

# EXPLORING RELATIONAL (AND REMAINING) AUTONOMY FOR PEOPLE WITH DEMENTIA

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## I INTRODUCTION

The law's conception of a person as being an 'individual autonomous agent' in a decision-making process often does not reflect the experience of persons with dementia and other long-term illnesses. It would appear from research studies involving people with cancer and with dementia that decisions in long-term illness are often made on a shared basis - shared both with healthcare professionals, and with families and loved ones. An alternative to the law's individualistic account of autonomy is 'relational autonomy,'<sup>1</sup> an account of autonomy which recognises our mutual inter-dependence and suggests that we are both enabled and constrained in our autonomous decision-making by our relationships with those around us. A relational account of autonomy may, for many people, provide an ethical foundation for decision-making that is more appropriate than the traditional individualistic account. This is perhaps particularly so in the case of people in the earlier stages of dementia for whom autonomous decision-making can be enabled and facilitated with support from others. For persons with more established dementia, however, a relational approach to autonomy may increase vulnerability to marginalisation in the decision-making process - whether intentionally or not - by shifting the focus away from the person with dementia. This article suggests that, for persons with more established dementia, an inability to make a *legally* autonomous decision (even with support) should be honestly acknowledged. In these circumstances, support for autonomy is best

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\* BA, LL.M, Lecturer, University of Limerick Faculty of Law<sup>1</sup>As MacKenzie and Stoljar suggest in the introduction to their seminal work *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self*, '[t]he term "relational autonomy", as we understand it, does not refer to a single unified conception of autonomy but is rather an umbrella term, designating a range of related perspectives. These perspectives are premised on a shared conviction, the conviction that persons are socially embedded and that agents' identities are formed within the context of social relationships and shaped by a complex of intersecting social determinants, such as race, class, gender and ethnicity.' Catriona Mackenzie and Natalie Stoljar, eds. *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self* (New York, USA: Oxford University Press, 2000).

achieved by ensuring that the person's *remaining* autonomy and her *previous* expression of autonomy are central to decision-making.<sup>2</sup>

Where *remaining* autonomy (referring to the views a person is currently able to express notwithstanding a lack of legal autonomy) comes into conflict with previous expressions of autonomy (before the loss of legal autonomy), this approach requires their reconciliation. The law has traditionally been protective of previously expressed wishes and feelings, beliefs and values,<sup>3</sup> but if we are serious about continuing to respect the autonomy of the person whose dementia is more advanced, we also have to find a way of ensuring that the person's current expressed wishes and feelings<sup>4</sup> or will and preferences<sup>5</sup> play an important role in the decision-making process.

## II LESSONS FROM PRACTICE

Decision-making in relation to medical care is naturally focused on the doctor-patient relationship,<sup>6</sup> but evidence suggests that families also play a key role in decision-making in the contexts of long-term and serious illness.<sup>7</sup> Gilbar conducted a widely-cited qualitative study in six NHS trusts in England measuring the degree to which patients with serious long term illnesses involved their families in decision-making in serious illness. The study was based on in-depth interviews with both patients and their relatives.<sup>8</sup> The results of this study, and a subsequent study conducted by Gilbar and others with breast cancer patients and their husbands,<sup>9</sup> found that families play an important part in decision-making, to differing degrees.

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<sup>2</sup> The standard under s 4 of the *Mental Capacity Act* 2005 c. 9 in England and Wales is best interests; the standard under the *Assisted Decision-Making Capacity Act* 2015 No. 64 of 2015 in Ireland is under s 8 a set of Guiding Principles.

<sup>3</sup> In Ireland as seen most recently in Ireland in *Governor of X Prison v PMcD* [2015] IEHC 259

<sup>4</sup> Under the *Mental Capacity Act* 2005 in England and Wales.

<sup>5</sup> Under the *Assisted Decision-Making Capacity Act* 2015 in Ireland. The author acknowledges that will and preferences is not one capable of easy definition see useful discussion in G. Szmukler "Capacity", "best interests", "will and preferences" and the UN Convention on the Rights of Persons with Disabilities" (2019) 18(34) *World Psychiatry* 1.

<sup>6</sup> Roy Gilbar, 'Family Involvement, Independence, and Patient Autonomy in Practice' (2011) 19 (Spring) *Medical Law Review* 192, 207.

<sup>7</sup> *Ibid.* 208.

<sup>8</sup> *Ibid.* 192.

<sup>9</sup> 'The majority of reported studies on the active and direct involvement of family members in medical decision-making focuses on the patient's spouse or partner.' *Ibid.* 208. Gilbar references a study involving 82 prostate cancer patients of whom 93% consulted their partners before they made their final treatment decision. SJ Srirangam et al, 'Partner's Influence on Patient Preference for Treatment in Early Prostate Cancer' (2003) 92(4) *BJU Int* 365. In Gilbar and Gilbar's study of breast cancer patients and their partners, 84% of the fifty-seven patients believed the involvement of their husbands in the decision-making process was important, while 89% believed their husband's agreement with their decision to be essential. R. Gilbar and O. Gilbar, "The Medical

In the NHS study,<sup>10</sup> Gilbar identified three categories of family involvement in decision-making (for patients whose capacity was not expressly in question):

- (i) ‘Substantial influence’: In some cases had their relatives not supported them, patients would have struggled to make the decisions they made.
- (ii) ‘Moderate influence’: The relatives’ views were important but not the overriding factor. The patients in this group made their decision in a social context.
- (iii) ‘Minimal influence’: The relatives provided emotional and functional support but did not have an impact on the decision.<sup>11</sup>

Gilbar concluded that the “relatives’ involvement in the process reflected a ‘relational’<sup>12</sup> rather than an individual perception of patient autonomy”.<sup>13</sup>

Persons with dementia are, as Harding observes, “more likely than most adults to be in specific relations of dependency: they are likely to be reliant on others for the provision of care and for support in order to retain their independence and dignity.”<sup>14</sup> Their relational context is therefore particularly important to them. There is relatively little research on the involvement of persons with dementia in decision-making processes; most studies so far have concentrated either on decision-making capacity or on the responsibilities of the substitute decision-maker. A body of research providing some insight into the decision-making process *from the perspective of the person with dementia*<sup>15</sup> and his/her family members and loved ones, is beginning to

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Decision-Making Process and the Family: The Case of Breast Cancer Patients and Their Husbands’ (2009) 23(3) *Bioethics* 183.

<sup>10</sup> Gilbar, *Ibid.*

<sup>11</sup> Interestingly, in the third category a particular patient who reported minimal family involvement had substantial professional influence in the decision-making process, thereby adhering to the shared decision-making model. *Ibid.*, at 211

<sup>12</sup> Gilbar notes (referring to Mackenzie and Stoljar, above note 1) ‘At the heart of relational autonomy is the notion that significant others have an influence on the decisions that the individual makes, for the individual is first and foremost a social being with an important network of people with whom she/he has a close relationship, forming part of his/her identity.’ *Ibid.* 198.

<sup>13</sup> *Ibid.* 220.

<sup>14</sup> Rosie Harding ‘Legal constructions of dementia: discourses of autonomy at the margins of capacity’ (2012) 34(4) *Journal of Social Welfare & Family Law* 425, 430.

<sup>15</sup> As Reamy et al’s findings suggest, ‘caregivers may become increasingly unable to make decisions that effectively represent the IWD [individual with dementia]s’ own preferences.’ A.M. Reamy, K. Kim, S.H. Zarit, & C.J. Whitlatch ‘Understanding discrepancy in perceptions of values: individuals with mild to moderate dementia and their family caregivers’ (2011) 53(2) *The Gerontologist* 293 at 293. See also, Lyndsey M. Miller, Carol J. Whitlatch & Karen S. Lyons ‘Shared decision-making in dementia: A review of patient and family carer involvement’ (2016) 15(5) *Dementia* 1141.

develop, however. In 2016 Miller et al<sup>16</sup> conducted a review of empirical findings concerning persons with dementia and their family carers in the health and social care decision-making process, with a particular focus on the involvement of the person with dementia in the decision-making.<sup>17</sup> The authors found that, while persons with dementia were frequently excluded<sup>18</sup> from the decision-making process, this was not always the case; in the earlier stages of dementia and for less serious decisions the process was often one of shared decision-making.<sup>19</sup> Miller et al found that “the most likely scenario for persons with mild dementia is a shared decision-making process and a consensus decision with a family carer”, and that for “persons with moderate dementia, family carers are more likely to either check-in before making final decisions or make the final decisions alone.”<sup>20</sup> In one Norwegian study researchers found that shared decision-making was the most common, while individually autonomous decision-making also occurred.<sup>21</sup> While people with dementia made decisions about simpler care decisions, major decisions such as medical treatment or moving decisions were inevitably shared or ultimately taken by the family.<sup>22</sup> The seven studies of dementia and medical treatment

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<sup>16</sup> Miller, Whitlatch & Lyons, Ibid.

<sup>17</sup> To be included in this review, studies needed to be published in peer-reviewed journals between 1999 and 2014, report empirical data from participants with dementia and/or their family carers, and pertain to the involvement of persons with dementia and their family carers in decisions about everyday care, medical care and treatment, or long-term care. A total of 36 studies were included. The authors note that the review was limited in that ‘no studies could be found that took place in an acute care or inpatient hospital setting, where the majority of major medical treatment decisions are made.’ Ibid. 1153.

<sup>18</sup> Ibid. Smebye et al have identified following factors as contributing to non-involvement: ‘[r]educed mental capacity, lack of available choices or not being given the opportunity to participate led to non-involvement.’ Kari Lislerud Smebye, Marit Kirkevold and Knut Engedal ‘How do persons with dementia participate in decision making related to health and daily care? A multi-case study’ (2012) 12(241) *BMC Health Services Research* 1.

<sup>19</sup> Miller, Whitlatch & Lyons, Ibid. Smebye et al describe a broad spectrum of what constitutes shared decision-making; ‘the most likely scenario for persons with mild dementia is a shared decision-making process and a consensus decision with a family carer’ Ibid. For persons with moderate dementia, family carers are more likely to either check-in before making final decisions or make the final decisions alone. See also, Scott Y.H. Kim, Jason H.T. Karlawish & Eric F. Kane ‘The State of Research on Decision-Making Competence of Cognitively Impaired Elderly Persons’ (2002) 10(2) *American Journ. Of Geriatric Psychiatry* 151; Kritika Samsi & Jill Manthorpe ‘Everyday Decision-making in dementia: findings from a longitudinal interview study of people with dementia and family carers’ (2013) 24(6) *International Psychogeriatrics* 946. The spectrum of shared decision-making also includes patterns that are more difficult to characterize. Smebye, Kirkevold, and Engedal identified patterns of pseudo- autonomous decision-making, whereby family carers made decisions based upon assumptions about preferences rather than confirming the current choice of the person with dementia directly.

<sup>20</sup> Miller, Whitlatch & Lyons, Ibid 1144

<sup>21</sup> Kari Lislerud Smebye, Marit Kirkevold and Knut Engedal ‘How do persons with dementia participate in decision making related to health and daily care? A multi-case study’ (2012) 12(241) *BMC Health Services Research* 1. The purpose of the study was to gain a better understanding of how persons with dementia participated in making decisions about health care and how their family carers and professional caregivers influenced decision making. The study had a qualitative multi-case design. The triad in each of the ten cases consisted of the person with dementia, the family carer and the professional caregiver, in all 30 participants. Inclusion criteria for the persons with dementia were: (1) 67 years or older (2) diagnosed with dementia (3) Clinical Dementia Rating score 2, moderate dementia; (3) able to communicate verbally. The family carers and professional caregivers were then asked to participate.

<sup>22</sup> Ibid.10.

specifically<sup>23</sup> found that persons with dementia prefer a process which is shared between their family carer, their doctor and themselves,<sup>24</sup> whereas the majority of family carers indicated that they would make the final medical decisions alone and may or may not involve the person with dementia in the process.<sup>25</sup> In the two medical treatment studies that involved both patients and their families, researchers found that although most people with dementia wanted to participate in decision-making together with their family carers they did not do so once their dementia progressed beyond the mild or early stages.<sup>26</sup> The studies examined suggest that while families tend to make the more serious decisions as dementia progresses, people with dementia want to be involved in decision-making processes during this period.

### III EXPLORING RELATIONAO AUTONOMY

The findings from Miller et al's survey of dementia research (in common with the findings from Gilbar's cancer studies) indicate that when autonomy is exercised by persons with dementia it is often exercised in a shared or supported way. This suggests a degree of disharmony between law's emphasis on 'individual autonomy' in decision-making and the way in which doctors, and patients and their families view autonomy and decision-making in the context of long-term illness, including dementia. This disharmony raises the question of whether law's emphasis on individual autonomy in the informed consent process reflects the reality of desired/chosen patient practice and, therefore, whether law is justified in continuing to prioritise individual autonomy. While a focus on individual autonomy arguably remains the best way to keep the person (with or without dementia) at the centre of the decision-making process, it 'seriously constrains how we may conceptualize those who are not fully autonomous and how they are treated as a result.'<sup>27</sup> The challenge is whether autonomy itself can be re-cast or re-interpreted<sup>28</sup> in a way that more accurately reflects decision-making in practice for people

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<sup>23</sup> Miller, Whitlach & Lyons (n 15) 1153. The survey was limited in that no studies could be found that took place in an acute care or inpatient hospital setting, where the majority of major medical treatment decisions are made.

<sup>24</sup> Ibid 1150. See also, Karen Hirschman wr L 'Do Alzheimer's Disease Patients Want to Participate in a Treatment Decision, and Would Their Caregivers Let Them?' (2005) 45(3) *The Gerontologist* 381.

<sup>25</sup> Miller Whitlach & Lyons, Ibid at 1150.

<sup>26</sup> Ibid 1152.

<sup>27</sup> Susan Dodds, 'Choice and Control in Feminist Bioethics' in Mackenzie & Stoljar (n 21) 217. "[T]he preferred adult legal subject is one that has the capacity to weigh up the advantages and disadvantages of a particular course of action, and to use higher-order reasoning to arrive at an informed decision." Harding (n 14) 426.

<sup>28</sup> Catriona Mackenzie and Natalie Stoljar, 'Autonomy Refigured' in Mackenzie & Natalie Stoljar, Ibid.

with long term-illnesses such as dementia, without divesting it of its essential meaning - of *auto nomos* or self-rule.<sup>29</sup>

Relational conceptions of autonomy (as an alternative to individualistic autonomy) provide the basis for re-thinking autonomy in a way that is conducive to the exercise of autonomy in dementia, particularly during the earlier stages. A relational approach to autonomy seeks to understand a person not as an isolated individual but rather as a person in the context of their relationships. It is an approach which, rather than prizing individualism, recognises that we are all inherently interdependent. A relational approach recognises that people are both enabled<sup>30</sup> and constrained<sup>31</sup> in the exercise of their autonomy by their relationship context. Most people, as the Nuffield Council on Bioethics observed in their report *Dementia: ethical issues*,<sup>32</sup> ‘do not make “autonomous” decisions in isolation: rather they come to decisions supported by those close to them and in the light of those relationships.’<sup>33</sup>

The origins of a relational approach to autonomy derive from cultural or difference feminism<sup>34</sup> and from the ‘ethic of care.’<sup>35</sup> The ethics of care is a normative ethical theory developed by and associated with the work of feminist theorist Carol Gilligan. In her seminal text *In a Different Voice*,<sup>36</sup> Gilligan drew on empirical research with women and girls to identify a female ‘different voice’ which prioritised and understood morality in terms of relationships and care for others rather than the traditional (male) conceptualisation of ethics and morality in terms of justice and individual rights.<sup>37</sup> An ethics of care approach, applied to healthcare, ‘rejects the centrality of autonomy in bioethical principlism’<sup>38</sup> in favour of ‘positively valu[ing] the activity of caring and responsibility to care.’<sup>39</sup> This effectively means that persons should not be entirely self-regarding when making decisions but that ethical decision-making

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<sup>29</sup> ‘The literal meaning of the word is to be ‘governed by one's own law.’ Jennifer Nedelsky, “Reconceiving Autonomy: Sources, Thoughts and Possibilities” (1989) 1 *Yale Journal of Law & Feminism* 7, 10.

<sup>30</sup> Ibid.

<sup>31</sup> Mackenzie & Stolja (n 1)..

<sup>32</sup> Nuffield Council on Bioethics, *Dementia: ethical issues* (London, UK: Nuffield Council on Bioethics, 2009)

<sup>33</sup> Ibid. 80.

<sup>34</sup> Raymond Wacks, *Understanding Jurisprudence: An Introduction to Legal Theory* (2<sup>nd</sup> ed, OUP, 2009) 367.

<sup>35</sup> The ethics of care emphasizes traits valued in intimate personal relationships such as sympathy, compassion, fidelity and love. *Caring*, in particular, refers to care for, emotional commitment to, and willingness to act on behalf of persons with whom one has a significant relationship. Tom L. Beauchamp & James F. Childress, *Principles of Biomedical Ethics* 7<sup>th</sup> Ed (New York, USA: Oxford University Press, 2013) 35.

<sup>36</sup> Carol Gilligan, *In a Different Voice: Psychological Theory and Women's Development* (Harvard, 1982).

<sup>37</sup> Wacks (n 34) 367.

<sup>38</sup> Principlism is the four principles as set out in Beauchamp & Childress’ *Principles of Biomedical Ethics* (n 35) 13.

<sup>39</sup> Dodds (n 27).

requires taking account of the interests of those who will be affected by those decisions. An individualist model of autonomy, in contrast, attempts ‘to deny the validity of many uninvited moral obligations that ordinary life with other people usually casts before us.’<sup>40</sup>

In her seminal article *Reconceiving Autonomy: Sources, Thoughts and Possibilities*, Jennifer Nedelsky<sup>41</sup> examined the *source* of autonomy, i.e. how and why are individuals enabled to be autonomous in the first place? ‘[T]he answer’, for Nedelsky, ‘is not isolation, but that relationships with parents, teachers, friends, and loved ones provide the support and guidance necessary for the development and experience of autonomy.’<sup>42</sup> Nedelsky traces this development to early childhood: ‘relatedness is not, as our tradition teaches, the antithesis of autonomy, but a literal precondition of autonomy, and interdependence a constant component of autonomy.’<sup>43</sup> Rather than relationships posing a challenge to our autonomy, our relationships are what enable us to flourish and to be self-directing.<sup>44</sup>

It is this *enabling* aspect of relational autonomy that is interesting to explore from the point of view of promoting the participation of people with dementia in decision-making, particularly for persons who can exercise autonomy or self-determination with the support of families and loved ones.<sup>45</sup> The law in England and Wales, and in Ireland, is starting to recognise that autonomy can be exercised relationally; both the *Mental Capacity Act 2005* in England and Wales and the *Assisted Decision-Making Capacity Act 2015* in Ireland enshrine principles of supported decision-making as a means of enabling the exercise of autonomy.<sup>46</sup> The *Assisted Decision-Making Capacity Act 2015* also provides for formal support agreements<sup>47</sup> through which the decision would be regarded legally as the person’s own autonomous decision, albeit a decision which the person would not have been able to make without support. In this way, formal support agreements have the potential to enable persons in the earlier stages of dementia to continue making their own decisions (with support as needed).

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<sup>40</sup> D. Callahan, “A Moral Good, Not a Moral Obsession” (1984) 14(5) *The Hastings Center Report* 40, 41.

<sup>41</sup> Nedelsky (n 29).

<sup>42</sup> *Ibid* 12.

<sup>43</sup> *Ibid*.

<sup>44</sup> *Ibid*.

<sup>45</sup> Families or loved ones are usually best placed to help a person navigate the decision-making process and offer assistance to healthcare professionals in interpreting and conveying the person’s wishes.

<sup>46</sup> s 1(3) of the MCA provides: “A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.” s. 8(3) of the ADMCA provides: ‘A relevant person...shall not be considered as unable to make a decision in respect of the matter concerned unless all practicable steps have been taken, without success, to help him or her to do so.’

<sup>47</sup> Assisted decision-making and co-decision-making agreements as set out in Part 3 and Part 4 of the ADMCA.

It is important to recognise that, at the same time, this shift in focus away from the individual engages the *constraining* aspect of a relational approach to autonomy, creating a risk that the views of the family or loved ones will overshadow or dominate the views of the person (especially as dementia progresses). As Miller et al's review of the empirical findings found 'there is a difficult balance between gaining the family carer's subtle support and having family carers take over the process completely.'<sup>48</sup> When relational autonomy is in reality more relational (in the sense of factoring in the interests of the family) than it is autonomous (in the sense of enabling the person to be autonomous),<sup>49</sup> it may not be *autonomous* in any true sense of the word. As Herring has suggested, 'supported decision-making carries with it dangers that the supporter makes the decision and labels it as P's.'<sup>50</sup> The precise meaning of autonomy in decision-making is contested,<sup>51</sup> but according to Beauchamp and Childress it necessarily 'encompasses self-rule that is free from both controlling interference by others and limitations that prevent meaningful choice, such as inadequate understanding.'<sup>52</sup> As Gilbar suggests, even in respect of patients whose capacity or ability to make decisions is not expressly in question, family involvement can sometimes compromise the patient's ability to express their own point of view:

Family involvement has many facets; a particular case can reflect its positive aspects, namely the mutual responsibility and support family members provide to each other when making a treatment decision, but also the less positive sides, i.e. the family pressure on patients to make a particular decision, and the coalitions formed by relatives with clinicians, which compromise the patient's sense of confidence and control over the situation.<sup>53</sup>

For a person with more established dementia, the (less positive) consequences of legitimising family involvement in decision-making (or of promoting a relational approach to the exercise of autonomy) range from permitting over-zealous encouragement on the part of supporters to effectively marginalising the person's effective input into the decision-making process (whether intentionally or not).<sup>54</sup> A key problem, therefore, as Harding notes, is 'how to deal

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<sup>48</sup> Miller, Whitlach & Lyons (n 15) 1145.

<sup>49</sup> 'Virtually all theories of autonomy view two conditions as essential for autonomy: *liberty* (independence from controlling influences) and *agency* (capacity for intentional action).' Beauchamp & Childress (n 15) 102.

<sup>50</sup> Jonathan Herring, *Vulnerable Adults and the Law* (Oxford, UK: Oxford University Press, 2016) at 65.

<sup>51</sup> Beauchamp & Childress (n 35) 101.

<sup>52</sup> *Ibid.*.

<sup>53</sup> Gilbar (n 6)230.

<sup>54</sup> As Donnelly suggests, in 'situating the individual at the centre of her web of relationships, one risks losing the individual altogether.' Mary Donnelly *Healthcare Decision Making and the Law: Autonomy, Capacity and the Limits of Liberalism* (Cambridge, UK: Cambridge University Press, 2010) 35. 'There is a difficult balance



with situations where a person's relational context is, *de facto*, deleterious of her autonomy.<sup>55</sup>

As Donnelly cautions:

Where decisions concern people whose capacity to assert their interests is profoundly reduced, the risks of any form of subterfuge are too significant to allow for anything other than an overt recognition of when and how power is being exercised and the maintenance of rigorous oversight of such exercise.<sup>56</sup>

If a person cannot make a legally autonomous decision, whether independently or with support, a best interests or principle-based decision-making framework (including safeguards to ensure the person's participation in decision-making)<sup>57</sup> may in reality be more protective of the person's *remaining* autonomy. Both the *Mental Capacity Act* and the *Assisted Decision-Making (Capacity) Act* 2015 provide explicit protection for a person's present or remaining autonomy within best interests based decision-making, protections that are not provided in the supported decision making context. The *Mental Capacity Act* framework in England and Wales provides that the person determining best interests must 'permit and encourage the person to participate' in the decision, or 'improve his ability to participate', and 'must consider, as far as is reasonably practicable, their past and present wishes and feelings (and in particular any relevant statement made by him when he had capacity), the beliefs and values, and the other factors that a person would be likely to consider if able to do so.'<sup>58</sup> Under the guiding principles of the *Assisted Decision-Making (Capacity) Act* 2015 in Ireland an intervener<sup>59</sup> shall 'permit and encourage and facilitate the person to participate, or improve his or her ability to participate'' and 'give effect, in so far as is practicable, to the past and present will and preferences'' 'tak[ing] into account the beliefs and values (in particular those expressed in

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between gaining the family carer's subtle support and having family carers take over the process completely.' Miller, Whitlach & Lyon (n 15) 1145.

<sup>55</sup> Rosie Harding, "'Relationality and Informal Carers' Experiences' in Charles Foster, Jonathan Herring and Israel Doron, eds. *The Law and Ethics of Dementia Care* 382 (Oxford, UK: Hart Publishing, 2014).

<sup>56</sup> Mary Donnelly, 'Best Interests in the Mental Capacity Act: Time to Say Goodbye?' (2016) 24(3) *Medical Law Review* 318. 328.

<sup>57</sup> With its attendant safeguards in respect of a person's wishes and feelings as it is in a best interests assessment under the *Mental Capacity Act* 2005 in England and Wales, or will and preferences under the *Assisted Decision-Making Capacity Act* 2015.

<sup>58</sup> In determining for the purposes of this Act what is in a person's best interests, the person making the determination must so far as reasonably practicable, permit and encourage the person to participate, or to improve his ability to participate, as fully as possible in any act done for him and any decision affecting him.

He must consider, so far as is reasonably ascertainable—

(a) the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),

(b) the beliefs and values that would be likely to influence his decision if he had capacity,

(c) the other factors that he would be likely to consider if he were able to do so.

<sup>59</sup> The person making the intervention under section 2 of the ADMCA.

writing) of the person and any other factors which the person would be likely to consider if able to do so,” while acting at all times for the benefit of the person.

The caution therefore in relation to persons with dementia is to be clear about which framework (supported or best interests based decision-making) will actually maximise a person’s autonomy in each individual case. It is particularly important to have express safeguards for participation when dementia is more established as it is then that it is harder to ensure that the person with dementia’s voice is being heard within decision-making processes.

#### IV REMAINING AUTONOMY

As discussed in the preceding section, legally autonomous decision-making (individual or supported) may become realistically impossible as dementia becomes more established; where this is the case, the specific protections for the person’s involvement in best-interests based decision-making will be more protective of that person’s remaining and past expressions of autonomy. This conclusion raises subsequent questions about how current/remaining (non-legally binding) expressions of autonomy can be reconciled with previous expressions where there is a conflict between the two, especially where those prior expressions are set out in documents that may be considered legally binding. While the law has traditionally been protective of previously expressed wishes, feelings, beliefs and values,<sup>60</sup> the current wishes expressed by the person with dementia are equally deserving of consideration and respect. As the English Law Commission has observed:

Realistically, the former views of a person who is without capacity cannot in every case be determinative of the decision which is now to be made. Past wishes and feelings may in any event conflict with feelings the person is still able to express in spite of incapacity. People who cannot make decisions can still experience pleasure and distress. Present wishes and feelings must therefore be taken into account, where necessary balanced with past wishes and feelings. One of the failings of a pure “substituted judgment” model is the unhelpful idea that a person who cannot make a decision should be treated as if his or her capacity were perfect and unimpaired, and as if present emotions need not also be considered.<sup>61</sup>

The Nuffield Council on Bioethics has emphasised that ‘when a person has been assessed as lacking legal capacity for a particular decision, it is still crucial to give full consideration to

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<sup>60</sup> ‘While the contemporaneous views of the person lacking capacity played little role in judicial determinations of best interests prior to the MCA, courts tended to be more facilitative in respect of views expressed prior to incapacity.’ M. Donnelly (n 54) 182. In Ireland, this approach can be seen most recently in Ireland in *Governor of X Prison v PMcD* [2015] IEHC 259.

<sup>61</sup> The Law Commission, *Mental Incapacity*, Law Commission Report No. 231 (London: HMSO, 1995) 45.

their current values, wishes and feelings.’<sup>62</sup> The difficult legal questions are how much, and how.

One of the key ethical and legal challenges in decision-making in dementia is whether to accept (or reject) the philosophical proposition that the person with dementia is now a different person in cognitive terms to their pre-dementia self,<sup>63</sup> and the extent to which prior wishes expressed pre loss of competence continue to represent the true self and should be treated as legally binding for that reason. This highlights the inherent tensions between attempting to honour the earlier autonomous wishes of the legally capable person, and respecting and recognising the views and the (remaining) autonomy or continuing personhood<sup>64</sup> of the now legally incompetent person.

In *Life's Dominion*, Dworkin theorised<sup>65</sup> that in decision-making there are two distinct types of interests, ‘critical’ and ‘experiential’.<sup>66</sup> Critical interests are enduring and are those which are central to individual belief systems, values and goals, and life purpose. Experiential interests are drawn from current experiences such as enjoying an activity or pursuing a hobby.<sup>67</sup> In his view, critical (and enduring) interests are the ones that must be protected, even at potential expense of current experiential interests. In *Life's Dominion*, he reflects on the case of Firlik’s Margo,<sup>68</sup> a woman with early-onset Alzheimer’s disease, who appears totally content ‘with her dog-eared mysteries, the single painting she repaints, and her peanut-butter-and-jelly sandwiches.’<sup>69</sup> He sets the reader the task of imagining that when competent she had executed a directive refusing life-saving treatment, and that she now requires antibiotic intervention for a chest infection. He contends that her prior competent and critical interests prevail and she

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<sup>62</sup> Nuffield Council on Bioethics (n 32) 75.

<sup>63</sup> ‘Dementia threatens those it strikes with the loss of the personality, of the “self”, to a greater degree than almost any other disease.’ J. Vollmann, ‘Advance directives in patients with Alzheimer’s disease: Ethical and clinical considerations’ (2001) 4 *Medicine, Health Care and Philosophy* 161, 163.

<sup>64</sup> Tom Kitwood described personhood as ‘a standing or status that is bestowed on one human being, by others, in the context of relationship and social being.’ *Dementia Reconsidered: The Person Comes First* (Buckingham, UK: Open University Press, 1997) 8. Kitwood challenged those working in the area of dementia to re-appraise the idea that people with dementia, even advanced dementia, could not participate in any meaningful way in decisions concerning them.

<sup>65</sup> Ronald Dworkin, *Life's Dominion: An Argument about Abortion, Euthanasia, and Individual Freedom* (New York, USA: Vintage Books, 1994).

<sup>66</sup> *Ibid.* 210-16

<sup>67</sup> *Ibid.*

<sup>68</sup> Andrew D. Firlik, “Margo's Logo,” (1991) 265(2) *Journal of the American Medical Association* 201.

<sup>69</sup> Dworkin (n 65) 226.

should not be treated irrespective of the consequences, as it is not in accordance with her previously expressed autonomous wishes.<sup>70</sup>

Rebecca Dresser on the other hand argues that far from having a concrete plan for life, peoples' critical interests change and that 'many people take life one day at a time.'<sup>71</sup> As she suggests, '[t]he goal of establishing a coherent narrative may be a less common life theme than the simple effort to accept and adjust to the changing natural and social circumstances that characterize a person's life.'<sup>72</sup> Dresser's argument is that a person such as Margo should not be treated on the basis of her prior wishes as that fails to respect her in the present.<sup>73</sup> The US President's Council on Bioethics, of which Dresser was a member, concludes, 'Margo's apparent happiness would seem to make the argument for overriding the living will morally compelling in this particular case.'<sup>74</sup> Or indeed as Dresser herself pithily puts it, '[h]appy and contented Margo will experience clear harm from the decision that purports to advance the critical interests she no longer cares about.'<sup>75</sup>

Derek Parfit contends that the psychological continuity required for a person to continue in any real sense requires in turn an ability to retain memories and in order to stay connected to one's core values. Once that ability is lost, the advance directive (rooted in previous core values) has no more authority to speak for the current incompetent person than anyone else.<sup>76</sup> According to Parfit, there must be some level of continuing link between the prior capacitated self and the current incapacitated self in order to hold previous wishes determinative. The idea of the person in dementia as a kind of mixed (rather than new) self is described by the Nuffield Council on Bioethics in the following passage, referring to 'a growing awareness of the abilities and emotions which are retained long into dementia, despite serious cognitive losses.'<sup>77</sup>

This increased understanding poses a strong challenge to past ideas of dementia as a 'death that leaves the body behind' and raises important questions as to the way in which people with dementia are currently regarded and respected<sup>78</sup>

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<sup>70</sup> Ibid.

<sup>71</sup> Rebecca Dresser, "Dworkin on Dementia: Elegant Theory, Questionable Policy" (1995) 25(6) The Hastings Center Report 32-36.

<sup>72</sup> Ibid.

<sup>73</sup> Ibid. 38

<sup>74</sup> Beauchamp & Childress(n 35) 229.

<sup>75</sup> Dresser (n 71) 38.

<sup>76</sup> Derek Parfit, *Reasons and Persons* (Oxford, UK: Oxford University Press, 1984) 205-207.

<sup>77</sup> Nuffield Council on Bioethics (n 32) xvii.

<sup>78</sup> Ibid.

In many cases, the past and present views of the person will not conflict,<sup>79</sup> but where they do the Nuffield Council maintain that both should be taken into account for the purpose of giving voice to a person's autonomy.<sup>80</sup> Past and present wishes and preferences should both be seen as expressions of a person's autonomy, at different points in the life course, and neither can easily be preferred over the other.<sup>81</sup> The Council takes a very firm view that the person with dementia is not a different person from the one who came before, even if aspects of her or his behaviour have changed. Persons with dementia are 'able to value particular experiences and relationships in a meaningful way even if they are no longer able to rationalise why this is the case.'<sup>82</sup> From this perspective, respecting the personhood of people with dementia requires identifying current views and giving those views due weight in decision-making pertaining to that person.

## V REMAINING AUTONOMY IN PRACTICE

In England and Wales the judgment of Eldergill J in the case of *Westminster City Council v Sykes*<sup>83</sup> is instructive as an example of how the remaining autonomy of a person with dementia can be weighed and made part of the decision-making process. In that case, Manuela Sykes, a political activist who had dementia, was transferred to a care home against her wishes as there were concerns that she was unable to look after herself in her London flat. This was done on foot of a deprivation of liberty authorisation<sup>84</sup> under the *Mental Capacity Act 2005*, to which Ms Sykes strenuously objected. Westminster Council asked the Court of Protection to review the deprivation of liberty authorisation because of Ms Sykes's objections to the care home placement. Eldergill J found that the authorisation could not be justified, observing:

MS is still able to appreciate and express the value of being at liberty and being allowed autonomy. The importance of individual liberty is of the same fundamental importance to incapacitated people who still have clear wishes and preferences about where and how they live as it is for those who remain able to make capacitous decisions. Ms S is 89 years old and her life

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<sup>79</sup> In many cases there will be clear continuity between the way people with dementia approach their life now and in the past.' Ibid. 81.

<sup>80</sup> Ibid. 83.

<sup>81</sup> Ibid.

<sup>82</sup> Nuffield Council on Bioethics (n 320 82-83.

<sup>83</sup> *Westminster City Council v Sykes* [2014] EWCOP B9 [*Sykes*].

<sup>84</sup> A deprivation of liberty authorisation is where a person who lacks legal capacity is lawfully deprived of their liberty following a determination that it is in their best interests to do so. *Mental Capacity (Deprivation of Liberty: Standard Authorisations, Assessments and Ordinary Residence) Regulations 2008*, SI 1858/2008.

is drawing to a close. It is her life. Several last months of freedom in one's own home at the end of one's life is worth having for many people with serious progressive illnesses, even if it comes at a cost of some distress.<sup>85</sup>

The judgment of Eldergill J expressly recognises the continuing personhood or remaining autonomy of Ms Sykes as an essential element of well-being. He did this not by expanding the common law, but within the best interests framework of the *Mental Capacity Act 2005*, which expressly states that a person's wishes and feelings, both past and present, and their beliefs and values are to be taken into account in making a best interests determination. Unfortunately, not everyone can enjoy the benefit of the deep and sensitive analysis of their situation which Ms Sykes received from the Court of Protection, a specialist court, in her case. In the case of Ms. Sykes, moreover, her expressed wishes and concerns remained constant and unwavering; as Holm has noted, the desires of a person with dementia can often be as inconstant as a small child's.<sup>86</sup> This inconsistency complicates the connection respecting autonomy and expressing an expression of wishes. As Ronald Dworkin has suggested:

While a mildly demented person's choices are reasonably stable, reasonably continuous with the general character of his prior life, and inconsistent and self-defeating only to the rough degree that the choices of fully competent people are, he can be seen as still in charge of his life, and he has a right to autonomy for that reason. But if his choices and demands, no matter how firmly expressed, systematically or randomly contradict one another, reflecting no coherent sense of self and no discernible even short-term aims, then he has presumably lost the capacity that is the point of autonomy to protect.<sup>87</sup>

In *Sykes*, a (reviewable) trial of continued living in her own home was proposed by Eldergill J. Decisions about medical treatment, in contrast, must often be made (relatively) immediately and cannot be reviewed. In this context, giving substantial legal weight to the person's current wishes confers on that person (who may not be in a position to fairly assume it) responsibility for assuming a significant risk with lasting consequences, even death.<sup>88</sup> Family members' desire to protect the person with dementia in this kind of decision-making context is complex:

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<sup>85</sup> *Sykes*, above note 83 at §10. *Westminster City Council v Sykes* [2014] EWCOP B9 [10].

<sup>86</sup> It is also well known that many desires of persons with severe dementia are not stable, in the sense that if the person is diverted, even for a very short period of time, the desire recedes or disappears. Søren Holm, 'Autonomy, authenticity, or best interest: Everyday decision-making and persons with dementia' (2001) 4(2) *Medicine, Health Care and Philosophy* 153, 155. 'The problem is further compounded by the empirical observation that the mental state of persons with dementia is fluctuating. One day they may be able to remember a lot and to be their "good old selves", while the next they may be totally different.' at 156.

<sup>87</sup> Dworkin (n 65) 225.

<sup>88</sup> As Molinari et al caution 'In the clinical setting, accepting the patient's refusal without rigorous inquiry may mistakenly lead clinicians not to identify and consider the patient's long-standing preferences that are in conflict with a decision based on current mood fluctuation or temporary reluctance.' Victor Molinari et al 'Geriatric Assent' (2004) 15(3) *The Journal of Clinical Ethics* 261,263.

family members or loved ones may feel they know better, or want the kinds of decisions that suit *them* better, but may also be acting on a desire to protect the person from assuming responsibility for the consequences of decisions that they cannot fully understand and appreciate. The binding legal nature of autonomous decisions is predicated on ‘the freedom of the patient as an individual to exercise her right to refuse treatment and *accept the consequences*<sup>89</sup> of her own decision’,<sup>90</sup> a legal and ethical basis that is missing where the person’s decision is not autonomous in this sense.

Ascertaining the current wishes and preferences of the person, to be factored in to the decision-making process, is absolutely vital but it is equally important (and more difficult) to determine how much legal weight should be given to them. This is especially difficult if current wishes and preferences conflict with previous expressions and/or if manifestly against the person’s own benefit. Current wishes and feelings (or will and preferences) of a person considered to be incapable of decision-making have tended to be excluded altogether where legal frameworks set out a decision-making ‘threshold’, an approach justified by the presumed non-autonomy of decision-incapable persons.<sup>91</sup> As noted by Hall:

Because autonomy is defined in terms of independent decision-making, the person whose cognitive ability to make decisions has been eroded by dementia is not, fully, autonomous. A person who is not capable of making decisions about X or Y can make (mere) choices, but because the individual does not have capacity to engage in the underlying process of deliberation that gives rise to genuine decisions, those choices are disconnected from his or her autonomous self.<sup>92</sup>

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<sup>89</sup> Emphasis added.

<sup>90</sup> *Malette v. Shulman* (1990) 72 OR (2d) 417; (1990) 67 DLR (4<sup>th</sup>) 321 (Ont CA). ‘Giving mentally disabled people exactly the same rights as mentally normal people would often result in the disabled harming themselves and others and becoming victims of exploitation and abuse. Protection from these consequences necessarily involves some curtailment of the rights that normal people enjoy. Indeed a certain level of protection may enhance the ability of the mentally disabled to enjoy their other rights to a greater extent.’ Scottish Law Commission, Discussion Paper No 94 *Mentally Disabled Adults: Legal Arrangements for Managing their Welfare and Finances* (Edinburgh, UK: Scottish Law Commission, 1991).

<sup>91</sup> Genevra Richardson, “Mental Capacity at the Margin: The Interface between Two Acts” (2010) 18(1) *Medical Law Review* 56, 62. ‘Persons are more or less able to perform a specific task to the extent that they possess a certain level or range of abilities, just as persons are more or less intelligent and athletic.... It would be confusing to view this continuum of abilities in terms of degrees of competency. For practical and policy reasons, we need *threshold levels* below which a person with a certain level of abilities for a particular task is incompetent.’ Beauchamp & Childress (n 35)t 117.

<sup>92</sup> Margaret Isabel Hall, ‘Dementia, Autonomy and Guardianship for the Old’ in Charles Foster, Jonathan Herring and Israel Doron, eds. *The Law and Ethics of Dementia Care* (Oxford, UK: Hart Publishing) at 339. To respect autonomy is to give weight to “considered opinions and choices”: National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, *The Belmont Report, Ethical Principles and Guidelines for the Protection of Human Subjects of Research* (Washington, DC: 1978). available at <http://ohsr.od.nih.gov/guidelines/belmont.html> (last accessed 1 June 2019)

Hall goes on to describe ‘standard’ representation agreements made pursuant to British Columbia’s *Representation Agreement Act*,<sup>93</sup> whereby a person can appoint a ‘representative’ (to support decision-making or make substitute decisions) primarily on the basis of will and preferences rather than decision-making capacity.<sup>94</sup> These instruments are more inclusive, but their nature creates a risk that they ‘can be misused as in many cases there are no supervision mechanisms for them, neither in law, nor in practice’.<sup>95</sup>

In summary, the person with more established dementia who is without legal decision-making capacity but who is able to express *choice*, will and preference deserves to have that expression play a role in the decision-making process. The weight to be given to that expression is a significantly more complex question, particularly where there is a conflict with previously expressed legally autonomous wishes and/or appear self-benefit. A decision with full legal consequences requires a deliberative process. *Auto nomos* requires the ability to self-rule. Thus it must remain the case in law that a person who cannot engage in a deliberative process is not capable of giving a legally binding decision, which is manifestly against their best interests, or not for their benefit, and which may also conflict with their own previously expressed legally valid views. What remains absolutely critical however is that their views on the decision are actively ascertained and carefully considered in the decision-making process.

## VI CONCLUSION

The objective of this article has been to critically appraise the contribution that relational autonomy makes to the debate on autonomy in the decision-making process for people with dementia, particularly in relation to healthcare decision-making. I have suggested that taking a relational approach to autonomy could enable a person with earlier stage dementia to continue to exercise their autonomy with support from family members or loved ones. For persons with more established dementia, however, a relational approach to autonomy has the potential to marginalise the person within the decision-making process, and for that reason caution must be exercised in too readily embracing a relational autonomy approach as the person’s dementia progresses. It will often be more supportive of the person’s autonomy to honestly acknowledge

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<sup>93</sup> *Representation Agreement Act*, RSBC 1996, c. 405.

<sup>94</sup> Hal (n 92) 354.

<sup>95</sup> Ibid. 355. ‘A further criticism, albeit one not confined to supported decision-making regimes, is the potential for abuse. For example, it is suggested that decision-making supporters may try to manipulate people to achieve their own ends.’ Law Commission *Mental Capacity and Deprivation of Liberty* Consultation Paper No 222 (London: HMSO, 2015) 156.



an inability on her or his part to make a *legally* autonomous decision but to ensure that, within the applicable best interests or principle-based decision-making framework, the person's that their remaining autonomy remains central to the decision-making process.

A best interests approach under the *Mental Capacity Act 2005* in England and Wales or a principle-based approach under the *Assisted Decision-Making (Capacity) Act 2015* in Ireland sets out protections for both the past and present views of the person without capacity. While determining how to balance past and present wishes and feelings in the decision-making process is often not a straightforward task, what is key is to maximise autonomy for each individual person with dementia. As the Nuffield Council on Bioethics reminds us, 'the person with dementia remains the same, equally valued person throughout the course of their illness, regardless of the extent of the changes in their mental abilities and other functions'<sup>96</sup> and it is necessary to recognise and respect the individual's remaining autonomy while taking into account previous expressions of autonomy. As observed by Miller et, '[f]or persons with dementia, being a part of the decision-making process may hold a grander meaning of validating their very existence or personhood, regardless of the outcome or who makes the final decision.'<sup>97</sup>

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<sup>96</sup> Nuffield Council on Bioethics (n 32).

<sup>97</sup> Miller, Whitlatch & Lyons (n 15) referencing Deirdre Fetherstonhaugh, Laura Tarzia, Rhonda Nay 'Being central to decision making means I am still here!: The essence of decision making for people with dementia' (2013) 27(2) *Journal of Aging Studies* 143.

