



Staying safe in summer

Sue Lyon, Chair, GSTTKPA

Welcome to the latest issue of Kidney Talk. As the days grow longer and the weather gets (mostly) warmer, life seems to be gradually becoming less confined even if it's just meeting a friend for a walk and a coffee in the local park.

At the same time, we know as 'clinically extremely vulnerable' kidney patients that we still need to take more care than other people. I know that we are going to find this more difficult as larger groups of people start to get together, restaurants, pubs and other venues re-open indoors, and people start to travel abroad. But we are able to continue with face coverings and social distancing, and we can also encourage the people we live with to be vaccinated.

There is also lots of advice tailored specially for kidney patients from Kidney Care UK and the Renal Association online at <https://bit.ly/2SLqB92>.

As society reopens, assessing our individual risk is going to be essential. Again, the Kidney Care website has some helpful advice, or you can ask one of your kidney doctors or nurses.

We all know how every member of our healthcare team has had to deal with the terrible pressures of Covid-19 during the past year –and how can we ever thank them? But don't feel that you will be 'bothering' the doctors and nurses; they want to take care of us and keep us safe.

The pandemic has affected every charity. For GSTTKPA, it has meant that we have had to cancel events we had planned for 2020-2021. At present, we do not know when it will be safe for us to return to face-to-face contact, so we are planning how we can better connect online.

If you'd like to keep in touch and join us online, sign up to our email newsletter (see below).

I hope that you enjoy this issue of Kidney Talk. Until the next issue, keep safe and enjoy the summer.

Join our mailing list for more GSTTKPA news

Receive regular email updates from GSTTKPA including the digital version of our newsletter, Kidney Talk, by signing up to our mailing list and registering as a member.

It's easy:

Complete the form at <https://gsttkpa.org/stay-in-touch-with-gsttkpa/>

Or email info@gsttkpa.org with your name, email, and postal address.

GSTTKPA will treat your details in confidence and in accordance with current data protection laws. By submitting your details, you consent to their use as set out in our Privacy Policy (<https://gsttkpa.org/privacy-policy>).

Going straight to the top



Are you a transplant patient or donor who has a passion for hiking and seeing the most beautiful landscapes? Then the Transplant Climbing Collaborative may be for you.

Members of the Transplant Climbing Collaborative are people who have had a transplant, donated an organ, or are involved in transplantation or climbing professionally.

Their objective is simple: to enjoy mountain climbing while creating new friendships.

Having a transplant or being a donor means you can face the toughest of physical and mental challenges – so you can do most things, including climbing a mountain!

The Collaborative plan to start with mountains in the UK, and then progress to the Alps and the larger ranges.

No previous climbing experience is necessary, so there's no need to worry if you're a complete beginner. You just need to be over 16 years old.

If you would like to get involved or have any questions, get in touch at www.transplantclimbing.com

A warrior's podcast

More people are listening to podcasts. Just like the radio, we can listen as we work or exercise, but we can choose the podcast topic to fit with our interests. Now you can listen to a podcast about kidney disease.

Dee Moore has stage 4 chronic kidney disease and is from Birmingham. Her weekly podcast, *Diary of a Kidney Warrior*, airs on Monday. The podcast is dedicated to raising awareness of kidney disease, kidney disease prevention and all aspects of chronic illness and health. In this way, Dee aims to empower her fellow 'kidney warriors' with knowledge to enable them to understand and manage their disease and thrive.

Dee interviews kidney patients and kidney professionals and the podcast has covered a wide range of topics including: chronic illness and mental health, sleep hygiene, understanding your kidney blood results and many more.

Diary of a Kidney Warrior is available through Apple podcasts, Google podcasts, Spotify, Podbean and other podcast channels.



LEAVING LOCKDOWN

Take back control

Dr Darragh O'Shea

Highly Specialist Health Psychologist, Renal Psychology Service, GSTT

During a very difficult and uncertain time like a pandemic, it is normal to experience a wide range of emotions (e.g. fear, sadness, frustration and loneliness). These feelings may be overwhelming for some people living with chronic kidney disease. It might feel like there is a lot outside of your control at the moment. This article gives some brief tips for managing your emotional wellbeing as we leave lockdown.

During periods of uncertainty and change, we know that focusing on what is in your control can help you to feel safe and steady.

- **Continue to adhere to your treatments and ask for help if you need it.** Take your medication as recommended, attend dialysis and follow dietary and fluid intake advice. Face-to-face appointments are limited, but don't hesitate to get support and advice from your kidney team or GP.
- **Be aware of the latest guidance and manage your media.** Regular handwashing, maintaining social distance and wearing a face covering are essential to keep you and your family safe and protected. Keep updated on Government guidance using reputable websites or news platforms, but don't spend too much time checking the news. It may actually make you feel more stressed and anxious. Taking control over your media consumption may help manage your stress/anxiety levels.
- **Create a structure and routine to your day.** It can feel difficult to motivate and organise when one day seems to run into the next. But waking at the same time each morning, showering, getting dressed and scheduling/planning activities can help add structure and familiarity to the day. This can help introduce some certainty and stability into life during this challenging time.
- **Think about the things you can do, not what you can't.** You may not be able to enjoy your usual activities. So be creative by trying to think about the things you can still do, such as cooking, drawing, listening to music, watching TV and chatting to friends or family on the phone or online.
- **Keep in touch with family and friends.** Perhaps the most challenging change during lockdown has been to socially distant or shield from family and friends. Understandably many people may feel isolated and lonely. Take control and speak with friends and

family via telephone, video calls, texts or social media, and follow government guidance on face to face contact as lockdown eases. This can help us feel closer and more connected to the people that matter to us most.

- **Find the time to unwind and de-stress.** Making sure you get sufficient sleep is particularly important. Practising relaxation/meditation can be particularly helpful, either to aid sleep or to manage stress during the day.
- **Keep moving.** Given the importance of physical activity for our overall wellbeing, it is particularly important to aim to maintain physical fitness. Just going for a regular walk can make you feel better. Or try Kidney Beam (<https://beamfeelgood.com/kidney-disease>) for ways to maintain and improve your fitness at home.
- **Be compassionate to yourself.** We have little control over the thoughts and images that we experience, however we do have control over how we RESPOND to them. Worrying thoughts and feelings of fear and anxiety are to be expected at this time. Name them and acknowledge that they are normal and natural reactions to an abnormal situation. Whether or not your thoughts and feelings are based in truth, try asking yourself if it is helpful to get caught up in them. Try taking a few deep breaths to help you feel settled

For professional emotional support, please ask:

- **Your GP**
- **Your local IAPT service:** see <https://bit.ly/3x96hOR>
- **Ask about counselling at GSTT kidney unit**
- **NHS websites**

Accurate and updated advice about coronavirus: www.nhs.uk/conditions/coronavirus-covid-19/

Looking after your mental health: www.nhs.uk/oneyou/every-mind-matters/

Mental wellbeing while staying at home: <https://bit.ly/3gs3vhy>

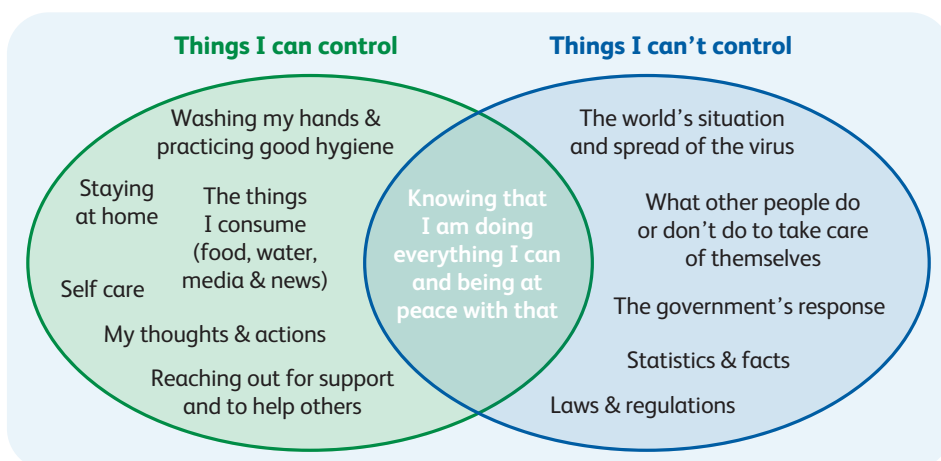
- **Kidney Care UK**

Regularly updated Government coronavirus guidance and other information relevant to kidney patients: <https://bit.ly/3v5XKu4>

Report on webinar on leaving lockdown: <https://bit.ly/32xrhAH>

and ask yourself how you would treat a friend if they were going through this. What might you say or do? Then, as best you can, try treating yourself with the same kindness and compassion.

- **Notice meaningful moments/cultivate gratitude.** Generating positive emotions during difficult times isn't necessarily intuitive, but it can be particularly helpful. It's a way for us to steady ourselves these difficult times, and to focus on what gives us meaning and purpose. One potential way to do this is by actively noticing things that we are grateful for in our lives. Keeping a journal where you write about three things that have happened in the day that were meaningful or you were grateful for: e.g. reading a book, speaking on the phone to a family member. This is a particularly effective way of generating positive emotions and gaining perspective during these challenging times.



Caring for your hands

We've all got used to washing or sanitising our hands regularly for at least 20 seconds, both at home and outdoors. Hand washing is crucial to prevent the spread of infection, but frequent contact with water and use of soap, alcohol hand gel and other detergents can cause your hands to become very dry.

Here are some tips to help you to reduce the impact on your skin of frequent handwashing:

Wash hands in line with government guidance, using soap and water if possible.



After washing, dry your hands fully by patting them dry, not rubbing.

A moisturising hand cream will help preserve the outer layer of the skin, locking moisture inside and keeping the hands soft and supple. Use the hand cream generously after washing and whenever the skin feels dry.

If your hands become very dry, you may find it helpful to try overnight moisturising. Apply a generous layer of a moisturising hand cream just before you go to bed, then put on a pair of clean cotton gloves and leave overnight.

Wear household gloves when your hands are going to come into contact with water or detergents, such as when washing up, shampooing a child's hair, or using cleaning products) If you're allergic to latex, try nitrile gloves, which you can buy online or from pharmacies.

It's important to prevent the skin of your hands becoming very dry to prevent irritant contact dermatitis—a form of eczema—or make existing dermatitis worse. Irritant contact dermatitis can cause the skin to itch, become sore and red, and develop small blisters or painful cracks. You may be particularly susceptible to this if you already have dry skin.

If you develop severe hand dermatitis or your skin looks infected check with your GP. You may need prescription treatments to deal with the problem.

PREM 2020 THE REPORT



Since 2016, the Renal Association and Kidney Care UK have worked with patients and kidney centres to produce the Kidney PREM, the chance for kidney patients to have their say about their care.

The PREM 2020 report shows that, despite all the challenges of the pandemic and COVID-19, most kidney patients continue to highly rate their overall experience of care.

Nearly 10,000 kidney patients responded to this year's online-only PREM survey. Nationally the key top performing areas of experience remain Privacy and Dignity, Access to the Renal Team and Patient Information. At the same time, areas that remain challenging include Transport, Shared Decision Making and Needling

There are also signs that the new ways of working made necessary by pandemic have affected some aspects of care, especially for patients whose care largely takes place outside hospital:

- Reported experience of Support and Sharing Decisions About Your Care fell in 2020.
- Scores for Support fell among chronic kidney disease (CKD), peritoneal dialysis, home haemodialysis and transplant patients compared to 2019.

- Experience of Sharing Decisions About Your Care was lowest in patients receiving in-centre or satellite haemodialysis.
- Patient reported experience of Transport improved for in-centre and satellite haemodialysis patients in 2020.
- The experience of patients living with CKD but not receiving dialysis or transplant notably decreased in 2020 compared to 2019, particularly for Overall Experience, Support and How the Team Treats You.

PREM 2020 also included open questions on COVID-19. The report on patients' responses will be published in June 2021.

The full PREM20 report is available at <https://renal.org/kidney-patient-reported-experience-measure>

Safe travels



We haven't been able to travel for many months, so the easing of lockdown brings thoughts of holidays. But kidney patients need to plan ahead carefully, especially as and when it's safe for us to travel outside the UK.

Dialysis away from base

New guidance has just been published by the Renal Association to enable dialysis units to safely admit visiting dialysis patients. Units are asked to consider reopening to dialysis away from base (DAFB) and let patients know whether it is available.

This new guidance only applies if shielding or local lockdown is not in place in base or destination units. Before making any arrangements for travel, talk to your clinical team. Kidney patients are vulnerable to COVID-19 infection and infections have sadly occurred at dialysis units.

EHIC becomes GHIC

Following to the Brexit Co-operation Agreement, made on Christmas Eve 2020, all UK residents are still able to use the European Health Insurance Card (EHIC) to receive emergency healthcare in the EU. This means that UK kidney patients can continue to access dialysis on presentation of your EHIC when travelling in the EU.

You can continue to use your EHIC until it expires. If you need a new card or are applying for the first time, you need to apply for the new, free-of-charge Global Healthcare Insurance Card (GHIC). Before you travel, check that EHIC/GHIC will cover you. Since the Brexit Co-operation Agreement was made with the EU, it applies to member countries only. It does not apply in countries like Norway, Switzerland, Liechtenstein or Iceland, which are associated with, but not members of, the EU.

EHIC/GHIC does not replace the need to take out travel insurance. In some countries you are expected to pay for treatment that would be free of charge on the NHS. EHIC/GHIC also won't cover you if you need emergency repatriation, which can be very expensive indeed.

Travel insurance advice

It's a good idea to have travel insurance even if you are travelling in the UK. It will cover you for lost or stolen bags, emergency medical expenses, personal liability and costs of cancelling or delaying your holiday. However, travel insurance can be

hard to find for kidney patients or anyone with a 'pre-existing medical condition'.

The website of the Money Advice Service, which offers free and impartial financial advice, now includes advice on travel insurance for people with a medical condition, and a Travel Insurance Directory of specialist travel insurers. There's also good advice on travel insurance policies and coronavirus.

More information

Guidance on dialysis away from base: <https://bit.ly/3nVuUuc>

Where EHIC applies and how to apply for your GHIC card, visit www.ghic.org.uk

When applying for GHIC avoid unofficial websites that may try to charge you for your card – **GHIC is FREE.**

The Money Advice Service advice on travel insurance: <https://bit.ly/3ulOhie>

INTRODUCING Sally Halford

GSTT recently said goodbye to Ros Tibbles, Service Improvement Lead at the kidney unit. We are very grateful to Ros for all her hard work and support for kidney patients at GSTT, and wish her a happy and relaxing retirement.

Ros has been succeeded by Sally Halford.

Sally writes: "I have been a nurse for nearly 20 years, much of that spent working in critical care. My new role is a new and exciting post as Matron for Patient Experience for the Transplant, Renal & Urology Directorate based at Guy's Hospital. Outside work I am kept busy being a mum to a two- and five-year-old!"



amazonsmile

Join AmazonSmile and help your KPA

Shopping online helps keep us safe during the pandemic, and now you can support your KPA when you shop at Amazon because GSTTKPA has signed up to AmazonSmile.

To shop at AmazonSmile:

- Go to smile.amazon.co.uk on your web browser or activate AmazonSmile on your Amazon Shopping app on your iOS or Android phone (found under 'settings' on your app).
- On your first visit to smile.amazon.co.uk, you need to select a charitable organisation to receive donations from eligible purchases before you begin shopping. In the 'Pick your own charitable organisation' box, search for Guy's and St Thomas' Hospital Kidney Patients' Association and click the 'Select' box on the next page.
- Amazon will remember your selection, and then every eligible purchase you make through AmazonSmile will result in a donation to GSTTKPA.
- On your internet browser, you may also want to add a bookmark to smile.amazon.co.uk to make it even easier to return and start your shopping at AmazonSmile. When you're using the app, always check for the AmazonSmile logo to ensure you're activated for AmazonSmile.

Thank you for your support!

**5-a-side Kidney
Transplant Football**

All Welcome

26/06/2021 10am

1 Coral Street, Waterloo
London, SE1 7BE

To register interest:
guystransplantteam@gmail.com

NHS
King's College Hospital
NHS Foundation Trust

NHS
Guy's and St Thomas'
NHS Foundation Trust

**SAVE
THE DATE**

GSTTKPA Annual General Meeting

Saturday 27th November
10.00-12.00

We will be meeting
virtually by Zoom

Meet your Committee
and listen to our speakers

Watch out for more information
and how to join the meeting in
the next issue of Kidney Talk.