

BOOKS AND IDEAS PODCAST

with Ginger Campbell, MD

Episode #29

Part 2 of the Interview with Dr. Robert Martensen, author of *A Life Worth Living: A Doctor's Reflections on Illness in a High-Tech Era*

Aired May 22, 2009

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INTRODUCTION

This is Episode 29 of *Books and Ideas*, and I'm your host, Dr. Ginger Campbell. Today I'm glad to welcome back Dr. Robert Martensen. Last month we talked a little bit about his career and his current work as the Director of the Office of History at the National Institutes of Health. Today we will talk about his book, *A Life Worth Living: A Doctor's Reflections on Illness in a High-Tech Era*.

One reason I invited Dr. Martensen on the podcast is that his book addresses some of the problems of high-tech medicine that concern me personally, both as a physician and as a person who might be a patient in the current American system. In my opinion too many Americans believe that more is always better. They assume that since we have the most expensive healthcare system in the world, this means that it's the best. But the numbers do not support this assumption. We will touch on some of these issues today.

One thing I appreciate about Dr. Martensen's book is that, while he focuses on the stories of real people, he puts their stories into an historical context. Also he points out how the American approach contrasts with the rest of the world. Since

I know that *Books and Ideas* has listeners all over the world, I would love to hear from both American and international listeners. You can send me email at docartemis@gmail.com, or leave a comment on the website at booksandideas.com. You can also get a transcript of this interview at booksandideas.com. I will back after the interview with some closing announcements.

INTERVIEW

GC: I'm happy to welcome Dr. Robert Martensen back to *Books and Ideas*. Robert, I sure am glad that you were able to come back, since we didn't get to talk about your book when you were here last month.

RM: Well, we covered a lot of ground. We didn't cover the book very much. I feel badly about the timing issue; I just had to be somewhere. But I'm glad to be back.

GC: Thanks. Let's get on into talking about your book. It's called *A Life Worth Living: A Doctor's Reflections on Illness in a High-Tech Era*. Do you want to just tell us a little bit about how this book came to be?

RM: The book came to be from wanting to write stories about being an ER physician, which I had been doing. And I had been talking with an agent—whom I found, incidentally, on the Internet—and the agent said, 'These are interesting stories, but a book of stories isn't enough. They have to have a theme and a point.'

That was in 2005, and the Terri Schiavo situation then emerged in the media. At the time I was Chair of Bioethics and Humanities at Tulane Medical School. So, I was asked, by virtue of being in that job, to talk with various TV reporters about the Schiavo situation; which I did. And the way the discussion happened in

public disappointed me a lot. I thought there was a lot of grandstanding by various parties.

And I decided I wanted to write about persistent vegetative state from the point of view of patients I had cared for. Then that led to writing other stories; which became the book. I wrote about patients I'd had with severe brain injuries, one of whom recovered and one of whom didn't. And I wrote a book proposal and was able to find a publisher, and just kept on writing. That's how it happened. But the Terri Schiavo situation really triggered things for me.

GC: I had a lot of negative reactions to the press coverage of that, too, so I can certainly appreciate why you would do that. What do you think the most important issue that you cover in this book is? It didn't turn out to be about Terri Schiavo at all.

RM: No, not at all. The main theme of the book—which is really for just general readers—is how does one cope with living with a life-threatening diagnosis. And what are the big questions and ways to respond from the first moment you learn the diagnosis—whether it's of you, someone you love, a child, a parent, a partner—what are the relevant acts for that illness? And then behind the scenes, what are the interests, and values, and voices that are shaping how you're cared for?

How do medical institutions operate? What are the beliefs of some medical leaders about what it means to be human; about what it means to get treatment; about what it means to be a patient? All of that is interwoven into these stories to try to give a 360 degree perspective on what it is to be sick these days. And if I were putting the book into words, there are six words—two phrases of three words each—that weave in the background throughout the book.

The first is 'finding a balance' between being alone and being with others. What is it like to be alone and feel alone—not in a good way, not in a quiet way—but

just alone, and lonely, and perhaps abandoned? How does that happen when one has a disease? How can one be surrounded by others—which you are if you're in a hospital, or a skilled nursing facility, or generally in medical spaces—and yet feel so alone? What is it that's going on in those spaces and those encounters that makes one feel isolated? How is one with others in good ways and in bad ways?

And the other phrase is 'having and being'—'having' meaning in an ordinary consumer sense of having more stuff, having more knowledge, having more friends, having more life, having more everything—that set of appetites balanced with what does it mean just to be; what is it about 'being?' And in the last 40 years—particularly in the United States—the balance has shifted between 'having and being,' to 'having' being favored, 'having' being privileged: 'I'm better if I have more.'

And then when one looks underneath the reality of that in terms of medicine, what one finds is having more treatments does not necessarily lead to better results, better outcomes, a better life. And that's empirical. Groups like the Dartmouth Atlas of Health Care have demonstrated that in a myriad of contexts, and the American healthcare system is oriented towards having more interventions—particularly, extensive interventions.

So, our whole system has become organized around 'having' as the highest good. And yet, it doesn't pan out in terms of our life expectancies, our quality-adjusted life years, our disability-adjusted life years; all these measures of effectiveness. I think the United States is now 44th in the world in life expectancy, and way down there in terms of things like qualies and dollies (?) —these conventional definitions of function.

GC: Right. Because spending more money on MRIs doesn't really do much for your quality of life, or even the length of your life.

RM: MRIs are fascinating to me in the sense that the science and technology is absolutely brilliant, and one would think because the resolutions are so good visually that the correlation between structure and function would be tight—you know, one sees something abnormal on a MRI of the spine and it correlates tightly with the patient’s symptoms. But the correlation is not tight.

I’ve had some problems with ruptured disks and problems in my spine. And my MRI looks awful, but my function is very good. And one can say the same about other imaging studies. So, yes, there is a sense in which more expensive diagnostic tests—that are just done without thinking as much as one should think about the patient’s situation, their symptoms, and signs—probably don’t add much to a good outcome. They consume a lot of money. They’re expensive.

GC: But that’s an example of where our system squeezes doctors in the wrong direction, because they’ll pay for the doctor to order an MRI but they won’t pay for you to spend an extra 15 minutes with the patient figuring out that actually they’ve had these headaches for 20 years and therefore they’re probably not anything life-threatening.

RM: Yes. This is true. To extend what you’re saying, Ginger, I talked with Diane Meier—a colleague of mine who’s a palliative care leader at Mount Sinai in New York—in December, and she said she can spend an hour-and-a-half with a patient and their family who have learned they have a life-threatening diagnosis, doing an exam, doing a history, and then talking, learning about the patient and the patient learning about the possibilities for treatments and life. For an hour-and-a-half doing that she is compensated \$18 by Medicaid in New York.

Certainly in the emergency room context we know that time often is finding out that the headache has been going on for 20 years, or that the 58-year-old widow’s chest pain which she’s experiencing acutely is on the first anniversary of her husband’s death from a heart attack. Learning those kinds of things about

patients takes a certain comfort level in conversation. That means a little time vs. just ordering this, that, and the other, which then leads to a higher acuity evaluation of the visit, a greater compensation to the emergency department, and so forth.

GC: And then when we get into discussing things like—and I apologize for jumping subjects—but when we get into something like discussing end of life decisions, then you have a double whammy because that takes a lot of time and it's a complicated decision where our system seem to be geared toward making everyone make the same decision.

RM: Well, it can be complicated intellectually. Sometimes it's not so complicated intellectually—it's complicated emotionally, it's complicated procedurally. For instance, for patients who are in end-stage metastatic cancer (about 25% of people die with cancer) by the time it's end-stage and metastatic there's a fairly predictable trajectory. One can with some—according to studies—reasonably predict the last six months of life.

I think it gets complicated because when one talks with patients in those situations the standard language is all about treatment in terms which the patients often hear as curative. That may not be said explicitly by the treating physician, but that's often how patients hear 'more treatment'—should we do another round of chemo; should we do radiation—all with the idea this will extend their existence. Evidence suggests it doesn't.

What's not in the conversation and what I want to emphasize is it all gets focused around longevity. And what often doesn't happen is to put longevity alongside two other parts of existence: comfort (that sense of all the ways in which one can be comfortable and uncomfortable, that the physicians will be there to make one as comfortable as possible) and function (what matters most to the patient, to the patient's family, in terms of life.) What do you want to be able to do? What is

your hope that you'll be able to do? How can we help you do that in realistic ways?

So often everything that the medical establishment does is just framed in longevity. The treatments may or may not provide additional existence, but typically those conversations don't happen with also including comfort and function. I'm using abstract terms, but I think those terms capture a good part of that existential terrain. And it's because we don't have those conversations that people keep getting treatment, treatment, treatment until their bodies just can't respond physiologically anymore and they die.

GC: One of the things that stood out for me in your book was the issue of this kind of communication between the doctor and the patient of making sure that the patient really has that information you talked about: that they understand this treatment may make them live longer, but it's not going to cure them. Doctors never seem to want to say that. You give the example of two stories of cancer patients in your book, one of whom understood exactly what the score was because he was a physician, and one of whom didn't, and at the end said—or their family member; I can't remember which—'If we'd really understood this we would have made different choices.'

RM: Right. Now, a lot of physicians will say—friends of mine, and it's in the literature—'Look, Robert, you can't take away people's hope.' As though what I'm proposing—a kind of balanced reporting with the patient, telling them what the situation actually is—takes away hope. They'll say, 'You keep offering treatments because you can't take away hope.' And I would say (and others have said) to counter that, 'You're right. You're absolutely right. But we need to be realistic in our hopes.'

And if you actually listen to patients, a 68-year-old woman with advanced metastatic cervical cancer may say, 'I'd love to get to my granddaughter's

graduation,' or, 'I'd love to get to my son's engagement party. That's three months off. Can you help me do that, doctor?' That's hope in a day-to-day context. When you actually listen to patients they may be content with that.

GC: And they also want to know that we're not going to abandon them at the end. I think sometimes they agree to keep on getting treatments because they intuitively know that the doctor may just say, 'Well, I can't do anything for you anymore,' which means goodbye—back to that being left alone.

RM: Yes. When that moment happens, saying, 'We're not going to do the fourth round of chemo; I'm sorry there's nothing more we can do for you,' that to me is, number one, if you're not going to continue care for the patient, as we know, morally and legally one is obliged to find another physician. But putting that aside, to say to somebody, 'There's nothing more I can do for you,' particularly if they're in the end stage of a disease process, is simply not true.

It may mean, 'I can't do any more for you of the kinds of things we've been doing,'—in the context of this situation, chemo—'but there's a whole lot I can do with you to keep you as comfortable and as functional in ways that matter to you as possible.' Patients fear being abandoned. But it's a reality-based fear, because there are a number of physicians who define their role so technically that they will say, 'Well, I can't do any more operating, I can't do any more of this, I don't have anything more to offer.' And I think that's inaccurate.

I also think it's irresponsible. Now, they may say, 'There are more things that can be done. I'm not so good at all that. Let me help you find somebody.' I can understand that response. What I can't understand—in a sense, when I stand back and judge, I suppose—is that sense of coldness: 'Well, we've done everything. Sorry. You're out of here.' It just seems to me inappropriate.

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GC: One of the things that's really unusual about your book—and I think it's relevant here—is that you bring historical context to the conversation. And after listening to what you just said, I almost think maybe part of the problem is that so many physicians today have no sense of historical context for our profession.

RM: I think there's something to that, Ginger; particularly when one looks at what patients expected of physicians if they knew they were going to die of their disease in the reasonable future, and the way physicians imagined that they should be with patients—their professional etiquette around the dying. And yes, there is a history there. Until quite recently—for an historian, recently—say, until the last 50 years, if patients were near the end of life they expected physicians to help keep them comfortable if they could. They didn't expect a whole lot else.

And the physicians would say, 'We've tried pretty much everything that we know might be of help, and we think now there's nothing more of that we can do. We certainly have pain medicines and there are a few things that can help you with nausea, and so forth.' Yes, there was a very different set of attitudes—an ethos, if you will—and practices around dying patients, 50 years ago, 100 years ago, 300 years ago.

In other words, there's a lot of continuity until one gets up to, say, the early 60's, when we have new technologies, and chemotherapies, and life-extending technologies come in—dialysis, ventilators, mask use, and so forth—and we can keep extending rather indefinitely a person's existence. And so, that has changed

the expectation around what it means to be a patient, what it means at the end of life, what one expects of physicians, and what physicians expect of patients.

You know, that sense of the norm is, if you have cancer are you going to fight it? And if you're a good soldier, a good fighter, then you'll keep fighting it—meaning you'll keep taking these treatments as long as we have them. And if you don't want to do that you're somehow less than a good fighter, which means less than a good patient. It's a cultural norm.

GC: It's not even the norm all over the world, is it?

RM: No. It's not the norm all over the world. It's the norm in the United States. And that's perhaps why in this country half of the money spent in Medicare is spent on patients in the last six months of their lives—which is just a staggering concept.

GC: And it would be one thing if that last six months was a great and wonderful six months that was really a gift to patients.

RM: Yes. If we as a society could say, 'This is how we're spending these resources, these are all these people we've mobilized, and there is nothing like the last six months of life in the United States. Granted, one has to die, but we do absolutely the best job in the world.' But in fact, often the last six months of life for Americans in those situations is an agonizing shuttle—a shuttle between the ER, the ICU –

GC: The nursing home.

RM: The nursing home; home, maybe; back to the ER, the ICU, the nursing home, back to the hospital. Those of us listening in medicine know you can see the chart of somebody in those situations. Imagine a man or woman in his or her late 80's who has an end-stage heart disease with kidney complications and a

metabolic problem—perhaps it's diabetes. It's not uncommon to see this is the 12th hospital admission for Mr. So-and-So in the last 14 months.

It's just this cycle. And I think it's brutal on the patients. And nobody ever says to the patient or their families, 'Are you aware Mrs. Smith or Mr. Smith is dying?' All these treatments can extend existence—maybe—but I think we're also in some sense extending the dying process.

GC: And we don't even have time to get into the issues that arise, once a person gets into a nursing home, that contribute to this.

RM: Well, the nursing homes face the problem: They will say, 'We're not equipped to do too much medical care,'—meaning an IV—so, as soon as the patient destabilizes a bit the nursing home sends them back to the hospital.

GC: But as soon as the person quits eating the nursing home insists that they have to have a feeding tube, because they're not allowed to lose weight if they live in the nursing home.

RM: I'm glad you brought that up. Yes, the skilled nursing facilities abide by Medicare/Medicaid regulations, and they are negatively sanctioned if their patients are losing weight. And the hospitals will say, 'Well, we're not compensated for delivering palliative care,' meaning allowing people to be comfortable when they withdraw from food. So, the net result is there's no space for patients who don't want more intensive medical treatments; what they want are some comfort support treatments and that kind of intense attention to comfort that shapes the last few weeks of a person's life.

GC: Our generation has seen this evolve and—I guess you're a few years ahead of me—but we've seen our parents go through this. Do you think there's anything we can do to change it?

RM: Yes. I think first of all if people want to change it, it can change. So, I'm an optimist that way. What specifically needs to be changed? Tiny adjustments in regulation would have a huge benefit. For instance, now a skilled nursing facility, or nursing home, would say unless the patient is in therapy of some kind Medicare won't reimburse this care beyond so many days.

Suppose there were a category in which the patient could continue receiving therapy but it would be understood they're in the palliative period. Now, there's Hospice that covers this, so maybe it's just a tweak of Hospice regulations. But that sense in which patients could have the normal withdrawal from life—gradually food loses interest; finally fluids lose interest; they don't need or want to have too much physical therapy—that wouldn't take much to change.

The same with the way we talk in acute care hospitals around end of life issues. Now we present it in terms of, 'Well, Mr. and Mrs. Smith, shall we withdraw life support from your mom or dad?' We use a very euphemistic language for these artificial technologies—the ventilators, the dialysis machines, the pharmacologic presses, the pacemakers, and so forth—instead of saying, 'Here's how this disease is going that your parent has. We don't know exactly what's going to happen when, but we know she is sinking.'

'There are some things that can be done to extend. Nothing will get her better—your mother, your grandmother. There are a lot of things we can do for comfort and some for function. So, let's talk about these artificial means.' You know, if it's presented that way vs. the way it is presented—'Well, so-and-so's on life support; do you want us to stop it?'—that isn't a huge change in terms of what one needs to do to accomplish that. But I think it can have a huge impact. I don't know. What do you think, Ginger?

GC: Yes, I definitely agree that how you present it makes a huge difference. One of the advantages of working in a small place is I generally have time to spend a

little bit more time with families around these decisions. And we're not facing somebody breathing down our neck for organs or anything, like in a big city place. And I'm very careful about how I speak to patients, and try to put it in a language that allows them to let go and concentrate on their family member's comfort. And it makes a difference.

So, I agree with you completely. But I also think there's a need for people to really have a true understanding of what goes on. It seems like I find people that with the first family member they want everything done, and once they understand what it really means they're much more receptive to the idea that maybe comfort measures would be the reasonable choice.

RM: Right. Some patients will say, 'I know I'm not going to have any comfort. I know I'm not going to have any dignity. I want you to do everything.' And I don't have much problem with that. What I have a problem with is the fact that so much goes unsaid, and it's just done in an unthinking way.

The default is, 'We will keep treating you, pretty aggressively in terms of the invasiveness of what we do, unless we hear explicitly otherwise. And we're not going to bring up the "otherwise," you're going to have to bring it up. We'll only bring it up'—'we' meaning the hospital and the treating physicians—'if there's an administrative reason we need to. Other than that we're not going to bring it up.'

Now, that to me is sad. And it also, in terms of consequence, is why people have these extended and rather agonizing deaths; which are unsatisfying final chapters in life for the patient, the patient's family, the treating physicians, and for society as a whole if you think of how we're spending our resources.

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to learn how you can support my work, please go to gingercampbellmd.com and click on the tab at the top labeled Donations and Subscriptions.

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GC: Coming back to your book—because I know you’re just about out of time—let’s just remind everybody that your book is really not abstract. It’s told through the stories of real people.

RM: Yes. I wrote about people I knew—I’ve disguised their identities—people I’ve taken care of, all the way through institutions I’ve worked in, positions I’ve held, stories from a variety of perspectives. And I also put in what I think of as relevant to things—as you mentioned earlier, from history—but also from bioethics and medical technology over the last 40 years.

GC: How long has your book been out?

RM: The book came out in September, 2008; and it’s coming out in paperback this August.

GC: I think it makes a valuable contribution to this very important discussion.

RM: Well, thanks. One of the things that’s been interesting, and may interest listeners a little bit, is I’ve gotten emails—people find me because I work at the NIH and email access is public—which is fine. But the point I want to make is about half the emails are from people within medicine, like physicians, nurses, occupational therapists, and half are from people who are not—from lay people.

But if I took away the degrees at the bottom after people’s names, you couldn’t tell the difference in the stories. Because what they’re emailing, along with a comment about the book, is typically a personal story about them or someone they’ve been close to. And that fascinates me. In other words, the situations I

describe are so deeply felt within the healing arts and also in the general public that everybody's kind of on the same wavelength as the people who've been responding to the book through emails to me.

GC: That's why when I heard you on *Fresh Air* I thought, 'I wish I had written that book.'

RM: Yes. Well, I think a lot of people could write that book. Because what I'm trying to do is convey situations and ways to handle them perhaps better, that are out there so broadly and deeply; and that there's really very little distinction, in some ways, between those delivering all the treatments—those of us in the system—and those experiencing the system. I wanted to have that sense of commonality that it is a 'we' book—it's not an 'us and them' book—that it's our common humanity that spreads across with these illness experiences.

GC: And if we're ever going to change things it's going to be 'we'—both us and our patients; because we can all be patients, or will probably be at some point.

RM: Yes, we will. And, yes, I think that the movement—in that sense—for change is coming perhaps at this point as much or more from the patient world as it is from organized medicine. Although certain groups—like surgeons through the American College of Surgeons, and perhaps some other specialties—are really embracing now a very broad concept of palliative care; which I find very encouraging.

GC: Well, thanks again for coming back. I'm glad we finally got to talk about your book. And I started reading your other book.

RM: Well, the other book could be a slog. It's fairly detailed.

GC: It definitely has that PhD dissertation look to it. But I wanted to ask you one thing before I let you go. You mentioned Roy Porter in that book?

RM: Yes.

GC: Did you know him?

RM: I knew Roy very well.

GC: I read, I think, what was his last book. But when I read it he was already dead. And I thought, ‘Gosh, he’s such a good writer, I can’t stand the fact that there will not be any more books by him, and I just discovered him.’

RM: Well, Porter was extraordinary. Porter died in his late 50’s. Now, he had written 50 books by the time he died—something like that; more than that—and had done hundreds of programs (he was English) on the BBC, and countless interviews. He just was a production machine.

He was a total hoot to hang out with. He kind of looked like a Las Vegas gambler after a long night in the casino. He favored that satin shirt, open at the neck, gold chains. He was that kind of a guy. He was a riot. But he also had been a brilliant student at the University of Cambridge in England—a scholarship student from East London—and was absolutely the same with everybody, whether he was talking to the top of the British establishment or the person in his pub. It didn’t matter.

GC: And that’s unusual.

RM: Yes, because he was at the top of the English university hierarchy. And he was a very generous guy. When I was writing my dissertation I was in San Francisco, he was in London, and we had met. He didn’t owe me anything. He wasn’t attached to the University of California system.

Nonetheless he read each chapter. I would get back email comments within a week. He was just extraordinary to me. And over the course of several years I

and hundreds of others considered him a real friend. So, I was devastated to learn he died. He had retired, and was biking to do his work in his community garden, and he had a heart attack on his bike and fell over dead.

GC: I have only read a few of his books, but I could see the influence.

RM: He did a wonderful history of London, and another one called *The Greatest Benefit to Mankind*.

GC: Did he write the one about the history of London? I didn't realize that. I'll have to get that. I've seen it and almost bought it in the past. Now that I know it's him I'll definitely read it.

RM: Right.

GC: Well, I'd better let you go. I've gone over again. But I hopefully haven't made you miss any airplane flights today.

RM: No. You know, what I missed was a bus. I was going to New York and I thought, the bus is \$25, the airplane is \$150. So, I just missed the bus and I ended up—because I had to be in New York—taking an airplane at the last minute. And it was \$300. And you didn't make me do it, I did it.

GC: So, I guess we're going to have to sell a few of your books to make that up. Well, I'm sure anybody that gets your book is going to be glad they did.

RM: Well, thanks, Ginger. I'm pleased that it's worked for you.

GC: Thanks a lot.

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I want to thank Dr. Martensen again for returning to talk about his book, *A Life Worth Living: A Doctor's Reflections on Illness in a High-Tech Era*. I highly recommend this book. Not only is it thought-provoking, but it's the sort of book that can stimulate conversation among physicians, between doctors and their patients, and among family members.

If you would like to explore these ideas with other listeners, feel free to join us in the Discussion Forum at brainscienceforum.com, where we have a special area devoted to the *Books and Ideas* podcast. Of course, you can also send me email feedback at docartemis@gmail.com. And don't forget to check out the Show Notes, including the episode transcript, at booksandideas.com.

The next episode of *Books and Ideas* will be out at the end of June, but I will be putting out a new episode of the *Brain Science Podcast* on June 5th. You can find that in iTunes or at brainsciencepodcast.com.

Finally, I'm going to close by playing a promo for a book by fellow podcaster, Christiana Ellis. To be honest, I originally bought *Nina Kimberly the Merciless* because I wanted to support Christiana's work. But then I couldn't put it down. I promise you, *Nina Kimberly the Merciless* is unlike anything else you have ever read.

Thanks again for listening. I look forward to talking to you again next month.

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Hello everyone. My name is Nina Kimberly the Merciless, teenage daughter of the most feared barbarian conquerer in history—Marcus the Merciless. I'm the star of Nina Kimberly the Merciless by Christiana Ellis, a comedic fantasy coming-of-age story, coming to print on May 15, 2009.

The story has got dragons, wizards, kings, knights, a tournament, magic spells, barbarian armies, evil advisors, all that good high fantasy stuff. But it's also got a contemporary girl-power sensibility that says that a girl doesn't have to wear a chain mail bikini in order to kick butt, and that sometimes waiting around for a quest to find you just isn't good enough.

My book is coming out on May 15, 2009, and I want to climb the charts at Amazon.com. So, please visit ninakimberly.com to find out more, including a free podcast audiobook of the whole story, and lots, lots more. Then, on Friday May 15th please purchase the book from Amazon.com. I'll see you on the battlefield.

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