

The road not taken – a journey down the path less chosen.

Aims and objectives

- To support John to experience the best possible end-of-life care and to show how this was achieved across multi-agency teams.
- To demonstrate a holistic multi-professional working case study led by the Learning Disability Nursing Team.
- To show how adapted NEWS (National Early Warning Score) could be used to support unqualified teams working in complex care.

Method

John was a 42-year-old man with a mild learning disability and multiple co-morbidities, including early onset dementia.

Due to his complex learning disability, dementia and physical and sensory needs, innovative care plans were needed to support him.

Adapted **NEWS** was developed to help record and respond appropriately to changes to John's health and wellbeing and to try to prevent unnecessary admissions to hospital.

Anticipatory care plans were drafted for support during the end-of-life phase.

National Early Warning Score pages

PHYSIOLOGICAL PARAMETERS	3	2	1	0	1	2	3
Respiration Rate	≤8		9 – 11	12 – 20		21 – 24	≥25
Oxygen Saturations	≤91	92 – 93	94 – 95	≥96			
Any Supplemental Oxygen		Yes		No			
Temperature	≤35.0		35.1 – 36.0	36.1 – 38.0	38.1 – 39.0	≥39.1	
Systolic BP	≤90	91 – 100	101 – 110	111 – 219			≥220
Heart Rate	≤40		41 – 50	51 – 90	91 – 110	111 – 130	≥131
Level of Consciousness				A			V, P, or U

Conclusion

The confidential inquiry into premature deaths of people with learning disabilities report recognises that people with a learning disability die younger than the general population.

While John did die young, this was related to his co-morbid physical conditions and, in his case, having the Learning Disability Nursing Team support him added quality and quantity to a life that was always going to be short.

The use of adapted NEWS opens significant possibilities for future work, along with advanced care planning for those who lack capacity.

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Other care provided to John by:
Maidstone and Tunbridge Wells NHS Trust
Kent and Medway NHS and Social Care Partnership Trust
Queen Victoria Hospital NHS Foundation Trust
Heart of Kent Hospice



Results

In the last year of his life, John was admitted to Littlebrook Hospital under the Mental Health Act due to severe aggression caused by a urinary tract infection (UTI). He was then supported with a move to his own home with 24-hour two-to-one care. This was put in place due to his high risk of falls, aggression and highly disordered sleep cycle. The aim was to provide the best quality of care in the best possible setting, to the end of his life.

Best interest decisions, with the support of an independent mental capacity advocate, enabled the team to provide comfortable adapted care, including long-term catheterisation, emergency surgery at East Grinstead for a damaged lip after a seizure, and finally to the difficult decision to fit a feeding tube for fluids and medication because of John's disordered sleep pattern and increasing confusion.

John was a young man and physically fit, so decisions had to be tailored to meet his complex dementia, which was life-limiting – this was a man who could stay awake for 48 hours.

Throughout, the Learning Disability Nursing Team provided support and advice and co-ordinated his care. As John entered the dying phase, the anticipatory care plans enabled the care team to recognise this and understand the need for end-of-life care.

John died peacefully in the company of his preferred carers after clearly communicating that he "wanted to die". Excellent care and support was given right to the end by the community nurses and the hospice team.

He was buried with his father and this was only achieved through the determination and consistency of the Learning Disability Nursing Team which had known John for seven years from his early diagnosis to his death.