



In a time when our population is aging quickly, most of us will be called upon to accompany a loved one through the dying process at some point. Living With Dying is a year-long series about how we do that.

New entries in the series are printed every other Tuesday. The full series can be found online at [www.caledonianrecord.com/living\\_with\\_dying](http://www.caledonianrecord.com/living_with_dying).

Leah Carey is a feature writer for The Caledonian-Record. She spent two years accompanying her mother through the cancer journey, which ultimately ended with her mother's death in December 2015. Though she had tremendous support from friends, loved ones, and the newspaper throughout the experience, she still found herself struggling with many questions, concerns, and regrets at the end of the experience. Exploring those issues became the inspiration for the Living With Dying series. You can share your own stories with Leah at [CareyL@caledonian-record.com](mailto:CareyL@caledonian-record.com).

**NEXT ENTRY IN THE LIVING WITH DYING SERIES: AUGUST 2, 2016**

BY LEAH CAREY  
Staff Reporter

Part 6 of 26

# WHAT WE NEED TO KNOW AS WE HELP OUR LOVED ONE TO DIE

Dr. Joshua Lakin has a fascinating convergence of skills: he is a palliative care doctor with a business and finance background and a special interest in both doctor/patient communication and systems analysis.

Lakin is a palliative care specialist at Dana Farber Cancer Institute in Boston. He is also a research team leader at Ariadne Labs in Boston, a joint venture of Brigham and Women's Hospital and the Harvard T. H. Chan School of Public Health, that works to "guide patients, doctors, and families through critical moments in their lives with compassionate, simple and practical solutions." Lakin was recruited to Ariadne labs by two giants in the field of end-of-life concerns: Dr. Atul Gawande and Dr. Susan Block.

As part of his work with Ariadne Labs, Lakin travels to discuss Gawande's bestseller "Being Mortal," teach clinicians about doctor/patient communication, and help communities discover their strengths and weaknesses in end-of-life care.

All of this allows him to speak authoritatively on several subjects that are of interest in this series. Today, we start with his perspective as a palliative care doctor and ask one BIG question: What would you like family members to know about accompanying our loved one through the dying process?

"Many things, if I could get it across. Some of them are really hard lessons, I think," Lakin said during a recent conversation during a trip to lead an end-of-life community conversation in St. Johnsbury, Vermont.

### Forgive yourself in advance

The most important lesson for families, Lakin said, is to let yourself off the hook.

"Number one, which is really important that I always tell families up front: just forgive yourself in advance," he said. "You want to be present, but it's chaos. You just can't fix that sometimes. So you just have to be willing to give yourself permission, and give each other permission, to just do your best."

And while having a larger family team can help distribute the burden, it can complicate it as well. "It's also really stressful, so our bad tendencies float up," Lakin explained. "Just know that there's going to be a ton of uncertainty in this process and try to make sure that you are understanding of each other - if you can be."

"Because it's stressful times," he continued. "Prepare to forgive each other. That's rule number one. It's not going to happen like you think it's going to happen. You're going to have regrets coming out of it. Hopefully you're going to have some beautiful and touching times too. But it's complicated. So

learn to cut yourself some slack from the start."

### It's going to be hard

"These are hard times," Lakin said. "It can be lots of good things - there can be lots of good elements to it. You can have very touching moments. You can deepen relationships. You can learn things about people that you never knew. I've seen so many wonderful human strengths and moments shine through all this work. But it's still hard. So I try to help families to set themselves up for a bit of a rollercoaster in some sense."

Lakin spends a lot of time in hospital rooms with families who are sorting out end-of-life decisions, and it is often fraught with much emotion.

"There's a lot of things we can do to make it better and to make it as comfortable as possible. And I think that there's lots of good that you can pull out of it. But at the end of the day, most people are experiencing a loss of someone who is really important to them," he said. "Fortunately we don't have to do it very often, but that also makes us not practiced. It's not easy. It's not all puppies and kittens. I think sometimes we sell hospice as magical and it's not. There's parts of it that are very wonderful. There are many things about that work that do fill me with wonder - the individual strengths and existential questions and a lot of it is really incredible. And other parts of it that are just kind of brutal daily tasks and hard work. And it is hard."

### Talk about what's really important

While the specifics of an advance directive - feeding tubes, life sustaining machinery, etc. - are important, Lakin wants families to have a deeper conversation.

"It's really hard to predict the future," he said. A person's dying process may never include a feeding tube, but a hundred other interventions that they couldn't predict at the outset. "[The advance directive] is set up as concrete steps - if *this* happens, then do this; if *this* happens, then do this. But the if almost never happens. It's always a different if."

That makes it imperative to understand the underlying desires of the patient, regardless of the medical specifics.

"The important thing is to communicate about what's important and the kinds of trade-offs that you make in your life, and the kinds of functional states that are really important to you and are absolutely unacceptable for people, and the kinds of things you're afraid of," he explained. "The question is not whether you want to have a feeding tube, it's *what makes life*

family conversations, visit [www.caledonianrecord.com/living\\_with\\_dying](http://www.caledonianrecord.com/living_with_dying) and read the week four package of articles on advance directives.]

### Dying is work

The entertainment industry have led us to believe in a sanitized version of death, Lakin said. "It is not like you often see in the movies where people just kind of lie back and are peaceful ... It's a process that we go through, just like birth. And there is labor. There is a labor to dying, for sure. It is work. You can see it in their bodies. Their bodies are working hard at that process."

"With our medicines I can keep people very comfortable, but it's hard to watch," he continued. "In my experience, it's a lot harder to sit vigil than it is for the patients to go through it ... People don't breathe normally. They have moments of clarity. Their fingers and toes and lips don't look normal. Nothing looks normal about it, except that's what normal death looks like."

### Stop trying to 'protect' each other

The final point Lakin shared is more for the patient than the family members, but it's something that can be important to everyone in the circle of care.

He said he frequently sees people who don't want to let their loved ones know that they are dying until the very last minute.

"I think the most common issue - I don't think we've researched this - but the most common issue is that people are protecting each other. Or trying to protect each other," Lakin said.

He tries to impress upon people that the end result is often the opposite. "At the end of the day it's extremely traumatic for people to find out in the last week that a loved one is dying from something. That's just hard. It's not protection. It's harder on people," he said. "They'll say, 'But I don't want to put them through it. But they're going to have to go through it. Period. They're going to go through grief. The more time you give them to do it, especially with you so you can tell them what's important to you, so you can tell them you love them and tell them goodbye and all these things that are really important. The sooner you start that, the easier it's going to be for all.'"

Join us again in two weeks when we explore doctor/patient communication with Dr. Lakin - how it works and how it doesn't.



Dr. Joshua Lakin

worth living to you?"

Lakin gives an example from Gawande's book that features Block's father. "He said, 'If I can't eat chocolate ice cream and watch football, then it's not worth it.' That's really useful information! It's not, 'Do you want a feeding tube? It's, 'What kinds of things do you need in order to make this a quality life? And then to recognize that this might change, so you've got to revisit it over time.'"

[Editor's note: For more insight into having these

While the goal (and usual outcome) of palliative care is to manage pain, in my mom's case, pain was a consistent problem.

And though we wanted her to be able to die at home, her symptoms became too significant for us to manage in the final hours and we had to take her to the hospital (where she was tended to by amazing nurses who were profiled in week 3 of the series at [www.caledonianrecord.com/living\\_with\\_dying](http://www.caledonianrecord.com/living_with_dying).)

By the time Mom died, we had built up a whole host of issues to beat ourselves up with. And for the past seven months, we have done just that - running through those last days and weeks of her life, wondering how we could have done it different/better/more courageously?

Even now, seven months later, it still occupies a lot of our conversations when we're together.

Dr. Lakin said these words to me a month ago and I'm still trying to find a place for them in my psyche. I'm running them over and over in my head, turning them into a mantra of sorts. I'm trying to remind myself that we did the absolute best that we could with what we knew at the time.

I wonder: if we had heard these words prior to our experience, would we have been more forgiving with ourselves?

So I'm highlighting these words so that you will have heard them before you get to that place: *forgive yourself in advance*. I'm really curious to know if they help.

Here is my request of you, dear readers: some of you reading this series will experience the death of a loved one sooner rather than later. Please let me know if these words help you through the experience. Email me at [CareyL@caledonian-record.com](mailto:CareyL@caledonian-record.com), whether it's a month or a year from now. I look forward to hearing from you.

## Training On Death In Medical School

We asked Dr. Lakin about how, with such a varied background, he ended up specializing in palliative care. His answer has a lot to tell us about how doctors are trained.

Here is our conversation.

**Leah Carey:** Did you get any training in med school about death?

**Joshua Lakin:** No. Not that I remember. I got a lot in residency.

**LC:** That seems like a huge hole.

**JL:** It's a huge hole. The students that I'm working with now at Harvard, they get more training in this. But it still is a hole. I guess the challenge is, when is the right time?

Read the rest of the conversation on our website at [www.caledonianrecord.com/living\\_with\\_dying](http://www.caledonianrecord.com/living_with_dying).

## A GRACEFUL GOODBYE

Personal reflections From Leah

When I sat down to talk with Dr. Lakin, I wasn't sure where the conversation would go. Over the course of the first 45 minutes, it bounced over all sorts of topics: his background, how the American medical system is funded, what the data shows about people's end-of-life preferences, when the right time is to train medical students about death, and so much more.

Our time was winding down when I asked the question that had been brewing in the back of my mind since the moment I learned that I'd have the opportunity to speak with him: What would you like family members to know about going through this process with their loved one?

I teared up as soon as he started answering the question: *forgive yourself in advance*.

Wow. It's something I wish someone had said to us in the final month of my mom's life.

Mom was always an extremely active and vocal participant in her own care. That remained true into those final weeks, but as she became weaker she became terribly confused - it was like all the right puzzle pieces were still inside her head, but they were in all the wrong places.

Mom's best friend Sue and I spent as much time managing her confusion as we did managing her health. It amped the already-high stress level through the roof.

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