

## House Standing Committee on Family, Community, Housing and Youth

### *Inquiry into better support for carers*

Committee Secretary  
Standing Committee on Family, Community, Housing and Youth  
House of Representatives  
Parliament House  
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### **Comment on challenges facing carers of sick children and in particular carers of children with rare chronic medical conditions.**

#### ***Introduction***

Our son, Jack was born with a problem in his immune system so he would keep getting infections from bugs (bacteria) that normal people wouldn't get sick from. Fortunately these problems are rare so you probably haven't met a child like Jack but Jack's condition was similar to the "bubble boy" in the song and movie. We could have put Jack into a plastic bubble like the "bubble boy" but this is no way to live. Instead Jack had a bone marrow transplant but it didn't work and he died on his third birthday which was about two years ago.

The government refused to believe that Jack was seriously ill and needed extra care because the government had made a mistake in their definition of serious medical conditions. Indeed other children like Jack also don't qualify. Doctors looking after these children have to lie to get the government to provide support. Jack's parents wrote to various people in the government to point out the mistake and provide evidence to get them to change the law but nobody listened because only a small number of children are affected.

Unfortunately our experience as we cared for our son with a serious immune deficiency like the "boy in a bubble" shows that such children can be forgotten by the system. He didn't qualify for carers allowance despite being sick enough to meet the very stringent requirements needed to qualify for a bone marrow transplant. We also know of other children with rare conditions who died but still didn't qualify for carers allowance.

It is too late to help our family but we can fix the problem for other children like him. The government has responded to the large amount of complaints about the Carers payments by setting up a taskforce but we are worried that the proposed solutions contained in the recommendations from the taskforce will not address the problems

we ran into nor the special issues faced by other children with rare conditions. We just ask for a fair process.

### ***Committee Submission on terms of reference -***

#### ***The important role played by carers of chronically ill children***

Very ill children often spend large amounts of time in hospital. Our longest stay was 14 continuous weeks. The important role carers of young children play when in hospital is often forgotten with an obvious conclusion that the carer role is suspended while the child is being cared for by the hospital. In reality the carer role is often as hands on as being at home. Hospital staffing would need to be greatly increased if parents did not actively participate in the care of their child. This saves the community considerable cost and provides a much better environment for an often distressed child. Actively engaged carers are also important to improve the quality of care received in a large hospital, providing continuity and quality control.

While society benefits, performing this role has costs for the family. There is the intangible cost of loss of normal family life and the economic cost of lost income and a range of direct and indirect costs incurred by virtually living in a hospital. Even in a public hospital these costs range from car parking, to TV hire to cafeteria meals for parents.

Even when at home very specialised hospital level caring is required through administration of IV drugs and management of feeding tubes, maintenance of dressing, wound care and infection control. Without the carer taking on this responsibility the child would need to spend longer periods in hospital, denying someone else the bed and increase the cost to the community.

Providing access to social security does not attempt to recognise the true value the carer provides the community. Above all as parents and carers going through such a traumatic experience we would expect to be treated fairly. Unfortunately we weren't.

#### **Barriers to Social and Economic Participation for carers**

Part of the role of being a carer for a young child with an immune disorder included preparing and administering medication via mouth, nasogastric or intravenous access as needed. When Jack had the nasogastric tube in (which was most of the time) the carer had to check position prior to administering any medications and flush afterwards to prevent blockage. It also needed to have the dressing to secure the position changed frequently to prevent it from falling out. Jack also had central venous catheters; a portacath and Hickmans catheter for administration of intravenous drugs. These needed to be kept clean and have dressings changed.

Children with immune disorders cannot socialise like other children. We had to ensure that Jack only had contact with a minimal number of children and they had to be well. This meant no childcare centres, playgroups, play centres, gymbaroo, music groups etc. It also meant not taking him to the shops to do "normal" shopping. We would have to get someone to look after Jack at home while we did that.

Jack could not go to crèche and due to the level of care required any type of child care would need to be individual in the home and a trained nurse. This made work impossible unless a relative who was a nurse could look work after Jack. Work was impossible while Jack was in hospital as one of us had to stay in with him.

The kind of immune disorder Jack had meant he wasn't allowed to play in dirt or tanbark so going to the park wasn't advisable. We made occasional visits but didn't let him walk in the tanbark and went straight on the play equipment.

We did look into having private activities such as music therapy in the home but these kind of things were very expensive.

### ***Practical Measures to better support Carers***

#### **The first challenge is getting the government to recognise your role as a Carer**

In May 2005 I wrote to Senator Patterson, the then Minister for Family and Community Services regarding the problems we had encountered in trying to obtain Carer Allowance for our seriously ill son, Jack. I thought it was important for you to hear of my families' subsequent experience trying to qualify for Carers Allowance as the recent taskforce's recommendations will not correct the problems we encountered.

Jack was born with a problem in his immune system so he would keep getting infections from bugs (bacteria) that normal people wouldn't get sick from. Fortunately these problems are rare so you probably haven't met a child like Jack but Jack's condition was similar to the "bubble boy" in the song and movie. We could have put Jack into a plastic bubble like the "bubble boy" but this is no way to live. Instead Jack had a bone marrow transplant but it didn't work and he died on his third birthday. A bone marrow transplant is a very serious procedure and rightly there are stringent guidelines administered by the Department of Health as to when it should be performed. Jack qualified as being seriously ill enough to warrant a transplant yet the department of FACS has refused to believe evidence that he was seriously ill.

FACS refused to believe that Jack was seriously ill and needed extra care because the department had made a mistake in their definition of serious medical conditions. Rather than remaining a simple problem that could be easily fixed, the government Ministers' lack of leadership and the government's general lack of response to the problems I raised, has led me to question our whole system of Government.

I hear of children with mild behaviour problems qualifying for Carers Allowance yet I personally know of a number of children with serious medical problems who have died but were not able to qualify for Carers Allowance. The Carers Allowance eligibility assessment system is biased towards children with physical or mental functional disabilities. Without taking away from the needs of disabled children, children with serious medical conditions do certainly need significantly more care and attention than a normal child and their carers are equally deserving of assistance. I

know Doctors in many cases are bending the truth to have seriously ill children qualify. I am sure the public at large would be shocked by these cases.

Clearly the current system has serious problems. The Child Disability Assessment tool (CDAT) test is focused on functional impairment which is directly in breach of the carers allowance legislation which places equal weight on disabilities and medical conditions. Medical conditions are mostly addressed by a one page list of Recognised Conditions which according to its guidelines is only supposed to cover common conditions but has now become the only way for most children with medical conditions to qualify. To expect to be able to condense all medical conditions into a one page list is ridiculous. Equally ridiculous is the fact that many children qualified via the recognised conditions would not qualify via the CDAT test.

Soon after my son's death Senator Patterson did meet with my wife and I. The Senator recognised that a mistake had been made but her letter to the current Minister was effectively ignored.

A review should be conducted into Carers Allowance and problems with the recognised conditions list which wasn't directly addressed by the recent taskforce. We first raised the problems with the Recognised conditions list some four years ago and despite providing quite detailed evidence (see appendix) the problem still hasn't been corrected.

A practical measure to better support carers of chronically ill children would be to totally overhaul the qualification process for Carers Allowance. The recent task force into the review of Carers Payment (child) decided to adopt a test similar to CDAT which in our experience has significant problems accessing young children or children with rare medical conditions. By its very nature CDAT is necessary a simple and relatively short test which cannot hope to cover the full range of medical problems or interventions that may be necessary. For example the "Boy in a bubble" would not qualify using CDAT. The department of FACSIA is well aware of these problems but chooses to further promote the CDAT test in particular as a one stop simplistic solution to a complex problem. With this approach we are concerned that children with rare medical conditions will again be left out.

Further highlighting problems with the CDAT test is that many children eligible for Carers Allowance through having a recognised condition would not be eligible if using the CDAT test alone.

### **Better Communication and Accountability in Centrelink**

The attitude and language used by Centrelink are not appropriate given the important role carers play in the community. Our experience of Centrelink is that they do not make it easy for a family with a sick child to deal with them. This is especially true when calling from hospital due to poor call centre performance such as being kept on hold for long periods. They did not respond to a letter asking for an ARO review for 9 months. Their record systems are a shambles with incorrect classification of medical conditions. The language used in many of the form letters from Centrelink stating that your child has been assessed as not having a serious enough condition when you

know they will be lucky to live is cruel heartless bureaucracy. Other form letters suggested that we follow an appeal process that had no legal standing to address our problems. This was negligent in that it should have directed us to the department of FACS.

### **Lack of Accountability in the department of FACS**

The lack of rigor in the Recognised Conditions and Child Disability Assessment tool process administered by the department of FACS (now FACSIA) is remarkable as is the lack of accountability of many public servants who ignored precise information that a mistake was about to be or had been made. These people are paid professional salaries to do a professional job and not ignore problems by putting them in the too hard basket.

In these circumstances an act of grace payment should be the last line of defence to address problems created by defective legislation. Our request for an act of grace payment was denied despite our circumstances being within the guidelines for when such payments should be approved.

Various Centrelink staff and even the Social Security Appeals Tribunal medical member suggested getting a GP to tick the wrong box. I am led to believe that this sometimes happens to correct obvious defects in the social security system. We have resisted resorting to a dis-honest practice to achieve a just and morally correct outcome. Instead we have put considerable effort into trying to change the system for the better, and for the benefit of other families in a similar position. I would have expected that the good faith we have shown would have been reciprocated by the government's fair application of an Act of Grace in our case.

### **Respite Care**

Respite Care for the family is needed to provide a break from hospital and in the case of immune deficiency problems from the home. Volunteers can provide temporary care but a nurse is required to cover the frequent medications.

The government should look at funding this specialist type of child care or home nursing which is outside the current child care funding arrangements which are based on child care centres not in home care. At least there should not be a disadvantage for parents with an immune deficient child not able to access child care centres. Providing other activities such as music therapy would also be valuable.

### **Support for Children's Charities**

It is important to note the important role that charities such as Very Special Kids, Challenge and TLC play providing practical support for families with sick children. These organisations and their volunteers improve the hospital experience and provide respite support for families when not in hospital. Government support for these organisations would be money well spent.

### **Transition from a Caring Role**

Carers are lucky if they have an understanding employer that allows them to balance caring and work. Not all employers are so supportive.

In addition Carers often need to confront the death of their child and concerns about having more children.

I am willing to appear before the committee at its Melbourne hearings to explain our experiences first hand. I can also provide copies of correspondence with Centrelink, and various Ministers if required.

### ***Attached Appendix***

Immune Deficiency Abridged.