

HEIDI-MAY HONESS — DISABILITY SUPPORT PENSION

Statement

HON SIMON O'BRIEN (South Metropolitan) [9.44 pm]: As a member for South Metropolitan Region and former Minister for Disability Services, my attention was naturally drawn to the front-page story on the *Weekend Courier*, a paper from Rockingham, of Friday, 16 June. The attention grabber was a picture of a little girl and these words —

Support sorely missed

LITTLE Heidi-May's rare condition means she needs a feeding peg and can never be left alone for fear the toddler might inadvertently block her airway-supporting tracheostomy. With a short-term future including multiple surgeries to break and then repair her jaw, how can it be that Heidi-May's condition does not qualify her for disability pension support?

Members can imagine that those words caught my attention. The article by Rachel Fenner continued on pages 6 and 7. I have made some copies of the article to which I refer. I ask them to be passed now to the Minister for Disability Services and also to the parliamentary secretary representing the Minister for Health, who I know is listening closely to this speech. When I went to the article on little Heidi-May, I discovered this. I quote in part from the story —

Heidi-May Honess is one of a kind and not just because of her cheeky personality or expressive blue eyes.

Heidi-May —

She is 22 months of age —

has a rare condition called micrognathia, which means her jaw has stopped growing.

“I knew from when she was born there was something wrong,” Heidi-May's mum Belinda said.

“She had a huge double chin and had problems breastfeeding.”

Her mother's instinct sent her to 16 different doctors—who diagnosed asthma and other issues.

She said it got to a point where she and husband Shane were taking turns staying awake to make sure she was alive.

In April, Heidi-May's health deteriorated rapidly and, tired of local doctors ignoring the problem, Mrs Honess rushed her to Princess Margaret Hospital.

“She needed an urgent tracheostomy,” she said.

“Her airways had almost closed by then.”

Then a feeding peg was put into Heidi-May's stomach because she could not eat solids.

Specialists believe Heidi-May is the only toddler in Australia with the condition.

It gets worse, members —

Heidi-May will face the first of many jaw surgeries in July where her jawbone will be broken in two places and bolts will be attached. Her jaw will be wired shut.

Mrs Honess is expected to turn these bolts twice a day to stimulate bone growth to increase the size of Heidi-May's jaw.

Mrs Honess changes Heidi-May's tracheostomy tape once a day, the tracheostomy needs suctioning and once a week it needs to be taken out and replaced.

Three times a day feeds through a peg mean Heidi-May needs to be distracted from pulling at the tubes through which she is nourish.

Members should bear in mind that she is 22 months old. Heidi-May cannot be left alone for even a moment. Can members imagine if any water or sand got into that trachy? It could block her airways and she is too young to understand.

I asked my office to be in touch and find out a bit more about this. Natalie from my office left a message and Belinda Honess returned a call. Laurissa from my office gave me some notes and I thank both Laurissa and Natalie for their efforts in this matter. Members can see what a difficult situation the Honess family is

encountering. It is not uncommon for any family to suddenly find that a member of the household requires high-care needs and assistance when recuperating or recovering or confronting some sort of disease or other medical condition that has arisen. Certainly the Honess family is going through some problems. From the notes that have been sourced by my office, I know that the family is asking for the presence of a tracheostomy to be recognised as a disability and, therefore, allow them to access the support that the family needs to continue to care for their child.

Obviously, Heidi-May requires significant care to maintain her health because of the tracheostomy and the peg feeding. However, a tracheostomy is a reversible procedure and it does not qualify as a disability. I know that the Disability Services Commission is being referred to in a lot of this, so I thought I would bring it to the minister's attention so that he can examine this a bit further. I think the newspaper article states that the minister was asked to comment but had not said anything. I think he ought to.

Hon Stephen Dawson: It said I did not respond to calls.

Hon SIMON O'BRIEN: I ask the minister to please take the opportunity to do so in due course, because I know that he is a caring person.

Heidi-May and her family have some support. Support workers from Princess Margaret Hospital for Children have been helping to guide them wherever they can, but even support workers are finding the situation frustrating and everyone is looking to a response from the Disability Services Commission for further assistance for this particular need. The email continues —

The Honess family have managed to get a little support through the not-for-profit provider Hannah's house —

Thanks to them —

with a registered nurse to help them for a few hours 3 days a week but this is not really enough for a young child who must never be left alone. They have been told if they are unable to care for their daughter at home for any reason that they need to return her to hospital immediately so the nurses can perform the procedures. Naturally the family would like to keep their daughter out of hospital for many reasons —

Not the least of which would be the many infections that could be picked up by a 22-month-old tracheostomy patient —

... she is otherwise healthy so does not need to be confined within a hospital unless ... she has already had many procedures and will be undergoing many more ...

I recognise that this is probably not a matter for the Disability Services Commission, but I raise it here in the presence of the Minister for Disability Services because I do not know what to do. I do not know how many constituents I have sought out in these circumstances and have managed to do something behind the scenes—a phone call here, a representation there—and members do not even know about it; things that other members do as well. However, frankly, with this one, I do not know what to do now. I do not have a telephone number to call, and I have just about every phone number in town. Minister, I am raising it with you and asking: what can we do that might give support to the Honess family? Knowing that it may not be, ultimately, technically, a disability matter, I am raising this matter with the parliamentary secretary to the Minister for Health, who I know is listening attentively. If it is not a DSC matter, maybe our colossal health system might have some other aspect that they might be able to provide to help Heidi-May and her family through a difficult phase in their lives.

For the record, I would not politicise this sort of thing. I would never come in here and say, "Isn't this terrible that this government is allowing this to happen!" No. These things happen; people find themselves in difficulty. However, I am saying, "You have access to the resources and the experts. Can you, in the respective portfolio areas, please have a look at this?" If it is another look, then have another look, because we need to come up with something.

Finally, before I sit down, I would like to raise this thought with members, and I think it is a good thought: if all that we have found in this information that has been sourced by my office and previously researched and reported in the paper is correct, we can all recognise that this family is in difficult circumstances. That is not to say other families are not in difficult circumstances, but these are the ones I am dealing with at the moment. I put this question to the parliamentary secretary: we go to colossal trouble and expense, do we not, as a state health system, to look after people in hospital, which is a far more expensive proposition? I am just wondering, if there is any way, to please find out and help her and her poor parents by having Heidi-May looked after at home rather

in a hospital. I would very much appreciate the parliamentary secretary letting us know something about that in due course.