



myrenalnutrition.com

NEWSLETTER

WHAT'S INSIDE...

LIVING WITH KIDNEY DISEASE

A patient's story

WHAT TAKEAWAYS CAN I HAVE?

MINDFULNESS PART 2



PARENT'S CORNER

Strategies to support a child's well-being

News, stories

hints & tips

for children with kidney disease and their families



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My Renal Nutrition NEWSLETTER

Welcome to the second edition of the myrenalnutrition newsletter - a newsletter devised by Vitaflo™ for children with kidney disease and their family, with content written by individuals who have personal experiences of living with kidney disease as well as healthcare professionals who work alongside patients with this condition.

In this edition of the newsletter you will find an inspirational piece written by an individual who has lived with kidney disease. There is also information on physical activity, a recipe idea and a section dedicated to mental health.

If you have a story to share or even a great recipe idea, please let your Dietitian know and we can be sure to include it in future newsletters.

Yours sincerely

The team at Vitaflo



WHAT'S INSIDE...

A PATIENT'S STORY

A young person discusses their experience of living with kidney disease.

WHAT TAKEAWAYS CAN I HAVE?

Options for when you eat out or have a takeaway.

RECIPE IDEA:

Turkey chilli and rice.

PHYSICAL ACTIVITY:

Keeping active in the garden.

MINDFULNESS PART 2

PARENT'S CORNER:

Strategies to support a child's well-being.



SOCIALISING

when you have kidney disease

by Aphria

Aphria was diagnosed with congenital nephrotic syndrome at one year of age. Congenital nephrotic syndrome is a kidney condition that begins in infancy and typically leads to irreversible kidney failure by early childhood. Both her kidneys were removed at 18 months old, and she was on dialysis until receiving a kidney from her dad. The kidney began failing when she was 17 years old, and after being on dialysis again, Aphria has just received her second successful kidney transplant.

Here Aphria shares her experience of living with kidney disease.

The development and presentation of kidney disease is different for everyone. Having had a transplant previously, my immune system was already suppressed, meaning as my kidney function dropped my susceptibility to infection increased. Splitting my time at university between hospital admissions, study commitments and socialising; three things that don't complement each other very well, was difficult. However, as time went on, **I learnt that health is ultimately the most important factor** and it's ok for things to take a backseat when

needed, and this is often out of your hands.

Eating out

Eating out with kidney disease, particularly towards the later stages of the condition, can be difficult. Prior to dialysis, I was retaining a lot of fluid and therefore my appetite was significantly suppressed, and drinking (both water and social drinking) was difficult as I felt so swollen. As dialysis began, I was then put on a one litre fluid restriction daily and a low salt, low potassium, and low phosphate diet. This, at times, was overwhelming and difficult to explain to people, but I would still go out and socialise with friends and just eat what I could or order side dishes; making the socialising more about spending time with people rather than the food and drink. This also helped give a



sense of normality. Dialysis helped manage the condition, making me feel more well and therefore more sociable than before dialysis. **I just tried to tailor the situation to myself where possible to make it easier!**

Discussing my condition with friends

In terms of discussing the condition with friends...this is a process, and one that improved alongside the development of the condition. At first, I thought it sounded monotonous, like a broken record, the constant hospital stories, and updates. But as my friends asked more questions, I realised this was in fact a great disservice to my friends who have continued to be supportive over the years and I gained confidence, **gradually feeling less self-conscious in talking about my ever changing health.** This is where the central line oddly gets credit. Renal failure suddenly didn't seem so invisible with a central line and having a physical 'thing' for others to relate a story to, like a visual aid, I think helped, and finally made me realise the extent of the situation, particularly during Covid. This seemed much easier to explain than my immune system just not being able to fight everyday community acquired diseases. Now, because of that, and because I am more secure in my relationships, and who I share my health updates with, there isn't a need for a physical representation, we

all just update each other on our lives and my health updates are a natural part of that! I also gained confidence in not always putting on a 'brave face' and ultimately being honest with those closest to me.

Talking about my feelings

Prior to starting dialysis, it was hard to talk about how I was feeling with my kidney disease, particularly in its later stages, because, or certainly for me, I felt so uncomfortable in my own skin it was almost unbearable to fully think or talk about. I remember just hoping the next chapter, whether that be dialysis, or a transplant would come round as soon as possible.

I always find it hard introducing people into the 'kidney part' of my life, particularly at the moment with a transplant and everything being so recent. But heart warming moments throughout my time on dialysis were those when my friends kept me company for those 4 hours, with snacks and laughs (or just their

company if I wasn't feeling great), and it never being seen as an inconvenience on our few and far between catch up weekends, or occasions. Moments like that are so important to make you realise you are not a burden and those close to you are with you every step of the way and there's no need to shy away from talking about it or showing people that side of your life.

Overcoming challenges

Some things make it particularly hard to talk about kidney disease. Alongside all the constant unknowns, difficulty making plans and common feelings of being a burden or feeling dismissed by others, is the instinct to 'protect people' and the constant consideration for other people's feelings, which on top of everything, can be unnecessarily exhausting. **But ultimately those who care will want to support you.** I realised my friends were more curious than expected and wanted to know all

the ins and outs, which was greatly appreciated and really helped with gaining confidence around talking about it. I can now safely say my closest friends really do know most details and we can laugh and joke around about it, which is refreshing.

A lot of the time it really is deciding between this or that. For me, I felt I could do it all but learnt the hard way that often that would never end well. I have really had to prioritise my health for the last 4 or so years, which made studying and socialising very difficult a lot of the time in an attempt not to tire myself out which happened too easily. **I am hoping this will gradually get easier as my body is much stronger post-transplant.** Don't get me wrong, health can cause relationships to become more distant and everyone has their own life complications to manage, but peering over the other side of it all now, 6 months post-transplant, I can safely say I have found people that are so supportive of me, as I am to them, as we all stumble through our 20's together!

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"I can safely say I have found people that are so supportive of me"





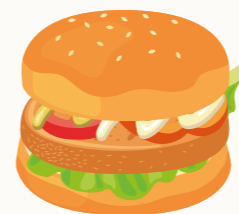
WHAT TAKEAWAYS CAN I HAVE?

Having takeaways with family and friends is always a lovely treat. As fast foods are often high in salt, potassium, phosphorus and sugar you will need to limit your intake of these. However, as we all enjoy a 'treat', the following information provides ideas for better options if you do eat out or have a takeaway meal.



BURGER RESTAURANTS

BEST CHOICES INCLUDE



- Plain meat sandwiches such as beef burgers and grilled chicken on a bun.
- Sides such as green salads, made up of lettuce, celery and green peppers.
- Choose water, lemonade or other clear fizzy drinks and flavoured waters. Try to choose low sugar options. Fruit teas are a refreshing option.

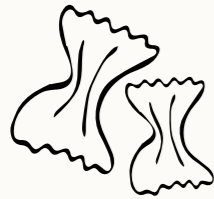
CHICKEN RESTAURANTS

BEST CHOICES INCLUDE



- Houmous with spicy drizzle.
- Chicken pieces or chicken wings.
- Chicken burger in a bun.
- Add a side such as rice, minted peas, corn on the cob or broccoli.

ITALIAN RESTAURANTS



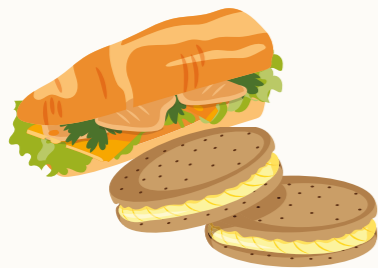
BEST CHOICES INCLUDE

Request that the sauce is put on the side so you can control the amount that you have.



- Pasta or noodles with a small amount of sauce. Choose creamy sauces instead of tomato based sauces.
- Green leafy salads that are a main dish served with a protein such as chicken or tuna.
- Half a pizza with some extra garlic bread or pasta. Avoid high potassium toppings as the pizza will already have a tomato puree base which will contain potassium.

SANDWICH RESTAURANTS



BEST CHOICES INCLUDE

- Sandwiches with fresh, cooked meat (instead of processed meats which are high in salt) and add lower potassium salad options.
- Wraps with chicken or tuna salad.
- Lower potassium fruit, plain cookies and flapjacks.



MEXICAN RESTAURANTS

BEST CHOICES INCLUDE

AVOID GUACAMOLE!



- Tacos with corn tortillas.
- Rice and beans.
- Unsalted tortilla chips.
- Nachos with small amounts of cheese and sauces.

SEAFOOD RESTAURANTS

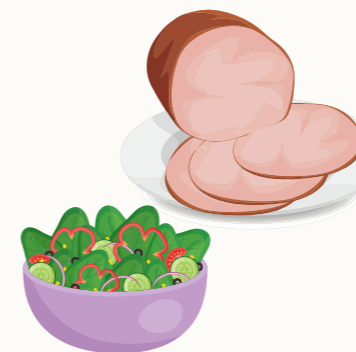


BEST CHOICES INCLUDE

- Fish fillets.
- Fish chowders in broth.

BUFFETS AND CARVERIES

BEST CHOICES INCLUDE



- Meats with a small amount of gravy or other sauces (not tomato based). Add boiled or mashed potato and lower potassium vegetables such as peas and carrots.
- Pasta or rice salads.
- Crackers and breads.
- Green salads with a small amount of dressing.
- Apple crumble or pie.
- Plain sponge cake.

DESSERT RESTAURANTS

BEST CHOICES INCLUDE

AVOID DESSERTS CONTAINING CHOCOLATE, RAISINS OR NUTS.

- Waffles with cream and syrup.
- Pancakes with stewed apple.
- A few berries with a sorbet.
- Fruit or herbal teas.

Always check with your dietitian who will understand your individualised needs and be able to offer advice that fits around the foods you like.

Turkey Chilli and Rice

Serves
4

Ingredients

1 tsp chilli powder
400g pack turkey mince
100g long grain rice, rinsed
600ml reduced salt chicken stock
140g frozen peas, boiled

Small bunch coriander, chopped
8 taco shells
½ iceberg lettuce, shredded
150ml pot soured cream

Try making this recipe



Method

1. Add the mince and chilli powder cooking until browned, breaking it up well, adding a splash of oil if you prefer. Stir in the uncooked rice and mix well, then add the reduced salt chicken stock.
2. Cover and simmer for 20-25 minutes until the rice is cooked, then stir in the pre-cooked peas and scatter over the coriander.
3. Serve with shredded lettuce and soured cream. Eat on its own or with unsalted taco shells, couscous or polenta.

Tip

Replace chilli powder for garlic granules for a different taste and a little less potassium.

This recipe is taken from the Kidney Friendly Cookbook produced by Dietitians and Dietetic Support Workers at a Paediatric Renal Unit in the UK. Please check with your Dietitian or Doctor that this recipe is suitable for you.

PHYSICAL ACTIVITY

Keeping active in the garden

Getting fresh air and being active is important. Here are a few ideas you may wish to try in your own garden:

SOW SOME SEEDS

Whether you have a garden, patio or just a small window space, anyone can try planting seeds. It is a great way to try growing your own food such as carrots, lettuce and onions.

You could also try sowing fast growing plants from seed such as sunflowers. You could have a competition to see which member of the family grows the tallest sunflower.



MAKING A TEDDY BEAR FOOTBALL TEAM



You and one family member could each pick 5 teddy bears. These will be your football team:

1. Put two socks into opposite corners of the garden – these will be the goal posts. This will need to be done at each end of the garden so you and your family member each have a goal. The garden is now your teddies football pitch.
2. Place your 5 teddy bears in different places on the football pitch - your teddies are your football players. Make sure you put one of your teddy bears in goal as the goalkeeper.
3. Crumple up a piece of paper into a ball – this is your teddy bears football.
4. Using your finger, flick the paper ball between the teddy bears and see who is the first to score a goal!!

SET UP AN OBSTACLE COURSE



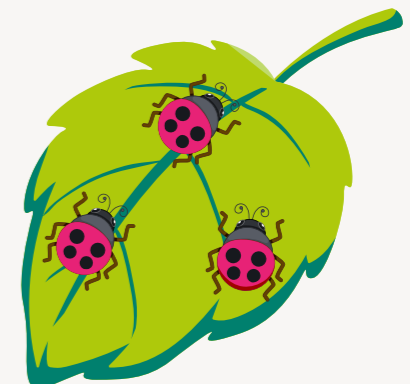
You can set up an obstacle course using everyday objects such as making jumps from buckets and yard brushes.

With a piece of paper and crayon, trace the bark of a tree (if you have one in your garden). You could also try tracing leaves and looking at the different shapes and patterns that you see through the tracing.



SPOT WILDLIFE

All gardens will have a hive of wildlife activity in them. See how many different types of birds you can spot. You could even make and put up a bird house and see if you have any visitors to it. For smaller creatures, lift up stones and pots and see what creepy crawlies lie underneath them.



MINDFULNESS PART 2



Maggie Murphy, a Dietitian from the USA, talks us through what mindful eating is.

What is Mindful Eating?

- Paying attention to the present moment when choosing, preparing, and eating your food.
- Being aware that food is more than just something to fill you up.
- Using all of your senses to explore, savour, and enjoy food.
- Noticing thoughts and feelings about food and yourself without judging.
- Listening to your body's signals of hunger and fullness to decide when you should start and stop eating.

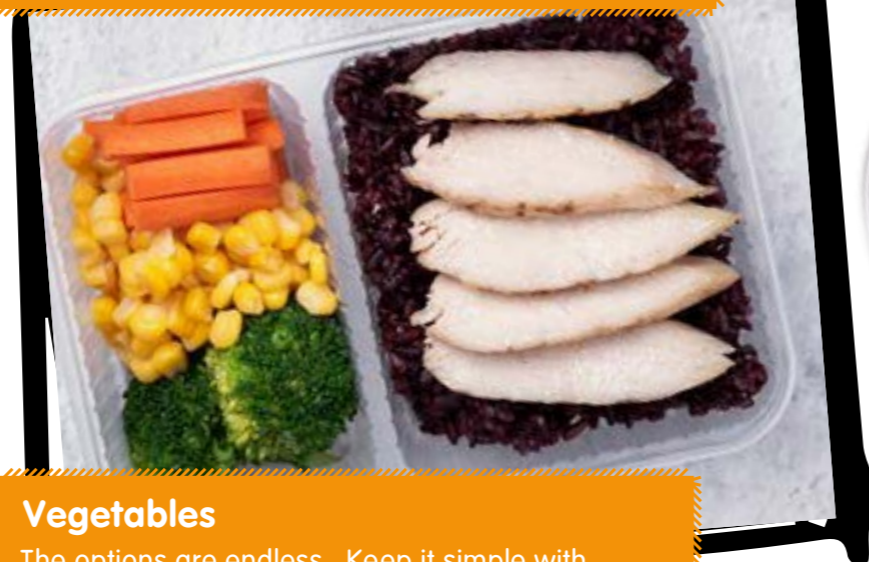
What is Mindful Eating?

- Focus on enjoying food and mealtimes.
- Maintain and enjoy cultural and family traditions.
- Learn to recognize a comfortable level of fullness.
- Respond to food cravings in healthful ways.



Protein

Choose lean meats and fish, like skinless rotisserie chicken, turkey, tuna, thinly grilled flank steak and cooked shrimp. Meatless options include peanut butter, hummus, quinoa, beans, and hard-boiled eggs.



Vegetables

The options are endless. Keep it simple with veggies like baby carrots, cherry tomatoes, roasted broccoli florets, steamed green beans, salad greens, cucumber slices or bell pepper slices, and pack a little dressing or hummus on the side for dipping.

Fruit

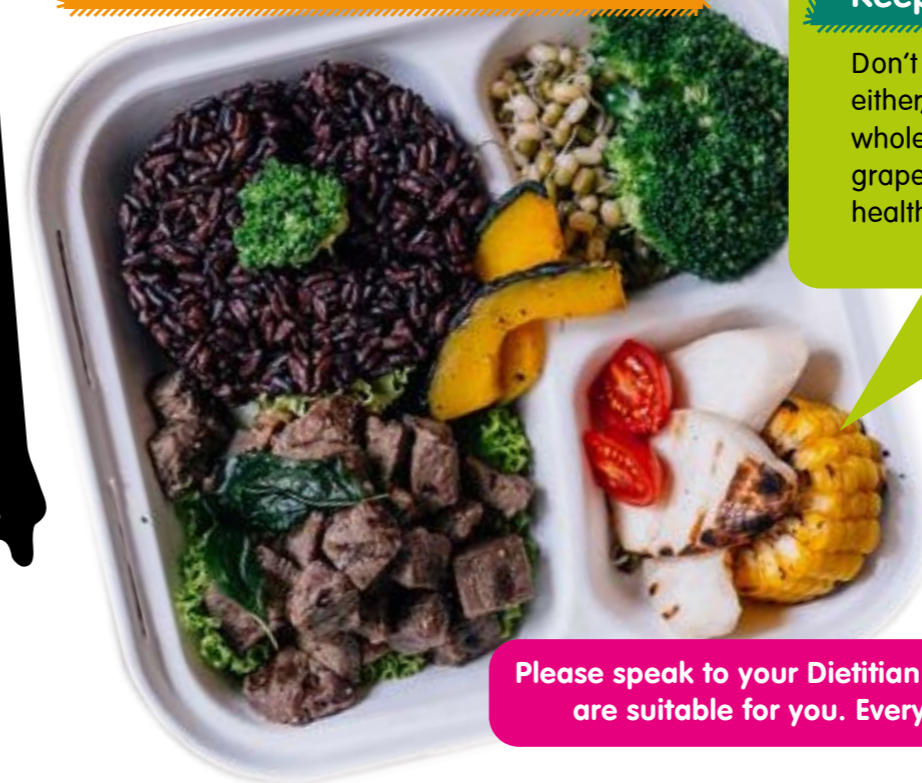
Fresh fruit includes berries, grapes, peach slices, clementines, and apples.

Any fruit that you like is a great option!



Extras

Add one more food to round out the meal and help you feel full. Foods to include are whole grain crackers, pita chips, a dairy item like Greek yogurt or a part-skim mozzarella cheese stick, or a small piece of chocolate.



Please speak to your Dietitian about which foods and drinks are suitable for you. Everyone's needs are different.

Learn to Multi-task:

Identifying a protein can be the biggest roadblock for some, so don't overthink it. An easy lunch protein is often the leftover protein from dinner the night before. Plan to cook a little extra at dinner to save for your bento box or make a quick chicken or tuna salad Sunday evening to have for lunch boxes.

Take Veggie Shortcuts:

Go ahead and prep some fresh veggies or roast extra veggies the night before to pack for lunch.

Mix It Up:

Don't feel like you have to keep food groups separate. The formula is simply a guide to ensure you eat a variety of foods. Mix tuna into a cooked grain, add almond butter to apple slices, or mix yogurt with nuts and berries.

Keep It Simple:

Don't feel like it's got to be fancy either, though. A lunch box with whole-grain crackers, turkey slices, grapes and yogurt can be just as healthy as a gourmet one.

PARENT'S CORNER

Supporting children's mental and behavioural health

by Rebecca Johnson



Rebecca Johnson, Clinical Psychologist from the USA, PhD, ABPP, talks us through how to look after a child's mental and behavioural health.

Children's emotional health has suffered during the stress of the COVID-19 pandemic. Here are some strategies that parents and other caregivers can use to support children's well-being:

Stick to a consistent routine as much as possible.

Everyone benefits from a consistent daily routine. Children in particular tend to cope with stress more effectively when their days are predictable and they know what to expect, when. If you have drifted away from consistent wake times, meal times, and bedtime routines, consider getting back on track, even if you have to do it gradually.

Encourage children to move their bodies.

Adding even a little bit of movement or physical activity to one's day has been shown to positively impact mental health. Going for a short walk or stopping by a park can boost mood and improve coping. Encourage your child to move in creative ways – try out a hula hoop, create your own at home "Olympic" events, or dance to upbeat music.

Limit screen time and try some new activities.

Having a consistent plan for screen time that includes daily limits makes this activity more predictable for children and can reduce the irritability that some children experience when they transition from screens to other activities. Engaging in a range of leisure activities promotes healthy minds and interaction with others. "Schedule" time for your child to draw, colour, or paint (and to "show off" their work to others), try out a potential new hobby, or play a board or card game with family or friends.

Make time for social support.

Especially as they reach the late elementary or middle school years, socializing outside the structure of the school day becomes important for children. They obtain social support, learn about navigating social relationships through trial and error, and develop social connections.

Practice self-care.

Finally, it is important that you, as a parent or caregiver, prioritize your own self-care whenever possible. Getting enough sleep, being active, and making time for social support are as important for caregivers as they are for children. You must take care of yourself to take care of others; thus, making your self-care a priority (at least sometimes!) is an act of generosity toward yourself, your child, and your family.

"The dialysis unit in the hospital is very sociable though and you meet a lot of friendly people!"

HELPING CHILDREN

Build resiliency through active coping



Learning how to cope with stress is an important part of child development. Here are some ideas to support your child's development of active coping skills:

Take a moment to be thankful.

Find moments, perhaps in the car or as you sit down to eat a meal, to model being thankful and to encourage your child to identify positive things that happened that day. It is easy to focus on what went wrong during the day; highlighting even small things for which to be thankful (a kind word, help from a teacher, a beautiful sunset) can shift the focus from the negative to more positive thinking.

Encourage relaxation.

When your child appears frustrated or stressed, encourage them to take slow, deep breaths, do a few stretches or yoga poses, or ask for a hug. Practicing relaxation daily strengthens these skills. Try a "5 senses" exercise with your child:

- 1) In a quiet location, ask your child to close their eyes and think about a pleasant time, place, or memory.

- 2) Have them talk about things they see, hear, touch, taste, and smell in that "place."
- 3) Finish with some slow, deep breaths.

Help your child "make a plan" to master the situation or worry.

If your child is facing a stressful situation, help them make a plan for getting through it. Identifying one or two things they can do (e.g., coaching themselves to think "I can do it," asking a friend to do it with them, breaking it down into steps, bringing a comfort object with them) helps them take a problem-solving approach rather than letting the worry take over.

Expect that your child can do hard things.

Communicating that you believe your child can do things that are hard increases their confidence and

self-efficacy. Let them know that they can ask for help. Encourage them to brainstorm solutions or use active coping skills to work through stressful or challenging situations. Highlight and praise both effort (even if things do not work out) and success.

Model active coping.

Children learn a lot from watching others, especially their parents or caregivers. Take a moment to label a situation that is stressful for you, and how you are coping with it. During stressful moments, do your best to stay calm and model your own version of active coping.

Vitaflo (International) Ltd is a clinical nutrition company who specialise in developing products and resources for those with kidney disease. The information in this newsletter is for general information only and must not be used as a substitute for professional medical advice or treatment. Your Dietitian and doctor will provide you with advice with regards to the management of your condition and it is important that you follow the advice that they provide.



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