



Kidney disease and mental health

Statement of intent from the

Centre for Mental Health and Kidney Research UK

"Once you're a kidney patient, you are a kidney patient for life... Every time you are admitted or have a procedure you go into that carrying all the trauma from previous procedures. Trauma that has had time to grow and solidify in your head. Then you are made to feel like you are overreacting. This often leads to you feeling even worse. Shame, self-doubt and criticism all mix in with the trauma and make de-escalating your reaction harder and harder. Is it any wonder those with long term health conditions are more likely to have a mental illness? I think all too often the medical professionals hugely underestimate the burden that we carry and minimise the psychological effects of this burden." (Sarah Green)

Living with chronic kidney disease makes every day a challenge. It is a life-threatening condition that never goes away, even after a successful transplant that unfortunately can fail over time. Kidney disease affects, and sometimes governs, every aspect of people's lives. It means undergoing extensive and sometimes traumatic medical and surgical treatments time and again. Kidney disease affects people of all ages and although more common in older people, the psychological impact may be greater in the young.

It is perhaps no surprise that mental health problems are much more common in patients living with kidney disease. For example, depression is three to four times more likely in people living with advanced kidney disease (1). Yet this is still rarely addressed by either physical or mental health services. It is time for this to change.

Kidney disease and mental health are linked

All long-term medical conditions put people at a higher risk of a mental health problem, even after successful treatment (2). As with people who have survived cancer treatment, depression is just as common among those who receive a kidney transplant as it is among those who are receiving dialysis (1). Yet good mental health is vital for people living with kidney disease. Without it, quality of life is much poorer, and treatment is less likely to be successful, with serious and potentially fatal consequences.

The increased risk of poor mental health among people with kidney disease has multiple causes, which are unique to the individual. Having a long-term condition that risks your life and limits your freedom in itself makes depression and anxiety more likely (2). The effects of illness, successive hospital admissions, A&E visits and intrusive treatments (for example routine dialysis) can also be traumatic and increase risk. Getting a transplant can also have consequences: from a feeling of guilt at benefiting from someone else's sacrifice, to fearing infection and immune rejection and limiting your world to stay safe.



For some people with kidney disease, poor mental health may have been a part of their life before they became unwell. Mental ill health too often leads to poor physical health, yet for many people with a mental illness their physical health is overlooked and neglected by health services until it reaches crisis point.

The consequences of poor mental health among people with kidney disease are serious and potentially life-threatening. As with any physical illness, poor mental health makes it less likely people will adhere to treatment plans (3). This means that for someone who needs regular life-preserving medication or dialysis, not taking treatment has immediate and serious implications.

"What use is the latest medication or treatment if the patient is so overwhelmed mentally that they are unable to commit to the regimen? I've seen 'difficult' patients die. People who skipped dialysis and were labelled as non-compliant. Doctors astounded at the seemingly stupid decisions that patients make that often lead to worsening health or death. And yet very rarely do they stop to question why. I'm certain that many 'difficult' patients are actually doing everything they can to fight the fires in their heads and simply don't have the energy to stick to rigid diet and treatment protocols. I'm certain that people are absolutely at their limit and dread anything else going wrong. I'm certain that people are dying because they are unable to manage their health alongside a serious mental health issue. I was very nearly one of them." (Sarah Green)

The importance of recognising the mental health challenges of people living with kidney disease has been the focus of clinical and research activities for some time. However, given COVID-19 and the direct and indirect consequences this pandemic has on the lives of kidney patients, never has the importance and impact of mental health been so alarmingly apparent. It is time to take the links between kidney disease and mental health seriously.

Work has begun, but there's more to do

We know that work has already begun in some places, yet there is still much more to do if we are to achieve effective integrated care. It is vital that more research is devoted to the mental health needs of people living with kidney disease. We urgently need to know how to routinely monitor the mental health of people living with kidney disease, to identify factors which increase the risk of poor mental health, and ultimately design and deliver, safe and effective evidence-based interventions.

But we also need to take action now to offer help to people struggling with their mental health today. Patient leaders have begun to take their own steps, for example through mentoring and peer support programmes.

"The concept of peer support was first introduced by a couple of older members of our Young Adult Kidney Group. Because we are quite vocal and proactive (largely as a result of having been part of the group in the first place I suspect!) we decided we wanted to pay it forwards in a tangible way, giving something back and continuing to stay at least a little bit connected to the group that had helped us so much.

And so our peer support team was formed. None of us ever actually officially applied for the role. Nobody really asked us to. We identified ourselves as people who wanted to do it, and



put our heads together to see what we could come up with." (Holly Loughton, *Secondhand Life* <https://www.secondhand-life.com/2019/11/personality-perfectionism-peer-support/>)

Clinical teams in some areas have also sought to innovate and reach out to improve mental and physical health support. This can include improving access to psychological and exercise-based rehabilitation interventions, putting in place liaison arrangements when specialist help is required or training kidney disease staff in mental health awareness. Small-scale innovation may help to identify a pathway forward for a longer-term programme of transformation to support people with kidney disease and their overall health and wellbeing.

"Chronic kidney disease is a life-long condition, even now I'm transplanted and doing quite well, I will never not have chronic kidney disease. It will always be there, needing to be factored in to how I live my life and influencing many decisions that I make. This is hard, but there are also times where it's not as overwhelming as it used to be." (Holly Loughton, *Secondhand Life* <https://www.secondhand-life.com/2019/11/personality-perfectionism-peer-support/>)

It's time to work together

Together, the Centre for Mental Health and Kidney Research UK want to bring about this transformation. Together we need:

- A commitment from key stakeholders both within the kidney community and beyond to fund mental health research in a number of areas, including developing evidence-based interventions for kidney patients.
- A commitment from the NHS in every part of the UK to fund and evaluate models of collaborative care and liaison services for people with kidney disease that can be implemented into clinical practice.
- To help patients to support each other, by funding and developing peer support networks and mentoring schemes.
- To ensure all staff in kidney disease services have the necessary knowledge and skill, and the right supervision, to look after patients' mental and physical health
- To secure access to psychological and physical rehabilitation therapies delivered by professionals who understand the specific circumstances of people living with kidney disease.
- To make kidney disease services fully trauma-informed, for example by creating clinical environments that promote wellbeing and a sense of safety.

From today, Kidney Research UK and the Centre for Mental Health will work together to better understand the links between mental health and kidney disease, to generate evidence of how we can improve treatment for those in need, and to promote this evidence to ensure the mental health needs of kidney patients are also addressed by others.

In terms of research, Kidney Research UK have already committed funds to a three-year mental health research programme that begins in the autumn and we hope to fund more work in this area in the future. We have also launched the [Andy Cole Fund](#) as part of our

approach to increasing the funds we have available to dedicate to mental health and wellbeing in kidney disease.

We know people with kidney disease struggling with their mental health today cannot wait for that to be completed. That's why we'll be supporting a range of programmes to help them now.

Read more about the [Centre for Mental Health](#) and [Kidney Research UK](#)

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We are delighted that the Renal Association and the British Renal Society are endorsing this important initiative.

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