Introduction

When we decided to look at out of pocket costs we wanted to get a better understanding of how much people pay, who pays and what impact these costs have on their health care and their lives. We asked people to give us their story as well as giving us some basic information through the survey.

The survey report, Out of Pocket Pain, includes the data collected through the survey and a thematic analysis of the stories, looking for common issues to try to highlight the key areas of concern. The stories carry a rich vein of information with many people giving us real insights into what was happening in their lives at the time of the story. The full stories show how individuals and families are impacted when faced with the double dilemma of difficult health decisions and high, sometimes unexpected, out of pocket expenses.

These stories present consumers’ experiences directly as they told them to us. The only edits that have been made to these are for spelling and grammar.

The Consumers Health Forum of Australia is the national peak body representing the interests of Australian healthcare consumers and those with an interest in health consumer affairs, with a network reaching millions of Australian consumers.

CHF has the capacity, credibility and authenticity to ensure that governments and decision makers hear and understand the consumer perspective. Our members are diverse: they cover organisations and individuals with key conditions and issues across the health system and include professional, research and other health sector bodies.

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CHF is funded by the Australian government as the peak healthcare consumer organisation under the Health Peak and Advisory Bodies Programme.
I was an uninsured patient with tumour in [my] thyroid, had it removed in metro hospital, had to travel from regional Australia several times for pre-surgery and follow up. Had ongoing integrative GP costs and Chiro costs.

Trudi

Out of pocket costs: $20 000
Health condition: Multiple auto immune
Location: Inner regional area of NSW
Education level: Bachelor’s degree

We have private health insurance. We are a self-funded retiree couple. My wife is [a] serious diabetic with heart problems and more recently diagnosed with liver problems coming from the diabetes. I recently had cataract surgery on my eyes. Apart from that I am very healthy except that during annual check-up with GP, he usually refers me to have colonoscopy or some other referral, which costs us money out of pocket.

I think it is getting extremely hard for either self funded retirees or older aged people to retain private health insurance and cover the increasing costs of health services required.

Peter

Out of pocket costs: $2000
Health condition: Chronic diabetes and heart issues
Location: Outer regional Queensland
Education level: Postgraduate degree

I suffer from MS about twice a year I require a MRI with an out of pocket cost of approximately $400 per MRI. I was hospitalised last year in a public hospital and on discharge I was handed an account for about $280 for discharge medications and asked to pay it before we left.

We have to travel to Melbourne approx. 400km each way several times a year to obtain medical treatment for my medical issues including MS.

My husband works 3 jobs to afford a reasonable standard or living for our family, pays 3 lots of tax and because of this we are not entitled to any support such as a health care card.

There is so much information broadcast on all the supports that are available to people with MS but once you enquire they all require you to have a health care card. We have even been advised for my husband to stop work and take up a carers pension and then we could get far more government support.

Why is it that a family like ours who wants to be as independent as possible is penalised because of this?

Patricia

Out of pocket costs: $2000
Health condition: Autoimmune
Location: Inner regional Victoria
Education level: Certificate or below

I have MS and require regular massage, osteopathy, swimming 4 times a week, supportive footwear, nutritional food, supplements, vitamin B injections, special mattress, cooling, heating, personal care, podiatry, grab rails in house, take away food when I can’t cook, exercise equipment, and handyman help.

Having a chronic illness means a lot of extra cost. I live on $400 a fortnight after rent for food, petrol, leisure fitness activities such as swimming to maintain a semblance of mobility, medicines etc. and there is no hope in the future that this will ever increase.

Elizabeth

Out of pocket costs: $2000
Health condition: Multiple sclerosis
Location: Outer regional Queensland
Education level: Bachelor’s degree
Really no choice in the matter, just had to pay up if I wanted the radio therapy as if I was to wait for the public hospital system it could have taken an unspecified time frame.

Other out of pocket expenses were after Medicare gap payments for mammograms, body scans and then there is the ongoing monthly expense of hormone blocking drugs which are around $39 per month.

Sue

Out of pocket costs: $4000
Incurred costs in hospital, had private health insurance
Knew about costs prior to going into hospital
Costs were discussed by a specialist
Health condition: Breast cancer
Location: Major City in South Australia
Education level: Certificate or below

I have Private Health for Hospital, but it is the X-rays I encounter the most cost before and after hospital. If I don’t book in on a bulk billing day, I am charged 700.00 for a Mammogram that I have yearly. I was diagnosed Dec 2015. Having special CT Scans and other X-rays and ultra-sounds etc, were costly with no help from Medicare or Private Health every time.

I was very lucky my working daughter helped in the initial costs, because I was in shock at the start, and test were fully on to find the breast cancer that could not be found - except Lymph node cancer - same treatment however with costs.

Maralyn

Out of pocket costs: $1500
Health condition: Breast cancer
Location: Inner regional Queensland
Education level: Other

I was diagnosed with breast cancer just before Christmas. The surgeon and oncologist have been helpful but out-of-pocket expenses for radiology, echocardiograms, physio, drugs etc. are adding up. I’m 62, get a pension from CSS, and have only been working casually and irregularly over the last two years. My income is just above the limit so I am unable to get a Health Care Card.

Consequently, I will be dipping into my super to fund my medical expenses.

It is very frustrating that I’ve worked hard and been disciplined and put extra money into my super and now I run the risk of spending a lot of it on health care when other people I know spend a lot on overseas holidays etc. but are entitled to a Health Care Card because they’re a little bit older than me or didn’t make the effort to save.

It also seems that, sometimes, the radiology/cardiology services attached to private hospitals charge more for their services than those in the community.

Sue

Out of pocket costs: around $3000
Costs were discussed by a specialist
Health condition: Breast cancer
Location: Major City in Western Australia
Education level: Other

Scans and MRI after the initial diagnosis but before MRI confirmation plus drugs after treatment.

Lynne

Out of pocket costs: $750
Health condition: Breast cancer and high blood pressure
Location: Major City in Queensland
Education level: Diploma
After my third diagnosis with breast cancer (first cancer and then 2 DCIS) I was advised to have a double mastectomy. I opted to have a reconstruction but as I have had radiotherapy on each breast my options were limited and I was advised to have a flap reconstruction, which involved lengthy plastic surgery. While my top-level private health insurance covered my hospital expenses and Medicare made a small payment towards the surgeons and anaesthetist fees, the gap was enormous, and greater than I had been advised. I had postoperative infections for which my plastic surgeon did not charge but regular visits to my local medical centre involved further gap payments. I did not consider reconstruction a luxury item but it turned out to be.

Nancy

Out of pocket costs: $30 000+
Incurred costs in hospital, had private health insurance
Knew about the costs prior to going into hospital
Costs were discussed by a specialist
Health condition: Breast cancer
Location: Major City in NSW
Education level: Bachelors degree

Medication and the gap between doctor’s charges. Just for my initial mammogram and ultrasound and the news I had cancer the bill came to $580 when I was already devastated by that news. Also had to leave our home to go to a larger city for treatment and still haven’t been able to return home.

The financial concern is one of the most stressful things during illness. People should be able to concentrate on getting well, not how they are going to pay their bills.

Alyssa

Out of pocket costs: $12 000
Health condition: Breast cancer
Location: Major City in NSW
Education level: Certificate or below

I have top private health insurance and chose to be treated through the private system. Other than an excess for the year and medicines dispensed whilst I was in the hospital, I have incurred no additional costs for my many hospital stays. The majority of my out of pocket expenses were specialists fees that Medicare didn’t return and medicines.

In addition to the cancer treatment, I was referred to a psychiatrist, psychologist and pain management specialist. There were out of pocket expenses associated with my oncologist and surgeon too.

I was living off my own money and Centrelink refused to provide me with a health care card so for the first year, I had to pay the full cost of the many medicines I was prescribed. Some of them didn’t work for me so different medicines were then prescribed wasting a minimum of $24 per abandoned bottle or packet of pills.

Once my bank account was almost empty, Centrelink approved my sickness allowance application and I now have a HCC, however there is still a gap payment for the five specialists I still see as part of routine follow up after breast cancer treatment.

The application process for the sickness allowance is quite arduous for someone who is ill from chemotherapy treatment. Frankly, I believe there should be a benefit specifically for cancer patients and that we all get a HCC, as there is a lot of medication involved in managing the symptoms caused by chemotherapy.

I remain very grateful for all the services and people that offer assistance to those of us diagnosed with breast cancer. I was quite overwhelmed by the number of new "friends" I made in those early weeks.

Despite the out of pocket costs, I would choose the private system again if I required further cancer treatment.

Simone

Out of pocket costs: $3000
Health condition: Breast cancer
Location: Outer regional Tasmania
Education level: Diploma
I chose to go private without cover for the operation and then move to the public system. My specialist supported this as she was going away and could not fit me in as a public patient for around a month. I was given a quote for around $12,000 it ended up being around $1,500 more due to the tests. I then thought that my radiation would cover 100% however I was given a bill for $2,000 out of pocket! I had to ask for a payment plan I had already borrowed the money and as a single mother I could not afford it. I was in luck as the ended up reducing my out of pockets to $1,000 and I pay $83 per week for 12 weeks.

**Angela**

**Out of pocket costs: $15 000**

**Incurred costs in hospital, did not have private health insurance**

**Costs were discussed by a specialist**

**Health condition: Breast cancer**

**Location: Outer regional Tasmania**

**Education level: No tertiary education**

Having a breast cancer diagnosis meant a whirlwind of tests and surgery. The out of pocket expenses kept coming even with top private health insurance. I think it cost me over $4000 and the cost is ongoing with yearly scans, specialist appointments etc. Sometimes I wonder why we bother with health insurance when doctors and test change above and beyond Medicare scheduled fee and health insurance wont cover the rest?? Last year my 17-year daughter was studying year 12 and had recurring chronic pelvic pain. After referral to a gynaecologist it was agreed that she needed surgery for endometriosis. The out of pocket for the surgery was $1600, the assistant $330, the pathology $115, the anaesthetist $225, and consultation $125. It is just so shameful that they all charge so much above the [schedule] particularly when we had no choice as the surgery was so important and necessary. In the same year my daughter had her wisdom teeth extracted - $1500 out of pocket! This is on top of our health insurance payments of $410 per month! There needs to be some protection of patients who do not have a choice and need to have the tests, surgery etc.

**Andrea**

**Out of pocket costs: $7000**

**Incurred costs in hospital, had private health insurance**

**Costs were discussed by ‘other’**

**Health condition: Breast cancer**

**Location: Major City in Victoria**

**Education level: Diploma**

The biggest one was the MRI, which my surgeon asked me to have although she did tell me that it would cost $600. Mammograms & ultrasounds cost me $175 per year also any additional scans required by oncologist such as CT and ultrasounds. Physio with experience in lymphedema was $90 each time. Hormone drug $35 per month and Vitamin D supplement required as the hormone tablet depletes the Vitamin D levels in your body $30 per month. Loss of salary after my sick leave ran out. Compression sleeves & head wear after losing hair due to chemo $500. This isn't taking into account any pain relief due to muscle pain from medications and peripheral neuropathy mostly in feet from the chemo. There are probably some things I have forgotten to mention.

I would like to say many thanks to our fantastic public hospital system who looked after me from day one of being diagnosed with breast cancer, all of my specialists and nursing staff are so wonderful and I will always be eternally grateful for their dedication and care. I was hospitalised 4 times during my treatment, 2 operations and 2 infections whilst on the chemotherapy, and on all occasions my treatment and stay at Gosford Hospital was excellent.

**Jayne**

**Out of pocket costs: $4000**

**Costs were discussed by a specialist**

**Health condition: Breast cancer**

**Location: Inner regional NSW**

**Education level: Certificate or below**
I went through the public health system, so my surgery and hospital specialists and radiation were covered. My out of pocket expenses were visits to my surgeon before and after my diagnosis. I don’t have private health insurance. My biggest expense was lost wages while having and recovering from breast cancer.

Lyn

Out of pocket costs: $3000
Health condition: Cancer
Location: Major City in NSW
Education level: No tertiary education

My medical out of pocket expenses were the gap fees from consultations with my GP and surgeon, and gap free for care at the private hospital where I had a lumpectomy and stayed two nights. For lumpectomy surgery the surgeon and anaesthetist did not charge any gap fee. The chemotherapy I received was at a clinic at a public hospital. The radiotherapy treatment I received was at a clinic at another public hospital. I had to travel to this clinic and stay away from home. I received financial support from Pink Angels and CanAssist. I was referred to this help by my McGrath Foundation Breast Care Nurse.

I have private health insurance; but the best and only treatment options in the regional centre where I live were as I have described above: private surgery and public chemotherapy and radiotherapy.

The other major difficulty for me has been overall finances; as my contract position finished when I was diagnosed and could not work for some time.

Jenny

Out of pocket costs: $500
Health condition: Breast cancer
Location: Inner regional NSW
Education level: Postgraduate degree

The $1150 given above was for the gap payment for radiation therapy. I do have private health cover, but they would pay nothing towards this treatment because it was not done in a hospital. Other than that, the only other costs involved were the $250 excess on my hospital cover and a gap of $150 to my surgeon.

All visits to Breast Screen Queensland cost nothing and were over and above my expectations. Cannot sing their praises highly enough.

Anne

Out of pocket costs: $1150
Health condition: Breast cancer
Location: Inner regional Queensland
Education level: Certificate or below

Have seen 3 different oncologist that all charge a fee, diagnosed with breast cancer, have been lucky enough to be accepted into a trial at Royal North Shore Hospital where treatment is free for me but they found a brain tumour which needed urgent attention, had radiation on this which was an upfront cost of $2500. Since July 2017 medical out of pocket expenses would have to be over $3500. I pay into a medical fund $200/month & have not been able to use this for anything yet, Medicare has subsidies tests etc., I had quickly met the threshold with the radiation but since it’s a new year I will be back to square one. I am a single female, I have now used up all my holidays, sick leave & long service. Have been accepted on the disability pension but my illness has definitely changed my life financially.

Melanie

Out of pocket costs: $3500 since July 2017 diagnosis
Health condition: Breast cancer
Location: Major City in NSW
Education level: Certificate or below
I have health insurance, so my out of pocket expenses were, the Excess gap for the health fund, the medications I had to take while having chemo that the hospital had for me to buy, the gap for my breast surgery x 2, as I had 2 surgeries, the cost of seeing the breast surgeon appointments, oncologist appointments, to get my port fitted, IVF costs, excess for IVF hospital, medications to prevent or stop reactions (i.e. gastro stop, numbing cream), scans

Melissa

Out of pocket costs: $15000
Health condition: Breast cancer
Location: Major City in NSW
Education level: Diploma

My out of pocket expenses were over $3500 for my breast cancer treatment being surgery and radiation therapy. I live in Cootamundra and we do not have radiation treatment available in the public hospital so my treatment was completed in the Riverina Cancer care Centre which is privately run. I the had to have cataract surgery on both eyes this surgery cost approx. $1500 out of pocket. We are in a private health fund and for these two treatments we were approx. $5000 out of pocket. I was very lucky and did not need chemo or medication or the out of pocket expenses would have been a lot more.

Cheryl

Out of pocket costs: $5000
Health condition: Breast cancer
Location: Outer regional NSW
Education level: Other

* Clothing in bigger size due to the swelling and putting on weight from medication
* Parking was subsidised at a lower rate but still expensive on a day-to-day basis.

Hospitals only recently have the exemption for parking if there for short period. I was paying $37.50 per week for 6 weeks just for radiotherapy besides the other appointments etc. I attended prior, which was paid at the full parking rate.

I have health insurance with public hospital, my choice doctor and some extras but I also see a chiropractor for other health issues. Even though I used 5 health care plan visits by the GP for the physiotherapist the first consult was over $100 then followed by $90 visits and then $80 visits (depending on time) Medicare would only give a rebate of $54.95. When having to visit regularly, it tends to add up.

Even the bras etc. that need to be purchased, I tried one type which did not help for too long due to the swelling of the seroma and lymphoma, then I bought another style which I purchased two of to be able to wash one and wear one. Now I have to look into buying another one for when the swelling is worse which will cost me around the $200 mark. Discussions were made in the Breast Cancer Care Clinics about what you may experience but it doesn’t take long for the expenses to add up which then cause other financial problems.

I really can’t understand why Ultrasounds, Mammograms and MRI’s for breasts need to be charged. I firmly believe that any person who has a medical condition should be exempt from the costs or have it subsidised, including any garments etc. that may be required. Bra’s you need at least 2 and even then a third is required for the really bad swelling days, the swell spot alone cost $35. It my sound a small amount but this is an ongoing treatment and I’m sure there will be more out of pocket expenses in the future. It would be great to see changes. Thank you.

Georgina

Out of pocket costs: approx. $1,000 for 11 months
Health condition: Breast cancer
Location: Major City in NSW
Education level: Certificate or below
Unfortunately I haven't the confidence to drive to Sydney to attend oncology department so committed to flying down every 28 days. Every 3 months there is overnight accommodation. No close family support

Helen

Out of pocket costs: $4000
Health condition: Cancer - other
Location: Major City in NSW
Education level: Diploma

I was made aware of out of pocket costs associated with my surgery by my surgeon and was fortunate to have the support of family financially. 2 weeks after my first surgery I was hospitalised with infection for four weeks, and the main "surprise" costs were always associated with scans, running into the hundreds to thousands of dollars out of pocket. These are a real ongoing concern because now I have been diagnosed I am no longer eligible for the free breast screening mammograms and ultrasounds. At a time when most women have been financially devastated by a cancer diagnoses we feel we are being abandoned when we need help the most. Diagnostic scans are the hardest and most expensive cost to come to terms with and cause a great deal of stress, as it's ongoing for many years to come.

Lori

Out of pocket costs: Roughly $12 000 but costs are ongoing
Incurred costs in hospital, had private health insurance
Costs were discussed by a specialist
Knew costs prior to treatment
Health condition: Breast cancer
Location: Major City in Queensland
Education level: Diploma

Having to pay for scans, doctor visits, medication, Uber to get to the hospital, parking. I haven't been able to get a job.

Veronica

Out of pocket costs: $5000+
Incurred costs in hospital, had private health insurance
Costs were discussed by no one
Didn't know costs prior to treatment
Health condition: Cancer - other
Location: Outer regional Queensland
Education level: Bachelors degree

PET & CT scans incur out of pocket costs.
Subsequent plastic surgery - to remove a lymphoma cancer was almost full cost paid at $1,800.

A couple of tests needed in amongst others that were needed blood pathology cost extra.

Significant gap fees incurred for day surgery - General anaesthetic for biopsies.

Extra costs in accommodation needed.

Train fares to and from hospital daily.

Being unable to work (both myself and my husband who travels with me for support).

I'm both a patient accessing the private health system and a nurse in the public sector. All information a patient can access during a significant health crisis is vital in the process.

I have been lucky enough to have had amazing care with all my specialists and other health care providers.

I always try to give as much information to patients I see in the same environment.

Karen

Out of pocket costs: $8,000-$10,000
Costs were discussed by a specialist
Health condition: Cancer - other
Location: Major City in Queensland
Education level: Bachelor’s degree
Out of pocket expenses were due to not being able to work therefore not being able to pay rent. There needs to be way more financial support for breast cancer patients as some people like myself had no sick leave or annual leave meaning not being able to work after chemo added a huge financial burden. We should be able to access our superannuation to help with the financial stress.

Paula

Out of pocket costs: $1600
Health condition: Cancer - other
Location: Major City in Queensland
Education level: Other

My out of pocket costs came from the hospital - even though I had top cover $500 excess, pathology, radiology, nuclear medicine and pharmacy. As well as the $800 that was paid to the surgeon that was not reclaimable.

I am one of the lucky ones I could afford to pay my costs but no warnings make the whole cancer experience more traumatic. I received no specific details of cost because you are told that treatment and operation depend on this and that and the costs aren't added up until after you are home when the bills start rolling in.

Lee

Out of pocket costs: Approximately $1500
Incurred costs in hospital, had private health insurance
Costs were discussed by no one
Didn't know costs prior to treatment
Health condition: Cancer - other
Location: Major City in Victoria
Education level: Other

I have no problem with paying but I am concerned that in regional Australia we have out of pocket expenses much greater than in the major cities. For example I need to have regular mammograms and ultrasounds, my out of pocket expenses in my home town is $280, only 1 provider, but a short drive to Campbelltown and my out of pocket expenses for the same test is $60... really it's OK for me I can drive but I am concerned for the people that are unable to drive to the metropolitan areas... I see a specialist who charges me $375 per visit and my rebate is $72, what! It's tough when you are told you have cancer but having to worry about the cost while you go through everything is another matter. I would be happy to be taxed more or be able to pay private cover but know I am covered not pay Medicare levy, private cover and still many thousands of dollars out of pocket if cancer chooses me for the 4th time (3 time survivor).

This website could also include information on where you can get assistance (not commonly mentioned by health providers) for example ITPAAS, Canassist, Cancer Council, these are all great support but people need to know what is available to them.

Kay

Out of pocket costs: Approx $4500
Health condition: Cancer - other
Location: Major City in NSW
Education level: Diploma

Husband aged 56 was hospitalised with a congenital heart defect. Had an ASD repaired and a mitral and tricuspid valve replacement. Lots of scans and X-rays plus surgery later he was discharged. Our out of pocket expenses about $24000. There is too much secrecy about true health costs.

Michele

Out of pocket costs: $400
Health condition: Heart disease
Location: Major City in Queensland
Education level: Diploma
The costs were discussed prior to admission however it made it virtually impossible to look at other options. I had been off work for 8 months by this time so I did request that they try and reduce my costs and most did by between 10 to 20% which was appreciated. My in hospital costs were still approx. $10k.

Then there was all the additional costs for follow up therapy (specialists, medication, physis, oncology massage, acupuncture) ... these costs in last 2 years have exceeded $8k

I am a single mum and all these costs have wiped out all my savings and I am now living week to week which is real worry given I have her2 metastatic cancer so treatment is ongoing

Somehow I think patients need to be able to see the different providers and their costs before they choose one as an indication

Jodie

Out of pocket costs: $10k
Incurred costs in hospital, had private health insurance
Costs were discussed by a specialist
Knew costs prior to treatment
Health condition: Cancer - other
Location: Major City in NSW
Education level: Diploma

I do have health insurance so that paid for my private hospital accommodation and theatre bills. However, it was the total cost of other necessary items that was a surprise - I did keep a record. There was the gap when I had the initial diagnosis, gaps between surgeon's cost and Medicare for both the initial surgery and the breast reconstruction, gaps for the ongoing specialist appointments, CT scans etc., special bras and prosthesis, prescriptions + other medication to deal with side effects, bandages, creams, physio, massages, arm sleeve - the list just goes on. Not sure how others who do not have savings manage! Thankfully I had the necessary money and also have the support of my family, which has meant that I have not had to forgo any treatment to date.

For what I understand talking to some of the specialists this is a real issue for a number of people - what happens when you get such a diagnosis and have no money or no one to fall back on? A cancer diagnosis is bad enough without having to worry about money on top of everything else.

Catherine

Out of pocket costs: Over $20 000
Health condition: Cancer - other
Location: Major City in Western Australia
Education level: Bachelor's degree

Mine isn't with hospital but allied health practitioners. I have extras cover with Health Partners and they have preferred practitioners. However, there is not a preferred physiotherapist in my area and I would have to travel approximately 70 kms to visit the preferred physiotherapist so I get a lower rebate from my health fund for see the one in my area. If I want to receive the same rebate, as member is the metropolitan area I would have to pay extra premiums.

We already have higher travel costs to visit health professionals - why should we also be slugged an extra charge by health funds just because there isn't a 'preferred professional' within 30 kms

Elizabeth

Out of pocket costs: $500
Health condition: Cancer - other
Location: Inner regional NSW
Education level: Bachelor's degree
We have found that even though you are fully covered with PHI the gap costs for hospital, specialist and diagnostic test are becoming unaffordable. I am currently sitting in a waiting room to have an ultrasound on a knee I can’t walk on because an MRI, which would give a better diagnostic result, would cost me $200 and on a pension with a number of chronic illness I am unable to afford it all. After the big bills we have had in the last two yrs I have to go for the cheap options now and probably will have to drop PHI and private specialists and go to public hospitals just to survive financially.

Kristine and Paul

Out of pocket costs: $15 000
Health condition: Chronic illness
Location: Major City in Queensland
Education level: Diploma

As a patient with a chronic and complex condition (including several autoimmune diseases and mental health issues) I have found that despite access to care plans, my out of pocket expenses have been unmanageable. I’ve often had to go without allied health and psychological treatment because I could not afford it working part time (and have been working part time due to my health concerns). I have lost time at work due to chronic pain and fatigue and this the income I need to get treatment. It’s unsustainable for people who have to have regular and consistent care to manage their pain and wellbeing.

Abbie

Out of pocket costs: $3000
Health condition: Chronic illness
Location: Major City in Victoria
Education level: Bachelor’s degree

I have a number of medical conditions and live in a rural area. GP bulk bills but most specialists don’t. They’re usually based in Melbourne so each visit requires a 700 km round trip. That means travel expenses plus overnight accommodation plus out of pocket cost for specialist. Sometimes the receptionist will mention cost when booking appointments, not always. Doctors don’t seem to consider this when making referrals.

The nearest centre for radiology always charges an out of pocket amount. I usually need to visit them a few times a year and each visit can result in around $100 out of pocket, many times it has been significantly more than this.

I also take multiple medications so my out of pocket expenses include over $100 a month at the chemist.

The local hospitals cover the out of pocket costs for patients who use their private insurance.

It would be great to look at the overall cost of health care especially for those in rural areas. There are many hidden expenses, which are not greater.

Rosemary

Out of pocket costs: At least $1500
Health condition: Chronic illness
Location: Inner regional Victoria
Education level: Bachelor’s degree

I am a 26 year old female and do not have private health insurance. I have recently been diagnosed with Chronic Fatigue, and this journey to diagnosis involved many visits to the GP (with approx. a $20 gap payment each time), and referrals to the chiropractor (covered under chronic condition GPMP with approx. $30 gap per visit), naturopath (approx. $80 per visit) and kinesiologist (approx. 80 per visit)

Lauren

Out of pocket costs: $200
Health condition: Chronic illness
Location: Major City in Victoria
Education level: Other
Once referred to a surgeon I have previously used I was given full information about how much the out of pocket cost would be. I was told that I needed to pay the amount up front or the surgery could be cancelled. I then made an appointment with the anaesthetist, as I have high risk of complications, and was relieved to be told that he would charge me at the no gap rate. He was going to try some new devices on me to alleviate any risk. As it turned out the devices didn’t work and it was a rather lengthy intubation process but still, no gap.

Even though I used a surgeon that I had previous experience with and trusted completely, it would have been useful to have an idea of what other surgeons, potentially in other hospitals, would have charged. We had to save very carefully before surgery to ensure we had the money. My employer gave me a specific period for time off and I couldn’t take any other time off if I couldn’t pay for the surgery. It would be most useful and transparent for all involved if there was a public access listing of surgeons and costs associated with particular types of surgery. This would certainly have allowed us to make our own decisions and reduce stress levels at a time that was already stressful enough.

Ben

Out of pocket costs: $3000
Incurred costs in hospital, had private health insurance
Costs were discussed by a specialist
Knew costs prior to treatment
Health condition: Chronic illness
Location: Major City in Western Australia
Education level: Certificate or below

I had spinal surgery including the consultation costs, the surgery process would have consisted of over $10k in out of pocket costs. This is with gold hospital cover with platinum extras. I wasn’t able to work and was relying on Newstart payments. Prior to the surgery, I was required to have a selective nerve block, however surgery was always going to be required, the steroid injection was unnecessary. That cost was not discussed. I had to borrow money from my parents so that I could get the surgery. Now that I am permanently disabled, I am not able to pay back the loan. I do not have any savings and I am being supported by my parents. I worry about when they die, because there is no way I can afford all of the treatment required. I tend to go without a lot of things and have to way up the costs of medication. I take 3 medications that are not on the PBS; tamgesic, arcoxia and Ondansetron. I often think, “do I really need relief from this medication, or can I go without so it lasts longer”.

I only see a physio, psychologists as often as the health plans and my insurance lasts, so I go without. Then due to my health problems and the medications, I require some extensive dental work. I couldn’t afford a root canal, so I had the tooth pulled out instead. I have 2 or 3 teeth that require root canals, but I’ll have to get them pulled out too. I need a dental splint to prevent further damage and pain, but the out of pocket fees are about $300, so I go without. There are so many other scenarios where I don’t get the treatment required because there just isn’t enough money. I am now a 35 year old, educated woman who depends on her parents.

Natalie

Out of pocket costs: over 15k both in and out of hospital
Health condition: Chronic illness
Location: Major City in Victoria
Education level: Bachelor’s degree
We have paid out of pocket expenses for GP consultations, specialist consultations allied health and dental expenses.

We are very fortunate to be able to afford additional costs but appreciate that for many people this is a serious issue that may inhibit utilisation of services.

Neville

Out of pocket costs: $1500
Health condition: Heart disease
Location: Major City in Victoria
Education level: No tertiary education

We were given printed costs with the refunds we could expect to get but the gaps came to $11,000.00. I was in so much pain that I had to go ahead with the spinal op and recently a carpel tunnel op. The spinal op was the bulk of the gap, being $10,000.00

Also any information on the doctors performance good or bad. What their success rate is.

Geoffrey

Out of pocket costs: $11000
Incurred costs in hospital, had private health insurance
Costs were discussed by a specialist
Knew costs prior to treatment
Health condition: Joint and bone
Location: Major City in NSW

Physio Gap of $78.00 per visit currently weekly
Psychiatrist out of pocket $30 per week
Podiatrist $17 per visit (monthly)
Remedial massage $80 per fortnight after reaching threshold

I have top table with Bupa, there was a rise in fees recently and they are now increasing again. My CPI increase in super was $10.50 per fortnight. The value of private Health cover has reduced the amount of cover for services. It's a lose/lose situation.

It comes down to eating and having and maintaining private health.

Private insurers are screwing us in every way. Price rises and the amount that you can claim for services has reduced. We are paying more for less cover. The fees are huge and the out of pocket expenses are also huge. The public who choose private cover will get to the point where they will be unable to maintain paying the premiums for that cover, that will put a lot of pressure on the public health system which is under pressure already, it will break.

Pauline

Out of pocket costs: $5000 minimum
Health condition: Multiple conditions
Location: Major City in South Australia
Education level: No tertiary below

Knee surgery at private hospital, overnight stay. Waiting time for this surgery was approximately one year (estimate from surgeon). This was not an option as I have a requirement within my work to have physical capacity minimum. It would be helpful to have hospital waiting times for surgery available online

Lisa

Out of pocket costs: $6000
Incurred costs in hospital, did not have private health insurance
Costs were discussed by a specialist
Health condition: Knee surgery
Location: Inner regional NSW
Education level: Diploma
I broke my leg and after 6 months visiting the fracture clinic at a public hospital they said it was healed but it was a non-union, which a private surgeon recognised. I had immediate surgery. But the private health and Medicare did not cover the high fees from the surgeon, anaesthetic and post surgery medications, physiotherapy or follow up visits. I also have a hip problem and MRI, cortisone injection and specialist’s visits have not been covered. I’m trying to find a surgeon who will do the op publically as I know the out of pocket costs of doing it with my private health insurance means I can’t afford it and I’m in daily pain.

It’s not the hospital; it’s all the post surgery follow-ups, medications and physio that are the real costs.

Liz

Out of pocket costs: $4500
In incurred costs in hospital, had private health insurance
Costs were discussed by no one
Didn’t know costs prior to treatment
Health condition: Joint and bone
Location: Major City in NSW
Education level: Postgraduate degree

The figure below is the out of pocket costs incurred when seeing specialists. At no time did anyone discuss these costs with me. I do have private health insurance. In December 2015 I had to have surgery on my cervical spine due to unrelenting pain in my right arm caused by a trapped nerve in my spine.

I waited six months to see a neurosurgeon in the public system, as I knew from previous experience how costly a first visit would be. He diagnosed the problem from an MRI and said I needed surgery but said it would be years before I could have this surgery through the public health system. I asked if he had a private practice and he said yes so I asked if I could have the surgery performed by him and he said yes.

When I asked about gaps he said his practice manager dealt with all the financial aspects. I made an appointment to see him in his rooms but before I had that appointment I was very ill with sepsis and an epidural abscess and was hospitalised for over a month on intravenous antibiotics and an infection specialist and a physician visiting me at least once a day. I was in a private hospital and that whole experience was gap free.

I then had to wait for eighteen months before I could see the neurosurgeon about my surgery as I was under the care of my infection specialist and taking five times the usual dose of an antibiotic for the whole of those 18months. I eventually was pronounced cured with a question mark so made the appointment with the neurosurgeon. Yes he said, I must have the surgery or the use of my arm could be compromised, I must see my infection specialist for swabs the day before surgery to ensure no bugs were present and my practice manager will talk you through the costs and book the hospital.

We went into the practice manager’s room and she passed me a previously prepared sheet of paper. I looked at it and there were a great deal of numbers on it and I looked at the bottom line which read $2000 and for a split second thought that was the total cost of the surgery before the private health and Medicare benefits were subtracted. With a deep sinking feeling I realised it was the gap. I looked at the practice manager and told her we had that amount saved for a holiday. Would she ask if the doctor would negotiate? Yes she would but she doubted he would. I was in a lot of pain. It was my right arm affected and I was right handed so therefore having lots of associated problems.

My husband looked at me and said, “you have to have this surgery, we have the money saved so we’ll bite the bullet”. We both felt pressured and didn’t even think of getting quotes from other neurosurgeons. When I’d had sepsis I nearly died and my husband was still recovering from that bout of worry as he was told that it could flare again during the 18mths of treatment. So we bit the bullet and went ahead with the surgery. It was successful thank goodness but the holiday we so badly needed was forsaken.
I am an Aged pensioner but go without a few luxuries to keep my private health insurance because of my poor health and also some bad experiences in the public hospital in my hometown.

One being when I had sepsis an ambulance took me to the public hospital. I was running a temperature and couldn’t put any weight on my left leg and was in excruciating pain. I was seen by two young interns who told me I had a virus and sent me home. Luckily my husband took me straight to our GP who got me admitted straight away to a private hospital. I don’t remember much about the first week, but when I was finally out of immediate danger my GP and the two specialists treating me told my husband and I on three separate occasions that had I got to hospital 24 hours later I wouldn’t be alive now as my organs would have started closing down.

Hence my distrust of the public system. I believe that we should have a public health system that works well for everyone. If this were the case there would be less people using private health. But it’s a catch 22. Less people using private health, more pressure on the public system. When we came to Australia 45 years ago from England with a broke and broken NHS we thought Australia had the best system in the world. It all seemed to work. We never heard about long waiting lists in the public system. If you had private health cover there were no gaps to pay. What went wrong?

Lyn

Out of pocket costs: $1817.75
Incurred costs in hospital, had private health insurance
Costs were discussed by a specialist
Knew costs prior to treatment
Health condition: Joint and bone
Location: Major City in South Australia
Education level: Diploma

Robotic prostatectomy. Had no choice really as the options were open surgery with a 6 to 12 month recovery and ongoing continence issues or a precise robotic surgery with a 2 month recovery period & virtually nil ongoing issues! Borrowed the money and got on with life! Obvious and clinical decision!

All based on individual choices! Do your own research & make your own decisions. Do not be afraid of second & even third opinions!

Anthony

Out of pocket costs: $12 000
Incurred costs in hospital, had private health insurance
Costs were discussed by a specialist
Health condition: Bachelor’s degree
Location: Major City in Victoria
Education level: Other

The biggest single out of pocket expense was for a Multipara metric MRI prostate scan. $400 with no rebate.
Other large out of pocket expenses have been for various specialists.

Jeffrey

Out of pocket costs: Perhaps $2000 to $3000
Location: Major City in NSW
Education level: Bachelor’s degree
After a partial knee replacement in September 2017, I was left close to $6000 out of pocket. I had expected $4000 for surgeon, but then there were extras such as X-rays, ultrasounds, and medications. They all added up. The anaesthetist was $1200 out of pocket. I really do think these costs are way too high, but unfortunately you have to pay to have such procedures done. I have wondered at times why private health insurance costs are so high. It’s been a struggle.

Dianne

Out of pocket costs: $6000
Incurred costs in hospital, had private health insurance
Costs were discussed by ‘other’
Didn’t know costs prior to treatment
Health condition: Joint and bone
Location: Major City in NSW
Education level: Certificate or below

I have Bipolar disorder and see my psychiatrist once per week at a cost of $450. I can claim back $154 from Medicare each visit until we reach the safety net (I have spent $2080 out of pocket). Once our family has reached the Safety Net we can claim $396.00 back from Medicare each visit.

I also see a Neurologist every 3 months as I have an autoimmune disease, which costs around $80 out of pocket. Plus of course GP visits for both my husband and myself. This puts enormous strain on our family especially in the first few months of the year.

I think it is criminal that specialists can charge whatever they like over the scheduled fee. There should be a limit.

Tina

Out of pocket costs: $10 000
Health condition: Bipolar disorder
Location: Major City in Queensland
Education level: Certificate or below

I had a hip replacement last year as a Private patient. I received PATS funding for my flights, however as a private patient I had to pay for my own airfares for follow up review by the treating surgeon, as this is not covered by PATS. This is poor after hospital care for treatment of osteoarthritis, which is potentially debilitating, as I grow older

Denise

Out of pocket costs: $2500
Incurred costs in hospital, had private health insurance
Costs were discussed by a specialist
Health condition: Joint and bone
Location: Major City in Western Australia
Education level: Other

I have kept a detailed spreadsheet of costs for all medical and not negotiable expenses since my diagnosis 18 months ago. After 8 surgeries, 16 rounds of chemo and 25 rounds of radiation, the gap expenses are more than $20k. It’s very hard to make ends meet, when you also consider lack of ability to work.

Anne Marie

Out of pocket costs: $20k
Incurred costs in hospital, had private health insurance
Costs were discussed by ‘other’
Knew costs prior to treatment
Health condition: Multiple conditions
Location: Major City in Western Australia
Education level: Other
Costs primarily associated with:

1. Radiology, specialist assessments and physiotherapy treatment for a torn shoulder tendon over 9 months (I don’t have private extras cover, just hospital)

2. Root canal treatment and crown on an upper molar tooth, plus a large restoration on neighbouring tooth

3. Hearing assessments *2

I’m financially well off but I feel for the many who are not. I would expect many if not most people would have to forego much of the valuable care that I’ve had access to.

* Bruce

**Out of pocket costs: $4000**

**Health condition:** Multiple conditions

**Location:** Major City in Northern Territory

**Education level:** Other

In the past two years I’ve had spine surgery for disc and nerve issues, cataracts removed from both eyes, and most recently straightening of six toes (both feet at the same time). The amounts of my out of pocket expenses could be a bit more than I’ve stated, but I’ve tried not to exaggerate!

For my back surgery, I was in the hospital for two nights. My out of pocket expenses were roughly $3,000 something. (Thank goodness I tend to forget these things and now just think about the wonderful results of the surgery as I could barely walk prior to the surgery.)

Then about six months ago, I had cataracts removed from both eyes, which was done as a day patient. Both eyes together cost about $1,000 out of pocket.

My most recent surgery was to correct painful hammertoes. This surgery involved a one-night stay in the hospital with a total out of pocket expense of about $4,000. After getting the estimate of costs, I’d called HCF to see if there were any alternatives. They gave me the names of some other doctors I might try; some were on the other side of Brisbane and others didn’t do the kind of surgery I required. So I ended up going with the doctor my GP had recommended even though the costs were high. Apparently the problem has been that the doctors are charging a lot more than the fees set by Medicare.

The costs of just an initial visit with a specialist are so high that it is very discouraging to even go to find out what your problem is and what options you have. You must pay for that initial consultation in order to get the information you need to decide whether or not you can afford further treatment. Then if you think the estimates to treat your condition are too high, you would have even more large charges to get a second opinion from another specialist. (With my US health insurance, there was no need for a referral from a GP to see a specialist, and the cost for an office visit with a specialist was about $10 more than the cost for a visit to the GP; $20 for a GP and $30 for a specialist.)

* Karen

**Out of pocket costs:** Close to $9000

**Incurred costs in hospital, had private health insurance**

**Costs were discussed by a specialist**

**Knew costs prior to treatment**

**Health condition:** Multiple conditions

**Location:** Major City in Queensland

**Education level:** Other

I have three children with ADHD requiring regular medication, psychologist appointments. My eldest so also has Juvenile arthritis and at times requires him to go to Sydney children’s hospital for out patient clinic appointments this is a very expensive appointment. The appointment is free it the three days of work to get him there.

Three meals for two of us, parking, petrol and night accommodation and two days of work. If my son sees an ophthalmologist locally it costs $250 dollars. He needs to get his eye checked every six months sometimes we just cannot afford this so we do not get it done.

My husband has had major surgery twice in Sydney and the cost was $12,000 out of pocket as we went private.
I did not even ask if they do the operation publically as it was a brain tumour and we were told it was life threatening with three young children I felt we had no option but to use our private health insurance as we were so frightened. Cost included surgeon out of pocket expenses, anaesthetist, intensivist, accommodation for me to live in Sydney for a week, airflight to and from Sydney.

The real cost would be good for country people though its not just hospital it regular appointments also in Sydney to access specialist care that is not available in the country.

Sally

Out of pocket costs: I suspect around $2000 but its difficult to estimate
Incurred costs in hospital, had private health insurance
Costs were discussed by no one
Health condition: Multiple conditions
Location: Major City in Western Australia
Education level: Postgraduate degree

We have had private health insurance all our lives and have 3 recent experiences to share:

Myself - following on from a routine dental appointment (approx. $350 out of pocket) I needed two teeth removed through a day procedure with an oral surgeon in hospital. This attracted a $500 hospital excess and $800 gap (after private health and Medicare) for the surgeon. Luckily the anaesthetist just charged the scheduled fee.

My husband - required a day procedure (investigation) with a urologist in hospital. This attracted a $500 hospital excess and $400 gap for the specialist and a further $350 for the anaesthetist.

Our son - is having a day procedure with an ENT surgeon tomorrow to remedy a tongue-tie and have his nose cauterised. There is no hospital excess as he is a dependant but there will again be nearly $400 gap for the specialist and a further $350 for the anaesthetist. My $5,000 estimate for the past two years includes out-of-pocket expenses for an urgent hysterectomy that I had last year through a gynaecological oncologist.

The problem is specialists charging well above the scheduled fee and they get away with this because there is no competition.

Sarah

Out of pocket costs: $5000
Incurred costs in hospital, had private health insurance
Costs were discussed by a specialist
Knew costs prior to treatment
Health condition: Multiple conditions
Location: Inner regional Tasmania
Education level: Other

We have not been able to tally up all our out-of-pocket expenses over two years, (estimated), but were able to be precise about the gap payments between private practitioner charges and repayments from Medicare or Private Health Fund for last year alone which amounted to over $5,700. As we are on a part pension this hit us considerably, plus many other costs in the first year and much of last year. We missed out on a holiday because we could no longer afford it.

All the tests and specialists visits have been through private organisations. There seem no other options. Some of them are all or partly covered by Medicare, but practitioners such as physiotherapists are only partly covered by the Fund e.g. cost of treatment $99.00. Refund $44.

Going twice a week as recommended was costing so much I had to give it up, I couldn’t afford it, but it would have been of huge benefit to me I believe.

Wendy

Out of pocket costs: Approximately $7000
Health condition: Multiple conditions
Location: Major City in NSW
Education level: Other
Yes I do currently hold the top-level cover for private health insurance and have always done, except for last year, which means unfortunately I need to serve the waiting period. I changed my level of cover to a lower one to include my baby because it was just so expensive for a family cover (approximately $4500 per annum for the three of us). I have now changed back to the top cover because I was not covered for major dentals and this is the first time that I am having to do this procedure.

If my root canal is not successful and I still have infection, I may have to be referred to an orthodontist and this means even higher out of pocket expenses. So far I have spent almost $2000 out of pocket on my root canal and I still need to see my dentist for the last stage. I am just hoping that I don’t have to be referred to the orthodontist and my dentist can get through these fine canals and complete the process.

Yes definitely a website that has a form of calculator which shows how much I am covered for the item numbers under my policy would be very useful.

Vimla

Out of pocket costs: Potentially more than $2000
Health condition: Multiple conditions
Location: Major City in Western Australia
Education level: Postgraduate degree

Extra over and above schedule fee for initial consult fee, surgery and anesthetist plus excess. Sometimes the quotes and invoices can be difficult to understand as well as item numbers.

James

Out of pocket costs: $1500
Incurred costs in hospital, had private health insurance
Costs were discussed by a specialist
Knew costs prior to treatment
Health condition: Not specified
Location: Remote Northern Territory
Education level: Postgraduate degree

The gap between Medicare and the neurologist visits - 4 times per year $125 each visit plus fuel and parking $100 per visit plus loss of husbands work time, food to be purchased each time even if we take fruit etc. Fuel and parking for hospital visits, pharmacy costs. Electricity increase due to air conditioning and/or heating needs due to MS to stop having to end up at hospital or doctor etc.

Being a single income household as I am unable to work plus apparently can't access a disability or part pension the monetary extras add a huge stress to the family. Private health insurance continues to rise every year income doesn't change to find extra has to come from the food budget.

Sharon

Out of pocket costs: $2500
Health condition: Neurological
Location: Major City in Queensland
Education level: Diploma

My son was diagnosed with epilepsy at 18 requiring 3 EEG and neurologist visits in the last 6 months alone. The practitioner is in Albury and does not bulk bill. The money we needed at first visit for EEG and consult was $570- my son is an apprentice and that is more than his weekly wage. The challenge for people is not only meeting the GAP but also having that full amount up front. We receive roughly $270 back on that first visit- paying a $300 gap. Subsequent visits have been $440 getting about $230 back ($210 gap). We have another visit scheduled in 3 weeks, which will amount to more than my son's weekly wage. My son is lucky to have us paying his medical costs but I do wonder about other people and if the cost is a barrier for those people accessing specialist medical care?

Lisa

Out of pocket costs: $1200
Health condition: Neurological
Location: Outer regional Victoria
Education level: Diploma
Living in rural area (Kangaroo Island) having to travel to mainland to access many specialist services costs a small fortune some covered by pats but not all being a pensioner or health care card holder makes it so hard to cope financially. Even visiting local GP is expensive as no bulk billing here and I for just one person living here out of pocket by $1000 for specialist services etc. before having knee surgery. I think it's time for all specialist services, GP to bulk bill pensioners and hcc holders.

Vicki

Out of pocket costs: $1000
Incurred costs in hospital, had private health insurance
Costs were discussed by a specialist
Health condition: Not specified
Location: Outer regional South Australia
Education level: Certificate or below

The health department does not cover most of the costs of the wife or carer while the patient is in hospital. As we do not drive to Brisbane we have to travel on the train. We receive a free trip but you still have to buy your meals. You need to be there so you have to stay in a motel close by. Taxi fares to and from each day plus you have to eat three time a day. Taxi fares at least $20.00 return, meals $60.00 per day eating from the hospital canteen. Motel $139.00 per night.

If the loved one is in hospital for a extended time this mounts up to a large expense. We are on a pension only so we find it very difficult as we have been travelling back and forwards to Brisbane on a regular basis for the last four years. These costs are only approximate and quite often cost more.

We really appreciate the help the health department does gives us but what we really need is more Specialist Doctors being encouraged to come and work in the rural areas like Bundaberg so the patients and their carers do not have to travel so far to get the help they require.

Most of the patients are elderly and find it very difficult to travel to Brisbane and back on a regular basis. You save money each fortnight just to have enough money put by for the next trip.

Kay

Out of pocket costs: $7500
Health condition: Not specified
Location: Major City in Queensland
Education level: Certificate or below

I took a lesser operation, as the out of pocket expenses would have been upwards of $45,000 (my private cover didn’t cover what I needed). I was going well for 5 weeks after the operation, however one Physio experience set me backwards, and now I need the $45,000 operation. So now I have higher cover and need to wait 12 months to have the operation I need. In the meantime, the drugs that mask my pain (that are not cheap) are potentially damaging my kidneys as I wait. Also, as a result of being impaired by the pain, I am stacking on weight and losing general fitness and overall health.

I have also moved to country Victoria for work, and have discovered that every visit to the doctor/imaging/specialist etc. costs so much more and the wait time is substantially increased.

Jeanne

Out of pocket costs: $5000 approximately
Incurred costs in hospital, had private health insurance
Costs were discussed by a specialist
Knew costs prior to treatment
Health condition: Not specified
Location: Major City in Victoria
Education level: Bachelor’s degree
Some out of pocket costs with GP who will bulk bill also. Recent colonoscopy. Specialist and procedure covered by private insurance. Anaesthetic bill was unexpected. Advised I would pay in Feb, as I had not budgeted. Received a threatening letter stating debt collection action would be undertaken.

Stephen

Out of pocket costs: $200
Inurred costs in hospital, had private health insurance, no one knew costs prior to treatment
Health condition: Multiple conditions
Location: Major City in Victoria
Education level: Postgraduate degree

Although holding Medibank extra premium in the NT very few private hospitals and they have limited services thus would require to go to public so why pay $271/month with MBF?

Ken

Out of pocket costs: $4400
Health condition: Not specified
Location: Major City in the Northern Territory
Education level: Diploma

My wife and I have private health insurance cover for hospital and extras. To reduce the ever-increasing premiums we negotiated a reduced monthly payment but the trade off was to increase our excess.

Each admission to hospital even for a day surgery requires a $500 out of pocket payment. I am involved in the Commonwealth Enhanced Primary Care Program to better manage my underlying health conditions.

The plan is coordinated through my local GP. At the annual review of my care plan I am able to choose five allied health professionals to provide me with additional services. I have noted that not all professionals accept the EPC payment through Medicare.

Increasingly they charge a gap fee. This adds to the out of pocket expenses incurred.

Ian

Out of pocket costs: $2000
Inurred costs in hospital, had private health insurance Costs were discussed by 'other'
Health condition: Not specified
Location: Major City in South Australia
Education level: Postgraduate degree
Income: $40 000 - $75 000

I do not have health insurance so have been treated as a public patient. I have an ongoing issue (undiagnosed for 10yrs, diagnosed in late 2015) that after 2 surgeries by the same 'expert' have not been rectified. This vascular surgeon will not use public diagnostics and has continually referred me to private hospital/specialists for testing.

I have had to delay testing in order to save the $ for the test. Mostly totally $300 each time. I am now at a time when I am revisiting diagnostics and I'm about ready to tell the surgeon to go stick it. Whilst I'm not fixed I am not his science experiment. My condition is not life threatening and I am extremely disappointed that I'm still undergoing treatment with absolutely no improvement to my condition.

Jones

Out of pocket costs: around $2200
Health condition: Not specified
Education level: Certificate or below
No bulk billing GPs in town, workplaces requiring a med cert for ALL time off, dental not covered by Medicare for most people are big problems. Also IPTAAS pay a pittance, lots of people chose no treatment if it means traveling away.

Advisory website would have to be so individualised due to Hospital charges, individuals PHI, doctors all charge differently etc.

Louise

Out of pocket costs: $500
Health condition: Not specified
Location: NSW
Education level: Bachelor's degree

My out of pocket expenses included hearing aids, which I need to work- don’t understand why I can’t claim them on tax.

Out of pocket for doctor appointment and the gap between the rebate increased over $10 last year, from 35 to now $45 per visit. One visit to the Dr cost me personally (after rebate) and including prescriptions $150, this was repeated 5 days later!

I was also told by the health insurance, that if I lived in a metro area, the gap with providers would be less as they have their own providers in the Metro areas. If that is not discrimination for rural people I don’t know what is!

I have a single income, mortgage, rising electricity prices, fuel costs, increasing house and car insurance and rates. I pay more for my private health insurance $255 per month and get nothing for it in Rural Areas.

I am supposed to have top-level hospital cover, but my last admission placed me in a shared room with four others (public patients) and I got "free TV &Newspaper", because no other beds were available. I could not be admitted to the Private hospital, as they could not respond to my surgical needs- no ICU. I feel extremely captive to this appalling Government influenced health system that is designed to "rip off" and take my small single income (single income household) into poverty. I can’t put money into superannuation as I am on average $6,000 in the negative each year in living costs alone. Middle female single income (household) earners are being forced into poverty.

I am concerned if I really knew what it was going to cost beforehand, I would freak and refuse to do what I needed to get done. Because I would worry about paying the next bill, or worry about how I am going to pay for groceries- sometime ignorance forces you to just "do" and worry later. Women are more likely to sacrifice their personal needs over and above other needs.

Jen

Out of pocket costs: $6255
Health condition: Not specified
Location: NSW
Education level: Postgraduate degree

We were given a fee that the specialist charges. We asked how much we would get back from Medicare. They said they didn't know and that we would have to call Medicare and ask them. That’s rubbish, they do this operation all the time and they must know the scheduled fee!! They charged us $7000 and we only got back $1200 from Medicare. The specialist also insisted on his personal anaesthetist, who also charged more than 5 times the Medicare fee. Day light robbery!

Scott

Out of pocket costs: $6000
Health condition: Not specified
Location: Major City in Victoria
Education level: Other
I have private insurance but many doctors and specialists charge over the scheduled fee. When you are ill you often have no choice. Prior to the last 2 years I ran up a $30000 excess, which I am still paying off. I have almost lost my home. I was told I should not work again but that is not an option when you have so many medical bills. I had to stay in motels in Sydney and walk to the hospital every day for blood tests. Motels, meals etc. are not covered if you are not an inpatient. My MRI's are all over the scheduled fee by at least $500 each time. Someone from the hospital calls beforehand to make sure you are able to pay.

In the country there are not many bulk billing doctors and most are over the scheduled fee. Then you have to travel to a regional centre or Sydney for medical treatment. This involves getting a family member to take time off work to drive you, meals, and petrol, accommodation then the excess.

I see many specialists many times a year due to ongoing condition and I estimate I pay about $300 per week at least each year in uncovered costs, even though I also pay top health cover. Many services I need are not available in public hospitals so unsure if I will ever be able to retire, as I could not afford the treatment I need on a pension.

I try to keep my health as good as possible but I don't do everything the doctors tell me because of money. As an Aboriginal person I am aware of the risks and want to close the gap but I cannot afford the ongoing tests and treatment I need. I work when I can but it is not enough to ensure a healthy lifestyle and security.

Debra

Out of pocket costs: $5000
Health condition: Not specified
Location: Major City in Western Australia
Education level: Postgraduate degree

I live and work in remote northern Australia where good dental, ophthalmology, neurological services all required by me are just not available. I travel to Melbourne for these services

William

Out of pocket costs: 'a lot'
Health condition: Not specified
Location: Remote Northern Territory
Education level: Postgraduate degree