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Centre for Mental Health & Kidney Research UK

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# Addressing the mental health challenges of life with kidney disease - Executive Summary

*The case for change*

**Jo Wilton**



# Foreword



## **Sandra Currie, chief executive, Kidney Research UK**

As a former mental health nurse, I know the importance of protecting mental health and the value of good emotional support. Focused care can transform patients' lives and enable them to live as well as possible with the burden of their physical health condition.

Kidney disease takes a huge toll on patients' mental health. Treatments are gruelling, and often fraught with multiple additional complications. In-centre dialysis requires three hospital visits each week lasting at least four hours. A transplant is not a cure, and for many, the fear of rejection hangs over them for the rest of their lives. Research also shows us that patients who are supported with their mental health have better physical health outcomes too.

Kidney patients need access to specialist mental health support – from professionals who understand the unique impact of kidney disease and its treatments, as well as how best to care for the patient's emotional wellbeing. At Kidney Research UK, we are determined to transform the mental health support offered to patients, by funding research to discover the best possible support, and campaigning for access to these essential services for all.

I would like to thank Andy Cole and everyone who has backed the Andy Cole Fund for making this report possible. We will be driving the recommendations forward in order that kidney patients have access to the mental health support they desperately need.



## **Andy Cole, ambassador, Kidney Research UK**

I developed kidney failure after contracting a virus on a trip to Vietnam in 2015. Having played professional football for over 20 years, I found it hard to adjust to living with a life-threatening condition. It took its toll on me – physically and emotionally.

I was very lucky to receive a donated kidney from my nephew. But it's not a cure and getting used to all the medication has been really difficult. I remember getting home after my transplant and looking at all the drugs I had been given and thinking, 'this is what I need to take for the rest of my life to stay alive.'

Living as a transplant patient and not knowing what's around the corner is not easy. But counselling has played a big part in my recovery, and I want everyone with kidney disease to have access to good mental health support like I did.

I'm proud the Andy Cole Fund has supported the development of this report. I want it to shine a light on the impact of kidney disease on people's mental health. It's a really tough disease to live with and patients deserve access to the best possible mental health support.



# Executive summary

## Purpose

Centre for Mental Health worked with Kidney Research UK to explore the psychosocial (psychological and social) health needs of people living with chronic kidney disease. We reviewed relevant literature and spoke with people living with kidney disease (between the ages of 12 and 88), family members, and professionals in renal (kidney) services, about their experiences. This report shares the key findings from that research and identifies the policy and practice implications for both renal and mental health services.

## Key findings

Kidney disease is a risk factor for poor mental wellbeing; and poor mental wellbeing is a risk factor for worse outcomes for people with kidney disease.

Kidney disease can affect people's relationships, their social life, their education, their work, their sense of identity, and their hopes for the future. It is understandable – and even to be expected – that a condition with such wide-reaching effects would also have an impact on people's emotional health, psychological wellbeing and quality of life. These effects can extend to the people who are most closely involved in their care.

**"The way I explain it to people is that I just feel like I've got this kidney cloud over my head. It's in my life every day. Every day, it's affecting something that I'm doing."**

In general, people living with kidney disease are recognised to be at risk of worse psychosocial outcomes than the general population. But the risk is not equally distributed; some groups are at higher risk than others. Moreover, these groups are often less well served by renal services because, for example, they may also be affected by other long-term health conditions, they may not speak English as their first language, and they may face more barriers to accessing care on the terms on which it is made available by mainstream services.

**"I don't think we [people from my community] are hard to reach, I just think we haven't been appropriately approached."**

Furthermore, children and young people are not just small adults. They have distinct needs, preferences and risk factors, which must be considered in their own right. The transition from paediatric (children's) to adult care is a time when having the right psychosocial support in place is especially important.







**"I always felt like kidney disease is stereotyped to the older generation. And sometimes I just feel that it's really emotionally draining to even explain that to my friends [...] so you just kind of hide it and go, 'Yeah I'm fine.'"**

There has been little research into the outcomes of specialised vs. generic psychosocial support, and there is limited availability of kidney-specific psychosocial support (it is a 'postcode lottery'). Yet, the people who spoke to us had a strong preference for kidney-specific psychosocial support.



**"Having someone you can talk to about your condition [who understands it], that would be life changing [...] You kind of feel like there is someone else in your corner and it's not like another counsellor who is like, 'Oh right, ok what is [kidney disease]? What does it mean?'"**

People's needs and preferences are as diverse as their circumstances and their experiences. There is no 'one size fits all' solution for psychosocial support in kidney disease; an individualised approach is needed.



**"I guess I just felt lost as a patient among all the specialities involved."**

Person-centred care co-created with patients (coproduction) can mitigate some of the negative impact of kidney disease treatment on psychological wellbeing. It can also help to ensure psychosocial care meets the needs of the people it is intended to support.

At its most basic, good psychosocial support involves having a range of options suitable for different levels of need (stepped care), and mechanisms for ensuring that people are matched to the option most suitable for their level of need (screening and assessment).

Pre-emptive and proactive psychosocial support is better for patients and better for services. There are evidence-based interventions and educational programmes available that can help people to maintain and promote their mental wellbeing. It is easier to protect and maintain mental wellbeing than restore it after it has been eroded.

There are gaps in the systems resulting from a lack of communication, coordination and integration within and between teams and specialisms. These gaps have a negative impact on patients' wellbeing.

Psychosocial support, when done well, is not just an add-on to kidney care, but a strand that runs through every part of it.





**"I can't recall one session where the medical doctor asked how I'm feeling mentally. It's just, 'Your kidneys aren't good, we are going to tackle your kidneys.' [...] So you're sent off without knowing what to do next."**

Psychosocial support will continue to be inadequate until it is recognised as being a core component of good care for kidney patients, and is funded and staffed accordingly.



**"I actually think that the awareness of mental health from the medical team, from the multi-disciplinary team, is actually very high. Whether they have the capacity to actually always deal with what they know is going to be an issue."**

## **Summary statements**

**All people living with kidney disease should have their psychosocial needs assessed using validated methods.** This screening should take place at diagnosis, at changes in treatment, as they go through different stages of kidney disease, at times of distress and annually. This assessment should include the psychosocial needs of family members and carers.

**All people living with kidney disease should have access to emotional, psychological and practical kidney-specific psychosocial support** appropriate to their level of need: effectively providing a 'stepped care' model. This will require investment in additional support where there are currently gaps, and the provision of a range of support offers so that people can choose the options most relevant to them. Reliable information about the support that is available should be easily accessible through a range of trusted channels, for example the NHS website's pages on chronic kidney disease.

**Psychosocial support should be available to those experiencing lower levels of distress and need**, and should not be dependent on a person meeting the threshold for a clinical diagnosis or qualifying for specialised social care. This will meet people's needs proactively and pre-emptively as a way of preventing the escalation of distress.

**All aspects of kidney care should be psychologically-informed**, with all renal health care professionals recognising the importance of psychosocial care, and having the skills (through tailored training), the resources (including time), and the managerial support and supervision to be able to engage with the psychosocial needs of people living with kidney disease.

**Psychosocial support for children and young people should be tailored to different development stages**, and include a psychologically-informed transition from paediatric to adult care.

**Groups at higher risk of kidney health care inequities should be identified so that gaps in provision can be filled.** Co-design and coproduction, where support is designed and delivered in an equal partnership between professionals and people using services, will be necessary to ensure support offers are relevant, culturally-competent, age-appropriate, and easily accessible.

**The quality of psychosocial support offered to people living with chronic kidney disease should be monitored routinely** so that local services can assess how well they are meeting people's needs (including by a range of equality characteristics).





Further research into the provision of psychosocial support for people with kidney disease is under way. It is essential that as the evidence base emerges, it is utilised appropriately to inform the ongoing development of services, and that more research follows to ensure that we continue to learn what works and in what circumstances.

## **Recommendations**

- 1.** The NHS must invest in expanded and improved psychosocial support for people with chronic kidney disease (and other long-term conditions).
  - A.** In England, this could be achieved through the next iteration of the NHS Long Term Plan or the Major Conditions Strategy.
  - B.** In Scotland, the forthcoming strategy on Mental Health and Wellbeing should address the specific needs of people with long-term conditions, including chronic kidney disease.
  - C.** In Wales, this could be included in an updated Together for Mental Health strategy, or a service specification on psychosocial support could be developed as part of the Quality Statement for Kidney Disease.
  - D.** The delivery of the Northern Ireland Mental Health Strategy 2021-2031 should include psychosocial services for people with kidney disease, including children and young people.
- 2.** Integrated Care Boards in England and Health Boards in Scotland and Wales should ensure that a stepped care model of psychosocial support is routinely available to everyone of all ages living with chronic kidney disease in their area.
- 3.** Renal treatment service providers should ensure all of their staff are trained, supported and supervised to identify patients' psychosocial needs, to practice in psychologically-informed ways, and to offer low-level support and rapid onward referral where more intensive support is required.
- 4.** Renal services should routinely assess the psychosocial health of their patients and ask regularly about the quality of psychosocial support they are offered.
- 5.** Government should invest more funding into research on kidney disease and mental health to increase our understanding, and aid the ongoing development of services.





# **CENTRE FOR MENTAL HEALTH**



## **Addressing the mental health challenges of life with kidney disease: The case for change**

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