

kidney society news



No. 229 January/February 2022

kidney society

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

'helping people with kidney failure get on with life'



Jenny Ili has been on dialysis for more than half her life. Read her story inside.

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Kidney Society “who, what, where”

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<p>Contributions to the Kidney Society News are always welcome. Why not write us a story or send us a photo!</p>		<p>John our Chief Executive Officer is responsible for managing the Society overall. John leads the staff as they go about supporting Kidney Society clients.</p>	
	<p>Gina our Office Manager is in charge of running the office, the community houses, raffles, events organising and general administration.</p>		<p>Tracey our Wellness Educator can help you keep mobile and feel good “the gentle” or “the active” way. She can find you a gym or give you exercises for at home.</p>
	<p>Brian our Community Health Educator can help you understand kidney failure and treatments and how these things affects you and your family.</p>		<p>Maria our Office Assistant works with Gina to keep everything in the office ticking over, leaflets printed, the News mailed out and more.</p>
	<p>Jenny keeps an eye on things at the dialysis houses, shows new people how things work and helps them settle in.</p>		<p>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!</p>

Deadline for the March/April News:

Wednesday 9th February. Contributions welcome!

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

0800 235 711

Kia ora and New Year greetings from the Kidney Society



I hope you have all been able to enjoy some quality time with family and whanau over the holiday period and to relax after the ups and downs of last year.

In a world where the pandemic seems to dominate so much of our lives there are few certainties about what this year will bring. However, from a Kidney Society perspective we remain committed to providing as much service and support as we can. Reconnecting with our clients is a top priority. So many of our patients' sessions and home visits have had to be postponed but we are looking forward to seeing you again in person and to getting out and about around our region.

You may have seen the recent campaign to increase the number of kidney transplants which was launched late last year. Unfortunately New Zealand has comparatively low rates of transplants when compared to other countries and the Society has been working with other like-minded health agencies to persuade the Government that more needs to be done to support kidney patients on the transplant waiting list. In the months ahead we intend to keep pushing this issue forward.

Finally I want to thank all our supporters. The Society is focused on providing free support, resources and information to our clients and we are grateful to all those people and organisations that make this possible.

Ngā mihi Regards,

John Loof, Chief Executive Officer

Kidney Society Events

Because of COVID uncertainties we do not know when we can re-start our usual series of events around the country. As soon as home visits or events are able to go ahead in your area, the plan is to invite people by mail or phone and then re-start Events pages in the News.



Jenny Ili has been on dialysis for more than half her life.

Recently Jenny was interviewed by Quiyi Tan, Diversity reporter, **NZ Herald**, following the release of a new report commissioned by Kidney Health NZ projects a 30 per cent increase in the number of dialysis patients over the next 10 years, largely driven by the increasing prevalence of type 2 diabetes, a leading cause of kidney failure together with high blood pressure. (Photo: Dean Purcell)

Jenny Ili was barely a teenager when she was diagnosed with a rare disorder that would fail her kidneys and tie her to a machine six hours a day, three times a week. It was nephrotic syndrome, the same disease that afflicted and eventually took the life of All Blacks legend Jonah Lomu. Now 41, Ili has been on dialysis for more than half her life.

"I've been on dialysis for 24 years," she told the Herald. "It came from out of nowhere."

Ili is one of 4,440 New Zealanders who used some form of dialysis in the past year, and the number is set to increase in what Kidney Health New Zealand calls a "tsunami of dialysis demand".

A new report commissioned by Kidney Health NZ projects a 30 per cent increase in the number of dialysis patients over the next 10 years, largely driven by the increasing prevalence of type 2 diabetes, a leading cause of kidney failure together with high blood pressure. The report "Transforming Lives and Saving Money" says the problem disproportionately affects Māori and Pasifika, who make up 60 per cent of dialysis patients today.

Ili's family had never seen anything like it before, not in Samoa, where her parents were born. "There was nothing in the family. Nothing from dad's side, nothing from mum's side." Ili said her mother did not believe it at first and called it "the white man's illness". She remembers the loneliness as a young person. "Not being able to talk to anyone and thinking that you're the only person that's on it, that's

had it. It felt just closed off. You wanted to join your cousins, doing things, like normal teenagers, but you couldn't."

She was lucky to get a kidney transplant in December the same year, but it didn't last.

"When I got that transplant, there was no support system. Being a teenager, thinking that you can do whatever you want to, drink, smoke, have fun, what a normal teenager would do, not knowing the consequences of not taking the tablets."

She had paid little attention to the plethora of immunosuppressant drugs needed to stop her body from rejecting her new kidney. She had one year of freedom from disease, then her transplant failed.

"I blame myself because it was me. I regretted and wanted to go back and [do things differently], but I couldn't."

Ili has been on dialysis since then. She recalls hitting her lowest point about 10 years ago in a dialysis room, her body desperate for a clean but she just could not find a vein. "I was so swollen I couldn't get the needle in."

Ili is in a good place now, with a full schedule on top of her six-hour dialysis sessions three times a week. She works as a support worker for dialysis patients at the Auckland Kidney Society, able to relate, understand, and lift spirits because she has been there before, even though everyone's journey is different.

"My routine is wake up, go to work, come back home, have something to eat, go throw some hoops, or go to dance fitness, go to gym, go home."

She says what's kept her going are her friends and family, the nurses, doctors, and other kidney patients she has met along the way.

Last year she put herself back on the waitlist for a kidney transplant, after saying no to herself for more than a decade. She had feared being disappointed again and had been comfortable with the life and routine that she had built around dialysis.

"When I turned 40 (last year), I thought, we have to do something. Life is too short."

Finding a match is difficult, she says, and doctors have told her she has antibodies that complicate the search. But she's waiting and living life day by day. "You never know when the call will come."

There are 462 New Zealanders currently waiting for a kidney transplant, according to the Kidney Health NZ report.

Despite being the majority of dialysis patients, Māori and Pasifika received far fewer transplants compared to other ethnic groups, and the equity gap is growing. Fourteen out of every 100 non-Māori and Pasifika dialysis patients secured a transplant in 2019. The figure was Māori was four, and for Pasifika 3.5.

"I look around Aotearoa's dialysis units and see far too many Māori and Pasifika patients who are clearly disadvantaged, who can't access the 'gold standard' treatment of a transplant" says Midcentral DHB nephrologist Dr Curtis Walker (Whakatōhea, Ngāti Porou).

Research shows Māori and Pasifika are less likely to be put on the transplant waitlist, and Walker says there's a need to look at the reasons why.

"There is clear disadvantage for Māori and Pasifika in terms of their ability to understand and navigate the system, get access to transplant waitlists, and get transplant surgery itself. We need to fix this - right now."

According to the Kidney Health NZ report, 221 transplants were carried out in 2019, and the health dollar savings of a transplant - which removes the need for costly dialysis - amounts to \$400,000 per patient over six years.

Kidney Health NZ is calling on the Government to tackle the equity gap and increase kidney transplants overall, warning that a 30 per cent increase in dialysis patients over the next 10 years could cost the country \$150m a year.

Ili supports other kidney patients at the Auckland Kidney Society by talking with them during their long dialysis sessions.

Ili says she sees the increase in her daily work at the dialysis centre.

"More people are coming in for dialysis than are getting transplants."

Māori and Pasifika know about diabetes and cancer, but there's just not enough awareness of kidney disease, she says.

"People don't realise you can donate your kidneys. And that's the main thing we need to get out, to push through."



Welcome to 2022!

Let's be honest, last year was a really tough year. The long lockdown and all the changes across the country impacted us all. Many people are feeling exhausted and quite the opposite of how they think they should be feeling at the beginning of a New Year!

It's easy to become stressed with expectations around goal setting at this time of year. This is a reminder to be gentle on yourselves and let go of

some of those harsh expectations.

Stop comparing your situation to others and remind yourself of what's important to you and what brings joy to your life. Consider what you are doing when you are feeling the most happy and find ways to bring those moments more frequently into your life. It might be creating something, having a stroll at the beach or reading a good book. In a world of hospital appointments or dialysis schedules, it's vital to have a bit of fun when you can. Pop on your favourite music, watch a silly movie or catch up with a good friend and have a laugh!

If you do want to set some fresh goals for yourself this year, then remember that little changes amount to big change over time so again, go gently on yourself and don't beat yourself up if you're not up for it some days.

When you're feeling unwell and fatigued it's very normal to start feeling low. It's important to check in with yourself around your mood and energy levels and reach out to family, friends, a social worker or the Kidney Society if you need support. There's no shame in asking for help when you need it. It's a vital part of your overall health and wellbeing.

Take care and wishing you all a better, brighter 2022

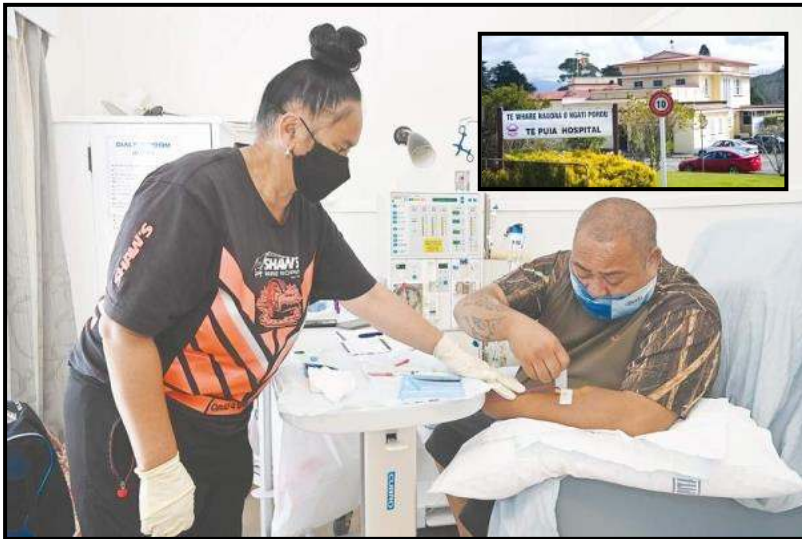
Kirsten Turnbull and Jo Barningham

Renal social workers, Waitemata DHB

**You can sometimes get what you need
if you know what you want, and then
have the courage to ask for it!**

Long-awaited haemodialysis units have arrived at Te Puia Springs Hospital

Last year a Tairawhiti Kidney Society client was talking with Brian about getting a place up the coast where two clients could do their own dialysis without having to go to Waikato or Gisborne. Neither could do it at home due to being on tank water and horrendous delivery cost. So the clients approached the hospital and started things rolling. Because they took this initiative, in November they had the opening at Te Puia Springs Hospital of a donated room set up so the 2 clients can do their own Home Therapy. It just goes to show what you can achieve when you ask and persevere!



(next page: from an article in the Gisborne Herald, 29 November 2021)

It comes as a huge relief to Joe and Amita Moana, who for three years have been commuting daily to Gisborne Hospital for Joe's haemodialysis.

Amita said the daily trips were a strain on the family because they consumed a good part of the day. *"Now it only takes us about 10 minutes . . . the machine is just up the road."*

Joe spent two and a half months at Waikato Hospital learning how to use the machine and to do his own dialysis.

"The hardest piece for me was the venous needle (inserting needle into the vein)," he said. "When I was in Gisborne I swore I would never do this but you get used to it. I had a good nurse and trainers who helped me."

Joe did it "for his family", said Amita. He could not have the unit at home because the process needs a continuous flow of water through the machine and they have tank supply.

"We are really thankful to the hospital and the team for allowing us to come here for the service."

Another dialysis patient Haapi Maxwell said there had been limited options for whānau on the East Coast.

"We either have to go to Waikato or to Gisborne Hospital for one of the machines. It made sense to have some machines at Te Puia.

"If we were to set up at our homes there would be a cost, to get bigger tanks to collect more rainwaters."

"When I discussed this with Rose Kahaki (Ngati Porou Hauora chief executive)", she felt the same way."

Te Puia Springs Hospital GP Dr Helen Gardyne said two patients were using the new units and "others coming next year".

It was wonderful to have the opportunity to provide this service for whānau, said hospital services manager Gwynette Ahmu.

"They normally would be travelling an hour to an hour-and-a-half each way (three hour round trip) four times a day.

"They are very tired after they've gone through a dialysis.

"They trained at Waikato Hospital for 10-12 weeks to be able to do self-dialysis. You actually need to meet the criteria to haemodialysis, because you are doing it all yourself.

"There's a criteria depending on your condition of renal failure at that time.

"Basically it's just like having it in their own home except at hospital we know the control of the water and we can also facilitate the continuous power which is absolutely critical for having a haemodialysis machine to keep working."

“The conversation started about two years ago and I guess the real big decisions came a year ago. Working with Waikato Hospital, Gisborne Hospital, and with our whānau we were able to get this service here.”

The service was funded by Waikato, Ngati Porou Hauora and Hauora Tairāwhiti. The machines came from Waikato.

The set-up at Te Puia Springs Hospital is for two units, but there is a spare unit “should we need it”.

Community dialysis is growing!

Many, many years ago a patient in **Raetihi in the Manawatu** dialysed in a room at the local hospital, and similar arrangements have worked for other home haemo trained patients over the years, such as at a medical centre on Waiheke Island.

In **Wairoa community dialysis was available in a local house for many years, before the house was sold** and community dialysis moved to a room at **Wairoa Hospital** in 2020 when the community wanted a better facility and improved site security.

Our three **Kidney Society community dialysis houses in South Auckland** are a different solution tailored to the needs of local South Auckland patients and circumstances – but with smaller numbers of patients in remote areas a single room is easier to achieve.

You would think that more regional renal services faced with growing numbers of haemodialysis patients in their units, would work towards providing dialysis rooms for communal use away from their hospitals, especially since this benefits both the renal service (less patients in their unit) and the people who can do their own treatment closer to home. Home (or community) dialysis is best for many!

The new **Kereru Unit in Glen Innes** and the **yet to be opened ADHB Kea House within Carrington Hospital grounds** are other examples of a more creative and community-focused approach.

Closer to home healthcare became the in-thing in 2011, maybe this is the time for people on home haemo themselves to give that another push nationwide, and maybe, just maybe, the latest success - getting a room at **Te Puia Hospital** set up, will inspire people like Joe and Haapi to take the initiative themselves, and talk to their own dialysis unit manager about community dialysis options!

Getting Motivated Again

Well we made it!.. We got through 2021. But many of us got to the end of last year feeling very drained and unmotivated.

Lockdowns, masks, cancelled surgeries and special events weighed down our lives.

Over the holiday season no matter how you celebrated it, many of us hit the OFF switch and just exhaled.

Now, at the beginning of the New Year, it is good to focus on moving forward and getting back on track with our lives.

Ok, so some of you are saying, well that's easier said than done! We all know that It can be very easy to get into what is sometimes called a negative cycle.



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



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

Sometimes though, getting started can be the challenge. If you set yourself a major goal it can seem a bit overwhelming. The key is to break the goal down into simple steps.

If you think of the main goal as being the top of the stairs and just taking one step at a time to reach, it may feel more achievable.



So what can you do to get started?

❖ **Keep it Simple**

Break your goal down into daily or weekly steps.

For example if your goal is to start a 30 minute daily walking programme,

- Start with a 10 minute program. Walk 5 minutes in one direction then turn around and walk back.
- Continue this for a week
- then increase it to 12 minutes for the next week and
- then each week add on a bit more time.

In 10 to 12 weeks you will have reached your goal.

❖ **Swap It Out - Swap a negative activity for a positive one**



Your goal may be to lose weight or improve your fitness; perhaps you would like to join a gym but this will stretch your budget.

For example:

- if you currently drink soft most day this is what you spend on soft drink
 - 1 x 330ml coke each day @ \$3.50 each is \$24.50 per week. And, at 140 calories per drink that's 980 calories a week.
- If you join a gym instead
 - The average gym membership is between \$10-20 per week

So if you

- change the coke to water (tap water is FREE),
- then add up the extra calories you will burn being at the gym,

then Swap it Out has the potential to assist you dropping a couple of kg a month:

changing the negative circle into a positive one!



❖ Dear Diary...

Writing things down can help you:

- get into a new routine
- be more organised
- keep on track
 - You can use the old-fashioned simple act of writing it down in a diary or notepad
 - A white board or calendar is another great method especially if you hang it somewhere that you will see it daily
 - You can use technology and put reminders on your phone to alert you at set times.
 - Take photos of what you are doing such as walks, classes or healthy food choices, these are great to look back on to help you keep positive about what you are doing.
 - There are activity trackers, smart watches and apps available such as MyFitnessPal and Mii Fit which can record your daily activity, food intake, sleep patterns and much more.



❖ Buddy Up



Having someone to share your journey or even just to chat to about what you are trying to achieve can help make things easier and more fun. Find someone to exercise with, share healthy recipes or help keep you both on track.

I recently spoke to a gentleman who had a goal of losing over 30kg. His family decided they would do it with him.

The entire house changed their meal plans and started an exercise programme. He said having their support made all the difference to him reaching his goal.

Not only did it help him succeed but the entire family have had health benefits from the changes.



❖ Theme Song



Music has the ability to make you feel energised just from listening.

Take the theme to the ROCKY movie. It is one of those songs that can really make you feel motivated and determined.

Pick a song or a playlist that motivates YOU. Not just for exercising to, but also during times when you are struggling to get motivated or stay on track. Press play, turn up the volume and listen!

❖ Visualise

There are many expressions used for taking time to think or reflect. Some people call it prayer, karakia, meditation or mindfulness. I like the expression Positive Daydreaming.

Take time each day to think about your goal. Find a suitable quiet place, set a timer for 2-3 minutes and close your eyes. Think about your goal and all the positive outcomes you will have, not just from reaching your goal but from the steps along the way.



You can even create your own Mantra. For instance, if your goal is to reduce your fluid intake you might start by taking a few deep breaths and repeating "with my reduced fluid intake I can breathe more freely" and finish with a few deep breaths and repeat this over the time.

❖ Celebrate your victories and accept the defeats...



As someone with a chronic health condition you are very aware that some days are definitely harder than others.

Motivation is also about reminding yourself of your achievements.

I often talk to clients who will say "I am not doing enough of the exercise" or "My fluid management is better but still not great".

I like to remind them of where they started. If you have managed to make some change and some improvements that is better than none.

Life just sometimes gets in the way of you keeping on track. If you have a day or a few not so successful ones that's ok...start again tomorrow.

Don't be afraid to ask for help. We all need the tool that support from others gives at times.

It is amazing how having a chat to someone about what you might be struggling with can often not only lighten your load but solve a problem. It might be advice from someone who has been on the same path, or a new idea to help you look outside the box.

Many of you will remember Leigh our previous social worker. One of her favourite sayings was "Talking is CLEANSING".



So if you have a wellness goal for 2022 and you need some support in getting started or staying on track, then call me. You are not bothering me... I LOVE MY JOB. The Kidney Society Wellness program was designed to support you with your exercise, fitness and wellness goals so that you have *the tools to SUCCEED!*

Tracey Drinkwater, Kidney Society Wellness Educator
0800 235 711 or tracey@adks.co.nz
Contact me if you need more ideas or help!

Free online tools to manage your wellbeing, in Te Reo and English.

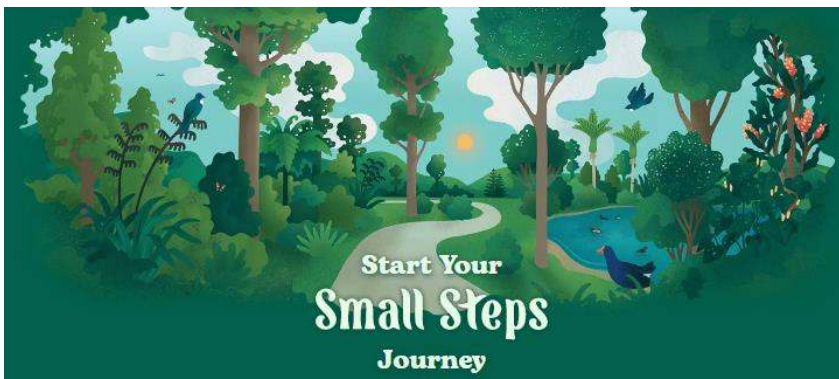
Te Hīringa Hauora | Health Promotion Agency has a new website, **Small Steps**, featuring locally developed digital wellbeing tools.

The SmallSteps website is a place where people of Aotearoa (and further abroad!) can take small steps on their journey to improve wellbeing.

<https://smallsteps.org.nz/>

Key Messages

- Small Steps is here to help you maintain or improve your mental health and wellbeing.
- The tools are free and easy to use as part of your daily routine, either on a one-off or an ongoing basis.
- Everyone has different preferences and needs for how they get support. Small Steps provides options so you can choose what works for you.
- Whether you're looking to maintain wellbeing, find relief, or get help - we're here with you, for you - he waka eke noa.





Manage your stress

We can all feel overwhelmed, busy, or stressed out. Here are small steps you can take to start understanding and managing stress.



Calm your mind

We all feel nervous, worried or anxious sometimes. Luckily, there are small steps you can take to calm these feelings.



Lift your mood

Everyone feels a little down or unmotivated now and then. Learn what contributes to this feeling and explore some tools to help.

It is worth taking your time exploring the website, it is full of tips and tools to make you feel better about life, and about your own ability to make the most of it.

<https://smallsteps.org.nz/> or simply google smallsteps.org.nz



Kidney Society PD BELTS: a simple, cost effective solution to keep your PD catheter safe.

Available in Small to Xlarge.

Cost \$35.00 + \$4.00 p&p

Phone Gina on 0800 235 711 to order. For information about the right size for you and how to wear them, phone Brian, 0800 235 711 for advice.



If you are ordering over the phone you can pay by either credit card, or directly into our Bank account, ASB Bank 12 3032 0705009 00

Remember to enclose your name and address details for posting.

When ordering you need to be sure of your size, as we cannot exchange pouches due to health reasons. If you are not sure call the office 09 278 1321 or toll free 0800 235 711 and ask to talk to BRIAN.

We stock five sizes of pouches – available in white only

- Xtra Small = 60 cm / 24 inches
- Small = 80 cm/ 32 inches
- Medium = 100 cm/38 inches
- Large = 110 cm/44 inches
- Xtra Large = 125 cm/49 inches

Looking after your fistula or graft with a fistula cover - for sale from the Kidney Society:

There are various reasons why people like to cover their fistula, especially if it is 'well used' and getting rather big. Some people don't like how it looks, others want to make sure they don't damage their fistula. It is only light protection for your fistula, but it helps avoid scratches and can help remind you it is there!



Our fistula cover is designed for the lower arm, and is available in black only. Length is 18 cm or 21 cm, longer or shorter by request.

Special price for Kidney Society registered haemodialysis patients only: \$5 each or 2 for \$10

Phone the Kidney Society on 0800 235 711 for information or to order send cash with your name and address to Kidney Society, P O Box 97026,

Manukau City, Auckland 2241, or call in at the Centre, 5 Swaffield Road, Papatoetoe, Auckland.

If you are ordering over the phone you can pay by either credit card, or directly into our Bank account, ASB Bank 12 3032 0705009 00

SORRY: BANKS NO LONGER ACCEPT CHEQUES....

We have found another pd belt online that looks comfortable but costs more. It is available to order online here: <https://www.pdbelts.com/>

Made of stretchy lycra, with a quick and easy velcro fastener this PD belt minimises the external appearance of your dialysis tube.



Available in small, medium and large but also special sizes.
Cost: one for \$39.99, or two for \$70.00 (AUD)

For info and to order online go to <https://www.pdbelts.com/>

For queries, or special waist sizes, email info@pdbelts.com



The best and easiest way to book a Total Mobility taxi in Auckland

- Find an approved Total Mobility taxi operator.
- Contact the taxi operator directly.
- Tell them you will be using a Total Mobility AT HOP card.
- Let them know if you will be using a wheelchair and need a hoist van or other assistance.

Hailing a taxi: When hailing a taxi, you must tell the driver you will be using a Total Mobility AT HOP card.

Taxi availability: At peak times and outside normal business hours there may not be a taxi available, so we encourage you to book ahead.

When the taxi arrives:

If getting into the taxi is difficult, ask the driver for help.

Before the trip starts, ask the driver to swipe your Total Mobility AT HOP card and give it back to you.

At the end of the trip,

- ask the driver to swipe your Total Mobility AT HOP card again and give it back to you.
- Pay the driver your portion of the taxi fare.

Please note, you cannot use HOP money on your Total Mobility AT HOP card to pay for the taxi fare.

Do not leave your Total Mobility AT HOP card in the vehicle

<https://at.govt.nz/bus-train-ferry/accessible-travel/total-mobility-scheme>

For information about travelling outside of Auckland or visitors to Auckland with the scheme, see our guidelines for Total Mobility travel on the website above.

Has your address or phone number changed?

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, Tairāwhiti/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

Name

Phoneemail

Address

.....

Please do the following: (tick box)

add my name to your mailing list (**free for Auckland/Northland/Waikato/Bay of Plenty/Lakes, Tairāwhiti/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



Beat the Heat and maintain fluid balance this summer season!

Everyone wants to enjoy the classic Kiwi summer! Your kidney team know that living with a fluid allowance is difficult at the best of times. Add into the mix hot summer weather, holidays, gatherings and celebrations and at times it may feel like such hard work to stick to your prescribed fluid allowance. What works for one person may not be best for another; as with everything in kidney disease, fluid management can be very individual.

Fluid Balance

Having too much fluid in your body can be quite uncomfortable and may cause swollen feet and legs, contribute to high blood pressure and long term fluid overload can also damage your heart. When the excess fluid needs to be removed with dialysis this can cause cramping and excessive thirst, starting the whole cycle again, so plenty of reasons to try & stay on top of controlling your fluid intake.

If you're someone who struggles with fluid balance (maintaining target weight) that urge to reach for that extra drink or the salty snack can be quite strong. When you find yourself in that situation try to take a moment and think about how much more comfortable you are when your fluid is in balance and how much better it is for your body. Try and divert your attention to something else (call a friend, play with the kids, take the dog for a walk, chew some gum). Preventing fluid overload is easier and better for your body than treating it. Check out the ideas below to find some helpful hints that work best for you!

Dehydration

Keep in mind that dehydration can also be a concern in the hot summer months. When you're outside for extended periods enjoying our beautiful summer ensure that you take water with you and watch out for signs of dehydration such as headaches, dry mouth,

light-headedness, nausea, cold extremities, increased heart rate, muscle cramps, or lower than normal BP (if you are experiencing these symptoms regularly please check with your doctor as they could be related to other causes as well).

If you've attempted the below ideas and you're still having difficulty over summer with thirst and fluid balance, check in with your nurse or physician to see if any adjustments to your treatment may be required.

Tips and Tricks for Managing Fluid

Summer is a great time to get together with your loved ones. If gathering with friends & Whānau, take your favourite cup or bottle with you so you can keep track of how much you are drinking, or even freeze your drink bottle so that you get small amounts of cold refreshing fluid throughout the day.

Remember anything that is liquid or becomes liquid at room temperature is a fluid! Large amounts of juicy fruit like watermelons, as well as summer treats like ice blocks & ice creams will contribute fluid to your daily intake, make sure to account for these when tallying up your fluids for the day.

The addition of lemon or lime into fluids adds a sourness which can make your drink taste more refreshing and quench your thirst better. Sucking or eating frozen fruit (low potassium if needed) rather than drinking fluids, or chewing a mint gum will make your mouth feel cooler.

Summer season is also BBQ season! Over summer you will likely find salty snacks and nibbles everywhere! Potato chips, crackers or nuts may be tempting at gatherings. Try to bring along some nibbles you can enjoy such as unsalted corn chips, popcorn or vegetable crudité's with homemade dip. Make salt-free marinades for meat or veggies with some delicious herbs & spices – don't be afraid to unleash that inner chef & experiment! This will ensure you're not tempted to overindulge with the salt & compromise the hard work you've done with restricting your fluids!

REMEMBER! If you have diabetes, regular meals & snacks can assist with maintaining stable blood glucose levels, preventing sugar highs which can lead to excessive thirst. Another great reason to experiment with new foods & recipes for gatherings.

A little bit of planning goes a long way, so plan ahead and choose the tips for you to make the most of the wonderful kiwi summer! Check out some of the recipes below for some inspiration.

Recipes

Flavoured ice cubes can be a real treat, check out the refreshing ideas below, not only will they taste good, but they look gorgeous too! Suck them alone or add to small cups of water or your favourite drink.

Step 1: Use fresh herbs, berries, and/or flowers (small flowers are good or use a few petals). Raid that herb garden & choose some of your favourites!

- Thyme, mint, rosemary, tarragon, basil are good options
- Berries, watermelon, lemon, lime, citrus peel & cucumber also make delicious ice cubes.
- Add a selection of your favourites to an ice cube tray.

Step 2: Add liquid

- Water, sparkling water, lemon/lime juice, zero sugar drinks, or tea

Step 3: Freeze & Serve!

Try these combinations: strawberry & basil, watermelon & mint with green tea, cucumber & lemon with fresh lemon juice, citrus peel & rosemary with sparkling water.

Or play about with your favourite flavours for a taste sensation!



*The Waikato Dietitians,
Aisha Wiles, Kristy Pemberton, Philippa Dingle and Michelle Vorster*

PKD Collective NZ

Private group · 22 members



Great news for people with Polycystic Kidney Disease:

Kidney Health NZ has just gone live with an on-line PKD support group called PKD Collective. This is a private group with currently 22 members.

Kidney Health NZ and researchers at the university of Otago are creating a collective partnership of PKD in Aotearoa New Zealand.

They have started with a support group so patients and families can connect. This support groups is private and has rules and regulation is place to make it a safe place to connect.

PKD collective support group is a place for Kiwis with PKD (Polycystic Kidney Disease) to connect with others on similar journeys, experiences and challenges. This is a friendly community that you are welcomed into to connect with others on the same path, share your experience and engage in peer support.

Connecting with those going through similar experiences is invaluable in feeling less isolated and more motivated and positive. Chatting to someone or joining a group of people who have walked in your shoes and understand your journey can be rewarding an inspiring.

The support network includes a buddy support program to link up with a buddy who may provide online, phone, or face to face connection to another member.

PKD Collective is also a home for patient stories and to feature upcoming events like Q&As with community leaders, medical professionals and the opportunity to hear the journeys of members first-hand. This support network is managed by Kidney Health New Zealand. For more information:

<https://www.facebook.com/groups/pkdcollective>

You can also find this on the Kidney Health NZ website:

www.kidney.health.nz/Patient-Support/Facebook-support-groups/

Or contact pkdcollectivenz@gmail.com



Thirst Quenching

Ideas for Summer



1. **Freeze fruit e.g. lemon slices, grapes and berries** and suck on them to cool down and moisten your mouth
2. **Mist spray** - fill a spray bottle with cold water and spray your face, arms or legs to cool down on hot days
3. **Water Bottle**- use a bottle with to track your fluid intake e.g. 500ml bottle
4. **Ice cubes** – use small ice cubes to make your fluid last longer and keep your mouth moist.
5. **Use less salt** – flavour with spices and herbs instead

For more information please ask your Renal Dietitian

Many thanks to the Auckland DHB renal dietitians who designed this great poster

NZ sunscreen advice for everyone, especially people with transplants

This is a summary of the article on the Cancer Society website, for the full article and detailed advice go to.

<https://www.cancer.org.nz/cancer/reducing-your-cancer-risk/sunsmart/>



SunSmart

Haumaru rā

melanoma skin cancer rates in the world.

Learn how to be SunSmart by enjoying the sun safely. Skin cancer is the most common cancer in Aotearoa New Zealand. Along with Australia, we have the highest

How can I protect my skin?

The cause of over 90% of skin cancer is too much exposure to ultra-violet (UV) radiation from the sun.

You can take steps to protect yourself, your whānau, and your community from harmful UV radiation by:

being SunSmart (Slip, Slop, Slap, and Wrap) creating sun-protective environments and events in your community

supporting our campaigns calling for more shade in public spaces and requiring safety standards for all sunscreen products.

Follow the Cancer Society's Slip, Slop, Slap and Wrap guidelines to reduce your exposure to UV radiation:



Slip on clothing / Kuhunga he kākahu parekiri

Slip on clothing that covers as much skin as possible

Slip into the shade /Whakaritea he wāhi marumaru

Slip into the shade of a leafy tree, building or shade sail. Plan your outdoor activities for early and later in the day when the sun's UV levels are lower.

Slip on sunscreen / Pania he kirīmi pare tikākā I mua I te putanga ki waho I te whare

Slip on plenty of broad-spectrum, water-resistant, sunscreen of at least SPF 30. Ensure the AS/NZ 2604 standard is on the label.

Do not rely on sunscreen alone – make sure you Slip, Slop, Slap and Wrap too!

Sunscreen protection depends on the correct application. Make sure you:

- **apply 20 minutes before you go outdoors**
- **reapply every two hours or after being in water or sweating**

The average sized adult should apply 1 teaspoon to each arm, and to the face (including the ears and neck); and at least a teaspoon to each leg, the front of the body, and the back of the body. That's 7 teaspoons for a full-body application.

make sure the kids apply their sunscreen correctly

check the expiry date on your sunscreen and make sure you store it in a cool, dark place (below 30°C)

Slap on hat / Whakamauria he pōtae whānui te peha

Slap on a hat that protects your face, head, neck and ears.

More people are sunburnt on the face and neck than any other part of the body. Broad-brimmed, bucket or legionnaire hats are best. We don't recommend caps.

Wrap on sunglasses / Kuhunga he mōwhiti rā

Wrap on close-fitting, wrap-around style, sunglasses.

Don't use sunbeds

Sunbeds (solaria) emit artificial UV radiation. Using sunbeds significantly increase your risk of melanoma (a serious form of skin cancer).

The Cancer Society advises against using sunbeds. It is illegal for people under the age of 18 to use commercial sunbeds.

When to be SunSmart

Protect yourself when you're outside from September to April, especially between the hours of 10am - 4pm when UV radiation levels are very high.

Protect yourself all year round when:

- ❖ UV Index (UVI) levels are 3 and above
- ❖ you are in the mountains, on the water, or around reflective surfaces like snow, ice, concrete and sand

❖ you have a health condition (such as an autoimmune disease) or you are an organ transplant recipient, or taking medicines (such as antibiotics) that make you sensitive to the sun

- ❖ Download the free UVNZ app or check the Sun Protection Alert to find the forecasted UVI level for your area. The UVI is a measure of the level of UV radiation from the sun.

How to check your skin for changes

Check your skin by looking over your entire body regularly. You're looking for changes to or new spots or moles on your skin.

Skin cancers can be in places you cannot see yourself, so you may need to ask someone to help you check or use a hand mirror.

Remember to check places that might not normally get exposed to the sun, such as:

- ❖ your armpits
- ❖ behind your ears
- ❖ your scalp
- ❖ the bottom of your feet
- ❖ your fingernails and toenails

It is a good idea to keep track of how spots and moles look, so you know if they have changed since you last checked your skin.

If you notice any changes in your skin changes or your general health, talk to your doctor.



Priya, manager of the Washing Well Laundry in Papatoetoe was presented with a well earned Kidney Society Community Service Award

Like during last year's COVID, Priya continues to provides us with a superb and reliable laundry service, making sure that there has never been a shortage of sheets and towels at the houses. Locked down once again... but dialysis at the

Society's three community dialysis houses in South Auckland continued without problems or interruptions – thanks to the people using the houses responsibly, our Kidney Society staff, the Middlemore home haemo staff, and Priya.

Fundraising

29th October to 31st December 21

Subscriptions	\$ 313.00
Member donations	\$ 983.00
IM donations	\$ 200.00
Raffles	\$2114.00
TOTAL	\$3,610.00

Raffle 195 Results (Christmas 2021)

Drawn Friday 17th December 2021 1.00pm

Congratulations to our Winners:

Paul Gray, ticket no. 2905 (book 485)

Ken Crean, ticket no. 0459 (book 77)

Colin Tukuitonga, ticket no. 3346 (book 558)

All winners have been notified by phone and prizes either collected or couriered



Fundraisers to benefit people with advanced kidney disease

The Society does not have the capacity to run any fundraising events, even for the services it offers, but we very occasionally support and publicise fundraising efforts by individual News readers, **provided proceeds benefit people with kidney disease generally.**

Sam Cash plans to do the Tour Aotearoa Brevet cycle ride (Cape Reinga to Bluff starting 1st March 2022) to raise \$30,000 to be shared equally between 3 charities that helped him and his late wife Marsaili through 28 years of kidney failure and dialysis (you may remember their story in the July 2021 News). He needs 1000 sponsors at \$0.01 a km (\$30 in total), so if you can help, phone **Sam Cash**, 078959491, or 0274 805325, or email sam.cash@xtra.co.nz

In Memoriam Donations

Donations received In memory of Ken McFarland and Sean Wright. These gifts, like all donations and gifts made in someone's memory are used with care towards our services for people with kidney failure.

A Very Special Donation

Late last year Wayne McDonald phoned, the day after what would have been his wife Sola's 74th birthday. Sola passed away in December 2016 just a day before she was to start dialysis. Wayne says that was hard at the time, but probably a blessing in disguise as she did not have to go through dialysis as well as continuing to live with

all her other health conditions. Wayne says the Waitemata service supported Sola and himself very well, and he is grateful for the care they received. Sola was one of our early members, joining the society in 2009.

Sola and Wayne always enjoyed the News and Wayne decided to make a donation of \$5,000 specifically towards the Newsletter as he is now able to do that.

Wayne keeps himself busy with 15 grandchildren and lots of his family's family homes to look after, do lawns etc.

The Kidney Society News is sent free of charge to some 3000 people every two months, but it is of course considerable ongoing cost to the Society. Emailing the News would be cheaper, but many people would miss out on being able to have it sitting on the table to read whenever they feel like it. Wayne's donation will be used towards the six issues for 2022.

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 gina@adks.co.nz – 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!



To all our known supporters and those who want to remain anonymous

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

**A BIG THANK YOU
TO ALL OUR SPONSORS AND SUPPORTERS!**

THE WORKGEAR COMPANY STIHL SHOP

MARLEY WOMEN'S INSTITUTES Tint-a-Car
...Home and Office

NEW ZEALAND COURIERS Pressprint

They all support the Society with products and services when we need them, and Pressprint makes it possible for us to bring you

THE KIDNEY SOCIETY NEWS IN COLOUR .