How one loss saved four lives:
A mothers’ story
Editor’s Note...

Welcome to the summer issue of Kidney Life. We have included inspirational stories, tips and mouth-watering recipes to enjoy this summer.

Summer brings with it bright blue breezy days, beautiful blooming flowers and long relaxing warm evenings. However, rising temperatures can also cause dehydration. For those who have received a kidney transplant, this of course means keeping yourself hydrated. Ensuring that your summer isn’t spent by being poorly, read about the importance of hydration and some tips to help you along on page 7.

The NKF is pleased that the opt-out organ donation system gained royal assent, read about the latest news on deemed consent and the year-long Pass It On campaign on page 14.

Diane Taylor, an award-winning volunteer and an avid campaigner shares her experience of losing her son Daniel and how the decision to donate his organs has helped her on page 10.

We often hear many inspirational stories from our patients, who are either on dialysis or transplanted. In this issue, we’d like to share the moving experience of Amara, who through the suffering of her close friend learnt the balance between caring for someone and being cared for on page 6.

Try out our mouth-watering recipes on pages 16 specially designed to renal patients.

As always, we have been inundated with your stories, support and compassion. We thank you for all your support.

Sumaya Masood
Editor

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The NKF would like to thank the following companies for their continued support.

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Vice Chairman James Barr, Lancashire and South Cumbria KPA
Treasurer Mark Davis, North Staffs and South Cheshire KPA
President Ken Tupling
Patrons Lawrence Keogh and Nina Wadia

NKF Officers and Executive members do usually belong to a KPA, but offer their services to NKF as individuals. As such NKF recognises that views expressed by its Officers and Executive members are expressed as individuals and do not necessarily represent the views of their KPA.
The NKF always endeavours to support carers, families and patients through challenging times. The NKF has a free dedicated helpline, providing support with two fully trained and experienced advisors. The helpline supports kidney patients, carers, healthcare professionals and Renal Units.

The NKF helpline is also the UK’s largest provider of kidney-related medical information leaflets with a library of over 200 titles written by Nephrologists in simple language for patients and carers.

So whether you require information on benefits, chronic kidney disease, dialysis, transplantation, dietary or holiday information then call the helpline today.

Our advisors, Pauline and Stephen are waiting for your call on 0800 169 09 36.

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- Norfolk

Our Helpline is free of charge to call on 0800 169 09 36

The NKF runs the only UK Helpline dedicated to kidney patients, with over 200 unique and regularly updated information leaflets and two fully trained, experienced advisors providing a 5 day a week service to kidney patients, carers and healthcare professionals.

The NKF Helpline is open from 9am until 5pm Monday to Friday on 0800 169 09 36 e: help2@kidney.org.uk

Registered Office:
The Point, Coach Road, Shireoaks,
Worksop, Nottinghamshire S81 8BW
T: 01909 544999
E: nkf@kidney.org.uk
Charity No. 1106735
Co. No. 5272349 reg. in England & Wales
Give as You Earn contribution No. CAF.GYS11

www.kidney.org.uk
HELPLINE 0800 169 09 36

If you want to raise funds for the NKF, plan an event, make a donation to the NKF or discuss leaving a legacy to the NKF please contact Pete Revell (NKF Head of Fundraising).
T: 01263 722287
E: pete@kidney.org.uk

All CALLS to the NKF Helpline are FREE of charge.
KC Holiday Dialysis Centre
(Bournemouth)

Established 1995

- Open all year round.
- Free treatment to NHS patients.
- Direct online booking so patients can check availability and book at a pace that suits them.
- Choose between morning and afternoon sessions.
- Help provided with your booking every step of the way.
- Can recommend accommodation depending on your needs.
- Providing a caring, professional and friendly service for over 22 years. Making your stay with us as comfortable as possible.
- Refreshments while on treatment.

The unit’s facilities offer the following:

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35 Southwood Avenue, Southbourne, Bournemouth, Dorset BH6 3QB

For further information telephone 01202 422311
www.kcdialysis.com
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Come and join us in this year’s Annual Patients’ Event which will be held at Radisson Blu Hotel, East Midlands Airport.

Taking place from the 4th to the 5th October 2019, we have an extremely inspiring programme in place for you, all taking place within Radisson Blu Hotel, East Midlands Airport.

The hotel is a great location that is just off the M1 motorway, making this easily accessible from wherever you may be travelling from.

Many of our delegates who wish to participate in this incredible event take away a brilliant experience that provides the opportunity to meet with hundreds of fellow patients and professionals. Delegates also have the opportunity to witness some heart-warming speeches from patient’s and also experience talks from influential speakers from the renal world.

The event starts off on Friday evening with a hot buffet and entertainment. Remember this year we are giving the Friday supper free of charge to the first 100 kidney patients who book.

On Saturday, the day is packed with fascinating professional and patient speakers who will share their expertise and experiences to benefit us all.

Questions and answers sessions will follow each of the morning and afternoon programmes, giving you an opportunity to get your voice heard. Throughout the day you will also have the opportunity to network with an array of individuals. You will also have the chance to explore the labyrinth of stalls, that will be on display throughout the event.

During your visit, you may also wish to use the hotel’s modern fitness centre, or use the complimentary access to the 12.5-metre heated pool, a steam room and sauna. You may also wish to invest in your well-being with a trip to the Serenity Spa, that offers a wide range of beauty and holistic treatments.

On Saturday evening, once you’ve rested, why not join us for the luxurious dinner, followed by a motivational speaker and a disco.

The NKF Annual Patients’ event is always very popular, occurs once a year and gives you the platform to be part of a wider community. So why not book your place early, to avoid disappointment.

A booking form outlining rates can be found on the back page of this issue of Kidney Life. Or you can call the NKF Head Office on 01909 544999 for further information. We look forward to seeing you there!

SOME OF THE EVENT SPEAKERS INCLUDE:

- Irene Bellini on ‘Creating access and Transplantation’
- The Role of a Holiday Coordinator
- Home Hemodialysis from a patient’s perspective
- David Coyle on ‘Kidney Patient Involvement Network (KPIN)’
- Empowering patients by shared decision making in their dialysis journey
- Kidney Kitchen – A collaborative project by Renal Dieticians and Social Workers (North Wales)
- Kirit Modi and Hope Clayton also discuss ‘Establishing a Peer Support Scheme: a Partnership Approach’

Thank you to all our sponsors of the Annual Patients’ Event.
The Balance Between Caring and Being Cared for

My lessons following a loved-ones suffering
by Amara Akram

Chronic kidney failure is a difficult situation not only for patients, but for families and caregivers as well. Those closest to the patient are also affected. Below is a personal account of someone who has been indirectly impacted and the adversity they faced.

At the age of 22, my childhood friend was diagnosed with kidney failure. I could never have anticipated how much helplessness, guilt and selfishness this journey would entail. While supporting her and trying to be there for her, it never felt enough for me. You see them go through pain and there isn’t a single thing you can do to ease the pain. Then there is your own pain, who do you talk to about your own pain? I’m hurting as well and how do I express that?

I went through many emotions and with time it never got easier. I tried to be present through her operations and dialysis, which was difficult. I felt emotionally tested. The selfish part of me didn’t know when I would get my friend back. I saw her gradually lose her confidence and her self-esteem. It’s like part of her just didn’t want to live anymore and that was hard.

Certain days I would breakdown, because I didn’t know what to say or feel. One feeling I always remember is an overwhelming abundance of sadness. I lived a double life, one life where I was pursuing my own goals and aspirations, the other where I was present for my friend in her illness.

Because of my own feelings, sometimes I intentionally chose not to go and see her. On those days, I wanted to hide from reality. The strength to keep her positive was diminishing, because I was sad. The reality of this new life was overwhelming for all.

Today, after two transplants, my best friend is better. The first time we leaned on denial and ignorance, we were completely oblivious to kidney disease. So I never really understood what was going to happen. The second time I somewhat knew what to expect which was more daunting. I knew a mountain of pain was on the horizon and now neither of us could lean on denial or ignorance. However, I promised myself that I cannot let my pain overwhelm me or overshadow her grief. I was more mentally prepared, and I knew we had to be practical, whatever the outcome was there had to be practical decisions.

But the art of living lies in a fine mingling of letting go and holding on. You start finding a new balance, but that feeling of sadness constantly lingers. It’s hard to put into words, the feelings I felt.

As a friend, you naturally play the role of being a support network, but in hindsight sometimes I needed support, and someone to tell me she was going to be okay. I remember meeting the surgeons to discuss putting myself forward as a donor. The nurse started going through questions and then asked me how I felt? I just cried hysterically. It was the first time someone had ever asked me how I felt.

Although we are not suffering the physical pain, the patient’s loved ones also suffer. We embark on the journey together and experience the highs and the lows. In all of that, trying to remember to be a pillar of strength isn’t always possible.

I felt emotionally tested. The selfish part of me didn’t know when I would get my friend back. I saw her gradually lose her confidence and her self-esteem. It’s like part of her just didn’t want to live anymore and that was hard.

“I felt emotionally tested. The selfish part of me didn’t know when I would get my friend back. I saw her gradually lose her confidence and her self-esteem. It’s like part of her just didn’t want to live anymore and that was hard.”
Summer is here and there’s no better time to remind ourselves about the importance of staying hydrated. With the help of NHS Scotland hydration campaign, here are some important facts and tips to keep in mind this summer!

Water makes up two-thirds of our body, so it is vital we drink enough fluid to maintain a healthy balance. This is particularly important for those who have received a kidney transplant because dehydration can cause various complexities. Drinking plenty of liquids, particularly water, will help to wash bacteria from your bladder and urinary tract, which will help prevent urine and kidney infections.

To stay hydrated, ensure that you drink plenty of fluids such as water, diluted squash and fruit juice. The key is to drink regularly throughout the day. If you’re active, or if the weather is particularly hot, there’s a greater risk that you will become dehydrated. To stay hydrated, increase your fluid intake.

The NHS hydration campaign has created the urine chart below to help identify dehydration. Signs of dehydration are visible in your urine. Dark and strong-smelling urine is a clear sign that you need to drink more fluids. Use the urine colour chart below to look out for signs of dehydration. A healthy urine is between 1 to 3, from 4 to 8 it means that you must hydrate, so increase your fluid intake.

Good hydration prevents:
- Urinary tract infections (UTIs)
- Headaches
- Dizziness that can lead to falls
- Kidney stones

Some symptoms of dehydration include:
- Pain when urinating (UTIs)
- Dry mouth, lips or eyes
- Thirst
- Dizziness
- Headaches
- Lack of concentration

If dehydration is left untreated, it can become severe. Severe dehydration is a medical emergency and requires immediate medical attention. If not treated immediately it can lead to complications such as secondary UTI symptoms like E. coli and bloodstream infections similar to sepsis.

If you would like more information call our friendly staff at the NKF helpline on 0800 169 09 36 or visit the NHS hydrate campaign page through the link below.

https://www.nhsinform.scot/campaigns/hydration
Booking holiday dialysis is now fast & easy for everyone!

The only booking engine in renal care supported by the European Union.

1. Enter your destination & treatment dates.
2. Find clinics that have availability for your treatment dates.
3. Select the right clinic & book your treatments instantly.
Summer is upon us and whilst we soak up the sun, we need to take precaution. Especially for transplant patients pre-emptive care is vital. Skin care is important all year round because of the immunosuppression treatment. Whilst the drugs are crucial for the success and the longevity of the organ, they do suppress the immune system and are re-absorbed into the skin, gradually impairing the immunological cells in the skin.

Dangers of the Sun
Ultra-violet (UV) light is the damaging force of the sun. The sun penetrates through the outer layer of the skin and continually bombards the cells that are growing. Throughout our life, this damage is repaired to a certain extent by white cells in our blood. Having a suppressed immune system means that white blood cells are restrained and fewer abnormal cells are destroyed, meaning that even lower levels of sun exposure can be dangerous.

Therefore, it is vital for all patients who are on such drugs to avoid exposing themselves to the sun.

It is important to be able to spot abnormalities on your skin and know how to take precaution.

Here are just a few things to look out for:

Skin Infections
A fungal infection is common for patients. Look out for pale or dark patches or rather liverish-looking spots. It’s easily treated so contact your health professional.

Warts
Common warts are often seen in patients but take longer to disappear, due to the reduced immune system. Early treatment is worthwhile, seek medical advice if in doubt.

Moles
These are easily recognisable and could be potentially dangerous. Seek medical advice if in doubt.

As with all illnesses, prevention is always better than the cure
- Check your skin regularly
- When you go out, always wear a high factor sunblock SPF 50 throughout the year, especially during March to October
- Even in the shade, you are prone to sun damage, you can wear cool clothes, but it is advised not to uncover completely
- Men who have little hair should wear a hat
- Never sun-bathe, however tempting it might be, remember a ‘healthy tan’ is not healthy at all

Should you have any doubts about your skin condition then please consult a healthcare professional immediately. For more information, please contact the NKF helpline on 0800 169 09 to request a leaflet on skin care.
How one loss saved four lives:

A mothers’ story

By Diane Taylor from the Isle of Man

Whilst organ donation is lifesaving, it is equally a difficult decision a family faces when confronted with the sudden loss of a loved one.

Diane Taylor, a mother, and an avid volunteer has recently won the 2019 Exceptional Volunteer award. She talks us through the tragic loss of her son Daniel, and how she came to the decision to gift his organs.

“Daniel was a normal, healthy, happy and very cheeky teenager. He did everything that a boy of his age would do,” she says.

Diane recalls: “The day of the accident was a Sunday. Daniel, his brother James and James’ girlfriend all came for a roast at tea time then Daniel decided to go back to his dad’s house which was around 10 minutes from us. When I got the call from James (about the accident), I raced to the scene. I ran down the road and hugged James and his girlfriend. I then watched as Daniel was put on a stretcher. I was not allowed near him and could only watch as he was trying to sit up and was sick. The sign of a big head injury. Daniel was stabilised at the scene, what seemed ages. I was not able to go in the ambulance with him, because of his injury, he was quite violent and had to be sedated.”

**Intensive care**

When Diane and Daniel’s father reached the hospital, they were taken into a side room.

“Looking back, I can see now how bad it must have been, but at that point, all I thought was that my son was being treated and he would be well again. He was kept unconscious to help stabilise him.”

Daniel Taylor – a cheeky, happy teenager
The doctor explained that the X-rays showed no other injuries apart from the one on the side of his head. We were encouraged to let him know we were there as he would be able to hear us. I’m so thankful we were told this, as that was possibly the last Daniel would hear from us,” says Diane.

Diane further explains: “He was taken for a scan and then to the intensive care unit. We were taken upstairs by a lovely nurse who looked after us. My legs seemed to buckle on the walk up as the shock set in. A senior doctor explained how serious Daniel’s condition was, so he was flown to the mainland for specialist care. I remember them saying he was critical, but Daniel was my son, and, in my head, that meant he would be OK.”

Diane recalls seeing Daniel before he was taken away, “My beautiful son was covered in tubes, but his only visible injury was a black eye. We were encouraged to touch and talk to him, I was so overwhelmed by it all. As we left the hospital, I watched as Daniel was put into the ambulance to go to the airport.”

Daniel’s parents caught the first flight and were with Daniel the following morning.

“I remember thinking how cold he felt and I wanted to cover him up. Throughout the day we were updated regularly. Looking back, I realise that we were being prepared for the worst. I did not or could not believe any of this was happening and just wanted him to wake up,” says Diane.

The News
With the afternoon came the worst news. “The consultant knelt on the floor and asked if I understood how serious Daniel’s condition was. He said that if Daniel’s heart stopped now they would not resuscitate him. His words were a shock but I will never forget how kind he was. A small incision was made in Daniel’s head and a device was put in to show if there was any brain activity. Late afternoon, we were told that nothing more could be done,” says Diane.

The Decision
At this point, Diane and her family were asked about organ donation.

“All I remember was saying yes,” recalls Diane.

The next step was talking to nurses from the organ donation team. “I remember them being kind, the conversation and decision on which organs to donate was not an awkward one. Organ donation was never something we had ever talked about, but we knew Daniel would have wanted to help others;” says Diane.

Daniel was pronounced brain-dead in the early hours of the following morning. His organs were retrieved and he was able to help four people. His heart and valves were used for medical science. The organ donation specialist nurses told Diane that they would be with him in theatre and afterward. Diane recalls: “These two women gained my trust in such a short time and I knew that Daniel would be looked after.”

Diane’s experience shows how donating Daniel’s organs has helped her cope because something positive has come out of her loss.

Diane says: “I hope that our story will help people see how important organ donation is, not just for the recipients but also for the grieving family. I look back to the consultant who asked us and I’m so grateful he did. His words: “Have you thought about organ donation” were not harsh, it is the reality of what can happen following a loss.”

Diane’s Message
“Only through the tragic loss of Daniel have I been able to hear about the success of organ donation. Having read letters from the people who received Daniel’s organs and how their lives before transplant revolved around hospital visits and medication, I can’t imagine how it was for them and their families. I watched as the medical team tried to save my son’s life and I know that everything that could be done to save him was done. I am left with the comfort of knowing that Daniel was treated with love, care, and respect from the scene of the accident to the retrieval of his organs. How would I feel if I was told Daniel needed a transplant to save his life and without an organ becoming available, he would die? I have two other children, five grandchildren and of course others that I love, what if I was faced with one of them getting ill and requiring a transplant in the future.

In 2013 I joined the Organ Donation committee at Nobles Hospital in the Isle of Man. We as the committee are raising awareness of this very sensitive subject on the Island. We would like everyone to talk to their loved ones and discuss this very sensitive subject.

The reality is on average three people in the UK die every day whilst waiting for a transplant. You are more likely to require a transplant than donate your organs.”

If you feel you need to talk to someone or get more information on organ donation please call our team on the NKF helpline on 0800 169 09 36.
Spring draw

Thank you to everyone that took part in the NKF spring draw. A special thanks to Dudley KPA that provided the second prize, which is a week’s holiday in the Cotswolds.

The draw took place on May 8th and the lucky winners are as follows:

**£1,000:** B Upton, Kent (048103)

A week’s holiday in the Cotswolds:
K Black, Surrey (022694)

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Water Challenge 2019

Thank you to everyone that took part in our first ever water challenge. Many people decided to give up tea, coffee, fizz and alcohol for the month of April! This raised over £3,000 and we have already decided this challenge will be repeated next April. But before then, don’t forget Choctober will be back in October!

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We need your help

The NKF relies completely on sponsorship and donations, we realise that not everyone can cycle to Paris or run a marathon, but you still could help us. We are looking for people to place collection pots in local shops and then empty them when needed.

If you could spare some time to help us out we would love to hear from you, please email pete@kidney.org.uk or call 01263 722287

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Would you like to advertise your business or products in Kidney Life?

If so, Kidney Life is the perfect platform that reaches thousands of readers, from patients to healthcare professionals. Advertising in Kidney Life can help increase your brand awareness and business growth.

To advertise in Kidney Life in 2019 please contact the NKF head office.
T-shirts

If you have had a kidney transplant or donated a kidney, you will love our new NKF t-shirts. Wear them with pride and the fact that you have given the gift of life or received the gift of life.

They are just £12 each and can be ordered through our website at https://store.kidney.org.uk/

A New NKF Event

National Park will be a lasting memory that will never be forgotten!

Trekking Mt Snowdon (1,085m) during the daytime forms a great challenge, but by the evening we’ll be using our head torches to light our way and the tranquility of experiencing this mountain at night will never be forgotten.

You will also see the sunrise across Snowdonia National Park and upon our descent, we will witness the breath-taking mountain range that offers glorious views.

THE SCHEDULE IS OUTLINED BELOW:

- Day 1 we meet in Llanberis in the evening for event registration and briefing. Walking straight to the start we use the Llanberis Path and our ascent should take about 5 to 7 hours.
- Day 2 once we summit, we will begin our descent using the same trail. The descent will take approximately 2 to 3 hours and upon reaching our finish line in Llanberis, we will celebrate our achievements with a well-earned breakfast.

Please visit the website using the following link for further information: https://www.kidney.org.uk/fundraising/sponsored-events/walking/snowdon-at-night-challenge/

Or alternatively for more details call 01263 722287 or email pete@kidney.org.uk

Interested in raising money for the NKF, this could be one of our organised events, a garden party, fundraising discos or you may just want some ideas. If so, please contact our Fundraising office on 01263 722287 or email pete@kidney.org.uk
Upcoming Changes in Organ Donation

• More than 25 million people have signed up as organ donors across the UK, though only a small percentage of people die in circumstances where they can donate – so every donor is precious

• Over 6,000 people in the UK are on the Transplant Waiting List but there are many more who would benefit from an organ transplant

On average across the UK, three people die every day in need of an organ transplant. Last year over 400 people died in the UK waiting for a transplant.

Therefore, to allow more people to pass on organs, the law around organ donation in England will change from spring 2020. Thereafter, it will be considered that all adults in England have agreed to be an organ donor after they die unless they specify otherwise or are listed as being in one of the excluded groups. Other common synonyms you may hear are ‘presumed consent’ or ‘opt-out’ system or even referred to as the ‘Max and Keira’s Law’.

Those excluded from the plans include:
• Children under 18
• People who lack the mental capacity to understand the changes for a significant period before their death
• People who have not lived in England for at least 12 months before their death

The NHS Blood and Transplant have launched a year-long public awareness campaign, called Pass It On. This will ensure that the general public is aware about the changes and the choices available to them. The Pass It On campaign will help raise awareness of the new system before it comes into force in spring 2020, and give people the time to have the conversations they need. NKF will fully support the campaign in publicising this to ensure the information is spread as far and as wide as possible.

The NHS Blood and Transplant have also stated:
“You can record a decision on the NHS Organ Donor Register to opt-in or opt-out, but your family will be asked to honour your decision when the time comes. If there is no recorded decision for you on the NHS Organ Donor Register, your family will be asked if they have any information that shows whether or not you wanted to donate.”

This means families are often left with a difficult decision when a loved one dies. Currently, less than half of families give consent for their loved one’s organs to be donated if they are unaware of their wishes. Whatever your decision, make your choice clear to your family to help ensure your choice is honoured. Over eight in ten people in England believe it is important to tell those closest to you your decision about donating, however just over a third of adults have told their partner or family that they want to donate their organs after they die.

The NKF is pleased that the Opt-Out Organ Donation Bill has been positive. To date, both the NKF and The All Party Parliamentary Kidney Group (APPKG) have campaigned tirelessly to increase living donation and in January 2018, the APPKG published a Manifesto to increase transplantation.

Irrespective to say, the changes in England are a positive paradigm shift in organ donation. This may be the catalyst to engage in conversations, but ultimately have a positive impact on people who are waiting for a life-changing transplant.

Please visit the NHS Organ Donation website for further information on English organ donation law:
From spring 2020 the law around organ donation in England is changing

Unless you choose to opt out, you will be considered to have agreed to be an organ donor when you die.

Whatever you choose, let close family or friends know to help ensure your decision is honoured.

To find out more about your choices, including how to opt out:
visit organdonation.nhs.uk or call 0300 303 2094

PASS IT ON
Food with Thought

Diet plays an essential role for renal patients.

Although overwhelming at first, following a healthy balanced diet quickly becomes a part of life. But a renal diet does not have to be boring, and that is why the NKF are delighted to have been involved with in the creation of a cookbook, 'Food with Thought'. We have shared some mouth-watering recipes for you to try this summer that neither lack in taste or flavour and most importantly are kind to your kidneys.

If you would like a copy of this cookbook, then please contact the NKF helpline.

Asparagus Bruschetta with Garlic and Basil
SERVES 2

Ingredients
1   Ciabatta loaf or any other uncut small white loaf
4   Fresh asparagus spears, boiled until tender*
1tbsp Olive oil
½   Garlic clove, crushed and finely chopped
1tbsp Basil, finely chopped
*Tinned asparagus may be used but should be well drained beforehand.

Method
1)  Cut four slices of bread from the loaf, approximately 2cm thick, and place on a baking tray. Lightly toast one side under a medium grill.
2)  Cut the asparagus spears in half lengthways and cut each strip into two or three shorter lengths.
3)  Mix the olive oil, garlic and basil together and spread on the untoasted side of the bread.
4)  Top with asparagus, brush lightly with olive oil and return to the grill until the edges are browned.

Serve immediately while still hot.

Analyses per portion
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<th>Fat (g)</th>
<th>Protein (g)</th>
<th>Energy (kcal)</th>
<th>Phosphorus (mmol)</th>
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<td>230</td>
<td>3</td>
<td>16</td>
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</table>
**Tomato Pasta** SERVES 2

**Method**

1) Fry the onion and garlic in the oil.
2) Add the tin of tomatoes, mixed herbs, black pepper and sugar. Simmer for 10-15 minutes.
3) Meanwhile, cook the pasta in boiling water until cooked. Drain and serve with the tomato sauce.

**Ingredients**

1 small Onion, chopped
1 Garlic clove, chopped
400g Tinned chopped tomatoes, drained
200g Dried pasta
Pinch Mixed herbs
Pinch Black pepper
1tbsp Olive oil

**Analyses per portion (with pasta)**

<table>
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<th>Energy (kcal)</th>
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<tbody>
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<td>Fat (g)</td>
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<tr>
<td>Sodium (mmol)</td>
<td>3</td>
</tr>
<tr>
<td>Potassium (mmol)</td>
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</tr>
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</table>

**Note:** On a reduced potassium diet, count the tomato sauce as two vegetable portions from your daily allowance. Do not serve with potatoes.

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**Easy Trifle** SERVES 4

**Ingredients**

1 small Plain sponge Swiss roll
75g Custard powder
400g Tinned mandarin segments in juice, drained
2-3tbsp Sherry (optional)
150ml Double cream
4 squares of chocolate, grated

**Method**

1) Place the custard powder into a measuring jug and add 300ml/½ pint of boiling water. Whisk briefly with a fork until smooth and creamy and leave to stand while you prepare the rest of the trifle.
2) Cut the Swiss roll into slices and use to cover the base of a large dish, or 4 individual serving dishes. Sprinkle the sherry over the sponge, if using.
3) Spread all but 6 of the mandarin segments evenly over the Swiss roll.
4) Pour or spoon the custard over the fruit.
5) Whip the double cream and spread over the custard.
6) Decorate with a little grated chocolate and the reserved mandarins.

**Analyses per portion**

<table>
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<tr>
<td>Potassium (mmol)</td>
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</table>
It has been nearly thirty years since I received a transplant. Prior to this, I had been on dialysis for four and a half years. It was then that my thoughts turned to the donor. I realised that as I was rejoicing at my good fortune, her family was in mourning. I had hope for the future, but they were aware of a daughter’s future unfulfilled.

It is profoundly humbling that a grieving family had the goodness and courage to think of helping people they would never know or meet.

So how does a recipient express thanks? I wrote a letter that was forwarded anonymously. It is a policy that donors and recipients must correspond anonymously. In due course, I heard back. Every year my donor’s family and I have exchanged letters. I now know my donor’s first name and telling little details. The family told me in one letter that a flowering cherry tree had been planted in her memory.

Those of us who have received that all-important gift of a transplant, find our own ways of offering thanks. The best thing any of us can do is to live life with renewed purpose, offering our thanks in our own individual ways.

I work as an artist and to celebrate my transplant, I created artwork in honour of all donors. I took the theme of the cherry tree and if you should ever go to Guy’s Hospital, it is on a wall in Atrium 2. It is created from various types of reflective cut steel. The blossom is coloured in such a way to suggest how a donated kidney changes colour on the operating table, as it is attached to the recipient. It was unveiled in 2015 by Alan Titchmarsh and blessed by the former Archbishop Lord Williams.

Three years later, I was asked to design another work for St Thomas’ Hospital. This was to be a bit different, in that it would become not just a general memorial to organ donors, but a more personal tribute to those whose organs had been given at that hospital. My design took the theme of ‘The Nightingale’. The hospital’s nurses are traditionally known as Nightingales after the founder of modern nursing Florence Nightingale. In the design, I included stars and leaves that had the initials and dates of donors discretely engraved on them. Over time new leaves and stars will be added so that families will have a focus for their own thoughts and memories.
Those of us who have received that all-important gift of a transplant, find our own ways of offering thanks. The best thing any of us can do is to live life with renewed purpose, offering our thanks in our own individual ways.

Again, I used reflective steel, but this time I softened the effect with a background of coloured felt. The work can be found in the main corridor of the hospital. In February of this year, the work was dedicated by the Bishop of London, herself a former St Thomas’ ‘Nightingale’ nurse.

A donated kidney is a tremendous gift. It is not always easy to come to terms emotionally with being a beneficiary of such undeserved generosity. There are inevitable feelings of unworthiness. If the kidney comes from a live donor one can say thank you face to face. If it comes from a deceased donor this is not possible. Thoughts might turn to the circumstances of the donor’s death. I know that my good fortune is the mirror image of someone else’s tragedy.

If the kidney comes from a live donor one can say thank you face to face. If it comes from a deceased donor this is not possible. Thoughts might turn to the circumstances of the donor’s death. I know that my good fortune is the mirror image of someone else’s tragedy.

It is important therefore to find ways of giving thanks. As recipients, we can all find ways that are appropriate to ourselves and best suited to our specific talents. Therefore, if any kidney patients’ groups would like to think of offering artwork to honour donors from their own region and can raise funds to meet the costs of materials and erection, I would be very happy to design and produce an appropriate artwork. This would be an ongoing gift of thanks to all donors.

For more information contact Ted Harrison on ted.harrison@btinternet.com

‘The Nightingale’ can be found at St. Thomas’ Hospital.
NKF Held its sixth annual KPA Day on the 6th April 2019. This year the day returned to the Glebe Hotel in the lovely village of Barford, Warwickshire.

Many KPAs were represented at the event, discussing important matters and sharing ideas and ways of working.

The day started with a welcome from the NKF Chairman, David Marshall. David went on to talk about BREXIT and how this may impact those using the EHIC card and the use of it after BREXIT.

The next speaker was Kirit Modi, Life Vice President of the NKF, he spoke about how deemed consent will be introduced in England. It was important that people still signed the register to opt-in or opt-out. The new law will come into place in April 2020. There is also a year-long campaign launched by the NHS Blood and Transplant, called Pass It On, to promote this to the general public.

The annual general meeting was held before lunch and the NKF Executive Committee were elected for the coming year.

Officers
David Marshall – NKF Chairman
James Barr – NKF Vice Chairman
Mark Davis – NKF Treasurer

Executive Committee members
John Burdett – Northamptonshire KPA
John Crossley – West Riding KPA
Jim Higgins – Northamptonshire KPA
Wajid Iqbal – Manchester Royal Infirmary KPA
Guy Richards – Exeter & District KPA
George Palmer – Exeter & District KPA
Brian Child – North East KPA
Richard Van Roon – Six Counties KPA

After lunch, David Coyle and Paula Ormandy spoke about the Kidney Patients Involvement Network (KPIN) and explained the work of the network and how KPAs could help with this.

Next on the agenda was the council meeting. This was another formal meeting, where KPA reps get an update of the work of the NKF since the last council meeting in October 2018.

The last speaker of the day was George Palmer from Exeter & District KPA. George spoke about what his KPA did with regards to having a citizen’s advice contact for patients. The KPA also funds specialist nurses to spend one day a week dealing with all aspects of helping young patients through the difficult transition into adult services. They also have Personal Health Transport Budgets for dialysis appointments, where patients are in charge of their own transport and also spoke about snacks that the KPA provides to the patients on dialysis.

NKF would like to thank all speakers and everyone that attended the day.
HOLIDAY DIALYSIS IN NORFOLK
FULLY NHS FUNDED
RELAXED AND QUIET ENVIRONMENT
EXPERIENCED STAFF
NEAR SANDRINGHAM AND THE COAST
PLEASE RING OR EMAIL FOR DETAILS

TEL: 01485 545719
info@norfolkdialysis.co.uk
www.norfolkholidaydialysis.co.uk
The NKF relies completely on sponsorship and donations to continue its vital work supporting kidney patients and carers.

Last year generosity from our supporters has helped us campaign for more living kidney donors, it helped us put a stop to dialysis patients being charged for travel costs for lifesaving treatment and we received over 3,000 calls to our Helpline, free of charge to the patient and carers, plus not forgetting tens of thousands of leaflets were printed and posted out free of charge.

Please help us continue our work and give kidney patients a brighter future.

We have different ways to help our charity...

Support NKF each month

£20 a month
Will help with the ever increasing printing costs to enable our Helpline to continue to produce, and distribute, patient information leaflets. There are over 150 titles in the Kidney Matters series which are printed ‘in-house’ and distributed, free of charge, to all patients calling our Helpline telephone 0800 169 0936.

£10 a month
Will help towards the ever increasing postage costs incurred in sending out information to patients, and renal units nationwide.

£5 a month
Will help the NKF to spread the word about the importance of Organ Donation.

£2 a month
Pays for your Kidney Life magazine.

Leave a Legacy to NKF

A will is a legal document, so it’s best to get the advice of a solicitor to make your instructions legally valid. To find a solicitor you can look in the Solicitors Regional Directory which is available in your local library.

You will find more information to help you make your will at:
www.solicitors-online.com
www.make-a-will.org.uk
The NKF Helpline on 0800 169 09 36 can give you advice on how to include NKF in your will.

Donate to the NKF - via Payroll Giving

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To give to us in this way, your Employer will need to operate a scheme, if you aren’t sure that they do, fill in the form anyway and we will let you know if they don’t and perhaps we can suggest to them that they introduce one.

One way of helping NKF is to include a legacy to the charity in your will. More than two thirds of adults die without a valid will, which results in their estates being allocated according to the law, instead of according to their wishes.

PAY No Tax – Because the donation is taken from your gross pay, every pound you give will only cost you 80p, or only 60p if you are a higher rate tax payer.

There are now FOUR ways to pay NKF...

1. Online at www.kidney.org.uk
2. Pay by Credit or Debit Card by calling 01909 544999
3. Pay by Direct Debit. Fill in the direct debit form overleaf and return to us
4. Send a cheque, made payable to ‘the National Kidney Federation’ (address overleaf)
DIRECT DEBIT INSTRUCTION

Name: ..........................................................................................................................................
Address: ........................................................................................................................................
....................................................................................................................................................Post Code: .............................................................
I would like to donate £ _____ every Month/Year (Delete as appropriate).
First donation to start Month: ............... Year: ............... 
Your direct debit to be withdrawn on the 20th of the month

Please claim Gift Aid on my donation. I confirm that I am a UK tax payer and have paid income and/or capital gains tax at least equal to the tax to be reclaimed in this tax year by the charity. I agree that Gift Aid can be claimed on all donations that I have made in the last four tax years, and all donations that I will make from this date until I notify you otherwise. I understand that I must pay an amount of income tax and/or capital gains tax in each year at least equal to the tax that the charity will reclaim from the HMRC on my gift aid donations.

Name of account holder: .............................................................................................................
Bank sort code: _______ My account no: _______
Name and full postal address of your bank: To the Manager: ......................................................
..........................................................................................................................................................Post Code: .............................................................
Signature: .........................................................................Date: ......................................................

Originators Identification no:

Instruction to your bank
Please pay National Kidney Federation Direct Debits from the account detailed in this Instruction subject to the safeguards assured by the Direct Debit Guarantee.
NKF Bank details:
Sort code: 306776 Account Number: 43986268
# 40 YEARS AND BEYOND

## Annual Patients' Event 2019
4th and 5th October
Radisson Blu Hotel, East Midlands Airport

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### BOOKING DETAILS AND COSTS

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**My donation to the work of the NKF**

**Grand total (amount sent with booking)**

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*Saturday 24 hour rate includes the day delegate rate of 3 x coffee/tea breaks and full buffet lunch, a 3 course dinner with a pre dinner drink of Prosecco or juice, after dinner coffee/tea, after dinner entertainment and bed and breakfast.

** Price is for two people

---

### 1st Delegate Details

<table>
<thead>
<tr>
<th>Title:</th>
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......... Postcode:  

Tel:  Email:  I am a member of:  KPA

**Special Requirements** (subject to availability) please TICK as appropriate

FULLY DISABLED  IMMOBILE  VEGETARIAN  OTHER ...

---

### 2nd Delegate Details

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......... Postcode:  

Tel:  Email:  I am a member of:  KPA

**Special Requirements** (subject to availability) please TICK as appropriate

FULLY DISABLED  IMMOBILE  VEGETARIAN  OTHER ...

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For any special dietary requirement please contact the office on 01909 544999.

**Please send the booking form with a cheque made payable to NKF and return to: NKF, The Point, Coach Road, Shireoaks, Worksop, Notts, S81 8BW.**

**You can also book online at www.kidney.org.uk or by calling 01909 544999.**

**Cancellation:** Any event booking cancellation must be confirmed in writing. The NKF is unable to offer refunds on bookings cancelled after 23rd August 2019 and recommends cancellation insurance is purchased.