

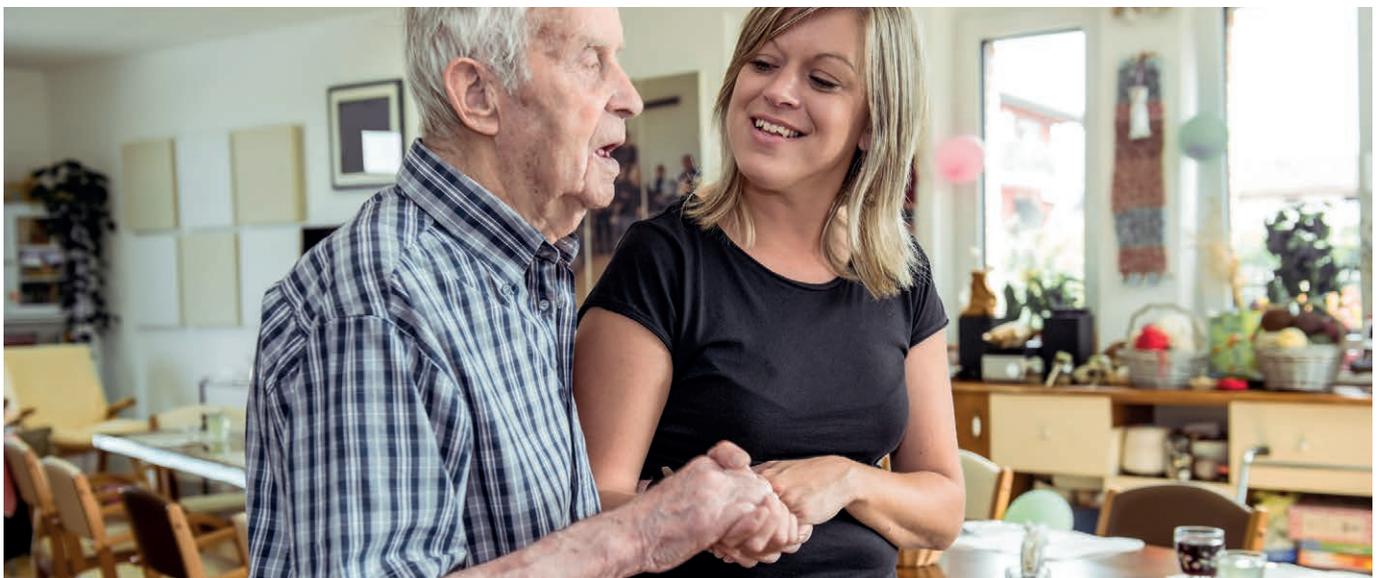


DUTIES TO CARE: WHY WE ALL HAVE A DUTY TO CARE ABOUT DEMENTIA

Rosie Harding, March 2017

'We must ensure that dementia care is understood as the responsibility of all of us, not simply of those who have the immediate and personal experience of supporting a person living with dementia.'

(Professor Rosie Harding)



As life expectancy increases and global populations age, growing numbers of people live with a diagnosis of dementia: up to 47.5 million people worldwide, according to World Health Organization figures in 2016, with anticipated growth to 135.5 million by 2050. 'Dementia' is a generic term, used to describe a range of different syndromes and disease processes that are characterised by common symptoms: deterioration in cognitive function, particularly relating to memory, thinking, understanding, calculation, language, judgement and orientation. Alzheimer's Disease is the most common form of

dementia, accounting for between 60–70% of dementia diagnoses worldwide. The progressive cognitive impairments associated with dementia lead to increasing needs for care and support.

In her research – *Duties to Care: Dementia, Relationality and Law* – Harding argues that the increasing prevalence of dementia generates a set of pressing socio-legal concerns about how best to regulate health and social care. We need to support those who care for family members and friends as

well as those living with dementia themselves. Harding's research maps the experience of caring for a family member with dementia from diagnosis to death. This Spotlight focuses on two aspects of Harding's research into family carers' experiences of the health and social care system: (a) the challenges of navigating the system; and (b) complaints about poor care. Her research shows that the current regulatory approach to dementia makes caring more difficult, and compounds the already devastating emotional and financial effects of dementia on families and carers.

THE PROJECT – WHO CARES?

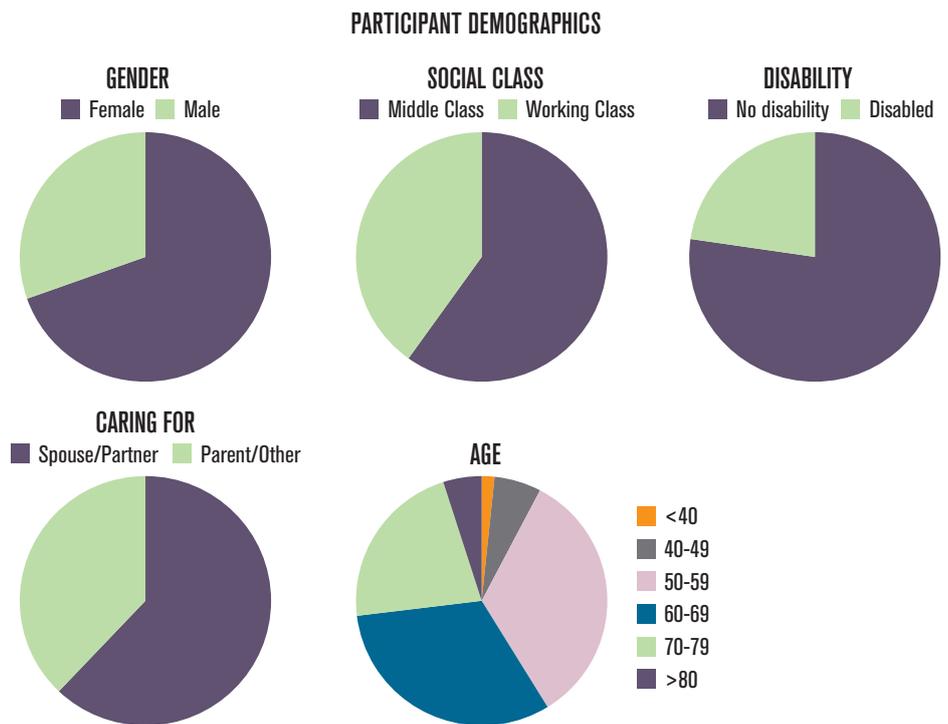
The Duties to Care project included questionnaires completed by 185 people and focus groups with 15 carers, representing the experience of 189 individual carers of people with dementia. The questionnaires covered a series of topics, including experiences of diagnosis and health care, financial aspects of caring, powers of attorney and complaints about health and social care.

DEMENTIA CARE: A RELATIONAL LEGAL PROBLEM

Through her analysis of the challenges faced by carers of people with dementia, Harding argues that we need to be more attentive to the nested regulatory influences (law, policy, regulation, social norms, community support, interpersonal networks) that contribute to everyday experiences of caring. She suggests that caring needs to be regulated in a way that takes more notice of the relational reality of care. What this means is that people with dementia need support from those around them, but so too do those family members and friends who provide care. Too often, law focuses on one party in the caring relationship, ignoring the multiple influences that affect their lives.

'The emotional side is the hardest for me. Feeling overwhelmed, feeling guilty, missing my Mum, feeling that I can't cope or can never be good enough to do everything for her. Wanting her to die because when we have clear conversation, that is what she wants too. Feeling guilty for wanting her to die. Feeling guilty if I take time away for myself.'

QUESTIONNAIRE RESPONDENT



'With insufficient access to support, or with support coming in the wrong forms and at the wrong times, family and friends who provide care are placed under unbearable pressure.'

PROFESSOR ROSIE HARDING

NAVIGATING THE DEMENTIA CARE SYSTEM

Harding's research shows that the complicated and fragmented nature of the health and social care regulatory system makes life more difficult for carers than it needs to be.

'It's a huge maze, the system, it's a terrible maze and you come up against, I won't say brick walls, but, you know, dead ends practically everywhere you turn.'

FOCUS GROUP PARTICIPANT, VIV, 64

Harding found that carers reported difficulties with repetitive 'needs assessments' that acted as gatekeepers towards access to services.

'You have to spend hours on the phone and that you, that you get thwarted the whole time and that you go through endless assessments with the same information that by now ought to be on a computer, ought to be accessible and that the different departments don't speak to each other, is the most frustrating thing. You just want to bang your head against the wall and say, "but you know this," you know, "Why am I going through this again, why am I having to do this?"'

FOCUS GROUP PARTICIPANT, SARAH, 67

Rather than having to provide the same information multiple times to different service providers, carers would prefer to have information shared across providers. Yet, Harding argues, the decentralised and fragmented nature of the contemporary health and social care system makes information sharing of this type very difficult. As different dimensions of care and support are provided by an increasingly large mix of public and private sector service providers, the problems faced by carers in accessing services are likely to be compounded, rather than solved. Creative solutions are needed to balance data protection concerns with appropriate levels of data sharing.

COMPLAINTS ABOUT POOR CARE

Participants in Harding's research reported high levels of incidents that gave them 'cause to complain' about the way the person they care for was treated by health and social care services. Nearly half (45%) of questionnaire respondents reported incidents giving rise to 'cause to complain'.

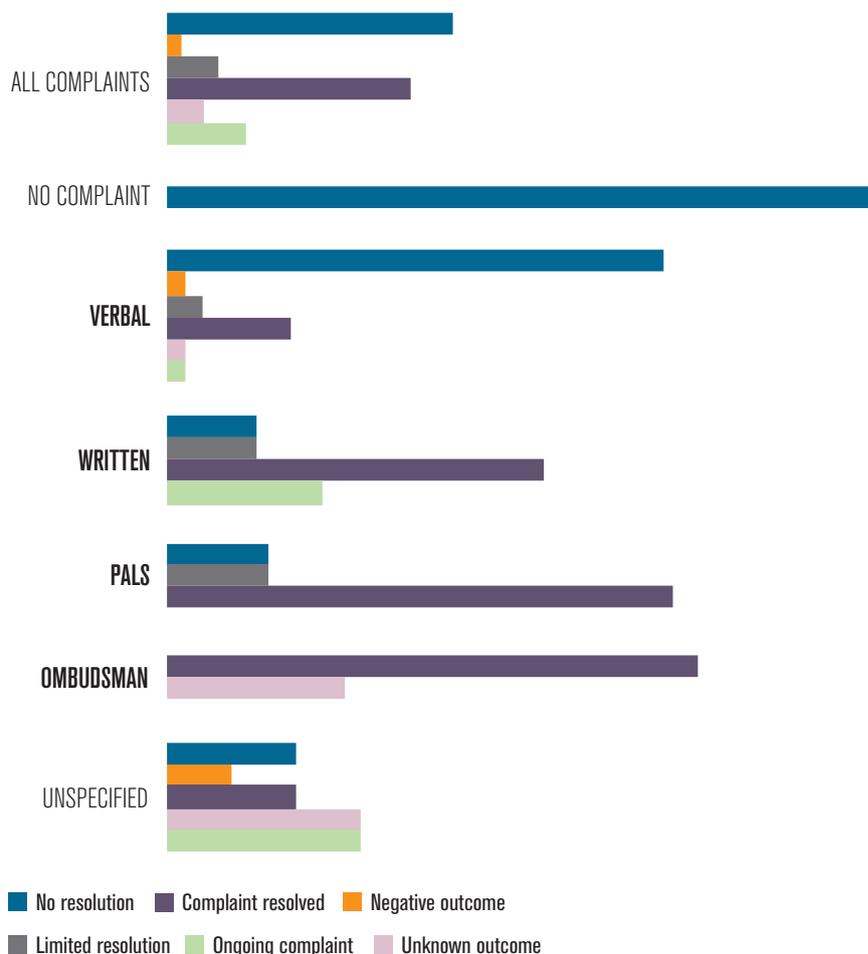
Around half of the problems giving 'cause to complain' reported in Harding's research were about health care (48%), with a further 48% about social care. The remaining 4% of complaints were about both health and social care together. Not all carers who experienced 'cause to complain' actually made a complaint, with some reporting being scared that if they did, care staff would 'take it out' on their relative.

'We had to raise concerns about our relative's care in a dementia ward in a hospital. We were too scared to put in a formal complaint as our relative may need hospital care in the future... No one seems to take complaints seriously and the complaints process seems to work against those complaining.'

QUESTIONNAIRE RESPONDENT

The way that complaints were made had a major influence on carers' levels of satisfaction with the way the complaint was responded to, addressed or resolved. Verbal complaints were often made by carers, but rarely resolved: 70% of verbal complaints noted in this research went unresolved. A higher proportion of the social care complaints (52%) were made verbally than health care complaints (31%), which suggests that social care complaints were less likely to be resolved. Complaints were much more likely to be resolved if carers drew on independent complaints mechanisms like PALS (the NHS Patient Advice and Liaison Service) or the Health or Social Care Ombudsmen. But very few carers mentioned these services, suggesting very low levels of usage and awareness of these independent complaints resolution mechanisms.

Complaints reported by participants in this research often concerned issues relating to the dignity of the person with dementia,



and their treatment in hospitals. Several complaints related to continence care, which is an area of personal care for family members that carers find very difficult to deal with.

'During his stay in hospital I visited my dad twice a day, this was because they didn't understand his needs – my dad is doubly incontinent, even though this was documented on all paperwork he was left without a pad on. One day I went in and they had sat him next to a window which was wide open because he had messed himself and they thought by sitting him next to the wide open window in January the smell would go away. I was furious as they did not seem to care about his health, dignity, his needs, or respect.'

QUESTIONNAIRE RESPONDENT

Respondents in Harding's research expressed concern about low levels of dementia awareness training on general hospital wards, which echo findings

of previous research into the experience of dementia care in hospitals. These participants also reported serious issues of neglect and poor treatment in care settings.

'He no longer goes to respite as he suffered neglect. The last time he went he nearly died. He was admitted to hospital unconscious, in sepsis shock and severely dehydrated.'

QUESTIONNAIRE RESPONDENT

Yet even where such serious issues are raised, these complaints often went unresolved. In one reported complaint, despite police involvement following a report of sexual assault by care staff at a nursing home, 'because of dementia nothing could be proved' (Questionnaire respondent). Harding argues that recent reforms in the Care Act 2014 which formalise safeguarding processes for vulnerable adults do not go far enough to address neglect and abuse in care contexts. She suggests that greater attention needs to be paid to ensuring an appropriate and proportionate criminal law response.

RESEARCH SPOTLIGHT

RECOMMENDATIONS

This research into carers' experiences of the regulatory systems surrounding dementia care leads Harding to make four regulatory recommendations:

- 1 Greater emphasis needs to be placed on data sharing across health and social care providers to help carers navigate 'the maze' and access support.
- 2 Health and social care complaints systems need to significantly improve response and resolution frameworks for verbal complaints.
- 3 Awareness-raising of the role of the Local Government Ombudsman as an independent arbiter of social care complaints is urgently required.
- 4 Legal reform is needed to ensure appropriate criminal law responses to abuse and neglect in care settings.



ABOUT THE AUTHOR

Rosie Harding: Rosie Harding is Professor of Law and Society at the University of Birmingham in the UK. Her research focuses on how law shapes everyday life, in the contexts of family law, disability, and mental capacity. Rosie is chair of the Socio-Legal Studies Association, and a 2016/17 British Academy Mid-Career Fellow. Her research has been funded by the British Academy, the Economic and Social Research Council and the Arts and Humanities Research

Council. She is author of *Duties to Care: Dementia, Relationality and Law* (2017, Cambridge University Press), and *Regulating Sexuality* (2011, Routledge, winner of the Hart-SLSA Book Prize and Early Career Prize). She is editor of *Law and Sexuality* (2016, Routledge), *Ageing & Sexuality* (2016, Routledge, with Elizabeth Peel) and *ReValuing Care in Theory, Law and Policy* (2017, Routledge, with Ruth Fletcher and Chris Beasley).

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