

Understanding the links between

# Oral health & Mental Health

Lived and living experience perspectives



Lived  
Experience  
AUSTRALIA



# Acknowledgements

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We also thank the 234 consumers, carers, families and kin for their brave sharing of in-depth personal experiences to help us better understand the links between oral health and mental health. Unfortunately we couldn't include all of the comments in this report, however we hope that you can see your valuable input reflected in our findings.

***'To Sarah' who was the inspiration for this project.  
Sarah's courage and advocacy is where the idea for this project began.***

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# Introduction

Oral health has important connections to overall health and wellbeing. It impacts health-related quality of life and is implicated in the development of several physical health conditions such as cardiovascular disease, diabetes and cancer.

It also plays a central role in everyday psychosocial aspects of our lives given so much of how we connect with others is through the words and gestures that our faces (including our mouths and teeth) express to others. The relationship between oral health and mental health is bi-directional; challenges and strengths in one can impact the other and vice versa. This is because self-esteem, social interaction, stigma and other processes have significant implications for both oral health and mental health.

Lived Experience Australia (LEA) commenced this research project to better understand oral health and mental health, the interconnections and the experiences of consumers, families, carers and kin.

A lived experience co-design group was established to identify the questions to include within the survey and support synthesis of results and identification of key themes. Co-design group members included consumers, carers, families and kin with lived -living experience of oral health and mental health concerns. Two separate surveys were created, one specifically for people with personal lived experience (consumers) and one for families, carers and kin (carers).

The survey was distributed within Australia over a five-week period between November and December 2024. The main distribution methods were LEA's mailing list (2,800 subscribers) and social networks (8,000 followers).

The survey explored information sources for oral health, looking after oral health, experiences with dentists and other oral health staff, experiences of dental visits, oral health and other health concerns, experiences with mental health professionals regarding oral health, and the health system.

The survey consisted of both free-text qualitative and quantitative questions.

We deeply appreciate every experience shared with us and wanted to include all in this report. However, due to the sheer volume of responses, this wasn't possible. If you don't see your words here, please know that your voice was heard—we read every single response. We hope we have captured the essence of your experiences and that those who read this report will gain meaningful insight from the stories and perspectives you so generously shared.

## Overview of respondents

There were 234 survey responses in total including 198 consumers and 36 carers participating in the survey. In the consumer survey, in addition to identifying with lived experience as a consumer, 16% of participants (n=24 of 153) also identified as a carer of someone with mental ill-health.

## Demographics of all respondents:

- 72% (n=165) of all respondents were located in a capital city/metropolitan area, 22% (n=50) in a regional city and 5% (n=13) in a rural or remote area.
- 83% (n=145) of all respondents were between 30-69 years of age, 10% were between 18-29 years, and 6% were 70+ years of age.
- 73% (n=129) of all respondents identified as woman/female; 19% (n=34) identified as man/male; 5% (n=9) identified as non-binary; 1 used a different term and 2 preferred not to say.
- 34% (n=51) of consumers identified as LGBTIQ+.
- 62% (n=93) of consumers and 38% (n=8) of carers identified as a person with a disability.

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2. Kang J, Wu J, Aggarwal VR, Shiers D, Doran T, Palmier-Claus J. Investigating the Relationship between Oral Health and Severe Mental Illness: Analysis of NHANES 1999-2016. *Dent J (Basel)*. 2024 Jun 24;12(7):191. doi: 10.3390/dj12070191. PMID: 39056978; PMCID: PMC11276391.

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# Key Themes

There is a strong bidirectional relationship between oral health and mental health. Poor mental health can lead to neglect of oral hygiene due to lack of motivation or energy, diet and side effects from medications. In turn, poor oral health can exacerbate mental health challenges by contributing to low self-esteem, social anxiety, and stigma. Key themes throughout the report include:

## Oral Health Impacts on Wellbeing

- Poor oral health has negative effects on self-esteem and confidence, leading to social withdrawal.
- Mental health challenges (e.g., energy levels, low motivation, self-neglect) can affect oral health care routines.
- Anxiety and past traumatic experiences are barriers to dental visits.
- Stigma and discrimination can be experienced from mental health professionals regarding oral health.

## Challenges in Applying Oral Health Advice

- Many understand oral health advice but struggle with practical application.
- Financial and personal challenges hinder proper oral care.
- Need for repeated demonstrations and concerns about judgment from dental professionals.

## Barriers to Accessing Oral Health Services

- Financial constraints are a significant barrier, preventing access to dental care, leading to worsening conditions.
- Difficulty maintaining daily oral care due to mental health impacts.
- Medication side effects (e.g., dry mouth) negatively impacting oral health.
- Stigma, judgment, and negative experiences with dental professionals.
- Past traumatic experiences with dentists and feelings of shame about oral health deterred many from seeking care.

- Limited affordability, with only a small fraction able to afford dental care.
- Public dental services perceived as rushed and focused on emergency care, while private services were reported to offer better experiences but were often unaffordable.

## Prioritising Oral Health

- Strong belief from almost all respondents that oral health should be prioritised in healthcare (e.g., included in Medicare).
- Need for compassionate and patient-centered dental care.
- Calls for mental health awareness and trauma informed care training for dental professionals and staff.

## Trauma-Informed Oral Health Care

- Importance of empathy, communication, and non-judgmental attitudes.
- Need for transparent fees, timely appointments, and a supportive environment.
- Suggestions for calming environments (e.g., gentle music, acknowledgment of anxiety).

***“When my mental health is under duress, I cannot brush my teeth at all.”***

***- Consumer***

***“It just adds to all the shame I already live with. My teeth are just one more reason to feel like I’m [worthless].”***

***- Consumer***



# Oral Health Information and Knowledge

## Sources of Oral Health Knowledge and Trusted Information

Over half of consumers (57%) reported learning about oral health from their dentist, while one-third (32%) stated that no one had provided them with this information. When looking for trusted oral health information, two-thirds (64%) of consumers turned to their dentist, while nearly one-third (29%) relied on Google or the internet. Other sources of information included Indigenous health services, dental hospitals, allied health services, and social media.

Carers reported similar trends, with most (70%), relying on a dentist and 40% using the internet for trusted oral health information.

## Understanding the Link Between Oral and Physical Health

More than half of consumers (52%) felt they did not have enough information about the connection between oral health and other physical health issues, while only 32% believed they did, and the remainder (16%) were unsure. Carers reflected similar concerns, with 59% indicating a lack of knowledge.

Of the 46 consumers who provided further comments, 12 said they had no knowledge of the links between oral and physical health, citing failure of health professionals to inform them or not recalling if they were informed due to their mental health status at the time.

*It's not something that I've ever really had discussions about. Well, if I have, I don't really recall them.*

*I don't really know. I don't want to know because I'm worried about what it might mean. It's overwhelming and just makes me feel worse.*

*I go for yearly check-ups, but I don't know any other physical stuff that happens. All my dentist does is cleans and fillings.*

Most consumers said they knew very general information about links between oral health and other health issues; some cited more detailed knowledge. What they all had in common was that virtually all had done their own homework to

improve their knowledge rather than it coming from health professionals. Some cited general knowledge about links with cardiac disease and blood infections, and others described further layers of knowledge about impact cycles, for example, between oral health, motivation and self-care, changed diet and decline in nutrition, leading to physical health problems in the longer term, which further impacts on mental health. Carers highlighted that the links between oral health and physical health had not been explained to them or that the person they care for did not want to know about the issues.

*I have worked in health and found most people do not know the links between mental health and dental health (both regarding how dental health can impact on their engagement in society and sense of wellbeing, as well as how a decline in dental health results in poorer nutrition which impacts on brain health).*

*I did a bunch of research because I know dental work is a major trigger for my CPTSD as a sexual abuse survivor and I wanted to work on my coping skills. It's always going to be awful but having the knowledge really does help/having some resources to give the dental office.*

*I know that in the depths of my mental health challenges, oral hygiene was probably the lowest ranked due to competing priorities of trying to sustain/maintain my relative level of mental wellbeing including suicidal crisis. Whilst not directly related to my spiral of mental ill-health, my multiple abscess and teeth that required removal costs where a huge contributor to my financial burden that played a role in my overall distress.*

## Discussions with Dentists on Oral and Dietary Health

Among consumers who visited a dentist, 59% reported that their dentist had discussed ways to improve their oral and dietary health, while 35% said they had not received such guidance. Only a small number (2 participants) described their dentist as being proactive in providing practical and detailed advice:

*They discuss it with me without me asking. E.g. you could floss better...this is how. You might benefit from an electric toothbrush...can you afford one?*

*I always have my teeth and gums cared for by the same holistic dentist, and yes, he is very efficient,*

*believing very much in educating the consumer.*

Most consumers reported that the information given was basic, often limited to brushing, flossing, and avoiding harmful habits (e.g., smoking, sugary drinks), without actionable dietary guidance.

*Only really the generic 'how to improve oral health' such as what kind of toothbrush to use and how to floss. Never anything about dietary or physical health.*

*Dental hospital went through how to brush my teeth and how much sugar to consume a day.*

*A little bit - they just recommend more brushing and flossing.*

*They told me to brush my teeth regularly and try to stop smoking and drinking so much soft drink.*

Consumer comments suggested further concerns with systems and how care was organised and delivered. Public dental services were perceived as offering only emergency care rather than preventive education, while private dentists were seen as more informative.

*Yes, but only when I could afford to pay for a dentist. Dental schools and free government dentists do not give you the same time, care and respect.*

*Public dentist did not explain how essential flossing is, or how they were really only doing emergency care, not preventative care.*

*As I am now working and able to pay for private dentist, they spent the time to explain flossing and high fluoride toothpaste and electronic toothbrush. They developed a care plan, with tx costs. They spoke of how black coffee discolours my teeth and to drink water right afterwards and not brush for half an hour as this would damage my enamel.*

Some respondents expressed concerns that dentists provided inconsistent advice, used a judgmental tone, or failed to consider factors like financial constraints and past trauma.

Consumers commented:

*It was unrealistic and unachievable for me, so I didn't do it. I also don't need a dentist giving me dietary advice, they often make me feel bad about myself and as someone with a history of an eating disorder that isn't fun.*

*They did but different dentists give different advice, and I am not sure who to trust.*

Carers commented:

*Yes, the dentist gave a lot of detail that was hard for me to take in since my child was shaking with anxiety and fear, so I was trying to co-regulate. The information was also geared towards neurotypical kids, not ADHD PDA kids.*

*They know what needs to happen but as a trans man they have been traumatised by the health system. With a significant CPSD history, dental work is particularly triggering let alone having stable accommodation for long enough to engage in a significant plan to address major dental issues.*

***"I did a bunch of research because I know dental work is a major major trigger for my CPTSD as a sexual abuse survivor and I wanted to work on my coping skills. It's always going to be awful but having the knowledge really does help/having some resources to give the dental office."***

***- Consumer***



One carer highlighted the ongoing relationship the person they support had with their dentist and the benefits of the dentist understanding their personal needs

*Our family has been going to this dentist since our children were young and so luckily, the son with schizophrenia trusts them. They also realise the constraints of his illness and do the best they can to inform him about his oral health. They also know that I am his carer and so discuss with me what is happening to his oral health.*

### Barriers to Applying Oral Health Advice

While 69% of consumers and 48% of carers said that the oral health advice received was understandable, many consumers struggled to apply it to their daily lives due to financial limitations or other personal challenges. Some consumers needed repeated demonstrations to reinforce learning, while others found advice unrealistic given their circumstances. Feelings of shame and judgment from dental professionals made it harder for some individuals to implement recommended oral health practices.

*It was information that I could understand but would be difficult to apply - to use the round electric toothbrush, which I could not afford.*

*It's always been provided in a way that I could understand, but I do find it difficult to apply to my daily life and haven't been given much information about that.*

*I cannot apply this advice as I now have very few teeth left. It is not tooth decay that is the problem, but gum disease caused by dry mouth and stress.*

*By continual demonstrations at each visit. I'm neurodiverse and I need information repeated several times to change my behaviour.*

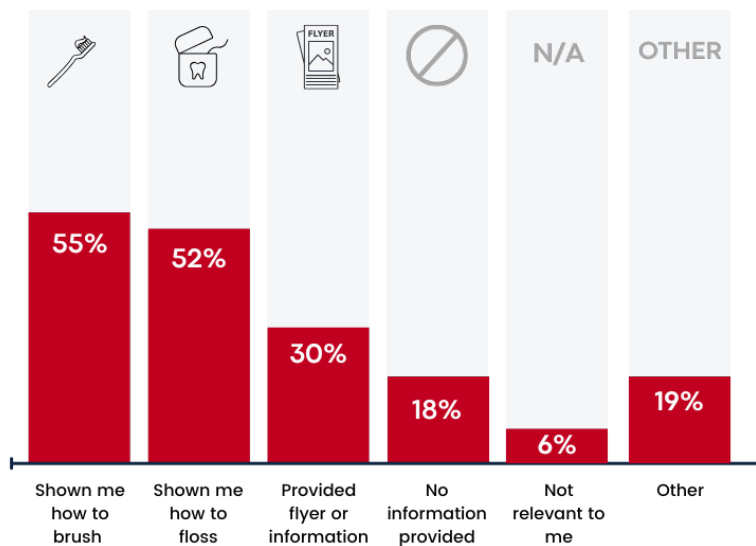
*I need realistic goals. I genuinely cannot floss every day and even the thought of it scares me. I also hate feeling judged by a dentist who doesn't understand why I find it hard.*

*They focused on my bad habits which just creates sense of shame making it less likely to implement new habits.*

*There was an assumption that things they found easy I would find easy, which was not the case. So, it couldn't be applied to my life.*

### Ways Dental Staff Provided Information

Both consumers and carers reported the most common method for delivering oral health information was demonstrating proper brushing and flossing techniques (Figure 1).



**Figure 1: How have dental staff provided information to you about looking after your oral health? (consumer survey)**

However, some noted that verbal-only advice was difficult to retain, especially for those with disabilities or cognitive challenges.

*Just verbal recommendations which is easily forgotten with my disability.*

*A few participants had more positive experiences of knowledge sharing:*

*At regular checkups with x-rays every two years explained what teeth may need more work...and why.*

*Discussed oral health matters germane to my mouth, teeth, gums, tongue and all aspects of whole-of-mouth care.*

One participant's comments indicate the importance of not assuming knowledge, of revisiting and reinforcing information over time:

*I was shown how to brush and floss when I was a teenager, but not more recently. I'm now in my 50s.*

Conversely, being mindful of how providing information was done was also important so that the person wasn't shamed or felt belittled:

*Talked to me about my teeth and oral health and how I should have done more in the past.*



*I found the tooth brushing demonstration extremely patronising, and it made me avoid going back to the dentist*

*I am phobic so I don't wish to be at the dentist for longer than necessary. I also am so anxious at the time I resent the how to prevent issues speeches and feel resentful as I honestly feel like I am being lectured.*

Four carers shared negative experiences regarding how dental staff provided information. Barriers to accessing care were a major issue, with some unable to engage with a dentist despite needing extensive treatment. Others felt that dental staff were overly critical rather than supportive. Additionally, pain and past negative experiences made it difficult for some individuals to receive necessary care, as they were too overwhelmed to engage with the process.

*Too many barriers yet to even engage with a dentist even though it's clear that a lot of work including multiple removals of teeth needs to occur*

*Presented my kid with sparkly handouts with unicorns. My son is Trans and emo. That did not go down well. He is overdue for the dentist, but I can't get him there because he's way too scared.*

*None. Just criticize for poor dental health.*

*The person I care for was being difficult as they were in pain from neglecting their teeth and were consumed with that and just wanted to get out of the 4th dentist after no joy at the previous dentists*

### Suggestions for Improving Oral Health Information

Eight-six consumers and 16 carers provided comments on what information would have been helpful. Several consumers expressed a need for more accessible and practical resources, such as video demonstrations of how to apply information, not be anxious about reading, have information explained more and revisit that information at their own convenience. Several participants spoke about wanting information earlier, to prevent oral health problem:

*Being given some of this information 15-20 years ago. This might have potentially stopped my teeth from being destroyed to the point they are now.*

*I wish I had been warned about the risks of overbrushing when I was younger. I now have very sensitive teeth.*

*If the Psychiatrist had told me about the effects of mental health drugs had on teeth.*

*Several spoke about wanting more nuanced information that was relevant to their circumstances and various mental and physical health conditions:*

*Advice for tooth health that was based around what equipment I already have (i.e., manual toothbrush) as well as easy-to-do/better-than-nothing actions to do for when in a depressive period.*

*How oral health could impact my complex PTSD and my osteoarthritis and chronic fatigue.*

*Someone to sit down, go through my medications, point out the problem areas and tips I could use to mitigate the side effects would have been helpful. Even now, thought my teeth are beyond repair, some tips to delay their complete decline would be good.*

*A small step toward better oral health rather than only getting information about the ideal way to care for my oral health which was too hard for me to manage.*

*Information is not helpful because the reasons for me struggling to care for my oral health have nothing to do with a lack of knowledge. My problem is implementing the routines due to a lack of executive function. I know what I should do, I just struggle to do it for very complex reasons. To have someone reduce my difficulties to a lack of knowledge is patronising, and it makes me avoid the dentist.*

*More time spent showing me. And showing me each time I visit.*

*I would like more mental health specialised dentists.*



*I really feel like for me specifically, more dentists/dental staff being trained on trauma (especially for sexual assault/abuse survivors) informed work would have taken a lot of the burden out of trying to go. As well as options around being able to see a female dentist.*

Sixteen carer survey participants highlighted the need for hands-on guidance from dental professionals, practical strategies for daily oral care, and alternatives when brushing isn't possible. They also sought condition-specific information (e.g., medication effects, smoking, diabetes) and more affordable dental care to enable regular check-ups. Additionally, they emphasized the importance of delivering information without shame.

*Free follow up visits at the dentist because cost is totally prohibitive and add that to reluctance and low adherence to self-care and you've got a real problem.*

*I'm inclined to say that this topic should be discussed during mental health planning, a common GP task which should look at all possible issues affecting the mental health consumer, i.e. a more holistic approach.*

*How to access cost effective dental services. Dental checkups are expensive and time consuming-this is why people put them off. Dental care that is more cost effective and provided in a calm environment would go a long way.*

## Oral Health Experiences and Challenges

### Learning and Childhood Oral Health Experiences

**Dentists as Primary Educators** – Most consumers (63%) and most carers (71%) reported learning about oral health from dentists. Caregivers were the second most common source, followed by self-learning. Some consumers also identified family, peer support workers, psychiatrists, news reports, and social media as other sources.

### **Varied Importance of Oral Health in Upbringing**

– Responses were evenly distributed with approximately one-third of consumers and one-third of carers rating high, some, and low importance being placed on oral health during childhood.

**Regular Dentist Visits During Childhood** – Around two-thirds of consumers (64%) had dentist visits in their healthcare routine growing up, while one-third

(31%) did not. Carers reported similar trends for the individuals they care for with 69% stating it did form part of their healthcare routine and 17% stating it did not.

**Access to School Dental Services** – Over half of consumers (53%) and carers (58%) indicated that they or the people they care for accessed school dental services, but a considerable proportion (42% consumers; 29% carers) did not.

**Cultural and Economic Barriers** – Some consumers highlighted cultural differences in oral health awareness before migrating to Australia.

*I grew up in China and Singapore and did not see a dentist until I was a teenager, I had cavities.*

*There was absolutely not discussion. Up to age 9 I lived in Kazakhstan where this was never a topic explored. I had no idea about foods or impacts on dental care.*

*My father immigrant from village in Calabria. Very poor. We were very poor also. School told us about brushing teeth. We told our dad.*

**Changing Oral Health Practices Over Time** – Several consumers spoke about the changing knowledge and practices over time, now compared with when they were children. Others described how brushing their teeth was an established routine, with or without the understanding of why behind it:

*Flossing was not even heard of when I was a child.*

*Toothpaste and brushes were expensive so rarely purchased.*

*Brushing twice a day was always required, but flossing was never taught as a child.*

*It was something that's always been drilled into me all my life, you brush your teeth at least twice a day.*

**Impact of Deprivation and Neglect** – Several consumers also spoke about experiences of deprivation during childhood that impacted their oral health as a child and then as an adult:

*I didn't have a toothbrush until after I left home.*

*My family took no notice of my oral health. It was only once I was looking after myself I learnt what to do.*

*No importance, often didn't own a toothbrush, did not visit a dentist until I could pay for an appointment myself. By then I had extensive oral problems.*

## Current Oral Health Experiences

Consumers were asked if they currently experience or previously experienced any challenges to looking after their oral health. Of the 141 consumers who provided comments, some cited cycles of adverse impacts from multiple challenges on multiple levels:

*Many! Dry mouth due to mental health medications. Long waiting lists to get in to see a specialist dentist through the public dental clinic, even for an emergency visit. Long waiting lists for public dental surgery, even for emergency. Financial challenges. Pain challenges. Sensory challenges. Ableism (not being listened to when describing oral ailments), etc.*

*Anxiety, Cost. Haven't seen a dentist for four years due to cost. Been on the public waiting list for two years.*

*~20 years of dental issues & trauma, including complex root canals on both sides due to facial trauma. Chronic pain while waiting 4+ years in the public dental system. Inability to afford private dental. 4+ years of Tramadol reliance due to chronic pain, resulting in losing job/unable to work, stigma etc. Now experience panic attacks when visiting dentist.*

*Living alone I don't have family or friends to provide support within medical appointments generally. This has caused me to be detained and treated against my will when I became distressed in the past. This has caused me to avoid attending non-emergency appointments over the last 4 years. Having access to a support person / advocate that I could employ to accompany me during all health and housing appointments would assist.*

*I forget to brush, have difficulty with mental health depression no shower = sometimes don't brush, unhealthy eating, eating disorder, drug and alcohol and medication issues resulting in worse teeth, I'm a fulltime carer and student, no time to care for self, can't afford treatment, dentures don't fit and dentist refused to take imprint again so only have bottom denture and stuck on waiting list. Age 43 no teeth makes it hard to get a job.*

*Dentists were physically rough and I soon correlated dentistry with pain and a loss of control. My parents resented having to PAY for a dentist. The caravan options via schools were often low standard care provision. And I recall my mother insisting a private dentist NOT use anaesthetic to reduce the fee.*

**Financial Barriers:** Cost was a major challenge for consumers, preventing regular dental visits. Long waiting lists for public dental services also meant prolonged pain and worsening conditions.

*We didn't have the money to see a dentist and I developed a lot of ongoing teeth and gums issues as a result. I am now 40 and I am still working on trying to correct some of those issues, but the cost and anxiety now seems insurmountable.*

*I couldn't afford to see a dentist so used the government Dental Scheme. You could only use it if you had pain, and they would fill the tooth or remove it. I am missing many teeth.*

Twenty-one carers experienced challenges supporting the person they care for to look after their oral health with eight citing cost and accessibility barriers, which was exacerbated with their reluctance to go to a dentist.

*Cost has been a huge barrier. Due to no dental care until an adult, then a bad experience with a public dentist, it took years to get them to be ok with going to the dentist again.*

*Finance is a huge problem for people such as my son who is on a disability pension. I am fortunate to have enough money to pay for his regular hygiene appointments. I am not well off but do without myself to make sure he can do this. There is a community dental service near us, but he only trusts the dentist he has always known.*

***“Cost has been a huge barrier. Due to no dental care until an adult, then a bad experience with a public dentist, it took years to get them to be ok with going to the dentist again.”***

***- Carer***



**Mental Health Impacts:** Depression, anxiety, addiction, and trauma were significant barriers to oral care with several describing longitudinal adverse impacts of delayed or absent oral health care.

*When I am struggling with my mental health, I am also struggling with my self-care; this includes oral care.*

*When my mental health is under duress, I cannot brush my teeth at all - I am in that situation now. I was also dependent on substances, stimulants for much of my life so there is significant damage to my teeth.*

*Looking after my oral health takes too much mental energy during depressive periods...there's just no motivation.*

*The combination of OCD and ADHD mean that I often avoid brushing because it takes so much effort to start but then I can't stop.*

*When I'm struggling mentally, I find it hard to maintain my oral health routine, often not brushing or flossing my teeth for days at a time. I have a lot of shame over that and therefore don't want to see the dentist because I'm afraid of what they will think/say.*

*As an adult in recovery with a relative high level of health literacy, I find the shame I have about oral health remains a barrier for engaging in care. I still wait for 'crisis' before seeking help. Despite having 'gold' private health insurance, the shame and fear of having to re-tell my story remains a barrier for me just to have regular check-ups. The memory of financial duress, internalised stigma of my HIV and mental health diagnosis/challenges compound to my avoidance of seeking care.*

*During addiction I was homeless and unable to care for my teeth.*

*Mental health issues prevented me from accessing dentist as an adult, leading to loss of all teeth (a decision made for me by others) at 25. Since then, it's a constant reminder every day that my smile is not my own, how mental health has made my world so small, and how others have made big decisions for me that I might have made differently had I been capable at the time.*

***“When I am struggling with my mental health, I am also struggling with my self-care; this includes oral care.”***

***- Consumer***

*It's a huge challenge for me. I experienced child sexual abuse and the dentist is terrifying to me. A whole lot about it brings up the abuse - laying down, heavy things put on my chest, hands in my mouth, the pain. I have avoided the dentist for 25 years because it is too frightening. I wish that I could afford sleep dentistry because then I would go, but that's impossible. So, I have really bad teeth. At least four teeth are broken badly, others have holes, I get regular tooth aches. I am scared what will happen when the pain gets too bad.*

*Years of alcoholic drinking had a huge impact on oral health, direct cause of serious dental problems... From ages 17 to early 40s, I didn't have a dental check-up at all. I used a public dental health service to have wisdom teeth removed and entered that service as an emergency case. Only since getting work in the last 3 years have I been going to a dentist regularly. (I'm now 55).*

**Medication Side Effects:** Dry mouth, teeth grinding, and tardive dyskinesia were common medication side effects that worsened oral health. Consumers also cited other challenges: experiencing sensory overload; nausea from brushing, fear of dentists (feeling trapped and triggered); difficulty brushing teeth due to physical and neurological disability; being a refugee in a war-torn country prior to Australia; being a single parent with no options for childcare during dental visits; and spending their childhood in care.

Almost half (49%) of consumers said side effects from medications or treatments for mental health in the past or currently had impacted their oral health; 26% were unsure and 20% said no.

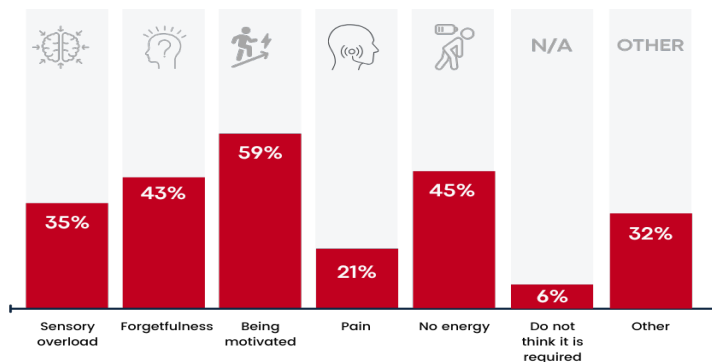
Several consumers and two carers commented on problems with dry mouth due to medications. Some mentioned teeth grinding, increased teeth sensitivity, tiredness and sleep problems that disrupted their oral health routines.

*ECT has led to me losing a number of teeth, cracked teeth and I am sure that the decades of medications have not been helpful either.*

*As I've said, my medication causes clenching and grinding. This became even worse during a recent course of TMS.*

Approximately one-third of carers said side effects from medications or treatments have impacted the oral health of the person they care for (36%, n=9) 16% (n=4) said no and 36% (n=9) were unsure.

**Self-Care Difficulties:** Over two-thirds (70%) of consumers said they had difficulty brushing their teeth each day. The main reasons for this were being motivated (59%), no energy (45%), and forgetfulness (30%). They could select more than one reason (Figure 2).



**Figure 2: Reasons for difficulty brushing teeth (consumer survey)**

Of the 36 consumers who provided comments about ‘other’ difficulties, these included problems with motivation, being homeless, disrupted or irregular sleep patterns, loss of routines and trauma induced vomiting. Some of these difficulties were described as intrinsically linked to mental health and self-worth:

*Sometimes due to family violence I drink to numb the pain. At times I forget to brush or feel too sick the next day.*

*I thought my teeth were ruined and going to get all pulled out anyway... I had no hope so what's the point, dentist gave me negative news at young age.*

*It is almost an act of self-harm at times, knowing and not doing an act of care to avoid self-care.*

*I try to brush at least once a day because I'm scared of all the decay I have. But I struggle a lot to look after my body. I think because I feel like I'm not worth it.*

A similar response was received from carers, with 84% identifying that the person they care for has difficulty brushing their teeth each day. The most common reasons identified included motivation (60%); energy (40%); forgetfulness (36%); and sensory overload (32%). Other reasons included pain, do not think it is required, intellectual disability, unstable housing or physically unable to. One carer survey respondent commented “Suffering from constant suicidal ideations which means they trivialise dental problems”.

Five carers identified barriers with selfcare for the person they care for; four identified trauma or anxiety impacting oral health and visiting a dentist two identified diet or lifestyle as barriers.

*Barrier after barrier. Oral health is expensive, scary especially for someone with mental health concerns and a significant trauma history, it's incredible triggering to have health professionals invade your private space (mouth) and to feel so powerless. As a neurodivergent person with seizures, the bright dental lights are traumatic and as a trans man who has experienced a lot of stigma and prejudice from health professionals, the thought of engaging in dental work is currently impossible. It will take finding a trusted case worker to start to unpick this and many other complex and interconnected health issues.*

*Yes. They've struggled to stop smoking and drinking soft drink excessive and to clean their teeth regularly due to a lot of anxiety and sleeping most of the time. They don't listen even though what I've said is also what many health professionals have then also said to them.*

**Drugs and Alcohol:** Drugs and alcohol were reported to impact past or current oral health by one-third of consumers (36%) and over half of carers (52%). Of the 28 consumers who provided further comments, most described the adverse impacts of alcohol use (particularly disrupting oral health routines), with others mentioning smoking, methamphetamine use, methadone, and coffee. Of the five carers who provided further comments, three identified smoking as an impact on oral health of the person they care for:

*When he is in psychosis he does not look after his teeth. He is a chain smoker, up to 50 cigarettes a day, even when stable and so his teeth become black even when brushed. He now goes three times a year to the hygienist.*

**Impact of diet:** Approximately one-third (36%) of consumers and over half of carers (60%) reported the impact (past or current) of consuming soft drinks (sugar, low sugar or sugar free) on oral health. This included decay, staining, acidity and crumbling teeth. Others said they tried to minimise consumption, and some said they drink water afterwards to minimise any adverse effects of soft drinks.



**Balancing decision making:** Participants were asked how they balance the choices or decisions they make each day that could impact their oral health (e.g. dry mouth from medication) and about the pros and cons of choices and potential impact on oral health. Comments from the 134 consumers varied with several saying they either ignore their oral health, don't think about it, muddle through, or don't prioritise it:

*Just face the day with whatever happens to my teeth.*

*Prioritise medication then eat drink what I feel I need to get through the day.*

*I don't. When you struggle with addiction and mental health each day is survival. It makes it difficult to follow up with dental care*

Several consumers indicated that they try to do what they can, given the conditions and options available to them to make positive decisions about their oral health. For some, this was described in a straightforward way (with many mentioning problems with dry mouth and drinking a lot of water), but for others the decisions were more difficult due to the complexities in their circumstances:

*Drink lots of water. Chew sugar-free gum to stimulate saliva. Ensuring mouth is not dry is important for good oral health.*

*Do what I can with the energy and knowledge I have. Also pain plays a part. Not sure it's a balance, it's just whatever I can do I'm that moment. I do attempt to brush my teeth at least once a day.*

*I try and do what I can, when I can, but it's tricky weighing up risks and benefits...I have a history of anorexia and have been doing really well in my recovery. Part of my recovery is snacking frequently throughout the day, which is much worse for your teeth than having set mealtimes. I've been told multiple times by dentists not to snack (I don't disclose my history) but disregard this advice because I know that any rules around eating could impact my recovery journey.*

*I am given no choice. The dentist says I am losing my teeth due to medications. The doctors say I have to stay on the medications and there is no option. They do not speak to each other, making me the middleman. I am forced to wait while my teeth fall out, taking medications I am opposed to, and they do nothing to help.*

*I just do my best. There are so many complex factors that get in the way of caring for my oral*

*health...my primary concern will always be for my mental health. If I have any headspace left after managing my mental health, then I can think about physical health, but there will always be complex barriers to caring for my physical health.*

Of the 19 carers that described how the person they care or balances choices that could impact their oral health, seven said they don't and two didn't know. Three said oral health was not a priority for them and three said the person they care for tries to balance decisions such as drinking more water.

*Oral health is not at the forefront of their decisions as alcohol and drugs are more important to solve their mental health issues*

*I think they find making any decisions overwhelming because they have so many different physical and mental health problems. I don't think they know where to start so they just don't do anything.*

### Hospital Experiences

Most consumers (75%) said they had never been admitted to hospital because of their oral health; 21% had been admitted, and 4% were unsure of couldn't recall. Three carers (12% 25) said the person they care for has been admitted to hospital for their oral health, with most (84%, saying they had not. A majority of consumers (88%) said they had never had their oral health attended to whilst in hospital for another health condition; only 8% said yes, and 4% were unsure or couldn't recall. Similarly, a majority of carers said the person they care for had not had their oral health attended to whilst in hospital for another health condition (88%); only 8% said yes.

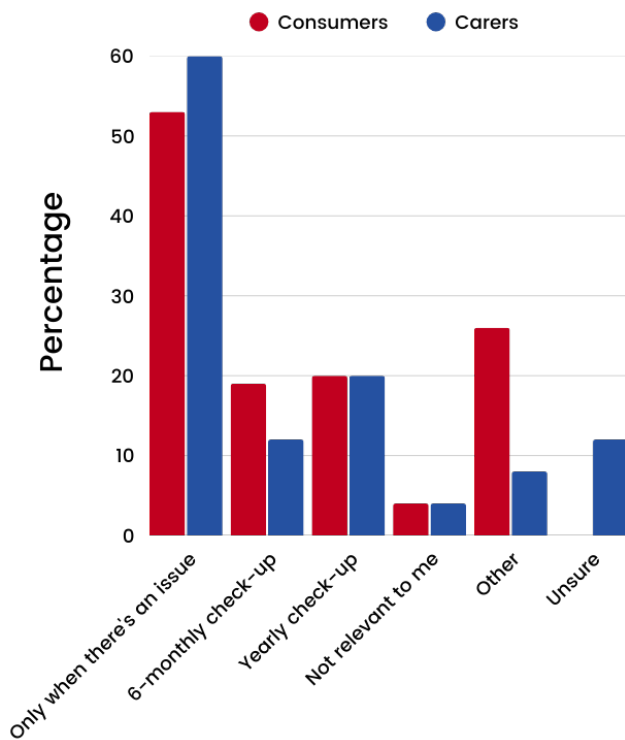
### Experiences with Pharmacists

Few consumers (18%) and carers (12.5%) said that, when collecting scripts for mental health medication, a pharmacist had discussed side effects such as dry mouth and the possible oral health impacts with them. Almost two-thirds of consumers (61%) and over half of carers (58%) said pharmacists had not discussed side effects.

# Experience of Contact with Dentists and Dental Staff

## Lifelong Dental Care and Access Patterns

Many consumers (68%) and carers (64%) reported that dental visits began in childhood. However, most consumers (53%) and carers (60%) reported dental care was only sought when they or the person they care for experienced oral health issues, rather than for routine check-ups. Far fewer, 20% of consumers and 32% of carers, reported having 6- or 12-monthly dental visits (Figure 3).



**Figure 3: Frequency of contact with dental services (consumer and carer surveys)**

Of the 44 consumers who selected 'other' their responses ranged from ignoring or avoiding them, sporadic contact, changed contact (less) as an adult compared with childhood pattern of contact, contact only when they can afford it, or contact only every few years (usually due to long wait times for public dental services):

*Regularly as a child, but irregularly and mostly only when there's an issue as an adult.*

*I tried doing the checkup thing, but I have so many health issues and it's so expensive.*

*I have an irregular history of dental treatment with large gaps between courses of treatments. Nowadays the gaps will be as long as the waiting list for public dental treatment.*

*As a child I had occasional checkups, and I went if I had pain. In my early adulthood I went every couple of years, but it just got too frightening to feel all the abuse come up every time, so I stopped going about 25 years ago.*

## Use of Dental Services

A majority of consumers (55%) use private dental services, 30% rely on public or government-funded clinics and 7% do not access any dental services. Three consumers use a combination of private and public dentists, two use a university and one uses Indigenous dental services. Among carers, 36% report that the person they care for uses a private dentist, 32% use public dental services, and 20% do not access dental care at all.

Eighty-nine consumers indicated that they had experienced free public dental services AND private dental services where they were required to pay for the service. They were then asked how these services compare in how they were treated. Comments from 89 consumers were mixed, with many only having experience of one or the other type of dental service but not both. Several consumers experienced similar problems regardless of which system they used, with general differences being increased wait times in public dental services and increased costs in private dental services. What was notable was the inconsistency in experiences across both systems, with positive experiences arising predominantly from positive non-judgmental relationships and person-centred treatment:

*I see no real difference apart from the wait time. There are ableist and ignorant individuals everywhere. There are people that judge in every aspect. The system is broken unfortunately, and the wait times are ridiculous. Sometimes in the public system I have been treated better but maybe because I see a specialist dentist.*

*The public system has been appreciated, and I feel blessed that we have it, but there was no hygiene education or cleaning of the teeth. I was treated fairly and kindly. Private is great but you do pay greatly for it.*



Both were good. Just price and waiting lists were different.

Public dental was brutal, long waits, lack of trauma informed care, unsupportive staff, traumatic experiences, long term issues not addressed only emergency, no education, sensory overwhelm. Very different in private, with most of these issues non-existent.

I found the public dental service at XXX Referral Hospital were very caring and empathetic. They went out of their way to make sure you felt comfortable and had little pain as possible. At private practices they tend to be more dismissive and lacked empathy.

Neither were safe and secure.

Private dentist is trauma informed, patient and takes time to explain. They stop and check in and don't rush. The public dentist feels like hospital everyone buzzing around and no one explaining.

Private dental services are much simpler, respectful and accommodating. I only attend public services in emergencies.

Treated worse in private system. I had a dentist joke about my weight (I'm obese). I didn't find it funny, and I had to pay a lot of money for the care. I never went back to them.

The public dental service was less judgmental and kinder than the very expensive private dentist.

I was treated better in the private system where I paid for dental services. In the free public dental service I felt like I was simply treated as a number.

I found the dentist I saw through the public clinic was more understanding in terms of my mental health impact on oral health.

Some differences were consistently apparent:

At the public clinic at the local hospital instead of saving teeth they would just extract them. The private dentist is for saving.

Public system: dentists are quick to fix immediate issue and send you away with limited to no follow up or checkups due to huge wait lists. Private: very very costly.

Of the 16 carers who provided comments regarding the comparison of private versus public dental services, many identified the increased costs of private dental services along with improved care. Three carers said the services were the same.

Private dental services have been paid for by the public system via vouchers for dental services.

The experience with private has been much better than public system. Some public dentists can be quite rude and consumers must do as they as the dentist tells them or there is no point in coming back to waste public money. Private dentist, as a rule, show more consideration for and spend more time talking about the patient about oral health care.

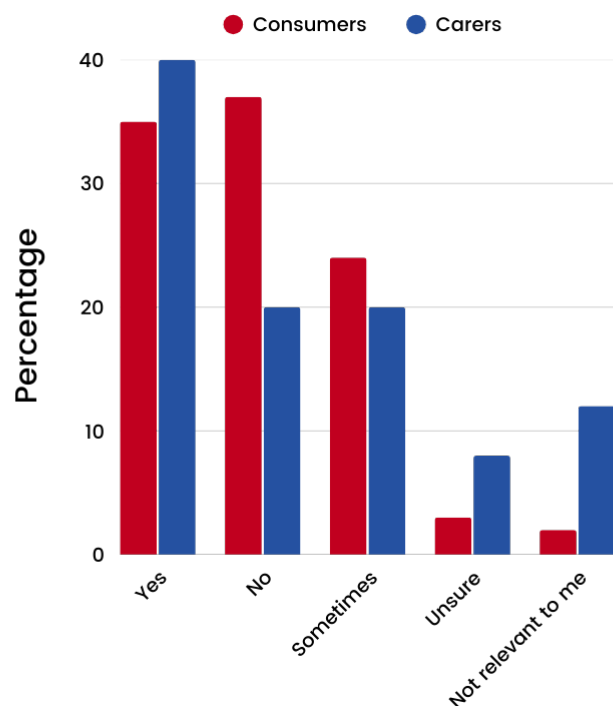
Chalk and cheese. Comfort v discomfort. No stigma at private

They current receive private dental services. They never would have been able to receive or afford the level of dental care previously if they had to rely on the public system like they did in the past. They now receive regular dental care. This didn't happen in the first 35 years of their life.

Very bad experience with a public dentist many years ago led to a life-long fear of dentists and has been hard to get them to attend appointments.

### Comfort and Communication with Dental Staff

While 67% of consumers and 56% of carers felt comfortable asking questions at dental visits, fewer (35% of consumers and 40% of carers) felt comfortable completing client information forms and talking to the dentist or dental hygienist about their mental health and medications (Figure 4).



**Figure 4: Comfort in talking with Dental Staff about Mental Health**



## Experiences of Trauma and Discrimination

Over half of consumers (56%) and more than a third of carers (37.5%) reported they, or the person they care for experienced trauma as a result of visiting the dentist.

A significant proportion (38% of consumers and 36% of carers) reported experiencing stigma or discrimination from dental staff when seeking help for their oral health, including assumptions based on socioeconomic status, mental health history, drug use, or past trauma.

Fifty-eight consumers shared personal experiences including feeling unheard or judged by dental staff, not being believed about their concerns, being belittled and the dentist being dismissive.

*I do find that I am met with some uncomfortable energy when I see a new dentist and explain my situation to them. I once stopped seeing one because she accused me of lying about being bulimic because she saw erosion on my back teeth, often associated with purging, but it was because I had habitual reflux due to an as-yet undiagnosed digestive issue.*

*I have not been believed about an open wound in my mouth down to my jaw (they said it was just an abscess) which almost turned into necrosis of the bone.*

*I had a dentist take a dislike to a supposed attitude when I was trying to tell her the pain meds she had administered weren't working. It felt like she was really rough afterwards and it's still the worst and most painful experience I've had with a dentist.*

*Socioeconomic discrimination. Looking poor.*

*There was a lot of racism back then towards pacific islander children [school dental service]. I've also experienced discrimination and racism from dentists I've visited as an adult. They've been dismissive, judgmental and you could tell that they didn't think I was going to succeed in looking after my teeth, so they didn't make any effort to show me, ask me or talk to me about my concerns about my teeth.*

*Stating that my cracked teeth, etc was not an urgent or emergency and that I would go on a wait list - which could be 3-7 years waiting... seriously????*

*When they hear the medication that caused the side effects, there is a lot of judgement about it, even just on their faces, and even though I tell them I haven't taken it for a long time.*

***“Being spoken to like I was a child when explaining the difficulties I have maintaining my oral hygiene and being told off for not looking after myself better with no understanding of the challenges I face due to my mental health conditions.”***

***- Consumer***

*Some dentists are dismissive if you have some oral health issues and are reluctant to do procedures to treat the affected tooth/teeth, preferring to simply pull out the tooth/teeth.*

*Being spoken to like I was a child when explaining the difficulties I have maintaining my oral hygiene and being told off for not looking after myself better with no understanding of the challenges I face due to my mental health conditions.*

*Definitely. Especially from gov dentists. I find them to be rude, too fast, never taking time to explain things. Feel like a number. I get massive anxiety when going to the dentist and it feels like gov dental schools or dentists don't give a hoot about my experience. It feels like they are judging me for my teeth.*

*Being treated like a child and instructions given in phrases a kid could understand. No extra info provided. I suppose infantilised expresses it best.*

*Reception staff are short tempered and talk down to me. If I need to change the time of a dental appointment reception staff are sharp & constantly put on hold for long periods.*

Consumers with an alcohol or drug history expressed particular concerns:

*I have not been believed about oral health pain and been called a drug seeker.*

*I had a public dentist refuse to treat me when they learnt I had Hepatitis C. I know this as he left after he asked me about, when I was in the chair, and I heard him say to a nurse outside he was no longer available.*

*They always think it's my fault I didn't look after my oral health better, treat me with judgement (druggo with no teeth).*

Consumers described this discrimination coming from a place of ignorance about mental health issues, and a lack of skills to work in a trauma-informed way:

*They look down on us for having bad teeth. Some don't realise it comes from our childhood where our parents never taught us, and we grew up continuing that. They also don't understand severe mental health.*

*I have felt a LOT of judgment. The dentist I saw as a child would chastise me for my poor oral hygiene, but not offer practical solutions except for the usual advice of brushing twice a day and so on. As an adult I've had similar experiences like being told by a dentist I have the teeth of a 60-year-old when I was 20. This doesn't stop me from seeking care...as I know the issue is their bedside manner and lack of professionalism. I'll simply find another dentist who knows that shame isn't a good motivator.*

*I've been laughed about when expressing my aversion to having stuff put in my mouth.*

*I have had reception staff treat me with contempt, and shouting at me, including personally denigrating me ("you need to fix your memory - I'm not here to remind you of what you can't remember") knowing I have an acquired brain injury. I have had dentists tell me I ask too many questions in an insulting manner. I have been almost in tears and feeling like walking out and not attending my appointment due to the cruel methods staff use to engage with patients, treating us like we are an inconvenience to their day, instead of the purpose they're there. My disability has been openly disclosed in front of the public waiting area without my permission, by admin/reception staff.*

Nine carers provided further comments with three identifying stigma related to mental illness, gender identity, housing situation and lifestyle choices. Three carers provided details regarding misunderstandings about sensory overload and personal struggles with self-care routines.

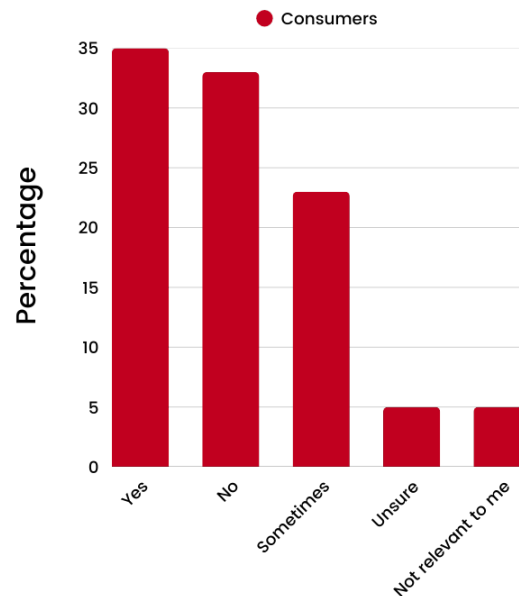
*I know at times dentists have struggled with understanding how much the person I care for struggles with teeth cleaning*

One carer commented positively, highlighting the relationship with dental staff "They know him and understand his illness. They are friendly and kind."

## Perception of Dental Care and Professionalism

Half of consumers (50%) and less than half of carers (40%) felt they or the person they care for had their oral health concerns taken seriously.

One-third of consumers (35%) said dental staff attitudes made them feel ashamed or to blame for the state of their oral health, with 23% saying sometimes, and 33% saying no (Figure 5).



**Figure 5: Feeling ashamed or to blame for their oral health status (consumer survey)**

Of the 40 consumers who made further comments, several described feeling shamed by dental staff:

*Due to my past drug use and my obesity, they can be judgmental. They would say "don't drink fizzy drinks" or "cut down on the junk food". I say "I don't drink fizzy drinks only water." They look at me with "oh yeah right" face.*

*There have been times that I felt judged by the condition of my oral health when I had poor motivation to look after it. I already felt ashamed about it but then the attitudes of some dental hygienists amplify that feeling.*

*Sometimes you get the vibe of – "If you looked after yourself properly then you wouldn't be here."*

*Some dentists in the past have been very judgmental and this has contributed to the extreme shame I feel about my teeth. In a way, I am to blame - most of my dental issues are caused by poor choices, but that doesn't make me any less worthy of care and compassion.*

*Judgement, either verbal or non-verbal but implied, due to state of teeth. I just need to try harder, apparently.*

Some consumers expressed it more as self-judgement and embarrassment shame:

*Not sure - there's little I can point to about their attitudes, but I judge myself harshly. I have felt ashamed leaving the dentist before.*

*Have felt embarrassed when explaining why I haven't brushed my teeth properly is because of mental health.*

Some consumers described how dental staff attitudes and behaviours had improved over time:

*In the past this was definitely the case. My current dentist and staff there spend more time and effort asking me if I have any concerns about my teeth.*

Some consumers described positive experiences from dental staff, though recognised that this wasn't a consistent experience:

*My general visits over my lifetime have always been positive with dentists being completely understanding.*

*Private dentist is good and tries to work a way round doing the work I can afford.*

*I don't think all dentists recognise the impact of traumatic treatment. I avoided dentists for many years after a dental procedure that caused me a lot of ongoing complications. I finally have dentist that I can discuss my oral and mental health with. I grind my teeth a lot (a byproduct of chronic anxiety) and this causes oral pain. I need a dentist that is open to conversations about mental health and oral health. In my experience not all dentists are.*

Five carers provided further comments which varied.

*Comments about teeth made loudly. Talking about the person in front of the person.*

*Not blame so much but I think they just assume that because my husband has many mental health problems that it will be inevitable that he'll have dental problems and won't follow through on changing his behaviours.*

*In respect to the person's poor oral hygiene, yes! It was relayed back to me by my son that the dentist has been harsh and said look at your filthy teeth, it's just lazy not to clean your teeth. This made him feel shame, and now he may never go back.*

*Some dentists have been very shaming, chiding them for not looking after their teeth, treating them like a child and speaking as if they are stupid or don't care.*

*I believe they are good dentists. All staff are friendly and approachable. They have known him since he was young. They are a private dental practice and are quite expensive, but I choose to pay it so that he is comfortable and well looked after.*

Some consumers and carers reported positive experiences with dental staff, particularly in private practices, where they felt understood and well cared for.

***"I don't think all dentists recognise the impact of traumatic treatment. I avoided dentists for many years after a dental procedure that caused me a lot of ongoing complications. I finally have dentist that I can discuss my oral and mental health with."***

***- Consumer***

## **Oral Health Affordability and Costs**

### Financial Burden of Dental Care

Majority of consumers (67%) pay for their own dental bills, with the remainder identifying a range of options and 2% relying on family or carers. The 22 consumers who provided further comments described a range of payment practices including: co-payments at times; a parent, sibling or adult child helping with payments sometimes; switching between private insurance and public dental service vouchers depending on funds or employment status at the time; and support from an Indigenous health service.

One third of carers said they or the family shares the payment of dental bills for the person they care for, with fewer (12%) saying the person they care for pays the bills. One carer commented on the impacts of affordability on their role as a carer:

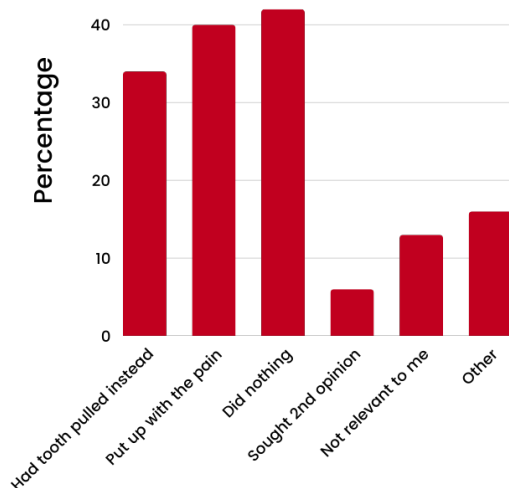
*As a carer I can only afford to see the dentist once a year myself. My oral health has suffered due to my caring role.*

### Inaccessibility of Specialist Dental Care

When consumers have needed to see a dental specialist or been referred to one by a general dentist, many (60% consumers and 58% carers) could not afford the cost with approximately one quarter (24% consumers, 25% carers) stating they or the person they care for could afford the cost for specialist dental services.

### Impact of Cost on Oral Health

When consumers could not afford a dental specialist, close to half either put up with the pain (40%), did nothing (42%) or had a tooth pulled instead (34%). They could select more than one reason. Only a small number (6%) sought a second opinion and 16% stated other reasons including waiting for public service, borrowing money from family, paying in instalments, seeking a government funded provider and accessing their superannuation (Figure 6).



**Figure 6: Response to being unable to afford specialist dental services (consumers)**

One-hundred and eighteen consumers made further comments on the cost of treatment and the impact on their oral health. Several participants said they delay treatments, limit the number of visits (including follow-up), opt for less expensive treatment options (e.g. extraction of teeth instead of having crowns), or simply don't go to the dentist. Several said they prioritised basic needs like housing, rent, and food; cost of living was a significant issue described by many, especially for the many who identified as receiving government benefits/pensions. Of note, only 8 of 118 participants said that they could afford to go to the dentist.

*Absolutely, for twenty years while raising my children and struggling with mental health, only went to public dentist for emergencies. During that time, I had 9 teeth pulled rather than saving them due to cost. Now 50 with ongoing dental issues.*

*Yes. I cannot afford to get root canals etc. Plus they are incredibly traumatic and invasive. I would rather put up with pain or an ugly toothless smile than go through the public system. Overall poor dental hygiene or bad teeth really affect my self-esteem overall. And also give me anxiety having it hanging over my head. I would love to just pay to get my mouth fixed but I could never afford it.*

*It makes it impossible to seek help. I do not have a concession card but that does not mean I don't experience financial struggles. I can't afford to seek dental supports. For 3 years I have had holes in 3 teeth and can't afford to get this fixed. Living costs are so high that we make the choice to feed our kids or have teeth looked after. I have lived in pain and feel like I have no choice.*

*Living on Disability Pension for over 20 years meant I could only access the public dentist system. They would only do emergency work. You'd get a few appointments, then have to wait at least 12 months, call back and get myself on the years long waitlist. They did no preventative care.*

Of the 19 carers who commented, almost all said the person they care for has had to make alternative choices including not getting treatment due to the cost of dental care.

*Yes. We've had to seriously think about whether to proceed with some treatments. I simply can't afford it. It's so expensive. Because of the state of my husband's teeth, it's like every tooth he has will eventually need root canal work done. It's simply untenable, especially because the problems will just keep occurring anyway.*

*Yes, it impacts us both. I know other carers who can't afford to see the dentist. This also impacts on our physical and mental health. My son is an adult he has to make his own choices but as a carer who is not on a carer's pension I really struggle.*

*He's on Centrelink. From that he has to pay child support, expensive rent, food, medication and clothing and any transport required. There's no money left for a dentist*

One carer commented that the private dentist provided affordable options so that treatment could be provided:

*No, only because the private dentist thought they needed more dental care than the public system was willing to pay for. The private dentist absorbed the extra cost of treatment. Private dentist was appalled the public system would not*

*let have a general anaesthetic for the procedure. It was done under a local, she passed several times during treatment, and it made recovery harder and longer.*

### Transparency and Communication About Costs

When asked if the costs of dental work were explained to them upfront and a way that was transparent and easy for them to understand, 42% of consumers said they had, however 31% said this occurred only sometimes and 20% said the costs hadn't been explained to them.

One-third of carers (37%) said the costs were explained to them and/or the person they care for in a transparent way that was easy to understand, 21% said no and 33% said sometimes. The remainder did not know, or it was not relevant to them.

### Dentist and Dental Clinic Staff Responses to Financial Struggles

Eighty-nine consumers provided comments about how the dentist/dental clinic staff have responded when/if they have become aware that the participant was experiencing financial issues or having trouble paying a dental bill. Some participants described the dentist as "rude" or "uninterested" or not allowing them to return for further work until their current bill had been paid. Several participants described the pressure they felt from dental staff to pay or find alternative means to pay for dental work, regardless of whether or not they could afford it. To do this, several said they paid in instalments (if it was offered), used AfterPay or similar loan process (which usually meant more debt), or accessed superannuation (if they had it):

*They don't care I'm having financial issues; they just want the bill paid.*

*For an Indigenous person, we are already pre-judged not to be able to afford this, so they really don't even pay attention or acknowledge us.*

*Sometimes compassionately, mostly no care factor.*

***"They offer a plan for both of us, but if you are on the breadline each week the plan doesn't help. The cost for dental services are way too high."***

***- Carer***

*They always say I don't have a choice, that I have to pay on the day of service or not receive treatment.*

*They just explain this is what it costs the alternative is to have it removed. That's it really.*

Some consumers described how their dentist would discuss a plan for treatment and payment options with them, clarifying priorities for what was essential or not, to help them make more informed decisions about finances:

*The private clinic was willing to offer a discount and then allow for split payment to be across the sessions rather than a bulk pay.*

*They are usually cutting the procedure to bare bones. Maybe having less painkillers as they're expensive. Putting up with more pain. Having a temporary procedure put in place until I come up with the money later with a job.*

*They created a plan of what was most pressing and to be dealt with first and spaced-out appointments based on my ability to afford them.*

Some consumers said they simply didn't raise their financial problems with the dentist because of personal shame opting to either have teeth pulled, not attending, or incurring debt:

*Too ashamed to tell them.*

*Never discussed. I just put up with the pain of the cost.*

*Never been in that position because I don't go if I can't afford and put up with it.*

*I have been ashamed to share this and have asked family for help to pay.*

One carer noted a small discount provided and another carer said a plan was offered for them, however it was still unaffordable:

*They offer a plan for both of us, but if you are on the breadline each week the plan doesn't help. The cost for dental services are way too high. I wish the government would offer a subsidy to carers on any form of Centrelink payment and the person they care for.*

Two carers noted there was no support provided:

*Do we have private cover? Why don't you sign up to this payment service we advertise for? Well, I guess you can put off this treatment, if your oral health is not important right now.*

*They've simply issued the bill and informed its payable immediately.*

# Accessing the Dentist

## Distance and Transport:

Most consumers (66%) and over half of carers (54%) did not have concerns regarding distance to the dental service or access to transport to get there. However, (32% consumers and 42% carers) found distance and transport an issue sometimes.

## Support to Attend Dental Appointments:

Consumers were asked about who supports them to attend the dentist, with many (43%) saying that they didn't need support, and 24% saying they didn't get support to attend but would like support.

Among the fifty-one consumers who received support, the primary source was family (63%), followed by carers (8%), friends (16%), NDIS workers (16%), a mental health worker (10%) or other support person (12%). Most carers (71%) reported being the main support for the person they care for.

## Role and Importance of Support:

Forty-five consumers described those who support them, their role and whether the support was helpful or not and if so, how it helped them.

Some consumers who did not have support said this would be valuable:

*I don't have any family, friends, social or community or health service supports. All people I have known decided to remove themselves from my life when they felt extremely uncomfortable with me having a brain injury and disability. I do everything alone. I need help, but NDIS have repeatedly rejected my applications.*

Some consumers described a detailed and interlinked set of supports provided by others, the following being the person's partner:

*It helps because they drive me. I don't have a licence, and I can't use public transport because I find it overwhelming to work out the steps and get paranoid on the bus too. They help listen to the dentist's instructions and help explain any things I'm having trouble with. They keep a diary for further appointments, and they pay the dentist bill too because I have not income of my own and no Centrelink because of their income.*

Almost all consumers described the support person's role, with several saying they provided practical support particularly transport to or from appointments. Many consumers described the

emotional support that others provided to them, to keep calm and help them implement coping strategies, to be a trusted person, to understand and remember the information the dentist provided:

*My hand holder and knowing I'm not alone. I have a fear of needles.*

*They talk to the dentist/me if there is a communication problem or if I go mute.*

*They assist in explaining, reminding me afterwards of what was discussed.*

*It is always good to have someone with you that you trust but not everyone does.*

*They can help keep me calmer and know the necessary strategies to ensure I don't go into a dissociative state. I suffer from situation mutism so they can speak on my behalf at times.*

*Emotional support- easier to know i am not alone in a scary process.*

*I need a lot of encouragement and moral support to book dental appointments and attend, but I don't need help once I get there.*

## Changes in Dental Experiences Over Time:

One-hundred and ten consumers explained whether or how their experience of going to the dentist has changed over time (i.e. when they were younger visiting the dentist compared to now). Fifteen consumers said there had been no change, and 1 consumer stated, "I don't remember most of my childhood". The remaining 94 consumers providing a range comments about change in dental services over time, were split approximately equally between positive and negative comments about current dental services compared to their past experiences. There was a variety of more negative current experiences:

*Younger it seemed easier and more supported and understanding. As an older adult it is far less comfortable and supportive.*

*Yes, as I've got older, I don't trust them as much as I did as a child due to the issues I've encountered.*

*I am less concerned with going regularly because I feel like I'm being taken advantage of (spending way more money than should be required).*

*It was easier when I was younger, it was organised and paid for by mum and I wasn't blamed for any dental issues.*

*More expensive.*

Of the 13 carers who provided comment, half indicated it was easier when the person they care for was younger and more difficult now.

*When a child they were good. As an adult, the public system have been more dictatorial and less caring.*

*There was no issue getting him to the dentist when he was younger. As an adult who has had bad experiences it is impossible.*

There was also a variety of positive current experiences from consumers:

*Yes, going to the dentist always meant having fewer teeth, but now I enjoy going to get my teeth cleaned and cared for.*

*Yes, not quite as scary due to new technology.*

*I have learned to meditate during procedures at the dentist, so they are nowhere near as traumatising as they were in the past.*

*Yes, I can now afford to go to a private dentist and am trying to repair years of damage and issues. I never knew about the greater health risks of poor oral hygiene, so trying to be better at looking after my teeth.*

*Dental care has improved considerably; much gentler care, and dentist now informs you of the work what needs to be done and the possible cause of the dental problem.*

*Yes. As a Child/teenager I was terrified. As an Adult, I choose the Dentist I see carefully & I ensure that I am always treated with respect.*

*Yes. Dentistry has changed. When I was a child, you were physically held down and told you were naughty while they extracted a tooth. I didn't go to the dentist until I had a toothache when I was about 35 because of this.*

One carer noted it was better now and another said their personal circumstances make the dentist more affordable to access now.

### Wait Times for Dental Appointments:

One-hundred and seventeen consumers described their experience of wait-time to get an appointment with a dentist; 64 consumers describing this positively (short or very acceptable/reasonable wait times) and 53 described this negatively (extremely long and unacceptable/unreasonable wait times).

Many consumers stated that their experience of wait times was more negative for public dental services (several months or years, except if they required emergency dental treatment which could still be several days or a few weeks' wait). Wait times for private dental services were usually much shorter (days or weeks), with several consumers describing how they still needed to ensure booking ahead to get an appointment, and some experiencing wait times of several months due to dentists' caseloads.

A small number of consumers described rural experiences specifically where they said demand was high but dental staff were few, meaning long wait times (more than a year) for general checkups, and lengthy travel time and expense experienced when required to travel to metropolitan centres to access emergency and specialist dental services.

Fourteen carers described their experience of wait-time to get an appointment with a dentist for the person they care for with many stating the wait-times are too long. Three said appointments were only quicker if it was an emergency, and two identified the need to book future appointments ahead of time. One carer commented: "12 months wait. Unbelievably the dentist was unwell on the date of the appt and now we have to wait again!!!!"

***"Yes, I can now afford to go to a private dentist and am trying to repair years of damage and issues. I never knew about the greater health risks of poor oral hygiene, so trying to be better at looking after my teeth."  
- Consumer***



# Attitudes of Dental Staff Towards Consumers with Mental Health and Alcohol and Other Drugs Issues

Ninety-five consumers and 13 carers provided comments about how the dentist/dental clinic staff behaved when/if they had become aware that they/the person they care for has a mental health condition. Twenty consumers and one carer said they didn't divulge information about mental health, or the dentist didn't ask / didn't know.

## Disclosure of Mental Health Conditions

Thirty-three consumers had positive experiences, describing dental staff as being kinder, gentler, more compassionate and reassuring, respectful, or just treating them as "normal":

*The government dental clinic a dentist was very comforting when I had a panic attack.*

*I am confident talking about my Mental Health usually I get inquisitive questions and generally understanding. I am a Peer Worker, so I have learnt that it's ok for some others to not understand.*

*In more recent visits I was treated by dental students. They were very eager to be supportive and accommodating, but they still had a lack of knowledge regarding how mental health conditions impact my ability to care for my oral health.*

*On the two occasions it was mentioned, both students treated me just as another patient really, as in it was fine.*

*I've only disclosed it once and it was the empathetic dentist previously mentioned. We'd had a few visits and I had an episode. The next time he asked if I would tell him about how my MH affects me and if he could help in any way while treating me. Legend.*

*Since I found out about my mental health issues, I've slowly introduced them to the dentist. When I do mention the dental problem and add it could have been my mental health issues, I can see they are trying to compute the information and start to ask for more information from their training.*

Five carers also had positive experiences, describing dental staff as being respectful and understanding.

*We've been lucky - the dentists he's been too have all taken it in their stride. In our experience dentists have been more understanding than some other health professionals we've seen.*

*We never disclose this. Enough stigma regarding oral health. Nothing about the experience signals that they would be understanding of mental health.*

Forty-two consumers and four carers had negative or ambiguous experiences, describing dental staff as less friendly, quieter, cautious, or more withdrawn. Consumers commented:

*Sometimes they act like it's contagious and blame it on anything they don't want to deal with. I'm autistic L2 and many think that it's a mental health condition and that adults can't be autistic, so they have no/little idea how to accommodate sensory overload.*

*Become very scared of me.*

*With some, I think they've tended to change how they talk to me, as if I'm intellectually disabled or something. It's a little bit condescending really. They're friendly enough and I know they don't mean it.*

*They become stand-offish and don't speak to me much.*

*Some dentists after learning this about me treat me like a child and will only speak to my partner instead of me.*

Carers commented:

*Lowered their voices. Whispered*

*They've been OK but sometimes I think they've talked down to my family member and deferred too much to me as if my family member isn't in the room or can't understand.*

## Disclosure of Alcohol and Drug Use

Seventy-seven consumers provided comments about how the dentist/dental clinic staff behaved when/if they have become aware that the consumer had experienced problems with alcohol and other drugs. Thirty-two consumers said NA/they didn't have problems with alcohol and other drugs, 9 said they didn't disclose and 5 said they had never been asked about their alcohol or drug use problems. Of the remaining 31 consumers, comments were mixed:



*I've brought this up quite a few times while explaining my history - my teeth are in extremely bad condition for someone my age, so I try and briefly explain how that's happened. I've never had a negative reaction, just neutral acknowledgement that it's a factor in my poor oral health.*

*I have only divulged once, and only to the treating dentist. she was extremely respectful.*

*They were actually proud of my achievements.*

*I was treated well by a receptionist when I turned up to an appointment so drunk I couldn't go ahead. She called a cab and made me another appointment. I always remember her kindness. The dental staff have the standard reaction to AOD - control your use. I have admitted to past AOD problems, and dental staff were generally supportive in the "well done" vein. Which is kind of nice, and discussion didn't go past that.*

*I felt very judged and the staff were rude.*

*I've received a lecture. In the chair is generally not the space to explore what is driving my drug misuse.*

*Not really discussed in any detail and again when mentioned no real discussion. Certainly, neither drug use or mental health has ever been discussed by private practitioners.*

Nine carers provided comments about how the dentist/dental clinic staff behaved when/if they have become aware that the person they care for had experienced problems with alcohol and other drugs. Five said it was not applicable to them, they could not comment, or they would not disclose this.

*Again, would never disclose this. Embarrassment, judgement, stigma - we feel their care of us would be negatively impacted if we disclosed this. We worry we would be looked down on (not just worry, we are sure we would be).*

Of the remaining carers, their experiences were negative:

*Felt judged as a Mum*

*Apprehensive. Probably unsure about potential reactions*

***"I don't smile in photos or in public anymore. I often talk with my hand across my mouth or with my head down."***

***- Consumer***

## Other Health and Wellbeing Impacts

Consumers and carers identified a significant connection between oral health, mental health, and overall well-being including reports of anxiety, stigma, trauma, and financial constraints preventing them from seeking treatment and leading to worsening health outcomes.

### Physical and Mental Health Conditions

Over half (58%) of consumers reported experiencing other health conditions, including respiratory conditions (43%), sleep apnoea (48%), autism (33%), cardiac conditions (29%), and diabetes (22%).

Many carers also reported the people they care for having autism (43%), respiratory conditions (35%), cardiac conditions (17%), and diabetes (9%).

### Impact of Oral Health on Wellbeing

Most consumers (73%) said oral health affected their self-esteem, self-worth, self-image and confidence. Many described this led to avoiding smiling, covering their mouth during interactions with others, feeling embarrassed in public, withdrawing from community and feeling shame and insecurity, especially if meeting new people for the first time.

*Don't smile. No confidence anymore. Limit exposure with people I don't know well.*

*My teeth look like the teeth of a poor person... there is significant stigma around teeth and oral health - it is definitely a marker of 'class' in Australia.*

*I couldn't afford to have my front tooth repaired where it had cracked in half so I felt stereotyped and disgusting and wouldn't smile and was afraid to speak less someone saw my tooth.*

*I don't smile in photos or in public anymore. I often talk with my hand across my mouth or with my head down. I stopped dating romantically because everyone always equates poor oral health with poor personal hygiene and assume I don't take personal care of myself.*

*I plan on looking for work soon for the first time in years and am worried the state of my teeth will make it harder to find employment (I know that statistically, this is true).*

*Teeth are one of the most visible things people see about each other. If you have bad teeth, others think less of you. Your confidence is always low and zero self-esteem.*

## Impact of Oral Health on Mental Health

60% of consumers reported that their oral health negatively impacted their mental health, causing stress, anxiety, shame, and depression. Over half of carers (52%) also observed mental health deterioration due to poor oral health (Figure 7).

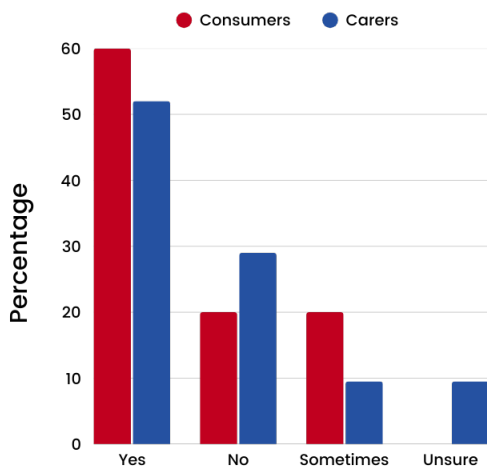


Figure 7: Oral Health Impacts on Mental Health

Consumers commented:

*I have enough trouble being perceived as it is. When I think about my oral health, my mental health takes a dive. Also, the cost of "fixing" things feeds into my financial anxieties.*

*More isolated and withdrawn, and lack of self-esteem made me more depressed and defeated.*

*Never forgotten trauma.*

*Absolutely! Anxiety (and trauma) from previous dental treatments has impacted on my seeking mental health care.*

Several consumers described impacts such as stress, shame, embarrassment, worry and anxiety, hopelessness and powerlessness. Several also described pain, clenching and grinding, and problems with sleep that then adversely impacted their ability to manage their everyday mental health.

*My clenching and grinding add to the feeling of agitation holding all the tension in my jaw.*

*When I go through periods of oral pain it impacts my mood.*

*It just adds to all the shame I already live with. My teeth are just one more reason to feel like I'm shit.*

*Hopelessness, powerlessness, increased PTSD symptoms, trouble falling and staying asleep, reduced social life, withdrawing, eating disorder, binge eating, starving.*

Five carers identified the person they care for is shy, embarrassed and their self-esteem is impacted, two commented on difficulties with eating/chewing so they avoid going out, and three identified anxiety as a result of their oral health problems.

*They have contemplated having their teeth pulled out due to the stress of dental visits and treatment. Pain and discomfort has had a massive negative impact on their mental health.*

*It's just been another thing for them to worry about on top of the many other physical health impacts of their mental health conditions. It's a vicious cycle.*

***"I have enough trouble being perceived as it is. When I think about my oral health, my mental health takes a dive."  
- Consumer***

## Impact of Mental Health on Oral Health

Almost three-quarters (71%) of consumers and 86% of carers reported that their mental health affected their oral health or the oral health of the person they care for, citing low motivation, forgetfulness, self-neglect, and trauma-related avoidance.

Consumers commented:

*Forgetfulness. Mostly depressed and don't feel am worthy and also isolated you lack the motivation.*

*I never brushed for about two years when I was very unwell.*

*Self-neglect and harming behaviours due to low self-image.*

*Had I been able to make choices when all my teeth were taken, I would have chosen differently to my mother, who made that choice for me.*

*I've had times when I've just slept most of the day and night. The anxiety and paranoia has made me smoke more and just forget to look after my teeth, not brushing them for days and weeks sometimes.*

*Because I vomit when I brush my teeth due to trauma, I only brush teeth only an empty stomach at beginning of day and if going out*

Several carers identified reduced self-care due to mental health impacting oral health care routines, one mentioned confusion or it being too hard due to mental health, one identified increased smoking when mental health is deteriorating and one carer said: “pain and suffering causes angry outbursts, lack of sleep, brings up feelings of being in a hopeless situation”.

### Barriers to Dental Care

**Anxiety:** Over half of consumers (57%) and most carers (86%) stated that anxiety was a barrier preventing them or the person they care for from visiting the dentist.

Fifty-four consumers made further comments; many describing being fearful and scared related to the cost, the uncertainty of how others may judge them, or just leaving the house:

*Fear of the experience has been paralyzing.*

*More just not wanting to leave the house, rather than a concern of how I'll be treated. Getting the chance of treatment isn't often, so you suck it up as you go back to the bottom of the list if you don't turn up.*

*I can't go without taking medication first.*

*Afraid of being told off for not caring for my teeth properly, afraid of being reclined in a chair with a person in my face and I can't escape. Afraid of the costs.*

Fear was also a common theme from the seven carers who provided further comments:

*They have worried about going and receiving bad news about their teeth.*

*It is an ongoing battle to get my daughter to the dentist. She is terrified of dentists as well as having to lean back in the chair.*

*Due to fear of the pain, stigma, cost.*

**“Afraid of being told off for not caring for my teeth properly, afraid of being reclined in a chair with a person in my face and I can't escape. Afraid of the costs.”**

**- Consumer**

**Self-Stigma:** 30% of consumers avoided the dentist due to self-stigma, feeling ashamed or fearing discrimination.

*Put off until I have felt well enough to deal with it.*

*Having to relive the trauma of explaining my mental health, physical health (including HIV diagnosis) all play a role as a barrier to consistent engagement with a dentist.*

*I don't want anyone to know and either lie or am at least dishonest about what medications I take.*

One consumer made a positive comment, resisting self-stigma:

*In fact, knowing about my mental health issues has been serving my healing journey.*

45% of carers said that self-stigma had prevented the person they care for from getting dental treatment. Two carers commented on embarrassment as a key reason for not getting dental treatment.

**Trauma:** Almost half (47%) of consumers reported avoiding dental care due to past traumatic experiences, including painful procedures and childhood dental trauma.

*When I was 19, I had a HORRIBLE dental experience. It was the first time I had gone since I was a kid...they also didn't listen to me when I said I could still feel what they were doing, so I was laying in the chair CRYING and they kept saying “you shouldn't be able to feel this.” I felt so awful, I am still working on through that trauma every time I go.*

*Terrible experiences of teeth being pulled without enough pain relief, painful injections, waking up from sedation with a dentist on my chest trying to pull a tooth.*

*Got nerve damage after an appointment, took several cries before anyone cared enough to help out. Got two wisdom teeth removed and then my blood didn't clot, face and neck swelled, fever, tachycardia which sent me to emergency for IV antibiotics and fluids.*

Several consumers related this trauma to past experiences triggered during contact with the dentist:

*Panic attack at going into the hospital and couldn't cope with the idea someone was going to stand over me for an hour.*

*I've been afraid of male dentist for a long time but improving with a female dentist.*

*The feeling of laying on my back, in a vulnerable position, unable to move or speak is really distressing to me. This has prevented me from visiting the Dentist to receive treatment many times in the past.*

*Childhood experiences have caused me to feel panic when I can't get away quickly when someone is bending over me.*

*Because of my status as a sexual abuse survivor, the entire dental experience is deeply triggering/traumatic - as is the process of having to disclose, which means that choosing to go or not go is often incredibly difficult.*

Over half of carers (59%) said that trauma had prevented the person they care for from visiting a dentist. One carer commented *"They have had a negative experience with a dentist in the past, causing an ongoing chronic dental issue"*. Other comments included:

*Need specialist trauma-informed dentists for priority populations. My friend in Holland is able to visit the public children's dentist and sit in a pirate ship during her dental appointments for this reason and it helps significantly with a hugely traumatic experience.*

*When she was young the globe from dentist light exploded.*

*When they were homeless and paranoid, it was a very traumatic time for them. They didn't trust any health services.*

*Trauma from the dental surgery itself.*

### Impact on social connections

Approximately half of consumers (49%) said that oral health has impacted their social connections and relationships with others (self-stigma, embarrassment).

Sixty consumers made further comments, with many describing embarrassment, social and community withdrawal, being excluded because of their appearance, being bullied, and avoiding interaction with others.

*I no longer seek out romantic relationships or friendships because I'm so embarrassed by my*

*teeth. Every time I meet new people, I'm worried they're looking at my teeth and judging me.*

*People treat you different because you look and talk different (teeth removed) no dentures, unsure how to treat you, stop looking you in the eyes, stop inviting you places, unable to get a job due to stigma and discrimination (judged based on looks), no longer offered same opportunities, career affected...shame, no close relationships except with children, no one will want to kiss someone toothless, assume you're a "junkie" or "druggo". Can't attend dining social functions due to struggling to eat, hence no longer invited.*

Over half of carers (55%) said that the oral health of the person they care for had impacted their social connections and relationships. Five carers provided further comments that included how the consumer experienced being put off engaging with others, social withdrawal, embarrassment, and fear of judgement from others.

### Impact on Confidence to Speak Up

One third of consumers (36%) said their oral health has impacted their confidence to speak up or communicate their needs to others, approximately half (46%) said it did and 18% said sometimes. Thirty consumers made further comments, with most describing avoidance, embarrassment and worry:

*I don't open my mouth unless I have to.*

*I'd love to belong to more groups but am not confident due to my teeth/missing teeth.*

*Afraid to talk to someone face to face or even smile or laugh in case my teeth show.*

Of the twenty-two carers who answered this question, 41% (n=9) said that the oral health of the person they care for has impacted their confidence to speak up or communicate their needs with one carer commenting: *"doesn't trust people if she feels they aren't being honest or making fun of her"*

***"The feeling of laying on my back, in a vulnerable position, unable to move or speak is really distressing to me."***

***- Consumer***

## Health Staff Understanding of Mental Health and Oral Health

Consumers were asked to rate oral health staff understanding of mental health, and mental health staff understanding of oral health. Overall, they perceived that oral health staff had a better understanding than mental health staff; however, both ratings indicated that both groups needed to improve their understanding significantly (Figure 8).

	Very negative/no understanding	Neither positive or negative/ or some understanding	Very positive/a lot of understanding	Unsure or not relevant to me	Total	Weighted Average
Oral health staff understanding of mental health	30%	39%	9%	21%	157	1.74
Mental health staff understanding of oral health	33%	36%	11%	20%	157	1.72

**Figure 8: Staff Understanding of Oral Health and Mental Health (consumer survey).**

Carers rated the same question with mixed responses. 41% said oral health staff had no understanding of mental health, 45% said some understanding and 14% said they had a lot of understanding.

When asked about mental health professionals understanding of oral health, 27% of carers said they had no understanding, 68% said some understanding and one (5%) said they had a lot of understanding.

### Discussing Impacts of Medications on Oral Health

Only 11% of consumers and 10% of carers said a psychiatrist, GP or other mental health professional had discussed potential impacts of medications on oral health with them when they or the person they care for was initially prescribed medications for their mental health

### Stigma and Discrimination in Mental Health Care

20% of consumers reported experiencing stigma or discrimination from mental health professionals (GPs, psychiatrists, mental health nurses, allied health professionals) when seeking help for their oral health. Twenty-four consumers made further comments, ranging from the topic not being raised, being ignored, being disbelieved, to being seen as a low priority:

*My oral health has never been spoken about with all mental health professionals.*

*I don't ask for help. For anything.*

*For an Indigenous person we get treated like that anyway so it's hard to try and define it.*

*When I mentioned dental issues, they just turn off.*

*They didn't believe my teeth were falling out.*

*They questioned the authenticity of my problem, minimised it and said it would have to wait until I was 'better'.*

Carers' responses were divided with one-third reporting the person they cared for experienced stigma, one-third reporting no and one-third were unsure, or it was irrelevant to them. Carers expressed that mental health professionals often did not see oral health as part of their responsibility, with comments such as:

*I don't think they felt this was their domain of expertise*

*They just didn't think it was going to make any difference to the person's overall situation. I think they didn't think the person would be able to change, that it was hopeless anyway.*

***“They questioned the authenticity of my problem, minimised it and said it would have to wait until I was ‘better’.”***

***- Consumer***



# Improving Oral Health Care

## Should Oral Health Be Given the Same Priority as Other Health Areas?

Almost all consumers (98%) and all carers (95%) said that oral health should be given the same priority as other health areas (given that oral health is not included in Medicare).

Seventy-eight consumers provided further comments, most arguing that it just made good sense for prevention, equity and future costs of care:

*Make it affordable to everyone.*

*That it is not is a tragedy for people - aside from the health impacts - the social impacts literally prevent people from living bigger and better lives.*

*I think poor oral health is a contributing factor to many social and health outcomes that costs the government a lot of money. An argument could be made a budgeting Medicare policy paradigm may reduce other Medicare health funded costs that are related consequences of poor oral health. Anything that governments can do to make a society and indeed a country more productive will ultimately benefit that country economically in the future.*

*YES!!!... It's extremely short sighted for oral health not to be prioritised, as lack of preventative care leads to physical health issues (death in some cases) which puts a huge financial strain on the healthcare system down the line.*

*My life would look VERY different if dental was covered by Medicare.*

*Creates a divide in our society and is an impediment to an equitable and just, rights-based society!!!*

***“The cost of dental treatment is the biggest barrier to seeking help and has a huge impact on physical and mental health.”***

***- Carer***

*It would have provided safety to me when I was most vulnerable.*

*It would provide an incentive for people to seek help for their teeth.*

*Absolutely! Private services are expensive, and this is prohibitive for those unemployed, who are caring for others who need oral health care. Check-ups at least should be covered by Medicare.*

*Our teeth are in our body - treating them as a separate issue is ridiculous. Imagine if someone said that all our body is covered for treatment but not our big toe - people would laugh and be up in arms. But teeth are somehow different?*

Ten carers provided further comments, also arguing that it is the same as other physical health needs and has significant impact on physical health:

*It has so many impacts on their life and other health issues. It's so important for prevention of so many other chronic conditions. It just makes sense.*

*The cost of dental treatment is the biggest barrier to seeking help and has a huge impact on physical and mental health.*

*Good dental hygiene is fundamental for self-confidence and also as preventive of any future medical issues*

## What can Government do to Improve Oral Health for Consumers, Families, Carers and Kin?

Consumers were asked what they think governments could do to improve oral health for people who experience mental health conditions. One-hundred and sixteen consumers provided comments, with several reiterating Medicare, and others emphasizing the need for more funding, improved education for dental staff and mental health staff, more information for consumers, more tailored service options, and overall improvements in affordability and accessibility:

*Having clinics go through mental health first aid training and be recognised as mental health safe clinics. Perhaps even having clinic rooms that are low stimulus for those who experience mental health conditions.*

*Safe clinics - let's have a list of dentists who have undertaken the extra training and created kinder spaces - like a rainbow tick.*

*More health promotion, education and awareness raising.*

*Sydney Local Health District- Oral Health Services is a collaborative partner in the Living Well Living*

*Longer and Centre for Cardiometabolic Health in Psychosis (ccCHiP) programs that offer oral health*

*treatment for people living with severe mental illness"...Such programs need to be made available to anybody in Australia who seeks access, rather than only people who live in a specific higher socio-economic area.*

*Have a HECS/NILS/Dental/Health loan available, so that people can obtain high quality services, and pay them off when their income reaches a certain level.*

*Make it cheaper and decrease waiting times by better funding public clinics or subsidising visits to private clinics! Also encourage GPs and other health care providers to check with mental health consumers whether they are due for a dental check-up and talk to them about any hesitation they're feeling.*

*Provide funding for more permanent options than dentures or provide dentist nil loans or payment plans that come out of Centrepay, more early intervention for oral health trauma survivors, compensation for oral health included in Victims Services compensation, inform people of the risks of medication and drugs and alcohol on oral health, test medication before releasing it to the market.*

*Provide referral pathways between mental health and oral health services. Education for both workforces.*

*More information - in 30 years, not one mental health professional (or GP) has spoken to me about oral health and any health risks associated with poor oral care.*

*Allow mental health care plans to include dentists.*

*The public system appears to be concerned about the cost of what they are doing rather than thinking the overall effect on the consumer. The consumer does not end up with best care possible.*

*Make dental care part of the health screening along with other physical health.*

*Specialist training for all dental staff for mental health of patients.*

*Better funded public dental options to shift the burden from Dental hospitals and Emergency departments.*

*Put oral care on Medicare.*

*Oral health affects physical health. Mental health medications and problems with mood can impact on oral health. I believe oral health should be considered as important as any other area of health. Everyone should be able to access dental services with dental services part of a wholistic healthcare plan.*

### Overall experience of going to the dentist

Consumers were asked, overall, what the experience of going to the dentist has been like for them.

One-hundred and twenty-five consumers provided comments, with many reiterating their responses to earlier questions; 74 responses being negative, 38 positive, and 13 a mix of both positive and negative experiences.

Nineteen carers provided comments on the overall experience of going to the dentist for the person they care for. Eleven had negative experiences with reasons reiterating earlier questions and six were positive experiences.

Carers were asked, overall, what was their experience as a carer of a person with oral health and mental health concerns been like. Seventeen provided comments, two expressed positive experiences including "For us dental health care has been ongoing and the dentists we've had over the years have been very supportive".

Twenty carers provided suggestions on what governments could do to improve oral health for people who experience mental health conditions:



Most carers describing difficulties including worry, cost impacts and impacts to their own mental health.

*My mental health is often compromised when I have to take my daughter to the dentist.*

*My youngest son has had severe and chronic Paranoid Schizophrenia since he was 17. He is now 40. He was gifted and had so much potential. So the experience has been sad and one ridden with anxiety. Now I am 80 and my worries are about what will happen to him when I am gone. But he still tells me and his father how he loves us and thanks us for looking after him. So we are well loved and rewarded.*

*Expensive!! Very expensive. Frustrating especially because health professionals don't seem to link up all of the health conditions that interact with each other, and their management that also interacts. They only seem to focus on their bit or body part.*

### How can health providers improve experiences?

Consumers were asked what advice they would give oral health and mental health service providers to improve experiences for people with mental health concerns. One-hundred and eight consumers provided comments. Again, they emphasized the importance of good communication, better education and training, full disclosure, collaboration across systems of care, honesty, compassion, understanding, cheaper dental costs. Many of the comments built on the ideas consumers shared about what they thought governments could do (Question 61). Together, the responses to these questions make for an impressive list of suggested reforms and recommendations.

*Don't ask for details. I was sexually abused as a child and have depression and PTSD. A dentist doesn't need to know my story, just that I have mental health issues that might impact my oral health and treatment.*

*Collaborate. Create and database of oral health providers who are trained in mental health.*

*Petition the government to add dentistry and orthodontics onto Medicare.*

*The culture at dental schools should be changed.*

*Teachers should teach students to put their clients' interests first. They need to teach them ethical and moral values, not just skills, nor how to get more pay from the insurance.*

*Just hold the judgement- people are not idiots and have already felt shame so by being so critical you are not helping. There is no attention or relevance placed on creating a therapeutic alliance.*

*Just listen, be gentle and explain.*

*Be more honest with patients and work with them to make it affordable.*

*On a general basis - dedicate the same time and energy used in children dentist to adults.*

*Try to understand we're doing the best we can.*

*Don't assume that the barriers we face can be overcome with simple solutions. Don't be patronising.*

*Don't assume that the barrier to us having good mental health is about a lack of knowledge. Don't give us a hard time for not being able to do our self-care, or for taking a long time to make an appointment.*

*Please don't underestimate us, guide us gently with lots of information and patience.*

*Create a neuro-inclusive environment so that over-stimulated folks can feel safe and secure.*

*Education about mental health. From lived experience would be very beneficial.*

*Learn about trauma informed care generally, and specifically for survivors of sexual assault, those with mental health challenges, and those with sensory processing differences.*

Eighteen carers provided comments on advice for oral health and mental health service providers to improve experiences for people with mental health concerns. Two commented on increasing mental health professionals' consideration of oral health care and physical health, listening to patients and their carers "A larger focus on physical health, which has up to now been terribly neglected."

One carer spoke about the need to experience it themselves: "every health professional should have to spend a day of training as a powerless, disadvantaged person trying to access health to see what the experience is like".



Many carers identified the need to be compassionate, patient and kind:

*Be patient, be compassionate, develop and understanding of how people are when they are unwell and an understanding of what extra support they may require.*

One carer commented specifically on understanding the impacts of medications: *“More awareness of the link between psychotropic medications and poor dental health. A wider understanding of how socioeconomic factors impact a persons’ ability to afford dental care”.*

### What Else Do You Want People to Know?

Consumers and carers were asked for any final comments about oral health that they would like to make. Thirty-nine consumers and 12 carers provided comments, with several reiterating earlier comments, some commenting directly on the experience of completing the survey, and some offering encouragement to others in their oral health. Consumer comments included:

*Consumers need to be aware!! As early as possible...save every tooth you have. Get help as soon as you can.*

*We need to put oral health care under Medicare - no debate needed, just do it!*

*This has been a very long, gruelling, and trauma provoking survey. While I understand that information on dental treatment is necessary, I feel you asking too much of those of us completing the survey...I have relived the same trauma in every question.*

*Thank you for doing this survey. It’s the first time I’ve been able to say some of the things I’ve said here.*

Carer comments included:

*It’s expensive to go private. It’s inadequate to go public.*

*Please make dental care accessible for all*

***“Be patient, be compassionate, develop an understanding of how people are when they are unwell and an understanding of what extra support they may require.”***

***- Carer***

## Safe, Trauma-Informed Oral Health Care

Ninety-six consumers described what safe, trauma-informed oral health care looks like to them. Across many responses the following were emphasized: open communication, honesty and transparency, empathy, information, non-judgmental attitude, responsive, compassionate, kind, gentle, seeking consent, and equal rights.

*Open communication at all stages. Pre-quoted fees...Not feeling rushed. Appointments starting on time.*

*The XXX hospital were very trauma informed. They informed what was going to happen each step of the way. Gave me choice and safety.*

*Option for online virtual tour of...the clinic. Online videos to introduce each staff member.*

*Online videos that can explain basic procedures, what tools are used and why, X-rays, fillings and extractions...Help clients understand their choices. Have a room where these can be discussed privately and discretely. Preserve your client’s dignity. Reception staff that don’t have a discriminating attitude. A waiting area that is low stimulation - low lighting, a little separate from main area. The dentist and all other staff need to explain what they are about to do and get approval to proceed at each stage.*

*Judgement free zone, not being blamed or shamed for the state of my teeth, caring nature and feeling like they listen to me when I share information about my personal life.*

*Responsive, compassionate, gentle, provision of information to facilitate me making informed decisions, validating of past experiences, accepting me where I’m at, no judgement, understanding trauma affects people differently, safety is considered, personal space is respected, consent is always sought and continuously.*

*I am not shamed for being fearful. All the options are given to me. I am not lectured.*

*Good communication, not doing anything without permission after explanation. Consideration of the expense and transparent explanation of breakdowns of cost.*

Some consumers suggested more mental health training, more opportunities for oral health and mental health staff to work together, and increased awareness of sexual assault survivor trauma.

Nineteen carers described what safe, trauma informed oral health looks like to them. Six identified the need for kindness, patience and respectfulness, two suggested clear communication and checking for understanding *“Listening to the person and respecting them. Not talking about them as if they’re not there. Including them in decisions and taking the time to explain things in a way that they can understand”*.

Six carers said being non-judgmental, bias or prejudice would support trauma informed practices:

*This is the golden question. I can only give you my opinion as someone who has been stigmatised as a result of being a carer. Well informed non-biased care prevents stigma and trauma.*

*Taking a non-judgmental approach and refraining from making comments such as “why haven’t you seen a dentist earlier” or “why have you allowed your teeth to rot” without understanding the many hurdles involved before attending dental clinics*

Four carers identified the need for staff training in mental health:

*The absolute need to take into account how intrusive lying in a dentist chair can be. The feeling of powerlessness of someone having total control*

*A dental practice that has a very good, up to date, understanding of all aspects of mental illness and medications. Friendly and kind staff. Free treatment for those on pensions.*

Two carers identified quiet and calming environments, taking time to support the person:

*A calming environment with gentle music, relaxing aromas and welcoming happy, kind staff*

*Time spent acknowledging the person and the anxiety. Normalising the anxiety. Posters addressing this. Music / headphones to block out the sound. Dentist whistling quietly.*

## Summary

The report highlights a strong bidirectional relationship between oral health and mental health. Poor mental health can lead to neglect of oral hygiene due to lack of motivation, self-care difficulties, and side effects from medications, while poor oral health exacerbates mental health issues through stigma, low self-esteem, and social anxiety.

Key barriers to accessing dental care include financial constraints, long public dental wait times, trauma from past experiences, stigma from healthcare providers, and lack of support for individuals with mental health conditions. Many consumers reported experiencing discrimination from dental staff, particularly when disclosing mental health conditions or substance use history.

Consumers and carers overwhelmingly support including dental care under Medicare to support affordability, emphasising that oral health is critical to overall well-being including physical health. There is also a need for trauma-informed care, improved communication between oral health and mental health professionals, and better education for both practitioners and consumers about the connection between oral and mental health.

# Recommendations

## 1. Policy and Systemic Changes

- Incorporate dental care into Medicare to improve accessibility and affordability.
- Increase funding for public dental services to reduce wait times and improve preventative care access.
- Develop integrated referral pathways between mental health and oral health services.
- Provide financial assistance or subsidies for vulnerable populations, including those on disability support pensions.
- Develop financial assistance programs to cover essential dental care for low-income individuals.

## 2. Training and Awareness

- Improve mental health training for dental professionals and staff to support trauma-informed, non-judgmental care.
- Enhance oral health education among mental health professionals to improve awareness of medication side effects and encourage preventive care.
- Create consumer-friendly resources about oral health and self-care strategies.

## 3. Improving Trauma-Informed Dental Care

- Establish “mental health-safe” dental clinics where staff are trained in trauma-informed care.
- Promote patient-centred communication to all staff in dental clinics that avoids stigma and judgment about oral health conditions.
- Offer flexible appointment options to accommodate individuals with anxiety and trauma histories.
- Encourage collaboration between mental health peer support workers and oral health services to provide emotional and practical support for consumers attending dental appointments.





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