

## **Music therapy and Dementia: Rethinking the Debate over Advance Directives**

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### *Abstract*

Ronald Dworkin argued that Advance Directives informed by a principle of autonomy ought to guide decisions in relation to the treatment of those in care for dementia. The principle of autonomy in play presupposes a form of competence that is tied to the individual person making the Directive. This paper challenges this individualist assumption. It does so by pointing out that the competence of a patient is inherently relational, and the key illustrative case to make this point is the case of music therapy. In music therapy, a relatively recent treatment modality in aged care, patients previously thought to be permanently unresponsive are shown on the contrary to be capable of significant levels of social agency. The conclusion to draw is that Advance Directives that fail to acknowledge the real possibility of such relational competence are misapplied.

**Keywords:** Music therapy, dementia, autonomy, advance directives

### *Introduction*

Music therapy is a treatment modality used in cases of cognitive loss, including dementia. It involves patients (or residential care clients) listening to, or actively participating in music, for example singing songs. Such therapy is on the rise and that is because it appears to be effective at alleviating problems in cognition and behaviour, as well as improving the well-being of patients, and it can do this in a relatively cost effective way by offsetting the need for sedatives, anti-anxiety medications and the like (DeLoach, 2005). These benefits have been known for some time (Tyson, 1981).<sup>1</sup> In addition to these positive outcomes, or perhaps as a

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<sup>1</sup> According to the American Music Therapy Association the earliest known reference to music therapy was in 1789 with an article in *Columbian Magazine* titled 'Music

partial explanation of them, music therapy appears to re-invigorate a dementia sufferer's sense of agency. By this I mean that exposure to music appears to arouse in patients awareness of their past, and it thereby reinvigorates their sense of themselves in the present. By thus providing a kind of scaffold for their narrative identity, such therapy also restores some of these patients to a level of social agency they otherwise might not have achieved.

In this paper I want to connect these two empirical observations in relation to music therapy and dementia – its role in personal identity and social agency – with a normative point about autonomy and competence. Ronald Dworkin (1986, 1993) famously argued that dementia-specific Advance Directives have moral authority. (Advance Directives are quasi-legal documents one signs directing people in the future to commit to certain instructions particularly regarding medical treatment.) Briefly, Dworkin thought that since Advance Directives are morally authoritative in virtue of the principle of autonomy, they are most authoritative when the competence presupposed by that autonomy is at its strongest, namely, the point pre-dementia when someone issues such an instruction. Dworkin's view on this question has been disputed (Dresser 1986, 1995; Jaworska 1999). I will also dispute it, however, I will do so not by occupying one of the positions in the literature opposed to Dworkin but rather by calling into question an assumption that is driving the debate on all sides: the assumption that the competency for decision-making in these cases ought in every case to be based on the psychological characteristics of the patient. If one assumes this individualist view when making an Advance Directive, then one will project it onto the state of one's future self with dementia, but the nature of this self, as the music therapy examples show, depends on competencies that are a function of the relationship between patient and carer. So this assumption is mistaken.

To unpack this a little more, and to gesture at my preferred view of the relation between decision-making and the distributed nature of competency that underlies it, consider that when dementia begins to take hold, one compensates for losses in mental agility first by

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Physically Considered.' In 1804 Edwin Atlee published on the therapeutic value of music, and then in 1806 this was followed up with a dissertation by Samuel Matthews. See <http://www.musictherapy.org/about/history/> (accessed 20/2/14).

externalising the tasks that used to be supported by one's brain. Diaries, even friends and carers, come to substitute for lapses in working memory and cognitive function. These external props come to play the role that was once played by the person unassisted. Thus, at least for a period, one remains autonomous by adjusting one's competency by adopting new and imaginative skill sets. This is a concept that ties together the capacity for self-determination and the ability to perform some task. In the context of dementia these tasks are gradually being taken over by others, but as we will see there is a therapy that works to both enhance and extend one's capacity for self-determination. The point is this: there is a close relation between the concepts of competence and autonomy, so much so that I would hazard a guess that most writers blithely assume an individual competence when they deploy notions of autonomy in debates within medical ethics and beyond. It is this assumption that is shaky, particularly in contexts where the value of autonomy continues to be upheld, but only because its foundations are propped up by others.

Using the case of music therapy to illustrate – we could use other cases of therapy, but this one is central – I want to argue that in fact the competence of a patient cannot be disentangled from their institutional environment. If this is correct, judgements about autonomous competency cannot be made endogenously, but must factor in treatment regimes which provide support for patients. Effectively, the challenge to those in this debate is that individualist assumptions about how to understand the competency status of patients are false because facts about the therapeutic environment cannot be separated from facts about that status.

The paper will proceed as follows. I first provide an overview of dementia. What is it? What is the extent of the public health problem? How is it experienced? Then consideration is given to the role music therapy plays in treating those in care, and in this section I will describe in detail the case of Henry, a patient whose music therapy is transformative. It is transformative in terms of restoring Henry to a level of functionality in which he is able to converse with those around him, where before he was virtually mute. In the sections following this we explore some putative explanatory hypotheses concerning the effect of music on the brain and the memory systems associated with restored identity and agency, before proceeding to the argument over autonomy and competence. In the last section, then, the focus will be on showing

that the autonomy and agency of a patient is not a question of individual ability; rather, we will use the case of music therapy as illustrative of a type of treatment in which the relational features of one's institution are required to scaffold agency. If this is true it calls into question quite directly the presupposition of individuality driving the debate over Advance Directives.

### *Dementia*

'Dementia' is an umbrella term associated with a range of diseases. Alzheimer's disease accounts for something like 50 percent of the cases of dementia. Vascular disease (mainly strokes) accounts for about 20 to 30 percent. In the typical case involving Alzheimer's, there is gradual onset, with sufferers sometimes noticing symptoms a year or two before a positive diagnosis; it is progressive, degenerative, and irreversible, involving three stages: a mild early stage, a moderate middle stage and a severe late stage. Advancing age is the main risk of Alzheimer's.<sup>2</sup>

There is no single experiential feature characterising this condition – no single thing it is like. Some sufferers are not disturbed by the changes taking place, however, about thirty per cent of people with dementia become depressed (some reports range up to fifty percent). About a fifth of people develop clinical symptoms of anxiety. These symptoms are not surprising when you think about the effects dementia has on memory, including especially the disorienting effects. Sufferers liken the feeling of disorientation to the feeling of being profoundly lost – think of the familiar experience of not knowing where your car is in a large multi-levelled car park – where this feeling is persistent. Those who experience dementia also lose the capacity to recognise objects (to read the face of a clock, for example), to manage money, or to speak. Everyday activities such as cooking become practically impossible and accidents can occur, e.g., if the gas is left on unattended.

The scope of the problem in Australia is not trivial, to say the least. In 2011, 298,000 Australians had a diagnosis of dementia. One hundred and seventy three new cases were diagnosed every day during that year. In 2020 the projection is for 400,000. By 2050 the projection is for

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<sup>2</sup> See Australian Institute of Health and Welfare report 2012, esp. pp 1-57.

900,000. Dementia was the third leading cause of death in 2010, and fourth on the burden of disease in 2011. \$4.9 billion was spent on dementia-related care in 2010, a relatively large slice of the annual health budget of around \$60 billion.<sup>3</sup>

### *Music therapy and the narrative self*

Music therapy, according to the Australian Music Therapy Association is 'the planned and creative use of music to attain and maintain health and wellbeing'.<sup>4</sup> It doesn't apply just to dementia patients; it can be used also for symptom onset delay in the treatment of diseases such as Parkinson's disease. In addition it is used for people who are recovering with a traumatic brain injury (Evans, 2002). But the focus here is on the more narrow application in dementia care.

Effective music therapy for dementia is specifically designed for individual needs, involving the creative utilisation of specific musical styles – often songs once known by the dementia sufferer – to attain and then maintain health and wellbeing. This is indeed primarily a therapeutic function; the music is not introduced for entertainment or education. Its purpose is sometimes to strengthen certain skills, social skills for example, and there is great interest in the way exposure to music can allow transfer of those strengthened skills into other areas, for example, reduction in agitation, in wandering or in depressed mood. The therapy can be receptive or active. In receptive music therapy one listens to music played or sung or listens to selections of recorded music. In active music therapy songs are sung or instruments played, and this may take place individually at home with a carer, one-on-one, or in a group situation, say in aged care residential settings.

To make this more concrete, consider the case of Henry, a ninety year old man with mid to late stage Alzheimer's, who is featured in the film *Alive Inside*.<sup>5</sup> Henry is first seen slumped in his chair and unable to respond to those around him, unable even to recognise his daughter.

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<sup>3</sup> See Australian Institute of Health and Welfare report 2012, p.138.

<sup>4</sup> <http://www.austmta.org.au/>. Viewed 18/2/14.

<sup>5</sup> Online footage of Henry is available:

<http://www.youtube.com/watch?v=fyZQf0p73QM>. Viewed 29/1/14.

Once exposed to his music, Henry is instantly transformed: he begins to move with the beat and to hum in animated response to what he is hearing. Remarkably, this newfound energy and responsiveness then translates into *social* responsiveness for a period beyond the exposure to music. His carers ask him about his music and among other things he proceeds (excitedly) to explain that Cab Calloway was his personal favourite, thereby showing an awareness of himself now in relation to this real past, a past involving Cab Calloway.

Henry's case is impressive; but is it properly representative? At the very least it does not appear to be an uncommon phenomenon, as Oliver Sacks comments:

Where I work at the hospital, and all of these old age homes...a lot of people there have Alzheimer's or dementias of one sort and another. Some of them are confused, some are agitated, some are lethargic. Some have almost lost language. But all of them, without exception, respond to music, especially to old songs, and songs they've once known, and these seem to touch springs of memory and emotion which may be completely inaccessible to them. And it is most amazing to see people who are out of it and dour...suddenly respond to a music therapist and to a familiar song. First they will smile and then perhaps start to keep time and they will join in and sort of regain that part, or that time of their lives and that identity they had when they first heard the song. So it's almost an amazing thing to see and of course to experience and that sort of lucidity and pleasure can last for hours afterwards...<sup>6</sup>

What we see, then, from such cases is that not only can such therapy improve the lives of those who engage in it, but that something unique appears to take place. Central to the dementia sufferer's problems is a loss of self, and this loss can be explained in terms of their inability to articulate to themselves a narrative understanding of who they are. That is, they are unable to situate their current self in a temporal framework structured by memory. An early dysfunctional aspect of dementia is

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<sup>6</sup> Interview transcription from <http://www.youtube.com/watch?v=MdYp1KQ4JBc>. Viewed 31/1/14. Sacks has pointed out elsewhere that exposure to music is restorative in other case types of cognitive degeneration, including especially Parkinson's Disease.

often the loss of autobiographical memory, so in a sense a person's loss of self is a loss of their story. They lose access to their past selves, and so, to put it in Lockean terms, they lose the ability to appropriate their past as a co-conscious element of their present.<sup>7</sup> This is an ability the unaffected person takes for granted, an ability to self-situate with respect to the wider narrative of one's life. We take for granted the ability to orient our present selves in relation to the past and the future, and thereby to function practically. Music therapy might be a way of getting it back even if briefly because it is a way of linking up two parts of consciousness.

### *Music, memory and the brain*

It is worth a short detour into two questions: What are the important therapeutic properties of music in this context? What is the role of memory and the brain in music therapy? The motivation for asking these questions is to see what makes true the link between therapy and recovered identity and agency. The link, roughly, is that music therapy recruits brain regions associated with memory, and memory and personal identity are conceptually linked (following Locke).

### **What are the important therapeutic properties of music in this context?**

Sacks points out that the most effective kinds of music (in its being able to cognitively arouse) has a lively rhythm. It is hard to find a better definition for rhythm than Plato's who, in the *Laws*, described it as the 'order in movement'<sup>8</sup>. We might elaborate on this by noting that rhythm in music is the sequence of short and long notes grouped together. Some famous rhythmic motifs would be the opening notes to Beethoven's Ninth Symphony – da-da-da-daaaaah – or the drum beat to Ravel's Bolero.) Nietzsche once said that we listen to music with our muscles.<sup>9</sup> He was referring to the rhythmic quality of music which infuses the listener's body. As Krueger (2009: 99) puts it,

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<sup>7</sup> As Locke put it: '...it is by the same self with this present one that now reflects on it, that that action was done'. (*Essay*, Book II, Chap 27, section 9).

<sup>8</sup> Saint Augustine described rhythm as 'the science of beautiful movements'. I prefer Plato's more intellectualist gloss.

<sup>9</sup> Quoted in Krueger (2009) and Sacks (2006).

...music listening episodes are instances of doings. They are instances of active perceiving, sensorimotor engagements with and manipulations of information-bearing structures in pieces of music.

Music moves us: we tap our feet to it, nod our heads, sway to the beat, dance, and so on. This response appears to be quite primitive, in so far as it is mediated through a brain region – the cerebellum – that is evolutionarily quite old. In those with dementia, this region is spared until later and so they are able to respond to music at its rhythmic level, even well after they have forgotten the words of a song, or the name of a tune. They still retain a kind of bodily recognition of it.

An important relational property of music is its social function. We attend music events *together*. Music plays a *cultural* role. In sub-saharan Africa, for instance, performances of traditional music involve audience participation. Songs are performed with cultural purpose as accompanying certain social rites such as marriage, hunting, childbirth, and so on. The communal function of music cannot be disentangled from the music itself.<sup>10</sup> Similarly western musical performance is culturally infused, when we consider its role in the context of marriage, or funeral, or certain ritualised events of national celebration say. More mundanely, dance music for instance requires its participants to move in synchronised fashion.

Third, music has a mesmerising quality. Not all music has this quality, but the idea is that in paying attention to the music it takes us out of ourselves, it takes us away from paying attention to our present surrounds. We even have a recent modern form called trance music where the rhythms are repeated and developed – usually over sixteen-bar sequences – the purpose being to introduce a repetitive hypnotic quality. (It is worth noting that there is a universal feature to this experience, that is, there are neuro-biological underpinnings for these processes that are in common with the processes occurring in other trance-like experiences, e.g., in religion (Becker 2004: 29).

### **What is the role of memory and the brain in music therapy?**

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<sup>10</sup> Waterman (1990: *passim*).



Whether music therapy can regenerate areas of the brain is not yet clear.<sup>11</sup> What appears to be the case is that it recruits areas of the brain still untouched by the pathology underlying dementia, and that such recruitment has a cascading effect on other systems, as Sacks describes above. There may be many factors in play here, so given space limitations, the focus will be on one area: preservation and stimulus of the cerebellum as related to the preservation of procedural memory.<sup>12</sup> This is an important focus in the present context because the cerebellum is preserved in early to mid-stage Alzheimer's.

Although the cerebellum has no direct role in consciousness, and the conscious processing of explicit memories, it is implicated in the processing of implicit memories (a concept explained below). When skilled actions are repeated, their related capacities strengthen, encoded as procedural memories, a subset of implicit memories. The distinction between implicit and explicit memories can be made with an example. Many people with the capacity for touch typing nevertheless cannot explicitly nominate the letters of the keyboard, say the top row. Yet, asked to type a sentence like 'quit your pew' they do it with ease. Since the letters from that phrase all derive from the top row of the keyboard, touch typers know *implicitly* what those letters are. They implicitly remember the procedure for that action, and in this case thereby implicitly remember some information as well. Again, we see the relevance of this distinction to failing neuro-cognition in dementia. Concetta Tomaino (2012: 313) has drawn attention to a demonstration neurologists may provide for relatives of dementia patients who have lost the capacity to speak (Broca's aphasia). The doctor will encourage the patient to sing a song in the presence of the relative, which he or she may do with ease. This ability is preserved because the brain areas it

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<sup>11</sup> That it can is controversial; but for a positive account see Fukui and Toyoshima (2008).

<sup>12</sup> The hippocampus is another important area associated with memory. Readers may be aware of a four-year study by Eleanor Maguire et al (2000) on London taxi drivers. Taxi drivers there take three or four years to become expert at navigating the spaghetti roads of central London. It is a highly cognitively taxing exercise to become proficient at such navigation. The Maguire study compared the brain MRIs of the participants at the beginning and at the end of their tuition, in order to ascertain whether a correlation existed between their acquired knowledge and their brain states. Lo and behold it was discovered that those who passed their exams exhibited ballooning hippocampi.

recruits are different to those degraded areas for speech. Remembering the words of the song (*as sung*) is thus a bit like remembering the letters of the keyboard (*as typed*). This is an example of what I meant above by there being cascading effects on other systems.

It is noteworthy in this connection that in the case of musicians we see brain evidence, for example in conductors, correlating their musical capacities with larger-than-usual cerebella (an important site for musical processing). Musicians are seen as models of the phenomenon of neuro-plasticity (see Munte et al 2002). Thus, degrees of musical training and/or exposure are correlated with neural capacity, and such capacity may remain in place (and perhaps hidden) post the onset of dementia. A patient thus remains disposed to responsiveness to musical experience after the onset of a neuro-pathology, and that fact is important for the planning of therapy.

The relevance of the cerebellum to music processing can also be seen when we contrast two syndromes. William's syndrome is relatively rare, about four times as rare as Down's syndrome. People with William's syndrome have a mild intellectual and physical disability but are highly social, gregarious, and very musical. They love nothing better than to get together in groups and play music together. Their cerebella are larger than the average. Contrast this group to those on the autistic spectrum. They are typically asocial, they have smaller cerebella, and they are typically amusical.<sup>13</sup> So what we have here is a double dissociation.<sup>14</sup> On the one hand we have a group with large cerebella, very social, very musical; on the other hand we have a group with smaller cerebella who are amusical, and asocial. This is evidence for its being likely that the cerebellum is playing a role in processing music, and since it is spared in early to mid-stage Alzheimer's this partly explains the continuation of the disposition for musical enjoyment, even after loss of explicit memories, language and other cognitive losses involved with planning, self-awareness, and self-regulation.

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<sup>13</sup> I qualify this by noting that some Asperger's patients are highly proficient at music. They find wonder in the mathematical precision of music. However, unlike Williams Syndrome individuals, they don't respond emotionally to the music. The famous autistic animal scientist Temple Grandin, for example, says she can see what's mathematically beautiful about music but she doesn't get it, and cannot process it in a way that seems to make sense for others without her condition.

<sup>14</sup> See Daniel Levitin (2006: 259).

Another way of putting the point in relation to music and procedural memory is in terms of its neuro-protective effect. What does this mean? At the first level of approximation the goal in dementia treatment is to delay the onset of, or slow down the progression of, neuro-degeneration. The means to achieve this goal are myriad. So, for example, in cases of neuro-degenerative illness a standard method of neuro-protection is the use of glutamate antagonists to inhibit the binding of that neurotransmitter to NMDA receptors. (When such binding occurs, excitotoxicity results, namely the build up of calcium in neurons, leading to their death.) The therapeutic mechanism in the case of music is not yet clear, however exposure to music and attenuation of neuro-degeneration seems to be dose-specific: the more one is exposed to it (particularly as an active participant) the more there is a tendency of mitigation of pathological impact, as measured by the clinical expression of dementia.<sup>15</sup>

We have been talking so far at the general level of cognitive neuroscience. Let me finish this section by connecting this more directly with the case of Henry, to see how the points about procedural memory connect to behaviour, therapy and the ethically relevant concepts of identity and agency.

Through exposure to music Henry was brought back to something like his former self. When we first see him he presents with near-catatonic immobility, and then he is given his listening device, and he is utterly transformed. He is immediately aroused, as we see his eyes light up, his feet tapping and his demeanour enlivened. Oliver Sacks, discussing the case, remarks that,

The effect of this doesn't stop when the headphones are taken off. In some sense, Henry is restored to himself. He has remembered who he is and he has reacquired his identity for a while through the power of music.

Henry is able to talk about the past, and he does so in two different ways. It evokes for him a remembrance of events and experiences past, of past songs that he had listened to and sung as a younger man. It's almost as though the music plays the role in him of a kind of *internal*

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<sup>15</sup> See Keith Wollen (2010) for a full discussion.

*memorial*. (External) memorials, such as tombstones, war memorials, statues and so on function to direct us to past events and experiences. They (metaphorically) point back to these pivotal points in personal or cultural time for the specific purpose of evoking a certain kind of experience now. They engage us now to reflect on a past event as something of significance in our own past. They function to unite us to the past, and we do this by identifying with it as our own. Memorials are thus identity-making in their function.

For Henry, then, the music is evocative and memorative: it functions as an internal memorial, pointing back to his past. His musical memories point back to pivotal points in his personal past thereby evoking a certain kind of experience now. It is striking to see Henry engaged now by music he recognises as his own. His musical memories function to unite him now with his past, and he does this by identifying with it as his own. His internal memorial is thus identity-making in *its* function as well.

In addition to the effects on Henry's identity, is the effect on his social agency. Whereas prior to the music he sits still, head down, uncommunicative, after the music he is responsive to questions and even effusive when he speaks about it. This newfound social agency – this openness to engage with those around him – depends on his relation to his carers and to the music given to him by them. And now we come to the normative point of interest. Such social agency constitutes an autonomy competence, unavailable to him absent the therapeutic relationship to his carers. This relationship thus enables a kind of *scaffolded agency*, and so assumptions about treatment and care that fail to acknowledge this possibility (in the context of thinking about autonomy in advance directives) will be incomplete, and so false.

#### *The debate over autonomy, competence and advance directives*

Let's take stock of where we have come. In cases of dementia where music therapy is applied, one effect is to connect a person to his past. When exposed to one's favourite music, particularly music embedded in one's latent sense of a narrative past, a patient can be brought back from being depressed and unresponsive to being aware of the social situation and engaged with it. The music heard in the present catalyses the connection between the routines and experiences once had in the past and the music remembered. The music thereby collects together

experiences from both the present and the past, and so this therapy has a role in bringing about a sense of *personal identity*. The second observation we made is that music therapy, in virtue of this identity-making feature has a *socially restorative* function. It can restore an individual to the status of *social agent*. A feature of the cases of interest is that exposure to music transforms the patient from being in an initially unresponsive condition to being aroused and in a state of engagement with the music and with other social participants. The normative point, then, emerges this way: music therapy acts as a kind of scaffold for re-integration of some elements of personal identity – the patient connects with the past – which in turn has the positive effect of re-admitting the dementia sufferer into the social world.

We are now in a position to see why this poses a challenge to those who make an individualist assumption in the debate over advance directives. It poses a challenge because the sense of personal (narrative) identity and agency in play in that debate are not conceived with a correct understanding of the way competence in those areas is enabled. So, let us consider again the central issue in dispute by reprising the position Ronald Dworkin defended.

In *Life's Dominion* (1993), Dworkin advocated a position in which the value of a life depends on the person who generates it. If I construct myself, the value of my life comes from me, and I thereby derive the authority requisite for making decisions about it. The argument for this idea begins with a distinction between our experiential interests – had in the present moment such as watching a film, eating a nice meal, sharing a pleasant conversation – and our critical interests. The latter are chosen through viewing our lives as a whole; they do not require an experiential outcome. In deciding what is best, set against the larger context of a life, we are exercising our capacities of critical reflection. From this whole-of-life perspective we of course do not discount completely the importance of having good experiences and avoiding bad ones, for we do set some store by the value of life's enjoyments. However, an enjoyable life should not take precedence in working out the fundamental aims one derives from the values attaching to the whole-of-life perspective.

It is from this whole-of-life view atop the mountain (so to say) – looking back at where we have come, and where we are headed – that we are best able to decide which of our reasons should take their place in a properly governed practical life. This perspective has authority because

it has a commanding position with respect to the collection of *all* our interests, be they experiential or critical. So, thinks Dworkin, it is this perspective – where we are most competent – which ought to take precedence in decisions in relation to an Advance Directive. I am most competent, he thinks, when I have a full view of my life – I can see how its narrative connections hang together – and such competence therefore is critical to the most authoritative expression of my autonomy.

Dworkin's argument, as Dresser (1995) notes, is elegant, and initially persuasive. Nevertheless, it is driven by an unquestioned assumption, namely that the resources from which I construct myself, and inform my decisions, come from me alone. This is dubious in the case of dementia, where as we have seen, a patient's capacities must work in tandem with the therapist to allow them to function as a minimal social agent. So the point to focus on is Dworkin's emphasis on *individual* autonomy. And indeed, he makes this individualism explicit: '...value cannot be poured into a life from the outside', he says, 'it must be generated by the person whose life it is' (1993, 230). And it is noteworthy that Dworkin's opponents do not appear to object to this individualist position; but it is here that *we* may object.<sup>16</sup>

That we should question this individualism, it should be noted, is not a new approach. Indeed, the idea of *relational autonomy* has been around for some time. For instance, McKenzie and Stoljar (2000: 21) wrote that an analysis of the self,

...must attend to the rich and complex social and historical context in which agents are embedded and to memory, imagination, emotional dispositions and attitudes. Analysing the way in which socialisation and social relationships impede or enhance an agent's capacities for autonomy has drawn attention to the connections among an agent's self-conception, her social context and her capacities for autonomy.

So in order to understand the proper sources of agency (and so autonomous agency), we will fail to provide a complete picture of the human agent if the focus is delimited too narrowly. Human agents are

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<sup>16</sup> Dresser (1995), Jaworska (1999).

not independent islands of thought and action, but are embedded in social life. So in the present context we must extend this relational notion to the carers and the setting, and to their role in scaffolding agency. Of course the claim is not that Henry is somehow restored to *full* agency. Agency is a matter of degree, and although Henry excels under the conditions of his therapy, he does remain dependent. Yet, the evidence is clear that music therapy is, at its best, spectacular in its effectiveness to bring about transformative change where none was thought possible. We might put it this way: having such knowledge, at least for some people, might well profoundly affect what declarations they are to make in an Advance Directive. If one knew of such a possibility one might well be less disposed, for example, to direct future carers to refrain from life-saving treatment in case of illness, contrary to what Dworkin offers as permissible practice.

If we are successful in questioning this individualist approach to the debate over advance directives, then decisions about future treatment under the conditions of a dementia illness must include the wider resources we have identified.<sup>17</sup> I must consider that the characteristics my future (possibly demented) self will have are tightly bound to the institutional relations in place then. This may well alter the way I frame my decision-making about this future. However, we can take this a step further. If the nature of the agency of dementia patients is relational in the ways discussed here, an important moral question arises: is there a moral demand in treatment to enable such social agency to flourish? The claim might be that dementia treatment calls for therapies that make the most of the residual capacities of the patient in order to fully realise their right to competence. There is an analogue here. Famously Thomas Jefferson advocated for those whose capacities in political education were not up to scratch. 'I know no safe depository', he said, 'of the ultimate powers of the society but the people themselves and if we think them not enlightened enough to exercise their control with a wholesome discretion the remedy is not to take it from them but to inform their discretion.'<sup>18</sup> Similarly, the claim might be that we have an

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<sup>17</sup> An anonymous referee added that there are implications also for overtly individualistic 'rational life plan' conceptions of autonomy. These have conceptual links to the *homo economicus* conception of prudential rationality.

<sup>18</sup> Spoken to William Jarvis in 1820.

obligation to restore the agency of the dementia patient. In the human rights education field this is called transformative learning (Mezirow 1997). Taking this as our cue we might refer to this as the right of transformative awareness. Thus given this view of the contingency of agency, and its transformative relational features, it becomes clear that the presuppositions driving the debate between Dworkin and his opponents are falsely conceived. My future agency is not just up to me. Indeed, if the right to transformative awareness is recognised, then others have an obligation to see to it that my agency is supported.

### *Conclusion*

Considerations informing future treatment decisions embodied in Advance Directives have focused on levels of competence that affect autonomy. Many people worry, and are right to worry (given the public health statistics seen above), that they will be subject to a dementia. When this worry motivates them to put in place an Advance Directive it is done so based on their assumption that lost competence is a purely endogenous property. They understandably feel that decisions while fully competent now have authority because this is an expression of their fully autonomous selves. This is what motivates Dworkin's position. In this paper, that has been called into question. For what we see, as illustrated in spectacular fashion in the case of Henry, is a patient whose cognitive losses appear severe and permanent; but in fact they are not, as is revealed under therapeutic conditions. The central lesson of the case is that we may be too hasty in our forecasts about the condition of our future selves if we limit them to losses we believe cannot be therapeutically compensated.

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