

The Kidney Society

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








My story of 'Thriving after live donation'

by Aly Gwynne

Aly donated her kidney through the Paired Exchange programme (ANZKX), see page 5

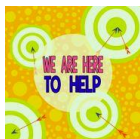
The Kidney Society “Who, what, where.”

PO Box 97026 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 to do at home.</p>	
	<p>Brian is our Community Health Educator who can help you understand kidney disease and treatments.</p>		<p>Niu our Social Worker can talk to you about “kidney disease and you”, money problems, family, housing, and many other things.</p>	 <p>Nora writes the News. Send us a story!</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>	

Deadline for the August/September/October 2024 News: Wednesday 24 July 2024. Contributions are very welcome!

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.



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

It seems appropriate to extend a warm welcome to the autumn edition of our magazine as we approach the colder months of the year.

As the old saying goes, “No organisation ever regretted listening to the people it serves”. The last Kidney Society magazine promoted our annual client survey and there was a fantastic response; so thanks to everyone who took the time to offer their thoughts and ideas. We are especially grateful to those who attended the discussion groups that were held at our office. All these insights will prove invaluable and on page 16 you’ll find a summary of the feedback we received.

Many clients told us they enjoy receiving this magazine. We remain committed to keeping it as a free resource for our community even though it is becoming increasingly expensive to produce and distribute. One way you can help us it to receive the magazine via email rather than through the post. If this idea appeals to you, then please contact Maria at Maria@Kidneysociety.org.nz and she will put you on our digital subscriber list.

This edition features a fascinating article about Ian Power who donated a kidney to Kidney Society board member David Wingate. Donating a kidney to a friend or family member can be one of the great gifts of a lifetime and we felt this was an inspirational story worth sharing.

Finally, a chance to say farewell and thank you! After almost three years as Chief Executive of the Kidney Society, I have decided to retire. It has been an honour and a pleasure to serve such a wonderful community. The new Chief Executive, Kath Eastwood, joins us in May and there will be a profile on her in the next edition.

Nga mihi,

Regards

John Loof, Chief Executive Officer

john@kidneysociety.org.nz

Kidney Society Events

Rotorua Home Visits

Wednesday 15 May and Thursday 16 May

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

Rotorua Advanced Kidney Care Session **Friday 17 May 2024**

For people heading for dialysis
(but anyone can attend)

Rotorua Arts Village Trust, 1240 Hinemaru Street,
Rotorua, Bay of Plenty 3010

For information please call 027 715 3949 or email
brian@kidneysociety.org.nz

Ngaruawahia, Huntly, Taupiri and Horotiu **home visits**

Thursday 30 May 2024

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

A first for Kidney Disease: **A New and Exciting Approach to Exercise!**

Now online!
See page 9 for details



My story of 'Thriving after live donation'

by Aly Gwynne



It's not something you ever really think about, but when faced with watching your husband of over 34 years slowly deteriorate it made my decision to donate easy, the process was a little more difficult and took a little longer!

Our story starts back many years where routine blood tests showed a reduced function in Brent's kidneys. He was referred to the Waikato Hospital team and this was monitored over a period of 15 years. Fast forward to 2022 and Brent's function had reduced to 8%.

We were still biking, he was still working full-time, 12-hour shifts and still golfing but it was obvious that all these things were getting harder, and his health was

deteriorating. We biked the Otago rail trail in Feb '23 on peddle power and loved every minute, life was fun and good, but reality was that dialysis was not too far off.

After talking with our adult children and letting them know the situation had deteriorated, both offered to be tested as donors, but with them both living overseas Brent would not consider it. I hadn't initially considered donating because (typical of misinformation) I had been told that a female could not donate to a male. During a routine visit, I asked Brent's specialist, she said absolutely I could be considered to donate. It made for an interesting drive home as Brent was not initially happy with my decision.

From my first appointment with the transplant coordinators, I have felt informed, and in control. The Waikato team gave me so much information and guidance and continually advised me of my right to withdraw at any stage. I went through thorough testing and monitoring, and as I went through each testing stage it was a great feeling to be 'one step closer'.

After nearly 12 months of testing, I got the message that I really didn't want to hear," Aly sorry You're not a match', and not close enough that Auckland will do the surgery." I was gutted, a bit angry and very

flat, but then Kirsty reminded me of our previous conversations around the Paired Exchange program (ANZKX). We (Brent & I) had just attended a meeting held by the Kidney Society who also outlined the ANZKX program, so we explored this as an option.

The basics of the ANZKX Australia New Zealand Paired exchange program is simple, I donate my kidney, but it couldn't go directly to Brent. It goes to someone who is a match. That someone has a volunteer donor who, if not a match for Brent, is a match for another donor, and so on, and so on. 13 couples later, Brent has a kidney that is compatible with him, and my kidney has gone on to a match for it. I think of it as the chain of life.

Brent and I were very lucky to find a match through AZZKX, and I can't say how life changing getting that phone call felt. With Brent at 61 years of age whilst he was on the deceased donor register it was not likely to be the solution for him.

From the minute we accepted the spot the wheels were in motion and the process was flawless. Appointments were made, timelines were set, nothing was missed.

I was contacted by the co-ordinators from the team who outlined the process.

I met with the surgical team, and they explained the physical process,

I met with the appointed psychologist; she explained the emotional process. I met with the social worker who outlined what was available to me in terms of financial compensation.

My surgery went very smoothly, once again so supported by the Auckland Surgical team and coordinators (many of whom I had met as I supported Brent through his surgery the week prior).

I never felt ill-informed, or unsupported in any way and can honestly say I would do it again if I had to or could.

Brent and I are both doing well, both back to work and living life, and I don't feel any different. Please don't get me wrong, this is not easy but at the same time not hard, it's just a process to go through and well worth it. I had the usual issues post-surgery such as tiredness and pain, but both were manageable. I was well organized. I precooked meals so we would just heat and eat and even at 57 years of age I am still so grateful for the amazing support from my Mum, family and friends, this was vital for the first couple of weeks and seeing the change in Brent is fantastic.

Thanks, and gratitude cannot be tabled enough for both Waikato and Auckland Transplant teams, and the support from the kidney society. They inform, advise, and offer guidance second to none, and it is so clear that they all work so well together.

My advice is having the conversation and consider live donation as an option, we need to open the lines of communication and information around live donation more.

Aly Gwynne

A First for Kidney Disease: SpinPoi - a New and Exciting Approach to Exercise! Now ONLINE!



We're BEYOND excited to share the full SpinPoi exercise routine that we've been working on alongside the brilliant SpinPoi team.

This very special resource has been designed just for you, our wonderful kidney community, and we couldn't be more excited to share it with you! Follow along with our wonderful clients (and staff) themselves, Awhi, Jenny and Siu, who feature in this routine.

Tracey Drinkwater, Wellness Educator at the Kidney Society, recognised the potential of SpinPoi to benefit their clients and spearheaded the collaboration. With a dedication to supporting physical and mental health while celebrating Kiwi and Pasifika cultures, Tracey worked closely with SpinPoi to develop a routine tailored to the specific needs of kidney disease patients.

"This project is a true collaboration that reflects the importance of community support for people with Chronic Kidney Disease. The combination of the beautiful music from Aro, the incredible SpinPoi programme from Kate, and the amazing mahi by the three clients who performed the routine have really been an incredible project to be part of. I am very excited about the development of the Kidney Society Poi project and the health and wellness benefits it will bring to the amazing people we support," says Wellness Educator, Tracey Drinkwater who led this project.

Dr. Kate Riegle van West, the Founder and CEO of SpinPoi, completed her PhD in the effects of poi on physical and cognitive function for older adults and specialises in working with poi as a therapeutic tool. Kate says "It has been an honour to work alongside the Kidney Society team in sharing the health benefits of this precious taonga. I really encourage everyone to give this poi routine a go, even if you've never twirled a poi in your life! The movements are designed to be accessible to everyone and to support cardiorespiratory fitness and physical motor function - key areas to be proactive about when trying to prevent or slow the progression of Kidney Disease. Plus, the routine is heaps of fun! Maybe build it into your daily routine to get a little dose of exercise and endorphin release every day."

We extend a special call to action, inviting each of you to join us in spreading the word through our exciting challenge. Join us in spreading awareness about kidney disease. Gather your friends and

whānau, master the routine, grab your camera, and record your performance. Share your videos with us by sending them over to the Kidney Society team at contact@kidneysociety.org.nz

Let's come together as a community to create an inspiring montage, showcasing our unity and dedication to raising awareness about kidney disease through this unique exercise crafted just for you.

Are you ready to accept the challenge and make a difference? Check out the full SpinPoi routine now and get ready to share your amazing performances with us!

You can find the video on our YouTube channel:
<https://www.youtube.com/@kidneysocietyadks>



<https://www.davita.com/>

On the American Davita website you can find a lot of very useful information and inspirational stuff as well as delicious recipes and cookbooks and other people's stories.

The article below has appeared in the News before, but a gentle reminder to those of you who rely on your partner can sometimes be helpful....

How to Support Your Home Dialysis Care Partner

If you are a home dialysis patient, it's likely that you have a care partner or a special person in your life who helps you with your at-home treatments and your health condition. It's often this person who helps you with dialysis and daily tasks. They may:

- set up your home dialysis equipment
- assist you with your home dialysis treatments
- cook your meals
- take you to your in-centre checkups
- run your errands
- pick up your medications
- love and support you

Although a care partner's role may vary from patient to patient, one thing remains the same: Care partners need encouragement too.

Here are some simple ways to support and encourage your home dialysis care partner and let him or her know you care.

Give thanks

Although you may not be able physically or financially to do everything you want to thank your care partner for the endless support, you can start by simply saying "thank you" every time he or she does something for you. It may seem like a small, insignificant gesture, but those two words are some of the nicest words to hear. No matter how many times your care partner does something for you throughout the day, remember to thank him or her verbally.

Other ways you can say thanks include sending thank you cards or leaving hand-written thank-you notes in places where your care partner will find them.

Lend a hand

Look for little ways to help your care partner out during the day. In the kitchen, give your care partner a "cooking break" by lending a hand every once in a while, to give him or her a break. If you are physically unable to cook a meal, try thinking outside of the box. Order take-out from a local deli or restaurant.

If your home dialysis care partner is the one who keeps the house clean, pitch in and offer to clean a part of the house for a month or hire a cleaning service to clean it. If your care partner is responsible for mowing the lawn and keeping the yard looking neat, get a neighbourhood kid to do it for a few dollars or, better yet, a plate of cookies.

You don't have to do these things every week if you don't have the resources but doing them for your care partner every once in a while shows your support and appreciation.

Give your partner some space

Give your care partner space for activities or interests that you may not be able to participate in. This may not always be possible if your medical needs require continuous help. However, there may be other family members or friends who can help out for a few hours or even days so your partner can take a break.



Laugh a little

Because end stage kidney disease (ESKD) is part of your day every day, it may begin to weigh heavily on you and your care partner. Although you may think that it affects only your life, you have to remember that your health condition is a huge part of your care partner's life as well. A great way to lighten things up and avoid getting caught up in the seriousness of the disease is to share a good laugh.

Studies show that laughter is good for the heart, immune system, and respiratory system. It also provides stress relief, pain relief and relaxation. Laughing with your care partner is a great way of relaxing and having fun. Share some jokes. Rent a funny movie. The gift of laughter can be shared in many ways. Whatever you do, make the decision to find something funny to laugh about with your home dialysis care partner every day.

Talk about it

Even though your partner cares for you on a daily basis and may never complain, that doesn't mean he or she doesn't have things on his or her mind related to your care. Make it a point to talk to your care partner regularly about how he or she is doing. Is there anything that your care partner finds too hard or time-consuming, or that he would rather not do? Maybe you can pitch in and help out. Does your care partner want to start a new hobby or class that would require time away on a certain day? Maybe you can get someone else to help you out on those days.

Communication is very important in a relationship such as the one you have. The only way you will know how things are going with your care partner is to talk about it. Because your care partner may not want to bother or worry you with issues or concerns, make it your responsibility to ask and help make the relationship a happy one for both of you.

Give a gift

Getting your care partner a gift is a great way to show your appreciation for all he or she does for you and let him or her know you care. If you'd like to give a gift, listen for little things your care partner might mention wanting or liking. For example, if your care partner mentions that his or her watch broke the other day, consider getting a replacement.

If you want to give a gift but don't want to spend too much money, consider your own talents. If you knit or scrapbook as a hobby, you may want to knit a scarf in your care partner's favourite colours or make a scrapbook.

Also, edible treats make great gifts. If you know your care partner loves your famous chocolate chip cookies, bake a batch from time to time. It's a gesture that doesn't require much time or money but shows that you pay attention to what he or she likes and that you value him or her.

Have some fun

To keep your care partner from feeling like his or her life revolves around your health condition, have some fun together. Even though the two of you probably spend plenty of time together during the day, ask yourself how much of that time is spent talking about, dealing with, or planning for your dialysis treatments. If the answer is more than 50 percent, it's time to have some fun.

There are plenty of ways to get your care partner's mind off of caring for you and instead having a good time together. Take a walk. Have a picnic. Take up a shared hobby. Do a puzzle. Play cards. Have a Scrabble® tournament.

Whether you want to go all out or do something small, take some time to think about what your care partner likes to do, and plan something fun that you can do together. Also, when you're out enjoying yourselves, try not to mention your health condition. Take this time to focus on your care partner.

Summary

Home dialysis care partners play a big part in the lives of patients with end stage kidney disease (ESKD) who choose to do dialysis at home. Many times, care partners sacrifice their own time and hobbies to take care of you and make sure you have the love and support you need to be your healthiest. It's important to remember, though, that care partners need support and encouragement, too. Make it a priority to look for ways to show your care partner how much you appreciate them.

<https://www.davita.com/treatment-services/home-dialysis/home-benefits/supporting-your-home-dialysis-care-partner>

Bed Exercises for Cold Mornings

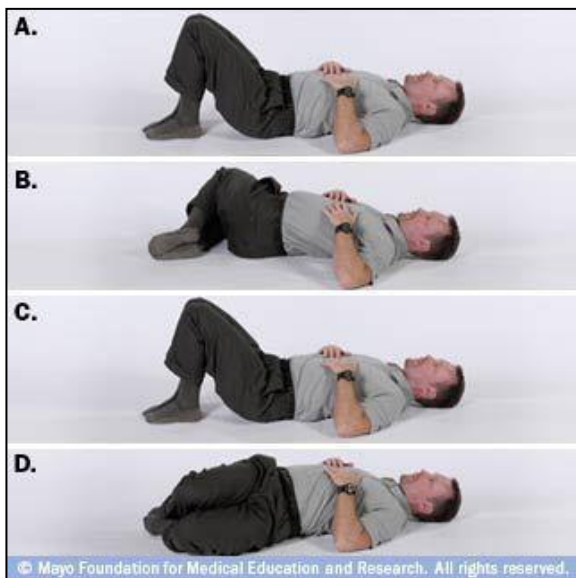
The colder mornings and bleak winter days can often make getting out of our warm beds very difficult.

However, you can take advantage of staying under the covers a bit longer and do some simple exercises before getting out of bed while you are still lovely and warm.

Wake Up the Back

Many people find their lower back tight and stiff first thing in the morning. So before throwing off the covers this is a good time to

“wake up” the back with a gentle back stretch.



Lay on your back with both feet on the bed and your knees bent. Gently & slowly let your knees fall to one side.

To add in an upper back and neck stretch turn your head to the opposite direction from your knees and if comfortable stretch your arms out to the side.

For those with tunnel lines or restricted shoulders keep your arms closer to your sides or across your chest as pictured.

If your back is very tight you may not be able to get your legs all the way to the bed but just go as far as it feels comfortable, and you can feel a NICE STRETCHING FEELING. Hold the position for a few good deep breaths and then change to the opposite. Do this 2-3 times each side.

Wake Up the Legs



Start **simply by wiggling your toes**, then pointing your toes and pulling your back like you are **pumping your feet**. Then start making circles with your feet in each direction to get the blood flowing into the legs.

From there keeping your heel on the bed slowly pull your foot along the mattress until you knee is bent. Slowly push the heel back along the mattress extending your leg until your leg is straight again then change to the other leg. Do this a few times on each side.



If you find it easy to do this and have no back pain, you can raise your leg slightly off the mattress keeping your heel off the mattress when pushing the leg straight and returning to the beginning position

If you are spending a lot more time in bed during the day to stay warm you can also use this time to do other exercises.

If you would like a specific exercise programme to do you can contact Tracey:

Tracey Drinkwater
Wellness Educator Kidney Society
0800 235 711, 027 378 4544 or tracey@kidneysociety.org.nz



2024 Client Survey - Thank you for your feedback!

Let us begin by saying a huge thank you to everyone who participated in our 2024 annual client survey. We were thrilled to receive over 80 responses that were full of valuable insights into the issues facing our clients and suggestions for improving Kidney Society services. There were also two group sessions where clients came into the office and shared their experiences directly with the team. We remain extremely grateful to all who got involved.



As mentioned, we were giving out a prize for entering so congrats to Robert Rajan who was the winner! Stay tuned for further details on your prize.

We wanted to share some of the feedback with you:

Promoting our range of services

Many clients don't know about all the services we offer, like the Wellness Programme, health education, social work support, and community dialysis houses. In the future, we will be making more of an effort to raise awareness of how we can support our community e.g. better promotion across our Facebook page and in our next magazine. In the meantime don't forget, you can find all our services on our website <https://www.kidneysociety.org.nz/> to explore them.

Travel

Travel can be tough for many of our clients. Some dream of going on trips or want to travel for important family gatherings but worry about access to dialysis. The best advice we can give is to get in touch with your renal team about your travel plans and give them as much notice as possible to organise your treatment when you're away from home. If you are having trouble making arrangements to travel, please get in touch with us as there may be other ways in which we can help. We have looked at the cost of setting up a campervan equipped with a dialysis machine, but unfortunately, the time and cost involved are more than we can afford.

Nourishing Body and Mind:

You said diet is a big deal for kidney patients. We're here to support you where we can with recipes and wellness videos. Please keep an eye on our website and YouTube channel to support you with this.

Your renal dietitian has access to important medical information, blood results etc and they are the best person to guide you through.

Community

Everyone wants to feel connected, right? That goes for patients and supporters alike. We hear you loud and clear. We will work to see if we can bring people together, whether it's through events or online groups.

Satisfaction

Over 90% of our clients are satisfied with the overall services which we are so happy to hear! But we know there are areas of improvement so again thank you for your feedback and we will continue to work on ways to make our services work better for you.

Ian's experience of donating a kidney

I donated a kidney to my wife's cousin's husband, David. I'd thought about organ donation before, but only in the context of carrying an organ donor card. I hadn't considered donating a kidney until David explained what it was like for him living with kidney failure. He had such a lot to offer, a wife and two young daughters, so much ahead of him; not helping him wasn't really an option.



I talked it over with Suzann, my wife, and after a short debate as to which one of us should donate, we agreed I would go ahead and start the screening process.

Before you can donate, they screen you very thoroughly, to assess your suitability both physically and mentally. The health professionals involved were incredibly supportive, and appreciative about what I was

volunteering for. I discovered I had a heart murmur (a minor one), but aside from that, was reasonably fit.

There were seven of us offering to donate for David, but only I passed the medical. And I guess that was the moment of real pause, when I thought, wow, okay this is going to happen.

The operation itself was okay. I wasn't in pain afterwards, and just had some discomfort that lasted about two weeks. Suzann described me as being foggy-headed for several months afterwards, but that cleared up. Today I feel as healthy as any man in his mid to late -fifties has any right to. I have stayed pretty fit but am not obsessive about it.

David is doing well – the transplant helped him get back focusing on his family and his business. I know he is very grateful for what I did, and it feels pretty special to know you were able to help save someone's life. I don't think I'm special for doing it – it was more a case of being in the right place at the right time. I don't think many people could have turned away and not offered to help, if they had been aware of the difference it would make.

If anyone is thinking about donating, I'd encourage them to take the first step and begin the screening process. That process will help you work out if you really are mentally ready to donate, as well as whether you are physically capable. You can always pull out, and no one will judge you if you change your mind. Just take the first step.

IAN POWER

Tips from Renal Dieticians

The kidney has many jobs in the body, one of which is the removal of waste products in the blood. When the kidneys' function declines, these waste products build up and can have a negative impact on a person's health and wellbeing. Symptoms can include nausea, vomiting, weight loss, difficulty concentrating, and fatigue. Some people can also experience changes in appetite, including a loss of appetite (anorexia) and a different or reduced sense of taste (dys/hypogeusia).

Below is a list of taste complications and some suggested strategies to try to improve your eating experience. As with the rest of a kidney-friendly diet, always remember that the strategies suggested

here should be done so in moderation, especially if consuming sugar to improve taste.

Maintain Good Oral Hygiene

Brush your teeth at least twice per day for at least two minutes. Remember to brush your tongue as well.

Try using a mouthwash after brushing. Remember not to swallow the mouthwash.

Metallic/bitter foods:

Avoid the use of storing foods in metal containers and steer clear of metal utensils. Try storing leftovers in glass or plastic containers and using wooden or plastic utensils when eating.

Try sweetening your meals with a small amount of fruit, honey, or syrup, or caramelize your vegetables.

When choosing protein options, red meat can taste more metallic than other choices. Instead, try chicken, pork, fish, or eggs. Marinating meats in something acidic such as vinegar can reduce the metallic or bitter taste.

Food tasting too sweet?

Include a savoury flavour with your meal, such as mushroom or tomato.

Try applying juice from a lemon or lime to your tongue before eating your meal. Alternatively, add something acidic into your meal – vinegar, citrus fruit and juice, plain yoghurt, berries.

Too much salt?

Remove salt from cooking and having salt at the table.

Combine sweet and acidic ingredients into your meals – lemon with maple syrup or honey and vinegar.

Is bland tasting food an issue?

Flavours such as pepper, herbs, spices, chillies, vinegar, and lemon are a great way to increase flavour without needing to add more salt.

Switch between different flavours on your plate, changing up the food of each mouthful.

Sour foods like pickled vegetables or yoghurt can be a good addition for improving flavour.

Recipe Ideas

Looking for some kidney friendly meal, snack and sauce ideas?

For some tasty and flavourful inspiration head to the Kidney Health Australia Website and download their quick and easy recipes. To find these recipes use the link below:

<https://kidney.org.au/your-kidneys/living-with-kidney-disease/health-and-wellbeing/recipes-and-meals>

Sweet and Sour Pork (serves 6)

Ingredients

- 425g canned pineapple pieces in juice (can substitute juice for water if on a potassium restriction)
- 2 tsp soy sauce, reduced-salt
- 1 ½ Tbsp vinegar
- 1 ½ Tbsp lite tomato paste
- 2 tsp brown sugar
- 1 tsp fresh ginger, grated
- 1 Tbsp cornflour
- 1 Tbsp vegetable oil
- 500g lean pork, sliced
- 1 medium onion, sliced
- 1 capsicum, chopped
- 2 medium carrots, peeled and sliced ½ head broccoli, cut into florets 1 cup cabbage, shredded OR 2-3 cups of frozen vegetables

Method

1. Place pineapple (with juice) soy sauce, vinegar, tomato sauce, brown sugar and ginger in a saucepan and heat until simmering.



2. Wet the cornflour with a little water. Slowly pour the cornflour mixture into the simmering sauce, stirring constantly until it reaches the desired thickness. Remove from the heat.
3. Heat oil in a large frying pan or wok. Add the pork and brown, then remove from the pan and set aside.
4. Add the vegetables to the pan and cook until tender.
5. Add the pork back into the pan with the sweet and sour sauce, and heat through.

*Recipe adapted from Kidney Health Australia

Matson McCauley and Briar Davies, Northland & Waikato Renal Dietitians

Kidney transplant quiz

Test your knowledge on the transplant process! Please mark 'Yes' or 'No' below and then check your answers on the bottom of page 27 to see if you're surprised by any answers.

1. Can a female donate their kidney to a male?
Yes No
2. Do the donor and recipient have to have the same blood group?
Yes No
3. Is there a certain BMI the donor must have to be able to donate their kidney?
Yes No
4. Are there age restrictions for the kidney donor?
Yes No



Cook for Life is a practical 'how to' cookbook written for the Shelford whānau. For many people, it can be challenging to cook to cater for a specific medical condition. This cookbook was created to cater for the entire family and it was specifically created for Brian Shelford who managed diabetes and went through haemodialysis. The cookbook evolved from family favourite recipes to include the detail that makes meals successful and healthful.

Learn more:

<https://www.northlanddhub.org.nz/your-health/health-resources/renal-health>

To **order** one, please email: communications@northlanddhub.org.nz to request a quote.

Body Image Issues and Peritoneal Dialysis

<https://www.davita.com/treatment-services/peritoneal-dialysis/body-image-issues>

People who treat their end stage renal disease (ESRD) with peritoneal dialysis (PD) must learn to adjust to a new reality. They may prefer this home dialysis treatment option because it gives them more freedom, a more flexible diet, fewer trips to a dialysis centre and a therapy that works similar to how their kidneys did. Although the benefits of PD are abundant, feelings of insecurity can be present when making this shift in lifestyle. One of the major challenges you may face are issues with your body image. A permanent catheter and weight gain, skin problems and sometimes hair changes may be part of the transition to PD. But there are ways to handle these changes and feel good about your body image.

Weight gain and peritoneal dialysis

PD dialysis solution contains dextrose (sugar) to help you lose excess fluid. It comes in three concentrations: 1.5, 2.5 and 4.25 percent dextrose. Because some of the dextrose will move from the dialysis solution into your blood stream, you receive extra calories not included in your diet. This could cause you to gain weight, especially if you use the dialysis solution with the higher dextrose concentration. If you avoid salt and stick to your recommended daily fluid intake you should be able to use the dialysis solution with a lower dextrose concentration, reduce the amount of extra calories and keep your peritoneal membrane healthier in the process. Talk to your renal dietitian about your eating plan and the amount of calories you should consume. Making time for exercise is another way to help limit weight gain, promote heart health and feel good about your body overall. However, it is important that you ask what types of exercises your doctor or nurse recommends before you start any physical activity.

Bloating from the dialysis solution is common when you're on PD. Patients who need to carry fluid in their abdomen during the day (called a long dwell) will notice a bulge and may have an uncomfortable feeling of fullness. This problem will be greater in

people who need to remove a lot of fluid by using higher concentration of dextrose solutions. Controlling your fluid intake will help reduce the amount of fluid you need to lose and leave you less full while you are dialyzing. In many cases, the dialysis prescription can be adjusted if bloating and fullness remain a problem.

PD catheter and body image

A catheter, which is necessary for performing PD, will be placed in your abdomen. The part of the catheter tubing that exits your body is usually 5-6 inches long and should be held in place with a PD belt or by other means to avoid trauma to the exit site. In general, your PD catheter should not interfere with most forms of exercise or sexual activity. Although you may feel self-conscious at first, you are likely to get used to the catheter and appreciate that it's now your lifeline to a better quality of life.

Skin problems, hair changes and peritoneal dialysis

When kidneys aren't working properly, waste products build up in the body. This can cause your skin tone to change. If you have a light complexion, you may see that your skin turns to a greyish or yellowish colour. When your complexion is dark, you may find that your skin tone appears darker. Because PD is a continuous therapy, working more like a regular kidney, your skin tone may not change at all or it may return to its original tone after you begin PD treatments. In the meantime, make-up products can correct skin tone if you need a quick solution.

Itchy, dry skin is another side effect of kidney failure. When picking out soap, avoid using products that are high in alcohol or heavily scented. Try a moisturizing soap for sensitive skin instead. Moisturizing creams that are high in water content are typically a better choice than regular body lotions. Ask your doctor or pharmacist which dry skin treatments they recommend.

When you first begin any form of dialysis, you may find that your hair thins out. Usually this is temporary, lasting just a few months. In the meantime, visit with a professional hair stylist who can recommend styling tips that make thinning hair less noticeable. A fresh hairstyle may help you feel more confident with your appearance.

Ways to improve body image

Changes in your body can be difficult to handle at first, especially during romantic moments, around swimsuit season or when dressing up for a special event. Although you cannot change the fact that you need dialysis, you can alter how you think about your situation. By focusing on how PD is improving your quality of life — you are more independent, can eat a less restrictive diet, feel better and have more energy — you'll be able to think positively about your treatments. Talking to your partner, friends and family about how you feel can also help ease the stress of PD and related body image issues.

You may want to find an online or local support group to connect with other PD patients who are going through similar experiences. Hearing others share their stories about intimacy, grooming habits, eating plans and daily living will likely provide insights to how you too can cope with body changes as a PD patient. The DaVita.com Forums has a sub-forum specifically for home dialysis patients with many active participants.

Summary

Although there are many body changes that you may have to deal with while on peritoneal dialysis, focusing on the positive—that PD is prolonging your life—can help you cope with image issues. There are steps you can take to manage or minimize the changes and the way you see yourself. Talking to other PD patients may prove valuable. Your healthcare team is also available to answer your questions, provide support and look into resources that can help you improve your overall quality of life on PD.

9. Understand the importance of insurance. Resources such as patient advocates, medical social workers, patient organizations, Medicare and your state insurance bureau can help.
10. If you have diabetes, controlling your blood sugar can help slow the progression of kidney disease. Find out what your target blood pressure should be, as well, and work with your doctor to do what you must to keep it there.
11. Be aware of the possible complications of kidney disease, including: anemia, metabolic acidosis, bone disease, cardiovascular disease, fluid overload, high potassium and phosphorus and others.
12. If your kidney disease is severe, understand your treatment options, from home dialysis to transplant. Call DaVita Guest Services at 1-800-244-0680 if you have any questions or want to visit a center.
13. If you're on dialysis, do all of the treatments your doctor prescribes to you so you can try to feel your best.
14. If you have a transplant, take all your medications on schedule. Watch for any signs of infection, rejection or other illness.
15. Pay attention to your emotions. Give yourself time to adjust and feel in control again. You may be dealing with uncertainty about the future or with changes in your lifestyle and relationships—these are normal feelings.

<https://www.davita.com/education/ckd-life/lifestyle-changes?p=1>

Do you find it hard to read some of the articles in the News?

Would you like to read it in large print?

The print in some of the pages is quite small and may be hard to read for some people.

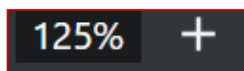
But there is a solution!

Go to our website:

<https://www.kidneysociety.org.nz/news-events>

Here you can find this magazine plus back issues at the bottom of the page.

If you click on the May/June issue (once it shows on the website) you can read this and every entire magazine in large or super large print by changing the print size at the top of the page.



Kidney transplant quiz answers (from page 21)

Numerous assumptions exist regarding the kidney transplant process, yet not all are accurate. With various factors and considerations involved, it's crucial to seek out accurate information for you.

Answers:

1. Yes
2. No
3. Yes
4. No

Manage Better, Feel Stronger



Our Manage Better, Feel Stronger courses are FREE 6-week long programmes, designed to help you and your family cope better with long-term health conditions.

APRIL - JUNE 2024 INTAKE NOW OPEN

6-WEEK, IN PERSON PROGRAMMES: 10AM-12:30PM

PUKEKOHE DIABETES	Franklin The Centre, 12 Massey Ave, Pukekohe Wednesdays, 1st May
TAKANINI DIABETES	Takanini HUB, 30 Walters Rd, Takanini Centre Thursdays, 2nd May
MT ROSKILL DIABETES	Mt Roskill Clinic, 445 Richardson Rd, Mt Roskill Thursdays, 16th May
OTARA GENERIC	Starcare Centre, 120 East Tamaki Rd, Otara, Level 1 Wednesdays, 8th May
RANUI GENERIC	Ranui Community Centre, 474 Swanson Rd, Ranui Fridays, 10th May
MANGERE DIABETES	Mangere Old School Hall, 299 Kirkbride Rd, Mangere Thursdays, 2nd May
MANUREWA DIABETES	Nathan Homestead, 70 Hill Road, Manurewa Thursdays, 16th May

ZOOM PROGRAMMES

CHRONIC PAIN Tuesdays, 14th May
10am - 12:30pm
6 consecutive weeks

MANAGE BETTER TOGETHER
Tuesdays, Tuesdays, 28th May
6pm-7.30pm
4 consecutive weeks



Te Whatu Ora
Health New Zealand

Local Doctors

Tāmaki Health

Join our 6-week Manage Better, Feel Stronger Course

The self-management course is for anyone who has a long-term condition (physical and/or mental health), and for caregivers of someone with a long-term condition, such as:

- Diabetes, asthma, arthritis, gout
- Heart disease, high blood pressure
- Depression, anxiety, stress

The course provides a self-management tool kit of support and information for:

- Healthy eating, physical activity, sleep
- Action planning, problem solving, decision making
- Communication, understanding emotions
- Medication, working with providers

People who attend the courses have reported:

- Better understanding of health behaviours
- Improved social life, sleep and reduced levels of pain
- Better understanding of diabetes and chronic pain
- Improved quality of life and confidence to take care of themselves and others

FREE for registered patients.

Courses available Auckland wide and via Zoom.

"It is way easier to log in, make a coffee and not have to leave the house" (Zoom Course)

"I gained confidence to talk to my doctor and family about my health" (In-person course)

"It felt like I was on the course physically" (Zoom Course).

"This course has been healing for my physical and emotional self" (In-person course)

INTERESTED?

Ask your doctor, nurse, wellness advisor,
health coach, or get in touch with:
Rita - SME Programme Coordinator
09 274 7823 ext 9540 | 027 836 5413
rita.tai@tamakihealth.co.nz



Te Whatu Ora
Health New Zealand

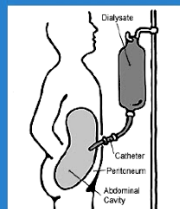
Local Doctors

Tāmaki Health



Are you starting peritoneal dialysis soon?

If you are a female aged 18 to 44 years, this study may be for you.



Study for treatment burden in peritoneal dialysis

Hello, **Kia Ora, Talofa Lava, Mālō e Lelei, Kia orana, Namaste and Ni Hao**

My name is Kitty Ko. I am a part-time PhD student at the University of Auckland and work full-time as Asian Health Gain Advisor at Te Whatu Ora – Counties Manukau. I am also a kidney transplant patient and was a peritoneal dialysis patient for 7.5 years beforehand. My personal experience as a young peritoneal dialysis (PD) patient shaped my study's focus on exploring the experience of treatment burden in female PD patients aged 18 to 44 years.

I am looking for female PD patients aged 18 to 44 years and their spouse/family/significant other to share their experiences with me, specifically at 1-month, 3-month and 12-month after starting dialysis. This research recommends improvement in clinical practice to better support female PD patients aged 18 to 44 years and their spouses/families/significant others in addressing the burden associated with treatment in the first 12 months after PD starts.

Participants will be asked to participate in:

- 3 one-on-one interviews in 12 months.
- At 1 month, 3 months and 12 months after starting dialysis.

Approved by the Auckland Health Research Ethics Committee for three years on 27.10.2023. Reference number **AH26451**.

Study flyer (Patients & Spouse/Family/Significant other) - Treatment Burden in Peritoneal Dialysis

Location

All interviews will be by Zoom or telephone.

Are you eligible:

- You are under the care of Te Whatu Ora – Waikato/Counties Manukau/Capital, Coast and Hutt Valley/ Te Toka Tumai Auckland /Waitematā.
- You will have a catheter insertion and start peritoneal dialysis soon, either continuous ambulatory peritoneal dialysis (CAPD) or automated peritoneal dialysis (APD).
- You are Māori, Pasifika, European or Asian.
- You self-identify as a female.

Participants will receive:

\$50 supermarket gift voucher for attending each interview.

If you're interested in participating or unsure if you meet the requirements, email Kitty Ko (PhD student):

kitty.ko@auckland.ac.nz



Organ Donation New Zealand

Thanksgiving Service 2024

in recognition of those who have given the gift of life to others.

Dunedin

Sunday 5th May 2024

St Pauls Cathedral

228 Stuart Street, Dunedin

12:30pm

RSVP by 19th April 2024

Auckland

Sunday 19th May 2024

Holy Trinity Cathedral

Cnr St Stephens Ave & Parnell Road

Parnell, Auckland

1:30pm

RSVP by 3rd May 2024

(this service will be live streamed for virtual attendance)

Wellington

Sunday 26th May 2024

Cathedral of St Paul

Cnr Hill and Molesworth Street

Wellington

1:30pm

RSVP by 10th May 2024

Afternoon tea will follow each service

Please indicate which service you would like to attend and RSVP to:

contactus@donor.co.nz

PO Box 99431, Newmarket, Auckland 1149

Phone: 0800 4 DONOR (0800 436 667)

Name:

Number of people attending the service:

Number of people attending afternoon tea:

For those who received a donated organ from a living donor,
will your donor be attending the service? Yes No

I would like to attend virtually: Yes No

Email:

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:

- **BlueSky Community Trust** **\$7,000**
- **Four Winds Foundation** **\$15,000**
- **Lotteries National** **\$30,000**
- **NH Taylor Charitable Trust** **\$7,000**
- **WEL Energy Trust** **\$5,000**

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

In Memoriam Donations have been received in memory of:

- June Shaw
- Patricia Morman
- Anthony Ward
- Mary Miller
- Brett Butterworth
- Fagafau Joe Loasa

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

* 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.