Consumer stories of patient experience and economic disadvantage in NSW

Report - October 2020

For NSW Council of Social Service (NSW)

By Health Consumers NSW

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Acknowledgments

We thank and acknowledge everyone who so graciously shared your stories with us. We are humbled by your generosity and hope that this work contributes to creating a fairer health system that does not leave people in the position of having to put off healthcare due to financial concerns.

This report was commissioned by the NSW Council of Social Service (NCOSS). The innovative methodology was collaboratively developed by HCNSW staff. Dr Anthony Brown and Julia Brockhausen conducted the interviews with health consumers.

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Acronyms used in this Report

ABS	Australian Bureau of Statistics
DFV	Domestic and Family Violence
HCNSW	Health Consumers NSW
MPHS	Multipurpose Household Survey
MRI	Magnetic Resonance Imaging
NATSEM	National Centre for Social and Economic Modelling
NCOSS	NSW Council of Social Service
NDIS	National Disability Insurance Scheme
PBS	Pharmaceutical Benefits Scheme

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Executive Summary

I suffer on, I reschedule, and have to cancel due to the cost.

- Respondent to cost of healthcare survey

This report complements Mapping Patient Experience and Economic Disadvantage in NSW[1] research produced by the National Centre for Social and Economic Modelling (NATSEM) for the NSW Council of Social Service (NCOSS). Mapping Patient Experience and Economic Disadvantage in NSW captures the extent to which people in NSW struggle with engaging with health services. It reveals the challenges that different groups, especially people who are unemployed, lone parents and those living in regional NSW, have with accessing health services.

This report complements the NATSEM research by showing the human experience behind the research findings. Health Consumers NSW (HCNSW) spoke to people who are struggling with out of pocket costs for healthcare. People told us about the ways that poor health and economic disadvantage impact on all areas of their lives. People told us stories about issues not covered in the original data set. In addition to the costs of care from GPs, specialists, and dentists we also heard from people struggling with the cost of medications, allied healthcare, private hospitals, scans and tests, supplements, and complementary healthcare. These healthcare costs compound other cost of living expenses.

At the end of this report are 6 in-depth stories of people from around NSW who shared their experiences with us. These stories were chosen to highlight the findings of the NATSEM research, but they also complemented the shorter stories received from the 105 people who responded to our online survey.

The costs of healthcare put many families in precarious situations. People told us of their struggles with having to choose between receiving much needed healthcare or some other necessity. The cost of housing, running a car, and purchasing food, are being weighed against the cost of needed surgery (in the private system), paying for scans and tests, private health insurance, and the ongoing cost of medications. These dilemmas are magnified for families who have multiple members with health challenges. These families are facing both increased costs but also the awful dilemma of having to decide which family member should receive healthcare in preference to others. Parents and carers told us they are delaying treatment for their own health conditions, to ensure that their children and the people they are caring for can receive treatment.

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[1] Vidyattama, Y., Prosser, B., Tanton, R., and NSW Council of Social Service (NCOSS)., (2020), Mapping Patient Experience and Economic Disadvantage in NSW, NATSEM & Institute for Governance and Policy Analysis, Canberra. Report commissioned by NCOSS.

The health system is not the only complicated system people experiencing economic disadvantage interact with. People told us about their dealings with disability services, the National Disability Insurance Scheme (NDIS), aged care, Centrelink, education, housing, and other social services. Interaction with other services and other sectors was, for some, a source of great support, but the overwhelming experience was that of frustration of having to deal with people in other systems that just 'didn't get' the health needs of the people they are working with.

People also told us about the shame and stigma they felt about being in these circumstances. For some it was embarrassment for not being able to pay (a situation that was new for some), while others describe feelings of shame for not being able to provide their family members with the care they need. In addition, there was the stigma associated with being unwell.

The COVID-19 pandemic has exacerbated this situation. We did not explicitly ask about COVID-19, but people did mention their increased concerns about being at increased risk of infection (due to existing health conditions). For others the pandemic had a more direct impact on their life, by further delaying their access to affordable healthcare and increasing their cost of living.

People's lives and experiences are complex. Listening to people's stories allowed us to uncover new issues, as well as add valuable context and community insight to NATSEM's findings.

Methodology

Health Consumers NSW (HCNSW) developed an iterative method of finding stories of people's experience that complemented the findings of the Mapping Patient Experience and Economic Disadvantage in NSW research[2]. While that research was based on analysis of the data from the Australian Bureau of Statistics (ABS) Multipurpose Household Survey (MPHS), this report sought to listen directly to health consumers in NSW.

HCNSW developed a simple online survey to collect people's experiences of accessing health services. Special emphasis was given to patients' experience of general practitioners (GPs), specialists, and dental services. Demographic questions were also asked, based on the demographics collected in the original MPHS.

HCNSW distributed the survey directly to our individual and organisational members. It was also featured in our August 2020 newsletter (the WRAP) and distributed via social media (Facebook, Twitter and LinkedIn). NCOSS also shared and amplified the distribution via social media, as did some of our organisational members.

The online survey ran in parallel to the NATSEM data analysis. Specific groups of health consumers and experiences were identified as preliminary findings emerged from the NATSEM analysis. HCNSW then created customised social media campaigns, designed to encourage people from these groups to participate in the survey (see Figure 1). To further encourage participation people were offered a $100 gift card, should they be chosen to be interviewed for the project.

Figure 1: Social media tiles developed to encourage lone parents and older people to respond to survey.

6 survey respondents, with experiences that aligned with key themes identified by the NATSEM research, were invited to share their stories in more detail. All 6 participants agreed to be interviewed. Participants were interviewed by a HCNSW staff member and their stories recorded and transcribed. The final stories were then returned to the participant to check for accuracy and to confirm that they consented to the stories to be published in this form. These stories are included in this report. People's names have been changed to pseudonyms they either chose or approved, and other identifying information has been removed.

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[2] Vidyattama, Y., Prosser, B., Tanton, R., and NSW Council of Social Service (NCOSS)., (2020), Mapping Patient Experience and Economic Disadvantage in NSW, NATSEM & Institute for Governance and Policy Analysis, Canberra. Report commissioned by NCOSS.

Findings

105 people responded to the online survey.

40 of the respondents were male (37.5%) and 65 were female (62.5%).

While most respondents were from the greater Sydney area, there was a good distribution from around NSW (see Figure 2). 1 respondent was from South Australia and 3 respondents lived outside of Australia.

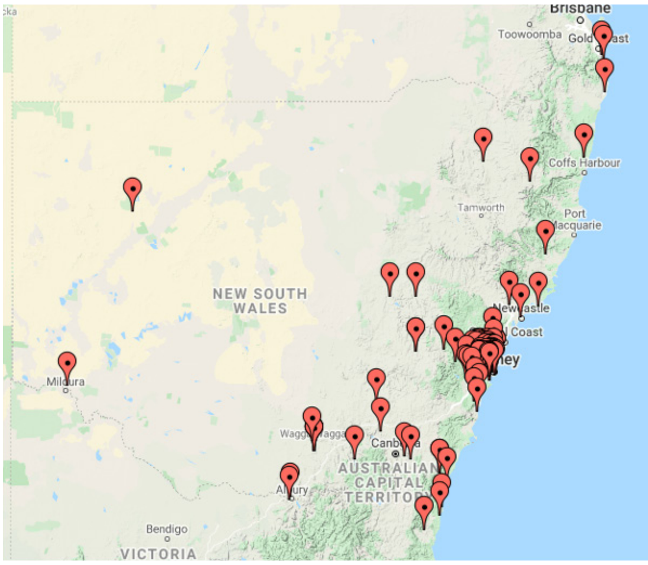

Figure 2: Distribution of responses in NSW.

People's living conditions were varied. 36.2% of respondents reported that they lived with their partners, 25.7% lived with their partner and dependent children, 7.6% were lone parents living with their dependent children, 17.1% lived by themselves, and 13.4% had other living arrangements. Other living arrangements included living with other family members, including adult children; living in a retirement village; or in shared living arrangements.

Key Themes

General Practitioners (GPs) and Specialists

The value of an ongoing relationship with a good, affordable GP who knows you and your health conditions was very important to many people who answered the survey:

> *The outcome [of my diagnosis] was positive and the complications were managed by my GP who organised a GP Management Plan*

> *My son is lucky to be able to access a Headspace GP.*

People reported difficulty finding a bulk billing GP. Many people are worried about not being able to afford a GP who does not bulk bill and the reduction in quality of care that comes from not having an ongoing relationships with a GP who does not know them or their medical history:

> *When my sons turned 18 the family GP they saw stopped bulk billing them.*

> *My GP does not have a complete picture of my heart health.*

> *I'm about to run out of scripts and I have no idea what to do as I cannot afford a GP or risk seeing someone who may not understand my complex mental health and trauma needs.*

Likewise, when it came to specialists, people had difficulty in finding specialists who bulk bill:

> *We could not find cardiologist who would bulk bill.*

> *No ENT (ear nose and throat specialist) in NSW bulk bills.*

> *I need to see an eye, ear, throat surgeon … but I have never gone to see him because it is too much money for me to see a specialist who doesn't bulk bill.*

> *I do not have any money to see an immunologist or continue testing and treatment with the specialists.*

And some had to stop or restrict treatment because of cost:

> *I started treatment with a private dermatologist. I have been unable to continue due to the costs.*

> *We did not attend many follow-up specialist appointments [for our son] because of the out of pocket costs.*

Dental Care

The cost of accessing private dentists, and the waiting lists for public dental services, has put dental treatment out of reach of many people:

> *I need urgent dental care and can't afford it.*
>
> *I have avoided going to the dentist due to cost.*
>
> *All of my children and I neglect our teeth due to lack of access.*
>
> *Dental treatment is recommended for people with my conditions as we are more susceptible and dental hygiene is imperative. None of this is subsidised and is totally out of reach.*

Very few people spoke about using the public system, and those that did had experienced long waiting times:

> *I also can only see the dentist about every 4 years because I need to wait on the public waiting list.*

Medications

The cost of medications was another difficult area for many people are either going without or limiting purchased medication:

> *The cost of medicine and living expenses is far beyond our means.*
>
> *There are fortnights when I have to decide which medications I go without, as I don't have sufficient funds to cover all of the different types of medications.*

A further complication was experienced by people who were prescribed medications that are not on the Pharmaceutical Benefits Scheme (PBS):

> *I require nuanced, tailored treatments that often involve non-PBS medications, which costs $70 per month or $140 on extra dosage.*

Scans and Tests

People are putting off scans and tests due to costs:

> *I have to shop around to find scans that bulk bill.*
>
> *I had to have a MRI [Magnetic Resonance Imaging] on my right knee, I did not have the money to be able to pay for it. My leg has got worse and impacts on my work and my ability to get around.*
>
> *I have had to delay getting a gastroscopy as I was unable to afford it privately and therefore had to wait over 6 months while experiencing ongoing reflux.*
>
> *I was to undergo colonoscopy & endoscopy procedures and was delayed as I was told I need to pay for the private hospital.*

Not receiving recommended tests and scans put people at increased risk of late diagnosis of a range of important and potentially life-limiting health conditions.

Multiple health issues and multiple health costs

People experiencing economic disadvantage are at increased risk of multiple chronic health conditions[3]. This means people are faced with out of pocket costs from multiple healthcare providers. Meeting all these challenges requires making difficult decisions over a range of areas:

> *I live with mental health issues as well as type 2 diabetes, osteoarthritis, and sleep apnoea.*
>
> *I am a survivor of DFV (domestic and family violence) and now as a consequence have complex lifelong chronic physical and mental health injuries. These require nuanced, tailored treatments.*
>
> *Our son was diagnosed with reflux and it was recommended we see a paediatrician. Over the next 6 months, our paediatrician referred us to a gastropaediatrician, dietitian, speech pathologist, ENT surgeon, paediatric allergist, hearing test and blood tests.*

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[3] Marmot, M. (2015). The health gap : the challenge of an unequal world, London : Bloomsbury Publishing, 2015.

More than one person with health concerns in same household

Many people are living with family members who also have chronic and complex health conditions. When faced with the dilemma of only being able to afford care for one person, parents and carers are prioritising their children's and partner's care over their own:

> *I have to prioritise my son's health and wellbeing. He has several disabilities and I ensure that he never misses out on the specialist and allied health services he needs.*
>
> *I have four sons who always got priority over my health needs.*
>
> *I would estimate over the course of the first year after my son's birth, we spent more than $6,000 on medical and related costs. Significant for a family dealing with the other costs of caring for a baby as well on reduced income with one parent not working.*
>
> *I have had to delay appointments and also choose what child needs to see the specialist most because the cost for all three to see her on one day was more than a week's wage.*

Private Health Insurance

Many people felt that they would have receive better healthcare if they were able to afford private health insurance:

Since I did not have private health scheme, I cannot afford it, I was denied [treatment in a] private hospital.

I have no private health insurance, so the physiotherapy for my son has been postponed indefinitely.

The cost of private treatment can be prohibitive.

For some, having private health insurance resulted in better care:

> *My son's assessment cost over a $1,000. If his partner was not in a health fund he would not have been diagnosed and would not have treatment.*

Yet for some people having private health insurance still meant healthcare was too expensive to access:

> *I have full top health cover but was fearful of the out of pocket costs that I might accrue.*
>
> *My health insurance didn't pay enough and I had to put it off.*
>
> *The medical insurance paid for my medical bills and it was a long wait*
>
> *Despite having private health insurance, I don't see my dentist.*

Interacting with multiple complex systems

Many of the people who contacted us interact with many different systems, in addition to healthcare. People told us about their interactions with Centrelink, public housing, the National Disability Insurance Scheme (NDIS), and aged care in order to receive some of the support they need.

Many people reported that they receive Disability Support Pensions or Carers Payments. These payments were welcome but did not cover people's cost of living and healthcare expenses:

> *I'm on disability pension and can't afford treatment.*
>
> *The treatments that do work for my chronic, episodic health conditions, are usually unaffordable on a pension.*

Many families were receiving support through the NDIS. People experienced mixed results with the NDIS. It gave some people the support they needed:

> *When I became an NDIS participant I had access to allied health.*

For others the interactions were difficult, as it meant some members of the family were not able to access the same levels of care depending on if they qualified for the NDIS or not:

> *I have two kids with significant needs one does not qualify for NDIS because of a chronic health condition. Her health condition impacts her mental health and I have pay $200 to see a good psych.*
>
> *I would like to see carers somehow come under the NDIS, because our role doesn't stop*

The complexities of dealing with multiple people in multiple systems was a source of frustration for many. People working in different systems did not always have a good understanding of the needs and experiences of people with particular health conditions, nor did people in the health system understand how their decisions impacted on people being able to easily access other systems.

One person reported that interaction with other sectors resulted in better outcomes for her and her family than she had received from years of interaction with health services. She was very frustrated that in her years of interactions with health services no one had referred her to these other services:

> *For our family the issue is more than making a decision based on poverty. We had no idea what people with good healthcare access could do. When I became an NDIS participant I had access to [new services]. I have been helped by a social worker as coordinator who was shocked I had not had case management or community assistance before.*

People are also frustrated by a lack of clear information about their conditions, prognoses, treatment options, and costs.

> *Now - nobody has come to me and said: this is what your options are. I would like to have some information. But you always have to go down a wormhole to find any information. It's like: go to this web page then that web page and that web page and the information is buried. It's very hard for me. I'm an articulate person, but I have a lot of difficulty reading. The information you get is hard to understand for a lay person, any lay person - make it easier for us!*

People in this situation are often mislabelled as having low health literacy, when in reality no one has offered them meaningful explanations or practical information.

Better support coordination or care navigation in healthcare would help provide people with much needed information, as well as assist in connecting them with much needed services and support.

Precariousness of many people's situations

Many of the issues reported here, especially the interactions between different aspects of people's lives, showed the precariousness of many people's situations. People living in precarious circumstances "have lives dominated by insecurity, uncertainty, debt and humiliation"[4].

People living in precarious circumstances are often not eligible to receive pensions, Health Care Cards, or other supports and services. Without these supports, one life challenge (such as a health scare, loss of job, eviction, or relationship breakdown) can impact negatively on all aspects of their lives. People are aware of the interconnectedness of all these factors and the precariousness of their circumstances:

> *Unfortunately, I fall into the category that works part-time and isn't "sick enough" to have a health care or concession card, which means I have to pay a large amount.*
>
> *I have recently lost my bulk billing GP of nine years due to being unable to travel to him as I can't afford a car anymore and there is no direct or safe public transport*

People in precarious circumstances often do not have the financial and other resources to bounce back from challenges. Sudden illness or injury, loss of work, or a relationship breakdown can impact negatively on all aspects of their lives.

COVID-19 Pandemic

The COVID-19 pandemic has exacerbated the situation for many people. While we did not explicitly ask about COVID-19, a few people mentioned their increased concern about being at increased risk of infection (due to their existing health conditions):

> *I don't go to health services because I am afraid of getting a virus.*

For others the pandemic had a more direct impact on their life; the suspension of elective surgery due to COVID-19 had further delayed their access to healthcare while others reported that support services in the home had been reduced or suspended. For some others COVID-19 has further increased their cost of living:

> *The cost of living for carers during COVID is extreme and we are getting minimal relief. I've had to go to local charities for doors to cover medical cost.*
>
> *I had an appointment at the public dental clinic, which is pocket-friendly, but it's closed because of COVID.*

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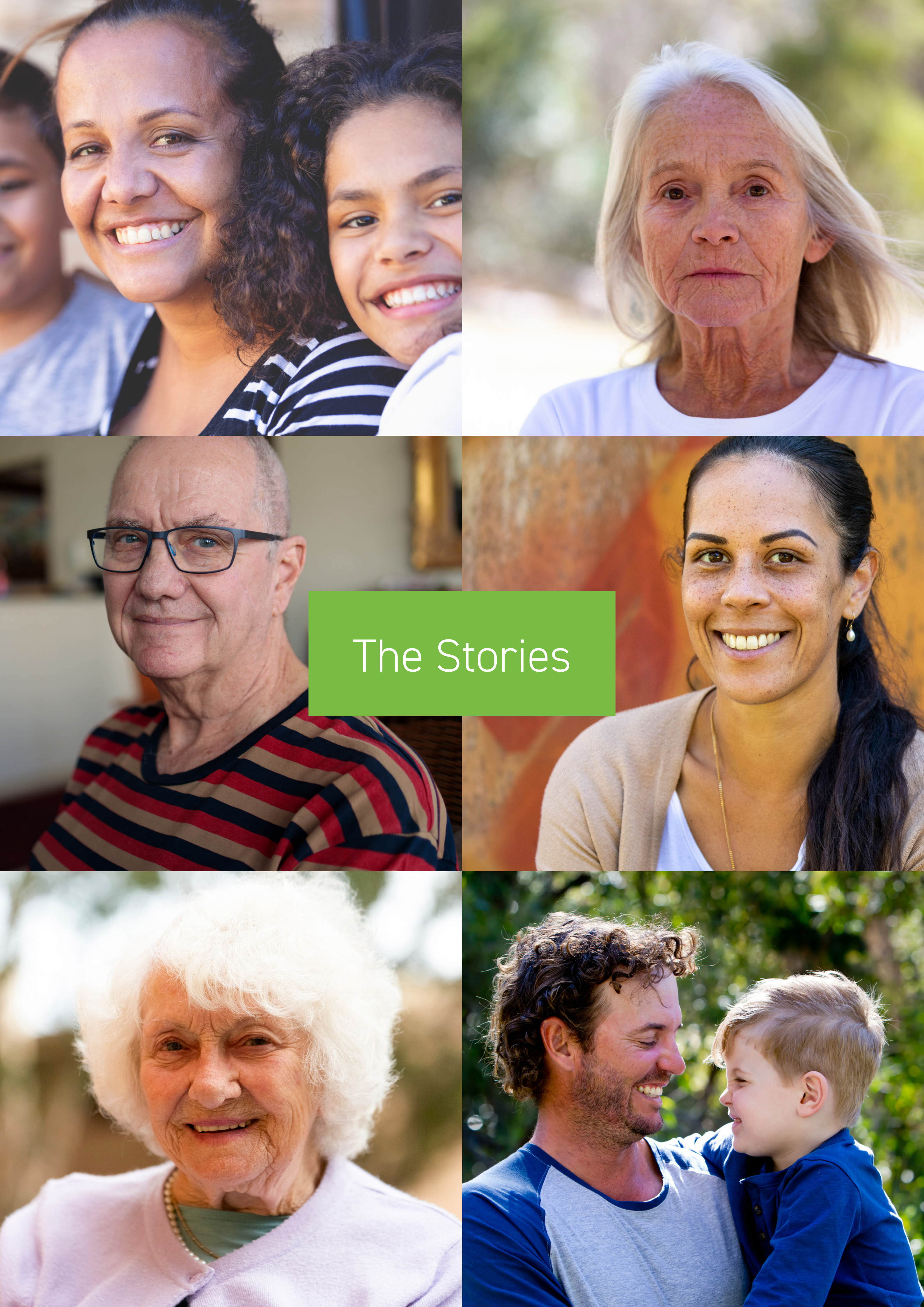
[4] Standing, G. (2011). The precariat: the new dangerous class. London, Bloomsbury Academic. (Bloomsbury Revelations edition, p.x)

Conclusion

This report started by listening to people's experience of poor health, healthcare, and the costs of healthcare. The main themes that emerged from listening to people's experience of the cost of healthcare are:

- Costs of different health services, especially:
    - General Practitioners
    - Specialists
    - Dental Care
    - Medications
    - Scans and Tests
- Multiple health issues and multiple health costs
- More than one person with health concerns in the same household
- Private Health Insurance
- Interacting with multiple complex systems
- Stigma, shame, and embarrassment
- Other cost of living expenses
- Precariousness of many people's situations
- COVID-19 Pandemic

The stories people shared with us show that people experiencing economic disadvantage in poor health are dealing with all these issues simultaneously. People are managing their own health conditions, their role as parents and carers, while dealing with other services and systems, and always being aware of the budget and making sure there is enough money to cover other cost of living expenses.



The Stories

Laila’s Story

Laila lives in far west NSW, she is retired, and lives in a house share arrangement.

Urgently needs dental work but old community health centre doesn’t do dental any longer

I am a pensioner on the Age Pension. I worked all my life, but I have got nothing. I still have a mortgage, so money is always in short supply. I need dental treatment badly; my teeth need major work. I had a few little jobs done at our community health centre. A couple of little clean-ups. Not far from here. They don’t have a dentist there anymore at the moment. So, I can’t go back there for major repairs. That was last year.

New community health centre does only emergency dental care

Recently, I had a bad toothache for five days and I couldn’t afford to go to the dentist. So, I went to a different community health centre. And they have dentists there. That centre is an emergency type clinic on Monday mornings, but they only do extractions. So, they wouldn’t fill the tooth.

First, they gave me antibiotics for a few days. Then, when I went back, they said it’s an emergency. This is an extraction clinic. We can either pull the tooth out or send you home. But I didn’t want it out. I wanted it filled. But they said this is an extraction clinic that’s all we’re doing today. That’s all we can do. We have to pull it out or we can’t help you. So, I had to get the tooth removed. Now I have one less tooth. It didn’t need to be removed.

Can’t afford private dentist

Since then, I have been to a private dentist in town. Because one of the caps I’ve had on my teeth for a long, long time, maybe 25 years, came off. I went to the private dentist and still had the cap to get him to fix it and put it back on. He said no, it can’t be done. It’s going to cost you 1,500 dollars to get a new cap and to get that put back on. He said that’s better. There was also some other dental work that needed to be done which was going to cost me another 1,500 dollars.

Problem with fallen-off cap on tooth

I went back to the second Community Health centre again because the cap had actually fallen off and the tooth was aching. They fitted me in under an emergency. And they repaired the cap that the normal dentist said couldn’t be repaired and put it back on. And they did that for 29 dollars where the normal dentist wanted to charge me 1,500 dollars.

Current problem with teeth

Now, I have a loose tooth. Actually, a couple of loose teeth that need repairing so they don’t either fall out or have to get pulled out or go rotten. I’ve got a bridge in my mouth that connects my eye tooth to a tooth a couple of teeth back because there was a little gap there. A dentist, years and years ago, talked me into putting a bridge in and hooking it onto the eye tooth, and then crossing the gap and hooking it onto the tooth in the back. Now the eye tooth is loose, and the bridge is all broken. The dentist in town quoted me once again a couple of thousand dollars to get the teeth pulled out and put in false teeth - dentures. I don’t want dentures. I want what’s in there fixed. I want to keep my teeth.

I said: what about fixing it? He said: Oh well, it would be better if you just got dentures in there. But I don't want dentures and I said what about screwing a false tooth in the gum just where the gap is? He said that's going to cost you about $12,000.

Can't afford the treatment needed

How are pensioners who have worked all their lives - I mean I started working when I was 13 years old. I am 71 now. How can pensioners afford that kind of dental work? I can't!

Long waiting lists to see public dentist

I can see the community health dentist only if it's an emergency. Otherwise, I'm on their waiting list. I joined the waiting list in April last year. They thought it was gonna be about 18 months from April last year. But now with COVID, they said it was going to be - from right now - a minimum of two years. By that time, my loose teeth will probably be dead.

Now - I don't know what to do next, I don't know. I can't live in pain for two years and not be able to eat. What do you do? Do you have any suggestions?

The community health centres won't do anything unless I go in there screaming with pain. And then they will put me on the emergency tooth extraction list and they pull the tooth out. But I don't want any more teeth out!

Keeping teeth priority – but can't afford it

I have a very sensitive mouth. I don't want dentures. And just because you're old, you shouldn't have to have all your teeth out. Just because you're not wealthy, you shouldn't have to have all your teeth out. Especially for someone who paid taxes all their life.

I don't have the money to go private. I'd have to sell my house or borrow money against my house to get the dental work done. And then how do you pay that back on an age pension? Is there no help for people who want to keep their teeth? Is their only help for people who want to get them all pulled out? And even then, you have to be prepared to wait for a couple of years as well to get them all pulled out and have plastic dentures put in. I don't want that.

Problem about getting dental care not resolved

When I paid huge taxes, I used to work seven days and seven nights a week. Purely bad luck caused me to be in the position that I am at the moment with no money. A couple of divorces and domestic violence and all the rest of it... I walked out and left a couple of houses behind. Bad stuff... so I ended up with nothing. Well, I ended up being alive with no more broken bones. I'm happy about that. But I need proper dental care at the moment.

Emma's Story

Emma lives with her children in a large regional centre in NSW.

Sons with autism and ADHD

I have a 17-year-old son, who is on the spectrum and has ADHD. He was diagnosed with both conditions when he was seven. I also have a 15-year-old son who has ADHD and he was diagnosed when he was five.

Regional – problems finding right providers

Being in a regional setting, 10 years ago now, there was... Well, as an ex-Intensive Care Nurse and an ex-university lecturer I was looking for the best available care that I could get for the boys. And at that time, where we live, there were no paediatricians who specialised in ADHD or kids on the spectrum.

When my eldest was diagnosed, early intervention wasn't a thing yet, so we missed out on early intervention for him. Back then, the understanding of kids on the spectrum was different. But I wanted to get the best available care which meant I had to go to Sydney. We found a specialist in the middle of the city who was recommended by our GP.

Problem with healthcare costs for both boys

From then on, the boys saw the specialist every six months. Each appointment was between $300 to $350 for each of the boys. They did specialised testing and learning assessments at the same time. But the only item covered by Medicare was seeing the doctor, so we would get around $80 back per child. The testing wasn't covered, not even by our top-rank private health fund.

Trying to find $750 - even when you know about it six months in advance but then you have a whole heap of other bills to pay that month - you go, crap, I don't think I can get $750 together to be able to go to the appointment.

Consequences when not having the money to attend appointments

So, sometimes, we had to cancel the appointment. But ADHD medication is very tightly regulated. If you can't go to your appointment that creates issues with getting the scripts. So, we were very much tied into this huge expense. We knew it was worthwhile because we were seeing someone who was very knowledgeable about ADHD and kids on the spectrum. But if we had to delay, we didn't get a script which meant the boys didn't have their medication.

Problems with cost of medication

There's a lot of negative stuff said about ADHD and about ADHD medication. It's a hard decision to make in the first place, to put them on medication. And then it's also very expensive. It's not fully covered by the PBS. A bottle of tablets is between $40 to $70 which lasts about a month. So, both of those costs are restrictive. But if we didn't go and get the scripts and they didn't have their tablets, they found it extremely difficult to function at school..

Problems with learning and school due to not getting healthcare/medication needed

My youngest son's ADHD is quite severe, particularly when he was little. When he didn't take his tablets, the school often would ring me and ask me to take him home, because he just couldn't sit still, couldn't concentrate on work and was distracting other kids. That was the implication if we couldn't afford to go to the appointment and I had issues with the scripts and we couldn't get the tablets: They didn't learn!

And of course there are the other costs: two days of missed school. Every time they had an appointment it was pretty much a whole day trip to go so, they lost that day of school. The cost of travel, food, train tickets… the costs really add up, it turned into a $1,000 day.

We always prioritised the medication because of its impact on our boys' learning. We just had to cut back on other things. Ever since they were little, we haven't really had any money to be able to go places. We haven't had a holiday since my eldest was five and youngest was three. We can't afford holidays because of the cost of medication and appointments and all that kind of stuff.

No change to situation over time

Now they're 15 and 17, we're still at the exact same point. Every six months or so an appointment and medication.

My eldest son's behavioural issues have kind of turned into teenage attitude stuff. But he's actually pretty high functioning at school. Apart from that, he finds it hard to motivate himself with things that he's not interested in.

School not having funds to support learning of younger son

My youngest son is now in year 9. He still needs medication. We have tried the highest strength medication he could have without too many negative side effects. But it still has not helped him fully. Learning-wise, he still struggles at school. He finds it very difficult.

There is a list of disabilities that schools can get funding for but ADHD is not on that list. The school gets nothing extra to be able to give him extra support. Unfortunately, he has kind of slipped through the cracks.

We tried to get tutors, but in the end, we couldn't afford it with all the other costs. We had to drop tutoring. I keep telling him that a lot of people bloom later in life, find education easier when they're a bit more mature. School isn't always the best learning environment for everybody.

I'm trying to instil that resilience in him: you are not dumb! He had teachers in primary school who were constantly implying that he was stupid or slow. He has a very bad self-image. I'm just trying to build up his resilience to realise that education doesn't end with formal schooling. There are a lot more opportunities to extend yourself when you're an adult and able to have more control over the learning environment.

Emma's Story (Cont.)

What will happen in future?

Not much has changed in the 10 years since we started this journey. The cost of tablets has sort of gone up and down over the years. Sometimes they had to take two or three different tablets - short acting and long acting ones. My oldest son ended up with quite severe anxiety and depression. So, he ended up on an antidepressant. That's another tablet added. The medication costs have varied over the years. And every six months, we still have to stump up the $350 for the appointments.

There are a couple of ADHD specialists where we live now and we contemplated swapping to one close by. But when you've been going to a specialist for 10 years, and they know your kids really well... You can call them and have a chat with them, and they know exactly who they're talking about. They know me well. You don't want to lose that relationship, even though you know that it's a big cost.

Now it's the question of what happens when they turn 18 because their specialist is a paediatrician. I haven't actually broached the matter with their specialist whether they can keep seeing her. I don't actually know what happens to be honest. The boys are not miraculously going to get better when they turn 18. Some people have ADHD their whole life, but others grow out of it. I don't think either of my boys are going to do that. So, I don't actually know what happens with management of care after they turn 18.

Consequences of stress on family

I'm currently going through a separation from my husband and the amount of stress we have been under definitely contributed to our marriage breakdown. My husband and I, when we talk about separating, luckily, it's quite amicable. We're trying to find a way to stay friends and co-parent well. We've talked about the stresses we've had over the last 10 years. And we've had huge amounts of stress.

My eldest son's behaviour is very difficult. It creates a lot of conflict in the family. We love him to bits but he's a very difficult child. Over the last 10 years, we've been constantly trying to go see the specialist, get the medications, try a different medication, try a higher dose, try a lower dose... go and see a psychologist.

Psychologist costs

That's the other costs that we have had on top of all this, we had specialised psychologist appointments for kids on the spectrum. The full cost of that isn't covered by Medicare either. If we were going through a really bad time with lots of issues at school, we had to see the psychologist once every two weeks. That was a $150 appointment. You want to do the best for your child, you want to help them and so we just had to scrape the money together.

Strain on marriage and family

The financial stress and the stress of constantly trying to find ways to help our children - particularly when they have conditions that aren't well understood or well-funded - that definitely put a big strain on our marriage. On family relationships as well. We haven't had the money to be able to go out with friends or family. If they've asked us to come on holidays or come out for dinner or that sort of thing we often had to say no, we can't afford it.

Suggests restrictions on specialists charging exorbitant fees

I think there needs to be some sort of restriction, applied by the government, on specialists charging exorbitant fees over the Medicare gap. I've seen lots of different specialists and an initial appointment of $400 - that you get $110 back from… Yes, you're a specialist and I know that these people have knowledge that is valuable, but that is not okay. People can't afford it!

When they ring up to make an appointment and hear that cost, there are a lot of people who say, I just can't do that. I'm going to have to wait six months to see a specialist in a public hospital instead. In the meantime, their condition may have deteriorated to the point where, if it had been done six months ago, they might have been a lot better.

I think there are a lot of kids out there, with ADHD in particular, who are very poorly managed because they are either not seeing a specialist at all. Or they go to a generalised paediatrician who just does not understand ADHD. Or they do find a specialist in their area, but they just can't afford the $750 for an appointment. And then these kids are falling through the cracks, having learning difficulties all their lives, because of that. I think it's really important that there needs to be limits put on how much a specialist can charge.

I don't think people realise it's not just about medication or it's not just about going to a doctor's appointment. This is about kids never learning well, all their lives. And the consequence is falling through the cracks very early on because their parents can't afford to get good care for them. You know it's huge. They can't get back those learning years once they're lost.

Paul's Story

Paul lives in a large regional centre with his partner and children. He is not working and is the carer of his 2 boys.

Carer of 2 boys

I've got two severely autistic boys, with other disabilities as well. It can get a little bit out of control in our household.

The boys are 17, so they're nearly men, they're not really boys anymore, but they can get violent towards each other or get violent towards me. And they were fighting so I went down to intervene. And one of them grabbed me on the side and I was sort of off balance and turned and I felt this tweak in me knee and I went "Uh-oh this it doesn't feel good!"

Cost of scans, impact on budget

I went and saw the GP. The GP sent me off for an X ray, and an MRI just in case the X ray didn't show anything up. The MRI showed that I had a strained meniscus. And I had to pay for the X ray and MRI, even though I've got a healthcare card, that affects the budget, y'know,. You look at it and go "Okay, well that's $500 or $600 that we haven't got now." It's gone and you can't get it back, but it leads to shortfalls elsewhere because you've got to juggle because we've got a budget. And we can't just go and say, "Okay, well, we're gonna borrow more money" or "we're going to lift our credit limit", we can't do that, we try to live within our means. And that's not always possible when you've got 2 boys with a disability.

Health insurance and waiting lists

The doctor says that I've strained my meniscus in the knee, so but because we don't have health insurance and you can't go private, were on a waiting list.

So there's all these, all these things. If we could afford private health insurance, then there would still be a huge chunk of money that we don't have, because it doesn't cover everything. At least in the public system, you've got a huge waiting list, but you don't get stuck with a bill at the end.

At one stage we did have private health insurance. But when we looked at the out of pocket expenses, we were probably spending more in out of pocket expenses than what we were getting back. So we thought, we really don't need it for the boys because they have their healthcare card. It really wasn't worth it.

Luckily, we haven't had anything serious happened to anyone in the family. But I'm sure they are other families that are doing exactly the same thing, they might have health insurance and it doesn't mean that you get any better service.

Surgeries cancelled due to COVID and waiting lists

So then you've got COVID's come in to and all sorts of non-urgent surgeries being cancelled.

All non-urgent, non-elective surgery is just on hold, because of the pandemic. So, now I'm on a waiting list. They said it could be 12 months, could be 18 months, might be 6, when they lift all the restrictions or things get back to normal, but then you've got people before me that are already on the waiting list and still waiting. And they can only do so many at a time.

NDIS doesn't support carers and their needs

And I mean, I know now that a lot of the stuff is covered by NDIS for the boys. I would like to see carers somehow come under the NDIS, because our role doesn't stop just because the boys have got funding for community inclusion, speech [pathology], OT, behaviour, we've still got to do the stuff that the speech, the OT have to do. If we get sick there's nobody there to pick up the slack. So, I would like to see some way that carers are able to claim small medical expenses, because [being injured] impacts on your caring role.

Support Worker

I need help, I can ask NDIS to get more help into the home but that then presents other problems because one of my boys doesn't like people in the house. So then that defeats the purpose of getting somebody in. We did try it before I was injured, I had an extra support worker coming in the mornings to help me with showering toileting, feeding, medication and that, and it was just a disaster. It was just a disaster. He absolutely hated having the extra person in and he would, he would hurt me and try to drag the support worker out of the house. We decided that it wasn't worth the hassle and so that that option's sort of taken off the board.

Injury impacts on caring role but can't get treatment

So there's days when my knee is really, really sore. I mean for the first couple weeks, the doctor gave me some painkillers, but they don't want you being on painkillers for any length of time because they can become addictive. They cause other problems. But with my role as the carer for the boys I have to be able to get somewhere as quick as possible. So that's not ideal at the moment.

And now my mobility is diminished and this impacts on my caring role, and because there's a waiting list, this could be a 24-month problem.

I can walk, with a limp but it's painful. I can't extend my knee right out, I can probably get to about 95% and then you can feel the meniscus or if I bend if I go to sit cross legged then you can feel it straining. The boys are not toilet trained and the easiest way for me is when they lay on the floor and I can wipe their bottom and change them. But getting down and up is difficult some days.

Some days, it's not a problem, and you just think "Oh yeah, the knee's getting better". But then there's days when you forget, and you've got to get to them quickly, and you got to take off and you go "uh-oh". Or if they want to go for a walk or go to the shops, you've got to realise that you haven't got that mobility. That you had.

The boys still get the same level of care but it's not delivered as quickly as it was.

Regina's Story

Regina is retired and lives with her husband in a coastal town in northern NSW

Dementia diagnosis

I was diagnosed with dementia in 2015. I found out about the Bredesen protocol, in about 2016/17. I was prepared to spend $4,000 and go down to Sydney to meet somebody I didn't really know. I went to Sydney in June 2016 to get tested and they basically told me that I don't have Alzheimer's. I nearly stepped in front of a train when I heard that. That was my momentary reaction. They got it so wrong.

Three weeks later, I was reassessed, and I got a level 3 assessment first go. He got it right. I think they first got it wrong because I present really well but my Activities of Daily Living (ADLs) are 17 out of 28. So, I could go into care and be fully looked after.

But then it just so happened that somebody said to me, why don't you try the local guy. He is good but he didn't have any spaces at first. I finally got in.

Initial problems with cost of dementia health program and supplements

Every time you go to see him, it's a couple of hundred dollars. And then the supplements were at least again a couple of hundred dollars a month. But I got the improvement. So, I was willing to pay the money because I was getting outcomes.

Initially, my husband was whingeing about how much money was being spent. But after 18 months, he had tears in his eyes. He said it's been worth everything.

Problems with recognition of diagnosis

I had a dummy spit earlier this year because I started to lose a bit of ground again. I had improved so much that people were doubting my dementia diagnosis. My husband doesn't and I don't because we are together, and we know about the bad days. But it was as a matter of justifying expenses and stuff.

Change of aged care systems provider makes treatment free

Then I changed my aged care systems provider in July. And with changing my care provider, we found out that now my ancillary expenses - so at the chemists and also my supplements - can be covered through my package. So, they are still expensive, but I'm not actually seeing it. It's not coming out of my pocket. So now, I'm not really fitting the bill of struggling with healthcare costs any longer. But I certainly did earlier.

Living situation when costs weren't covered

When I was still paying for all the costs myself, I still went to some conferences [as a health consumer representative] but I stayed in backpackers. I was the grandma in the backpackers. I only shopped in op-shops and I went to the foodbank. We didn't do without, but we certainly didn't do top of the range.

When I did that dummy spit back in February, I asked my healthcare provider to go through my list. Because each time you go, stuff gets added. I asked him to cut it down to the very, very basic of what do I need and what can I do without as I needed to cut cost back then. But there was not much double up. They all have a scientific reason why I take them. My inflammatory factor went up during the time I cut down on some supplements. Now I take them again, because I don't have to find the money myself any longer, the inflammatory factor has halved.

It's still early days on the new package. But it just means now that I can start on some of my supplements again which I had to drop due to cost - a powder to improve the really fine vessel circulation in your brain. My last scan showed like fine white chalk on the surface of my brain, but I stopped buying the powder and some other things that helped me because it was too expensive.

Living situation now costs are covered

I'm today making the appointment to see my doctor again and do all of my major blood testing: chasing glucose tolerance because I'm hypoglycemic, even though I'm not a diabetic. He chases all the fine details, assumes nothing. He got me on a CPAP machine and I've got my life back. I was hypomanic because I wasn't sleeping. When I went to sleep, my oxygen levels went down to 73%. I had the most horrific nightmares getting me out of bed, so I thought I have Lewy body dementia. I'm just fortunate that he's local.

I'm also saving money to go up and see a psychiatric geriatrician, up at the Gold Coast when we finally get some borders loosened and we can go to appointments [due to COVID]. And that's gonna be big money too. But I've got a little bit of slack because the supplements are covered by my package now. So, I finally got around to be thinking well I am worth it again.

Now, my situation is almost too good to be true. I'm waiting for the first accounts to come through and see they've been paid. But I know it's happening because when I go to the chemist, they bring out an account and write on it. It's a tremendous relief. It's just helped me to focus on being as well as I possibly can. Just chasing those one percents, if you get 1 percent improvement over about 15 different areas, you will see a big improvement.

When I had to make the call about what I could afford and what I could not, I really hated it. It almost put me in a state of depression, you know. I had to prioritise my husband's needs and our household needs over my needs. And as a woman who's invisible anyway, because I'm over 55 with silver hair, it's very easy to fall into that role of 'your needs are last'. I had to work on not seeing myself as that.

Bob’s Story

Bob is retired, he lives in south western Sydney with his wife, who he cares for.

Wife is diagnosed

I met my wife and we moved to Queensland and in Queensland she started to get dizzy spells. I used to come home and find her under the clothesline because she’d passed out and doctors couldn’t find out what the problem was. They did scans and everything and they didn’t know, no idea. Her legs kept swelling. She had problems with her legs that nobody dealt with. It’s been 35 years and it’s only recently that we’ve been able to pin down the issue with her legs.

We left Queensland and came back to Sydney they tried to deal with issues again, they couldn’t deal with them. We tried to pursue it further. Then we moved to Western Australia and it in Western Australia she became sick. She suffered rheumatoid and osteoarthritis they gave her all these medications. She had severe reactions to the medications. Consequently, it built up into a portfolio of adverse reactions to medications. I was working and looking after my wife, making her comfortable before I went to work. And when I came home and started to look after her. I ended up having to do all the washing, cooking cleaning, ironing helping her and still going to work.

Then we decided we’ll come back to Sydney because we had family here and we thought the family would assist us in some way. But no that wasn’t to happen. We came here but she nearly died twice at home. I managed to get the ambulance to her.

Stopped work and became carer

I was full time employed, and then suddenly I had to stop work [to care for my wife] and that made a dramatic cut in income. Then I had to start thinking about where’s the money gonna come from? Where’s the information gonna come from to help me?

The process of the transition for her from being reasonably capable of doing things for herself [to having to rely on others] has been quite traumatic.

So what I had to start to think about was to readjust my life to deal with the current circumstances my wife was going through and being able to cope with this. And that’s not an easy road to follow sometimes. It’s not only just it’s just your wife is sick, it’s the transition the carer has to make and that’s like hitting a brick wall. I think this is overlooked.

You have to learn about her conditions you have to learn about her problems. Then there is a side of the feminine hygiene part that women keep to themselves that you now have to take over and learn about, [it’s a] dramatic learning curve in that sense. There is not a real lot of guidance in how to deal with these things.

There’s carers’ outings and things like that that I could possibly go to have a reprieve from the situation but no, I’ve doing this now 2 year’s part time 5 years full time. I’ve been a full time carer since we came back from Western Australia and it’s just a constant, constant demand. My day starts usually starts about 7:30 to 8 o’clock in the morning and finishes round about between 1 to 2 the following morning.

Costs of living

Now I get a carers pension and all my carers pension goes towards paying the rent. My wife adds $100 from her pension to mine so that I can put money aside out of my pension for paying the electricity bill. So we will live off my wife's pension. Now the issue we have is that we have expenses for medication and seeing specialists. I started recording this expenditure when we applied for public housing and we had to have evidence of what our expenses were.

Housing

Pubic housing offered us a unit, we rejected the unit they provided for us. The previous owner had dogs in there and there's this foul stench of dogs in the carpet. My wife is susceptible to infection. Therefore, we couldn't accept the property, and we've been waiting for quite a while on this, and eventually we rejected the property because it was unsafe for my wife. So we ended up having to take out a private rental through a real estate agency. And the cost of that rental sort of swallows up my income from the pension.

We both need to see specialists

I see a specialist for a respiratory condition, I'm classified as a severe asthmatic. It becomes a struggle to trying to get things done.

Just recently we've been trying to get a problem with my wife's legs dealt with the doctors for some reason wouldn't deal with it until my wife had an appointment to visit the cardiologist and the cardiologist mentioned to her that she had a hardening of the skin on her legs. And so I don't know what that really meant and so when I got home I studied up on hardening of the skin and what that could be. And only a few weeks back we ended up seeing a lymphedema specialist at the hospital. And we have had to start now seeing a cardiovascular surgeon and so there's a whole range of other specialists that she now has to see, on top of a cardiologist and a rheumatologist. And the cost of seeing these specialists is quite high.

Even though we get some of what we pay to see the specialists back it still takes a bite out of the budget. We're still paying for keeping the car on the road, registration, insurance. All these other incidentals all come out of her income. And on top of that, her medications and the things we need for her and for myself takes a big slug out of the budget. So it becomes a struggle.

I still see my respiratory specialist, I do that through my local hospital. I've got a problem with getting lightheaded when I exert myself and I had to go see a cardiologist and have all these tests done. Luckily my heart is okay. But they're further out of pocket expenses. I've also started to develop an issue with memory loss, so I need referrals for that. I have a bilateral inguinal hernia I need to see a specialist for that. I can't afford to see them. But even if I did, I couldn't spend the time in surgery because nobody's there to look after my wife.

Bob's Story (Cont.)

Aged Care

We had a look at a nursing home. We wanted to set up a program whereby if something happened to me that my wife would be going to a nursing home. And we had looked at a couple of nursing homes, where they were going to put her temporarily. The places were not very satisfactory.

My mother died from dementia not long ago. While she was in the nursing home we found a few issues and I confronted one of the nurses, asked them to see one of the nurses, my mum was tangled in her bed sheets and everything and she hadn't been cleaned for a while, you know? And the fella said to me "I'm sorry that there's only me looking after this entire floor and I also have to help somebody else on the next floor", and I said "That's not bloody good enough". I said I wanted that fixed up right now and I went down and made a complaint down to the office. This hasn't been an isolated case, there's been a number of things that either myself or my brother picked up on. When you see that sort of thing you're sort of reluctant or reticent to put your next to kin into a nursing home, they're not getting the proper care. And I'm not prepared to put my wife there.

I couldn't trust them, no I won't trust them.

Doing it for ourselves

So I saw I have to work out ways of doing things myself without aggravating our existing problems so that we can afford to keep her at home.

Particularly my mum died before the virus came out and now you're hearing a lot of issues on the nursing homes. It needs a massive shake up I mean a massive shake up, I know they're in the business of making money, but to let the patients they care for suffer as a result of saving that money is not acceptable and I'm not prepared to put my wife into that situation.

I'm not sure she's going to get the right care at the right time. She needs special handling, I have to help her in the bed I have to help her on the commode, I have to help her out of it. And there's certain ways you do that without causing her pain. And a lot of other places just simply wouldn't go through the process I do. They don't do it in nursing home and they don't do in hospital.

She was put on the commode in the hospital and no one came back to help her off. She has arthritis in both her legs and was in pain from of that sitting on the bed pan. I'm not blaming the nurses because there's only so many nurses that's employed to do the work. They also have a lot of other patients and that has to be understood that can't be there specifically to cater for everyone's needs. But to me, well that's not acceptable.

So these are issues that we've come across and dealing with, with my wife's condition. So for me I would love nothing more than to be able to get myself treated, but in the process I need to make sure my wife is safe.

Maggie's Story

Maggie is a single mum living in Sydney.

Son with Inflammatory Bowel Disease

One of my children requires a stool sample test. The cost is $90. Myself and my ex-husband share the care of my children but he refuses to pay. He has a private health fund, whereas I'm on a pension and I don't have one. I can't afford the cost. I have to pay my rent. And that's just one of many tests that my child needs. He has Inflammatory Bowel Disease (IBD).

The test is needed to assess the status of his condition which hasn't been assessed for more than five years. He is bleeding from the bowel. I don't really know what they use the test for but as I understand it, it's to get another picture of his condition. To assess the severity, without having to be too invasive. Like a colonoscopy which we'll have to do soon. That will be another thing. Hopefully I won't have to pay for that.

Can't afford tests for son

The public hospitals don't really have time to do them right now, as you know, due to COVID. So, they will likely send us to a private one. We did go there several years ago, when the condition was first found and we had to have an emergency colonoscopy. Luckily, the costs were covered.

But there was one possibility that came up. We were recently at the hospital and they offered that we could bring a stool sample into the hospital and that the test would be covered by the hospital. That has just been suggested which is good. But my child is reluctant. We must get the test done quickly as he's becoming a teenager. It is getting harder and harder for him to be willing and cooperative. That's an issue. Subsequently, we got the stool sample and delivered it in over 3 weeks ago. We have not yet heard the result, either verbally or in writing.

Can't afford a heart monitor

My GP suggested a heart monitor test for me as my immediate family has a history of heart failure. My father had a bypass. I have to get a cholesterol reading and need to get monitored for cholesterol. So, your GP calls you and makes the suggestion to you and then I ask them about the cost. So, in relation to the heart-thing, that's just gonna have to wait. I can't do anything about it as Medicare doesn't cover that. Maybe until I have a heart attack, then it will be covered.

Only getting treatment once condition is critical

I had another experience like that. I was having issues to do with my gallbladder. And it was only because I had a few episodes and was hospitalised that I was finally able to be referred through and put on an emergency list for gallbladder removal. That was in 2018.

Maggie's Story (Cont.)

Brother died, lack of social support (inside and outside of hospital)

My brother passed away in January this year. He had a triple bypass, but he was in a much worse situation than me. I'm terribly, terribly upset about that and I do feel that there was something not quite right.

He was living in social housing and he was not in great health. He had leukemia as a child, which was an underlying condition. Then he had some other type of cancer in his bladder in his 50s, and now the issue was cancer in his mouth. But it was a manageable condition. He would still walk but he seemed to deteriorate a little. One day, he was returning from the doctor quite late. And he was having difficulty breathing. He then was admitted to hospital, and they asked him if he was consenting to heart surgery. We visited him in hospital, and everything seemed to go well. He agreed to surgery and he had a triple bypass. After the operation, the doctor told me that the surgery went well.

I was away for a few days and when I came back, I heard he had discharged himself. Gone home. He was in intensive care and he was particularly upset about being isolated. I think one day later he discharged himself, went home and passed away. I was very shocked. We were all shocked, absolutely shocked, because up to that point, my understanding was that he was still there, in their care. Of course, you can't force anybody to stay in hospital but there was something that wasn't quite right with that. How is it possible that somebody has very serious conditions and was discharged?

Teenage daughter problem with teeth and skin

My teenage daughter has problems with her teeth - overcrowding in her bottom jaw and issues with acne and her skin. But we can't see a dermatologist because of cost and that's ok.

But with the teeth, that concerns me because it could impact on her cleaning and maintenance and could lead to future issues. It was suggested that she sees an orthodontist. I don't want her to suffer what I suffered, having to have a tooth removed, after my pregnancies. We might explore the possibility to get into a program through a charity for her to see an orthodontist.

Dental care is not affordable

But I know I'm lucky. I've been able to access some free dental attention. If I'm in pain I can go to my local hospital. The dental hygienists can look at me and take an X-ray. That's great. I would like a replacement denture as I'm still a youngish woman, and I need to be able to speak and eat properly but the ones they offer are not suited.

If I want proper ones, I'm looking at $1,500 dollars. I can't afford that. I lost another tooth and I had to have a wire snip. They didn't charge me for that, aren't I lucky? So, if anything in my jaw changes or my teeth shift again, I'm up for a huge wack of cost. It would take me months and months and months to save up for that.

Daughter turning 18 soon – won't have free dental any longer

My daughter has just turned 18. And that means she is off the free dental care and she will have to bear those costs herself. Since she's left school she's no longer a student at school and apparently TAFE doesn't count. They say that if you're at TAFE you stopped studying and you're no longer eligible for those benefits. That's outrageous!

Problems with finding information

Now - nobody has come to me and said: this is what your options are. I would like to have some information. But you always have to go down a wormhole to find any information. It's like: go to this web page then that web page and that web page and the information is buried. It's very hard for me. I'm an articulate person, but I have a lot of difficulty reading... The information you get is hard to understand for a lay person, any lay person - make it easier for us!

Thankful for free healthcare they do receive/ parking costs are a problem

I don't want to complain, we are very fortunate. We've been able to go to a clinic and get proper advice for my son. We have been able to park there for very little cost. Thank goodness they made us eligible for reduced parking. I mean parking is a huge imposition on people to visit other people ...for people that need to access day clinics.

My son had to go to hospital on Monday for an iron infusion. Fortunately, we got onto the free parking list and: fantastic! It went really smoothly. That's what I want, because my son has a lot of anxiety about going to hospital. It was very fortunate we didn't have to pay anything at all for the infusion. How brilliant is that? And the nurses were just fantastic.

Survey: Cost of Healthcare in NSW

Introduction

Health Consumers NSW (HCNSW), in partnership with the NSW Council of Social Service (NCOSS), wants to find out more about people's experience of the cost of healthcare in NSW.

If you, or someone you are looking after, has had to delay seeing a GP, specialist, dentist or other healthcare provider because of cost we would like to hear from you.

Please tell us your story and if your story is chosen to be included in the project you will receive a $100 gift card. You will need to tell us your story and leave your email address to be eligible for the gift card. Please note this survey is only open to people who live in, or receive healthcare, in NSW.

If your story is chosen you will be contacted by HCNSW and asked to tell your story in more detail. We will not publish people's names or identifying details.

This survey should only take about 5 minutes to complete

About you

Please tell us a little bit about yourself and where you live. This information will help us determine what factors impact on people's experience of healthcare

1. Whats your age?

○ 15 - 24

○ 25 – 64

○ 65+

2. Are you:

○ Male

○ Female

○ Other

3. I am:

○ Employed full-time

○ Employed part-time

○ Not working

4. Which best describes your living arrangements?

○ I live with my partner

○ I live with my partner and dependent children

○ I am a lone parent with dependent children

○ I live by myself

○ Other (please specify)

☐

5. Do you identify with any of the following groups? (please check as many as apply)

☐ I am an Aboriginal or Torres Strait Islander person
☐ My family speaks a language other than English at home
☐ I am a member of the LGBTI* communities
☐ I have a disability
☐ I have a chronic (long-term) illness
☐ I am a carer for someone with a disability or chronic illness

6. What town or suburb do you live in? (name or postcode)

7. Have you, or someone you care for, ever not been able to use a health service because it cost too much?

○ Yes
○ No

8. Have you, or someone you care for, had to delay using health care when you needed it because of cost?

○ Yes
○ No

9. Which service did you have to delay or not use? (tick as many apply)?

☐ a GP
☐ a specialist
☐ a dentist (public or private)
☐ a scan (such as an X-ray, MRI, CAT scan)
☐ a test (such as blood or urine test)
☐ a private hospital
☐ an allied health service (such as physiotherapist, podiatrist, etc)
☐ Somewhere else (please specify)

10. Please tell us, in your own words, what happened?

11. Please let us know the email we can contact you on should your story be selected.

12. Would you like to receive HCNSW's regular newsletter about our work and news of interest to health consumers in NSW?

○ Yes
○ No

About Health Consumers NSW

Health Consumers NSW is a membership-based, independent, not-for-profit organisation that promotes and practises consumer engagement in the NSW health sector. We create meaningful partnerships between consumers, the health sector and policy makers.

Our mission: Consumers shaping health in NSW.

We promote the best quality, appropriate health outcomes for consumers of healthcare services. We believe that all perspectives are important and necessary to create better health outcomes for people. Consumer engagement leads to better health outcomes, more efficient and effective services, consumer-centred care and happier patients and staff. We work to ensure that health consumers are involved in the design and delivery of healthcare in NSW.

About NCOSS

The NSW Council of Social Service is the peak body for health and community services in NSW.

NCOSS works to progress social justice and shape positive change toward a NSW free from inequality and disadvantage. We are an independent voice advocating for the wellbeing of NSW communities. At NCOSS, we believe that a diverse, well-resourced and knowledgeable social service sector is fundamental to reducing economic and social inequality.

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HEALTH CONSUMERS NSW

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NSW Council of Social Service