QUEENSLAND
COURTS

CORONERS COURT OF QUEENSLAND

FINDINGS OF INVESTIGATION

CITATION:	**Non-inquest findings into the death of David Orton**
TITLE OF COURT:	Coroners Court
JURISDICTION:	BRISBANE
DATE:	11/05/2018
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FINDINGS OF:	John Lock, Deputy State Coroner
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Background

David Orton was aged 41. There was a long history of cerebral palsy, intellectual disability, anxiety, persisting gastrointestinal problems presenting as constipation and evidence of a dilated tonic colon. He also suffered from severe kyphoscoliosis which had a significant effect on movement and lifestyle. There had been progressive neurological and functional decline over 18 months with weight loss, increasing agitation, decreasing mobility, chronic abdominal pain and constipation.

Mr Orton received 24-hour care by Residential Facility at Currimundi funded by Disability Services Queensland. He had been there since 2005. Up until 2000 he had been cared for by family and then at other supported accommodation until 2005.

Mr Orton died on 26 January 2016. Because of his disability and residential arrangements his death was reportable as a Death in Care.

Mr Orton's family also had expressed concerns regarding his deterioration over a period of 18 months with very little clarity on his diagnosis. They were concerned that he had been inappropriately discharged from hospital at times and there were difficulties regarding the support provided to him. They were concerned that the obvious pain David had was disregarded as "behavioural".

Review by Clinical Forensic Medicine Unit

David Orton was a 41 year old gentleman with a history of cerebral palsy. He lived in supportive accommodation with another client and carers however had been showing evidence of decline functionally (unable to walk), behaviourally and possibly cognitively over about 18 months. He also had significant muscular wasting. It was believed that carers and medical attendants expressed concern that he was unable to be managed in the community and may require residential care placement, but it was thought he was not suitable for nursing home care. He was admitted on a number of occasions in the preceding 18 months, however a diagnosis for his functional decline was not forthcoming.

Mr Orton was transferred from a private hospital to a Queensland Health run hospital on 7 January 2016 for reasons of functional decline and abdominal distension. He was diagnosed as having a pseudo-obstruction in his sigmoid colon and treated with a rectal tube; enemas and rigid sigmoidoscopy to manage what seemed to be excessive constipation (yet abdominal distension continued).

He was appropriately reviewed by speech therapy (swallow); dietician; physiotherapists and occupational therapists. Initial dietetic involvement diagnosed severe malnutrition due to poor oral intake yet his mother told staff he “ate like a horse” and food chart review found that he was eating 90-100% of his daily food requirements. Blood tests revealed elevated liver function tests (blamed on recent antibiotic use - although never returning to baseline despite ceasing same). He also appeared to “writhe” his right shoulder, which his mother and carers ascribed to pain, although medical staff were assured that active and passive movement range was normal and he was not tender. Medical staff ascribed the writhing due to tardive dyskinesia due to past use of haloperidol and one person questioned possible Huntington’s disease (ordering tests to be done but which appeared not to have been completed). Mr Orton's family advised a specialist told them it was decided not to do the test because there was no family history of this disease.

Mr Orton’s condition did not improve. He slept on a mattress on the floor as he could not walk and tended to crawl on the floor. He developed a fever and tachycardia on 23 January and blood cultures revealed Staph aureus in the blood for which he was appropriately treated with antibiotics in reasonable time. Source of infection was believed to be cellulitis in his right hand due to abrasions/lacerations from frictional injury with floor-crawling. It was noted that a further blood culture on 26 January showed a gram negative bacillus (for which he was given gentamicin - not unreasonably). His condition continued to deteriorate despite hospital staff escalating antibiotic cover and intravenous fluids. Mr Orton passed away on 26 January.

Subsequent cultures diagnosed the gram negative organism as Salmonella species.

The CFMU noted there were issues relating to public health with respect to Salmonella infection together with a possible failure to diagnose an underlying disease such as malignancy.

That being stated his decline may well have been a progression- natural or otherwise of his cerebral palsy. The CFMU review found no issues in his medical care that suggest Mr Orton was not treated with dignity and respect. His medical care was very good and there was no suggestion that reasonable care was withheld.

Autopsy Examination

A full internal autopsy examination was ordered.

The examination included a review of the advice from the CFMU. A subsequent review of medical records confirms the reported history.

For some time there was reporting that unusual movement of the right shoulder and arm was persistent and it was never clear whether this was due to undiagnosed pain or a movement disorder. Several episodes of pneumonia were also reported and was thought to be due to aspiration of orogastric contents.

The autopsy examination confirmed severe kyphoscoliosis and dramatic dilatation of the large bowel, which was full of soft faecal material and which was associated with a wide open anus. There was no evidence of anatomical obstruction of the bowel although the lower sigmoid colon and rectum were dilated but there was a segment of normal large bowel above it, and then a second shorter dilated segment within the descending colon. The caecum and ascending colon together with the small intestine appeared to be of normal diameter. Additionally, there was no evidence of perforation and the outside surface of the dilated bowel was smooth and shiny.

Examination of the chest showed extensive scarring around the left lung consistent with earlier infections and some induration of both lungs suggestive of an infective process. The diagnosis of bronchopneumonia was confirmed microscopically.

The brain appeared swollen but was of normal overall external appearance. A subsequent examination by a neuropathologist revealed the condition known as polymicrogyria, which is a common substrate to the clinical presentation of cerebral palsy. No obvious acute ischaemia or other acute neurological observations were made by the neuropathologist.

Specific examination of the right shoulder showed no obvious abnormalities. There was no evidence of bony change and the muscles, while obviously wasted, appeared otherwise normal. There was no obvious nerve abnormality although it must be recorded that functional changes within nerve activity cannot be assessed at autopsy.

Biochemical analysis revealed some evidence of mild impairment of kidney function. This would not be surprising given the significant gastrointestinal issues and the effect that such abnormal colon structure and function can have on electrolytes and other chemicals within the blood.

There was no evidence of biliary atresia. The issues of malabsorption and Whipple's disease were raised. These conditions are non-specific disorders of impaired absorption of nutrients caused by various underlying problems including structural and bacterial factors. The presence of significantly dilated and abnormal colon indicates there may well have been problems with absorption of nutrients, although this had been fully investigated clinically and no specific underlying cause could be determined. There is no doubt that patients with megacolon have abnormal electrolyte and chemical control and abnormal kidney function is not unexpected.

The final cause of death appears to have been cerebral hypoxia induced by pneumonia, although this is likely to have been secondary to the various chemical changes induced by the enlargement of the large intestine as well as the chronic infection by Salmonella.

The forensic pathologist noted that toxic megacolon, Salmonella typhimurium infection and cerebral palsy were contributing factors although it is difficult to determine which, if any, were more culpable than the others.

Further Review by CFMU

CFMU reviewed the case subsequent to the completion of the autopsy report and receipt of further concerns of family.

Staphylococcus aureus infection was picked up on blood culture in hospital and this was managed with appropriate antibiotics. This was being treated by the time the autopsy was completed.

There was no clinical indication that Mr Orton had Salmonella. It was picked up on a blood test in hospital. The CFMU considered it is likely this was not an acute infection and Mr Orton was possibly a carrier of the organism. There was no evidence of Salmonella infection when he was treated for a gastrointestinal disorder in December 2015. It is possible the bacteria was becoming clinically apparent at the time of his death as it was in the blood stream and therefore potentially could lead to septicaemia. There did not appear to be much physical evidence of acute sepsis on autopsy.

The pneumonia described at autopsy was microscopic. The effects of bronchopneumonia were only evident under the microscope. In practice this would not be evident on clinical grounds, so most likely there would have been no findings listing to his chest and likely no findings on chest x-ray.

The cause of shoulder pain was not identified at autopsy therefore was not likely to be found before death. The CFMU stated that one might assume that the scoliosis contributed to the pain in the absence of physical findings but this cannot be stated with any degree of certainty.

The brain swelling was apparent but not acutely pathological as described at autopsy. This may not show up on CT scan.

The family had concerns as to the possibility of a malabsorption syndrome. The CFMU stated that this was feasible and could explain weight lost. This would require tests such as faecal testing for fats, endoscopy (this was completed) and other pathological parameters on blood testing. This was not directly related to his death.

Review by Expert Review Panel

An expert panel was convened to review 11 apparent natural causes deaths in care of people who were residents in supported residential accommodation and in which potential concerns were identified about the adequacy of the health care management prior to death. The death of David Orton was one of those deaths that were considered.

The Public Advocate report Upholding the right to life and health: a review of the deaths in care of people with disability in Queensland (2016) highlighted that people with intellectual or cognitive disability have more complex health needs and a higher mortality rate than the general population, while also correspondingly facing significant barriers in accessing appropriate health care, and experiencing the health impacts associated with poverty and social exclusion.

This was attributed to a lack of appropriate supports including to access health care and appropriate health care providers, as well as ineffective coordination between disability and health services.

Unsurprisingly, many of the recommendations for improvement identified by the Expert Panel also accord with those outlined within the Public Advocate report, including:

- That support staff and carers needs to be aware of the signs of serious illness, and be appropriately equipped with the necessary education and training to be able to carry out basic observations on a person (i.e temperature, pulse and heart rate)
- The need to ensure professions working in the area are aware of, and comply with, their obligations to report deaths in care to the Coroner to ensure a better understanding of the prevalence and circumstances of these types of deaths.
- People with a disability who reside in residential care should have a designated person/role to take responsibility for coordinating and reviewing their health care (in consultation with the person and/or their substitute decision maker).
- The critical importance of Annual Health reviews for people with a disability, including that service organisations should prioritise and allocate resources to ensure people with a disability in residential care are supported to access regular medical check-ups (including dental) and annual comprehensive health reviews.
- That disability residential services have a designated person/role that takes responsibility for coordinating the health care for each resident with a disability. The role should be responsible for ensuring health care strategies are being carried out, health appointments are booked and attended, annual health checks are conducted, hand held records are maintained and behavioural support is coordinated to attend health appointments if necessary.

Such findings are consistent with mortality reviews conducted in other jurisdictions and are highlighted again within this Expert Panel Report.

Research indicates that health conditions in people with an intellectual disability are more likely to be undiagnosed and under-treated and that they:

- have more multiple, chronic and complex health conditions than the general population
- have a higher prevalence of particular medical conditions as well as more lifestyle related health risks, such as obesity and poor physical fitness
- are less likely to be offered preventative health measures and experience greater barriers in accessing health care

Factors identified as contributing to this under diagnosis and under treatment include communication or cognitive difficulties that make it hard for a person with an intellectual disability to recognise and communicate pain and an associated reliance by clinicians on family or support staff to be able to articulate this for them; even though they may not be aware of symptoms and an accurate history may be difficult to obtain from staff (due to turnover and high workloads etc).

It may also be hard for clinical staff to physically examine a person with an intellectual disability due to anxiety or challenging behaviours; the person's symptoms may be attributed to their intellectual disability with limited exploration of other physical or mental health disorders (as alleged to be the case with Mr Orton); and a comprehensive assessment is likely to take longer than for other persons, which may not always be considered practical in busy practices or hospitals.

As this was one death in the cluster of eleven, the Panel did not explore issues regarding the provision of care and support in these settings in substantial detail. The Panel determined that given that there was only one death, which occurred within a DSQ funded facility they would be unable to consider whether there was any opportunities for systemic reform with respect to the supported accommodation services funded by DSQ, outside of consistent standards with respect to a resident's personal care support needs.

Departmental funded services are required to deliver services in accordance to the *Disability Services Act 2006*, which is an Act that aims to protect and promote the rights of people with a disability, and the Human Services Quality Framework (HSQF). The HSQF is a system for assessing and improving the quality of human services and applies to organisations delivering services under a service agreement with the Department of Communities, Child Safety and Disability Services (DCCSDS) or other specified arrangements. It incorporates:

- A set of quality standards, known as the Human Services Quality Standards, which cover the core elements of human service delivery
- An assessment process to review the performance of service providers against the standards
- A continuous improvement framework, which supports the participation of customers in quality improvement.

The HSQF aims to increase consistency in service quality and ensure public confidence in service delivery, and is designed to increase administrative efficiency and enable service providers to focus their resources on service provision and continued quality improvements. Applicable to the provision of services in disability, child safety, community and community care services, the framework contains six Human Services Quality Standards:

1. Governance and management: sound governance and management systems maximise outcomes for stakeholders.

2. Service access: sound eligibility, entry and exit processes facilitate access to services on the basis of relative needs and available resources.
3. Responding to individual need: the assessed needs of the individual are being appropriately addressed and responded to within resource capacity.
4. Safety, wellbeing and rights: the safety, well-being and human and legal rights of people using services are protected and promoted.
5. Feedback, complaints and appeals: effective feedback, complaints and appeals processes that lead to improvements in service delivery.
6. Human resources: effective human resource management systems, including recruitment, induction and supervisory processes result in quality service provision.

The HSQF is the approved certification framework for disability service providers but does not contain specific reference to any health care, medication management or other personal care needs. As part of the implementation of the National Disability Insurance Scheme (NDIS), a new national quality and safeguards framework is being developed so that there are consistent standards and safeguards across Australia.

Accommodation support delivered by the Department is through an Accommodation Support and Respite Service (AS&RS). The AS&RS provide accommodation support to adults with a disability in their own homes through public housing, the DCCSDS funded services or the private rental market.

Typically two to four people sharing a home are supported by Residential Care Officer's (RSO's) who provide day-to-day assistance and support to people with an intellectual disability focusing on a person-centred approach. Support systems reflect individual needs and may include occupational or speech therapy, physiotherapy, social work, psychologists or other community services.

There was a noted deterioration in Mr Orton's health and functioning in the 18 months prior to his death. By the time of his death, Mr Orton was sleeping on a mattress on the floor as he no longer had full mobility so he tended to crawl on the floor. In early January 2016 he was transferred from the Private Hospital to the Public Hospital due to functional decline and abdominal distension.

On 23 January 2016, while still in hospital he developed a fever and tachycardia. It was noted on records that the source of the infection was believed to be cellulitis in his right hand due to abrasions/lacerations from frictional injury with floor-crawling. His condition continued to deteriorate despite medical intervention and he passed away four days later.

The CFMU review that was conducted identified two possible issues with this death that needed to be addressed;

(1) a possible public health issue with a salmonella infection; and
(2) a possible failure to diagnose an underlying disease such as malignancy.

For the latter, the Dr conducting the review noted that such a diagnosis would be high on the agenda in normal circumstances, however the issues associated with behavioural and functional decline in persons with cerebral palsy may have led investigators to pursue a neurologic cause rather than follow a path that they may well have pursued in the absence of his pre-existing condition.

According to his mother's communication to the Coroner's office, David had full mobility and could originally walk while in the facility, and she has provided video evidence to that effect.

She states further that: "Disability Services reported in May 2014 that David needed more assistance, equipment and support at home however did not action this at any time. No case manager was assigned until the Public Hospital enforced this 1-2 weeks ago. Having no case manager until the week before his death meant there was no consistency in his treatment, deterioration was ignored, carers were distressed and the obvious pain David had was disregarded as ‘behavioural’. We felt that because David could not speak, the medical teams over the past year or so had no urgency except to send him home to allow his residential facility to deal with."

It is clear that the residential facility staff were supportive and attempted to advocate for David and his family within the hospital setting. Unlike other cases considered within this review, records were available to indicate that Mr Orton was provided with hygiene management and health care support (although they predominantly referred to wound care).

Records were obtained from DCCSDS relating to the care and support pertaining to Mr Orton. Four critical incident reports were provided as part of this documentation for the following matters:

- 12 September 2012: Mr Orton resided in a co-tenancy arrangement with another resident, and a staff member reported that he has struck his flatmate with a closed fist a number of times. Mr Orton also reportedly kicked a staff member in the face. The Residential facility was noted to have conducted an assessment and review of the arrangement, and strategies were subsequently successfully implemented to the satisfaction of all parties.
- 17 September 2012: Mr Orton was observed to be sitting beside his bed in the morning by a support worker. He was noted to have blood over his face with his hand from a small cut over his left eye. Mr Orton had been in bed and the cause of the injury was unidentified. Background notes indicate that: his behaviour regarding his personal hygiene and his requirement for high rapport with staff adds an increased level of complexity to meeting his support needs…he has displayed increased aggressive physical behaviour over the past three years…he has resided in current setting for the past five years with support from the residential facility commencing in 2009. The vast change in his support environment coincides with his increase in behavioural incidents. Appropriate medical assistance was provided to Mr Orton, although his behaviours were noted as hampering the provision of assistance. His mother was contacted and subsequently transported him to hospital the following morning.
- 27 November 2013: Mr Orton was observed as continuing to present as unwell after receiving medical treatment on the 23 and the 25 November of that year. Staff contacted QAS reporting that he was refusing personal care assistance, was not eating and appeared unwell. He was subsequently transported to a different Public Hospital with a large faecal mass being noted. He was transferred to a Public Hospital and was discharged the following morning. Background notes indicate that Mr Orton requires pervasive support to manage his complex behaviour and meet his daily living requirements.
- 26 January 2016: a critical incident report was completed relating to the death, and it noted that Mr Orton had been admitted to the Public Hospital on 6 January 2016 for investigation and treatment of health concerns. Planning was underway for Mr Orton’s discharge between hospital staff, the residential facility and Disability Services who had met on Thursday 21 January; however his condition deteriorated after this point as a result of a Staphylococcus infection.

It is evident from a review of the care needs of Mr Orton that issues were identified as early as 2012, specifically that his support needs were increasing and he required more intensive assistance from staff, although this was attributed in larger part to his behaviours.

Records from the complaint in 2012 highlight the extent of training and an example of the intensive support provided to Mr Orton within the DSQ funded service including that:

- Staff were rostered 24/7, with the majority of shifts being one staff member for two clients
- While difficulties with retention of staff was acknowledged, in addition to mandatory training staff also undertook a range of courses and workshops (including Bowel management, Behavioural Support, Sensory Modulation and Active Support and Key Word Signing, Professional Boundaries, Non-Violence Crisis Intervention and learning about continuous improvement)
- Clients had a lifestyle folder and a health folder which contained vital information regarding the client's health and well-being, including consultation records and appointment register
- The presence of recording at the time was noted as excellent with respect to the use of various residential facility templates (inclusive of Bowel Management Charts, Behaviour Forms, Health and Well-being Consultation Records and Health and Wellbeing Appointment Register). The importance of this monitoring to inform the identification of evidence based reasons to for the challenging behaviours was also identified at the time (including the potential for them to be associated with an underlying health issue)
- It also identified that Comprehensive Health Assessment Programs (CHAPS) were being completed for both clients annually and that professional hygiene practices were of a good standard

This is particularly relevant given that only eight (11%) of the cases within the cluster reviewed by the Public Advocate were in Level 3 Residential Care facilities with the majority residing in DSQ funded services (specifically 65 individuals). Of these persons, 26 were in government supported AS&RS and 39 were in supported accommodation provided by a non-government organisation

According to David's Occupational Therapy report completed on 4 August 2014, David's mobility had deteriorated over the past twelve months and it was noted that he required an increased amount of effort to walk, negotiate stairs and transfer in and out of the bath when assisted to shower. Walking and standing for sustained periods was difficult and David has a preference for squatting. Several recommendations were made as an outcome of this assessment.

Mr Orton experienced a significant decline in overall health and wellbeing after this point. Mr Orton would crawl on his knees and elbows, which would cause tearing to his skin. References were identified in the medical files and in the DSQ consultation notes that Mr Orton had cuts and bruises on knees, (as well as other injuries from falls, a swollen forearm etc) and that this was being treated with medication, being moisturised and being cleaned. It was also noted that Mr Orton was supervised and monitored closely.

As such, the residential facility requested support from the Department of Housing for modifications of the home environment to occur to ensure Mr Orton was able to access his bathroom more appropriately and for other modifications to occur if and where necessary to promote Mr Orton's mobility and overall health and wellbeing . It is noted that the residential facility had been proactive in engaging various health professionals for further examination, and that "the cause of this deterioration has yet to be identified."

In the residential facility Positive Behaviour Support Plan (PBSP) dated June 2015 it states that "David is able to sit still and appears comfortable when his podiatrist is attending to his feet and clipping his toe nails. David is able to independently sit, stand and walk around his home environment and for short distances in the community, although he has an unsteady gait and substantial issues with posture. His preferred position appears to be squatting, kneeling or lying on the ground. David can stand with support for changing duties and will lift each leg with tapping from staff as a prompt along with verbal reassurance".

The Panel questioned why the relevant regulatory authorities did not seem to notice, or respond to, Mr Orton's deterioration in function to the point that he was crawling along the floor. His family report that they had complained about Mr Orton not being in the right facility (with respect to his care needs, including requesting his transition to a palliative care facility) but nothing happened, and that this request should have been escalated, but the Panel were unable to identify the obstruction to this occurring from the available records. It was evident however that Mr Orton should have been moved out of the disability facility a lot earlier, or screened out with revised criteria.

Given there are similarities in support needs for those residing in both Level 3 Residential Care facilities and DSQ funded services, greater standardisation in practice is required for the management of personal care needs and eligibility requirements for entry into these facilities, with prompt transition to a higher care facility if required. Any such processes need to be developed and reviewed with input from appropriately qualified medical personnel.

Mr Orton had cerebral palsy, anxiety, severe kyphoscoliosis, epilepsy, atonic bowel, insomnia and a progressive neurological and functional decline over 18 months with weight loss, increasing agitation, decreasing mobility, chronic abdominal pain and constipation.

Mr Orton's family has raised significant concerns regarding the clinical care provided to him in the 16 months prior to the death, specifically that:

- Mr Orton was non-verbal meaning that his family and support carer's would have to advocate for him
- That he had been losing weight for over 16 months even though he ate 'more and more' and the low weight made him vulnerable to infection
- They requested multiple tests to try and work out what was wrong with him
- Clinical staff refused to provide appropriate pain management for him, up until his death and denied that he was in pain, attributing it to behavioural problems.
- Clinical staff refusing to discuss palliative care as it was 'just for cancer patients'

His family further allege that hospital staff were not proactive and discharged Mr Orton on many occasions without effective pain relief and without conducting tests they felt were obvious and necessary for his diagnosis. They felt that the hospital staff consistently 'passed the buck' to the residential facility staff to care for Mr Orton as they wanted him out of hospital quickly, he was discharged at inappropriate times and without the tests/pain management they felt he required.

Disability Services reported in May 2014 that David needed more assistance, equipment and support at home however available records do not reflect what actions were taken to manage this. According to his mother, no case manager was assigned to Mr Orton until the public Hospital enforced this requirement one to two weeks prior to his death. Having no case manager until this time, in their opinion, meant there was no consistency in Mr Orton's treatment, his deterioration was minimised or not detected, his carers and family were distressed and the obvious pain David had was disregarded as 'behavioural'.

His family state further that "we felt that because David could not speak, the medical teams over the past year or so had no urgency except to send him home to the residential facility to deal with …This is a situation that we never want another family or human being to go through. We also believe it is happening every day in hospitals across Australia and we want to ensure that something changes in the minds of Doctors, nurses and also Disability Services. To change the way clients without a voice are diagnosed and how the admission process is undertaken for anyone without a voice or is too ill to speak. Not only was his voice not heard but his wonderful carers in his house and his family spoke out but also were ignored. This is double disregard for his welfare and his valuable life".

Consensus was unable to be reached by the Panel as to the quality of the treatment provided to Mr Orton prior to the death with one reviewing clinician identifying that he did not agree with other members that there was a substandard level of care by some providers. For example, it was evident from a review of the files that the GP was trying different things on different occasions to try and address Mr Orton’s recurring constipation, including referrals to appropriate specialists.

As the clinician further clarified Mr Orton’s decline may well have been a progression-natural or otherwise of his cerebral palsy.

Based on currently available records, key issues identified by some Panel Members within this case included a loss of interaction with appropriate specialist teams (such as a gastroenterologist and palliative care support), and this lack of engagement may have been potentially responsible for his prolonged poor care. Videos provided by family members taken approximately 12 months apart do show a person who was independently mobile and shows a progressive decline. From the latter video footage Panel members suggested that Mr Orton appeared to be carrying a malignancy and his abdomen has become distended. Autopsy results however found no evidence of a malignancy.

The pathologist found that the cause of death was 1 (cerebral) hypoxia and (b) bronchopneumonia and 2. Toxic megacolon, cerebral palsy and salmonella typhimurium infection. Given that Mr Orton was being treated for constipation the Panel could not identify why the Toxic megacolon was not detected earlier. Indeed constipation had factored heavily in Mr Orton’s health care management for years prior to this death.

It was noted by the Panel that most services do not take constipation seriously even though it can be a clinical symptom indicative of a range of different (and serious) conditions.

As the Public Advocate report noted, people with a disability may be prone to constipation due to sedentary behaviours, poor diet, and medications, however they also may not be able to articulate their symptoms to health practitioners, carers or their supportive others . Recommendations outlined in the report include that carers and support staff should be more aware of the signs, symptoms and risks associated with chronic constipation, and to actively seek medical advice and intervention as required. Where chronic constipation is a concern, appropriate tools must be used to monitor daily bowel motions.

They further make the recommendation that health practitioners should be alert to the possibility of chronic constipation in patients with intellectual and cognitive disabilities who may not be able to describe the typical symptoms but experience behavioural changes, changes to sleeping patters, refusal to eat, weight loss, nausea and vomiting.

The Panel also identified, as evident with the case of Mr Orton, the critical need for constipation to be appropriately managed by specialists (i.e. gastroenterologist) and that while there may be a lack of responsiveness to what can be seen as a relatively minor issue, constipation may have serious, and fatal outcomes.

In 2012, available records indicate that David was having one Movical sachet daily with support workers continuing to monitor his bowel motions, and a plan in place for escalation as required. There had been medical appointments throughout 2012 in relation to this issue.

Changes to his diet were also recommended at this time, with a dietician being consulted and advising dietary restrictions.

The critical incident in 2013 described above related to staff contacting the Ambulance as Mr Orton was refusing personal care assistance and was not eating and appeared unwell. He was transported to a Public Hospital where x-rays revealed he had a large faecal mass. He was subsequently transferred to another public hospital and admitted for medical treatment. It was noted at this time that Mr Orton had a medical history of faecal impactment and has dietary restrictions and required medical supplements to assist to manage his condition.

There was also a suggestion to refer Mr Orton to palliative care a year before he died, with a discrepancy in available records as to whether a referral had occurred but it is clear that he was not transitioned to such a facility. If this had occurred, even if the service could not have done anything to address his clinical condition, they could have dealt with his comfort care needs and ensured that appropriate pain management strategies were implemented.

The Panel identified that a health care reassessment may have resulted in Mr Orton's degeneration being identified earlier and his care being prioritised, however this may not have changed the clinical course of his condition/s.

Best practice approaches are founded on regular engagement with services, and a referral to a specialist if there is no associated improvement in the condition (notably Mr Orton's GP did make such referrals and expressed concern at not being able to alleviate the deterioration in his patient notes).

Increased engagement with available specialist services are critical, however this is not always a clear care pathway. At an operational level, the Panel identified that sometimes hospitals may 'push back' as they may not recognise the severity of a person's condition based on the referral or they may have limited resources to be able to assist. As such there is no clear-cut culpability with respect to this case.

Due to a need to prioritise referrals by hospitals, some specialist outpatient departments will assign a triaging process and won't automatically make an appointment. The person will subsequently be assigned to a waiting list, sent a letter and the GP would be accordingly notified. It is salient to note with respect to persons with a cognitive impairment or intellectual disability that they may not always have the capacity to follow up with these letters and attend an appointment without additional support.

The Panel identified that Mr Orton's Cerebral Palsy put him at risk of constipation due to his lack of mobility, and this issue rarely just spontaneously emerges, it was present for a while. Metabolic and gastrointestinal processes are also affected with the prescription of antipsychotics for persons with mobility issues increasing the risk of constipation.

While constipation may be trivialised in the general population there is an overrepresentation in people with a disability, and it is critical that they are appropriately triaged to see specialist services when required. The Panel identified that because of this increased vulnerability, persons with a disability with multiple and complex needs should be prioritised during any triaging process within a health care setting, as there is an overrepresentation of gastrointestinal issues in this population associated with restricted mobility, and the regular prescribing of pharmaceuticals known to increase constipation.

In terms of other specialist supports that were missing in the provision of care prior to this death, given that in this case Mr Orton was experiencing malnutrition, dieticians should have also been involved in his care to try and address this issue, however records do not indicate this occurred in the immediate time leading up to the death (although they had previously been involved at earlier points in time).

Some members of the Panel found there were aspects of the care provided to Mr Orton that were substandard. With enhanced assessment processes, improved clinical management, coordinated care and improved shared care arrangements it is likely that there would have been improvements in the health and well-being of these persons.

Response of family

David Orton's family have expressed their thanks to all the carers and medical staff who helped David over the years and they acknowledge his disability and health issues were demanding and complicated. They stated David had a long and difficult journey with his disability and medical conditions.

The family also welcomed that David's case to be published for all the medical community to learn more about pain management, and the most important issue, of diagnosing people who are nonverbal both at a general clinic, or at a hospital level.

They believe that diagnostics for this minority group may have better outcomes, if a nonverbal method of diagnostics could be trialled and eventually implemented.

David was an important person in our lives and the family believes that all humans regardless of their disability have the right to fairness and equity concerning pain management and care. David deserved pain management, a caseworker, appropriate residential care, and comfort in the last weeks of his life.

Instead, they are concerned he did not receive timely diagnostics, pain management, not being assigned a case worker and most distressing to his family, in his final weeks of his life he did not receive palliative care.

The improvements the family would like to suggest include:

- that the hospitals are better equipped to handle records, and allocate case workers to patients that have been sick for a long period of time
- that the future of diagnostics for nonverbal disabled people be reviewed and a standard be developed that is adopted and embraced by the medical profession?
- that a standard is developed - on follow up on patients in David’s category of undiagnosed or continuing declining health issues longer that 6 weeks - including thorough sweep of investigative tests eg blood tests, X-rays, scans, colonoscopy, endoscopy, and in particular listening to family and carers as they have a long association with the patient.
- Communication with medical staff is improved between patients and family ie it would have helped David considerably if medical staff had obtained collateral history regarding his scoliosis and large bowel, his predominant medical conditions.

Conclusion

David Orton had significant vulnerable physical and intellectual disabilities. He was receiving care by well meaning and dedicated carers and he died in circumstances which meant his case was a reportable death in care requiring investigation and review.

His medical care was reviewed by the Clinical Forensic Medicine Unit and his overall care was also the subject of an in-depth review by an Expert Panel. The issues identified by the Expert panel were also largely identified as issues by the Public Advocate who conducted its own review of deaths in care of people with a disability.

This finding sets out many of the recommendations made in those reviews and are supported by the family and the Coroner. Mr Orton's family have generously agreed that this finding be published to highlight the need for vigilance in the care of vulnerable people such as David Orton. This is particularly significant as the National Disability Insurance Scheme commences its operation and roll out over the next short while.

Findings required by s. 45

Identity of the deceased: David Orton

How he died: David Orton had significant vulnerable physical and intellectual disabilities. He was receiving care by well meaning and dedicated carers and he died in circumstances which meant his case was a reportable death in care requiring investigation and review.

Place of death: Public Hospital QLD AUSTRALIA

Date of death: 26 January 2016

Cause of death:

1(a) Cerebral hypoxia
1(b) Bronchopneumonia

2 Toxic megacolon, cerebral palsy, salmonella typhimurium infection

I close the investigations.

John Lock
Deputy State Coroner
CORONERS COURT OF QUEENSLAND
11 May 2018