

APPG on Brain Tumour

Inquiry into the Social and Economic Impact of Brain Tumours

Evidence session: 5 June 2018



The sudden death of my husband, Carlton Dale, at the age of only 53 from a glioblastoma on 12 December 2016 was brutal. His degeneration was fast and traumatic for him and my family.

I was away working with my colleagues from Headway on the morning of 22 March 2016. Unknown to me, that morning Carlton had woken up struggling for words with some memory loss. Predictably, he waited for my return before action was taken. In my role as Director of Fundraising for Headway, I was fully aware of the need to get Carlton to hospital quickly, believing it to be a stroke. At 6pm that evening we arrived at Leicester Royal Infirmary. At midnight, a curtain was drawn round our cubicle and we were informed of the presence of a large brain tumour - our world imploded.

We began a journey in what I can only describe as a relentless series of battles. A battle for a timely and specific diagnosis (5.3 weeks from initial diagnoses), a battle to then slow down the growth of the tumour (treatment commenced 2 months from initial diagnoses), a repeated battle for a hospital bed following seizures (on one instance waiting to be admitted into A&E with 17 ambulances ahead of us), a battle for information despite repeated requests, a battle for emotional and practical support, a battle for end of life care (9 out of 16 NICE quality standards not met).

From day one when we presented ourselves to the receptionist at the Leicester Royal Infirmary, the social and economic impacts of Carlton's brain tumour were significant.

At a time when you are at the emotional depths of despair and desperate, I and our family had to draw strength from wherever we could. We had to battle at every step of Carlton's 265 day journey.

- Uncertainty clouded everything – we were given very few “rough estimates” or ideas about what Carlton's journey would be like, what milestones we should look out for. Being told things will happen “as soon as possible” is meaningless – does this mean in 2 days, 2 weeks or 2 months? What is normal? Our expectations were not managed.
- Our constant need to fight for what Carlton and our family needed meant precious time away from him. That time is lost forever.
- We were unable to completely focus on his practical and emotional needs.
- The hospital settings which Carlton attended as an outpatient were completely unsuitable for someone with a brain tumour. The clinic waiting areas were noisy, crowded and brightly lit. For patients with neurofatigue, sensory issues and, often, problems with mobility, having to wait and then be called for across a large, busy clinic waiting area made our trips to hospital even harder for Carlton to endure.
- We encountered a lack of insight and empathy from some professionals on this journey – this contributed to Carlton's anxieties and fears.
- The cognitive impairment and lack of insight which are classic effects of brain tumour led to issues during our appointments with the clinical staff: it would have been more helpful to have consultations separately as well as together, or be given a clear route for me to communicate directly with the clinical team away from Carlton. In the end, I managed to find the consultant's secretary's email address and I tried to feed in information ahead of appointments, but I could not be certain this information was read or taken into account.
- I had additional emotional stress as his main carer as well as being solely responsible for the day-to-day management of the household and “life laundry” – responsibilities Carlton and I had always shared.
- Our 5 grown up children and wider family had to be called on to take time off work to help care for Carlton, due to the lack of support, particularly at the end of his life.
- We needed to provide financial support to our adult children, to help with their added expenditure – hospital parking, travel, food and some household bills.
- Following his traumatic death, two of our children were unable to access timely bereavement support in their locality, resulting in absences from their workplaces.

My husband, Carlton Dale was a caring, kind and clever man who gave a great deal to our local community and charities. He served on the National Council of Independent Monitoring Boards as well as on the Independent Monitoring Board locally at Gartree Prison in Leicestershire. This was as well as his full time work as Head of Facilities at Global Radio.

He believed, as I do, that you should give back to society.

I count myself a little more fortunate than most by working with my colleagues at Headway – the brain injury association. I was given extended paid leave, as well as their friendship and guidance. For the majority of families devastated by brain tumour this is not the case, and from my work at the charity I know they too face daily social and economic battles.

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