



No. 228 November/December 2021

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'

Faapito says:



"Large Size Aqua Shirts are here!"

Sizes

3XLB TO 6XLB

See inside for details



SELF*ish



The Kidney Society News is proudly supported by our printers



Kidney Society “who, what, where”

P O Box 97026 Manukau City, Auckland 2241;

Phone 09 278 1321, or FREEPHONE 0800 235 711

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

Kidney Society Centre, Auckland: 5 Swaffield Road, Papatoetoe, Auckland 2025. Office hours: generally 9 - 5 Monday to Friday, Answerphone a/hrs

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.		Matt our Caretaker is responsible for maintaining our centre and our community houses, vehicles and equipment.
	Jenny keeps an eye on things at the dialysis houses, shows new people how things work and helps them settle in.	We do not have a social worker at the moment – you can contact your hospital social worker for help, or phone the Kidney Society to find out who that is.	
	Maria our Office Assistant works with Gina to keep everything in the office ticking over, leaflets printed, the News mailed out and more.		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!
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			

REMINDER – for your diary

Annual General Meeting

This year's meeting will be held at 6.00 pm Tuesday 7 December.

Due to uncertainty around Covid restrictions, the Board has determined that this year the meeting will be held on-line using Zoom.

Financial members who wish to attend will need to pre-register and they will then be given a link to the meeting.

Please let us know you would like to register by calling the office on 0800 235 711 or by emailing John Loof CEO at John@adks.co.nz.

Financial members will also receive a notice in the mail.



Eating healthy during the summer holiday season

Whether it's the summer holidays, Christmas, New Years, Thanksgiving, or Hanukkah, the holidays come with traditions that revolve around delicious food. Try the following tips from your dietitians to eat healthy food to nourish your body so that you can make the most of the summer holidays with your family and friends!

Be mindful of portion sizes

- At dinners and parties use a smaller plate to help control your portion size.
- If you want a second serving, wait 10 minutes before getting a second plate of food.
- Eat slowly and take your time.
- Don't forget to eat breakfast – this will help control your hunger



for the rest of the day.

- Remember the Healthy Plate model shown here!

Consider hidden sources of fluid

Remember that anything that is liquid at room temperature counts as part of your fluid restriction (e.g. ice cream, jelly, and gravy). Certain fruits eaten in large amounts can contribute fluids (e.g. watermelon). You do not have to avoid these foods entirely, just remember to keep track and keep to smaller portion sizes. Ask your dietitian for more information about this.

Watch the salt

Fluid and sodium (salt) go hand in hand. Eating too much sodium can make you very thirsty and you may drink more than your recommended fluid allowance. Enjoy only small servings of salty meats (e.g. corned beef, sausages, and bacon), potato chips and store-bought stuffing/gravies. Don't add salt at the table. Try to make food from scratch as much as possible.

Consider your potassium intake

If you struggle with your blood potassium levels, remember that there are common holiday foods that are very high in potassium. These include: roast potatoes, kumara, and pumpkin, fruit juices, dried fruit, wine, grape juice, coconut products, and chocolate. You may need to limit these foods. You can boil potatoes and other vegetables to reduce their potassium content, don't forget to drain them and throw away the liquid.

Don't forget your phosphate binders

If you are on phosphate binders (Alu-tab or Calci-tab), they need to be taken with food to work. Don't forget to pack them with you if you are leaving your home for a meal.

Enjoy some exercise

Remember to be physically active for at least 30 minutes a day – even in the holidays! This may be a walk with family, friends, or pets, or throw/kick around a ball in the park.



Warm summer days call for summery meal ideas. Check out these tasty summer recipes:

Easy Cold Overnight Oats - to serve 1

An easy cold breakfast to enjoy on a hot summers morning. Check out this recipe from dietitian Madi Rich!

⅓ cup oats (any kind is fine)

⅓ cup of any liquid - try water, milk, or plant based milk

Flavour ideas:

¼- ½ cup fresh or frozen berries

½ apple, grated, a pinch of cinnamon

2-3 slices of tinned peaches

½ tsp cocoa powder

½ small banana, sliced or mashed

1 tsp peanut butter or another nut based spread



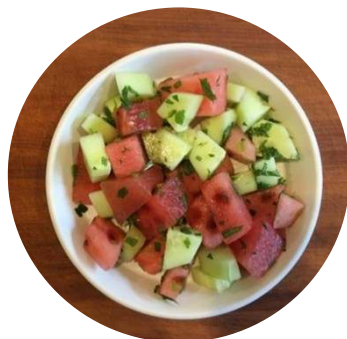
1. Combine ingredients in a jar or container with a lid.
2. Leave in the fridge overnight so the oats get soft and the liquid is absorbed.
3. Serve for breakfast at home or take with you on the go
4. The flavour options are endless, you could even add grated carrot, cinnamon, and a few sultanas for carrot cake flavoured oats!

Watermelon Mint Cucumber Salad

A refreshing salad for a hot day.

Keep to ½ cup serving per person

1. Chop mint, cucumber, and watermelon.
2. Mix and enjoy!



Tuna pasta salad- to serve 4

Enjoy this delicious recipe from the heart foundation 'Cheap Eats' booklet.

185g plain tinned tuna in spring water, drained

2/3 cup corn kernels (canned, fresh or cooked from frozen)

3 Tbsp mayonnaise or plain unsweetened yoghurt

½ small red onion, chopped

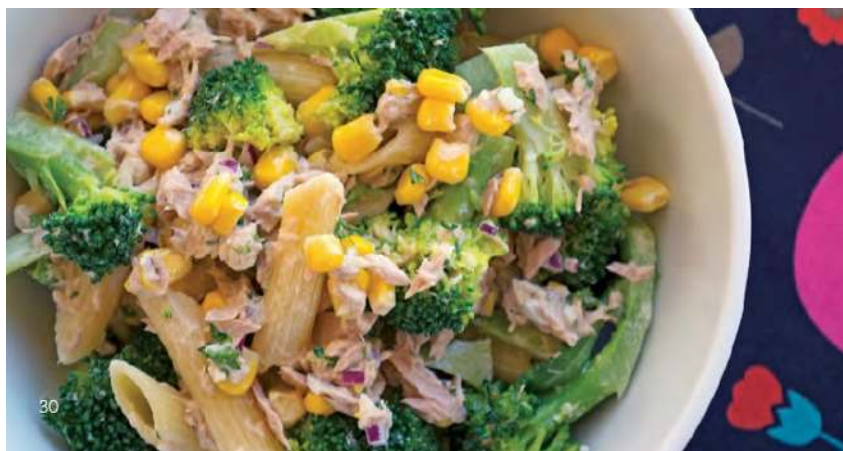
1-2 spring onions, chopped

2 Tbsp chopped parsley

2 cups dried pasta

Seasonal vegetables e.g. chopped asparagus, broccoli, and capsicum

1. Prepare pasta and leave to cook
2. Mix with the tuna, corn, mayonnaise, red onions, spring onions, parsley
3. Add precooked seasonal vegetables
4. Mix well and enjoy



Trishala Varma, Auckland City Hospital (on behalf of Auckland Regional Renal Dietitians (ARRD)) December 2021

Large Size Aqua Shirts are HERE!!!!



We mentioned a few magazines ago that one of the kidney society clients **Faapito and his family** were starting a small business to supply affordable aqua shirts in larger sizes.

With a few Covid setbacks they are now up and running! So if you are looking for a good quality aqua shirt in larger sizes visit their website below.

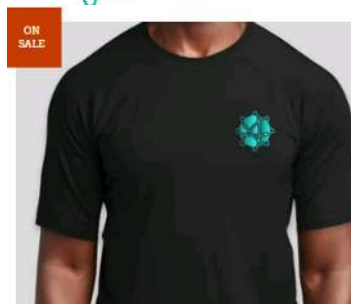
It is a great way to support a local NZ family business too!

www.selfishstorenz.com

<https://www.selfishstorenz.com/products>



SELF*ish



Sizes 3XLB TO 6XLB

\$64.99

"We are a family business made up of three directors. Myself, my wife and her sister.

Being of Pacific Island descent we were blessed with a larger-than-most body type and the challenges that comes along with it.

One of these challenges is fashion. I am sure our larger customers can relate.... "

Kidney Society Events

The big event getting in the way of normal life is once again.... COVID-19, as our Auckland staff cannot run events in Auckland, and cannot cross the Auckland borders. Who would have thought that there would be such things as borders within NZ!

Clearly there is no point in giving you details for events that may well have to be cancelled, but we can always send out individual invites if things change.

At the time of writing the News all our staff are working at home. They can be contacted by phone, text or email and they make many outgoing calls themselves.

Phone or text Brian on 027 715 3949 or email brian@adks.co.nz

Phone or text Tracey on 027 378 4544 or email tracey@adks.co.nz

Call Gina on 0800 235 711 or email gina@adks.co.nz

As soon as home visits or events are able to go ahead in your area, the plan is to invite you by mail or phone.



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!

Fistula Cover, lower arm, black only. Length 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....

Great support from Trusts and Foundations continues

Foundation North- \$20,000 for services in Auckland and North-land

Trillian Trust - \$6,000 for prepaid News envelopes

Eastern & Central Community Trust - \$7,000 for Hawke's Bay services

Bay Trust - \$20,000 for services in the Bay of Plenty and Lakes regions

Milestone Foundation - \$5.000 for Salaries

Subs and donations,

Subscriptions	\$365
Member donations	\$405
IM donations	\$150
Total	\$920

Donations were received in memory of Des Schollum.

YouTube Exercise Links

Lockdown has been challenging for many people over the past couple of years.

We have been stuck in our bubbles and out of our usual routines. Our gyms and pools are closed, so trying to find suitable and affordable exercise equipment has also been another challenge. The wet windy weather has made it even more difficult to get out for a walk.

For people with chronic kidney disease and a lowered immune system getting out and about even for a masked walk may not be ideal. For some it has meant less physical activity, lowered fitness levels and an increased waist line.

However as modern people with access to YouTube there are so many wonderful programmes you can do from the privacy of your home.

The difficult thing with this is ensuring the programme is suitable for people with CKD.

Over the past year I have done some deep YouTube dives to find suitable exercise programmes for our clients which I will share with you all below.

BUT it is important to remember with any exercise programme you should check with your medical team that it is safe for you to exercise. Only do what you feel comfortable doing and STOP and REST when you need to.

You may only be able to do a couple of minutes of a programme and then sit and watch the rest to begin with. Then gradually over a few weeks build up what you can do.

YOU ARE THE EXPERT IN YOU!

Listen to your body and if something doesn't feel comfortable for you, STOP!

I will also put a list below of some specific guidelines for exercise and CKD.

You may also find other programmes than the ones I have listed and if you are unsure if they are suitable feel free to contact me and I can check it out for you.

- Avoid push ups or body weight exercises that can put pressure on your access; that includes fistulas, tunnel lines, femoral lines, catheters and recent transplants.
- For PD clients avoid direct abdominal exercises and any exercises that require you to lay on your stomach.
- Avoid lifting heavy weights; a general rule is do not lift over 10kg.
- LESS IS MORE; it is better to do small amounts of exercise regularly than go hard out. Remember you can always slowly increase your exercise intensity and amounts over a few weeks.

- Avoid high impact work; having Chronic Kidney Disease affects your bones and joints so avoiding exercises such as running, jumping and hard hitting like boxing and plyometrics.
- HAVE FUN!!...exercise is playtime for adults!

Below you may find a few different programmes to try until you can find something you enjoy doing.

Curtis Adams



This fantastic YouTube exercise host has many videos to choose from. His target audience is people with diabetes, older people and people with health conditions. He has standing and seated programmes to choose from too. This is a great place to start if you haven't done exercise for awhile.

1. **Curtis Adams 10 min chair core programme**
<https://www.youtube.com/watch?v=ewPltpogda0>
2. **Curtis Adams 30 minute standing programme**
<https://www.youtube.com/watch?v=MiOBDA08f0M&t=781s>
3. **Curtis Adams 20 minute standing and seated option programme**
<https://www.youtube.com/watch?v=KbFz38FUuiA>

Leslie Sansome Walking Channel



This YouTube channel makes walking on the spot a lot of FUN! She keeps it very simple so there are only a few basic steps to do so for those of you who are not too coordinated it is easy to follow. There are choices from beginner's level to more advanced options too. There is also a family walk which could be a good way to wear out the kids on a rainy day.

This is also a good way to increase your walking ability as you can start by walking for a long as you can then when you need to STOP and sit down and watch the rest. You can slowly increase how long you can walk for over a few weeks.

- **Beginners 1 mile Walk, 15 min**

https://www.youtube.com/watch?v=k_SoCdUIBvM

- **Family Walk 14 min**

<https://www.youtube.com/watch?v=JPNIPf32m1E>

Paul Eugene

Paul Eugene has many programmes to choose from and he is a lot of fun. His energy and smile are infectious.

I have only put a couple of his links below that are great workouts for people with limited mobility and wheelchair users. But I highly recommend that you check out some of his other videos too.

- <https://www.youtube.com/watch?v=vU902J3KYI4>
- https://www.youtube.com/watch?v=Sn57z_sAls4



Exercise as Medicine Balance Programme

This great NZ REPS registered group has a few different exercise options available, ranging from fitness to health condition based programmes.. Their Brain and Balance programme is very good and definitely something that you can work on a couple times a week over a few months to get some great benefits.



<https://www.youtube.com/watch?v=lbBwTOFzP5w>



This is a FANTASTIC 5 minute relaxation and breathing programme. A lot of the clients I have recommended this to have found it very helpful.

Just press play, close your eyes and follow the very calm voice. Great for improving your breathing, relaxation and helping you get to sleep.

<https://www.youtube.com/watch?v=nmFUDkj1Aq0>



Great News: Kidney Society Wellness Video Channel

We have been developing our own video channel with exercises and videos.

Unfortunately like many things it has been delayed due to Covid restrictions.

But once we are able we will be ready to start filming and we should have more information next year.

For Wellness information and help to find the right exercise programme or equipment for you, call or text

Tracey Drinkwater, Kidney Society Auckland

Mobile 027 378 4544, FREE 0800 235 711

or email tracey@adks.co.nz

International Virtual Fun Walk Invitation

SOMETHING VERY DIFFERENT, ORGANISED BY THE AMERICAN
ASSOCIATION OF KIDNEY PATIENTS FOR PEOPLE EVERYWHERE!!



Fun Walk

**AAKP'S 3RD ANNUAL FUN WALK
DECEMBER 6-17, 2021**

#AAKPFunWalk21

Whether you are based in the U.S. or across the globe, the America Association of Kidney Patients (AAKP) has made it easy for you to join in on the fun!

December 6-17, 2021

REGISTER NOW!

This year's **virtual AAKP Fun Walk** will be hosted **December 6-17, 2021**, to allow for participants to make the most out of the experience and participate in activities at their own pace and schedule!

The AAKP Fun Walk is a unique opportunity for individuals affected by kidney diseases, their friends, family members, and local communities **across the globe to come together to raise awareness of this chronic illness** that impacts an estimated 850 million people worldwide and **support the great work of AAKP**.

Registration is \$25 per person, and **all registrants will receive AAKP swag, including AAKP socks and shoe laces**, so you can gear up! For an additional \$5 donation, receive an **AAKP Decade of the Kidney™ commemorative coin!**

<https://aakp.org/programs-and-events/fun-walk/> **Virtual mind and body OnDemand sessions**

Social media activities

Raise funds to support AAKP's programs and services!

<https://secure.qgiv.com/event/funwalk2021/>



New Zealand Clinical Research is looking for people with kidney disease (or people who are on dialysis) for medical research.

What are we?

NZCR is one of New Zealand's largest medical research organizations, studying medications that are used to treat important disease such as diabetes and liver disease. We have over 100 studies going at the moment. Some of these are "simple" studies, such as ones to make sure that cheaper "biosimilar" drugs are as good as the original. We also do some of the world's most ground-breaking studies, such as gene-editing for incurable hereditary diseases.

NZCR has been going since 1999, and over that time has performed over 500 studies, dosed over 15,000 participants, and made many important achievements on the global stage. For instance, NZCR has the world record for the largest ever biosimilar study, the world's first-ever safe and effective use of (CRISPR) gene editing in humans, and single-handedly establishing dosing protocols for the use of anti-hepatitis medications in dialysis patients.

Who are we?

NZCR is a large organization with 60 nurses, and full-time staffed laboratory, and a sophisticated pharmacy with 8 pharmacists. Importantly, NZCR is doctor led. The Chief Executive Officer is a surgeon, Dr Christian Schwabe; the Chief Medical Officer a liver specialist, Professor Ed Gane; the Chief Scientific Officer a kidney specialist, Dr Richard Robson; the Chief Operative Officer a cancer specialist, Dr Chris Wynne. On the "shop floor", there are many other doctors, including several public health specialists, clinical pharmacologists, two more kidney specialists, diabetes and obesity profes-

sors and specialists, all doing the day-to-day work to make sure all the studies the done.

Where are we?

We have two research centres in New Zealand, one in Christchurch and one in Grafton, Auckland, with a total of close to 40 in-patient beds and extensive outpatient facilities.

Why are we looking for people with kidney disease (or on dialysis)?

Over the years, NZCR has done close to 50 studies in people with kidney disease but is looking to do more. These studies come in different shapes and sizes. Some studies involve medications that might directly benefit your health condition (such as improving kidney function in those with kidney disease). Some involve treatments that need to be studied in certain people, so that they can be dosed properly (such as studies to work out the right dosing for new antibiotics in dialysis patients). In either case, people who participate are reimbursed for their time and efforts, which often amounts to several thousand dollars. Whatever the study is, we discuss things fully with you, so you know what is going on. The studies that we do are unquestionably the most carefully monitored ones in New Zealand, with the most thorough oversight of any study in this country by both national and international regulatory bodies.

How do I get involved?

If this is something that might be interesting to you, please let us know and have a chat! You can let us know by either calling us on 0800 STUDIES (0800 788 3437), or email us on kidney@nzcr.co.nz or dialysis@nzcr.co.nz. You can check out our website too: <https://www.nzcr.co.nz/>

On next page: details about the research for dialysis patients

Anyone interested should contact their GP, their dialysis nurse and/or dialysis renal physician for advice if the study is safe for you to participate.

Interested in participating in medical research?

Help us research new medicines for haemodialysis patients!

We are looking for haemodialysis patients who would be interested in taking part in studies of how new medicines are affected by dialysis

What is involved?

Having several dialysis treatments at NZCR, while staying for a few days in our wards, with medication that is administered before and/ or after dialysis, along with blood tests to determine levels of medications in the body

Will I be paid?

You will be paid for your travel, your time staying in the wards, your visits to and from NZCR. This typically amounts to a between one and several thousand dollars

When /where is it done?

We are located at NZCR house in the city (Grafton), and we usually have a few of the studies ongoing at any one point in time. Their dates and reimbursements are on our website

I'm interested!

To know more, register at

www.nzcr.co.nz or email dialysis@nzcr.co.nz or
call **0800 STUDIES (0800 788 3437)**



Dr Mark Marshall, Senior Nephrologist and dialysis expert
Shuruthi Balachandran, study co-ordination Team Leader



NEW ZEALAND
CLINICAL RESEARCH
Advancing global health

Is Kidney Failure making you struggle financially

Help with living expenses may be available from Work and Income NZ (WINZ), depending on your circumstances.

Your renal social worker is the first person you should talk to about your situation. If you don't know who this is ask your kidney nurse or doctor how to contact them.

For information you can also

- phone WINZ on **0800 559 009** (For people under 65) or **0800 552 002** (for people 65 and over), Monday to Friday: 7am – 6pm, Saturday: 8am – 1pm
- visit the WINZ website www.workandincome.govt.nz/individuals

Applying for a benefit

Work and Income New Zealand (WINZ) is where you can get financial support.

Anyone who has financial problems can apply for a benefit, but not everyone is entitled to one. Kidney failure alone does not automatically mean you need to be on a benefit.

Whether you qualify for a benefit and how much you can get depends on your circumstances.

Get your assistance as soon as possible. WINZ may be able to grant you assistance from when you first contact them (so long as you complete your form within 20 working days of that date) or from when you submit your application, whichever comes first.

IMPORTANT – before you spend your holiday pay, redundancy pay or other income, find out how this might affect your benefit if you think you will need help from WINZ

To qualify for any WINZ benefit you need to:

- be a New Zealand citizen or permanent resident who normally lives here
- have been here for at least two years at any one time since becoming a New Zealand citizen or permanent resident
- Meet income and sometimes other criteria

Income and Asset Tests

Most benefits are income tested. Income includes your partner's incomes, income from rental properties, interest on money in the bank, income from insurance payments etc. Depending on your income you can get a full benefit, a part benefit or, if your income is over a certain limit, no benefit at all.

Some benefits are also asset tested. Assets are cash or savings, investments or shares, loans made to other people (including family trusts), boats, caravans and campervans, investment properties and under certain circumstance your house and car.

What benefits are available?

Benefits most commonly used by renal patients are:

- Jobseeker Support - previously known as Sickness benefit
- Supported Living Benefit
- Disability Allowance
- Extra entitlement's such as Accommodation supplement, Temporary Additional Assistance etc.

Please note: information on travel and accommodation assistance is available in another brochure in this series.

Jobseeker Support:

<http://www.workandincome.govt.nz/individuals/a-z-benefits/jobseeker-support.html>

This benefit helps people with general living costs when they have financial difficulties because of limited or no employment due to sickness.

It is income tested.

It is important that you are aware of any extra entitlements you may be eligible for.

You may get the sickness benefit if, because you are sick you.

- have had to reduce your hours
- have had to stop working
- are not working, or are working part-time and find it hard to look for and do full time work.

Supported Living Payment:

<http://www.workandincome.govt.nz/individuals/a-z-benefits/supported-living-payment.html>

If you have a permanent sickness, injury or disability that stops you working you may be able to get the invalid's benefit to help meet your living costs.

It is income tested

It is slightly more than the sickness benefit.

Disability allowance:

<http://www.workandincome.govt.nz/individuals/a-z-benefits/disability-allowance.html>

Disability Allowance is a weekly payment for people who have regular ongoing costs because of a disability, such as visits to the doctor or hospital, medicines, extra clothing or travel.

It is available to people who qualify for a Community Services Card including those on a benefit or people who are working.

There is an income and asset test for this.

You may get a Disability Allowance if you:

- have an ongoing disability, that is likely to continue for a minimum of six months
- have regular, ongoing costs because of your disability which are not fully covered by another agency, for example ACC

Extra assistance

You may qualify for extra assistance depending on your circumstances. For a full list of extra assistance see the WINZ website under A-Z benefits.

Working for Families Tax Credits is a package designed to make it easier to work and raise a family.

<http://www.workandincome.govt.nz/individuals/a-z-benefits/working-for-families.html>

Here are some examples:

Accommodation Supplement -

<http://www.workandincome.govt.nz/individuals/a-z-benefits/accommodation-supplement.html>

Anyone on a benefit has an entitlement that can be assessed for assistance for such things as dental, glasses, car repairs etc. You will need to check with your social worker or WINZ Case Manager about entitlements.

Temporary Additional Support is a weekly payment which helps someone who can't meet their essential living costs from what they earn or from other sources.

<http://www.workandincome.govt.nz/individuals/a-z-benefits/temporary-additional-support.html>

Recoverable Assistance Payment Grant is a one off payment for people who are struggling to pay for as essential things such food power, clothing, furniture and other costs.

<http://workandincome.govt.nz/a-zbenefits/recoverable-assistance-payment-grant.html>

Live Donor Organ Assistance is a payment which helps people who are donating a kidney or liver tissue for transplant within New Zealand and experience loss of income and/or childcare costs.

<http://www.workandincome.govt.nz/individuals/a-z-benefits/live-organ-donor-assistance.html>

Civilian Amputee Assistance is help for amputees, or those born without a limb(s), with travel and/or accommodation costs if they need to go to an Artificial Limb Centre.

<http://www.workandincome.govt.nz/individuals/a-z-benefits/civilian-amputee-assistance.html>

Do you have a kidney transplant?
You may need a third Covid-19
vaccination to be fully protected
Ask your transplant coordinator or doctor
to find out if you need this!

COVID-19: Advice for higher risk people

Information for people considered at higher risk of the effects of COVID-19 and their whānau.

<https://www.health.govt.nz/our-work/diseases-and-conditions/covid-19-novel-coronavirus/covid-19-information-specific-audiences/covid-19-advice-higher-risk-people>

Last updated: 21 September 2021

What you and your whānau need to know to stay safe and healthy

COVID-19 is an illness that can affect your lungs and airways. It's caused by a type of coronavirus that's spread like the flu from person to person.

Older people and people with some existing health conditions have a higher risk of more severe symptoms if they contract COVID-19. You can work with your doctor or specialist if you need help understanding your level of risk and how best to stay healthy.

Protecting yourself through vaccination

Getting your vaccination is an important step you can take to protect yourself and others from COVID-19.

Vaccines help prevent the spread of COVID-19 and reduce your chances of getting seriously ill or dying if you do get COVID-19. This is why vaccination has been offered to the most vulnerable to COVID-19 from the earliest opportunity.

Protecting yourself in other ways

Even if you are vaccinated, you should still take precautions, including limiting interactions with others, wearing a face covering in public, and staying home where possible.

When you leave the house, you should maintain physical distance and good hygiene practices at all Alert Levels.

People at risk of severe illness from COVID-19

If you are working, and are considered to be at risk of severe illness from COVID-19, talk with your employer about doing a risk assessment in your workplace to look at what the risk is for you and how it can be reduced. If you can't safely work at your workplace, and you aren't able to work from home, you will need to agree with your employer what your leave from work and pay arrangements will be. You can find further information on the Employment New Zealand website: <https://www.workandincome.govt.nz/covid-19/leave-support-scheme/index.html>

People with medical conditions and compromised immunity

The main reason for COVID-19 becoming a severe illness is the presence of underlying medical conditions, especially if these conditions are not well controlled.

Relevant medical conditions include:

- chronic lung disease such as cystic fibrosis, bronchiectasis, chronic obstructive respiratory disease and emphysema, severe asthma that needs multiple medications and medical care
- serious heart conditions such as congestive heart failure
- hypertension that isn't well controlled

- **diabetes that isn't well controlled**
 - **chronic kidney disease**
 - liver disease.
- Conditions and treatments that weaken the immune system include:
- having chemotherapy or radiotherapy
 - **bone marrow or organ transplantation**
 - some blood cancers
 - immune deficiencies including HIV infection
 - immunity weakening medications such as high-dose corticosteroids and disease-modifying anti-rheumatic drugs that treat inflammatory forms of arthritis.

Talk with your GP or other health service provider about whether your medical condition means you are more at risk of severe illness from COVID-19 and how to best manage your condition.

You should continue to access care for your medical condition. Health services such as your GP and hospitals have measures in place to keep both you and staff safe.

Getting vaccinated

If you're severely immunocompromised, you have a higher risk of getting serious infection if you're exposed to COVID-19.

You can get the Pfizer vaccine (Comirnaty) when receiving medication or therapy that affects your immune system (immunosuppressive therapy). While you may not respond as strongly as someone with a fully functioning immune system, it can protect you from becoming very unwell if you get COVID-19.

The best time to be vaccinated is before any planned immunosuppression, but this is not always possible so do not delay treatment.

If you're severely immunocompromised, discuss the timing of your vaccination with your doctor or specialist. While the vaccine can be given at any stage of treatment, you may be able to time your vaccination appointments between rounds of treatment to optimise your immune response.

To help protect yourself, encourage your family and the people you live with to also get vaccinated.

Third primary dose for severely immunocompromised people

Some people aged 12 and over who are severely immunocompromised are eligible to receive a third primary dose of the Pfizer COVID-19 vaccine, and we recommend they have this additional dose to get their best possible protection.

The third primary dose should be given at least 8 weeks after the second dose.

The eligibility criteria to access a third primary dose is complex, and applies to only the group of people who are severely immunocompromised.

Your health practitioner can also look at the criteria and review whether your health conditions mean that you are recommended to have this third primary dose. If you think you might qualify, speak with your GP or specialist.

How to access a third primary dose

A prescription must be provided by a GP or Specialist before people who are severely immunocompromised can access a third primary dose.

If you think you qualify, we recommend scheduling an appointment with your usual health care provider.

You might be able to receive the third primary dose at the same time as your consultation – check with your medical practitioner to see if they offer the Pfizer COVID-19 vaccine.

If your GP doesn't offer Pfizer COVID-19 vaccination, you can take the script and consent form to any vaccination clinic, including a vaccinating pharmacy.

Appointments with a medical practitioner for a third primary dose are free.

Access to the 3rd Primary Dose for people with severe immunocompromise

This slide outlines how an eligible consumer will access a 3rd primary dose of the Covid-19 vaccine.



THERE ARE FOUR KEY COMPONENTS TO ACCESS A 3RD PRIMARY DOSE:

1. Eligibility



1a The practice contacts the person to let them know they are eligible for a 3rd primary dose. If the person is interested, they are invited to make an appointment with their GP/Specialist for a consultation.

1b A person is aware of a 3rd primary dose for severely immunocompromised people and contacts their GP or Specialist to understand if they are eligible.

2. Consumer Consent



2 The Medical Practitioner, gathers written consent using the 3rd primary dose consent form provided by the Ministry of Health, prior to providing the person with a prescription. The medical practitioner documents the consent in their patient medical record. The consultation will be at no cost to the person.

3. Script & Consent Form



3 The medical practitioner provides the person with the prescription and the co-signed consent form.

4. Confirm Consent & Administer Vaccine



4a If the facility where the person gave their consent and received prescription is a Covid-19 vaccination site, usual vaccination processes should be followed to administer the vaccine.

4b If the consumer is to be vaccinated at a different time or place, the prescription and consent form must be taken or sent to the vaccination site. The consent form must be confirmed and signed by the on-site Clinical Lead prior to vaccination. Refer to section 18.2 of the Operating Guidelines on written consent forms.



Consumer and Community Advisory Committee Expression of Interest for Membership

What is BEAT-Calci?

Better Evidence And Translation for Calciphylaxis (BEAT-Calci) is the name of a clinical trial that aims to find the best treatments for a condition called calciphylaxis. Calciphylaxis is a rare disease, involving painful skin wounds, that occurs in some people with end-stage kidney disease. Treatments for calciphylaxis, that are currently available, have not been fully studied yet, so doctors caring for patients with calciphylaxis are unsure what the most effective treatments are or what the best approach to patient care is.

The trial uses a new design that tests multiple treatments at once, making evidence discovery happen quicker. BEAT-Calci is a global trial and will continue to recruit patients until the potential treatments have generated strong evidence. Patients that participate in BEAT-Calci will receive treatment over a period of 26 weeks, with initial treatments including drugs or new dialysis technology. The researchers will look at whether participants receiving treatment have an improved calciphylaxis outcome, which will be measured by an assessment of the skin wound.

Why do we need a Consumer and Community Advisory Committee?

The BEAT-Calci team understand that research needs to be performed in collaboration with consumers. The researchers want to ensure that the trial is designed in an appropriate way, with a focus on outcomes that are important to consumers with kidney disease and their community. The BEAT-Calci Consumer and Community Advisory Committee (CCAC) will facilitate links with the kidney community, work with the BEAT-Calci research team to review trial documentation and make sure findings are communicated appropriately to consumers and the wider community.

Who are we looking for?

BEAT-Calci needs 4-6 people who want to contribute to research and:

- Have direct experience and an active interest in kidney disease
- Have an interest in being involved in planning research and communicating evidence

What does it involve?

- A one hour meeting every 3-4 months, via teleconference.
- Contributing to tasks in between meetings, such as reviewing participant and community facing documentation.
- Contribution for a minimum 2-3-year period.

When does it all start?

The CCAC is established but is looking for additional members.

Will members be acknowledged for their input?

With permission, members will have their contribution acknowledged on the BEAT-Calci website and other trial documents.

How do I become involved?

To express interest, please contact: BEAT-Calci.study@sydney.edu.au, telling us a little bit about your experience, and interests relevant to the research.

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

Kidney Society Christmas Raffle



1st Prize: Variety Hamper, value \$300.00
2nd Prize: Variety Hamper, value \$300.00
3rd Prize: Variety Hamper, value \$300.00

Total Prize Value: \$900.00

\$1.00 per ticket or \$5.00 for a book of 6.
4,500 tickets only.

Closes: 15th December, Drawn: 17th December 2021
Winners will be notified by phone

Buy your tickets now from
the Kidney Society, 5 Swaffield Road, Papatoetoe.
If you want some books to sell,
Phone Gina or Maria on: 09 278 1321.

Order your tickets today! It may be a bit of challenge, but let's see if we can get the tickets sold by the 15th of December. If t all possible the raffle will be drawn and the prizes delivered before Christmas!



Are you ready for your new kidney?

The Kidney Society has a Transplant Be Ready Kit to help you get organised.

If you are on the Transplant Waiting List, you may already have been given a Be Ready Kit. If for some reason you have missed out, phone us at 278 1321 or 0800 235 711, or email gina@adks.co.nz and we will send you one.

The very nature of the waiting list means that the kidney that's best for you may become available maybe next month, next year, or within five minutes from reading this page. People often get caught unprepared. They are so excited about the transplant that they forget to arrange all the important things in advance, such as who will feed the cat, who will water the plants, what should you take to hospital? Have you ever tried to remember important phone numbers when you're excited or in a hurry? Exactly.

The name says it all: "Transplant Be Ready Kit", it is full of all the vital bits and pieces you need "when the phone call comes". A quick read of the information provided and you'll remember what you need to do.

You can add your own information, phone lists, spare cash, petrol vouchers, check lists and packing lists and keep it handy in a drawer. When there is a kidney for you, out comes your folder – and your Transplant Plan can be put into action right away.

All you need to do is keep the lists up to date, and keep the kit handy – in an obvious place of course!

The Kit also contains some general information that may not be up to date by the time you are called for a transplant such as how to get to hospital, travel and accommodation arrangements etc.

However as there may be many months or even years between you getting the transplant be ready kit and actually getting a kidney, information about these things in the Be Ready Kit may well be out of date. Still, even out of date information reminds you that there is much you need to organise.

There is a Kit for people living in Auckland who will have their transplant there, and one for people who need to travel to Auckland for their transplant.



Kidney Society staff will be on leave and the Kidney Society centre will be closed from **Tuesday 21 December** until **Monday 10 January**

We look forward to seeing or talking to you all again in the new year.



Enjoy your summer!



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!



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 .