Chapter 8

ASSESSMENT OF COMPETENCY AND ADVANCE DIRECTIVES

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1 Introduction

A discussion dealing with competency assessment and advance directives might best begin by addressing the concept of competence. The assessment of competence would then lead us to consider the definition and the criteria that have to be met in order to say someone is competent. In this case we are considering the idea of competence to complete an advance directive; so having stipulated the criteria, we should then consider what would constitute an appropriate test of this competence in accordance with these criteria. However, we should start, not just by thinking about advance directives, but also by thinking about their ultimate objectives: what is the end or aim of an advance directive? Afterwards, we shall hopefully have gained a perspective that enables us to say more about competence with respect to advance directives. I shall argue that we need the broadest possible view, which will amount to a perspective of the person. In which case, the assessment of competence will seem less like a test of the legal notion of decision-making capacity and more like an evaluative interpretation involving the person’s normative narrative.

This decision process, however, immediately raises complications. For, if the aim is to control the future, it is to be controlled by the present. Another way of putting the aim, therefore, is to say that the advance directive is all about how my present wishes should be enacted in the future. However, this line of reasoning would imply that the aim has at least as much to do with the present as it does with the future.

This might not pose any sort of difficulty: my clear present wishes might turn out to be fully applicable to the circumstances that arise in the future and so my advance directive is enacted. However, even trying to put things in as practical and straightforward a manner as this does not satisfy what we were hoping to achieve. I need to add that my clear present wish is fully applicable to the future circumstances and that the present wish remains my clear wish in the future. There is nothing wrong with this, of course, as it may well represent the truth. It does, however, impose an obligation on clinicians, to make sure that the previous wish would still be the present wish. For this reason the Mental Capacity Act 2005, which governs the law in England and Wales from 2007, states that an advance decision is invalid if the person has done anything that is inconsistent with the previous refusal of treatment. For similar reasons the Act states that the specific circumstances of the advance refusal must obtain and that, if there have been any changes in circumstance not anticipated when the advance refusal was made that would have affected the person’s decision, then the advance refusal is not applicable. A complicating issue, therefore, is the finding that people’s preferences for life-sustaining treatment increase as cognitive function worsens (Fazel et al., 2000). All of this, therefore, has

2 The end of an advance decision

The aim or point of an advance decision might seem quite straightforward. If I am concerned now that I should not be kept alive if, in the future, I were to have a massive stroke, I can stipulate this in an advance directive, or (more formally) an advance refusal of treatment. The aim, therefore, concerns the future.
to be considered very carefully: in practice the particular details of individual cases will be vital.

There is still, however, a conceptual problem. In a preliminary manner, I previously concluded that the aim of advance decisions has at least as much to do with present wishes as with future actions. But I went on to stress how essential it was that the present wish should remain the clear future wish. Therefore, the main point seems to be the connection between the present and the future wish. However, the essential point is the future wish – and the present wish only inasmuch as it sheds light on the future wish. This function of shedding light is nonetheless crucial given that, when the decision has to be made, what is deemed to be best might be surrounded by darkness. The advance directive then comes into its own as a guide.

To return to the idea of the connection between the present and the future wish, the conceptual point (but one with considerable practical relevance) concerns how this connection is maintained. The situation will be this: the doctors and nurses stand around my bedside after my major stroke debating how far to go in their attempts to keep me alive. They cannot know my present wishes. (For the sake of the argument this has to be presumed, but it’s a weighty presumption.) They know my past wishes, but to what extent do my past wishes affect what my present wishes would be if I were able to communicate them? What is the connection between the past wishes and what would be my present wishes?

The rather jejune point to make is that the connection can hardly be regarded as the piece of paper on which the advance directive is written, even if in extreme cases it might be all that the clinicians have to go on. But this alone is also not the whole story. Perhaps the advance directive has been renewed every year for the last twenty years and the views it expresses have been discussed fairly frequently with my family and close friends. In short, the connection between the past wishes and the present wishes is more substantially maintained by the fullest possible account of the person’s story or narrative. Accordingly, the end of an advance decision becomes the end of a story. And the authenticity of the ending will depend in large measure on the accuracy and detail of the story.

3 The underpinning person

My contention is that we must understand the person’s story as fully as possible in order to understand whether the ending is, in some sense of the word, authentic. (But the exact sense of “authentic” with respect to advance directives is difficult to pin down: it certainly does not equate to “reasonable” or “rational”, see Vollmann, 2001.) A purely ethical question is: is the decision to withhold treatment right (is it the moral thing to do)? It is interesting to note how understanding the person’s story interrelates with this question. If we can understand the person’s story right, so that the ending is as authentic (as in keeping with the person’s life) as possible, we are likely to make the morally correct decision. Once again there is a caveat to be added, to which I shall return.

For now, however, there are two points. First, there is a connection to be made between the narrative and the decision at the end of the person’s life. There is a sense in which the narrative carries normative weight. In other words, it is not simply that there is a story that has an ending; rather, only some endings will be right, true, or authentic. The story leads us in some direction or other and the ending cannot be simply gratuitous, not if it is to be the right ending (although there is no reason to presuppose a single possible right ending). There is some element of normative constraint embedded in the narrative concerning how things might go.

This leads to the second point, which is that correctly understanding the person’s story, so that we make the right moral decisions, entails that we understand the person. Even if not determinative of the decision at the end of the person’s life, almost any detail might be relevant so that clinicians making these sorts of decision need to be as open as possible to every facet of the person’s makeup. This is part of what it means to act in the person’s best interests.