

OUT OF POCKET EXPENSES

In the year that the previous Federal Government was reviewing pensions, I attended one of the consultations. It was commented by one of the people attending that pensioners on a Disability Pension receive it because they have sufficient disability to qualify. However there is no additional amount in the pension to cover the costs of that illness or disability. The exception to that, which has come in since, is the Essential Medical Equipment Payment of about \$140 per annum.

Regarding out-of-pocket expenses, I went to my Medicare record and printed off the details for the past three years. In the past 3 years, my out-of-pocket expenses were \$801. In the past 12 months, it was \$160. However, doctors' bills alone are not the whole picture of out-of-pocket expenses. I am immensely grateful that my GP bulk bills.

SPECIALISTS

Because of several chronic health conditions, I see a number of specialists and allied health professionals (physiotherapy, optometrist, counsellor).

Most specialists charge a concessional rate because I am a pensioner (Disability Support Pension). Most payments are for consultations. Sometimes these can lead to further tests and treatment. In the case of the Sleep Apnoea physician, as well as consulting room consultations, in 2011 and in previous years this included an overnight investigation at a sleep laboratory. The out-of-pocket cost for the last was \$198.85.

As well, in the case of sleep apnoea there are occasional visits to the clinic for review of CPAP (Continuous Positive Airway Pressure) equipment. These visits are charged at a concessional rate of \$20. In the past year I have had 2 or 3 visits. These visits entail taking the rather bulky and heavy CPAP equipment to the other side of town for the visits. I do not have a car and have difficulty carrying the equipment. Sometimes I have struggled over there on a bus, at other times I have paid for a taxi, about \$25 each way. I have tried using community transport but this is not always convenient or available.

CPAP EQUIPMENT

Under the Domiciliary Oxygen and Respiratory Support Scheme (DORSS), part of the ACT Equipment Service, by the great generosity of the ACT Government, the machines are lent to pensioners under a free hire scheme.

The first CPAP mask is provided. Unfortunately, the first one prescribed in 2007 was not suitable for me. A second mask was prescribed, which I purchased at a cost of about \$300; that one also was not suitable. A third mask was prescribed, which I purchased, again around \$300, and it has worked fine ever since. From time to time, replacement parts are needed, e.g. silicone mask cushion, \$95. I would very much like to purchase a complete new mask, as the old one has been in constant use since 2008, however this is not in my budget in the conceivable future. I have other ongoing costs with CPAP. I have extremely sensitive skin and need special cushions, Gecko nasal pads, which cost \$24.95 per month plus postage. As an additional factor in using CPAP, I can't bear the smell of

the local tap water as it comes from the humidifier into my mask at night. I buy Brita replacement filters, about \$13 per month. I make the purchases on alternate months to help spread out the cost. 2 Gecko one month; 2 Brita the next.

In the winter, cold air makes the water in the CPAP tube condense and fall onto the sleeper's face. I have bought a polar fleece wrap for the tube, \$49.95, which keeps the tube warm in autumn and spring. That is a one-off expense. For winter, in Canberra's cold climate, an electric heated tube is necessary, at a cost of \$150. These last a few years and then the electric wiring can kink or fail. I am on my second or third one since 2008.

PHYSIOTHERAPY

As I have a musculoskeletal condition, I have chronic pain and muscle stiffness. The GP can refer me to a private physiotherapist under an Extended Care Plan or Allied Health Plan for 5 visits a calendar year. These are charged at a normal rate by the physiotherapist but I can claim from Medicare for a partial refund. In 2014: 2 visits so far; cost to me \$110 and \$90; refund \$52.95 and \$52.95. I can have three more visits this calendar year.

REMEDIAL MASSAGE

Because of chronic pain I see a qualified remedial therapist. This is when I can afford it and when I am driven to it by desperation at the pain and stiffness. I am not in a health fund, so there is no refund. The cost for an hour treatment is \$82. If I am not able to afford that, I see one of the local massage places in the mall for about \$40 for a half hour. These are not always reliable in their efficacy.

COUNSELLOR

The burden of constant pain and financial stress can be very trying. On the advice of the doctor, I see a counsellor regularly. The cost is a (much appreciated) concessional rate of \$50 per visit, approximately every two months.

SPECTACLES

Subsidised cost of \$22 per 2 years if needed.

DENTAL HEALTH

I am eligible to use the public dental health scheme. There is a co-payment for this; last year I paid approx. \$95 for treatment.

CUMULATIVE EFFECT.

I budget careful and make provision for these costs as much as I am able. Yes, Medicare refunds are available for specialists' visits. What makes it particularly difficult is if several medical visits come close together. For instance, over the next six weeks, I have three specialists' visits. Any small amount of savings I have will be used up. (I'm referring to savings of about \$100, not huge amounts).

MEDICARE REFUNDS

It's even harder if the specialist's visit comes late in the pension fortnight. You get a Medicare refund but first you have to have the money to pay the account. After the visit, I

can make the Medicare claim. However if the pension is paid, for example, on the 17th of the month, the medical visit might be on the 24th or later. Money has to be kept aside for that. This makes it hard to buy groceries, for example, or medications, until the Medicare claim is paid. If the Medicare refund is under \$100, I can claim it online and it is paid very quickly (thank you, Medicare, this speedy payment is a huge improvement). But if the refund is over \$100, I need to submit the claim in other ways.

Not having a car, I cannot drive to the Medicare office. It is possible to make the claim by phone, and then post in the relevant document. The payment won't be made until the document is received. Otherwise I can go to a Medicare office. It is very difficult physically for me to do this. There is no direct bus route that goes to my nearest Medicare office (Braddon, ACT). If I'm well, I may be able to walk, but as I get older that is becoming more difficult. My recent bright idea is travel by the Red Rapid bus to the Gungahlin office for Centrelink/Medicare business. This is achievable but means I have to set aside some considerable time to travel over there and back, plus the connecting bus routes from my home. Also if it's a day when I have extreme fatigue, then the journey is not possible.

This month is particularly tight as I budget for the three upcoming medical visits and two physiotherapy visits (plus, coincidentally, two family birthdays and a family member staying at my home). I have made a budget and keep going over it, to make sure everything gets covered. I should really have had another physio appointment but cannot do it this fortnight; I need to keep money aside for a specialist visit. At one stage I wrote down a list for every day, and what possible expenses there would be. Then I found \$20 that I had put aside and forgotten about, so that was a big relief. You try also to budget for the expected Medicare refunds. Sometimes you know what this will be. In other circumstances, Medicare isn't able to tell you in advance, until they know the item number. Also I need several prescriptions. Even at the subsidised cost of \$6, they can be hard to fit into the budget at a time like this. I keep working out the dates, how long till the next pension and the one after that, and carefully count up the number of tablets and medications left, to see how long I can defer getting the next prescription. This is stressful and can lead to mix-ups and mistakes.

Low-FODMAPS.

Along with this, I am currently on a special diet suggested by my GP for IBS (Irritable Bowel Syndrome). I am seeing a nutritionist who is supervising me on this exclusion diet. This diet is extremely restricted for an initial period of time – usually 6 weeks, but because it is a public health nutritionist, the appointments are spaced more widely apart. The costs of this diet have been extremely expensive. For instance, on one pension fortnight I had run out of food by the second week. I went to the supermarket and bought about half a trolley of food, which I estimated to be about \$45 or \$50. It cost \$95, which was frightening to me, as I wasn't sure I had that much in the bank. Thankfully the payment went through. On the next fortnight, instead of \$180, which is my usual budgeted amount, it came in at over \$230. Some of the usual budgetary measures are not possible. e.g. dried milk powder to replace whole milk is not allowed, as it is not lactose-free. Once the exclusion period is over, I may be able to reintroduce some normal foods

and cut out the more expensive ones. In the meantime it has been challenging and stressful on many levels, not least of which is the cost.

One of the most difficult, unanticipated aspects was that few low-FODMAP foods are on the supermarket shelf. Those that are, are expensive. Hence I have done a lot more cooking myself. This means typing to look up recipes online, food preparation, chopping, cooking and washing up. In consequence, because of this extra muscle activity, I've had extreme pain in my hands, arms and back, which necessitated the allied physiotherapy treatments. I initially made physio appointments through ACT Health, but they were not available for another two months. One treatment I do find helpful, is that some years ago I purchased a warm wax bath for treatment of painful hands. I can't recall the exact amount, about \$100. Later I purchased refills of wax, around \$25 plus postage.

FIBROMYALGIA. One of my main medical conditions is fibromyalgia, a condition of chronic pain and fatigue. As well, it has a lot of sensitivities. Hence I have to buy earplugs to use at the movies to dampen the sound; I use special toothbrushes so as not to hurt my gums. I need special hand wash, creams and skin care for super-sensitive skin. Plus special eye drops, as I have an eye condition. And so on. At least I don't have to buy perfume (am allergic)! Or use hair colour (again, allergic – in fact, I have to go to the hairdresser's early in the day before other people are using dyes and sprays).

MedicAlert

Some years ago I had a bad reaction to penicillin. I was referred to an immunologist, who made the diagnosis of Stevens-Johnson syndrome. He strongly suggested I join MedicAlert and wear a piece of medical and identification jewellery. I have done this, purchased some jewellery and pay an annual membership. The 2014 membership is \$30. The initial jewellery (\$50) didn't suit my lifestyle as well as I hoped – can't get wet. I tended to take it off and leave it off. Now I have a metal bracelet (\$45), which is ideal.

For this review, I planned to go through my records and detail my expenses more precisely, but as my hands are particularly sore right now, I'm not able to look back through bank statements. Also I won't write of the expenses which other people might also have, pensioners or not: a walking stick, pain relief medication, antihistamines, fish oil supplements for arthritis (suggested by rheumatologist), Vitamin D.

NDIS

As I move into the age range for Aged Care, I had hoped to qualify for the NDIS, so that I might have more access and choice to help that was tailor made for me. My circumstances are such that it would be helpful for me to choose the assistance which is best suited to my needs. Unfortunately, as the ACT has delayed the introduction of the NDIS, I will have reached 65 by the time the scheme starts here. That means I will be excluded from the scheme.