

# EDKPA Newsletter

Summer 2022 edition

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



*Blackpool Sands beach, South Devon*

*I think I'll sit for a while,  
Here by this aqua blue sea.  
Hang up my chores and 'to do' list,  
Lease my mind to the breeze...*

### Grants, Support Groups, an Orchestral Treat and more . . .

As time changes and things become more difficult for us all on a day-to-day basis, we have teamed up with Kidney Care UK to provide welfare grants for local patients on low incomes who are struggling to make ends meet. We partly fund these grants in conjunction with Kidney Care and is another strand to the support we can provide as an Association. You'll find more details about how to apply for funding further on in the Newsletter.

If you are on home dialysis, you might be interested in Chris Rolfe's peer support group for home dialysis patients ~ a great initiative and one well worth joining in with if you are dialysing at home, especially as it's possible to become even more isolated when dialysing at home. I know it was very different for me when I was so used to going into the unit three times a week and then started at home. Chris (who is also our treasurer) will email details of the next one, due in early July, if you contact him.

On a lighter note, we were treated to a terrific evening with Devon Philharmonic Orchestra who played in the Cathedral in late April. The Devon Philharmonic played to support the EDKPA in a wide-ranging concert from 19th-century romantic music to 1920's jazz. Sally Hulin (a member and trustee of the orchestra) is the wife of a patient due to start dialysis and we appreciate her and the orchestra's support for the EDKPA.

Finally, I hope we'll all be out this Summer at outdoor events and hope (if you got there) you had a good time at Glastonbury. If you need a break and are having difficulty, please contact our secretary (see contacts page). We all need a break, let's hope for more sun!

### DISCLAIMER

*The EDKPA Newsletter is provided by Exeter and District Kidney Patients and its members. It is for information purposes only. You should not rely on the information in the Newsletter as an alternative to medical advice from an appropriately qualified professional. If you have any specific questions about any such matter you should consult an appropriately qualified professional.*

*You should never delay seeking legal advice, disregard legal advice, or commence or discontinue any legal action because of information in the Newsletter.*



# If you need financial support, we're here for you

**Kidney Care UK and Exeter & District KPA are working together to support Exeter kidney patients at this challenging time.**

We may be able to help towards:



Purchasing essential items



The rising cost of living and paying bills



Improving your quality of life, such as with mobility aids



Funding higher education or training schemes



A holiday or respite break



SCAN ME

**If we could help improve your quality of life, we want to hear from you. To find out if you qualify for a grant, contact us on**

**01420 541424**

info@kidneycareuk.org | www.kidneycareuk.org

To find out more about joining the Exeter & District Kidney Patients' Association, please contact the secretary Jean Aplin at 13 Crowden Crescent Tiverton EX16 4ET, email: jeanaplin@live.co.uk or visit [www.edkpa.org.uk](http://www.edkpa.org.uk)

### Welfare Grants for Exeter patients

The cost of living crisis is affecting many people at the moment, but we at the Exeter & District Kidney Patients' Association are keenly aware that it is affecting kidney patients more than most. We know that life can be hard when you are coping with kidney disease and that this can affect your ability to work. You may also be faced with the burden of additional financial costs related to your illness.

At EDKPA we're wanting to help as much as we can, so we've teamed up with major national charity Kidney Care



UK to provide welfare grants to kidney patients on low incomes who are struggling to make ends meet. Although these grants are administered by KCUK, we are contributing towards their funding for patients who are currently being treated at the Exeter Renal Unit. These grants are intended to avert a crisis, make a purchase that improves your quality of life or take a respite break or holiday. They include grants to help pay for:

- Domestic bills
- Household items
- Travel expenses
- Higher education/training etc.

#### How do I apply for a grant?

Before applying for a grant it's a good idea to have a read through the "Applying for a Grant" leaflet on the KCUK website which can be found here: <https://www.kidneycareuk.org/get-support/financial-support/>. You'll then need to contact a member of your kidney care team because all applications submitted must be

submitted on a form completed by them. An application form can be obtained from your kidney care team but can also be downloaded here: <https://www.kidneycareuk.org/get-support/financial-support/>

Once received the application will be reviewed by KCUK and if granted you should receive the money within a few days. Any grants above £100, however, will be made payable to the company or shop supplying the goods or services.

We hope that many of you will take advantage of these grants. We know we can't solve the cost of living situation, but we hope that these grants will at least go a little way to help patients who may be struggling.

### **Anything else?**

For really urgent applications we at EDKPA still provide emergency funds and any such applications should be made to our secretary Jean Aplin on 01884 254260 ~ 13 Crowden Crescent, Tiverton EX16 4ET.

*George Palmer  
Chair, EDKPA*



### Changes at the renal units

News of new appointments from our committee member Ria (Clinical Matron for renal and dermatology).

Congratulations to our new staff appointments:



- We have a new **ALM (Admin Line Manager)**, previously Ali Wilson) ~ **Vicky Ferris**.
- **Claire Wing** is the new **Clinical Nurse Manager** for the South Devon Satellite Kidney Unit.
- **Charlotte Callaghan** is the new **Senior Renal Community Nurse Specialist**.
- **Paula D'Souza** is the **Senior AKI (Acute Kidney Injury) Nurse Specialist**.

### Young Adults

*I received this email from Ria:* It is with great sadness to report that Eve the renal young adult worker is leaving. I would like to say a huge thank you to Eve for her dedicated work with young adults and we will be sad to see her go. We will be advertising her role soon.

The young adult clinics continue to grow and Eve has been in regular contact with many young adults face to face, virtually and by text. We are hoping to restart social events, which has been missed over the last two years.

The young adult residential is hopefully going ahead this year. I will update you when we have more information and a poster with contact information.

Thank you once again Eve and good luck in your new ventures.



### Home dialysis ~ want to meet up?

**Are you on haemodialysis at home?**

**Are you thinking about this treatment?**

Our treasurer, Chris Rolfe, is one of the NKF peer support group for home haemodialysis patients. He has organised several discussion groups for local home haemodialysis patients, working with the team at Heavitree. The idea is simply to chat about treatment, problems with the equipment and any other related issues, but



also to provide an opportunity to meet fellow patients. New patients and long term dialysers have all found these discussion groups useful and enjoyable.

Discussions have also been set up to assist people thinking about starting haemodialysis at home.

Chris has built up a list of patients who are interested in joining these discussions from time to time. If you would like to join in, please get in touch by e-mail if you have not already done so.

The next session will be in early July and Chris will e-mail details of time and date once this is fixed.

Contact Chris through the [EDKPA site](#), emailing [info@edkpa.org.uk](mailto:info@edkpa.org.uk) or via our secretary (01884 254260).

*See also “Bridging the Gap” item on page 18.*

### What an evening! ~ Devon Philharmonic Orchestra



The [Devon Philharmonic Orchestra](#) played a wonderful concert supporting the EDKPA on Saturday 30th April. A celebration of being able to play live again, plus some terrific uplifting music from 19th century romantic through 1920's jazz and some modern classical composers.

Over 500 people attended and Dr Sally Hulin, who plays and is a trustee of the orchestra and whose husband is about to start dialysis, addressed the audience. She read our Chair's speech (George was unfortunately not able to attend), and our secretary attended on behalf of the EDKPA.



### at Exeter Cathedral



It has raised £568.70, plus further sums to come from Sally who had set up a Just-Giving page. The EDKPA are grateful to the Philharmonic Orchestra and the effort by the members and organisers and selecting the EDKPA to be the chosen charity for the concert.

Sally also created an additional JustGiving website for extra donations [here](#) ~ please feel free to donate if you attended (or perhaps even if you didn't!).

From the programme: "The spring concert offers a full-length programme, featuring Copland's evocative *El Salon Mexico*, Gershwin's ever-popular *Rhapsody in Blue* and rounding off the evening with Tchaikovsky's powerful epic *Symphony No. 4*.

DPO is delighted to welcome Robin Stephenson, pianist with Ensemble Philéa, as the soloist in Gershwin's *Rhapsody in Blue*, a 1920s classic, which fuses symphonic music with American jazz.

Through this event, DPO is proud to be supporting the Exeter and District Kidney Patients' Association, which supports pre-dialysis, dialysis and transplant patients and their carers in Devon, Cornwall, Somerset and Dorset."

Feel like going to any of their concerts? Their programme is [here](#).



### Local staff attended UK Kidney Week (UKKW)

#### Reflections from our local staff

UKKW was attended in person by **Angeline Taylor**, **Sharon Huish**, **Jennifer Williams** and **Christine Budd** from Exeter (and attended virtually by others).

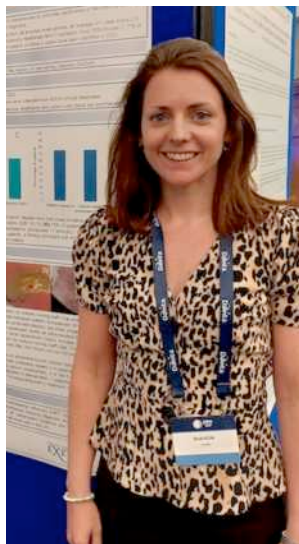
*Angeline Taylor, Renal Dietitian:*

“I was delighted to finally meet Dee from ‘Diary of a Kidney Warrior’ where they have been privileged to feature on her podcast twice and have been asked for another interview on plant-based diets in CKD.”

*Chris Budd, Trainee Advanced Clinical Practitioner:*

“UKKW was an inspirational experience. The three days were intense but now the work starts in disseminating the information and reflecting on our own practice to further improve the care we deliver.”

**UKKW ~ Sharon Huish** (*lead renal dietitian and speaker at the conference*)



Sharon gave a talk within the vitamin D session which discussed the evidence from the past 20 years around vitamin D in CKD. As part of her research work, Sharon is planning a study which she hopes will generate better evidence to inform how we can best manage vitamin D deficiency in kidney patients. Sharon also presented a poster looking at risk factors for calciphylaxis (a condition occurring mainly in kidney patients) and hopes to increase awareness of this condition, to improve understanding and care.

Note: [Diary of a Kidney Warrior](#) is recommended ~ on the NKF site, it's a great read.

## LOCAL NEWS

## “Diary of a Kidney Warrior”

I was fascinated by Dee Moore's YouTube channel about being a kidney patient for 18 months. She has documented her journey which includes the light and dark side of dialysis, and what keeps her going.

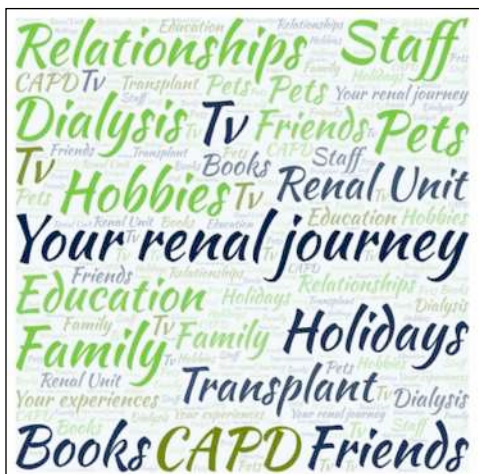
Well worth checking out.

The link to the Kidney Care UK article (and photo above/below) is here: [Diary of a Kidney Warrior](#).

You can follow her on  
[@diaryofakidneywarrior](#).



## We want you!



Send your story to [admin@edkpa.org.uk](mailto:admin@edkpa.org.uk) Send your story to [admin@edkpa.org.uk](mailto:admin@edkpa.org.uk)  
Send your story to [admin@edkpa.org.uk](mailto:admin@edkpa.org.uk) Send your story to [admin@edkpa.org.uk](mailto:admin@edkpa.org.uk)  
Send your story to [admin@edkpa.org.uk](mailto:admin@edkpa.org.uk) Send your story to [admin@edkpa.org.uk](mailto:admin@edkpa.org.uk)  
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Send your story to [admin@edkpa.org.uk](mailto:admin@edkpa.org.uk) Send your story to [admin@edkpa.org.uk](mailto:admin@edkpa.org.uk)

### Dietician appointed Head of Renal Nutrition Group

We are lucky to have such a great team of dietitians attached to the unit. See below for details of their recent success. I received the below from Dr Sharon Huish, our renal lead dietitian:



**Angeline Taylor**, renal dietitian, has been appointed as chair for the British Dietetic Association's Renal Nutrition Group (RNG). The RNG, which has over 360 members, works to promote the renal dietitian role to service users and other health professionals. The RNG facilitates the sharing of practice and training to help deliver better the dietetic care delivered to patients. We are very proud of Angeline for taking on this prestigious role, and we are excited about the opportunities this will bring to our profession both locally and nationally. Well done Angeline!





### Exeter University Research Project

We have heard from a research student from Exeter University who is leading a project about unpaid carers of someone who has a kidney condition. She would like to develop a self-help programme. What is it?



“A survey to understand your preferences for self-help programmes aimed at supporting people who provide unpaid care, help and support for someone with a kidney condition.”

How long does it take? About 15 to 20 minutes to complete. Please see [this site](#) to contact Chelsea at [c.coumoundouros@exeter.ac.uk](mailto:c.coumoundouros@exeter.ac.uk) to learn more.

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### RD&E and North Devon Trust merge



Integration of the two Trusts was approved and they merged on 1st April 2022 to become the Royal Devon University Healthcare NHS Foundation Trust.

Suzanne Tracey (Chief Executive Officer) of the merged trust, said:

“Formally bringing our organisations together unlocks opportunities to improve the resilience and sustainability of the healthcare we deliver to our patients across all of the areas we serve, from North, to Mid, to East Devon.”

Will we see a difference?

“Staff and patients will see very little difference from day one. The same services will still be offered from all of our hospitals and teams. Over the next 2–3 years teams will be working together to merge their corporate and clinical services to serve our combined population.”

More information [here](#).



### Letter from a transplant outpatient

If you have been to Heavitree hospital, it reminds you a little of how hospitals used to be.

It's a lovely hospital which was a workhouse in the 17th century, but was developed into an in-patient hospital and now has dialysis facilities for day patients...



“ I had a telephone call from the consultant renal nephrologist today following my visit to take bloods etc at Heavitree. I'd just like to say I appreciated the time and care over the phone. It lasted much longer than I thought and went over in detail and addressed all the issues I had, plus a couple of queries. No 'next please' attitude, and think we are lucky to have such caring staff (that includes all the staff I come across as a transplant patient).

It's been a very tough time for them throughout the last two years (and us too!), but just like to say that it's good to know we are ~ and have been ~ looked after very well down here.

P.S. Noticed all results were added two days later and summary was on MyCare the same day.”

What do you think? Do you have any experiences you'd like us to know about? Contact [info@edkpa.org.uk](mailto:info@edkpa.org.uk).





# 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.



SOCIAL  
DISTANCE  
LANYARDS

£1



FACE MASKS

£1.50



AVAILABLE TO BUY ONLINE NOW

[www.kidney.org.uk/shop](http://www.kidney.org.uk/shop) or call 01909 544999

Registered Charity Nos. 1106735 SC049431

Company No. 5272349 Registered in England & Wales

### Be part of it ~ new EDKPA website

For the new EDKPA website, we'd like some of your stories. If you can write anything about your experiences of dialysis or just 'your world' in the EDKPA area, please let Joanne know. A few ideas . . .



- ❖ **Families/friends:** there are always stories there.
- ❖ **Passing the time:** What are you watching/reading at the moment?
- ❖ **Unusual hobbies/pets** or interests.
- ❖ **Holidays:** Best and worst.
- ❖ **Relationships:** Best/worst, best/worst dates.
- ❖ **Education:** your journey through school/college/university.
- ❖ **Pastimes:** How do you spend your time?
- ❖ **Pets:** the best . . . and worst.
- ❖ **Starting dialysis:** How did you feel when you were told you would become a kidney patient?
- ❖ **Being on dialysis:** How do you feel about coming into dialysis, what support did you have?
- ❖ **Your treatment:** What has gone well . . . what hasn't been so good?
- ❖ **Staff/Wards:** How are they?
- ❖ **Transplants:** What do you think? Everything worked out?
- ❖ **Your thoughts:** Has treatment changed you?

Long, small, tall or short, your stories are welcome!

Please email [admin@edkpa.org.uk](mailto:admin@edkpa.org.uk) and let us know, or send articles by post to our secretary (see Contacts page).



Exeter & District  
**KIDNEY PATIENTS' ASSOCIATION**  
*Registered Charity No 276981*

## ADVICE AND INFORMATION

**Citizens Advice Exeter.** The EDKPA funds a service provided by Citizens Advice Exeter for an expert benefits adviser to advise on all aspects of claiming benefits specifically for people suffering from kidney diseases. An appointment can be made by contacting our secretary Jean who will check you are eligible, and then pass your details to the adviser. The adviser will then contact you, from a withheld number, to arrange a telephone appointment for advice. In some cases, a face to face appointment may be made if telephone is not suitable. Jean can also suggest other organisations that may be able to assist. You do have to be a member of EDKPA but you can join when you contact Jean.



Contact Jean Aplin on **01884 254260** or **07936 069988** or [jeanaplin@live.co.uk](mailto:jeanaplin@live.co.uk). There is also a referral form to download on our website at [www.edkpa.org.uk](http://www.edkpa.org.uk) which you can then email to Jean.

**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 a very extensive range of over 100 information leaflets which they can send to you and which are available to download from their website at [www.kidney.org.uk](http://www.kidney.org.uk).



**Kidney Care UK** has a good website with lots of help and up to date information. They can also 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**, or website [www.kidneycareuk.org](http://www.kidneycareuk.org).



### Increasing Home Dialysis in the face of Covid ~ Ask your MP to attend

The NKF are hoping to deliver further changes and improvements to dialysis treatment.

Please ask your MP to attend our reception taking place in July by downloading our template from our website which can be found [here](#).

The report “Increasing Home Dialysis in the Context of Covid-19 in the UK” can be downloaded [here](#).



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### Bridging the Gap ~ home dialysis

Interesting paper published by Quanta has many useful facts about UK's home dialysis programme.

“In 2021, the NHS's Getting it Right First Time (GIRFT) programme recommended that a minimum of 20% of patients should be on home dialysis in every dialysis centre.”

The survey (by Quanta) concludes that 34% of patients have never been offered home dialysis.

You can [download the report here](#).

(For people who receive the paper copy of the newsletter, please email [info@edkpa.org.uk](mailto:info@edkpa.org.uk) and we will send you the whole report.

What are your thoughts?





### Mother's Government Petition

A mother of a CKD daughter has created a petition under the UK Government and Parliament site.

It currently has over 20,000 votes. At 10,000 signatures, the government will respond, and at 100,000 signatures, the issue can be debated in parliament. Will you sign? If you haven't, please take time to read this petition and sign.



“My daughter has CKD and is at end stage renal failure for the second time. There are around 3 million people suffering with Chronic Kidney Disease (CKD) in the UK and every day is a fight for survival for them; unfortunately there is no cure.

I have started a petition asking the government to put more money into Kidney Research and to make the public aware of this wretched disease that has no cure.

With enough signatures this will be debated in Parliament. If you do sign, please confirm on your email and share.

Thank you. ”

To vote, click [here](#).



**Petitions**

UK Government and Parliament

#### Something to keep your mind active:

1. A man pushes his car to a hotel and tells the owner he's bankrupt. Why?
2. Paul's height is six feet, he's an assistant at a butcher's shop, and wears size 9 shoes. What does he weigh?

*Answers on page 32*

### Skills Launchpad ~ want to brush up your skills?

As part of the IT Skills Community Renewal Fund, LearnDevon are launching courses for people who want to start or improve their computer skills.

From their community [website](#):

“Bite sized face-to-face and online workshops and individual help sessions will be delivered by our team of friendly, supportive staff. These can be accessed remotely or in community venues in your local area. Our workshops are delivered in small welcoming groups.”



If you'd like to express an interest in a course, complete [this form](#).

Highly recommended.



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### Exeter man thanks donor after kidney transplant



There was an article on the [BBC Website](#) about Sam, who had a transplant in Exeter.

If you have had a transplant, have you thanked the donor's family/friends? If you feel like writing or videoing your experience, please contact

[admin@edkpa.org.uk](mailto:admin@edkpa.org.uk)

## NATIONAL NEWS

A kidney transplant recipient has thanked the person who donated a kidney to him and urged people to think of doing the same for others.

Sam Manicom (*pictured on page 20*) from Exeter had been on the waiting list for years before he had his life-changing transplant in 2010.

He said within a few months he was “bouncing” again and described himself as a “very lucky guy”.

Mr Manicom spoke on World Kidney Day after the number of kidney transplants dropped by a third during the pandemic.

He said: “I can’t thank the young man who signed up to the Organ Donor Register enough, nor can I thank his family enough for letting the operation go ahead.

“I’m firing at all cylinders. I actually feel like I’m contributing to life again.”

This means around 1,100 fewer patients received a kidney transplant in 2020/2021 compared to the year before, said the service.

Usually, kidney donation is something that happens after you die, but it is also [possible to give the gift of a living kidney donation](#), said the NHS.

Mr Manicom said: “Please get yourself signed up to be an organ donor, make sure your family know exactly what you want to happen.

“It’s one of the best gifts you can give in your lifetime.

“And when you die you don’t need your organs any more and you can make a lot of people very happy again.”

### Kidney Kitchen

# Chicken Kebabs with herby couscous salad

~ serves 4 ~

Low in potassium and high in protein makes it an ideal meal for those having dialysis



### INGREDIENTS

2 garlic cloves  
Fresh ginger, 3cm  
1 tablespoon clear honey  
1 tablespoon reduced salt soy sauce  
400g chicken breasts, skinless  
1 large green pepper  
8 button mushrooms  
1 red onion  
6 wooden or metal skewers  
2 tablespoons olive oil

### Herby couscous salad

200g couscous  
½ pomegranate  
2 tablespoons fresh coriander  
2 tablespoons fresh mint  
Juice and zest of 1 small orange  
Zest of 1 lemon  
Pinch of ground cinnamon  
Pinch of ground cumin  
2 tablespoons white wine vinegar  
2 tablespoons olive oil

### METHOD

1. Finely chop the garlic and ginger. Mix with honey and soy sauce then add cubed chicken. Cover, marinate for min. 1 hour, but preferably overnight.
2. After marinating, dice the onion and pepper into large chunks. Thread the chicken, green pepper, mushrooms and onion equally onto 8 skewers.
3. Add olive oil to a griddle or frying pan and cook the kebabs for 10 mins on each side or until the chicken is thoroughly cooked and golden brown. Cook in batches and turn the kebabs frequently.
4. Place couscous in a shallow bowl, add the cinnamon and cumin and pour over 200ml boiling water. Stir, cover the bowl for 5 min. until the couscous has swelled up and absorbed all the water. Ruffle with a fork to separate the grains, then stir through the pomegranate seeds, orange and lemon zest, coriander and mint.
5. Make a dressing by mixing the orange juice, white wine vinegar and olive oil together, then stir into the couscous and season with pepper.
6. Divide the couscous and kebabs into four servings and enjoy.

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Other recipes can be found in the Kidney Care UK Kidney Kitchen at [www.kidneykitchen.org](http://www.kidneykitchen.org)

### Kidney Kitchen

# ETON MESS

serves 6

**This traditional English dessert is quick to make and doesn't need cooking**



***Adding blueberries to this traditional summer dessert keeps the overall potassium low.***

### INGREDIENTS

- 4 individual meringue nests
- 400ml double cream
- 1 teaspoon vanilla extract
- 150g fresh raspberries
- 150g fresh blueberries
- 1 teaspoon ginger cordial (optional)
- 2–4 ginger nuts (optional)

### For the raspberry coulis

- 200g frozen raspberries
- 30g caster sugar
- 1 tablespoon lemon juice

### METHOD

1. For the coulis, tip all of the ingredients into a saucepan and heat for 5–7 mins. Blend in a food processor until smooth, then pass through a sieve to remove the pips. Set aside until ready to serve.
2. Break up the meringues into pieces and set aside. Lightly whip the cream until soft peaks form. Be careful not to over whip it. Gently fold in the raspberries, blueberries and meringue pieces.
3. Add the vanilla extract and ginger cordial if using. Stir through some of the raspberry coulis. You want a ripple effect with the raspberry.
4. Serve drizzled with the raspberry coulis. For an extra flourish, crumble the ginger biscuits over the top.

**Carbohydrate:** The carbohydrate value of this dish has been provided for those who have been trained in insulin adjustment.

**Phosphate/potassium:** If you have been prescribed a phosphate binder, ensure you take them with this dish. If you prefer you can swap the raspberries for strawberries. Using blueberries makes this a low potassium dessert choice.

Other recipes can be found in the Kidney Care UK Kidney Kitchen at [www.kidneykitchen.org](http://www.kidneykitchen.org)





### The **Kidney Kitchen Recipe Book** has arrived!

We're delighted to share that our brand new Kidney Kitchen Recipe Book is now available for you to purchase. To be able to enjoy a tasty Sunday brunch with a partner, a hearty meal with our family or a piece of cake now and again is important to everyone; it's personal and connects us with the people who matter to us. This doesn't change when you are diagnosed with chronic kidney disease. We believe kidney disease should not be a barrier to delicious food.

### Kidney-friendly recipes

Over the past three years, Kidney Care UK and the Renal Nutrition Group of the British Dietetic Association) have been working hard to develop a collection of tasty kidney friendly recipes for you and our kidney community. By providing renal dietetic guidance to the whole Kidney Kitchen team, we have created over 100 exciting and tasty meals and recipes that better suit the needs of you or your loved ones. With step-by-step instructions, nutritional information and world flavours to help you modify each recipe to your individual needs and your tastebuds, our book is all about what you can eat, not what you can't. The recipes are easily displayed in the free-standing recipe book. Perfect to pop up in your kitchen! *We hope you enjoy it as much as we did creating it!*

At Kidney Care UK, we know that living with kidney disease can mean additional financial pressure. We asked our supporters whether they could gift a recipe book to someone who couldn't otherwise afford it. We're delighted to have a supply of gifted Kidney Kitchen Recipe Books available, please contact [fundraising@kidneycareuk.org](mailto:fundraising@kidneycareuk.org).

### How to get your Kidney Kitchen Recipe Book

To purchase your Kidney Kitchen Recipe Book, please visit [www.kidneycareuk.org/shop](http://www.kidneycareuk.org/shop). The Kidney Kitchen Recipe Book is £10 plus £3.50 P&P. It's for beginners, foodies and anyone looking to eat well and feel well. Don't forget our resident dietician team if you need advice.

## Just for fun

### School Homework Howlers

A selection of Spelling Slip-Ups and Homework Howlers:

In geography we learned that countries with sea round them are islands and ones without sea are incontinents.

In wartime, children who lived in big cities had to be evaporated because it was safer in the country.

My gran has a huge chest. We keep our toys in it.

Sir Walter Raleigh circumcised the world with a big clipper.

Helicopters, are, cleverer, than, planes., Not, onl , can, the , fl , through, the, air,, the , can, also, hoover.

In, the, alden, da s, cars, were, not, aloud, to, go, fast. The, first, cars, had, to, follow, a. man, with, a, bag, in, his, hand.

If it is less than 90 degrees it is a cute angel.

My brother fell off his bicycle and broked a bone in his back called his cocksticks.

If you marry two people you are a pigamist, but morons are allowed to do this.

My mum goes to jim every fireday. She always comes home too tired to do anything.

My tummy rambles after school so I have a chocklet suggestive when I get home.

## Just for fun

### Well-known Sayings Dingbats

"Say what you see" to reveal 15 well-known sayings. *Answers on page 32*

you just me

1

TH↑CK  
TH↑IN

2

9pm = £14

3

→ E  
ORD R

4

Bidden Orange  
Bidden Plum  
Bidden Grape  
Bidden Peach

5

Take a pets

6

oLD

7

Touching  
Planet Earth

8

3 { 2

9

$6 \div 4 = 15$

10

Paddington  
Must-haves

11

lacerate  
nap

12

R.I.P.  
Doorbell

13

the sand

14

① Monday  
② Friday  
④ Sunday

15

## What does 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 arrange to book you into the next available appointment with our benefits advisor at Citizens Advice.
- ♦ We help to fund the Clinical Nurse Specialist and Renal Young Adult/Transition nurse (Eve has moved on).
- ♦ For a 12-month period we are paying and supplying some 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 and Torquay 24) and remote controls.
- ♦ 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 (see Contacts page).*

## 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 email [jeanaplin@live.co.uk](mailto: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



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.

Their helpline is dedicated to kidney patients and has two fully trained, experienced advisers providing a Monday to Friday service to kidney patients, carers and healthcare professionals and renal units.

They also have an extensive range of information leaflets which can either be sent to you or downloaded from their website at [www.kidneyorg.uk](http://www.kidneyorg.uk).

### 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.transplantsupportnetwork.org.uk/>



## NEED SUPPORT?

### 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:

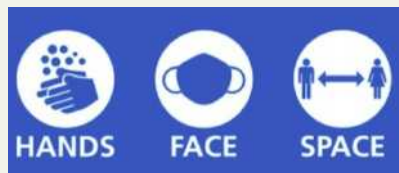
<http://www.edkpa.org/donate/>

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.**

# YOUR EDKPA ~ who are we?

PRESIDENT	<b>DR LUCY SMYTH</b>	
VICE-PRESIDENT	<b>DR CORALIE BINGHAM</b>	
SECRETARY	<b>Mrs Jean Aplin</b>	13 Crowden Crescent, Tiverton, Devon EX16 4ET Tel: 01884 254260 <a href="mailto:Jeanaplin@live.co.uk">Jeanaplin@live.co.uk</a>
CHAIRMAN	<b>George Palmer</b>	<a href="mailto:george@edkpa.org.uk">george@edkpa.org.uk</a>
TREASURER	<b>Chris Rolfe</b>	<a href="mailto:cdrolfe@aol.com">cdrolfe@aol.com</a>
COMMITTEE MEMBERS	Kate Cresswell (Kidney Care UK), Keith Forbes, Jackie Garry, Sandie Hampshire, Jake Johns, Danny O'Sullivan, Joanne Robbins, Chris Rolfe, Nick Wood	
Co-opted	Ria Taylor (Clinical Matron for Renal and Dermatology)	
Other contacts	Website/Newsletter	Nick Wood <a href="mailto:info@edkpa.org.uk">info@edkpa.org.uk</a>
	Taunton Group	Danny O'Sullivan <a href="mailto:danny.wellerswick@btinternet.com">danny.wellerswick@btinternet.com</a>

## North Devon Kidney Support Group

Chairman	Donald Lynch	Tel: 01271 812300 <a href="mailto:lynchydon@gmail.com">lynchydon@gmail.com</a>
Secretary	Roy Sibley	<a href="mailto:roysibley@dsl.pipex.com">roysibley@dsl.pipex.com</a>
Social Secretary	Cherie Merryfield	Tel: 01271 343887 <a href="mailto:fj.merryfield@btinternet.com">fj.merryfield@btinternet.com</a>

**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](mailto:CotswoldComputing@live.co.uk)*

## 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](mailto:jeanaplin@live.co.uk)

**Membership of the EDKPA is free!**



## Newsletter postage



If you are reading this newsletter with a cup of tea and turning the pages over(!) could you consider whether you would like it receive it by email? We will always have a paper copy for members who want it, but if you have an email address and would like the electronic copy, please let us know (it's also possible you are receiving the paper copy because your email has bounced).

Please contact [info@edkpa.org.uk](mailto:info@edkpa.org.uk).

Nick Wood, Newsletter editor

### Answers to Well Known Sayings Dingbats on page 26

15. Days are numbered
14. Head in the sand
13. Dead ringer
12. Cut above the rest
11. Bare necessities
10. Missing the point
9. Pieces of eight
8. Feeling on top of the world
7. Growing old
6. Take a step backwards
5. Forbidden fruits
4. Out of order
3. Time means money
2. Through thick and thin
1. Just between you and me

### Answers to Keeping your Mind Active on page 19

1. He's playing Monopoly.
2. Meat.

## Diary Dates

A summary of what's coming up. If you want to keep updated, visit our EDKPA members' Facebook page (search 'EDKPA').

**Thursday 28th July to Sunday 31st July 2022**

British Transplant Games (Leeds).

**Sunday 8th January 2023**

Pantomime *Sleeping Beauty* at Plymouth's Theatre Royal at 1 pm.