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DEMENTIA AND PATIENT SAFETY: A GEWIRTHIAN ANALYSIS

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ABSTRACT

This article deals with the relationship between dementia and patient safety and proposes that measures to promote patient safety should be situated within a rights-based framework. This article calls for the current perspectives on patient safety to be broadened to further encompass patient safety procedures that encompass a holistic and individualistic view of the patient. Alan Gewirth’s Principle of Generic Consistency, as an underpinning moral principle, is applied in order to assess the appropriateness of current law, policy and practice. The article promotes the adoption of this principle as a moral justification for decisions that are taken in respect of patients with dementia and that are purported to protect their safety. It is argued that greater consideration needs to be given to ensuring that patient safety protocols are based upon a principled and empowering stance that does not impede the patient’s realisation of self-fulfilment. This process will be facilitated by adopting rights-based patient safety measures that promotes empowerment. Through the narrative of a fictional patient, Molly, the article presents a novel way of conceptualising patients with dementia, involving the movement from presenting the patient in terms of a linear, declining progression towards a conceptualisation of the patient as a persisting self.

INTRODUCTION

There is a green light flickering on the ceiling of the nursing home bed. Molly is confused about this light—where is she? She is distressed. The nurse arrives. She wants to check Molly’s pulse, but Molly, in a state of some agitation, does not recognise that she is in a nursing home and that the person in front of her is the nurse. Molly is thirsty, her mouth is dry, but she does not tell the nurse that. It’s noisy here with people coming and going outside her room. Molly wants to go home—she shouts for her daughter. The woman in the white trouser suit at her bedside tells her not to talk out loud because she will wake the other residents. Molly feels her heart racing, her pulse getting faster, her agitation getting stronger. The nurse has gone, she has not taken her pulse...

Ensuring the safety of patients is always problematic and ensuring the safety of patients with dementia is even more so. The intersection between patient safety and dementia is difficult to navigate, often beset by grave instances of inappropriate care. This paper interrogates this challenging terrain, which can be characterised by an overuse of well-meaning, but paternalistic, patient safety arguments that can potentially inhibit the autonomy of people with dementia. The article arbitrates for a rights-based approach to the implementation of patient safety regimes that empowers patients with dementia and that facilitates their self-fulfilment – the bringing to fruition of the deepest desires and most valuable capacities so that all that is best within the person in terms of aspirations and potential is realised.¹ This approach involves

the application of Alan Geiwirth’s Principle of Generic Consistency (PGC). The achievement of this self-fulfilment will be facilitated by the implementation of measures that support the idea of the empowerment of vulnerable patients.\(^2\)

This rights-based approach will involve a balance being achieved between applying patient safety measures so that they maximise the safety of patients with dementia and inhibiting those measures that impede the exercise of autonomy. The pitfalls, challenges and possibilities formed within this intersection will be discussed. The article will frame these arguments through the lens of Molly, a fictional 87-year-old patient with advancing dementia and contextualise these lines of reasoning from the viewpoint of someone whose competence is diminishing, whose apparent agency is changing, but whose self remains constant and persisting. Reminiscent of Dworkin’s ‘Margo’, the story of Molly is used as a conduit through which a number of issues can be illustrated within a real-life context.\(^3\)

This article analyses the measures that are taken to promote patient safety and also proposes a new ethical paradigm that will help enhance regulation and practice. This ethical perspective heralds a new and original approach to patient safety and to the construction of a framework that supports best practice in patient safety and celebrates autonomy in the protection of vulnerable patients. This rights-based focus has not featured prominently in the current literature pertaining to either patient safety or dementia. What is addressed by and large is the identification and analysis of what those who have medical responsibility for people with dementia should do, rather than why particular actions should take place. Rights-based actions will require reform to the current regulatory response.

It is argued that decisions taken about patient safety should not be as procedural in nature as they are currently are, but should instead be based on a moral rights-based framework that allows for, promotes, and mediates the empowerment of people with dementia. This will help to ensure that actions that are taken to enhance their safety in healthcare contexts do not impede the attainment of self-fulfilment. To this end, Part I questions the suitability of the current legal approaches that apply to people with dementia, particularly the Mental Capacity Act 2005 (MCA). It also analyses the conflict that can exist between concerns for their safety and the need to empower them so that their voices are heard in the decision-making process. Part II uses Alan Gewirth’s Principle of Generic Consistency (PGC) to provide a moral framework to underpin patient safety measures in respect of people with dementia. Part III assesses the degree to which the relevant law complies with the PGC and makes a number of recommendations to empower patients and maximise the attainment of self-fulfilment.

**PART I: THE LEGAL BACKDROP TO THE CONFLICT BETWEEN THE SAFETY AND WISHES OF (INCAPACITATED) PATIENTS**

Dementia is a neurodegenerative disease that primarily relates to those over the age of 60, although it is not confined to older people.\(^4\) Alzheimer’s disease is the most prominent

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\(^3\) R. Dworkin, ‘Life Past Reason’ in P. Singer & H. Kuhse (eds), *Bioethics: An Anthology* (West Sussex: Wiley Blackwell, 2016) pp 333-340. Fictional Molly had been a second level teacher and her diagnosis of dementia has led to her recent change in living circumstances. She is now resident in a nursing home and her cognitive decline is rapid.

\(^4\) Note that over 42,000 people in the UK under the age of 65 have dementia. See M. Prince et al, *Dementia UK* (2nd ed report produced by King’s College London and the London School of Economics for the Alzheimer’s Society, 2014).
neurodegenerative disease that results in dementia.\(^5\) Patients with dementia often lack capacity. Capacity concerns the legal test used to satisfy competence, which exists when the patient has sufficient cognitive faculties to be able to make a task-specific decision.\(^6\) The main vehicle that is used to determine incapacity is the MCA. It provides both the test for incapacity and the *best interests* test. Under s 1 MCA, a presumption exists that patients have capacity, until it is shown that they lack capacity. Simply making an unwise or irrational decision does not necessarily mean that the patient lacks capacity. Sections 2 and 3 of the Act set out a two-stage test. Section 2 says that a person lacks specific capacity if he or she is unable to make a decision because of an ‘impairment of, a disturbance in the functioning of, the mind or brain’. This could certainly include dementia.\(^7\) Section 3 is a functional test: for a finding of incapacity, the person concerned must be unable to ‘understand the information relevant to the decision’, ‘to retain the information’, ‘to use or weigh that information as part of the process of making the decision’ or ‘to communicate his decision’.\(^8\)

The decision-specific nature of the MCA is evidenced in the case of *Cardiff County Council v Ross*. The court held that an 82-year-old woman, Mrs Peggy Ross, who was living with dementia had the capacity to decide to go on a cruise, even though she lacked capacity for other decisions.\(^9\) If it is determined that the patient lacks capacity, the best interests test is applied. Section 4 states that the person making the decision needs to take all relevant circumstances into account. Under s 4(6) MCA the decision maker must consider, as far as possible, ‘the person’s past and present wishes and feelings’. Therefore, the patient’s views prior to his or her lack of capacity are relevant.\(^10\) In cases where it has been determined that patients lack capacity, then others may make decisions on their behalf. This includes the need to invoke Power of Attorney and to give decision-making powers to proxy decision-makers who must act in the patient’s best interests. Where the capacity is deemed to be borderline, the inherent jurisdiction of the courts comes into play.

Arising from incapacity instances, patients with dementia can sometimes be detached from decision-making processes and some patients require some form of *empowerment* to ensure that they are active participants. Cave analyses the empowering nature of the MCA in the context of vulnerable people. She points to the fact that the MCA involves both empowerment and safeguards, but current practices place a dominant focus on safeguarding patients to the detriment of their empowerment.\(^11\) She argues, essentially, that the focus of the MCA on individual autonomy can lead to ‘a simplistic binary interpretation of capacity’.\(^12\) A situation can arise where the decision-making process is not augmented by facilitation and discussion and the final decision can ultimately be made by a person other than the patient.\(^13\) While the empowerment of patients is accepted as a stated aim for the MCA, no wording delineating a process of empowerment appears within the Act itself. Alghrani, Case and Fanning contend

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\(^5\) There are other neurodegenerative diseases resulting in dementia. These include vascular dementia.


\(^7\) Dementia has been recognised as an ‘impairment’ in recent cases such as *TB v KB and LH* [2019] EWCOP 14 and *RAO v ROO, Royal Devon and Exeter NHS Foundation Trust* [2018] EWCOP 33.

\(^8\) Also see Department for Constitutional Affairs, *Mental Capacity Act Code of Practice*, (2007, Department for Constitutional Affairs) p 38-63. For further information on capacity, see Pattinson, *Medical Law and Ethics*, chapter 5.

\(^9\) *Cardiff County Council v Ross* (2011) COP 28/10/11 12063905.

\(^10\) Also see *Re S and P (Protected Persons) Cases* 11475121 and 11475138 (COP) (25 November 2008), *Re S and S (Protected Persons)* and *Re P* [2009] EWHC 163 (Ch).


\(^12\) Op. cic., p 95.

\(^13\) Op. cic.
that the MCA has a ‘mixed record’. They allude to the positive approach of including the incapacitated patient in making best interests decisions, as indicated in *Aintree University Hospital v James*. According to them, *Aintree* ‘demonstrated explicit judicial acceptance of the fundamental principle that decisions should be taken through the prism of patients’ interests rather than for reasons of practical expediency or according to paternalistic instincts’. Judicial action in respect of the MCA is often admirably patient-focused and autonomy-directed. However, the MCA is not only used in litigious judicial decision-making contexts, but is applied in healthcare settings where healthcare professionals, sometimes alongside patients, have to make decisions that are compatible with the MCA. It is primarily within this arena that problems exist. Alghrani, Case and Fanning contrast the approach adopted in *Aintree* to the House of Lords Select Committee for Health’s review of the implementation of the Act and their opinion that the application of the Act does not reflect its ‘empowering ethos’. The Select Committee found that healthcare professionals struggle with the application of the core MCA principles in practice. The Committee contended that the ‘concept of unwise decision-making faces institutional obstruction due to prevailing cultures of risk-aversion and paternalism’. They were concerned that the wishes, thoughts and feelings of patients are not given priority and ‘[t]his lack of empowerment for those affected by the Act is underlined by the fact that many responsible for its implementation continue to consider it as part of the safeguarding agenda’. They made a number of recommendations and repeatedly stated that a greater focus needs to be placed on empowerment in the context of the implementation of the Act: ‘[p]revailing professional cultures of risk aversion and paternalism have inhibited the aspiration of empowerment from being realised’. Equally, according to the Law Commission, there is a failure to sufficiently consider the patient’s wishes and feelings. The Commission argued that s 4 ought to be amended ‘to attract a level of primacy to a person’s wishes and feelings’.

An amalgam of both positive appraisal and disquiet is demonstrated by Jackson. On a positive note, she considers that the MCA is a ‘staging post on… [the] drive towards respect for the patient’s point of view’. She demonstrates how, in many cases, the judiciary has taken this positive direction even further. She considers that the current law encompassing the MCA is flexible enough to allow the patient’s point of view to be heard, but demonstrates how other considerations can trump this. She is concerned that the MCA does not direct decision-makers to give any priority to the wishes and beliefs of patients and teases out the complexities that apply to patients whose capacity is wavering, indicating how labour-intensive it could be to assess, engage and empower people without capacity so that they bring their own wishes to the fore in decisions that are made about them. She points to the many benefits that could apply if determined efforts were made to really engage patients in this manner and to prevent them

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15 *Aintree University Hospital v James* [2013] UKSC 67, especially at [45].


19 Op. cic., para. 104


being, what Wolff describes as ‘passive subjects’. Such benefits include improvements in wellbeing, improvements in the quality of relationships with others and better outcomes for them in general. Recognising the ‘humanity’ of patients is at the core of this and the MCA as a tool has, in general, been well used by the court. Accordingly, it is not within case law or the court system that many of difficulties apply. Healthcare settings can be places where the patient-focused intent of the MCA is absent in practice. Therein lies the difficulty.

In the context of capacity and best interests, in Local Authority X v MM & Anor (No 1) Munby J stresses the need to balance patient safety concerns with actions that achieve the ‘vital good’ of the patient:

…. we must avoid the temptation always to put the physical health and safety of the elderly and the vulnerable before everything else. Often it will be appropriate to do so, but not always. Physical health and safety can sometimes be bought at too high a price in happiness and emotional welfare. The emphasis must be on sensible risk appraisal, not striving to avoid all risk, whatever the price, but instead seeking a proper balance and being willing to tolerate manageable or acceptable risks as the price appropriately to be paid in order to achieve some other good – in particular to achieve the vital good of the elderly or vulnerable person's happiness. What good is it making someone safer if it merely makes them miserable?

This is akin to Jackson J in Re M, a case that involved M, a 67-year-old patient, who challenged a Deprivation of Liberty Standard Authorisation which did not allow her to leave a care home and return to the home she shared with her partner. This wish was opposed due to M’s identified significant medical requirements. Peter Jackson J accepted that she lacked the capacity to decide where she should reside, primarily due to the risks associated with living at home in comparison to living in a nursing home, where her diabetes would be supervised by professionals. However, he stated that it would be in M’s best interests to return home with two daily visits from district nurses. When discussing risk, he stated: ‘[i]n M's case there is little to be said for a solution that attempts, without any guarantee of success, to preserve for her a daily life without meaning or happiness and which she, with some justification, regards as insupportable’.

This resonates with KK v STCC where Baker J warned that ‘there is a risk that all professionals involved with treating and helping that person – including, of course, a judge in the Court of Protection – may feel drawn towards an outcome that is more protective of the adult and thus, in certain circumstances, fail to carry out an assessment of capacity that is detached and objective’. This case involved an 82-year-old woman (KK) who lived in a nursing home, but wanted to go home. KK had developed Parkinson’s disease and vascular dementia and required a wheelchair. Following a fall and hospital admittance, it was determined by a psychiatrist that she lacked capacity to make decisions in relation to her ‘care needs and residence

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25 E.g. Aintree; Wye Valley NHS Trust v B [2015] EWCOP 60 where Peter Jackson J stated (at [11]) that ‘the wishes and feelings, beliefs and values of people with a mental disability are as important to them as they are to anyone else, and may even be more important’. In Cambridge University Hospitals NHS Foundation Trust v BF [2016] EWCOP 26, MacDonald J stated: ‘I have done the best I can to consider the position from BF’s point of view’.
26 Jackson, ‘From “Doctor Knows Best” to Dignity’, p. 256.
27 Local Authority X v MM & Anor (No 1) (2007) EWHC 2003 (Fam) at [120].
28 Re M (Best Interests: Deprivation of Liberty) [2013] EWCOP 3456 at [38].
29 KK v STCC [2012] EWCOP 2136 at [25].
It was initially decided that it was in KK’s best interests to live in a nursing home. Baker J, however, found to the contrary. He determined that it was not necessary to understand the nuances of issues in order to show capacity. KK might not have demonstrated full understanding of some factors, but she understood the ‘salient features’. He referred to the key principle of s 1(2) MCA, where a person is assumed to have capacity unless it can be shown to the contrary. A person with dementia is just as entitled as others to this presumption. Assessment in this regard is, according to Baker J, issue-specific and time-specific. In all likelihood, KK would deteriorate, but, at this point in time, the local authority had not proven that she lacked capacity. In determining the next steps, it is interesting that the judge noted that it was not for him to ‘determine or even advise’ but, rather, the onus was on the local authority and KK herself to determine a course of action, which he suggested might include trial overnight stays.

In relation to issues pertaining to s 4(6), Peter Jackson J in the case of Wye Valley NHS Trust v B recognised that ‘the wishes and feelings, beliefs and values of people with a mental disability are as important to them as they are to anyone else, and may even be more important’ and, thus, it would be inappropriate to automatically discount, minimise or trivialise their wishes. He made reference to the Law Commission’s consultation paper number 222, Mental Capacity and Deprivation of Liberty, where it states that, under the current regime, the wishes and feelings of patients ought to be prioritised and reflect more closely the United Nations Convention on the Rights of Persons with Disabilities’ (UNCRPD) approach whose aim is to ‘promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity’. In the context of dementia, Article 12(4)’s approach to capacity and safeguards to prevent abuse is linked to respect for rights where ‘[t]he safeguards shall be proportional to the degree to which such measures affect the person’s rights and interests’. However, a different attitude was adopted by Peter Jackson J who held that ‘[a]ll that is needed to protect the rights of the individual is to properly apply the Act as it stands’. There are small differences between the MCA and the UNCRPD, but it could argued that they both hold to the need to uphold the rights of people with disability. What is possibly required is more effectively applying the holistic approach originally conceived within the MCA and which holds within it the rights-based approach of the UNCRPD, albeit that the articulation of these rights is more tangible in the latter.

Many of the day-to-day healthcare decisions that involve application of the MCA are connected to the desire of healthcare professionals to ensure that the incapacitated patient is safe and secure. Patient safety is about preventing adverse effects in an era where older people are able to be kept alive longer than in previous eras, due to advancing technologies. Potential adverse

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33 Op. cit., at [75].
37 Article 1, United Nations Convention on the Rights of Persons with Disabilities
38 Wye Valley NHS Trust v B at [17].
39 The World Health Organisation (WHO) describes patient safety as: ‘… the prevention of errors and adverse effects to patients associated with health care…’. World Health Organisation, ‘Patient Safety’
effects include wrong dosage of medication, inability of the patient to take medication as prescribed, deprivation of liberty and inadequacies in fall prevention. Patient safety measures try to ensure that patients are safe and that they are safeguarded from unintended or unexpected harm. This involves the use of initiatives to protect patients and to ensure that they are given treatment in suitable environments. Patient safety is at the epicentre of many of the interventions that are put in place or are planned to be put in place for a person who has been diagnosed with dementia. Unfortunately, acting in accordance with this concern can contradict the wishes of the patient, leading to a potential conflict between patient safety and autonomy.

To illustrate this, let us return to the story of Molly when she was in the early stages of dementia. An initial diagnosis from a visiting nurse included the filling out of a form where Molly and/or family members were asked whether and to what degree Molly had difficulties negotiating a number of physical tasks, such as getting out of the bed or using the shower. Further intervention by the occupational therapist included an analysis of Molly’s social functioning, whether Molly could turn the cooker on and off, use the kettle appropriately, get in and out of the chair safety and, accordingly, some aids were recommended to support her safety. Another field of evaluation or treatment included input from the physiotherapist, who determined the degree to which a danger existed of falling or of breaking a bone. Assessment by the General Practitioner (GP) included assessment of Molly’s ability to cope with daily tasks and so assure her safety. Psychiatric evaluation looked in detail at the degree to which Molly could cope psychologically with a range of cognitive tasks that were related to her personal safety. Dementia represents a wheel that keeps turning invidiously and interminably, in a downhill trajectory towards an existence that, in Shakespearean parlance, is sans teeth, sans eyes, sans everything. It is interesting, however, to note the opinions of neurologist Jules Montague, who is concerned that much of this assessment process involves the tabulation of what the patient cannot do rather than including a specific focus on what the patient can do—a mismatch, from the onset, between recorded abilities and recorded disabilities. All too often the core elements of the cross-over between patient safety and dementia relate to an over-concentration on the disability presented by the patient, rather than a recognition of disability within the context of multiple historical abilities that may be dormant or, indeed, defunct, but still matter to that person. Presumably, however, there is an unspoken assumption that a patient with capacity can do everything—and it is a much easier task to compile a list of incompetencies rather than to record everything a person can do. The difficulties of evaluating competency of patients and the related conceptual, ethical and political questions that arise from this process are delineated by Secker. She demonstrates how the determination of incompetency divests a person of the right to consent to or refuse medical treatment or decide upon a place to reside. Pepper-Smith et al explore the idea of competence, recognising that for many this concept ‘remains confused and open to capricious interpretation and application.’ The patient may have a sense that the loss of independent living, through removal from her own house, can be constituted as more of a threat to her integrity than the health and safety risks articulated by the medical team. This gives rise to a difficulty with


40 J. Montague, Lost and Found: Memory, Identity, and Who We Become When We’re No Longer Ourselves, (London, Sceptre, 2018), especially chapter 7.
prescriptive taxonomy: ‘[s]o much depends upon articulated belief’. Unless the patient can explain her beliefs competently, then the evaluation of risk may well be less than if she is unable to give this coherent explanation. They identify the paradox that those who assess capacity are often also involved in risk and safety assessment. For patients with dementia, patient safety and exercise of rights need a very specific alignment. The absence of this alignment can have serious consequences for the patient, as is evident in this vignette:

Molly has taken a fall in her room in the nursing home. She can hear the muffled sound of running feet. Someone is talking to her, but no one has put in her hearing aid, so she can’t answer. She is put on a big narrow bed that walks. Her mouth is parched, and she can’t speak properly – she knows her teeth are not in. Where are they? She sits up in the stretcher and tries to get out in order to get her teeth. They were on her dressing table, she remembers, but no one knows this. Someone pushes her back onto the stretcher and then she is in a big white van. When she gets to the hospital, someone talks to her about where she fell and if it hurts. She can’t really hear them properly, so she can’t tell them about the very bad pain in her stomach.

Mistakes can happen when there is insufficient mediation between the patient with dementia and medical staff. This creates a functioning gap between the patient and the healthcare professional and it constitutes a potential harm-causing factor. When the patient with dementia presents in a confused and agitated manner, bereft of context and familiarity, all the professional can potentially see is the disability/illness. There is usually no advocate or trained person present who can mediate their needs: there is great potential here for mistakes to be made because a complete medical picture can’t be painted. The harm-causing factors are primarily communicative: the patient has difficulty communicating needs and healthcare professionals can lack the time and, sometimes, the expertise to fill in the communicative gaps.

These instances underline the fact that decisions for the patient with dementia, rather than with and alongside, are often made because of fears of patient safety being compromised. Ensuring that a patient-centred approach is adopted by the instigation of positive dementia-specific procedures and practices, however, would not, in itself, necessarily result in meaningful enhancement of patient safety for patients with dementia. Actions alone, no matter how well planned and policy-driven, are not going to change the cultural values that underpin how people with dementia are treated in hospital or nursing home settings. Solutions are not to be found solely or primarily at policy or procedural level, but, rather, resolution could be found at ethical level. This apparent dichotomy between procedure and ethics is not a false or illogical one. It reflects a reality that the individual and autonomous rights of patients are not given sufficient consideration when implementing patient safety measures. The Equality and Human Rights Commission (EHRC) alluded to this in their finding that: ‘[o]lder people expressed a widespread desire to be treated as a person rather than as ‘a task to be undertaken’’.  

45 George et al identify the following factors as contributing to poor patient safety: unsuitable intervention, poor staff training, inadequate assessment as well as treatment of dementia, and discrimination. They claim that there is no magic solution, but ‘but what is needed is a multifactorial, multilevel approach at the seven levels of care – patient, task, staff, team, environment, organisation and institution’. See George et al, ‘How can we keep patients safe in our acute hospitals? A review of challenges and solutions’ 106(9) (2013) Journal of the Royal Society of Medicine, 355-361, p. 355.
There is no specific overarching law governing patient safety. Essentially, its protections are rooted in what might be classified as ‘soft law’, in other words developing policy and practice.\textsuperscript{47} The concepts of openness, transparency and candour, as explored and articulated by Herring, should be constituent elements of the legal framework that is married to policy and practice.\textsuperscript{48} In addition to this, best practice in healthcare provision includes patient-centred leadership and the provision of accurate, useful and relevant information.\textsuperscript{49} However, for patients with dementia, many of these concepts remain ideologically adrift from them because such patients almost always lack capacity to make decisions. George et al argue that ‘[p]atients with dementia do badly in hospital with frequent adverse events resulting in the geriatric syndromes of falls, delirium and loss of function with increased length of stay and increased mortality’.\textsuperscript{50} They indicate that insufficient progress has been made in respect of the key causes of harm. These include ‘[i]nadequate assessment and treatment’ and ‘inappropriate interventions’.\textsuperscript{51} For patients with dementia, additional contributing factors include discrimination, based upon prior perceptions of personnel in respect of dementia and a lack of trained staff.\textsuperscript{52} These patients are frequently faced with adverse events that result in ‘the geriatric syndromes of falls, delirium and loss of function with increased length of stay and increased mortality’.\textsuperscript{53} These causes of harm do not solely derive from gaps in patient safety procedures, but can also be linked to insufficient consideration of the enduring personhood of the patient. This matter will be addressed in more detail in Part II, as it forms the crux of the debate within this article.

Issues such as practical expediency, paternalism, risk aversion and a safeguarding agenda can sometimes appear to fly in the face of the wishes of the patient. Thus, a conflict can exist between acting in accordance with the patient’s wishes in line with s 4 MCA and acting in a manner that promotes safety. The application of the MCA is not sufficiently empowering, and the law is sometimes applied in a way that prizes patient safety over patient autonomy and the bringing to fruition of the patient’s desires. Patient safety cannot be the most determining feature in the care of a person with dementia. It must be aligned with an effort to empower the patient to make decisions for herself and it must not too readily act in line with risk assessment to the detriment of acting in accordance with vindicating the patient’s rights. To flesh out the difficulties that apply to actualising patient safety in respect of patients with dementia and, thereby, to address the imbalance between patient safety measures and the exercise of autonomy, let us focus attention on a moral principle that has the potential to resolve the mismatch.

\textbf{PART II: THE APPLICATION OF THE PRINCIPLE OF GENERIC CONSISTENCY TO PATIENTS WITH DEMENTIA IN THE CONTEXT OF THEIR SAFETY}

I am now going to refer to a moral theory that will help to examine the problematic question of patient safety measures and the ways they might conflict with individual autonomy - Gewirth’s PGC. It is one of a variety of possible moral solutions that exist within moral theory,
and these theories could all offer potentially acceptable solutions to the same conundrum. For example, Herring’s ideas about relational autonomy and the role of people in the construction of that almost-shared autonomy would be one way of interrogating this subject.\(^{54}\) However, this solution and others of its ilk are not proposed here due to the fact that this author takes a position of ethical rationalism, which places more importance on the idea of individual agency and autonomy than other perspectives. This emphasis on individual agency and autonomy found within the PGC provides a rights-based approach to vulnerable patients and their care. It is important to situate this debate on patient safety and dementia within rights-based theory and to recognise that the positive law needs to take account of such an approach. The need for the positive law to address the question of why law should reflect a moral justification for rights has been discussed in Beyleveld and Brownword’s *Law as a Moral Judgment*.\(^{55}\) They contend that it is a logical necessity for this connection to be respected, and so, in many ways, the jump from legal positivism towards legal idealism is justified.\(^{56}\)

The PGC is being used here because gaps have been identified in approaches to patient safety in the context of dementia. These gaps relate to the failure to act upon individualised rights, based often upon communicative difficulties. The PGC attempts to prove that it is dialectically necessary that all agents must claim the generic rights as generic conditions of agency at risk of denying their own status as agents. An agent can infringe the rights of others, but only with their express consent. Proponents of the PGC have demonstrated the use of this principle to assess moral dilemmas and to provide a balancing scale in the weighing of rights. They claim that it is the supreme principle of morality.\(^{57}\) The PGC uses a number of terms that must be described in order to understand how the principle operates and is justified. First, the PGC is concerned with the concept of agency. An agent is a being who pursues purposes chosen on a voluntary basis and must, as seen from the perspective of the dialectically necessary argument, act in accordance with the PGC.\(^{58}\) An agent who does not act in accordance with the PGC is deemed to act immorally, but does not stop being an agent. The agent possesses the generic conditions of agency. According to Beyleveld and Brownword, these conditions ‘consist of what…agents need, irrespective of what their purpose might be, in order to be able to act at all or in order to be able to act with general chances of success’.\(^{59}\) Such conditions can be categorised as ‘voluntariness’ and ‘purposiveness’. Agents possess generic rights, which are rights to the generic conditions of agency.\(^{60}\)

There are two ways of justifying the argument for the PGC—the dialectically necessary and contingent arguments. The reasoning for the PGC is dialectical in the sense that it involves a theoretical dialogue from the perspective of the claims of an individual agent, made from the standpoint of a first-person viewpoint. In *Reason and Morality*, Gewirth used a dialectically necessary argument to justify this position (which has been further developed by others).\(^{61}\) This involves logical and, consequently, necessary steps of an argument that arise from premises

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\(^{54}\) Herring, ‘The Health Law, Ethics and Patient Safety Interface’.


\(^{56}\) See Ó Néill, *Religion, Medicine and the Law*, pp. 4-5 for further discussion of the need to consider legal idealism as an approach for evaluating the adequacy of legal protections.


that cannot be rejected with any degree of coherence.62 Deryck Beyleveld has put forward dialectically contingent arguments.63 These dialectical arguments are contingent in nature by virtue of the fact that their starting point consists of moral premises that can be coherently denied.64 These arguments apply logical necessity, but start from contingent premises. To summarise Beyleveld’s recent dialectically contingent argument, it involves acceptance of stage one of Gewirth’s dialectically necessary argument (‘I am an agent’ and ‘I (categorically instrumentally) ought to defend and pursue my having the generic conditions of agency’) and acceptance that all agents are equal in dignity and rights (i.e. Beyleveld’s impartiality assumption).65 This contingent argument is used here because it is easier for people to accept stage 1 of the dialectically necessary argument and the impartiality assumption that all agents have equal dignity and rights than it is for them to accept all stages of the dialectically necessary argument. The use of Beyleveld’s contingent argument works by leading to justification for the PGC and is also compatible with many of the ideas of those who support rights-based arguments. It is accepted that agential purposiveness and voluntariness are generic conditions of agency. Essentially, they are things that we must look for in order to see whether an action is undertaken by an agent at all (as opposed to, for example, the result of a reflex or natural impulse). Generic rights come in two different forms: ‘interest-rights’ and ‘will-rights’.66 These refer to the will and choice conceptions of claim-rights. The generic conditions are aligned with the concept of competence. A competent adult, who possesses the characteristics of agency, has will-rights, which means that he or she can waive the benefits of his or her generic rights. In other words, a competent patient has the self-determined will to act in accordance with her self-determined will, as long as doing so does not interfere with the generic interests of others. An incompetent patient only has interest-rights. This is true for matters for which she is incompetent. In considering whether the patient with dementia has will-rights or only interest-rights, it is necessary to examine the sliding scale (characteristics) of agency that may exist. Just because someone lacks task-specific competence does not mean that they are not an apparent agent, or as Pattinson explains:

Only those who display the attributes of agency (ostensible agents) can meaningfully be treated as acting for the purpose of exercising a right, and the specific cognitive-functional abilities required will depend on the particular right and context. In other words, what is required to make a decision on a specific purpose is not simply agency, but (specific task) competence: the cognitive-functional ability to act for that task in that context.67

Let us illustrate this in respect of Molly. If Molly is considered incapable of making a decision to refuse life-sustaining treatment (i.e. incompetent with regard to that specific task), that could be because she is considered incapable of making any decisions at all (i.e. not an ostensible

64 Pattinson, Medical Law and Ethics, p. 581.
65 Beyleveld, ‘The Principle of Generic Consistency as the Supreme Principle of Human Rights’, states that: ‘...if Stage I is sound it is dialectically necessary for human rights to be interpreted and effected in ways consistent with the PGC, on pain of denying that all human beings are equal in dignity and rights’ (p 3). Also see pp. 7-8.
66 Op. cic., p 11. Also see Ó Néill, Religion, Medicine and the Law, pp. 31-32
agent) or merely because she is incapable of making that decision (i.e. an ostensible agent who lacks competence to make that decision).

The PGC suggests that competent people possess purposefulness and voluntariness, which are synonymous with 'competence' in this context because competence denotes the ability to act voluntarily and with purpose. These apparent agents have will-rights. The person with advanced dementia will likely be deemed to be incompetent and only possess interest rights. Thus, this patient is unable to waive the benefits of her generic rights. A duty of protection is owed to her and, in line with the principle of precaution, those who possess more characteristics of agency (i.e. the healthcare professional/carer) have a stronger claim to decision-making rights. All this necessitates viewing the apparent agent as a matter of moral obligation rather than as a matter of epistemology.

From a Gewirthian viewpoint, we know that there is a hierarchy of rights, what Gewirth calls the 'criterion of degrees of needfulness for action'. This hierarchy positions rights as having three forms: basic, non-subtractive and additive. To exemplify these rights, Pattinson and Capps give the following explanation: '[t]o act at all, an agent has basic needs, such as her life. To act successfully, she has nonsubtractive needs to those things required for her to maintain her current level of purpose-fulfilment and additive needs to those things required to increase her current level of purpose-fulfilment'. Ensuring the safety of patients entails ensuring their basic rights. They need to be safe in order to live. This right is positioned higher in the hierarchy of rights than the other two rights. In practical terms, this means that if Molly wants to go out the door at night without a coat, then it is permissible, under the hierarchy of rights, for an apparent agent to prevent her so doing because her wish for liberty is only an additive right whereas Molly’s positive right to protection of her health is a basic right.

It is clear that this is the position for a patient with advanced dementia. Does the same apply to the ongoing trajectory of dementia from early onset to mid-phase to moderate? This leads us back to the definition of dementia, where we need to understand that it is, essentially, a process, and losing characteristics of agency is yet another sad part of that often-invidious process. Even though people with dementia may be seen to lose these characteristics of agency, this does not, however, automatically mean that they are non-agents. Pattinson delineates the scale that exists in relation to characteristics of agency and suggests that patients with advanced dementia cannot be identified as non-agents by third parties. To illustrate this, let us try plot this loss in respect of Molly who now presents with moderately severe dementia.

There are, I suggest, different ways of plotting this loss. In the first instance, we will follow and slightly adapt the approach adopted by Pattinson and represent Molly in two forms: We can think of her as Molly now with moderately severe cognitive impairment as a result of advancing Alzheimer’s and Molly then, jovial, spirited, knowledgeable, learned, empathetic.

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now only has interest-rights and Molly then had will rights. What about Molly in the middle, still retaining some of that essence that characterised her nature but diminishing in her abilities? Was she an apparent agent then? The answer to this is dependent upon her specific characteristics at that time. At that stage, she was closer to behaving as an agent than she is now (Molly now), but further away from behaving as an agent than she was then (Molly then) and, so, it is likely that she had only interest-rights. The point of this precautionary thesis is that we do not know whether anyone else is or is not an agent. This would give Molly less of a voice at that stage of development in her Alzheimer’s than the voice of the healthcare professionals and family, but neither would or should her voice be negated because she still displayed some of the characteristics of agency. While she has interest-rights, she is owed a duty of protection as if she had the characteristics of agency. However, the duty that is afforded to her is less than the attention that is given to the voice of those who have apparent agency.

If we revert to the story of Molly without her hearing aid, unaccompanied and unable to give a full medical history – is the carelessness depicted an infringement of her generic rights? Yes, it interferes with her ability to act voluntarily and purposefully. It is arguably appropriate to make decisions for Molly now, in line with what family members would consider to be an accurate reflection of her wishes when she possessed the characteristics of agency (Molly then)? The rights of Molly now, as expressed through family members who are trying to substitute her previous judgement in her current situation, need to be respected because they are trying to be true to her characteristics of agency. In other words, they are trying to achieve her voluntariness and purposefulness.

In the context of consideration of whether an individual can be considered as one or two people, pre- or post-dementia, we will now consider Dworkin’s analysis of the dilemma. He sets out the moral rights that people in the late stages of dementia have, or retain, and determines what is best for them. He asks a number of significant moral questions (many of which go beyond the scope of this article); the most pertinent is the query: ‘do mentally incapacitated people [in this case, those with advanced dementia] have the same rights as normally competent people, or are their rights altered or diminished or extended in some way in virtue of their disease?’ Dworkin finds answers to this conundrum from the perspective of an integrity-based and authenticity-focused view of competence. His reasoning is outlined through the story of Margo, who originally stated her desire to be killed if she were to enter the realms of advanced dementia. However, having succumbed to that very state, she now seems to be relatively happy. Given this state of apparent ease, is her advance directive or her previously articulated wishes still valid? A moral conundrum arises as to whether it is moral to act in accordance with the wishes of her earlier life or to act in line with her current life, but in doing so, reject the autonomy of her previously delineated wishes. Dworkin has presented an argument for giving effect to the prior wishes of Margo, even though she appears to obtain value from the life she has as a person who is living with dementia. Thus, her advance directive should be followed. Dresser, however, offers a contradictory approach to Dworkin arguing that, when patients are able to enjoy and participate in their lives, directives that are aimed at hastening death should

74 Beyleveld and Pattinson, ‘Defending moral precaution as a solution to the problem of other minds: a reply to Holm and Coggon’, argue that the theory of precautionary reasoning means that those who behave like agents should be treated like agents and those who do not behave like agents ought to be treated as having moral status proportionate to the behaviours and characteristics that they display.
75 Op. cic.
sometimes be disregarded. She outlines problems with the autonomy-based model suggested by Dworkin and shows how most people do not have a coherent narrative to sustain the decisions they make in life. Put simply, many people ‘take life one day at a time’.78

Let us think further of Molly. Molly then (clever, dynamic, energised person) and Molly now (forgetful, aggressive, retaining pieces of memory) and future Molly (as yet to be) are on a continuum, where both the characteristics of agency possessed, and the rights awarded and duties owed are on the same conveyor belt. The Irish poet Sean Ó Riordáin, speaking of his mental illness, said “Is mó mé i mise amháin” (there are many people in me). The continuum that is the personhood of Molly is reflected in this concept of different conceptions and realisations of self. The PGC, equally, recognises the differing rights of and duties owed to that ever-changing self. Taylor provides an historical overview of the self and describes how the self, particularly as it relates to its conception with the perception of ‘good’ is perceived within literary and historical traditions throughout the annals of time.79 His main precept is that our perception of the self and its goodness or otherwise has an impact upon how we treat others. How we treat others and how we treat human beings is, in some way, grounded upon how we conceive the inner self to be and the value we give that self. How we treat patients with dementia may, in many ways, relate to the degree to which we can see the self within what seems to be the diminishing self. If we follow Taylor’s argument, there is a need to pursue that self in order to pursue the infinity of humanity.

It is not argued here that a person can be divided into person 1 and 2. I suggest that a continuity of being exists, but I certainly recognise that patient safety protocols need to change as the disease of dementia progresses. What is required is both a holistic and individualistic approach. The holistic approach is the one that recognises all the complexities of being that exist in the patient. The individualistic approach is the one that adapts patient safety procedures to meet the needs of that particular patient, at that point in time. In terms of patient safety, thus, other people can make decisions for Molly now so long as they are doing so with the purpose of helping her achieve the characteristics of agency. Using arguments relating to patient safety as a means of justifying, for example, the deprivation of liberty in a manner which does not afford appropriate duty of care to Molly or negates the achievement of the characteristics of agency is not in accordance with the PGC and so has no ethical basis. When it comes to making a decision for a person with dementia, competing rights come into play as to whose voice has precedence. Medical professionals who are involved in the treatment of the patient have one voice. Family members have an associated voice. The patient with dementia who, in many cases, may lack the capacity and ability to legally make medical decisions that have an impact upon her care, has yet another voice. However, when contention exists, as often happens when recommendations are made about abandoning independent living in favour of supported living, on the basis of infringements to patient safety, then, whose voices should prevail? Even when these voices are aligned, some complexities also still exist. For example, consider a situation where the patient with dementia does not really know what she wants, and her proxy just wants her dead so that he can inherit her house! The proxy does not want medical intervention, whereas the patient might require and desire it if she had the competence to articulate this desire. But how does an external medical person know the innermost motivations of the concerned family member? All of this points to challenges for those who, for medical, social or familial reasons, are charged with making decisions to support the safety of a patient with dementia. It strikes me that a much more robust and overarching view of patients and their role in their own safety is required. An improved patient safety culture and infrastructure would

78 Op. cic., p 36
include, for that patient, a full patient history, a listing of competencies and incompetencies, a list of risk factors and their progression, and a consideration of the ways in which the patient’s autonomy to carry out tasks can be vindicated and promoted.

GEWIRTH’S CONCEPT OF ‘SELF-FULFILLMENT’

To elucidate this point further, Gewirth speaks of the end goal and the journey to the end goal being a journey towards what he calls ‘self-fulfillment’.

He argues that self-fulfilment:

…consists in carrying to fruition one’s deepest desires or one’s worthiest capacities. It is a bringing of oneself to flourishing completion, an unfolding of what is strongest or best in oneself, so that it represents the successful culmination of one’s aspirations or potentialities. In this way self-fulfillment betokens a life well lived, a life that is deeply satisfying, fruitful, and worthwhile.

Is the self that is encapsulated within the person with dementia a constant? There are a number of arguments here. One is that: the self might change its form, but its essence remains the same and the rights that are ascribed to the self should remain the same irrespective of the iterations of the self. The next is that the self can reflect different characteristics of agency as it is the same self, but you will have rights in line with the characteristics of agency. Griffin is interested in the foundation of human rights and sees that as being linked to personhood. He argues that personhood, itself, has three different values: ‘autonomy, liberty and minimum provision’.

Critics argue about the way these values can be interpreted differently. Suffice, at this juncture, to state that the value that is placed upon personhood is, to a large degree, based upon a person being allowed to act with normative agency and with a purpose that might not lead to a flourishing life, but would, at the very least, lead to a ‘worthwhile life’. The alignment of personhood as it applies to vulnerable adults is complex and the complexities multiply when personhood is perceived as something that is within a cognitively-declining linear continuum.

Buchanan sets out a number of explicit criteria that must be met in order to beget the achievement of personal identity. However, in my view, Buchanan’s ideas of personhood and personal identity too rigidly set out a bar that cannot be reached by many people with dementia. They may not have logical historical memory and, if they do, it is convoluted. They may not have continuity of personal memory. The severing of connection to past memory and to the continuity of that past memory should not deny a person of their own individual essence, of their own persisting self. Pattinson also rejects adhering to these rigid criteria on the basis that they go beyond giving effect to the generic conditions of agency. I propose that the persisting self that is argued for here does not have to comply with Buchanan’s personal identity criteria. It is enough that the persisting self had, at one stage, the generic conditions of agency and, at different stages, has differing rights under the PGC. This article juxtaposes the self with the innate goals and aspirations and beliefs and values held by the person at some stage, considered

80 Gewirth uses the American spelling. See Gewirth, Self-Fulfillment. This article uses the non-American English language spelling of ‘self-fulfilment’, unlike Gewirth.
81 Op. cic., p. 3.
to be part of the agency of the self, rather than with a series of competencies or incompetencies. The important factor is not that the characteristics of agency change and that the rights change, but that the self remains constant. The whole idea of agency works in parallel to the idea of a constant self, to the idea of *persisting Molly*.

Gewirth proposes that the idea of the self involves ‘a continuing or enduring embodied entity that is aware of itself as a distinct person, can anticipate a future for itself, and that has desires on which it can reflect’. 87 Psychological well-being, however, can be impaired over one’s lifetime, e.g. through dementia or depression. 88 Thus, Gewirth points to the vulnerability of agency: ‘in this way, our agency is inherently vulnerable, and mental health is no less vulnerable than any other of the other ‘generic features of action’’. 89

Two modes exist within the pathway to the actualisation of potentiality. In the first instance, *aspirational-fulfilment* asks the question: what will satisfy my deepest desire? Secondly, *capacity-fulfilment* asks a different, but related question: how can I make the best of myself? In the context of people with dementia, this latter concept of capacity-fulfilment is pivotal. They may not be able to achieve their deepest desires because they might, quite simply, have forgotten what the objects or the goals were that were worthy of pursuit. But they can and should be enabled to ‘make the best of themselves’. 90 Patient safety measures should allow for and promote the actions of the patient and the person and the self to carry out actions in accordance with their capacities and capabilities that allow them to achieve their goals. Gewirth explains how Plato, Aristotle and Freud all had different views of the self, but his view of the self as encompassing aspirational-fulfilment and capacity-fulfilment is one that can encompass *persisting Molly* because *persisting Molly* had goals, aspirations and values that were dear to her, but may be dormant or forgotten. Those processes exterior to her, including healthcare, should promote her capacity to make the best of herself at all stages in the progression and regression of her dementia. Patient safety measures, if aligned with this view of the self, would include empowering mechanisms that would mediate the fractured discourse between the patient with dementia and the healthcare provider and promote ‘the highest development of one’s best capacities’. 91 The view of capacity-fulfilment relates to the goals one ought to have, not the ones one has or could have. In other words, Gewirth does not set down a marker for higher or lower-order aspirations or more moral goals. Rather, he suggests that all should be done to allow for the realisation of the best of one’s capacities.

The aspiration of *Molly now* to living a life that is as rich and as meaningful as she aspires to now or as she aspired to then or to as she might aspire to in the future yet to come is a valid and purposeful goal. That is not to say that Molly’s irrational wishes, reflecting cognitive impairment, reflecting debilitating capacities are heeded to the exclusion of other competing realities. Rather, the essence of the life affirming goals that typified the personhood within her needs to be supported in a manner that promotes Molly’s self-fulfilment. That means, in a practical way, that it’s not so much a question of a linear progression of *Molly then* and *Molly into the future* and affording rights at different stages within that continuum, as much as it is affording rights within a concentric circle where the nucleus of the circle is self-fulfilment and the actions, rights, duties form the concentric circle that emanates from this nucleus. It is the duty of apparent agents, who work alongside Molly (healthcare professionals and the family

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91 Op. cic., p. 15.
members) to ensure that the actions that they instigate and on which Molly, as a vulnerable person, is dependent are focused on helping Molly to achieve this self-fulfilment. She will not be able to achieve it on her own, but somewhere within the sliding scale of her diminishing competence, she still has goals, goals that are not confined to a temporal definition of Molly then or now, but that reflect the totality of her being and, indeed, the totality of her agency. Acting to make sure that she is safe will help her achieve self-fulfilment in so far as, at its most basic level, patient safety is about ensuring that there are no errors in her care or harm meted out to her. But patient safety cannot only be seen from within the very narrow confines of harm and error. I have argued elsewhere that patient safety needs also to encompass a broader definition where the new definition includes a greater focus on the role of the patients themselves in the formation of their safety. The new definition I have proposed extends the WHO definition, as earlier cited, to encompass the role of patients as well as healthcare professionals; thus, patient safety is concerned with the ‘prevention of errors and adverse effects to patients associated with health care and decisions taken by healthcare personnel and/or patients’. If we follow the self-fulfilment argument, it can be seen from this vista that patient safety is not only about external people ensuring, for example, that the patient does not fall. It can also encompass the actions that the patient himself can take or not take to prevent falling. Even broader than this, patient safety can be redefined as encompassing, in some way, self-fulfilment. In other ways, actions that are taken or not taken in respect of people with dementia that purport to support their safety should not be actions that deprive them of their self-fulfilment. From a practical point of view, this means that the care-giver really needs to get to know the patient to see beyond the disability, to see the ability that is retained and to empathise with the plurality of personhood and the aspirations and goals within that ever-changing personhood and act, as far as is possible and practicable, to promote self-fulfilment. Acting in this way would surely mitigate against many of the cases of harm, as outlined by George et al earlier in the paper.

This entails a movement from seeing Molly as part of a continuum from then to now to future to perceiving her as a person of many capacities that are not fixed at temporal times, but possessing of a right to pursue of her own self-fulfilment. So, this article has suggested a movement from the continuum of the person with dementia, from a pre-dementia phase to a severe dementia phase and all the phases in between, as encapsulated by the idea of Molly then, Molly now and future Molly towards a view of a non-linear persisting Molly, possessing differing manifestations of the same personhood, but having different characteristics of agency at different times that reflect the same essential self. The patient safety agenda needs to further reflect upon the degree to which medical treatments, procedures and protocols support this persisting Molly to attain her fulfilment. It will be necessary for external apparent agents to support the achievement of this self-fulfilment because persisting Molly will be dependent upon other agents who have the characteristics of agency to give a duty of protection to her and so allow persisting Molly to achieve the purposefulness and voluntariness that will propel her purposefully on the road to self-fulfilment. Patient safety procedures that help this process fall within the ambit of the PGC and are ethically permissible, even if such procedures may be perceived to include deprivation of liberty. However, patient safety procedures and policies that do not give a duty of protection to persisting Molly and that negate her self-fulfilment do not accord to the PGC and are not ethically sound. The path towards this self-fulfilment is an emerging and evolving one, beset with joys and challenges, disappointments, steps forward,

93 George et al., ‘How can we keep patients safe in our acute hospitals?’. 
steps backwards, moments of lucidity, longer moments of senility, but the path remains a valid one.

**PART III: COMPLIANCE OF EXISTING LEGAL INSTRUMENTS WITH THE PGC AND RECOMMENDATIONS FOR CHANGE**

It has been concluded here that the best way to engage with the medical needs of patients with dementia is to use protocols/procedures/practices in a way that embraces the totality of personhood, promotes the search for self-fulfilment and respects the generic rights of patients. Adopting a version of this approach would constitute an indirect application of the PGC. Are the legal instruments that currently exist suitably constructed and do they provide for this indirect application of the PGC?

Considering past/present feelings and wishes, as well as how the patient might have acted if he had capacity, is PGC-compliant. This approach recognises the fact that we are not talking about Molly now or Molly then, but are attempting to fuse both past and present wishes. Section 4(6) MCA says that the decision-maker must do this in a ‘reasonably ascertainable’ manner. This, also, is consistent with the reality that viewpoints can be contradictory, confusing and illogical. The fact that s 4(7) states that the decision-maker must consult, as far as possible, carers, family members and others associated with the patient in order to decide what is in the patient’s best interests is also compliant with the PGC. In the context of self-fulfilment, the MCA incapacity test and its related best interests test, if well used, support persisting Molly. This test considers the past and the present person and, in so doing, it does not negate the personal history, the values, motivations, historical wishes of the patient. The main danger to impeding the self-fulfilment of the patient is that the patient safety argument, when used sometimes inappropriately and to excess by medical professionals and family members, can impede self-fulfilment in so far as what could be factored in are the wishes of the family members, wishes that almost always reflect a genuine desire to ensure that their relation is safe in hospital or home care settings. But these wishes and concerns about patient safety have the potential to be given disproportionate weight. The test needs to be applied in a manner that recognises persisting Molly and does not give a weighting to patient safety that is at variance with the values of Molly and everything she holds or held dear.

Not all situations concerning decision-making are covered by the MCA. Courts may also exercise their inherent jurisdiction in instances where the patient has borderline capacity. These may occur, for example, in early stages of dementia. This inherent jurisdiction allows the courts to safeguard vulnerable adult patients. In essence, this means that the scope of inherent jurisdiction is broader than might have been perceived previously. That is because there may be instances where an incompetent patient could be deemed to have the capacity to make medical decisions. Notwithstanding some of the reservations articulated by Cave, for the most part, this common law approach to borderline capacity complies with the approach advocated in this article. It is noted that the MCA introduced Independent Mental Capacity Advocates, who are mainly used when there are no family members or friends to advocate for the patient. In parallel, s 67 of the Care Act 2014 requires local authorities to organise

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94 There are two ways to apply the PGC: one is the direct application in scenarios where Gewirthians do not disagree. However, in situations where there is a conflict between Gewirthian viewpoints, then it is necessary to indirectly apply the PGC i.e. through particular instruments/tools, including legislation/policy etc. It is necessary that the rule (e.g. the policy or law) acts as a good faith attempt at applying the PGC.

95 See DL v A Local Authority & Others [2012] EWCA Civ 235.

96 Cave, ‘Determining Capacity to Make Medical Treatment decisions’.

97 Implemented under ss. 35-41 MCA.
independent advocacy if the local authority believes that the patient would experience ‘substantial difficulty’ in engaging with assessment and/or the care plan’s preparation. This does not apply when the local authority recognises that a family member/friend/representative is advocating on behalf of the vulnerable patient. This provision, however, does not go far enough, as this support is confined a small number of patients. The addition of a supportive process, such as court-assigned advocates for patients with borderline capacity (e.g. early-mid stage dementia) would allow for even more patient empowerment and provide justification of the PGC principles. All patients with dementia, not just those who have no one to fight their corner, could be supported in their decision-making and become better able to express their wishes coherently. This would lead to an alignment with self-fulfilment and act as an indirect application of the PGC. Of course, there are serious resource implications here, discussion of which is outside the scope of this article, but in the interests of upholding the rights of people with dementia, policy makers should be mindful of the need to provide such resources as will support this necessary empowerment-based approach.

Cave believes that the failure to ‘apply the principles of empowerment and facilitation central to the MCA and the denial of capacity on the basis of status leads to pressure for reform’.98 Such reforms might consider aligning assessment practices for incapacity more closely with the more rights-focused approach found in Article 12(4) of the UNCRPD. A consideration of the PGC and its rights-based approach in the application of the MCA could lead to a greater alignment between the principles of the UNCRPD and the MCA, could foster greater discussion on the need for decision-making to be compliant with the persisting self of the individual and, so, promote greater autonomy by virtue of the empowerment that is brought about by discursive and facilitative approaches. There is potential to use current vehicles to improve the assessment and care of patients with dementia.

The legal instruments that are in place, therefore, provide some protection of the rights of patients with dementia. A number of questions, however, still need resolution: does the inherent jurisdiction provide scope for taking into account past and current wishes in patients with dementia and, subsequently, weight these up against the harm that the patient may suffer if their wishes are followed? There is a question of weighting competing values here. The resolution of appropriate patient safety for people with dementia can come down to the issue of balancing control and inhibition, control of the patient safety related measures that protect a person with dementia, but inhibiting the measures that take away autonomy.99 Gaps certainly exist in praxis. Practice and protocols do not give the same attention to the entirety of the person as is implicit and implied/intended by the legal instruments. Efforts on the part of hospital personnel to ensure the actions to support the patient are in the best interests of the patient are often not reflective of the whole person.100

An ethical dilemma exists where there is an imbalance between the exercise of autonomy and patient safety. At the moment, the fulcrum is too heavily weighted on patient safety and insufficiently weighted on the autonomy side. There is a need to bring patient safety back to

\[98\] Cave, ‘Determining Capacity to Make Medical Treatment decisions’, p 97.
\[99\] Op. cit.,
persisting Molly. The essence of treatment is treating the whole person. Having a holistic attitude to medicine means that you are not just looking at the incompetent person. If we work for self-fulfilment, it will limit the adverse effects, which will be less likely to happen when time is devoted to this whole patient. The provision of this time, however, will require procedural change at policy level. This means that doctors or nurses dealing with patients with dementia should be allocated more time to deal with them and/or specifically trained advocates who are knowledgeable in the ways of the non-paternalistic mediation of the wishes of the patient should be available. An application of this framework will mean that healthcare professionals should be supported in looking beyond that patient at that point in time towards viewing that patient in the holistic sense. In line with the stated desire to optimise care of people with dementia, applying the PGC involves stressing the totality of the patient and so, ultimately, helps support both autonomy and patient safety.

The procedures implemented to promote patient safety, particularly in care home settings, should not be so constrictive and prescriptive as to inhibit the attainment of self-fulfilment – the perusal of pastimes, the dreaming of dreams. I would suggest that the first point of change is the modification of clinical guidance. Guidance to doctors, nurses and personnel in homecare settings as to how to deal with the safety of patients with dementia could include a requirement to make significant efforts to understand the whole patient, to gain insights from family members, to seek trained advocates to support the communicative process. The current clinical modes of assessment for the diagnosis of dementia should include a stronger focus on the whole person, to include an evaluation of past competencies, latent abilities and potential future abilities. In other words, an attempt should be made to encompass persisting Molly within the diagnostic procedure. Such a deep-rooted diagnosis would have a positive impact on safety measures that are adopted.

CONCLUSION

I have set out here the need for a principled approach to underpin the procedures that are in place to ensure the safety of patients with dementia. The challenge for hospitals and care homes and those charged with the protection of the safety of those with dementia is not to abandon a principled approach in the face of practical realities, but to seek to change the reality so it can assume principlism as the bedrock on which all action is based. Legal positivism or medical pragmatism will not, in themselves, cut it for patients with dementia. Such patients are vulnerable, sometimes voiceless, often agitated and they need hospital personnel to be advocates of their rights, particularly when they, themselves, lack the competence to be able to articulate those rights in a coherent way. It is only through this principled process that persisting Molly and her inarticulate search for self-fulfilment can be championed and protected in a secure healthcare setting.

Consideration of a conceptual framework, which is currently lacking in the literature and the procedures governing patient safety, is called for. The conceptual framework advocated here is based on ethical rationalism and is supportive of autonomy but recognises the validity of actions to promote patient safety that may be seen to contradict autonomy, so long as these actions comply with the PGC. The article also calls for a movement way from the linear and chronological portrayal of the patient whose dementia is deteriorating temporally towards a conceptualisation of a persisting patient, with a persisting nucleus and possessed of aspirational fulfilment, but exhibiting different characteristics of agency at different times. Recognition of this plurality of being could result in changes in practice, particularly at assessment level.
Somewhere between the righteous impeding of liberty and the purposeful approval of the search for the generic conditions of agency, the patient safety debate stands precariously. Those charged with ensuring patient safety would be aghast at proposals to limit safety measures imposed upon patients with dementia. Those concerned with patient autonomy and the rights of people with diminishing or diminished competence to self-determine their movements would be, equally, anxious about the patient safety measures that impede the rights of those patients. However, those who advocate for and work with and those who love and, sometimes, live with patients with dementia know that there are no explicit lines of demarcation in the sand between theoretical perspectives. Indeed, the sand shifts forwards and backwards, from moments and days of lucidity to points of terminal regression.

In the end, all concerned with the safety of patients with dementia journey forward and backwards. Ensuring that patients are safe, secure, respected, provided with dignity, encouraged to live in accordance with their long-held values towards purposes and goals that are deeply rooted is a challenging part of that journey, but, surely, a rewarding part.

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