



21st October 2024

Inquiry into the Prevalence, causes and impacts of loneliness in New South Wales

Submitted to:

NSW Government Parliamentary Standing Committee on Social Issues

Chair - the Hon Dr. Sarah Kaine

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Introduction

Lived Experience Australia Ltd (LEA) is a national representative organisation for Australian mental health consumers and carers, families and kin, formed in 2002. Our 'friends' include more than 9000 people with lived experience of mental health concerns, including suicide and suicidality, across Australia. This includes lived experiences with the NDIS and with the needs and experiences of mental health, NDIS and support availability, access and provision in rural, regional and remote Australia. All members of our Board and staff have mental health lived experience as either a consumer, family carer or both.

Lived Experience is core to our advocacy, recognising that the impacts of policy and practice are felt not only by individuals, but also by families and whole communities. Our core business is to advocate for effective policies and systemic change to improve mental health care, services and support across the whole Australian health and social care system, including within State and Territory jurisdictions.

We welcome the opportunity to provide our feedback to this crucially important issue for people with mental health concerns and their families, carers and kin.

Purpose of this Consultation

This inquiry has been called for by the NSW Minister for Mental Health in response to rising concerns about loneliness. The inquiry aims to:

- Examine the extent, causes and impacts of loneliness
- Review how other regions are addressing loneliness
- Assist in identifying those most at risk of social isolation in the state
- Identify steps for the NSW Government and community can take to reduce its prevalence and impacts

The inquiry will examine:

- How individuals have personally experienced, or witnessed others experiencing, feelings of loneliness or isolation
- How individuals describe connection to others in their life.
- What factors contribute to feelings of loneliness or social connection in general.
- How loneliness impacts physical and mental health.
- Awareness of any services or resources designed to address loneliness and what individuals think of their effectiveness.
- How technology and social media influence feelings of loneliness and social connection.
- Which groups of people are most affected by loneliness and why.
- Whether there have been noticed changes in experiences of loneliness or social connection over the past few years and, if so, what these changes can be attributed to.
- Strategies or activities found or observed to be helpful in coping with loneliness.
- What could be done to help reduce loneliness in society.

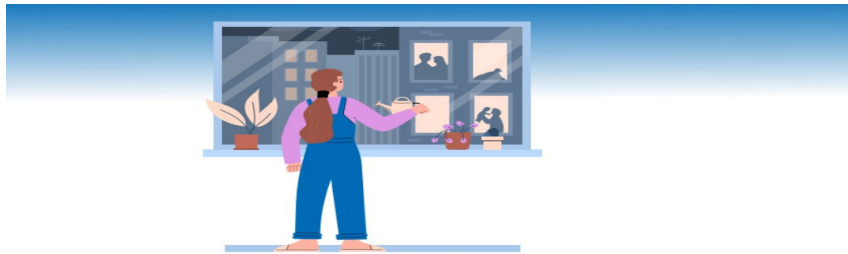
Our response to the Inquiry Questions

In 2022, Lived Experience Australia undertook a national survey with mental health consumers and family/carers asking them what loneliness means to them. In total, 322 people took part in this national survey, including people in NSW. **The full Report is attached to this submission below.**

This project represents the first exploration of its kind from a mental health lived experience perspective on this important issue. We are extremely proud of this work and privileged to have the opportunity to elevate the voices of the people we represent on this significant issue.

We have made a number of presentations on this work, including symposia at the RANZCP Annual Congress and the Ending Loneliness Together Annual Research Forum. Excerpts from these are included below, with specific reference to the unique experiences and impacts for people who experience mental health concerns and the embeddedness of loneliness with issues of stigma, shame, discrimination, having a mental health diagnosis, and living with mental distress.

Being Invisible Like I don't matter to anyone



Having no-one, being invisible

Feeling like no-one else sees me - cares for me - that I don't matter to anyone or have anyone there I can lean on, catch up with, get support from. Living in a bubble of my own that no-one cares about. Silence with own mind yet no-one to share that with.



It is deeply connected with stigma & shame



Not knowing what it is you are doing wrong or how to fix it...There must be something inherently wrong with you

Sometimes being alone feels safer than being around people, but in the long-term loneliness makes me feel guilty and ashamed. It makes me feel that I haven't worked hard enough on friendships and relationships, that I am not a kind or warm enough person.



Marginalised and Excluded



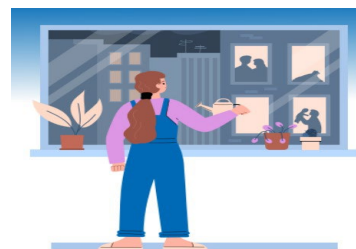
Loneliness means that I have lost my tribe

“
Feeling like I need to hide my authentic self and wear a mask. Feeling rejected, ignored, different, being an outsider (Self-stigma, Stigma and Discrimination).
”



The Physicality of Loneliness

- *It bleeds into everything you are.*
- *You live with your thoughts in your head and you don't get a break.*
- *When I'm around others and feel the hollow and empty feeling of loneliness it scares me.*
- *Sometimes loneliness is so painful that it actually hurts deep in my chest and stomach... There are times I will not eat because I feel I should just fade away.*
- *I feel rejected and that I must be disgusting. That spirals into negative invasive thoughts. I feel less human, that I'm not part of the community.*



Everyday Physical Impacts

- *It has a big impact on feelings of worth, hopelessness and helplessness. When you are not travelling well mentally, it is really difficult to manage the basics of personal care, eating well, exercising, showering, and healthy sleeping patterns.*





Conclusions

Loneliness is an experience deeply embedded with the experience of mental ill-health.

Loneliness, physical and MH were often inseparable / highly interconnected.

Loneliness aligned with deep despair, hopefulness, and thoughts of suicide as a common, regular experience.

These relationships were complex, bi-directional and multidirectional, further complicated by experiences of stigma and self-stigma.

Hence, interconnected responses and solutions are needed (see the whole person).



Further detailed accounts of the experiences of loneliness and what people said would help overcome loneliness are contained within the attached report.

Further contributions to this submission are provided below, with permission, from the lived experience perspective of one of Lived Experience Australia's NSW friends who has experienced loneliness and social isolation and reflected deeply on its causes and potential solutions. I have provided them here unabridged to honour the contributions of the person who provide them for this inquiry:

"Here's my thoughts on some of the structural causes of loneliness:

The price of coffee keeps going up. Coffee is social ritual glue in Sydney.

Becoming a volunteer used to be a way for folk to expand their social networks.

Volunteering has become professionalised and structurally unable to meet unmet social needs of volunteers.

A lot of social services are now telehealth and web rather than face to face in person appointments.

Social entertainment in family budgets is shrinking due to cost-of-living pressures.

Folk rarely invite someone to visit them at home these days in Sydney.

Political views are becoming polarising rather than uniting and reasoned debate.

The professional services industry is meeting needs that were once met through marriage.

Some churches are decreasing their social and pastoral role due to staffing issues.

These are my partial, tentative, "solutions" to the loneliness crisis:

The first one is that everyone needing psychosocial support needs an Aunty Jas

The second one is that the Grow program for mental health has long promoted value-based friendship in its mutual help meetings.

The third is the arts. I think the arts may offer new possibilities for ways to connect... Think public artworks, community art making, choirs, etc. Team sport has long been "social glue". I think the arts could do parallel things.

The fourth is daily neighbourhood walking. I think this is a very old idea. It used to be called the daily constitutional."

Contact

We thank the Committee for the opportunity to put our views forward. We wish you well with the next steps and would be pleased to contribute our lived experience perspectives to any future discussions about this important topic.

Your sincerely

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Understanding loneliness and mental health



A report by Lived Experience Australia to better understand experiences of loneliness for those with lived/living experience of mental ill-health and their carers, families, and whānau



Lived Experience
AUSTRALIA



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ISBN: 978-0-6450753-8-0

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The suggested citation for this document is:

Lawn, S. & Kaine, C. (2022) Understanding Loneliness and Mental Health, Lived Experience Australia Ltd: Oaklands Park, South Australia, Australia.

This project received ethics approval from the Flinders University Human Research Ethics Committee (No. 5424)



Dedication - to Chris Grylls

It is our sincere privilege to dedicate this report to Chris Grylls, his partner and her children, and Wendy Grylls, Chris's mother. Wendy is a passionate New Zealand mental health carer advocate who was a longstanding member of the Royal Australian and New Zealand College of Psychiatrists (RANZCP) Community Collaboration Committee (CCC). Sadly, Wendy's beloved son Chris passed away from suicide in September this year (2022).

Chris was an accomplished musician and much-loved partner and son. The photo above was taken at Bodega Bar in Wellington after Chris had finished playing a gig in 2011. Wendy was instrumental in seeding the idea that the CCC

should undertake a focused advocacy piece on loneliness. This came out of her experience with her son whom she and her husband supported. Wendy worried that her son would be socially isolated once his parents passed, and she was keen for the College to think about how psychiatrists could support people like her son who was at high risk of loneliness in the future when his partner, (who was older than him) and parents died. Wendy's determination led to a symposium on the Lived Experience of Loneliness delivered by members of the CCC at the RANZCP Annual Congress in Cairns in 2019. The current report on a recent survey with lived experience communities across Australia and New Zealand continues to shine a light on loneliness.

"Shine On You Crazy Diamond"

- Pink Floyd

Acknowledgement

We wish to acknowledge the many people with mental health lived experience as a consumer, family carer and whānau who participated in this project. We feel enormously privileged by the courage, trust and integrity you showed towards us in sharing your experiences of loneliness.

We also acknowledge the generous contributions of the members of the Royal Australian and New Zealand College of Psychiatrists (RANZCP) Community Collaboration Committee (CCC) subcommittee who collaborated with us on the development of the loneliness survey reported here: De Backman-Hoyle, Simon Stafrace, Eileen Lavranos, Bronte Jeffries, Simon Byrne, and Sharon Lawn.

We also wish to note that reports like this that provide a lived experience perspective are rare and are often not funded. Lived Experience Australia was not directly funded to complete this research. This project was undertaken as part of our collaboration with the RANZCP which provides a small donation to support the activities of our lived experience systemic advocacy organisation.

This project was undertaken because of our determination to explore loneliness and mental health from a lived experience perspective, address gaps in existing understanding and evidence of loneliness, and to inform and improve the RANZCP Education and Continuing Professional Development programs.

If you or someone you know needs help, contact one of the helplines below:

In Australia: contact Lifeline on 13 11 14 or www.lifeline.org.au or the Suicide Callback Service on 1300 659 467 or www.suicidecallbackservice.org.au.

In Aotearoa New Zealand: contact 1737 for free Mental Health. You can also contact Lifeline NZ on 0800 543 354 or www.lifeline.org.nz or the Suicide Crisis Helpline on 0508 828 865 or www.lifeline.org.nz/suicide-prevention.

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- Don't rely on medication to fix everything
- Use more humanistic and holistic approaches to care
- Understand what supports are available and help people to connect with them
- Be compassionate, non-judgmental, and instil hope
- Recognise that talking about loneliness may be difficult for the person
- Be aware of professional privilege, the clinical environment, and address power imbalance
- Help people to develop confidence and practical skills to overcome loneliness
- Consider Peer Support Options
- Involve families/carers/Whānau

Q8 What can psychiatrists do to help families/whānau/communities to flourish? - 40

- Provide more whole-of-family psychoeducation and support options and see the person in the context of their family/community/whānau
- Raise awareness, advocate, and challenge the stigma surrounding mental ill-health
- Broaden practices beyond a clinical 'illness' focus.
- Be a practical source of information, education, and skill development
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'Our social fabric can fray at the edges, like a yarn that comes loose at the end of a crocheted sweater ... interventions to reduce loneliness in our society may benefit by aggressively targeting the people in the periphery to help repair their social networks. By helping them, we might create a protective barrier against loneliness that can keep the whole network from unravelling' ¹

Introduction

Loneliness and perceived social isolation refer to the person's subjective perception of their social world and connection to it.² Loneliness is an issue that has become more evident with the onset of COVID-19; however, the experience of loneliness is not new. Loneliness is understood to be both a cause and consequence of becoming disconnected. Loneliness is different from social isolation, although the two can be very interlinked. While some individuals may feel lonely due to physical or social isolation, others can feel intense loneliness when surrounded by others, including loved ones. Peoples' experience of loneliness is unique and the effects of loneliness on individuals varies greatly.

Almost a quarter of people living in Australia report that they rarely or never feel close to people, rarely or never have someone to talk to, and rarely or never have people they can turn to.³ Individuals who are socially isolated are up to five times more likely to die prematurely than individuals with strong social ties.⁴ People who experience severe mental illness experience have much higher rates of

reported loneliness, with studies reporting them between 2 and 8 times greater than the general population, and 20-fold for people with more than one mental health condition.⁵

⁶ Conversely, a sense of social connection and belonging, meaning and purpose, strengthens physical and mental health, and builds resilience to deal with adversity, addiction, and mental health challenges.^{7 8 9}

Research by Cacioppo and colleagues, drawn from the seminal Framington Heart Study, has confirmed that loneliness spreads through social networks more readily than social connectedness and that, as humans, we tend to drive away lonely members of the group to preserve the group; hence people who feel socially isolated can lead to them becoming objectively isolated. Loneliness reduces the ties that such individuals may have within the broader community network. Stigma, discrimination, and marginalisation are embedded in these processes.¹⁰ Loneliness is significantly associated with self-stigma and perceived discrimination, and self-esteem directly influences loneliness.^{11 12}

1 Cacioppo, J.T., Fowler, J.H., Christakis, N.A. (2009) Alone in the crowd: the structure and spread of loneliness in a large social network. *Journal of Personality and Social Psychology*, 97(6), 977-991. P.788.

2 M. R., Mann, F., Wang, J., Lloyd-Evans, B., Terhune, J., Al-Shihabi, A., Johnson, S. (2020) The effectiveness of interventions for reducing subjective and objective social isolation among people with mental health problems: a systematic review. *Social Psychiatry and Psychiatric Epidemiology*, 55, 839-876.

3 Psychweek.org.au (2018) Australian loneliness report. <https://psychweek.org.au/wp/wp-content/uploads/2018/11/Psychology-Week-2018-Australian-Loneliness-Report-1.pdf>

4 Marmot, M., Allen, J., Goldblatt, P., Boyce, T., McNeish, D., Grady, M., Geddes, I. (2010) Fair society, healthy lives: the Marmot review. <https://www.parliament.uk/globalassets/documents/fair-society-healthy-lives-full-report.pdf>

5 Perese, E. Wolf, M. (2005) Combating loneliness among persons with severe mental illness: social network interventions' characteristics, effectiveness and applicability. *Issues in Mental Health Nursing*, 26, 591-609.

6 Meltzer, H., Bebbington, P., Dennis, M.S., Jenkins, R., McManus, S., Brugha, T.S. (2013) Feelings of loneliness among adults with mental disorder. *Social Psychiatry and Social Epidemiology*, 48, 5-13.

7 Petite, T., Mallow, J., Barnes, E., Petrone, A., Barr, T., Theeke, L. (2015) A systematic review of loneliness and common chronic physical conditions in adults. *The Open Psychology Journal*, 8(Suppl 2), 113-132.

8 Dingle, G. (2018) Addiction and the importance of belonging. *The Psychologist*, 31, 36-39.

9 Meltzer et al. Op Cit.

10 Cacioppo, Fowler and Christakis. Op Cit.

11 Świtaj, P., Grygiel, P., Anczewska, M., Wciórka, J. (2014) Loneliness mediates the relationship between internalised stigma and depression among patients with psychotic disorders. *International Journal of Social Psychiatry*, 60, 733-740.

12 Świtaj, P., Grygiel, P., M, Wciórka J. (2015) Experiences of discrimination and the feelings of loneliness in people with psychotic disorders: the mediating effects of self-esteem and support seeking. *Comprehensive Psychiatry*, 59, 73-79.

These processes can have adverse impacts on recovery when the person who experiences loneliness withdraws from social activities to avoid feelings of shame and worthlessness.¹³

Hence, loneliness arises from broad social forces, and efforts to reduce loneliness in our society would benefit from focusing on nurturing, protecting and building the social networks of people who are likely to be more marginalised in the broader community.¹⁴ Strengths-based approaches that enhance wellbeing are likely to be of benefit.¹⁵ Peers with lived experience of mental ill-health and loneliness may also be of benefit, though research is limited.¹⁶ The UK Royal College of Psychiatrists and British Geriatric Society¹⁷ have suggested a range of ways to help alleviate loneliness:

- Improved access to high quality health and social care
- Improved identification of loneliness
- Implementation of social prescribing into routines, holistic care, and support
- Building the volunteer support sector and range of support options in the community
- Recognising loneliness as a health issue
- Recognising loneliness as a broader society-wide issue

In Australia, four key calls for action have been identified¹⁸

- Development of a strategic framework for social connection, inclusive of nationally agreed definitions, indicators, and outcome measures
- Improved coordination of government and community organisations with Ending Loneliness Together as the coordinating body, including strengthened workforce capacity across all sectors
- A national campaign to talk about social health to reduce stigma associated with loneliness and empower communities to help each other
- More Australian-based research to build the evidence base

The present study

Lived Experience Australia (LEA), in collaboration with the Royal Australian and New Zealand College of Psychiatrists (RANZCP) Community Collaboration Committee (CCC), commenced this research project to better understand loneliness and its effects, particularly in relation to mental health, physical health, families, wellbeing, and what support may help to overcome loneliness.

The survey was distributed within both Australia and New Zealand over a six-week period between 16 May and 27 June 2022. The main distribution methods were LEA's mailing list and social networks (approximately 2,400) and the RANZCP which shared the survey via Psyche, the RANZCP's monthly e-newsletter, and through RANZCP Committee agendas. The CCC was also emailed and its lived experience members from across Australia and New Zealand were asked to share it among their networks.

The first part of the survey consisted of eight questions enabling free-text qualitative responses about the person's lived experience of loneliness. The survey focused on what loneliness means to the respondent, what helps in avoiding or overcoming loneliness, the impact of loneliness on mental and physical health and what they would want people to know about loneliness. The survey also asked about what psychiatrists could do to help people reduce their sense of loneliness and to help families/whānau²⁰/communities to flourish. These questions were followed by six general demographic questions asking about identification as a consumer and/or carer, location (Australia, New Zealand, metropolitan or non-metropolitan region), gender, age range, and household type.

Everyone who responded to the questions we asked about loneliness did so with profound generosity, depth of reflection, and heart. They shared their most private and personal thoughts. Some spoke directly to us through their responses, and many directed their responses to others with messages of support and hope.

We were worried that talking so openly about their experiences would be upsetting and we didn't want people to feel more trauma. Some, like the following participant, reassured us *'This survey is also a segment of a really important conversation. It feels good to be real with you all right now (whoever that may be).'*

We wanted to include all comments received in this report, to honour all respondents' words; however, this was not possible due to the large number of responses received. If you are reading this and cannot find your contributions here, please know that you were heard; we read every single word. We hope we have done justice to your experiences of loneliness and that others reading this report will gain a greater understanding from what you have shared with us.

13 Amering, M. Schmolke, M. (2009) Recovery in mental health: reshaping scientific and clinical responsibilities. World Psychiatry Association. Wiley: Chichester

14 Cacioppo, Fowler and Christakis. Op Cit.

15 Tse, S., Tsoi, E.W., Hamilton, B. O'Hagan, M., Shepherd, G., Slade, M., Whitley, R., Petrakis, M. (2016) Uses of strength-based interventions for people with serious mental illness: a critical review. International Journal of Social Psychiatry, 62, 281-291.

16 Fortuna, K.L., Ferron, J., Pratt, S.J., Muralidharan, A., Aschbrenner, K.A., Williams, A.M., Deegan, P.E., Salzer, M. (2019) Unmet needs of people with serious mental illness: perspectives from certified peer specialists. Psychiatric Quarterly, 90, 579-586.

17 British Geriatric Society & Royal College of Psychiatrists (2019) Position statement on loneliness and social isolation. London: BGS/RCPsych. https://www.bgs.org.uk/sites/default/files/content/attachment/2019-12-16/BGS%20Loneliness%20position%20statement%202019%20FINAL_0.pdf

18 Ending Loneliness Together (2022) Strengthening social connection to accelerate social recovery: a white paper. https://endingloneliness.com.au/wp-content/uploads/2022/08/ELT_Whitepaper_July2022-1.pdf

19 Consumer Health Forum (2021) Loneliness through leadership roundtable report: roadmap to addressing loneliness in Australia. https://chf.org.au/sites/default/files/chf_loneliness_roundtable_final_report_v2.pdf

20 Whānau is the collective of people connected through a common ancestor who are bound together to fulfill a common purpose. They can include family, extended family and wider groups connected by culture.

Overview of respondents

Responses to the survey were received from 322 people with direct experience of mental ill-health and loneliness (consumers) and carers, family and whānau (carers), with almost all respondents answering every question in the survey. 197 consumers and 96 carers completed the demographic questions. Of the 96 carer respondents, 67% also identified as being a consumer.

Demographics of respondents:

- 91% located in Australia, and 9% located in New Zealand.
- 69% located in metro areas (e.g., capital city), and 31% located in regional, rural or remote areas.
- 78% female, 17% male, 0.4% transgender, 2.6% non-binary/non-confirming and 2% preferred not to answer
- 64.5% aged 31-59 years, 26% aged 60 or over, 9% aged 19-30 years, and 0.5% aged under 18 years.
- 50% live with a partner or other family members, 36% live alone, 7% live with housemates, 6% have living arrangements not specified here, and 1% preferred not to answer.

Key themes

Responses to each question are provided as they appeared in the survey, with key themes that were evident within these responses to each question.

Within each theme, we have distinguished between responses for people who identified as a consumer, as a consumer and carer, or as a carer.





Loneliness is being invisible...

What does loneliness mean to you?

Q1. What does loneliness mean to you?

Of the 197 consumer respondents who described what loneliness means to them, most overwhelmingly described a sense of being the odd one out, longing for connection with others, feeling unloved, invisible, misunderstood, disrespected, left out, unable to be one's authentic self, emptiness, having no purpose or value to others, disconnected, worthless, and lost. These words and more were mentioned repeatedly in their reflections on what loneliness meant to them. Many expressed that being alone and loneliness, whilst connected processes, were not the same thing; the above range of feelings whilst being in the presence of interacting with others and their community heightened their sense of loneliness. Their responses can be grouped within several themes, as described briefly below. Many of the ideas are interconnected, act upon each other in cyclic ways that perpetuate feelings of loneliness.

Of the 96 carers, families and whānau who described what loneliness means for them, all the above themes were also identified. Over half spoke of loneliness as being isolated, having no-one to check in on you, being isolated from your community, having a lack of support systems or others who understand what it is like to be a carer. Some also spoke of loneliness due to discrimination and stigma, not feeling welcomed or accepted by others and feeling undervalued by society.

1. Having no-one, being invisible

Both consumer and carer respondents described a core feeling of having no-one who saw, heard, or understood them. Having no-one who they could share their innermost thoughts with, without judgment, making them feel invisible to others and themselves.

Consumers said:

- *Having no-one to talk to about things that matter, having no-one to go out and have coffee with; actually no-one.*
- *I don't have 'a person' to turn to with any problem, especially emotional & mental stuff...The people who know the most about me are my therapists and I go about life feeling very unseen, lowly, disrespected, and unloved.*
- *Being alone without being sure of having someone to turn to whenever you want or the feeling of being abandoned or not having anyone to begin with.*
- *The feeling that I am invisible to others. Feeling as though no-one understands.*
- *Feeling like no-one else sees me- cares for me - that I don't matter to anyone or have anyone there I can lean on, catch up with, get support from. Living in a bubble of my own that no-one cares about. Silence with own mind yet no-one to share that with.*
- *Feeling that there is no-one who knows or cares in the world about where you are, what you are doing or what is happening to you - the sensation that you aren't connected in any way to others and the world is going on without you and all the other people in it are doing things with their families or friends without any idea or interest in you. A sense of being completely on your own and unable to reach out to other people. It is about emptiness and a sense of not mattering to anyone.*
- *Feeling like you're invisible and not worthy. Feeling unheard, unseen, and unimportant.*



*Feeling that I don't matter to anyone or
have anyone there I can lean on*

- consumer



Consumer and carers said:

- Loneliness means there is nobody hearing me or acknowledging I exist or that anything about me is of any relevance or importance.
- Loneliness for me means I don't feel needed or part of another's life. It feels as if I don't have any real value to others and makes it difficult to maintain my self-esteem and furthermore, myself confidence.
- Not having anyone to tell my deepest thoughts and concerns to.

Carers said:

- A feeling of darkness even when people are near. Frozen in a space of time. Watching days, weeks, months, years going by without fulfilment. Cannot think of anyone to reach out for. Nobody contacting you. Crying alone. Everything is just too hard. Everything is an effort. Being alone feels safe. Nobody coming so no need to clean, look good or watch not to say something wrong.
- Loneliness means being isolated, being insular, being on your own, being unable or unwilling to reach out to other people, being in need of company and friendship and not being able to reach out to other people. It makes you shut down and withdraw from the world. It is a downward spiral.
- Not having anyone to share any sort of activity or interest with - no-one to talk to about anything, superficial or deep; not having anyone to spend time with - for a cuppa & a chat, a hobby or sport etc.
- Having nobody that I feel I can talk to about good or bad things happening in my life. Finishing every day feeling empty with a lack of human connection.
- When I want company but there's none to be had. When I feel alone and sad.
- It is an internal feeling that I feel no one can understand me, share interest with me or listen to me when I need it.

2. Being alone in a room full of people

Over one-third of carers described loneliness as being surrounded by people, which could include family, friends, colleagues or loved ones, but feeling completely alone, having no-one who understands what you are going through, not feeling connected to those you love, feeling othered.

- When you feel alone and nobody cares. You can be in a room full of people and feel lonely in you feel isolated and no one is interested in you or what is happening for you. They may listen to you but in there is no connection in they are not actively listening but just lightly engaging. Or they might say it just is and get over it when it is so much more for you and you would get over it if you could"
- Not having people around you that you can really talk to and share your thoughts with. You can have acquaintances and still be lonely.

- Loss of identity and feelings of connection. Being amongst others, and feeling like I'm never fully there, or able to be myself. Feeling scared, but not knowing how to express that to anyone... so further isolating.
- I could be in a room with my dearest family members, knowing I'm supported, but still feel alone.
- Feeling alone, beyond being around people. I can feel connected when I am all by myself. I can feel alone when I am in a room full of people. Lack of belonging is loneliness
- It's different from being alone. Loneliness is not belonging, even when in a crowded room. Loneliness is not feeling others can relate to your experience of the world, and maybe wouldn't even want to. Loneliness is feeling othered.



Being amongst others, and feeling like I'm never fully there, or able to be myself.

- carer



3. Having no sense of purpose, contribution, identity and value

Consumer respondents described how the lack of connection with others and perceived invisibility led them to feel a lack of purpose in life, reinforcing their sense that they 'don't matter' to others, and feelings of having no value to others and their community.

Consumers said:

- A sense of being separate from the world outside and not being seen for who you are. A part of the mass rather than an individual. It comes from both being physically on my own and also from not being understood or heard when with other people...the yearning for human connection, that goes beyond the surface of daily interactions, is the strongest emotion I can feel pulling at my consciousness.
- It's disassociation... feeling like I don't belong, that I have no purpose.
- Feeling disconnected from my place and purpose in the world.
- Feeling that I do not matter. Feeling not being heard.
- I feel most alone when I don't feel seen or known for who I am. I think it's an odd thing where I can feel most lonely surrounded by people, and less alone when I'm by myself.
- Sitting by myself with thoughts I'm not good enough for anything.
- Feeling small, insignificant, or inconsequential in the wider scheme of life.
- A feeling that my time has no significance, that it

can be wasted by me without recourse. That I elicit no desire from anyone else, either to make contact with me or to spend time with me. That I am misunderstood and ignored.

Consumers and carers said:

- *Watching days, weeks, months, years going by without fulfilment.*
- *Being amongst others, and feeling like I'm never fully there, or able to be myself. Feeling scared, but not knowing how to express that to anyone... so further isolating.*
- *Feeling disconnected from others. Feeling as though I don't matter. Feeling that no-one wants to be my friend. Thoughts of 'I'm worthless'.*

4. Lack of intimacy, understanding, unconditional love and care

Respondents described having no-one who understands you, who really 'gets you', who you can feel safe in knowing that you are loved unconditionally by another person.

Consumers said:

- *Loneliness is not being able to have that special someone to share experiences with.*
- *Feeling that no-one truly knows and understands me. Not having a partner to come home to that is my person and the one who shares my burdens. Living alone and having many friends to reach out to but not that one person who just gets you.*
- *Not being understood, accepted or cared for.*
- *Feeling like you have no-one to care for or be cared about.*
- *To me, loneliness is a sense of disconnection from other people. It can mean missing touch and hugs or sleeping next to someone.*
- *Nobody to talk to at the end of the day. Nobody to share worries and happy moments with. The silence in my home. Feeling as if no-one is there for you specifically.*
- *Feeling like I am on my own, that I find it hard to connect in any meaningful way with anyone and can't trust anyone to open up to.*
- *After the loss of my wife to cancer, loneliness crystallised in me as a loss of freedom to be candid and dopey, freedom to be silly and frivolous and soft, all the things a man can't be in their everyday interactions with the world. I realised I had very few people and places in the world I could be totally free of judgements and to have acceptance without condition.*
- *The sensation of a hug is one of the most amazing things and when your body aches for it it's truly painful. I'm a natural introvert so my mind doesn't mind being on own and I enjoy solo time but the human connection emotionally and physically is the truly painful part. Feeling also that no-one is thinking about you. That you aren't in the forefront of someone else's mind.*

Consumers and carers said:

- *Questioning why I am here if there is no meaning in life. Being desperate, feeling that you have lost everything, nothing matters anymore because your heart has been*

broken. You can't talk about it because it is too hard and humiliating and nobody understands or wants to hear.

- *Loneliness means that I have lost my tribe, that there is no-one who loves me unconditionally and accepts me for who I am and loves me for who I am so when conversing with people sometimes have to put up a front that I think may be more acceptable as I feel that I cannot be myself around people for fear of rejection.*

Carers said:

- *Not having anyone to share any sort of activity or interest with - no-one to talk to about anything, superficial or deep; not having anyone to spend time with - for a cuppa & a chat, a hobby or sport etc.*
- *Having nobody that I feel I can talk to about good or bad things happening in my life. Finishing every day feeling empty with a lack of human connection.*
- *It is an internal feeling that I feel no one can understand me, share interest with me or listen to me when I need it.*



Loneliness means that I have lost my tribe.

- consumer



5. Wanting to be my authentic self but needing to wear a mask

Several consumer and carer respondents described how the absence of meaningful unconditional connection with others meant that they felt they had to suppress their true feelings and self when in the company of others. They saw this as being unauthentic and it exacerbated their feelings of loneliness, particularly when around others.

Consumers said:

- *Feeling as though I cannot talk with, share experiences with, be open and authentic with others even when I have people in my life. A feeling of isolation within myself even when I'm not alone.*
- *I always feel like I don't have a right to break into their lives and am the perfect people pleaser, all the while masking my longing to be truly known, since even the people who appear to listen to morsels do nothing meaningful/helpful with them anyway.*
- *Not having anyone around that you feel you can be your true self/share your experiences with.*
- *Having no-one to relate to with honestly and in confidence.*
- *You can be in a family or social group and not feel authentically you. So, you play out a role to fit in...It is a feeling of not being seen.*
- *Loneliness means lack of support and lack of network in order to be able to share your experiences and be your authentic self...suppress aspects of your identity such as your mental illness, sexuality or values and beliefs that*

are close to you in order not to be socially rejected or punished by exclusion.

- Not seeing or speaking to people for days; Not feeling connected to anyone in my life, like no-one understands me or really knows me; Dark isolation where I feel so alone and unwell, and nobody reaches out; Smiling while screaming inside and covering up injuries.

Consumers and carers said:

- I have friends at a superficial level, but not someone I can talk to about how I am REALLY feeling.
- Loneliness can be isolation and feeling isolated. But it is also isolating the scars, shame, and guilt where few others can see it.

Carers said:

- I feel lonely when there's things I cannot share with families or friends even though it is nothing so serious or it's something other people would share with their families or friends, so I'd keep things to myself.
- Being misunderstood. Being with a group of people who don't understand me or who I feel I need to put on a happy face / strong face for.
- Being sure that people can see you're a fake just by looking at you and that's why they don't want to go beyond small talk.

6. Self-Stigma and Discrimination – Feeling rejected, ignored, different, being an outsider

Consumer respondents described a strong sense of feeling different, marginalised and stigmatised as a consequence of their mental health. This was expressed in terms of self-stigma, shame and fear of rejection, or actual experiences of rejection, stigma, and discrimination by others.

Consumers said:

- Feeling different from those around me, having experience a severe mental illness only others who have had a similar experience and have also experienced the loss of their freedom loss of consent and loss of rights fully understanding the resulting trauma and sense of being alone. Having to masquerade as someone I am not so I am accepted, not showing anger or resentment over being treated for decades as somewhat stupid and irrelevant in my care, loneliness is being a lone voice as in my time mental illness carried enormous stigma.
- It is a feeling of being different. Not knowing how to connect to other people around me. In a way, feeling invisible in a room full of people. It is an inability knowing what to say or how to say it.
- Sometimes being alone feels safer than being around people, but in the long-term loneliness makes me feel guilty and ashamed. It makes me feel that I haven't worked hard enough on friendships and relationships, that I am not a kind or warm enough person. Loneliness reinforces the fear I feel about being

with other people - about not being understood or accepted.

- Feeling like no-one really knows you or cares to get to know you. A sense of being alienated from the whole world as if you come from a different planet with no way of going home. Realising that something about you, the way you talk, look or act makes other people want to avoid you but not knowing what it is you are doing wrong or how to fix it...There must be something inherently wrong with you. A belief that if you dare to speak your truth you will be rejected. Needing company but being terrified of being around others. Being sure that people can see you're a fake just by looking at you and that's why they don't want to go beyond small talk.

“Not knowing what it is you are doing wrong or how to fix it...There must be something inherently wrong with you”
- consumer

Consumers and Carers said:

- I am a people person, people are attracted to me, but when I am unwell, I feel like I am put back on shelf and people don't want to play with me anymore.
- Feeling isolated, separate and rejected.
- When I feel like this its often because of experiencing discrimination based on being gender diverse and/or disabled. Another is not feeling welcomed or accepted by people around me, friends, family, class/work mates - especially when there is so much openly displayed transphobia present at the moment, particularly on social media and news. Unvalued by society

One carer spoke of loneliness from disconnection with her culture

- As a non-Australian I felt a keen sense of displacement for the first two years that I lived here in Brisbane and even though English is my first language I have not been able to replace the friends and acquaintances that I left behind in Ireland and also have been unable to link in with Irish here because the few that I have met seem to have their own lives and friends and even though they are friendly on meeting they do not progress a meeting into a friendship.

7. Loneliness as an opportunity for reflection

Two consumer respondents described how they used their experiences of loneliness to reflect, grow and learn how to move forward with their lives in more positive ways.

- *For me to closely identify with loneliness, examining “things” that are missing and the “importance” I place upon them, enables me to understand the role they have played & now do play in my life. Loneliness for me is a “feeling” and exciting evolution for me to meet head on and shift through it. As a survivor of historical sexual abuse...I have had the opportunity to re-write how I believe my life to be and its direct purpose. To not only survive horrific trauma, but to also thrive as a direct result of the trauma.*
- *Loneliness breaks your self-worth and your self-esteem into pieces with all the questions “why am I not good enough” etc but this is all based on an assumption that we are meant to have company to be around others... Nobody should base their value on how many and what quality of people they have around themselves. I have seen terrible people with hundreds and thousands of friends I’ve met the best people with few. If you want to find the secret to loneliness and how to beat it - embrace it, become your own best friend, get up close and personal with the most amazing human on the planet YOURSELF.*

8. Loneliness as a carer

Some carer respondents spoke of loneliness coming from their role as a carer, being expected to know all the answers, putting everything they have into the caring role that they have no time or space left for themselves.

- *Isolation, lack of connectedness with friends and community, recent death of child to suicide aloneness, financial security and lack of access to socialisation*
- *Carer of a person with Mental Health loneliness means; being over whelmed, expecting to know the right answers, alone, no-one understands what you are going through, being given unhelpful advice, trying to understand Clinicians talk (sometimes like a different language), educating myself, no time for myself and I don’t matter as much as the person you are caring for.*
- *Loneliness means a sense of isolation. I don’t mind being alone, but I equate feeling lonely with disconnection and isolation from people in my life, and perhaps the society that I live within. It feels lonely when it seems that I have no one to connect with who have a similar experience to me, or who are able to be empathetic with regard to my situation rather than judgmental.*
- *Loneliness to me can mean many things. It can mean being by myself more than I would like to be, but more so, it’s a feeling of emptiness; of feeling like nobody wants me around, even if I’m in a group of people; it’s a feeling of nobody really caring about how I’m feeling....I have recently been feeling lonely because I lost my adult son due to AOD dependency. That for me has created a feeling of not fitting in with my usual social circle because my grief is not totally understood by others.*
- *Isolating myself away from people in order to cope with everything I have in front of me. Feeling unloved and that because I have isolated myself for so long without realising it I struggle to reach out. It means sadness when I think of the person I was, high energy, very creative, self motivated and like there weren’t enough hours in the day for all of my ideas... but after caring for someone for 22years I’m over it, I want my life back... resentment, frustration and anxiety is all that’s left.*
- *No one to talk to, no one who gets what it’s like to be a carer.*





Connect with other humans...

What do you do to help avoid feeling lonely?

Q2. What do you do to help avoid feeling lonely?

Consumer and carer respondents shared many ideas about what they believed was helpful or had found helpful in alleviating their sense of loneliness, with similar themes found across both groups. Many shared self-care suggestions that involved self-nurturing and self-work to re-frame thoughts and experiences. Other prominent suggested strategies were connecting with others, pursuing activities in the home to distract thoughts of loneliness, or in the community either individually or in groups. Many spoke of the companionship that comes from pets and a few suggested seeking professional help. Again, their ideas were often interconnected (e.g., self-care, re-framing, distraction, connecting with others), as the following responses demonstrates:

Consumers said:

- *Remain connected to others and to nature, surround myself with positive people and engage in activities which make me happy: going to movies, art galleries, walking, eating out, etc.*
- *Go for a walk in nature and say hello to people that I meet on the way. Talk to shop assistants when I'm buying groceries. "Ask how their day is". Even at the bus stop, get a conversation going. Write letters to family members, children, and friends. Keep warm, as it helps to improve my mood. Get some sunshine and relax in the warmth every day. Read books daily. Listen to ABC's Radio National and learn something new, listen to a life story from an ordinary person doing extraordinary things. Find new groups to join. Exercise. Have a spiritual practice.*

Consumers and carers said:

- *Nourish the things that give me a sense of meaning. For me that's the spiritual path I practice. I try and remember that people are sometimes caught up in the pressures of*

their own experience of life, and not everyone is naturally good at being inclusive - not everyone is thoughtful, and that's simply the way of the world. I choose to try and do better, being inclusive and thoughtful of others. I nurture connections I've made with people who share my values of kindness, compassion, generosity and respect.



*Nourish the things that give me
a sense of meaning*

- carer



1. Put self-care into action to care for myself

Respondents described a range of ways that they took conscious steps to nurture and care for themselves.

Consumers said:

- *Walk through the gardens, beach, parks and really noticing the beauty around you.*
- *Use mindfulness practices to get more comfortable with solitude.*
- *I plan my days more when I know I am going to be alone.*
- *Minimise alcohol consumption. Have contact with individuals who have positive attitudes.*
- *I'll try to make solo plans like visiting the art gallery or watching my favourite TV show with snacks. Kind of like "self dates". Just acting kindly towards myself and trying to avoid blaming myself for how I'm feeling or the circumstances...I have various coping strategies derived from ACT or CBT. Usually a combination of breathing*

exercises, self-compassion, and “unhooking”. Although sometimes it becomes too much and I fall into eating sweets or becoming couch ridden to cope.

- I often wake in the early hours haunted by past memories so I get up make a hot drink, put on the heater as warmth bring comfort as does a heat bag and can usually find a movie or Talk Show on the TV.

Consumers and carers said

- Mindfulness. Having a written plan list for the next day. Although, I often find this exhausting to do.

Carers said:

- Teach myself TOOLS on coping in certain situations and having Boundaries. Self care is a big one.
- Walk and sit with my thoughts and reflect and talk myself out of it which can take an hour or can takes a month. Keep busy as much as I can so the thoughts are better controlled and not over taking me in that I have no other thoughts.
- Free yourself from negativity and focus on positives, learn meditation and living in the moment here and now, making the best of every moment you have. If there is nobody to talk about your problems, start to write the issues on a paper, positives and negatives. Try to find the positives also from the negatives and you might see the first flicker of light in the end of the dark tunnel.
- Practice mindfulness including mindful compassion to help me feel part of the community and remind myself that I’m not the only one with issues.
- To avoid feeling lonely I try to look into why I am feeling lonely and accept what feelings are there. I practice self-love and self-compassion. I also try to spend some time in nature or with my dog. Sometimes listening to a good podcast helps me feel like I’m surrounded by friends too.

Some respondents mentioned actions that they undertook to alleviate their loneliness that could be considered as unhelpful, such as ‘playing the pokies’, ‘alcohol’, ‘sleep’, ‘take substances’ and ‘eating’.

Three consumer respondents mentioned how spirituality helped them with loneliness; for example: ‘Faith gives me assurance of God’s purpose in every aspect of my life’ and ‘I try to fill the absence of other people with the presence of God’ and one carer commented ‘Nourish the things that give me a sense of meaning. For me that’s the spiritual path I practice’.

2. Distraction – filling time and space

Respondents also suggested individual creative activities that they pursued to distract themselves from thoughts of loneliness, and for personal fulfilment, pleasure and relaxation. These activities included art, music, movies, hobbies, writing, social media, and so forth.

Consumers said:

- Making time for my own interests and hobbies - being my own best friend means that even when I’m alone I don’t have to be lonely.
- Join in activities. Watch a funny movie. Listen to music. Go on Facebook! Read a book. Call a friend. Volunteer, be creative, craft, write etc to keep distracted, podcasts, journaling. Keep busy.
- I work far too much - which is really bad for me in other ways but it does stop the sense of emptiness and loneliness - when you are working then you have a sense of purpose and being needed.
- Spend time on social media.

Consumers and carers said:

- Get out of the house, a walk or up to the library nearby or to grab a takeaway coffee. Get off social media: it makes everything worse.
- Filling your days with work and other activities, art, crafts, music, walking, swimming aqua aerobics.



I work far too much – which is really bad for me in other ways but it does stop the sense of emptiness and loneliness

- consumer



Carers said:

- Distracting the mind with gardening or being with my pets.
- Watch movies, YouTube, or find something out of my interest to do
- Keep myself busy. Even though I can recognise that I am feeling lonely, it does not impact me as much because I am preoccupied with other tasks and meeting short deadlines.
- Re-organise your days so you don’t have too much free time to worry and mull over what has happened.
- Turn on the tv. Not so much avoiding feeling lonely, cause you don’t know you’re lonely till it’s there. THEN.... you have to get up and do something different to love yourself

Two carers suggested keeping yourself so busy that it has a negative impact such as exhaustion from overworking or having too many things on the go at once, that you simply collapse. Another carer commented ‘I generally don’t have time to feel lonely, caring is a full-time job’

3. Connecting with other humans

Many respondents talked about establishing routines to keep contact with others, and pushing themselves to connect with family, friends or simply other humans in the community. Getting out of the house in any form was seen as an important circuit breaker to alleviate feelings of loneliness. Some suggested a further aspect of that contact with others was a focus on giving to and caring about others and contributing to others in the community.

Consumers said:

- *Go outside. Go for a walk. Go to the shopping centre. I think sometimes just seeing other people can give you a sense of connectedness.*
- *Keep active and go to things where there are others around (gym, sports classes as an example).*
- *Hug my kids.*
- *I make sure to check in with my partner, my parents, and my closest friends regularly.*
- *I ask my friends for hugs and tell my friends and family that I love them. I communicate openly about my gender identity and sexuality.*
- *I may just go to the letterbox.*
- *I try to keep routines that make me to connect with people. I make sure I pick my child up from school because that will make me speak with people. It helps me feel connected to the school community, parents have a way of understanding each other's challenges and also bringing some light heartedness to life's challenges. I would say that I have made some good friends this way.*
- *Focus on what I can do to help others (for connection and as an antidote to potentially feeling 'forgotten' or overlooked by others) - turn my attention to others.*
- *I meet fortnightly on zoom with a group of single ladies in similar circumstances.*
- *Share food with a neighbour being intentional to listen to people you meet.*
- *Always looking for ways I might be able to help someone or show an act of kindness - like helping an elderly person with their shopping or telling a parent with a crying child they are doing a good job keeping their head above water.*
- *I am a regular at The Men's Shed which has been a really great thing for me as I get to be mates with other blokes. Lots of them too are lonely and we get along well.*
- *Making friends with people I feel a close sense of kinship to and spending less time with people that leave me feeling uncomfortable or inadequate.*

Consumer and carers said:

- *Take a walk and smile at strangers. Make small talk with people.*

- *Walking in the community.*
- *Text friends, participate in online forums, make sure I have plans to see friends and family coming up in the future.*

Carers said:

- *Do activities with people. I swim 2x a week with masters swimming. Try and bike ride with a buddy once a week. Some weekends I go hunting with a couple of guys.*
- *Talk to service staff (shop keepers etc)*
- *Try to find activities in my community that I can attend for free (prefer in early mornings) early morning starts are helpful to force me to wake up and get out of the house. The loneliness feelings are much worse if I am left to lay in bed and dwell on them.*
- *Getting out in the garden is very relaxing for me and I can connect with the people walking past my gate too.*
- *Two carers highlighted the impact of exercise 'Sometimes I might go for a walk as exercise releases the feel good hormones' and 'exercise makes me feel good and when I feel happy loneliness doesn't seem such a high priority'. Some carers spoke of the benefits of social media 'I do link in with my old friends at home using Whatsapp' while commented 'Get off social media: it makes everything worse'.*



Share food with a neighbour being intentional to listen to people you meet.

- consumer



4. Connecting with pets

Several respondents spoke about the importance of pets in their lives, as companions, to help them build structure and purpose in their day by needing to care for another, and to replace a lack of close relationships, physical contact, and unconditional regard that may have been elsewhere absent in their lives.

Consumers said:

- *I have a dog that fills the void.*
- *Talk to the cat.*
- *I have two dogs who love pats and cuddles.*

Consumers and carers said:

- *Sometimes having a pet or a soft toy to cuddle helps me feel less lonely, as it is like I am with a friend.*
- *Spending time with my animals, or out with animals in nature.*

Carers said:

- *Get a pet, if you don't have one yet. They understand and they don't judge you*
- *For my son his dog is the difference between feeling lonely and feeling like something/someone cares for you.*

5. Re-frame how I think and feel about loneliness

Respondents spoke about how they used strategies to think differently about their circumstances and about loneliness to lessen its negative impact on them.

Consumers said:

- *Remind myself that it is better to be lonely than be around people you don't like.*
- *Challenge my thoughts and feelings particularly around avoidance and anxiety.*
- *Re-frame 'people pleasing' and feeling taken advantage of; or at least start interrogating the motives. Try not to wear the mask everywhere, but at the same time, try not to drop it in the wrong places.*
- *I no longer avoid feeling lonely, instead I give the emotion space to be present. I try to flip the narrative and see it as less negative and more of a neutral state... remind myself that soothing needs to come from within, rather than externally.*

Consumer and carers said:

- *Start to write the issues on a paper, positives and negatives.*
- *I try to maintain a sense of humour*
- *Adopt bigger picture thinking. Stop myself grieving by just accepting this is how my life is. Forget my own need for social connection and put my mind on projects and problem solving useful for the entire community or the entire world. Change my social connection goals.*
- *Allow myself to have a lazy day without feeling guilty.*

Carers said:

- *Learning to be alone and to be in relationship with myself and my environment has been key. Shifting my understanding of what it is to be alone.*
- *I work on my own connections with nature and being comfortable in solitude. I have a circle of friends who understand my preferences and are often responsive via social media.*

6. Seek professional support

Only a few consumers said that they sought help from professionals to alleviate loneliness.

- *Professional help in the form of psychologist and group therapy to address my insecurities around shame feelings.*

- *Work on myself through therapy - as much as I'd like to lay blame at everyone else's feet, I have done lots of healing and growing and am sure there's more to do.*
- *I choose my health professionals carefully, and if they invalidate my experience, I see different ones.*
- *I panic less about the lonely feeling now that I know where it comes from (childhood neglect – and genuine lack of connection, so grew up expecting that was how relationships were, have had to learn to be different in relationship). Good therapy with a very skilled therapist has helped a great deal.*
- *I talk about loneliness with my therapist very regularly too.*



I no longer avoid feeling lonely, instead I give the emotion space to be present. I try to flip the narrative and see it as less negative and more of a neutral state...

- consumer



7. Join support groups or community activities

Accessing groups featured highly among carers with a focus on linking with like-minded people.

- *I have joined support groups for those in similar circumstances*
- *Keep in touch with other people in the Lived Experience Community. Do voluntary work.*
- *Join a mental health support group e.g. Grow, who understand mental health and have 'friendship' as one of their key objectives. Attend any course that is face to face to connect to others with similar interests.*



Loneliness is hard...

What would you want others to know about loneliness?

Q3. What would you want others to know about loneliness?

Many of responses to this question from both consumers and carers were expressed in a succinct and forthright manner, as if determined to build understanding in the reading audience. Some made comments connected directly to themselves; though many were expressed like 'lessons learned'. Some were expressed as advice to others and/or spoke to others directly to provide support, as one participant put it: 'so they can have compassion for people who feel lonely and also recognise in themselves when they are feeling lonely'.

1. Loneliness is hard

Many consumers and carers talked about how hard loneliness is to live with.

Consumers said:

- *That it can feel debilitating. But I want understanding and empathy, not pity. But I do want people to acknowledge how tough it is.*
- *It's easy to fall into and much harder to get out of.*
- *That it isn't as simple as "going out" or "just make friends". When you don't have any family, it is very hard.*

Consumer and carers said:

- *It sucks.*
- *It is the saddest feeling of all emotions.*
- *It's a deep pain.*
- *It's really hard to deal with & you can't just be "jollied out of it".*
- *At times it can be crippling.*

Four carers also referenced loneliness as a physical pain.

- *That it can be physically felt, in your chest. And can feel overwhelming at times.*
- *I want people to know it's like a disease. It's deadly, toxic, difficult to solve, it's insidious. It's like smoking a pack of cigarettes a day (maybe less but you get the idea). So many poor outcomes associated with loneliness. I think it takes a pretty concerted effort to solve it. Need to be pretty committed and proactive. It's not going to fix itself.*
- *That loneliness hurts, physically, and that no one should have to bear this on their own especially as they get older and weaker*
- *Loneliness isn't a matter of going out and seeing friends, it's a deep pain that seems to isolate you even amongst your closest friends and family. It's a torture I wouldn't wish upon anyone. It's a form of isolation that often feels as though it has no end or way through.*

2. Loneliness can be hidden

Consumer respondents described how loneliness is not always visible or obvious; people can hide their sense of loneliness.

Consumers said:

- *That just because you socialise with others and appear extroverted and outgoing it doesn't mean that you feel like you belong and that you are not lonely.*
- *Even though you may have lots of people in your life, you may still experience loneliness.*

Consumers and carers said:

- *That it needs to be talked about more because it tends to get overlooked.*

- *Even though I am a friendly, chatty, personable type and work outside of the home I still experience loneliness. I don't present as if this could be a problem, but it is.*
- *That it isn't just something people experience when they have no family/friends, you can feel lonely even surrounded by those you know and love.*
- *Loneliness can happen because of a trauma background and not being able to trust people. It cannot be forced on people as that's not safe. Please be sensitive to this.*

Carers said:

- *If I told you I was lonely you'd be surprised and say "You? I had no idea"*
- *That we may present as extroverted, resilient, accomplished, and happy within our lives. That 'fake it til you make it' masks are not true reflections of the inner loneliness felt...once a working day ends, many of us return to an empty home and not the energy to connect*
- *You can appear busy, involved in lots of things and yet be dying inside from a sense of not been seen, heard, and accepted.*
- *Others see you as vibrant and fun and happy when you can in fact feel like you are dying inside.*
- *You can keep smiling and appear happy, even when you are lonely. Loneliness is not always visible to others.*

3. Loneliness is a social problem, not an individual one of being alone

Some respondents emphasised the causes and solutions for loneliness as situated in the social fabric of society and how we treat each other and connect with each other, beyond the individual, and solutions must be shared endeavours.

Consumers said:

- *Loneliness is the product of a society so focused on individual rewards, wants and needs that the social and community bonds are broken...Loneliness cannot be fixed without genuine and authentic connection.*
- *Don't withdraw when people are going through a rough time. Don't feel like you're intruding. Be there for them.*
- *It's not their fault, very powerful rich people and governments have created a society that excludes worthless people who don't work purposely.*
- *Loneliness is not something to be solved by sitting in a health professionals office. Safe and comfortable housing is the first part of dealing with loneliness, and more needs to be done by government and health/support services to make that happen, rather than making band-aid approaches through medication, forced hospitalisation, temporary support programmes, etc.*

Consumers and carers said:

- *That simply saying 'hello' as you pass me in the street really helps, even if you don't know me.*

“
If I told you I was lonely you'd be surprised and say "You? I had no idea"
 ”
 - carer

Carers said:

- *It is a social problem that we could all deal with and help fix. It is the saddest feeling of all emotions. It feels like it cannot be overcome at the time you are experiencing it.*
- *Loneliness is - a sensitive issue. When you have not heard from someone for a long time. Please do not judge or give advice. When someone reacts with irritability, making it difficult to approach them. When someone is leaving things incomplete. When you notice the need to check-in on someone. When a cup of tea together or watching a movie together may be just enough to break the loneliness.*
- *Look out for the people around us and check if they are okay. Sometimes people are going through struggles that we cannot imagine, but they feel ashamed to reach out for help. Also, there is not an easy solution, so do not treat people feeling lonely like they are using their unfortunate situation as an excuse/crutch.*
- *Being kind to others, saying positive things, showing compassion towards others, even strangers, an act of kindness goes a long way and may save somebody's life without us ever knowing.*
- *That you don't have to "fix" us. We just need to be seen and heard and allowed to feel and think what we feel and think.*
- *I would want others to know about loneliness so they can have compassion for people who feel lonely and also recognise in themselves when they are feeling lonely.*

4. Loneliness is common, but that doesn't make it OK

Several respondents stressed loneliness is a common and 'normal' feeling, some saying that it can affect people in different ways, at any age and in any context. Whilst some then also suggested that it 'would pass', others expressed strongly that such statements didn't help the person.

Consumers said:

- *It's not okay. It is perhaps the most grievous condition a person can be afflicted with. Stop telling people to "be okay" with it; stop telling them to "accept" it; stop telling them to "learn to live with" it.*

Consumers and carers said:

- *I would want others to know that it's okay to feel lonely sometimes and not to feel shame in it.*
- *It is not unusual. It is common. Everyone feels lonely at some time in their life.*

Carers said:

- *We all have periods of being lonely, especially when friends have other things on their minds. This doesn't mean there's anything wrong with us, just that people are busy*
- *You are never alone in feeling loneliness... even though it feels like it*

5. Loneliness is harmful

Consumer respondents' comments about the harms arising from loneliness were powerful.

- *That it can kill. Literally.*
- *It's incredibly detrimental for your wellbeing.*

Consumer and carer respondents said:

- *It can be a dangerous thing for your mental health.*
- *Loneliness is dangerous and can lead to suicide attempts.*
- *It is extremely emotionally painful and can be debilitating. It has been something that has been at the core of suicidal distress, dissociative response and fear-based reactions which have prevented me from taking so many opportunities.*

One carer commented 'It affects my mood. It's like holding back tears and very isolating.... I know loneliness affects my wellbeing - physical, mental, social, financial and spiritual'.



6. Loneliness, stigma, and shame share space

Respondents spoke about the interconnections between loneliness and feelings of stigma, shame, judgment, and sense of self-worth, particularly in the context of living with mental ill-health.

Consumers said:

- *That it's not that I'm not interested in others or think about others, it's that I don't feel I'm able to connect, it seems too hard, too challenging, and as such I often feel anxious about having that connection and so avoid it. It's also not that I'm lazy or uninterested in life and events, I want to do more, to be useful, it often just seems too overwhelming.*
- *We don't choose to feel lonely.*

Consumers and carers said:

- *Sometimes people are going through struggles that we cannot imagine, but they feel ashamed to reach out for help. Also, there is not an easy solution, so do not treat people feeling lonely like they are using their unfortunate situation as an excuse/crutch.*
- *That's it's really hard to reach out for support and admit I'm lonely. So much shame.*
- *Please do not judge or give advice.*



That it's not that I'm not interested in others or think about others, it's that I don't feel I'm able to connect, it seems too hard, too challenging...

- consumer



- *Chronic loneliness comes from feeling inherently flawed, unworthy, and unacceptable. You want to connect but somehow push because you're terrified that if they get too close that they will realise the truth - that you are unlovable....Loneliness has its roots in a deep sense of unworthiness and cannot be eradicated by thinking positively or repeating affirmations. Being told that we should just Act Belong Commitment is useless until the core reason for our loneliness is addressed...you don't have to "fix" us. We just need to be seen and heard and allowed to feel and think what we feel and think. When this happens consistently over a fair bit of time, we eventually find ways to accept ourselves and there begins the slow climb out of our prison of loneliness and self-hatred.*

- *As I support family with mental health distress, I have less time to engage in my interests, people don't understand the stress we live with and supporting others is very isolating and lonely. Loneliness can happen because of a trauma background and not being able to trust people. It cannot be forced on people as that's not safe. Please be sensitive to this.*

7. Loneliness can be overcome

Several respondents made statements that seemed intended to provide support and reassurance to their peers to help overcome loneliness. Some responses were advice to others about how they could offer help to people experiencing loneliness.

Consumers said:

- *That you're never alone, that a friend is as close as the nearest phone, that there's many things to do to get above feelings of loneliness.*
- *It doesn't take much of your time to make a person feel wanted.*
- *How isolating it is and how a text or phone call or a meet for coffee means so much.*
- *God is always present.*
- *You are never truly alone, to be alone, to be truly alone would mean you could not be reading or hearing this. So right now, you are not alone, you are with me. And I'm good company.*
- *Follow up if someone leaves a group.*

Consumers and carers said:

- *Sometimes all I need is for someone to hold space with me and listen.*
- *It can be prevented.*
- *Sometimes it is a hole you can't get out of by yourself, you need others to help lift you out of loneliness.*



It bleeds into everything you are..

How does loneliness or social isolation impact on mental and physical health?

Q4 How do you feel that experiences of loneliness or social isolation impact on mental and physical health?

All consumer respondents who answered this question provided strong comments about the impact of loneliness on their mental and physical health, as evidenced by the frequent use of adjectives such as ‘terribly’, ‘enormously’, ‘significantly’, ‘exponentially’, ‘greatly’. Several consumer respondents described loneliness aligning with deep despair, hopelessness, and thoughts of suicide as a common and regular experience. These relationships were complex, bi-directional and multi-directional, further complicated by experiences of stigma and self-stigma. The use of metaphors was prominent within many responses to this question. Respondents stressed that loneliness and social isolation, mental health and physical health definitely go hand in hand.

1. Impacts on mental health

Many consumer and carer respondents described several ways that loneliness directly impacted their mental health; the three areas were often inseparable and interconnected.

Consumers said:

- *You can't shake the feeling of true loneliness and social isolation once you have felt it. It bleeds into everything you are – or thought you were. You are constantly left questioning yourself. And if you start to socialise again, you try to make friends well f#^^ you have a battle on your hands between what your now damaged mental health believes is real and what is real.*
- *You live with your thoughts in your head and you don't get a break.*
- *WISH I WAS DEAD EVERY DAY except I am being rejected and ostracised by society because I'm a worthless piece*

of garbage abuse victim. And because I can't get mental health care, I am entitled to by law I can't return to work - and everybody knows people who don't work are the MOST HATED people in society.

- *Not a day goes by that I don't notice my negative mood in direct connection with loneliness. When more triggered than usual I find myself wanting to run away from my life, yes to escape, but more so because it is easier to be alone, and therefore lonely, among people I don't know because I don't expect them to know me, I don't expect them to genuinely enquire how I am.*
- *For me, loneliness & social isolation and low self-esteem reinforce each other. Loneliness, depression, and isolation can turn into a loop that's hard to break.*



You live with your thoughts in your head and you don't get a break.

- consumer



- *I also believe that a lack of time spent in the company of others can make anxiety worse. In the case of social anxiety, which is often a cause of loneliness, further avoidance of others can exacerbate it, making it even harder to overcome. Without others to provide perspective and context, mental health issues can start to feel magnified in scale.*
- *The burden is carried alone and there aren't people to help test unhelpful thinking.*
- *It's easy for my own thoughts to run rampant.*

- *Being lonely or socially isolated can lead to someone feeling like there is no hope which can lead to someone's death.*
- *I become depressed and anxious, I worry a lot more and I catastrophize. I can begin to think/feel that nothing I do matters and that nothing I do will make a difference.*

Consumers and carers said:

- *We are pack animals, and we need to be part of a community, but it is hard to find your community, and place in the world sometimes. It makes people anxious and unable to reach out to other people. It makes you silent. Mental illness and depression can make people brittle and intolerant and difficult to relate to.*
- *Being lonely can mean people dwell too much on themselves and their problems. Problems become bigger than they really are. Loneliness can cause suicide. Pain can cause suicide. Loneliness can cause alcohol abuse and drug abuse.*
- *Greatly. I feel rejected and that I must be disgusting. That spirals into many negative invasive thoughts. I feel less human, that I'm not part of this community or species. Feeds psychosis symptoms as there is no interruption of human connection to reality check. Feeds depression as it feels like exclusion and worthlessness. Overeat for something to do. Hopelessness of isolation start to ask what's the point.*
- *Enormously. I start to overthink things. Relive the trauma. Become physically sick and unable to control emotions or outbursts. Can develop into self-harm.*
- *If I'm alone I sometimes ruminate too much in my thoughts, my anxiety heightens and then I socially isolate more -don't go to work, cancel family dinners or coffee outings.*

Carers said:

- *It reduces a person's feeling of wellbeing and worth. Contributes to anxiety and depression.*
- *Closely linked to depression.*
- *Deadly. Maybe not so much physical health, but if you lose your mental health, you'll lose your physical health as well.*
- *I think that when we're lonely or socially isolated we feel sad and don't have a healthy view of ourselves which eats away at our self-worth.*
- *Huge impact on mental health. Depression, frustration with the world, sadness, and loss of connection.*

2. Impacts on physical health

Respondents described several ways that loneliness directly impacted their physical health, particularly in relation to self-care such as exercise, nutrition, hygiene, etc.

Consumers said:

- *I am still after years of attempting to increase my social*

participation suffering from the physical deterioration my body endured after spending years in isolation and loneliness. And that doesn't help making friends! "Hey I can only stay for an hour because my back will break if I don't have back support for longer than two hours." Wow what a great ice breaker -let's be best friends???!"

- *There is no space or energy for physical exercise or self-care routines when you are consumed by loneliness and that loneliness is tied to your self-image and self-worth.*

Carers said:

- *It makes me feel less lightly to care about my physical health (diet etc.), hygiene and appearance. It contributes to a lack of motivation to care for myself. I become desponded and feeling of despair surface. I become more depressed and to try and avoid the pain I have thoughts of suicide.*
- *Nutrition, well-being exercise, ability to effectively communicate, adopting self care practices, all becomes negatively impacted which reduces opportunity to engage in caring and relationships*
- *When I feel lonely my mental health is poorer, and I am more likely to feel depressed, irritated and want to withdraw further. I don't feel like putting in effort and therefore eating well and exercising also devolves.*
- *Impacts on physical health, because one can easily talk oneself into not going for that walk today. ... or tomorrow, or making the effort to do things, like make a decent meal, cause you don't deserve to have that, or to put that time into your well-being. Impacts on mental health by indulging your brain in stinking thinking and can be hard to climb out of that well.*

One carer commented 'it can lead to isolation and increasingly not wanting to leave your home. It can reduce motivation to be active and doing things and neglecting things such as hygiene, cooking etc. It can have a very negative impact on your physical and mental health...'

“
There is no space or energy for physical exercise or self-care routines when you are consumed by loneliness
 ”
 - consumer

3. A complex cycle of impacts on mental and physical health

Many respondents described how interlinked mental health physical health impacts were for them, with many describing these impacts as a 'vicious cycle' in which depression and anxiety, self-worth, self-care, and hope, amongst the many experiences that they were confronted

with, were negatively impacted. The direction of causal links between loneliness, mental health and physical health (which experience came first, and which was consequential) were difficult to determine, given the complex cycle in which each was present. However, several indicated that disconnection led to poor mental health, and disconnected people may be less likely to care for their own physical health.

Consumers said:

- *It makes me feel less likely to care about my physical health (diet etc.), hygiene and appearance. It contributes to a lack of motivation to care for myself. I become desponded and feeling of despair surface. I become more depressed and to try and avoid the pain I have thoughts of suicide.*
- *Having a relationship that proves to me that human life can have value would greatly improve my mental health. I realize that many people reading this, and my other answers on this survey will probably be likely to think: "This guy sounds like an asshole! No wonder he's lonely!" And you're probably not wrong. But please keep in mind that what you are reading here are the *consequences* of loneliness, not the initial cause. My outlook and attitudes were far more optimistic and generous when I was in my youth, presuming that a full life filled with love and meaningful friendships lay ahead of me. Had you spoken to me back then, you would've thought me almost normal. How does loneliness impact my physical health? Because I have no one of value in my life, I have no reason to live. Consequently, I abstain from exercise, and eat the unhealthiest foods I can, hoping to induce a fatal heart attack, cancer, or other route to natural death. As a result, I am obese, and I imagine that a doctor would tell you I am very physically unhealthy.*
- *Loneliness has contributed to feelings of depression (clinically significant), suicidal thoughts, and loss of interest in life. When making connections with others becomes so forced and difficult, particularly as we get older, living feels like a burden. When one feels this way other activities seem less enjoyable - exercise, eating, going to the doctor (because I'm just a Medicare payment not a person), and so physical health deteriorates.*
- *Loneliness and social isolation make a person feel like a fringe dweller, excluded, irrelevant people can experience fear, anxiety, depression, self-loathing, poor self-confidence, and low self-image. It is well known that poor mental health results in poor physical health as individuals think they are not worth the effort of looking after their physical health. Depression and anxiety results in poor sleep and eating habits and often abuse alcohol and high calorie foods in an attempt to feel better which results in chronic illness and chronic dental problems.*
- *Has a big impact on feelings of worth, hopelessness*

and helplessness. When you are not travelling well mentally, it is really difficult to manage the basics of personal care, eating well, exercising, showering, healthy sleep patterns.



When I am around others and feel the hollow and empty feelings of loneliness, it scares me!

- consumer



Consumers and carers said:

- *When I am around others and feel the hollow and empty feelings of loneliness, it scares me! It makes me not want to go out again, afraid that others will not like me. It makes me constantly worry about burdening others, or making others feel unappreciated or cared for. Physically I feel more anxious, so my body often is overcome by aches and pains. My heart often races, I get dizzy and my digestion goes "wack". It's so hard to focus and everything can feel like a tiresome slog. Similar to fighting the tide, walking against the currents of a muddy beach.*
- *Sometimes loneliness is so painful that it actually hurts deep in my chest and stomach...There's a savage beast inside me that raises its head to the sound of happiness: envy. There are times I will not eat because I feel I should just fade away.*
- *I think loneliness is the number one cause of damage to mental and physical health. In my opinion, it is the most overlooked cause of health ailments. We are social creatures by nature. Our current society has caused great separation in family systems, leaving younger generations unable to feel connected.*
- *Loneliness causes people to overuse and misuse food and/or medication and/or legal/illegal drugs to provide comfort which leads to other health problems. Loneliness affects our sense of hope for the future which is critical to mental health. Loneliness affects our ability to appreciate and care for ourselves as we feel unloved and alone and not worthy of care and attention and there is also no one there to talk to or notice us when we are presenting as unwell so health issues can go unnoticed.*

Carers said:

- *It reduces a person's feeling of wellbeing and worth. Contributes to anxiety and depression. Increases aches and pains or exacerbates existing physical and mental health conditions. May contribute to falls, deconditioning of the body, nutritional status. A person may be less likely to seek help for their situation*

- *The experience of loneliness results in low self-esteem and low energy. One can become easily irritable. One feels sad and tearful. Physical health deteriorates, having aches and pain. Always feeling tired, yet not doing much. Have sleep problems. Feel suicidal.*
- *Makes it harder to get out the door to get physical exercise (although it's always better if I do walk out the door and do it!). Makes me feel unwanted, unloved, that no-one cares much and that makes it harder to reach out and ask for help - the cycle continues*
- *A person starts to feel depressed and more isolated. Their world shrinks or reduces and is a vicious circle. People sit and eat more while watching TV. Are not motivated to go for walks or to go out therefore their physical health starts to deteriorate.*
- *Hugely! It's a downward spiral. It affects confidence which then serves to drive oneself further into isolation which perpetuates loneliness.*
- *So interconnected. If I'm lonely my mood can become low, then I don't want to do the things that make me feel good, and my mental health suffers. I've learnt if I just get started, I do feel better, become busy and the feelings of loneliness go away a little. But sometimes I just don't feel understood, even when doing things or with people, and the loneliness feelings are still there. If I'm alone I sometimes ruminate too much in my thoughts, my anxiety heightens and then I socially isolate more -don't go to work, cancel family dinners or coffee outings.*

4. Impacts over time

The concept of 'time' was apparent in the comments of several consumer respondents, describing the insidious development of mental and physical health problems as a consequence of longstanding experiences loneliness and social isolation.

Consumers said:

- *I was forced into social isolation for years by my partner and the impact of this lasted long after the relationship ended. My mental health was so bad that I had convinced myself that I deserve to not have people in my life because I was worthless, and no one would want to be in my life by choice. I had stopped getting out of bed in the morning and I put on weight. My partner introduced me to drugs and that was the only way I could escape the feelings of depression and loneliness. Once again, the emotional and physical impacts have lasted long after the relationship.*
- *It has a cyclical effect. I feel bad about how I look so I don't care about what I eat or exercise. I feel bad about not eating well or exercising and then eat poorly to try and get some emotional relief. I think I'll deal with my physical health after I sort my mental health, but two decades later and I'm still waiting.*
- *People don't understand how difficult it is to kill yourself. I think about it a lot as a solution, and I don't fear the*

day I'm dead at all. I suppose I just don't want to 'do the wrong thing', and that thought stops me. But I'm over 50 now and it's getting harder to stay with no supports.

Consumers and carers said:

- *If it becomes long term or deeply rooted, it affects your mental state and you get caught up in your own mind, and limited way of thinking. You become negative and judgmental. Chronic loneliness leads to depression and anxiety, and depression and anxiety lead to more loneliness and isolation. Years of loneliness and the complex coping mechanisms I have employed to escape the pain have resulted in two mental & physical breakdowns in my middle age. I am now a burden on the public health and welfare systems because I can no longer work full time and have multiple various psychosomatic and immune system disorders. I have tried to take my life twice.*

Carers said:

- *Personally, it took me more than 40 years to realise how much I have hidden from others and myself...*
- *It created huge mental and physical health issues for me. It is taking hard work to challenge what I believe, how I see myself and who I trust.*



Personally, it took me more than 40 years to realise how much I have hidden from others and myself

- carer



5. Loneliness in shared supported housing spaces

A small number of consumer respondents spoke about loneliness and its impacts in relation to life in Supported Residential Facilities:

- *Life in a boarding house is definitely stressful. For those without work the stress is compounded. Loneliness has been said to be comparable to obesity in terms of its impact on mental and physical health. For those of us who use antipsychotic medication the tendency towards obesity is often accompanied by loneliness. The impact compounded.*
- *I have a lived experience of schizophrenia and so loneliness is a major impact on my mental health. I just moved out of a boarding house after 3.5 years. I found the experience difficult. We lived together but were lonely.*

6. Loneliness, coping and self

A small number of consumer respondents described impacts that appeared to be beyond the more direct impacts on mental health and physical health; these particularly related to them finding ways to explain and cope with the overall experience of the many impacts for them:

- *For me, nothing I enjoy more than being alone. It might sound selfish and arrogant, but I have trained myself to be content with my own company, the little things, walks alone with my pets, listening to a podcast in my back yard. I feel human connection for me is too painful and mentally draining.*
- *I want to die because a life without any meaningful human connection has no value. By the way, being suicidal in this fashion is not “mental illness”, it is a fair and rational appraisal of the situation at hand. I challenge anyone to decisively prove that my preference for death over a lonely life is wrong/unwise/irrational/etc.*
- *I hide away in my room and don't want to talk to people. Which is probably an unhealthy thing to do. But it's what gets me by.*
- *Loneliness makes it harder to leave the house and it reminds me of how much my disabilities affect me.*

Carers said:

- *It affects everyday you live it so much so that you just accept that this is life & I just have to keep going & roll with every single frustratingly random day where anything happens & planning any time out almost becomes impossible...*
- *I think loneliness is the number one cause of damage to mental and physical health. In my opinion, it is the most overlooked cause of health ailments. We are social creatures by nature. Our current society has caused great separation in family systems, leaving younger generations unable to feel connected. If you look at studies of people who have overcome massive trauma, you will find they all had a support network.*
- *If I start feeling sorry for myself, it can really pull me down, so I try to observe my thoughts, pause and reflect - where is this taking me? Sometimes it might be something I have to recognise, acknowledge and allow to be (like grief in its many forms). If I'm having difficulty working through it then I get help.....If I didn't take these steps I would definitely become unwell (as I have autoimmune issues). I guess I have learned this over the years and that is the advantage of age/experience and learning from when I didn't cope so well.*

7. COVID-19 and its impacts

A small number of consumer respondents described impacts related to COVID-19:

- *Social isolation definitely increases loneliness and can make mental health symptoms feel far more intense than they are. I find when I am lonely, I am far less likely to do anything productive, and more likely to binge watch and binge eat - bad for both my mental and physical health. Coming out of isolation can be difficult too - physical health has decreased, no longer used to people and I feel very anxious.*
- *I feel that 'loneliness' and 'social isolation' are two different things. In the VIC lockdowns, I appreciated the reason why we were asked to lockdown. I was philosophical; I was 'part of the solution'. I experienced 'social isolation' but I felt safe at home; perhaps because I had a purpose, to be 'part of the solution' and we were 'all in this together'. So, I was alone, and did not feel lonely. I think I feel lonelier when there is capacity to go out and for others to make contact with me. However, I recognise that in that example loneliness is a mindset. My mental health can decline when I 'allow myself' to feel lonely. In essence, I mitigate poor mental health by 'deciding' not to be lonely, or by not accepting loneliness. Deciding not to be lonely and not accepting loneliness hinges on my ability to thwart symptoms like depression. It can be a daily battle unless I abide by the contract to keep pushing forward, to not give in to the feeling of loneliness and as such to not succumb to depression.*

Carers said:

- *Covid has made things much worse, people need to stay connected in order to know that they are ok and not let the negative feelings and fear get into thought processes too often.*
- *Covid has taught more people what lonely people have always know. Loneliness sucks. Covid also taught or reminded people that people can help other people.... Making sure people have the necessities of life can help them feel worthy as human beings. We all want to be seen as worthy of other peoples interest....*

8. Loneliness as an opportunity for self-care

In contrast to most respondents, just 3 described loneliness positively in relation to their mental and physical health:

Consumers said:

- *'Loneliness is an opportunity for self-care and compassion'.*
- *My feeling is that loneliness is a wonderful opportunity to explore living life differently, from that which I was taught to live.*

One carer said *'In some ways, great! Allowed for me to really try out, assess and develop some of the coping techniques in my kete (basket). However, if it wasn't for having internet and two kids who kept me busy and distracted; it would have really strained my mental health'.*



It impacts on the strength and health of relationships...

How does loneliness or social isolation impact on families/whānau as a group?

Q5 How do you feel that experiences of loneliness or social isolation might impact on families/whānau as a group?

Most respondents responded to this question, of note, 14 respondents skipped this question and 17 responded indicating that they didn't have family, were estranged from family, or 'didn't know'. Respondents' descriptions of impacts on family were predominantly negative.

1. Fundamental sense of being part of a family is adversely impacted

Both consumer and carer respondents described how loneliness can impact the core structures that define and hold families together and exacerbate existing family vulnerabilities.

Consumers said:

- *Reduce sense of belonging, relationships, and trust.*
- *It would have a profound effect on families maybe drifting them apart.*
- *It can tear families apart through lack of understanding, ignorance, and social supports.*
- *A lot of traditions can get lost - things that used to be celebrated together in person. Family members can begin to forget about things in that are important to other family members, as a result of lack of contact.*
- *It impacts on the strength and health of relationships. I've also found the less I see or interact with a person, the less they occupy my thoughts regardless of how close I am with them. In cases like that, I feel I can get really bad anxiety before seeing them which can make it a little awkward.*
- *Those from differing cultural backgrounds may feel isolated from their culture and/or society.*

- *Intensifies the feelings if that group is experiencing disconnection.*
- *I feel that my sense of loneliness creates a vacuum in which I live, while others live outside that vacuum (i.e. my sons). More often than not I feel isolated from my sons; the thread that connects us can be very thin when loneliness or depression is present. If I do not make an effort, I remain in my home, without connection to my family or friends. It is emotionally hard to reach out and easier to be stoic and push on alone. Therefore, the impact on my family group is that I am missing. My son's wife's family (her Mo and Fa) are outgoing and actively connected to my son, his wife, and daughter, and I feel isolated from that group. I am not invited into that family group who have dinners at my son's home. Yes, I wonder why. However, I do not allow my thoughts to wonder why or to ruminate as there is potentially no reason why.*

Consumers and carers said:

- *Loneliness can hide within families and everyone there can feel more marginalised and isolated from each other and from the community. People can lose connection with each other without realising. Families can fracture or simply lose touch. As people get older, their family may just assume or expect that feeling lonely is 'normal'. Life can just get too busy and we all forget to stop and connect with the people who are most important to us, our family.*
- *I think that life decisions and choices can have a very real effect on inter-generational feelings of shame or pride and continually subtract or add to the reputation or defamation of families, long-term. If I allow myself to wonder why, my sense of social isolation increases, and my sense of belonging diminishes, and creates a void where loneliness can creep in.*

Carers said:

- *Those around could become frustrated or intolerant of the constant “one-sided” efforts to help the person. Efforts to keep in touch/ offers of help may dry up. Family/friends may become burnt out and even resent the person.*
- *It would worry those around the person as they try to help but not really understanding what would actually be helpful, and the person unable to verbalise their needs.*
- *Families can’t always understand or assist, especially if they’re unaware. Some families shield personal problems from the outside world.*
- *People can get tired if they can’t help you.*
- *Can cause friction within the unit as you might be the only one feeling lonely and not communicate this clearly to enable people to understand and assist you.*
- *We can appear as if we don’t care/love our families, that our solo lives are more important to us than our family members lives. Family slowly disengage due to feeling neglected or insignificant. Or, family are left with impressions that we don’t require their input into our lives. Family relationships become superficial.*

One participant described how their loneliness helped to forge and strengthen family bonds; though this also came with a sense of isolation from the community outside of the family structure ‘Closer family bonds, but also difficulty socialising outside of the family/household’.

2. Everyone in the family struggles

Respondents overwhelmingly described how the experience of loneliness and its impacts can have ripple effects for the whole family including adverse impacts on family mental and physical health, increased sense of isolation and burden, disempowerment, and a range of psychosocial impacts.

Consumers said:

- *Existing loneliness can get in the way of connection, further compounding loneliness. Entire whānau struggle when any of us is struggling.*
- *Adds collective trauma. Our family feels very isolated.*
- *Not being connected to others means that my family have to deal with all my social and emotional needs - I feel sorry for the when this happens because at that stage, I am usually feeling very crappy about myself. It causes a bit of a pressure cooker at home.*
- *If one person in a household is very isolated, it can sometimes be ‘contagious’. Our family of three adults has had to make a concerted effort to reconnect and be more socially and physically active after building housebound routines during the lockdowns.*
- *Co-dependence, lack of healthy relationships and boundaries.*

- *May make them more inward looking and less likely to reach out potentially have an impact on the mental health of the rest of the family.*
- *It may impact on a family when the sufferer distances from everyone else. Depending on depth of loneliness, possible health problems could arise in other members.*
- *It may impact on the family unit, by increased family interpersonal conflict, generational conflict and generational unemployment.*



I worry that I upset my Whānau!... I can tell they feel helpless and upset and I feel so guilty and ashamed that I’m not able to connect in the ways that I wish I could.

- consumer & carer



- *Hugely. It ripples down whether one tries to keep a sunny face and a bright look. Everyone pays the price.*
- *I think they can amplify individual feelings and possibly a collective feeling of loneliness and isolation.*
- *Tensions can arise within a family when some or all of its members are feeling socially isolated. This compounds the problem at a time when providing each other with support is important.*
- *I think it makes families feel more responsible for your welfare, and that’s not right. It makes them feel obligated to take care of you.*

Consumers and carers said:

- *The group performance decreases as motivation decreases. Families, collectively, have feelings of despair.*
- *I worry that I upset my Whānau! They often express that they don’t feel “enough” and that they feel guilty and upset that I can’t be happy. I can tell they feel helpless and upset and I feel so guilty and ashamed that I’m not able to connect in the ways that I wish I could. Loneliness causes a new sense of isolation separate to the original form. It’s isolating for both the person feeling lonely, and the person who wishes they could help them to feel less lonely again. It’s an exhausting and painful situation for everyone involved. Often causing further isolation when misunderstandings arise, as they understandably could!*

- *I feel experiences of loneliness can impact on families by: contributing towards addiction and then increased financial, relationship problems; relationship breakdowns due to mental illness; increased domestic violence - one family member being left to do all the caring causing resentment and exclusion from others.*
- *Draining and sometimes have no answers- impact other family members mental / emotional / psychological health- increases worry- increases fear of ? suicidality- feelings of helplessness- have to give up sometimes as if 'someone won't help themselves' - ? how can I help them.- acceptance that this is the way of life for their loved one - ? acceptance as not aware of where to get help / support.*
- *Confusion, lack of understanding, sadness, helplessness, stress. Needing to take leave from work to provide support and care, reducing incomes.*
- *Put strain on family relationships. Cause disconnection. Cause disharmony. Lead to negativity between individuals.*
- *Maybe no one wants to talk about it as different family backgrounds most likely don't know how to talk about it either. Everyone has different ideas regarding loneliness & social isolation as they might not fully understand the family member reason for not interacting socially either.*
- *I think family either get closer or torn apart. I realise I need people and people don't need me.*
- *As a family member you can be shunned or excluded from family life.*
- *Everything, not even family and friends don't wanna know me. They run a mile.*

Carers said:

- *When people around me are not feeling great, that impacts me and I tend to feel worse as a result. If there are multiple people feeling down, lonely and isolated in one family, then it would potentially have an impact on the mental health of the rest of the family.*
- *It can impede authentic and positive communication between each other and the more you disengage the more isolated you can feel. Disengaging can disrupt the ability to maintain close and transparent relationships*
- *I feel experiences of loneliness or social isolation might impact on families by causing separation that we don't know how to overcome.*

3. Strain on relationships, withdrawal, and exclusion by family

Respondents described in detail how the struggles that families experience can manifest as strain and conflict between family members, families not understanding or feeling unable to help the person overcome their loneliness, which can lead to silencing conversations about loneliness, families withdrawing from the person or excluding the person from many aspects of family life in order to cope.

Consumers said:

- *They probably grow tired of me and can't/don't want to have me around. I may seem like a burden.*
- *They become numb and ignore you.*
- *My family is divided between those who "understand" and those who don't about living as a single person with issues. Those who don't, have no idea of how hard I work to be the best I can.*
- *Families feel they cannot talk about their loved one who is experiencing this condition and they themselves are isolated.*

Families either get closer or torn apart
- consumer

- *Hard to relate to other family members who don't feel socially isolated or have an experience of illness, mental health or other. Lonely people in a family often find other lonely people – which can be supportive or negative depending on individual mindset. Families can get frustrated and not know what to do to support their loved one or think they can just snap out of it.*

Consumers and carers said:

- *Everyone picks up on something not being right. It's vicious.*
- *You notice the other person is acting different but often when you try to support them they are too far inside the hurt for you to bring them out. They then need to do the work themselves to get out the other side (reflection). Their behaviour then impacts the event/gathering when others who don't understand mental health challenges get upset at their changed behaviour or open sadness which results in them trying to force them to join in. This only makes them feel more isolated and alone. Then often harsh words are shared or said under the breath that cannot be taken back. It is a loop for exasperating the loneliness and isolation.*
- *It depends on the family's culture and beliefs in this area. To some family, they may not like talking about it and that will become a barrier to communications and worsen the situation.*
- *Debilitating process. People get sick of you and your sorrow so quickly. Stop listening. Stop caring. Think you are being self-centred and pathetic.*
- *If families can't grasp the real reason why a loved one feels lonely or is isolating themselves, there could be conflict within the group. If these lead to arguments, the family member will withdraw further and isolate more.*

Carers said:

- *The never ending story. Everyone picks up on something not being right. It's vicious.*
- *Everyone including your family step away because they don't know how to approach him... well I'd say there was no handbook given to me on how to deal with any of it you just have to be there and go with it but nope... the impact of friends & family giving no support brought anger!*
- *Fragmented and splintered. Builds resentment and opens up potential of harm occurring. Families and Whānau cease to thrive and flourish*

4. The person withdraws from family

Respondents also described how they withdraw emotionally and physically from their families in order to cope with the impacts of loneliness on them and their families.

Consumers said:

- *Lonely person can push those close to them further away.*
- *It can make families feel like the person experiencing the loneliness of social isolation doesn't care or love them but that isn't always true; sometimes they're just struggling and might push you away but try not to take it personally.*
- *I think if you have a family, you can support each other and check in but if you have a dysfunctional family i.e., abuse, neglect or DV, it would be impossible not to experience loneliness or isolation. It would be the worst thing and I would want to know how to get out. Alternatively, you could feel a burden on your family and try to cover it up. It could make you go down into the rabbit hole even further.*
- *It creates a barrier and makes you more cut off from your informal supports.*
- *Loneliness or social isolation could lead to someone feeling disconnected to their family and not wanting to engage with their family. Loneliness or social isolation could lead to anxiety therefore it's easier to stay at home instead of socialising with family.*

Consumers and carers said:

- *People tend to withdraw when lonely.*
- *You become resentful or negative towards others, and don't want to connect or contribute meaningfully.*
- *Losing interest in everyday activities, not joining in. It is overwhelming to socialise, missing out on family get-togethers. Lacking communication skills, making it hard to be approached. Not being there for others. Not reliable. Not functioning with everyday life.*

Carers said:

- *It can impede authentic and positive communication between each other and the more you disengage the more isolated you can feel. Disengaging can disrupt the ability to maintain close and transparent relationships*
- *We can appear as if we don't care/love our families, that our solo lives are more important to us than our family members lives. Family slowly disengage due to feeling neglected or insignificant. Or, family are left with impressions that we don't require their input into our lives. Family relationships become superficial.*

5. Impacts on Children

Some consumer respondents described particular concerns they held about how their own sense of loneliness impacted their children; guilt was a prominently expressed feeling.

Consumers said:

- *Families need a village to raise children. The children of a family which is isolated will find integration into the wider community difficult.*
- *Big impact. You're not spending time with them. And they don't see you as your happy self.*
- *There is limited socialisation and attachment for children, with impacts rippling throughout later life.*

Consumers and carers said:

- *I feel guilty that so became a parent, as my lack of social life is now my child's lack of one. I see people having play dates and my heart hurts for my son.*
- *Loneliness and family isolation could affect young children in the family as they are not connecting with people within their own age group, therefore not developing their social skills within friendship groups. It could affect parents because they are not connecting with other parents who may be experiencing similar anxieties in bringing up children.*

6. Families/Whānau can help overcome loneliness

Some carers spoke of the need for families/Whānau at times of loneliness and how family relationships and connections are important.

- *If you are with your family you won't feel so lonely. If you are isolated and lonely you need your family and friends and community.*
- *I have a close connection with some of my family (enough) and we can clarify things even when we are not happy with each other (most of the time)*
- *Families can help each other by sticking together.*
- *I think if you're family relationships are good, then it's probably sufficient to stave off loneliness.*



Support to find places to reach out to and connect with...

What do you think would help overcome loneliness?

Q6 What do you think would help people with lived experience of mental distress or mental ill-health overcome loneliness?

Respondents offered many practical suggestions about what would help people to overcome loneliness; most being directed to the individual, such as self-care strategies, regular follow-up and check-in with others, connecting with group programs. Some comments called for improving understanding and acceptance and addressing social exclusion and stigma; contact with others with lived experience was noted by several respondents. A few mentioned formal clinical support providers, with most emphasising interpersonal and social solutions, or addressing underlying causes of loneliness. Again, several provided messages of hope to others. One carer highlighted the importance of a no one-size-fits-all approach 'I think we need to be careful to explore people's experiences and desires, as the area is quite complex. Loneliness itself is a very complex social phenomenon, and there is no uniformity at all to people's experiences of mental illness. Exploring what people need in terms of their connections to self, family, community, nature and country'.

1. Lived experience support

Respondents described links with people who are like minded, or have lived/living experience of loneliness, people who understand and get what it is like to be lonely.

Consumers said:

- Lived experience communities, community spaces facilitated by peers, support to build strong reciprocal networks of support with people who understand and or share their experiences.
- Surround themselves and make friends with other people with mental distress or mental ill-health. Who better to understand loneliness than ones who are lonely themselves.

- More lived experience given the chance to share their stories to help others who were in the same position before



Who better to understand loneliness than ones who are lonely themselves.

- consumer



Consumers and carers said:

- A warm line.
- Perhaps an outreach program to check in with people who identify as being lonely. It could involve having an online support group and accessing funding to have a venue or mobile van to set up tables and chairs for coffee and chat and possibly some simple activities or guest speakers that people with mental health can relate to. But it needs to be done in a way that doesn't feel tokenistic. Have it led by lived experience mentors and involve them in the design with people who identify themselves as lonely.

Carers said:

- To be able to use their living experience to help others. This is what I do....and this helps my energy levels and I get the contact with others. So I am not isolated and neither are they for that period of time I am with them.
- Free activities where people feeling lonely can just meet up together and spend time together. This can be offered by a specific organisation or the local council. Identify opportunities to meet up and interact with less judgmental people.

- *Being supported to find places to reach out to and to connect with, and for that support to continue until the person with lived experience feels that they have made connections they can trust*
- *Join others in the same position. Support groups. Social groups.*
- *Having communication with others who have had similar lived experiences (might need facilitation by someone objective)*
- *Communication with other people within the Lived Experience Community. An understanding that their situation is not unique. An ability to help others as well as ourselves.*
- *People need to find other people who experience similar things and can understand. Joining some sort of group that you can relate to.*
- *Knowing options that can help connect people to others, to community etc in ways that are safe for them, on their terms and have meaning to them. Having someone who knows what it feels like to live it to walk alongside them - connecting with others who have lived experience of loneliness and mental health challenges so they feel safe and not judged. Having access to opportunities that anyone else would have.*

2. Acceptance and inclusion

Respondents described the need to accept and include people the way they are, to break down the stigma and discrimination and move towards normalisation.

Consumers said:

- *CHIME: connection, hope, a sense of identity, meaning and purpose, and feeling empowered.*
- *For us to be seen as valuable members of society with something to offer.*

Consumers and carers said:

- *Less stigma.*
- *Accepting them as they are and what they are going through.*
- *We have to break the generally held perception that mental health conditions are a sign of weakness and an unwillingness to just get over it. I long for the day when loneliness, depression, anxiety are seen in the same way cancer, asthma or a broken leg are seen.*

Carers said:

- *More compassion & kindness.*
- *Empathy. Support to ensure that any treatment plans can be implemented, including social prescribing.de-stigmatisation.*
- *A serious normalisation of mental health conditions in general. We have to break the generally held perception that mental health conditions are a sign*

of weakness and an unwillingness to just get over it. I long for the day when loneliness, depression, anxiety are seen in the same way cancer, asthma or a broken leg are seen.

- *Society needs to change too. Discrimination is real - racism, transphobia etc. My trans son experienced school, work and community bullying and discrimination which led to much mental distress and loneliness. If he lived in a different world of acceptance he would thrive and be able to be himself safely.*
- *Accepting them as they are and what they are going through. Continue to offer to include them in normal events. Accept what they feel they need and give them unconditional love.*



For us to be seen as valuable members of society with something to offer.

- consumer



3. More community spaces that promote meaningful individual and group connection

Many respondents identified the need for community spaces where like-minded people can come together and build connections and social supports.

Consumers said:

- *We need more shared community spaces for people that have experienced serious mental illness. Such as places like Toi Ora, or other community art spaces. If you don't have anywhere to go or anywhere that you feel welcome, it exacerbates loneliness.*
- *I would love drop-in centres where you can go for coffee catch ups or activities like games/crosswords, guest speakers, etc, interactive safe places to drop-in...People reaching out before you have the full breakdown.*
- *More community places for me to go where people 'drop in' to be around others.*
- *Ensuring a sense of connection. Not working alone as well as living alone (if they do).*
- *Grass roots local initiatives with funding and support from bigger govt bodies make sure the community needs are met and addressed in real ways. Digital literacy classes and training to help people connect online if they currently are unable.*
- *The Grow program is very helpful for people experiencing mental distress or loneliness.*
- *Education around the impact of loneliness on the brain, workshops on how to build real life connections*

(e.g., groups), practicing self-kindness, taking a break from social media (which can warp our perception of social norms), and try something new (attend a new place, join a group).

Consumers and carers said:

- *Create more meaningful community connections that aren't just about a service or worker 'taking the person out for a coffee'. 'Clienthood' can make people feel even more lonely. Helping people build structure in their day that is purposeful. Improved employment options and volunteering options for people to give them purpose, a sense of being valued and contribution.*
- *Keep trying to push yourself out into the community. Work, volunteer, keep in touch with family and friends. Don't give up on yourself.*
- *Safe spaces where the shame is not a party to the process.*
- *Having places of connection in our community. Community houses and interest groups, affordable creative classes where people can meet and connect.*
- *Organised interest groups. Meeting people with shared interests and life experience. But it needs to be organised/orchestrated by a competent person.*
- *Support groups not focused on clinical diagnosis but sharing and learning.*



Safe spaces where the shame is not a party to the process.

- consumer & carer



Carers said:

- *More funding for groups where people can be themselves and have some fun! Fun and laughter break down the barriers and help us feel good about ourselves and connect with others*
- *Free activities where people feeling lonely can just meet up together and spend time together. This can be offered by a specific organisation or the local council*
- *Joining a professionally organised mental health support group such as Grow. Grow's structured groups promote personal growth and provides information on how to cope with mental health issues and loneliness. They place emphasis on friendship as they promote follow-up calls to participants, during the week, following a meeting.*
- *Groups such as ours: Inner South Family and Friends - where relationships can be fostered over a long period are enormously beneficial.*

4. Improved understanding and education

Some respondents described having more understanding of what loneliness is, what can make you feel lonely and what the underlying causes of loneliness might be.

Consumers said:

- *Need to enjoy our own company more, be content with the simple things in life, and society to stop emphasising the need of groups, couples, friendships and looking for others approval and connection. If we stop emphasising being alone as something abnormal and undesirable, it may curve the need for dependence and connection.*

Consumers and carers said:

- *Understanding how important it is to be around other people even if you don't feel like it.*
- *Loneliness isn't a fault of yours! It's a feeling that is indicative of a need that deserves to be addressed with compassion and kindness. It's not your fault! You're not broken, and you can feel connection again! You will!!! Loneliness isn't the enemy! Your brain is trying hard to guide you towards feelings of safeness and acceptance! There's nothing wrong with wanting those things! It may linger around for a while, and that really hurts! However, please know it can, and it will pass! You will get through this! I say this because your people are out there! And they will love you for you! Anyone who treats you as anything less than the amazing person you are, they aren't your people! Kia Kaha! [be strong].*

Carers said:

- *Tapping into the individual meaning of loneliness to them. Unpacking the effects and flipping it over to look at preventions. identifying skills and traits they already have, highlighting strengths, creating a plan to refer back to.*
- *Recognise what's making you lonely and take the necessary steps to help the feelings of loneliness subside. It would be great if there was a therapy group or life coach or a mentor who could show you that others are feeling like you to.*
- *Knowing that sometimes it is an internal state. Knowing you aren't the only one feeling it. Having a purpose, getting together with others in the same situation.*

5. Help from others

Some respondents described overcoming loneliness by receiving help from others. This could be a regular check-in, or more formal professional support options.

Consumers said:

- *Having some-one who can check in with the person on a regular basis and try to encourage interaction with society.*
- *Check in with medical professionals on a regular basis even if through telehealth.*

- *For me the best thing I have done is being involved in church.*
- *Have supports available to attend alongside person, not speak for or do things for, totally, but to prompt, remind and give a friendly nudge in the right direction.*

Consumers and carers said:

- *Seek professional help early. Get a good sleep routine. Reach out to someone who understands and is not judgmental. Have someone check-in on them.*
- *Trauma work that promotes reconnection to self and others through recognition of healthy adaptation techniques to historical experiences of exclusion and othering. Peer support that has extensive training in relationally based approaches like IPS. Creating emotionally safe language and approaches to treatment. More group work that is centred around building relationships. Better parenting information on how to support children in families.*

Carers said:

- *Ongoing and regular support by a counsellor or wellness centre*
- *They need others to help them. Especially people who have severe and chronic mental illness. A case manager for life. It is very difficult, for people with a mental illness are often not easy to be around and find it hard to keep friends. Some people thrive in clubhouse situations, but others cannot bear the noise or activity....With my son who has severe and chronic schizophrenia, it is very hard to get it right. His only 'friends' are at a coffee shop.*
- *Speaking to their GP and asking for help...Having a public health nurse and/or community worker in the community who can identify persons who are socially isolated and at risk and to provide home visits to make isolated persons aware of supports and resources and to monitor these persons physical and mental wellbeing and living conditions*
- *One carer commented on the need for 'sharing information between the person's health team professionals so that all are on the same page'.*

6. Close relationships of safety, trust and intimacy

Some respondents described the need for close relationships that support them to feel safe would support them to overcome loneliness.

One consumer said *'For me it would be having a romantic partner/boyfriend as have been single for a long time and I truly miss the intimacy of having someone special. That for me would help so much. The rest would be for friends to be more empathetic to being single, and that can only come with understanding. And that's down to you, the lonely person, to explain which is hard as is admitting your vulnerability.'*

Carers said:

- *A person that they feel safe with and trust, being there for them, with them and willing to explore different activities that the person feeling lonely may connect with*
- *Profound Faith. Another wonderful husband. NOT time. Kindness & Gentleness. Paying attention, not platitudes. Cuddles. Tender Loving Care*

7. Self-care, skills and persistence

A number of consumer and carer respondents identified self-care strategies, although motivation and energy to implement these can be difficult, sometimes small steps can help bring you out of loneliness.

Consumers said:

- *Exercise, have good nutrition and practice being grateful daily. Meditation and relation will also help.*
- *There are heaps of online courses, some are free! Like Futurelearn. Take action! Don't remain passive and become disconnected from life. If one door closes, try another. Believe in yourself and your abilities. You deserve a fulfilling life like everyone else. Keep going. Be persistent.*

Consumers and carers said:

- *You have to overcome the motivation barrier first.*
- *Make short term plans, small steps, to socialise. List some things you enjoy doing.*
- *I'm not sure you can ever overcome it, but you can walk with it. You know how to, when you are really low you know how to deal with it, but you don't. We need to talk more, but I'm not too sure because, when I'm in that place of loneliness, I have been there before, but I have no energy to get back to where I was before. And that makes it worse, because I don't reach out, and then I physically can't reach out. And my thoughts go round like rats in your head.*

Carers said:

- *Tapping into the individual meaning of loneliness to them. Unpacking the effects and flipping it over to look at preventions. Identifying skills and traits they already have, highlighting strengths, creating a plan to refer back to.*
- *It is important for individuals dealing with social isolation to have self-care strategies.*
- *Teaching people how to breathe and use mindfulness and meditation to cope with issues of social isolation and loneliness and appreciate their own company and feel easy in themselves so as to be alone rather than to be lonely.*

Two carers mentioned social prescribing to support overcoming loneliness.



Acknowledge and validate feelings...

What can psychiatrists do to help people reduce their sense of loneliness?

Q7 What can psychiatrists do to help people reduce their sense of loneliness?

Both consumer and carer responses to this question centred around clear recommendations to listen to the person, validate the person's experiences, and refer them to supports, though they were not always in agreement about what actions psychiatrists should take. Of note, 26 consumers and 9 carers said psychiatrists had no role to play, or they didn't know what psychiatrists could do. Some respondents felt harmed by their interactions with psychiatrists or felt that psychiatrists did not have sufficient empathy or understanding of loneliness as experienced by the person or their family/carer, whilst others felt loneliness needed more than a 'clinical' or 'medical' response. The remaining respondents suggested many actions at the individual and systems level that psychiatrists could take to help the person to overcome loneliness. Some made several suggestions, as the following example demonstrates:

Listen to them. Stop viewing their loneliness as a symptom of psychiatric illness and acknowledge the broader social issues. I'm not lonely because I have a psychiatric diagnosis. I'm lonely because of stigma and a society that doesn't care. Stop telling me to join a group and work on myself. Start advocating for social change. Psychiatrists need to be authentic and genuine in their therapeutic relationship with us.

1. Listen, ask about loneliness, normalise and validate the person's experience of loneliness

Many respondents highlighted their need for psychiatrists to listen to their experiences, to enquire about loneliness and to understand them.

Consumers said:

- Really connect with clients.

- Explore what triggers the sense of loneliness and address those circumstances.
- Acknowledge and validate feelings.
- Get out of their "head", feel with their heart, and show their own vulnerabilities openly to everyone.
- If we stop emphasising being alone as something abnormal and undesirable.

Consumers and carers said:

- *I think that sometimes feelings of loneliness aren't truly indicative of people being alone...sometimes just feeling heard and understood is all someone wants!*
- *I think psychiatrists could talk to their clients more and be more human.*
- *Stop typing on their keyboard. Make clear concise eye contact with the person the whole time you are speaking with them. Don't dismiss their feelings as they are real for them in that time*
- *Avoid making token suggestions about 'activities' that they could or should try. Often, people can feel more stigma in some support type environments, which then only exacerbate their sense of loneliness. Just stop and ask and listen to the person. Create a space for them to talk about their feelings of loneliness and don't brush it off quickly with suggestions and advice. You don't really know what it's like in their shoes.*
- *Listen to what they are saying, I mean really listen and think of what is not being said. Treat them with value and not as an interruption or time waster, help them to articulate their story. Reframe from the urge to be condescending and telling them what they are feeling. Do not talk above them in your gobbledegook - speak plainly and to the point, your patients are not stupid they are just not that overawed by your brilliant mind.*

- *Normalise the experience so that we don't feel so far separated from community that we feel we cannot re-join or participate.*

Carers said:

- *Listen to the person and their family/carers. Allow time.*
- *Help them to understand that this is a VERY common feeling. A lot of people walk around pretending their life is great but have strong feelings of loneliness. Knowing this helps people to reach out of their comfort zone and talk/engage with others.*

2. Don't rely on medication to fix everything

There was a consistent theme from both consumers and carers regarding their experience of psychiatrists being focused on medications and having a desire for more holistic approaches.

Consumers said:

- *Psychiatrists could stop drugging us into a stupor.*
- *Validate and understand where the distress is coming from. Treat trauma by skilled interventions when needed...try social prescribing before drugs.*
- *Stop placing them on debilitating medication.*
- *Explain there's more than just medication available to reduce loneliness. Eg. Mindfulness, yoga etc*

Consumers and carers said:

- *Don't use medication as the first and only treatment. It may be useful and needed for a short period of time in smallest possible doses. It will not treat the cause of mental illness.*
- *Investigate the reasons why. Get to the root of the problem, rather than just medicating to mask over it.*

Carers said:

- *I don't think medication from them is that helpful, it can stigmatise the person who has low esteem anyway. They do really need to listen to their clients.*
- *Advocate better for the holistic needs of people. Not just focus on medication.*



Explain there's more than just medication available to reduce loneliness.

- consumer



- *Psychiatrists need to be aware of all of the holistic treatments and supports to help people and to be able to link them in with members of their team who can progress them to access all of the above.*
- *They shouldn't sell medication as a solution because this is misleading. Medication may be one of many things that helps, but there are pros and cons to medication - honesty.*
- *Use medication responsibly with a plan for reduction as people get help with above mentioned*

Two respondents highlighted the link that medication side effects can have on motivation and isolation.

One carer said '*Identify whether there is any side effect of medication can reduce a person's motivation to participate in activities. Encourage a person to explore other ways and interests to feel being part of the community*'

One consumer and carer said '*Stop prescribing drugs that have side effects that exclude and isolate them further. Research constantly for better treatments that actually promise a better delivery of practice and promotes wellbeing not over drugged blindness. Keep your prescription pad closed if you cannot enhance their wellbeing*'.

3. Use more humanistic and holistic approaches to care

Consumers and carers emphasised the importance of seeing the person beyond the clinical diagnosis and responding to their concerns with more human compassion.

Consumers said:

- *Look bigger than biomedical models of recovery i.e., social and spiritual recovery options need to be considered and recommended.*
- *Understand that mental illness is a social illness.*
- *Ensure the person has 'wrap around' support from services starting with social determinants.*
- *Help clients to understand that they can self soothe and how to identify where the feeling of loneliness is coming from.... Acknowledge that loneliness is painful, difficult and hard to admit. Help people to remove the idea of them being alone from their self-worth, value and image.*

Consumers and carers said:

- *Not isolate their communication to the patient-only. Have some appointments open for people close to the patient to attend with the patient so that there is an understanding of the health problem and the social problems.*

- *Psychiatrists need to stop medicalising issues that are natural and normal when persons are experiencing social isolation and loss and help people to understand all of the holistic components that feed into their physical and mental health and wellbeing and the mental health service needs to be less fragmented and more user friendly.*
- *Maybe have a bit more empathy. Work from a less clinical and more human approach. Work from a space of peer learning and support, not clinical diagnosis and tablets.*
- *Group therapies are good. Provide information for ways to combat loneliness in their local area - i.e. coffee clubs, hobbies, etc*
- *Maybe you could run group therapy for people who are single and don't have families. Because then we could meet other people like ourselves.*
- *Ensure the person is connected to something outside of the therapy room. Such as a sports team, a gardening club, gaming, something other than AOD. It's not an interest, it's an illness.*
- *Have a district list of options that are gifted for dipping in to when Tangata Whaiora are ready.*

4. Understand what supports are available and help people to connect with them

Many consumers and carers expressed a desire for psychiatrists to support them to link with services, groups, or social activities.

Consumers said:

- *Support people to connect with the community, resources, encouraging people's hobbies.*
- *Refer people to a Grow Group.*
- *I had a psychiatrist that suggested I volunteer and that they would provide a supporting reference. Later I required a supporting reference when I applied for studying and the psychiatrist again provided a supporting reference. Next, I required a referee for a job and was again provided with a reference. I would suggest positive guidance and practical support.*

Carers said:

- *They can connect their patients with other beneficial organisations.*
- *They can connect their patients with support groups and with organisations where they can become more educated about the issues confronting their family members and friends.*
- *Check in to see if they have enough support and help them to organise more.*
- *Encourage people to go outside, spend time in nature, and with other people. Eg: a group of carers can schedule a catch-up together at a cafe.*
- *Give them information as to where they can go for supports.*
- *Prompting they are not alone and encourage to join groups or learn new things.*



- Work in a system that cares about peoples' loneliness and with a team that can wrap health and social services and interventions around the person and can help that person develop connections with others in their communities.
- Provide resources and suggestions such as mental health support groups, interest groups etc. Encourage participation to such groups with follow-up interest in the person's progress. Explain the benefits of joining such groups, both from other patient's experiences and research information. Include group therapy as a prescription.
- Make sure their consumers are well-connected to any supports available in the community and have an action plan of how to combat the mental ill-health caused by loneliness and isolation.

5. Be compassionate, non-judgmental, and instill hope

Many respondents described a need for trauma-informed approaches, where psychiatrists are non-judgmental and support to consumers to feel hope for their future.

Consumers said:

- Promote that there is hope for recovery.
- Inform those they diagnose that their life isn't over when they affix a label- put it in context.
- Mine offers a safe place when I am at my worst (without judgement) and they are one of the only people that knows me. They provide me with guidance and support, and they foster my self-esteem and ability to connect with others (more authentically than I have in the past)...Offer sanctuary, guidance, and support without judgement.

Consumers and carers said:

- Establish trauma-informed, safe relationships with the people they serve. LISTEN and understand what is happening for someone, their hopes and dreams and desires beyond the symptoms and diagnosis. And understanding the referral options and linkages that might be helpful, including non-medical model supports, then working with the person to ensure a safe, warm referral occurs rather than just leaving it to the person to organise. GIVE THEM HOPE.
- Reflect compassionately - as human beings, we all experience suffering. We all want to avoid suffering, yet it is an unavoidable part of human life. This gives us a common ground to relate to one another on, human to human. Not clinician to patient. Not doctor to sick person. Stop pathologising suffering, be a caring human.
- Help people emancipate themselves from Psychiatry. Have the attitude of wanting to do themselves out of a job. And tell a story that they'd like to one day have

the person not need them at all. This would promote people connecting with their authentic self.

Carers said:

- Become more trauma aware and practice emotionally safe support in sessions. Use less othering language.
- Compassionate, non-judgmental, trauma-informed, REAL recovery focused care will help a person feel valued and heard. This would be the beginning of addressing why people have disconnected from life and community.

6. Recognise that talking about loneliness may be difficult for the person

Consumers also emphasised the need for creating safe space to talk about loneliness.

One consumer said 'Providing a safe place'.

Consumers and carers said:

- A lot of lonely people feel humiliated when informing people that they are lonely.
- Take the shame out of it and you take the self-blame out of it.



Take the shame out of it and you take the self-blame out of it.

- consumer & carer



7. Be aware of professional privilege, the clinical environment, and address power imbalance

The environment and the manner of contact with services and health professionals was also seen as a space where loneliness could be explored or silenced, depending on the health professionals' awareness of the power imbalance present in their interactions with people who seek support.

Consumers said:

- Psychiatrists are just people like anyone else, I know of some who have depression and suffer loneliness and isolation. . . But I'm not sure most can comprehend true isolation. . .like most humans, people have very little comprehension of having 'no-one'.
- Help patients to explore their options and ensuring they don't simply dismiss things in a "superior" manner. Working WITH the patient instead of TO the patient and trying to decrease the power imbalance of some of the doctor/patient relationships which

just increases the sense of separation between the individual and the world.

- Soften the way their offices and clinics appear...Make them more warm, comfortable appealing so people don't feel so alone and daunted all the time when there.

One consumer and carer said 'Create more aesthetically pleasing environments for clients and participants to come in so they are soft spaces that you can feel warmth. Use of colour, pictures, soft cushions rugs etc. Take the clinical edge off the service so people feel more comfortable attending and are likely to return to services'.

8. Help people to develop confidence and practical skills to overcome loneliness

Consumers and carers identified many practical ways that health professionals and services could help the person address loneliness.

Consumers said:

- Work on confidence and social skills to help meet people. Suggest animal companions.
- Deal with any self-worth/self-confidence issues, as well as any past trauma etc in order to deal with any discontent/core unhappiness that may be preventing them from opening up to people or causing them to self-sabotage for example. They could also help them with any specific fears or problems with communication.
- Not focus on the illness. Do a bit more therapeutic work to help us identify what we can contribute to relationships and how to engage with people.
- Check in with a message or something between appointments when they know a client lives alone and is struggling.

Consumers and carers said:

- Teach the person about friendships and how to be a good friend e.g. conversation skills, interaction skills. Explain to the person who a good friend is and who isn't. Provide a peer support person to become a friend of the person in need. Explain to the person what loneliness is and the negative effects it is having on the person.
- Giving them strategies and restoring confidence, self-acceptance so they can reach out to make connections.

Carers said:

- Find out what the barriers are to building relationships and give people skills to overcome those barriers. Coaching, goal setting, planning.
- Assist and find opportunities to push self out of comfort zone- understanding & small steps. Acknowledge and validate feelings.
- Teach the person about friendships and how to be a good friend e.g., conversation skills, interaction skills. Explain to the person who a good friend is and who isn't.

- Listen, direct to safe networks and guide people to gently accept and forgive themselves

9. Consider Peer Support Options

Many respondents touched on the importance of understanding where they are coming from, with some referencing the value of lived experience. Four respondents suggested that psychiatrists could consider peer support options as part of the treatment plan.

Consumers said:

- Ensure follow up from a range of peer services so there is connection with humans rather than a focus on what is wrong with them
- Refer to LEW [Lived Experience Workforce]

Carers said:

- Work from a space of peer learning and support, not clinical diagnosis and tablets.
- Ensure they are connected with support / peer groups.

10. Involve families/carers/Whānau

Four carers specifically described the importance of psychiatrists including families, carers, Whānau.

- Listen to the person and their family/carers.
- Incorporate family and friends (with permission) into care planning.
- Have some appointments open for people close to the patient to attend with the patient so that there is an understanding of the health problem and the social problems.
- Involve families or friends with their progress and care. Have some family group meetings if appropriate to see what might be helpful



Find out what the barriers are to building relationships and give people skills to overcome those barriers.

- carer





Teach people to communicate effectively with their loved ones...

What can psychiatrists do to help families/whānau/communities to flourish?

Q8 What can psychiatrists do to help families/whānau/communities to flourish?

Consumer responses to this question were diverse. Of the 185 who responded, only a few talked about the clinical role that psychiatrists play as part of their interactions with families; most emphasised the importance of understanding the holistic lived world of the person and their families/whānau/communities. Respondents suggested many actions at the individual and systems level that psychiatrists can take to help families/whānau/communities to flourish. Of the 90 carers who responded, many emphasised the importance of including and engaging families in care planning and therapy, a smaller number of carers suggested self-care strategies for family members, skill development, resources, reducing stigma and seeing the person in the context of their family/whānau/community. 14 carers did not see a role for psychiatrists in helping families/whānau/communities to flourish or were uncertain how they could assist.

1. Provide more whole-of-family psychoeducation and support options and see the person in the context of their family/community/whānau

Both consumers and carers highlighted the importance of instilling hope, improving mental health literacy and understanding within families, and to improve partnerships with families. Some spoke of helping families to connect and stay positively connected with one another.

Consumers said:

- *Talk with the families and encourage a positive outlook and reassurance that there can be a future for the person. Answer questions honestly and provide information with clarity and check that all have an understanding. Suggest ways the family can encourage and support the person*

but also that they themselves do not lose focus of their own dreams and expectations. Education to develop understanding and acceptance, open conversations to demystify both mental illness and psychiatry.

- *Make psychiatry approachable, understandable, less scary/strange.*
- *Helping family and loved ones to find strategies that they can use to reach out and support a person. Especially strategies that aren't smothering but just show you are there and willing.*
- *Teach people to communicate effectively with their loved ones. Teach older people about trauma and how to be a good listener.*
- *Psychiatrists could help families understand that it is not just the person feels sorry for themselves, but they may lack the skills, or are too frightened to re-engage with society.*
- *Communication and education is key. Especially in families -silence is corrosive, especially where loneliness is involved.*
- *Get in very very early - when women are pregnant, teach the parents good parenting skills and help them build good connections with their children.*
- *Fully listen to what a person is saying and don't assume that they will be okay once they leave the office. Try to look and treat the person as a whole being not just the 'illness' that they are consulting you for. Find out what can help the person with their life at the time eg hobbies/ interests, what gives them joy. Then try to find programs/ people who can assist.*
- *Treat the WHOLE family as it is never just the patient that suffers but the whole family is impacted.*

- *Involve families in the healing process, instead of treating the person as an individual.*

Consumers and carers said:

- *Demystify psychiatric illnesses. Talk to patients, families and communities. Help everyone know how to provide support and understanding to each other. Don't just give patients medication and send them on their way. All psychiatrists need to spend time talking to their patients and involve the patients support people in their treatment as much as possible. Mental illness is not something that can be dealt with in isolation.*
- *They can teach families how to actively listen and respect one another.*
- *Work with the whole family and not just one consumer. Make sure the carers are connected into supports. Help care planning that emphasises family connectedness.*
- *Look and reflect on the families / Whānau / communities and think...What can I do to help these people in a meaningful way. Remember your patient is connected to a family/ Whānau/community that is also suffering the effects of what has happened to your patient. EVERYONE SUFFERS*
- *Recognise the boundaries: their role is to support the individual and focus on their recovery. Explore with the person what their relationship with their family looks like from their perspective, as it may be a different view to that of the family. Respect the involvement/ no-involvement decision they have regarding their family after seeking to understand the reasons behind it. Understand and acknowledge the tension - families often have a different view of the person's support and treatment/recovery than the person themselves. Know appropriate referral options and linkages that might be helpful for carers/family, including non-medical model supports, then work with them to ensure a safe, warm referral occurs.*

Carers said:

- *Listen to and involve them in a person's care.*
- *Bring them together and separately and validate the feelings for everyone. Work with Peers who can help them see what else might be going on for the person at that time.*



Demystify psychiatric illnesses. Talk to patients, families and communities. Help everyone know how to provide support and understanding to each other.

- consumer & carer



- *Psychiatrists: Can seek approval for family therapy. Can have resources on what a person enjoys to do with their family and in their community. Can have a treatment plan that GP, family, specialists can incorporate.*
- *Bring the person/(s) feeling lonely together with members of their family. Give them a safe space to express their experiences and help facilitate that everyone can feel heard in this conversation.*
- *Acknowledge and understand that families are often the 'first responders' and know more than you think. There are many reasons why a person feels loneliness, and, with the person's consent, a psychiatrist/counsellor etc could find out certain triggers / behaviours that has brought about the loneliness.*
- *They can develop practises which are far more holistic and they should be including families (and friends) of their clients in discussion as to how to help their clients to heal.*

2. Raise awareness, advocate, and challenge the stigma surrounding mental ill-health.

A small number of consumers and carers suggested a larger role that psychiatrics could play in challenging the stigma associated with mental ill-health and to raise awareness of the issues and impacts of loneliness. This is a responsibility that could be demonstrated at individual, service, and community levels.

Consumers said:

- *Stop telling families that the problem is within the person with a psychiatric diagnosis and start helping families think about developing genuine connections past the label of 'disorder'. Change the way they talk about mental illness to psychological distress and help people understand that a diagnosis is just a starting place for understanding, not a problem or a burden.*
- *Raise awareness about the issue of loneliness in an attempt to reduce any shame or taboo around the issues that may be preventing lonely people from seeking help.*
- *Provide information to the government of the effects of loneliness on society. Suggest to governments that they provide more group activities to communities.*
- *Help to reduce the stigma and normalise mental health. Promote conversations within communities.*

Carers said:

- *Advocate better for the holistic needs of people.*
- *Make resources available by communicating, advocating with the community and Government who make the decisions on the types of resources required.*

3. Broaden practices beyond a clinical 'illness' focus.

Consumers and carers again stressed the importance of psychiatrists taking a more holistic focus to their delivery of care.

Consumers said:

- *Stop relying on pharmaceuticals to do their job for them.*
- *See them as a family with unique and rich dynamics and interactions, histories and layers as a family. Don't focus on the clinical negative issues all the time. Often the solutions are in seeing the person and their family as a network of relationships with a long history. Ask about their strengths too.*
- *Acknowledge the importance of wellbeing and community connections other than psychiatric and clinical treatment.*
- *By being better at seeming like approachable humans and not overly powerful doctor figures.*
- *Be people instead of experts.*

Consumers and carers said:

- *Respect and understand the horrific impact loneliness can actually have on people, and don't discount those feelings just because a person has people physically around them.*

Carers said:

- *Don't think that medication solves everything. In fact, it solves nothing and can sometimes make things worse. It can, however, be an important part of some people's recovery. But it doesn't fix things like a magic pill.*
- *Demystify psychiatric illnesses. Talk to patients, families and communities. Help everyone know how to provide support and understanding to each other. Don't just give patients medication and send them on their way. All psychiatrists need to spend time talking to their patients and involve the patients support people in their treatment as much as possible. Mental illness is not something that can be dealt with in isolation.*
- *Focus on solutions not the illness and all individuals have the ability to thrive if they feel they have value and purpose.*

4. Be a practical source of information, education, and skill development.

Several respondents identified that psychiatrists could provide practical information, community links, referrals, education, and skill development.

Consumers said:

- *Have a regularly updated resource pamphlet or website where the person can learn about local activities, groups, supports.*
- *Provide practical advice and support and realistic exercises or activities that can be done in the home or within a small group setting.*
- *Direct families and carers to helpful resources that will provide them with guidance on some of the best ways to support their loved ones.*
- *Introduce the families to others of like experience.*

Carers said:

- *Educate - skills, resources, suggestions*
- *Encourage connection with other families and communities who experience similar challenges, education supports and promote self-care.*
- *Provide more accessible and affordable assistance. Even if the psychiatrist is not able to help patients one-on-one, it is helpful if information is made available to the wider community.*

5. Partner with other mental health support providers.

A small number of consumers and carers suggests partnerships with other mental health support providers would help families, communities, whānau to flourish.

Consumers said:

- *Engage people with a lived/living experience in community services to help the person have choice and control over what services and activities the person can access.*
- *If they were more connected to community-based organisations and worked together with whole team approach to support that may have an impact.*

Carers said:

- *Can have a treatment plan that GP, family, specialists can incorporate.*
- *Keeping up to date with organisations that help target those at risk of loneliness.*

6. Psychiatrists can be more accessible and available

Three respondents who identified as both a consumer and carer highlighted the need for affordability and accessibility of psychiatrists.

- *Be accessible and affordable. No long wait lists. To be seen when you need it (within the week) or at least a phone/video chat.*
- *Be part of the community, not fly in fly out.*
- *Be less expensive & more accessible.*



Summary & Recommendations

Summary

The people who responded to this survey shared many thoughts about loneliness and what to do about it. Overall, they emphasised that:

Loneliness is a deeply personal experience, within the person and how they see themselves, and as they look out to the world around them and view their place within it.

Loneliness is hard and hidden, yet common. It's a social problem, not an individual one of being alone. It's harmful and shares space with stigma, discrimination, and shame.

Loneliness is alleviated by striving to build self-care and self-worth, and by nurturing a sense of meaning and purpose. Routinely connecting with other 'humans', nature, and pets was emphasised.

Loneliness, physical health and mental health are very interconnected, more than is realised.

Loneliness means that everyone in the family struggles. Loneliness can lead to family strain, conflict, silencing and withdrawal; family members can become closer or move further apart to cope.

There are many suggestions for ways that individuals, families, mental healthcare providers and communities can help address loneliness.

Recommendations

What communities can do:

- Build greater acceptance and inclusion in the community.
- Improve understanding and education about loneliness.
- Tackling stigma and discrimination about mental illness.
- Create more community spaces that promote meaningful connections with others.
- Nurture relationships that help people feel safety and trust and membership of the community.

What psychiatrists (and other mental health professionals) can do:

- Listen, ask about loneliness, and validate the person's experiences of loneliness. This builds the person's sense of trust and hope and helps them to address self-stigma and low self-worth associated with loneliness.
- Recognise that talking about loneliness may be difficult.
- Help people to develop confidence and practical skills to overcome loneliness.
- Use more humanistic and holistic approaches to care.
- Be compassionate, non-judgmental, and instill hope.
- Consider lived experience peer support options.
- Understand what supports are available and provide tangible support to help people to connect with them.
- Be aware of professional privilege and address power imbalance in interactions and shared environments of care to ensure safety, trust, and trauma-informed contact.
- Don't rely on medications alone to fix everything.
- Involve families, carers and whānau where possible and agreed by the person.
- Provide whole-of-family psychoeducation and support options, see the person in the context of their family, community and whānau.



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