

Submission No. 1113

(Inq into better support for carers)

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Committee Secretary
Standing Committee on Family, Community, Housing and Youth
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SUBMISSION : Inquiry into better support for carers.

Please find attached our submission to the above Committee.

The particular areas of concern outlined in this submission are transport, ACAT assessment procedures, (after hours) medical care, and respite or alternative care.

Your sincerely

Sharonie and David

26 June 2008

SUBMISSION

Preamble

I have been the chief care provider for my sister for almost nine years. She lives with me and my husband. My sister suffers a chronic illness, MS, which is described as 'progressive, non-remitting'. At this point in time, she is in very good health physically, but is quadriplegic with very limited use of her hands and arms. She suffers the discomforts that are associated with her disease, but there is no mental deterioration.

My sister has been assessed by ACAT as being in need of high level nursing home care, or the equivalent at home. She is presently receiving an EACH care package. This outside assistance consists of two carers coming daily to shower and dress her, and lift her from her commode chair into her electric chair, and prepare a light breakfast. The carers also return two days per week to give her lunch, prepare her for bed, and lift her into bed, and one day per week to give her dinner. The nurse from the facility comes three times per week to administer an enema and help me to lift her into the commode chair from her bed, and once every three weeks to change her SPC. In addition, the facility has undertaken to keep her bathroom tidy after each shower, and clean the bathroom and her bedroom one day per week. Owing to the particular OHS concerns of the facility providing the EACH package, two carers attend to operate the electric lifter that is used to transfer my sister from chair to bed, etc. This apparently impacts on the amount of time the facility can devote to attending to her needs.

My duties as primary carer consist of lifting her out of bed into the commode each morning (with the assistance of the nurse three days per week), prepare lunch and feed her five days per week, prepare her for bed and lift her in at lunchtime five days per week, and prepare and feed her dinner six days per week. I ensure she has taken her medication, and assist where necessary. I am on 24-hour call for any assistance she needs outside her normal daily routine, and naturally am on duty seven days per week.

I also work outside the home for ten hours per week, and my husband, who is retired, has taken the reins for the majority of the housework, cooking and washing. He also undertakes to stay with my sister while I am at work, and assists with the things that he can, such as preparing meals for her, and occasionally feeding her.

We have been provided with an electric lifter, an electric chair with a roho cushion, a commode chair, and an electric bed with an air mattress. These items have been donated by various community groups, or hired through the hospital equipment hire scheme. As these are all items which we would have been unable to afford, we are very grateful for the assistance we have received in acquiring them.

As you can see, we have received a high level of assistance. However, we do have some concerns still.

Issue 1

Transport is a major issue, and has been since I have been unable to lift my sister in and out of the car for around six or seven years now. We have been provided with taxi vouchers, so the cost of using taxis is certainly within reason. Unfortunately, the reliability of the taxi service is so poor, we just don't attempt to use the service any more. My sister has a very small window of being able to actually leave the house for any purpose, be it shopping or medical appointments. She is usually only out of bed for around five or six hours per day, less if she is not coping well. The last time we attempted to use the taxi service was in November last year.

Case study : My sister had been booked into a respite centre so that I could take a short break. We pre-booked a taxi in order for her to inspect the facility, but on the day the taxi was unable to pick us up at the agreed time, so the visit had to be cancelled. On the day that she was to enter the facility, we also pre-booked a taxi to take her there, which it did, some hour and a half after the agreed time. On the day that she was to return home from the facility, we did not pre-book the taxi, but rang when all discharge details had been completed. Over a period of three hours, during which time we were sitting outside the facility waiting, we telephoned the taxi companies several more times, only to be told that there were no wheelchair taxis available, and none expected any time soon. My 69 year old husband had to push her electric wheelchair (which is not registered for on-road use) manually home, along the highway where footpaths are not accessible.

As a consequence, we are just not brave enough to risk leaving the house in a taxi, as we have no guarantee that we will be able to return home in a reasonable condition. When my sister is pushed past her physical limit, it is more physically difficult for me to perform the tasks I need to do in order to settle and get her in to bed.

Luckily, my sister has a doctor who is willing to do limited home visits, but we are unable to attend any other medical appointments that may be required, unless they are at the hospital, and through the emergency department. The ambulance service is willing to transport her to and from the hospital, which is very helpful. It does get a little difficult when you have to sit up until 2am, which is the only time the ambulance was able to transport my sister home on one occasion.

Issue 2

Our second difficulty is with the ACAT Assessment system. Understandably, the assessment must be carried out each year in order to determine that recipients are receiving their entitlements, or conversely are not receiving things they are not entitled to. However, it would appear that the department providing this service is seriously understaffed/overworked. We had our last assessment in March 2007. I telephoned to arrange this year's assessment in March or April of this year, and we still have not been given an appointment.

It would seem to me to be rather more sensible if the department took note of the conditions of applicants, and in chronic cases where no improvement is expected in the

condition of the patient, possibly they could look at assessing patients on a less frequent basis, such as the motor registry does with driving licences. This could assist in lightening their load.

Without a current ACAT assessment, we are unable to access respite care, and while this is not something we plan to do unless I become physically unable to care for my sister, if that happens tomorrow, where do we stand?

I do understand the constraints that affect our wider health and community system. However, while I sympathise with staff who are overworked and little appreciated, I feel that at least they usually get a day or two off each week, and are usually able to take some weeks annual leave each year to rest and rejuvenate. Unfortunately, those of us who have undertaken to provide care for our family members are not in that enviable position.

Issue 3

The respite facilities available in the ACT are sadly not in a position to provide adequate care for someone who is not elderly, but requires a high level of care. My sister has stayed in two different facilities since coming to live with me. On both occasions she has been extremely distressed, which is not at all satisfactory. The first facility put her in the high dependence wing, in other words the wing where dementia patients are cared for, and her distress was so great that she did not stay the full week she had booked, and I brought her home. The second facility housed her in a suitable location, but sadly appeared not to have a staff willing or able to tend to her needs properly, so she was returned to bed straight after her shower each day, and my daughter visited each day in order to feed her.

There are a multitude of requirements to take into account before putting a family member into respite care, and I must admit that I was in need of a break by the time I had done all the running around last year. First, the ACAT assessment must be current and in place, then a booking has to be made with the selected facility. Up until last year her age caused problems as she was under 60, so there were few facilities available that were willing to take her.

The booking usually needs to be made some months before the intended stay. Then it is my responsibility to obtain a current medical history from her GP, and ensure that prescriptions are obtained for her medications, then organise with a pharmacy to get all medications put into Webster packs, ensure every item she is taking with her is labelled, and transport my sister, her luggage and all equipment requested by the facility to the facility, and leave notes pertaining to her regular routine (usually ignored), with staff, and receive assurances that the concept of quadriplegia is familiar (wrong - I've lost count of the number of hospital and respite facility staff who ask my sister why she hasn't got out of bed yet!).

I realise that rules need to be followed, but what happens in the instance that I am injured or taken ill suddenly, and my sister needs to be put into respite care, either on a short- or long-term basis? I would not be in a position to undertake all the legwork, so what steps

could be taken.

Issue 4

After hours medical treatment is a major problem. Our only choice here is to telephone the ambulance service and request that they take my sister to the outpatients department of the hospital. As her problems to date have been what is considered low priority, she is forced to lie in a corridor in the outpatients department until a doctor is able to attend to her needs, then left until an ambulance is free to return her home. Naturally, the ambulance cannot transport her wheelchair. We have usually found that her problems are unable to be dealt with by a doctor or nurse attending the house; even after we can get someone to make a visit, we then have to call the ambulance anyway. The fact that one doesn't always have the \$80+ on hand that CAHLMS require before they will make a home visit tempts me to cut out the middleman completely, but the hospital doesn't welcome family members turning up and announcing that the catheter has packed it in and needs to be changed, or the bowels are impacted and a fleet enema is required. We are laymen.

Conclusion

I am approaching my 60th birthday, and my husband is approaching his 70th. I have undertaken a role that precludes us from contemplating any form of 'normal' retirement. We rarely have a holiday together, and we occasionally go to Sydney for a show or some such, leaving home on a Saturday morning, and returning home on Sunday. We did have two weeks in England together in 2005, and a week on the coast followed by a week at home last November. Involvement in family gatherings is restricted, unless we host the event, or another family member absents themselves so we can attend.

If I do decide to have a night or a few days away, I usually conscript a sister for the duration. As the sister who is most able to take on the role for me is working full time, I do not feel that I have the right to ask her to take leave in order for me to have a break.

In the early days of my sister's moving to live with me, I enquired about having someone to stay with her should I wish to have a break. I'm still waiting to win Lotto.

You will note that my submission is mainly concerned with the services that are available to my sister. These are the services that most impact on me as a carer, as I am the one who has to sort them out, and deal with the circumstances when problems occur.

My major personal concern, as is probably the case with the majority of family carers, is the inability to have a decent, regular break. I don't believe that your Committee has been convened with such a mundane care in mind.

I am not chained to the house. As I stated before, I work 10 hours per week. I also visit the shops, visit family members who live close to me, and my husband and I go out to dinner one night each week. We are careful to ensure that we do not travel far, and are

only away for short periods of time. My sister is able to contact me at all times as I carry a mobile phone wherever I go. If she is not well, or is suffering particular discomfort, we stay at home.

I do not feel that I am providing a service for the community, I am caring for my sister. We receive the many benefits available for people in our circumstances. We have also spent our lives contributing to the economy of our country, so we do not feel that we are bludging off the system by taking the pensions and services that are offered to us.

My major worry as a carer is that, owing to my age, I may one day be unable to continue to provide the care that my sister requires. When that day comes, what options is she going to have with regard to receiving the care that she is entitled to? Who is going to undertake that she is not just thrown into a home where she must be treated as a number - or an irascible old lady who is impossible to please, because she has needs that must be looked to regardless of how the care giver is feeling?

There are no other family members able to assume my role, and this must be the case for other carers in the community.

My thanks for the opportunity to make this submission to your Committee.

Sharonie and David

26 June 2008