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

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Sick, lonely and left behind

Submission into
NSW Inquiry into the prevalence, causes and impacts of loneliness in New South Wales.
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1. Introduction

We welcome the opportunity to contribute to the *NSW Inquiry into the prevalence, causes and impacts of loneliness in New South Wales*. We are a multidisciplinary team of experts, with more than ten years of research into patient experiences of long-term conditions. Our submission to the Inquiry draws on our research examining the lived experiences of loneliness among people living with long-term conditions in Australia. Our research has also examined the experiences of informal carers and health and community care professionals who provide care and support to people who are lonely. While we have undertaken several studies, this response to the Inquiry draws primarily on our ARC funded project: Sick, lonely and left behind? (DP200101872), led by Dr Sophie Lewis.

1.1 Project Outputs

> Lewis, S., Willis, K., Smith, L., Dubbin, L., Rogers, A., Moensted, M.L. & Smallwood, N. (2024), There but not really involved: The meanings of loneliness for people with chronic illness, Social Science & Medicine, vol. 343, doi:10.1016/j.socscimed.2024.116596.

> Moensted, M.L., Lewis, S., Willis, K., Leslie Dubbin, L., Rogers, L. and Smith, L. (2023) Friendship, connectedness and (in)authenticity for those with chronic illness: Trading in one social gain for another, SSM - Qualitative Research in Health, vol. 3, doi:10.1016/j.ssmqr.2023.100246.

> Cheung. M., Lewis, S., Raja, R., Willis, K., Dubbin, L., Rogers, A., Moensted, M.L. & Smith, L. (2024), Disruption and Improvisation: Experiences of Loneliness for People with Chronic Illness. Qualitative Health Research, doi:10.1177/10497323241265.

> Lewis, S. Willis K, Smith L, Moensted M, Rogers A, Franklin M, Dubbin. (2024), Unravelling the layers of loneliness and chronic illness. Palgrave. (Forthcoming)

1.2 Accounting for social factors linked to loneliness

Prior to addressing five of the 11 terms of reference, we draw attention to the need to include social factors when addressing the issue of loneliness. Key findings from our research into the lived

experience of chronic illness demonstrate that social factors are inextricably linked to the experience of loneliness for people who have chronic conditions:

1. Loneliness is often conceptualised and measured in research and policy as a personal emotional experience of feeling alone. Yet, our research shows that loneliness is powerfully shaped by structural conditions and deeply embedded in interpersonal relationships.

2. Complex cultural, social and systemic factors, such as employment status, financial security, healthcare costs, social support, accessibility of green spaces, availability of safe and quality housing, condition-related factors, and cultural ideals around healthy bodies, socialisation and independence significantly influence people's experience of chronic illness and loneliness.

3. Our research shows that people may feel ashamed about their loneliness, believing it is their own fault.

4. Loneliness is often stigmatised, not discussed, and overlooked. At the same time, it is downplayed and not taken seriously enough by health professionals, friends and family.

5. Understanding loneliness as an individual concern and responsibility can prevent individuals from seeking out social support.

6. There is often a disconnect between the perceptions of people with chronic conditions and health professionals on what it means to 'live well' with a chronic condition, with clinical aspects of care prioritised over social aspects, marginalising issues such as loneliness.

7. Supporting people with chronic conditions to *live well* requires addressing the complex interplay of social and structural factors, yet healthcare systems are designed to attend to acute and specific issues, rather than the complexities inherent to chronic condition care.

8. Reforms are needed across the health, community, and political sectors to ensure people experiencing loneliness receive adequate care to address both their health and social needs.

2. Response to Terms of Reference

Drawing on our research we attend to the following terms of reference:

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

c) Evidence of the psychological and physiological impacts of loneliness on people

d) Evidence linking social connection to physical health

e) Factors that contribute to the development of transient loneliness into chronic loneliness

g) The identification of existing initiatives by government and non-government organisations to mitigate and reduce loneliness and social isolation

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

Living with chronic conditions is closely linked to experiences of loneliness. Studies show that loneliness and social isolation are significant predictors of poorer health outcomes, including cardiovascular disease and Type 2 diabetes (Hold-Lunstad., et al., 2015). Additionally, a lack of social support for people with chronic conditions, is associated with increased comorbidity, and mental health challenges such as anxiety and depression, which can further exacerbate feelings of loneliness (Manera et al., 2022; Wang et al 2018). These factors underscore the complex interplay between chronic illness and social isolation, emphasising the need for comprehensive support systems to address both physical and emotional well-being.

Our extensive research conducted with people living with long term conditions, highlights a strong link between loneliness and poor health outcomes. The following examples from our research demonstrate ways in which chronic illness and the risk of loneliness interact:

- The onset of a chronic condition or a marked acceleration in physical or mental decline can results in a noticeable break from prior experiences of social connections. Changes in cognitive ability, mood and mobility also impact people's social connections and engagement.

- Physical vulnerability and extended periods of being home-bound exacerbate loneliness and social isolation.

- Barriers in society (e.g. limited accessibility, wheelchair access, difficulties with entering buildings) can limit social participation and connections with family and friends for people with chronic conditions.

- Living with chronic conditions and/or loneliness can carry significant social stigma, making it difficult to share feelings of loneliness with others and to reach out for support.

- Living with a chronic condition and feeling lonely can affect each other in a circular way, often resulting in long-term loneliness.

- A medical focus in healthcare interactions often overlooks people's social and emotional needs, such that people's experiences of loneliness are not well attended to.

- Managing chronic conditions can deplete emotional, physical and financial resources required for social connection and activities as they are often directed at managing clinical rather than social aspects of living.

- Complex care systems can result in fragmentation and siloing of services, which can be isolating and overwhelming for people living with chronic conditions and loneliness.

2.2 (c) Evidence of the psychological and physiological impacts of loneliness on people living with chronic conditions

The narratives of people we have spoken to in our research over the years, exemplify the multi-faceted and interconnected social, psychological and physiological impacts of living with chronic conditions AND loneliness. Embedded within participants' accounts of loneliness are experiences of vulnerability, unsafety, hopelessness and not wanting to be confronted with physical losses. The following domains capture the social dimensions of these experiences:

<u>Socialising and friendships</u>

- Participants told us they often must maintain a "brave face" and limit how much they share about their illness with friends, family and colleagues.

- Many report experiencing high levels of distress from managing their social presentations and emotions to fit social norms (e.g., hiding their pain, not showing visible signs of fatigue, not "complaining" about health issues, engaging in typical social activities).

- Participants described having to make difficult choices between maintaining a sense of dignity and social connections. For instance, by not disclosing their loneliness or physical symptoms out of fear of losing the friendship.

- Participants also spoke of having to manage disclosure of their chronic condition due to the potential for stigma. While being able to disclose information about one's chronic condition was described as an antidote to loneliness, it also carried risk of judgement and/or advice which could exacerbate feelings of loneliness. For example, people spoke of not disclosing their condition and hiding the use of health aids during social interactions, due to shame and embarrassment or avoiding social situations to avoid comments and advice about their health status or behaviours.

<u>Mental and physical health</u>

- Participants talked about having to manage a persistent sense of being "unreliable" or a "burden" to others and described how this contributes to feelings of depression and anxiety.

- Participants spoke of their sense of self-worth being eroded due to ongoing challenges with chronic illness and loneliness.

- Participants reported they often feel physically and emotionally depleted due to managing their condition, leaving little capacity to attend to loneliness.

- Living with chronic illness and loneliness was referred to as a feedback loop, complicating and compounding both the experience of living with a chronic condition and loneliness.

<u>Grief and identity loss</u>

- Participants spoke of the loss of friendships after diagnosis or as the illness progressed. Friends distanced themselves due to a lack of understanding or discomfort with their chronic condition.

- Many participants spoke of a shrinking life and social circle.

- Participants also spoke of living with profound sense of grief and identity loss due to constant comparison between their actual life and the life they had anticipated.

- Participants' regular comparisons with "normal" life milestones and activities, contributed to them feeling socially displaced and "on the sidelines" of mainstream life.

2.3 (d) Evidence linking social connection to physical health

Our research demonstrates the relationship between physical and social connection in the experiences of people with chronic conditions through the following observations:

- Fatigue and pain were a common feature of life for people in our research, with participants reporting a profound sense of loneliness stemming from trying to convey these experiences to people who could not relate to them or invalidated these experiences.

- Having a body with reduced capabilities, for many was associated with diminished accessibility to shops or locations that had previously been important and familiar, and which provided incidental and/or ongoing connection.

- Feeling excluded from communal places due to physical barriers and lack of assistance was associated with feelings of loneliness and marginalisation.

- Fluctuating and changing symptoms impact on people's ability to sustain social connections and engagement in meaningful activities.

2.4 (e) Factors that contribute to the development of transient loneliness into chronic loneliness

Through our research we have identified key pathways through which transient loneliness can develop into chronic loneliness for people with chronic illness. Participants' accounts of loneliness show that becoming chronically lonely is not just a matter of time. The quality of social recognition is crucial, with validation of their lived experiences being a key factor. This link is demonstrated in our research in the following ways:

- Initial feelings of being "excluded, invisible and overlooked" can become chronic over time.

- A lack of recognition of illness experiences reinforces feelings of isolation.

- People living with chronic conditions can feel lonely within close relationships due to the loss of a shared understanding.

- Limited social integration, inability to participate in the labour market and having a disabled body lead to reduced opportunities for participation and a sense of belonging.

- Transient social isolation can evolve into chronic emotional loneliness, characterised by sustained feelings of "abandonment and neglect", due to limited opportunities to socialise and social integration.

- Living with a chronic illness is often accompanied by a sense of alienation from society. Participants told us they felt increasingly unimportant to their social group, and by extension, to greater society. Life seems meaningless when participants were unable to contribute and feel valuable to others.

- Loneliness is also experienced as social alienation due to limited social integration, inability to participate in the labour market and having a disabled body. The dwindling opportunities for participation, such as being unable to pursue one's vocation or participate in a book club or sporting activities left participants with a reduced feeling of context and belonging.

- Living with a chronic illness often leads to a sense of alienation from society, making life seem meaningless when unable to contribute and feel valuable.

- Momentary disconnection from friends and family can evolve into persistent isolation and a permanent state of loneliness.

- The fluctuating nature of living with chronic conditions, can foster patterns of isolation and loss, which accumulate over time.

- Preexisting trauma and grief compound the experiences of loneliness. In the absence of appropriate support and treatment, trauma can cast long shadows throughout the life course leading to difficulty connecting with others and maintaining good relationships, increasing the risk of loneliness.

2.5 <u>Recommendations for Terms of Reference (b) to (e):</u>

i) **Increase community-based support groups and social networks specifically for individuals with chronic conditions.**
   o In some instances, and for some people, social groups can provide a safe space for sharing experiences, reducing feelings of exclusion, and fostering a sense of belonging.
   o Individual preferences and condition related factors need to be accounted for in establishing these groups and referral pathways.

ii) **Increase Public Awareness and Health Professional Education**:
   o Public awareness campaigns to educate the broader community about the challenges faced by people with chronic conditions, to reduce stigma associated with chronic conditions and loneliness, and foster empathy and support.
   o Training and education for health professionals about the challenges faced by people with chronic conditions, the importance of recognising and validating people's illness experiences, and how to have conversations with people about loneliness.
   o Promote inclusiveness for people living with chronic conditions in all aspects of society.

iii) **Facilitate Accessible Social Engagement Opportunities**:
   o Improve accessibility for social activities and events by tailoring access and support to the specific and diverse needs of individuals with chronic conditions.

- o Ensure physical accessibility, transportation options, and activities accommodate people with varying energy levels and abilities.
- o Make social engagement more accessible to prevent transient loneliness from becoming chronic.

2.6 (g) The identification of existing initiatives by government and non-government organisations to mitigate and reduce loneliness and social isolation

Despite numerous government and non-government initiatives to mitigate and reduce loneliness, our research points to significant gaps for people living with chronic conditions. Contributing to this problem, is the fast-paced, fragmented, and resource-scarce nature of the healthcare system (Franklin et al.; 2019a; 2019b). A consequence of this type of health care system, are the pressures placed on individuals with chronic conditions to be responsible for preventing and mitigating loneliness.

A central theme in the Australian discourse on chronic condition management, is individual responsibility (Franklin et al., 2019a; b; Hughes et al., 2019; 2020) With varying levels of support, individuals are required to manage their symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living with a chronic illness. Individuals are encouraged to actively participate in their own care, to make informed decisions, and maintain a positive approach to coping with their condition. Our research into loneliness and broader research in the context of chronic condition care (see also Franklin et al., 2019a; b; 2024; Hughes et al., 2019; 2020) indicates:

- Expectations embedded within contemporary discourse can be problematic, especially for people with fewer emotional, physical and economic resources (Franklin et al.,2019).

- For those with limited resources, expectations of individual responsibility can lead to increased stress and a sense of failure if they are unable to meet these expectations.

- An emphasis on individual responsibility often overlooks the social and emotional dimensions of chronic illness.

- People who are lonely may struggle to find motivation and support, making it harder to manage their chronic condition, particularly given social and structural barriers discussed above.

- The lack of social recognition and validation of people's experiences can further deepen their sense of isolation and hopelessness when living with a chronic condition.

In this context, it is crucial to recognise that support should not be a one-size-fits-all approach. Tailoring support to address the unique challenges faced by individuals with chronic conditions and loneliness is essential. This includes providing emotional support, facilitating social connections, and ensuring access to necessary resources and healthcare services, and revising models of care.

The following issues are also evident in our research:

- Professionals and people with chronic conditions face significant challenges in finding the right supports at the right time, within the health and community sectors alike.

- Limitations in training, time, resources and routinised nature of healthcare interactions constrain professionals' capacity to attend to the complexities in chronic condition management, which includes attending to loneliness.

- People with more resources tend to be better equipped to meet the expectations of individual responsibility.

- With limited capacity to attend to the social aspects of patients' lives, health professionals often rely on the skills and knowledge at their disposal, leading them to focus on treatment regimens and lifestyle recommendations, which may place greater responsibility on individuals themselves to tackle their loneliness.

- Gaps in training, resources, skills, knowhow and institutional support to be able to support people experiencing loneliness are widespread among professionals.

2.7 Recommendations

These recommendations are aimed at creating a more supportive and integrated approach to managing chronic conditions and loneliness, ensuring that both healthcare providers and people with chronic conditions are better equipped to handle these challenges.

iv) **Define Healthcare Boundaries**:

- Clearly delineate what is and is not possible within the healthcare system to support people living with chronic conditions and loneliness.

- This may help to manage expectations and ensure that both patients and healthcare providers have a realistic understanding of the support available.

v) **Address Social and Structural Factors**:
- Focus on the complex social and structural components that influence how people live with chronic conditions, including addressing social isolation, economic barriers, and access to community resources to improve overall well-being for people living with chronic conditions.

vi) **Enhance Education and Training**:

- Provide further education, training, and resources for healthcare professionals on how to attend to loneliness in the context of chronic condition management.

- Strengthen the connections between health and social/community services to better equip professionals to care for loneliness among people with chronic conditions.

vii) **Innovate and Fund New Models of Care**:

- Allocate funding to trial different models of care that involve closer collaboration amongst healthcare providers and across sectors.

- This could include initiatives that provide up-to-date information to healthcare professionals on community supports and explore new ways to integrate social and emotional support into medical care.

viii) **Implement Academic Detailing**:

- Adopt strategies similar to those used by pharmaceutical companies, such as academic detailing, to 'market' current initiatives and solutions to healthcare providers (Wells et al., 2016).

- Academic detailing involves trained healthcare professionals, often pharmacists, providing personalised, evidence-based educational outreach to other healthcare providers to improve clinical decision-making and patient care (Rowett, 2020; Wells et al., 2016).

- This approach can help update general practitioners on what they can do to address social issues and loneliness within the limited time they have with patients.

3. **Call to action**

Addressing the intertwined issues of chronic conditions and loneliness requires a multifaceted approach that goes beyond traditional healthcare boundaries. Our recommendations emphasise the need for greater focus on the social and structural determinants of health, enhanced education and training for healthcare professionals on the illness experience, innovative care models, and empathy and understanding throughout all levels of society. Implementing these measures, may create a more inclusive and supportive environment for individuals living with chronic conditions, to improve their quality of life and reduce the pervasive impact of loneliness for this group of people. We urge the NSW government to consider these recommendations and take decisive action to foster a more

compassionate and comprehensive healthcare system for people living with chronic conditions and loneliness.

4. Author Biographies

Dr Sophie Lewis (<u>corresponding author</u>) is a Senior Lecturer at Faculty of Medicine and Health, University of Sydney. A health sociologist and qualitative researcher, her research broadly focuses on understanding the experiences of living with long-term, often life limiting health conditions, and how to support people to live well with these conditions. This includes current Australian Research Council and NH&MRC projects exploring the experiences of loneliness for people living with chronic illnesses, living with uncertainty in the context of advanced incurable cancer, and end of life care decision-making. **E:**

Dr Marika Franklin is a Lecturer and Research Fellow at Faculty of Medicine and Health, University of Sydney. With over ten years of experience, as an interdisciplinary (psychology/sociology) qualitative researcher, her research examines what it means to care well for people living with chronic conditions under the constraints of care. Her expertise incudes self-management, supportive care and patient-centredness in the context of chronic condition management, with a particular focus on understanding these concepts in relation to the social determinants of health. **E:**

Dr Maja Lindegaard Moensted is a Research Fellow at Faculty of Medicine and Health, University of Sydney. With more than 15 years of experience, her research broadly focusses on health equity, and the linkage of marginalised communities into health and welfare services. Taking a sociological and qualitative approach her research aims to address complex challenges in communities such as the relationship between loneliness, social connectedness and health; health equity and social determinants of health; youth disadvantage; substance use and homelessness and integrated care for vulnerable people. **E:**

Professor Karen Willis is Professor of Public Health at Victoria University, Melbourne. With expertise in health sociology and qualitative research methods, her research examines how seemingly personal choices and actions are influenced by broader social ideas and structures. Her expertise includes the Australian health care system and the experiences of frontline healthcare workers, during and beyond health crises (such as the COVID-19 pandemic). **E:**

Professor Lorraine Smith is a research psychologist and Professor of Patient Self-Management at the University of Sydney. Her research has focused on patient experiences of long-term conditions, chronic disease self-management, and developing, implementing and evaluating healthcare professional interventions that enhance patient well-being. **E:**

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