

# **INQUIRY INTO PREVALENCE, CAUSES AND IMPACTS OF LONELINESS IN NEW SOUTH WALES**

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Secretariat

Legislative Council Standing Committee on Social Issues

Dear Committee Members,

**Re: Submission in response to the Parliamentary inquiry into prevalence, causes and impacts of loneliness in New South Wales.**

My name is Amanda Sluiter I am a Research Assistant for the Centre of Kidney Research Sydney and PhD candidate at the Sydney School of Public Health, The University of Sydney. The focus of my studies is to improve social connections among patients with kidney disease. I am also a kidney transplant recipient. I was first diagnosed with chronic kidney disease at the age of 18 and have undergone many procedures, treatments and medications in my journey, including dialysis. I live with my husband and two children, both of whom were born super prematurely at 29 and 27 weeks. Shortly after the birth of my second child, I went into total kidney failure and was fortunate to receive a living-donor kidney transplant, donated by my first cousin. I am degree-qualified in Medical Science and Reproductive Medicine and was an embryologist for many years before turning to research after having children.

I was treated at Westmead hospital. A point to note is that the major of the quotes and data was collected from patients and caregivers treated at Western Sydney Health district NSW.

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In this submission, I address:

- Terms of Reference b. the identification of populations most at risk of loneliness and social isolation
- Terms of Reference c. evidence of the psychological and physiological impacts of loneliness on people, including young people, the elderly, those living with a disability, those living in regional areas and the bereaved
- Terms of Reference i. steps the State Government can take to reduce the prevalence and impacts of loneliness in the community
- Terms of Reference j. that community, technology/social media companies, organisations, and individuals can take to reduce impact of loneliness on individuals and the community.

Sincerely,

Amanda Sluiter & Dr Karine Manera

## Introduction

I am a person who wears two hats: a patient and a researcher. I am passionate to help improve the prevalence of loneliness in society especially for the chronic kidney disease (CKD) community. As part of my research, I have communicated with many patients and read many papers highlighting the perspectives of patients, and strategies and interventions to improve their quality of life (QOL) including social connections while battling the consequences of chronic kidney disease.

Kidney failure, also known as end-stage kidney disease, is a rare, and severely debilitating condition. Kidney failure is also extremely burdensome and disruptive to people's lifestyles and social roles. Many patients with chronic kidney disease (CKD) experience loneliness and social isolation, which are associated with an increased risk of mortality, morbidity, and poor mental health. The prevalence and burden of chronic kidney disease is increasing globally and unsustainably, contributing to over 10% of deaths in Australia each year. The impacts of CKD on the social health and well-being of patients are immense and under recognised in practice and policy. Little is known about how to enhance social connections in people with kidney failure. In the below sections we highlight emerging data, some of which I am leading, on loneliness in people with chronic kidney disease.

## Terms of reference

### **(b) The identification of populations most at risk of loneliness and social isolation**

The life-long treatment required to manage CKD leads to profound disruptions to social roles. Medications and side effects, symptoms such as fatigue and pain, as well as kidney replacement therapies including dialysis and kidney transplantation, lead to restrictions in patient's life participation and increase the risk of loneliness and social isolation (1, 2). Caregivers of people with CKD may experience significant burden due to their ongoing responsibilities, contributing to the deterioration of social relationships outside of their caregiving role (3).



***“When a patient feels tired, they often get withdrawn. This can lead to depression as when we are fatigued, we don't often get to enjoy the things that we used to and it can leave us feeling helpless, like a burden to others.” (Person receiving dialysis)***

Patients across all stages of CKD are at high risk of loneliness, as are their caregivers. For newly diagnosed patients, poor social connections may reduce one's coping skills (4). Among patients receiving dialysis, the decision to withdraw from treatment, ultimately leading to death, has been linked to depression and may be influenced by a person's social connections and sense of loneliness (5, 6). Informal caregivers, i.e., family members or friends, take on a broad range of care coordination tasks for patients. These ongoing responsibilities contribute to isolation, loneliness and poor quality of life, which has negative implications for the health of caregivers as well as patients (7-9).

***“I see her health deteriorating and she needs help with everything.... I have no contacts with others and feel left alone”(10).***

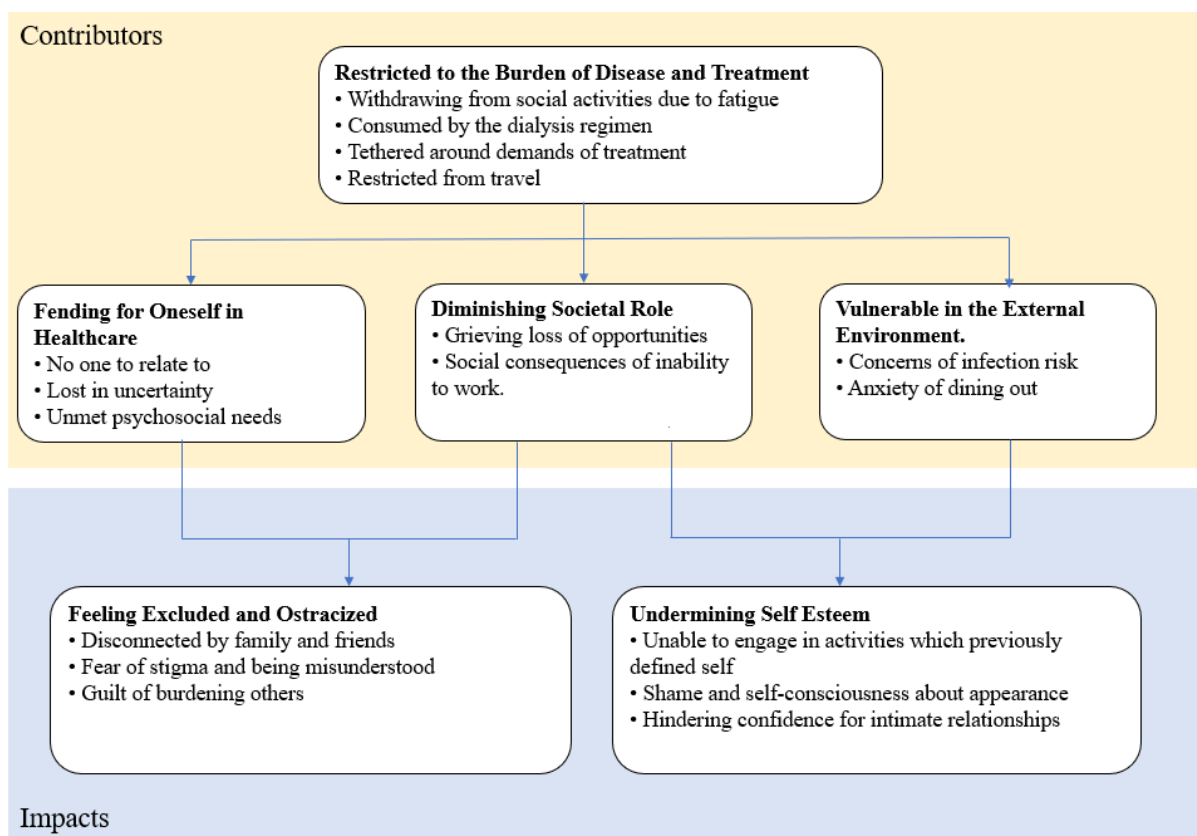
Dialysis inflicts substantial negative physical and psychosocial impacts on patients. (11).

***“Now, I feel like I have no life – just go dialysis, come home, sleep, eat that's it – tired, sleep.”  
(Person receiving dialysis)***

Patients receiving dialysis may spend 20 to 80 hours per week attached to a machine, have tightly controlled nutrition and fluid intake, and experience severe symptoms and side effects including pain, fatigue and cognitive impairment (12, 13), which greatly increases their risk of loneliness.

***“You feel so alone because no matter how much support someone gives you, no matter how much love they show you, they are not going through what you're going through” (Person receiving dialysis)***

***Figure 1. Themes established from a patient and caregivers perspective.***



The themes in the yellow box describe the external influences that contribute to the patient and caregivers' experiences of loneliness and social isolation, including healthcare disempowerment, lack of societal role and feeling vulnerable in external environments. The impacts shown in the lower boxes are feelings or emotions that are produced within an individual, including feeling excluded and ostracized, and loss of self-esteem. Arrows represent a downstream effect from the disease-related burdens leading to changes to lifestyle and ultimately exacerbating internal feelings of loneliness and isolation.

- **Recommendations:**

Recognise chronic kidney disease patients as a population at high risk of loneliness and social isolation.

There is a need for increased initiatives in clinical practice and policy to tackle poor social connections, fostering improved patient-centred care and outcomes among culturally and linguistically diverse patients with CKD.

Considering the detrimental effects of loneliness and social isolation among the caregivers of people with CKD, it is important to emphasize and create awareness of the physical and psychological wellbeing of the caregivers. Comprehensive support plans and tailored interventions to address the specific emotional and social needs of caregivers with CKD would be beneficial in reducing social isolation, loneliness, and associated complications.

### **(c) Evidence of the psychological and physiological impacts of loneliness**

In patients with chronic kidney disease (CKD), loneliness and social isolation are associated with an increased risk of mortality, reduced quality of life and kidney function decline (14-16). Poor social connectedness can also undermine patient's capacities for self-care and treatment adherence (17).

Loneliness has been associated with high blood pressure (18), inflammation (19), and is a recognised risk factor for cardiovascular disease (CVD)(20). There is increasing evidence that low social connection has negative psychological and behavioural impacts, contributing to poor outcomes in patients with CKD. Loneliness is linked to poor mental health and sleep fragmentation (21-23), which are known risk factors for progression to end-stage kidney disease (24, 25). People experiencing loneliness are more likely to smoke, be overweight and less physically active (26, 27), which are critical factors affecting disease progression (28, 29). Limited existing evidence from patients with CKD indicates that self-care behaviours are adversely affected in patients who are lonely (17). Self-care and self-efficacy are essential for the management of symptoms and adherence to treatments in CKD. Disruptions in self-care behaviours and decreased self-efficacy lead to adverse outcomes, higher symptom burden and poor quality of life (17, 30).

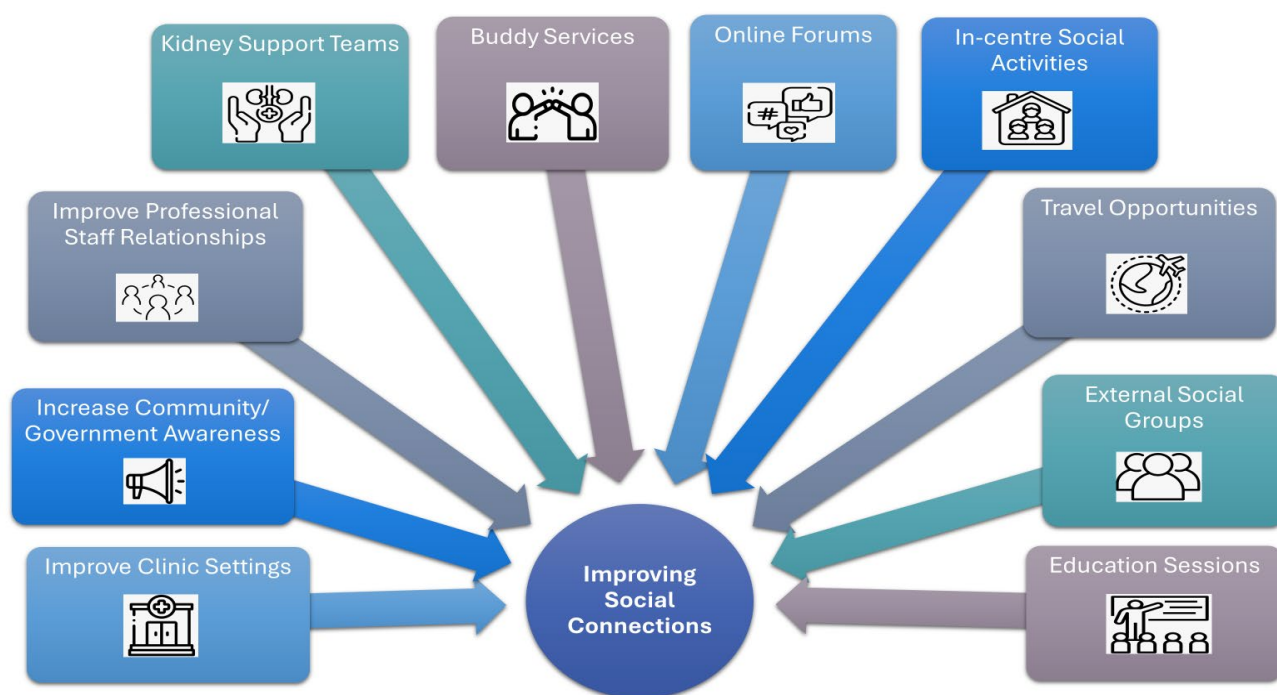
The psychological and behavioural impacts of low social connection contribute to poor outcomes in patients with kidney failure. Loneliness is closely associated with depression, which is an established risk factor for mortality and hospitalisation in dialysis patients (31). Notably, psychosocial reasons are the most cited reasons for withdrawal from dialysis therapy in Australia (32). Withdrawal from dialysis can be considered a form of passive suicide, and understanding ways to improve the psychosocial well-

being of patients may improve quality of life and survival on dialysis. Despite increasing recognition of the burden of poor social connections in kidney disease and the influence this has upon mental well-being, self-care and treatment adherence, a review of interventions has shown that there is a major gap in evidence regarding how to enhance social connections in people with kidney failure (33).

- **Recommendations:**

Increase funding for interventions and or social support services within the clinic and community settings. Here is a figure that summarizes interventions and strategies suggested in interviews with patients being treated in Western Sydney, NSW.

**Figure 2** **Interventions and Strategies**



**(i) steps the State Government can take to reduce the prevalence and impacts of loneliness in the community**

Studies have found that a lack of awareness and understanding of the chronic disease by others made patients feel ostracized, abandoned by friends and avoided in public, which led them to avoid social events and thus exacerbated loneliness and isolation (34, 35).



*“I lost a lot of friends in that who surprisingly still didn't understand I was on dialysis or not well, and I think they were upset that I wasn't accepting invitations or showing up or agreeing to come, but then not coming and sending last minute apologies.” (Transplant patient)*

Patients have also expressed that kidney disease isn't as publicly recognized like other illness such as cancer, cardiovascular disease and diabetes.

*“Ads on TV for the kidney. I know there's a Kidney Foundation or whatever. But I just don't think the message is getting out there enough.” (Transplant patient)*

### **Recommendations:**

Advocacy from government bodies is needed to help improve funding to use within kidney clinics to provide psychological support for already diagnosed patients and their caregivers and prevention campaigns to notify public to self-advocate their health. Government bodies could also aid CKD patients with more community assistance, to help with homecare, medication discounts, psychological care, financial support and continuous education.

*“I'd like to see a big national campaign that is accompanied by the launch of these additional services. And the two main areas are community education that goes into having a whole of, what do I call it, whole of patient approach.” “And let's have specialized people trained and equipped to do that. That's what I'd like to see, national... And I think we need to put pressure on the government to fund that. It's a big health issue and it's a commercially wise thing because it saves the community billions of dollars every year helping keep alive people with chronic diseases who are not being well managed, and it's only getting worse for them and more expensive to keep them alive.”*

*(Transplant patient)*

*“The other direct impact was my parents. They were under incredible pressure, and they had absolutely no domestic, social, psychological or financial support. It was very expensive. They spent their savings because I wasn't working. Remember, I had worked for myself, so I had no income, I had no sick leave, nothing.”*

*(Transplant patient)*

**(j). community, technology/social media companies, organisations, and individuals can take to reduce impact of loneliness on individuals and the community.**

Providing opportunities for patients to connect with other patients of a similar demographic may help to prevent or reduce loneliness and social isolation. Establishing one-to-one peer mentoring or group support programs for patients within clinics has been shown to have benefits for improving quality of life, psychological well-being and treatment adherence (36, 37).

***“Maybe a Facebook group, or other people from your clinic or your center or something.” (Patient receiving dialysis)***

Providing referrals or promoting information about existing support programs offered by national organisations such as The National Kidney Foundation (38), Kidney Care UK (39) and Kidney Health Australia (40), may further help patients and their caregivers who are experiencing loneliness or social isolation. Further directions for research, practice and policy are shown in Table 1.

***“So, maybe even having a buddy system with someone that knows and can reassure you or something also.” (Transplant patient)***

Participants in our study felt that social well-being was not addressed by their healthcare providers in medical appointments.

***No one called and checked up on me.” (Patient receiving dialysis)***

Novel strategies used to address loneliness and social isolation in the general population should be investigated in CKD. For example, social prescribing facilitated by link workers (i.e. a non-healthcare professional who supports people to engage with community activities and resources) has been increasingly promoted in a bid to address the social determinants contributing to poor health outcomes. Social prescribing is now being implemented nationally through the UK National Health Service (NHS) (41) and is gaining prominence in the Australia and the USA (42). For patients with CKD and their healthcare providers, this has the potential to improve patients’ psychosocial well-being without

adding extra burden to the kidney care team. Future research should aim to understand the feasibility, acceptability, and efficacy of social prescribing for patients with CKD.

## Recommendations

**Table 1 Suggestions for research, practice, and policy**

<b>Research</b>	<ul style="list-style-type: none"> <li>• Identify the prevalence, predictors and drivers of loneliness and social isolation in CKD</li> <li>• Identify pediatric experiences and perspectives of loneliness and social isolation in CKD</li> <li>• Co-design patient-centered interventions to enhance social connections</li> <li>• Establish valid and reliable measures to measure and screen loneliness and social isolation</li> </ul>
<b>Clinical Practice</b>	<ul style="list-style-type: none"> <li>• Promote person-centered discussion of social wellbeing in clinic visits</li> <li>• Improve lines of referral to existing kidney support programs and groups (e.g. Kidney Health Australia peer support programs)</li> <li>• Establish support groups or peer-buddy system within clinics</li> <li>• Enhance referral to psychological services in kidney units</li> <li>• Organise social events within clinics</li> <li>• Include information on social wellbeing in patient education (e.g. pre-dialysis education sessions)</li> </ul>
<b>Policy</b>	<ul style="list-style-type: none"> <li>• Establish best practice models of social support service provision</li> <li>• Increase awareness and advocacy for improved psychosocial support</li> <li>• Increase investment and funding for kidney psychologists, social workers, counsellors, and patient/community navigators</li> </ul>

## Conclusion:

People with CKD and their caregivers are a vulnerable population where loneliness and social isolation is of high prevalence but not necessarily noticed within health professionals and communities. Changes to recognise and prioritise loneliness and social isolation would assist patients to improve their QOL and well-being whilst enduring the trajectories of the disease journey.

Government bodies, community groups and support services can help advocate change and education in this area for both the public, patients and health professionals if funding, time and resources are available.

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