

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](#).

CC63: Ymateb gan: | Response from: Arennau Cymru/ Kidney Wales



Supporting people with chronic conditions Response

Ross Evans, Managing Director Kidney Wales.
Evidence submitted on behalf of Kidney Wales.

About Kidney Wales

Kidney Wales vision is to unite the Welsh kidney community to enable pioneering world class care, support and well-being services.

The objectives for our work are to generate and use diverse resources sustainably and responsibly to:

- *Deliver education and awareness raising activity
- *Work in partnership with other organisations to enhance the experience and well-being of the kidney community
- *Invest our funds in support services and enhancing facilities and equipment to add value to statutory funding and improve patient care and well-being
- *Develop innovative programmes in research for the benefit of kidney patients in the Welsh community

With the significant help of our supporters, Kidney Wales helps patients by:

- *Providing information, advice and assistance to patients and their families;
- *Making grants available through a Well-being Fund for patients;
- *Working alongside the NHS to invest in targeted support for kidney patients;
- *Running research projects that benefit Welsh kidney patients.

About Kidney Disease

Across the UK, there are 3.5million people living with Chronic Kidney Disease (CKD). In Wales there are 93,722 people diagnosed with CKD, of which 3,316 are receiving renal replacement therapy in the form of dialysis, transplant or conservative management.

CKD is a lifelong condition, and can be very isolating for those suffering with the condition, dramatically affecting their physical health, mental health and overall-wellbeing.

There is no cure for Kidney Disease, a fact that is often unknown, and there is little awareness amongst the general public of the condition. In a recent survey conducted by our friends in Kidney Research UK, with over 2000 respondents, 81% of people couldn't identify correctly the position of where their kidneys are. A further 73% of people felt they were not at risk of CKD and only 9% knew that a transplant, dialysis or anti-biotics were not cures for CKD.

Impact of Additional Factors

The cost of living crisis is placing further pressure onto those living with CKD across Wales. This has resulted to patients having to make some very difficult decisions and choices. In 2022/2023 we supported patients with £5,000 of wellbeing food vouchers, £13,000 of financial assistance grants purchasing household items, and £20,000 in total towards the cost of energy payments for those on Home Dialysis.

As a small Welsh based charity, there is only so much that we can do to support, and we need others to start taking action now as well.

Unlike in England, Wales has a fantastic reimbursement scheme for those travelling to units for dialysis and for those who have made the decision to dialyse at home.

However, the rising costs of utility bills, has put an added pressure onto those living with CKD, as they look to make ends meet. Why is this having such an impact on CKD patients? Well, the 3,000 people living in Wales, receiving renal replacement therapy will feel the cold more than others. The 115 individuals that have selected to have home dialysis will use as much as 7,000 litres of water per week.

Anecdotally we have heard from patients that without the additional support we have been able to provide, via our Financial Assistance and Well-Being food vouchers, they would have had to make unimaginable choices about how to spend their money, and have said they would go without putting the heating on if it meant being able to buy food, or vice versa. Again many people we have spoken to have raised how they are concerned about becoming increasingly unwell, how their own mental health will become worse, and how they will go about feeding themselves and their families.

A revision to the reimbursement rate, for those on Home Dialysis, came into effect in April 2022 which accounts for the unprecedented rise in electric costs in 2021/2022. However a commitment must be made to review this on at least a yearly basis.

Likewise, all patients in Wales should receive access to transport to the unit for their dialysis sessions, whether this be via non-emergency transport or receiving increased reimbursement for fuel costs.

NHS & Social Care Services

CKD is a condition that disproportionately affects those from ethnic minority communities, and lower socio-economic communities. As a result, people from these groups tend to have poorer access to organs for transplantation, poorer outcomes and high incidence levels.

Wales led the way on the changing organ donation legislation within the UK, and on 1st December 2013, the Human Transplantation Act (2013) came into affect. As a Nation and a system this is something that we should be proud of, but having led the way we need to ask ourselves if we are doing enough to raise awareness around organ transplantation, particularly for those in South Asian ethnic minority communities.

At current there is no specific awareness work or campaign to support information sharing for those in South Asian ethnic minority communities, such as there is in Scotland. A quick review of the Scottish Government organ donation page (<https://organdonation.scot/about-donation/does-my-religion-support-it>) and the Welsh Government organ donation page (<https://www.gov.wales/organ-donation-guide>) highlights some stark differences.

The Scottish Government page provides patients with resources and leaflets for all faiths eg Islamic faith [Organ Donation and Religious Beliefs - Islam Leaflet 0.pdf](#) and videos. Yet such detailed information doesn't appear on the Welsh Government page.

More culturally appropriate information and awareness should be provided, and we would like to see Welsh Government make a commitment to providing the necessary resources for this.

Prevention & Lifestyle/Multiple Conditions

CKD is invisible and often overlooked, most often with the diagnosis coming as a huge shock to the patient and their friends and families.

In the recently launched Quality statement for Kidney Disease, both diabetes and hypertension are mentioned as two of the leading causes of CKD. Within the same document there is reference given to the creation of a Kidney Integrated Care Pathway, all the way through from prevention to helping patients decide which form of replacement kidney therapy is most relevant to them.

We highlight this point, as when we asked patients last year what they would like to see happen more of, and the response in general was "increased information about kidney disease, so that less people have to go through what I have gone through". Translated this highlights that more needs to be done around awareness of the condition, particularly for those with diabetes and hypertension.

As already noted the impact of CKD on individuals can take many forms, however with the early detection of the disease, progress can be slowed, through preventative measures and lifestyle changes. Unfortunately as highlighted by many Health Care Practitioners, they often see patients in the later stages of disease. If earlier detection had occurred, more effective ways to slow the progress of CKD could have been implemented.

For patients with Diabetes a simple urine check, as part of a yearly screening process, can be used to check for albumin in the urine. For those who have damaged kidneys, albumin will be detected in this urine test. However, anecdotally we have heard that many diabetes patients are not completing or being asked to undergo the urine screen. Whilst more investigative work needs to be conducted into this area, it is concerning to believe the urine screen may not be taking place.



As a result we feel that a commitment needs to be made to identification and consistent screening of at-risk groups, including the embedding of best practice in blood pressure measurement across all settings.