



Housing LIN

Connecting people, ideas and resources

Home is where the heart is

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It is important to listen. When people who are supported by the community care system in England have family members or friends who have something to say, it is important to listen. These are the people who speak up because they care deeply. They are not paid to care, and they choose to spend their time, energy and emotions willingly on the person who is in receipt of care. The organisations who are paid to provide the care should welcome, value and celebrate this voluntary involvement. And, in relation to public finances, estimates show that the care provided by friends and family members to ill, frail or disabled relatives saves the public purse £132 billion per year¹.

However, a listening approach has often not been adopted by organisations in my experience. My brother has profound and multiple learning disabilities and has lived in a variety of residential care homes in England since 2002. If our input is not welcomed, it begs the question: Why?

If we were to place a stethoscope against the heart of an organisation providing care, may we hope that it beats because it cares about the person being cared for and not because it cares about what they represent financially to the organisation. We live in a world of scarce resources, which need to be allocated efficiently – even as parents, siblings or other family relations or friends, we are aware that funding needs to cover costs, and that money talks. We are not ignorant. But too often our loved ones are spoken of as if they are an ‘asset’ or a ‘debt’ on the balance sheet, and care seems to have become a commodity.

As highlighted by a BBC investigation last month², “hundreds of care homes are banning relatives from visiting elderly residents over complaints about quality of care”. From my own experience, I must say that I am not surprised. I dare to venture that many relatives and friends who have a loved one in a care home are also not surprised by this finding. It is frightening to consider this reason why relatives are banned: to ‘bully’ into silence those that witness the daily realities of the care provided and courageously speak up when they wish the care to improve. It is frightening that care homes are able to do so.

I know many people who visit their relative in a residential care setting several times a week, or often even daily. I have seen the emotional stress and physical exhaustion this has caused. If their concerns are not listened to, this can severely affect their own quality of life, with a cost to the National Health Service, as highlighted above.

¹ Carers UK and University of Leeds (2015) Valuing Carers. And NHS England (2014) NHS England's Commitment for Carers.

² Myska, S. (2 November 2016) *Care home bans relatives who complain*. BBC's Victoria Derbyshire Programme. <http://www.bbc.co.uk/news/health-37825745>

According to the updated government policy paper on carers' health in 2015, "The demands of being a carer can affect a person's quality of life, including their ability to study and work, their finances and their health. People providing high levels of care are twice as likely to be permanently sick or disabled, and 625,000 people have health problems because of their caring responsibilities".³

When we choose to stay involved even though we could easily relegate all responsibilities to the care provider, then this input is a gift (or free resource) that should not be scorned. Often, we 'prop up' the underfunded system by providing the care we see is lacking or inadequate, rather than allowing our loved ones to suffer. Too often unfortunately, care providers will not see such input as helpful but as complaining and they will react negatively or defensively. Sometimes, if the resident is publicly funded, the organisations place extreme pressure on relatives to fight for more money from social services departments if they wish the care for their relative to improve. If the situation does not improve and family members continue to seek improvements, then the relationship may even break down between families and providers, as highlighted by the recent BBC investigation.

Even if our concerns as relatives cannot be alleviated in the short-term, we can understand if we see that the organisations at least endeavor to listen to us. If relatives and friends are afraid to speak up because of the consequences, the system is in danger of silencing those who listen to whether the heart of the care system is still beating with compassion. I personally know of families who have been threatened that their relatives' placement is vulnerable at their current care home. For people with profound and multiple learning disabilities, it can be extremely difficult to find new placements in the same local area.

Family members or friends will have known the person in receipt of care for many years - longer than the organisation now providing the care. Staff may change at the organisation and high staff turnover and inexperienced staff may characterize an organisation. Organisations are dynamic and fluid. Family members will have a longer shared history with the person, and often are a more stable and consistent anchor in their lives. It is these characteristics, which mean that family members have earned the right to be listened to. Yet, I have experienced that many families have come to the end of their strength and have found no source of external, independent support.

The Care Quality Commission (CQC)⁴ states, "we can't make complaints for you or take them up on your behalf. That may seem confusing but it's because we don't have powers to investigate or resolve them". This leaves families feeling extremely vulnerable when they encounter an organisation, where they feel that their resident's care is consistently inadequate. I personally was recently told that the CQC would only step in if I wished to raise a safeguarding concern, but because I love my brother I do everything in my power to sustain his health and wellbeing so that such a situation does not develop.

³ Department of Health (2015) *2010 to 2015 Government policy: carers' health*
<https://www.gov.uk/government/publications/2010-to-2015-government-policy-carers-health/2010-to-2015-government-policy-carers-health>

⁴ Care Quality Commission (4 November 2016) *Visiting someone in a care home*.
<http://www.cqc.org.uk/content/visiting-someone-care-home>

In the light of the above, it has left me trusting in no other option for my brother's future, than to leave my previous work and start a small non-profit company where the person cared for, and also their families, are at the heart of the services and support provided. It is our dream to move him into a small house with two other friends with disabilities, where they are able to live a full and joyful life and where they, and their families, have more control over their lives than in a residential care home.

It is well documented that people with disabilities flourish when they have the level of control they want over their lives, homes and support⁵. Moreover, it has been highlighted that personalisation of services requires a: "broad range of choice in the local care and support market, including housing options, and a person-centred way in which care and support services are delivered wherever people live"⁶. In many areas of the country however, there is an acute lack of suitable housing for people with physical and learning disabilities.

Thus, it is important to listen, not only to family members or friends who are concerned about the quality of care, but also to the needs of people with learning disabilities. It is also important to continue to create more choice and control for them in where they live and how they are supported.

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⁵ Social Care Institute for Excellence (2012) *At a glance 8: Personalisation briefing: Implications for housing providers. Briefing co-produced with the National Housing Federation.*

⁶ Think Local, Act Personal (2011) *Think local, act personal: A sector-wide commitment to moving forward with personalisation and community-based support.*