Addressing the human and economic cost of kidney disease: a manifesto for change

Kidney Research UK has an urgent mission to end kidney disease. Over the last ten years we have invested more than £65 million in research. We campaign for governments and decision makers to change policy and practice to ensure everyone with kidney disease can access effective care and treatment, and to make kidney disease a priority.

As we approach the upcoming general election, we call on the next government to:

1. Support our NHS to prioritise the prevention and early diagnosis of kidney disease, enabling people to access early treatment to stay healthier for longer.
2. Support our NHS to ensure kidney patients receive individualised mental health support to enable them to maximise their physical and emotional health.
3. Increase investment in kidney research to £50m per annum to reflect the human and economic cost of the disease and accelerate progress towards new scientific discoveries and treatments.

The scale of the challenge

In the UK, there are an estimated 7.2 million people living with chronic kidney disease (CKD)\(^1\).

When kidneys fail, patients need either dialysis or a transplant to survive. Both options, if available, are gruelling, requiring regular, extensive medical treatment. Dialysis is life-limiting and six people die every week waiting for a transplant. A transplant is not a cure, lasting on average 20 years. The fear of infection or rejection of the transplant has a significant impact on patients’ mental health.

The annual economic burden of kidney disease in the UK is £7.0 billion, with £6.4 billion being direct costs to the NHS – about 3.2% of NHS budgets\(^1\). These costs could grow to £13.9 billion and £10.9 billion respectively over the next 10 years, primarily due to the need to increase dialysis capacity by nearly 400% if we fail to take steps now to prevent kidney failure\(^1\).

Kidney disease disproportionally impacts people from deprived communities and ethnic minority groups. They are more likely to develop kidney disease, progress faster to kidney failure and require dialysis or a transplant.

CKD is also closely linked to other major health conditions such as diabetes, high blood pressure and cardiovascular disease. Around 40% of people with type 2 diabetes will develop kidney disease\(^2\) and people with kidney failure are eight times more likely to have a heart attack and four times more likely to have a stroke than those without the condition, with women at greater risk\(^3\).

Data on current and future prevalence, cost and demand for dialysis and transplantation for each local area can be accessed via our interactive dashboards.
What needs to change?

Support our NHS to prioritise the prevention and early diagnosis of kidney disease, enabling people to access early treatment to stay healthier for longer.

The next government needs to do more to prevent kidney disease arising by reducing the risk factors associated with CKD, such as high blood pressure, diabetes, cardiovascular disease and obesity. The NHS should monitor those at risk of CKD and diagnose it earlier, giving valuable time to stop decline in kidney function. Earlier diagnosis and intervention would lead to better patient outcomes and a reduced cost to the NHS and wider economy. Our report Chronic kidney disease and prevention: Harnessing the potential of early intervention and disease management\(^4\) outlines the changes needed, namely:

1. **Incentivising primary care to increase the number of adults at risk of kidney disease receiving annual blood and urine tests to detect kidney damage.** This should include people with diabetes, high blood pressure, cardiovascular disease and obesity.

2. **Increasing the uptake of new medicines designed to slow kidney decline and prevent heart attacks and strokes in kidney patients (including SGLT2 inhibitors).**

3. **Collect more consistent data on patient ethnicity and socioeconomic status to help identify those at risk of CKD and to ensure equity of access to interventions.**

4. **Invest in education and awareness for healthcare professionals, across disciplines, to improve the diagnosis and management of people with, or at risk of, CKD.**

5. **Support community pharmacists to play a greater role in the testing and monitoring of CKD.**

One patient’s story:

Life changed overnight for Nicole and her family when, in 2019, she was diagnosed with a rare form of kidney disease, IgA nephropathy. Dialysis has been a necessity to keep Nicole alive while she waits for a kidney transplant.

Nicole says: “It is very stressful and scary, to go from being perfectly healthy to kidney failure. Before kidney disease I had a normal life. I have three children, I was studying at university and working. Dialysis has put a lot of limits on our lives. My eldest daughter remembers me being this fun and bouncy mum, so it has been scary for her to see me go from jumping on trampolines to being bed-bound, using dialysis equipment and being visited by nurses.”

Kidney disease has created lots of anxiety for Nicole and her family. No longer being able to work has made supporting their young family challenging, particularly during the ongoing cost-of-living crisis. Nicole says: “Mentally and emotionally, it has been difficult and taken a toll on us. We shouldn’t have to be worrying about how we’re going to feed our children.”

There is no cure for kidney disease, so for Nicole, the most important thing is receiving the right treatment so she can continue to be here for her children. She says: “I want to be around to see them grow up, have their own children, have careers, have achievements and I just want to see them be happy. At their Christmas concert I was sat there thinking I really hope this isn’t my last one, I hope I get to be here this time next year to watch them.”
Support our NHS to ensure kidney patients receive individualised mental health support

Kidney disease is a risk factor for poor mental wellbeing and, in turn, poor mental wellbeing is a risk factor for worse outcomes for people with kidney disease. Our own survey of over 1,000 kidney patients showed that 36% can’t fully take care of their physical health because of mental health problems, and 27% have considered self-harm or suicide. Support from professionals who are both experts in psychotherapy and trained in understanding kidney disease is vital. Our report Addressing the mental health challenges of life with kidney disease: The case for change[5] outlines the changes needed to improve outcomes, namely:

1. Investing in the mental health workforce so psycho-social support is a key component of the renal multi-disciplinary team.
2. Implementation of a tailored approach to mental health support through a stepped model of care that becomes more specialised as needs increase.
3. Investment in all renal services to ensure staff are trained and supported to assess and refer patients for further mental health help.
4. Increased government funding for research into the relationship between kidney disease and mental health to enable the ongoing development of essential services.

Increase investment in kidney research

The government currently invests very limited resources into kidney research – £17.7 million in 2021/22. This represents just 1.4% of relevant public healthcare research funding and contrasts with kidney disease costing the NHS 3.2% of its budget.

We are calling for the UK government to:

1. Increase funding for kidney research to £50m per annum to reflect the significant human and economic cost of the disease.
2. Ensure rare, hereditary and paediatric renal diseases are recognised and addressed by the life sciences sector.
3. Ensure patients have access to new and innovative diagnostic and treatment options as quickly as possible.

Research in action:

Kidney Research UK-funded researchers at the University of Cambridge successfully altered the blood type of three deceased donor kidneys. This groundbreaking discovery could lead to an increase in the supply of kidneys available for transplant, particularly for ethnic minority groups who wait longer for a suitable match. The wide-ranging impact of innovative research into kidney disease is clear but more investment is vital.

Every year thousands of lives are devastated by kidney disease. The next government must take urgent action to protect patients, their families and the NHS.
About Kidney Research UK

Kidney Research UK is the leading charity in the UK focused on funding research into the prevention, treatment and management of kidney disease. Our vision is the day when everyone lives free from kidney disease and for more than 60 years the research it funds has been making an impact. But kidney disease is increasing as are the factors contributing to it, such as diabetes, cardiovascular disease and obesity, making the charity’s work more essential than ever.

Kidney Research UK works with clinicians and scientists across the UK. It collaborates with partners across the public, private and third sectors to prevent kidney disease and drive innovation to transform treatments.

Over the last ten years the charity has invested more than £65 million into research. We lobby governments and decision makers to change policy and practice to ensure the estimated 7.2 million people living with kidney disease in the UK have access to the most effective care and treatment, and to make kidney disease a priority.

Most importantly, the patient voice is at the centre of everything at Kidney Research UK. Patients, carers and families inspire and inform the charity’s mission and push it forward to make a difference and change the future of kidney disease.

References


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