

[Emails exchanged between Robin and Ilena Silverman, her editor]

Ilena to Robin: March 27

Hey robin. I ended up rereading this again carefully and writing lots of notes to you in caps. I also suggested some cuts which I've put in bold.

Generally, I think that you really need to beef up Peggy's part of the story. Brooke's perspective is interesting but it's more familiar. I think what makes this story unusual is the fact that you have a person whose thought a lot about these issues from a theoretical perspective for years and now she's faced with her invalid husband. That's the heart of the story: what she thinks now that she's entangled. How perhaps ideas you have about all of this get blurred when you're faced with it. She's been championing patients right to die, based at least some on the idea that there are certain lives not worth living, and then there's Brooke and he feels differently. I imagine that Peggy has many mixed feelings about this. She says it wouldn't be worth living for her — so you figure she wonders why he wants to live this life. And maybe that it's also really hard for her. There is rarely just the disabled person whose affected. In this case, it has a huge impact on Peggy's life too. And you need to address and explore that. How the disabled person is intertwined with the non-disabled person and the question of what does the disabled person want is complicated — just as the question of what the non-disabled person want is complicated too. You can see this with Peggy both saying to you that she wouldn't want this life and saying to Brooke that he's depressed because it's winter. So you need to tease all this out. As to the affect on her: Perhaps she believes that it doesn't matter what affect it has on caregivers that the disabled person has to be free to decide what he wants — that's the way to avoid the slippery slope. But she must know how hard that is. (maybe by having so many helpers she actually helps to make autonomy possible. If she was shouldering a huge burden it might just feel like too much for her and she might be rooting for his death. Anyway, take a look at all this. If you want to talk, just let me know.

Ilena to Robin: March 29

Hey robin. In thinking more about your story it occurs to me that I think it might be worth talking to Peggy about her thinking behind having so many people work for her and Brooke. I edited a story a few years ago by Katy Butler -- http://www.nytimes.com/2010/06/20/magazine/20pacemaker-t.html?pagewanted=all&_r=0 -- about the toll on her mother of her father's alzheimers and other disabilities. The burden of care that her mother shouldered eventually killed her. I'm struck that on some level Peggy must know that and has figured out a way to avoid a complete abandonment of her own life in order for Brooke to be cared for. Obviously there are all sorts of ways that Peggy's life is compromised too, but I imagine that having all that help makes it easier to appreciate the good even as she has to deal with the sadness and difficulty of having such a severely disabled spouse.

Robin to Ilena

I loved that Katy Butler story, and she and I entered into a rewarding correspondence after I sent her a fan email. I'm not surprised that you edited it -- it was great. She turned it into a book, right?

Peggy is very aware of how important it is to have round-the-clock caregivers, and I think the fact that they're mostly young and mostly trained specifically to work with Brooke has been a big boost for both of them -- it's almost like having an extended family moving in and out of the house. She also stays really busy with work (it's probably as much the reason she holds onto her full-time job as the health insurance is), travels alone to conferences (which is where she is now), and built herself a bedroom upstairs, along with a balcony, that she thinks of as a retreat.

Actually, Peggy's sister -- whom I didn't mention at all in this version, even though she's a hospice nurse with her own story to tell, her husband having had almost exactly the same injury as Brooke last summer in a boogie-boarding accident in the Hamptons -- thinks that because of how Peggy has had to manage Brooke's care, she will be less isolated after he dies than she would have been if he had died right away. Her sister says Peggy never had all that many friends, it was Brooke who was the social butterfly. But now that she's had to force herself to be social, and to keep friends coming over for Brooke's sake, these folks now think of themselves as Peggy's friends, too, and won't abandon her.

So in a way, Peggy has had almost the opposite of Katy's mother's experience -- possibly precisely because she didn't take it all on alone but shared the burden and was careful to carve out time for herself.

By the way, another problem Katy's parents faced, trying to turn off the pacemaker when her father was ready to die, might be something Brooke faces, too. He not only has a heart pacemaker, but also a pacemaker for his diaphragm. I'll ask Peggy what she thinks about whether turning off those two devices will be an added complication.

Ilena to Robin

Yes, kate did turn her story into a book that's coming out in september. Very interesting about peggy not being that social before this. And I admire how she's kept up her life. Seems important. And I did think about the pace maker issue when you mentioned it in your story. Love when the thoughts from one story lead you to thoughts in another.

Ilena to Robin: May 21

Hi robin. Attached is an edit of your story. As I've said, I think you have a lot of great material and I think this will ultimately be a terrific story. There are several things that I think you need to address this next round.

The first is getting a much deeper sense of Peggy's thinking about right to die issues. What was her philosophical position. What were her books about? Who were her mentors? It would be great to have a bit of an intellectual biography of her thinking. And then throughout the piece we want to see her thinking evolve so we have a clear sense of

how it's changed. i'd be happy to talk with you about this. I realize that I really don't have much sense, beyond a simplistic one, of peggy's thinking on the issue. In general, the story needs to meld the story telling part — and there are a few dramatic scenes which can be the spine of the story (I'll get to that later) -- and a sense of the evolution of peggy's ideas and thinking about the issue.

The second thing to focus on is the writing sentence by sentence. I know you've been focused on getting all the information and narrative down, but I think there are a bunch of places where you can push to write in a more elegant and imaginative way. I've marked a bunch of them.

A few times in the story you summarize the issues for Brooke and Peggy. Instead of doing that I think you should just give us detailed scenes that get at these issue. There seem to me to be three key scenes and the story should hang primarily on those 3 moments:

- * Brooke having a bad night teaching and Peggy pushing to help him even though he says he feels fine — this seems like it should be connected to scene when Brooke says he doesn't like anyone talking for him.

- * Peggy's sending Brooke to the hospital after he dictates his Final Letter.

- * The scene toward the end when she takes him off the ventilator.

One thing that feels like it's missing is a deep self-awareness on Peggy's part. Obviously she wants what's best for Brooke but that often feels like it gets tangled up with what she wants — Brooke to stay alive. We need her to think out loud about that. About how the lines get blurred over whether she's doing what's best for him or best for her (like when she sends him to the hospital even though he's said he doesn't want to go back.) Their relationship is clearly very complicated — she rationalizes why what's she's doing is right for him and then he often agrees with her. We need to see Peggy grappling with all this. Seeing how the needs of the patient and the needs of the caretaker can get entangled. In addition, she needs to grapple with the tension between her theoretical ideas about right to die (which, as I said, I don't think you write enough about) and the realities of caring for Brooke and wanting him to stay alive.

There's this interesting paradox in the piece: at one point she tells you that if she were brooke she wouldn't want to live that way. And yet, at other points she is keeping him alive when he might rather die. We need her (and/or you) to grapple with those seeming contradictions.

This edit, I know, has lots and lots of notes in it. So maybe it makes sense for you to read through it all and then for us to have a conversation before you dive back in. look forward to discussing.

Ilena to Robin

[I asked her for a few more details]

We want it to go deeper —we want a "philosophical richness" — to have a better sense of how she's evolved in her thinking. So that a reader would be able to really compare what she thought pre-accident and what she thinks now.

And we wanted to see peggy grappling more with the issues and having some insight in her own role in the complicated dynamic that they have.

I don't think we need a nut graph — at least for now I'd like to try it without.

I was on the fence about the assisted suicide legislation but the story was already so long that I ended up cutting it. I also thought about cutting the examples of Nickleson and Bauby but left them for now. I'm not sure length, but it's a little hard to imagine the story running at more than 6,000 words so I'd try to keep it as close to that as you can. But if you find you can't then you can send it at 7,000.

As to when it will run. Unfortunately, I can't guarantee anything. I should be able to read and circulate it when you get it back to me but I don't know when it will be scheduled. It's not on the schedule at the moment, but stories drop out and then we're scrambling and something that's not on the schedule can be placed there quickly. On the other hand, as you know, sometimes things can slip. I know that's frustrating but it is how things can go here. I hope it'll be published this summer but if it weren't you would have to tinker with the end — update your reporting by phone. If it's too difficult to work this week with the beginning of teaching, you should take the time you need and get it back to me when you can.

Ilena to Robin: May 28

Hi Robin. I was thinking about your story again this morning and was wondering whether perhaps the core of the story is that before Brooke's accident Peggy believed that the way to think about end of life issues was to allow the disabled person himself complete autonomy. That the disabled person gets to decide what he wants and make his own decisions. And that since Brooke's injury it's become clear to her that the whole concept of there being some pureness about what a disabled person wants doesn't really reflect reality. What a given person wants when it comes to life or death for a disabled person can be murky. Sometimes it's clear, no doubt, but often I imagine that the person is mixed about it and that's connected to their spouses own wishes — which may also be mixed. This is what we see so powerfully in your story. Peggy often has her own agenda — it may come out of love and compassion — but it's hard to separate what she's doing for Brooke from what's she's doing for herself. I don't blame her for that. It's a very complicated dynamic. But she is making decisions about what's best for him and then often, he's jumping on board and agreeing with her. Who knows whether it's really the right decision. But they both rationalize that it is. (or perhaps it really is.) I imagine the reality of all the day to day decision making has turned out to be much more complex than she thought when she was writing.

All this is a bit of a guess when it comes to Peggy and her writing and thoughts. If you want to talk through what her philosophical and ethical position has been and how to write about it in contrast to what she thinks today, I'd be happy to.

Robin to Ilena

Hi, Ilena -- Funny, your email came in just as I was sitting here re-reading "The Journalist and the Murderer" in preparation for my first NYU class tomorrow. (Have you read it? It's amazing.) I was just at the part where Janet Malcolm talks about how hard it is for a journalist to deal with a real-life character who's not at all like the literary characters we're used to, who have nice clear characteristics and interesting narrative

arcs. Real life is more confused and ambiguous than literature, so Joe McGuiness was forced to turn his character, Jeff MacDonald, into a more recognizable mold than was probably entirely true. I was wondering if I'm at risk of doing something like that to Peggy -- and then there was your email!

One problem I keep running into in trying to describe how Peggy's thinking has changed since the accident is that even before the accident she was unwilling to commit to one particular point of view in her writings. She always emphasized how ambiguous many of these issues are, and was able to see valid arguments on all sides, so there are no easy quotations that indicate, Yeah, THIS is what she was thinking.

But you might have come up with a solution to my problem by suggesting a focus on the concept of autonomy -- though I'm not sure she was every arguing for COMPLETE patient autonomy, since so much of her thinking has always been so nuanced. I'll have to go back and see. I did have another phone interview with Peggy last week and we talked about whether pure autonomy is possible -- I came up with the word "duonomy" to describe what she and Brooke are now experiencing, and she seemed to like that -- so that might be a promising way to explore this.

It would indeed help to talk about this, but I'd like to put it off until after my class tomorrow afternoon so I can focus more on class prep (it's the first time I've ever taught a college course, and I'm a little nervous). I have a date to talk to Brooke via Skype at 1:30 on Thursday -- he listened in on my interview with Peggy last week, and now he apparently has some things he wants to tell me more directly, though I'm not sure he's up to it, since there's yet another urinary tract infection that's making him logey again. Maybe you and I can talk on Thursday morning before I talk to Brooke? Or any time Thursday afternoon or evening.

Interesting Bergner story, by the way -- I'm sure you're getting tons of responses to it. I especially liked the thinky bits at the end.

Ilena to Robin

Hi robin. I did read the journalist and the murderer and it rocked my mind back then. So yes, I can see the trickiness of all of this. In capturing the nuances of peggy's thinking then and now. But sure, why don't we talk on Thursday after you talk to brooke. Good luck with your class. I bet it will be fun. Just get them talking.

Ilena to Robin: July 3

Hi robin. Here's the edit. I've made a bunch of notes throughout, which represent places that we hoped you could go a bit deeper. They don't require a ton of writing, but just some here and there to continue to try to deepen this. The one specific thing we wanted was a bit that discussed the finances of all of this. It seems like it would cost a fortune to keep someone alive the way brooke is kept alive. All the help, equipment etc. is that paid

for by insurance? Did they have catastrophic? Do they have money? Have they had to, say, raid their retirement account. Any details about that would be great. The other deepenings are in the later part of the piece. Especially toward the end. That stuff is the most powerful so just want to milk it intellectually and philosophically and psychologically for all it's worth. We're not working Friday but you can reach me on my cell at XXX XXX XXXX. It would be great to have the piece back on my desk first thing Monday so I can dive back in and we'll have time to go back and forth on Monday. Have a great 4th.