

# The Kidney Bean

NEWSLETTER

*Summer Edition*



Sponsored by the Norfolk Renal Fund

# Editor's Note

Dear reader,

As the warm embrace of summer envelops us, it brings with it a burst of vibrant energy, endless possibilities, and a kaleidoscope of experiences. Welcome to the Summer Edition of our newsletter, where we aim to capture the essence of this sun-kissed season and deliver a dose of inspiration, information, and community spirit.

In these pages, you'll find a treasure trove of articles, features, and stories that celebrate the beauty of summer. From travel escapades to delicious seasonal recipes, we've curated a collection that mirrors the diversity of this extraordinary time of year.

We also invite you to share your summer experiences with us. Whether it's a cherished tradition, a favourite summer recipe, or a memorable journey, we want to hear from you. Your stories are what make this community vibrant and diverse, and we look forward to featuring some of them in our upcoming editions.

Thank you for being part of our community and for allowing us to be a part of your summer journey. We hope this edition adds a touch of sunshine to your day and inspires you to make the most of the long, warm days ahead.

Wishing you a summer filled with joy, laughter, and unforgettable moments.

Becci  
Specialist Nurse/Editor

If you would like to share your story,  
give feedback,  
or anything else in between for the next edition,  
please email:  
[norfolkkidneybean@gmail.com](mailto:norfolkkidneybean@gmail.com)

## UPCOMING EVENTS & INFO



**Do you drive your own vehicle to get to your dialysis treatment?\***

**Are you aware you can claim mileage?\*\*\***

\*Must be registered with a GP and attending for in-centre haemodialysis.

Car parking is free to outpatients attending for haemodialysis.

\*\*\*Ask our reception or nursing team for more information.

## Step into Spring!

CHALLENGE

FINAL LEADERBOARD

1	Pao. E	543,269
2	Lisa. S	467,261
3	Alex. G	265,260
	Becci. L	210,234
	Hannah. E	113,205

Thank you so much to those that took part – we will hopefully see more of you involved for the 'March in March' step challenge next year!

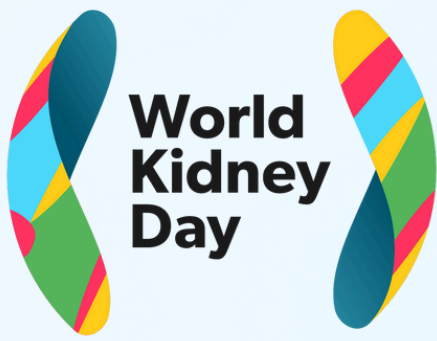
You are invited to...



Renal Home Therapies Team  
**Home Huddle**

Drop in, enjoy a beverage and share your experience

**Thursday 23rd May**  
**09:30 - 11:30**  
**Norfolk and Norwich Kidney Centre**



# World Kidney Day at the Norfolk and Norwich University Hospital

In celebration of World Kidney Day on 14 March, our Renal team held an event at the Benjamin Gooch Lecture Theatre that included stalls showcasing different aspects of the renal care we provide at NNUH and the Norfolk and Norwich Kidney Centre alongside our partners and provided opportunities for clinicians and the public to learn more.

“The kidneys are the organs responsible for controlling the flow of waste products and balancing the body’s fluid levels,” said Rebecca Lorimer, Patient Education Nurse Specialist. “They also help maintain bone health, alongside producing vital hormones.

“It’s been amazing to see such a good showing of clinicians and members of the public, who are all getting involved and having discussions about the world of renal medicine.”

The Norfolk Renal Fund showcased how they assist patients by providing equipment not supplied by the NHS, funding staff training, and offering financial support to patients and carers who are living with kidney disease.

Long-time NNUH partners Kidney Care UK provide a team of Patient Support and Advocacy Officers who help with concerns about treatment choice, transport and benefits. Financial and counselling services to comfort and support people during their management of kidney disease are also offered.

The Renal Dietitians were also present because diabetes is the number one single cause of kidney disease, with roughly one in three adults with diabetes having a kidney disease. A renal dietician can help a patient understand what diet works best for them to help the treatment and complications of kidney disease.

Rachel, who has been in the care of the NNUH renal department since childhood, said: “Having a team that is so compassionate and caring really means the world to me. I can’t thank them enough for everything. When I have come into A&E in the past, it was so reassuring to see all of the staff know exactly what they needed to do to deal with the complications that come with my condition.”

**A HUGE thank you to everyone who came along to support - next year we go bigger and better!**

**#watchthisspace**



# The benefits of Peer Support



## What challenges do people with kidney disease face?

- Health complications such as high blood pressure, anaemia, poor nutrition or bone disorders
  - Adjustment to dietary/fluid restrictions
- Trying to maintain a 'normal' life with respect to family, job and friends
  - Disruption of their lifestyle due to dialysis treatment schedule
- Coping with emotions such as fear, anxiety, frustration and sadness of having a chronic illness

## What is Peer Support?

Research shows that people often cope better when they interact with peers who share common experiences. Peer support occurs when a person who has lived through a specific experience, is able to provide knowledge, experience, emotional, social or practical support to help someone new to that particular experience.

**Please note: Peer Mentors do not offer medical advice.**

## What are the benefits?

There are a huge number of benefits for both parties in the peer mentorship scheme:

### For the mentee:

- Adjust to living with a chronic illness
  - Better self-management
- Improvement of overall wellbeing and survival
- Decrease feelings of isolation and depression

### For the mentor:

- Provides a sense of purpose
  - Improves wellbeing
  - Reinforces self-health skills
- Improves confidence and knowledge
- Helps you to come to terms with your own illness



Do you have access to a telephone/email address?  
Are you happy to share your experience of dialysis?  
Have you made a positive adjustment to living with kidney disease on dialysis?  
Are you a positive role model that others can relate to and learn from?

If YES, then we would like you to join our group of willing volunteers to help others in their dialysis journey...

Email [norfolkkidneybean@gmail.com](mailto:norfolkkidneybean@gmail.com) to sign up!

# HAEMODIALYSIS EXPLAINED

**Haemodialysis (HD)** is a treatment that removes waste products and excess fluids from the blood when the kidneys are no longer able to perform this function adequately. This process involves using a machine called a **dialysis machine**.

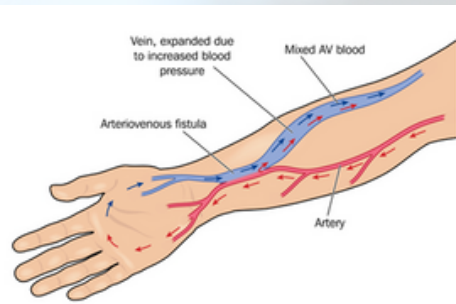
Haemodialysis can be carried out in-centre OR in your own home.



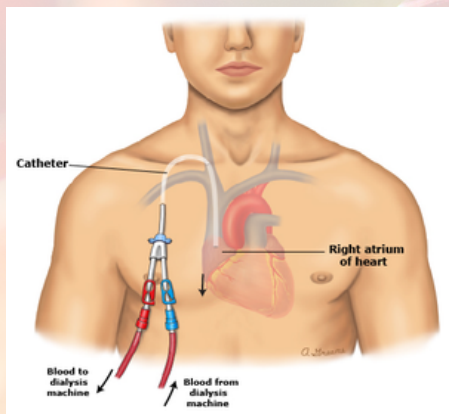
During haemodialysis, blood is taken out of your body via an **arteriovenous fistula** or a **neck line**.

A fistula is a special connection that is made by joining a vein onto an artery, usually in your arm. This creates a large, robust blood vessel that can be needed regularly for use during haemodialysis.

A neck line, also called a central venous catheter, is a soft plastic tube which is inserted into one of the large veins in your neck or, occasionally, in your groin. This tube gives your dialysis team access to your blood, so that it can circulate around the HD machine to be filtered.



<https://www.vfdunsw.com/cannulation>



<https://www.uptodate.com/services/app/contents/graphic/view/PI/69685/CentralvenouscathPI.jpg>

The blood is passed through an artificial kidney (called a **dialyser**) where the toxins and waste is filtered out. This 'clean' blood is then returned to you.

The dialyser has two parts, one for your blood and one for fluid called dialysate. A thin membrane separates these two parts. Blood cells, protein and other important things remain in your blood because they are too big to pass through the membrane. Smaller waste products in the blood, such as urea, creatinine, potassium and extra fluid pass through the membrane and are washed away.



# PERITONEAL DIALYSIS EXPLAINED

**Peritoneal dialysis (PD)** works by using the **peritoneum**, a membrane lining the abdominal cavity, as a natural filter to remove waste products and excess fluids from the blood. The process involves the use of a special dialysis solution (**dialysate**) and minor surgery that involves inserting a catheter into the abdominal cavity.

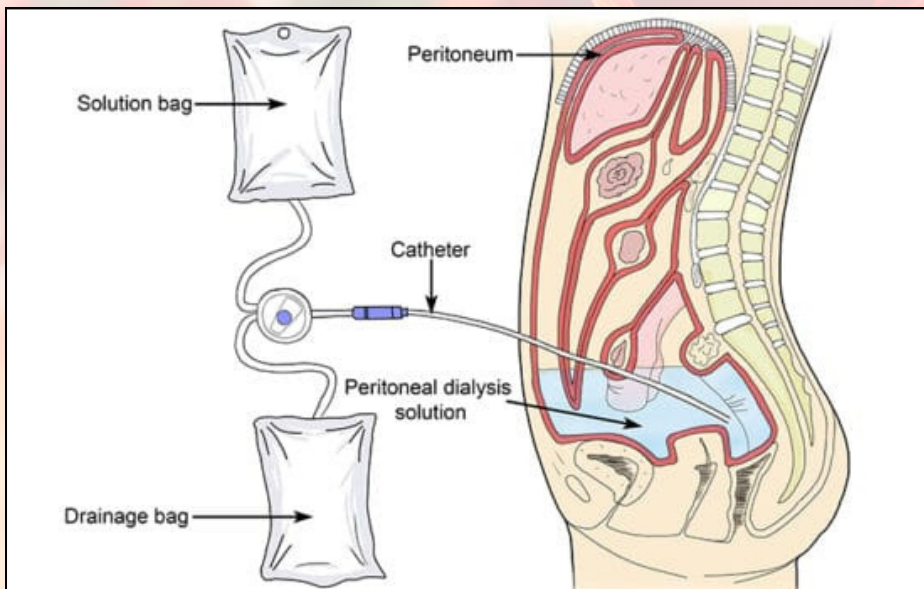
The peritoneum lets waste products (such as potassium, creatinine and urea) and extra fluid that is in your blood pass through it - essentially cleaning the blood. At the same time, the lining of the peritoneum holds back the important things that your body needs, such as red blood cells and nutrients... pretty amazing hey?



To do its job properly, the dialysate fluid needs to be left in your belly for 4-6 hours - this is called a **dwel**.

When this time is up, the fluid is drained from your body into the drainage bag (see picture). A new 2L of fluid will be drained in straight away, so there will continuously be fluid in your belly.

This process takes around 30 minutes and is called an **exchange**.



[https://www.healthcommunitiesproviderservices.com/wp-content/uploads/2023/08/peritoneal-dialysis-1-AdobeStock\\_199722901.jpeg](https://www.healthcommunitiesproviderservices.com/wp-content/uploads/2023/08/peritoneal-dialysis-1-AdobeStock_199722901.jpeg) bit of body text

There are two types of peritoneal dialysis:

- Continuous Ambulatory Peritoneal Dialysis (CAPD)** - manual exchanges 4x day, every day
- Automated Peritoneal Dialysis (APD)** - a machine will dialyse you overnight whilst you sleep

The training staff at your dialysis centre will teach you everything you need to know, including how to do exchanges, order supplies, clean your catheter, and guard against infection. Once you and the staff are comfortable with your ability to do PD alone, you can start doing your own treatments at home.

# Difficult conversations: Advanced Care Planning

Advanced care planning (ACP) is a process through which individuals make decisions about the healthcare they would like to receive in the future, especially in the event that they become unable to communicate or make decisions for themselves. It involves discussions and documentation of one's values, preferences, and goals related to medical treatment and care.

Advanced care planning is not solely focused on end-of-life decisions but encompasses a broad range of healthcare choices that individuals may face due to illness, injury, or other medical circumstances. Engaging in ACP empowers individuals to have a say in their medical care, even when they cannot communicate their preferences, and it helps facilitate a more patient-centred and informed approach to healthcare decision-making.

What are the benefits?

1. **Clarifying Personal Values and Goals:** Advanced care planning allows individuals to articulate and document their personal values, beliefs, and goals related to healthcare. This ensures that medical decisions align with their preferences, even if they are unable to communicate them later.
2. **Ensuring Personalised Care:** By discussing and documenting preferences for medical treatments and interventions in advance, individuals can ensure that healthcare providers deliver care that is aligned with their values, enhancing the likelihood of receiving personalised and patient-centred treatment.
3. **Reducing Family and Caregiver Stress:** Advanced care planning can alleviate the burden on family members and caregivers by providing clear guidance on a person's healthcare preferences. This reduces the emotional stress and uncertainty that loved ones may face when making medical decisions on behalf of someone who is unable to communicate.
4. **Avoiding Unwanted Interventions:** Through advanced care directives such as living wills and power of attorney for healthcare, individuals can specify their preferences regarding certain medical interventions, potentially avoiding unnecessary or unwanted treatments.
5. **Enhancing Communication with Healthcare Providers:** Having documented advanced care plans encourages open communication between individuals, their families, and healthcare providers. This ensures that everyone involved in the care process is aware of the individual's wishes, promoting a collaborative and informed approach to decision-making.
6. **Promoting Autonomy and Empowerment:** Advanced care planning empowers individuals to take an active role in their healthcare decisions. It allows them to express their autonomy and have a say in the course of their medical treatment, even when they may be unable to communicate their preferences.

Speak to your nursing team if you wish to discuss this further.



# Summiting for a Cause: A Woman's Climb up Kilimanjaro to Fundraise and Inspire

**Julie Stekelenburg decided to climb Kilimanjaro for her 50th birthday and raise money for the Norfolk Renal Fund (NRF) whilst doing so.**

**She raised a huge £3,181.96 in total. This is her story...**



50th birthday challenge. Mid-life crisis I hear you say? Maybe 😊, but there is more to the story as you will see below and I hope you will dig deep and support my cause to raise money for Renal Unit support.

## Why Renal Patient Support?

1985 - I was 13 years old, living in Malawi and at boarding school in Blantyre when I got the phone call from my Mom to tell me that my Dad was being medically evacuated to South Africa. Various tests and investigations resulted in the removal of one of his kidneys, which the Doctor's thought had likely been under developed from birth and had finally given up.

Fast forward to 2000, another phone call and another medivac, this time from Uganda to Kenya and this time it was kidney failure - the prognosis dialysis. Dad's only option to return to the UK, get the treatment he needed to keep him alive and have the chance to be on the transplant list (sadly my Mom, sister and I were not suitable matches). The Norfolk & Norwich University Hospital's renal centre supported Dad throughout his time on dialysis. The Norfolk Renal Fund is strongly linked to this Renal centre and was established to supplement the NHS. Sadly, Dad never got a transplant and died in 2005.

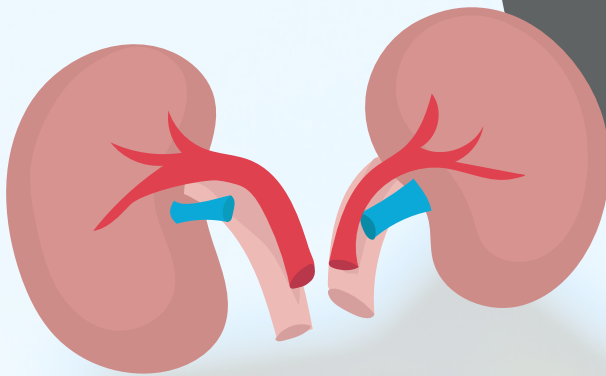
## Why Kilimanjaro?

Dad took a job in Malawi in 1979 and we emigrated from the UK; I was 7 years old. For the next 23 years on each flight I took back to the UK I would be haunted by the beauty of Kilimanjaro (and the pilot's reminder that it on the left ☺) and vowed one day to climb it and embrace the beauty that taunted me most of my life.

It seems fitting to do it on my 50th birthday (I plan to summit on the actual day), in memory of my Dad, raising money for a unit that will help to support, protect and treat those that are susceptible to kidney disease.



# PHOSPHATE AND YOUR KIDNEYS



Phosphate is a mineral found in your bones; it is needed alongside calcium to build strong, healthy bones.

Extra phosphate in the blood will pull calcium out of the bones, making them weak. High phosphate and calcium levels can also lead to harmful calcium deposits found in blood vessels, lungs, eyes and heart which over time, can lead to heart attack or stroke.

**Not everyone needs to restrict their phosphate intake - please discuss with one of the dieticians if you would like further information.**

## Higher Phosphate Foods



## Lower Phosphate Foods



Look out for phosphate additives such as the ones below:

**Disphosphates** - cakes, instant mashed potato, cheese

**Triphosphates** - fish fingers

**Polyphosphates** - dried foods and desserts

**Monostarch phosphate** - ice cream, pizza, battered fish, salad dressing

**Phosphoric acid** - beer, processed meats, fizzy drinks

**Calcium phosphate** - self-raising flour, instant pasta & sauces

**Ammonium phosphate** - baked goods, frozen desserts, alcoholic drinks

**Magnesium phosphate** - salt substitute

**Speak to one of our renal dieticians for an additive card to take home with you!**



# Medication Buster: PHOSPHATE BINDERS

**When might someone be prescribed a phosphate binder?** Phosphate binders are needed when the levels of phosphate are too high in the blood and dietary modifications are not enough.

Usually phosphate binders are taken within 5 to 10 minutes before or immediately after meals and snacks. Your renal dietitian will tell you when you should take your phosphate binders and discuss how many you need to take when you eat.

There are a few different types of phosphate binders, but the main two groups that you may come across are:

## 1. Calcium-Based Binders:

Examples: Calcium carbonate, calcium acetate.

These binders work by providing a source of calcium that binds with phosphate in the gastrointestinal tract, which prevents the phosphate from getting into the bloodstream, instead being eliminated in the stool. These are effective but should be used with caution in individuals with high calcium and/or those at risk of developing high levels of calcium in the blood.

## 2. Non-Calcium-Based Binders:

Examples: Sevelamer, Lanthanum carbonate.

These binders do not contain calcium and are preferred in patients with high calcium or those who require limiting calcium intake.

They work by binding to phosphate in the gut, similar to calcium-based binders.

The choice of phosphate binder depends on various factors, including the patient's overall health, calcium levels, and individual preferences. It's important for individuals to take phosphate binders as prescribed by their healthcare provider and to follow dietary recommendations to help control phosphate intake.

Phosphate binder	When to take	Common side effects
Calcium acetate (Renacet®, Phosex®)	Swallow whole 10-15 minutes before meals	Feeling sick, can raise calcium levels
Calcium carbonate (Calcichew®)	Chew 10-15 minutes before meals	Chalky taste, can raise calcium levels
Lanthanum (Fosrenol®)	Chew during, or just after, meals	Feeling sick if taken on an empty stomach
Sevelamer (Renvela®, 'Renagel®)	Swallow whole just before meals	Feeling sick
Sucroferric oxyhydroxide (Velporo®)	Chew just before meals	Black stools (poo)

## SUMMER RECIPIES: MAIN MEAL

# PORK MEDALLIONS WITH APPLE & MUSTARD

Prep time: 15 minutes    Cook time: 30 minutes    Serves: 4

### INGREDIENTS:

- 4 PORK MEDALLIONS (APPROX. 140G EACH)
- 1 TABLESPOON OLIVE OIL
- 1 EATING APPLE
- 1 ONION, HALVED AND SLICED
- 100ML LOW SALT CHICKEN STOCK
- 2 TEASPOONS DIJON OR WHOLEGRAIN MUSTARD
- 50G UNSALTED BUTTER
- BLACK PEPPER
- 2 TEASPOONS DRIED SAGE
- 300G SAVOY CABBAGE, FINELY SLICED
- 1 SWEDE (APPROX. 600G)



<https://kidneycareuk.org/get-support/healthy-diet-support/kidney-kitchen/recipe-index/pork-medallions-with-apples-and-mustard/body.text>

### METHOD:

1. Peel and cut the swede into 2.5cm chunks. Put in a large saucepan and fill with enough water to cover. Cover with a lid and bring to a boil then reduce heat and simmer for 20 minutes, or until the swede is soft. Drain and discard the water, leave to stand with the lid on.
2. Meanwhile, rub the pork steaks with a little oil and season with pepper to taste. Heat a large frying pan and fry the pork for 2 minutes on each side until golden brown. Transfer to a plate to rest.
3. Peel and core the apple and cut into eight segments. Peel and slice the onion. Adding a little more oil to the pan, fry the apples, onions and sage for 5 minutes or until the apples have softened.
4. Make up the stock and pour over the mixture and spoon in the mustard, then return the pork to the pan and simmer for 10 minutes until the sauce has reduced by about a third and pork is cooked through.
5. While the pork is cooking, finely slice and add the savoy cabbage to a saucepan of water and boil for 10-15 minutes until cooked, then drain and discard the water.
6. Remove the lid on the swede, mash until smooth. Season with pepper and cook for a 1-2 minutes. Serve the pork with the mashed swede, boiled savoy cabbage and the mustard and apple mixture.



Low Phosphate, Low Potassium, Low Salt, Low Fat

## SUMMER RECIPIES: DESSERT

# PEAR & BLACKBERRY CRUMBLE

Prep time: 15 minutes    Cook time: 25 minutes    Serves: 6

### INGREDIENTS:

#### CRUMBLE FILLING

- 5 LARGE PEARS
- 25G UNSALTED BUTTER
- 100G FRESH OR FROZEN BLACKBERRIES
- 50G CASTER SUGAR

#### CRUMBLE

- 75G UNSALTED BUTTER
- 40G GROUND ALMONDS
- 40G PORRIDGE OATS
- 160G PLAIN FLOUR
- 40G SOFT DARK BROWN SUGAR
- 40G DEMERARA SUGAR
- 1 PINCH GROUND GINGER



<https://kidneycareuk.org/get-support/healthy-diet-support/kidney-kitchen/recipe-index/pear-and-blackberry-crumble/>

### METHOD:

1. Pre-heat your oven to 160C /gas mark 4. Peel, core and roughly chop the pears.
2. Melt the butter in a pan and add the pears. Cook until soft, turning frequently until most of the liquid has evaporated. Add the blackberries and sugar and stir until the sugar has dissolved. Remove from the heat.
3. Mix all the crumble topping ingredients in a food processor or mixer, or in a bowl, rub together using the tips of your fingers until the mixture resembles breadcrumbs. It is okay to leave a few little lumpy bits as these add character to the finished dish.
4. Fill an oven-proof serving dish with the fruit mixture and spoon the crumble mix over the top.
5. Bake for 20 minutes until topping is golden brown and bubbling.
6. Serve with cream (clotted cream if you are feeling indulgent) or a low-fat crème fraiche.



Low Fat, Low Protein, Low Salt