



myrenalnutrition.com

NEWSLETTER

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**FOLLOWING A
LOW SALT DIET**

**KEEPING
ACTIVE THIS
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MINDFULNESS

Looking after your mental health
Information regarding mindfulness



RECIPE IDEA

**News, stories
hints & tips**

for children with kidney disease and their families



Enhancing Lives Together
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My Renal Nutrition NEWSLETTER

Welcome to the very first edition of the myrenalnutrition newsletter – a newsletter devised by Vitaflo™ for children with kidney disease and their families, with content written by people who have kidney disease as well as healthcare professionals who work alongside patients with this condition.

The newsletter aims to provide information and resources that you may find useful as you learn about your condition and its management. This includes information on diet, activity, everyday life and fun games and recipes.

We aim to provide the newsletter twice per year – if you have a recipe, story or idea that you think would be useful to include in future newsletters 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...

WHAT I WISH I KNEW

Insights from an individual with kidney disease.

FOLLOWING A LOW SALT DIET

Tips on how to follow a low salt diet from an individual who has experience of living with kidney disease.

KEEPING ACTIVE THIS SPRING

We have fun ideas regarding how to keep active this Spring.

MINDFULNESS

We have information regarding mindfulness, a technique which can be used to help your mental well-being.

RECIPE IDEA: POPCORN BALLS

Try making this easy recipe.



WHAT I WISH I KNEW

when I was first diagnosed with 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 experiences and tips for living with kidney disease.

My recent transplant was just 4 months ago; it's quite tricky to talk about my first transplant as I was only two years of age at the time. I wish I had been more informed of the effects of kidney disease; I guess that's the type of thing you only know if you go through it! How chronic kidney disease will change you, physically and mentally, on a constant basis, (I know it's impossible to predict for anyone).

For the years building up to transplant, the changes were quite obvious early on and my body retained a significant amount of fluid, making me breathless; very quickly and I just didn't feel myself! This affected many other areas of my life too. The focus you take to your health in general alongside your kidney health is time consuming. Dialysis, for me, gave a sense of routine and security as it was, at long last, the management

of chronic kidney disease I needed to settle my mind and to think things were on their way up.

I wish I knew how beneficial dialysis was going to be. It was always sold to me as it being the absolute last resort, as the 'big bad wolf'. However, I was unwell for so long beforehand, that it really was a relief to finally be at the stage when I could start it. Despite needing an emergency line fitting, such a weight was lifted, it felt oddly euphoric.

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

Don't get me wrong dialysis has its ups and down, but it was the next step in treatment and a change which excited me. The thought of

feeling more unwell on dialysis scared me on the build-up as I thought, 'how is it possible? To be more unwell when this is already such a struggle?'. Although I didn't manage morning dialysis at the hospital very well, I started haemodialysis at home which worked well and gave me some independence back, whilst helping stabilize my body and giving me more freedom. The dialysis unit in the hospital is very sociable though and you meet a lot of friendly people!

I wish I'd known dialysis was going to make things better and not worse. The year leading up to dialysis was tricky and I thought I was going to feel more unwell. However, through dialysis I lost the fluid I was carrying, making me comfortable and less breathless.

Aphria's hints and tips FOR FOLLOWING A LOW SALT DIET

For a patient with kidney disease with fluid and food limitations, salt cravings can be strong and consistent. Salt was one of the only cravings I had so it could be a challenge to keep to a low salt diet. Here are my top tips to help follow a low salt diet:



1. Prepare meals at home

Prepare meals at home and do not add extra salt. If this is not possible, check the labels on food to try to ensure you are choosing the best options. Compare products to find out which ones contain the least amount of salt.

2. Distraction technique

If I had a salt craving I would fully distract myself; go for a walk, meet up with family or friends or do some errands. If you don't have the energy for this, try eating something completely different or drink some water (although fluid restrictions can make this tricky at times).

3. Avoid having salty snacks in the house

Maybe avoid having salty snacks in the house, so they physically can't be reached for, and have suitable meals / snacks available that you can tuck into with minimal effort.

There are always small steps you can take to help reduce salt in the diet and never feel daunted by this as it is very possible, and you might find cooking quite relaxing amongst everything going on!

Please speak to your dietitian or doctor regarding your diet and any dietary changes that you wish to make. Your dietitian and doctor can provide you with individualised advice. Everyone's dietary needs are different.

KEEPING ACTIVE this spring

Having kidney disease can make you feel tired. However it is important to try to be as active as possible to try to keep yourself healthy.

Research has shown that young people with kidney disease may not get enough exercise. Being more active can be fun and make you feel better, stronger and healthier.

Remember to check with your medical team before trying any new sport or exercise.

Doing a variety of different types of exercise is important to keep your muscles and bones strong and it helps to keep your heart and lungs healthy.

You can exercise through many fun activities:

- Tug of war with friends
- Going for a walk
- Running with friends
- Trying yoga
- Dancing to your favourite songs
- Setting up an obstacle course and seeing if you can complete it
- Activities with pets and other animals can also be great fun e.g. walk the dog, try horse riding



BEING MINDFUL



Maggie Murphy, a Dietitian from the USA, talks us through what Mindfulness is, how it can help you and provides a quick 5 minute mindfulness activity for you to try.

What is Mindfulness?

When we're distracted or stressed, we can become upset without realizing what's happening. However, practicing mindfulness can strengthen our abilities to have positive feelings and stay focused on the present moment instead of thinking about the past or worrying about the future. **Mindfulness is paying close attention to what is happening now and noticing when your attention drifts away.**

Mindfulness practices include breathing exercises and activities that increase your ability to focus and stay calm.



MINDFULNESS ACTIVITY: BODY SCAN (5 MINUTES)

- **Connecting with our physical body is just as important as exploring our minds and thoughts.**
- **It can be easy to ignore what our bodies are trying to tell us.**
- **The body scan involves focusing on different parts of the body to notice bodily sensations.**
- **The Body Scan is used to help us be aware of our body, to feel what's happening moment-to-moment which is different from thinking about our bodies.**

Description:

This exercise helps you observe your body so you can relax the areas that have tension or where you feel pain, aches, or any discomfort.

Introduction:

You can do a body scan either lying down or sitting up. If you're sitting up, find a comfortable chair, sitting up tall without leaning on the back of the chair. Place both feet flat on the floor.



Still sitting up tall, you can close your eyes if you're comfortable or keep them open with a soft gaze (don't need to stare at anything). Your ears should be over your shoulders and your shoulders over your hips. If you're lying down, place your arms by your sides. Start to relax your

face by not clenching your jaw or neck muscles. Relax your eyes, imagining that they're sinking back into their sockets.

Exercise:

Check-in to notice how your body feels. Try to focus on your toes. Notice if you feel anything in your toes. Start to trace up through your feet, then your ankle and your knees. (If you're sitting, notice how your knees are stacked over your ankles. If you're lying down, feel the weight of gravity resting down on your legs.) Continue to travel up your body, notice if there's any tension in your hips or lower belly. Try to relax.

Let's move to the hands. Wiggle your fingers and then relax them. Soften your hands and notice how any feeling in your wrists, your lower arms, or your upper arms. Notice if there's any tension in your shoulders. Take note of how your neck feels. Become aware of the sense organs of your ears, your mouth, your nose, and your eyes.

Now, turn your attention to your breath. Notice the speed of your breath. Is it shallow or fast? If so, try to take deeper and slower breaths. Turn your attention to your heart rate. Try to use deep breaths to calm yourself and slow your heart rate. Now focus on your entire body. How do you feel? Try to use your breath to help your body and mind feel better.



Closing:

Take a deep breath through your nose and move your shoulders up to your ears. Exhale through your mouth and roll your shoulders back and down. Gently blink your eyes open.

Popcorn Balls

Makes
15

Ingredients

50g unsalted butter
150g marshmallows
1-2 drops of vanilla extract
90g unsalted, popped popcorn

Method

1. Place butter and marshmallows in a saucepan and melt over a gentle heat, stirring continuously. Remove from heat and stir in the vanilla extract.
2. Place popped popcorn in a large bowl, pour over the marshmallow mixture and stir using a long wooden spoon.
3. Allow to cool before handling. When no longer hot to touch, to make popcorn balls, grease hands with butter and take a handful of the mixture at a time and form into balls.
4. Place into cupcake cases and pop into the fridge to cool. Once cooled serve or store in an airtight container.



Press the mixture into a greased baking tray, drizzle with a low potassium chocolate substitute and once cooled, cut into bars instead of balls.



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.

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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