

## Distress in Dialysis

Psychological distress, including feelings of sadness, worry, and frustration, are common in people with chronic kidney disease (CKD). It is completely normal to experience these feelings when stressful events happen. Feelings of distress are common in kidney patients because of the many challenges they face in managing their health, especially dialysis. If these feelings last for a long time, they can begin to affect other aspects of your life. For example, your motivation to carry out daily tasks and leisure activities - over time both your emotional and physical health can suffer.

### The Improving Distress in Dialysis (iDiD) study

Psychological therapies are treatments that do not involve prescription drugs, and they can help people manage their feelings of distress. Cognitive behavioural therapy (CBT) is one type of psychological therapy. CBT teaches you skills and techniques to help you to improve how you manage your emotional feelings in response to stressful situations. The iDiD study uses an online self-help website to teach people these CBT skills. The website consists of seven online sessions each designed to last one hour, for people on haemodialysis to work through at their own pace. The sessions include the following information and skills:

- Understanding your CKD
- Assessing why you feel distressed
- Looking at positive ways of coping with your negative feelings
- Improving your sleep quality
- Managing unhelpful thoughts about CKD and other areas in your life
- Identifying positive goals to work towards, using problem solving skills
- Looking at ways of improving your social support from those around you
- Preparing for the future

**Guy's & St. Thomas' Kidney Patients' Association**

# All Weather Picnic!

SUNDAY 23<sup>RD</sup> AUGUST 2015 1PM–6PM

Join the Guy's & St. Thomas' KPA afternoon of fun for all the family

**BBO Games** **Bouncy Castle**  
**ACTIVITIES** **sports**  
**Face Painting**

**FREE ENTRY!**

**Kings College Sports Ground, Stillness Road, SE23 1NW**  
**(Nearest Station: Honor Oak Park. Buses: P4, 122, 185)**  
**Wheelchair Access**

**Please contact us with numbers in your part so we know how many people to expect.**

### Aims of the iDiD study

The iDiD study is testing whether the online CBT self-help website is suitable, useful, and relevant to the emotional needs of people who attend for haemodialysis. The study will also test whether the website can support the emotional needs of patients when they work through the sessions completely on their own or whether the use of the website needs to be supplemented with three telephone support calls, lasting approximately 30 minutes each.

### Who can take part?

The iDiD study is gradually being rolled out across the haemodialysis units at Guy's. Patients are asked to complete a screening questionnaire to assess their levels of emotional distress. If the screening questionnaire tells the study team that a person is experiencing mild to moderate symptoms of distress, then they will be offered access to the iDiD online self-help CBT website.

### Who helped to set up the iDiD study?

Dr Joseph Chilcot is chief investigator. Dr Chilcot is a leading researcher on the subject of psychological distress in kidney disease and is based at the Health Psychology Section, within the Institute of Psychiatry, Psychology, and Neuroscience at King's College London. The study co-ordinator is Dr Joanna Hudson, also based at King's College London. Dr David Game, Consultant Kidney doctor and, Dr Amy Carroll Renal Clinical Psychologist are also on the team. We received substantial input from patients in the development of this website including Nick Palmer, Head of Patient Advocacy, at the National Kidney Federation and GSTTKPA Committee Member.

### Contact information

For more information about the study please contact Dr Joanna Hudson. Email: [Joanna.Hudson@kcl.ac.uk](mailto:Joanna.Hudson@kcl.ac.uk) or telephone: 0207 188 1189.

# KEEPING IN TOUCH

Communication is at the heart of what the charity does. We want to keep in touch with all our members and supporters and we are very keen to hear from you so please contact us with any stories, requests for information or fundraising ideas you might have ...we are all ears!

### Here is a list of the various ways you can contact the GSTTKPA

T: 020 7188 7552  
E: [chair@gsttkpa.org](mailto:chair@gsttkpa.org)

Guy's & St. Thomas' Kidney Patients Association, Renal Offices, 6th Floor Borough Wing, Guy's Hospital, London SE1 9RT.

**Facebook:** Search Guy's & St Thomas' Kidney Patients Assoc. and 'like' our page.

This is regularly updated with latest news and information from the charity and the wider renal community.

**Twitter:** @gsttkpa Follow us on Twitter to remain updated on our activities.

**www.gsttkpa.org** Our website is updated regularly to publicise our activities; there are also links to our latest Kidney Talk newsletter, the MyKidneyCare smartphone app, Patient View and other kidney related information for adults and children. You can also register as a KPA member and receive regular email updates from us.

### Notice Board in the Kidney Clinic

(opposite the urgent bloods seating)

Here we post information about upcoming events. All of the dialysis units have the GSTTKPA banner on display together with our information leaflet. The Kidney Talk newsletters are distributed to all kidney wards, clinics and dialysis units three times a year.

## What do Clinical Psychologists do?

By Dr Amy Carroll

Psychologists are part of the kidney care team and contribute to your overall health and emotional well being. We help patients who are having difficulties in adjusting to living with kidney disease or coping with dialysis or other treatments. We are different from psychiatrists who are medical doctors that can prescribe medications.

### Why would I choose to see a Clinical Psychologist?

It is normal to feel a range of emotions when you are told you have a long term health condition such as kidney disease. These may include feelings of anger, sadness, worry and disbelief. If you are finding it difficult to cope with these changing emotions and would like some support you may wish to see a psychologist.

We can help you at any point during your kidney care journey, if you are experiencing any of the following:

- Low mood or depression
- Anxiety or stress
- Difficulties coming to terms with your diagnosis
- Difficulties coping with uncertainty about your health and treatment
- Difficulties adjusting to everyday life while living with kidney disease
- Difficulties keeping to your prescribed treatment
- Fears about the future

It may also be necessary to see you for an assessment as part of your pre transplant preparation.

### Are my sessions confidential?

Yes, unless we feel there is a serious risk to yourself or others, such as the risk of self-harm, physical, emotional, or financial abuse. If a risk is identified, we have a professional responsibility to take appropriate action to protect yourself and/or others.

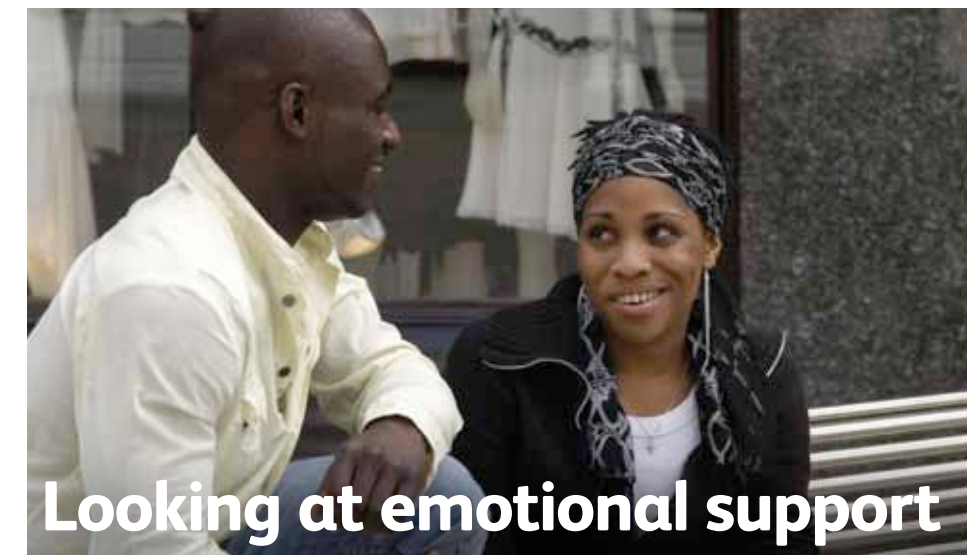
### How do I contact a Clinical Psychologist?

Talk to your Kidney Care Doctor or Nurse who can contact the Psychologists on your behalf. Alternatively you can contact us directly, details below.

### Can I see a Clinical Psychologist local to where I live?

Talk to your GP, as they may have a clinical psychologist or counsellor in their practice, or they may refer you to Improving Access to Psychological Therapies (IAPT), or to a local Community Mental Health Centre (depending on available local services).

For further information please telephone: 0207 188 9770 or 0207 188 7845



## Looking at emotional support

**The theme of this issue is emotional support, which addresses the feedback received from attendees at our Annual General Meeting held in November 2014.**

The GSTTKPA Committee consists of kidney patients, carers and kidney staff, who all know managing a serious and long-term condition cannot only be distressing but can affect the ability to work, where you live, whether you can take a holiday, finances and family and/or other relationships.

This edition gives details about some current research regarding emotional distress and kidney patients. There is also an informative contribution from Dr Amy Carroll, Guy's and St Thomas' Hospital, Kidney Psychologist. Nick Palmer has, poignantly, written about the support services provided by the National Kidney Federation (NKF) from the perspective of being the Lead of the NKF Advocacy Service and as a patient, who is also a member of the GSTTKPA Committee.

Annette Newman, also a kidney patient, has narrated how she combines informing audiences about kidney disease and organ donation, and, at the same time, raises money for the GSTTKPA. I would like to take this opportunity to thank some of our other fundraisers: London Marathon, North London Half Marathon and 10k runners; a lady who dyed her hair purple; a man, who at

the time of writing, is climbing a 6,900ft mountain in France; a couple who set up a donation page instead of receiving wedding gifts; Ride London cyclists (2nd August 2015); individuals who donate in thanks for the care they have received or who give to support our work and to the many families, who make 'in memory' gifts. The Trust holds a memorial service every November to support bereaved family members.

Emotional support can mean something different to each of us. On the one hand, it could mean getting additional information to enable and/or improve coping with kidney disease. On the other hand, it might require professional help from your GP and/or other health professionals. Alternatively, emotional support may mean being able to contact someone, who knows what it feels like to be a kidney patient. The Guy's and St Thomas' Peer Support programme is subject to additional recruitment to provide more opportunities for kidney patients to speak either by telephone or in person with another kidney patient.

I hope you will find this newsletter helpful. Sonia Moorhouse – [chair@gsttkpa.org](mailto:chair@gsttkpa.org) or 020 7188 7552

## How I promote organ donation

By Annette Newman

At the same time as looking for ways to promote organ donation by giving talks on the subject, I found a good way of fundraising for the KPA.

A friend suggested I joined the local council speakers list. We looked at this and found that some people charged, some did not and some just asked for a donation to charity. I signed up and decided to ask for a small donation to the KPA in return for my services as a guest speaker. My first step was to make sure I was fully informed about organ donation so I looked up every thing I needed to know on the organ donation website [www.organdonation.nhs.uk](http://www.organdonation.nhs.uk) I also ordered materials (organ donation leaflets) free of charge to distribute at my talks.

I talk about my own experience as a kidney transplant patient and I also explain about signing up to the organ donor register. I give the audience some facts and figures about the numbers of people waiting for organ transplants and I include other information that may encourage people to sign up, for example: "there is no upper age limit for joining the register and recording your wish to be a donor. It is the donor's physical condition, not age, which is the deciding factor for most donations".

I emphasise the importance of speaking to close family and friends about registering so that they know what people would like to happen after death.

Finally I include a Question and Answer session, which allows people to ask anything that may not have been covered, if they come up with questions I can't answer at the time I tell them that I will find out and get back to them. Overall this is an extremely rewarding and enjoyable volunteering experience which I know is directly supporting a cause that I strongly believe in.

If you think you could do something similar in your local area to raise awareness of organ donation AND raise a few pennies for the GSTTKPA then please contact us:

E: [info@gsttkpa.org](mailto:info@gsttkpa.org) or tel: 020 7188 7552.



# Supporting patients, carers and staff following a death

By Deborah Mundle, Matron

A thought provoking and powerful article was recently published in KidneyLife, the magazine of the National Kidney Federation, about grief and bereavement in haemodialysis units. The article was written by Zandria Richards, a haemodialysis Patient.

The dialysis unit family can be a close one and sometimes staff and patients see each other more often than they see some of their own relatives or friends. The bond developed between people who are sharing the same experience on a weekly basis is strong and the “empty chair” can be a painful reminder of a life cut short. We thought it might be helpful to outline how we help support our haemodialysis patients at Guy’s and St Thomas’ following a death in the unit.

We always try to inform people that a fellow patient has died, especially those who were being treated alongside that person on a regular basis however for confidentiality reasons staff cannot discuss the nature or cause of death. If the family is agreeable we would also pass on details of the funeral in case any patients or staff wish to attend. We also try to make contact with the family to express our condolences in the form of a phone call, letter or card.

A memorial service is held once a year, usually in November, in the Guy’s Chapel to remember all kidney patients who have passed away in the previous 12 months. This is a moving and uplifting experience, well attended by patients, families and staff. Bereaved families are personally invited and many have commented on how helpful they have found it as part of their bereavement journey.

The Kidney Care Team provide ongoing support for bereaved families, patients and staff as part of their service and our Social Workers and Psychologists also offer emotional support to families and carers.

They can be contacted by the Kidney Care Team.



## What is peer support and how could it help me?

By Ros Tibbles and Sue Cox

Peer support aims to provide support for kidney patients, their families or carers by providing an opportunity to talk to an experienced kidney patient on a one-to-one basis.

### Who are peer supporters?

Peer supporters are unpaid kidney patient volunteers. They have completed formal training to offer one-to-one support; they are registered Trust Volunteers and have undergone criminal records checks to enable them to do this.

### How can I meet a peer supporter?

Ask your kidney doctor or nurse or call Sue Cox, Consultant Nurse directly tel: 020 7188 7924. They will match you with a peer supporter and arrange contact.

### Will I have anything in common with my supporter?

Yes, you will share your common experiences as a kidney patient. If you wish, you can ask to be put in touch with someone of a similar age or background or someone undergoing a specific type of treatment.

### Can I request peer support at any time?

Yes, as a kidney patient there may be many times when you may wish to talk to a Peer supporter such as:

- when you are first given your diagnosis
- when you are considering treatment choices
- any time that you feel it may be helpful to talk to another patient.

### Is peer support only available for patients?

No, it is also available for families and carers of kidney patients.

### Is peer support confidential?

All discussions between you and the Peer Supporter will be treated sensitively. However, the peer supporter is obliged to speak to a kidney doctor or nurse if they feel that you or someone else is at risk of harm.

### What can peer supporters not offer?

Peer supporters cannot offer advice about medical treatments. You should get medical advice from a health professional such as:

- your GP
- your kidney doctor
- your kidney nurse
- an appropriate member of the healthcare team.

Peer supporters cannot offer counselling. Professional psychological help and counselling is available through the healthcare team or by contacting the renal psychologists

If you think you would like to train to be a Peer Supporter please contact Ros Tibbles, Service Improvement Nurse tel: 020 7188 7552.

# The role of the NKF<sup>1</sup>/BKPA<sup>2</sup> Advocacy Service in supporting patients at times of distress



By Nick Palmer

For kidney patients like you and me, generally our ‘mental’ health can be described more informally as our mood and how happy or sad we feel. Living with chronic kidney disease and being treated with dialysis or a transplant often means our mood can fluctuate. At times we may feel distressed or frustrated with dialysis, angry about deteriorating transplant function or exhausted trying to cope with complicated family, work or money issues.

The NKF know that many patients and carers cope admirably, living well or to the best of their ability, with a condition that can test the patience of a saint! It may often feel like your voice or problem isn’t heard or there isn’t the opportunity to talk. We know that talking about your problems can really help and could open the door to reducing the stress you may experience.

The NKF run the National Kidney Patient Helpline tel: 0845 601 02 09 (free service when phoning from a landline), where patients or carers can discuss their kidney-health related issues. People with complicated problems are transferred to their regional Advocacy Officer.

As Head of Advocacy, I cover London, the South East and South Central England in a wide-ranging role where I listen, support, advise and advocate

for patients on a range of issues covering dialysis, transplantation, benefits and holiday dialysis for instance - what I am unable to provide is medical advice. The service is confidential, treated with utmost sensitivity, respect and empathy, and importantly for many, independent from the NHS.

Talking to an Advocacy Officer can often feel like a relief, where patients or carers have the time and space which may not always be available in a hospital setting. People say they have benefited enormously from talking to someone who has themselves experienced many aspects of treatment. They also feel more confident and knowledgeable after they have been in contact with the service - ultimately feeling happier and supported then when they first called – this is the aim of the service.

If you are feeling emotionally distressed the following details below provide an opportunity to seek support, advice and further information:

- Talk to your kidney care team at your dialysis centre or at the Kidney Clinic.
- Talk to your GP – they can discuss opportunities to access help around emotional support tools and therapy such as Mindfulness, Compassion Focused Therapy, or Cognitive Behavioural Therapy

- Talk to your regional NKF/BKPA Advocacy Officer, Nick Palmer tel: 0208 764 1069 or via email [nicholaspalmer.nkf@btinternet.com](mailto:nicholaspalmer.nkf@btinternet.com)
- Talk to The British Kidney Patient Association Counsellor, Jacqui Fraser via tel: 01420 541 424 or email at [Jacqueline.fraser@britishkidney-pa.co.uk](mailto:Jacqueline.fraser@britishkidney-pa.co.uk)

You could also consider taking up a new hobby, re-establishing an old one or take time out dedicated to yourself. Try yoga, walking, join a singing group, take time to read a book; meet a friend or join a community group or event.

Further support is also available nationally from:

- Mind – tel: 0300 123 33 93 [www.mind.org.uk](http://www.mind.org.uk)
- Rethink Mental Illness – tel: 0300 5000 927 [www.rethink.org](http://www.rethink.org)
- The Samaritans provides 24-hour emotional support for people who are experiencing feelings of distress or thoughts of suicide – tel: 08457 90 90 90 [www.samaritans.org](http://www.samaritans.org)

The British Kidney Patient Association provides funding for five of the eight Advocacy Officers in the UK.

<sup>1</sup> National Kidney Federation  
<sup>2</sup> British Kidney Patient Association

## Integrating Mental & Physical healthcare: Research Training & Services (IMPARTS)

By Dr Amy Carroll

If you are having dialysis in one of the Guy’s dialysis units or you attend the transplant review or transplant support clinics, the chances are that you have been invited to complete a short questionnaire using an electronic tablet or ipad. The questionnaire asks about symptoms of low mood and anxiety. This is part of an initiative to integrate mental and physical healthcare at Guy’s, St Thomas’ and King’s College Hospitals

in collaboration with King’s College London.

It is common for people with physical health problems to experience anxiety and / or low mood and the aim of the questionnaire is to identify those who may benefit from some extra support. This support could come from the Kidney Care Team, your GP, a Clinical Psychologist or a Psychiatrist. Alternatively you may be offered access to an online self-help website as part of

the Improving Stress In Dialysis (iDiD) project which you can read more about in this newsletter.

This innovative approach to detecting and managing common mental health problems is just one way in which we are trying to improve the emotional support we offer patients. It is also helping us to identify the level of psychological need in our patient so that we can plan how we meet that need now and into the future.

# PAVE the way to a better quality of life on haemodialysis



[ Paclitaxel assisted balloon Angioplasty of Venous Stenosis in haEmodialysis access ]

The PAVE Trial is a randomised controlled trial (people taking part are put into one or other group at random - see below). It aims to preserve arteriovenous fistulae (AVF), used for haemodialysis. We plan to start recruiting haemodialysis patients in October 2015.

### Vascular access for haemodialysis

Haemodialysis requires access to the circulation (blood stream) and the best option for this is an AVF, which is made by surgically joining an artery and a vein. However, these AVFs have a limited life and may develop narrowed segments. This can lead to thrombosis (blockage), which may result in admission to hospital and the insertion of temporary dialysis lines which are prone to infection. The standard treatment for the narrowed segments is to use a special balloon to stretch the segment. This is done in the X-ray department. Unfortunately, the narrowing can return.

### PAVE trial

The aim of the PAVE trial is to test whether using a drug-coated balloon can delay the return of the narrowing and keep the AVF in use for longer.

The trial is funded through the National Institute for Health Research (NIHR), with the balloons provided by a company called Bard. King’s College London together with Guy’s and St Thomas’ NHS Foundation Trust co-ordinate the trial.

### The facts

If you take part in the trial you will be randomly placed into one of two groups. Immediately after treatment with the standard balloon that is normally used, one group will receive another treatment with the drug-coated balloon and the other group will receive another treatment with a balloon which is not drug-coated. You will then be followed up for at least one year.

The two groups can then be compared to see if the AVFs of people in one group last longer than those in the other group. The trial will gather evidence of the safety and potential benefit of using the drug-coated balloon. The outcome of the trial will be evidence to identify the best method to use, so that we can safely improve patients’ quality of life on dialysis.

We will recruit 211 haemodialysis patients, from six kidney units across the UK. The chief investigator is Dr Michael Robson, the lead surgeon is Mr Francis Calder, and the lead radiologist is Dr Narayan Karunanithy. These three doctors are all based at Guy’s Hospital. There is a safety committee of experts who will check the data and ensure that no patient is placed at risk.

For more information about the PAVE trial, please contact Vikki Semik, the PAVE Clinical Trial Manager, at [vikki.semik@kcl.ac.uk](mailto:vikki.semik@kcl.ac.uk).

## Optimised TracrolimuS and MMF for HLA Antibodies after Renal Transplantation

By Dr Leanne Gardner - Trial Manager

### Background to OutSMART

OutSMART is a clinical trial that will determine if screening a marker in the blood of patients’ with kidney transplants, and then changing their treatment accordingly, can stop premature failure of kidney transplants. Human Leukocyte Antigen (HLA) antibodies are associated with chronic transplant rejection. These HLA antibodies alert the immune system that a donor kidney is ‘foreign’ and are involved in the process that causes the body to reject the kidney. These HLA antibodies are the marker in the blood that this trial will monitor in 2800 participants throughout the UK.

### Who is involved in OutSMART?

This study started in 2013 and is led by Chief investigator, Professor Anthony Dorling, based at Guy’s Hospital and King’s College London. Patients who have had their kidney transplant for more than one year are being invited to join the trial. Patients recruited to the trial will see research nurses at their routine clinic visits for three years. This is to assess if their kidney transplant is remaining healthy or if the body is starting to reject their kidney transplant.

Some patients with HLA antibodies will have their immunosuppression drugs adjusted to prevent rejection.

The trial is being conducted in a total of eight kidney transplant clinics in the UK including Guy’s and King’s College Hospitals.

The study is supported by Mr Paul Newton, a kidney patient from Guy’s Hospital and former KPA committee member. His input and involvement on the trial committee is invaluable and he provides continual insight into patients’ thoughts and ideas about being involved in a trial such as OutSMART.

### OutSMART at Guy’s Hospital

A total of 454 kidney transplant patients have joined the trial at Guy’s, our target is 600 participants. If you attend the kidney clinic and think you may be eligible, please ask about OutSMART. Members of the research team including nurses and doctors are in clinic every morning and we are happy to answer questions and about the trial. Those attending the clinic will be sent information about OutSMART in the post and will then be approached by Prof Dorling or a research nurse in the clinic.



Professor Anthony Dorling (Chief Investigator)

### Acknowledgement

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Written by: Dr Leanne Gardner (Trial Manager) and Professor Anthony Dorling (Chief Investigator).