

Piloting Compassion in Caregiving with Jonathan Knaul

Candace Dellacona: Welcome to The Sandwich Generation Survival Guide. I am your host, Candace Dellacona, and I have a special treat for all of our listeners today. I'm going to introduce him and probably embarrass him because his background is so impressive. But please allow me to introduce all of you to Dr. Jonathan Knaul.

Not only does Jonathan have his PhD from the Royal Military College of Canada. He is a graduate of the French Military of Defense Test Pilot School. He served in the Royal Canadian Air Force as a pilot commander for more than 30 years, and he flew tactical helicopter missions in Kosovo and Afghanistan, for the NATO joint task force.

Jonathan's currently retired, but he's not stopped flying. He's based here in California in the US and he continues to train pilots at the national test pilot school in the Mojave. If that's not enough, Jonathan is an author of a memoir and a guide for caregivers called "Final Approach, a Test Pilot Story for Caring for Loved Ones." So, Jonathan, that is the longest intro I've ever had the pleasure of introducing a guest. Welcome.

Jonathan Knaul: Thank you.

Candace Dellacona: We're so happy to have you here. Really, it's just such a treat. And I have to say I never thought that I'd have a wartime test pilot providing advice on surviving the sandwich generation, but here we are.

Jonathan Knaul: It's really exciting to be here, Candace, and we had a great discussion yesterday and thank you for this wonderful introduction. It's very flattering and thank you very much. And I wish I was truly retired, but I'm certainly not. My job keeps me very, very busy as we talked about.

Anyways, I'll just say I'm very happy to be here. It's a real honor and a real pleasure and, tell the listeners thank you very much for tuning in and giving me this opportunity to speak with you.

Candace Dellacona: Yeah, so let's just jump right into it. When you think of a person who you know has all this knowledge to impart in this particular space, I don't think many of us would presume it would be a pilot to provide it.

Obviously my first question is what led you to write your book?

Jonathan Knaul: It definitely came from the heart. I, it was a few things. Probably first and foremost, I felt a duty to give back to the community about what I learned from caregiving because it's so hard and which pairs with just my personality, I suppose, which is one of the reasons why I joined the Canadian forces was to serve. So I, I felt I had a duty of care literally to transmit this message. And at the same time, I so much wanted to, record, chronicle, my parents' lives. It's a love letter to them in many ways. And, I wanted to tell their stories, their extraordinary live stories. And I wanted to wrap in a bit of my story too, of my career, which has been very unique as you highlighted.

And it's a real honor to do what I do. And I'm lucky to be able to do it. There's a lot of luck that goes in there. I wanted to, I saw a platform to wrap all that together and I really saw a way to tell that story of caregiving, based on the story of three lives, mine, and my parents to do that in an interesting way. Again, there were some wonderful guides out there, outstanding guides on caregiving. And I wanted to give

something that was truly interesting and, I'm a vulnerable guy. I am, I'm happy to be vulnerable and to do that story. So I saw that opportunity as well to write a book that while it is about me, it's for the reader, and I could do that.

And if that answers your question a very long-winded way.

Candace Dellacona: So first of all, we're so lucky that you actually took that opportunity to write this story, and in some ways it's a cross between a memoir and a guide for those of us who find our selves in similar situations and caring for older relatives or older loved ones.

I really admire the way that you framed it, saying it's kind of a love letter to your parents.

Why don't you tell us a little bit about your mom and your dad?

Jonathan Knaul: Uh, I might get a little choked up. I tend to do that. I cry at movies. I cried watching ET so, I'm that type of person.

They're really amazing people. Uh, no specific order. My father first, who really was an extraordinary man, if anybody was a Renaissance man, it was my father, Sigma Knaul.

He was born in Poland in 19, uh, well actually it could be 23 or 24. There's a debate on the records, but, he was born, in that year timeframe and, so his family was rounded up in, late 1939. And, off to ghettos and then off to camps and of a very large family, only he survived.

He survived a year in Auschwitz. From Auschwitz, he was transferred to Dachau, out of the frying pan and into the fire literally. He survived Dachau as well. He and a half brother survived from a very large family. His story of what he went through and his story of survival on their own are extraordinary.

And then he came to Canada and became, a successful, businessman, if you will. And, he was an Olympic level skier. Had it not been for the war, I'm sure he would've been in the Olympics for downhill skiing. He taught himself skiing on wooden boards and leather boots and, he could dance on skis. And he spoke six, seven, I have to look again, six or seven languages, literally of all fluently. And he was a handsome guy too. And so handsome devil. He was quite amazing. An athlete, he suffered terrible PTSD, and at a time when, in the seventies, through the fifties, sixties, seventies, Holocaust survivors were not talking about, what they went through outside of a very closed circle.

And generally they weren't speaking about that. And my father was one of them. And the treatment wasn't there either in the recognition of PTSD. So my childhood with him as much as I. I loved and adored my father was very challenging and he was very much a monster. Not his fault. Very challenging, childhood for me with him. But he was an amazing man and, I could go on and talk about him for a long time.

My mother was British and she was born in definitely 1923. They were essentially the same age and, she lived through the bombing in London. She went and helped out at the evacuation at Dunkirk at age 16. Just got on a boat and went out and helped. That gets me a little cracked up. Uh, pardon. And. She lived through the whole bombing. She was a breadwinner of the family, during a very challenging time. And, she was a cross between, queen Elizabeth and Betty White. Her sense of humor was extraordinary, and so witty.

And she was so graceful and, regal, I would say regal. And, so she lived all the way till, she almost made it to 99 and she was, really quite something. Um, And of course I adored my mother and she, despite all what she went through, was, a very mentally healthy person and really a rock and, if I turned out well, I'm, I'm thankful to both my parents, but certainly my mother played a big role in that. So she was, she was very special. Yeah.

Candace Dellacona: Yeah.

I think, it's interesting when you talk about your relationship with your parents and in the context of caregiving where you know you can have complicated relationships with your parents and your loved ones and still love them and when it comes to the caregiving space and you take on this role for someone who you may have a complicated relationship with, one can see why it could be so challenging aside from the fact that it's just challenging to start.

So I love how candid you are when you talk about the complexity of that relationship. One of the things that we talked about earlier was the impact that the older generation, and their trauma had on them, because it's a generation of people who by and large never really had the accessibility to therapy and things like that, that we have and those resources.

So our heart goes out to that older generation that didn't have the same support perhaps that your dad obviously deserved and very much needed. It's wonderful that he found someone as extraordinary as your mom and he was able to create a life with her. I know your father had passed away, significantly earlier than your mom did, and you were a caregiver for your mom. Is that right?

Jonathan Knaul: Yeah, I was, and I care for my father too. And so I bring that out in the book. I can mention that too here. My father died at age 60. It started, it was very fast. He lasted about six months. It was stomach cancer, probably related, largely in part to, malnutrition suffered, during the Holocaust. So he was well taken care of in Mount Sinai Hospital in downtown Toronto. But, my sister and I, you know, this was the 1980s. Cancer wards were not as advanced as they are now. They were really pretty good, but still it was the eighties. So a lot of support from my sister, myself, and my mother.

Healthcare workers, are always, under-resourced in most places, so I did do a lot of my father's care in the hospital, full on even for his most private needs. And I was 15 at the time. So that was, a baptism by fire, if you will.

Candace Dellacona: Yeah, I'll say.

Jonathan Knaul: And, despite his, the complicated relationship, I was, it was not only my duty, but I loved him and I was gonna do that for him, for sure.

And so we made him comfortable until the end. And yes, my mother, that was much later in life. And that it really went on for about 10 or 15 years. She had a slow decline and then it picked up in the last, the rate of decline picked up in the last couple years. So, and I did take care of her, moved in with her and took care of her full on as well.

Candace Dellacona: As a caregiver in the context of your caregiving, there were two very different roles that you played. One, you were child still when you were taking care of your dad, and then, when you became the caregiver for your mom. You were obviously very much an adult and she suffered a disease of the aged and someone who was more vulnerable probably because of her mental compromise.

And so in the context of, you writing this book and, providing advice and the guide to the readers, what is something as a caregiver that, you were able to do for your mom that makes you maybe the most proud?

Jonathan Knaul: Hmm. I think there's a lot of things, if I could wrap it up in one, I believe it was retaining her dignity for her. My mother was a very dignified person. Anybody who gets ill and now needs care and can't care for themselves, is vulnerable to losing their dignity and really, across the spectrum of human beings, we all, strive to retain a certain level of dignity. And dignity is so important. So I really strove to do that for her, even when I was, you know, um, dementia. People with dementia communicate in different ways, but there's a person, no matter how bad the symptoms are, and their condition, there's still a person inside. There was a heart pumping and there is an emotional and a spiritual heart in there too. And so, when I had to take care of her very private needs, as much as that was hard for me, it was probably harder for her to have her son do that. And I approached in a way that, would provide her with dignity. Is what I was thinking of, when I moved her into dementia care, which was a very difficult thing to do. I still strove to do that and so I made sure that her hair was really important to her. I made sure that her hair was taken care of. I made sure that they dressed her in her clothes, and did the little things I knew made a difference for her.

If I could, use a good example. My sister loves this one. I sewed her stockings for her, her legs got particularly, she lost a lot of weight in the last year. But I still, I knew that she wanted to be dressed well. Her stockings were stay up stockings and her legs had gotten quite a bit skinnier and they weren't staying up anymore, and we couldn't find a size for her.

So I sowed them at the top. So they were just tight enough that they would stay up because, seeing her when I walked around and saw her one day in the dementia care facility and her stockings were around her ankles, I'm like, that's just not, I knew that at some level that would bother her. So, um, to make a simple example.

Candace Dellacona: Yeah, that's a great example and I think advocacy also can look, different in so many different ways than what you just described is really an act of love, but an act of advocacy as well, because. It was really important to you for the outside world to see your mother as this regal and dignified person because you knew it was important to her.

So it's a really beautiful gesture for any of our listeners when they think that, perhaps they're at their end of their rope and they're looking for ways to help their loved one when they're so far away, because of their mental incapacity. These small gestures really can mean so much, and, truly is, can be an act of love.

So I really admire that answer.

You're coming at this as a son, as someone who has been in sort of these high pressure situations your entire career. You're making all of these really split second decisions as a pilot, really stressful decisions. And so how do you think your career as a pilot, if at all, helped you in your caregiving role?

Jonathan Knaul: Yeah, it, it helped me out tremendously. I have developed, mechanisms to deal with, stress. For sure. I've had to and I've had training in it as well too in my military career. And, in all that experience I've had, builds on that. All that helped. I wrote a chapter in the book just about decision making, and in there I tried to break it down in time because here's the key with tough decisions is, use the time available. So the split second decisions, that wasn't, that did help me in a certain regard in caring for my mom. And, I also have experience in a healthcare first responder role too.

So that helped. But, the thing where the longer term decisions, those are the tough ones. And in your background as an estate, lawyer, you'll well understand things like making decisions on powers of attorney, that sort of thing. I really tried to look at those bigger decisions and understand about the time I had available and always understand, and I worked with my sister on this and I love my sister dearly.

And thankfully we were, we are, we were close and we were able to, we had our challenges for sure, but we were able to meet in the middle and realize that the decisions we were making. Ones that we had more time with, which was most of the time were in, had to be in our mother's best interest. And that's a tough time, the tough one when you're caregiving, you can get very, we all get very emotional. We're humans and we're under stress. And to recognize that those are normal emotions, responding to stress, and to try and recognize them, put them over on the side and then say, what's the best decision that I can make in the patient or the loved one's interest and gosh, do I have time? So can I wait till tomorrow? And, and if it can, let's get all the facts that we can. So I think that it wasn't just as a test pilot that helped me. It was more as a military commander because, especially in places like Afghanistan, I was responsible for a lot of people and I had to send, I went out the door, into threat environments with them. And oftentimes, I had to send them out while I stayed, inside the wire. And so you have to make some really tough decisions in those cases. And, so that, that helped me.

Candace Dellacona: So, it's interesting you bring up your role as a commander, right? Because in, in a way, when we become a caregiver for someone who is not able to advocate for themselves, that's who we become in their lives to the outside world. And maybe even to our siblings in a way that our siblings don't love.

Let's talk a little bit about how to share that commander role and taking charge and having someone else who may not see eye to eye on the way perhaps things should be done. Do you have any advice for our caregivers who are trying to get along with their fellow caregivers, whether it's a sibling or a spouse or someone like that.

Jonathan Knaul: It's really some of the most difficult thing or things to do. I think first and foremost is to take care of yourself. It's like the oxygen mask, council that you get when you board an airplane. Put on your oxygen mask before you put on your kids' oxygen mask. You gotta take care of yourself first, because when we don't take care of ourselves, then emotions start to run higher. And, we're just less able. And if you're not in the best position, then you can't give the best care to the loved one. And so it becomes harder to work with the people you have to work with, whether it be siblings or whoever. So find those ways to take care of yourself. And the other thing I had to do sometimes was I really, I had to take those breaks to say that those were emotions and I need to put them aside. And the other thing I really had to realize too, this is a tough one. Is that despite what you're sensing from the other person, it's like any negotiation you do. Despite the challenges I might have been feeling, getting from my sister, I had to realize that my sister's goal in all of this was the same as mine. She wanted the best for our mother. And, and she was doing the best she could to try and parlay that, to transmit that. And maybe I wasn't seeing that as a result. And so I had to step back and recognize that. And when I did that, things got easier. And then I would also say to her, Felicia, I adore my sister.

She's, I look up to her too. She's amazing. I would say, Felicia, hey. We're in violent agreement, and all. And then things will cool off. And also I think a key term is, disagreement. I would say this to my subordinates too. My troops, disagreement does not equal disloyalty.

Please not in front of everybody. Don't tell me that you disagree and you're, take me aside. Let's do this privately and you can tell me about all your disagreement. And that's good. Disagreement is healthy and it does not equal disloyalty, and there's a time and place to do that. I'll add that it's not only with a sibling or

somebody you love, but I employed personal support workers. And working with them could be really, really difficult at times. And they were my employees and I could not treat them like military troops. And the biggest thing for me to recognize was, which is often the case in the personal support worker industry, is that these folks, traditionally, I look to pay them well, but traditionally are not paid well. They do not. Come from wealthy environments and they're often living in multi-generational homes where they are also taking care of a loved one. So after they take care of your loved one for eight to 12 hours a day, they go home and they're taking care of a loved one in their own home. Plus they multi-generational.

They have kids, they have spouses, and so their life is incredibly complex. And so I had to recognize that.

Candace Dellacona: I've had a lot of, guests, and we talk often about caregivers and the personal needs attendant or the home care attendant, whatever the term you wanna give them. And something that you just said, Jonathan, I don't think anyone else has really thought of is, and you're right, that, the caregivers that we're employing to help us advocate and care for our loved ones are also dealing with similar issues.

So that's a really nice reminder for those of us on the other side to think about it as well as seeing it from Felicia's side in your experience and looking at your sister and knowing that she too has the best of intentions to advocate for your mother, just as all of our listeners who have siblings or other people in their family who are trying to help.

If you take a step back and think about, your ability to advocate together and what that might look like and it is hard to give up control and delegate, and I'm sure it was. For someone like you too, who was used to being the commander, and certainly that was what you were relied on to do.

You certainly couldn't back down on making a decisions because people were relying on you in the same way your mother was relying on you. And one of the things that you also said, which I loved, was when you have the time to make these decisions. And I think that's really important because when you love somebody with dementia, it doesn't mean that they can't participate in the decisions being made for them, and that's one of the things that you also pointed out.

Jonathan Knaul: Yeah, if I've, can I give you a quick example? Is there time for that? Yeah,

Candace Dellacona: Yeah.

Jonathan Knaul: We had a real challenge, with my mother had put in her will that she wanted to be cremated and she had revisited that will many times over the years. And, was a very exhausting and adamant I want to be cremated. And she had even bought herself a plot, to be buried next to our father. Except that the Jewish religion doesn't allow for cremation, and the plot she purchased didn't allow for cremated remains. And so this caused a lot of confusion. Because of my legal position I had access to the will early on, and I knew that my sister asked for the will I gave it to her right away when she did ask for. And, she found out about that, which I hadn't really thought about. And this was a problem. And so we really had this controversial over our mom must be cremated. And one of us was like, that's okay. And the other one was like, we can't do that.

And it became quite heated. But ultimately I said, let's ask mom what she really wants now, but Mom has dementia. I said, but yeah, she can still communicate. And where my mother was really good at communicating was if we got into anything that was logical or technical she lost that capability. But anything that was emotional, she was right there. I'm like, dementia defied. And she was there with us. So we had that discussion with her.

We brought the rabbi into that discussion and and my mother, we got to a place where it was my mother said, we, difficult discussion. We had to do it two or three times, but we broached it carefully. We brought her into the discussion. She said if it makes you all happier, I'm okay to be buried. And that's what we went with. And, it really just reduced a whole lot of things. It was very hard to do. Where we knew our mother was probably only gonna last another year. We had to sit down and talk with her about what she wants to be done with herself. And, we did it, over the course of three conversations during COVID. Me sitting with my mother like I am with you now, the rabbi, virtual, my sister virtual. 'cause I was back in Toronto with my mom. My, my sister was in Miami where she lived at the time with her family. But we got there and, gosh, when the day came that my mother died, having that sorted ahead of time when things are really emotional, when somebody passes, we didn't have to worry about that. Because we have it sort.

Candace Dellacona: Yeah. And it's sort of a masterclass example of, dealing with a difficult topic, dealing with somebody who doesn't have full capacity, dealing with, the possible disagreement among family members. And it sounds like despite the fact that it was probably pretty charged, you had a really successful outcome.

And it's a great lesson to all of us that there really shouldn't be a topic that's off limits as hard as it is. And I think that's one of the things that, you brought out in your book and our conversations have been, you can ask me anything that, this should be a subject that is brought out of the shadows.

And you can talk about the most difficult and intimate things to make sure that you can advocate. Because what you did there too is you preserved her dignity. So going back to advocacy and dignity and determining the way in which she would be dispositioned is really a beautiful gift that you provided to her.

Jonathan Knaul: Yeah, it worked out well. And I think the other thing there I had to realize was. For all those out there who are not, single children who have, siblings. We all have default mechanisms still to this day. My sister says a certain something and I have this reaction inside myself.

I'm like, why am I reacting that way, what I did when I was five or seven years old? But I recognize it. And that's what I did. I tried to recognize those default mechanisms and to take myself back to being an adult and say, that's my honorable, lovely sister who's communicating in her own way and, I need to meet her there

Candace Dellacona: Absolutely. I think that's a lesson for all of us, right? That it's really hard not to revert to those roles, that we once played and really try to put someone else's needs above ours, even our own personality, perhaps defects. So I love that you're right, and just stepping out of your way, taking the breath, taking a break, looking at somebody else with appreciation.

All of these are good lessons. I think what I'll ask you, for the final question, and I really encourage all of you to go out and get yourself a copy of Jonathan's book because it really is such a beautiful, memento to his parents' story and his own journey. Can therefore serve as a guide to everyone else who's out there struggling and wants a different perspective.

But one thing I wanna know, Jonathan, is is there something that you wish you knew when you first became a caregiver that kind of came to you slowly, that may have made it easier on you if you knew it maybe before?

Jonathan Knaul: Yeah, and I, I think we spoke about this yesterday. I wish I knew how vulnerable I was gonna be to caregiver burnout. In my career, well, I grew up with a father who had PTSD and in my career

I didn't suffer PTSD. I'm very lucky. It's individualistic. Many of my colleagues, subordinates did. I have many friends, who have PTSD. I understood it. It's in the family of, there's a family there along with PTSD of operational stress, and caregiver burnout is in there as well too. And then I experienced that with my mother. When I did experience it, I recognized it for what it was, and I got the help I needed, thankfully, thankful to my, like I needed to do that.

But I just didn't expect it. So thankfully I had some training there, so I recognized it, and dealt with it. But, I just didn't expect it. I really just thought this, I was going to go forward as little soldier, me and, soldier on and take care of my mom. And, it was a bit of a slow onset and it just, all of a sudden there it was.

And, and the effects are quite. It can be quite pronounced, frankly, both physically and mentally when that happens. I just didn't expect it

Candace Dellacona: It and it goes to show you, you have this incredible background in training and how to deal with stress and really be able to metabolize information and make those decisions quickly, and it affected you in the same way it affects most of us. So I hope that gives, our listeners a feeling of a little bit of solace, that even among the best of us, none of us are immune from that burnout, and it's so important to recognize it and ask for help and really that's why I do the podcast. I think that's why you wrote the book. Really because creating a sense of community around a really difficult topic can make it a little better.

Jonathan Knaul: Yeah, it is. I'll say, I'm really trying with that community. It's all about the community. I grew up in a boarding school that was Quaker and preached that idea of community. And I grew up that way, and I'm all about that. And so if I could add that, thank you for promoting part of me listeners to get the book, and I hope they do and it helps 'em.

Please. Also, I recommend listeners to go to my website. one word, finalapproachbook.com. And if you subscribe, you'll get my free caregiving plan and my newsletter, which is all about, you are not alone as a caregiver. And I really, I take pride in joy in, building that community, and getting the word out to folks that I hope is really helpful to them.

Candace Dellacona: Well, we are lucky to have you as part of that community, Jonathan, and from the bottom of my heart, thank you so much for being so vulnerable and sharing your story. And sharing your parents' story as well and your path to get here. Your book Final Approach, a Test Pilot Story of Caring for Loved Ones is out.

And I really do recommend that everybody pick up a copy. And thank you so much for spending time with us, Jonathan. I really appreciate it. It was so much fun to get to know you, and fly safe.

Jonathan Knaul: Thanks. It's been my honor and pleasure to be here on this podcast, Candace. You've been brilliant as, an interviewer and it's just really nice and again, absolutely my honor. And thank you to all listeners for tuning in once again, I really appreciate it. This has been a pleasure.