THE LEGISLATIVE COUNCIL GOVERNMENT ADMINISTRATION COMMITTEE A MET IN COMMITTEE ROOM 2, PARLIAMENT HOUSE, HOBART, ON THURSDAY 9 NOVEMBER 2017

ACUTE HEALTH SERVICES IN TASMANIA

Ms DEBORAH BYRNE, EXECUTIVE OFFICER, NEUROLOGICAL ALLIANCE TASMANIA, **Ms PAM CUMMINGS**, PRESIDENT, HUNTINGTON'S TASMANIA, **Ms GEMMA KITSOS**, STROKE FOUNDATION, **Ms WENDY GROOT**, EPILEPSY TASMANIA AND **Ms HELEN CONNER-KENDRAY**, PRESIDENT PARKINSON'S TASMANIA, WERE CALLED, MADE THE STATUTORY DECLARATION AND WERE EXAMINED.

CHAIR (Mr Valentine) - Welcome to the Government Administration A Committee Inquiry into Acute Health Services in Tasmania. Thanks for taking the time to come and present to us; it is appreciated. Today we are taking sworn evidence and it is being recorded by *Hansard*. For that purpose we need you to give a statutory declaration.

All evidence taken at the hearing is protected by parliamentary privilege, which means you can speak here without any fear of legal repercussions. If you are to go outside this building and make those sorts of statements then you may not be protected by parliamentary privilege. A copy of the information for witnesses statement has been circulated, are you aware of that statement and have read that? Good.

The evidence you present is being recorded and will be published on the committee website when it becomes available. Today we will allow you to make some opening statements and we will have questions for you following that.

Ms BYRNE - We have prepared an opening statement. As you are aware, the Neurological Alliance Tasmania is an alliance of 10 not-for-profit organisations supporting many thousands of Tasmanians living with, or affected by, neurological or progressive neuromuscular conditions. The members that make up the alliance are: Alzheimer's Australia (Tasmania); The Brain Injury Association of Tasmania; Epilepsy Tasmania; Huntington's Disease Association Tasmania; Motor Neurone Disease Association of Tasmania; Multiple Sclerosis Limited Tasmania; Muscular Dystrophy Association Tasmania; Parkinson's Tasmania; Spina Bifida Association of Tasmania; and the Stroke Foundation of Tasmania.

CHAIR - Before you go any further, if during the hearing you reach a point where you feel there is something you wish to tell us in camera, confidentially, let us know and we will assess whether we allow that. You have that opportunity if you reach a point you feel you need to do that.

Ms BYRNE - The Neurological Alliance Tasmania welcomes the opportunity to respond to the Acute Health Services in Tasmania inquiry and to provide the perspective of Tasmanians living with neurological conditions or progressive neuromuscular conditions. The quality of services for these people varies across Tasmania with many areas having insufficient expertise in hospitals and in the community, particularly.

You may be aware that neurological disorders are common. Neurological disorders account for one-in-five emergency hospital admissions and one-in-eight general practice consultations, and account for a high proportion of disability in the general population.

For a variety of reasons, neurological services in Tasmania have lagged behind neurological services in Australia and future demands on inpatient and outpatient neurological services in Tasmania are likely to increase.

Neurological Alliance Tasmania's position is equity of access to timely, appropriate, effective and high quality health care for all Tasmanians. Our priorities are -

1. A well-resourced, financially and human, statewide service hub of neurological excellence based in Hobart, with knowledge in a broad range of neurological conditions.

2. Regular neurological clinics in regional areas with neurologists; relevant allied health and nursing staff fully supported to travel to these clinics.

3. Where people need to travel to Hobart or are able to travel to Hobart for neurological appointments, they are supported to do so on the understanding that additional time, accommodation and/or family support may be needed to maximise appointment outcomes.

4. Community neurological nurses and coordinators need to be located in regional health centres and provide ongoing clinical support.

5. Three full-time community liaison officers to work from the three major hospitals to liaise with community neurological nurses and to bridge the gap between the acute care and the community and access to specialist neurological care in the event of an acute hospital admission.

The rate of emergency admissions for an existing long-term neurological condition is indicative of poorly integrated acute health and community care services. There are three key factors vital to preventable neurological admissions: early intervention; a multiple disciplinary team approach to care; and preventable admissions through effective person-centred care plans.

To summarise, our main issue is the inequity in services across Tasmania. It is very much a postcode lottery that exists in terms of neurology services across Tasmania. Whilst we recognise there is a need to look at the acute care sector, it cannot be looked at in isolation in terms of people living with neurological conditions in Tasmania. You need to look at greater support in the community to prevent people being admitted to hospital in the first place.

Ms FORREST - You were putting forward what you thought would be the right system and not the current system?

Ms BYRNE - Yes. In our submission we provided some case studies that showed what the current system is, what we see as what best practice would look like, and the outcomes of that from an economic sense and from a social and emotional sense. It is about supporting people in the community to prevent them needing to go to hospital. Having said that, recognising there are some people who need to be hospitalised, but if they are hospitalised that those neurological supports are there for them in the hospital so their outcomes are not worse once they are in hospital than prior to going into hospital.

Ms GROOT - Further to that, once people are released from hospital it is important to ensure they have the services readily available in whatever way they can access them in an equitable way, so they do not need to return to hospital for things that can be well-served for them at home or in their community setting.

Ms FORREST - You talked about a statewide service hub in Hobart and regional neurological clinics. One of the challenges we hear about all the time is bringing specialist staff like neurologists to Hobart, let alone into the regions. What is the best model for that? Ideally, we would have high quality internet links and that sort of thing. Is that adequate, or do you need the physical presence of people?

Ms BYRNE - I am sure others can comment, but we understand the mentality of a lot of Tasmanians is they expect a school and a hospital at the end of the street. It is not about equality. We are talking about equity of access. We think having that specialist neurology hub in Hobart, which is your centre of excellence for neurology, would be the way to go, but you also need to have access to the services. My understanding is that at the moment the neurologists are prepared to travel but they are not supported to travel. By 'supported', we mean for them to be resourced to travel but for someone to also backfill their positions while they are travelling to other parts of the state.

Ms FORREST - This is not a problem only for neurologists. This is a problem for specialist gynaecologists; all specialists. Now that we don't have a regular intrastate flight from Hobart to the north-west, for example, that option has gone. I have been told by other specialists they are required to drive themselves. On that basis, it is not a good use of time or resources. Why wouldn't you be based in Launceston?

Ms BYRNE - We think there should also be neurologists in Launceston but they would be supported through that specialist hub in Hobart.

Ms FORREST - You would have another hub in Launceston that is more accessible for people in the north of the state?

Ms BYRNE - Yes. Gemma, it might be worth talking about what could happen with stroke care.

Ms KITSOS - Strokes sit a bit differently to these other neurological conditions, so I will start by speaking generally across the board. Telemedicine is a no-brainer for resource management and the future for consultations. Having said that, these neurological conditions are highly complex and often difficult to diagnose. The idea of this hub and spoke model is you could have your neurologists in Hobart; you have met them, had your diagnosis and treatment plan outlined. There is a huge level of medication management that happens with things such as Parkinson's and MS and they need regular monitoring. To teleconference back to the neurologist in Hobart who already knows their case may be a model that is sustainable but there needs to be some kind of face-to-face consult that does happen with that patient.

From a stroke point of view, stroke is a time-critical medical emergency. We have four-and-a-half hours only from symptom onset to deliver life-saving, clot-busting therapies. You can imagine in Hobart alone, for the community to recognise a stroke, call an ambulance, the ambulance to prioritise that call, notify the ED, turn up, conduct a scan and have drug drawn; four-and-a-half hours becomes a tight window and that is in Hobart where the treatment is available. If you look at Launceston -

CHAIR - Strahan?

Ms KITSOS - No chance. I had a phone call from the North West Regional Hospital recently and the person on the other end of the line said, 'We are killing patients. We have no treatment for stroke in the north-west of Tasmania.'. If you turn up to the North West Regional Hospital with a stroke, there is no time-critical therapy they can administer because they lack the neurological expertise. We are working as a stroke foundation, combined with the Florey Institute in Melbourne, to link into the Victoria VST - a telethrombolysis service. This is specific to stroke.

CHAIR - You are working with them to deliver that but they haven't delivered it yet?

Ms KITSOS - There is no funding. If we can find the funding - it is about $140 000 a year, $500 000 over the projected estimates - we could potentially link in with the already existing telethrombolysis network in Victoria, which gives us access to 24/7 neurologist care. This is expert stroke neurologists and the neurologists who are on the roster are there because they want to be there and thrombolysis is their passion. It gives you immediate access to that pool of expertise, which is something rural areas are crying out for.

CHAIR - I was reading that component of your submission, that it needs that specialist to say, 'Yes, you can give that clot-busting drug.'. Do the clot-busting drugs exist in the north-west?

Ms KITSOS - Yes, it is like any other drug.

CHAIR - I just wanted to clarify that.

Ms KITSOS - The point that most people miss with this thrombolysis treatment is that it is not black and white. You don't say you've got A, we do B. It is a matter of interpreting the scan and looking at all of the patient.

CHAIR - You need a specialist to do that.

Ms KITSOS - Absolutely. These specialists that are on the roster for the VST Program have access to the software on their computers in real time, so they can see the patient's brain image straight from the CT scanner and say yes, or no, to thrombolysis treatment. The North West Regional Hospital believe they have capacity to keep the patients at the hospital once they are treated, so you avoid a lot of unnecessary transfers.

Ms FORREST - There is capacity for the current staff at the North West Regional Hospital to treat and care for these patients during and after thrombolysis?

Ms KITSOS - Correct, yes.

CHAIR - Would any others care to make opening statements?

Ms CONNER-KENDRAY - I would like to say something about people living with Parkinson's and their problems with acute care, especially at the moment in Tasmania. We're now introducing what we call advanced therapies. We are not just looking at someone being set up on oral medication and having to monitor that, see where it goes and look for all the side effects. We are now looking at deep brain stimulation, we're looking at several new treatments that benefit people with Parkinson's. Without somebody on the ground, and in this case they are specialist nurses working from the community, we cannot do that. We cannot accept these people because the services just aren't there.

Some of the new medications coming in can cause side effects, such as compulsive disorders that we have had before that weren't picked up. We've had people go bankrupt and get into other sorts of trouble. If there had been specialist nurses out there able to monitor that, it would not have happened. Why should people in Tasmania not be able to have the same advanced therapies as people interstate, where they've been available for quite some time?

CHAIR - Can you just expand on the level of services provided here as opposed to other states in your disciplines, or areas of interest?

Ms CONNER-KENDRAY - Yes. If you're looking at the north or the north-west, of course, we haven't got any neurologists. We have one geriatrician who specialises in Parkinson's and who travels up for a clinic -

Ms FORREST - From Hobart?

Ms CONNER-KENDRAY - From Hobart. One in Launceston and one in the north-west. Working alongside that doctor is the specialist nurse who is there with the patient and then goes out and follows up afterwards. For these people to go into acute care with Parkinson's, they may go in with something quite simple but because the health people in acute care don't understand medications - and you can't just say this is the medication, this is what you do because they are changing from time-to-time, depending on the condition of that person.

Ms FORREST - Just on that point, Helen, does the patient manage that at home? When you say the medications change, I would argue that every nurse who is registered would be able to administer the medications. Are you alluding to something that requires an adjustment or a change?

Ms CONNER-KENDRAY - Yes.

Ms FORREST - How would it be managed at home?

Ms CONNER-KENDRAY - One of the issues around medication management is that they must be given on time, every time, and away from meals, because they have to get where they need to go and the meal interferes with that. In acute care there is the medication round. You're not going to get the staff there to say this medication round is for this person and this medication round is for that person. Then you get into a situation where the Parkinson's disease gets totally out of hand. These people develop hallucinations, delusional behaviour, and they are then seen as being long-term acute care and possibly end up in residential care. Whereas, if they had been managed outside of acute care with neurologists and with specialist services on the ground - this is looking at a multidisciplinary services right across the board for all these neurological disorders and with Parkinson's - these people would not be ending up in acute care. You would reduce the number of admissions and you would reduce the number of long stays in acute care. Tasmania has the highest percentage per head of population of Parkinson's than any other state and the highest percentage on the north-west coast.

CHAIR - You talk about multidisciplinary services. Are we talking about specialist trained nurses out in the community delivering this, or are we talking about clinicians being a part of that but maybe on a less regular basis? Are we talking about people who have training in multiple conditions, or do they need to have a specialist niche in a condition?

Ms CONNER-KENDRAY - One of the difficulties is some of the conditions will fall in line and be similar. Then you look at MS, for instance, which requires another specialty and Parkinson's requires another specialty. You do have sub-groups in the neurological disorders bracket where some of them fit together, but others are more distinct in their needs. When you are looking at multidisciplinary services, you are looking at physios, OT, speech pathologists. Swallowing is a major issue with quite a few of our conditions and very much in Parkinson's. You swallow, you inhale, you get inhalation pneumonia and you are back in again.

Whilst we say we have a specialist neurological nurse, that is a misnomer because that specialist neurological nurse probably would spend 5 to 10 per cent of their time looking at any of the other conditions at the moment, because their time is all taken up with Parkinson's. This means you have people with Huntington's, I know the specialist nurses in the north and north-west do see some people with Huntington's, but that -

CHAIR - Is it a rarer occurrence?

Ms CONNER-KENDRAY - Yes. The knowledge, skills and the services Huntington's need do not necessarily fall into all of Parkinson's. Yet, I know a psychogeriatrician that was working at the north-west worked very closely with our people with Parkinson's as well as Huntington's. Some of them swap over. I firmly believe if there were neurologists there who knew they had specialist nurses on the ground working out of community, who could work with them and support them, the question is, would they be more inclined to travel there and be part of that team? Is it because they see there are no services there at all, so why is it all going to fall on them without anybody to discuss or corroborate with?

Ms KITSOS - In terms of what you are saying, the question you were asking about whether the nurses can specialise or whether they are a generalised neurological nurse, it would depend on what you are modelling it on. In a metropolitan hub where staffing is not an issue and there is a larger population, you would have a CNC, a clinical nursing specialist, for each of these neurological conditions.

CHAIR - For each of those conditions.

Ms KITSOS - Yes. Can we do that here? I do not know and I guess that is what you are looking to find out. A generalised neurological nurse is going to be a step in the right direction.

CHAIR - Before we go much further, our terms of reference are about acute health services delivery across the four major hospitals in the state. A part of that is the level of engagement with the private sector in the delivery of acute health services to find out what engagement happens. To a degree this comes into term of reference 4 as much as it might touch on some of the others. I will let you continue with your opening remarks.

Pam, you may wish to add something in regard to Huntington's.

Ms CUMMINGS - Because of the degenerative nature of Huntington's and because it's a long span of time, it's around 15 years that these people are going to need health services, it doesn't really fall into the acute as much. Because of their degeneration they still need to see a neurologist on a regular basis. Most of our people on the north-west haven't seen a neurologist for two years since Andrew Churchard stopped coming from Melbourne with the TasReach Program that was running at that time.

What we need to establish is a multidisciplinary clinic, which I've seen in other states and works very well. There you have a neurologist -

CHAIR - Can you name which states?

Ms CUMMINGS - Certainly Queensland - I think they were the original state that had this multidisciplinary clinic. I've been involved in that clinic and it runs extremely well. They have a neurologist, a neuropsychologist, a psychiatrist, a neurological specialist nurse, and they have a dietician and a speech pathologist. They all attend on the same day. Most of our people, unfortunately, don't like to wait or can't wait and they certainly can't travel. For most of our people their condition is so poor they couldn't travel from Devonport to Launceston. We really need to have that service available.

CHAIR - That is being confined within a vehicle for that period of time? Is it a toilet issue, can you explain?

Ms CUMMINGS - Almost every physical problem you can think of. Many of them can't sit up, most of them couldn't walk and sitting in a confined space for that amount of time would be very difficult. It's not much use saying there is a great clinic down there, there is a great clinic in Launceston; it wouldn't help a lot of the people on the north and the north-west. Some of them in the early stages can travel, by all means, but as the degenerative activity of their condition takes hold it's an impossibility.

CHAIR - Apart from the external multidisciplinary service you are talking about, is there anything within the hospital system you see as being an issue we can focus on?

Ms CUMMINGS - There are no services in the hospital and most of the staff in the hospital, including the medical staff, know nothing or very little about Huntington's.

CHAIR - Is this across the state?

Ms CUMMINGS - Absolutely. Certainly, if you're looking at where our people are in the north-west, but it would be all over the state. I've heard people in Hobart say the same thing, and

I know our families have problems in Launceston. If we had that multidisciplinary clinic with a specialist neurological nurse. I believe well trained nurses can cross over quite a lot. I know there are peculiarities with Parkinson's and MS where there is a lot of medication involved, and they would need to have that special quality there. Most well-trained neurological nurses can cross over lots of barriers. If we had that specialty neurological nurse in the clinic she could liaise with GPs at the end of the clinic. That is what happened in the clinical I was involved in. We had a clinical nurse consultant. At the end of the clinic there was a collaboration of all the specialists and that nurse would relay to each GP for the client that was seen on that day. It worked very well.

I believe it's just started up again, the TasReach people coming from Melbourne, which is not a very good service. They come once every two or three months. Sometimes they only see a handful of people and then they go back to Melbourne. It really is not a practical service.

CHAIR - In that circumstance is this something that could be done through teleconferencing and the like, or do they have to be there with the individual?

Ms CUMMINGS - Teleconferencing could work in lots of areas. We've started that with a couple of GPs. One of our GPs recently saw a young lady in her early thirties who is in a very bad way. She has the most difficult career I've ever experienced. You cannot even hold her on a chair, her legs are behind her ears and it's absolutely horrific to see this young lady. We couldn't get any help for her. She is much too ill to travel anywhere, so one of our GPs put a message out, sent an email out, 'Is there anybody that can help me to help this girl?'. She got one reply and that was from somebody in Sydney. We have had a teleconference with them.

CHAIR - I suppose I mean telemedicine as opposed to verbal.

Ms CUMMINGS - We are desperately in need, absolutely.

Ms FORREST - In that case, Pam, it is really more about managing the symptoms. There is not a cure, as we know. Generally, is that all managed in the community? The only reason a person with Huntington's, Parkinson's or many of these others go into the acute health setting is if something else went wrong.

Ms BYRNE - I wonder if I can just come in. To clarify, we understand the terms of reference is around looking at the hospital, but our position is that I don't think you can look at the acute health care system without thinking about it. It's a bit like saying let's have a look at building in your prison without looking at why people are getting into prison. We're saying you would have less burden on the acute health sector or the acute care, the hospitals, if we can keep people out of hospitals.

Our premise is around preventable admissions and our solutions for those preventable admissions is having better services in the community, showing those services could be in the community and would get better outcomes for people. It would be more cost-effective because we know that when people have to go to hospital unnecessarily, their outcomes are worse. The main premise of our submission was around preventable admissions.

Ms FORREST - Can we talk about community-based, as it is one of the key aspects here, because it is about the end case?

CHAIR - We ran a whole inquiry on this.

Ms FORREST - We looked at preventative health, which was the same argument from the other side. The only way to manage preventative health is to keep people out of the hospital in the first place.

If we look at the interface between acute and community-based health services, when the crossover happens and people with a neurological chronic illness have to present to hospital for something else, such as a fall or pneumonia, what are the specific barriers or challenges in patient outcomes and so on, for people with neurological conditions?

Ms CONNER-KENDRAY - For Parkinson's, we've always said to our people, if you're needing to go into outpatients then either ring your specialist or ring your specialist nurse to say that, 'I've had a fall', or, 'I've done something, I have to go to outpatients.'.

Ms FORREST - Or to the emergency department.

Ms CONNER-KENDRAY - Or to the emergency department. Then the specialist nurse would contact the emergency department or even go to the emergency department and manage that person from there, through.

Ms FORREST - These nurses can go with the patient?

Ms CONNER-KENDRAY - They will meet them there. The good thing at the moment, the way we've worked with Parkinson's Tasmania is that they are community-based but they work across all sectors. Once they've introduced themselves to the hospital, if there is an issue with that person, they know that this is the specialist nurse to ring and will ring them and find out what's going on, what's happening with the medications and that sort of stuff.

Ms FORREST - Are there enough specialist nurses in the state?

Ms CONNER-KENDRAY - No.

Ms FORREST - How many do you have and how many do we need?

Ms BYRNE - We had a meeting recently with the minister. Nat is in the process of compiling what we believe the situation is, and the Minister for Health's adviser is having a look at what they believe the situation is. We're going to get together to compare notes, so to speak, so that we can get a clearer understanding around what does exist and what needs to exist to get good outcomes for people.

CHAIR - You are having that conversation, which is good.

Ms BYRNE - Yes, with the Health minister at the moment. I was looking at our submission and can remember Jen Lowe from MS gave an example in another jurisdiction; when a person presenting to the Emergency Department with a neurological condition, there is a service they can contact that is able to provide that specialist knowledge.

The other issue from a brain injury perspective and we have talked about in our submission, it is not just people coming into hospital but also people exiting the hospital. Where we have talked about that community liaison role, the Brain Injury Association was funded for 12 months through the Tasmanian Community Fund to have a liaison person working from the neurosurgical unit, specifically for families and linking them, as that liaison in the hospital, and once they leave the hospital, also linking them into that fragmented community area to get those better outcomes. There was a comprehensive report done on that, looking at care burden. There were about 80 families serviced in a 10-month period and it did get good outcomes. Being supported by the Tasmanian Community Fund, the funding was time-limited and it was done as a pilot.

CHAIR - How long did that run for?

Ms BYRNE - That went for 12 months. When we went to see the Health minister and said, 'really great outcomes, preventable admissions, good outcomes for families.' He said, 'But it is brain injury, go and speak to the Human Services minister.' When we went to see Jacquie Petrusma, it was, 'But the person is working from the hospital, you need to go and see the Health minister.'. One of the things we have talked about in our submission is those silos that currently exist that create barriers for people, and the need to have that more holistic approach.

CHAIR - Wendy, you have not had a chance to make a statement.

Ms GROOT - That is alright. One of the things we have been told, from Epilepsy Tasmania's perspective, is we have just done some research and we have identified that one-in-nine people that are presenting to emergency departments, across Australia, are Tasmanian residents and it is preventable. Admission is preventable if people are able to access some services with their GPs. We are having people presenting; such as, the highest number we recognised were many in their mid-40s who are presenting with injuries as a result of undiagnosed epilepsy. You need to be having three seizures in a 12-month period before you can get diagnosed with epilepsy but it is impossible to get seen by a neurologist after each seizure, to be identified. We have that significant issue. Epilepsy Tasmania's position is that we need to have people who can quickly access a GP to get a referral to a neurologist and for the neurologist to be there. That is the link, for us. The pressure on the acute system could be alleviated if there was some way of having an acute system that works in the community health space.

At the moment the focus on acute is in terms of the hospitals but we think there is an acute focus that would be good if it was identified for people in that community setting. When they are having an acute seizure for the first time, the injury as a result of that could be preventable if they could be diagnosed and appropriately referred to a neurologist.

Ms FORREST - Did you say they have to have three seizures before they can be diagnosed?

Ms GROOT - In a 12-month period. That is a GP recognising it as a seizure. That means you have to go to the GP for the GP to say, yes, that is what happened. You need to have a health plan in that focus. For us, that is the process around that acute plan.

We had a young child on the north-west coast who was trying to be diagnosed, could not get in to see a neurologist and was provided with medication by the GP. He ended up having significant liver issues - this was a child who was 11 or 13 - as a result of the medication because he could not be diagnosed properly. He became life-threateningly acute as a result of there not being community access for the acute systems he was needing. That person is another one that is getting services from Melbourne. That is fine as long as it is the right services.

The focus is on the pressure within the hospital system. We need to focus on the acute pressure in the community system.

CHAIR - It eventually impacts on how many people end up in the acute system.

Ms CONNER-KENDRAY - The acute system length of stay in the community would be significantly less than by the time somebody rocks up accident and emergency, because by then they could have multiple things wrong with them.

CHAIR - I note mention a number of times in your submission about the intervention the GPs will provide. Is there a need for greater training of GPs in this space?

Ms CONNER-KENDRAY - It is a difficult thing, Rob, because GPs are so time-poor. Parkinson's Australia, with GP organisations, put together an online education package for rural and remote area GPs and allied health staff. They earn points for Medicare if they complete the course. They are done in about 20-minute sections so it is not taking them a long time and I think it takes about six months. It was expensive to set up but this is trying to get education to GPs. The answer you will get is that they do not have time.

We have run GPs sessions and brought interstate speakers over and we have had a good result but the treatments and medications for people with Parkinson's change, so that all changes and you have to go back to square one.

The specialist nurses work very closely with the GPs, or try to, as part of that education building. It is the same with community-based nurses, hospital nurses and residential aged care. ANF has worked with us to set up education. Education needs to be ongoing and there are the time and finances associated with that.

GPs will tell you they are time poor and they do not have the time. If you are looking at being across all the neurological disorders and everything else they come across in their practice and try to keep up with that, it is a major thing.

CHAIR - We understand they are not superman or superwoman and they have such a lot to cope with.

Ms CONNER-KENDRAY - That is where you go back to having neurologists and people who are specialised in that area.

CHAIR - I was interested to hear whether there is a gap in their training.

Ms GROOT - For me, there is almost a discharge planning model that needs to happen within GP-land. At the moment you have a discharge planning model that operates when people are being discharged from the hospital but it is almost as if too much expectation is placed on GPs to do the whole plan that somebody might need. If somebody is presenting with any one of the neurological conditions, there is another layer within the GPs where it is a bit like a community liaison person who understands the multidisciplinary model and can say, here is where we can ensure you have your bases covered for these needs. It is like an NDIS plan or whatever it might be, so you have somebody that is a layering between those two and acts as a bit of a bridge between.

CHAIR - Someone who supports GPs in their role?

Ms GROOT - To me, there needs to be another layer that supports people through that transitioning process, whether they are transitioning in or transitioning out, to get that support -

Ms FORREST - I sat on an acute health service committee a few years ago. I will come back to one of the points raised and may still be an issue. Discharge planning and discharge summaries being sent from hospitals to GPs was a nightmare. It has improved. Some GPs still do not seem to be able to use email, which is a shame because that is a very instant way of sharing the information. It is better, so I hear.

The discharge plan and the discharge summary from an acute hospital admission predominantly relates to the reason for that admission, which would not be Parkinson's, Huntington's or epilepsy. It would be because they fell over when they were having a seizure or whatever. If they had had a medication change while in there, for example, that would be reported. Other than that, it would not be preparing a plan for care of the pre-existing underlying condition.

I hear what you are saying about the GP having to be responsible for that. If there were enough neurologically trained nurses that could undertake that role, would that address that? That is, when that patient is discharged, the discharge summary goes to the GP and the nurse that provides that care for them, whether it be a Parkinson's nurse -

Ms CONNER-KENDRAY - That happens with us now.

Ms FORREST - Is that effective? If it is, is that something we need more of?

Ms CONNER-KENDRAY - Any communication or any change the specialist nurse may see out there is immediately written down and sent to the GP and it is sent to the specialist. Any hospital admission is the same and coming back the other way. We find the specialist nurse is the coordinator, if you like. They have the care plan, they refer out to allied health and wherever else it needs to go but there are not enough of them.

Ms FORREST - That is the point I am making.

Ms BYRNE - That is where that community liaison role, as we talked about in the hospital, can make sure that that connection is being made with the specialist.

Ms FORREST - It is all part of good discharge planning.

Ms BYRNE - The position we had was part of that discharge plan meeting. We were very fortunate, for the role we had in that pilot, that we had a neurological nurse that had role. That is why it works really well.

CHAIR - If you have a community liaison person who communicates with the hospital -

Ms BYRNE - They work from the hospital.

Ms FORREST - Liaising back out.

CHAIR - Liaising back out, but it seems you saying if a person in that role existed outside the hospital it might prevent admissions?

Ms BYRNE - We are saying both. There are still going to be people that come through your neurosurgical ward with tumours, brain injury, stroke, et cetera, so they need to be connected into the right services. It would also be for people that are coming in with other neurological conditions, also making sure they are connected to those right services; the neurological nurses, the community nurses, in the community.

CHAIR - I am making sure you are talking about two people and not one doing both roles.

Ms BYRNE - No, two different roles.

Ms KITSOS - You made an interesting point with the discharge summary issue. In my experience, often the hospital discharge summary written by the registrar overseeing the patient is very brief and very targeted to what has happened with that particular incident. Our stroke data shows that, where we have done a lot of work in the space trying to encourage a stroke care discharge plan separate to that document, a lot of people get confused when we are auditing between the two different ideas. We are talking about a much more comprehensive plan that links them with services and deals with all the deficits they are going home with.

We have found from our acute audit data that only 22 per cent of Tasmanian patients are receiving any kind of discharge care planning after they have had a stroke. This is a huge problem because having an acute incident, there is no warning that this event takes place, they are in hospital for anything from a week if it is a mild stroke - with no rehabilitation services in the north-west - and then sent home with the family. The patient is reeling as to what has just happened and has no plan as to how to link in with any other services. You are going to expect a high rate of readmission.

Ms FORREST - Or other complications. The other point was raised a few years ago, I would be interested in your views on the challenges associated with dual funding. We have a lot of primary and preventative health being funded by the Commonwealth and the acute health services funded by the state. If we can push these patients out into the community sector again fairly quickly it reduces the cost from the state to the Commonwealth. Do you have any comments on that? Is it better or worse, and is there a solution?

Ms BYRNE - I am not quite sure, from the health perspective. Others may be able to comment but from the NDIS perspective and that demarcation between the NDIS and health, a lot of our services are funded by disability services. You talked about someone in the community to be able to provide that information, that referral, where people can go. Our services are at risk because we are block funded under disability services. Once the NDIS rolls in that risk of losing that pocket of expertise is going to be significant. That social capital will be very difficult to get back. That interface between Commonwealth and state is going to be a problem. I'm not quite sure, perhaps others can comment, purely from a health perspective about the differences between Commonwealth and state, but from the NDIS perspective -

Ms FORREST - It sounds as if it might add another layer of complexity to all of that.

Ms BYRNE - Even if you look from a brain injury perspective and that definition of rehabilitation - we talk about rehabilitation coming under disability but if it comes under health, from the NDIS perspective, what will they fund and what won't they fund? As soon as someone with a disability enters the hospital system, if they're getting any disability support under NDIS, that stops. You have people with complex disabilities that don't end up with any support in the hospital system. If there are behavioural issues that can be quite problematic.

Ms FORREST - If that package of care, and the services within that, follow that patient into hospital, could that have benefits? If you have a person with Huntington's who needs to be admitted for dental surgery - that probably wouldn't be uncommon, I imagine - there are a lot of challenges around that. That person would need to have anaesthetic, so you have a range of services that person would have outside hospital, through the NDIS, that stop as soon as they go through that door. Whereas, if that service followed them into the hospital and provided some care in the hospital and then got them back out more quickly and safely - I say safely because hospitals are dangerous places - then that could have a benefit. Is there an issue we need to look at in allowing NDIS funding to follow a patient into the acute system and back out again without the funding stopping?

Ms BYRNE - Yes.

Ms CUMMINGS - Continuity of care is so important.

CHAIR - There's no demarcation, it is end-to-end service.

Ms FORREST - That's not happening; it stops. Does it restart immediately on discharge? How does that restart? The patient has gone in had their dental surgery and probably been there longer than they needed to be because of that. They end up being discharged, so when does it start?

Ms BYRNE - When they are discharged from hospital and the person then renegotiates with their service provider.

Ms FORREST - They have to renegotiate?

Ms BYRNE - They negotiate to start again. I'm not quite sure how that affects plans. I don't know whether there's a time limit, such as if they're not getting a service. You also have issues, such as if you're a service provider and you've engaged someone to work with someone and they go into hospital. There are those issues around engaging a staff member and what happens to that staff person.

Ms FORREST - This is something we can follow up with others. I am interested in the lived experience of your people. If OTs, physios or other allied health professionals come and see patients in hospital, physios will come and see a person in hospital post-stroke and that sort of thing, is there a barrier to saying that person can't come and see them in hospital, do you know?

Ms BYRNE - It would be more say, for example, if you have someone that needs 24/7 support or needs some disability support and has that funded support under an NDIS package. The person goes into hospital and the hospital isn't able to fund someone to sit with that person or to support them, but NDIS stops once the person goes into hospital, so that support person -

Ms FORREST - That person could go in. We have fathers staying with mothers when they have their babies.

Ms BYRNE - As part of their package they could go in, but they're not funded to go in. The service provider can't pay the support worker to go into the hospital because they don't get funding. They can't draw on that person's plan.

Ms FORREST - Why can't they?

Ms BYRNE - Because the NDIS plan stops when that person goes into hospital. That NDIS funding stops.

Ms FORREST - Who makes that decision? Where is that decision made? You might not know the answer and you want to follow up and look at other questions, but I want to understand which bright spark thought that simply because someone goes into an acute health setting they don't need their chronic support?

Ms BYRNE - I don't know who the bright spark was, but yes.

CHAIR - They're looking too much on a service delivery perspective, rather than the whole.

Ms BYRNE - Yes.

Ms BYRNE - You check your NDIS package at the door if you go into prison and you check your NDIS package at the door when you go into hospital. There is demarcation around aged care and around education. There are still issues being ironed out along with a whole range of other issues around that interface. There is a whole range of issues around the NDIS but from a hospital perspective, it makes a person particularly vulnerable because they are not able to access their familial supports.

Ms GROOT - When you are in hospital, the duty of care is the responsibility of the hospital, not the service provider because you are not in that context. It is because the context changes. The person who can deliver care in hospital is the hospital itself, not a support worker from your program.

Ms FORREST - Yes. It does beg the question, when you are looking at patient outcomes, and that is what I am interested in. What is really important is that where continuity is necessary, there is a process to facilitate that. I can understand the hospital not wanting to pay for the care that is being provided by others. I need to understand the barriers to allowing other people -

Ms BYRNE - Which is really stupid, because there was a client that was going into hospital; they did not have a neurological condition, they had an intellectual disability. The hospital said that they would pay one of their staff to sit with that person.

Ms FORREST - The hospital said that?

Ms BYRNE - They would pay one of their staff but they would not pay to have the disability support staff that the person was familiar with.

You have a Commonwealth/state demarcation but even as an example, we had a situation where we have people with brain or neurological injury that need to come out of hospital and transition back to communities. If I use brain injury as an example, they have had an injury to their brain and they need to re-learn their skills again. To transition back to the community, we had a house in the community that was set up as a transition house; for that person to come back into that house they needed disability support.

You are transferring a person to come out of hospital, disability said, 'we do not have the funding to support that person', so that person then sits in the hospital system, bed-blocking, longer than they need, at a greater cost, not getting rehabilitation, not getting good outcomes, getting sicker in hospital because disability services say, 'well, we cannot fund the support for that person to come back, re-learn their skills, to be able to become -

Ms FORREST - Aren't they eligible for a package of care?

Ms GROOT - If they have been through the process.

Ms BYRNE - This was prior to the NDIS. Even now, unless you are in the age cohort, no. You could have someone that falls outside the age cohort that will either sit in the hospital or end up in residential aged care because disability will not fund that at the moment. It is Health and Human Services. It is the same bucket of money.

CHAIR - It is the same thing but I imagine it is involved with the way they charge their services back to the Commonwealth through what is called casemix.

Ms BYRNE - But this was not Commonwealth, this was state.

CHAIR - They work out what this event is worth and they charge the Commonwealth for that. They cannot do that if they have other people coming into the system and doing part of that job. It makes it harder for them to handle. I can understand how it happens, but it is not to say it is a good thing. There needs to be a way through it, doesn't there? For the benefit of the patient, there needs to be a better system.

Ms FORREST - Shorten up the patient journey and you see a better outcome for the patient.

Ms KITSON - It is a sustainable model for clinicians in the hospital. If you are talking about someone in the community living with a brain injury and has behavioural issues, they have an attendant carer who knows exactly how to manage that. They have developed this relationship over years, and I am talking intricate relationships that have been built on trust, and the nursing staff on that ward are going to be forever grateful if they have their attendant carer with them, rather than having no idea how to handle this person.

CHAIR - It is an interesting point you raise.

Ms CONNER-KENDRAY - From a Huntington's point of view, we would rather not see our patients go into acute care. They come out worse than they go in.

Ms FORREST - Someone involved in the NDIS package of care, someone with Parkinson's, for example, if they were able to make sure the medications were taken on time, every time, could that prevent the deterioration of the patient's Parkinson's? It doesn't deal with their broken hip, but the nursing staff in the hospital are well trained, equipped and able to manage a broken hip and the recovery associated with it.

Ms CONNER-KENDRAY - One of the issues we have with NDIS, which is minimal in comparison to these others, is our young people still in the workforce with Parkinson's. They will need NDIS before they are 65 and won't be able to get onto NDIS. They will not be considered bad enough, even though you can show what the progression of their Parkinson's is likely to be, and that this would be preventive and help them stay in the workforce. It is a difficult one. We've not gone there with Parkinson's; they all know about NDIS, they have all looked into it and can't be bothered even applying because they know they will be knocked backed because they are not bad enough yet, but they will be.

CHAIR - On page 5 of your submission you say -

> NAT has concerns on how and what data is collected, and whether it is truly representative of the number of the people living with neurological or progressive neuromuscular conditions being admitted to hospital.

Can you expand a bit on your concerns about data?

Ms CONNER-KENDRAY - If someone with Parkinson's goes in with a broken hip, the fact they have Parkinson's won't be listed on there, so it is never recorded. We have raised this a few times with some of the people in THS. It would be a way of capturing the number of people who get admitted, how long they have to stay and what their course is whilst they are there. It would only be a matter of setting up the data in the admissions part of hospital and it would go across -

Ms FORREST - The data is collected. When you go in with a broken hip they ask you what pre-existing conditions you have. It would be there, it is how it is recorded back to the system.

Ms BYRNE - It is how it is extracted. You could have a car accident and, say, break your leg and also have a brain injury. If your main presenting -

Ms FORREST - A pre-existing brain injury?

Ms BYRNE - No, you could get both in a car accident. If your main presenting condition is your broken hip or leg, you are admitted under orthopaedics and your brain injury is secondary even though that could be the lasting impact. Getting that data on the brain injury can be very difficult.

Ms CONNER-KENDRAY - We should be able to get the number of people, say, with Parkinson's, stroke, epilepsy or these sorts of things.

Ms GROOT - We have been working with Primary Health trying to establish, in terms of people who are presenting with a brain injury, whether they have epilepsy. The issue is it is not something people are being asked. Let's say people are presenting with a broken arm and they might come back six months later with a broken head, but never in those points are they being asked, 'Have you ever been diagnosed with epilepsy?'.

Ms FORREST - I find that staggering.

Ms GROOT - But it's accurate, from our collections. We have the same issue with NDIS because epilepsy is not recognised as a criteria under the NDIS. People with epilepsy will not receive any support through the NDIS unless they have a functioning impairment. It is a major issue for us.

Ms FORREST - Is the patient or their family not being asked? I can't imagine a doctor admitting a patient without asking what their medical history is. However, they may be being asked but it is not being coded because they are not there for that, they are there because they have broken something.

Ms GROOT - That's right, or they haven't been diagnosed. The history is, 'The last 12 to 18 months you keep coming in with results as a result of a fall, maybe that's a trigger for us.'. That would be one of the issues, the reason why, which is again preventing the acute admission; the reason people are presenting for these is not being asked. I don't know hard a process that would be to ask that question, whether it is a resource issue or things to ask on the tick list.

CHAIR - Like you, I'm amazed they don't. I remember that I was asked on a couple of visits I've had. I am pretty sure I was asked whether I had any other conditions, but you are telling me the experience is that they're not.

Ms KITSOS - Some of the things we take for granted is that there's a very low level of general literacy. There's a generally low level of health literacy here. You have huge staff turnover in rural areas as well, so you may not have a consistent GP. You may have heard somebody mention this word 'epilepsy' in your patient journey, but when you present at the ED you may not remember what that was, or what that has to do with this thing that's just happened.

Ms GROOT - It's also a really big stigma issue, too. It's part of the whole stigma thing that people don't necessarily want to own up -

CHAIR - People aren't revealing it even if they do know it.

Ms GROOT - Because of the implications of it.

Ms BYRNE - Then there's issues - I know if someone suspects they have a brain injury and in terms of getting a diagnosis, if they need a neuro-psych assessment. We have a considerable paucity of neuropsychologists in the state and the number is decreasing, but the cost of getting a neuropsychological assessment is prohibitive. We put a submission in to try to get it recognised or funded under Medicare, but that didn't happen. Someone who might need an assessment to get a diagnosis to then get some help and support are unable to do that.

Ms FORREST - If you think of the number of kids with fetal alcohol syndrome with an acquired brain injury that's really quite concerning. Do you have any good news?

Ms BYRNE - We wouldn't be here if we did. Actually, we do have some good news. We have good news in that we found out today, some of us have had to look at alternative office location, we're moving into the ABC building. There's MS, there's epilepsy, there's stroke and brain injury, so we will have a little neuro-hub of information.

CHAIR - At the roundabout there?

Ms BYRNE - Yes, the ABC head office approved it today, so that's good news for us because we'll be able to have a neuro-hub.

Ms FORREST - A collaborative approach.

Ms GROOT - One of the things for me in the process is that there is becoming a much stronger, united voice in terms of raising issues around neurology and neurological issues. From the NATs perspective, what we've tried to do in the submissions is say we don't want to only bring you problems. We've tried to bring you some solutions about what we think might be some ways forward. That's a really helpful process for us to be going through and the inquiry has allowed us to do that. Often you are only responding in a reactive way rather than a proactive way. What we and the alliance is trying to do is to say we want to be proactive in the space.

Ms CONNER-KENDRAY - We can find the problem but we will also give you a solution.

Ms FORREST - We need to agree on what the problem is and clearly identify the barriers to good patient care and outcomes. If you don't identify the problem properly you might have a solution that doesn't fix the problem.

Ms GROOT - I would say that the inquiry is a positive, from my background, as you would know, as it is giving us the opportunity to raise the prevention and early intervention issue again. That is one of the reasons why we keep having these significant issues within the acute setting. We keep dropping the ball on the prevention and early intervention. If we keep dropping that ball, the acute issue keeps raising its head stronger. This inquiry gets me back on that soapbox of saying, 'Can we please stop dropping the ball?'.

Ms FORREST - There are two aspects, particularly with stroke. The initial stroke is very much an acute health matter, so there are different components to that. The initial acute epilepsy incident may be an acute health issue as well.

Ms GROOT - The early intervention proponent of that would probably be reasonably similar. You've talked about being able to have access to the medication for the [inaudible] blocking. For epilepsy, it is being able to get diagnosed so that you don't have recurring seizures. The example we gave was for this young boy on the north-west coast, for his liver to not get into significant issues that will affect his entire life. If he had some early intervention it would have stopped that from happening, hopefully.

Ms BYRNE - I know from Jen Lowe, who is the Secretary of NAT from MS, she was talking about medications that people, particularly with early onset diagnosis of MS, can mean they can have a really good quality of life over a longer period but those medications need regular monitoring by the neurological nurses. As we don't have the nurses to be able to do that, we have a situation at the moment where, ethically, the neurologist cannot prescribe this medication to people as there aren't the supports to monitor that. You then are basically giving people are very poor quality of life or outcome and risking that, because of that, they are going to present to the hospital, which could be avoided.

Ms KITSOS - If I go back to what you were saying about the diagnosis issue and the availability of neurologists, one of the things that is so appealing to me about linking in with the telestroke/telemedicine initiative is that the technology that is integrated into the hospital system can be used for any other purpose as it is not stroke specific.

The data pulled from the Victorian study has found that one-in-five of these phone calls going to neurologists result in an alternative diagnosis. That is where you are picking up your Huntington's, your Parkinson's, your bulbar palsies or your Guillain-Barré's. Even if you look at it as you are not calling necessarily for stroke treatment, you are picking up the phone to call for help from a neurologist and that is pretty cool.

Ms FORREST - I know, as you have said, you have had some discussions with the Health minister about the number neurology specialist nurses you believe are necessary. Once you have finalised your view on that, it would be very helpful for us to have that. Clearly, there is a real need. It is a community-based need but there are also then the community liaison nurses that would be important, too. If you have suggestions of the number of those, do you need one in each major hospital or do you need two? That is the sort of thing we, as a committee, can look at; how do we take people out of hospital who shouldn't be there, the bed block issues and how to improve patient outcomes on their journey.

CHAIR - On page 6, if I can go back to your submission. Under the headings of Recommendation and Multidisciplinary team approach to care, you make the statement -

> People represented by NAT live longer with better quality of life when they are supported by a co-ordinated specialised multidisciplinary team approach to care ...

Do you have any statistics to back that up? Is there any data you can -

Ms CONNOR-KENDRAY - All I could say is, yes, there is one multidisciplinary team - I am speaking regarding people with Parkinson's in the south. There are no multidisciplinary teams in the north-west or the north.

Ms KITSOS - I think there is discipline-specific data to back it up.

Ms CONNOR-KENDRAY - There is no data.

Ms KITSOS - Not Tasmanian data, no.

CHAIR - It doesn't have to be Tasmanian data.

Ms KITSOS - Exactly. If you pulled the evidence to say that MS patients who have the support of a multidisciplinary team have less attendance to the ED, the evidence is definitely up there.

CHAIR - Is there any chance of seeing some of that?

Ms KITSOS - Yes, sure.

CHAIR - It would be good to table that and add it to your submission as an appendix. We could then use that evidence.

Could we have the number of people across the state that have these conditions - I don't think I saw any data on that - represented in your membership, I suppose, would be the only way to do it? You can't put people down that you don't know have it but you would know how many in your membership have these conditions. How many in the north-west, the north and south? Do you have an understanding, statewide?

Ms CONNOR-KENDRAY - There was a study done in Tasmania of people living with Parkinson's going back about 15 years, which is where we saw the highest percentage and the highest number in the north-west. But I don't have those numbers. It is a study that needs to be done, statewide. I know the national Neurological Alliance tried to get it listed on the last Census, to see if we could see where people with neurological disorders were, how many and which particular condition they had. The ABS wasn't happy to do it at that time. The national alliance is going to have a go at it again with the next Census. It is something we are sadly lacking.

Ms GROOT - The data we can provide - we need to provide statistics into the Tasmanian disability statistics each quarter and in the last 12 months we have had quite a spike in terms of people that are accessing the services. We can show it in terms of the spike, I think that is in terms of -

CHAIR - Is that because they are finding out about the services or there is an increase in occurrence?

Ms GROOT - It is because they now know there is somewhere they can go. It is a bit of both, yes.

Ms BYRNE - We could collectively come together and give you a bit of a rough idea.

CHAIR - We are talking about a broad idea.

Ms CONNER-KENDRAY - You will not always get it from the membership because in our situation you do not have to be a member to ring up and get the service or to get the journal or anything else. Whereas, interstate you do have to, you have to be a financial member. I agree with Deb, we would probably be able to pull something together.

Ms KITSOS - We have the stroke figures. There are about 1500 strokes a year in Tasmania. There are 12 300 current stroke survivors in the community. The majority are in Hobart but there are well over, nudging well over, 150 strokes that are presenting to the North West Regional Hospital without treatment.

Ms FORREST - Per year?

Ms KITSOS - Yes. We are about to roll out our 2017 acute audit data, which is the first year where we have, with consent of the hospital, been able to de-identify each hospital about their acute stroke practices. That is coming out in the next fortnight.

CHAIR - We have a time line to try to bring this information together as quick as we can. If there is something you can provide us in a couple of weeks that would be great.

Ms BYRNE - Collectively, we are talking about many thousands of Tasmanians impacted.

CHAIR - There were two occasions where it could have been me.

Ms CONNER-KENDRAY - It is not only the person that is diagnosed. You extend that out to probably 10 family members, and then another 20 in the community involved in helping and supporting that person. It is very large.

Ms FORREST - Then there are the undiagnosed.

Ms CONNER-KENDRAY - That is exactly right.

Ms BYRNE - You have statistics that up to 80 per cent of your prison population have brain injuries. If you look at your statistics around family violence and those intersecting areas. There are diagnosed and undiagnosed as well. You mentioned foetal alcohol syndrome.

CHAIR - We have probably covered your concerns, unless there is something you feel you want to bring to our attention?

Ms BYRNE - Only if there are any other questions you had of our submission?

CHAIR - On page 9 -

> In handing down its submission to this Inquiry, NAT strongly requests that the Legislative Council Sub-Committee ascertains whether and where the Government states it is willing to make real changes; to allocate or re-direct the necessary funds to support the services and supports that are more than bandaid solutions for the many thousands of Tasmanians ...

Ms FORREST - That is a question for the minister.

CHAIR - He will come and talk to us, no doubt.

Ms BYRNE - I would echo Wendy's sentiments around that early intervention and prevention. Those preventable admissions are huge contributing factors to looking at the impact on the acute care sector or the hospitals.

Ms CONNER-KENDRAY - Preventing admissions is the big thing, isn't it? Keep them out and do not keep them in.

Ms FORREST - Correct.

CHAIR - I think we have asked the questions.

Ms BYRNE - If people have to go in then let us get really good outcomes for them so that they come out and that they not more sick than when they went in.

Ms CONNER-KENDRAY - Or go straight to residential aged care, do not pass go, you cannot go home again.

CHAIR - Who provides the respite care for the Huntington's case study? I note here you talk about best practice, 'John receives extensive multidisciplinary community agency support to assist his mother with his care. He attends occasional respite ...'. You are talking about a scenario, but who would be providing that? Who is providing respite care for Huntington's?

Ms CUMMINGS - It is very much hit and miss. It is where you can find a respite services willing to take them. Rural Health, I think, has been the most supportive, particularly in that scenario you are talking about. Rural Health was very good but for most of the others it is very difficult. Huntington's patients do not do well in group homes, so that is difficult and you have to find something very specific.

CHAIR - With people who have the expertise to understand the issues for that individual?

Ms CUMMINGS - That is right. Even for people who have care packages, it is very hit and miss. The people who are caring for them, most times you will hear from our families, come into the homes and they have no idea what Huntington's is and are given no instruction. The other thing is there is no continuity of care.

Ms GROOT - One last question I forgot to ask. We talked about equity, access and timely responses for a person who is living with one of these conditions. It seems that one of the things you are also raising is that availability being there for neurologists or neurologist nurses as well, for them to have access, equity and timely approaches. You talked at the beginning about the intrastate flight processes not available now and people are having to drive themselves around, wasting time. Is this inquiry able to ask some of those questions, about being able to make it easier by bringing back some of those, whether it is helicopter flight processes or whatever else, so that we make it easy for people; rather than spend four hours in the car, spending half-an-hour in a plane?

CHAIR - It can be added as a point in our findings, as an issue.

Ms GROOT - It seems to be an important thing, we need to try to open the door for the neurologists to provide that access and equity, how they would like to do it as well.

Ms FORREST - They are coming from Hobart. If they are coming from Melbourne there are commercial flights and they can easily take one, but from Hobart you can charter flights. If there is some coordination you could coordinate so the neurologists, the other oncology specialists, the gynaecology specialist - whoever it is needed to provide a service in the north or the north-west of the state - can charter a flight. They could do it together, all come on one day. Then you have a plane load and it makes it feasible. When you think about the cost of running a car up and down the Midland Highway, all the way to Burnie and back, the time associated with that and lost productivity, there is no argument around cost.

Ms GROOT - I remember many years ago that used to operate on the west coast. There would be a flight that would be chartered from Hobart, it would take all of the specialists into Queenstown. They would then hop across to Strahan or wherever they went, but that stopped. That made a huge different on the west coast. You have talked about it not happening, so I suppose I am out of line of the submission, but to me that is a red flag we might need to reverse.

CHAIR - It is a verbal submission; that counts. Do not worry about that.

Ms GROOT - Yes.

Ms BYRNE - It comes under the other key issue for us, which is that equity of access. The current situation is it is a postcode lottery. We tell people if you are going to have a brain injury, you do not have it on the north-west coast, or a stroke or anything like that. There needs to be that equity of access so people should not be disadvantaged in situations that are beyond their control, such as where they live.

CHAIR - Thank you for that. That was a fulsome presentation and I hope you put across all those things you wanted to.

Ms FORREST - If there are other things, feel free to send the information through.

CHAIR - Yes, you can send it through. If there is something you think you did not bring up, you can always add to it.

Ms BYRNE - In regard to the community liaison position we had in the hospital, we did a full evaluation of that. I would be happy to provide a copy if you think that would be useful.

Ms FORREST - How long ago was that?

Ms BYRNE - We did the evaluation late last year. It is only fairly recent.

CHAIR - That is excellent. Please send that through to Jenny Mannering, the secretary. Thank you, much appreciated.

<u>THE WITNESSES WITHDREW</u>.