Exeter & District Kidney Patients' Association

EDKPA Newsletter

Winter 2021 edition

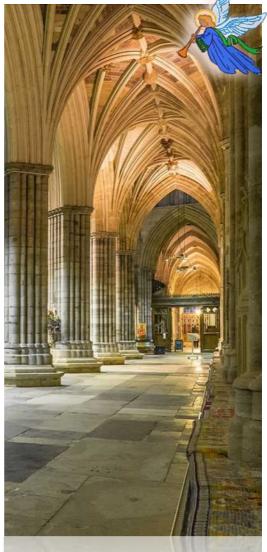
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The South Aisle of Exeter's magnificent Cathedral



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.





Love came down at Christmas, Love all lovely, Love Divine. Love was born at Christmas, Star and Angels gave the sign.

CHRISTINA ROSSETTI

EDITORIAL

For this edition, we have asked Kate to reflect on her nine years as Advocacy Officer with Kidney Care (previously the British Kidney Patient Association). Kate has been on the EDKPA committee for a long time, but also has responsibilities for kidney patients in a much wider arena.

I came into the rôle with scant knowledge of chronic kidney disease. I had had many years' experience working in the health field, both in Primary and Secondary care sectors, and so had a very broad understanding of different health conditions, but very little specific to kidney disease.

My father ended up in Stage 5 towards the end of his life, at age 84, following removal of a kidney because of a tumour. Being a long-standing heart patient, his one remaining kidney couldn't cope and so he started haemodialysis and despite challenging health lived to 90.

I witnessed at first hand how challenging and burdensome CKD is. My father, being retired, had none of the financial struggles that those of working age experience, but nonetheless his thrice-weekly trips to dialysis were onerous and I quickly realised that whilst his advanced years were a contributing factor, the sheer fatigue which Stage 5 patients suffer is par for the course ~ and unlike any other "tiredness".

Over the ensuing years I took great delight in enabling those whom I believed should qualify for health-related benefits (Personal Independence Payment or Attendance Allowance) successfully win their applications. Not always easy, but my premise was never to take "no" for an answer. I have been more than ably supported in this mission by the link between the Exeter & District KPA and Citizen's Advice Exeter as folk are able to get first-class help in applying for these benefits and I only became involved when the appeals process was necessary because of the "wrong" decision.

Benefits advice has been a large part of the rôle ~ although, as mentioned, for a lot of Exeter and district patients this need has been met by Citizen's Advice Exeter. Beyond benefits support the

workload has been across the board ~ trying to solve misunderstandings between patient and their renal team (thankfully not a common situation), transport difficulties: always a thorny issue with early and late pick-ups before and after haemodialysis, and signposting for information about holiday dialysis, amongst other general enquiries. Clinical advice was never given, even though it might have been sought ~ such enquiries were always sent back to the renal team.

The rôle has been enormously rewarding: Kidney Care UK is a smallish charity (around 40 employees now) but was well set-up by its founder, Elizabeth Ward. She was a very well-connected and persuasive woman whose son was a kidney patient. Not only was she instrumental in setting up the Kidney Donor Card, but in 1979 persuaded the Duke of Westminster to become Patron. Thus, the charity was established and has been supporting kidney patients in all manner of ways ever since. The history of the charity can be read in full detail here: https://www.kidneycareuk.org/about-us/our-history/.

Enough from me! My successor, Trish, can be contacted at patricia.moroney@kidneycareuk.org. I have complete faith that whatever small part I have played will continue well into the future and beyond.

OBITUARY ~ Peter Shearman



Peter (past chairman of EDKPA) passed away peacefully on Friday 19th November in Exeter's RD&E hospital with Sue, his wife, by his side.

Peter was always cheerful and an active chairman and believed in supporting kidney patients in any way he could. Peter had been a patient for 34 years

(haemodialysis followed by a transplant), and enjoyed many holidays and weekend breaks with the Association.

He was a kind and caring figure and was the sort of person everyone would warm to. We will all miss him terribly and our thoughts are with his family. His funeral is on 7th December.

A Message from our Chairman, George Palmer



Hello and welcome to our Christmas edition of the Exeter & District Kidney Patients' Association Newsletter 2021. I hope you enjoy reading it ~ but, as always, please let us know what you think as we do appreciate your feedback.

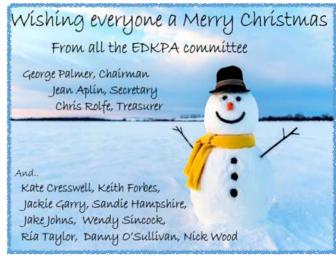
As we approach the end of the year, it gives us the chance to reflect on the last 12 months. And what a year it's been! When I wrote a similar piece last

year, I said I was optimistic that 2021 would be better than 2020 (which I think it was). But I don't think that I was still expecting us to be so affected by Covid as we remain today. As kidney patients we don't need reminding that the pandemic is far from over. Rates of infection remain high, particularly in the West Country. The onus continues to be on us to remain vigilant.

I am still optimistic though. The vaccination programme means we are in a much better position than we were last year. So once again I am confidently predicting that 2022 will be better than 2021 and that we shall continue inching our way back to some sort of normality. Whatever happens though, we will continue representing your interests both at local and national levels to ensure that kidney patients and their carers are never forgotten.

Christmas is a time for celebration and I think many of us will be able to celebrate it this year in a more relaxed way than last year. So on behalf of everyone at EDKPA, may I wish you all a very happy and healthy Christmas and New Year. George Palmer

George Palmer Chair EDKPA



Oh, yes it is . . . pantomime time!!



The pantomime at the Theatre Royal, Plymouth this year is Aladdin, with Joe Pasquale, and Jean, our secretary, is once again arranging a trip on Sunday, 9th January 2022 for the 1 p.m. performance.

Tickets to members (patient and partner) are £10 each. Friends and family are welcome to join us £19.20 per person. We will be running a coach from Exeter and everyone is welcome to travel on it free of charge with pick-ups en route if possible, or you may drive there yourself if you wish.

A total of 40 tickets are available on a 'first come, first served'

basis. Please use the booking form overleaf (page 6).

Goodness, we have all been through so much this year . . . so why not come along and forget things for a while? We have always gone regularly to the pantomime and it is always fun, plus you often come back with new friends.







Photocopies acceptable

Pantomime Booking Form

Aladdin ~ with Joe Pasquale, Sunday 9th January 2022 at 1 p.m.

Please return by 1st January 2022

Coach will leave South West Water Headquarters, Rydon Lane, Exeter at

<u>11 a.m. pro</u>	<u>ompt</u> . We can pı	ck-up en r	oute. Pleas	e bring a pad	cked lunch.	
Name:						
Address:						
Postcode:			Tel:			_
Number c	of tickets requir	red:				
	Members	(@ £10.00 e	ach = £		
•	Non Members	(@ £19.20 e	ach = £		
			T	otal £		

Please make your cheque payable to:

Exeter & District Kidney Patients Association

and send to: Mrs J Aplin, 13 Crowden Crescent, Tiverton. EX16 4ET to arrive by <u>1st January 2022</u> latest.



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



Kidney Kitchen Traditional Mince Pies serves 12



Using apple and less dried fruit makes this is a great festive treat that is low in potassium, phosphate and salt

INGREDIENTS

Homemade mincemeat

- 1 large Bramley apple
- 25g low fat margarine
- 50g glace cherries
- 50g dark soft brown sugar
- 1 teaspoon mixed spice
- 100g mixed fruit peel
- 1 tablespoon brandy or rum

Pastry

- 225g plain flour
- 150g butter
- 2 tablespoons caster sugar
- 1 egg
- 3 tablespoons cold water

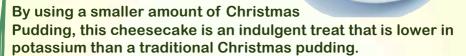
METHOD

- Pastry ~ sift flour and rub in the butter until the mixture resembles coarse breadcrumbs. Stir in the sugar. Separate the egg and mix the egg yolk with the water and add to the dry ingredients to form a smooth dough. Wrap the dough in cling film and chill in the fridge for 30 minutes.
- 2. Meanwhile, grate the apple, roughly chop the cherries then combine all the homemade mincemeat ingredients in a bowl and stir well.
- Flour a surface and roll out half the pastry to 3mm thick. Using an 8cm fluted cutter, stamp out 12 circles of pastry. Press into a greased patty tin. Cut out 12 smaller circles using the rest of the pastry and a 6cm cutter.
- Drop a teaspoon of mincemeat into each round, brush the edges with water and then stick the lids on top, pressing together to seal.
- Brush the tops with egg white and make a small hole in the top for any air to escape.
- 6. Bake at 190°C / gas mark 5 for about 20 minutes. Leave in the tin for 5 minutes then transfer to a wire rack.

Uncooked mince pies can be frozen for up to 3 months. Cook from frozen and allow an additional 10–15 minutes cooking time in the oven. They can be kept in an airtight container for up to a week.

Kidney Kitchen Christmas Pudding Cheesecake

serves 10



INGREDIENTS

- 110g unsalted butter
- 200g ginger nut biscuits, crushed
- 1 teaspoon flaky sea salt (optional)
- 240g Christmas Pudding
- Zest of 1 orange
- 560g full fat cream cheese

- 300ml double cream
- 100g light muscovado sugar
- 2 vanilla pods
- 30ml brandy (optional)
- 30ml stout (optional)
- 2 clementines

METHOD

- To make the base, melt the butter in a pan. Crush the ginger nut biscuits and add to the flaky salt (if using) and melted butter. Mix in a bowl to form a biscuit crumb.
- Press into a 20cm round spring form cake tin, spreading the mixture in an even layer to the sides of the tin. Chill in the fridge for 30 minutes until set.
- 3. Put the Christmas pudding, brandy and stout (if using), with the orange zest into a blender and whizz to a puree.
- 4. Using an electric whisk, beat the cream cheese with the double cream, sugar and vanilla seeds and fold through the puree. Spread the mixture over the biscuit base and leave to chill in the fridge overnight.
- 5. The next day, peel the clementines, slice into rounds and place on a baking tray. Sprinkle them with a little muscovado sugar, then blowtorch or place under a grill until caramelised. Leave them too cool.
- 6. Release the cheesecake from the tin and arrange the clementines on top. Store in an airtight container in the fridge for up to 2 days.

Healthier option ~ If you want to reduce the amount of sugar or fat you eat, you could use reduced fat cream cheese, use low fat spread instead of butter for the base and try using a sweetener in place of sugar.

Virgin Moneygiving



Virgin Moneygiving are closing their fundraising website. This means we have to change our fundraising platform.

If you are a regular donor or have any regular fundraising activities, we will have contacted you in November about this and how to transfer to the new site.

We apologise for the inconvenience, but thank our loyal donors and fundraisers from the bottom of our heart. It is people like you who keep the EDKPA going and means we are able to support renal patients in the area. Thank you.

PREM 2021 ~ Have your say



You might not have heard of PREM, but it's a UK Renal Association project which is supported/funded by Kidney Care UK and they want to hear about your

experiences as a kidney patient. This is something that the renal department always encourages patients to complete as the results are all collated by The Renal Registry and used extensively by the NHS.

"The Kidney Patient Reported Experience Measure (PREM) survey is co-ordinated by the UK Kidney Association and Kidney Care UK and has been created by patients and professionals working together to produce a report on how kidney patients experience care across the UK. It's by listening to you and getting your feedback that we can make change happen and improve services. It does not include your name and has nothing on it that could identify you, so please feel free to answer as honestly as possible."

You can take the survey here until Sunday 12th December.

Why do we celebrate Boxing Day?

It began sometime in the 1800s when Christmas gifts were received in a 'Christmas box'. The following day, wealthier classes would fill the box with gifts to give to the poor ~ often servants and staff from their home who would traditionally be given Boxing Day off as a holiday.

My Care Blood Results



Following the feedback we received regarding blood results being put on My Care two weeks after they were taken, our Chairman (George Palmer) wrote to Dr Lucy Smyth (Consultant Nephrologist and Lead Clinician).

She replied that the results will be released automatically 'imminently'~ just for renal patients for standard renal bloods (not radiology). By the time you read this, it should have been launched for some time. With thanks to Dr Smyth and the renal team.



Do you have any further comments about My Care? If so, let us know on info@edkpa,org.uk or phone Jean, our secretary ~ see contact details in this Newsletter.

OBITUARY ~ Wendy Sincock

Wendy has been on the committee for a long time and has been a central part of the Exeter Transplant Games team every year,



managing the team and taking them to the Games all over England. She also competed internationally very successfully.

She was a cheerful, tireless fundraiser and an advocate for transplantation. She will be missed by many of us who knew her cheerful outlook and ever-present sense of humour. Our thoughts are with her family.

We will be writing more about Peter Shearman and Wendy in our next Newsletter.

This photo of Wendy was taken at the Chagford Show, one of many such events she organised.

Kidney Transplant? You could be part of "Research into Kidney Replacement Therapy on your Mental Health"



One in three people on kidney replacement therapy experience depression, which is linked with poor physical health. Worryingly, this includes a 50% increase in mortality. Despite this, kidney services do not routinely look for mental health problems. Researchers have developed an intervention aimed at proactive detection and prevention of common mental health difficulties for people with kidney disease. The aim of this study is to assess whether the study design is appropriate prior to a full trial.

Who can participate?

Adults under the care of a kidney specialist will be approached to undergo self-report screening for depression and anxiety. If they have some evidence of common mental health difficulty and do not meet the self-report exclusion criteria, they will be offered participation.

Where is the study run from?

Royal Devon and Exeter NHS Foundation Trust (UK).

When is the study starting and how long is it expected to run for? February 2021 to September 2022.

Who is funding the study?

The Kidney Patient Research Partnership (British Renal Society and Kidney Care UK).

Who is the main contact?

If you are interested, please contact Karen at karen.pike5@nhs.net

For a full summary of the research, see <u>ISRCTN - ISRCTN82492510</u>: <u>Kidney-specific psychosocial assessment and support</u>

Social Events for younger people

Eve ClaireVue (whose post the EDKPA support) sent the article below ~ she'd like your thoughts and also start arranging some social events. She has some words for those of us over 30, but still young at heart!

It has been really lovely to get to meet many of the young adults face to face and also really start having a presence and being able to offer support and signpost solutions for additional leads, e.g. funding assistance for the young adults.

I have been lucky enough to shadow Ali at Southmead Hospital and be present with the transplant clinic and gain a better understanding on the experience and the facilities for our transplant patients in Bristol.

As you might imagine, there is a fair amount of outreach work and establishing my presence, especially with patients that are not currently being seen at RD&E Hospital and patients that are transitioning from paediatrics to the adult services, in Bristol for example.

I am working towards organising some social events for the young adults, as social interaction is so positive for mental well-being and vital for having fun engaging connections... which I'm sure all of us feel we could do with more of, but is especially important to the under-30 age group.

There seem to be many more patients, so the challenge is being as effective as possible in the time we have.

If any of you reading this are currently under renal care and age 30 or under*, I would value feedback on what is good with the care you receive and what would benefit from an improvement (or just want to share your experiences). I know that many had raised the issue of bloodwork availability, but this will be resolved now. Feedback is important in providing a service that meets end user needs.

Take care of yourselves this winter, stay warm and well and I look forward to our next Newsletter.

* For those of you who, like me, are young adults at heart but over 30 ~ keep on celebrating yourselves and keep the spirit of fun alive. Sorry I don't get to work with you too!

Citizen's Advice ~ Exeter (CAE)



The service the EDKPA commission from the Exeter section of the Citizen's Advice is working very well. A few things came out from the annual meeting we have with them to make sure things are running well:

- These were generally working well as a result of the excellent relationship between Freya and Jean [our secretary]. Freya asked if Jean could ensure that patients were aware that Freya would be using a withheld number when contact is made and that consent should be specifically obtained for Freya to leave a message.
- We are printing leaflets about the service and how to contact CAE though the EDKPA. This is printed on the next page. Please also see the 'Support' section on the EDKPA website.
- Our committee member Kate Cresswell (read her editorial in this Newsletter) is retiring. She has put in a staggering amount of hard work behind the scenes for EDKPA members and has contributed greatly towards the functioning of the very successful service the EDKPA provide to renal patients. She will be very much missed and we wish her well.
- The EDKPA would like to thank
 Freya from CAE for the work she
 has done for a huge number of
 EDKPA members. She has
 supported members in completing
 various forms and offering other
 advice has been much
 appreciated. She and Kate have
 had a very high success rate in
 supporting kidney patients in
 their applications for various
 funds. (Freya is currently unwell,
 but the service will continue. We
 wish Freya well.)





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. There is also a referral form to download on our website at 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.



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 are uk website www.kidneycareuk.org.

So what is it like to have a transplant?



The Winter Edition of
Kidney Life (the magazine
of the National Kidney
Federation) has an excellent
article (one of three) about
'The Kidney Transplant
Journey'.

Part 1 (of three) which is titled 'The Transplant Call' is in this edition. Those who have ~ or are waiting ~ for a

transplant will know the feeling waiting for the call...

If you have wondered what it is like, I'd recommend it.

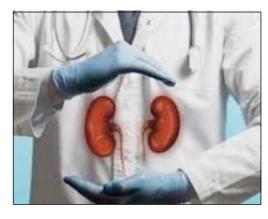
As a side note, I remember actually hearing about a kidney which was available for me. I was in 'C Block' in Whipton (where the dialysis unit and in-patient unit for renal patients was).

It was near Christmas and I was taking in an offering for the staff, who were so supportive at a very difficult time. They gave me a queer look when I entered and went quiet. Ignoring my presents, they asked why on earth was I there... 'Had I heard already?'...

It turned out they had just heard that there was a kidney available for me after years on dialysis.

Goodness, what a shock, but I then had to get ready for the transplant (they were then performed in the RD&E).

Since when I have been very lucky. Thirty-nine years later, it is still working and ~ to this very day ~ I remain grateful every day for what I have been given.



Our support for Kidney Research

George Palmer (our chairman) has received a letter following our support for Kidney Research. Kidney Research UK The following is an extract:



Dear George,

I wanted to thank you again for your support for the COVID-19 Vaccine Research Fund. We were delighted to have the support from your KPA and it was very generous of you to contribute to this collaboration. I am also writing to provide an update on how the project is going.

What has happened so far: We are investigating how well the Covid-19 vaccines provide immunity to Covid-19 infection. Blood samples from more than 1,200 haemodialysis patients across the UK are being studied before and after each dose of vaccine. We are delighted that data from the first 180 patients was accepted for publication in The Lancet. The researchers concluded: "The level of neutralising antibody to Delta made by haemodialysis patients, who have not had a prior Covid-19 infection and received the Oxford-AstraZeneca vaccine, might not be enough to prevent infection with Delta. We've found that this group (without prior infection) responds well to mRNA vaccines such as the Pfizer vaccine and we can use this information to inform future vaccination strategies."

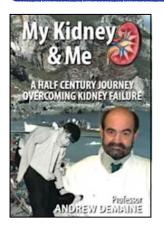
How this research is helping patients: Knowing the way in which patients respond to the different vaccines is crucial to ensuring the best outcomes are obtained for the kidney community. The evidence provided by our study is so far helping to inform scientists and clinicians with decisions about future vaccinations. The JCVI has now recommended that immunosuppressed people should have a third dose of an mRNA vaccine as part of their primary Covid-19 vaccination schedule. Armed with the evidence from the study you have helped to fund, the UKKA has now advised renal professionals that all dialysis patients should also be invited for a third dose, which hadn't been made clear by the JCVI. We know this is now underway.

Next steps: The plan is to invite 36,000 immunocompromised people to participate, with approximately half of these expected to be kidney patients. This would be a kidney-led study with the opportunity to work in partnership with several non-renal charities. This work is crucial to identify which groups of patients may be in need of further interventions in order to stay safe from Covid-19.

If you would like further details, please contact George Palmer (see 'Contacts' section.)

executive

My Kidney and Me: A Half Century Journey Overcoming Kidney Failure



Andy Demain's book is finally published. Andy is a passionate supporter of kidney patients, working as a member of the Kidney Care UK Patient Advisory Panel. He is also on a hospital transplant committee and is training as a buddy to support teenagers and young adults.

He came down to Exeter to visit our committee when I believe he was on a whistle-stop tour of as many KPA's as possible. The book is highly recommended

and is available both as paperback and a Kindle version. You can read about on Amazon it here. It's a good read, and as you can imagine, Exeter features quite highly in the book, which charts his story as a boy, a man and a scientist (I think he enjoyed coming down to see us in Exeter as it is his local area when he was not working for Kidney Care). Any profit will go to kidney charities.

Here is extract of its description:

... It is over half a century since first becoming ill on 7th July, swimming for my school. A few days later I had kidney failure; the local hospital had a new dialysis unit and was prepared to start me on a rudimentary form of dialysis. Most would have refused and I would not have written this book.

... Saturday 9th November brought the call offering me a cadaver kidney and back to Cambridge I went for the operation. It did not work until day 12, which worried the doctors, but not me, I never doubted its success. Months later I returned home and back to school. This kidney changed my perspective on life becoming an activated patient and volunteer despite my age. I helped publicise the Donor Card scheme to increase donation awareness and took part in the 2nd British Kidney Transplant Games, now the British Transplant Games.

... My kidney journey is a patient perspective on changing practice in the NHS and along the way highlights how treatments have changed in half a century.

Prison versus Work

Just in case you ever get these two environments mixed up, this should make things a little bit clearer!

PRISON	OFFICE
You spend the majority of your time in a 10×10 cell.	You spend the majority of your time in a 6×6 cubicle/office.
You get three meals a day fully paid for.	You get a break for one meal and you have to pay for it.
You get time off for good behaviour.	You get more work for good behaviour.
The guard locks and unlocks all the doors for you.	You must often carry a security card and open all the doors for yourself.
You can watch TV and play games.	You could get fired for watching TV and playing games.
You get your own toilet.	You have to share the toilet with some people who pee on the seat.
They allow your family and friends to visit.	You aren't even supposed to speak to your family.
All expenses are paid by the taxpayers with no work required.	You get to pay all your expenses to go to work and they deduct taxes from your salary to pay for prisoners.
You spend most of your time inside bars wanting to get out.	You spend most of your time wanting to get out and go inside bars.
You must deal with sadistic guards.	They are called managers.

Now get back to work.
You're not getting paid to waste time reading this!

Being British

Being British is about driving in a German or Japanese car to an Irish pub for a Belgian beer; then travelling home, grabbing an Indian curry or a Turkish kebab on the way, to sit on Swedish-made furniture and watch American shows on a Japanese-made TV.

And the most British thing of all? Suspicion of anything foreign!

Oh, and . . .

- ▶ Only in Britain . . . do supermarkets make sick people walk all the way to the back of the shop to get their prescriptions while healthy people can buy cigarettes at the front.
- ▶ Only in Britain . . . do people order double cheeseburgers, large fries and a DIET coke.
- ▶ Only in Britain . . . do banks leave both doors open and chain the pens to the counters.
- ▶ Only in Britain . . . do we leave cars worth thousands of pounds on the driveway and lock our junk and cheap lawn mower in the garage.
- ▶ Only in Britain . . . do we use answering machines to screen calls and then have call waiting so we won't miss a call from someone we didn't want to talk to in the first place.
- ▶ Only in Britain . . . are four seasons in one day considered quite normal.

NOT TO MENTION . . .

- ▶ 142 Brits were injured last year by not removing all pins from new shirts.
- ▶ 58 Brits are injured each year by using sharp knives instead of screwdrivers.
- ▶ 31 Brits have been electrocuted since 2004 by watering their Christmas tree while the fairy lights were plugged in.
- ▶ 19 Brits have been poisoned in the last three years believing that Christmas decorations were chocolate.
- ▶ 105 Brits since 2002 have had broken parts of plastic toys pulled out of the soles of their feet.
- ▶ 8 Brits were injured last year in accidents involving out of control Scalectrix cars.
- ▶ 12 Brits were injured last year after accidents suffered whilst pulling Christmas crackers.





Mixed up Christmas Films

Solving the 25 anagrams below will lead to popular film titles. All are shown regularly on television over the Christmas holidays.

	Anagram	Film title
1	MR SINGLE (8)	
2	TEACHES A SULTAN (3,5,6)	
3	SMITH WRIST ACHE (5,9)	
4	THE CHALK SLED (4,3,5)	
5	LANDSCAPE GRIT (7,6)	
6	A DEFINITE WOLF SLUR (3,1,9,4)	
7	A VALLEY CLOUT (4,8)	
8	CHARCOAL ARM SITS (1,9,5)	
9	ENEMIES OMIT LUST (4,2,2,2,5)	
10	HIRE DAD (3,4)	
11	MARCH SITARS HURT (6,9)	
12	HOLY INDIAN (7,3)	
13	ONE HAM OLE (4,5	
14	CHOIRMASTER FUSS (4,12)	
15	RICH HOME MISLABEL FROST (3,2,4,3,9)	
16	BARMAN RUN TEST (6,7)	
17	HOT NEWSMAN (3,7)	
18	CODERS GO (8)	
19	PROPHETESS RELAX (3,5,7)	
20	A ANT DABS (3,5)	
21	A MISMATCHING SCORE (3,5,9)	
22	A CHESSMAN TESTS RIVERS (6,5,9)	
23	IVY TITAN (8)	
24	THE SHARK HELLS (5,3,5)	
25	GIANT JELLY WHALE (6,3,3,3)	

Cautionary Tales...

A man bought a new kitchen fridge. To get rid of his old fridge, he put it in his front garden and hung a sign on it saying: "Free to good home. You want it, you take it." For three days the fridge sat there without even one person looking twice at it. He eventually decided that people were too untrusting of this deal. It looked too good to be true, so he changed the sign to read: "Fridge for sale, £10". The next day someone stole it.

Caution! . . . These people Vote!

Whilst viewing a house for sale, my brother asked the estate agent which direction was north because, as he explained, he didn't want the sun waking him up every morning. She asked, "Does the sun rise in the north?" When my brother explained that the sun rises in the east (and has done for some time), she shook her head and said, "Oh, I don't keep up with all that stuff."

She ALSO votes!

My colleague and I were eating our lunch in a café when we overheard a young lady talking about the sunburn she got on her summer weekend drive to the coast. She drove down in an open-top car, but didn't think she'd get sunburned "because the car was moving". She ALSO votes!

My sister has a lifesaving tool in her car. It's designed to cut through a seat belt if she gets trapped. She keeps it in the boot.

My sister ALSO votes!

My friends and I were buying some cases of beer at a supermarket and noticed that the cases were discounted 10%. Since it was a big party, we bought two cases. The cashier multiplied two times 10% and gave us a 20% discount.

He ALSO votes!

I couldn't find my luggage at the airport baggage area. So I went to the lost luggage office and told the woman there that my bags never showed up. She smiled and told me not to worry because she was a trained professional and I was in good hands. "Now," she asked me, "has your plane arrived yet?"

She ALSO votes!

While sitting in a cafe, I observed a man ordering a small pizza. He appeared to be alone and the waitress asked him if he would like it cut into four pieces or six. He thought about it for some time before responding "Just cut it into four pieces, I don't think I'm hungry enough to eat six."



Yes, he votes too!

So now you know who elects our politicians!

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 email 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.

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/

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 predialysis, 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 <u>info@edkpa.org</u> 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.

And finally . . . It's been quite a tough year for all of us, one way and another . . .

We hope you all have a really good

Christmas and all our best wishes for the New Year.

Solution to Mixed up Christmas Films on page 21

24. Shrek the Halls 25. Jingle All the Way

23. Nativity

21. One Magic Christmas 22. Ernest Saves Christmas

20. Bad Santa

19. The Polar Express

18. Scrooged

17. The Snowman

16. Batman Returns

14. Four Christmasses 15. I'll be Home for Christmas

13, Home Alone

12. Holiday Inn 12. Holiday Inn

11. Arthur Christmas

10. Die Hard

9. Meet Me in St. Louis

8. A Christmas Carol

7. Love Actually

5. Trading Places 6. It's a Wonderful Life

4. Deck the Halls

3. White Christmas

2. The Santa Clause

. Gremlins

Thank you

...to the people who have contributed to the newsletter over the last year. Too many to mention (and some people prefer not to be known), but we appreciate your support in making the newsletter what it is today.



Nick Wood Newsletter editor

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 <u>jeanaplin@live.co.uk</u>
Membership of the EDKPA is free!

Your EDKPA – who are we?

PRESIDENT DR LUCY SMYTH

DR CORALIE BINGHAM VICE-PRESIDENT

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

Chris Rolfe cdrolfe@aol.com TREASURER

COMMITTEE Kate Cresswell (Kidney Care UK), Keith Forbes, **MEMBERS**

Jackie Garry, Sandie Hampshire, Jake Johns, Danny

O'Sullivan, Chris Rolfe, 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

North Devon Kidney Support Group

Donald Lynch Tel: 01271 812300 lynchydon@gmail.com Chairman

Roy Sibley <u>roysibley@dsl.pipex.com</u> Secretary 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