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Response

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The caregiving scenario in Dr Winch's paper provokes a response, not because it is new to us but because we do not ask enough questions. Stroke is but one of a spectrum of chronic life-limiting illnesses (CLLIs) that seem to creep in with age and longevity in more developed countries. The likelihood of having to care for someone with a CLLI increases with the rising prevalence of CLLIs, as the author has noted. It is not new for humans to care for one another, but moving the location of more demanding levels of care from professional settings into the home revolutionises the time and space of carers' personal lives. We have normalised this.

As a society and as a body of health professionals we think "patient-first" about the person with the CLLI, but perhaps fail to think deeply enough about what this mind-set imposes on the health of those whom we now call "carers". They are now required to comply with normative expectations without the preparation, resourcing and relief that health professionals can rely upon. It is as if we have assumed that older spouses of the chronically ill routinely have a place in the package of non-acute care delivery simply because they have a relationship with the person receiving care, and that this is okay. It may be acceptable for some, but it is useful to take a step back and think about what is happening here. We offer carer supports and relief as band-aids when something more radical is needed. It is as if we are saying "Let us provide you with listening ears, a stream of visiting helpers and other services, but we cannot address the root cause of your distress by providing 24/7 care of the person with CLLI so that you can reclaim what remains of your relationship, your home life and your health". Put in these terms, it almost sounds like abuse.

This disturbing but not uncommon scenario goes almost unchallenged, perhaps because we are so busy and expediency prevails. It is troubling that carers who wish to restore something of the former normality of their lives feel inhibited by a sense of accountability to the care advisors who are now part of their domestic landscape. What is it going to take for us to want to move beyond the anecdotes and rhetoric and make applied bioethical research a reality that changes current policy and practice?

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