NEUROLOGICAL ALLIANCE
TASMANIA

ACHIEVING BETTER OUTCOMES FOR TASMANIANS
LIVING WITH NEUROLOGICAL OR PROGRESSIVE
NEUROMUSCULAR CONDITIONS

…MORE THAN JUST A BANDAID SOLUTION

Definition:- Bandaid Approach

- *Hasty solution that covers up the symptoms but does little or nothing to mitigate the underlying problem;*
- *To cover up a problem but not fix it;*
- *A fast solution to prevent a symptom from showing. The problem is not solved by this action.*

AUGUST 2017

NEUROLOGICAL ALLIANCE TASMANIA'S SUMISSION TO THE LEGISLATIVE COUNCIL SESSIONAL COMMITTEE
GOVERNMENT ADMINISTRATION A SUB-COMMITTEE ACUTE HEALTH SERVICES IN TASMANIA

NEUROLOGICAL ALLIANCE TASMANIA

Neurological Alliance Tasmania (NAT) is an alliance of 10 not-for-profit organisations representing or supporting many thousands of Tasmanians living with or affected by neurological or progressive neuromuscular conditions.

NAT members:

- Alzheimer's Australia Tasmania
- Brain Injury Association of Tasmania
- Epilepsy Tasmania
- Huntington's Disease Association Tasmania
- Motor Neurone Disease Tasmania
- Multiple Sclerosis Limited (Tasmania)
- Muscular Dystrophy Association Tasmania
- Parkinson's Tasmania
- Spina Bifda Association Tasmania
- Stroke Foundation - Tasmania

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INTRODUCTION

Neurological Alliance Tasmania (NAT) welcomes the opportunity to respond to the Acute Health Services in Tasmania Inquiry to provide the perspective of Tasmanians living with neurological or progressive neuromuscular conditions.

The quality of services for people with neurological or progressive neuromuscular conditions varies across Tasmania, with some areas having insufficient expertise both in hospitals and in the community. The Alliance is supportive of *'One State, One Health System, Better Outcomes'*. However, with the postcode lottery that currently exists in Tasmania in respect to neurology services, ***NAT's position is that of: Equity of access to timely, appropriate, effective and high quality health care for all Tasmanians***.

NAT understand the purpose of the Inquiry is to "Inquire and report upon the resourcing of Tasmania's major hospitals to deliver acute health services, including mental health services, to the people of Tasmania", however NAT believe the acute health system cannot be viewed in isolation. With the inquiry's focus on the acute setting, there is a risk of under-valuing the role of community services as frontline and essential service providers. As stated in NAT's (formerly Neuro Muscular Alliance Tasmania (NMAT)) submission to the DHHS White Paper Exposure Draft in 2015:

"…we look forward to a subsequent consultative process concerning the vital under-resourced, fragmented and less researched community/primary health services outside acute inpatient care."

The **key message** throughout NAT's submission is one of **'preventable admissions'**- what should be done in the community to keep people living with neurological or progressive neuromuscular conditions out of hospital where, for many, a hospital admission results in them being worse off.

This submission includes **six compelling 'sliding door' case studies** from our members which, while evidencing the adverse human impacts of the current system, also provide solutions to the issues raised.

TERMS OF REFERENCE - RESPONSE

"To inquire into and report upon the resourcing of Tasmania's major hospitals to deliver acute health services, including mental health services, to the people of Tasmania, with particular reference to:

(1) Current and projected state demand for acute health services

NAT's expectation is that for the Tasmanian Government to deliver *'One State, One Health System, Better Outcomes'* data should not only be known but readily accessible. Regarding people with neurological or progressive neuromuscular conditions we draw the inquiry's attention to the Neurology and Stroke Clinical Advisory Group Green Paper Response:

Neurological disorders are common. Neurological disorders account for one in five (5) emergency hospital admissions and one in eight (8) 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. Future demands on inpatient and outpatient Neurological services in Tasmania are likely to increase.

Neurodegenerative conditions such as Dementia and Parkinson's Disease are driven by an aging population and rising rates of conditions such as Type 2 Diabetes Mellitus with neurological complications which will increase demand for inpatient and outpatient neurology services. Tasmania has the highest prevalence of Parkinson's Disease and Multiple Sclerosis in Australia. The rates of certain neurological conditions such as Epilepsy are likely to remain unchanged.

An increase in therapeutic complexity associated with newer treatment options can also be expected to drive demand for specialist neurology services. These will include both medical treatments and assessment of patients for surgical interventions. Similarly, the neurological side effects and consequences of new therapies used to treat non-neurological disorders (e.g. anti-neoplastic agents and antipsychotics drugs) will also increase demand for inpatient and outpatient neurology services.

It is recognised that patients with neurological conditions are most effectively dealt with by a specialist neurologist. Utilisation and resource demand for specialised services and expertise for specialised care requires Level 4-6 services.

NAT has concerns on how and what data is collected, and whether it is truly representative of the number of people living with neurological or progressive neuromuscular conditions being admitted to hospital. For example, if a person with Parkinson's Disease is admitted to hospital for a urinary tract infection (common for people living with Parkinson's) is comorbidity data collected in relation to their Parkinson's? This would then, for example, enable a better understanding of the numbers of people with Parkinson's being admitted, the length of their admission and any adverse outcomes, particularly in relation to medication changes.

With an appropriate level of resourcing to do so, NAT member associations welcome the opportunity to work with Tasmanian Health Service (THS) to gain a better understanding of the prevalence and needs (hospital and community) of people living with the neurological conditions NAT members represent.

(2) Factors impacting on the capacity of each hospital to meet the current and projected demand in the provision of acute health services

The rate of emergency admissions and readmissions for an existing long-term neurological condition, where patients require unplanned hospital treatment, is an indicator of poor quality health or community care services, or both, or poorly integrated health and community care. There are many factors here and this submission focusses on just three -

i. Early intervention

Early intervention is a feature of best practice for people living with neurological or progressive neuromuscular conditions.

There is currently a dangerous and unacceptable delay in people being even able to obtain a diagnosis. Motor Neurone Disease (MND) for example, usually progresses rapidly and when there is no access to, or a lengthy wait time for, a neurologist in the North and North West, people are not receiving a diagnosis unless they have been able to access a neurology service in Hobart or Melbourne. The Patient Assistance Travel Scheme relies on the capacity of people to travel. However, many people with Huntington's Disease and Multiple Sclerosis for example, are too unwell to travel to either Hobart or Melbourne. The impact of this is illustrated in the case studies in the Appendix.

Recommendation

THS should improve timely access to neurology services for all Tasmanians, irrespective of where they live.

ii. Multidisciplinary team approach to care

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 (Traynor et al 2003, Van den Berg et al 2005). Professionals providing multidisciplinary care may be from the same organisation, a range of organisations or from private practice. They can work in the community, hospital, clinic, residential and other care settings. Each discipline-specific team member enriches the knowledge base of the team as a whole and the composition of the team can change over time to reflect changes in the person's needs. (Mitchell et al 2008).

Recommendation

The recruitment and retention of suitably qualified health professionals into multidisciplinary teams can only be successfully addressed if services are of a sustainable critical mass. Hence NAT believes in the efficacy of Statewide clinical and community services rather than the fragmented and incomplete small services currently operating in these sectors in Tasmania.

iii. Preventable admissions through more effective person centered care plans

Individual care is often poorly coordinated, with few people with neuromuscular conditions having a personal care plan. Specialist coordinators can play an important role in helping people navigate their way through the range of support they need.

Recommendations

Every person with a neurological condition should be offered a personal care plan, covering both health and community care. The evidence suggests that this is best done by a single professional, for example a specialist nurse or care coordinator.

The current THS Neurological Nurse practitioners have a good knowledge and network and communication pathways with organisations and services across clinical and community settings.

This service should be increased and enhanced to cover more people with neurological conditions but it should be placed under a single medical supervisor and manager (Currently 3 Neurological Nurses in 3 regions are managed by 3 managers and clinical accountability is obscure).

(3) The adequacy and efficacy of current state and commonwealth funding arrangements

NAT is not in a position, nor does it have the expertise, to comment on the adequacy and efficacy of current State and Australian government funding arrangements as they pertain to hospitals in Tasmania. Nevertheless, NAT would like to see greater accountability and transparency in these arrangements.

Due to the funding silos, barriers are frequently experienced in accessing the vital services and supports that are often instrumental in preventing hospital admissions.

The transition to full scheme National Disability Insurance Scheme (NDIS), is one such area that potentially could have a significant impact on the rate of hospital admission for people living with neurological or progressive neuromuscular conditions.

In supporting a 'One State, One Health System' approach, NAT recognises that Tasmanians do not need a hospital, or neurologist, 'at the end of every street'. NAT also recognises that the recruitment and retention of two neurologists for Launceston, as proposed by the State government, could prove difficult.

Recommendations

- A well-resourced (financially and human) State-wide service hub of neurological excellence based in Hobart, with knowledge in and working across a broad range of neurological conditions
- Regular neurology clinics in regional areas with neurologists with relevant allied health and nursing staff fully supported to travel to these clinics
- Where people can travel to Hobart for neurological appointments, they are supported to do so with minimal red tape, and on the understanding that additional time, accommodation, and/or family support may be needed to maximise the outcomes of those appointments

- Community neurological nurses/coordinators be located in regional health centres to provided ongoing clinical support
- Three full-time community liaison officers (CLOs) to work from the three major hospitals, to liaise with the community neurological nurses/coordinators and bridge the gap between the acute care and community (Hospital CLO Final Evaluation Report, BIAT)

(4) The level of engagement with the private sector in the delivery of acute health services

As in section (3) above, there are 'false silos' caused by different sources of funding of services in the private sector.

The NAT recommendations listed above under (3) should apply irrespective of funding sources, with the patient at the centre of care, supported at a local primary level by their GP and community neurological nurse/coordinator.

(5) The impact, extent of and factors contributing to adverse patient outcomes in the delivery of acute health services

The 'sliding door' case studies from our member associations included in the Appendix to this submission, clearly show the impact, extent and factors contributing to adverse patient outcomes for the people that NAT member associations represent. More importantly, the 'sliding door' perspectives highlight the favourable outcomes that could be achieved should a best practice approach be adopted.

CONCLUSION

NAT acknowledge the health system in Tasmania is complex and operates under considerable pressure. NAT also recognises that the challenges to providing the right service, in the right place, at the right time to all Tasmanians are substantial and both financial and systemic. The current government's approach seems to reflect hurried, reactive decision making that does not adequately plan for unintended consequences.

Hospitals are not intended to make the journey for a sick person a harder one than it already is. People with life-limiting conditions should not have to wait months for a diagnosis, or be denied treatments because they can't be monitored. Leaving a neurology appointment following a life changing diagnosis with only medications, no follow-up plan, and little else in hand is like leaving an emergency department with a band-aid for a severed finger.

NAT acknowledge there are times when a hospital admission is necessary. However, with a clear preventative, community based, and early intervention focus and approach, many hospital admissions for people with neurological or progressive neuromuscular conditions can be prevented. Recognition of the need for, and provision of an appropriate level of resourcing for, the community organisations who know, understand and have many years of expertise in their respective conditions would result in significant financial cost savings to the health system in Tasmania and more importantly, deliver immeasurable and lasting social and emotional benefits to individuals and their families and carers.

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 living with or impacted by neurological or progressive neurological conditions.

This submission includes **six compelling 'sliding door' case studies** from our members in the **Appendix** which illustrate the differences in real life between living with a neurological condition in Tasmania now and how it could and should be in the future.

REFERENCES

Mitchell GK, Tieman JJ, Shelby-James TM 2008, 'Multidisciplinary care planning and teamwork in primary care', Med J Aust 188(8Suppl).

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APPENDIX

CURRENT PRACTICE VS BEST PRACTICE

CURRENT PRACTICE

Jim is a 42-year-old man from the North West coast of Tasmania. He is married and has three school aged children. He is the primary breadwinner for his family, and a third-generation farmer.

Jim presents at DEM, NWRH with extreme fatigue and breathlessness. A detailed clinical history and a raft of tests are performed as Jim is otherwise a fit and active man. Although his symptoms have been worse in the past few days, he does remark to the assessing clinician that he has noticed a general decline in energy in the past year. He has lost some weight, but he's been overweight in the past few years so he and his wife are not displeased about this.

X-rays confirm Jim has pneumonia, so he is prescribed antibiotics and told to follow up with his GP. Having visited his GP and having completed his course of antibiotics, Jim returns to his work.

Jim's fatigue grows and he starts to do little outside of his work, not eat as much and falls to sleep early. He's had the odd choking fit when he's drinking or eating dry foods but doesn't think much of it. He notices he's starting to have some trouble manipulating some of the tools he uses on agricultural machinery but he doesn't mention this to anyone. His wife thinks his voice is a bit slurry and suggests he goes to the doctor but he's not keen.

A few months later, his fatigue is severe again and this time he has chest pain and a headache. Again, he presents to DEM, this time in an Ambulance. Again, Jim has pneumonia and he is admitted to the NWRH for further investigation and treatment. A Neurological consultation is required which involves a 4-hour trip from NWRH to Hobart (and 5.5 hours from Jim's home), with a several days' stay and arrangements needed for the care of their children. This takes some weeks to arrange.

The Neurologist arranges more tests and subsequently diagnoses Jim with a progressive bulbar palsy form of Motor Neurone Disease (MND). Unwittingly, Jim has been aspirating fluids into his lungs which now have permanent damage. His lung function has regressed to the extent that a PEG (feeding) tube cannot be safely inserted, limiting his projected lifespan.

Jim and his family are distraught.

The local multidisciplinary team works with Jim but as his condition is already quite advanced, the supportive relationships are hard to build as his condition deteriorates rapidly. Jim and his family struggle to cope with their rapidly changing circumstances.

Jim dies in NWRH 6 months after diagnosis following another bout of pneumonia aggravated by his poor nutritional and respiratory status. Jim's family are angry that this wasn't picked up sooner and have lost confidence in their health system.

BEST PRACTICE

Jim is a 42 year old man from the North West coast of Tasmania. He is married and has three school aged children. He is the primary breadwinner for his family, and a third-generation farmer.

Jim presents at DEM, NWRH with extreme fatigue and breathlessness. A detailed clinical history and a raft of tests are performed as Jim is otherwise a fit and active man. Although his symptoms have been worse in the past few days, he does remark to the assessing clinician that he has noticed a general decline in energy in the past year. He has lost some weight, but he's been overweight in the past few years so he and his wife are not displeased about this.

X-rays confirm Jim has pneumonia, so he is prescribed antibiotics and told to follow up with his GP. More detailed questions alert the clinician and she refers him to the Neurological Registrar who refers him for a Neurological consultation and some further testing to eliminate any other causes of the symptoms he's described.

Having visited his GP and having completed his course of antibiotics, Jim returns to his work. Jim attends the monthly multidisciplinary Neurological Clinic at the NWRH and the Neurologist confirms that Jim has progressive bulbar palsy, a form of Motor Neurone Disease (MND).

Jim and his family are distraught.

However, his early diagnosis allows the early introduction of the multidisciplinary team to provide care and support that meets best practice guidelines. Jim and his family have time to work out how he best wants to live his final years and to put their family, farm and financial affairs in order.

Jim dies at home 2 years after diagnosis, surrounded by friends and family.

His family report that while the diagnosis was traumatic they felt well supported by their health system.

STROKE FOUNDATION TASMANIA CASE STUDY

These two scenarios are based on true case studies. All names have been changed. Currently there is no capacity to administer clot busting stroke treatment in the North West. Discussions are underway to implement stroke telemedicine, however funding continues to be an issue.

CURRENT PRACTICE

It was just over a month ago a training session turned terrible, leaving James unable to feel the left side of his body. "My mate noticed that I was acting weird. Then he realised that my face had dropped and I had slurred speech and was slobbery at the mouth".

Friends at the football club recognised the symptoms of stroke and telephoned triple zero.

The team at the North West Regional Hospital knew immediately that James had suffered a stroke. James underwent a CT scan and it was noted that a blood clot was blocking blood flow to his brain. He was a suitable candidate to receive a clot-busting drug, however this service was not available at the Hospital in Burnie.

A helicopter was called to take James to the Royal Hobart Hospital however, the helicopter was called away to a motorcycle accident so James had to continue to wait; 2 million brain cells die every minute. When James finally arrived in Hobart, it was too late for time critical treatment.

Doctors at The Royal Hobart Hospital said to James 'if only you had got here faster' to which you can imagine the reply from his family.

James has been left with physical, communication and some cognitive deficits – i.e. fatigue and memory loss. He is in a wheelchair, however can walk with a cane for small distances. He is unable to work or drive and he has moved back home with his parents who are struggling with his full time care.

James has been re-admitted to hospital on several occasions with post stroke complications. He will never play football again.

BEST PRACTICE

It was just over a month ago a training session turned terrible, leaving James unable to feel the left side of his body. "My mate noticed that I was acting weird. Then he realised that my face had dropped and I had slurred speech and was slobbery at the mouth”. Friends at the club recognised the symptoms of stroke and telephoned triple zero.

The team at the North West Regional Hospital knew immediately that James had suffered a stroke. James underwent a CT scan and it was noted that a blood clot was blocking blood flow to his brain. He was assessed by a Melbourne neurologist via video conference and administered a clot-busting drug.

Around 24 hours later, James regained movement in his left side. "I could move my leg, I could move my hand, I had full strength back," he said. "That was amazing. I didn't think I was going to be able to do that straight away. I was very relieved."

"I've been very well looked after and feel 100 per cent at the moment, I'm just keen to get back into everything."

The video technology accessed by James at the North West Regional Hospital is part of a state-wide telemedicine initiative by the Florey Institute of Neuroscience and Mental Health to give country patients better access to high-quality stroke care.

Through the program, once a stroke patient is given a CT scan, the image can be sent to a server and an on-call neurologist in Melbourne can assess it immediately to determine the type of stroke and advise the administration of clot-busting drugs, which need to be given within four-and-a-half hours of the stroke. It brings the neurologist to the patient, despite where they might be located

“I’ve had pretty much complete resolution of my symptoms, which is just remarkable" He praised the actions of his friends who recognised the 'FAST' acronym for signs of stroke: Face, Arms, Speech, and Time, and the paramedics who took him to the right hospital at the right time.

Today, James has returned to work as a diesel mechanic and is driving a car again. James takes to the footy field. This time, it's not just as a ruckman, it's as a 22-year-old stroke survivor who is celebrating a remarkable recovery.

MULTIPLE SCLEROSIS (TASMANIA) CASE STUDY

CURRENT PRACTICE

Kelly is a 34-year-old woman residing in the north of Tasmania. She has been experiencing numbness in her fingers for approximately three months, as well as extreme fatigue, which she has put down to being busy at work. Kelly works as a manager at a homewares shop four days per week and stays home to look after her three-year-old daughter one day a week. Kelly's husband has become increasingly concerned as Kelly is often asleep when he returns home from work on the day Kelly cares for their daughter.

After a discussion with her husband, Kelly goes to her GP to discuss the numbness in her fingers and her fatigue. Her GP puts it down to being the mother of a young child and working on her feet; he tells Kelly to rest more.

The numbness in Kelly's fingers spreads down her hand and to part of her wrists, and the fatigue has persisted over the past few months since visiting her GP. Exhausted, Kelly calls her GP surgery and makes an appointment with another GP. She is told the same thing again.

Kelly becomes worse over the following week and decides to present at the department of emergency at her local hospital. Kelly has to wait six hours to be seen. Kelly's symptoms have now included extreme dizziness, which does not subside even when she sits down. Kelly finally gets seen at the emergency department. A registrar examines Kelly, and tells her her symptoms are consistent with multiple sclerosis; however, no neurologist is available to see her, and he will organise a locum to see her the following week. Kelly stays overnight at the hospital and goes home the following day, unable to walk.

Kelly spends the next week unable to work, or care for her three-year-old daughter. Her husband needs to take time off work to care for them both, which puts stress on the entire family. Added to that stress is the anxiety of a possible diagnosis of a chronic and lifelong disability, Kelly begins to experience depression and is anxious about what her future may look like.

Kelly attends her locum neurologist appointment at the end of the following week. He examines Kelly, makes a referral for her to get an MRI. He asks her to make another appointment a neurologist after the MRI is completed. Kelly waits another month to get an MRI. After her MRI is completed, she gets to see another locum neurologist, who tells her based on her MRI she has multiple sclerosis, but to be sure she needs to get a lumbar puncture and visual evoked potential test which takes another two months.

Six months after her initial GP visit, Kelly finally has a diagnosis of multiple sclerosis. Her locum neurologist talked to her about her choice of medications, but she has not been referred on to anyone to talk about this so she is unsure about what her care plan is. Kelly, her husband and daughter have endued incredible stress, financial difficulty and are left feeling disillusioned and angry.

BEST PRACTICE

Kelly is a 34-year-old woman residing in the north of Tasmania. She has been experiencing numbness in her fingers for approximately three months, as well as extreme fatigue, which she has put down to being busy at work. Kelly works as a manager at a homewares shop four days per week and stays home to look after her three-year-old daughter one day a week. Kelly's husband has become increasingly concerned as Kelly is often asleep when he returns home from work on the day Kelly cares for their daughter.

After a discussion with her husband, Kelly goes to her GP to discuss the numbness in her fingers and her fatigue. The GP listens to her clinical history, explains he has some concerns about her presentation, and promptly refers her to a neurologist at LGH.

Kelly presents the next day at the LGH neurology clinic and is seen by a neurologist who refers her to get a same day MRI. The MRI shows lesions in her brain and spinal cord. The neurologist diagnoses Kelly with Multiple Sclerosis, and advises she is most likely having a relapse. He and the neurology nurse explain MS to Kelly, and tell her she will need four days of intravenous steroids at the day procedure unit at the LGH; the neurologist explains this will shorten the length of the relapse. He starts her on a disease modifying therapy which will be monitored by the neurology nurse, with the nurse reminding Kelly of when her bloods need to be taken, and that she will follow up with Kelly regarding the results.

The neurology clinic provides Kelly with the number for MS Connect, where she can link in with the local MS service which provides social and emotional support, as well as education and peer support if needed. Because Kelly's relapse was treated quickly, her symptoms subside after approximately one month.

HUNTINGTONS TASMANIA CASE STUDY

CURRENT PRACTICE

John is a 36-year-old fit active male, living with his with partner in their own home on the north-west coast. He is employed as a field worker for Forester Tasmania.

He is aware of his risk of Huntington's disease having watched his Grandfather, Father and older brother die from the disease.

After his family, his greatest love is surfing which he would do as often as he could, football was also a passion and played for his local club from a small boy until his symptoms became evident and he was forced to retire.

After having Genetic counselling, he was diagnosed as gene positive. He continued to run every day and spend as much time as possible at the beach.

As his symptoms increased his relationship with his partner became strained, eventually the relationship ended. No longer able to care for himself he returned home to be cared for by his elderly mother. Other than his mother his greatest companion was his border Collie who never left his side.

As his condition, deteriorated life became difficult for them both. He attended the Huntington's disease (HD) clinic in Devonport, provided 3/12 by a visiting specialist from Melbourne until it ceased in early 2016, no Neurology service were available after this.

Around this time his case worker, (a young Social Worker) decided, against both he and his mother's wishes, that he should be taken into care and applied to the Guardianship and Administration Tribunal for Guardianship. This application was so devastating, causing extreme anxiety to the family. Both he and his mother had discussed that he was to be cared for at home. Fortunately, the application was dismissed, but the anger and distress it caused his family will remain with them always.

As his condition deteriorated, visits to the beach, running and walking soon became impossible, and carer support was provided for short periods only. He was admitted to North West regional hospital by his GP suffering a urinary tract infection and Pneumonia. There was a general lack of knowledge amongst staff concerning Huntington's disease, no Neurologist consultation was sought. After 3 weeks, he was discharged home, now unable to walk as before his admission. A hospital bed was arranged which was very inadequate as it was much too small. Community nurses visited second daily, some carer support was provided but was insufficient.

As his condition deteriorated Palliative care was commenced, however the service is limited to 9-5, after hours service, including phone advice was not available which put great strain on both he and his mother. His death from Pneumonia, which occurred during the night, was traumatic leaving terrible lasting memories for his family.

BEST PRACTICE

John is a 36-year-old male, living with partner in their own home on the North-west coast. He is employed as a field worker for Forestry Tasmania.

He is aware of his risk of Huntington's disease having watched his Grandfather, Father and older brother die from the disease.

After his family, his greatest love is surfing which he would do as often as he could. Football was also a passion, playing for his social club from a small boy until symptoms became evident and he was forced to retire.

After having genetic counselling, he was diagnosed gene positive. He was committed to living a healthy life, eating well, running on the beach and maintaining regular exercise.

As his symptoms increased his relationship with his partner became strained, eventually ending. No longer to care for himself he returned home to live with his mother. Other than his mother his greatest companion was his border collie dog, who he walked as often as he could.

He attended the multidisciplinary HD clinic held regularly in the NW of the state which provided support for both he and his mother. Appropriate medication is prescribed and monitored as necessary. Communication between his Neurologist and GP is well established and is ongoing. This provides information and support between specialist clinic visits.

John receives extensive multidisciplinary community agency support to assist his mother with his care. He attends occasional respite, allowing his mother to have short breaks.

He plans for his future care, giving his mother Power of Attorney and Guardianship, he also expresses his wishes to be cared for at home. On admission to hospital suffering from Pneumonia he is treated by staff who are well educated in his care needs. On discharge, appropriate discharge planning is in place, Neurology Nurse Practitioner and Palliative home visits arranged.

Community nurses visit daily providing care and support to John and his family. Palliative care is available for advice 24 hours a day.

John's death, which occurs at home during the night is peaceful, surrounded by family.

BRAIN INJURY ASSOCIATION OF TASMANIA CASE SCENARIO

CURRENT PRACTICE

Jack is married and has a 17-year-old son living at home. He has a job as a motor mechanic, enjoys playing football, and his hobbies include woodwork and carpentry. At the age of 45 Jack falls from a ladder while cleaning out his gutters at home and sustains a brain injury.

Following time in ICU, Jack is transferred to the Neurosurgical Unit of the Royal Hobart Hospital where he spends some time before being discharged home. Jack and his family are not given any information about brain injury or where to go to get assistance should they need it.

Jack experiences significant effects from his brain injury. His personality is changed. He is unable to continue with his work or his hobbies, in part due to problems with his memory, balance and executive functioning. He loses his passion for life and becomes very depressed. This has a significant impact on his relationship with his wife who believes Jack has become lazy.

Jack also displays disinhibited, sometime aggressive behaviour, however as his brain injury is 'invisible' his behaviour results in him being the victim of physical and verbal abuse when he is out in public. Jack is not aware this is a problem.

Jack's brain injury and the effect it has on him has a significant impact on his wife and son. It not only affects their health and the relationships the family have with each other, but also their relationship with their extended family and friends, as they do not understand the changes in Jack. The family become socially isolated, and Jack becomes very critical of his teenage son. His son leaves home as soon as he can.

Despite numerous visits to his GP, Jack is not referred to a neuropsychologist or specialist brain injury service provider. The GP prescribes him anti-depressants for his depression. Because Jack has little insight into the effects of his brain injury, and is able to walk, talk and joke with medical professionals during appointments, the GP and other medical specialists he sees speak directly to him and do not include his wife in information sharing or decision making about his current needs.

Jack sustains numerous secondary brain injuries from falls in his home, and as a consequence of the physical assaults he experiences.

Several years after Jack sustained his brain injury his wife, a school teacher, learns of the Brain Injury Association of Tasmania (BIAT) through a Heads Up 2 Brain Injury session delivered to students at her school.

She contacts the Brain Injury Association of Tasmania who refer Jack and the family to the brain injury Hospital Community Liaison Officer (CLO). The CLO provides them with direct emotional and practical support including information and education about brain injury, and referrals to service providers.

This is the first brain injury specific support Jack and his family have received.

The ABI Hospital Community Liaison Officer supports the family by:

- Referring Jack to a rehabilitation physician who specialises in brain injury
- Making the family aware of the Community Rehabilitation Unit in Hobart which has a dedicated brain injury clinic
- Referring Jack and his family to a specialist brain injury service provider who are able to support the family through a (block funded) community outreach program
- Referring Jack's wife to Carers Tasmania where she attends a self-care workshop, and relaxation classes which she finds helpful in coping with being Jack's carer.
- Referring Jack's son to Anglicare for counselling.

Jack dies aged 53 years old from injuries he sustains following another fall in his home caused by his balance problems. His death comes 8 months after the family made contact with the BIAT Hospital Community Liaison Program, and began receiving brain injury specific support, and 8 years after the accident in which he first sustained a brain injury.

The Hospital CLO Program was funded by the Tasmanian Community Fund (TCF) for a 12 month pilot. Despite a comprehensive evaluation report detailing the long term economic, social and emotional benefits of the hospital CLO program, BIAT has been unable to secure funding from the State Government to re-instate the program. It is no longer available to support families and people impacted by brain injury at the point of diagnosis and post their discharge to the community.

BEST PRACTICE

Jack is married and has a 17 year old son living at home. He has a job as a motor vehicle mechanic, enjoys playing football and his hobbies include woodwork and carpentry. At the age of 45 Jack falls from a ladder while cleaning out his gutters at home and sustains a brain injury.

Following time in ICU, Jack is transferred to the Neurosurgical Unit of the Royal Hobart Hospital where he spends some time before being discharged home.

Upon transfer to the Neurosurgical Unit, the Brain Injury Community Liaison Officer (CLO) makes contact with Jack and his family.

The CLO talks to Jack's family about the services the program offers and the family feel reassured that support is available to them while Jack is in the hospital and once he is discharged.

The CLO liaises with medical staff within the hospital and is able to respond to any questions the family has in regard to Jack's brain injury. The CLO is able to gauge what information the family needs and when the best time is for this information to be provided.

The CLO attends multi-disciplinary team meetings about Jack and is also involved in Jack's discharge planning so is able to talk to Jack's family about what is available to both Jack and them in the community.

When Jack is discharged from hospital he becomes an outpatient of the Community Rehabilitation Unit (CRU) in Hobart and has regular appointments with a rehabilitation physician who specialises in brain injury.

Jack experiences significant effects from his brain injury. His personality is changed. He is unable to continue with his work or his hobbies, in part due to problems with his memory, balance and executive functioning.

The CRU team, which includes a neuropsychologist, work with Jack to understand the impact his brain injury has had on his life. An OT visit Jack at home and conduct an assessment. Modifications are made to the family home which assist Jack with his balance problems and prevent further falls.

The CLO links Jack and his family to the National Disability Insurance Agency in Tasmania resulting in Jack receiving becoming an NDIS participant and accessing a service provider with an understanding of brain injury and expertise in supporting people with brain injury. The service provider works with Jack to determine what his goals are now that he can no longer work as a mechanic. He is supported to attend his local men's shed and enjoys going there several times a week. Jack is also supported to participate in a range of other activities in his local community.

The CLO keeps in regular contact with the family and is able to provide them with information and education about brain injury, helping them to understand the changes Jack is experiencing, and may experience in the future. They are provided with strategies and referrals to other services, including Carers Tasmania and Anglicare's Counselling services.

Through Carers Tasmania, Jack's wife attends a self-care workshop, and relaxation classes. She is also put in touch with a peer support group for partners of people with brain injury. She finds these services and supports very helpful in coping with being Jack's carer. Jack's son finds the counselling provided by Anglicare to be beneficial in coping with the changes to his father and his family.

Community awareness around brain injury is enhanced by a funded campaign, which reduces stigma and raises knowledge and understanding of brain injury as an often 'invisible' disability. This results in Jack receiving community support rather than verbal and physical abuse in response to the disinhibited behaviour he exhibits in public.

As a consequence of his brain injury and associated sequelae Jack has many visits to his GP and other non-brain injury related specialists. Mandatory brain injury training for GPs and other medical professionals means that although Jack is able to walk, talk and joke during appointments, the medical professionals are aware that brain injury often has hidden symptoms and that people with brain injury are often not aware of the effect their brain injury has on them. Consequently, the GP and medical specialists ensure that they speak with both Jack and his wife in relation to information sharing and decision making about Jack's current needs.

Eight years after Jack's accident, Jack and his family continue to be supported. Jack's wife continues to attend the peer support group for partners of people living with brain injury. Jack's son has moved out of home, however has a good relationship with both his parents; he is happy to step in and give his mother a break from time to time. The CLO continues to touch base with the family every 6 months to ensure they are ok and still connected to the services they need.

EPILEPSY TASMANIA CASE STUDIES

CURRENT PRACTICE

June 2017 – James (16 yrs) was just diagnosed with epilepsy and last seizure was 2 days prior to phone call. He had seen Launceston neurologist, 1 month ago and he had prescribed 2 lots of medication for him after an EEG and MRI. The medication prescribed was interfering with his behavioural patterns and making him physically ill. The mother tried to make another appointment with the neurologist, however was too late, as he had already left his position.

Together they saw a GP who advised them to go through Emergency at the Launceston hospital, as it would be quicker for a referral. On their arrival, there they found it to be full of people waiting and so joined the wait, after several hours waiting and her son getting more and more agitated, they decided to go home and let the boy rest and calm down and start again the next day through normal channels and not the emergency route, as this was a complete failure for them, as staff were obviously overloaded. James's GP and 2 others he had seen, have been of no real help for him, as they don't specialise in epilepsy and weren't understanding the mother and son's struggle.

One GP advised the mother, she was far too overprotective and just calm down. On a visit with this GP she asked if he could call Hobart Hospital and speak with neurologist on call and ask about medications, he declined said the neuro would be too busy for such a call to be made.

Mother still distraught, with another phone call to Epilepsy Tasmania social worker, advised that she wasn't sure of the time limits of the tests that her son needed to have, in order to get the best and correct medication for him. After much discussion, on what she was looking for as support, I advised her to wait for my call and I would find out information in regards to other neurologists that we could see in the North.

After many phone calls social worker found out Launceston neurologist would only be available for treating patients one day, every fortnight from August, 2017. I was advised that there would be difficulty in getting appointments as he has around 700 patients on his books. There were no other neurologists available for visitation and treatment in the North since the neurologist left his position. Through Launceston Hospital I was advised, there are 2 locums now travelling to Launceston every fortnight from Melbourne. There are nine neurologists in Hobart, only 4 are specialists in Epilepsy and they currently have a waiting list of up to 1 year and triage their patients. Two of these specialists only work on a Wednesday, so therefore clients son's health is getting worse, as medications need to be checked.

Client has written a letter to Health Minister of Tasmania for some help, but has decided that she will look for another job over on the mainland, and be closer to the care for her son, so that his health needs are met. Currently my client and her son are travelling to Melbourne once a month for visitation with a neurologist so his medications are able to be consistent, until she is able to secure employment and relocate interstate.

BEST PRACTICE

June 2017 – James (16 yrs) was just diagnosed with epilepsy and last seizure was 2 days prior to phone call. He had seen Launceston based neurologist, 1 month ago and he had prescribed 2 lots of medication for him after an EEG and MRI. The medication prescribed was interfering with his behavioural patterns and making him physically ill. The mother made an appointment with the referral given by neurologist to a second neurologist for within a week. In that appointment, James's medication was checked and updated to allow him to feel more comfortable and another appointment was made for one month to review the medication.

In that month, James has a nocturnal tonic clonic seizure and was taken to hospital by ambulance and seen immediately in the emergency department, his neurologist visiting and reviewed medication again along with an EEG and an MRI. James was allowed to go home after 4 days. James's mother was struggling after what they had just been through and had asked for some counselling, and through this, she is feeling better for being able to talk things through about the impact of James's epilepsy on the family and home.

James continues to see his neurologist and has his medications checked each month, and his seizures have been limited with this, his mother feels that she now, no longer needs counselling as she feels on top of the situation with the education and support that has been given to her. James now, has an alarm support, both at home and on his person, to advise of next seizure, so is comfortable to be back at school and his mother feels more at ease about his independence with these products as she is alerted immediately to James situation.