

# Chapter 1: Beginning at the End

*“We are discussing no small matter but how we ought to live.”*

– Socrates via Plato in ‘The Republic’

Mrs. P is a 74-year-old resident in a long term care home. She suffers from moderate to severe Alzheimer’s disease, with the result that she is often disoriented. She does not recognize her family, who visit her often. She has formed a very strong, mutual attachment to another resident of the home. Mr. Q is 76 years old. He also has Alzheimer’s, but his disease is less advanced. Mrs. P and Mr. Q are always together. They seek each other out, sit together, hold hands and show many visible signs of affection. Most mornings, when Mrs. P gets up from her bed, she will walk down the corridor and slip into Mr. Q’s bed. They have often been found together in various states of undress and have been discovered engaging in sexual activity. Any attempts to separate them cause severe distress, especially for Mrs. P. If she is prevented from seeing Mr. Q she cries and pulls at her clothes and hair. In his presence she is calm, comfortable and looks happy and content.

## What is the problem?

Mrs. P’s husband, Mr. P, lives alone in the community. He visits his wife often and is mortified to see her with Mr. Q. He knows that her behaviour is connected to her disease, but, as he says, “Nothing can remove the gut-wrenching feeling of seeing your wife with another man after 40 years of happy marriage.”

Mr. P asks the long term care home staff to intervene.

“Stop her!” he says. “This is not her. For 50 years she has railed against the immorality of adultery. She attended church all of her life. This is not my wife. She would never do this.”

The staff try to comply. After all, if the matter under discussion had been a treatment and Mr. P had been Mrs. P’s substitute decision-maker (or power of attorney for personal care) there would be no hesitation in complying with Mr. P’s wishes. A substitute decision-maker is supposed to make decisions in accordance with the previously expressed wishes or the previously lived and expressed values of the person concerned.

However, Mrs. P is distraught at the separation from Mr. Q. The only practical method of separating the two would be to sedate Mrs. P until she is quiet and long enough for her to forget Mr. Q. But that

doesn’t seem right to anybody.

When Mr. P sees Mrs. P’s distress at being separated from Mr. Q he gradually reduces his visits and ends up not visiting at all.

“My wife is dead,” says Mr. P.

## Managing ‘inappropriate’ relationships

This situation (and its variants) is not uncommon and, with increasing numbers of people living longer and living in long term care homes, its incidence is likely to increase rather than decrease.

The situation raises a number of practical problems. How should a long term care home manage relationships between residents, especially if those relationships are ‘inappropriately’ expressed or if the relationships cause distress or discomfort to others—family members, other residents or staff? How should relationships be presented and explained to families, residents and staff?

Behind these ‘how’ questions lurk the more important ‘should’ questions. What should staff and managers of long term care homes be doing—or trying to do—in these types of situations? What ethical principles should govern their discussions?

Before we can even get to the starting point in an ethical discussion, however, we will have to do some metaphysics. First of all, who is Mrs. P and what could Mr. P mean when he says that his wife is “dead”?

## Puzzles of personhood

When Mr. P says that his wife is dead he means that the person he knew—the person he had shared his life with—is no longer

here. Her body is all too obviously physically present, but he believes her person is not.

What is a person and when does a person die? This is one of the great questions of metaphysics. Whether we have a theory of the person fully worked out or not, as the long term care home makes its decisions about what it will do next—and as Mr. P decides his reactions—each of the actors in this perfectly real and everyday drama will be acting out and acting on a series of assumptions about the nature of a person. When does a person begin and end? What do we mean by ‘continuity of the person’? (What makes a person the same now as he was 20 years or even 20 minutes ago?)

## Dualism

Broadly speaking, there are three main approaches to the concept of a ‘person.’

- materialism—not the grubby pursuit of material wealth but rather the view that the person is just physical stuff, a body, something of a ‘what you see is what you get’ idea;
- idealism—which is less often articulated but is the idea that we are really just disembodied spirits or ideas; and
- dualism—probably the most common approach and the one that lies behind our ordinary language descriptions of people and their choices.

In dualism, a person is a mysterious combination of a physical part—a body that includes the brain—and a non-physical part, which can be thought of as the ‘mind,’ ‘spirit’ or ‘soul.’ (For the purposes of this article, ‘mind’ will be used to refer to any of

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the non-physical parts of a person.)

The key ideas in dualism are that there are two distinguishable parts to a person—a physical part and a non-physical part—and that these two parts can interact. In dualism the mind, carrying a person's personal identity and character, inhabits the body.

The mind can act on and is acted upon by the body. If a person, Mr. A, decides to go to the kitchen to get a cup of coffee, his mind makes the decision and then issues an order to his legs to get up and start walking, and so on through the process of getting the coffee.

The process works the other way, too. If Mr. A sips the coffee and finds that it is too hot, the adverse sensation of scalding transmitted through his tongue to his mind will create an order from his mind to move the hand, and his hand will remove the coffee cup from his lips.

Volition, choice and ultimately character all reside in the mind. If Mr. A 'makes up his mind' not to remove the scalding coffee, he could deliberately cause himself physical damage and pain. It is not a particularly good idea, but it is possible.

## Consent

In our discussion of Mrs. P, one place to go is the doctrine of consent. The doctrine of consent says that a competent adult is entitled to be asked for and give (or refuse) his or her consent to a treatment before that treatment can commence.

The doctrine of consent can readily be seen as a method of respecting persons. If people can be treated without their consent then those people fail to have control over that which is most central to their status as persons—their bodies. Treating people without their consent strips them of their personhood.

There are, of course, some exceptions, the most notable of which is the emergency exception—if you have no reason to believe that the person would not want the treatment and if the treatment is required in an emergency and it is not possible to get consent, then generally treatment would be permitted.

The doctrine of consent also comes with some conditions. It applies in its fullest form only to competent adults. In order to consent one must have the capacity to

consent. Capacity is usually thought of as the ability to understand the question being asked, the consequences of action or inaction and the alternatives, and the ability to express a choice. So, in the spirit of respecting persons, we could apply the doctrine of consent to sexual interaction in long term care homes.

Does Mrs. P consent to her sexual interaction and relationship with Mr. Q? The answer here, in the scenario described above, is clearly yes. She seeks out the relationship and the interaction. She is happy and content when she is with Mr. Q and she shows signs of distress when she is prevented from seeing him. But does she have the capacity to consent to the relationship?

This question is a little more difficult. Capacity is not an all or nothing matter. One might be capable of making some decisions but incapable of making others. Mrs. P might be incapable of making her own decisions about some of her treatments, but she is capable of expressing preferences about how she lives and how she spends her time. Her relationship is not harmful to her and while it may cause some distress to others, there seems to be no good reason for preventing her from making her own choice.

That is one version of the doctrine of consent. If we treat Mrs. P as a person—if we respect her choices as she is right now—we would not stand in the way of her relationship with Mr. Q. There may be issues of appropriateness of expression and location, but there would be no interference with the relationship itself.

However, there are other elements to the doctrine of consent. If a person is not able to make decisions then we typically turn to a substitute decision-maker. There are various ways of conceptualizing the relationship between the substitute decision-maker and the person, but generally the intention is to respect and protect the autonomy of the person when he or she is unable to articulate his or her own choices.

## To be continued...

There is much more to the ethical dilemma of Mrs. P and her 'choice' to have a physical relationship outside of her marriage, so we will resume the discussion in the next issue. **LTC**

# Aging Is Living

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By Irene Borins Ash and Irv Ash

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Holocaust survivor, a seniors' advocate, and others who speak about living with aging and the role of long term care

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Irene Borins Ash (M.S.W., R.S.W.) is a Toronto social worker, speaker and photographer with a passion for exploring the contradictions and realities of aging. *Aging is Living* builds on her debut work *Treasured Legacies—Older & Still Great*. Her work has been featured in various publications. Her website is [ireneborinsash.com](http://ireneborinsash.com).

To order copies of *Aging is Living*, please contact Irene Borins Ash at: [ireneborinsash@rogers.com](mailto:ireneborinsash@rogers.com)

