

EDKPA Newsletter

Autumn 2021 edition

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*Wild gorse and heather on the
cliffs of North Devon near
Lynmouth* →



Visit our website at
<http://www.edkpa.org.uk>

The EDKPA newsletter is provided by Exeter and District Kidney Patients and its members. It is for information purposes only. It should not be a substitute for professional medical advice, examination, diagnosis or treatment.



*Oh, to holiday in Britain,
Visit Devon and take your rest;
No fairer place to spend your days,
Than in the warmth of England's
south-west.*

EDITORIAL

~ from Jean Aplin (our secretary for 44 years) reflects on some memories



The EDKPA was started on 7th February 1970. I didn't become involved at the outset, but in 1972 I became the EDKPA's treasurer, as I used to work in the accounts department of an insurance company. Then in 1977 I became the EDKPA's secretary and have been ever since.

By then the Association were raising funds by making bags, slippers, mats, etc. from offcuts of shirt material which a patient from North Devon supplied (he worked in a shirt factory). We held an annual fête in the grounds of Whipton Hospital, which brought many patients together and many friendships were made. Members of the staff also joined in. We always seemed to be lucky with the weather and it was only after the move to the RD&E from Whipton that we ceased to hold them.

For several years I was on the committee of the National Kidney Federation, which involved travelling to London by train four times a year. A shortage of suitable people to become Chairman meant that I became a joint Chairman. Unfortunately, my husband died in 1994 halfway through our term of office (3 years), but with the help of the staff in the office and a certain amount of common sense, I felt able to carry on. I remained with the NKF for many more years.

You may ask why have I continued as secretary. I enjoy the job ~ it gives me satisfaction when I am able to help patients. I also think that my experience of dialysis for so long (my husband was 22 years on dialysis and three years with a transplant) helps me to understand and is also my way of saying thank you for the wonderful treatment and care that we received from the unit.

As secretary of the KPA you may ask how I can help you? Well, sometimes it is just for a chat, holiday insurance, benefits, transport costs, complaints, or pointing you in the right direction ~ the list is endless. So do feel free to get in touch if you feel I could be of help to you. I am here on the end of the telephone 01884 254260, or you can email me at jeanaplin@live.co.uk.

I hope to continue for a few more years as secretary as it gives me a purpose in life.

Young Adult Service



Did you realise we had a US Firefighter amongst us?

Nor did I!

As you probably know, we have a new Young Adult Transitional Nurse, Eve Clairevue.

I asked her (very nicely!), if she could take some time from her busy day to let us know how she got here.

Where are you from?

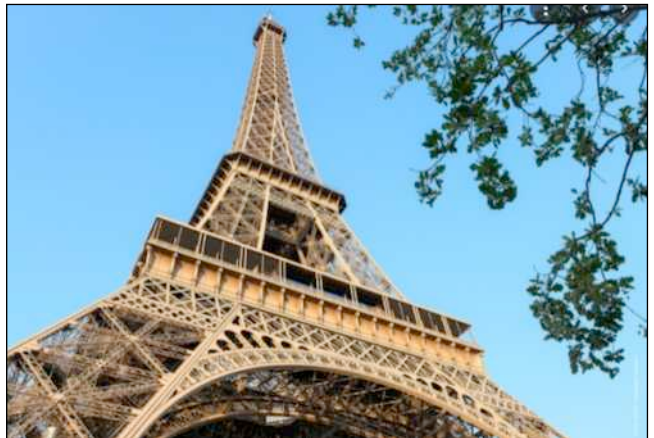
Originally from Oxford, UK

How did you get here?

My initial nursing experience was working in a surgical specialty, rotating between theatres, wards and outpatients. I progressed to a management role but was lucky to be able to continue hands-on clinical duties.

I left the NHS for a period of time, doing clinical consultancy and change management, in a commercial environment, educating and advising on a number of subjects. I was also lucky to be involved on an international project, networking and refining project management skills. Luckily for me I learnt a lot of additional skills at a time when this was not readily available within the NHS setting.

I worked as a school nurse in France, specifically providing nursing care and counselling services to the 12- to 24-year-old age group, educating and supporting on key adolescent and young adult issues, such as gaming and drug addiction, contraception, eating





disorders and welfare issues, and setting up nurse led services for these, utilising art therapy as a valuable adjunct to my clinical duties.

I worked as a firefighter/EMT in the States, which taught me many things, but dealing with stressful situations and refining my approach to

managing multidisciplinary situations and learning new skills were the most prominent ones.

Whilst in the States I also worked coaching individuals, helping them achieve their well-being and professional goals and it enabled me to draw on all of the experience I had gained thus far, and helped the individuals become empowered to achieve their goals. It's hard enough for most people to lead an optimal life, but for anyone with additional requirements, it can be daunting, especially when we are younger.

What do you love about the job?

I am passionate about empowering individuals, about understanding where they have weak points (or where they need support) and working with them to transform them into strengths. I have a special affinity with younger adults and children, most of my roles up to this point have always had either an element of that or have exclusively comprised of working with those age groups. I love the role because it perfectly marries my natural attributes with the type of support and interactions required by our young adult renal patients.

What you are hoping to bring to the job?

A fresh approach to how we interact and learn from and support our young adults.

Anything else?

I think, personally, that we often see youngsters isolating themselves behind screens and feeling left out. Covid has not improved the ability or opportunities to interact, but I do feel that sharing experiences and working together raises the understanding of the community, and the well-being of the individual. I find we often think it has to be the experts, that share their information but if we reflect on how much we have

all learnt and how we adapted with our current condition(s) we realise there is a wealth of personal experience (that we have) that we can share. After all...often it's finding someone with whom we can click with, that helps us make sense of things, not necessarily the most qualified individual. What works for each of us is as varied as we are as individuals, but clearly there are some commonalities. Feeling supported and understood is one of the core values of being that we all benefit from, irrespective of our challenges.

Any challenges? The biggest challenge is having a dynamic and responsive patient service with one day a week. It's a fabulous opportunity, but so much more is needed. There really is a need for more counselling and support, especially for the more vulnerable individuals. I am very, very glad that I was selected and am happy to see how we can achieve change in a positive sense.

EDITOR'S FOOTNOTE: Eve is doing a sponsored Skydive for the RD&E Charity on Saturday 16th October. She says: *"Anyone who knows me knows that I like to keep my feet firmly on the ground and I'm a no-nonsense soul ~ but nothing ventured, nothing gained, right? So in order to change things up, I am going to be doing something I have never done, to achieve some results for a very worthwhile cause."*



If you would like to sponsor her, please follow this link:
<https://rdecharity.enthuse.com/pf/eve-clairevue-skysthelimit-jumpingwithjoy>





Exeter & District KIDNEY PATIENTS' ASSOCIATION

ADVICE AND INFORMATION

Citizens Advice Exeter can provide expert financial advice on all aspects of claiming state benefits that you may be entitled to through an advisor specialising in the sort of issues specific to people suffering from kidney diseases. This is a service available only through EDKPA.

But you do need to book first which you can do by contacting our secretary Jean Aplin by email on jeanaplin@live.co.uk or telephone **01884 254260** or **07936 069988** (mobile).

If appropriate Jean will be able to book you an appointment, either in person at the CAE's offices in Exeter, or over the telephone, or suggest other organisations for you to contact. This is a free service provided by us to our members.

The National Kidney Federation has a free telephone helpline on **0800 169 09 36** where you can speak to an advisor on all aspects of life as a kidney patient from medical to social issues. They have an extensive range of over 100 information leaflets which they can send to you and which are available to download on www.kidney.org.uk.



Kidney Care UK has a website www.kidneycareuk.org with lots of help and advice as well as up to date information, recipes etc. They can provide the services of a South West based advocacy officer who can support and help with applications for grants etc. They can be contacted on **01420 541424**.



Exeter & District Kidney Patients' Association
Registered Charity No 276981



HELP to STAY SAFE with the NKF

AS MORE **CORONAVIRUS** MEASURES
TAKE EFFECT IN THE UK, WE HAVE **SOCIAL
DISTANCING LANYARDS** AND **FACE MASKS**
TO **HELP YOU FEEL SAFER** WHEN OUTSIDE.

This section features a large, detailed illustration of a coronavirus particle on the left. To its right are two circular callouts. The first is a blue circle containing a yellow lanyard and the text 'SOCIAL DISTANCING LANYARDS' and '£1'. The second is an orange circle containing a black face mask with the NKF logo and the text 'FACE MASKS' and '£1.50'. The background is a warm, orange-to-red gradient with several small, stylized virus icons scattered throughout.

AVAILABLE TO BUY ONLINE NOW

www.kidney.org.uk/shop or call 01909 544999

Registered Charity Nos. 1106735 SC049431

Company No. 5272349 Registered in England & Wales

My Care ~ You care



Quite a few of you got back to us about the new RD&E My Care system. Some positive, others negative. It looks like ~ whatever we think ~ we have to live with it (but that does not stop us asking for improvements).

Here are some comments:

☞ *Initially I found it very tiresome and trying. After using patient view for a long time, which I felt would be irreplaceable, the initial teething problems I experienced were pretty brutal and I was just about to call it quits and unsubscribe when I contacted the help line, who I must say lived up to their job description after around some 45 minutes with a very patient lady. Eureka! I had it tamed, all the initial problems were lack of guidance and maybe confidence.*

I now feel it is of enormous help and once I had mastered the navigation issues and familiarised myself with all aspects, it's been great. I am only a novice when it comes to computers and IT, but with the My Care help team I am fairly proficient.

I recommend perseverance and consult the team.

Another user said:

☞ *I find it very useful, especially for appointments and test results (they do put what is a 'normal' range for test results so you can check yourself).*

It doesn't seem to have any history, which is very frustrating, but it's useful for anything which happened from Spring 2021.

And another:

👤 On the positive side, reminding people of their appointments is a good thing.

As a renal patient I was previously on patient view.

The two main problems with My Care are waiting one to two weeks for results when previously you received them in 24 to 48 hours.

I don't call that progress! If anything as a kidney patient of a few years, it can make you anxious.

... it was a shame the Patient View records had to be wiped ~ you could compare previous results, some going back a few years. With My Care you have to start again.

And another:

👤 I've recently been diagnosed with AKI and am now on my fourth week of dialysis. I also suffer from Type 1 Diabetes....

The lack of the blood test results the day after they have been taken is extremely frustrating as one does not know how to refine one's diet or if you are taking enough phosphate binders. Having to wait two weeks is just too long. Knowing what the blood test from Monday's dialysis are on the Tuesday tells you immediately how well (or badly) you did last week. Only being able to find out information that is a fortnight old prolongs the process and might well slow down recovery.

I appreciate that the hospital might have a problem with some patients panicking when they see test results and that for those people the information might need to be filtered to stop spurious anxieties adding to the load of the clinicians, but surely consultants are good judges of a patient's mental abilities/state and should be allowed to flag a patient as able to recover his results from My Care as soon as they are available.

And another:

👤 ... Is it me or ~ when I have a notification I have a new message. I cannot find it?(!!)

We'll pass these comments onto the My Care team ~ keep them coming in. It's not easy to implement a huge system, but it's helpful to make them aware of our frustrations.

Kidney Kitchen

Pork medallions with apples and mustard

serves 4



This is a delicious and hearty high protein dish, low in salt, potassium and phosphate, which makes it perfect as a post dialysis meal.

INGREDIENTS

- 4 pork medallions approx. 140g each
- 1 tablespoon olive oil
- 1 eating apple
- 50g unsalted butter
- 1 onion, halved and sliced
- 100ml low salt chicken stock
- 2 teaspoons Dijon or wholegrain mustard
- Black pepper
- 2 teaspoons dried sage
- 300g savoy cabbage, finely sliced
- 1 swede (approx. 600g)

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 1–2 minutes. Serve the pork with the mashed swede, boiled savoy cabbage and the mustard and apple mixture.

*Other friendly recipes may be found in the
Kidney Care UK Kidney Kitchen at www.kidneykitchen.org*

So who are our Dieticians?



We wanted to know who the renal dieticians were who advise us on how to keep as well as possible through what we eat.

Sharon Huish was kind enough in her busy day to send the biographies below and a list of Mythbusters.

You can contact them on 01392 402524
or email: rde-tr.renaldiicians@nhs.net



Hello, I'm **Angeline**, Renal Dietician.

I've been working at the RD&E as a renal dietician for the last 10 years.

I absolutely love my job and all the challenges it can bring. I'm lucky to work with so many professional people and wonderful patients.

I am particularly interested in transplantation, plant-based nutrition in kidney disease and weight management.

I have been fortunate enough to be part of the Kidney Kitchen team (part of Kidney Care UK) formed in 2018 and love creating exciting and interesting recipes that can inspire people to enjoy food on a renal diet.



Hi, I'm **Ruth**, Renal Dietician.

I worked in the RD&E renal dietetic team for many years; last year stepping down into a more part-time role.

I really enjoy working closely with our patients and still get a buzz from the challenges of working in a busy area. I feel so lucky to be part of a great dietetic team and wider renal multidisciplinary team.



Hello, I'm **Sharon**.

I started working as a renal dietician in Birmingham in 2010 and quickly developed a passion for the job.

I always had the goal of moving home to Taunton and working at RD&E one day; this became a reality in 2019.

I love working as part of the renal family at RD&E, it's a fantastic and supportive department and I feel so grateful to be doing a job

I love. I am particularly interested in vitamin D and bone health, as well as research; but the most satisfying part of my job is working closely with and helping people.



Hello, I'm **Sarah**, the Renal Diet and Exercise Assistant Practitioner working in the renal dietician's team at the RD&E.

I joined the Trust nearly two years ago into this newly created role. I'm passionate about improving the well-being of renal patients (and staff if they're interested!) through diet and physical activity.

I act as a resource of support to the renal dieticians and the wider renal unit.

I feel extremely lucky to work with such great colleagues and patients in a job I love.

... and here are their Mythbusters ...



Diet Mythbuster: Rock salt is better for kidney patients

All types of salt including Rock, Table, Garlic and Sea can contribute to increasing your blood pressure, formation of kidney stones and making you thirsty if you are on a fluid restriction. Your taste buds will adjust quickly to reducing your salt intake and flavour can be achieved through using pepper, herbs, spices and lemon juice instead of salt. It's also worth mentioning that kidney patients should avoid low salt alternatives because they contain potassium.

Diet Mythbuster: Decaffeinated coffee is okay on a renal diet

Unfortunately if you need to watch the potassium content of your diet then there is no difference between the potassium content of caffeinated and decaffeinated coffee. On a low potassium diet you can enjoy one cup of coffee daily.

Diet Mythbuster: Skimmed milk is better for kidney patients

Cow's milk is a good source of both potassium and phosphate. Semi-skimmed and skimmed milk contain the same amount of potassium and phosphate as whole milk (the only difference is the fat content). Lower potassium and phosphate options include rice, oat and some soya milks. Often people with kidney problems need plenty of calories to meet their nutritional requirements, so you may be advised to use full fat milk rather than skimmed versions; the advice varies between individuals according to needs.

Diet Mythbuster: Ice cubes are a good way of quenching thirst

They can be, as they are low volume compared to a larger drink, but remember they are fluid and should be counted in your allowance usually as 30 or 40mls, depending on the size of your ice cube tray. Other foods to remember to count as fluid includes sauces, gravies, ice cream, yoghurts and jelly.

Diet Mythbuster: Diet can't help to protect kidneys

In the earlier stages of Chronic Kidney Disease (CKD) you may be able to slow the disease progression (slow the decline in your kidney function) by having a healthy diet which is lower in salt and protein. If you are overweight achieving a healthy weight and if you have diabetes keeping your blood sugar levels well controlled will also be helpful. Throughout the various stages of CKD, diet and nutrition are an important part of your treatment. Optimising nutrition can help prevent nutrition related complications and also give you a better quality of life.

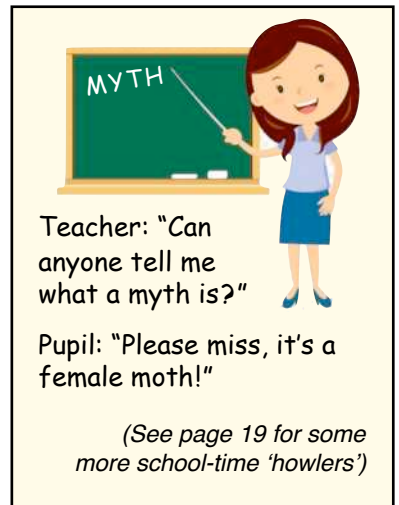
Diet Mythbuster: Eating a low potassium diet will improve my kidney function

Sadly eating a low potassium diet will not improve your kidney function; it can, however, help to lower the potassium level in your blood, which is still an important part of staying safe and well. When your kidney function starts to decline, you are less able to remove waste from the blood and this waste can start to build-up in the blood. Potassium is part of this waste. Although potassium is an important mineral that is needed by the body, when levels get too high it can cause problems with your heart, hence the need for a low potassium diet.

So, in summary, there is no benefit to your kidney function and you should only follow a low potassium diet if you have been advised to do so.

Diet Mythbuster: Switching to a white bread from wholemeal will be better for my potassium and phosphate levels

We see so many people that have changed from wholemeal bread to white bread based on this old and out-dated advice. On paper, white bread is lower in potassium and phosphate, when compared to wholemeal bread. However, the way these breads behave in the body is what really matters. I will attempt to explain...



Potassium: White bread is much lower in fibre than wholemeal bread; fibre helps to keep our bowels moving. Keeping our bowels moving is an important part of lowering potassium as we are able to lose potassium via the bowel. In addition to this, for those with diabetes, fibre can help to stabilise blood sugars. When blood sugars are high this can also cause high potassium! So, please enjoy your wholemeal bread while eating a low potassium diet.

Phosphate: With regards to phosphate and wholemeal bread (wholemeal anything...pasta, rice, crackers etc), the easy explanation is that not all phosphates are created equally! For example, there are forms of phosphate that are added to processed foods or cola style drinks: this type of phosphate is very easy for your body to absorb, up to 100%. Meanwhile, up to 80% of the phosphate you find in meat, fish, eggs and dairy is absorbed by the body. However, only 10–30% of the phosphate found in wholemeal breads (or other wholemeal foods) is absorbed by the body. So, please enjoy wholemeal bread and foods as part of your diet.

Exercise Mythbuster: I'm already tired, exercise will only make me more tired

Many people with renal failure say they are too tired to exercise. They think if they exercise it will make them more tired. The fact is, even a little bit of exercise, 15–20 minutes a day, will actually help you feel LESS tired. Start slowly and do what you can ~ you aren't aiming to become a marathon runner! As long as you keep doing it regularly (at least 3–4 times a week), you will gradually get stronger and able to do more and more.

Exercise Mythbuster: I need expensive equipment to exercise at home

Everyday items around the house can be used, for example: food tins as weights and milk bottles filled up with water. Even a chair can be used to do chair squats or seated exercises, or a stair step to do step ups. Also, remember that housework and gardening are also forms of exercise. Maintaining proper technique is important doing resistance exercises.

There are many free resources online to help you with this and other forms of physical activity, including those on the following websites NHS live well, Kidney Care UK and the National Kidney Federation.

National News



A date for your diary ~ NKF Virtual Patients' Event, Saturday 9th October, 10 a.m. to 2 p.m.

The National Kidney Federation are having an annual get-together for all patients . . . but virtually in this new world.

Everyone is invited and you're encouraged to go. There will be a number of informative patient and professional speakers lined up.

10.00 – 10.10	Welcome
10.10 – 10.25	NKF Update
10.25 – 10.50	Kidney sharing scheme ~ NHS Blood and Transplant
10.50 – 11.15	Rally together to make change
11.15 – 11.30	Comfort Break
11.30 – 11.55	What does my kidney pharmacist do?
11.55 – 12.20	Endovascular fistula for haemodialysis
12.20 – 12.45	<p>My Kidney Journey</p> <p>Stephen Higgins was diagnosed with Stage 4 kidney failure in 2016 and is currently on the transplant waiting list. Having grown up in South London, raised by a mother who was a shop steward at Ford. Stephen Higgins is a lifelong activist. Cutting his teeth with various Trade Unions over the years. He has found himself advocating for those without a voice. More recently, Stephen has rediscovered his love of film making and intends to use that as a way of raising awareness around issues close to his heart.</p>
12.45 – 13.10	Lunch Break / Networking
13.10 – 13.30	<p>My Life: football and kidney disease</p> <p>Nina Nannar, Arts Editor at ITV News, will be talking to former professional footballer Andrew Cole. Their conversation will focus on his experience of kidney disease, from diagnosis to transplant and the importance of mental health and wellbeing for kidney patients. He will talk about his life prior to kidney disease, his life following and the importance of research and awareness.</p>
13.30 – 13.55	Covid-19 and its impact on dialysis
13.55 – 14.00	Close of Conference

More information on their [web page](#).

As ever, if you would like web pages printed and sent to you, please contact our secretary, Jean Aplin (see Contacts page).

Patient Transport ~ Good News!



From the [NHS UK website](https://www.nhs.uk) ...



Every patient who needs kidney dialysis will benefit from free transport to and from vital hospital appointments, the NHS in England announced today (2nd August 2021).

New rules will also come into place to make it simpler for other patients to get free transport, including those with long term conditions and mobility problems.

After a full public consultation period, the updated criteria would mean all 21,000 kidney dialysis patients will be eligible for free transport to hospital appointments.

... For non-emergency patient transport services, which help people who need regular hospital care but who can't travel by themselves, to attend important hospital appointments. It includes those who have:

- a medical need for transport, for example because they require oxygen while travelling which needs specialised equipment or support;
- a cognitive or sensory impairment that requires the support of patient transport staff or a trained driver;
- no other suitable transport option given their wider mobility or medical needs, and treatment or discharge would be missed or severely delayed.



Thanks to [Kidney Care UK](https://www.kidney-care.org.uk) who were instrumental in lobbying for this change.

Britain in the 1950s: what was it really like?

It's only around 65 years since . . .

- ▶ Pasta, curry and yoghurt hadn't been heard of.
- ▶ Turkeys were definitely only seasonal.
- ▶ A takeaway was a mathematical problem.
- ▶ A pizza was something to do with a leaning tower.
- ▶ Coconuts were generally only seen at fairgrounds.
- ▶ Oranges and dates only appeared at Christmas time.
- ▶ Olive oil was kept in the medicine cabinet, not in the kitchen larder.
- ▶ All crisps were plain and they came with a little blue bag of salt.
- ▶ Coke was something you mixed with coal to make it last longer.
- ▶ Rice was a milk pudding and never, ever part of dinner.
- ▶ A Big Mac was what you wore when it was raining.
- ▶ A microwave was something out of a science fiction film.
- ▶ Oil was for lubricating your bike, not for cooking ~ lard was for cooking.
- ▶ Tea was made in a teapot using loose tea leaves, not perforated bags.
- ▶ Coffee was only drunk when you had no tea and it was called Camp and came in a square-shaped tall thin bottle (and it's still available!).
- ▶ Salad cream was a dressing for salads; mayonnaise did not exist.
- ▶ Fish was only eaten on Fridays and frozen fish fingers were unheard of.
- ▶ For the best taste, fish and chips bought from a fish and chip shop had to be wrapped in and eaten out of old newspapers.
- ▶ People who didn't peel potatoes were regarded as lazy so and so's.
- ▶ Eating outside was called a picnic, not a barbecue.
- ▶ Cooking out of doors was called camping.
- ▶ Hot Cross Buns were only eaten at Easter time.
- ▶ Pancakes were only eaten on Shrove Tuesday (and almost compulsory!).
- ▶ Surprisingly muesli was readily available in those days ~ but then we called it cattle feed.
- ▶ Water came out of the tap: if someone had suggested bottling it and charging more than the cost of milk for it, they would have become a laughing stock.
- ▶ Food hygiene was all about washing your hands before meals.



However, there was one thing that they never, ever allowed on their tables in the 1950s . . . elbows!

Must try harder! 😊

A selection of ‘howlers’ from school essays and exam papers

Joan of Arc was Noah’s wife. She was eventually burnt to a steak.
The inhabitants of Egypt were called mummies. They lived in the Sarah Dessert and travelled by Camelot.

The Greeks invented three kinds of columns ~ Corinthian, Doric and Ironic.

The Greeks also had myths. A myth is a female moth.

Another Greek myth was Jason And The Golden Fleas.

Sir Francis Drake circumcised the world with a 100 foot clipper.

All modern cars now have Catholic converters.

Milton wrote Paradise Lost. Then his wife died and he wrote Paradise Regained.

David was a Hebrew king skilled at playing the liar. He fought with the Philatelists, a race of people who lived in Biblical times.

Solomon had three hundred wives and seven hundred porcupines.

Christians have only one spouse. This is called monotony.

Moses went up on Mount Cyanide to get the Ten Commandments.

The seventh commandment is “Thou shall not admit adultery”.

The Philistines are islands in the Pacific.

Beethoven wrote very loud music because he was deaf.

A primate is a Prime Minister’s wife.

Shakespeare married Anne Hathaway, but he mostly lived at Windsor with his merry wives.

Charles Darwin was a naturalist who wrote the Organ of the Species.

Queen Victoria sat on a thorn for 63 years.

Louis Pasteur discovered a cure for rabbis.

Madman Curie discovered radium.

Karl Marx became one of the Marx brothers.



EDKPA Supports Kidney Research on Covid

The EDKPA and other KPAs helped to fund some research work on Covid for kidney patients. The conclusion was that kidney dialysis patients could benefit from third doses of mRNA Covid-19 vaccines.



... “The research by London’s Francis Crick Institute found that in patients who had not been previously infected with the Covid-19 virus (Coronavirus) those who had received the ‘Pfizer-BioNTech’ mRNA vaccine had six-times higher levels of neutralising antibodies (proteins that defend a human cell from infectious particles such as viruses by neutralising any effect they have biologically) against the more contagious Covid-19 ‘Delta’ variant, compared to people vaccinated with the ‘Oxford-AstraZeneca’ vaccine.

The levels induced by the mRNA vaccine were comparable to those seen in healthy controls after both vaccine doses. In patients who had already had Covid-19 prior to vaccination, both vaccines induced detectable levels of neutralising antibodies.”

[You can read more in the Lancet here.](#)

(Please contact us if you would like a paper copy)



Have a go at this Cryptic Food and Drink



1	Batchelors, Campbells and Heinz all make this	
2	Pastry covered dish eaten by Ms Fitzgerald?	
3	Cow meat in this fast food king joint?	
4	You kill a vampire with this, a renal filled pastry dish?	
5	Twirl or circle when you want to scratch?	
6	This will keep vampires away, a bakers best seller?	
7	An automobile and Jovi saying part goodbye in Chinese?	
8	Northern Dales and desserts	
9	Mother could?	
10	Yellowbellied Ukraine capital?	
11	Type of stew from North West England?	
12	Bringing about a lawsuit on her?	
13	Telling cockney lies?	
14	Mice love this: marble, chocolate or Madeira?	
15	A noisy wrecked car crushed	
16	A small bird goes to the toilet?	
17	Mary had a little one in Shaw Redemption film?	
18	A condiment that sounds like a pony?	
19	This border herding dog likes to bloom?	
20	Small green vegetable able to know 3.14159?	
21	Granny Smith is fragmenting?	
22	Used to blow up tyres with a relative?	
23	A cow wearing wet weather boots?	
24	Scoring system in golf getting a clip?	
25	Mother's pub	

Answers on page 26

New Parking System at the RD&E



CASHLESS PARKING PAY WHEN YOU EXIT

When you have downloaded the app:

1. Enter your registration number (e.g., 2380)
2. Select your vehicle type
3. Select your payment method

APCGA APPROVED

Patient & Visitor Car Park
Pay on exit (or pre-arrange payment with a receptionist at the hospital)

Parking tariff

Pay by	Pay by
APCGA	APCGA
Up to 1 Hour	£ 1.50
Up to 2 Hours	£ 2.50
Up to 3 Hours	£ 3.50
Up to 4 Hours	£ 4.50
Up to 5 Hours	£ 5.50
Up to 6 Hours	£ 6.50
Up to 7 Hours	£ 7.50
Up to 8 Hours	£ 8.50

The new parking system at the RD&E will ask you to pay on your exit. This could be more useful as you don't always know how long you will be. You will be asked to put in your registration when you leave and pay the fees for the time used.

The following is from the [Devon Live](#) site:

New ANPR cameras are to be introduced at the Royal Devon and Exeter Hospital, which means patients and visitors will have to pay on exit. Car park users will be required to enter their registration at the car park terminal when they return to their cars at the end of their hospital visit, and pay for the time used. Payment can be made with cash, card or contactless, or via mobile phone app.

Blue Badge Holders ~ simply take your Blue Badge to a reception desk on entering the hospital and your vehicle registration will be registered for free parking. You will not need to do anything further on leaving the car park.

Volunteer drivers ~ will be able to register for a 12 month permit via the staff Parking Portal, but in the meantime you can just check your vehicle registration number in at a reception desk.

Carers and parents with children in hospital overnight ~ register your vehicle at reception or at Bramble Ward.

Remember, if you are a kidney patient, you are entitled to free parking ~ check with the Ward, or phone our secretary (Jean Aplin, see contact page) for more details.



If you want to appeal a parking ticket, read [the guide from Moneysaving Expert here](#). (if you do not have an internet connection, phone Jean (our secretary ~ see 'Contacts' and we will send you one).

What does the EDKPA do for you?

Here are some examples:

- ◆ We pay for Information and Advice Service with Exeter CAB. We do this as we have no social worker and patients can get the best advice on benefits etc. Jean Aplin (our secretary) can book you into the next available appointment with our benefits advisor at Citizens Advice.
- ◆ Eve Clairevue (CKD Clinical Nurse Specialist and Renal Young Adult/Transition Nurse) ~ we pay part of her salary.
- ◆ For a 12-month period we are paying and supplying snacks for patients on Sid Ward to have with their morning cuppa.
- ◆ We provide 111 television sets (Sid Ward 17, Heavitree 24, Day Care 9, Creedy 29, Honiton 8, Torquay 24) and remote controls. There is an annual cost which includes a rolling schedule of replacements (the NHS do not pay for televisions).
- ◆ The Newsletter ~ this is our main means of communicating with our members. Whilst we have cut costs as far as possible by sending this out by email, some members still prefer to have printed copies with the additional cost that this involves.
- ◆ Website and associated internet charges.
- ◆ Social functions, e.g. the Summer Party and the PD Patients' Party at Copplestone.bkpa
- ◆ One-off purchases and grants, e.g. the purchase of a dialysis machine (whether this is for inside the hospital or for individual kidney patients in their homes) and other essential hospital equipment.
- ◆ Secretary ~ providing an invaluable service to our members both in organisational terms and often being the first point of contact for anyone wanting to be in touch.
- ◆ Subsidised trips, e.g. weekend/day trips and trips to the pantomime.
- ◆ We provide financial support to members taking part in the Transplant Games.
- ◆ We pay for an interpreter for a young deaf boy to take part in the annual activities weekend (that is half the cost, Kidney Care pay the rest).
- ◆ We have a small Welfare Fund which can be used to help patients quickly, e.g. helping a patient with transport costs where they may be unable to meet this cost from their own resources.

The above are just a few of the things we help fund. If you feel like joining us, contact George Palmer, our Chairman, george@edkpa.org.uk

Need Support?

EDKPA Information and Advice Service



EDKPA offers advice and assistance on financial problems and claiming benefits, through the help of Citizens Advice Exeter. If your treatment is supervised by the Renal Department at the RD&E you can telephone **01884 254260** or send an email to jeanaplin@live.co.uk and Jean will ring you back to either book an appointment or provide any other information and advice by telephone.

Kidney Care UK and the NKF



In addition you can contact Kate Cresswell, Kidney Care's South West Advocacy Officer on **01420 541424** if you need advice and support or to apply for a patient's grant. Kate can also provide counselling services and advice on holiday grants etc.

The National Kidney Federation has a free helpline on **0800 169 09 36** where they can give advice on all aspects of life as a kidney patient from medical issues to holiday insurance.

They can also provide to you, on request, a large variety of informative leaflets.

Transplant Support Network



The Transplant Support Network (TSN) is the only nationwide network that provides support ~ usually over the telephone ~ to patients, family and carers of all solid organ transplants and mechanical implants.

As well as giving patients access to someone who has undergone the same transplantation process as them, it provides the same unique opportunity for family and carers, who live through the many ups and downs before, during and after a transplant.

TSN has trained a number of volunteers from around the country. They offer an ear to listen to your individual situation and to give reassurance, understanding and non-medical advice and information.

Telephone **0800 027 4490** or **0800 027 4491** for free advice (calls are free from a landline).

More details at <http://www.transplant.supportnetwork.org.uk/>

Support EDKPA by Regular Giving

You can help the EDKPA by a regular giving donation. If you are a tax-payer, the EDKPA will receive your donation plus the tax amount on top.

Please download a form at:

<https://www.edkpa.org.uk/fundraise-donate/>

Thank you.

Support EDKPA by Gift Aid



Using Gift Aid means that for every pound that you as a taxpayer give, we get an extra 25p from the Inland Revenue.

This means that £10 can be turned into £12.50, as long as donations are made through Gift Aid and you are a taxpayer. Just imagine what a difference that could make and it does not cost you a thing.

You can download a form here:

<http://www.edkpa.org/donate/>

or a form is available from our Secretary Jean Aplin, 13 Crowden Crescent, Tiverton EX16 4ET.
Tel: 01884 254260.

The form can be used with a donation to enable EDKPA to claim the extra tax automatically.

Need Covid Advice?



The best place to start is your hospital ~ they have all the most recent, up-to-date information.

Try the NKF website “[Covid 19 Latest Information](#)” too ~ it has the most up-to-date advice for pre-dialysis, dialysis patients and transplant patients. It covers a huge range of topics:

- *Shielding advice*
- *Vaccination information*
- *Latest information for patients*
- *National restrictions*
- *Travel*
- *Research*
- *Diet*
- *Stress and anxiety*
- *Exercise for shielding patients*
- *Research from NHS Blood and Transplant*
- *Latest NHS information and advice*
- *Support for the extremely vulnerable*
- *Further general advice*

Please call our freephone helpline if you would like to chat to one of our advisers about your concerns ~ telephone 0800 169 09 36.

Subscription details

Whether you receive this Newsletter by post or by email, do we have your correct postal or email address? If you have changed your address recently, please send your updated address details to info@edkpa.org.uk. Also a contact telephone number would be appreciated.

The cost of sending out a paper Newsletter is significant to the Association. Whilst we realise this is essential for many people, if you have an email address and would like to receive the Newsletter by email, please let me know ~ send an email to info@edkpa.org.uk.

If you do not wish to receive this Newsletter any more, please email info@edkpa.org or contact Jean Aplin (see Contact section).

Whilst we do our best to avoid sending the Newsletter to members who have passed away, due to the Data Protection Act we have to rely on information from members.

Thanks to all the people who help compile this Newsletter and help to get it out to you.

Keith Forbes for sending out the Newsletters . . . and finally YOU ~ many people send in an article and we are very grateful.

Nick Wood
Newsletter editor

Solution to the Trivia Quiz on page 21

1. Soup
2. Paella
3. Beef burger
4. Steak & kidney pie
5. Spinach
6. Garlic bread
7. Carbonara
8. Yorkshire pudding
9. Marmite
10. Chicken Kiev
11. Lancashire hotpot
12. Sushi
13. Pork pies
14. Cheesecake
15. Bangers & mash
16. Chickpeas
17. Lamb shank
18. Pepperni
19. Cauliflower
20. Pecan pie
21. Apple crumble
22. Pumpkin
23. Beef Wellington
24. Parsnip
25. Mars bar

GENUINE CALL CENTRE CONVERSATIONS

TRAVEL AGENCY

Customer: "I've been ringing 0800-1800 for two days and can't get through to enquiries, can you help?"

Operator: "Where did you get that number from, sir?"

Customer: "It was on the door to the Travel Centre."

Operator: "Sir, they are our opening hours."

RAC MOTORING SERVICES

Caller: "Does your European Breakdown Policy cover me when I'm travelling in Australia?"

Operator: "Doesn't the title of the policy give you a clue?"

Join us!

If you are a pre-dialysis, dialysis, transplant patient or friend/carer, come and join us!

Benefits include organised holidays and trips, supply of televisions for the dialysis unit, social events and automatic membership of the National Kidney Federation.

You will also receive this newsletter letting you know what is going on ~ plus, it's free to sign up!

If possible, please let us have your email address to save on printing/postage



I would like to become a member of the Exeter and District Kidney Patients' Association and receive a copy of the Newsletter and be eligible for support.

I would also like to become a member of the National Kidney Federation and receive their magazine *Kidney Life*.

(Please let us know if you do not wish to become a member of the NKF when joining.)

NAME _____

ADDRESS _____

POSTCODE _____ TEL. _____

EMAIL _____

Please try and include an email address ~ it saves postage for the Newsletter. We never use your email address for anything except EDKPA communications.

DATE OF BIRTH _____

Please send to:

Jean Aplin, 13 Crowden Crescent, Tiverton, Devon. EX16 4ET

or send an email with the above details to jeanaplin@live.co.uk

Membership of the EDKPA is free!

Your EDKPA – who are we?

PRESIDENT	DR LUCY SMYTH	
VICE-PRESIDENT	DR CORALIE BINGHAM	
SECRETARY	Mrs Jean Aplin	13 Crowden Crescent, Tiverton, Devon EX16 4ET Tel: 01884 254260 Jeanaplin@live.co.uk
CHAIRMAN	George Palmer	george@edkpa.org.uk
TREASURER	Chris Rolfe	cdrolfe@aol.com
COMMITTEE MEMBERS	Kate Cresswell (Kidney Care UK), Keith Forbes, Jackie Garry, Sandie Hampshire, Jake Johns, Danny O'Sullivan, Chris Rolfe, Wendy Sincock, Nick Wood	
Co-opted	Ria Taylor (Renal young adult/transition worker)	
Other contacts	Website/Newsletter	Nick Wood info@edkpa.org.uk
	Taunton Group	Danny O'Sullivan danny.wellerswick@btinternet.com
	Transplant Games	Wendy Sincock Tel: 01647 231597 scissorhandssincock@yahoo.com

North Devon Kidney Support Group

Chairman	Donald Lynch Tel: 01271 812300	lynchydon@gmail.com
Secretary	Roy Sibley	roysibley@dsl.pipex.com
Social Secretary	Cherie Merryfield Tel: 01271 343887	fj.merryfield@btinternet.com

Visit our website at <http://www.edkpa.org.uk>



*This newsletter is printed by Garfield Barnett.
If you have any queries about printing the newsletter,
or general PC problems of your own, I'd recommend giving him a ring:
Garfield Barnett, Cotswold Computing, 49, Park Hill, Tiverton, EX16 6RW
Home: 01884 253148 Mobile 07964 303368
Email: CotswoldComputing@live.co.uk*