables.co.nz/>

Waikato and Northland Renal Dietitians

Well, where to begin?



Me and my life long partner 🧘 we spend every night together

I remember a period of about 3 weeks, back in early June 2019, when I was suffering from severe lethargy. I would wake after a full night's sleep, shower and have to go back to bed as I had used all my energy just showering.

Towards the end of June, I had a period of 3 days where I remember nothing. I had conversations with my sons that I do not remember. Eventually, I went to see my doctor as I thought I was just fatigued. I was running my own marine engineering business and working 14-18 hour days, six days a week. The doctor sent me for a chest X-ray and told me to go to hospital as he thought I had pneumonia in both lungs. I drove home and packed a few things before going to hospital. I had another X-ray and was told they thought it was pneumonia too. They tried to take blood, but it was very hard. I was admitted to the short stay ward at north shore and spent a restless night. In the morning, I met an amazing doctor called Emad Mayer. He informed me that I had end stage kidney failure caused by a condition called vasculitis. He also told me that, had I not come into hospital on the Thursday, I would have been dead by the Sunday.

What followed was a whirlwind of treatments. I had a tunnel line fitted, was started on dialysis and also told I need to have my immune system suppressed to prevent the vasculitis causing more damage. The drug they administered was called cyclophosphamide and I underwent 6 treatments.

During the first few months, I was in and out of hospital with lung infections and fluid retention issues. I remained on dialysis for two and a half months when my kidneys showed signs of progress. The dialysis stopped and the tunnel line was removed. I continued to spend time in hospital with lung infections and water retention problems.

In late December, I had a very severe breathing problem which took me back to hospital. An amazing doctor, whose surname I have forgotten, was not happy with the 'pneumonia' diagnosis, asked for an echo on my heart. It showed I had suffered heart failure which

was caused by the drug cyclophosphamide. My heart's output, instead of being around 60% was down at just 19%. This had been the cause of the infections in the lungs.

The new treatments to help my heart meant that my kidneys suffered again and started to drop off. I spent months in and out of hospital trying to fix my heart condition whilst also trying to promote my kidneys to 'hang in there'.

I managed to stay clear of hospital for a few months then had an appointment with my new consultant, Jo Dunlop. I met her on the Wednesday, had a meeting with a PD nurse on the Thursday and was admitted to Middlemore on the Friday. A Tinkoff line was fitted and I started manual PD.

A few months later, I was admitted to hospital again needing a blood transfusion. It was then discovered that my heart was not doing as well as they had hoped. I was offered a place on a healthy heart programme to see if this would benefit me. I met a new cardiologist called Jamie Voss who told me it would take about 5 years for my heart to recover, if it did at all. Fortunately, with the help of some medicine, some absolutely amazing cardio physios and some awesome cardiac nurses, my heart repaired itself within 12 months. I owe those nurses and physios more than I could ever repay them.

Fast forward two years and I am happily on APD. I have just received confirmation that I am on the transplant list and I am living a good life. It has been hard at times. Mentally, I hit rock bottom and wondered if it was worth going on. Heart failure, kidney failure, mental issues and relationship problems all combined at once. I was lucky. I spoke to the psychotherapist that was offered and she helped me to realise that it was worth it to fight it. I lost my business as I was physically unable to do the work anymore. Despite all of this, I feel I am lucky. I have met some of the most amazing, caring nurses at the dialysis unit and on the renal ward. The support network available is the superb and it all combines to make you realise that kidney failure is just a condition. It does not rule your life. You can live a perfectly normal life if you just listen to the doctors, take the medicines they prescribe and talk to people that are there to help. I look at every day that I open my eyes as a bonus. Remember, every day that you are looking at a flower's petals, rather than being buried under their roots, is a day to savour.

Phillip Munn

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:

- J M Thompson Charitable Trust - \$35,000
- Chenery Memorial Trust - \$5,000
- Foundation North - \$20,000
- Maurice Paykel Charitable Trust - \$5,000
- Dragon Community Trust - \$5,000

Vital funding has also been received from Community Organisation Grants Scheme (COGS). This scheme provides government-funded grants to community and charitable organisations working in local communities and neighbourhoods. The Kidney Society has been very fortunate to secure the COGS grants from the following local community groups:

- Far North - \$2,000
- Tongariro - \$3,500
- Waikato West - \$2,500
- Rotorua - \$2,000
- Kirikiriroa/Hamilton - \$2,000
- South Waikato - \$2,000
- Manukau - \$5,000
- Auckland - \$4,000
- Papakura - \$3,000
- Tairāwhiti - \$3,500
- Waitakere - \$2,000
- Rodney / North Shore - \$3,000

- Whangarei - \$2,500
- Mataatua - \$3,500
- Tauranga - \$3,500
- Kahungunu Ki Heretaunga - \$3,500

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

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:.

- Web address is kidneysociety.co.nz
- 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 021 663 435 or John@adks.co.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



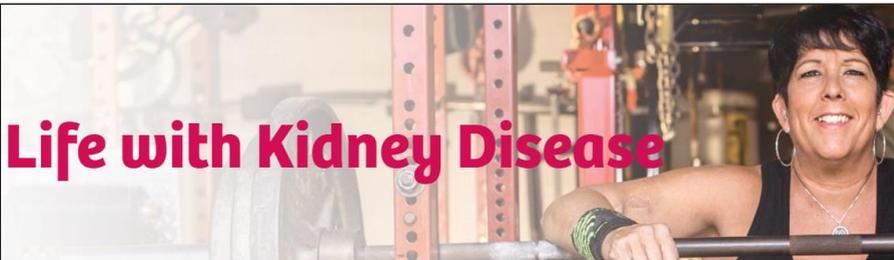
Articles in the News and websites we mention are intended to interest and inform. Play it safe! Listen, read, learn, talk to others, ask, take advice and then decide what's right for you!

Personal stories: the way people experience a treatment, a situation, or life with kidney disease in general depends on their personal circumstances, remember: everyone is different!



From diet and health management tools to kidney disease education classes, DaVita

Kidney Care has a wealth of tools for people touched by kidney disease.



Take Control After a Kidney Disease Diagnosis

Go to <https://www.davita.com/> to explore the website – there is a wide range of topics covered – and even though this is an American website, most of the material is suitable for people with kidney disease anywhere.

One great feature is the **Kidney Life Plan**.

This is a treatment plan based on your medical and personal needs. It is developed by you, your loved one(s) and your medical caregivers to help you succeed in living with kidney disease. You can find it here:

<https://mykidneylifeplan.org/>

What is a Life Plan? |

A Life Plan is a treatment plan based on your medical and personal needs. It is developed by you, your loved one(s) and your medical caregivers to help you succeed in living with kidney disease.

Think of a Life Plan as a type of navigation system for your life. If you know your destination, or goals—such as getting a kidney transplant, going back to school, etc.—a Life Plan can provide step-by-step guidance to help you get there.

Manage Your Kidney Health with myDaVita

Access Kidney Diet Tools



Download free kidney-friendly cookbooks, get access to Dining Out Guides and more.

Connect with Others



Join our forums to connect with other people with kidney disease and care partners.

Take Control of Your Health



Access DaVita dialysis lab reports, health records and more in the DaVita® Health Portal.

On the website you can complete the 'choices' below, then click the NEXT button, and for the boxes ticked in in bigger print!

Feel Well

Progress: 2 of 4



I want to...

Feel well from day to day

Rate how well each treatment fits this value.

My Lifestyle Values: I Want To...	My Health Values: I Want To...
<input checked="" type="checkbox"/> Work or Go to School	<input type="checkbox"/> Sleep well
<input type="checkbox"/> Travel	<input checked="" type="checkbox"/> Get a transplant
<input type="checkbox"/> Eat and drink what I like	<input type="checkbox"/> Take as few medicines as I can
<input type="checkbox"/> Swim and/or take tub baths	<input type="checkbox"/> Protect my bones
<input type="checkbox"/> Have my pets	<input type="checkbox"/> Protect my heart
<input checked="" type="checkbox"/> Feel well from day to day	<input type="checkbox"/> Protect my brain and nerves
<input type="checkbox"/> Afford my care	<input type="checkbox"/> Stay out of the hospital
<input checked="" type="checkbox"/> Feel in control of my time and life	<input type="checkbox"/> Live as long as I can
<input type="checkbox"/> Not turn my home into a clinic	
<input type="checkbox"/> Avoid needles	
<input type="checkbox"/> Have professionals take care of me	
My Relationship Values: I Want To...	
<input type="checkbox"/> Have a healthy sex life	
<input type="checkbox"/> Have or father a child	
<input type="checkbox"/> Take care of someone else	
<input type="checkbox"/> Not be a burden	

Next >

"No wonder I was such a 'bad' patient in the beginning..."

"Being told that I had to change my diet was like telling me that my life was over. Food was a huge part of my family dynamic. To us, food meant love; everything that we did revolved around good old soul food."

“When diagnosed, beer and pizza were a main part of my daily diet. Managing kidney disease at that point was unbelievably challenging; the foods that I was told that I should eat were not readily available in my neighbourhood.

Finding good, healthy produce was a challenge and food that wasn't processed was almost impossible. So, I ate the best that I could and continued my dialysis treatments, and naturally I felt worse and worse as time progressed.”

“I knew I was going to be one of those people that would ‘make it’ in life, and the only way I knew how to do that was by being singularly focused on my career. I wanted a better life for myself and refused any distractions.

When I was first diagnosed, I treated this like any other problem: I saw my health as a threat to my success, and I ignored it. I could not imagine myself on disability, collecting a check; I wanted to achieve on my own.

No wonder I was such a ‘bad’ patient in the beginning...

Dialysis: Dry, Itchy Skin

<https://www.kidney.org/atoz/content/dialysis-dry-itchy-skin#what-causes-dry-itchy-skin>

Have you noticed that your skin is itchy or dry since starting dialysis? If so, you are not alone. Many dialysis patients have these issues. It is called *uremic pruritis*. Itchy skin is different for everyone, and it can happen at any time of day, on any part of the body, and be a bother for some more than others. Some dialysis patients say they feel itchy in one area, and others feel itchy all over. What's important is trying to understand what may be causing it and finding the best way to manage it.

What causes dry, itchy skin

A combination of things can cause your skin to be itchy and dry. Some issues are:

- Limited fluid intake: Your dialysis treatment removes extra water from your body, and your limited fluid intake between treatments can cause dry skin and trigger itchiness.
- Unmanaged phosphorous: Often, itching is caused by high blood levels of phosphorus. In your body, extra phosphorus can bind with calcium and lead to feeling itchy. If your healthcare provider has given you phosphate binders, taking them as instructed, and at the same time every day, will help.
- Not enough dialysis: Talk to your healthcare team about your symptoms and find out if you are getting the right amount of dialysis. Sometimes too much or too little dialysis can lead to symptoms like dry, itchy skin.
- Allergies and other causes: Be sure you are not sensitive to the soaps, laundry detergents, lotions, or perfumes you may be using. Sometimes the dyes and fragrances in these products can cause allergic reactions that make skin itchy. Also, taking baths with water that is too hot can leave your skin too dry and lead to itchy skin.

Make a complaint to the Health and Disability Commissioner



The Advocacy Service is a free and independent service.

The Nationwide Health and Disability Advocacy Service is a free service that operates independently from all health and disability service providers, government agencies and HDC. If you want to know more about your rights when using health or disability services, get questions answered, or make a complaint, we can help.

Freephone: 0800 555 050 Email: advocacy@advocacy.org.nz

<https://www.hdc.org.nz/making-a-complaint/make-a-complaint-to-hdc/>

If you're unhappy about a health or disability service you or someone else has received, you have the right to complain to HDC. Before making a complaint, you may wish to talk to the person or organisation you're unhappy with. This is often the quickest and easiest way to address your concerns.

Before you complete the online form:

To make a complaint to HDC, you can complete the online form or send the details to us by email, post or by calling us, using the online form as a guide.

Making complaints

Our online tool will put you in touch with the right people when making a complaint.

National Freephone: 0800 11 22 33, Monday to Friday, 8am-6pm

Postal address: P O Box 1791, Auckland 1140

General enquiries email: hdc@hdc.org.nz

Please be aware that we may discuss your complaint and clinical records with the person and/or organisation you are complaining about, including their employer. This may include forwarding them a copy of your complaint and clinical records.

Need help? You can get help from an advocate to resolve your complaint directly with the person or organisation you are unhappy with, or they can help you make a complaint to HDC. This service is free of charge.

You can fill in this online form in any language and we will have it translated.

Our team treats all complainants with fairness and respect. We acknowledge you may be feeling distressed or angry in making a complaint, however, we take a zero-tolerance approach to violence and abuse towards staff.

Deep breathing

- ▶ Deep breathing, or breathing into your stomach, can make you feel better and help you to relax.
- ▶ This is also called diaphragmatic breathing.



Deep breathing technique - this can be done sitting or lying down

1



Lie on your back on a flat surface or in bed, with your knees bent and your head on a pillow.

You can also put a pillow under your knees to support your legs.

Place one hand on your upper chest and the other just below your rib cage. This will allow you to feel your diaphragm move as you breathe.

2



Breathe in slowly through your nose so that your stomach moves out against your hand.

The hand on your chest should remain as still as possible.

3



Tighten your stomach muscles, letting them fall inward as you breathe out through your lips like you are going to whistle.

The hand on your chest should remain as still as possible.

You may notice an increased effort is needed to use the diaphragm correctly. At first, you might get tired doing this exercise but keep at it because, with continued practice, diaphragmatic breathing will become easy and automatic.

Practise for 5–10 minutes, about 3–4 times per day. Gradually increase the amount of time you spend doing this exercise, and perhaps even increase the effort by placing a book on your stomach/puku.

August 17, 2022

Presenter identifies next steps in kidney xenotransplantation

By Julie S. Keenan

Fact checked by Gina Brockenbrough, MA

Source: Locke J. Making the impossible possible: The road to clinical trials of porcine kidney xenotransplantation. Presented at: IDEAS; Aug. 15-16, 2022; Seattle (hybrid meeting).

Disclosures: Locke reports receiving grant support and funding from United Therapeutics, Lung Biotechnology and Revivcor.

Several knowledge gaps remain in xenotransplantation despite the successful procedure of a porcine kidney into a brain-dead recipient, according to a presentation at the 2022 Innovations in Dialysis: Expediting Advances Symposium.

“We would argue that xenotransplantation could be viewed as sort of an artificial transplantation, and perhaps it is an impossible solution that we can make possible,” **Jayme E. Locke, MD, MPH, FACS, FAST**, a transplant surgeon and the director of the division of transplantation surgery at the University of Alabama at Birmingham and the director of the Comprehensive Transplant Institute at the university, said in the presentation.

Future studies are needed to determine long-term function of a transplanted kidney in a living human. Data were derived from Locke J. Making the impossible possible: The road to clinical trials of porcine kidney xenotransplantation. Presented at: IDEAS; Aug. 15-16, 2022; Seattle (hybrid meeting).

Because pig kidney function is similar to that of a human, pigs are considered the ideal animal for kidney xenotransplantation. Additional reasons include the animal's ability to reproduce large litters quickly, rapid growth and a long-life span.

As Healio has previously reported, the University of Alabama at Birmingham Comprehensive Transplant Institute received \$19.5 million grant in 2016 to launch a xenotransplantation program. At the time, Locke and colleagues identified challenges of xenotransplantation as immunological incompatibility and viral transmission.

To combat viral transmission from donor pigs and recipients, a pathogen-free facility was designed and built for the program. All pigs in this study were genetically modified to be blood type O, and researchers bred the pigs in the facility.

“We realized that we needed a human model to be able to test our genetic edits,” Locke said. “But we needed a human model that wouldn't risk a living person, so this is where we began to think about the concept of human brain death as a novel preclinical human model.”

Knowledge gaps in porcine kidney xenotransplantation include:



- Function in a living human
- Durability of transplant
- Optimal immunosuppression regimen
- Cross-sensitization in living human



Considering patients who were declared brain dead allowed the team to test the engineering and immunosuppression without harming a living person. However, enrolling a brain dead patient restricted research approval.

Locke's team at UAB enrolled a patient who was brain dead for 5 days and conducted the study for 77 hours. The team performed a successful xenotransplant on Sept. 30, 2021.

Within 20 minutes of reperfusion, the kidney began to produce urine.

With this study, Locke and colleagues set the model for kidney xenotransplantation. Additionally, they established the first flow crossmatch for human use in this setting.

In 2022, the University of Maryland School of Medicine and the University of Maryland Medical Center made headway in xenotransplantation after using a genetically modified pig's heart in a transplant with a living recipient. Locke noted that the pig used in the heart xenotransplantation differed from the pig in Locke's study because it was bred in a bio-secure facility, not a pathogen-free one. Locke suggested that is how the pig used in the heart xenotransplantation may have been exposed to porcine cytomegalovirus.

Locke said, "The knowledge gaps that we have filled by moving this into a preclinical human model are that we know that we can avoid hyperacute rejection in humans and we know that the alpha galactose knockout is, in fact, a critical gene deletion."

Although the xenotransplant was successful, Locke said future studies need to address long-term function of the transplanted kidney in a living human, the durability of the transplant, predictive capabilities of difference crossmatch techniques, optimal immunosuppression regimen, gene edits, molecular mechanisms of graft damage in human recipients, porcine endogenous retroviruses infection in living humans and cross-sensitization in living humans.

Therefore, this model will eventually need to be moved to a living human recipient to receive further approval.

"We still don't know if there's creatinine clearance after pig-to-human kidney transplant. We also don't understand the histologic changes seen in the study," Lock said. "I think this should be done in the setting of a phase 1 clinical trial as opposed to emergency authorization uses."

<https://www.healio.com/news/nephrology/20220817/presente-r-identifies-next-steps-in-kidney-xenotransplantation>

Receiving a kidney from a deceased donor

Deciding who gets a kidney is based on two things:

1. Time on dialysis.
2. Best match.

Example where the deceased donor has Blood Group A

400

People are on the active waiting list

-350

People cannot receive this kidney

200



People are blood group O – cannot receive this kidney

90



People are blood group B – cannot receive this kidney

60



People have antibodies that react to this kidney. This is called a positive cross match. So these people cannot receive this kidney.

= 50

People could receive this kidney

The computer system checks how long these 50 people have been waiting and how close a match they are to the kidney.

These people are ranked from 1 to 50 and the top two people will be the first people to be offered a kidney from this donor.





Information about the deceased donor list

Even though it is called a waiting list a kidney is not always given to the person who has been waiting the longest. The list is like a pool of people who might be offered a kidney from a deceased donor.

Kidneys from non-directed donors are also allocated through the deceased donor list (often via the kidney exchange).

Non-directed donors are people who are alive and decide to donate one of their kidneys to someone they don't know.

How do I get on to the list?

Once you get to the stage when your kidneys are only just working the team looking after you will talk to you about dialysis and transplant.

Many people who have end stage kidney disease can go on the list for a kidney transplant from a deceased donor.

However, not everyone is suitable for a kidney transplant from a deceased donor. Some people may be told that they can have a kidney transplant from a live donor but not from a deceased donor because of:

- Previous transplants
- Other health conditions
- The person's overall health
- How their kidney disease has affected the rest of their body
- Other surgery the person may need at the time of transplant.
- Lower than 80% chance of living more than 5 years after a deceased donor transplant.

How do they work out my chance of living more than 5 years?

Usually there are more than 400 people on the active waiting list. In New Zealand about 100 kidneys are donated each year from deceased donors. This means only people with a good chance of doing well after a transplant are able to go on the list.

Your kidney doctor and the team at your transplant centre will discuss:

- your health
- your test results
- how your kidney disease has affected your heart and the rest of your body.

This checks you are fit enough to have a transplant at any time. This is called your Comorbidity Score.

Looking at all these things helps doctors to make the same decisions across New Zealand. This means deciding who gets a kidney from a deceased donor is as fair as possible.

If you are assessed as having a lower than 80% chance and your doctor doesn't think that is correct, your doctor can ask for the decision to be reviewed.

Everyone on the waiting list is reviewed every one to two years to make sure they are still well enough to stay on the list.

So what are my chances of getting a kidney?

You may be lucky and get a kidney quickly. However most people will wait for several years. Sometimes this is because of your blood group or antibodies. Some people on the waiting list may never be offered a kidney from a deceased donor.

Deciding who gets a kidney

When a family offers a kidney for transplant the New Zealand Blood Service uses the information from your monthly blood tests as well as how long people have been waiting to decide who gets offered the kidney.

Kidneys are offered to people based on two things. First who has been waiting the longest time on dialysis and secondly the best match. There is no way of guessing the blood group of the next donor and what antibodies a person needing a transplant might have against that kidney.

What other transplant options do I have?

If your health is not good enough to be on the deceased donor list you could still be well enough for a transplant from a live donor. These sorts of transplants are more likely to happen, happen more quickly and you do not always need to have the same blood group. Talk to your family and friends about them donating a kidney to you.

You can find out more information about live kidney donations at <http://kidneydonor.org.nz/orbycallingyourlocaltransplantcoordinator>.

More information

You can see information used by health professionals working in kidney transplantation at <http://www.health.govt.nz/about-ministry/leadership-ministry/clinical-groups/national-renal-transplant-service>.

Kidney Failure: When Should I Start Dialysis?

You may want to have a say in this decision, or you may simply want to follow your doctor's recommendation. Either way, this information will help you understand what your choices are so that you can talk to your doctor about them.

Kidney Failure: When Should I Start Dialysis?

1 Get the Facts	2 Compare Options	3 Your Feelings	4 Your Decision	5 Quiz Yourself	6 Your Summary
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Your Summary

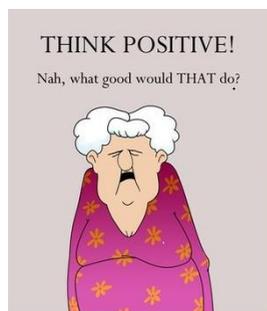
Here's a record of your answers. You can use it to talk with your doctor or loved ones about your decision.

Hello! We

This is a nice easy to use and understand online tool if you are in the process of making decisions about your treatment.

Go to <https://www.uofmhealth.org/health-library/abo2705>

or google: **Kidney failure when should I start dialysis?**



How to think positive when everything is going wrong

Trying to be positive when you're grieving or experiencing other serious distress can seem impossible. During these times, it's important to take the

pressure off of yourself to find the silver lining. Instead, channel that energy into getting support from others.

Positive thinking isn't about burying every negative thought or emotion you have or avoiding difficult feelings. The lowest points in our lives are often the ones that motivate us to move on and make positive changes.

When going through such a time, try to see yourself as if you were a good friend in need of comfort and sound advice. What would you say to her? You'd likely acknowledge her feelings and remind her she has every right to feel sad or angry in her situation, and then offer support with a gentle reminder that things will get better.

Side effects of negative thinking

Negative thinking and the many feelings that can accompany it, such as pessimism, stress, and anger, can cause a number of physical symptoms and increase your risk of diseases and a shortened lifespan.

Stress and other negative emotions trigger several processes in our bodies, including stress hormone release, metabolism, and immune function. Long periods of stress increase inflammation in your body, which has also been implicated in a number of serious diseases.

Some of the symptoms of stress include:

headache, body aches, nausea, fatigue and difficulty sleeping.

<https://www.healthline.com/health/how-to-think-positive#side-effects-of-negativity>

Do dialysis patients feel normal?

'Many patients live normal lives except for the time needed for treatments. Dialysis usually makes you feel better because it helps many of the problems caused by kidney failure. You and your family will need time to get used to dialysis.'

You will soon realise that no two days are the same...



Any age, any background, anyone...

If you've got kidney disease, you can find someone to talk to at the Kidney Society.

Phone 0800 235 711 weekdays 9-5
