

Kidney Wales feels like coming home

In Wales, approximately 20,000 people live with chronic kidney disease: a life-long condition that has no cure. For approximately 4,000 of those patients, their kidneys have failed completely and they require life saving Renal Replacement Therapy, either in the form of a kidney transplant or regular dialysis treatment in hospital or at home.

The majority of these patients receive exceptional medical care and support from NHS Wales. But it's Kidney Wales, and similar charities, that step forward to provide wraparound care that can help patients live well with their illness.

Kidney Wales provides information,

expert guidance, practical and financial assistance for people with kidney disease, and investments in research and resources for the NHS, such as funding for a specialist Renal Psychologist.

The charity supports people like 36-year-old Kate Dunsford, who has lived with the disease since childhood, and who has seen it 'impact on every sphere' of her life. For her, Kidney Wales 'feels like coming home – that wonderful feeling where you no longer need to pretend that everything is okay. You don't have to hide your scars. Or your pain. Or your disappointment. Because they understand, they just know.'

Patients can turn to Kidney Wales to help process complex information,



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Kate Dunsford

come to terms with a diagnosis, find straightforward answers to insidious questions, meet other people with similar conditions who can really understand the pressures, and to meet their needs for emotional needs.

As Kate says: 'Kidney disease has undoubtedly changed the shape of my life, but has made me a stronger, more determined person. Kidney Wales has played an integral part in my road to recovery, and I can't thank them enough.'

The Covid 19 pandemic has not stopped Kidney Wales and its fine work. If anything, they have redoubled their efforts. Most patients – particularly transplant recipients – have been classified as being extremely vulnerable to Covid 19 and have been advised to shield on medical grounds for 12 weeks, which means staying at home, some locked in their bedrooms, away from their own families.

Meanwhile, approximately 1,200 dialysis patients were mistakenly omitted from NHS Wales' initial 'shielding list', which has led to a great deal of confusion and anxiety for patients who have to travel to hospitals to receive life saving dialysis treatment three times a week.

In response, Kidney Wales has developed a lockdown community facebook group, signing up 350 members in the first fortnight, to

deliver official information specific to the needs of people with kidney disease and provide a forum for patients to share health and wellbeing advice. As part of the initiative, the charity arranged a live Q&A session with a transplant surgeon – a first of its kind in the UK, with 99 live viewers and 300 total views to date.

With many NHS Workers taken off their normal duties to meet the emergency Covid demand, this is just one way that Kidney Wales is working with specialist Renal Social Workers, Psychologists, Physios and Dieticians to co-ordinate and deliver expert support during lock down.



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Dr Catherine O'Leary

Clinical Psychologist, Dr Kate Shakespeare, says: 'I think the biggest thing for me is that Kidney Wales pushes the patient wellbeing agenda throughout all of this [Covid 19] and thought of new ways for us to support patients from afar. This has been hugely helpful to me as my focus has

had to shift to working in the new Staff Wellbeing Support Service (SWSS).'
Consultant Clinical Psychologist, Dr Catherine O'Leary, agrees: 'These are difficult times but Kidney Wales has been a great source of support and it's been really helpful to direct my patients to their resources.'

Kidney Wales has also collaborated with Kidney Care UK, Paul Popham Fund, the Welsh Kidney Research Unit and the Welsh Renal Clinical Network to create a physical newsletter, so that most patients – the overwhelming

majority of whom are over 50 years with limited online skills – can get the vital information they need to keep themselves safe and well.

In working together, Kidney Wales and NHS Wales deliver quality healthcare that not only treats the illness but also supports the individual and their family to adjust to a new way of life and find mutual support within the Welsh kidney community. After a devastating diagnosis, this is what patients need – not a leaflet hastily pressed into their hand.

To learn more about WCVA's Health and Social Care work, email Sally Rees, National third Sector Health & Social Care Coordinator, on: srees@wcva.cymru

For more information about Kidney Wales and its services go to:
www.kidneywales.cymru



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