'Compassion doesn't cost a dollar'

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Lying in hospital after a horrific car crash, teenager Chloe Youngson could see nothing but the ceiling tiles. Specialists marvelled that she was even alive after smashing the top two vertebrae in her neck. The formerly active 18-year-old was put in traction – immobilised to let her badly injured neck heal – for three months. Chloe was unable to see who entered her room, to watch television or even read a book.

Her dad, Auckland anaesthetist Robin Youngson, was working at the hospital when she was admitted after the accident four years ago. And although he was part of the management team, he and his wife, Meredith, became increasingly concerned about some staff's lack of interest in their daughter's psychological well-being.

"In our opinion, if we didn't do something urgently, she was going to become severely clinically depressed. I was a powerful person in the system; I had been a senior specialist in the hospital and I worked in management and I was on a national committee. It doesn't

matter which hospital it was because I think these things can happen in any hospital. I thought I could get this system to recognise how to meet her needs, and I completely failed."

In the end, Robin and Meredith - and a wide circle of family and friends - helped restore a semblance of life for Chloe. Youngson resigned his anaesthetist's position and set to work building disability aids for his daughter. He bought an expensive laptop computer and a mobile phone and suspended them above Chloe's bed so she had access to the outside world. Yet even then, things didn't run smoothly, he says.

"When we asked the hospital for an internet connection, they said you can't have that and listed all the reasons why it couldn't happen, even though there was a computer dataport a metre away from her bed. Eventually, I pulled rank and insisted that it had to be done.

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And just connecting her to the internet, the email and movies was fantastic."

But more shocks were in store. The family discovered the system of delivering food to patients rooms was unsuitable for a patient like Chloe, "There's a really good system to ensure a meal-tray is delivered to a room and taken away an hour later," says Youngson, "but Chloe could not feed herself and a tray would be left out of reach and out of sight and taken away again. Many days she'd go hungry and the food was such poor quality - it was essential for her healing, for her injuries and her fractures to get the best quality nutrition."

The Youngsons drew up a roster of family and friends

Robin Youngson: shocked.





who visited the hospital over 100 days to take her tasty, nutritious food. They were charged more than \$1000 at the hospital carpark for the privilege.

After Chloe was discharged, the family complained to Health and Disability Commissioner Ron Paterson, believing that her rights to humane treatment had been breached.

"If you did this to a prisoner in Abu Ghraib prison in Iraq, you'd be sent to jail for 20 years for torture and abuse of human rights," Youngson says. "There's a right to be treated with respect and treated with dignity and have your needs assessed and met. We thought this was such a flagrant breach of rights that it was obvious ... but the Health and Disability Commissioner was not able to find a breach of rights on the basis of the code and evidence available."

The decision prompted Youngson to last year establish the Compassion in Healthcare charitable trust, which aims to emphasise the importance of compassion among health workers. More recently, he has been trying to get the Health and Disability patients' code of rights altered to include the word "compassion". He hopes Paterson will support the wording change and he plans to seek cross-party support so that the law can be changed to reflect the importance of compassion.

Paterson says the British Medical Journal refers to the divide between patients and health professionals as "an invisible barrier". He says complaints his office receives sometimes involve concerns about nurses taking a "mechanistic approach to their role".

Much of that, Paterson believes, is due to workforce stresses as well as a tendency to be tied to systems that do not work. He says nurses are well placed to take the lead in the return to caring, because patients trust them. "They will say they haven't got time to care, but we are still running hospitals in the way we did in the early 20th century. We need to redesign our systems and use our

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ROBIN YOUNGSON

time more effectively ... I think there is a challenge to restore the lost art of caring within the health profession."

Robin Youngson says his family is grateful for the technical care Chloe received, but he shares Paterson's concerns about systemic failures. He says one day Chloe was in agony but her "carers" appeared unable to help: "How can you create a system that makes individual practitioners feel so helpless? So that they can see someone screaming in agony and they just run away and hide because they feel so helpless? There's a learned helplessness in the system."

It's time those in authority emphasised compassion in the workplace, between

patients and staff and between staff, Youngson says. "If you were a fly on the wall in various wards and tearooms, I think you'd be fairly shocked at what an unhealthy and unsafe environment hospitals are to work in. There's a great deal of bullying, and there's very little support from the leaders of organisations for the emotional needs of staff."

And he says upholding the importance of compassion ultimately improves a patient's recovery and reduces costs. "If people are secure and rested in their mind, and believing of the ability to get through this and heal and recover, that has a very profound influence on the body."

Chloe is now 22 and studying urban design at university, aptly finding an interest in creating healthy environments. Her dad says she is a testament to extraordinary courage and determination – a week after getting out of traction, she walked unaided out of hospital.

"If it hadn't been for the actions of her family, I believe Chloe would have been profoundly clinically depressed and severely malnourished," Youngson says. "She would have required months of rehab which would have cost the hospital system tens of thousands of dollars ...

"There's a real lesson in that. This is not about a lack of resources; compassion doesn't cost a dollar. It's more of an attitude and approach and something from the heart. Even if you're really busy, you can be compassionate."