

BHMA ESSAY 2014

“Coping with your own vulnerability in caring for a person who has a long-term condition”

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“So he kept his mother’s trouble secret. There were times when she was calmer and clearer than others, and he took care to learn... how to shop and cook and keep the house clean, so that he could do it when she was confused and frightened. And he learned how to conceal himself too, how to remain unnoticed at school... What Will feared more than anything was that the authorities would find out... and take her away, and put him in a home among strangers. Any difficulty was better than that. Because there were times when the darkness cleared from her mind, and... [she] blessed him for looking after her so well; and she was so full of love and sweetness then...”¹

Little of my childhood was unaffected by the impacts of caring for another. It seems still, looking back, that there was little else. I was a child who helped to look after someone who required support for a medical condition – a “young carer”. There is increasing awareness of the 166,363² young carers in England, and available support. As the Carers Strategy 2010 acknowledged, there are many more “hidden” young carers, unobserved by national statistics and not in receipt of support;³ a 2010 survey estimated the figure at 700,000.⁴ Caring for another can be a positive experience, a means to grow into adulthood, to develop resilience, and self-sufficiency. Yet ‘self-sufficiency can go against the need to belong... [and] young carers may not acknowledge their limitations or fully grasp... support’⁵ when offered. These young people may experience extremes of ‘isolation, social exclusion and stigmatisation... with limited opportunities to socialise with peers as a consequence of their caring duties, often compounded’ by other factors such as financial concerns, and ‘reluctant[ce] to invite friends to their homes or exchange confidences about their circumstances, which can hinder the development of friendships.’⁶ Young carers are placed into constant confrontation with vulnerabilities: of their care recipient, of those who seek to support them, and their own.

My father turned 70 when I was 13, and suffered with many of the conditions of old age. His poor health appeared insignificant as a child; he could not kick a football or travel easily, but he was a father of stories (often of the war), Radio 4, and copious cups of tea. Quietly and steadily, my mother cared. The meals were made, the homework assisted, the house sparkling... and the tablets taken. He was cared for, as was I. One warm summer afternoon, life changed irrevocably. My mother stumbled down the stairs, tears on her face, doubled in pain. An ambulance rushed her to hospital. I remember the scent of lavender rising from the pavement, sprigs from nearby bushes crushed by the paramedics’ boots.

On her return post-surgery, she withered and shrunk. Each day became a cycle of phone calls, night doctors, and desperate hope. She was eventually rushed back into hospital for further extensive surgery, and her recovery was painfully slow. I was told to prepare for her death by doctors, every week. The daily responsibilities of caring for both parents – cooking, cleaning, paperwork – became my “normal”, defined and guided by bonds of love, reciprocity, and above all, duty. Pressures were endless, finances tight, and social engagement entirely unfamiliar. There was never a choice.

I had never heard about “young carers” as a phenomenon, and had no contact with fellow carers, nor with those able to explain that this was not the norm. There was simply no time to reflect on circumstance, only swiftly subsume a developing teenage identity with adult, near-parental responsibility. Societal norms dictate that most adults are expected to be care-givers to children and the elderly, rather than care recipients.⁷ When this relationship is disturbed, national policies and support networks may show their cracks, and young carers may remain “hidden” and beyond the reach of services and supports designed to help them in their caring role.⁸ I was one of those children hidden from the carer statistics, unknown to social support systems, initially by chance, and later by choice. The situation for carers has improved. A major change to the law in October 2013 dictates that:

...when a child is identified as a young carer, the needs of everyone in the family will be considered. This will trigger both children’s and adults support services into action – assessing why a child is caring, what needs to change and what would help the family to prevent children from taking on this responsibility in the first place.⁹

I feared doctors, I feared social services, I feared teachers, and above all, I feared losing my home and family. Young carers have significantly lower educational success than their peers,¹⁰ and I was no exception. Parental ill health and disability remains the third most common cause for admission to care services in England.¹¹ The fear of stigmatisation and discrimination associated with physical and mental disability, compounded with the potential actions of those in positions of authority, leads many young carers to fear the consequences of honesty – as did I.¹² To conceal oneself within the context of this fear is to safeguard oneself and others, to remain invulnerable and reinforce one’s identity as protector. There is an irony that when faced with caring for an adult in their extreme vulnerability, the child’s vulnerability is often shielded from view.

Regardless of age, ‘our relationship with awareness of our own vulnerability is far from comfortable – we have a natural tendency to locate it in other people – it is he, not me, who is in need, it is she, not me, who is vulnerable.’¹³ In my case, my identity – and thus vulnerability – revolved entirely around the others whom required my care. In the internalisation of responsibility for (in many cases) life itself, the young carer necessarily displaces their vulnerability, whether through repression, via support networks, or through the embodiment and gratification of their own needs in their care for another. The carer’s vulnerability remains however; in an 2003 Edinburgh study¹⁴ of 61 young carers, 67% had concerns about their own health, 60% suffered with sleep disturbance, 30% with problems eating, and over 30% had experienced suicidal ideation or had self-harmed.

How is one to explain the immense challenges faced by young carers to those unimpacted: a peer, an adult, a stranger? Young carers further may face challenges socialising with other children due to lack of time or

overbearing responsibilities, which may result in restricted peer networks, isolation, and bullying. Conflict or disparity between the needs of the carer and care recipient 'may lead to feelings of guilt, anger, isolation... or being trapped..., that there is nobody there for them, that professionals do not listen or include them..., and that their contribution is not recognised or respected,'¹⁵ despite their often high maturity level. Young carers are trapped by contradictory expectations; an adult at home with the constant pull of family responsibility, whilst a child at school surrounded by peers with entirely different lives.

Self-definition as a young carer begins for most through contact with other carers or support services,¹⁶ connections that clear space for an acknowledgement of the extreme extent of responsibility carried, the emotions entailed, and the first opportunity to show true vulnerability. Sadly, there is 'no strong evidence that young carers are more likely than their peers to come into contact with support agencies, despite government recognition that this needs to happen.'¹⁷

The personal revelation years later through national press and media campaigns that I had not been alone in such experiences granted some sense of imagined community, but also a poignant and troublesome personal identity. The term initially felt an act of aggression, a false statement that my childhood was insufficient or harsh, and I refused it. Eventually, it became the label through which to explain what I had faced – the easy explanation, but one I gave grudgingly. "Young carer" felt a simplification of personal, individual years, a phrase deeply layered with a universal story of thousands of children, which needed no further explanation. It was easily spoken, and easily forgotten. As the older yet ever-guarded child, adopting this identity was simultaneously a means to avoid repeated tiresome explanation, and a bold, vulnerable act, an "'affirmation [of why] things have been so hard'",¹⁸ a statement of pride. Identifying as a young carer also became less 'about [the personal struggle of] embracing a label, but rather an acknowledgement that the normative relationships of familial care-giving sit at the heart of [my] identity.'¹⁹

It is precisely this heart I carry into a medical career. I hope always to perceive the subtleties of life, to see the bigger picture, and always to ask the carer how they are keeping, as I never was. My life has been irrevocably shaped by my experiences, and I continue to grow into immense pride of that fact. Without years of being a young carer, I wonder if I would have considered a lifetime of medications, interventions, witnessing, hand-holding, and utter awe and fascination throughout. The identity I hold, proudly, awkwardly, boldly, is that of a carer.

This statement, as with the rest of my life, is my act of strength, humility, and radical vulnerability.

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- ¹ Pullman, P. (1997). *The subtle knife*. New York: Knopf. p.11.
- ² Office for National Statistics. (2014). *2001 Census - ONS*. Retrieved from: <http://www.ons.gov.uk/ons/guide-method/census/census-2001/index.html> [Accessed: 1 Apr 2014].
- ³ Department of Health, *Recognised, valued and supported: Next steps for the Carers Strategy*. 2010, London.
- ⁴ BBC (2010). *Newsbeat - Young carers are 'four times' the official UK number*. Retrieved from: <http://www.bbc.co.uk/newsbeat/11758368> [Accessed: 1 Apr 2014].
- ⁵ Barry, M. (2011). 'I realised that I wasn't alone': the views and experiences of young carers from a social capital perspective. *Journal Of Youth Studies*, 14 (5), pp. 523--539.
- ⁶ Smyth, C., Blaxl & Cass, B. (2011). 'So that's how I found out I was a young carer and that I actually had been a carer most of my life'. Identifying and supporting hidden young carers. *Journal Of Youth Studies*, 14 (2), p. 151.
- ⁷ Becker, S. (2007). Global perspectives on children's unpaid caregiving in the family research and policy on 'young carers' in the UK, Australia, the USA and Sub-Saharan Africa. *Global Social Policy*, 7 (1), pp. 23--50.
- ⁸ Smyth, C., Blaxl & Cass, B. (2011). 'So that's how I found out I was a young carer and that I actually had been a carer most of my life'. Identifying and supporting hidden young carers. *Journal Of Youth Studies*, 14 (2), p. 151.
- ⁹ The Children's Society. (2014). *Historic change in law signals new era for young carers*. Retrieved from: <http://www.childrensociety.org.uk/news-views/press-release/historic-change-law-signals-new-era-young-carers> [Accessed: 1 Apr 2014].
- ¹⁰ Underdown, A. (2002). 'I'm growing up too fast': messages from young carers. *Children & Society*, 16 (1), pp. 57--60.
- ¹¹ Dearden, C. & Becker, S. (2005). Growing up caring: young carers and vulnerability to social exclusion. *Youth Policy And Social Inclusion: Critical Debates With Young People*, pp. 251--266.
- ¹² Rose, H. D. & Cohen, K. (2010). The experiences of young carers: a meta-synthesis of qualitative findings. *Journal Of Youth Studies*, 13 (4), pp. 473--487.
- ¹³ Guardian. (2010). *Welfare state expresses an ideal of the good society*. Retrieved from: <http://www.theguardian.com/society/joepublic/2010/nov/03/welfare-state-ideal-good-society> [Accessed: 1 Apr 2014].
- ¹⁴ Cree, V. E. (2003). Worries and problems of young carers: issues for mental health. *Child & Family Social Work*, 8 (4), pp. 301--309.
- ¹⁵ Simon, C. and Slatyer, C., 2011. Young Carers. *InnovAiT: Education and inspiration for general practice*. 4(8), p. 459.
- ¹⁶ O'connor, D. L. (2007). Self-identifying as a caregiver: Exploring the positioning process. *Journal Of Aging Studies*, 21 (2), pp. 165--174.
- ¹⁷ The Children's Society (2013) *Hidden from view: the experiences of young carers in England*, London: The Children's Society, Retrieved from: http://www.youngadultcarers.eu/docs/report_hidden-from-view_young-carers_final1.pdf, p.4.
- ¹⁸ Smyth, C., Blaxl & Cass, B. (2011). 'So that's how I found out I was a young carer and that I actually had been a carer most of my life'. Identifying and supporting hidden young carers. *Journal Of Youth Studies*, 14 (2), p. 151.
- ¹⁹ Smyth, C., Blaxl & Cass, B. (2011). 'So that's how I found out I was a young carer and that I actually had been a carer most of my life'. Identifying and supporting hidden young carers. *Journal Of Youth Studies*, 14 (2), p. 150.