# new society



No. 230 March/April 2022

## kidney society

(Auckland based), covering the Northland, Auckland, Waikato, Bay of Plenty, Lakes, Tairawhiti & Hawke's Bay regions

'helping people with kidney failure get on with life'



## **Elaine Smith**

is very
grateful for
her new
Kidney which
she received
over twenty
years ago.
On page 4
she reflects
on those 20

years.

The Kidney Society News is proudly supported by our printers



## Kidney Society "who, what, where"

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# Contributions to the Kidney Society News are always welcome. Why not write us a story or send us a photo!



John our Chief Executive
Officer is responsible for
managing the Society overall.
John leads the staff as they
go about supporting Kidney
Society clients.



Gina our Office Manager is in charge of running the office, the community houses, raffles, events organising and general administration.



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.



Brian our Community
Health Educator can help
you understand kidney
failure and treatments and
how these things affects
you and your family.



Maria our Office Assistant works with Gina to keep everything in the office ticking over, leaflets printed, the News mailed out and more.



Jenny keeps an eye on things at the dialysis houses, shows new people how things work and helps them settle in.



These days Nora just writes the News. She likes getting people's stories because she knows how much our readers appreciate those. Send her your story for the next News!

## Deadline for the May/June News:

Wednesday 13th April. Contributions very welcome!

Contact us for information or a chat, weekdays 9-5, phone 0800 235 711, email <a href="mailto:kidneysociety@adks.co.nz">kidneysociety@adks.co.nz</a> or just come to the Kidney Society Centre, 5 Swaffield Road, Papatoetoe, Auckland

0800 235 711



## Kia ora, Kia orāna, Bula, Mālō e lelei, Talofa and greetings to you all,

For most of us it's been a pretty good summer so far; hopefully you have been able to enjoy some of the nice weather!

Recently I visited several of the treatment centres in the region. It was interesting to

talk with the staff and learn of the pressures they are facing at the moment

We know that all parts of our health system are under strain and the next few months could be a very challenging time – remember the Kidney Society is here to help so please keep in contact with our team if you have any questions or concerns about your health.

I met some amazing staff at the various clinics would like to give them a 'shout out' and acknowledge their dedication and commitment to providing the best care they can.

Finally, I would like to extend my good wishes to members of the Kidney Society's Tongan family who have been affected by the devastating volcanic eruption in their beautiful homeland.

Ngā mihi Regards,

John Loof

Chief Executive Officer

## Sharing your story

Contributions to the News are always welcome. Good ideas, inter-



esting news, but especially 'real life stories about living well with kidney disease. These, like Elaine's story on page 4, are especially appreciated by our readers. Please think about sharing your experiences – and help make the News special for others!

Deadline for the May News: Wednesday 13th April.



## TWENTY YEARS ON.

I am very grateful for my new Kidney which I received over twenty years ago. Always busy with a growing family, we don't have the time to concentrate on our own needs. Haemodialysis for 2 ½ years before I had a phone call to come on in to the Auckland Hospital. Learning my new medica-

tions, anti rejection tablets and more for my other ailments, high blood pressure etc. Yoga many years before taught me to be in tune with my body. Also my father was a type one diabetic so I was brought up on a sugar free diet. I knew to enjoy a healthy lifestyle, eat healthy, rest when tired and drink water. Too many spices, biscuits take a toll. I enjoyed playing golf, walking, ladies' clubs, looking at gardens and now exercising for over 65yr olds. To see my children grow up then marry, to welcome our grandchildren. The support of our Renal doctors, my GP, the Kidney Society and of course family and friends, it has all been worth it.

PS Yes we do think about our donor family, also I now celebrate 2 birthdays a year.

Eat well – stay well Elaine Smith

## Home Dialysis Backup Plan

Are you on Home Haemo or CAPD (the Bags)?

Do you need help to do your treatment?

Do you rely on someone to do your treatment for you?

## COVID OR NOT...

## YOU need to have a plan B:

 in case one day your support person cannot assist you or you cannot manage your dialysis yourself.

## This is especially important with COVID now in the community:

- You could become too unwell to do your own dialysis
- Your support person could become too unwell to assist you

If your support person does not live in your household, they
may not be able to come and help with your dialysis if they
need to isolate at home.

Dialysis units will have planned for such situations and you may have been told already what to do if you cannot manage dialysis at home.

However: it is YOUR responsibility to think ahead and make a plan for YOU.

- Think about how you would manage your dialysis and make a plan for your own situation
- Talk it over with your dialysis nurse or your Hospital Social Worker before it is needed!

It is all about being prepared "In Case"!

A backup plan is also needed for people who get regular Government funded community support services, such as <u>help with housework and personal care</u>:

## You too need a Backup Plan!

With more and more people having to isolate at home every day, think about how you would manage if your personal care support person could not come...

Make a plan for your own situation.

Maybe you have family/whanau or friends who are willing to be part of your backup team?

You should have received a letter to say that this service may be reduced or stopped for a short while if support workers get unwell or have to isolate. This may mean that some of the support you are currently receiving will be reduced or suspended for a short period of time. The letter said:

"It is important to let you know in advance that providers will need to prioritise services for clients who require support to remain safe in their home. This may mean that some of the support you are currently receiving will be reduced or suspended for a short period of time,".

You may want to contact family members and/or friends to plan for your support, should a support worker not be available to provide your usual care."

If you receive home and community support services and are concerned about what this might mean, please contact your usual community support services provider about your needs and their ability to meet those needs over the next few months.

(source: Ministry of Health website)

## Who can receive home support services?

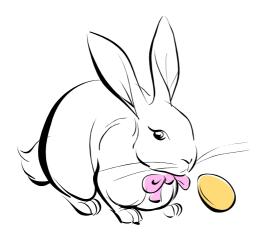
If you are wondering whether you too could - once things are back to normal - qualify for MoH funded community support services such as help with house work and personal care, you can find information here:

https://www.health.govt.nz/your-health/services-and-support/health-care-services/services-older-people/what-you-can-expect-home-support-services#hss

or google Ministry of Health community support services, or contact your hospital social worker to find out if you might qualify.

You must meet certain eligibility criteria to receive publicly funded home support services. You will be assessed to make sure you are eligible for home support and to make sure that the service can meet your needs.

For more information for older people, google Needs Assessment and Support Services for Older People: What you need to know, or contact your hospital social worker.



## HOPPING INTO THE EASTER SEASON

Easter is just around the corner, meaning it is time to prepare for traditions that come with this holiday! As with most holidays, Easter revolves around traditions that include food.

For patients with kidney disease watching your diet is very important since it is easy to eat more salt, potassium, and phosphorous than usual. Here are some tips to ensure a happy and healthy Easter holiday season.

**Main Dish**: Roasted chicken, lamb, or fish can make for a tasty dish. Be mindful of processed ham, seasoned poultry or other seasoned meats, since they will be higher in sodium and phosphorous.

**Vegetables:** There are many vegetables that can make for a great side dish. Examples are cauliflower, raw cabbage in a coleslaw, sautéed capsicums, broccoli, and asparagus, and grilled corn. If you are having any starchy vegetables such as potato, kumara or taro, remember to boil them first and throw away the water to lower the amount of potassium in these foods (if you need to reduce your potassium intake).

**Desserts:** Desserts with apples, lemons, or berries are great choices. Try choosing cakes or cookies without dried fruits. Homemade short bread or sugar cookies are delicious and low in potassium.

Here are some recipe ideas for a healthy Easter meal to share with family and friends

#### QUICK AND EASY BROWN RICE SALAD RECIPE

#### Makes 4 servings

#### Ingredients for salad

3 cups cooked brown rice

2 spring onions, sliced

1 red capsicum, diced

1 celery stalk, finely chopped

1 carrot

1/4 cup sliced almonds

½ cup fresh coriander or parsley, chopped

1tablespoon chopped ginger

1 tablespoon olive oil

1 tablespoon soy sauce

2 tablespoon lemon juice



#### Ingredients for salad dressing

1 teaspoon sesame oil 1 teaspoon of olive oil Juice of 1 lemon 1 garlic clove, crushed Salt and black pepper

#### Method:

- 1. Cook the brown rice first and let it cool down
- 2. Place the cooled rice in a large bowl and add all the salad ingredients in together
- 3. To make the dressing, mix all the dressing ingredients together in a jar and shake well to blend Kids love to give this a go!
- 4. To serve, drizzle dressing over the salad and toss well

**Optional:** Adding some cooked chicken or tuna would be a great addition of protein to this salad

## Recipe adapted from the Heart Foundation NZ

#### **RUSTIC AND WARM HOMEMADE APPLE PIES**



#### To serve

Plain yoghurt or whipped cream

### **Ingredients**

- 6 apples granny smith or cooking apples
- 3 tablespoons butter
- 4 tablespoons brown sugar
- 2 teaspoons ground cinnamon
- 1 lemon, zest and juice 500g ready rolled puff pastry
- 2 tablespoons fresh walnuts

#### Method:

- 1. Cut apples into quarters. Remove the core and pips.
- 2. Melt butter in a frying pan and add the apples. Cook for 5 minutes, then add sugar and 1 teaspoon of cinnamon. Toss and cook for 2 more minutes.
- 3. Add grated lemon zest and lemon juice. Toss well and cool.
- Cut the pastry into six squares (12cm by 12cm). Lay in a greased oven tray. Carefully spoon the apple filling in the centre of the pastry.
- 5. Scatter the walnuts and remaining cinnamon on the top.
- 6. Pull up the pastry corners and crimp the edges with your fingertips to form the parcels. Brush pastry with the beaten egg.
- 7. Refrigerate the pies for at least one hour to rest the pastry
- 8. Preheat the oven to 200°C. When ready for baking place the tray in the middle of the oven and bake for 30 minutes or until the pies are crisp, and golden and cooked underneath. Serve warm with yogurt or whipped cream.

## Recipe adapted from Love Food Hate Waste

## **EASTER WORD SEARCH**

F Ε Ε R Ν G 0  $\circ$ G Ε W В 0 U U Ε Ε Q Τ Н Υ M A G S Υ Ζ С С U Ν D Α Η U R Η Χ MGGO L Ε S U В S - 1 Ν G S F S S D G 0 0 D R Υ Ρ Ν D F F L 0 W F R S U Τ J F 0 Ε J U IJ 0 Χ Χ 7 Н 0 D Α Υ Α Т Т C D H O T R O S S В U Ν S S Ν Υ U J Τ R В - 1 Τ U В Κ Τ Τ Υ Α В C M F M L Υ С Н 0 C 0 L Τ Ε S Ν S Н Н  $\bigcirc$ Ε Χ Ε G G Н U Ν Τ Μ Н R M G В A S Κ E Τ 1 В

Find the following words in the puzzle.

Words are hidden  $\rightarrow \Psi$  and  $\checkmark$  .

AUTUMN DAFFODILS
BASKET EASTER
BLESSINGS EGG HUNT
BOUQUET EGGS
BUNNY FAMILY
CELEBRATION FLOWERS
CHOCOLATES GOOD FRIDAY

CHURCH

HOPE HOT CROSS BUNS IOY

JOY RABBIT SUNDAY

This article was put together by Andrea Malto on behalf of the Counties Manukau Renal Dietitians.

**HOLIDAY** 

## Portable Leg and Arm Peddle Machine

This is a great alternative to a standard exercise bike and one of my favourite low-cost pieces of equipment.

It is mostly suitable for those who have low fitness and mobility and need to get their legs (and arms) moving at a gentle level.



It is affordable, light weight... and portable. You do not have to worry about trying to get on and off it or getting a sore bottom from a bike seat. And it takes up very little space.

As one very clever client showed me, it can also be used for your upper body by just picking it up, putting it on the kitchen table and using it to go forwards and backwards! Brilliant!!!! (above picture) You might just need to put it on a non-slip mat or against a wall so it doesn't slide away.

Peddle machines have also been suggested as a tool to assist with restless leg syndrome, increasing the circulation and muscle movement.

To use it as a leg peddler you can try it using different seats/chairs to find the best angle for you. Many people find a dinning chair or even their walker (WITH BRAKES ON!!!) are the perfect height. However, it pays to try different chairs until you find the perfect position for you. Once again, a non-slip mat or towel under it can make it more stable.

The downside is that he pedals are not very big and with most of them the strap doesn't adjust very far.

For those of you who have extra-large feet you may find them unsuitable. You can turn the pedal around to use the other side and not use the support strap if that works for you.

Also there does not seem to be a big range to the resistance so people who are a bit stronger or fitter may find them too light. They are really designed for light exercise, circulation and movement.



Kmart have them but you cannot buy them in-store - they are available on-line only.

They do go in and out of stock, but I have found that if they come up as 'sold out' it is usually only a couple of weeks before they are back in stock.

The one in the picture on this and the previous page is the Kmart model.

The cost is \$35 and then shipping is \$5 subur-

ban and up to \$10 for rural courier.

https://www.kmart.co.nz/product/mini-exercise-bike/911877

#### The Cubii

Some of you may have seen the Cubii on TV.

It is a type of mini pedal machine that is more like cross trainer pedals.

It is quite heavy and difficult to move.

My biggest issue with it is the price...At \$400-\$600, in my opinion it is not worth the money.

## There are a few different types available online.

I have had a few clients mention they have found them on Trade-Me, but the price does vary.

There are some 'flasher' models around too (pictured below). Some offer a bit more resistance and stability than the Kmart model, so it does pay to shop around.

Independent Living Services have the same style as the Kmart version for \$79.

If you want help or advice about "keeping mobile", phone, text or email me:

Tracey Drinkwater, Kidney Society Wellness Educator tracey@adks.co.nz

0800 235 711 or 027 378 4544

## Mental & Emotional Wellness

## The CALM Program

Recommended by Tracey, Kidney Society Wellness Educator



There are many exercise programs out there for our physical fitness, strength and flexibility.

But what about exercises for our mental and emotional fitness?

Auckland University has an online program available for just that.

The program is called CALM and stands for Computer Assisted Learning for the Mind.

"Mental resilience is like being physically fit. With mental resilience, people are able to handle the stress and difficulties that are inevitable in life. Most of us are not born with 6- packs and strong biceps. We have to work on these. It is the same with mental resilience. We can work on mental skills to cultivate positive emotions and skilful perspectives."

#### https://www.calm.auckland.ac.nz/7.html

- Mental resilience
- Managing stress, anxiety and depression
- Healthy relationships
- Finding meaning in life

Each section is broken down and there are "exercises" to help you with the different areas.

I personally really like some of the audio programs. There are lots of different ones to choose from, guided mediations, relaxation, mindful breathing and even an audio program on self-hypnosis. They range in time from a few minutes to over an hour depending on which programs you would like to try.

I must admit it did take me a few times on the website to learn to navigate it but once you get going there is a lot of wonderful information, advice, links to other support programs and practical exercises you can attempt.

I did like that as a "busy" person It is important to make time to sit, breathe and STOP.

I just found a quiet place, popped in some headphones, listened, and breathed.

There is a warning with some of the audio exercises not to listen to them when driving or similar. And I can understand why as it was often hard to keep my eyes open....

So, if you think you might benefit from a mental exercise program it is definitely worth checking out.

https://www.calm.auckland.ac.nz/index.html#16

## Staying Engaged and Active on Dialysis

https://www.freseniuskidneycare.com/thriving-on-dialysis/staying-active

Life on dialysis doesn't mean you have to give up the activities or work you love. In fact, there are plenty of advantages to <u>continuing</u> to work and staying active and productive in general. Staying engaged and busy with the things you like to do can be a great way to maintain some normalcy in your life—and thrive on dialysis.

There are big benefits to home dialysis—including greater flexibility and fewer restrictions, so you can keep the lifestyle you love.

Why not find out if starting or switching to home dialysis treatment is right for you?



People who work, or volunteer or stay involved in activities while on dialysis may experience:

- Improved self-esteem
- Increased physical activity
- Heightened mental stimulation
- More socialization
- Continued income from employment
- Greater personal satisfaction
- Pursue your interests—and some fun

To reap the benefits of staying active, consider getting involved with hobbies or groups that mean something to you. If you belonged to a social or church group in the past, reach out and reconnect. Look into hobby groups like knitting, painting or clubs in your area. Start a book club. Volunteer for a cause that's important to you. Check out your local senior or community centres for classes or activities.



### Balancing life, work and dialysis

Whether you're working, volunteering or simply living actively, you can find ways to balance the demands of life and dialysis.

If you are working and want to continue working, ask your doctor or social worker for advice on ways to balance your work and treatment.

Working or having a busy schedule may also impact the type of treatment options you will need to consider. For example, if you work during the day, you may wish to dialyze at night, in the comfort

of your own home or at one of our dialysis centres. Talk to your doctor about the right treatment for your health and your lifestyle.

#### KIDNEY SOCIETY NOTE re the above article:

## NOT ONLY PEOPLE ON HOME DIALYSIS CAN BE ACTIVE AND ENGAGED!

While home dialysis gives you more freedom and possibly more energy than centre dialysis, everybody can become more active and engaged!

If you want to find out how, contact TRACEY OUR WELLNESS EDUCATOR, 0800 235 711 or email <a href="mailto:tracey@adks.co.nz">tracey@adks.co.nz</a>

Men: you may also want to ask Tracey about:



https://menzshed.org.nz/



Wayne McDonald's donation, in memory of his wife Sola, helps fund the Kidney Society News in 2022 (see story in the January/February News)

If any other readers would like to support the News with a targeted one-off or regular contribution towards its printing and mailing, please contact Gina, 0800 235711 or email <a href="mailto:gina@adks.co.nz">gina@adks.co.nz</a> – or simply make a donation via our website or directly into our Bank account, ASB Bank 12 3032 0705009 00. It would be a great help!

## Some stories are timeless.... such as this one called "Are you ruining my Life?"

This article was published in the News many years ago, atter it first appeared in "Kidney Life", the magazine of the National Kidney Federation, UK, Autumn 1998. It is as relevant today as it was then....

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

Peter's polycystic kidneys were diagnosed in 1977 when he was 46. There were many anxious and tearful moments as dialysis became part of a different life. I left my teaching job to become a home tutor to sick children in the mornings. I became a clock- watcher - any delay getting Peter 'on' the machine meant a later time getting him 'off' after 8 hours.

I became a keen gardener - a shout from the bedroom window was enough to bring me running! I went to a weekly art class, a hobby I could practice confined to the house. We got hardened to explaining to wine waiters that Peter shouldn't drink wine and my mother never could accept that he didn't want a full cup of tea. It's not all sweetness and light being a carer........... Tempers become frayed by both partners.

One has to put up with irritability and unfair criticism, but if the partner says 'sorry', then it alleviates hurt feelings. One can only be ill on non-dialysis days and 36 hours in bed with 'flu is the maximum. Even with a streaming cold, needles have to be put in - and you stand on one leg if you have sprained your ankle! The mental and physical strain is tiring. My husband had a breakdown and took early retirement. A transplant in 1995 failed after 7 months and he was back on dialysis, very anaemic, lethargic and apathetic. It was hard not to give in to despair.

I am back to manoeuvring a very heavy machine and, being 20 years older, I don't find it easy. But, Peter now dialyses for 4 hours; he is feeling better mentally and physically and I am happier to see improvements in his condition. Yes, my life has been restricted to an extent, but not entirely. It certainly has not been ruined.

Sybil Humphreys, 1998

## Nora's memories

# I too started out as a 'home haemo carer', (actually, I have always preferred the word 'partner") and my life changed direction...



Today I look back at well over 30 years' involvement with the Kidney Society, starting shortly after my husband Hans began home haemodialysis. As a supporter I was very much in need of Kidney Society support myself, but I soon became involved as a volunteer and was later also employed in a paid capacity.



Hans continued on home haemo for 22 years, interrupted only by several short lived and unsuccessful transplants until he died in 2002 – a proud home haemo person till the very end.

By then I had become the Society's first paid employee

in 1999 – coming full circle at the end of last year when I finally, and I have to say reluctantly and with very mixed feelings, admitted that working on much beyond my  $75^{th}$  birthday would be a bit ridiculous...

The Society, having grown to a sizeable organisation with some 3000 clients at any one time including a few hundred financial members, a small team of long-term highly experienced and dedicated staff and owning the Centre in Papatoetoe as well as three community dialysis houses, now demanded more of my time and energy than I could expect to be able to commit to much longer. I also had many other things I had put off for years – so I retired at the end of 2021.

I look back with pride on what we achieved - our small team of staff and volunteers - growing and shrinking over the years depending on available funding - with the support of a succession of often long serving Board members. The tiny patient support group called 'Kidney Kapers' (founded in 1979) has mushroomed into something much bigger than any of us could have dreamed in those early days.

As well as supporting individual people, increasingly much of our work over the years involved representing people as a group – and our opinion and input was increasingly sought by renal staff as they worked towards delivering the best possible service to their renal patients. Those opportunities did benefit people with kidney failure regionally and often nationally as well.

What never changed over all those years has been the absolute commitment that our staff developed and maintain to this day, to treating and supporting patients and their families as individuals deserving their attention and time above all else - no matter who or what else needs doing or what marvellous or exciting opportunities present themselves to achieve bigger and better things.

Having lived with kidney failure and dialysis within my family and having seen first-hand the effect - good and bad - this had on my children and also myself, I have always been adamant that under my leadership the Society would never compromise its support for people as individuals for the sake of, for instance, obtaining more funding, or achieving greater fame or recognition.

I am especially proud of the work of the very best of our past and present employees who, having developed deep insight into the many and diverse ways in which people experience and live with advanced kidney disease, until this day treat every one of our clients irrespective of their needs, their background or their 'likeability' as individuals who need a hand to live life to the full according to what is most important to them – no matter what others might think.

I especially want to mention Rachel, Brian, Gina, Beryl, Leigh, Lynda and Tracey – exceptional people, some of whom will hopefully continue well into the future, who made our service as excellent as it is today, learning from our clients and each other to become experts in supporting people to live a good life around their health and life challenges. Some of our readers will remember them all.

Our approach to practical and emotional support approach has been learned from the best – even today Leigh's common sense and down to earth 'talking is cleansing' approach to social work still guides our staff as they help people tackle difficult or distressing situations.

I still vividly remember one visionary board member called Charles Barroclough who in the very early years had ideas and plans for the Society which were considered quite ridiculous by our Board at the time – but almost all of which have since come to fruition. Charles would be proud! Some might not ever have come to fruition, but the examples below were certainly part of his plans. Some like our houses are long term successes, and those that did not continue for good reason were nevertheless successful, worthwhile, and appreciated.

A holiday home was the first achievement.. our Wellness Programme started off as an idea that grew and flourished ... our community dialysis houses were an opportunity waiting to be grabbed... our dialysis camps were never-to-be forgotten although exhausting events... strongly supported by some exceptional renal staff members – many people will recall Dave Lilley, but that's a story for another day....

It is my greatest wish for the Society's future that its exceptional approach to delivering client services continues – it is what makes the Society unique and of most value to the thousands of people who access and continue to experience the Society's very special support that empowers and encourages people to find their own way around life's challenges.

I am fortunate to be able to continue to write the News for a while longer, once again as a volunteer, it's always been one of my favourite jobs. Meanwhile I am starting to enjoy ... sitting in the sun, getting stuck into my waiting jigsaws, reading, gardening and lots more...

Sounds quite nice, doesn't it?

I do however really miss the 'doing things for other people" – my focus in life for so many years. Fortunately, my two little darlings at home quite like the more relaxed

me and know exactly how to keep me in one place!

## Nora Van der Schrieck



Like it or not, Omicron is invading our homes....

Being ready helps to keep us safe

Here is a summary of useful advice and

information – more can of course be found on Covid an Ministry of Social Development websites.

Most people who get COVID-19 will have a mild to moderate illness, and will fully recover in their own home. For those who need help, the healthcare system will always be available.

Omicron spreads fast — everyone in your house may catch the virus. Being ready for getting COVID-19 is about making sure you and your household have a plan and know what to do. It will mean your whānau and community can help each other if needed.

#### https://covid19.govt.nz/isolation-and-care/care-in-the-community/

Here is some of the advice available on the Covid website – the full version is available by following the link below, including a **downloadable isolation plan and checklist:** 

https://covid19.govt.nz/prepare-and-stay-safe/be-prepared-for-covid-19/#being-ready-helps-to-keep-us-all-safe

## What you need to plan for

You need to work out what you will do if someone in your household tests positive for COVID-19, because your entire household will need to stay home.

Google **Help and support if you have COVID-19** to find out how to get help. <a href="https://covid19.govt.nz/isolation-and-care/getting-extra-support-if-you-have-covid-19-or-are-self-isolating/">https://covid19.govt.nz/isolation-and-care/getting-extra-support-if-you-have-covid-19-or-are-self-isolating/</a>

Practice healthy habits like coughing and sneezing into your elbow, and washing hands to reduce the spread of germs.

## Get things ready to isolate

Work out what you will need to help yourself and those around you.

**Know and share your plan :** Kōrero together — make sure everyone in your household, including children, knows what will happen when

you need to isolate. Share plans with those supporting and helping you (or who you are supporting).

Share your plan with wider whānau, neighbours and regular manuhiri/visitors and talk to them about what you will need them to do and how you can help each other.

#### Let people know you are isolating

Work out how to let people know your household is isolating. This could be a sign for your front door or fence and having a QR code poster so people can keep track of where they have been. If people are helping with contactless drop-offs, do you want them to text or message before they arrive? Beep the car horn from the gate? Use an agreed entrance?

#### **COVID-19 welfare support**

The Ministry of Social Development (MSD) can co-ordinate extra support for you if you are self-isolating because you have COVID-19 or are identified as a Close Contact.

## You can call the COVID-19 Welfare phone line on 0800 512 337, 7 days a week.

It is important that you answer all calls when you are self-isolating, as your healthcare provider, MSD or another service may be trying to contact you.

#### IN CASE OF EMERGENCY

Most people can recover safely at home.I

- If you need advice or your symptoms worsen, call your doctor, health provider or Healthline on 0800 358 5453.
- If you are having trouble breathing, call 111 immediately.
- Have personal information ready, including:
  - full names, birth dates/ages, NHI numbers, medical conditions and prescriptions,
  - GPs/health providers and other emergency contact details
  - Prepare instructions for pets, plants or paying bills, just in case you need to recover away from home.
- And of course: if you are on haemo, PD or have a transplant contact your unit staff or transplant coordinator for advice.

# Do You Continue to Make Urine After Starting Dialysis?

https://www.verywellhealth.com/do-you-continue-to-make-urine-after-starting-dialysis-2085853

By Veeraish Chauhan, MD Updated on July 31, 2020, Medically reviewed by Matthew Wosnitzer, MD on August 01, 2020



Unless your kidneys have completely shut down and the glomerular filtration rate (GFR) has gone down to absolute zero, many patients will continue to produce urine even after starting dialysis. However, just because you make urine does not necessarily mean that you don't need dialysis. The decision to initiate and maintain dialysis is based on multiple factors including lab tests and patient's symptoms and not necessarily on the volume of urine one makes.

In simple terms, kidney function that remains after one starts dialysis is called **residual renal function**. It could be a very small fraction of what normal kidney function is.

Factors that determine whether one might preserve residual renal function could include:

- In general, patients on peritoneal dialysis will tend to make urine from their kidneys longer than patients on hemodialysis.<sup>3</sup>
- Cause of kidney failure makes a difference
- Blood pressure control: Drops in blood pressure will tend to accelerate the loss of one's residual renal function
- Medications: certain ones could help your cause, while others could hurt (see below)
- Non-white race is associated with a faster loss of residual kidney function
- Female sex

It's Important to Preserve Residual Renal Function

As insignificant as it might seem, residual renal function is a big deal and maintaining it is of utmost importance.

These are some reasons why maintaining even a little kidney function after someone gets started on dialysis could make a big difference:

- 1. Patients who have significant residual renal function tend to live longer. Multiple studies have corroborated this.
- Patients with intact residual renal function are more likely to receive an adequate dosage of dialysis (yes, like any other medication, there is a certain minimum amount/dose of dialysis that one needs to receive to get its benefits).
- 3. Quality of life is better. This is partly related to the patient's ability to get away with less strict dietary restrictions. They can also be a little more liberal with their fluid intake.

#### How to Preserve Residual Renal Function for Longer

This is an active area of research in nephrology. What we do know so far is that certain interventions can help preserve residual renal function better and longer, and therefore might translate into a longer lifespan and a better quality of life for dialysis patients. Some of these interventions are:

- Good blood pressure control
- Tight blood sugar control if you have diabetes
- Use of certain medications, called ACE inhibitors has been shown to help
- Conversely, avoiding certain medications that are known to be toxic to the kidneys makes sense; like NSAIDs (or nonsteroidal anti-inflammatory drugs), aminoglycosides, Amphotericin B, etc.
- Considering starting kidney failure patients preferentially on peritoneal dialysis (the so-called peritoneal dialysis-first strategy. However, this remains a subject of debate).
- There are suggestions from some studies that a gradual incremental increase of haemodialysis might lead to better preservation of residual renal function.<sup>5</sup>

#### **Bottom Line**

Consider yourself lucky if you still continue to make some urine after starting dialysis. Even though it might seem insignificant, having even a little bit of urine output could make a big difference to your life expectancy as well as a quality-of-life. So if you are on dialysis but still make some urine, please do not have an "I have nothing to lose" attitude when it comes to maintaining your residual kidney function.

# What is a "pre-emptive" or "early" transplant?

Getting a transplant before you need to start dialysis is called a **pre-emptive transplant**. It allows you to avoid dialysis altogether. Getting a transplant not long after kidneys fail (but with some time on dialysis) is referred to as an **early transplant**. Both have benefits. Some research shows that a pre-emptive or early transplant, with little or no time spent on dialysis, can lead to better long-term health. It may also allow you to keep working, save time and money, and have a better quality of life.



Find lots of useful and interesting information on this American website and sign up for their email news:

https://www.kidney.org/atoz/content/kidney-transplant

or google: kidney.org/atoz/content/kidney-transplant



https://carers.net.nz/

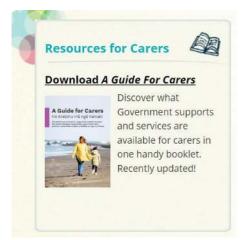
Carers NZ Helpline 0800 777 797

Established in the early 1990s by and for family carers, Carers NZ acts as the national peak body providing information, advice, learning and support for carers in our network.

Today Carers NZ is a national not for profit supporting a network of approximately 490,000 individual carers and supporting organisations. There is no membership fee and Carers NZ fundraise to share their support resources freely with family carers.

The primary role of Carers NZ is to ensure awareness about carers, their role, and their needs within New Zealand and internationally. We participate in government reference and working groups and promote the interests of family carers to decision-makers in health, education, employment, social services, housing, transport, and other important areas.

## A Guide for Carers He Aratohu mā ngā Kaitiaki





Sign up for free to receive electronic newsletters, alert bulletins, special offers, and other information.

Just send Carers NZ your details! Email your name, email address, physical/mailing address, post code, and phone number to <a href="mailto:centre@carers.net.nz">centre@carers.net.nz</a>. Alternatively, phone the National Carer Resource Centre to join the carers network, 0800 777 797.

When contacting us, you can request a free printed information pack for family carers, or download the information.

Family Care magazine: To request a copy of Family Care, or if you have questions, phone 0800 777 797 or email <a href="mailto:centre@carers.net.nz">centre@carers.net.nz</a> - View he latest issue online.

'Time Out' is a downloadable Guide that lets you know about a range of help available for people who care for and support family, whānau, āiga or friends with a physical or mental health condition, a

disability, an injury or an illness.



As a family, or whanau or aiga carer, you'll know how important it is to find time for yourself to rest, for wellbeing, and to renew your energy. But finding this time isn't always easy! We have developed Time Out to help carers proactively plan and organise respite breaks for themselves. While we hope you find the ideas in this resource useful, we realise that it won't have answers for every carer. Respite is as individual as carers themselves, the needs of those they support,

and other life circumstances.

Most of the advice in Time Out has been provided by carers, many of whom have been providing support for loved ones for many years. Their feedback, taken from hundreds of carer responses to our comprehensive respite survey, plus ongoing discussions, reflects the diversity of caring across age groups, support situations, cultures, and locations. The common thread in survey responses from carers is that breaks don't plan themselves. All carers need to take respite opportunities as they arise, while planning for others. As one carer commented: "Plan, plan, plan, and then be prepared for change!" We hope Time Out encourages you to plan the breaks you need and make sure they happen!

## My Experience With PD

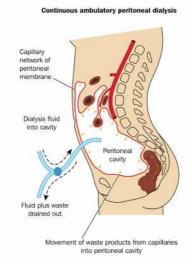
https://homedialysis.org/news-and-research/blog/431-my-experience-with-pd

This blog post was made by Craig Jacobs on May 20, 2021.

I remember the day I was told that I was going to have to eventually go on dialysis. I remember telling my family, "Oh no, I really don't want to be stuck with 2 large needles or have a giant gross fistula in my arm" (even though I have one now and you can barely see it.) Once I learned about PD and how there were no needles or no blood I was sold! The drawback though...a nice little catheter sticking out of your stomach. "That's no big deal! I can handle that! It's better than getting stuck with 2 needles every other day!" I told myself. So, this is where my story begins.

I remember going into pre-op to have my catheter placed. They gave me an IV and wheeled me back to the OR. I remember falling asleep quickly. The whole surgery took about 40 minutes. I woke up in recovery with a little pain in my abdomen and a nice new catheter installed and coiled up and taped to my belly. I went home later that afternoon to eat lunch and take a nap. I felt fine by the next day, however at that time I was still urinating, and it took me about 36 hours before it started to come back around and I was able to go again.

I had to wait about 4 weeks for the catheter to settle and fully heal, and then it was off to training! Training lasted about 2 weeks and was a couple hours a day of teaching you how to hook up properly, fill, drain and disconnect. Once training was over, I had to do manual exchanges at home for 2 more weeks before I could start to use my cycler. Once I started using my cycler, it was a breeze to set up. After a few weeks I could almost do it with my eyes closed. I



started out going every night when I went to bed, 4 exchanges, 2500ml each for 8.5 hours in total and it was great! I felt great, no needle sticks.

I eventually even went back to work full time. However, over time I started to urinate less and less and my prescription became more and more. At the end, I was doing 5 exchanges at 3000ml for 10.5 hours a night. It got to be too much for me and I decided to have my catheter removed and went back to haemodialysis.

My only other issue with PD was the amount of supplies and garbage. Every month, I would have about 40 boxes of supplies delivered to my house, and they would take up an entire spare bedroom. Also, you had empty boxes, plastic bags and empty tubing that had to be thrown out every day. What I started to do was put a 55 gallon trash can in my room and would put all the waste in there and take it all out to the curb on trash night. It saved a lot of time and energy for me to do it that way.

You also need to make sure you keep your exit site, where the catheter comes out of your body, clean and sterile. You can get an infection called "peritonitis," and it isn't fun. I had it once and spent 3 days in the hospital in constant pain. I was told by a nurse that they were told that the pain is comparable to childbirth. So take care of

your exit site!



Another good thing I enjoyed about being on PD is I didn't have as much of a dietary restriction as I do being on hemo. I was able to eat a little more freely and drink a little more freely because of the nightly cleaning. However, you still need to watch your fluid intake because it can and will still creep up

on you.

One last thing I can say is that I also have diabetes, so if you do, too, you're going to have to watch your night time blood sugar. What I would do is take a little extra long acting insulin before I went to bed to cover for all the Dextrose in the solution. I also thought it would be a good idea for someone who uses an insuln pump to up their basal dosage so it'll cover you throughout the night.

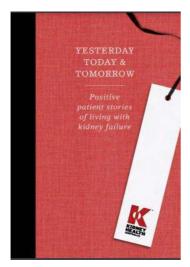
All in all, I think PD is a good solution for someone who is either young, still working, or doesn't want to get poked with lots of needles.

## Has your address or phone number changed?

We have no way of knowing unless you tell us. Please remember to let us know BEFORE you move, or as soon as you have a new phone number.

## The Kidney Society NEWS is FREE for Auckland/Northland/Waikato/Bay of Plenty/Lakes, Tairawhiti/ Gisborne and Hawke's Bay people who are pre-dialysis, on dialysis, supportive care or who have a transplant. Others, including supporters, are welcome to subscribe to the Kidney Society News for \$25 per year (6 issues). For changes to our mailing list, to have your name taken off the list or added to it, or to subscribe, please fill in the form below and send to: FREEPOST 1875, Kidney Society, P O Box 97026, Manukau City, Auckland 2241. You can also phone 09 278 1321 or 0800 235 711, or email kidneysociety@adks.co.nz .....email ..... Please do the following: (tick box) add my name to your mailing list (free for Auckland) Northland/Waikato/Bay of Plenty/Lakes, Tairawhiti/Gisborne and Hawke's Bay people who are pre-dialysis, on dialysis or supportive care, or have a kidney transplant). I have kidney failure please change my contact details as per above please take my name off your mailing list I am a supporter, or a person with kidney failure not living in one of the regions above. I would like to receive the magazine, please sign me up as a paying News subscriber, \$25 enclosed. OPTIONAL: please sign me up as a Kidney Society Financial Member, \$20 annual subscription enclosed, or pay to our bank: 123032 0705009 00, remember to add your name and 'subs'.

Use of your name, address and any other information about you is exclusive to the Society and its staff for use in the provision of our services to you



# Yesterday Today & Tomorrow

## Personal accounts of people living with kidney failure

This is a wonderful collection of stories from people with kidney problems and their families gathered with love and care by Melissa Darnley, it is downloadable or can be read on the Kidney Health Australia website:

https://kidney.org.au/

Here is a little taster, written by Bill

Peckham, 43, Trade Show Specialist:

"As I squatted in the windblown privy, yet again, I invented the 'Misery Index'. On a scale of one to ten, this was a ten; I could not imagine being more miserable. It was the dark hours of early morning on a nameless Himalayan ridge with only a piece of canvas between me and a howling sleet storm and I realised that, if I lived, it could only get better. I could not imagine anything ever being as bad as dysentery during an entire three week Nepalese trek. This was quite a change from two weeks earlier when while scuba diving on Australia's Great Barrier Reef I was pretty sure my life would never be any better. I was young of course and as it has turned out I was only half right, I have never been that miserable. I can forgive myself for thinking that I had peaked on the happiness side of the equation.

Eighteen months before that night in Nepal, I had been told that my kidneys were failing and that I would have End Stage Renal Disease within three years. End Stage Renal Disease is not a term anyone wants to hear from their doctor, much less a twenty two year old with wanderlust, just out of college. End Stage sounded very final, so once the initial shock of the diagnosis passed I began planning what I thought would be my first and last trip abroad.....

Google Kidney Health Australia, then search for **yesterday today & tomorrow**, **you can download it or** read it online on the KHA Website.

## **Fundraising**

## 1st January - 21st February 2022

Subscriptions	\$35
Member donations	\$819
IM donations	\$570
TOTAL	\$1,424

Since the last News we received the following grants:

- Frimley Foundation \$5,000 for Hawkes Bay services
- Pub Charity \$50,000 for salaries

#### In Memoriam:

Donations were received in memory of Bruce Burn. These gifts, like all donations and gifts made in someone's memory are sued with care towards our services for people with advanced kidney disease.

## To all our known supporters and thos who want to remain anonymous

Some of you – individuals, businesses and communi organisations - support the Kidney Society without even telling usery year we receive numerous gifts in kind and cash to help us deliver our services, manage our properties and keep our costs down.

