

# Preparing for the Unexpected: Advance Serious Illness Planning

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SPEAKER	TRANSCRIPTION
N/A	<p data-bbox="522 674 1526 730"><b>[00:00:00.00]</b></p> <p data-bbox="522 730 1526 800">[MUSIC PLAYING]</p>
DORETTA THOMPSON:	<p data-bbox="522 800 1526 863"><b>[00:00:10.69]</b></p> <p data-bbox="522 863 1526 1073">Hi, you're listening to Mastering Money where we explore the many aspects of good financial decision making. I'm Doretta Thompson, financial literacy leader for Chartered Professional Accountants of Canada. We provide no-cost programs and free online resources that help Canadians own their finances and learn the language of money.</p> <p data-bbox="522 1073 1526 1136"><b>[00:00:31.61]</b></p> <p data-bbox="522 1136 1526 1283">This season, we're focusing on important money conversations. Why? Because discussing finances may be uncomfortable. And in some circles, talking about money can even be taboo, but it really shouldn't be. It's important to start conversations about money and keep those conversations going.</p> <p data-bbox="522 1283 1526 1346"><b>[00:00:52.87]</b></p> <p data-bbox="522 1346 1526 1619">Today I'm joined by Dr. Daren Heyland-- critical care physician, professor of medicine at Queen's University, and creator of the Plan Well Guide. Dr. Heyland is here to talk about the importance of planning ahead in case you or a loved one falls critically ill and is no longer fully capable of making decisions-- including decisions around level of care when in the ICU. And why it's important for accountants, financial planners, lawyers, and other advisors to be aware of the importance and the impact of these conversations.</p> <p data-bbox="522 1619 1526 1682"><b>[00:01:27.74]</b></p> <p data-bbox="522 1682 1526 1745">Dr. Heyland, thanks so much for doing this today.</p>
DR. DAREN HEYLAND:	<p data-bbox="522 1745 1526 1808"><b>[00:01:30.87]</b></p> <p data-bbox="522 1808 1526 1869">Thanks for having me on your program, Doretta.</p>

**SPEAKER****TRANSCRIPTION**

DORETTA THOMPSON:

**[00:01:33.74]**

Tell me before we begin, a little bit about yourself and your career path, and how you came to the conclusion that we need to find a way to talk about not dying.

DR. DAREN HEYLAND:

**[00:01:44.56]**

Yeah. Well, it was really based on my professional experience as a clinician where working in an intensive care unit where people are super sick and having to make life and death decisions. And in that context, people who are sick aren't able really to interact with us, right?

**[00:02:03.37]**

And so we're co-opting a family member-- usually a family member or a substitute decision maker of some sort. But usually, a family member to make those life and death decisions. And oh, my gosh. Those poor family members are already super stressed out because they have a loved one who's critically ill.

**[00:02:19.03]**

And then on top of that, we had that burden of making these life and death decisions with us. Because we want to make sure we're giving the treatments that are right for that individual. And so it involves knowing that person's, their values, and their preferences. And so we need someone to represent them.

**[00:02:34.72]**

And after so many years of doing this and realizing that we're stressing people out at a very stressful time of their lives, it occurred to me, why can't we back this up a little bit and work upstream and help people think ahead and plan ahead for if and when they are seriously ill. They have prepared and capacitated their loved one to best represent them.

**[00:02:57.67]**

Could we diminish or alleviate some of that suffering that occurs in the context of serious illness by working upstream? And so that's what led me to start this project or this program. For many years, I did a lot of research. I'm also a medical researcher, and so I try to understand and find ways of improving communication, and decision making, and preparation of that substitute decision maker. And that's really what led to the evolution of Plan Well Guide.

DORETTA THOMPSON:

**[00:03:26.40]**

And why is it important-- do you think for accountants, financial planners, lawyers, other advisors, to be aware of this?

DR. DAREN HEYLAND:

**[00:03:34.23]**

I really would appreciate their support and interest in this space because they sit knee to knee with their clients at a time when people are open to thinking ahead and planning ahead. And people are most concerned about two things-- their health and their finances. And right now we're working in silos, right?

**[00:03:52.03]**

Like I sit there with my patients and I say, oh, you should do this and accountants, financial planners, others sit there and work on their finances. But it would really add value to your relationship with your clients if you put a nudge in to hey, go off and do your health planning too. It's going to impact your finances too, right? Like if you have a critical illness or you become disabled from a serious illness, it's going to impact your financial planning.

**[00:04:17.09]**

So it kind of makes sense to go hand in hand. And we're not asking accountants to be doctors and to do health planning. No, we're asking them to nudge their client, to go off and be virtually led by myself through this process that will help them be better prepared if something untoward happens to them. So it seems to me like a good fit.

DORETTA THOMPSON:

**[00:04:39.21]**

And it's something that we in the financial literacy world are very, very aware of. The importance of behavioral nudges. Things that help people make good decisions at the right time when they're open to that kind of thought process, et cetera.

DR. DAREN HEYLAND:

**[00:04:51.81]**

Exactly.

DORETTA THOMPSON:

**[00:04:52.81]**

So can you give us a quick look at what actually happens when somebody falls critically ill? What's that environment like? Because I think for a lot of us, our idea of what critical illness might be comes from television or it might come from very outdated experiences. Or we may have these preconceptions about end-of-life care and critical care is not necessarily about end-of-life care.

DR. DAREN HEYLAND:

**[00:05:20.88]**

Actually if I could start there, Doretta, I'll make that point that there is some confusion in this space because the average person thinks they're planning for their death. They go to lawyers, for example, and they fill out forms where they're naming their substitute decision maker and they're giving instructions in those forms-- whether it be a power of attorney in some provinces or a personal directive in Alberta or whatever.

**[00:05:46.19]**

But in the language of that form is, if I am dying, then this is what I want, or this is what I don't want. Or if I am in this persistent vegetative state or this hopeless state, this is what I want, or this is what I don't want. And unfortunately, that's not the lived reality when you get seriously ill. As you know, you probably end up in an emergency room somewhere where a doctor is assessing you and saying, oh, this is critical.

DR. DAREN HEYLAND:

**[00:06:10.98]**

Or in other words, your organs are failing and we need to Institute treatments that will hopefully allow you to recover. There's a probability that you can die from this because it's serious, right? Whether that be from a COVID pneumonia as is a real issue for us today, or get hit by a bus crossing the street, or a major heart attack, or a severe stroke. Those kinds of serious conditions where there's a probability that you could die.

**[00:06:41.22]**

But there's also a probability that you can recover. And this is one of the most common mistakes that people make is they think they're planning their death. So they write something or they say something to somebody that says, when I'm dying, I don't want to go to an ICU, I don't want to be on a machine.

**[00:06:58.77]**

And then I say, well, did they know that with some treatments in the ICU and some days maybe, we could turn them around, we could get them back out the door the way they were. And I go oh, no, no. I don't think that's what was being understood. And so I'm trying to correct that by framing it as advanced serious illness planning. This is not end of life planning.

**[00:07:22.68]**

Another major reason why I, as a critical care doctor, I'm doing that, is because at the point where I have to make decisions, at the point where I have to decide, do I put you in the ICU? Do I use my powerful medications and my technology to support your failing organs, to give you a chance of this? At the point where I have to make that decision, again, I don't know if you're dying.

**[00:07:44.88]**

So that statement that you made or are you express to somebody, in the heat of the moment, trying to apply those end-of-life plans to now this new context-- in the heat of the moment. Under the stressful conditions, under conditions where we don't have time to really have a full conversation.

**[00:08:03.76]**

And so rather than trying and keep doing what we've been doing-- which is helping people think about their end-of-life wishes, we're reframing this as advance serious illness planning, thinking ahead that, when I get critically ill-- and there's going to be decisions made by an emergency room doctor, or an ICU doctor, or some other specialists, that you need powerful medications or powerful machines to support your failing organs, we need a plan.

**[00:08:27.94]**

We need to know what your values and preferences are. And like I said earlier, people are so sick. They're not able to express them. So we need someone to advocate or represent that person. And so what Plan Well Guide does is enable that. It educates people to have their really informed treatment preferences and their authentic values come to the table, come to that discussion with that ICU doctor or that ER doctor so that the person gets the medical treatment that's right for them.

DR. DAREN HEYLAND:

**[00:08:56.10]**

If I can just segue into that a little bit, that's another main reason why doing this planning in advance is so important because, unfortunately, there's a lot of medical error happening in acute care today where people are receiving invasive or intensive treatments that they didn't sign up for or that they wouldn't have wanted had they had had more comprehensive planning conversation.

**[00:09:16.59]**

And that too adds suffering to the person, to the family-- let alone is a waste of our precious health care resources. So the more people lean into the space of think ahead, plan ahead the, more likely they are to get the medical care that's right for them, the more likely their family member or the person representing them is going to have a better experience.

DORETTA THOMPSON:

**[00:09:37.56]**

So with an alternate decision maker-- I know they're called different things in different provinces. But let's just call it that for convenience. As an alternate decision maker, what kinds of questions are the doctors going to be asking you?

DR. DAREN HEYLAND:

**[00:09:50.70]**

Yeah, great question. And it really depends on the context or there could be decisions about their medical care-- which I have some expertise over. But there also could be questions about personal care. If you survive in an incapacitated state now-- not able to think for yourself, look after yourself. You still need those alternative or substitute decision makers to decide where you live, what you eat, who could have access to you, what kinds of things might happen to you.

**[00:10:16.61]**

And then there's the financial decisions too if you're not able to look after yourself. But let me come back and talk about the kind of medical decisions, which I think maybe your question was more pointed towards. And generally, it's the application or not of life-sustaining treatments.

**[00:10:32.62]**

Or if those treatments got initiated by an ambulance attendant or an emergency room person because there was no time to talk and make decisions-- let's say they came in in short of breath and in extremis and they needed to be intubated-- which is putting someone on a breathing machine, then that decision still needs to be made about the continuance or the withdrawal of life-sustaining treatment.

**[00:10:55.87]**

So there's lots of other medical decisions that are less important. And oftentimes, we don't even involve patient and family in which antibiotic or how much Lasix or those sorts of things. But generally speaking, we're talking about these big overall goals of care. Are we striving to use our technologies and our tools to keep this person alive at all costs? Or rather is this someone that's aiming for a comfortable dignity-preserving exit out of life, or somewhere in between where we're not sure?

DR. DAREN HEYLAND:

**[00:11:29.77]**

And so let's try it for a while and see what happens and stay in dialogue. And as the case as the person's illness trajectory evolves. We often get greater clarity in terms of what's going to happen. What kind of outcome might we expect? And once we have a better idea as to what that outcome be at death in the one instance or disability and the other instance-- whether that's major or minor, we need someone to represent that person and say hmm, given this scenario, what would this person would have wanted?

**[00:12:01.28]**

So again, if they've done their planning and they've documented their values and preferences, it becomes an easier decision for all parties involved. But you can imagine that poor person who's a family member put in those circumstances of making these life and death-- life-prolonging or death-causing decisions when they've never talked about it with that family member. When they don't really know their wishes.

**[00:12:23.95]**

And so that's what we're trying to avoid. That's suffering that comes from not having thought about it, planned for it, and discussed it broadly with the family or social circle around you.

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DORETTA THOMPSON:

**[00:12:33.99]**

I'm very interested in what you had to say about values and the importance of values and articulating values. Because that is something that from a financial planning perspective, we try to get people to step back and think about what your core values are and then to align your decisions along with your core values. And I find it very interesting and sort of inspirational that that's the same kind of compass that you're looking for, is values.

**[00:13:03.22]**

How often do people-- in your experience, have they actually stepped back and thought about their values and talked about that with their loved ones?

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DR. DAREN HEYLAND:

**[00:13:12.53]**

There's two dimensions to the problem. One is that haven't thought about it and that's very frequent, by the way, to answer your question directly. The other is they thought about it in a way that isn't helpful or doesn't guide decision making. I'll give an example of speaking to a woman whose older husband was mechanically ventilated with COVID in the ICU for two weeks.

**[00:13:35.99]**

And trying to approach that decision of do we continue or not? And probing her to say, has your husband ever talked to you about his wishes for medical care if he were seriously ill? And she said to me, yeah, he said that if he were ever in a coma, that he would never want to live on machines.

DR. DAREN HEYLAND:

**[00:13:58.76]**

And as if that is sufficient in being able to express one's value structure, that should inform my treatment decisions. And I'm not trying to be critical of that laypersons understanding of what goes on in ICU, but I'm trying to illustrate that, well, we wouldn't offer long term machines to someone in a permanent coma in the first place.

**[00:14:19.35]**

And so the scenario that's described there's really relevant to what we're talking about today. And it caused me to think, how can I better extract values information in a way that informs treatment decisions in a very transparent way? Can I use a financial example? I just met with a financial planner not too long ago and there were some questions about risk versus return. What kind of person are you?

**[00:14:45.89]**

If you just sort of ask me in a unidimensional way, how much risk are you open for and I say, small, moderate, or large, the financial planner would then have to make a translational step to say, well, OK, if that's what he's saying, well, then this is the product or process that I would recommend that has a certain level of risk and a certain return on investment.

**[00:15:05.84]**

But a better way to approach that question is to very transparently show the trade-off. If I am willing to take more risk, I'm going to get a greater return on the investment. So the way you ask that question tries to highlight that tension or trade off between risk and return on investment. And even a much better way would be to-- in a very transparent way, well, if this is the level of risk, this is the level of return of investment, this is exactly the product that I would recommend.

**[00:15:31.21]**

And there must be tools and ways of having that very reliable transparent conversation. That's what I've done with Plan Well Guide in the context of medical decision making. I've tried to ask the values questions in a way that I highlight the competition between two competing values. For example, quality and quantity of life.

**[00:15:51.61]**

If you tell me, I'm the kind of person that wants to live at all costs, well, that's going to come at the expense of your quality of life-- the quality of life you experience during critical illness and if you survive, depending on certain circumstances, you're going to survive in a much reduced quality of life.

**00:16:08.99]**

And so I want to be able to elicit values in a way that highlights that trade-off and transparently connects then-- what the person says is their value statement to the preferred or to the recommended medical treatment. So in Plan Well Guide, that's exactly where we use constraining values, clarification tools, and we connect those values questions or their answers to their values questions to a grid-- which in a very transparent way, shows what medical treatment might be right for someone.

DR. DAREN HEYLAND:

**[00:16:37.66]**

I say “might” be right for someone because I don’t expect a layperson to figure this out all by themselves. I try to provide information so that they’re informed and they think they have a leaning or a preference. But just like, well, I guess there’s a lot of do it yourself or is in the financial planner space, but I mean, they would still go to a professional and get reassurance, if not other input, that shapes their decision.

**[00:17:02.24]**

And so it’s the same in the medical space. We have this construct we call shared medical decision making and the idea is that ICU doctor and that family member would collaborate to make the best decisions so that the patient gets the right medical treatment. While that family member has to bring those values and preferences into the conversation the doctor brings his or her expertise and recommendation into the conversations.

**[00:17:24.56]**

But what Plan Well Guide does is make that process very transparent. It brings the values and the preferences into the equation in a very transparent way so that, again, the person gets the medical treatments that are right for them. Just like in the financial space, the goal is to get the person the right financial portfolio that is right for them given their level of risk tolerance. I hope that makes sense to you.

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DORETTA THOMPSON:

**[00:17:47.44]**

It does. I actually did the Plan Well Guide. I learned a lot. I’m going to probe that a little bit with you in a minute, but I think one of the things that will be helpful to give a little bit of context to this for our listeners, is if you could take a minute to explain what critical care is like from a patient perspective? What things are going on in there that’s likely to affect them? And how doctors manage that.

**[00:18:12.43]**

Because I found the connection between values and then translating that into a care level. I’m going, wait, I’m not there yet.

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DR.DAREN HEYLAND:

**[00:18:20.23]**

Yeah, yeah.

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DORETTA THOMPSON:

**[00:18:21.30]**

A really interesting kind of process. So I think it might be helpful just to talk about what critical care looks like first today really in the real world as opposed to what it looks like on TV. And then we can talk about how the Plan Well Guide helps you to really empower your decision makers, your alternate decision maker to make the kinds of decisions that you want made for your care.

DR.DAREN HEYLAND:

**[00:18:44.17]**

Maybe I'll just start by talking about ICU care or critical care as the care that's provided in a geographically distinct place in the hospital. So it's not kind of the care provided on a regular medical floor, it's not the kind of care you get at home, it's when you are so super sick, your organs are failing, you need our tools, our technology, our trained health care professionals to be able to assess and manage all sorts of organs that are failing.

**[00:19:15.07]**

If your heart's failing, you can imagine how life-threatening that is. We can stick catheters through veins or into arteries to measure and to monitor or to provide powerful medications to stimulate the heart. Yeah, we'll hook you up to a number of monitors so that we can read your respiratory rate, your heart rate, your blood oxygenation levels.

**[00:19:36.94]**

Most commonly, people are failing with their lungs as well. They're not able to breathe adequately. And so again, we put a tube down their throat, hook them up to a machine. The machine breathes for them, provides more oxygen than it can get from room air. As you can imagine, a lot of these procedures are uncomfortable or actually may cause pain or distress.

**[00:19:58.52]**

And so very commonly, we're sedating people to be able to tolerate all the tubes in the different parts of their body to support the different organs that might be failing. And so we try and keep people as comfortable as possible, but I think it's fair to say that it is an uncomfortable process to be confined to bed with tubes in every orifice and having the machines do the breathing and do the work for you. So yes, we try and sedate them.

**[00:20:26.21]**

And therefore, the patient rapidly diminishes awareness of what's happening to them. And it becomes a matter of now working with the family to make decisions, but also to work with the family to ongoing care issues and needs. And so it's more of the family that retains that memory of the intensification of care, particularly if the patient goes on and dies.

**[00:20:49.23]**

They're left with that, what was that all about? That 10-day period when my loved one was in the ICU receiving this very intensified care and then subsequently dies. So it's a difficult journey for many and for many months or years afterwards are left with those poignant if not traumatic memories of what went on.

**[00:21:10.79]**

So part of what we're trying to do on Plan Well Guide is educate people on the processes of care, you know? What happens like I just described. But also more importantly, the outcomes. Well, on average, what happens to people who go into an ICU? And TV is very misinforming about what happens when people get critically ill.

DR.DAREN HEYLAND:

**[00:21:29.30]**

You see people on TV undergo cardiac arrest and then there's a few thump, thumps on the chest and then they're up and running again. And that's not the case. I mean, if you undergo cardiac arrest and you're successfully revived, you end up in an ICU with tubes in every orifice. And you're usually in ICU for some period of time. And there is a risk that you've sustained brain injury because of that period when your heart wasn't beating. There's a risk that there's some damage to the brain from not having enough oxygen.

**[00:21:59.18]**

So we go through our Plan Well Guide not in a super detailed way that, well, hopefully, it doesn't overwhelm you, but we try and give you a sense of, if you go to the ICU, here's your chances of your recovery. If you just get regular medical care, here's your chances of recovery, if you undergo comfort care only, here's your chances. And so it gives you a sense of the outcomes-- both from a mortality and a quality of life point of view.

**[00:22:22.10]**

That way when people say oh, I think I prefer x. It's more likely an informed treatment preference than currently what they're saying. Is that helpful?

DORETTA THOMPSON:

**[00:22:32.08]**

It is, it is. And I think that having worked through the guide myself, I know that it really opened my eyes to the pressure that is on that alternate decision maker who is seeing their loved one either absent, in a sense, or physically suffering and trying to find a context for decision making.

**[00:22:52.46]**

I don't to what extent all doctors are able to share that with people in aiding them in making decisions, for example. What the chances are of particular outcomes, et cetera. And I found that really educational when I was working through the plan.

DR. DAREN HEYLAND:

**[00:23:08.09]**

There's one important point that I want to make as it speaks to, again, why this is so important that a layperson educates themselves a little bit. Because there is a bit of a faith-based way of looking at the world that when I get sick, my doctors will do well for me, my family knows me and they'll know how to care for me.

**[00:23:28.31]**

And that isn't the reality of the situation. Families don't know how to make these life and death decisions without knowing your voice. And so you need to talk about it. And I'm not trying to besmirch my doctor colleagues, but I know from years of research, we document medical errors and errors in communication, errors and decision making that there are mistakes made.

DR. DAREN HEYLAND:

**[00:23:48.72]**

And so if you're not informed, if you're not advocating for self, or having that family member who's informed advocating for you, you're at risk of getting the wrong medical treatment. So it's worth leaning into this space so that you can work more effectively with doctors to get the medical care that's right for them.

**[00:24:07.89]**

Unfortunately, a lot of them treat you as a patient as an informed consumer. And so they will say things like, what do you want us to do? If your heart stops beating, do you want to be resuscitated? As if the implications of the answer to that question. And so I reject that language strategy. I try and train the doctors that I have influence on not to speak like that because people don't know what they're signing up for.

**[00:24:32.00]**

And so that's part of Plan Well Guide is trying to educate people about CPR, about ICU medicine, about medical care, and about comfort care. That we can't rely on doctors or our family. We've got to educate ourselves and then capacitate the person that's going to be represented as if we're going to get the medical treatment that's right for us.

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DORETTA THOMPSON:

**[00:24:50.89]**

And I think that the guide does a good job in that. From my experience in working through it, it really does make those connections between what care looks like, what possible outcomes are, and what that may do to your quality of life afterwards. And what does that really mean to you. So I thought it was a really powerful way of thinking about it.

**[00:25:13.66]**

So let's talk about the guide for a moment. And how the Plan Well Guide can help ensure that we are treated the way that we would have wanted to be treated. And that our loved ones who are making these decisions for us feel that they have the knowledge of our values and what we would want at heart when they're making the decisions. Because they're terribly difficult decisions to make.

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DR. DAREN HEYLAND:

**[00:25:38.49]**

Yeah. Our research shows that if laypeople are given the right amount of information and the right amount of encouragement or things that build their sense of self confidence that I can do this and then collaborative tools-- tools that enable them to effectively function with people who in a social hierarchy are-- these are doctors and they know what they're talking-- well, in fact, we're trying to level the playing field a little bit by giving you some collaborative tools so that you can effectively collaborate with doctors.

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DR. DAREN HEYLAND:

**[00:26:09.28]**

So what Plan Well Guide does is there's a lot of information exchange where we're educating people on the difference between serious illness and end-of-life care because that's super important when you're trying to lay down your serious illness plans. We go through a process of helping people think through those values and I've alluded to already the values constraining clarification tools where I'm showing you how these things compete or trade-off. And you have to tell me what kind of person you are.

**[00:26:33.24]**

You're the kind of person that is OK with machines or are you the kind of person that is seeking a natural dignified death when that time comes. Because you can't have both, right? And then we go through that educative process of explaining to people, this is what ICU medicine is. This is the treatments that are delivered, this is the risks, the benefits, the possible outcomes.

**[00:26:55.57]**

These are the kind of people that kind of usually sign up for ICU medicine. Again, not trying to say, this is right for you or this is wrong for you because it's really up to you. But I'm trying to educate you on what that package of goods and services looks like. Same with medical care, same with comfort care. And then we go through a process of trying to help you finalize your plan, your event serious illness plan.

**[00:27:18.99]**

And that comes out in the form of a written document. One is called the Dear Doctor letter. It's for that future doctor that you're-- either you or your substitute decision maker is interacting with to make medical decisions. And it has a preamble that says something like, Dear Doctor, I've been through this serious illness planning. I know I'm not planning for my end of life, but rather, when I'm seriously ill and here are the values, and preferences, and outstanding comments that I want you to consider when putting together my treatment pathway.

**[00:27:50.41]**

The second planning output is another letter and this time it's the Dear Substitute Decision-Maker letter. Thank you for taking on this responsibility. Here are my values and preferences for both medical care and now there's another dimension which is personal care. So the substitute decision maker may be talking to other stakeholders, other professionals to execute the wishes for personal care, for financial care, and there's some language in there where we've elicited values and had their user denote their preferences for different things.

**[00:28:23.35]**

And so the written down documentation of both the medical and the personal care enable that substitute decision maker then to move forward and work with doctors in the one instances or other professionals in the other instance to make sure the person gets the medical and personal care that's right for them. That's the goal, anyway.

DORETTA THOMPSON:

**[00:28:42.33]**

One of the things that can happen is your perceptions of these things can change over time. What may be a way of living that you may consider not worth living when you're 25 may be very different from what you think might be worth living or not worth living when you're 65. Can you update the plan regularly? Do you recommend a regular review of the plan?

DR.DAREN HEYLAND:

**[00:29:03.45]**

Yeah. I mean, just like with any other financial plan, you want to come back to it and revisit it and make sure you're feeling the same way and that the plan is still sensible for the age and stage of life if you acquire a new diagnosis, particularly, a terminal diagnosis. That might trigger a change in your plan. So you can go back on the Plan Well Guide at any time to update those values and preferences statements and re-download the Dear Doctor and Dear Substitute Decision Maker letter for sure.

DORETTA THOMPSON:

**[00:29:32.00]**

Do you think that it's important to actually sit down with the person who's going to be your alternate decision maker and discuss these things through with them as opposed to just handing them a letter and say here, do this?

DR. DAREN HEYLAND:

**[00:29:44.94]**

Well, let me just tell you that I've been working downstream for 20 years and I've also talked to a lot of lawyers who are also on that downstream of families fighting, or having conflict, or just frankly ill-prepared. And so they're very stressful. We've talked about that point. But there's too much failure of the system right now. Whatever we're doing right now to prepare our families so that they can-- with the least stress, with the least conflict, with the least cost, help these incapacitated people to make treatment decisions or make personal care decisions. Whatever we're doing it now, it isn't working.

**[00:30:22.39]**

Courts are full of cases of conflict and the medical doctors like myself are witnesses to the suffering because people aren't prepared for it. So we've got to do something different. We've got to work upstream. In my experience, about a third of the time a substitute decision maker that we had to call out to make decisions with us, didn't know that they were in the substitute decision maker.

**[00:30:44.20]**

About a third of the time, the substitute decision maker would say, oh, yeah. He asked me to do that or he or she asked me to do that. But I don't know anything. I mean, we never talked about it. And then a third of the time, when that family member who has that responsibility knows they have the responsibility and have had the conversations or even have the documentation, it's a lot easier, it's a lot better.

DR. DAREN HEYLAND:

**[00:31:09.29]**

And so it's not as simple as send an email, here you're my substitute decision maker, read this. I mean, that's better than nothing. But I would strongly encourage people to sit down with family-- and not just substitute decision maker, but likely that's up to this decision maker exists in a broader social context.

**[00:31:27.59]**

And so who are all the stakeholders that are going to care and be involved in the care of you if you get seriously ill and make sure they're all on the same page. Unfortunately, at society, we sort of have an adverse reaction to talking about this. It's part of that adverse reaction. Talking about death and dying. And whilst this isn't about death and dying, it's about serious illness. It kind of has the same connotation or overtones.

**[00:31:52.78]**

And yet at the same time, a lot of people don't want to be a burden on their children and/or on their spouses, on their loved ones. And so how do I communicate that with embracing a little bit of negativity because you're going to talk about getting sick and what if I got sick and what if I died? How do I encourage people to embrace a little bit of that to save a lot of suffering downstream?

**[00:32:16.91]**

And so I strongly encourage people to have comprehensive conversations. Everything's out on the open so that downstream, there's no discord conflict and less trauma in trying to execute or fulfill the wishes of your loved one.

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DORETTA THOMPSON:

**[00:32:33.60]**

Do you have any advice on how one might choose an alternate decision maker? I know it generally falls to a family member but many people have more than one family member. Sort of some general advice on what qualities you're looking for to be able to do these kinds of difficult decisions.

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DR. DAREN HEYLAND:

**[00:32:51.33]**

Yeah. And again, it's contextual and so are we talking about medical decisions, personal care decisions, or financial decisions? And there's the obvious question of competency. I mean, is this person competent to understand and negotiate or discuss or collaborate with the planning professionals-- with the doctors in the one instance, or home care workers in another, or financial banks, et cetera?

**[00:33:15.59]**

So I think you have to look for people in your circles who have that competency. You have to understand this space that they're getting into. It's a stressful space and it requires clear communication and good decision making. So naturally, I would look-- I have a son who's a doctor. And so I have him appointed as the person that's going to be making my medical decisions for me. But I have another son who's a lawyer and a real quick thinker. And so he's going to make my personal care and my financial decisions for me.

DR. DAREN HEYLAND:

**[00:33:43.72]**

So we look at people that we trust, who have good communication skills, good collaboration skills, can think, well under pressure, and have some of the core competencies in those spaces that we've been talking about. One thing that we have to just be really clear about is you're capacitating the substitute decision maker to act on your behalf to fulfill your values and wishes.

**[00:34:08.29]**

It's not about what they want. So for example, some children who are making some decisions for their older parents, they're clouded by what they want to have happen. I want mom to live. Whereas mom was saying, hey, first chance that I get to leave, you know, I want to punch my ticket and leave in a peaceful dignity-preserving way. And so you have to have confidence that that person that you're picking is going to respect that and will fulfill your wishes and not be too overcome with what they want to have happen.

DORETTA THOMPSON:

**[00:34:40.59]**

One of the things that is also included in the Plan Well Guide is that you have an ICU guide for family members to help them through this difficult time. And I wonder if you'd like to share a little bit about that with us.

DR.DAREN HEYLAND:

**[00:34:52.90]**

Yeah, sure. Plan Well Guide is for pre-ICU, right? It's for advanced serious illness planning. And if and when you have your serious illness and you end up in the ICU, like I said, we're now talking to a family member. And so what can I do to educate? First off, build your sense of confidence and your sense of wellness that you can navigate the space as a family member who's making decisions and give you the collaborative tools to help you engage with ICU doctors to make those medical treatments that are right for you.

**[00:35:24.64]**

A big portion of my ICU guide is coaching people on preserving their own wellness. You can imagine having a spouse, or a child, or a loved one-- the parent, in the ICU. Is so stressful that you're stressed out. And if you're not able to function, then you're not able to function as a collaborator in decision making. And so we're trying to explain to people the role in the ICU that you play in making decisions and the importance of staying well and how you can contribute to the person's care and wellbeing.

**[00:35:55.78]**

And then we go through a similar process like with Plan Well Guide where we're asking you about the person's values and preferences and any other comments that they want to make so that the doctors have that information in advance of making these kind of life and death decisions. So these are two distinct tools-- one is Plan Well Guide, the other is My ICU Guide, but My ICU Guide is more for, now that the patient is in the ICU, how do I support families through this decision making journey?

DORETTA THOMPSON:

**[00:36:23.76]**

If you're comfortable sharing, as a critical care physician who is very familiar with what actually happens in ICUs, what the outcomes can be, et cetera, have you completed the guide yourself? And where do you end up?

DR.DAREN HEYLAND:

**[00:36:37.81]**

Right now I'm almost 60. I'm healthy. I love life. I've lived a good life. I've got great relationships. I'm not afraid to die. Having said that, if I got a serious illness, I'd like a kick at the can. I'd like a try at critical care. But I've signed up for a short term trial.

**[00:36:55.61]**

Meaning, if I end up in ICU for three or four weeks or I end up being dependent in an institution on machines for three, or four, or five weeks and I know that I'm not going to get back to a reasonable functional quality of life, I'd like my substitute decision maker who's my wife to say thanks but no thanks, let's change goals and focus on comfort measures.

**[00:37:15.79]**

So I'm OK with a short term trial of ICU. So if it looks like I'm getting better, great. Go for it, go for it. But if it looks like I'm going down that curve towards-- I could be alive but in a health state that isn't worth much, I'd rather move on to the next phase of my existence. Yeah. That's kind of what I've signed up for.

**[00:37:33.86]**

There's a point, though, I'd like to emphasize and comes back to why are we having this conversation with people from the financial industry? From a person's point of view, if something untoward happens to them, they need to think ahead and plan ahead for the medical the side of things, the financial side of things, and the legal side of things, right? Because there's documents to support all of these naming of individuals, for example.

**[00:38:01.81]**

So I'm having separate conversations with lawyers to try and say, hey, what you do in terms of filling out these forms to name somebody as a power of attorney is important, but don't do health planning. Just refer them to Plan Well Guide where we'll codify their values and-- we'll codified the script that the power of attorney needs to use when they effectuate their duties.

**[00:38:24.87]**

And similarly, with people in the financial planning space, you are already doing this. You're already helping people think ahead and plan ahead for a rainy day. And so I think it's a natural conversation just to invite them. Again, you don't have to be a health planner. Invite your client to go off to this website. It's free, it's supported by research, it'll lead to a greater peace of mind for that client, therefore they'll think positively about as their planning professional.

DR.DAREN HEYLAND:

**[00:38:51.15]**

And so we're evolving this concept of advanced serious illness planning is like a three-legged stool. Each of those legs-- finance, legal, and medical, all needs to be done and done in sync so that the stool works, right? Because if one of those legs is missing, no matter what financial plans you laid and have down in pad, you may be missing a big piece because you didn't think about the medical part or the implications of the medical part.

**[00:39:17.10]**

That's my request is that people embrace this broader sort of conceptualization of advance serious illness planning to be this three-legged stool and let's work together rather than in silos-- which is what normally happens. I mean, how many times have you had a doctor on your podcast, for example?

DORETTA THOMPSON:

**[00:39:35.16]**

You're the first.

DR. DAREN HEYLAND:

**[00:39:36.41]**

Well, OK. That's great, right? I'm breaking down the silos, we're talking, we're collaborating in a way that benefits your clients and my future patients. We have, on our website, a part where you, as a planning professional, can get informed about what this is all about, and how you might operationalize it in your practice setting. And there's a toolkit of different things that you might use to engage your clients.

**[00:40:02.01]**

Be it a postcard that you give them manually, a pamphlet that you give them manually, or a PDF that you can electronically engage and say, hey, this would be a good idea for you to think about. Go to Plan Well Guide and fill out your advance serious illness plan and we can talk about it next time I see you in the context of our regular whatever.

**[00:40:18.76]**

So I just want to make that pitch that we try to make it easy for you as financial planning professionals to engage with us. We'd ask your support to help us get the word out. If, at any time, you have questions, or comments, or feedback on how I could do better in providing tools that make it more efficient and more impactful for you and your client interactions, please let me know. My email is on the website and I welcome people engaging with me if they have suggestions to improve what we're trying to do.

DORETTA THOMPSON:

**[00:40:48.14]**

How often should one look at this plan? And are there particular life events that really when they happen, you should reexamine your plan.

**SPEAKER****TRANSCRIPTION**

DR. DAREN HEYLAND:

**[00:40:57.21]**

From the medical side, yes. Obviously, when you're young and healthy, one way of looking at life but as you acquire diseases, as you become older, maybe as you have frailty or declining function, likely, your value structure, your preferences are going to change.

**[00:41:15.85]**

So it really depends on where you're starting at. If you're starting at this point at 72, then you're looking at probably an annual review. If you're starting at this point of view at 25, then until you get a lot older or till you get diseases is not a big deal. However, the big dimension to this is also that preparing of the substitute decision maker.

**[00:41:35.41]**

And so you've got to keep an eye on that ball because that substitute decision maker has a life journey too. And are they still the right person or have they had life events? Have they moved away, for example, or have they become frail, or lost capacity, or whatever? And so it's not just your values for health and the treatment preferences that you want, but it's, how's my substitute decision maker doing?

**[00:42:00.04]**

And so I think that requires-- it may be annual for people on the later stages of life, but regular, every five years as a younger person, you should think that, through same with a will, you've named somebody to be guardian of your kids and executor of your assets. Well, you should make sure that they're still capable, and still around, and still able to function.

DORETTA THOMPSON:

**[00:42:21.51]**

Dr. Heyland, thank you so much for joining us today.

DR.DAREN HEYLAND:

**[00:42:24.81]**

Thank you for having me.

N/A

**[00:42:26.31]**

[MUSIC PLAYING]

DORETTA THOMPSON:

**[00:42:29.08]**

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**SPEAKER****TRANSCRIPTION**

DORETTA THOMPSON:

**[00:42:46.46]**

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N/A

**[00:43:16.82]**

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