



## Commentary on Sasha McAllum Pilkington's "Deciding how to die":

### What's *Right* for Finn

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When Sasha first arrives at Finn's house, she wants "to search for what might be right for him in his decision making," and to qualify what she means, she cites a short piece I wrote about how people hold a sense of *rightness*. Near the end, Finn uses the same word to describe his decision to cease dialysis and be admitted to the hospice in-patient unit: "it feels right in here." I want to let Finn's story help me to develop what's meant by *right* and then consider how our idea of what counts as being therapeutic might be affected if we think of people holding rightness not as an idea or even an aspiration, but as what I can best call a *telos of alignment*. That's a dense phrase that I will work my way back to.

The article of mine that Sasha cites sought to counterbalance the way that academic bioethics and moral philosophy often imagine moral decision-making, including how people hold themselves accountable for their decisions. Much of bioethics treats people as if they were responsive to arguments phrased in terms of principles. Instead, I imagine people to be making decisions and holding themselves accountable for their actions based on a sense of rightness that is not principled. Rightness is *felt* as something embodied. People express their sense of rightness affirmatively in phrases like "It's just what you do," and negatively in "It's not who I am." Rightness is the unspecified but deeply felt standard that people hold themselves to, and the standard they expect others to follow to varying degrees—whom we expect to act according to our sense of rightness, in which situations, is a subtle, nuanced issue.

People may describe their sense of rightness as being intuitive, and so it feels to them. I understand rightness as a sedimentation of multiple lines of feedback, including hearing both explicit and tacit messages to oneself and to others, as well as experiences of how past acts have worked out. Messages about rightness begin in the first parental responses of "good" and "bad," and such messages proliferate in schools, religious institutions, and forms of what we can call civic education. Crucially, rightness is group specific, reflecting an individual's sense of what people "like me" are supposed to do and find it possible to do. In that *supposed to do*, rightness reflects membership: any person maintains



membership in a group—families, workplaces and occupational groups, clubs and community groups, affiliations of gender and ethnicity—by doing what counts as right in the eyes of that group. Groups have spokespersons, either self-appointed or formally selected, who express rightness both tacitly and explicitly. The sense of rightness thus becomes deeply inscribed in anyone's sense of self and self-expectation, but it is not immutable. People seek therapy when their sense of rightness runs up against some reality that is undeniable. That's a dilemma people need help with—it's Finn's dilemma that he needs Sasha's help with.

To put all this another way: the American Shaker hymn *Simple Gifts* has a line: "And when we find ourselves, in the place just right...." When we hear that being sung, we don't ask questions. We don't inquire as to the geographical coordinates of that place or what the local economy is based on. Hymns don't ask theological questions; they make such questions seem secondary to living everyday faith. The hymn's line bypasses those left-brain concerns by appealing to an intuitive part of ourselves that has a vague memory of being in a place just right and a hope of eventual return.

I recall the novelist John Fowles writing that for him, what instigates works of art is human memory of an infantile, possibly fetal, wholeness without concern. On Fowles's account, which many others express in different ways, art works give us a transitory sense of again being there, where nothing needs to be questioned. Wholly absorbed in the painting, or the music, or the poem, we are for that moment in this place just right. Forms of worship may have their appeal by giving us that sense of being in the place just right, which is why the line from the hymn *works*, both on us and for us. The line is what philosophers would call performative: the words themselves enact what they call for (Austin 1965). Instead of imagining some actual if otherworldly place, maybe the place-just-right exists only in the words and music of the hymn, and the closest we will get to this place is when we sing or play or just listen to that hymn, and let it take us there. The aspiration of hospice care is similar: to make dying feel right; if not just right, at least right enough.

To consider Sasha and Finn, I think about how each is situated as an actor. Each is in a place between, a place of uncertainty as to what their respective tasks are. Finn's situation reminds me of one of the most significant lines I remember in a bioethics case report I read years ago. A woman in the early stage of pregnancy was informed that ultrasound tests showed her baby had a fetal abnormality. She



had to make a decision, based on uncertain information. When she was told all this, she responded by saying that this is *a choice no one should have to make*. Finn faces that sort of choice. Modern medicine has, by offering dialysis, given him some years of living what's called a reasonable quality of life. But that's a time limited offer, which life itself is for all of us, and now that Finn's time has reached its limit, he *must* make a decision. He either perseveres living what has become a terrible quality of life, or he decides to end dialysis. His death will be his decision, rather than what simply befalls him.

Finn's choice fits the parameters defined by Gregory Bateson and his colleagues (1972), at the beginning of the family therapy movement, as a double bind: if he does (x) he loses; if he does (y) he loses; and he can't leave the field, because to make no choice brings about an outcome. If Finn continues dialysis, he suffers. If he ends dialysis, he tells Sasha that he will feel like a quitter or a coward; thus he suffers from the prospect of acting in a way that contradicts his sense of the identity he feels right upholding. And Finn suffers from indecision itself: it becomes difficult to distinguish whether he feels like a coward for wanting to stop dialysis, or if it's his indecision that he considers cowardly. The issues conflate, as one feeds another.

Finn's double bind is produced by an institutionalized technology. Bateson understood families as the source of double binds. For Finn, the double bind began when medical institutions offered him a Faustian bargain: he can have longer life, but he sells his soul in the sense that some day—and that day is when Sasha enters Finn's life—he will have to make a choice that nobody should have to make. We get a sense of how much this bargain has cost Finn when he tells Sasha about seeing a person who is just starting dialysis: "I watched him come in and I thought, 'if it was me doing it again, I would never start.'" That's a sobering line for medical clinicians.

People did not have to make choices that are structured as Finn's choice is—a technologically produced double bind—until the second half of the twentieth century. That has given us only about two generations to develop a moral vocabulary with which we can talk about what we call choices, although that word is seriously inadequate in its implication that individuals make decisions alone in our heads. We make decisions in response to people and situations; we respond to explicit and tacit messages expressing expectations. To make decisions that others have some stake in—and others do have a stake in almost all our



decisions—we need words that can express what’s going on. Words weigh possibilities. We may have to decide we don’t like how the received descriptive terms are directing us, but to do that we need alternative words and phrases.

Finn represents all the people who are put in situations where their moral vocabulary hasn’t had time to catch up to what the situation demands. It’s by linguistic default that Finn gets stuck using a descriptive term like “quitter.” He needs a word that can describe deciding to stop dialysis as an act of managing his life on his own terms. He and Sasha spend considerable time talking around the absence of a word that describes someone who makes an *affirmative refusal* of treatment.

Or, phrased differently, people in Finn’s situation are living a story for which they do not yet have an overarching narrative that gives us a sense of where such a story ought to lead and how it gets there. Sasha’s article is one step in creating that narrative as a cultural resource.

Sasha’s work as a hospice counsellor is complementary to Finn’s situation in its ambiguity or in-betweenness. She is neither a bioethicist, nor is she a psychotherapist in the sense of mental health professional, nor does she advise, although she calls herself a counsellor. In terms preferred by narrative therapy, Finn is not visited by a Problem like bed wetting, or physical abusiveness, or anorexia. Instead, he confronts a dilemma: again, a choice no one should have to choose, a distinctly modern choice, with an inadequate moral vocabulary. Sasha is not trying to work with Finn to control a Problem or get it out of his life. A geographical metaphor seems to fit better. Sasha is working with Finn to get somewhere, which happily is where he ends up: finally able to say, “it feels right in here.” Finn’s dilemma, his double bind, will never be resolved, but it might somehow be surpassed: it might just cease to matter.

Because processes of change are subtle, it’s not surprising that the moment when Finn gets beyond “feeling like I’d copped out” occurs during a gap in Sasha’s narrative. Sasha experiences this gap when she hears that Finn has stopped dialysis and been admitted to the hospice in-patient unit. The gap is where Finn’s sense of rightness shifts; his sense of what he should do, to be who it’s right to be, changes. Sasha’s colleagues congratulate her on her good work, but she feels uncertain. That uncertainty may be where she asks too much of herself and perhaps expects too much step-by-step continuity in Finn’s story. Sasha tries to fill in that uncertainty with reasons for Finn’s decision, and Finn cooperatively offers



her a few such reasons, but—significantly for my understanding of what’s going on—Finn’s decision seems underdetermined by any specific reasons. That underdetermination might be a problem for some bioethicists; to me, it’s inevitable, and bioethics often goes wrong when it tries to fill uncertainty with moral principles applicable to a category of cases that professionals consider alike.

Finn’s situation—his life, not his “case”—requires not a solution but a response, and the response cannot be strictly rational. On my account, vague as it is to put it this way: Finn gets to a point where doing what he did felt right; I call that place a good death, a phrase people use to express their sense of rightness. But Finn did not get there alone. Sasha’s non-Problem-oriented work was to get Finn to a place where he could trust that it felt right. The elusiveness of Sasha’s work is that at the end all Finn can say is “it feels right in here.” There’s no outcome metric, only a feeling.

If Sasha is not doing therapy, her counselling has a therapeutic effect, and she tells us a good deal about how she achieves this effect; in particular, how she phrases questions so as to create *spaces*, as she describes it. Sasha does not follow any map; she follows Finn’s leads, cueing him in response to cues he gives her. Her cues direct him to think of himself as ... what? *Capable* is one word, as in capable of agency, even after his physical capacities are seriously reduced. After Finn has made his decision, Sasha asks his son Liam what kind of a person his father is. “Organised,” Liam says. “He always liked to be in the driver’s seat. He is a bright active man who always managed everything on his own terms.” Sasha is enlisting Liam as a witness, a role he plays later when he affirms that Finn’s stopping dialysis is his way of acting on his own terms.

I will risk an analytic summary of how, or maybe where, the therapeutic happens in Sasha’s work with Finn. The therapeutic effect, equally a palliative effect, takes place in Finn’s subliminal uptake of potential narratives for his life that Sasha embeds in her questions that are always offered as responses to Finn’s lead. Sasha’s implied narrative is that Finn has lived a life that has prepared him to know, when he gets there, that he is in the place just right. He just needs to let himself get there, as he will in his own time. Time and space must conjoin, and they will: the place can be just right only at the right time.

*Rightness* is not cognitive and getting there is not “behavioural” in the sense of changing how one acts. Early in this comment I used the awkward phrase *telos of*



*articulation*. Rightness is an articulation, but it's not about being articulate in speech. The articulation involved in rightness is the sense of a *fitting together* of time, place, action, and relationships—at least these, but also more than we can list, including a person's sense of who, present or absent, expects what from them, and what self-expectations they must honour.

This articulation is a *telos* insofar as it's an end state that life is *felt* to be all about reaching; we describe that feeling with phrases like saying the self is finally *true to itself*. When Sasha asks Finn, "Do you feel more yourself?", I hear that less as a question and more as the gentlest way of offering permission. Two points deserve emphasis. First, Sasha's presence during the period of time leading up to this moment has *earned* her the right to offer that permission; it's earned in real time spent *attending*. Institutionalized medical care often neglects that need to earn in real time. Second, Sasha's permission still leaves space for Finn to add something else, to want something more before he can feel fully himself. Medical decision-making often wants finalized end points.

Sasha's work, however skilled as a practice, is simple to describe: she shows up, asks questions that follow what Finn and his surroundings suggest, and in those questions she reflects back to him a version of the person he indicates is most himself. I understand *feeling most yourself* as being another performative act: I am most myself because I pronounce myself feeling that way when I act. The act affirms the self as being most itself, and being that particular self warrants the rightness of the act.

Finn, or any of us, has to earn that pronouncement of feeling himself, and that earning generally takes place within a relationship of mutual response with another person—a witness. That's the subtlety of it: it's only words, but I can't just say it. Saying it requires believing it, and none of us can get to believing it on our own. I have to feel that where I am is the end at which I was supposed to arrive. That arrival is joint, until one person goes on alone, as must be.

In the end, as Finn dies, he takes Sasha's hand. She is there as his companion and his witness. She is a crucial part of the articulation. Sasha *makes* the place just right.



## References

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