

In Touch

Information from the National Kidney Federation. Supporting kidney patients, their friends & family.

Welcome to the February 2022 In Touch newsletter. If you are receiving this newsletter from someone else and not the NKF, you can contact us and request to be added to our mailing list.

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Is there something you would like to share in the next newsletter? Email in to sharney@kidney.org.uk by Tuesday 8th March 2022.



NKF Peer Support Service

Our NKF Peer Support Service is a free service aimed to support people who:

- Would like someone to talk to regarding the options of dialysis at home or have just started home dialysis and would like further support

"I was fortunate to have had a kidney transplant. After 14 years though, my kidney transplant failed, so now I am back on dialysis for the second time.

Home haemodialysis was the natural choice for me for 3 main reasons:

1) I had been on it before because I value my independence and work part-time.

2) I think it's the next best thing to a transplant when it comes to freedom of choice and flexibility. I choose when to dialyse.

3) Managing my condition, I have a better quality of life. I look and feel fabulous, 99% of the time. And that's priceless!"

- Kasonde NKF Peer Supporter



For help, advice or just some reassurance, you are very welcome to contact us via our NKF Helpline for more information on **0800 169 09 36** available from 9am to 5pm Monday to Friday. For more information please visit our Peer Support web page [here](#).

All Party Parliamentary Kidney Group (APPKG) Update



Our first meeting with the APPKG group took place on Monday 31st January 2022 with Brendan Clarke-Smith MP.

Speakers that attended the meeting included; Dr Michelle Willicombe who discussed COVID-19 vaccine efficacy for kidney patients, Dr Rachel Middleton highlighting COVID vaccines deployment from a renal hospital perspective, NKF Honorary President and transplant patient Kirit Modi and in centre dialysis patient Norman Harding, on their experiences of being kidney patients who have been vaccinated and who have recently had COVID-19.

The next APPKG meeting will be held in May, this will be a parliamentary reception where we will be able to meet the MPs face to face.

KPA of the Month

Continuing to explore the history of our Kidney Patient Associations (KPAs) by including a monthly feature dedicated to a specific region.

Six Counties Kidney Patient Association (SCKPA)

In 1966 Dr Desmond Oliver was given the task of organising and equipping a dialysis unit at the Churchill Hospital. The unit was set up as a “Pilot” unit and remained a “Pilot” unit for 9 years. By the end of 1968 19 patients were dialysing at home, and by May 1975 this number had grown to 126.



In 1969, at the instigation of Dr Oliver, Harry Thomas, a home HD patient who was later awarded an MBE for his work for kidney patients, set up a self-help group with dialysis patients to provide support to patients and their families and to raise funds for much needed equipment. The first meetings of the association were held in the seminar room in the Churchill Hospital. As numbers grew, meetings moved to a room in the White Horse in Bicester and to the restaurant in the Churchill.

From the outset, Dr Oliver was adamant that there should be no paid or professional fundraisers involved. This remains true today. Every penny raised by the association is used for the benefit of the patients. The first patients were nursed as in-patients for approximately three months in Ward 1 of the main Churchill Hospital and dialysis took place in the wooden building next to what is now the Tarver Ward. The small dialysis room held four machines, and often three more patients were treated on dialysis machines while they sat on recliner chairs in what is now a photocopier room. In those days, patients dialysed for 10 hours. This was reduced to six hours around 1972.

Later Chairpersons included Ruth Lupton, Fred Tring, Allen Newey, Cathy Raff, Molly Bowerman, Bob Price, David Benoliel, Gemma Benoliel and John Champion.

In 1970, at the suggestion of Dr Oliver, the association set up a holiday dialysis portakabin in Lymington. This was at a time when the availability of holiday dialysis away from home was very limited. A second holiday dialysis unit was set up in Hereford and a third at St Leonard's near Bournemouth. More caravans followed later at St Leonard's, Milford-on-Sea, Goodrington Sands and Durdle Door. The portakabins and caravans were fitted with HD machines and water softeners.

In 1982 the SCKPA bought and converted a mobile static home and shipped it down to Domaine de la Bergerie, Le Beausset, in the South of France where it was fitted with a Cobe dialysis machine. It was used for the first time in March 1983. The association later had a caravan at Cobbs in the New Forest. This provided accommodation for patients using the KC dialysis unit.

Over time, holiday dialysis facilities at dialysis centres around the UK, and indeed overseas, became much more readily available and the demand for the SCKPA's holiday dialysis caravans and portakabins declined.

Meanwhile, the 'Pilot' dialysis unit at the Churchill Hospital had been growing. Staff had been using a little caravan next to the unit as a staff room and in 1970 two portakabins had been installed to house secretaries and technicians.

In 1975 the Oxford Transplant programme was started under Professor Peter Morris, Nuffield Professor of Surgery, who had come from a renowned transplant unit in Melbourne Australia. The first kidney transplant took place on 30th January 1975 and the second the very next day.

With the increasing number of kidney patients being treated at the Churchill Hospital, a new Transplant & Renal Ward was required. The Patients Association came to the rescue by raising £100,000, a quarter of the cost of the building, in just eighteen months. Officially opened by Sir Peter Medawar in August 1977, coinciding with the tenth anniversary of the opening of the original Pilot Unit.

In 1978 the SCKPA was one of the fourteen Kidney Patient Associations that got together to help create the National Kidney Federation. Membership of the SCKPA brings with it membership of the NKF.

In the late 1980s to early 1990s, the association opened a charity shop in Headington, manned entirely by volunteer patients their families and friends. This brought in much needed income but had to close after a few years.

The SCKPA's most recent, and most enduring campaign has been a new renal ward at the Churchill Hospital to replace the 1970s ward which all agreed had become "sub-optimal". The campaign ran over 10 years with the SCKPA working with the Hospital Trust to bring the campaign to a successful conclusion in May 2021. We now have a new renal ward sitting right alongside a new transplant ward in the main building at the Churchill. The SCKPA was able to contribute more than £30,000 from it's resources to cover the cost of four additional remote cardiac monitors that have been installed in the new ward to enhance its facilities.

The SCKPA continues to be run on a voluntary basis by and for the benefit of kidney patients, their family members and carers. It is there to provide advice, help and support to kidney patients, to represent their interests in discussions with local hospital authorities and to campaign for more and better facilities.

Jose Rico-Diaz (Co Chairman SCKPA)



World Kidney Day

On 10th March 2022 it's World Kidney Day!

In September 2020 the NKF hosted a home dialysis webinar, produced a 28 page report making seven key recommendations, and now for 2022, we are producing another report to show the progress of the campaign. In the report it will include interesting figures on home dialysis plus, not only reflecting on the work of the NKF, but the future plans to increase home dialysis. This new report will be published on World Kidney Day.

Show your support this World Kidney Day and help to spread awareness of kidney disease to friends and family.

If you don't already, follow us on social media...

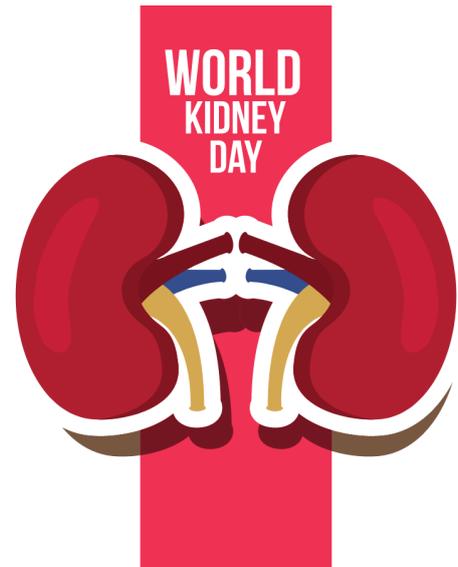
[Facebook](#)

[Twitter](#)

[Instagram](#)

Join our [Facebook closed group](#), have a natter with our kidney community on anything kidney related whether that be for support, tips or to find new friends.

Let us know what you are doing this World Kidney Day by emailing sharney@kidney.org.uk. We may be able to provide posters and materials to you. **It's also super helpful to know how you are sharing to your networks too!**



Northern Ireland Organ Donation Bill Passes Legislation

We are delighted to see that the soft opt-out organ donation system for Northern Ireland has now been passed. After years of so many charities campaigning, it is great to see this pass into legislation which will help to save so many lives.

The legislation, which will align Northern Ireland with the rest of the UK passed its final stage in the assembly on Tuesday 8th February 2022.

The bill, which has been a long awaited move at Stormont, will still need to receive royal assent before it can come into force.

We are pleased to invite you to join a free webinar on 21st February at 5pm

Increasing Organ Utilisation: An ethnic minority perspective



This webinar is hosted by the NBTA (National Black, Asian, Mixed Race and Minority Ethnic Transplant Alliance) in partnership with NHS Blood and Transplant (NHSBT).

This webinar will provide information on the current situation regarding the number of organs donated per donor after death in the UK, consider issues from an ethnic minority perspective and explore how we can increase organ utilisation.

The webinar will be chaired by **Lord Jitesh Gadhia**, NBTA Ambassador.

Speakers will include:

John Forsythe, NHSBT

Chris Callaghan, Assoc. Med. Dir. for Organ Utilisation

Orin Lewis, Chair, NBTA

Kirit Modi, Hon. President, NBTA

David Makanjuola, Consultant Nephrologist

Sina Patel, Mother of an organ donor

Winnie Andango, NHSBT Diversity Lead Nurse - ODT

Time: 5 – 6.15pm, Monday 21st February 2022

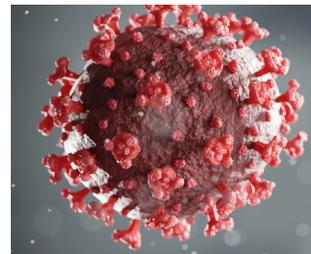
Please register to attend via the link below, or through scanning the QR code by **12pm, 21st February 2022**

<https://forms.office.com/r/m7QKn1sraF>



COVID-19 Updates

To find the latest guidance and updates for kidney patients please [visit our website](#). We regularly update our COVID-19 web page in response to any further announcements or developments.



KPA Day - Registration Open!

Registration is now open for this year's KPA day. This event will be held virtually on Saturday 9th April starting at 10am and coming to a close at 1pm.

Speakers for the day will be from the Renal Services Transformation Programme (RSTP) NKF Honorary President, Kirit Modi and NKF Helpline Advisor, Stephen Emmerson giving an update on the NKF home dialysis campaign and the home dialysis peer support service. As part of the KPA day we will give an update on the KPA working group.

During the morning our AGM will be held and executive committee members will be elected. In the final hour the council meeting will be held.

To register your place please visit [here](#) or email nkf@kidney.org.uk or call us on **01909 544999**, you will be sent the link to join once you have registered.

Do You Want to Join the NKF Executive Committee?

The NKF has a strong and active Executive Committee.

Executive members are the Trustees of the NKF.

We are looking for an Executive Committee, which is representative of the diversity within our society including:

- A good independent judgement
- A willingness to speak your mind
- The ability to work effectively as a member of a team and can contribute actively to the board of trustees role in setting an overall policy for the NKF

There are up to six meetings per year - all expenses paid.

Completed nomination forms for the executive committee must be received by Friday 25th February 2022.

If you would like to discuss the role of an executive member please do not hesitate to contact Kirit Modi, Hon President by email: kiritmodi1@hotmail.com, or call the NKF on: **01909 544999**.



Your Kidney Love Stories

We recently shared a post on our Facebook and Instagram accounts asking whether you have; met the love of your life due to your kidney, met your life partner or best friend during dialysis, met your special person at a KPA meeting, or maybe even met the person that gave you the greatest gift of all, a kidney. Find below some wonderful kidney love stories that have been sent in to us.

"The photo to the right is when we first got married. I met my husband in the year 2000 via a chatroom, I was at university in Preston and lived in West Yorkshire. We were married in Gretna Green in December 2001, I was on my second kidney transplant when we met which I had since June 1991.



My transplant failed after having viral encephalitis in 2009, but didn't start dialysis again until 2013, after being on the waiting list for almost 4 years and being told I was unlikely to get another kidney due to high antibodies, my husband suggested getting tested to be a live donor. The process in total was 8 months and he was a good match. He gave me his kidney on 16th September 2016. I was only in hospital a week and my kidney function has been amazing ever since. I cannot thank my husband enough for giving me this amazing gift. We've been married 20 years now." - **Tracy Bielby**



"My kidneys failed in 2002 due to hypovolemic shock during an emergency C section when our daughter Isabel was born. Despite previously saying we weren't going to get married, I proposed to my hubby on a LOT of morphine. As my chances of survival had been given 50/50 he couldn't really say no and then I miraculously bounced back!

I went straight on to emergency dialysis but luckily after 9 months my kidneys picked up enough to try a weekend off, which turned into a week, a month and then 14 years!

We were married in 2003 in our local village church and walked home to my parents' house where we had a marquee in the garden for the reception. There were a LOT of tears!

I'd always been told I'd need a transplant in the future but it came quicker than expected and John immediately said he would get tested. I kept saying it was very unlikely that we would be a match, but he said he knew we would be and he was right! I can't thank Mr Tavakoli and the whole team at Manchester Royal Infirmary enough, they were so caring. We are coming up to our 5th kidney anniversary this year and we always make a bigger fuss of it than our actual wedding anniversary!" - **Lucy Hatherell**



"Love blossomed for my Hubster and I over a dialysis machine.

My husband received his transplant in 2001, he was a photographer by trade and as he'd been 'out of the game' for a while was unable to get work.

He'd always had an interest in the dialysis machines and so applied for a job on the dialysis unit - he got the job!



Meanwhile I'd been doing CAPD successfully for 5 years sadly I got an infection, so I had to return to haemodialysis the rest as they say is history.

I received my transplant in 2007 she's called Barbie, as my husband's is called Ken.

We married in 2011 and love life. Both Ken & Barbie (our gifts) are doing well. There's been some bumps in the road as there always will be, but we are a terrific team.

Miracles do happen if you stay positive.

There's someone for everyone out there." - **Emma & Clint**



Share with us your kidney love story, to send in your stories please email sharney@kidney.org.uk.

PANORAMIC Study

PANORAMIC is a clinical study open to those who meet the eligibility criteria described below. The trial can be carried out remotely. This means you can participate from home, with all packs posted directly to you from our trial team. Questionnaires and diaries can be filled out online or if needed via phone call with one of our team. To check if you are eligible to join the trial please [click here](#).



The graphic features a dark blue background with a yellow pill-shaped graphic on the left containing the University of Oxford logo, a plus sign, and the word 'You'. To the right, the text reads: 'Without you we can't do it. Finding new effective antiviral treatments for COVID-19'. Below this are two bullet points with checkmarks: 'Tested positive for COVID-19 and are experiencing symptoms, starting in the last five days?' and 'Aged 50 or over? Or 18 or over with an underlying health condition?'. Further text states: 'Then you could join the PANORAMIC Study and help to find new antiviral treatments for COVID-19 to improve symptoms early and reduce hospital admissions for people with COVID-19.' At the bottom, it says 'Find out more www.panoramictrial.org or register at: [08081 560017](tel:08081560017)'.

Without you we can't do it.

Finding new effective antiviral treatments for COVID-19

- ✓ Tested positive for COVID-19 and are experiencing symptoms, starting in the last five days?
- ✓ Aged 50 or over? Or 18 or over with an underlying health condition?

Then you could join the PANORAMIC Study and help to find new antiviral treatments for COVID-19 to improve symptoms early and reduce hospital admissions for people with COVID-19.

Find out more www.panoramictrial.org or register at: [08081 560017](tel:08081560017)

Empowering Patients to Lead Conversations Around Hyperkalaemia

The NKF are working with a pharmaceutical company who will be providing a series of patient films, helping to empower patients to lead conversations around hyperkalaemia with their healthcare professionals.

Participation will include discussing your background, your diagnosis of hyperkalaemia, how this came about, any changes you have made because of your diagnosis, and the challenges you may have faced.

If you have been diagnosed with hyperkalaemia and are interested in finding out more information about this project, please email NKF Head of Marketing & Fundraising pete@kidney.org.uk.

Study On Young People and Parents' Emotional and Spiritual Care

Having a serious medical condition, such as kidney disease, can affect emotional and spiritual well-being in lots of different ways. Researchers at the University of York are doing a study which will develop recommendations for the NHS on how they can best meet families' emotional and spiritual needs.

The researchers would like to speak to **young people (16-18 years)** living with kidney disease, and **parents (child aged 0-18 years)**. They're keen to hear from young people and parents with good experiences of emotional and spiritual care, and those where these needs have not been met, or support received was unhelpful.

These videos explain a bit about the **SPARK** project and what taking part involves.

Video for young people:

https://youtu.be/wi_8hEif9AI

Video for parents:

<https://youtu.be/oqAkmUbML2U>

If you'd like to find out more, you can contact the research team via text (07544 568791), email (natalie.richardson@york.ac.uk) or via the [SPARK Project Response Form](#).

Are you helping someone who has a kidney condition?

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

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

Helping with their medical care or talking with their care team



Helping around the house like cooking or cleaning



Listening to them if they are worried or stressed



If you are interested in participating please use the QR code or click this link to go to our survey!

https://exetercles.eu.qualtrics.com/jfe/form/SV_725d9rMSoarmOr4

Need more information? Contact Chelsea at: c.coumoundouros@exeter.ac.uk



Who can participate? Anyone who is...

- At least 18 years old
- Living in the UK
- Helping someone with a kidney condition who is also at least 18 years old

You can be connected to the person with a kidney condition in any way – they could be your family member, friend, neighbour or colleague.

The survey will take around 15-20 minutes to complete.

Thank you!

Are You Feeling Frustrated That Travelling on Dialysis Is So Difficult To Arrange? We Want To Hear From You!



For dialysis patients, arranging dialysis away from base can be daunting and time consuming. As a result, travel for most patients tends to be severely limited. As the government loosens Covid restrictions, most of the population will regain their freedom to roam. But for many dialysis patients, unless changes are made, there is a risk that life may continue to feel like a permanent lockdown.

At DialysisAway they are working with the NHS and kidney patient organisations to develop ways to free dialysis patients from the travel constraints they face. To help with this, we want to hear from patients about their experiences with arranging dialysis away from base. We know this issue is important to many patients, but other surveys do not give you the opportunity to share your experiences of this aspect of life on dialysis.

Please complete this very short survey, using the link below. It should take less than 5 minutes to complete, and your input will be used to highlight this issue with policy makers and develop new initiatives to help dialysis patients enjoy the freedom that others take for granted. The more responses we get, the better.

Survey responses, including comments, will be included in a report that will be circulated to NHS policy makers and communicated in various forums to raise awareness of this important issue for dialysis patients. Your contributions will always remain anonymous.

If you would like to receive a copy of the report, please let DialysisAway know by sending an email to info@dialysisaway.com and they will add you to their mailing list.

[Take the survey now](#)

DialysisAway is a new online platform, backed by the UK government, aimed at helping patients to travel more freely through easier coordination of the paperwork required by clinics. Learn more at: www.dialysisaway.com

High Blood Pressure

Getting blood pressure down is one of the most important actions to protect against damage to the kidneys, heart and circulation. Normal blood pressure should be about 120/80 to 140/90. You may want to consider buying a blood pressure monitor to help keep track of your blood pressure.

What is blood pressure?

Each time your heart beats it pumps blood around the body. High blood pressure, or hypertension, rarely has noticeable symptoms but if left untreated it increases your risk of serious health problems such as heart attacks and strokes. Blood pressure is recorded with two numbers. The **systolic** pressure (higher number) is the force at which your heart pumps blood around your body. The diastolic pressure (lower number) is the resistance to the blood flow in the blood vessels.

Around a third of adults in the UK have high blood pressure although many will not realise it. The only way to find out if your blood pressure is high is to have your blood pressure checked.

Blood pressure varies from minute to minute according to the demands on the circulation and the need for blood and oxygen to be delivered around the body. Stress can cause high blood pressure even if you do not feel stressed. This is sometimes called white coat hypertension though it can still occur if your doctor does not wear a white coat. Blood pressure should be measured after you have been sitting quietly for a few minutes.

Keeping good blood pressure is one of the most important things we can do to keep a stable kidney function and reduced chances of heart attack or stroke.

Problems which can occur due to high blood pressure

- Kidney damage
- Stroke
- Heart disease
- Hardening and narrowing of arteries anywhere in the body which could lead to reduced blood flow and gangrene in the feet or problems with blood flow to the eyes.

Ways you can help to reduce your blood pressure

- Lose weight
- Reduce the amount of salt in the diet
- Alcohol should only be taken in accordance with the national recommended units
- Drink an appropriate amount of fluid every day.

A full list of all our patient information titles and Information packs can be provided [online](#) or by request helpline@kidney.org.uk or call 0800 169 0936. ***The National Kidney Federation cannot accept responsibility for information provided. The above is for guidance only. Patients are advised to seek further information from their own doctor.***

NKF Fundraising

Events

Are you thinking of starting a brand new challenge? Why not take a look at some of the upcoming fundraising events that are available on our website for 2022?

Events include local running events such as 5k or 10k runs, inflatable events, treks including the Northern Lights and the Great Wall of China and much more!

[View NKF events page here](#)



Weather Lottery

Take part in our NKF Weather Lottery, you can have as many entries as you like for £1.00 per week and you could win up to £25,000!

By signing up you can win cash prizes whilst supporting the NKF, so we can continue our vital work with kidney patients, families and carers in the UK.

Interested in signing up? Visit our [web page](#) to see more on the Weather Lottery.



NKF Water Bottles

Are you thinking about joining our Water Challenge in April? Why not get yourself your own NKF branded 800ml sports water bottle for only £6.50 plus postage and packaging.

To order your water bottle visit our [online shop here](#).



NKF 2023 Calendar

Photography Competition

The theme is Adorable Animals! From kittens to squirrels to dogs to dolphins send your amazing animal photos to: catherine@kidney.org.uk to be in with a chance of being featured! All featured photos will receive a free calendar!



NKF Ambassador Hattie Stiff Puts On Her Walking Boots in Aid of the NKF

"I'm walking 100 miles in 6 weeks! I'm going to be raising money as an ambassador for the NKF through JustGiving.

This is a massive personal challenge for me, as I'm only 6 months post transplant, it's the biggest physical thing I've done, and I want to prove to myself that anything is possible if you put your mind to it!

This whole challenge and the NKF mean so much to me.

The link to my JustGiving page can be found [here](#) and [my Instagram channel](#) is also available for other kidney patients to follow.

I'm doing the challenge through Conqueror Challenge, which is 100 miles through the French Riviera. Let's go and do some walking!"



This April

WE WANT YOU TO
TAKE PART IN THE
30 Day Water
Challenge

**Raising Money to
Support Kidney Patients**



All you have to do is

Drink Water for a Month

but... No TEA! No COFFEE! No FIZZ! No ALCOHOL!

(Normal intake of food is required)

If you do take up the challenge you could...

- Keep your Kidneys Healthy
- Keep Hydrated
- Boost your Metabolism
- Save Money
- See Weight Loss
- Slow Down Ageing

+
GIVE YOUR
KIDNEYS
A MAJOR
DETOX

To register, please email: nkf@kidney.org.uk
with your **name** and **address** and we will send you a fundraising pack.

National Kidney Federation

Registered Office: The Point, Coach Road, Shireoaks, Worksop, Nottinghamshire S81 8BW

Telephone: 01909 544999 • Email: nkf@kidney.org.uk • Helpline: 0800 169 09 36 • Website: www.kidney.org.uk

Registrations: Registered in England & Wales Charity Number: 1106735, Scottish Charity Number: SC049431, Company Number: 5272349

Give as You Earn contributions number: CAF GY511

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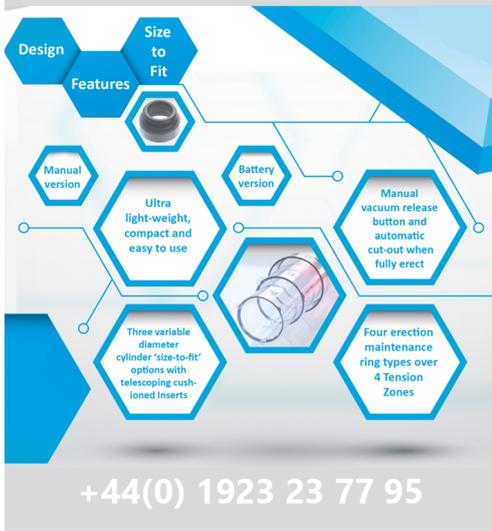


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www.MyPelvicHealth.co.uk



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For a booking enquiry or more information please contact us on **01900 822 888** e-mail info@lakelanddialysis.co.uk or look at our website www.lakelanddialysis.co.uk where you can access patient recommended accommodation as well as details of our own 4-6 berth static caravan which is situated on a quiet local park and only available to book for patients visiting the clinic.



'I love it and will be back, such a good place.'
CF 2021

Follow us on social media






The NKF – the largest Kidney Patient Charity in the UK
A FEDERATION OF MORE THAN FIFTY PATIENT CHARITIES, SUPPORTING KIDNEY PATIENTS & CARERS

Registered Office: **The Point, Coach Road, Shireoaks, Worksop, Nottinghamshire, S81 8BW**
Registrations: Registered in England & Wales, Charity Number: **1106735**, Scottish Charity Number: **SC049431**.
 Company Number: **5272349**. Give as You Earn contributions number: **CAF GY511**.