

Agreement in Principle

Mr ANDREW CONSTANCE (Bega) [10.04 a.m.]: I move:

That this bill be now agreed to in principle.

We can test the heart of society by looking at the response of government to community needs and the recognition of carers. For too long in New South Wales we have failed in that duty. We have failed to recognise those who contribute in ways that we can only imagine. For this reason I have introduced the Carers Recognition Bill 2010. I do so on behalf of the 750,000 carers in New South Wales. During my time as shadow Minister for Disability Services I have seen carers commit to their loved ones in ways that would amaze the rest of society. They give of their time, their finances, their social existence and their own health to look after and care for their loved ones. It is high time that the New South Wales Parliament recognises carers, in the same way that other Australian and international jurisdictions have. We must do better than we have in the past.

For too long, we have failed to recognise many of the challenges that exist in a carer's relationship. For too long, carers have fought hard to obtain services for their loved ones, without acknowledging the recognition and support they need from the wider community and government. The glue that holds family carers together is the heart-stopping love they have for the person they provide care for. Their love is intangible but it defines their humanity in a unique way. I see people who love so much that someone else's needs always take priority over their own. In our jobs as members of Parliament we see that every day. Carers wear their humanity in ways that most of us cannot comprehend. If we have not walked in their shoes we will never truly understand that raw love and care that guides a person to give up so much in order to assist another.

I hope that the legislation before the House receives bipartisan support. I hope that Government members—the Australian Labor Party—will join the Coalition and support this legislation. We cannot turn our backs on carers in New South Wales. It is for that reason that I want to ensure that this bill is passed. I call on every member of the Government to consider this legislation carefully and in a bipartisan way. With the passage of this bill we can take the first step forward in recognising the roles and responsibilities of carers in New South Wales.

I am joined today in the House by the shadow Minister for healthy lifestyles, mental health, and aboriginal affairs. Together we are working our way around the State to promote this legislation and engage with carers on it. It may not be a perfect bill but it is an important start. Through our consultation process we have learnt of the strong desire of carers for the enactment of this legislation. Over many years we have heard about the individual stories and, all too often, the pain and suffering associated with providing their love, care and support. All too often we have heard about carers fighting for services for their loved ones. But we do not hear all too often about the impact that the caring role has on the individual carer. I note that the State has a carers plan. All too often in the past politicians have promised so much. For that reason I hope this legislation goes one step further in two ways: first, by enacting a carers charter; and, secondly, by enacting a ministerial advisory council for carers. I will speak about that further in a moment.

I will refer to a number of stories that have been brought to my attention, because I think it is important to put into context why and how this proposed legislation came to be before the House. I recognise all carers who have lobbied hard for the State Government to introduce this legislation. I particularly acknowledge Carers NSW for the role it has played, as the peak organisation for carers in New South Wales, in bringing this to the table this morning. This is not my bill; this is a bill for carers in this State. It is a carers' bill. It is important that we acknowledge that key point in a bipartisan way. There are thousands upon thousands of stories about care in New South Wales. I will touch on a couple of them because I think it is important to do so. One carer's story is as follows:

Nineteen years ago my son Alex was a happy, healthy, normal two-year-old. My life changed forever the day his preschool called telling me he had a high temperature. I went immediately to the school to get him and take him home. His temperature was 39.7 degrees. I stripped him, gave him Panadol and ran a cool bath. As I lowered him into the water, he started to convulse. Quickly I wrapped him in a towel and ran across the road to Balmain Hospital. Thirty-five minutes later four doctors had been unable to get a cannula into his vein and he was still in the grip of the seizure.

Eventually the seizure stopped of its own accord and we went to the children's hospital at Camperdown. Here the seizures started again and continued. The many tests performed were inconclusive. After two weeks in hospital they retested Alex's spinal fluid which showed he was suffering from viral meningitis.

As a result of this illness, Alex is severely intellectually disabled and suffers from uncontrollable epilepsy. From that fateful day, sixteen years ago, the lives of four people have irreversibly changed. I don't know what our lives would have been like had this not happened but I do know they would have held more joy and less stress.

We all have dreams - mine died during the year following Alex's first seizure, when I realized that he was never going to get better. Hope dies slowly. It took my husband longer to accept Alex's condition as he had less contact with him and with the doctors.

I have devoted my life to the care of Alex to the detriment of my family, especially my other son Peter who suffered in his early years from my neglect. I feel guilty about this, but I don't know what I could have done differently. My relationship with my husband is very difficult because in order to keep going I have shut down all aspects of my life except the essential. I know he misses the happy, optimistic person I used to be, a person with a sense of humour. I have become a machine who every now and then breaks down and cries.

I don't know how long I can continue to live my life like this, but I know it is not long as there are cracks appearing in the walls of my will. Every day I cry more often and I have become completely antisocial. I fear these are signs of a deep depression, a depression caused by a lack of hope that my future might be different.

My day begins with that adrenaline pump and muscle clench I always feel when I hear Alex first stir in the morning. Perhaps you can imagine a 6-foot 100-kg three-year-old going through that terrible time when they want your constant attention, except Alex isn't a toddler you can pick up and put down somewhere safe while you take a break or catch your breath.

The things most people take for granted like taking a shower, talking to a friend on the phone or simply doing the housework I cannot do without first making sure that Alex is entertained or someone else is caring for him. My subconscious is always focused on Alex no matter what I am doing. That kind of constant vigilance is exhausting.

This is my story. But I am just one of many parents or carers in the same or similar situation in NSW.

Last year Alex had a stroke and now needs a wheelchair when going on outings and needs physical assistance to get around the home. I need help. My son is now twenty-one years old. He is big and strong and severely disabled. He needs constant attention. I cannot look after him on my own!

Disability can touch any one of us without warning, and compassion is one of the many human traits that separate us from the animals. My son, my family and I need your compassion.

I am sure Maree will not mind me reading that into the *Hansard*. She continues:

Alex is now 24 and little has changed. Every day I fight to get the support I need to care for Alex and it falls on deaf ears. My son has been reassessed for services 4 times in the past three years. Every assessment is the same, Alex is regressing, I cannot continue the level of care needed for Alex and he is assessed as being of the highest need. Instead of giving the support to us that Alex has been assessed as needing, ADHC just orders another assessment of Alex in order to put off helping us.

If Alex was in care he would have one on one care 24 hours per day because his needs are so high. The NSW government expect that I, a middle aged woman can continue to provide the supports of 4 shifts of workers all by myself.

I still cry every night and brace myself to get through each day.

I wonder how much longer I can cope.

I put in an FOI for my files. I had been told that Alex was on the high priority list for accommodation. Reading the file, Alex is not even on the priority list. ADHC have been lying to me for years.

I am often distraught. The Australian people think caring is by choice. My body said years ago that I cannot go on and no-one is listening to me. There is no choice here, my pleas are ignored. I am not caring for someone at the climax of their life. I am caring for someone so that they can live their life.

I am not caring for someone I have an adult relationship with. Nor is the care I give Alex time limited. He is not ill with the likely hood of recovery. He is not terminal. This care is not short term, it is not a blip on my life. It is my life. There is no acknowledgement of the difference, anywhere.

I repeat that sentence, "There is no acknowledgement of the difference, anywhere." She continues:

It seems that all care is placed in the same basket as having the same burden on the carer. That is the greatest of the lies portrayed about carers. My days are relentlessly the same.

I am a prisoner of my love for Alex and the NSW government is my gaoler. This government just do not give a damn. I think this government believes that while I have breath in my body they can ignore my pain. I simply do not know what to do. Please help me as I cannot go on, I am exhausted and in pain. I am totally demoralized. Am I being selfish for wanting some peace of mind and quality to my life?

All of my friends are now carers who care for their adult children with no support. Over the years the others have just melted away and they exist in the periphery of my mind like a dream. I, along with Alex have been placed in the too hard basket. Where I go, Alex also has to go, he cannot be left alone. Not even for a second. My body supports Alex. If I move away from him he stumbles. He has fallen through plate glass, down stairs, even straight through interior doors.

Lack of help has relegated my life to the NSW dust bin. I am a non person. I am now only one thing as far as my government is concerned. I am the person they fight with to ensure they don't have to spend money on assisting Alex.

Unfortunately, Alex's story is all too commonplace in this State. We have an obligation today to pass this bill, not only because it is the right thing to do but because it is the humane, decent and honourable thing that we can do to start to improve the quality of life for the State's 750,000 carers.

As I said, there are many stories. Bureaucrats and policymakers fail to understand that families have always provided the majority of support for the most vulnerable in our community. However, all too often it is becoming impossible to continue to do so. Today is historic because this legislation is the first step in what I hope are many to address this injustice. I feel very sorry for what has transpired under this Government, particularly given the legislation that other jurisdictions have enacted. We cannot continue to believe that carers will fulfil the roles that society and government should fulfil and not offer support. There are countless heart-rending stories, including in the mental health area, which the member for Barwon will address in his contribution to the debate. We must do what is right and do it in a bipartisan way. I make no apologies for my passionate pursuit of Government support for this legislation. It is time that the State had this legislation.

As I said, the bill seeks to enact a New South Wales carers' charter to recognise the contribution made to society by persons who care for other persons who have a disability or a mental or chronic illness or who are frail. The aim of the charter is to enable carers to achieve their maximum potential as members of the community. It will also require New South Wales Government agencies to take action to reflect the principles of the charter when providing services that affect carers and to establish a ministerial advisory council for carers. The objects of the bill are to recognise the valuable contribution of carers to our society and to the people they care for, and to recognise the benefits, including the social and economic benefits, provided by carers to the community. The figures that have been provided to me by Carers New South Wales indicate that carers contribute in the order of \$10 billion in unpaid care. The national figure is about \$30 billion.

We all want to keep families together and we also recognise that the Government is there to provide a safety net. However, all too often carers must provide that safety net themselves. The bill is also designed to ensure the provision of services necessary to enable carers to achieve their maximum potential as members of the community and to provide for carers' assessment of their interests, needs and choices to be considered in decision making about the provision of services that impact on their role. The bill is also designed to identify and address the specific needs of families with children and younger people who are carers and to deliver culturally appropriate services for Aboriginal and Torres Strait Islander carers, and carers from culturally and linguistically diverse backgrounds.

For the purposes of the bill, a person is a carer if the person is an individual who provides ongoing care or assistance to any of the following: A person in the target group as referred to in section 5 (1) of the Disability Services Act 1993; a person with mental illness or chronic illness and a person who because of frailty requires assistance to carry out everyday tasks. For the purposes of the bill, a person is not a carer if he or she provides ongoing care or assistance as part of a designated service or under a contract of service, or if he or she provides the ongoing care or assistance as a volunteer with a volunteer organisation or charity, or only because the person is a spouse of a person to whom ongoing care or assistance is being provided or is in a de facto relationship with the person or is a parent or guardian of that person. That is within the meaning of the Property Relations Act 1984.

The bill has two key functions: first, to introduce a carers' charter; and, secondly, to establish a ministerial advisory council for carers. I will put the objectives of the proposed carers' charter on the record because it is important that it is in *Hansard* so that anyone reading this debate will be fully aware of it. The charter provides: first, that a carer must be treated with respect and dignity; secondly, that carers must be recognised as having their own unique and individual needs; thirdly, that carers' health and wellbeing is to be given due consideration; fourthly—and this is an important aspect of the carers' charter—that carers' needs are to undergo assessment with the aim to provide timely and appropriate support and assistance; and, fifthly, that the views and knowledge that carers have in regard to the individual needs of the persons they care for must be recognised and included in the assessment, planning, delivery and review of services that impact on them in their role as carers.

In addition, the community, service providers and government should respect the relationship between carers and the persons they care for. The diversity of carers' individual needs should be identified and acknowledged, taking into consideration cultural differences, age, disability, religion, socioeconomic status, gender identification and place of residence. The responsibilities of children and young people as carers should be minimised. Remote and rurally based carers face additional difficulties caused by isolation that should be given due consideration in service delivery. New South Wales government agencies must also ensure that programs and services provided to carers are responsive, timely, coordinated, innovative, flexible and appropriate. Complaints made by carers about services that impact on them and the persons they care for must be given due attention and consideration. Services provided to Aboriginal and Torres Strait Islander carers and carers from culturally and linguistically diverse backgrounds must be culturally relevant and information must be provided to carers on their rights when dealing with government agencies.

With the charter in place, under this legislation there will be an obligation on New South Wales government agencies to take reasonable steps to ensure that officers, employees and agents of the agencies have an awareness and understanding of the charter and that the agency must take action to reflect the principles of the charter when providing services that affect carers. A New South Wales government agency must consult with the advisory council and other such bodies representing carers as the agency considers appropriate when making strategic policy or planning decisions relevant to carers. This is an important aspect of the legislation,

because for too long agencies—including NSW Health and the Department of Human Services—have not taken that need into consideration when they have developed public policy.

I make one clear point about the proposed ministerial advisory council for carers: The majority of the membership of the council will be carers. That is an important point. It will not have a membership comprising political appointees—that is, people the Government knows will say what it wants to hear. It will hear directly from the carers. The advisory council will have a direct channel to the key decision makers in government—that is, the Ministers responsible for carers. The council will be co-chaired by the Ministers responsible. The responsible Ministers will be at the meetings and will have to take on board the advice of the advisory council. It is important that the advisory council look closely at the charter and at what is required in carers' assessments into the future so that we can ensure we have a much better system to assist carers.

ACTING-SPEAKER (Mr Thomas George): Order! I remind the member for Bega that pursuant to the standing orders this debate will be interrupted at 10.30 a.m. to allow the House to consider Government business.

Mr ANDREW CONSTANCE: I seek leave to conclude my speech prior to the commencement of Government business.

Leave granted.

I thank the Leader of the House for granting leave. I recognise there are many carers in the gallery today who have obviously had to change their plans to be here, so I thank the member. The advisory council will have the following functions: to work to advance the interests of carers and promote compliance by New South Wales Government agencies within this Act; to make recommendations to the Minister on fostering compliance by New South Wales Government agencies within this Act; to provide general advice to the Minister on matters relating to carers; and to carry out such other functions relating to carers as may be directed by the Minister. Any recommendation given to the Minister may be given either at the request of the Minister or without any such request. The advisory council must also, as soon as practical after the beginning of each year or on any other occasion requested by the Minister, prepare a report for the Minister outlining the performance by New South Wales Government agencies of their obligations under this Act and the compliance or non-compliance of Government agencies within this Act.

I hope that gives a brief overview of what the legislation hopes to achieve. It is important, as I said earlier and will keep saying, for the legislation to have bipartisan support. There is no doubt that carers in New South Wales have not been recognised by government, and it is time for that to change. As I indicated before, New South Wales 748,000 carers. That is, one in 10 of us are carers. Of those, 149,700 are primary carers, and 12.4 per cent of the New South Wales indigenous population are carers. It is important to recognise that many carers suffer in silence. They suffer social isolation. They cannot have the types of relationships that the rest of us do. Laraine Toms best summed it up to me yesterday from Carers New South Wales when she said to me, "Carers are denied what the rest of us are taking for granted." No truer statement can be given of the situation carers face in New South Wales.

The financial disadvantage carers face is also important to be acknowledged in this debate. Caring responsibilities adversely affect carers' financial situations—drops in income, no superannuation and the ability to accumulate savings. Some interesting Australian Bureau of Statistics figures are also important to note: 44 per cent of all carers of workforce age are not in the labour force, compared with 34 per cent of the total population; the gross household weekly income of 41 per cent of all carers is less than \$453, compared with 28 per cent of the general population. It is also important to acknowledge the additional costs associated with caring—everything from medical through to transport—that have a direct impact on carers financially. The average income for carers is more than 25 per cent lower than it is for non-carers, and it is estimated that carers lose earnings in excess of \$4.9 billion per year.

It is also important to acknowledge that with the ageing of the community—all too often I argue with the Government that we must have a plan for demographic ageing in New South Wales—we also have ageing carers in our community who, all too often, have to make the difficult decision about their own future and the future of their loved ones. I will never ever forget many instances people have found themselves in when dealing with government agencies because of their age and the challenges before them. We cannot continue to allow a situation in New South Wales where you have to declare your loved one homeless to get the services that are required for the person you are responsible for. Therein lies one of the greatest injustices in this State, and we all—every member of the community and every member of this House—have an obligation to rectify the situation. With the ageing of the community we see the ageing of carers and, as we all know, with the ageing of the community at the current rate and with the projections for the years ahead we are going to see increasingly more people falling through the cracks unless we act now, which is my greatest fear.

Carers New South Wales provided me with some information in relation to the Deakin national survey of carers health and wellbeing. It is important to note this information. Findings of the survey showed that carers have the lowest levels of wellbeing of any Australian group. More than half reported some level of depression, with one-third found to be severely or extremely depressed. More than one-third of carers are experiencing severe or

extreme stress. Caring does not get any easier with time and caring compounds the effects of other factors that lead to reduced wellbeing. The survey also found any level of consistent, daily, immediate caring responsibility is sufficient to severely damage wellbeing. Wellbeing decreases as the number of hours spent caring increases. The presence of a person in the household who requires care severely compromises the wellbeing of other family members, whether they have primary carer responsibility or not.

The findings of such research are obviously very telling. I expect the Government, should this bill pass, to make the advisory council look very closely at some of this research and start to devise the necessary strategies to address some of the survey findings. One of the key things about this legislation that is very important relates to assessment. Again, information provided to me by Carers New South Wales referred to the United States model of carer assessment. In the United States, carer assessment refers to a systemic process of gathering information that describes a caring situation and identifies the particular problems, needs, resources and strengths of the family carer.

It approaches issues from the carer's perspective and culture. It focuses on what assistance the carer may need and the outcomes the family member wants for support. It seeks to maintain the carer's own health and wellbeing. Some government agencies have an ad hoc process with respect to a carer's assessment. One of the key agenda items for the ministerial advisory council will be to examine the carer's assessment, the process around a carer's assessment, the content of it, the form it should take, and how it should be tailored based on the caring context and service setting program. That important initial step must occur. It was essential to include the assessment in the bill otherwise the Government would not have the requisite, focus and attention to better support carers into the future, which has been included in the carer's charter. I hope that the Government will promptly examine those aspects associated with the carer's assessment.

In conclusion, I reiterate that I am happy for the Government to step up to the plate and join the Liberal-Nationals in supporting the bill. The Government has three courses of action open to it: it can oppose the bill, it can support the bill or it can introduce its own legislation. If the bill passes this Chamber I am confident that it will pass in the upper House without the Government's support. I hope the Ministers who have responsibility for carers under their portfolios consider this bill carefully over the next week. At that time the Government may then give an indication of who will take responsibility for the bill, because I am not sure the Government has worked that out yet.

It is extremely important to carers that the bill is passed because if not it will be an enormous injustice to carers around the State. I acknowledge the contribution of carers who, for many years, have fought for the introduction of this bill. It is my privilege to have done so on behalf of the Liberal-Nationals and in my capacity as the member for Bega. I acknowledge all carers but particularly Carers New South Wales. I pay tribute to Laraine Toms and Elena Katrakis for the enormous work they have done in preparing briefs, doorknocking and lobbying government over many years. Their efforts behind the scenes over many years should be acknowledged.

I hope this bill will give some hope to carers, who get on with their work, day in and day out. I hope they understand that this is but a first step. In my capacity as the shadow Minister for Disability Services and Ageing, I am well aware of the frustration and degree of cynicism that exists in politicians and their response to issues that directly impact on the loved ones of carers and on them. I hope that this bill provides some beacon of hope towards correcting the injustice in the future. This bill is about humanity; it is about human dignity and human rights. I hope that the Parliament today, in a bipartisan way, will take that first step to rectify the injustice.