**“This man with dementia”[[1]](#footnote-1) – ‘Othering’ the person with dementia in the Court of Protection.**

**Abstract:** In recent years, dementia has been subjected to an increasing ethical, legal and political gaze. This article analyses how the Court of Protection considers the perspective of the person with dementia when making best interests decisions on their behalf under the Mental Capacity Act 2005. The article draws upon feminist and disability literature to highlight how the Court has, on occasions, ‘othered’ the person with dementia during the process of making best interests decisions. This is despite law and policy increasingly emphasising that the views of the person who lacks capacity should be central to any best interests decision, as well as emphasising the importance of de-stigmatisation of cognitive impairments, such as dementia. Finally, using examples from recent cases, it is argued that by adopting an intersubjective approach, and by recognising and exploring the complexity of the relationships that the person with dementia has, the Court can go some way to avoiding the process of ‘othering’.

**Keywords:** best interests, dementia, Mental Capacity Act 2005, othering, values and beliefs, wishes and feelings.

I. INTRODUCTION.

The number of people with dementia[[2]](#footnote-2) in the United Kingdom stands at approximately 800,000, and is estimated to reach 1 million by 2025. The prevalence of dementia doubles for every five-year age group meaning the oldest age groups are those most likely to be affected, and it currently costs the economy an estimated £26 billion a year[[3]](#footnote-3). Furthermore, dementia impacts the older individual in unique and significant ways, gradually causing memory loss, alterations in mood, as well as changes in personality and emotions, and frequently leading to other mental health issues such as clinical depression, paranoid delusions, or neurologically debilitating illnesses such as strokes.[[4]](#footnote-4) The overall effect of dementia, then, is a gradual decline in cognitive functioning such that the individual becomes increasingly reliant on caregivers to meet their everyday needs.

Given the prevalence and form that dementia takes, it is unsurprising that there has been a lengthy academic debate over how the illness interacts with an older person’s decision-making capabilities. To date, the ethico-legal literature has been predominantly concerned with the validity of medical advance directives – and more specifically, the extent to which advance directives by someone *without* dementia can be binding on their later self *with* dementia. In this respect, the debate has focussed on the ‘personhood problem’ – whether the person with dementia is the same ‘person’ as their former ‘un-demented’ self.[[5]](#footnote-5) If they are not the same person, as Dresser argues[[6]](#footnote-6), then previously stated wishes have little normative force and should have minimal impact on their ‘post-dementia’ selves. A key problem with this literature, however, is that dichotomises the dementia patient, and frequently presents them at two extremes: the ‘un-demented’, and the ‘entirely demented’ person.[[7]](#footnote-7) This approach masks the spectrum of symptoms that a person with dementia in fact experiences. Persons with dementia experience a gradual change in cognitive functioning, with fluctuations and lucid periods during their illness.

Furthermore, the existing bioethics literature focuses heavily on assessing the importance of cognitive functioning and psychological continuity for personhood,[[8]](#footnote-8) which is also problematic for those with dementia, who, by virtue of the illness, experience a decline in both.[[9]](#footnote-9) It is therefore, as Rai argues, ‘important…to recognise that loss of cognitive functions does not mean total loss of emotion and human values’.[[10]](#footnote-10) The fact that a person with dementia will have declining rational thought processes, ‘does not mean they have lost the ability to feel, care, or value’.[[11]](#footnote-11) Focussing on cognitive functions as a key marker of ‘personhood’ arguably reduces the person with dementia to an isolated individual and pays little attention to their feelings, emotions and relationships. This is an approach that has been criticised for ignoring the reality of life for those with dementia – they are, as is any individual, always situated within a complex web of relationships with other individuals, organisations and the state.[[12]](#footnote-12) To adopt Hughes’ term, they are a ‘situated embodied agent’ – a person ‘who acts and interacts in a cultural and historical context in which he or she is embedded’.[[13]](#footnote-13)

Although dementia has become increasingly subjected to a political and legal gaze in recent years, as yet there has been little systematic engagement with the way in which the courts interact with persons with dementia.[[14]](#footnote-14) This article analyses how the Court of Protection engages with the person with dementia when making best interests decisions on their behalf under section 4 of the the Mental Capacity Act 2005,[[15]](#footnote-15) and in particular, how the Court considers the perspective of the person with dementia. Although the person’s own wishes are also an important feature of the initial capacity assessment process, many people with dementia who come before the Court *will* be deemed to lack capacity and it is therefore especially salient to consider these issues in relation to best interests decision-making.

Through an analysis of these decisions it is argued that the Court’s approach to the person with dementia has, on occasions, been constructed around a ‘comparator’ that renders the person with dementia as ‘Other’ – unjustifiably marginalising them, and portraying them as ‘deviant’.[[16]](#footnote-16) In this respect, the argument presented in this paper goes beyond Donnelly’s early concerns that section 4 of the Act risked paying only ‘tokenistic’ regard to the views of the person lacking capacity.[[17]](#footnote-17) This is notwithstanding the fact that ‘best interests’ as a legal tool has developed over a number of years to better incorporate the person’s own views into the decision-making process, and remove stigma associated with cognitive impairments,[[18]](#footnote-18) thereby developing in such a way as to avoid opportunities for ‘othering’. In Section V, it is argued that by adopting an intersubjective approach, and by exploring the complex labyrinth of relations that an individual with dementia has, the Court can go some way to avoiding this process of ‘othering’. It is worth noting from the outset that this paper is not concerned with judgments emanating from the Court as to whether a person has capacity or not – nor, therefore, is it concerned with an in depth of analysis of the binary notion of capacity contained within the Act for persons with dementia. This has been discussed elsewhere.[[19]](#footnote-19) The paper focusses on the issue of whether the Court of Protection utilises the process of ‘othering’ when making best interests decisions on behalf of persons with dementia who are deemed to lack capacity.

II. ‘Othering’ the Person with Dementia.

The notion that certain individuals are ‘othered’, or that they somehow hold a fundamentally lower moral status because of differences in their embodiment or psychological functioning is well documented in a number of scholarly domains. Feminist and disability theorists, among others, have long argued that because of the masculine, healthy bodied, rational, autonomous, and self-sufficient ideal that is inherent within law and society, anybody who does not conform to this is considered ‘Other’ – deviant from this pre-defined and idealistic norm.[[20]](#footnote-20) As Shildrick argues in respect of disability and illness ‘[o]nce it is broken, that is diseased, damaged, or otherwise unwhole…[t]he body is now perceived, but is experienced as other’.[[21]](#footnote-21) In effect, when a person does not conform to what is perceived to be the ideal, they are categorised as ‘abnormal’ *because of* their difference - something to be contained, feared and kept at arm’s length, and in a legal context, this impacts how the court perceives and interacts with the person. This process, as Keywood argues in relation to anorexia nervosa, ‘….produces an identity of madness, of otherness, which of itself purports to necessitate her differential medical treatment’.[[22]](#footnote-22) They are deemed to have a fundamentally lower moral status because of differences in their corporeal or cognitive functioning, which, in turn, serves to reaffirm the initial idealistic paradigm, and further entrench power imbalances between the person and the Court.

The very terms of the Mental Capacity Act potentially make this process of ‘othering’ in mental capacity jurisprudence more likely. In distinguishing a binary between those who have or do not have capacity based, in part, on a diagnostic element,[[23]](#footnote-23) and only intervening in relation to those who do *not* have capacity, the Act itself already explicitly recognises and asserts a ‘difference’.[[24]](#footnote-24) This difference is between the person with dementia, for example, who is found to lack capacity and therefore loses decision-making power under the Act, as opposed to ‘normal’ persons who have capacity[[25]](#footnote-25) - and for whom the Act does not deem intervention appropriate and who therefore retain the power to make their own decisions.[[26]](#footnote-26) Moreover, when a person *does* lack capacity, there is already clear evidence before the Court of how they fail to live up to the standard contained within the Act itself – their failure to fulfil the functional test contained in section 3.[[27]](#footnote-27)

At this point, however, it is important to note a distinction. Asserting a ‘difference’ is, in itself, unproblematic. Indeed one prominent disability theorist, Tom Shakespeare, citing Lennard Davis, argues that impairments *should* be understood as differences: ‘Disability is not so much the lack of a sense or the presence of a physical or mental impairment as it is the reception and construction of that difference’.[[28]](#footnote-28) Moreover, Shakespeare goes on to argue that impairments should also be taken into consideration, for example, in the allocation of welfare benefits, or psychological and social support mechanisms.[[29]](#footnote-29) What the literature on ‘othering’ is keen to stress, however, is that this process of differentiation becomes ‘othering’ - and therefore problematic - when negative moral judgments and assumptions are assigned to the ‘Other’ so as to marginalise or dehumanise them, or assert that they have a lower moral status, because of such differences. As MacKinnon notes in a feminist context,[[30]](#footnote-30) the problem of ‘othering’, lies in the voice of the ‘Other’ being at the bottom. This may occur, for example, when the Court constructs its own ideal and paints a picture of the person with dementia as ‘falling short’ of this, so as to reaffirm the correctness of its original paradigmatic standard, and, to adopt Keywood’s terminology, to *validate* their ‘differential treatment’.[[31]](#footnote-31)

Used in this manner, ‘othering’ essentially requires two elements. The first is the presence of a comparator – or some ideal of what a ‘normal person’ should be able to do – an entity not entirely unfamiliar in mental capacity law.[[32]](#footnote-32) In feminist discourse this comparator is the self-sufficient, rational and autonomous, masculine identity. In disability discourse, particularly for critics of the medical model of disability, this is the construction of the norm as the fully functioning, healthy and unimpaired body. The second crucial feature of such an ‘othering’ analysis is that there must be stigma associated with the person by virtue of their failure to meet this standard. As Weicht notes,[[33]](#footnote-33) in the case of dementia, it is that it is undesirable, feared and rejected – the ‘confused, helpless’ dementia sufferer.[[34]](#footnote-34) As will be shown in Section IV, these two elements to the process of ‘othering’ are not mutually exclusive. Indeed, they are mutually dependent for the process of ‘othering’ to occur, and they operate in a circular way. The reason a person or class of persons can be marginalised or classed as deviant is *because of* the initial comparator, and their failure to meet this ideal, which is then used as evidence to prove the correctness of the idealistic standard. ‘Othering’ as a process, then, does not take place between individuals – someone who lacks capacity is not necessarily deemed ‘other’ to someone with capacity. ‘Othering’, as characterised for the purpose of this paper, is between persons or groups of persons, and the more abstract and invidious notion of the rational and able-bodied ideal outlined above.

This process of ‘othering’ is particularly prevalent among persons with dementia in society more generally. As both Francis[[35]](#footnote-35) and Kitwood[[36]](#footnote-36) note, the loss of cognitive functions because of dementia ultimately ends up depersonalising or medicalising the individual such that they become almost a non-human entity – ‘a pathetic ghost’,[[37]](#footnote-37) or suffering a ‘living death, a never ending funeral, and a private hell of devastation’[[38]](#footnote-38) – forsaking the “unified” person in favour of a medicalised and stigmatised notion of the person with dementia*.*[[39]](#footnote-39) Empirical research also suggests that this is an existential reality for those living with dementia. Given their diagnosis and subsequent declining abilities, there remains a constant struggle for the person with dementia. This struggle is between, on the one hand, feeling like a valued and meaningful member of society who can continue to perform the everyday tasks they were able to perform before they had dementia, and, on the other, feeling worthless and disempowered because of social attitudes about dementia and because of the symptoms associated with condition. This devaluation can occur to a large extent from how others interact with the person with dementia, and consequently impacts negatively on a person’s sense of self-worth.[[40]](#footnote-40) Identifying an individual in terms of their diagnosis creates a moral and psychological distance between what is considered ‘them’ (the person with dementia) and ‘us’ (the healthy person).[[41]](#footnote-41) Sabat and Harréconvincingly argue that if, for example, perceived difficult behaviour by persons with dementia

…is founded on story lines that paint the sufferer as inadequate, confused, helpless…then that person will be so positioned and will have his…behaviour interpreted by others in such a way as to confirm the initial storyline…’.[[42]](#footnote-42)

Rather than seeing behaviours such as aggression or frustration as ‘just another symptom of dementia’, greater emphasis should be placed on *understanding* what are perceived to be the symptoms of dementia. In order to do this there is no choice but to better understand the current lived experiences of the person with dementia, and as shall be explored and argued later, one way this could be achieved is by adopting an intersubjective approach.[[43]](#footnote-43)

If, as is contended in this paper, ‘othering’ is indeed present within certain Court of Protection judgments, then not only is such ‘othering’ problematic because it goes against the very ethos of empowerment that underpins the Mental Capacity Act - but also perpetuates the marginalisation widespread in society more generally of persons with dementia. Empirical research also indicates that such marginalisation based on their medical condition adds to feelings of disempowerment for persons with dementia. In a recent survey by the Alzheimer’s Society into awareness of the Mental Capacity Act among persons with dementia and their carers, one respondent with dementia notes this in a particularly powerful statement:

I don’t understand why people don’t think to tell us such important things, yes I have a diagnosis of dementia but that doesn’t mean I shouldn’t be told about my rights and the things that affect me. From what you have told me today I can use the law to plan ahead for my future, as well as to know that I should be involved in decisions and helped to make them. Everybody with dementia should be told about this, and a failure is just making assumptions about our condition, something you said this law said shouldn’t happen.[[44]](#footnote-44)

In light of these arguments, the next section of the paper considers how the law has in fact developed so as to better incorporate the person’s own perspective into the decision-making process, thereby explicitly attempting to avoid opportunities for such ‘othering’.

III. INTEGRATING THE PERSON LACKING CAPACITY INTO BEST INTERESTS DECISION-MAKING: AN ATTEMPT TO AVOID ‘OTHERING’?

The best interests of a person lacking capacity were originally determined by the *Bolam* standard - that is, ‘a practice accepted as proper by a responsible body of medical men skilled in that particular art.’[[45]](#footnote-45) Towards the end of the 1990s, however, the courts began to move towards a broader welfare-based conceptualisation of best interests - coinciding with the extension of best interests decision-making from medical issues, to residence and contact decisions,[[46]](#footnote-46) as well as policy impetus to expressly include the wishes of the individual.[[47]](#footnote-47) In *Re A (Mental Patient: Sterilisation)*[[48]](#footnote-48) for example, which involved the proposed sterilisation of a young man with Down’s Syndrome, Butler-Sloss LJ held that ‘best interests encompasses medical, emotional and all other welfare issues’.[[49]](#footnote-49) It is important to understand this shift as it represents the origins of the conceptual analysis ventured in this paper. Critics rightly argued that a purely *Bolam* approach to best interests was too paternalistic and devalued and silenced the person lacking capacity – leaving decision-making in the hands of professionals based on medical best interests with little or no input from the person themselves, or their carers.[[50]](#footnote-50) As Martha Holstein argues in the context of caregiving relationships, ‘[i]f one is not asked about how one feels about the arrangements that control one’s life, then one is reduced to a zero.’[[51]](#footnote-51) Consequently, as Munro argues,[[52]](#footnote-52) if we do *not* want to treat someone as a ‘zero’ under the Mental Capacity Act, if we want to respect them as persons, then it is logical that we should seek their perspective on decisions, and moreover, that their perspective should be taken seriously.

In line with this retreat from *Bolam*, and following the Law Commission’s 1995 proposals for reform of the law in relation to mental incapacity,[[53]](#footnote-53) also came greater elucidation on what factors to consider when assessing best interests. This included the ‘balance-sheet approach’ which involved striking a balance between any benefits of the proposed treatment or intervention, and any counterbalancing dis-benefits.[[54]](#footnote-54) Although oft cited with approval,[[55]](#footnote-55) a key problem with the ‘balance-sheet’ method is that it does not expressly state where an individual’s own perspective on the issues fit in to the best interests determination.[[56]](#footnote-56) In *Local Authority X v MM and KM,*[[57]](#footnote-57) however, decided before the 2005 Act entered in to force, the Court held that:

One of the most important factors to be taken into account is the vulnerable adult's wishes and feelings. The fact that [she] lacks the relevant capacity does not mean that her wishes and feelings simply fall out of account...[[58]](#footnote-58)

That the patient’s own perspective is of importance in best interests decision-making is now statutorily enshrined in the Mental Capacity Act 2005, which, as Quigley notes,[[59]](#footnote-59) has made huge strides forward. To this effect, the Act states that the decision maker must consider the person’s past and present wishes and feelings, as well as any beliefs and values that would be likely to influence their decision if they had capacity (as far as they are ascertainable) when making best interests decisions.[[60]](#footnote-60) Moreover, the Act also attempts to tackle stigmatising attitudes by stating that best interests, nor a finding of a lack of capacity, is to be determined ‘merely’ by a person’s age, appearance or any aspect of their behaviour[[61]](#footnote-61) – although utilising the word ‘merely’ indicates that a person’s age, appearance or behaviour may be *a* consideration when making best interests decisions.[[62]](#footnote-62)

The importance of the individual’s perspective being taken into consideration during best interests decision-making has recently been strenuously reiterated by the House of Lords Select Committee post-legislative scrutiny of the Mental Capacity Act,[[63]](#footnote-63) and by the Supreme Court in *Aintree University Hospitals NHS Trust v James.*[[64]](#footnote-64) In light of these, the views of the person concerned have been increasingly seen as central to the decision to be made with the Court of Protection recently stating that ‘[t]he onset of mental incapacity is not an opportunity for moral correction’,[[65]](#footnote-65) and, more emphatically:

…a conclusion that a person lacks decision-making capacity is not an *“off-switch”* [emphasis in original] for his rights and freedoms…the wishes and feelings, beliefs and values of people with a mental disability *are as important to them as they are to anyone else* [emphasis added], and may even be more important. It would therefore be wrong in principle to apply any automatic discount to their point of view.[[66]](#footnote-66)

There are, in addition, other policy programmes and legislation that enshrine the importance of the person’s own views, as well as attempting to remove the stigma associated with cognitive impairments, and are especially relevant for older persons with dementia. Article 12 of the UNCRPD, which the United Kingdom has both signed and ratified, emphasises that measures relating to the exercising of legal capacity for persons with disabilities are to be made based on the individual’s will and preferences, and if these are not ascertainable, then the ‘best interpretation of an individual’s will and preferences’.[[67]](#footnote-67) Moreover, a recent statement by the Committee on the Rights of Persons with Disabilities states that detention *based on* the presence of a disability should be prohibited.[[68]](#footnote-68) Similarly the Mental Health Act 1983 Code of Practice also states that a patient should be involved in their treatment planning and supported to participate in decision-making, and have their views considered and fully recorded.[[69]](#footnote-69) Initiatives specifically aimed at older individuals also emphasise the importance of having the right to make their own decisions in old age, rather than having decisions made for them. Although not legally binding, the recent Welsh Declaration on the Rights of Older Persons, for example, states that ‘I have the right to exercise my free will and make choices. My opinion is the most important when decisions are being made about me and my life’,[[70]](#footnote-70) and the Charter of Rights for People with Dementia and their Carers in Scotland[[71]](#footnote-71) emphasises the importance of ‘full and effective participation and inclusion in society’, as well as ‘respect for difference and acceptance of persons with disabilities’.[[72]](#footnote-72)

This legal, political, and social shift - particularly in respect of best interests - from a medicalised version to one that centralises the voice of the individual concerned is particularly welcome for those with dementia. Much research indicates that a diagnosis of dementia brings with it stigma, and perceived ‘social death’[[73]](#footnote-73), and, perhaps linked to this stigmatisation, that persons with dementia are still frequently denied the respect they are due whether they are deemed to lack capacity or not. The Alzheimer’s Society,[[74]](#footnote-74) for example, recently found that a majority of participants with dementia often felt excluded from decision-making processes, a finding that mirrors an abundance of other research in this area.[[75]](#footnote-75) This perhaps indicates a failure in translating legal standards into practice.[[76]](#footnote-76) Where individual instances have presented themselves to the Court of Protection, the Court has taken a dim view of such failures. In *Essex County Council v RF,*[[77]](#footnote-77) for example, DJ Mort was particularly critical of the local authority, which had deprived a 91-year-old gentleman with dementia of his liberty for seventeen months. Not only had the authority failed to record RF’s wishes and feelings during the initial capacity assessment, but he had been forcibly removed from his home in a state of partial undress, being told he was being taken to a hotel and threatened with police intervention if he failed to cooperate, and was, naturally, in a very distressed state throughout.[[78]](#footnote-78) In awarding significant damages to RF in light of the violation of his article 5 and 8 rights, the judge stated that ‘[i]t is hard to imagine a more depressing and inexcusable state of affairs. A defenceless 90-year-old gentleman in the final years of his life was removed from his home of 50 years and detained…against his wishes’.[[79]](#footnote-79)

The presence of dementia and old age, then, has been viewed, by some members of the judiciary, as a *particularly* aggravating feature of such cases – and as a time of life where one of the fundamental goals must be to ensure respect for a person’s identity and personal relationships. According to Hedley J, in residence decisions for the elderly, there is ‘…an importance in place which is not generally recognised by others; not only physical place but also the relational structure that is associated with place’.[[80]](#footnote-80) The developments purveyed in this section are therefore to be welcomed, both legally and socially, - even if they are still in the process of being fully implemented on the ground - particularly for persons with dementia. Ethically, they are perhaps of even greater significance – they send a symbolic message that individuals with dementia are still persons, and moreover, they are still persons with an identity; both emotionally and psychologically, where they have, on occasions, previously been denied this status.[[81]](#footnote-81) The development of the best interests framework for decision-making has become increasingly targeted towards avoiding ‘othering’, or more specifically, avoiding unjustifiably portraying those who are deemed to lack capacity as ‘deviant’, or stigmatised, based on the fact that they have dementia. As Donnelly argues, it has moved towards recognising that the person remains able to contribute to the decision-making process, and shows respect for *their* autonomy, even after they lack capacity.[[82]](#footnote-82)

Despite the increasing importance that is given to the voice of the person who lacks capacity in best interests decision-making outlined above, there remain a number of barriers to fully integrating them in to the decision-making process – barriers to viewing the voice of the person lacking capacity as central to the decision. As both Herring[[83]](#footnote-83) and Series[[84]](#footnote-84) point out, and as Baroness Hale remarked in *Aintree University Hospitals NHS Trust v James,*[[85]](#footnote-85) the views of the person lacking capacity are not *themselves* definitive of best interests – they are not constitutive of what is in an individual’s best interests and consequently there is no legal obligation on the Court to facilitate them unconditionally. They only carry weight in relation to what they can tell the assessor about what may or may not be in this person’s best interests, and to the extent that they can be accommodated within the overall best interests assessment.[[86]](#footnote-86)

To this end, different courts have interpreted the weight to be attached to the individual’s wishes and feelings differently – from having ‘great’[[87]](#footnote-87) or ‘significant’[[88]](#footnote-88) weight, to only being a part of the overall balancing exercise.[[89]](#footnote-89) In *ITW v Z[[90]](#footnote-90)* it was held that the actual weight attributed to them is always case and fact specific, and will be assessed in light of all the circumstances of the case, including the degree of the person’s incapacity (the more borderline the incapacity the greater the weight to be attributed to them), the strength and consistency of the views, the effect on the person if they thought their wishes were not being implemented, the extent to which the wishes and feelings are rational or sensible, and the extent to which the wishes and feelings can be accommodated in the court’s overall assessment of best interests.[[91]](#footnote-91) Given this guidance, those with milder dementia may have greater weight attached to their wishes and feelings than those in the more advanced stages of dementia, but either way, their own subjective perspective – their wishes, feelings, values and beliefs – must always ‘fit’ within the objective best interests framework. It is this ambivalence that has led some commentators to criticise the lack of hierarchy within the considerations contained in section 4 of the Mental Capacity Act. Ruck Keene states that it ‘…routinely…lead[s] to undervaluing…the individual’s wishes and feelings and decisions being made that are very far from right for that individual as an individual human being’,[[92]](#footnote-92) although the current proposals by the Law Commission are that section 4 of the Act should be amended so as to allow a presumption in favour of the person’s views, unless there is ‘good reason’ to depart from them.[[93]](#footnote-93)

A final barrier to fully integrating the person with dementia who lacks capacity into the decision-making process is that, at the time of writing, there is no legal obligation to join the person as a party to proceedings in the Court of Protection.[[94]](#footnote-94) This is an issue, which again, has its critics,[[95]](#footnote-95) and may be a violation of the right to a fair trial guaranteed by article 6 of the European Convention on Human Rights. [[96]](#footnote-96) It has, however, recently been subjected to debate by the courts,[[97]](#footnote-97) and the current position is that the person involved need not be joined to proceedings, but efforts *must* be made, inter alia*,* to elicit the person’s wishes and feelings and make these known to the Court without causing the person unnecessary distress.[[98]](#footnote-98)

The majority (although as noted above, not the entirety) of the shift in best interests has therefore been aimed at centralising the person lacking capacity in the decision-making process, and portraying them as persons whose views are inherently valuable, *in their own right,* in shaping best interests decisions, rather than as passive, deviant, and stigmatised based on their cognitive impairment. In the next section, however, it is argued that on occasions, the courts have failed to use best interests decisions involving persons with dementia to this effect. It is argued that ‘othering’ remains both implicit and explicit in some best interests judgments.

IV. ‘OTHERING’ THE PERSON WITH DEMENTIA THROUGH BEST INTERESTS.

*A. Creating the Comparator.*

The first aspect of ‘othering’, outlined above, is creating an idealised standard by which the Court can measure those who come before it in best interests decision-making. *Dorset County Council v EH,*[[99]](#footnote-99)a case involving the residence of an 82-year-old woman, EH, with dementia,highlights this well.In deciding that it would be in EH’s best interests to be placed in a care home, Parker J states that:

…EH’s circumstances are such that she cannot be considered to have true independence or autonomy at present. Many of her actions and reactions are not volitional…Her independence and autonomy is causing her emotional and physical distress. It is her “independence and autonomy” that puts her at risk.[[100]](#footnote-100)

According the Court, then, there is a perceived ambivalence between having independence and autonomy as the Court conceptualises them, and the type of independence and autonomy that EH *seems* to have. Despite indicating that she does not view EH as really having independence or autonomy (*i.e.* already EH does not have the qualities that mark out the qualities the ‘normal’ person should have because of her dementia), if we look more closely at the wording, what the Court is in fact stating is that she *does* have some form of independence and autonomy, it is just not the *type* of independence or autonomy that she should have. It is not, according to the Court, the valuable kind of independence and autonomy that is enjoyed by normal healthy individuals without dementia – it is not, to use Parker J’s language, ‘true’ autonomy, characterised by ‘volitional’ actions and reactions.[[101]](#footnote-101) Similarly, although EH goes out every morning to buy a paper, this is qualified by the fact that ‘it is not clear that she reads it or appreciates it’[[102]](#footnote-102) – implying that it would only be a meaningful activity if she could do with the paper what ‘ordinary’ people could do – further entrenching the ideal of what an independent and autonomous person *should* be able to do. Furthermore, and as Harding[[103]](#footnote-103) argues, through the use of language such as ‘wandering’, the Court transforms EH from someone with purpose – who enjoyed ‘walking’ – to someone without purpose, who simply wanders aimlessly to the local shop. Indeed, recent literature on dementia care has emphasised the need for a shift in such discursive practices given the ability of the term ‘wandering’ to pathologise persons with dementia.[[104]](#footnote-104)

Although *Dorset County Council v EH* was an early case under the Mental Capacity Act 2005, it is argued that this element of ‘othering’ – the comparator – still manifests itself in subtler ways. In *IIBCC v LG,*[[105]](#footnote-105) which concerned the contact and residence of LG, a 96-year-old woman with dementia, the judge states that the world of an individual with dementia is a ‘bewildering’ and ‘frightening’ place.[[106]](#footnote-106) It is a world in which ‘personal autonomy is no longer realistically possible’[[107]](#footnote-107) and one that is characterised only by LG’s ‘ravaged memory.’[[108]](#footnote-108) In effect, the world that LG now inhabits is not the world that most people without dementia supposedly inhabit – a world that is supposedly *not* bewildering or frightening – and a world characterised by the presence of the ability to act autonomously. In adopting this approach, the Court not only explicitly differentiates LG by stating that she exists in a completely different world, but, in a manner reminiscent of the medicalised individual with dementia criticised above, also identifies LG by her dementia and the impact it has on her memory.[[109]](#footnote-109) In both *Dorset County Council v EH* and *IIBCC v LG* then, one may see Shildrick’s argument that ‘[t]he integrated and fully functioning body remains an implicit standard’[[110]](#footnote-110) coming to life in the Court’s judgments. In effect, there appears to be a version of ‘normal’ that the Court has in its mind when making best interests decisions for persons with dementia. Not only does it use this version of ‘normality’ to create a distance between itself and the person with dementia, but also to reaffirm the correctness of the abilities that purportedly inhere in this idealistic standard.

*B. Deviance and Marginalisation*

As Jennings notes, ‘[i]n too much dementia care today we ask how to come to terms with a diminished thing, when instead we should seek to attain a re-placed plenitude’.[[111]](#footnote-111) In effect, because we – or in this instance, the Court – have an idea of what qualities this ideal paradigm possesses, the person with dementia is characterised as deviant from this by focusing on their failures – the fact that they fail to meet this standard, or fail to ‘see’ what they shouldsee, because of their dementia. The person with dementia is measured up to a supposedly objective standard of what a reasonable person would be able to do and see, a standard they may fail to meet precisely because of their dementia, and such failure is used as evidence of their deviance from the ideal standard outlined above. This ‘deficiency’ approach to dementia has been heavily criticised; Goodin and Gibson argue that ‘[e]ven in the case of elders with moderately advanced dementia, we ought not ride roughshod over such evaluative capacities as they still retain’,[[112]](#footnote-112) a point that the paper will return to in due course.

The language used in the cases already criticised above highlights this element of ‘othering’ well; ‘a world where *personal autonomy is no longer realistically possible*’ and where, in *IIBCC v LG,* LG has a ‘*ravaged’* memory. A number of additional cases perhaps demonstrate this in a subtler manner, however. *EM v SC & CM*[[113]](#footnote-113) involved the residence of EM, a 92-year-old man with dementia who had an abusive and neglectful son. Both the social worker, and the consultant psychiatrist emphasised what they perceived to be EM’s deficiencies: ‘he appeared *unable to appreciate or assimilate the information* *and opinions of others* about the potential risks and potential difficulties in returning home…’[[114]](#footnote-114) (emphasis added). In effect, he was unable to accept what other people thought were in his best interests, or other individuals’ perceptions of his situation. In *SCC v LM,*[[115]](#footnote-115) a case involving the residence of JM, a 79-year-old man with Alzheimer’s, Cardinal HHJ declared that it would be in JM’s best interests to remain at the care home. During the very brief attempt made to summarise JM’s wishes at paragraph 79, they are referred to as ‘inconsistent’ twice, and although he undoubtedly wanted to live elsewhere, this again is qualified because ‘he is by no means certain of where…his view is inconsistent’,[[116]](#footnote-116) and later,

[j]ust because he expresses a wish to live with her, *about which he is not consistent anyway*, does not mean he has a capacity to make a decision on the matter’.[[117]](#footnote-117) (emphasis added)

One final aspect of the cases which highlights even subtler ways the Court ‘others’ the person with dementia in best interests decision-making, is how, on occasions, they have been marginalised through the camouflaging or outright hiding of the person’s wishes and feelings from the litigation because they are considered unable to contribute to the decision-making process in a manner the Court can comprehend. *Milton Keynes Council v RR*[[118]](#footnote-118) involved a decision by the Court of Protection that RR, an 81-year-old woman with vascular dementia, had been unlawfully deprived of her liberty, following unsubstantiated safeguarding concerns. In doing so, they limited contact with her son, SS, her main carer, for a significant period of time. Although painting a very vivid picture of what type of lady RR has been throughout her life, portraying her as someone who was ‘very independent’[[119]](#footnote-119) but had ‘put her roots down and engaged actively with her local community, her friends and her local church’,[[120]](#footnote-120) in effect, painting the picture of how she was before she had dementia - again, arguably that of the ‘pre-dementia’ comparator - the court explicitly states that she cannot express her wishes and feelings as to contact with SS,[[121]](#footnote-121) without explaining whythis is the case. There is no exploration as to whether she can express herself in her own particular ways – displaying contentment in the home, or a lack of distress, for example. This evidence would have been at the very least indicative of her feelings towards her current care arrangements. One is left with the impression from the Court’s processes that perhaps because RR is unable to communicate verbally, or rationally, in a manner that is in accordance with the idealistic paradigm, she is deemed as unable to express her wishes and feelings at all – or even as not having any views at all given her advanced state of dementia.

Indeed, ascertaining a person’s current perspective is not impossible even in the most advanced stages of dementia - novel approaches to ascertaining an individual’s current perspective have been utilised in other cases. In *WCC v GS,*[[122]](#footnote-122)for example, involving the residence of an 83-year-old woman with Alzheimer’s, the Court noted that at the care home, ‘GS appears to be happy and settled,’[[123]](#footnote-123) and received images of the individual in question in her care home, which demonstrated her contentment – even going so far as to say that ‘given her age and physical and mental condition, it would probably be very dangerous to undertake such a move.’[[124]](#footnote-124)

The picture painted by both the Courts and some of the professional opinion throughout these cases is characterised by an inability to see things the way the local authority or the Court sees things, and this is used as evidence of the correctness of the idealistic standard that forms the original comparator. It is a failure to respect the unique subjective character of experience[[125]](#footnote-125) - in this case, the subjective character of experience of the person with dementia before the Court. As noted throughout this paper, the experience of dementia *does* entail a change in functioning, and it is important that the courts confront the strength of an individual’s particular abilities when making best interests decisions. As such, the paper does not seek to argue that exactly the same weight should be given to every wish enunciated by the person with dementia in the decision-making process, or that the wishes of the person with dementia should override all other concerns that feed in to the decision-making process. Because of how dementia, as a cognitive impairment, operates, in some cases, particularly in the more advanced stage of the condition, their wishes may conflict or change on a regular basis, for example. The way the Court has considered the perspective of the person with dementia in the cases purveyed here, however, risks pathologising the person with dementia, or rendering them the ‘Other’ – and it is focusing on their deficiencies and their diagnosis as evidence of their ‘otherness’ that is problematic. It is a mechanism by which the Court reinforces the correctness of the idealistic standard. To return to Weicht’s quote, it ‘enables a reaffirmation of all that is valued’[[126]](#footnote-126) – of the rational, competent, functionally intact comparator. This, in turn, highlights the need to be wary of Coggon’s assertion that ‘[s]ometimes…it is perfectly legitimate to recommend a situation informed by existing social and institutional norms and practices’,[[127]](#footnote-127) particularly where existing social norms and practices devalue the voice of the person with dementia, which, in turn, take hold within the Court’s decision-making processes. In the next section I argue that by adopting an intersubjective approach, there may be the possibility of being more attuned to the person’s own perspective, and, furthermore, has the potential to subvert the idealised image of the ‘secure, distinct, closed and autonomous’[[128]](#footnote-128) individual that remains an implicit standard in such cases. While such an approach may not necessarily combat every difficulty in incorporating the person’s own voice into the best interests decision-making process undertaken by the Court, it is argued here that it may provide the Court with a lens by which it can, to adopt Atkins’ language, be more ‘appropriately subjective’.[[129]](#footnote-129)

V. “I was ever a fighter, so - one fight more”[[130]](#footnote-130) – THE POTENTIAL OF AN INTERSUBJECTIVE APPROACH.

As noted earlier, a central aspect of 'othering' is understanding relationships – and particularly, as Stefan notes,[[131]](#footnote-131) relationships of dominance and subordination. In order to ‘other’, there has to be something by which we other – a standard by which we measure those with dementia as deficient. This is the essence of the critique provided thus far. In this section, however, I argue that this process can be subverted by adopting what is termed an ‘intersubjective’ approach, derived predominantly from the work of Thomas Nagel[[132]](#footnote-132) and Kim Atkins.[[133]](#footnote-133) Such an approach entails a recognition that in addition to wishes, feelings, values, and beliefs, each person also has a certain ‘perspective’ on things – a subjective way of experiencing life. Atkins elaborates on this by stating that

…in the case of human subjectivity our subjective sense of self is not *merely* bodily. That is, we gain a sense of self and a concrete understanding of our bodily states intersubjectively. *That means that what it is like to be in any particular state is always informed by a familial, social and historical context*. (emphasis added)[[134]](#footnote-134)

By focussing more clearly on contextual information about a person’s relationships, and embeddedness within their network of relationships, and by focussing in on what Nagel terms their ‘subjective character of experience’[[135]](#footnote-135) – that is, focusing on what it is like to be *that particular person with dementia*, the Court can go some way to subverting the process of ‘othering’ that, it is argued, inheres in the cases above.

On a practical level, relationships also have a legal role within the best interests decision-making process - under section 4(7) of the Act, the Court must take into account the views, *inter alia,* of anyone engaged in caring for the person with dementia who lacks capacity, for example.[[136]](#footnote-136) This is for obvious reasons - as Donnelly notes, ‘[a] carer who is a family member may have a nuanced and complex understanding of the person which a professional may lack’.[[137]](#footnote-137) This is not to deny that the position of persons with dementia does indeed pose challenges for the Court of Protection – and other best interests assessors – in making best interests decisions. It challenges because of the nature of the illness, and in certain circumstances it may well be particularly difficult to ascertain an individual’s perspective, especially during the later stages of dementia – although as I have indicated above, this is not necessarily an impossible task if the Court takes more innovative approaches.

Dementia also poses opportunities for best interests decision-makers, however, which must be seized upon by the Court of Protection during the decision-making process. Although there is a tendency to view persons with dementia as experiencing a loss of social identity,[[138]](#footnote-138) given their age they in fact frequently have a lifetime of experience, beliefs, values, and relationships, that can inform the best interests decision-making process and help maintain their social identity. It is argued, however, that only when the Court takes an intersubjective approach, which necessarily entails focusing on these relationships - both on a macro level (relationships with organisations or institutions such as the state or their church, for example), and a micro level (relationships with other individuals or self-relations) - will they be able to overcome the characterisation of persons with dementia as ‘Other’. This is not to say that such an approach helps the Court pay *more* attention to their perspective understood in a technical manner – that is, it does not require the Court to simply look at ‘wishes, feelings, values, and beliefs’ understood in a narrow sense. Nor does it suggest that a person’s own wishes should always be the trump card in the decision-making process. What a proper application of this idea does is ensure that the Court avoids ‘othering’ by being sensitive to the different ways each person, including persons with dementia, choose to live their lives. In effect, it allows the Court to pay *appropriate*[[139]](#footnote-139)attention to the person’s perspective, by exploring the relationships – both positive and negative – that form their subjective character of experience. In the cases analysed here, it is suggested that there are two ways an intersubjective approach as defined in this section can achieve this goal. The first is that such an approach requires ‘unifying’ the person with dementia, to use Stirling’s terminology.[[140]](#footnote-140) This entails exploring the person in both their past *and* their present states as one entity - recognising that the background of the person with dementia does not simply ‘fall away’ at a particular point in time - rather than being viewed in isolation as their ‘undemented’ or ‘demented’ states as the preceding section suggested the courts have had a tendency to do. As Nedelsky notes[[141]](#footnote-141), however, this requires far greater attention to detail, and in particular far greater attention to detail than has been seen in the judgments criticised above. Second, in requiring greater analysis of their subjective character of experience, the Courts must place a greater emphasis on examining the effects of dementia *on that particular person,* rather than the Court holding out a generic idea of what it is like to have dementia, which emerges from the cases criticised above*.*[[142]](#footnote-142)

To highlight the potential of this approach, three particular judgments are considered: *A London Borough v VT*[[143]](#footnote-143) *(VT*), *A Local Authority v JH*[[144]](#footnote-144)(*JH*) and *Westminster City Council v Sykes*[[145]](#footnote-145)(*Sykes*).All three cases concerned the residence of persons with dementia. In *VT,* the Court was asked to determine whether it was in the best interests of a 78-year-old man with ‘significant’[[146]](#footnote-146) dementia, to reside in care accommodation in London, or be returned, as per his past and present wishes and intentions, to live the remainder of his life in Nigeria - his country of birth. The Court decided that it would be in his best interests to return to Nigeria. In *JH*, the issue was whether it was in the best interests of a 75-year-old woman, Mrs H, with a number of medical conditions, one of which was vascular dementia, to return home to live with her husband of 30 years, Mr H, or be moved to a care home. In a lengthy, detailed and sensitive judgment, Eldergill J determined that it would be in her best interests to return home, with a package of care provided by the local authority. Finally, *Sykes* involved the issue of whether it was in the best interests of Manuela Sykes, an 89-year-old woman with no close family but with a close network of relationships with friends and through her church, and who had been an active and outspoken political campaigner in the past, to reside in a care home, or return home with a package of care from the local authority, and furthermore, whether her identity should be made public. The Court, in a judgment again by DJ Eldergill, declared that she should be allowed to return home with a package of care, and, in a rare occurrence, that her identity should be made public.

*A. ‘Unifying’ the Person with Dementia.*

All three cases involved adults from different contexts and lives characterised by different relationships, but with an identical issue for the Court to determine – where would it be in the best interests of these adults with dementia to reside? The biographical detail presented in all three judgments is thorough, but moreover, the judges in each case are keen to emphasise how the views expressed by the individuals on their residence have been brought about *because* of their biography – because of how they have lived their lives and the unique web of relationships they are situated within. In effect, they attempt to ‘understand’ the standpoint or the ‘story’[[147]](#footnote-147) of the person, rather than simply dismissing their views as irrational, or a ‘symptom’ of their dementia. This is an approach that has, in fact, long been advocated by researchers on selfhood in dementia. Sabat and Harré argue,[[148]](#footnote-148) for example, that this background contextual information is essential to co-operating in constructing selfhood – and particularly a self that the person with dementia can remain actively and reciprocally involved in creating.

In discussing ST’s wishes and feelings in *VT*, for example, DJ Ralton indicates that it is a value held by many Nigerians of ST’s generation that they would expect to retire back to Nigeria at some point, as well as being customary for families to look after each other, only using outside caregivers as and when they need, as well as ST having expressed a ‘consistent rational intention and wish’[[149]](#footnote-149) to return to Nigeria to ‘end his days’ there. Although use of language such as ‘consistent and rational’ might imply the presence of the comparator criticised earlier, the judge is keen to stress that this is *internal* consistency and rationality – that is, it is consistent and rational according to what ST’s wishes have been previously. It is not only cognisant of ST’s expressed past *and* present wishes, but also takes account of his heritage, and the customs of his place of birth – rather than simply relying on wishes expressed when he is deemed to lack capacity. It considers whether such wishes are or are not consistent with *his* prior wishes, and *his* more widely held values of returning to his home country. In emphasising ST’s cultural background and, importantly, ST’s relationship to his culture, the approach taken by DJ Ralton presents neither a fixed image of ST either previously, or in his current state as a person with dementia, but is a ‘unified’ approach to ST’s life – linking and explaining his attitudes before he was diagnosed with dementia to the same views being expressed now. The identity of ST with dementia,in effectST *now,* may be seen to assume a subsidiary role to ST’s life viewed in its entirety, and his lifelong relationship with his culture.[[150]](#footnote-150)

In a similar vein, the judgment in *JH* is also sensitive to the priority that both Mr and Mrs H afford to their marriage, as well as the value of Ms Sykes’ self-relations *Westminster City Council v Sykes*. In *JH,* Eldergill J outlines in detail Mrs H’s commitment and dedication both to her husband and to her marriage – at one point stating that both *Mr and* Mrs H ‘…take a traditional view of marriage and their vows and have never regarded it as a provisional and reviewable arrangement which could and might be brought to an end…’.[[151]](#footnote-151) In *Sykes*, this approach is particularly pronounced. The Court relies heavily on the continuity of Ms Sykes’ identity, frequently describing her as a ‘fighter’, as having a ‘strong sense of self and identity’ and opinionated, with a ‘strong will to change the world, to influence others and to draw their attention to the plight of those she believes need and deserve more care, such as…people experiencing dementia’,[[152]](#footnote-152) and uses this, as well as evidence of her previous openness in discussing her own dementia and her experience of caring for her mother who had dementia, to authorise both a trial period at home and the release of her identity, emphatically stating that being named ‘confers dignity, the dignity of being heard, rather than undermines her dignity, the indignity of being forgotten’.[[153]](#footnote-153)

Finally, the Court employs a greater attempt to understand the current perspective of the person with dementia on its own evidentiary merit, rather than masking it, or as portraying their perspective as evidence of an idealistic paradigm. In *JH,* Eldergill J states that Mrs H is ‘generally happy at home in [Mr H’s] company. She watches television and whilst watching talks about what is on. She enjoys listening to music…’.[[154]](#footnote-154) In *Sykes*, the Court notes that Ms Sykes may become distressed in the care home given her clear and strong wishes to return home. Furthermore, and as alluded to above, the Court justifies these grounded pictures of those with dementia by reference to broader ethical values and beliefs. For example, the Court notes that Mrs H is ‘still able to appreciate and express the value of being at liberty and being allowed autonomy’[[155]](#footnote-155) – according to what autonomy and liberty now mean to *her,* not the idealistic notions of autonomy and liberty that are present in the judgments in *Dorset County Council v EH* and *IIBCC v LG*. This is also a feature of *Sykes,* where DJ Eldergill states that her ‘…strong sense of self, her belief in the importance of the individual, her desire for freedom and autonomy are magnetic factors, operating at positive and negative poles by providing both the pull of freedom and the counterforce of resistance to outside care’. [[156]](#footnote-156) In effect, the Courts in these cases do not focus on the person as being an ‘either/or’ entity – ‘either’ someone *without* dementia, ‘or’ someone *with* dementia; they do not focus on the artificiality of distinguishing the person in both their pre- and post-dementia states, nor hold them up to some unattainable ideal. They focus on emphasising ST, Mrs JH, and Ms Sykes’ subjective character of experience through an analysis of what values such as autonomy mean to them, through an analysis of their inter- and intra-personal relationships over time, thereby arguably transcending the binary that allows for the construction of the person with dementia as ‘Other’.

*B. Understanding the effects of dementia.*

If an intersubjective approach requires the Court to focus on the person’s subjective character of experience, then this particular element of that process is crucial – it effectively entails a consideration of what it is like to have dementia for *that particular person* before the Court*,* not what the Court suspects it might be like to have dementia in general as they arguably do in the decisions criticised above. As noted earlier, dementia does entail declines and changes in cognition and abilities, but the critical question is, as Kitwood argues,[[157]](#footnote-157) how the evidence of such changes should be interpreted and used by the courts. Rather than focusing on the person’s deficiencies as standalone evidence of what is in their best interests, or as evidence of their ‘deviance’, an intersubjective approach necessitates a greater focus on aspects of the individual’s current circumstances that may *explain* ‘challenging’ behaviour, for example – such as, in *VT* for example*,* the environment in L Care Home (ST’s current place of residence). DJ Ralton notes that, at the care home, ST has presented such ‘challenging’ behaviour, such as barricading himself in his bedroom. This, it is suggested, is due to the fact that ST is unhelpfully but unavoidably surrounded by other residents with more advanced dementia, is under a high degree of control, and is demonstrably unhappy in the care home.[[158]](#footnote-158) It goes further, however, and points out that ST is in fact more co-operative when attended to by caregivers he recognises.[[159]](#footnote-159)

Likewise in *JH*, Eldergill J explains why Mrs H’s behaviour may have sometimes been uncooperative during her time in hospital (such as refusing to eat or drink, or to leave her bed), rather than characterising it solely as a symptom of her dementia. He indicates that the lack of co-operation may be due to the hospital environment, stating that the evidence indicates that Mr H is able to elicit her co-operation at home because of the long established routine they have – preferring to sleep in and remain undisturbed until midday. As such, given that her long-established routine does not fit with that of an institution, the chances of her co-operating in a residential facility is also minimal. Similarly, in *Sykes,* the Court demonstrates sensitivity to both the emotional and personal aspects of having dementia, as well as its cognitive impacts. The judge remains sensitive to the ways in which dementia does indeed affect cognitive functions, and crucially, *how* this may explain an individual’s behaviour and interactions with professionals. For example, in discussing Ms Sykes’ care needs, the judge states that:

It is recorded that she has a tendency to become defiant when [issues around Ms Sykes’ residence] are raised. This is logical and understandable because, unless one has a memory of previous difficulties, the professional view must appear patronising and intrusive, and the problems made-up or grossly-exaggerated.[[160]](#footnote-160)

If it is indeed true, as Atkins argues, ‘the individuality, the specificity, of each person’s perceptual and cognitive faculties endows each subject with a certain unique “take” on experiences which are nonetheless socially and historically situated’,[[161]](#footnote-161) - then the discussion of the three cases here highlights the importance of exploring relationships (familial, social and historical), on alllevels - between the persons with dementia, their spouses, the local authorities as well as with their past and present identities and culture or religion – for the Court to gain a better understanding of the person’s “take” on their experiences. They also highlight the need to be more sensitive to the interactions that take place between professionals - including the Court - and persons with dementia. As DJ Eldergill states in *Sykes,* ‘[t]he law requires objective analysis of a subject not an object’.[[162]](#footnote-162)This is the essence of an intersubjective approach.In adopting such an approach, it is argued that the Court can make ‘a place within our collaborative existences for each other’s specific values and differences’.[[163]](#footnote-163) They make room for the perspective of the person with dementia, while avoiding the ‘othering’ process.

VI. Difficulties with this Approach.

Adopting an intersubjective approach to cases involving persons with dementia as has been advocated in this paper is not necessarily a panacea, and it is therefore important to note some of the potential difficulties with such an approach. Some may argue that such an approach leaves the individual with dementia at the mercy of potentially abusive relationships either individually or institutionally. As Nedelsky notes[[164]](#footnote-164) however, approaches that emphasise the importance of exploring relationships, such as advocated in this paper, necessarily require attention to detail, and are simply good practice whoever the decision maker is.[[165]](#footnote-165) We must have confidence that such detail would highlight potentially abusive relationships to the Court as it has done in other cases.[[166]](#footnote-166) Similarly, by undertaking this level of detail, the Court will be more transparent as to those relationships that are beneficial for the wellbeing of the person with dementia overall*,* even if the relationship may be detrimental on some counts – and example of which is *Re MM.[[167]](#footnote-167)* This case concerned the suspension of contact between MM, an 80-year-old woman with dementia residing in a care home, and RS, her close friend. Contact had been suspended following a misinterpretation of the Mental Capacity Act by the care home in which she was residing, who believed that it was for MM’s next of kin – her daughters – to make best interests decisions on their mother’s behalf if she lacked capacity. MM’s daughters then initiated the suspension of contact between MM and RS. This was held to be a violation of the RS’s Article 8 rights, and that, notwithstanding the fact that there were some concerns over RS’ aggressive behaviour around MM, that contact should be reinstated given MM’s demonstrable happiness when seeing RS:

“As soon as she saw RS face her face lit up in a smile. She called him by name and when asked if she recognised him she commented I knew him as soon as I saw him. She held his hand firmly and asked what he has been doing with himself…MM interacted extremely well with RS.”[[168]](#footnote-168)

Neither must we be quixotic about the practicalities of such an approach in terms of the ultimate decision that *can* be made in light of the increasingly contentious issue of local authority resources. The Court of Appeal in *Re MN*[[169]](#footnote-169)recently affirmed that the Court of Protection ‘…has no more power, just because it is acting on behalf of an adult who lacks capacity, to obtain resources or facilities from a third party…than the adult if he had capacity would be able to obtain himself.’[[170]](#footnote-170) In effect, best interests is confined to the options in front of the Court, and the Court cannot direct a local authority to provide a particular care plan unless it is already an option before the Court. The decision in *Re MN,* recently applied in *North Yorkshire County Council v MAG[[171]](#footnote-171)* may therefore prove to be particularly problematic in residence decisions where a local authority refuses to provide a care plan at home, and where the individual in question has only a small network of family caregivers to rely upon, yet an intersubjective approach indicates that it would be in the person’s best interests to continue to reside at home, if that option were available. If a package of a care plan at home is *not* an option before the Court, then under *Re MN,* the Court cannot direct that it would be in the person’s best interests. This tension is a valid one, and unfortunately remains until, or even *if,* the decision in *Re MN* is reconsidered.

VII. Conclusion

The Court’s approach in the cases outlined above have led, on occasions, to a portrayal of the person with dementia as ‘Other’ during the best interests decision-making process. The argument put forward here is that by adopting an intersubjective approach - emphasising the importance and complexity of their relationships, as well trying to *understand* the symptoms, behaviour and personalities of those with dementia - the Court can be more attentive to their subjective character of experience. This will begin to dismantle the binaries that exist between those ‘with’ dementia and those ‘without’, which can lead to their labelling as ‘Other’. What is required for the Court to do this effectively, however, is explicit recognition of the fact that for those with dementia - and indeed those without - life is inescapably and overwhelmingly characterised and defined by a labyrinth of intra- and inter-personal relationships and connections; both personally and societally. The Court of Protection must be prepared to examine those relationships in detail if it wants to make a decision that is, to use Lady Hale’s language, right for that person ‘as an individual human being’.[[172]](#footnote-172) In essence, what this entails is ‘instead of trying to pull people with dementia into your world, you have to enter theirs’.[[173]](#footnote-173)

1. *SCC v LM* [2012] EWHC 1137 (COP) [84]. [↑](#footnote-ref-1)
2. Dementia is used to refer to a collection of similar symptoms, caused by different illnesses, such as Alzheimer’s, vascular dementia, Lewy Bodies Dementia, Parkinson’s and Huntington’s. [↑](#footnote-ref-2)
3. Alzheimer’s Society, *Dementia 2014: Opportunity for Change,* (Alzheimer’s Society, 2014) 1. [↑](#footnote-ref-3)
4. Nuffield Council on Bioethics, *Dementia: Ethical Issues,* (Nuffield Council on Bioethics, 2009) 1.18, G Boyle, ‘The Role of Autonomy in Explaining Mental Ill-Health and Depression among Older People in Long-Term Care Settings’, (2005) 25 Ageing & Society 731-748; M Cook *et al*, ‘Incidence of Stroke and Seizure in Alzheimer’s Disease Dementia’, (2015) 44(4) Age & Ageing700-704. [↑](#footnote-ref-4)
5. See, for example: R Dworkin, ‘Autonomy and the Demented Self’, (1986) 64(2) The MillbankQuarterly 4-16; R Dworkin, *Life’s Dominion*, (HarperCollins: London, 1993); MJ Newton, ‘Precedent Autonomy: Life Sustaining Intervention and the Demented Patient’, (1999) 8 Cambridge Quarterly of Healthcare Ethics 189-199; D Degrazia, ‘Advance Directives, Dementia, and ‘the Someone Else Problem’, (1999) 13(5) Bioethics 373-391; AR Maclean, ‘Advance Directives, Future Selves and Decision-Making’, (2006) 14 Med LR 291-320; S Holm, ‘Autonomy, Authenticity or Best Interest: Everyday Decision-Making and Persons with Dementia’, (2001) 4 Medicine, Health Care and Philosophy153-159. [↑](#footnote-ref-5)
6. R Dresser, ‘Dworkin on Dementia: Elegant Theory, Questionable Policy’, (1995) 25(6) Hastings Center Report 32-38; R Dresser, ‘Missing Persons: Legal Perceptions of Incompetent Patients’, (1994) 46(2) Rutgers Law Review 609-719. [↑](#footnote-ref-6)
7. In England and Wales, an individual is legally treated as being the ‘same’ person, therefore in law the literature on the personhood problem is only hypothetically relevant. [↑](#footnote-ref-7)
8. This reliance on cognitive functioning for personhood is replicated in some areas of law. As Herring notes, legal death is related to the death of the brain stem, which implies that …once the brain stem has gone, all that gives life value has been lost…’: J Herring, *Medical Law and Ethics,* (OUP: Oxford, 5th edn, 2014) 479. [↑](#footnote-ref-8)
9. It is such concerns that have led to some developing a ‘relational’ theory of personhood. See, for example, KJ Gergen, *Relational Being: Beyond Self and Community,* (OUP: Oxford, 2009). [↑](#footnote-ref-9)
10. GS Rai, *Medical Ethics and the Elderly*, (Radcliffe Medical Press: Oxford, 2nd edn, 2004) 125. [↑](#footnote-ref-10)
11. J Herring, *Older People in Law and Society*, (OUP: Oxford, 2009) 92. This is a similar argument made by Dresser, who seeks to move away from cognitive functioning alone as the marker of personhood: see Dresser, above (n 6). [↑](#footnote-ref-11)
12. JC Hughes, ‘Views of the Person with Dementia’, (2001) 27(2) Journal of Medical Ethics86-91; A Jaworska, ‘Respecting the Margins of Agency: Alzheimer’s Patients and the Capacity to Value’, (1999) 28(2) Philosophy & Public Affairs105-138. [↑](#footnote-ref-12)
13. Hughes *ibid.* 87. [↑](#footnote-ref-13)
14. This paper focuses predominantly on health and welfare decisions, which represent only a small minority of contested best interests decisions. [↑](#footnote-ref-14)
15. See also: P Bartlett, ‘Sex, Dementia, Capacity and Care Homes’, (2010) 31 Liverpool Law Review 137-154; C Foster, J Herring and I Doron, *The Law and Ethics of Dementia*, (Hart: Oxford, 2014); J Herring, ‘Losing It? Losing What? The Law and Dementia’, (2009) 21 CFLQ 3-29. [↑](#footnote-ref-15)
16. Although these tensions are ones that have had a large corpus of academic literature dedicated to them, they have yet to be applied to a concrete legal context such as proffered in this paper. [↑](#footnote-ref-16)
17. M Donnelly, ‘Best Interests, Patient Participation and the Mental Capacity Act 2005’, (2009) 17(1) Med LR 1-29. [↑](#footnote-ref-17)
18. B Winick, ‘The Side Effects of Incompetency Labelling and the Implications for Mental Health Law’, (1995) 1(1) Psychology, Public Policy and Law6-42. [↑](#footnote-ref-18)
19. Herring, above (n 15), and more broadly, see: J Herring and J Wall, ‘Autonomy, Capacity and Vulnerable Adults: Filling the Gaps in the Mental Capacity Act’, (2015) 35(4) Legal Studies 698-719. [↑](#footnote-ref-19)
20. S de Beauvoir, *The Second Sex,* (HM Parshley tr, Penguin: Harmondsworth, 1972); S de Beauvoir, *Old Age,* (P O’Brien tr, Penguin: Middlesex, 1977); C Gilligan, *In a Different Voice,* (Harvard University Press: Cambridge, 1982); N Naffine, *Law and the Sexes: Explorations in Feminist Jurisprudence*, (Allen & Unwin: London, 1990); C Smart, ‘The Woman of Legal Discourse’, (1992) 1(1) Social & Legal Studies 29-44, B Turner, *Vulnerability and Human Rights,* (Pennsylvania State University Press: Pennsylvania, 2006). In a specifically medico-legal context, see: K Keywood, ‘More Than a Woman? Embodiment and Sexual Difference in Medical Law’, (2000) 8(3) Feminist Legal Studies319-342; S Stefan, ‘Silencing the Different Voice: Competence, Feminist Theory and Law’, (1993) 47 University of Miami Law Review 763-815, M Thomson, ‘Legislating for the Monstrous: Access to Reproductive Services and the Monstrous Feminine’, (1997) 6(3) Social & Legal Studies 401-424. [↑](#footnote-ref-20)
21. M Shildrick, *Embodying the Monster: Encounters with the Vulnerable Self*, (Sage: London, 2002) 49. [↑](#footnote-ref-21)
22. K Keywood, ‘My Body and Other Stories: Anorexia Nervosa and the Legal Politics of Embodiment’, (2000) 9(4) Social & Legal Studies 495-513, 499. [↑](#footnote-ref-22)
23. Section 2(1) of the Mental Capacity Act 2005 states that: ‘…a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.’ [↑](#footnote-ref-23)
24. For a discussion of this point from the standpoint of the social model of disability see: B Clough, ‘“People Like That”: Realising the Social Model in Mental Capacity Jurisprudence’, (2015) 23(1) Med LR53-80. [↑](#footnote-ref-24)
25. There is a presumption of capacity until proven otherwise: Mental Capacity Act 2005, s 1(2). [↑](#footnote-ref-25)
26. This is not akin to arguing for the removal of the threshold of mental (in)capacity. For such an argument, see: G den Hartogh, ‘Do we Need a Threshold Conception of Competence?’, (2015) 19(1) Medicine, Health Care and Philosophy 71-83. Indeed it is argued in Section V that even within the framework of the Act, the Court of Protection is able to avoid the process of ‘othering’. [↑](#footnote-ref-26)
27. A person is deemed unable to make a decision if they are unable to understand or retain information relevant to the decision, to use or weight the information, or communicate their decision: s 3(1)(a)-(d). [↑](#footnote-ref-27)
28. L Davis, *Bending Over Backwards: Disability, Dismodernism and Other Difficult Positions,* (New York University Press: New York, 2002) 50, cited in T Shakespeare, *Disability Rights and Wrongs Revisited,* (Routledge: Abingdon, 2nd edn, 2014) 50. [↑](#footnote-ref-28)
29. Shakespeare *ibid.* 63. [↑](#footnote-ref-29)
30. C MacKinnon, ‘Reflections on Sex Equality Under Law’, (1991) 100(5) Yale Law Journal*,* 1281-1328, 1294. [↑](#footnote-ref-30)
31. Above (n 22). [↑](#footnote-ref-31)
32. In *Re C (A Patient)* [1992] 1 FLR 51it was held that if there was no indication of the person’s wishes prior to becoming incapacitated, the Court could explicitly assume the standard of ‘a normal decent person, acting in accordance with contemporary standards of morality’. In *Aintree University Hospitals NHS Trust v James* [2013] EWCA Civ 65 [59]*,* Arden LJ held that*‘*[i]f the court has any doubt as to an individual's wishes or as to whether treatment should be given, it should proceed on the basis that the individual would act as a reasonable individual would act’. The Supreme Court reversed this aspect of the Court of Appeal’s decision. [↑](#footnote-ref-32)
33. B Weicht, ‘Embracing Dependency: Rethinking (In)dependence in the Discourse of Care’, (2011) 58(2) The Sociological Review205-224, 210. [↑](#footnote-ref-33)
34. SR Sabat and R Harré, ‘The Construction and Deconstruction of Self in Alzheimer’s Disease’, (1992) 12 Ageing & Society443-461, 456. [↑](#footnote-ref-34)
35. LP Francis, ‘Decisionmaking at the End of Life: Patients with Alzheimer’s or other Dementias’, (2000-2001) 35 Georgia Law Review539-592, 541. [↑](#footnote-ref-35)
36. T Kitwood, *Dementia Reconsidered: The Person Comes First*, (Open University Press: Buckingham, 1997). [↑](#footnote-ref-36)
37. Dresser, ‘Missing Persons: Legal Perceptions of Incompetent Patients’ (n 6) 663. [↑](#footnote-ref-37)
38. PC Kontos, ‘Embodied Selfhood: An Ethnographic Exploration’ in A Leibing and L Cohen (eds), *Thinking about Dementia: Culture, Loss, and the Anthropology of Senility*, (Rutgers University Press: New Brunswick, 2006). [↑](#footnote-ref-38)
39. T Kitwood and K Bredin, ‘Towards a Theory of Dementia Care: Personhood and Well-being’, (1992) 12 Ageing & Society269-287. Similarly, Nedelsky argues that ‘...when a “syndrome” is recognized it invites individual psychological analysis – rather than systematic relational analysis.’ J Nedelsky, *Law’s Relations: A Relational Theory of Self, Autonomy and Law,* (OUP: Oxford, 2012) 312. See also J Stirling, ‘Dementia, Discourse, Difference and Denial: “Who Did I Become?” (1995) 2 Law Text Culture 147-159, 155. [↑](#footnote-ref-39)
40. G Boyle, ‘Facilitating Decision-Making by People with Dementia: Is Spousal Support Gendered?’, (2013) 35(2) Journal of Social Welfare and Family Law 227-243; E Mackinlay, ‘Journeys with People who have Dementia: Connecting and Finding Meaning in the Journey’, (2015) Journal of Spirituality & AgingDOI:10.1080/15528030.2015.1046632 (Online First); CR Macquarrie, ‘Experiences in Early Stage Alzheimer’s Disease: Understanding the Paradox of Acceptance and Denial’, (2005) 9(5) Aging & Mental Health 430-441; E Steeman *et al*, ‘Living with Dementia from the Perspective of Older People: Is it a Positive Story?’, (2007), 11(2) Aging & Mental Health 119-130. [↑](#footnote-ref-40)
41. U Naue and T Kroll, ‘The Demented Other’: Identity and Difference in Dementia’, (2008) 10 Nursing Philosophy 26-33. [↑](#footnote-ref-41)
42. Above (n 34) 460. [↑](#footnote-ref-42)
43. In light of this, even if ‘will and preferences’ does replace best interests, the courts may still face the same sort of interpretative problems: United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) Article 12, and UNCRPD General Comment No 1 ‘Equal recognition before the law (art. 12)’ (11 April 2014) CRPD/C/GC/1. [↑](#footnote-ref-43)
44. S Cox, ‘Decision-Making and Dementia – How well does the Mental Capacity Act Serve People Living with the Condition?’, (2015) 5(1) Elder Law Journal 74-83, 75-76. [↑](#footnote-ref-44)
45. *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582 [587]; *Re F (Mental Patient: Sterilisation)* [1990] 2 AC 1 [78]. This approach continued throughout the early 1990s: *Airedale NHS Trust v Bland* [1993] AC 789. [↑](#footnote-ref-45)
46. *Re F* [2000] EWCA Civ 192; *Re S* [2002] EWHC 2278; *Re S* [2003] EWHC 1909 (Fam). [↑](#footnote-ref-46)
47. Lord Chancellor’s Department, *Who Decides: Making Decisions on Behalf of Mentally Incapacitated Adults,* (The Stationery Office: London, 1997) 3.23. [↑](#footnote-ref-47)
48. [2000] 1 FLR 549. [↑](#footnote-ref-48)
49. *ibid.* [555], echoing her earlier approach to best interests in *Re MB (Medical Treatment)* [1997] EWCA Civ 3093. [↑](#footnote-ref-49)
50. M Dunn *et al*, ‘Constructing and Reconstructing ‘Best Interests’: An Interpretative Examination of Substitute Decision-Making under the Mental Capacity Act’, (2007) 29(2*)* Journal of Social Welfare and Family Law 117-133; P Fennell, ‘Best Interests and Treatment for Mental Disorder’, (2008) 16 Health Care Analysis 255-267; M Brazier and J Miola, ‘Bye-Bye Bolam: A Medical Litigation Revolution?’, (2000) 8 Med LR 85-114. [↑](#footnote-ref-50)
51. M Holstein, ‘Home Care, Women and Aging’ in MU Walker (ed), *Mother Time: Women, Aging, Ethics,* (Rowman & Littlefield: Oxford, 2000) 232, citing J Shklar, *The Faces of Injustice,* (Yale University Press: New Haven, 1990). [↑](#footnote-ref-51)
52. N Munro, ‘Taking Wishes and Feelings Seriously: The Views of People Lacking Capacity in Court of Protection Decision-Making’, (2014) 36(1) Journal of Social Welfare and Family Law 59-75. [↑](#footnote-ref-52)
53. Law Commission, *Mentally Incapacitated Adults and Decision-Making: A New Jurisdiction* (Law Com No 128, 1995). [↑](#footnote-ref-53)
54. Above (n 48) [560]. [↑](#footnote-ref-54)
55. See, for example: *Local Authority X v MM and KM* [2007] EWHC 2003 (Fam), *An NHS Trust v A* [2013] EWHC 2442 (COP). [↑](#footnote-ref-55)
56. It is also potentially problematic (albeit necessary given the nature of the inherent jurisdiction) that this approach *begins* with the proposed treatment or intervention, and *then* follows with the question of whether this is in the individual’s best interests. It does not ask ‘what is in this person’s best interests?’ but instead asks ‘is procedure X in this person’s best interests?’ In effect, it already begins its best interests analysis from an overtly biased position. [↑](#footnote-ref-56)
57. *Local Authority X v MM and KM* (n 55). [↑](#footnote-ref-57)
58. *ibid.* [121]. [↑](#footnote-ref-58)
59. M Quigley, ‘Best Interests, the Power of the Medical Profession, and the Power of the Judiciary’, (2008) 16 Health Care Analysis233-239, 235. [↑](#footnote-ref-59)
60. Mental Capacity Act, s 4(6)(a)-(b). [↑](#footnote-ref-60)
61. Mental Capacity Act, s 1(3), and Mental Capacity Act 2005, s 4(1) respectively. [↑](#footnote-ref-61)
62. As noted above, a similar tension exists in the capacity assessment process. Section 1(3) of the Act states that ‘person is not to be treated as unable to make a decision *merely* because he makes an unwise decision’ (emphasis added). Skowron indicates that ‘[t]his begs the question of how much reliance on the outcome of a person’s decision *is* acceptable’ (emphasis added): P Skowron, ‘Evidence and Causation in Mental Capacity Assessments: *PC v City of York Council* [2013] EWCA Civ 478’, (2014) 22(4) Med LR631-639, 634. [↑](#footnote-ref-62)
63. ‘The general lack of awareness of the provisions of the Act has…allowed decision-making to be dominated by professionals, without the required input from families and carers about P’s wishes and feelings’.House of Lords Select Committee on the Mental Capacity Act 2005, *Mental Capacity Act 2005: Post-Legislative Scrutiny* (The Stationery Office: London, 2014) para 107. [↑](#footnote-ref-63)
64. *Aintree University Hospitals NHS Trust v James* [2013] UKSC 67 [45]. [↑](#footnote-ref-64)
65. *Re Peter Jones* [2014] EWCOP 59 [65]. [↑](#footnote-ref-65)
66. *Wye Valley NHS Trust v B* [2015] EWCOP 60 [11]. See also at paragraph 13: ‘In some cases…the wishes and feelings, beliefs and values of a person with a mental illness can be of such long standing that they are an inextricable part of the person that he is. In this situation…[i]t is more real and more respectful to recognise him for who he is: a person with his own intrinsic beliefs and values. It is no more meaningful to think of Mr B without his illnesses and idiosyncratic beliefs than it is to speak of an unmusical Mozart.’ [↑](#footnote-ref-66)
67. UNCRPD General Comment 1 (n 43) para 21. There has been significant debate on the meaning of these provisions, see: P Bartlett, ‘The United Nations Convention on the Rights of Persons with Disabilities and Mental Health Law’, (2012) 75(5) MLR752-778; P Gooding, ‘Navigating the ‘Flashing Amber Lights’ of the Right to Legal Capacity in the United Nations Convention on the Rights of Persons with Disabilities: Responding to Major Concerns’, (2015) 15 HRLR45-71. [↑](#footnote-ref-67)
68. Committee on the Rights of Persons with Disabilities, ‘Statement on Article 14 of the Convention on the Rights of Persons with Disabilities’*,* <http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=15183&LangID=E> accessed 10 April 2016. It might also be suggested that having a diagnostic element of the Mental Capacity Act 2005, such as in section 2, also goes against the idea of de-stigmatisation. [↑](#footnote-ref-68)
69. Department of Health, *Mental Health Act 1983: Code of Practice* (The Stationery Office: London, 2015) 1.7 - 1.10. The Care Act 2014 also states that in promoting an individual’s well-being, the relevant local authority must begin with the assumption that the individual is best placed to judge her own well-being (Care Act 2014, s 1(3)(a)), and must have regard to the individual’s views, wishes, feelings and beliefs when assessing their care needs (Care Act 2014, s 1(3)(b)). [↑](#footnote-ref-69)
70. Declaration of Rights for Older People in Wales (2014), available at: <http://gov.wales/docs/dhss/publications/140716olderen.pdf> accessed 25 August 2015. [↑](#footnote-ref-70)
71. Scotland has its own legislation on incapacity: Adults with Incapacity (Scotland) Act 2000, and issues concerning incapacity do not fall under the Mental Capacity Act 2005. [↑](#footnote-ref-71)
72. Charter of Rights for People with Dementia and their Carers in Scotland, (2009), available at: <http://www.scottishhumanrights.com/application/resources/documents/FINALCharterofRights.pdf> accessed 14 October 2015. [↑](#footnote-ref-72)
73. T Brannelly, ‘Sustaining Citizenship: People with Dementia and the Phenomenon of Social Death’, (2011) 18(5) Dementia 662-671. See also: Nuffield Council on Bioethics, above (n4) Ch 4, D Gove *et al,* ‘General Practitioners’ Perceptions of the Stigma of Dementia and the Role of Reciprocity’, (2015) Dementia DOI: 10.1177/1471301215625657 (Online First). [↑](#footnote-ref-73)
74. Above (n 44). [↑](#footnote-ref-74)
75. Boyle, above (n 40); V Williams *et al,* ‘Making Best Interests Decisions: People and Processes’, (Mental Health Foundation: London, 2012); T Williamson *et al*, ‘Listening to the lady in the bed: The Mental Capacity Act 2005 in Practice for Older People’, (2012) 2(2)Elder Law Journal185-192; C Emmett *et al*, ‘Homeward Bound or Bound for a Home? Assessing the Capacity of Dementia Patients to Make Decisions about Hospital Discharge: Comparing Practice with Legal Standards’, (2013) 36 International Journal of Law and Psychiatry 73-82; M Poole *et al*, ‘Going Home? An Ethnographic Study of Assessment Capacity and Best Interests in People with Dementia being Discharged from Hospital’, (2014) 14 BMC Geriatrics 56-71. [↑](#footnote-ref-75)
76. This was also a major theme in the recent House of Lords post-legislative scrutiny on the Act: Above (n 63). [↑](#footnote-ref-76)
77. [2015] EWCOP 1. [↑](#footnote-ref-77)
78. *ibid.* [15]. [↑](#footnote-ref-78)
79. *ibid.* [68]. See also *Re MM* [2011] 1 FLR 712, which involved the suspension of contact between a woman with dementia residing in a care home, MM, and her partner, RS. It was held to be a violation of RS’s article 8 rights. [↑](#footnote-ref-79)
80. *Re GC* [2008] EWHC 3402 (Fam) [21]. [↑](#footnote-ref-80)
81. Following recent scandals at a number of south Wales care homes, as well as the Mid-Staffordshire inquiry, there have been many instances of this type of treatment being reported in the media: ‘Stafford Hospital Worker ‘called patient an animal’, *BBC News* (London, 12 February 2013) <http://www.bbc.co.uk/news/uk-england-stoke-staffordshire-21430513> accessed 25 August 2015; ‘Care home nurse struck off after abusing patients’, *The Northern Echo* (14 March 2013), <http://www.thenorthernecho.co.uk/news/10291382.print/> accessed 25 August 2015; Patrick Sawer, ‘Bullying care worker jailed after attacking dementia patients’, *The Telegraph* (19 December 2014). .<http://www.telegraph.co.uk/news/uknews/crime/11304361/Bullying-care-worker-jailed-after-attacking-dementia-patients.html> accessed 25 August 2015. [↑](#footnote-ref-81)
82. Donnelly (n 17). [↑](#footnote-ref-82)
83. J Herring, ‘Legal Issues Surrounding Dementia’, (2011) 1(2) Elder Law Journal 182-189. [↑](#footnote-ref-83)
84. L Series, ‘Relationships, Autonomy and Legal Capacity: Mental Capacity and Support Paradigms’, (2015) 40 International Journal of Law and Psychiatry80-91*,* 87. [↑](#footnote-ref-84)
85. Above (n 64). [↑](#footnote-ref-85)
86. See also: Department of Health, *Mental Capacity Act 2005 Code of Practice.* (The Stationery Office: London, 2007) 5.38. [↑](#footnote-ref-86)
87. *Re S and S (Protected Persons)* [2008] EWHC B16 (Fam) [55]. The court went on to say that there is a presumption in their favour where the views are not irrational. [↑](#footnote-ref-87)
88. *ITW v Z* [2009] EWHC 2525 (Fam) [35]. [↑](#footnote-ref-88)
89. *Re P* *(Statutory Will)* [2009] EWHC 163 (Ch). [↑](#footnote-ref-89)
90. Above (n 88). [↑](#footnote-ref-90)
91. *ibid.* [35]. [↑](#footnote-ref-91)
92. A Ruck Keene, ‘Capacity is Not an Off-Switch’, (*Mental Capacity Law and Policy,* 1 October 2015), available at: <http://www.mentalcapacitylawandpolicy.org.uk/capacity-is-not-an-off-switch/> accessed 15 October 2015. See also: A Ruck Keene and C Auckland, ‘More Presumptions Please? Wishes, Feelings and Best Interests Decision-Making’, (2015) 5(3) Elder Law Journal293-301, 295. [↑](#footnote-ref-92)
93. Law Commission, *Mental Capacity and Deprivation of Liberty* (Law Com CP No 222, 2015) para 12.47. This position has, however, been criticised by Jackson J in *Wye Valley* based on the uncertainty as to what is meant by ‘good reason’: Above (n 66) [17]. [↑](#footnote-ref-93)
94. The Court of Protection (Amendment) Rules 2015, s 3A. [↑](#footnote-ref-94)
95. A Ruck Keene, ‘(Re)presenting P before the Court of Protection’, (The Mental Capacity Act 20115 – Ten Years On Conference, Liverpool, September 2015). [↑](#footnote-ref-95)
96. Munro argues that such a position may be in conflict with the decision of the European Court of Human Rights in *Shtukaturov v Russia* (2012) 54 EHRR 27, which held that representative of a person’s wishes by an ‘interested party’ was inadequate: Munro (n 52) 69. [↑](#footnote-ref-96)
97. *Re X* [2014] EWCOP 25; *Re X* [2015] EWCA Civ 599. [↑](#footnote-ref-97)
98. *Re NRA* [2015] EWCOP 59 [164]. [↑](#footnote-ref-98)
99. [2009] EWHC 784 (Fam). [↑](#footnote-ref-99)
100. *ibid.* [128]. [↑](#footnote-ref-100)
101. Although not involving a person with dementia, this approach is also present in *NCC v PB and TB* [2014] EWCOP 14 [113]: ‘…[t]he inherent jurisdiction exists to protect, liberate and enhance personal autonomy...[t]o be maintained in optimum health, safe, warm, free from physical indignity and cared for is in itself an enhancement of autonomy’. [↑](#footnote-ref-101)
102. Above (n 99) [46]. [↑](#footnote-ref-102)
103. R Harding, ‘Legal Constructions of Dementia: Discourses of Autonomy at the Margins of Capacity’, (2012) 34(4) Journal of Social Welfare & Family Law425-442. [↑](#footnote-ref-103)
104. ME Graham, ‘From Wandering to Wayfaring: Reconsidering Movement in People with Dementia in Long-Term Care’, (2015) Dementia DOI: 10.1177/1471301215614572(Online First). [↑](#footnote-ref-104)
105. [2010] EWHC 1527 (Fam). [↑](#footnote-ref-105)
106. *ibid.* [109] and [116]. [↑](#footnote-ref-106)
107. *ibid.* [122]. [↑](#footnote-ref-107)
108. *ibid.* [155]. [↑](#footnote-ref-108)
109. A more radical interpretation of *IIBCC v LG* suggests that the behaviour of the daughter, who is suffering with mental health issues, is also interpreted in the same manner. At paragraph 103 the Court states that ‘[t]he court is left with a lady presenting as profoundly disabled and behaving bizarrely’. [↑](#footnote-ref-109)
110. Shildrick (n 21) 50. This approach is even present in *Re S and S* (n 87), one of the most favourable cases to wishes and feelings, where Judge Marshall QC states at paragraph 57 that there could be a presumption in favour of P’s wishes and feelings: ‘…where P can and does express a wish or view which is not irrational (*in the sense of being a wish which a person with full capacity might reasonably have*)’ (emphasis added). [↑](#footnote-ref-110)
111. B Jennings, ‘Agency and Moral Relationships in Dementia’ in EF Kittay and L Carlson (eds), *Cognitive Disability and its Challenge to Moral Philosophy*, (Wiley-Blackwell: Oxford, 2010) 171. [↑](#footnote-ref-111)
112. RE Goodin and D Gibson, ‘The Decasualisation of Eldercare’ in EF Kittay and EK Feder (eds), *The Subject of Care: Feminist Perspectives on Dependency,* (Rowman & Littlefield: Oxford, 2002) 248. [↑](#footnote-ref-112)
113. [2012] EWHC 1518 (COP). [↑](#footnote-ref-113)
114. *ibid.* [25]. [↑](#footnote-ref-114)
115. [2012] EWHC 1137 (COP). [↑](#footnote-ref-115)
116. *ibid.* [80]. [↑](#footnote-ref-116)
117. *ibid.* [113]. Other judgments indicate that this may also be a feature of other cases emanating from the Court of Protection. Another example this is present in the assessment by the social worker of the capacity of Mrs Ross, an 82-year-old woman with dementia, in *Cardiff County Council v Ross* [2011] Case No. 12063905. Although the court ultimately declared that it would be in her best interests to go on the cruise that was the subject of the litigation, the social worker that initially assessed her capacity determined that ‘…her ideas/beliefs are not based in reality and she has no insight into her need’ (at [7]). [↑](#footnote-ref-117)
118. [2014] EWCOP B19. [↑](#footnote-ref-118)
119. *ibid.* [4]. [↑](#footnote-ref-119)
120. *ibid.* [5]. [↑](#footnote-ref-120)
121. *ibid.* [30]. It is also perplexing as to why a return to her home to be cared for by her son, SS, and his partner, TT, not examined given that the safeguarding concerns were unsubstantiated. [↑](#footnote-ref-121)
122. [2011] EWHC 2244 (COP). [↑](#footnote-ref-122)
123. *ibid.* [19]. [↑](#footnote-ref-123)
124. *ibid.* [48]. Although not involving a person with dementia, Jackson J took a similar approach in *Wye Valley NHS Trust v B* (n 66), by visiting and speaking with B himself. [↑](#footnote-ref-124)
125. T Nagel, ‘What is it Like to be a Bat?’, (1974) 83(4) The Philosophical Review 435-450, 436. [↑](#footnote-ref-125)
126. Weicht (n 33) 213. [↑](#footnote-ref-126)
127. J Coggon, ‘Best Interests, Public Interest, and the Power of the Medical Profession’, (2008) 16(3) Health Care Analysis219-232, 229. [↑](#footnote-ref-127)
128. Shildrick (n 21) 51. [↑](#footnote-ref-128)
129. K Atkins, ‘Autonomy and the Subjective Character of Experience’, (2000) 17(1) Journal of Applied Philosophy 71-79, 78. [↑](#footnote-ref-129)
130. *Westminster City Council v Sykes* [2014] EWHC B9 (COP) [§13]. [↑](#footnote-ref-130)
131. Stefan (n 20). [↑](#footnote-ref-131)
132. Above (n 125). [↑](#footnote-ref-132)
133. Above (n 129). [↑](#footnote-ref-133)
134. *ibid.* 73 (citation omitted). [↑](#footnote-ref-134)
135. Above (n 125). [↑](#footnote-ref-135)
136. A failure to do so where practicable, will result in the Court imposing liability: *Winspear v City Hospitals Sunderland NHS Foundation Trust* [2015] EWHC 3250 (QB). [↑](#footnote-ref-136)
137. Donnelly (n 17) 18. In this context Donnelly is discussing the requirement to consult with a range of different people in making best interests decisions under s 4(7), however it could also be argued that the same point applies in relation to abstract values such as religious beliefs: A Ho, ‘“They Just Don’t Get It!” When Family Disagrees with Expert Opinion’, (2009) 35(8) Journal of Medical Ethics497-501. [↑](#footnote-ref-137)
138. Jennings (n 111) 173. [↑](#footnote-ref-138)
139. Above (n 129) 78. [↑](#footnote-ref-139)
140. Stirling (n 39) 155. [↑](#footnote-ref-140)
141. Nedelsky (n 39) 79. [↑](#footnote-ref-141)
142. It may be that the greater practical potential for this argument lies in section 4(6)(b) of the Mental Capacity Act – values and beliefs. If wishes and feelings are interpreted as pertaining to a particular decision, then values and beliefs may be interpreted as wider ranging – they relate more to the identity of the person with dementia, and may pose less potential for conflict than wishes and feelings. For a fuller analysis of the difference between ‘wishes and feelings’ and ‘values and beliefs’ see: Munro (n 52) 61, and for a philosophical argument regarding the capacity to ‘value’ during dementia, see: Jaworska (n 12). [↑](#footnote-ref-142)
143. [2011] EWHC 3806 (COP). [↑](#footnote-ref-143)
144. [2011] EWCOP 2420. [↑](#footnote-ref-144)
145. [2014] EWHC B9 (COP). [↑](#footnote-ref-145)
146. Above (n 143) [24]. [↑](#footnote-ref-146)
147. This language is akin to narrative identity theory – a full discussion of which is outside the scope of this paper. The approach advocated here does highlight how relationships can illustrate a person’s narrative continuity. See: J Blustein, ‘Choosing for Others as Continuing a Life Story: The Problem of Personal Identity Revisited’, (1999) 27 Journal of Law, Medicine & Ethics 20-31. For an interesting personal reflection on this in the context of old age and death generally see: A Gawande, *Being Mortal: Illness, Medicine and What Matters in the End,* (Profile Books: London, 2014). [↑](#footnote-ref-147)
148. Sabat and Harré (n 34) 453. [↑](#footnote-ref-148)
149. Above (n 143) [35]-[37]. [↑](#footnote-ref-149)
150. Similar declarations are made in *London Borough of Redbridge v G* [2014] EWCOP 17*,* where the Court emphasises the importance of G’s ‘church family,’ and declaring that it would be in G’s best interests to be reintegrated in to her social networks (at [84]), and in *Sykes*, where the judge highlights the importance of her engagement with her friends, family and members of her church, ‘to help establish relationships and habits’ [§10]. [↑](#footnote-ref-150)
151. Above (n 144) [§14]. [↑](#footnote-ref-151)
152. Above (n 145) [§10]. Feminist criticisms of this approach may nonetheless argue that the Court still presents a picture of the masculine ideal in articulating this particular image of Ms Sykes – the image of the strong willed public persona. [↑](#footnote-ref-152)
153. Above (n 145) [§13]. [↑](#footnote-ref-153)
154. Above (n 144) [§14]. [↑](#footnote-ref-154)
155. *ibid.* [§14]. He also adopts a similar stance in the recent similar case of *Bedford Borough Council v C* [2015] EWCOP 25. Although finding that there have been strained relations with Mr C in the past, he highlights how Mrs C’s distress over certain emotional topics does not necessarily mean she is scared of her husband and could be attributable to other features, such as being separated from him (at [89]). The Court backs this up by examining the fact that Mrs C appears ‘happy and content at the matrimonial home during…visits…she is more animated and verbally responsive when at home; she often expresses a wish to have…contact with her husband; she is generally responsive to Mr C and initiates affectionate contact…’ (at [90]), and is even ‘downcast’ after her visits home are over (at [88]). [↑](#footnote-ref-155)
156. Above (n 145) [§10]. [↑](#footnote-ref-156)
157. Above (n 36). [↑](#footnote-ref-157)
158. Above (n 143) [39]. In *Sykes* the judge also acknowledges her view that paid carers who visited her at home had been ‘patronising and insensitive’ and ‘offensive or inconsiderate’: Above (n 145) [§10]. [↑](#footnote-ref-158)
159. Above (n 143) [39]. [↑](#footnote-ref-159)
160. Above (n 145) [§7]. In some respects, however, one of these judgments in fact goes much further than simply trying to understand the person with dementia. In *JH,* Eldergill J also goes some way to trying to understand *Mr H’s* ‘difficult’ and ‘uncooperative’ behaviour. This behaviour is explained not only because of the ‘trauma’ Mr H has had to endure due to his wife’s declining health, but also because of the hostility, and entrenchment of his dealings with the local authority and its representatives.Eldergill J is critical of the local authority’s assertions that Mr H has never been willing to compromise his position, stating that ‘[w]hat [the local authority] mean is that he is not willing to concede the relevant point and neither are they’: (at [§14]). He goes on to describe the local authority’s approach as ‘entrenched’ (at [§14]). [↑](#footnote-ref-160)
161. Above (n 129) 73. [↑](#footnote-ref-161)
162. Above (n 145) [§10]. [↑](#footnote-ref-162)
163. Above (n 129) 75. [↑](#footnote-ref-163)
164. Above (n 141). For an argument on the importance of such contextual information in capacity assessments, see: NF Banner and G Szmukler, ‘”Radical Interpretation” and the Assessment of Decision-Making Capacity’, (2013) 30(4) Journal of Applied Philosophy379-394. [↑](#footnote-ref-164)
165. Quigley (n 59) 237. [↑](#footnote-ref-165)
166. See, for example, *IIBCC v LG* (n 105), *EM v SC and CM* (n 113) and *Stoke City Council v Maddocks* [2012] EWCOP B31. [↑](#footnote-ref-166)
167. Above (n 79). [↑](#footnote-ref-167)
168. *ibid.* [28]. [↑](#footnote-ref-168)
169. *Re MN* [2015] EWCA Civ 411. [↑](#footnote-ref-169)
170. *ibid.* [80]. [↑](#footnote-ref-170)
171. [2016] EWCOP 5. [↑](#footnote-ref-171)
172. Above (n 64) [45]. [↑](#footnote-ref-172)
173. C Eccleston, ‘Dementia Dismantled my Father’s Personality’, *The Guardian,* (31 May 2015), available at <http://www.theguardian.com/lifeandstyle/2015/may/31/christopher-eccleston-father-dementia-disease-dismantled-his-personality> accessed 17 July 2015. [↑](#footnote-ref-173)