

EDKPA Newsletter

Spring 2022 edition

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Photo: Peak Hill in sunny Sidmouth

*The grass is green across the hill,
But yellow blooms the daffodil.
It's sunshine on a little stalk,
A friendly flower, I bet they talk...*



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

WELCOME!



This edition has a mix from the past, the present and the future. Where we were once, where we are now and where we are going.

From current times, we have news of changes in units, news for younger people and details of an outing from the EDKPA.

For the future, we have a concert in Exeter Cathedral supporting us (please try and attend), plus the Transplant Games coming up in July. We also have a new member on the committee, Joanne Robbins, who can help shape the web-based future of the EDKPA, modernising the new site to make it suitable for the future. There is also an element of the past for Joanne, whose husband was a dialysis patient at the old Whipton unit (I remember Joanne visiting her husband when I was on dialysis, a long, long time ago). As for the future, we are asking you for content for the new website she is developing and suggestions for a new logo. Please send us your thoughts, articles and logos (see page 16).

From the past and have very much changed our present, we have tributes to Peter Shearman and Wendy Sincock, who have been such a part of the EDKPA for a long time as chairman and team manager/committee member for so long. They have been a large part of the EDKPA's past and affect all of us now. Their legacy to the EDKPA will live on long into the future. They are both dearly missed by us all, and our thoughts are with their families.

Nick Wood, Newsletter editor

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.

A Tribute to Peter Shearman



Peter was a quiet chairman, allowing people to have their say during meetings before a way forward was reached. He quietly dealt with conflicts that arose, talking to those concerned to resolve issues. He was a pleasure to work with. We occasionally had chats after I finished on the committee, as we both suffered from bad backs.

A charming and caring man and always smiling. Below is a tribute by George Palmer, our present Chairman:

Peter Shearman was chairman of the Exeter & District Kidney Patients' Association from 2009 to 2014 and died on 20th November 2021 aged 69. He had been a member of EDKPA since 1987. He leaves a wife Sue, three children Andrew, Michelle and Mark, and five grandchildren Jamie, Lewis, Jodie, Jake and Mara.

Pete was just 34 when he was first diagnosed with kidney failure in 1987. After spending six months on dialysis, he received his first transplant in November of that year which transformed his life for the next nine years. He then returned to dialysis before receiving a further transplant in April 2001. This was a perfect match for him which meant that he never needed dialysis again. Pete had many health issues over the years, the worst of which was losing his mobility and his failing eyesight. Despite this, he never lost his sense of humour, took everything in his stride and enjoyed life as best as he could. His love of gardening grew over time and he could often be found tending to his tomato and cucumber plants which were distributed far and wide and for which he became renowned.

Pete remained continually grateful to the families of the people who kindly agreed to donate their organs and which made such a difference to his life. He was always grateful as well to the Renal team in Exeter for taking such good care of him and for never giving him up. Being diagnosed at such a young age, he never really expected to see his children grow up, let alone get to know his grandchildren.

Pete's funeral took place on 7th December 2021 at Exeter Crematorium. Pete's successor as chairman George Palmer attended on behalf of EDKPA. A collection was made on behalf of EDKPA which raised a total of £750.

George Palmer

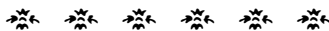
A Tribute to Wendy Sincock

A hugely happy, hard working and friendly person who never gave up supporting kidney patients. She was a tower of strength for everyone and will be missed. You can see her page notice [here](#).



I must acknowledge Wendy's absolute commitment to the Transplant Games and the help and support she gave to so many. I have one enduring memory of her trying to get an old dialysis machine to be used for promotional work from my Land Rover Discovery to her estate car at Okehampton Services! It's amazing what can be done with determination and Wendy had plenty of that.

My thoughts go out to both families at this difficult time.



Below is a tribute by George Palmer, our present Chairman:

Wendy Sincock, kidney patient and long time member of the EDKPA committee, died on 23rd November 2021, aged just 63. There aren't many people like Wendy. To those of us who knew her through the committee, she appeared to have endless amounts of energy, enthusiasm and generosity. She was always the first person to volunteer for anything that needed to be done and then to go and do it. In particular she was known to us as the



Team Manager of the Exeter Transplant Games Team.

Wendy was diagnosed with kidney failure in July 1993 and was lucky enough to receive a transplant in October 1998. It was only some eight months thereafter

that she took part in her first transplant games in Birmingham 1999. This was the start of her winning numerous medals in swimming, athletics, cycling and canoeing at British, European and World Games. Indeed, Wendy and her husband John travelled the world with Wendy representing GB in Japan, France, Canada, South Africa, China, Thailand and Sweden.

As well as her transplant games medals, she was also awarded the Express & Echo Achievement Over Adversity Award. Wendy and John were then invited to attend one of the Queen's garden parties where she was introduced to the Queen for a "chat". After explaining about her activities following her transplant, the Queen turned to John and said "How do you keep up with her?"

The truth is that none of us really kept up with her. But at EDKPA we greatly appreciated all her contributions and it goes without saying that she will be greatly missed. We hope to find someone else to fulfil her role as Team Manager to our transplant team so that we can continue to build on all her hard work in managing such a successful team. Her fundraising will also be missed as she raised so much over the years for us.

Wendy's funeral took place at St Michael's Church, Spreyton in December, where she lived. Much of the village was there and the church was packed. A collection was made for EDKPA which raised over £1,600, for which we are extremely grateful.

Our thoughts and sympathies go out to John and all her family and friends.

George Palmer

LOCAL NEWS ~ Introducing Joanne

We are lucky enough to have a new committee member, Joanne Robbins, who brings a wealth of skills and experience to the committee. I remember her visiting the Unit to see Pete (see below) when we dialysed in Whipton ~ now Whipton Community Hospital (the dialysis unit and ‘C-Block’ was based there in the 1980s).

Joanne is also developing a new website for the EDKPA and is requesting your thoughts and ideas.

Hi members,

I thought I'd introduce myself and why I care about kidney failure.

I'm Joanne Robbins (formerly Campbell). I was really pleased to join the EDKPA committee in late 2021. Doing something for the Kidney Charity once I'd retired (which I did last summer) was always my wish ~ to be able to give something back, in some way or another.

Some 40 years ago my late husband Peter Campbell and I had recently married and were setting up a home in Torquay. We had saved up for our first holiday abroad which was wonderful and shortly after our return Peter fell ill. It took a while to diagnose the condition and a further two years for his kidneys to finally fail; he then lost his job.

Like most of you will know, the acceptance of kidney failure and living with it was so daunting, especially before the internet was available to find out more about kidney failure. However, thanks to the staff at Whipton Hospital in Exeter, we soon learnt the ropes and moved home where we spent three sessions a week on home haemodialysis.

Gradually life sorted itself out, Pete went to college and retrained as a graphic designer, I carried on working in a bank, dialysing Pete in the evenings and at weekends. Jean Aplin, our secretary all those years ago, planned a holiday in the South of France where a group of us



went to enjoy the sunshine and relax. Myself and the other carers all had a wonderful break and our other halves joined us following their dialysis in the local unit. It was such an unexpected treat, a break from the routine, we had fun thanks to those who made it possible.

There were fêtes, coffee mornings, social events and we felt supported by those in the same situation. The home sisters were caring and funny, especially ours; we enjoyed Mary's visits, with the exception of her finding new places to needle!

Over the years that followed Pete received a transplant from his brother, a strapping rugby player at the time! Two years later our son was born: we were on top of the world, so fortunate and great to see Pete's energy and drive return. Now a fully qualified designer, Pete set up a business and when it grew, I joined the work force too.

A transplant baby was quite unusual at the time and when our son was four he was invited to be a mascot for Exeter City football club who sponsored this event for the EDKPA. I still have the photos tucked away!



Time passed and a few years later Pete was back on dialysis, CAPD this time. He took it in his stride and managed the bag exchanges whilst he worked during the day. We had some holidays by getting the dialysate delivered to Jersey and Brittany. We realised all of these things don't just happen; it takes people to organise, negotiate and deliver, all of which we were grateful for.

We worked hard and our business became more successful, our team grew. I guess we both knew we needed to make our future as secure as possible due to the uncertain nature of being a kidney patient.

After several years we had that “unexpected phone call” ~ a cadaver kidney had been found to be a good match and off we went to Sid Ward for tests. Despite a few teething problems, the transplant was successful and once again we found ourselves thankful to so many people who made this possible on all levels. We were gifted time to enjoy all of those things you miss when undergoing a dialysis regime.

With renewed energy we changed the business model to focus solely on website design, which we were to become well known for, not only locally but through the franchise network we set up on a national

level. Employing talented developers and designers, we were soon creating 50-100 websites a month from our head office in Torquay, with franchisees creating sales far and wide, from Cornwall, Hull, London, and even Dublin!

When Pete reached 54 he needed to have an operation, from which he never fully recovered sufficiently enough to work again. It was upsetting for him to see me going off to work in the mornings while he stayed at home and I was torn, both working to keep the business operating whilst trying my best to care for him. Fortunately, our son Josh was at university by this time and starting his own career path in the music industry.

Sadly, Pete didn't see Josh graduate, or live long enough to know what a successful company we'd grown when I finally retired some 12 years later. I'm happy to know however that he lived life for the day: he achieved things we never thought would be possible, he was both inspirational and courageous, despite the limitations he lived with. A lot of that was due to having the security of a caring renal team at the RD&E and knowing what other kidney patients had achieved and going for it!

I'm very happily remarried now. However I have never forgotten the challenges of kidney failure and all the emotions of coping with a life on dialysis.

So ... I'm currently in the planning stages, with the help of others, to create a brand-new website for the EDKPA to enable patients to find



out not only lots of useful information, but local news, patient stories, new recipes, fundraising events and anything else you feel would be welcomed by the members!

This is all about you and making you feel connected with others in the same situation. Let's do this together and make the EDKPA news-worthy on a national level by sharing some of the accomplishments you've achieved!

Please let me know your thoughts and stories by emailing me at admin@edkpa.org.uk



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Ria is moving on . . .

We recently wrote about Ria's replacement (the ex-firefighter and parachute jumper Eve ClaireVue), but thought it would be interesting to let you know where Ria is going.

Hello all,

I hope this latest addition of the Newsletter finds you well.

Since I last wrote an article for the Newsletter, my clinical role has changed. I have been the nurse link for the EDKPA for many years and worked as the CKD nurse, senior AKI nurse and young adult worker for the RD&E.

I am very happy to announce that I have been successful in being appointed as the Clinical Matron for Renal and Dermatology. I started in my new role on 14th February and I am enjoying every moment. I feel I can bring a vast amount of skill and knowledge to this role and want to continue our high standard of care and compassion to you, our renal patients and families/carers.

I would like to take this opportunity to thank Mickie Dicks for her time as Clinical Matron and we wish her well in her new role as Programme Manager and Lead Nurse for the South West Renal Operational Delivery Network.

Best wishes and take care.

Ria Taylor

Clinical Matron for Renal and Dermatology

Luckily for us, Ria is staying on the committee of the EDKPA.

Younger People

A new young transplant clinic is being opened in order to reach out and help new young patients. There are also steps to smooth the link between young people and adults so the transition is more seamless at what can be a very difficult time in terms of development and also transitioning to the 'adult' world, including social care etc.

What good news?

Doctor to Patient: "Which do you want first, the good news or the bad news?"

Patient: "Give me the good news."

Doctor: "You're about to have a disease named after you."

Transplant Games ~ we need a new manager

Sadly, as reported in the December edition, Wendy Sincock passed away, leaving a huge pair of shoes to fill. Wendy was already planning for the team to go to Leeds and we would like her massive legacy in this (amongst other) areas to continue and the Leeds Games are coming up in July.

Exeter has always been an enthusiastic participant in the Games and has always sent a team from the very early days, when they started in Portsmouth.

Wendy picked up the captaincy in the early days and has shepherded a team to the Games ~ wherever they have been (this year, they are in Leeds). The leader generally keeps the team in order and arranges the accommodation and ensures the team has the correct medical forms etc. The website below has more details. Everything is already managed by Transplant UK.

If you have been a past participant, or feel like going this year, please consider being the team manager. You will be surprised at how much you will enjoy it and also meet many other people at the Games themselves.

If you think you can lead the team, please contact info@edkpa.org.uk for further details. You can find out more about the [Games here](#).



From Wales with love ... Auctioneers raise £1,500

One of our committee members, Sandie Hampshire's son Charles, works for Auctioneers, Rogers Jones in Cardiff.

In 2021, they selected Kidney Wales as their charity and raised £1,550.

Charles' father was on dialysis in Exeter and Charles was always aware of kidney disease from a young age when he was on dialysis here.



Devon Philharmonic Orchestra 🎵🎶🎷

A Concert for EDKPA on Saturday 30th April, 2022

We have received an email from Dr Sally Hulin, whose husband is about to start kidney dialysis. The concert is supporting the EDKPA with a wonderful programme of music from Copland to Tchaikovsky. The performance is sure to be a real treat in Exeter Cathedral, which is a wonderful venue for the music, as well as a well-ventilated one! There will be a collection at the exit.

After a packed November concert, Devon Philharmonic Orchestra is delighted to be returning to Exeter Cathedral on Saturday 30th April at 7:30 p.m. 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.

Tickets for the concert are on sale now priced at £20, £17, £15 and £13, which includes a programme for the concert and are available from <https://www.ticketsource.co.uk/devonphilharmonicorchestra/t-onlnko> or by linking through from <https://www.devonphilharmonicorchestra.co.uk/whatson>.

For more information about Devon Philharmonic Orchestra please visit <https://www.devonphilharmonicorchestra.co.uk>, find us on Facebook or Instagram or follow us on Twitter.





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 website www.kidneycareuk.org.



The new Bridgwater Clinic

Danny O’Sullivan (one of the committee members) sent this report on the new Bridgwater Clinic:

The clinic has been up and running now for just over six months. It is nice and light and coping well with Covid cases, even with a constant change in many of the staff for various reasons. Having said that, the staff are very good and cheerful, considering all they have to contend with.

The beds do not have the same provisions for adjustments to comfort/positions and are inferior to those beds at the Bathpool clinic; several patients have made adverse comments about them.

I have asked on several occasions when will there be facilities to place outer clothes, because at present the patients have to bundle up their coats etc and place them on a window sill or shelf ~ not a good idea if wet. I was informed that the necessary items required were to hand, but no one was available to fit or install them.

The winter edition of the N.L. was distributed as far as possible by the receptionist, at my request, which I thought was preferable to them staying in the magazine racks as has happened previously.

Quick update: coat hangers have now been installed in the waiting/reception area. We now appear to be fully staffed with less reliance on temp/agency/pool staff.

You can find the clinic at Bridgwater Satellite Dialysis Unit, Salmon Parade, Bridgwater, TA6 5JT.

Let us know if you have [any comments](#), or put any feedback on our Facebook site. Thank you.



‘Oh, yes it was!’ . . . great fun for all at Aladdin

Jean (our Secretary) sent in this report of this year’s pantomime in Plymouth (a regular outing offered to all EDKPA members):



Since 1998 our Association have been making an annual trip to see the annual pantomime at Plymouth Theatre Royal. Yes, we did miss last year (2021), but that was because of Covid and the pantomime was cancelled. This year 30 of us travelled to see Joe Pasquale in *Aladdin*, several of the regulars deciding not to come for fear of catching the virus, which was quite understandable.

The coach arrived at the theatre in plenty of time to allow you to purchase a cup of tea or coffee, or if you preferred something stronger. We claimed our seats and the show began. The scenery and costumes were magnificent throughout and Joe Pasquale and the supporting cast kept us well entertained. You were requested to wear a face mask throughout the performance, but one soon forgot you had it on as you enjoyed the dancing, jokes and banter.

Missing this year was the young children on stage from the audience and the sing-along with the comic ~ due to Covid, I guess.

The pantomime finished just after 3 o’clock and our coach was waiting outside to take us home. Andy, our driver, who has been taking us for many years, had dealt with the draw prizes (we always hold a draw on the coach, people know this and we had a lovely lot of prizes) and ~ as always ~ we drove off and stopped in a layby on the way home to give out the prizes. I won a photo frame. It was with sadness that Andy announced that this would be the last time he would be driving for us as he retires in two weeks. I just hope we will get such a good and helpful driver next year.

That leads me on to inform you that the 2023 pantomime *Sleeping Beauty* has been booked for Sunday 8th January at 1 pm. Why not put the date in your diary and join us? It really is well worth coming and so much more enjoyable than sitting in front of the television!

WE NEED YOU!



Joanne is redeveloping our current website. You can read about her experience and long-held connections with the EDKPA on pages 6 to 8.

We were one of the first KPA's to have their own site ~ created in March 2012 (ten years old!). It's grown quite a bit in content, but we are looking to modernise it. It's a huge task and needs a lot of input from everyone...including you!

We need three things:

Your Views, Your Content and Ideas for a new Logo:

Your Views

About what you want for a website.

If you are a recent member, what did you look for when you found the site? What was missing, what was useful?



What should make the site being local mean (there are many national sites with excellent articles, but what do you want from your site?)

Would you like more social media contact ~ if so, what and through which channel?

Your Content

We've got quite a few of your stories, but we'd like to add to them. If you have some stories ~ no matter how strange, funny, sad, awkward ~



and would like to share it, please let us know. We have all been through so much to get where we are now. There must be some interesting stories out there. You might have a skill that you think would make a good story ~ cooking, design, travel, etc ~ we'd like to hear.

New/Updated Logo



With the new website, it's time to look at the logo →
What do you think of the existing one?

Would you like to have a go at creating a new one or modernising the current one?

It doesn't matter if you cannot design/draw well, we just need the idea and we can take it from there.

It should reflect and purpose the values of the EDKPA:

- * It is local (Devon and beyond its boundaries)
- * It supports local pre dialysis, dialysis and transplant kidney patients and their partners/carers.
- * It provides additional support that the NHS cannot (or will not), see the 'What does the EDKPA do for you?' page in this Newsletter.

You can create a logo by either drawing it, using a logo application



(Google 'free logo creator' or see [this page](#) for a selection), or using Photoshop or an excellent free alternative like [Photpea](#).

Post your entry/s to the secretary (see Contacts) or email them to admin@edkpa.org.uk by 28th April. Your logo could be the future look of the EDKPA. Thank you and good luck!

We would particularly like to hear from our younger members. We would like you to be part of this new site and communications (Facebook, blogging, YouTube, LinkedIn etc). Whatever you do online, would you like to be part of the EDKPA and use your skills to help out? Please talk to Eve or email Joanne on admin@edkpaorg.uk.

If your particular speciality includes design, story-telling, blogging ... anything. Let us know.



WELLBEING / GENERAL INFORMATION

KPA Day for all Kidney Patients

Registration now open!

Always worth attending, even if virtually (saves the train fare)



Registration is now open for this year's KPA day. This event will be held virtually on Saturday 9th April starting at 10.00am and coming to a close at 1pm. Speakers for the day will be from the Renal Services Transformation Programme (RSTP) NKF honorary president, Kirit Modi and NKF Helpline Advisor, Stephen Emmerson, giving an update on the NKF home dialysis campaign and the home dialysis peer support service. During the morning our AGM will be held and executive committee members will be elected. In the final hour the council meeting will be held.

To register your place, please see the link below or email nkf@kidney.org.uk or call us on 01909 544999. You will be sent the link to join once you have registered.

Link: [KPA Day \(Virtual Event\) | National Kidney Federation](#)

10.00 – 10.05	Welcome ~ Chair NKF Jim Higgins
10.05 – 10.35	Renal Services Transformation Programme ~ <i>speaker to be confirmed</i>
10.35 – 11.20	AGM
11.20 – 11.30	Comfort break
11.30 – 12.00	NKF Home Dialysis Campaign and Peer Support Update ~ <i>Kirit Modi and Stephen Emmerson</i>
12.00 – 13.00	Council Meeting and Open Forum



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. Last Christmas 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. To find out more, please contact fundraising@kidneycareuk.org.

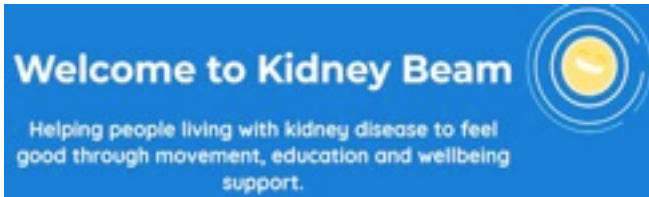
How to get your Kidney Kitchen Recipe Book

To purchase your Kidney Kitchen Recipe Book, please visit 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.

Want to feel good? Try Kidney Beam

[Kidney Beam](#) is a new website helping people living with kidney disease to feel good through movement, education and wellbeing support.

Created in conjunction with the NKF and Kidney Research (amongst others), there are live classes, blogs, beginner's programmes and a 12 week rehabilitation exercise plan for programmes for people.

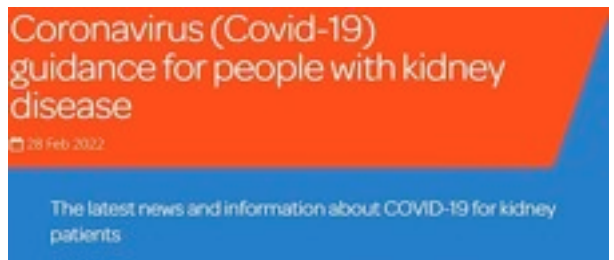


... If you want to be active, or continue, this is a useful site to go on and find exercises and engage with others.

Covid-19 advice from Kidney Care UK

There is a very useful [Kidney Care page which has all the most recent advice for kidney patients about Covid and how it affects us all](#).

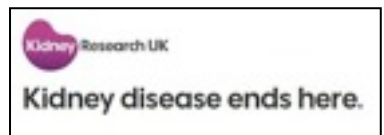
Highly recommended and well worth a read, especially now rules have been changed and we have to think about what we do. It has a list of Frequently Asked Questions for kidney



patients, and advice and what to do if you test positive. Probably one of the best websites I've seen for kidney patients.

If you want to sign up for their latest advice, you can do so [here](#).

Further advice about testing and also for those who are working can be found on the [Kidney Research UK website](#) ~ another great source of comprehensive



information aimed at kidney patients, including [Latest evidence on the risk of Covid-19 for kidney patients - Kidney Research UK](#). You can find all of the above (and more details of local support) are on the home page of the [EDKPA website](#).

Requests for feedback ~ research/local surveys

Local Patient Representatives:

Can you help improve our local service?

We received an email from Mickie Dicks (Programme Manager and Lead Nurse, South West Renal Operational Delivery Network) about the SW Renal Operational Delivery Network and her recruitment of representative patients to help to improve the services that are provided to renal patients in our area.

As part of the setting up of the South West Renal Operational Delivery Network we will be planning to visit all units and introduce ourselves over the next few months and we would be very pleased to attend any KPA meetings.

We are looking to form a Network of patients from units in the Southwest from all *treatment experiences, ages and with a diversity of backgrounds*. We hope this will give us the most rounded feedback to make sure we are doing what patients want us to do.

The commitment may vary depending on your interests with a minimum two hour meeting once every two months to make connections with each other and talk about your units strengths and areas to develop.

A potential time for the main patient group meetings would be 10am to 12 noon on 28th March, 23rd May, 18th July, 12th Sept and 7th Nov 2022 and via teams, unless the group decides to have some meetings face to face.

There will be further opportunities for interested individuals to join the Network work streams (increasing the equity of access to home therapies, increasing the transplantation rate while decreasing the waiting time to transplantation and improving the rates of permanent vascular access for those on haemodialysis) which may be a further two hour meeting every three months. We will also be looking for a representative from this patient group to join our quarterly board meetings.

We are able to provide payment for out of pocket expenses to enable people to attend these meetings.

There are a couple of documents which would be useful to check if you are thinking of this:

[Patient and public voice advertisement](#)

[Requirements of the person volunteering](#)

Transplant recipients ~ Research into Covid relevant for transplant recipients (MELODY)

Please find time to complete the below if you have time. It all contributes to the common good for all kidney patients:

We received the item below from Dr Aisling McMahon about a research project involving immunosuppressed people. Please join if you can:

“We are supporting a new national study to investigate and identify those who may still be at risk. As our valued supporters, we wanted you to hear this important news fast. The study, known as ‘MELODY’, will involve 36,000 immunocompromised patients across the UK, starting with those with kidney and other organ transplants, and then later including patients with cancer and auto-immune diseases. We strongly encourage transplant recipients to consider taking part, patients’ participation will be invaluable. Registration is open here: www.melodystudy.org.

[Find out more about the study](#) on our website and please share this news with anyone you think will be interested. Thank you for your ongoing support, without which we could not fund vital studies like this.”

The MELODY Study is funded by



Partners/Carers ~ Are you helping someone with a kidney condition (Exeter University)?

We received this request from Chelsea Coumoundouros at Exeter University. [The survey takes about 15 – 20 minutes to complete](#). Forward this on Facebook if you can.

“Thank you so much for being able to share the information about the survey. Sharing the survey both via Facebook and your Newsletter would be very much appreciated! We have some posts about the study on our Facebook page that can be shared if that makes things easier.”

<https://www.facebook.com/KidneyCarePartnerResearchProject/>



Are you helping someone who has a kidney condition?

We are designing a support programme for people who help someone with a kidney condition. What would you want in a programme like this? Tell us in our online survey!

What do we mean by "helping someone with a kidney condition"? It could mean something like...

- Helping with their medical care or talking with their care team
- Helping around the house like cooking or cleaning
- Listening to them if they are worried or stressed



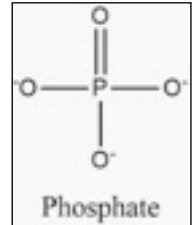
The PHOSPHATE Study

Sharon Huish contacted me regarding patient involvement roles for a new phosphate study. You need to be able to be available for quite a time and devote significant time, but there are rewards.

This study will examine whether reducing phosphate levels in dialysis patients will improve:

- Life expectancy
- Heart health
- How patients feel or function

You can find further details and who to contact [here](#) if you would like to take part.



[Note: You have to give them credit for creating a relevant name for the study: Pragmatic randomised trial of High Or Standard PHosphAte Targets in End[1]stage kidney disease ~ The PHOSPHATE Study.]

Covering all possible outcomes

Whilst waiting at the dentist's surgery for a difficult wisdom tooth extraction, I was handed a couple of forms to fill out. As I signed the first one, I joked with the receptionist: "Does this say that even if you pull my head completely off, I can't sue you?"

"No, that's the next sheet," she said. "This one says you still have to pay us."

Watch this space ...

As your support organisation, we are looking at other ways to ensure the support we provide is as relevant and efficient as possible. We hope very shortly to announce an agreement with a fellow charity to enhance financial support available for patients finding themselves in difficulties.

Keep watching for the Newsletter and our Facebook page!

Something to keep your mind active:

1. Can you name three consecutive days without using the words Monday, Tuesday, Wednesday, Thursday, Friday, Saturday, Sunday?

2. What works better once it is broken?

Answers on page 32

How to stay young . . .

1. Throw out non-essential numbers.

This includes age, weight and height. Let the doctors worry about them. That is why they are paid.

2. Keep only cheerful friends.

The grouches in life only pull you down.

3. Keep learning.

Learn more about the computer, crafts, gardening, whatever . . . never leave the brain idle. “An idle mind is the devil’s workshop” ~ and the devil’s name here is Alzheimer’s.

4. Enjoy the simple things. Don’t over-complicate it, the simpler the better.

5. Laugh often, long and loud. Laugh until you gasp for breath.

6. The tears happen. Endure, grieve and move on. The only person who is with us for our entire life is ourselves. Be ALIVE while you are alive.

7. Surround yourself with what you love, whether it’s family, pets, keepsakes, music, plants, hobbies, whatever. Your home is your refuge.

8. Cherish your health: If it’s good, preserve it. If it’s unstable, improve it. If it’s beyond what you can improve, get help.

9. Don’t take guilt trips. Take a trip to the shops, even to the next county; or to a foreign country ~ but NOT to where the guilt is.

10. Tell people that you love them, at every opportunity.

**AND
ALWAYS
REMEMBER:**

Life is not measured by the number of breaths we take, but by the moments that take our breath away!



Famous Films Dingbats

“Say what you see” to reveal 15 famous films.

Answers on page 32

mid-day

1

NERO
ROOF

2

here → for
ever

3

Fib
George V

4

cam cam cam
cam cam cam
cam cam cam
cam cam cam

5

Oz Zo Oz
Oz Zo Oz

6

BA CK
Everest

7

Dr. Do

8

First
Floor



9

chorus

10

→XX←

11

→GUN
GUN
GUN

12

PANTHER

13

CLOCKWORK

14

October
31

15

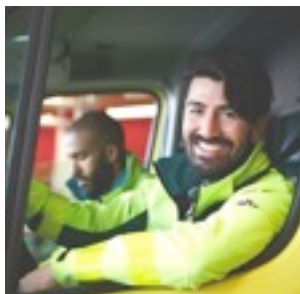
Did you know we were one of the oldest KPA's in the country?

I found this article written by George Palmer, our chairman in the 'In Touch' magazine from the National Kidney Federation. You can download the magazine here: [In Touch Newsletter](#) (Jan 2022, page 3). In this issue George discusses the history of their KPA:

The Exeter & District KPA was formed in 1970, making it one of the oldest KPAs in the country. Back then annual membership cost 15 shillings (75p) and there were 28 members. We now have a membership of around 350 to 400 and it's free. Our secretary, Jean Aplin, was not present at that first meeting, but her husband Pete was. However, Jean did become treasurer in 1972 and subsequently secretary in 1977. She has been the secretary of the association ever since ~ although Pete sadly died in 1993.

In the early days, Jean remembers fundraising with volunteers including knitting bags, slippers etc and sewing together items from offcuts of shirt materials that were supplied by a patient who worked in a shirt factory. Since then we have been able to build up our reserves from other fundraising events, through people kindly leaving us legacies in their wills and fundraising websites. These monies have been wisely invested over the years which means we have been able to assist patients in our area who suffer from all forms of kidney disease.

The “& District” in our name refers to the whole of Devon (excluding Plymouth) and most of Somerset. It is largely rural so transport issues are of particular importance to our members. We have a good relationship with our local CCG and are therefore able to help sort out transport problems as quickly as possible. We have assisted in the rollout of the personal transport budget scheme, putting patients in charge rather than the NHS. We have also entered into an agreement with Citizens Advice Exeter, whereby we fund an advisor to assist our members in all aspects of claiming benefits. This is a service tailored for renal patients and covers everything from initial advice through to completing application forms and arranging advocacy if required at appeal hearings.



We also use our funds to try and fill in the gaps missed by the NHS. This includes the purchase of TVs, hospital equipment and the funding of a specialist nurse. We also fund a quarterly Newsletter, social functions, grants to members who find it difficult to make ends meet and subsidised trips to the pantomime etc. This year we are looking to revamp our website and to upgrade our IT systems and our social media presence.

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 arrange to 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 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 Copplesstone.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.kidney.org.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.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.

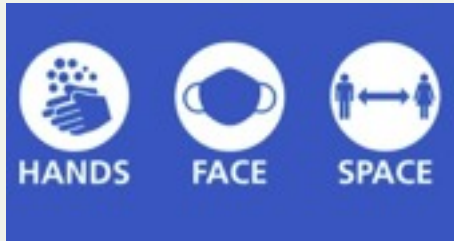
You can download a form here:

<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.**

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, Joanne Robbins, Chris Rolfe, Nick Wood	
Co-opted	Ria Taylor (Clinical Matron for Renal and Dermatology)	
Other contacts	Website/Newsletter	Nick Wood info@edkpa.org.uk
	Taunton Group	Danny O'Sullivan danny.wellerswick@btinternet.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*

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!



Newsletter ~ do you receive it via post?



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.

Nick Wood, Newsletter editor

Answers to Famous Films Dingbats on page 25

1. High Noon
2. Fiddler on the Roof
3. From Here to Eternity
4. Lion King
5. Camelot
6. Return to Oz
7. Brokeback Mountain
8. Doctor Dolittle
9. West Side Story
10. A Chorus Line
11. Kismet
12. Top Gun
13. The Pink Panther
14. A Clockwork Orange
15. Halloween

Answers to Keeping your Mind Active on page 23

1. Yesterday, today, tomorrow.
2. An egg.

Diary Dates

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

Saturday 30th April 2022

Devon Philharmonic Orchestra ~ a concert for EDKPA at Exeter Cathedral, 7.30 p.m. (see page 12 for full details).

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.