

To Elton Humphrey
Secretary Senate
Community Affairs References Committee
community.affairs.sen@aph.gov.au

We'll call him Charlie. That's not his real name; his name is not important because what has happened and is happening to Charlie could just as easily happen to anybody else in his age group. Charlie is 51 years of age.

Charlie was a dentist; he was entrepreneurial, very ambitious, quite successful for a time; he lived in a well to do suburb in Sydney, the same suburb where his dental practice was located. He was, and still is, married with two young daughters. He was well liked by his patients.

When Charlie was 44 years of age, disaster struck (dis) courtesy of a genetic inheritance from his Father. Huntingtons Chorea. Symptoms had commenced to manifest prior to diagnosis. Upon formal diagnosis, Charlie resigned from his practice; he lost everything except for the support of his family. His house, his castle was sold; he received nothing; he had significant debts and still has. The family moved to rented accommodation; his wife worked to support the family; Charlie was not eligible for a pension because his wife "earnt too much" even though her income was scarcely sufficient to cover household expenses.

The condition affected Charlie at a cognitive and emotional level and therefore it was very difficult, well impossible, to engage him in any programmes or therapies that may have assisted either him personally or his family. His behaviour could be quite disruptive.

The only way that he could maintain any sense of dignity was to live as if he was a well-to-do retired dentist which only contributed to the pathos. He could not accept the diagnosis although the symptoms were painfully obvious to the observer.

Eventually the Guardianship Tribunal became involved and the day came when Charlie was physically removed from his home, in effect arrested by four police officers and taken to a secure Nursing Home in close proximity to where he had been living. A "mug shot" was taken of him at the time of his admission/incarceration. His expression was one of overwhelming fear and panic, like a rabbit in headlights about to become crow food. He was 50 years of age at the time.

The Nursing Home where he has subsisted for the past 12 months mainly comprises elderly senile dementia patients; the place smells of excrement; most of the patients in the section where Charlie is accommodated are a generation older than him.

Other patients within the Nursing Home are patients with serious psychiatric issues, some of them are around Charlie's age, but the issues are different; he is in a different category but shares the same asylum.

His family visits him frequently but this is upsetting for them, because the place smells bad, some of the other patients are troublesome and there is no area within the Home for privacy.

Charlie now receives a full Disability pension but of this \$450 per fortnight, 80% goes towards his accommodation, leaving him \$45 per week for himself, a long fall for a man who had it not been for circumstances beyond his control, could have had reasonable expectation of absolute financial security by this stage in his life.

There is only one Hospital in Sydney that specifically caters for Huntingtons Chorea patients; Lottie Stewart Hospital only has places for fifteen and even then Charlie would not be considered because at 51 he is actually too old(!). Lottie Stewart only takes Huntington's patients to 50 years of age.

There are specific specialised care needs but those are not affordable and not available in any event. Ideally Charlie should be entitled to individual specialised care in a nurturing comfortable environment or at least facilities should be made available for him to be accommodated in a place where he or his family do not have to be troubled by the inevitable cost of the requisite care, resources and facilities.

Sadly the concept of Charlie's living as a productive member of the community seems an impossibility; but then perhaps if Charlie was with the assistance of Government resources, taken out of the too-hard-basket, there might yet be a chance.

Submitted by

Daniel Habermann