

This response was submitted to the consultation held by the Nuffield Council on Bioethics on *Dementia: ethical issues* between May 2008 and July 2008. The views expressed are solely those of the respondent(s) and not those of the Council.

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### **Introduction**

Thank you for this welcome opportunity to comment on the Consultation Paper, 'Dementia: Ethical Issues', and for the important inquiry which the Nuffield Council on Bioethics is undertaking in this area. I hope that the reflections, observations and comments set out below, and the references to supporting literature provided, will be helpful, interesting and constructive to the Council.

For the sake of brevity, this response focuses on presenting, in the most succinct and introductory terms, an account of the emerging concept of 'relational autonomy'. It seeks to use that concept as a focus or springboard for reflecting on some of the key issues and questions raised in the Consultation Paper. While this response only addresses directly a selection of specific topics drawn from the Consultation Paper, I hope that the notion of relational autonomy may have wider relevance and utility to the Council in its thinking around the topic of dementia and dementia care more generally.

The account of relational autonomy presented in this response draws exclusively from two forthcoming pieces – a book chapter<sup>1</sup> and an article<sup>2</sup> – written by Mr Jonathan Herring, Exeter College, Oxford.<sup>3</sup> I am indebted to Jonathan Herring for providing me with these manuscripts in their final form, and for permitting me to cite them and to use them as the scholarly foundation for this paper. All of the supporting literature references provided in the footnotes below are drawn from his forthcoming book chapter.<sup>4</sup> However, any errors or omissions made below remain entirely my own.

The three specific sections of the Consultation Paper touched upon in this response are:

- Section 2 – Person-centred care and personal identity
- Section 3 – Making decisions
- Section 6 – Research

### **Relational autonomy – an introductory outline**

The concept of 'relational autonomy' has been developed by scholars (led initially by feminist and communitarian writers in particular) who consider traditional liberal accounts of autonomy to be unduly individualistic and atomistic.<sup>5</sup> Rather than seeing autonomy as being principally about the *self* – self-realisation, the self-authored life, self-government, individual freedom of choice, self-sovereignty, moral independence, and so forth – relational autonomy is built around the notion of *interdependence*. Because people are embedded within social networks, proponents of relational autonomy argue, sufficient weight must be given to the fact that people make decisions within the context

of those relationships with others, and also to the obligations and responsibilities that flow from those interconnections.

Relational autonomy is not a 'single unified conception'.<sup>6</sup> Instead, it is 'an umbrella term with a range of related perspectives'.<sup>7</sup> It has attracted adherents from a wide and growing range of academic disciplines and theoretical traditions.

Key aspects of the relational autonomy concept are expanded and discussed in the analysis below. Before turning to that, however, it is important to note that, while relational autonomy is becoming increasingly prominent and popular, several criticisms have been levelled against it.<sup>8</sup> One key problem highlighted is its (historically) rather abstract and fluid quality. This potentially makes it difficult to apply to concrete situations in a theoretically satisfactory and robust way. Another leading criticism is the obvious danger of swinging the pendulum too far towards over-emphasising interrelationships, thereby overlooking or insufficiently valuing the importance that people attach to their private 'self' and self-determination. A related danger is that people's individual rights and interests potentially could be overridden improperly in the name of the 'family' or 'community' under a supposed relational autonomy justificatory banner.<sup>9</sup>

So long as such dangers and potential pitfalls are borne in mind and guarded against, relational autonomy arguably offers a powerful alternative intellectual framework to the more traditional individualistic accounts of autonomy, and one which carries numerous benefits. In the dementia context in particular, the concept of relational autonomy may well offer an extremely helpful tool for framing, probing, understanding better and even perhaps resolving some of the most difficult issues to do with caring for people with dementia and their carers. Some of these are considered now.

### **Person-centred care (Section 2)**

One area where relational autonomy may be particularly illuminating and helpful is the question of how best to handle those situation where apparent conflicts or clashes arise because of a divergence between the 'best interests' of people with dementia, and the interests of their loved ones or others with whom their lives are intertwined or who care for them. Here, relational autonomy could well provide a valuable alternative prism. This is because, as Herring has observed,<sup>10</sup> while traditional individualistic models of autonomy can lead to situations being framed and constructed as involving 'clashes' of competing individual rights,

a relational autonomy model argues that such an image misconceives how people understand their lives, especially when in close emotional relationships. We are not constantly clashing rights with those we live with, rather our interests are intertwined. People in close relationships seek a compromise which is good for "us" and do not see it as a matter of weighing up competing interests.

Viewed from this perspective, some apparent 'clashes' of rights or interests could turn out to be inaccurate or misleading, generated and imposed by an overly individualistic model of autonomy that, in reality, fails to appreciate the true ways in which people order and live their lives. Rather than seeking to adjudicate which of two or more people's 'competing' individual rights or interests ought to take precedence, then, what is needed in a given case may instead be to begin with an entirely different formulation of the issues at stake – one which rests on an entirely different starting-point foundation.

In this regard, relational autonomy clearly tests how the concept of 'person-centred care' ought to be defined, interpreted and applied. Arguably, it suggests that the stress should be placed more on the term 'centred', rather than on the term 'person', if the term is to be retained and used, and (if so) if it is to be employed in the best possible way.

### **Personal identity (Section 2)**

In the dementia context, relational autonomy may also provide a helpful theoretical model or tool for helping us to define the meaning of 'identity'. Frazer and Lacey, for example, have argued from a relational autonomy perspective that our relationships with others – and also with relevant practices and institutions – are central to our personal 'identity' and to our 'sense of ourselves'.<sup>11</sup>

The concept also serves to remind us of the need to attribute proper significance to the role of 'personal identity' in shaping who people are, and in influencing how they make decisions (as well as the substantive content of those decisions). Leading on from this, relational autonomy could help to guide us in assessing how pre-dementia personal identities, values, decisions and so forth might be compared with, and/or evaluated or weighed against, those that emerge or present themselves after the onset of dementia.

### **Making decisions – advance directives (Section 3)**

According to Herring's overview of relational autonomy, six interlinked themes lie at its heart.<sup>12</sup> Each is touched upon briefly below, simply to illustrate how they may potentially be relevant within the dementia context, particularly (although not exclusively) in relation to making and enforcing decisions.

The first theme identified by Herring is that 'relational life is inevitable'. Rather than being free simply to live as we each may choose, our decision-making is to some extent constrained by the responsibilities and relationships within which we are embedded.<sup>13</sup> This may include caring for dependents, and the benefits and sacrifices of friendship.<sup>14</sup> A second theme is that, alongside autonomy, other important values also need to be respected. Those values may include trust,<sup>15</sup> responsibility, care,<sup>16</sup> and attention to the needs of others. According to Herring, such values are seen by relational autonomy scholars as being essential to the maintenance of relationships – which, in turn, are themselves essential to genuine autonomy.

Taken together, these two themes might suggest that prior decisions taken by people with dementia – including advance directives – should not automatically be applied (at least, not on the justificatory basis of respecting their ‘autonomy’) if the social context around the person has changed materially, or if the impact on them, their family or their care-givers would violate significant values that people hold or have held dear – such as care, responsibility, trust, or attending to others’ needs.

A third key theme is that people’s decisions cannot properly be understood except within a social context. Our social structures fundamentally shape our identities, desires, beliefs and emotional attitudes<sup>17</sup> – and, hence, the decisions that we make. Potentially, this insight has important implications for the role of the state in promoting citizen’s autonomy; not least, for people who develop dementia. As Herring argues:

Ensuring autonomy means that the state must not only ensure that an individual is not subject to improper threats from others, but that the social and community structures are such that a person is free to develop with others a community or set of relationships within which to develop a vision of the good life. In other words maximising autonomy does not require giving people the time and space to sit quietly and reach decisions for themselves free from outside disturbance, but rather developing social and community based structures which will enable human interactions to flourish. Autonomy then is not a psychological state so much as a social one (Oshana, 1998).<sup>18</sup>

Once again, this vision of autonomy potentially calls into question current policies and practices surrounding the active promotion of advance directives, including under the Mental Capacity Act 2005 and its Code of Practice. It may also help to explain that Act’s apparent conceptual inconsistency in terms of how advance directives should be treated under the law – in particular, in relation to when they should, or should not, be enforced.

A fourth relational autonomy theme is that emotions, attitudes, desires, creativity, feelings, memory and so forth are all important parts of autonomy alongside rationality.<sup>19</sup> While, then, traditional versions of autonomy emphasise rationality above everything else, relational autonomy sees emotional factors and emotional states as being equally valid, significant, and worthy of respect and treatment as such. In the dementia context, adopting such a perspective could potentially require a fundamental reappraisal of how we define what constitutes a ‘sound’ judgment or decision. It might also suggest that previous options chosen in advance by people while they possessed rational capacity should not necessarily be enforced or prioritised after their rational capacity has been compromised or lost, simply on the grounds of respecting their autonomy.

This suggestion gains further support from a fifth theme embedded in the notion of relational autonomy – namely, that autonomy is not a static ‘attribute’, ‘state’ or ‘quality’ that one either ‘has’ or ‘does not have’. It is a capacity that is acquired, and one that must be sustained and developed through social forms,

relationships and personal practices that foster it.<sup>20</sup> As Herring puts it, autonomy 'ebbs and flows with the changing of relationships', and it is 'in and through relationships that the skills needed to exercise autonomy are learned and developed'.

A final theme which raises some important caveats in the dementia context is that while, generally speaking, relational life is 'good', and beneficial relationships are vital for genuine autonomy to flourish, relationships and social structures can also be oppressive or abusive. A core part of relational autonomy therefore emphasises protecting people from harmful relationships and their consequences.<sup>21</sup> Once again, this insight may have ramifications for the role and responsibility of the state, social agencies, courts and other third parties in caring for people with dementia, and particularly in assessing the soundness of their decisions, and the wisdom and legitimacy (or otherwise) of enforcing those decisions, given the factors that may have shaped or improperly influenced them.

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- 1 J Herring, 'Relational Autonomy and Rape', unpublished manuscript due to appear as a chapter in Jackson et al (eds), *Autonomy* (Hart Publishing, forthcoming, book title and date TBC).
- 2 J Herring, 'Losing It? Losing What? The Law and Dementia' (2008) 20 *Child and Family Law Quarterly* (forthcoming). Inter alia, this article sets out a detailed critical appraisal of current UK laws, guidelines and policies relating to capacity, decision-making and enforcing advance directives in the dementia context.
- 3 See also J Herring, 'The Place of Carers' in M Freeman (ed), *Law and Bioethics* (Oxford: OUP, 2009, forthcoming).
- 4 Above n 1.
- 5 L McClain, "'Atomistic man" Revisited: Liberalism, Connection, and Feminist Jurisprudence' (1992) 65 *Southern California Law Review* 1171.
- 6 C Mackenzie and N Stoljar, 'Autonomy Refigured' in C Mackenzie and N Stoljar (eds), *Relational Autonomy* (Oxford: OUP, 2000) at 4.
- 7 Herring, above n 1.
- 8 For a more extensive and detailed summary, together with responses and defences to the leading criticisms, see Herring, above n 1.
- 9 N Binder, 'Taking Relationships Seriously: Children, Autonomy, and the Right to a Relationship' (1994) 69 *New York University Law Review* 1150.
- 10 Herring, above n 1.
- 11 E Frazer and N Lacey, *The Politics of Community: A Feminist Critique of the Liberal Communitarian Debate* (Hemel Hempstead: Harvester Wheatsheaf, 1993) at 178.
- 12 Herring, above n 1.
- 13 J Nedelsky, 'Reconceiving Autonomy: Sources, Thoughts and Possibilities' (1989) 1 *Yale Journal of Law and Feminism* 7.
- 14 S Sevenhuijsen, 'The Place of Care: The Relevance of the Feminist Ethic of Care for Social Policy' (2003) 4 *Feminist Theory* 179.
- 15 O O'Neill, *Autonomy and Trust in Bioethics* (Cambridge: CUP, 2002).
- 16 K Franke, (2001) 'Taking Care' (2001) 76 *Chicago-Kent Law Review* 1541.
- 17 MacKenzie & Stoljar, above n 6.
- 18 M Oshana, 'Personal Autonomy and Society' (1998) 29 *Journal of Social Philosophy* 81.
- 19 See, eg, M Friedman, 'Autonomy, Social Disruption, and Women' in C Mackenzie and N Stoljar (eds), *Relational Autonomy* (Oxford: OUP, 2000) pp 35–51.
- 20 D Meyers, *Self, Society, and Personal Choice* (New York: Columbia UP, 1989); Nedelsky, above n 13, at 10.
- 21 M Chen-Wishart, 'Undue Influence: Vindicating Relationships of Influence' in (Eds J Holder & C O'Connell (eds), *Current Legal Problems* (Oxford: OUP, 2006) pp 231–266.