

**Exeter and District Kidney Patient Association
Newsletter – Winter 2022**

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This newsletter is available as a download on the [EDKPA website](#).

Editorial


It is with great sadness that we record the death of our chairman, George Palmer. George took over from Mel McColm and did a huge amount for the EDKPA and had the patients at his heart, having been experienced life as one. Not one to shout, he worked tirelessly and effectively for the wellbeing of local patients and also nationally as secretary of the National Kidney Federation. His obituary is below in the newsletter.

*For this festive version of the newsletter,
we have news of times past, times present and future*

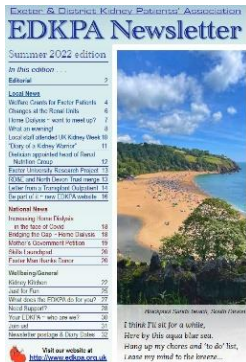
Of times past....

On another matter, you might think the newsletter is looking rather 'old Skool' (as [Molesworth](#) would say). This is the last edition in the current version before we modernise the look and feel of it. Over the years, this publication has been printed in a number of formats. The earliest I can find by Jean (EDKPA secretary, then and now) in September 2007 which included the transplant figures in (16 in the first half of 2007), a seasonal draw, fundraising from Drewsteignton Fayre (£2,000). There were also details in the edition of how well the team did in the Transplant Games (1 gold, three silvers and three bronze) and details of the pantomime trip from Jean Aplin.... Just as there are in this edition(!). Plus ça change.....



<p>Exeter & District Kidney Patients' Association September 2007</p> <p>Secretary: Mrs J. Aplin, 24 Cranford Crescent, Tipton, Devon. EX16 4ET Tel: 01584 254260 E-Mail: japlina@edkpa.org.uk</p> <p>President: Hilary Prosser Tel: 01584 272402</p> <p>Chairman: Geoffrey Deane, Nelson Park, South Molton, Devon. EX36 1ZP Tel: 01584 272402</p> <p>Flora Batters Peter Stannard, 29 Plover Avenue, Torquay, Devon. TQ1 1Q4 Tel: 01584 262626</p>	<p> Theatre Royal - Plymouth Peter Pan Sunday 13th January 2008 1.00 p.m. performance</p> <p>Catch will have tickets 12.15 Tickets: Members £11.00 Non-Members £18.00 Price includes coach.</p> <p><small>September is here and our thoughts turn to the Plymouth Pantomime. Tickets have been reserved since January! I have sent to home if you wish to book. One seat left in the stalls, the best available, the coach stops right outside the Theatre, so very little distance to walk. Come and join us. I must have your bookings with Fall announced for the Newsletter.</small></p>
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Of times present...



The newsletter has been through a few iterations (including being written in Germany for quite a while). The most recent version has been designed by Tom, who brought a new, fresh look to the newsletter which was more attractive for members to read from 2019. Tom always wanted to remain in the background, but we are extremely grateful for the changes he brought about to make the newsletter so much more appealing. His eye for design and experience in the printed word have been greatly appreciated. We also introduced items which were always popular but had somehow got lost in the interim including jokes and recipes (now provided by our own renal dieticians). One change you will notice is the replacement of Sidney Kidney with the new EDKPA logo below.

and of the future



One of George's legacies is the rebranding of the EDKPA which has been integral to the design of the new EDKPA website and replacement logo. Joanne Robbins (a recently joined committee member who used to visit her husband while dialysing in C-Block for those who remember it) has also introduced a new automated mailing system which is far more effective than the original method of mailing we used. She is also responsible for the new-look website which brings the EDKPA brand much more up-to-date together with a much more effective social media and communication tools. If you want to be part of this, please contact her at admin@edkpa.org.uk.

Obituaries

We offer our sincerest condolences to the family and friends of those below.

George Palmer

He knew what was important and did what he could to represent and support local kidney patients. George was also the secretary of the National Kidney Federation and used much time and effort supporting patients at a national level in addition to doing much for local patients and was often in contact with renal managers/staff to ensure the best for kidney patients.

One of his legacies will be the new website for the EDKPA, which he designed with Joanne Robbins (who initiated the project) and is the start of a modernisation of the EDKPA.

Here are some extracts from the Nicky and Kate from the funeral:

.... and then there was surfing, surfing, surfing. ...As a teenager, he started making surfboards at the cottage and strapped them to the top of the blue Morris Minor which he drove around for years, with the very non pc sticker of 'no fat chicks' on it.

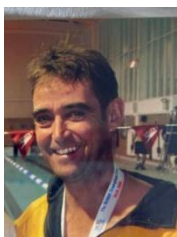
..There was a theme - it was why he ended up working in Exeter. He loved to head off for a surf after work. He continued playing golf, tennis, squash and swimming right until he was taken ill with kidney failure at the age of 44.

In May 2003 he went to his GP feeling generally unwell and complaining of regular headaches. He was sent straight to A&E where he was rapidly diagnosed with IgA nephropathy. In 2008 he had his first kidney transplant which rejected after 12 months; and a second in 2015, which was much more successful. In between kidney transplants he was dialysing six times a week. A big thank you goes to all the doctors and nurses who have looked after him for all these years.

George did some work with the Exeter Homes Trust and was also very actively involved with the Exeter Kidney Patients Association. He put in an enormous amount of work, both locally and nationally, to try and support other people struggling with kidney issues similar to his own. It gave him great pride and a sense of purpose. Latterly, he become involved with counselling recently diagnosed end-stage renal patients.

Mark Harrison

It is with sadness that we heard that Mark Harrison a previous treasurer of the KPA (2004 to 2019) died recently.



Mark was on dialysis for a few months then had a successful Kidney transplant in May 1993, his kidney was donated by his mum. He was also a member of the Exeter Transplant Games Team and attended his first Games in Sheffield in 1995. It was where he met Debbie who at the time was working on the Plymouth Renal Unit and was their Games Team Manager and exactly 12 months after their first meeting they married. Mark won several Games medals in swimming and canoeing and also took part in Volleyball and Badminton events.

Mark and Debbie had 2 daughters together - Zoe and Molly - and he also had an older daughter Amy and 2 young grandchildren

Mark had 29 years with a successful Transplant and a happy family life. He never complained, enjoyed life to the full and would do anything to help others. Mark was a loving husband, a fantastic dad, and is missed by his family and friends.

Our thoughts are with Debbie (previously a renal nurse/matron) and her family

Gilad Jackson

We also received this email from Yvonne Jackman, wife of Gilad, who used to be an EDKPA committee member and who provided benefits advice to kidney patients.

Dear EDKPA

My darling Gilad died at home on Thursday 3rd November after 33 years on dialysis and then recently diagnosed with terminal pulmonary cancer. He survived an almost unheard of 8 days without dialysis, showing the measure of his power of survival.

We gave him a beautiful Jewish burial at Exwick cemetery and over 70 people attended.

He was loved and cherished by so many and our sadness profound.

He served renal patients as a benefits advisor through EDKPA diligently for over 16 years.

Yvonne Jackman

Guy Richards

Guy was one of our longest patients on dialysis, at a guess over 40 years, a single man who loved reading and was willing to try his hand at almost anything. Knowledgeable about gardening, plants and flowers, only recently had to give up his allotment due to his failing health, breed dog and served as a committee member for us and for the NKF.

Always politically aware and vocal over a number of issues for kidney patients.

In Memory of Sharon

I received the below from Jennie Brown, Renal homecare nurse specialist.



Sharon was one of my peritoneal dialysis patients for approximately 3 years and sadly 2 years ago she passed away at the age of 55. She was a vibrant and independent lady who ran The Coopers Arms Public House in Highbridge with her long-term partner Ian. Even when Sharon's health was failing she tried to make it down to the bar for a social chat or prepare food for the skittles team. For the last year of her life after her eyesight failed the Peritoneal Dialysis Assisted Team were going in everyday to help set up her APD machine and care for her dialysis needs. Both Sharon and Ian were very grateful for this as it took a few caring responsibilities from Ian and it gave Sharon contact with the outside world, she always had stories to share with us and loved all the team and made us laugh as well as keeping us on our toes!.



Since Sharon's untimely passing Ian has been very busy fundraising at The Coopers Arms and has raised an enormous amount of money for The Exeter Kidney Unit. He has raised £3000 with killer pool, pub quizzes and charity skittles and he has no plans for the fund raising to stop. Helen Broom assisted practitioner, Ian Bodman and myself Jennie Brown are pictured with Winston the gorgeous dog accepting the very large cheque. The money will be spent benefitting other peritoneal dialysis patients and community renal patients, as well as staff education. Thank you Ian for all your hard work and to Sharon who is missed dearly.

Ian has given his permission to share this information. Written by Jennie Brown Renal Clinical Nurse Specialist for Somerset.

Sidney Kidney – a brief history



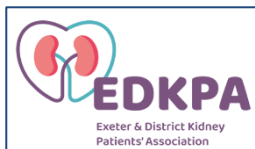
I always wondered where the emblem (later named after Sid Ward when it came to the RD&E) came from. Jean sent me this:

Sidney was created by Henry Phillips a transplant patient, sadly no longer with us. Sidney was made from chicken wire and cover in papier-mâché and was original designed for a carnival float at Honiton near where Henry lived. He was so popular that it was decided to bring him to Exeter and have him on display outside of W.H.Smith when we were trying to promote the Donor Cards. The children loved him and kept touching and cuddling him, by the end of the day he was a sorry state.

Your committee at the time decided as he was so popular to adopt him as our logo and he has served us well over the years. He appeared on our letterhead, collecting boxes, flags, badges tracksuits and nurse's uniforms in our area. His smiling face has done good service for the EDKPA but has been replaced as part of the new branding of the EDKPA.

Our new website – take a look!

Joanna Robbins has - together with George - designed a new website which provides a fresh view of the EDKPA.



Our [new website](#) was launched on 12th September, if you haven't already had a look why not check it out now? We hope you like it and will engage with it and will let us know of anything you'd like to find on it that we haven't thought of.

Even more important we'd like to hear from you so you can share your experiences and achievements with other patients who want to know how others with kidney failure are managing their treatment, hobbies and lifestyles. Our first story is [here](#), yours will be very different no doubt but that's what makes for interesting reading, get in touch the more we receive the better!



<https://www.edkpa.org.uk/>

As the newest committee member of the EDKPA, when I was collating the content for the new website I found it quite astonishing how few volunteers we have to cover the numerous tasks needed to keep the EDKPA operating. I really appreciate just how much the existing volunteers currently do to keep our members informed and up to date with everything available and of interest to our patients and their carers'.

My goal is to maintain the update of the website on a regular basis and to help with fund raising initiatives in the future. We aim to increase our current membership of 390 which we know is far lower than the number of patients (approx. 900) currently under the care of the hospital trust we support. A key problem has been the data protection rules, which prevented the hospital sharing a mailing list with us.

We'd love for some of the younger kidney patients to get more involved by sharing and supporting any fundraising events we plan in the future. We will be promoting these both online on the website and via Facebook so it's important you keep in touch to find out how you, your family and friends can help us, to help those in need.

Can You Help?

Volunteers are so important to the association, if you, or anyone you know could offer a small amount of time we are looking for reliable helpers. We need, in particular, to strengthen the Committee which [administers our work](#). We meet every other month, usually online for an hour or so. please [contact us](#) via the website to let us know if you'd like to join us.

<https://www.edkpa.org.uk/contact-us/>.

If you haven't already shared your email address to sign up to on [our online membership form](#) please be sure to do it now: <http://eepurl.com/h-npwj>. If you want a paper copy, use this bit.ly/3HwYGkP or the form later in the newsletter.

Transplant Games



This year, the Exeter team joined the Plymouth team. The EDKPA supported two members from Exeter to go with them. It's possible we could merge with the Plymouth team – see below for details. Also, a huge 'thank you' to Claire West, who sent the pictures and did a huge amount in organising the team/trip. Not an easy task 😊



We received this full report from Claire West (Research Delivery Manager NIHR Clinical Research Network Southwest Peninsula NHS)

At the end of July four competitors plus supporters, including two from the previous Exeter Transplant Games Team, attended the Westfield Health British Transplant Games in Leeds. They were successful in winning four Gold Medals, six silver medals and one bronze medals. Martin and Mark, kindly sponsored by the Exeter Kidney Patients Association, were successful in gaining six of these medals.



The Games started with Martin competing in the Volleyball and Mark in the Archery. After a hard-fought battle Martin was successful in gaining a bronze medal. Martin also had a tough afternoon at the Archery and unfortunately finished 4th.



The Opening Ceremony was well attended, and the biggest cheer as always went to the Donor Families. During the Ceremony there was a two-minute applause for all fellow transplantees that we have lost in the past few years and I am sure I was not the only one in thinking of the lovely Wendy Sincock, the Exeter Team Manager who sadly passed away in 2021, but will always be remembered.

Friday saw Mark competing in the Ten Pin Bowling, whilst other team members supported other events across the city of Leeds. Friday also saw the arrival of Shaun and Bobby, Shaun being a liver transplantee who is followed up at Derriford Hospital and Bobby is his son.



Saturday was a busy sporting day for the team with Mark competing in the football tournament as the goalkeeper and Mark, Serena and Louise competing in the swimming. Again, at the start of the swimming there was a two-minute applause for the swimmers of the transplant community that are no longer with us – another very

poignant moment. This turned into a day for collecting medals – Gold for Martin in the football, Silver for Mark in the 50m backstroke, Gold for Serena (a live donor) in the 25m Freestyle and Gold for Louise (a kidney transplantee, who is followed up at Derriford Hospital) in the 50m backstroke and Silver in the 50m freestyle, 100m freestyle and 200m freestyle. She also joined the Papworth Transplant Team in the relay race.



Sunday, the final day of the Games saw all the competitors and supporters (adults and children) in the same place at the Athletics. Mark and Martin both competed in the Javelin and were successful in both gaining silver medals and Mark gained a Gold medal in the Cricket Ball Throw (Picture – Martin at cricket ball with medal).

Shaun, along with his son, supported the Children’s social events – football, basketball, archery, sport stacking, badminton.

Highlight of the Event was the Yorkshire Air Ambulance landing at the Track to deliver the first ever Yorkshire Organ Donor Card – a local initiative with the aim of encourage people to have the conversation with their families about organ donation.



The

Gala Dinner on the Sunday Evening saw the team dressed in the fine clothes, bringing the four day event to a close for another year.

The Westfield Health British Transplant Games is an annual event and next year is being held in Coventry. A video of this year’s event can be found at <https://www.youtube.com/watch?v=AiHDuLbm9oo>

The Plymouth Team and Exeter Team are currently in discussion about merging and becoming the Devon and Cornwall Transplant Team, to enable a critical mass to promote the importance of organ donation and show the benefits of exercise post transplant operation.

Want to join the team next year? Please email team@transplantees.co.uk

Photos kindly provided by team members and Richard Hall Photography

Cost of Living Crisis

The EDKPA are here to support you. If you need help, please see the ‘Contact us’ pages in this newsletter or the link on our new website which has details of [financial help and support](#). Including details of our joint venture with Kidney Care UK.



If you need any details of support or the application form for applying for a grant by post, please contact our secretary (Jean Aplin).



You can also find local support on your local authority web pages. For example, Exeter City Council have [this page](#) which contains details of “A package of advice and support measures aimed at helping Exeter residents through the cost-of-living crisis is being coordinated by the City Council.

The Council is looking to coordinate the response of the community and voluntary sector to the ongoing crisis, which could leave households struggling to pay energy and other bills this winter.



Working with the community and voluntary sector, all options will be explored including providing access to warm community spaces and expanding community food larder schemes.”

<https://news.exeter.gov.uk/plans-to-coordinate-support-for-residents-during-cost-of-living-crisis/>

It's Pantomime (Oh yes it is!)

Jean is arranging the annual trip to Cinderella in Plymouth for members. One of the many things she does as secretary for the association, and would encourage you to go – it's a great day out.



The EDKPA offer a discount to members for tickets and transport (there is usually a bus which takes everyone down.)

The cost of pantomime is £15.00 for members and children in full time education free. Non-members are £19.20. There will be a coach from Exeter Southwest Water Board at 11 am or you might choose to drive yourself. Due to the postal strikes, payment can be made on the coach or in the foyer at the theatre, when you collect your ticket.

The seat allocated to the Association are excellent, in the stalls on the ground floor – very easy access.

Just phone or email to book. 01884 254260 Email: jeanaplin@live.co.uk

Do join us it is a great day out.

Budlake Building, Whipton Community Hospital

The Budlake building is now being used for out-patient appointments for patients. A few details which might help:

- 1) It's at Exeter Community Hospital (Whipton), Hospital Lane, Exeter EX1 3RB (right at the end of the campus). [Link here.](#)
- 2) There is plenty of parking. Just carry on straight ahead to the end and use that car park. The one on your immediate right when you enter is too small)
- 3) Usual bloods/urine sample are taken, plus a consultation with the usual renal staff.
- 4) It is very near the very old Whipton dialysis unit*



*The building on the right as you go there was the original site of the dialysis unit – a huge open room with several old dialysis machines. On one occasion, Garfield Dullam (a farmer and patient, who raised £1m ..yes – million. For the EDKPA) brought in a hay bale to sit on as it was more comfortable. (Around the back in 'C Block' was where in patients were treated, and transplant patients recovered from their operation which were then performed at the RD&E.

Shane Cross website

Shane Cross writes:

"I am an Exeter unit patient have been for over nearly 30 years and we have a website with all of my Kidney experience from dialysis to transplant that I would like to [share the address:](#)



<https://sidneykidney2009.webs.com/shanesstory.htm?fbclid=IwAR37IGzWUjV8qvLU-LqNqNwAnOyMGyDi LZLsX8L9c8h5zUOUbXIRStFneo>

It's a great site and fascinating story. Highly recommended.

Scam targeting Kidney Patients

We received this from Ria (our Clinical Matron for Renal and Dermatology)



I have received information today that a patient has been contacted and asked to give their bank details regarding delivery of renal supplies. The patient is not from our renal unit, but I would be grateful if you could share this with the EDKPA.

The NWKN have been alerted to an incident were a kidney patient has been asked for personal bank details. The scammer has used delivery of Aranesp injection as a means of asking for bank details. Please can you highlight this to your Anaemia teams and all kidney units. Please can you advise that renal departments or services linked to the treatment of kidney disease will not ask for bank details and these should never be shared.

U Drains – EDKPA supporting



[U Drains](#) are designed to avoid carrying heavy bags of liquid for people who dialyse at home.

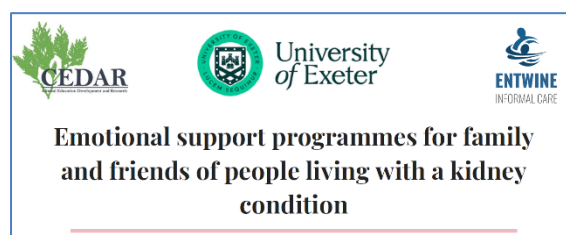
The EDKPA has agreed to help fund the installation of these drains for EDKPA patients together with the hospital University Trust. There will be an initial run of 20 patients to check they work as designed.

22 existing patients had expressed an interest so far making an initial contribution from the EDKPA of £7,700. All new patients using the overnight PD machine at home will be offered the installation. This will be until 2025 when the unit's existing contract with Baxter expires

This is a big step forward for patients and also the environment and we're excited that progress has been made in getting underway.

Emotional support for kidney patients - Exeter University Research results:

Chelsea Coumoundouros contacted me earlier in the year to say she had a survey about emotional support. Recently, she sent me the results which are interesting reading:



Emotional Support Programmes for Family and Friends of people living with a kidney condition

What did participants do to support their family member or friend living with a kidney condition?

Emotional support
Running errands
Cooking

Going to medical appointments
Cleaning/gardening
Helping with symptom management

In addition to supporting someone with a kidney condition...

- **51% of participants were working full- or part-time**
- **38% of participants were providing care to someone else in addition to caring for someone living with a kidney condition**

How were people feeling?

- **38% were experiencing symptoms of anxiety**
- **46% were experiencing symptoms of stress**
- **58% were experiencing symptoms of depression**

How should emotional support programmes be delivered?

- Participants were most interested in using a programme that was available:
- Online (e.g., website)
- What information should be in an emotional support programme?
- Living with a kidney condition
- Support services for family and friends of people living with a kidney condition
- Diet and physical health

Want to learn more?

Any questions, please contact Chelsea Coumoundouros - c.coumoundouros@exeter.ac.uk

Study Twitter page: @Kidney_Carers (https://twitter.com/Kidney_Carers)

Study Facebook page: <https://www.facebook.com/KidneyCarePartnerResearchProject>

General News

NKF Webinars



I didn't realise, but there are a few very useful webinars on the NKF (National Kidney Federation) site which you can play back or attend. Entry is free and they are aimed at patients (not professionals). Previous topics (linked below) have included:

- [Benefits for kidney patients webinar](#)
- [NBTA – Opt out in England](#)
- [Patient Choice - Vascular Access](#)
- [Keeping active with kidney disease webinar](#)
- [Help - I Need somebody, Help webinar](#)
- [Healthy Eating for your kidneys webinar](#)

You can find them [here](#).

NKF 2023 Calendar – we are June 😊



We sponsored June in next year's NKF calendar and received this from the NKF (our governing body):

Firstly I would like to thank everyone at Exeter & District KPA for sponsoring the month of June in the NKF 2023 calendar. This year's calendar photography competition was my personal project and I am so proud of the end result!

The calendars are on sale for only £5.00 at [https://www.kidney.org.uk/shop/nkf-](https://www.kidney.org.uk/shop/nkf-2023-calendar)

[2023-calendar](#)

Between 19 and 25 and need help with maths?



If you are a care leaver and care-experienced person aged 19-25 and need support to obtain your GCSE Maths, please get in touch. There will be projects aimed at providing free tuition so that you can pass your GCSE maths. Please contact us at info@edkpa.org.uk.

(Also, if you feel like managing a project to deliver this, there are grants available – please check out [this website: https://www.devon.gov.uk/economy/employment-inward-investment/devon-multiply-grant-scheme/](https://www.devon.gov.uk/economy/employment-inward-investment/devon-multiply-grant-scheme/)

NKF Home Haemodialysis Reimbursement Survey

I received this request from the NKF – if you dialyse at home, please take time to complete the survey:



The National Kidney Federation have created a survey to collate some information with NHS England to ask home haemodialysis patients about whether they are reimbursed or not for their home haemodialysis treatment so we can continue to help patients to be suitably reimbursed.

We would be grateful if you could help us share the survey link on your social channels and also share the survey link out to your members.

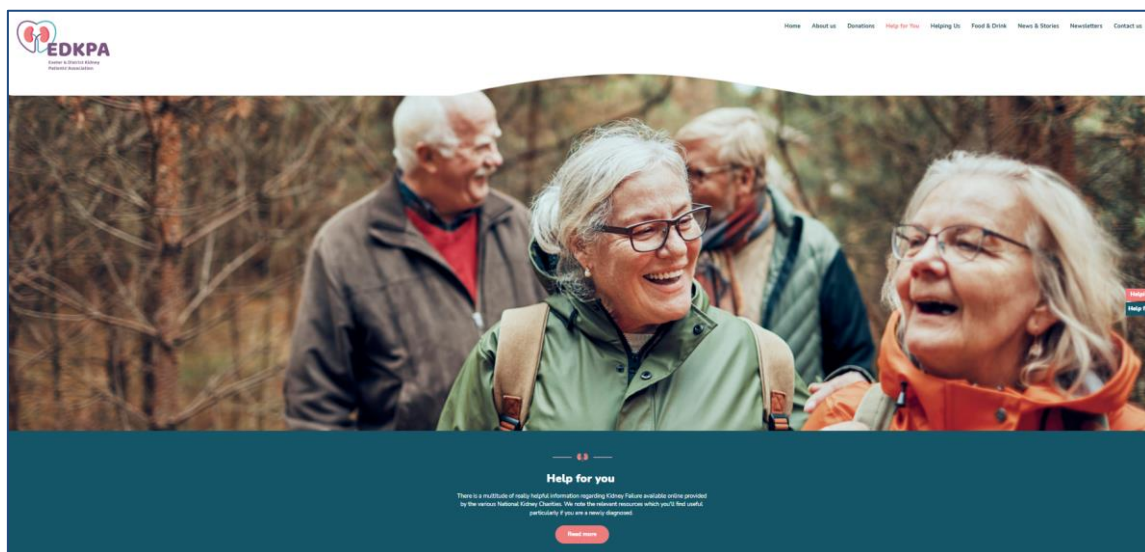
Survey link: <https://www.kidney.org.uk/home-haemodialysis-survey>

Need to Talk? – NKF are now online



While looking at the NKF site (highly recommended for patients), I noticed they now have a webchat function. Although they have a helpline (0800 169 09 36) you can now contact them online. Great development 😊

... Check out our new website [‘Help for You’](#) page:



<https://www.edkpa.org.uk/help-for-you/>

Steamed Christmas Pudding



Special occasion

Vegetarian

	Low phosphate	✓	Low protein
✓	Low potassium	✓	Low salt
43.6g	Carbohydrate	288Kcal	Energy



Nutrition values are calculated per serving • Kidney diet guidelines vary for each individual • Consult your dietitian or doctor for the specific diet that is right for you.

Steamed Christmas pudding

Prep: 1hr 30 mins • Cook: 1hr 30 mins • Serves: 8

This low potassium version of a traditional Christmas makes it an ideal dessert for a festive treat.

Ingredients

250g pineapple pieces in juice

100g demerara sugar

50g glacé cherries

175g self raising flour

1 unwaxed lemon

100g unsalted butter

2 eggs

50g sultanas

2-3 teaspoons mixed spice

Extra butter for greasing

Carbohydrate The main sources of carbohydrates in this dish are the flour, sugar and fruit. Carbohydrate values have been provided for those trained in insulin adjustment.

Phosphate/ potassium Tinned fruit has been used as it is lower in potassium than dried fruit. This helps to keep the overall potassium content of the pudding low.

Serve with double cream or brandy butter rather than custard to keep the potassium level low.

As eggs contain phosphate there is still some phosphate in this recipe. If you have been prescribed a phosphate binder, ensure you take them with this dish.

Protein This pudding is a suitable treat for those on a low protein diet.

Special diets

Gluten free: Use a gluten free flour.

Healthier option If you wish to reduce the amount of fat, use a low fat spread in place of the butter. One serving contains half a portion of fruit.

Storage We would not recommend cooking this pudding weeks in advance as with a traditional Christmas pudding. However, once cooked it can be kept in an airtight container for 2-3 days. Reheat before serving in the oven or microwave.

Tip To cook the pudding if you don't have a steamer you can place a saucer in the bottom of a large saucepan. Put the pudding basin on the saucer and fill with water until it is halfway up the side of the bowl.

Traditional Mince Pies



Special occasion

Vegetarian

✓	Low phosphate	✓	Low protein
✓	Low potassium	✓	Low salt
27g	Carbohydrate	246Kcal	Energy
<i>Nutrition values are calculated per serving • Kidney diet guidelines vary for each individual • Consult your dietitian or doctor for the specific diet that is right for you.</i>			



Traditional mince pies

Prep: 45 mins • Cook: 20 mins • Serves: 12

Using apple and less dried fruit makes this is a great festive treat that is low potassium, low phosphate and low 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 tablespoon caster sugar
1 egg
3 tablespoons cold water

Carbohydrate The pastry along with the sugar and fruit from the mincemeat are the main sources of carbohydrate. Carbohydrate values have been provided for those trained in insulin adjustment.

Phosphate/ potassium As apples are a low potassium fruit, they are used to form the base of this mincemeat alternative, making these lower in potassium than traditional mince pies. There is very little phosphate in each mince pie and they are therefore a suitable snack if you are following a low phosphate diet.

Protein Each mince pie is low in protein.

Special diets

Gluten free: Use gluten free flour.

Vegan: Use a dairy free margarine. Buy a ready rolled vegan pastry or omit the egg from the pastry and brush with a plant based milk alternative.

Healthier option For a healthier option leave the pastry tops off the mince pies, or alternatively use filo pastry for a lower fat alternative. You may wish to consider omitting the sugar from the pastry to reduce the sugar content.

Cheaper option You don't need to use the brandy or rum, but a cheaper option is to buy a miniature bottle to avoid needing to buy a larger bottle.

Storage 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.

Tips To save time you can buy ready rolled shortcrust pastry to use in this recipe.

Try using the pastry recipe and filling with Jam in place of mincemeat for a fruit tart alternative.

Gingerbread Christmas Log



Special occasion

Vegetarian

4	Low phosphate	4	Low protein
4	Low potassium	4	Low salt
47g	Carbohydrate	350 Kcal	Energy



Nutrition values are calculated per serving • Kidney diet guidelines vary for each individual • Consult your dietitian or doctor for the specific diet that is right for you.

Gingerbread Christmas Log

Prep: 20 mins • Cook: 12 mins • Serves: 12

A twist on the traditional yule log, this version is made without chocolate or dried fruit making it a great low potassium festive indulgence suitable for everyone. .

Ingredients

50g unsalted butter

50g treacle

50g golden syrup

2 balls stem ginger, jar

2 tablespoons stem ginger syrup

4 large eggs

100g dark muscovado sugar

100g plain flour

1/2 teaspoon baking powder

2 teaspoons ground ginger

2 teaspoons ground cinnamon

Icing

200g unsalted Butter, softened

250g Icing sugar

2tsp vanilla extract

3 tablespoons stem ginger syrup

Additional butter for greasing

Carbohydrate The carbohydrates in this recipe come mainly from the refined sugars and flour. The total carbohydrate value has been provided for those who are trained in insulin adjustment.

Phosphate/potassium This cake is low in both potassium and phosphate but full of flavour from the ginger and spices.

Protein This Christmas log is a suitable treat if you are on a low protein diet.

Special diets

Gluten free: Use gluten free flour.

Healthier option Like many cakes this is high in refined sugar and should be eaten as an occasional treat and portion sizes should be kept small.

Storage Once made the log can be kept in a sealed container for up to 5 days. To freeze simply re-roll in the parchment, then in foil and freeze for up to two months. Defrost at room temperature before serving.

Tips If you don't have an icing bag, trying using a plastic sandwich bag and snip off one corner to make a hole about 1cm wide.

And finally, from Sharon, our team lead dietician...

First, some recommended recipes from Sharon Huish, our Team Lead Renal Dietician, who has never failed to reply promptly for requests for recipes when I have requested them – thank you Karen 😊

Karen also wishes everyone a very happy Christmas from the Renal Dietician Team.

PS Karen is running the London Marathon in April 2023.

Her story: Working (as a kidney dietitian) with inspirational patients, and NHS colleagues, is an absolute honour and privilege. Seeing the many challenges faced by people living with kidney disease makes the challenge of running London marathon appear comparatively small - even though for me it's pretty huge!



I regularly reach out to Kidney Care UK (KCUK), seeking their advice, support, and financial assistance for local patients under my care. KCUK support over 100 patients every week, offering a lifeline (and bringing smiles) to so many.



I feel lucky to have the opportunity to run London marathon for such a fantastic charity. I'm looking forward to the challenge; I hope I can make the charity, and all the people they support, proud through raising awareness and money.

I have committed to raising a minimum of £2000. If you are able to support me in reaching this target then you can do so by visiting <https://2023tcsllondonmarathon.enthuse.com/pf/sharon-huish> (also accessed via the QR code above). Cash donations can be made at your local dialysis unit, the Exeter renal unit, or through EDKPA. Thank you for your support - it will help keep me going 🏃 and most importantly will help the lives of people living with kidney disease.

If you want to learn more about our dieticians, go to the new website under ['Food and Drink' page](#) You'll find photos and a brief background of the team.

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Our Renal Dietitians

Sharon
Team Lead Renal Dietitian
[READ MORE](#)

Ruth
Renal Dietitian
[READ MORE](#)

Angeline
Renal Dietitian
[READ MORE](#)

Helping Us
Help for you

Contacts and Support

Local support: If you need support and are a patient or carer of a patient, please contact Jean Aplin (01884 254260) or email her at info@edkpa.org.uk. You can also visit the EDKPA website for help and support. [EDKPA - Kidney Patient Help/Support - Exeter](https://www.edkpa.org.uk/) <https://www.edkpa.org.uk/>

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](http://www.transplantsupportnetwork.org.uk) (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 several 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/](http://www.transplantsupportnetwork.org.uk)

Your EDKPA – who we are

Exeter and District Kidney Patient Association

President	Dr Lucy Smyth
Vice President	Dr Coralie Bingham
Secretary	Mrs Jean Aplin 13 Crowden Crescent, Tiverton, Devon EX16 4ET Tel: 01884 254260 info@edkpa.org.uk
Chairman	Chris Rolfe chris.rolfe@edkpa.org.uk
Treasurer	Vacant (Chris Rolfe acting treasurer)
Committee	Trish Moroney (Kidney Care UK), Keith Forbes, Jackie Garry, Sandie Hampshire, Jake Johns, Danny O'Sullivan, Joanne Robbins, Nick Wood

North Devon Kidney Support Group

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

If you would like to join us on the committee, please contact Jean, our secretary who can fill you in on how you could contribute.

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

1 Happy Christmas to all our members.

How 2022 has been for you?....

There will be some good memories, and some thoughtful and sometimes sad ones...

Our committee hope you have a good Christmas and a healthy new 2023.



And a healthy and happy new year..




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 can download this form [here](#).

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

We never use your email address for anything except EDKPA communications.



EDKPA

Exeter & District Kidney
Patients' Association

Registered Charity No 276981

Application Form

Name: _____

Address: _____

Tel: _____ Email Address: _____

Type of treatment: Pre-dialysis / CAPD / Haemodialysis / Transplant (delete as appropriate)
I WOULD LIKE TO BECOME A MEMBER OF THE EXETER & DISTRICT KIDNEY PATIENTS' ASSOCIATION (EDKPA) and to receive their newsletters and other communications.

To comply with the General Data Protection Regulations EDKPA requires your consent to contact you. Please tick the appropriate box(es) to indicate that you agree to be contacted by the following method(s):

- I consent to EDKPA contacting me by post
- I consent to EDKPA contacting me by telephone
- consent to EDKPA contacting me by email

I understand that this consent will be refreshed after 5 years and should I wish to opt out I can inform the EDKPA (by phone email or in writing) at any time.

EDKPA would normally share your personal data with our national body the National Kidney Federation (NKF) of whom we are a member and whose registered office is at The Point Coach Road Shireoaks Worksop S81 8BW. They will then send you free copies of their magazine (Kidney Life) and other communications. Only tick the following box if you would like EDKPA to do this. Otherwise EDKPA will not share your personal data with any third parties.

- I consent to EDKPA sharing my personal data with NKF 1=1

Signed: _____ Dated: _____

Please send to: Jean Aplin, 13 Crowden Crescent, Tiverton, Devon. EX16 4ET

or send an email with the above details to info@edkpa.org.uk.

Membership of the EDKPA is free.



[Exeter and District Kidney Patient Association \(EDKPA\) \(list-manage.com\)
https://edkpa.us17.list-manage.com/subscribe?u=d9e8f57d36293fd112d0b4cf3&id=8dae69ef6c](https://edkpa.us17.list-manage.com/subscribe?u=d9e8f57d36293fd112d0b4cf3&id=8dae69ef6c)