

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Cefnogi pobl sydd â chyflyrau cronig](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [supporting people with chronic conditions](#).

CC27: Ymateb gan: | Response from: Kidney Care UK



24 May 2023

Dear Sir/ Madam,

Attached is our organisation's submission to the Welsh Senedd's Health and Social Care Committee, Chronic Conditions Strategy Consultation:

Organisation: Kidney Care UK

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Best Wishes
Judith Connell

Policy Officer

Welsh Senedd's Health and Social Care Committee - Chronic Conditions Strategy Consultation: Kidney Care UK submission

Chronic kidney disease (CKD) affects 6%–8% of the Welsh population (around 200, 000 people).¹ More than 3000 people are currently being treated for kidney failure in Wales with this number increasing year on year.

1. Summary

- 1.1. Chronic kidney disease (CKD) is a chronic condition for which there is no cure and makes a significant life-changing impact on patients' health, wellbeing and quality of life. In Wales, CKD affects around 6-8% of the population, placing them at a greatly increased risk of death and cardiovascular illness. The condition is a driver of healthcare inequalities as Black and South Asian communities are five times more likely to be affected by CKD. CKD also places significant economic burdens on individuals, many of whom are already facing financial hardship because of their condition and is closely linked to widespread co-morbidities such as diabetes and cardiovascular disease (CVD). The improvements we describe could nevertheless significantly change the health outcomes and quality of life for thousands of Welsh citizens, while simultaneously delivering benefits for the wider economy by reducing burdens on the health service and supporting the economic activity of those living with CKD.

1.2. Our understanding of the support that kidney patients need is based on our extensive policy work and the numerous experiences of people living with CKD have shared with us on a regular basis. To help meet the challenges they face and to support the future-proofing of the NHS in Wales, we ask:

- 1.2.1. Take active steps to reduce waiting times for patients to receive kidney transplants, which remains the best available option to extend and improve patients' lives.
- 1.2.2. Introduce additional measures to alleviate unique financial pressures on kidney patients brought on by the cost-of-living crisis, particularly amongst those who choose to dialyse at home – while also reducing costs to the NHS.
- 1.2.3. Incorporate psychosocial support measures into treatment plans for CKD patients to protect their mental health and wellbeing.
- 1.2.4. Pursue a regular testing regime for CKD amongst those who are at risk of developing the condition, particularly amongst people from Black, Asian and other minority ethnic groups, as well as those who present with co-morbid conditions such as diabetes and high blood pressure.

2. NHS and Social Care Services

- 2.1. CKD costs the NHS across the UK in the region of £1.5 billion a year. In Wales, [research indicates](#) that CKD affects 6% to 8% of the population, or around 200,000 people, with more than 3,000 people currently being treated for kidney failure – a number that is increasing every year. There are around 10,000 people receiving follow up support in renal secondary care, including 2,000 people dependent on Renal Replacement Therapy to stay alive. These numbers will grow significantly over the next decade due to the expected increase in key risk factors such as diabetes, high blood pressure and cardiovascular disease.
- 2.2. Black, Asian and other minority ethnic communities are five times more likely to develop CKD, representing an unmet need that leads to a disproportionate number from these groups being represented on the transplant waiting list and waiting longer for a transplant.
- 2.3. The COVID-19 pandemic has had a devastating impact on kidney transplants, with the waiting list regressing to what it was at least five years ago. With there being no cure for CKD, transplants remain the best available option to protect patients' lives and improve their health and wellbeing. However, according to [NHS Wales](#), the current average waiting time for a kidney transplant is 2 to 3 years, and the demand is greater amongst people of South Asian, African and Caribbean ethnic origin, as there are not enough donors from these communities.
- 2.4. As a serious life-changing condition, CKD can be a significant detriment on patients' mental health and their ability to live fully independent lives. Kidney Care UK's research, as outlined in our report on psychosocial care '[Caring for people with kidney disease](#)', indicates that:

- 2.4.1. Depression in early-stage kidney disease increases risk of progressing to late-stage kidney disease, leading to the need for dialysis or a kidney transplant.
- 2.4.2. Nearly half of all dialysis patients experience some form of psychological distress.
- 2.4.3. Depression increases the risk of hospitalisation and in people receiving dialysis and in kidney transplant patients increases the risk of dying by approximately 50% and 65% respectively.
- 2.4.4. Research shows that supporting the psychological and social needs of people with kidney disease helps them live longer in much better health.
- 2.4.5. Most kidney patients are unable to access much needed psychological or social care support. Undertaking action on this will lead to improved medical outcomes and money saves for the NHS.

2.5. Policy actions: To address these concerns, we ask that the Welsh Government and NHS Wales:

- 2.5.1. Introduce annual checks for those at high risk of CKD, particularly amongst Black, Asian and other Minority Ethnic communities, to allow for early detection of cases and an efficient response to improve health outcomes and avoid the need for life-saving dialysis.
- 2.5.2. Take active steps to reduce transplant waiting lists by improving transplant services as a good economic alternative to dialysis that is cheaper and allows for more patients to return to work – as well as improving patient quality of life.
- 2.5.3. For those who are able, offer home dialysis as an alternative to in-centre dialysis, so that patients do not need to spend three days a week in hospital, can dialyse overnight and increase their employment opportunities as well as quality of life. For this to be successful, the energy bills incurred by the patient must be fully reimbursed by the hospital, at a considerable saving to the hospital compared with in-centre dialysis.
- 2.5.4. Enhance and expand psychosocial support that specifically considers the unique challenges faced by CKD patients, including:
 - Identification and assessment of the psychosocial care needs of patients throughout the patient journey
 - Provision of appropriate psychosocial care for all kidney patients that fully supports their level of need as part of their standard care - increasing with a patient's level of need.
 - Integration of psychosocial care needs into kidney patient care plans
 - Monitoring of staffing levels to support access and equality to psychosocial care
 - Training for all renal staff in the mental health needs of kidney patients so that they are able to act as “first responders” and know who and where to refer patients.

3. Multiple Conditions

3.1. CKD is typically co-morbid with diabetes and cardiovascular disease (CVD) – these conditions are the leading risk factors associated with CKD. While diabetes and CVD

are leading causes of CKD, CKD can also lead to these conditions. More people with CKD die from CVD than from end stage kidney failure. Research suggests that one in five people admitted to a hospital in Wales will have a serious problem with their kidneys as part of their illness. While between 6-8% of the Welsh population have CKD, half will not be aware of their diagnosis and so will not be taking measures to slow progression and avoid future morbidity.

3.2. As outlined above (Point 2.4 & 2.5.4.) and below (Point 4), CKD often has a significant negative impact on patients' mental health and wellbeing, with many patients feeling isolated, vulnerable, lonely, anxious, stressed and depressed as a consequence of their condition but unable to access the psychosocial support they need.

3.3. Policy actions: To address these concerns, we ask that the Welsh Government and NHS Wales:

3.3.1. Incorporate individuals who present with diabetes and high blood pressure into CKD risk assessments as high-risk groups

3.3.2. Take action to provide targeted psychosocial support for patients with CKD to help them manage the impact of their condition on their mental health and wellbeing

3.3.3. Take steps to improve public awareness of the risks of CKD in relation to diabetes and high blood pressure, including messaging about discussing kidney health with primary healthcare professionals and healthy lifestyle choices to help mitigate co-morbidity risks

4. Impact of additional factors

4.1. People with CKD are experiencing increased financial hardship due to their condition as a result of unique pressures that are exacerbated by the ongoing cost of living crisis. Key findings within Kidney Care UK's ['Cost of Staying Alive'](#) report indicate that 98% of kidney patients are worried about the rising cost of living and 79% report that this is now having an impact on their physical health and 87% report that it is having an impact on their mental health. 44% report that they have missed meals with 1 in 10 saying they have skipped meals regularly.

4.2. Patients with CKD are typically dependent on high-energy consumption in order to manage their condition, including maintaining a warm home, running a dialysis machine if on home dialysis and requiring a special high-cost diet. Rising cost of living pressures are negatively affecting their capabilities to meet these needs as evidenced in Kidney Care UK's ['Cost of Staying Alive'](#) report, [Priced out of Existence Campaign](#) and the experiences of [patients](#). 'The Welsh Government previously [predicted](#) that up to 45% of Welsh households (614,000) could be in fuel poverty following the next energy price cap rise, compared with 14% of households in October 2021. As a consequence more CKD patients will be obliged to forego basic living requirements to protect their health and wellbeing, including maintaining adequate heating and diet.

- 4.3. Patients who undertake renal replacement therapy in the UK are more likely to experience deprivation as almost half (47%) are in the two most deprived quartiles of the population. Barriers to employment for people on dialysis (frequency and length of treatment, physical toll of treatment, intense fatigue) compound financial insecurity.
- 4.4. Financial pressures are particularly alarming for those who undertake dialysis treatment at home, due to the high energy consumption of dialysis machines, which can add up to £1,000 or more to utility costs per year, and the need to keep the room adequately warm during dialysis sessions. Kidney Care UK's recent '[Left out in the Cold](#)' report found that:
- 4.4.1. 73% of people who do their dialysis at home have been worried about the cost of home dialysis this winter
 - 4.4.2. 95% of people with kidney disease had kept their homes colder during the winter than they would like due to worries about cost
 - 4.4.3. 43% of home haemodialysis patients were considering going back to hospital-based dialysis due to difficulties in receiving reimbursement for their treatment
- 4.5. Covid-19 has disproportionately affected patients with kidney disease, causing significant challenges in disease management, leading to a marked loss of transplant opportunities and a significantly larger national waiting list which has currently regressed to what it was at least 5 years ago. The existing strain on dialysis capacity has consequently been exacerbated as patients remain on dialysis as the only available form of renal replacement therapy.
- 4.6. The pandemic has impacted on kidney patients' long term mental health and wellbeing, with shielding and the fear of contracting and dying from covid-19 increasing the incidence of stress, anxiety, depression and social isolation. Kidney Care UK's Covid survey '[Lifting lockdown](#)' found that:
- 4.6.1 40% of patients reported being concerned about their emotional wellbeing
 - 4.6.2 33% felt lonely or isolated
 - 4.6.3 68% wanted peer or professional mental health support to help manage their worries.
- 4.7. Policy actions: To address these concerns, we ask that the Welsh Government and NHS Wales to:
- 4.7.1. Introduce additional measures to protect CKD patients from their ability to manage their condition from being severely impacted by the cost-of-living crisis.
 - 4.7.2. Consider heating costs a key part of the cost of home dialysis in-order to maintain patient safety and to ensure home dialysis remains a choice for all regardless of income.

- 4.7.3. Regularly review the rate of reimbursement for home dialysis as and when energy prices change to avoid patients, due to adverse financial circumstance, having to resort back to in-centre dialysis, which increases the financial burden on the health system and is a limit on patients' personal freedom and wellbeing – to align with [A Healthier Wales: Our Plan for Health and Social Care](#) that more services should be provided outside of hospitals at home, helping people manage their own health, and manage long term illnesses, making it easier for people to remain active and independent in their homes and communities.
- 4.7.4. Examine steps to improve and reduce waiting times on the kidney transplant waiting list.
- 4.7.5. Take action to provide targeted mental health support for patients with CKD to help them manage the impact of the pandemic and their condition on their mental health and wellbeing.

5. Prevention and Lifestyle

- 5.1. CKD is a leading cause of premature death, health inequalities and burdens upon the NHS; as it has no cure, for many kidney transplants remain the only way of preventing serious illness.
- 5.2. Diabetes and cardiovascular disease (CVD) are leading causes of CKD, but CKD can also lead to these conditions – more people with CKD die from cardiovascular disease than from end-stage kidney failure. Therefore, prevention of CKD and control over its progression is vital and there must be scrutiny of what is being done to promote early detection and treatment of CKD.
- 5.3. Recent audits have found that only 54% of people with diabetes receive the NICE recommended urine tests to detect early kidney problems and only 25% of people with CKD had the NICE-recommended annual kidney test, to monitor the disease and identify those at risk of progression to kidney failure.
- 5.4. Policy actions: To address these concerns, we suggest that the Welsh Government and NHS Wales:
 - 5.4.1. Take action to ensure early detection of CKD, including annual testing of those in high-risk groups, which will reduce the number of people needing lifesaving dialysis treatment
 - 5.4.2. Public Health Wales stated priorities that include addressing prevention, early intervention and promoting health behaviours must include a stated focus in reducing CKD in Wales, where effective action in these three areas can help reduce the numbers of people living with the disease.