

WEBVTT

00:02:20.213 --> 00:05:17.360 Testing,
00:05:17.360 --> 00:05:20.157 Welcome,
00:05:20.157 --> 00:05:22.409 everyone.
00:05:22.409 --> 00:05:25.410 I am Anna Reisman.
00:05:25.410 --> 00:05:29.007 I'm the director of the Program for
00:05:29.007 --> 00:05:32.808 Humanities in Medicine at the Yale
00:05:32.808 --> 00:05:38.808 School
00:05:38.808 --> 00:06:31.160 of Medicine.
00:06:31.160 --> 00:06:47.159 Currently, she sees patients as a primary care
physician with the Alameda Health System Division of Ambulatory and Preven-
tive Medicine, a regular contributor to the California Health Care Foundation
blog and working on her next book projects.
00:06:47.159 --> 00:06:52.808 I met Dr.
00:06:52.808 --> 00:06:55.058 Grubbs in 2009 at a conference of
00:06:55.058 --> 00:06:57.157 policy makers,
00:06:57.157 --> 00:06:59.409 journalists,
00:06:59.409 --> 00:07:02.610 health care professionals celebrating
00:07:02.610 --> 00:07:06.458 10 years of narratives in health.
00:07:06.458 --> 00:07:11.059 She was one of the speakers.
00:07:11.059 --> 00:07:14.508 She spoke about how people of color
00:07:14.508 --> 00:07:18.658 are popular sources for harvesting organs.
00:07:18.658 --> 00:07:23.008 We'll talk about this later this afternoon.
00:07:23.008 --> 00:07:27.959 I've been a fan of her writing since then.
00:07:27.959 --> 00:07:30.408 You may have attended a roundtable in
00:07:30.408 --> 00:07:34.708 2020 where Dr.
00:07:34.708 --> 00:07:40.160 Grubbs spoke on black academic medicine.
00:07:40.160 --> 00:07:44.808 She was featured as the ground round
00:07:44.808 --> 00:07:46.808 speaker in internal medicine last week
00:07:46.808 --> 00:07:50.458 here at Yale.
00:07:50.458 --> 00:07:52.657 I'm grateful for the opportunity to
00:07:52.657 --> 00:07:58.308 talk here last week.

00:07:58.308 --> 00:08:00.508 I am grateful for our ASL providers
00:08:00.508 --> 00:08:02.758 and transcriber.
00:08:02.758 --> 00:08:04.758 Welcome,
00:08:04.758 --> 00:08:06.960 Vanessa.
00:08:06.960 --> 00:08:11.208 Thank you for your generosity in coming
00:08:11.208 --> 00:08:13.258 back after last week's disaster for
00:08:13.258 --> 00:08:15.859 those who were here.
00:08:15.859 --> 00:08:21.359 Here we are.
00:08:21.359 --> 00:08:24.258 Give us an overview of the book.
00:08:24.258 --> 00:08:26.658 Dr.
00:08:26.658 --> 00:08:29.059 Vanessa Grubbs: When I was a primary
00:08:29.059 --> 00:08:31.259 care director,
00:08:31.259 --> 00:08:34.009 I met my husband.
00:08:34.009 --> 00:08:38.260 He had been on dialysis for five years.
00:08:38.260 --> 00:08:43.009 Through the course of our relationship,
00:08:43.009 --> 00:08:48.407 I got a look at what life is like for
00:08:48.407 --> 00:08:53.166 someone living with end-stage kidney
00:08:53.166 --> 00:08:55.559 disease as well as the kidney
00:08:55.559 --> 00:08:59.658 transplant system.
00:08:59.658 --> 00:09:02.958 I got a sense for why there are
00:09:02.958 --> 00:09:05.108 racial disparities.
00:09:05.108 --> 00:09:09.608 My decision was to donate a kidney to him.
00:09:09.608 --> 00:09:11.808 I wanted to pursue research.
00:09:11.808 --> 00:09:15.059 I was doing research naira.
00:09:15.059 --> 00:09:21.408 Different field and wanted to shift
00:09:21.408 --> 00:09:23.759 that over to working on how to solve
00:09:23.759 --> 00:09:31.509 these disparities.
00:09:31.509 --> 00:09:37.259 I ended up going to nephrology fellowship.
00:09:37.259 --> 00:09:41.658 I became a nephrologist.
00:09:41.658 --> 00:09:44.610 It changed how I saw nephrology and
00:09:44.610 --> 00:09:49.659 how people received my work.

00:09:49.659 --> 00:09:53.558 I had no idea the kinds of things
00:09:53.558 --> 00:09:58.960 that happen within nephrology
00:09:58.960 --> 00:10:03.259 . That's what led me to write the book,
00:10:03.259 --> 00:10:07.859 to have this as a platform to educate
00:10:07.859 --> 00:10:10.358 people about the realities of
00:10:10.358 --> 00:10:15.209 nephrology disease and end stage kidney disease.
00:10:15.209 --> 00:10:22.008 Thinking about dialysis and transplant.
00:10:22.008 --> 00:10:25.659 Anna Reisman: Thank you.
00:10:25.659 --> 00:10:28.608 That was a great outline.
00:10:28.608 --> 00:10:31.308 I wanted to start with some questions
00:10:31.308 --> 00:10:35.809 about you and Robert,
00:10:35.809 --> 00:10:39.708 who becomes your husband and how his
00:10:39.708 --> 00:10:42.158 kidney disease affected your early
00:10:42.158 --> 00:10:44.308 times together.
00:10:44.308 --> 00:10:48.959 There were two scenes that stood out
00:10:48.959 --> 00:10:53.208 to me that gave you a glimpse and you a
00:10:53.208 --> 00:10:57.808 glimpse of living with end stage kidney disease.
00:10:57.808 --> 00:11:00.158 You were interested in each other.
00:11:00.158 --> 00:11:03.058 You had a date.
00:11:03.058 --> 00:11:05.459 You called him the next day.
00:11:05.459 --> 00:11:08.408 It was early afternoon and he was
00:11:08.408 --> 00:11:11.908 groggy and you were surprised that he
00:11:11.908 --> 00:11:16.658 was at dialysis.
00:11:16.658 --> 00:11:19.958 You felt awkward that you had interrupted some-
thing.
00:11:19.958 --> 00:11:21.909 On another early date,
00:11:21.909 --> 00:11:28.408 you were out Dr.
00:11:28.408 --> 00:11:33.808 having drinks.
00:11:33.808 --> 00:11:36.307 You didn't know about the nausea,
00:11:36.307 --> 00:11:38.608 vomiting,
00:11:38.608 --> 00:11:40.407 and shortness of breath he would deal

00:11:40.407 --> 00:11:47.460 with as a result of drinking.
00:11:47.460 --> 00:11:50.458 Those seem to be your first inklings on
00:11:50.458 --> 00:11:53.610 how to live as a person with dialysis.
00:11:53.610 --> 00:11:55.808 Dr.
00:11:55.808 --> 00:11:57.908 Vanessa Grubbs: Like many people in
00:11:57.908 --> 00:12:03.458 residency training,
00:12:03.458 --> 00:12:06.858 we're so inundated with the day to day
00:12:06.858 --> 00:12:12.358 of taking care of patients in the hospital.
00:12:12.358 --> 00:12:15.708 I'm embarrassed that I was more
00:12:15.708 --> 00:12:18.858 focused on the numbers and orders and
00:12:18.858 --> 00:12:21.859 those details than finding out what it
00:12:21.859 --> 00:12:24.908 was like for people who were on dialysis.
00:12:24.908 --> 00:12:34.358 I did my training
00:12:34.358 --> 00:12:36.708 at the County Hospital.
00:12:36.708 --> 00:12:39.808 Most of those who came in on the
00:12:39.808 --> 00:12:43.510 kidney service who had issues with
00:12:43.510 --> 00:12:47.259 dialysis were mostly black men.
00:12:47.259 --> 00:12:53.458 Their access had failed.
00:12:53.458 --> 00:12:55.708 They had issues with their outpatient
00:12:55.708 --> 00:13:02.609 dialysis units.
00:13:02.609 --> 00:13:04.858 It was a struggle to find a place that
00:13:04.858 --> 00:13:16.359 would take them.
00:13:16.359 --> 00:13:19.809 As far as what to expect it to be like
00:13:19.809 --> 00:13:25.059 in a relationship with someone on dialysis,
00:13:25.059 --> 00:13:29.308 I have to give it careful thought to
00:13:29.308 --> 00:13:31.459 be involved with someone who was
00:13:31.459 --> 00:13:34.110 seriously ill.
00:13:34.110 --> 00:13:38.458 Robert told me he had a lot of first
00:13:38.458 --> 00:13:46.110 dates and not too many second plus dates.
00:13:46.110 --> 00:13:49.658 Most people weren't able to deal with
00:13:49.658 --> 00:13:52.358 the situation he was in.

00:13:52.358 --> 00:13:58.408 That was sixteen years ago.
00:13:58.408 --> 00:14:00.908 We'll celebrate year 17 transplant
00:14:00.908 --> 00:14:09.609 anniversary in April.
00:14:09.609 --> 00:14:14.809 Anna Reisman: You captured how primary
00:14:14.809 --> 00:14:20.359 care doctors and the rest of us
00:14:20.359 --> 00:14:25.660 don't know what it's like.
00:14:25.660 --> 00:14:27.759 You have this unique ability to see
00:14:27.759 --> 00:14:29.609 what it's like.
00:14:29.609 --> 00:14:34.008 As a primary care director,
00:14:34.008 --> 00:14:36.108 I think it was in grand rounds last
00:14:36.108 --> 00:14:46.562 week to see
00:14:46.562 --> 00:14:48.559 that you offered wonderful insights
00:14:48.559 --> 00:14:50.907 into what it is like for them.
00:14:50.907 --> 00:14:53.208 Dr.
00:14:53.208 --> 00:15:01.058 Vanessa Grubbs: Before my nephrology fellow-
ship,
00:15:01.058 --> 00:15:03.059 I was probably really horrible at this.
00:15:03.059 --> 00:15:06.559 Like primary care doctors,
00:15:06.559 --> 00:15:10.409 there's so much to think about and
00:15:10.409 --> 00:15:15.909 have at least some level of expertise
00:15:15.909 --> 00:15:21.659 in the details that a specialist would have.
00:15:21.659 --> 00:15:25.008 I think being a nephrologist has made
00:15:25.008 --> 00:15:28.809 me a better primary care director.
00:15:28.809 --> 00:15:31.009 octor.
00:15:31.009 --> 00:15:33.860 There are many people who know a
00:15:33.860 --> 00:15:36.609 little bit.
00:15:36.609 --> 00:15:39.008 They have kidney failure and can't
00:15:39.008 --> 00:15:43.709 take this medication.
00:15:43.709 --> 00:15:46.708 Their creatinine was 1.4.
00:15:46.708 --> 00:15:51.258 They have some chronic kidney disease.
00:15:51.258 --> 00:15:53.959 It's safe to take this medication for

00:15:53.959 --> 00:15:57.760 a limited amount of time.
00:15:57.760 --> 00:16:02.110 Being a resource for my colleagues in
00:16:02.110 --> 00:16:04.009 terms of basic things like blood
00:16:04.009 --> 00:16:08.808 pressure management.
00:16:08.808 --> 00:16:10.957 I do it very differently now that I
00:16:10.957 --> 00:16:17.958 have nephrology experience.
00:16:17.958 --> 00:16:20.458 Anna Reisman: I want to talk about your
00:16:20.458 --> 00:16:33.259 writing style.
00:16:33.259 --> 00:16:37.510 You're a candid writer and are honest
00:16:37.510 --> 00:16:43.909 about your feelings on a page as well as virtually.
You put everything out there. You put everything out there.
00:16:43.909 --> 00:16:50.460 One part I love early on in the book is
00:16:50.460 --> 00:16:52.711 your discussion about Robert being a
00:16:52.711 --> 00:16:54.609 guy you like,
00:16:54.609 --> 00:16:57.209 but is on dialysis.
00:16:57.209 --> 00:17:01.308 You are asking yourself and your
00:17:01.308 --> 00:17:03.359 close friends whether that should be a
00:17:03.359 --> 00:17:07.959 factor in letting things go beyond that first date.
00:17:07.959 --> 00:17:13.258 You had so many first dates only.
00:17:13.258 --> 00:17:18.259 Dr.
00:17:18.259 --> 00:17:20.359 Vanessa Grubbs: That's her in every conversation.
00:17:20.359 --> 00:17:27.259 She's a good front.
00:17:27.259 --> 00:17:30.409 You mentioned being open personally.
00:17:30.409 --> 00:17:35.660 When I set out to write the book,
00:17:35.660 --> 00:17:37.959 I was not going to include my personal story.
00:17:37.959 --> 00:17:45.758 Robert is a private person.
00:17:45.758 --> 00:17:49.009 I was trying to talk to some of his
00:17:49.009 --> 00:17:51.957 friends in his life before me to get a
00:17:51.957 --> 00:17:56.908 sense of who he was then and what he was like.
00:17:56.908 --> 00:17:59.058 People who thought they were close
00:17:59.058 --> 00:18:05.209 friends with him

00:18:05.209 --> 00:18:07.559 did not share very much.
00:18:07.559 --> 00:18:12.459 It was not very fruitful.
00:18:12.459 --> 00:18:16.510 My original thoughts about the book was
00:18:16.510 --> 00:18:18.861 that I was going to write about chronic
00:18:18.861 --> 00:18:22.559 kidney disease,
00:18:22.559 --> 00:18:24.459 decision making,
00:18:24.459 --> 00:18:29.209 etc.
00:18:29.209 --> 00:18:31.058 My literary agent told me they loved
00:18:31.058 --> 00:18:33.858 my writing style,
00:18:33.858 --> 00:18:41.707 but no one wanted
00:18:41.707 --> 00:18:44.809 to read it unless it was a personal story.
00:18:44.809 --> 00:18:51.459 I wasn't resistant to it.
00:18:51.459 --> 00:18:54.459 One of the things I noticed about other
00:18:54.459 --> 00:18:58.509 people's memoirs
00:18:58.509 --> 00:19:00.710 is that you can tell when they're
00:19:00.710 --> 00:19:02.759 holding back.
00:19:02.759 --> 00:19:07.058 I didn't want to come across like that.
00:19:07.058 --> 00:19:09.759 I wanted to be really honest about
00:19:09.759 --> 00:19:13.558 things I was thinking and feeling.
00:19:13.558 --> 00:19:17.958 I did see
00:19:17.958 --> 00:19:29.760 it as a potential resource for other people.
00:19:29.760 --> 00:19:32.359 I don't think
00:19:32.359 --> 00:19:34.357 I was that unusual.
00:19:34.357 --> 00:19:37.107 You have to put the male specimen before
00:19:37.107 --> 00:19:39.257 your panel of girlfriends to decide if
00:19:39.257 --> 00:19:42.157 he passes or not.
00:19:42.157 --> 00:19:48.107 Robert had this extra
00:19:48.107 --> 00:19:50.857 detail going on that made me second guess.
00:19:50.857 --> 00:19:59.708 In the book
00:19:59.708 --> 00:20:03.109 , we ask people's opinions to find
00:20:03.109 --> 00:20:06.408 someone who says something that

00:20:06.408 --> 00:20:12.809 resonates with what we already believe and do.
 00:20:12.809 --> 00:20:15.108 The girlfriends who were like "he's a
 00:20:15.108 --> 00:20:17.707 great guy,
 00:20:17.707 --> 00:20:22.909 why would you hold back?"
 00:20:22.909 --> 00:20:24.758 You'll find yourself taking care of
 00:20:24.758 --> 00:20:30.259 him later in life. Don't do it.
 00:20:30.259 --> 00:20:33.259 Author friend said "
 00:20:33.259 --> 00:20:36.508 Another
 00:20:36.508 --> 00:20:39.259 friend said "You'll find yourself taking care of him
 later in life.
 00:20:39.259 --> 00:20:42.358 Don't do it."
 00:20:42.358 --> 00:20:45.009 I decided to take the leap.
 00:20:45.009 --> 00:20:50.108 To be honest,
 00:20:50.108 --> 00:20:52.859 one of my friends who was a physician
 00:20:52.859 --> 00:20:55.058 said "he just needs a kidney,
 00:20:55.058 --> 00:20:57.057 then he's good,
 00:20:57.057 --> 00:21:04.958 right?"
 00:21:04.958 --> 00:21:10.309 Regular people looking at transplant as
 00:21:10.309 --> 00:21:21.560 a miracle thing that solves all
 00:21:21.560 --> 00:21:24.608 problems could not be further from the truth.
 00:21:24.608 --> 00:21:26.758 It is so much better than a life on dialysis
 00:21:26.758 --> 00:21:33.059 and kidney failure. A lot of things have come up
 over the years.
 00:21:33.059 --> 00:21:35.859 Sometimes I think about what that
 00:21:35.859 --> 00:21:40.708 friend said to me.
 00:21:40.708 --> 00:21:45.409 I guess in some sense she was right.
 00:21:45.409 --> 00:21:48.709 Lots of things have come up where
 00:21:48.709 --> 00:21:50.708 we've been in that caregiver role.
 00:21:50.708 --> 00:21:53.808 It's a joy for me.
 00:21:53.808 --> 00:22:21.561 I want to be someone
 00:22:21.561 --> 00:22:24.109 care for someone I deeply care about.

00:22:24.109 --> 00:22:25.960 I want him to have the longest and fullest life possible.

00:22:25.960 --> 00:22:27.959 Most of us have seen people who become ill.

00:22:27.959 --> 00:22:31.409 Till death do us part partners leave.

00:22:31.409 --> 00:22:38.259 I think that was in part how

00:22:38.259 --> 00:22:41.009 Robert and me coming together was different.

00:22:41.009 --> 00:22:49.159 I was already in medicine.

00:22:49.159 --> 00:22:56.609 I wasn't afraid of every little thing.

00:22:56.609 --> 00:23:03.909

Things that come across as big deals for those not in medicine.

00:23:03.909 --> 00:23:06.809

It was supposed to be.

00:23:06.809 --> 00:23:08.859 Anna Reisman: That's great.

00:23:08.859 --> 00:23:11.559 Building off of that, I wanted to take one question about

00:23:11.559 --> 00:23:15.364 your writing style.

00:23:15.364 --> 00:23:17.209 When you write about Robert,

00:23:17.209 --> 00:23:26.908 you write from his point of view.

00:23:26.908 --> 00:23:30.209 , which is really interesting.

00:23:30.209 --> 00:23:35.709 There's no question that u

00:23:35.709 --> 00:23:38.707 you know his experience.

00:23:38.707 --> 00:23:40.408 This is someone you know and are

00:23:40.408 --> 00:23:45.259 incredibly close to.

00:23:45.259 --> 00:23:48.508 I'm assuming he would tell you

00:23:48.508 --> 00:23:51.359 something and you would read it back to him.

00:23:51.359 --> 00:23:53.759 Dr.

00:23:53.759 --> 00:23:55.709 Vanessa Grubbs: Oh yeah.

00:23:55.709 --> 00:24:00.359 He's a private person.

00:24:00.359 --> 00:24:02.259 I'm amazed that he was willing to be

00:24:02.259 --> 00:24:06.808 so out there.

00:24:06.808 --> 00:24:12.809 The way I was able to gather so much

00:24:12.809 --> 00:24:24.311 information was . . . he loves trains.
 00:24:24.311 --> 00:24:26.658 We have family in New York.
 00:24:26.658 --> 00:24:30.958 It's a long trip there.
 00:24:30.958 --> 00:24:33.257 I would turn on my recorder and ask
 00:24:33.257 --> 00:24:36.708 him questions.
 00:24:36.708 --> 00:24:39.358 He has a tendency to be brief in how
 00:24:39.358 --> 00:24:42.308 he answers things.
 00:24:42.308 --> 00:24:44.558 I asked him to take me to that place.
 00:24:44.558 --> 00:24:46.358 "What did you see?
 00:24:46.358 --> 00:24:52.509 What did you smell?"
 00:24:52.509 --> 00:24:54.908 It is really interesting.
 00:24:54.908 --> 00:25:01.408 This might happen to be
 00:25:01.408 --> 00:25:04.858 in these more real reality shows.
 00:25:04.858 --> 00:25:07.008 You forget someone is recording
 00:25:07.008 --> 00:25:10.809 .
 00:25:10.809 --> 00:25:17.209 There were a couple of moments in
 00:25:17.209 --> 00:25:21.108 there where I was taken aback at how
 00:25:21.108 --> 00:25:24.959 honest he was about what he was really feeling.
 00:25:24.959 --> 00:25:31.859 One of those moments in particular I rmmbr
 00:25:31.859 --> 00:25:34.958 emember in the first chapter when he
 00:25:34.958 --> 00:25:39.157 was talking about
 00:25:39.157 --> 00:25:47.208 being told either he'd get a catheter or die.
 00:25:47.208 --> 00:25:52.008 He woke up with this catheter in his
 00:25:52.008 --> 00:25:57.907 chest and felt like . . . he was 26 at
 00:25:57.907 --> 00:26:00.758 the time . . . he thought he was
 00:26:00.758 --> 00:26:02.959 starting his life and had all these
 00:26:02.959 --> 00:26:05.457 career plans.
 00:26:05.457 --> 00:26:07.159 "Who's going to date me with this
 00:26:07.159 --> 00:26:13.807 thing out of my chest?"
 00:26:13.807 --> 00:26:19.259 I had never heard him say that.
 00:26:19.259 --> 00:26:27.709 We were coming up on ten years of marriage.

00:26:27.709 --> 00:26:33.459 I had him read things
00:26:33.459 --> 00:26:35.961 to get his approval about whether or
00:26:35.961 --> 00:26:43.608 not I could publish what I said.
00:26:43.608 --> 00:26:45.708 I remember a chapter . . . I can't remember
00:26:45.708 --> 00:26:47.859 the number.
00:26:47.859 --> 00:26:54.908 I'm writing about how we argu
00:26:54.908 --> 00:26:59.557 ed how to celebrate our transplant anniversary.
00:26:59.557 --> 00:27:12.808 I wrote this chapter from my point of view.
00:27:12.808 --> 00:27:22.708 I had him read it.
00:27:22.708 --> 00:27:25.209 We had the fight all over again.
00:27:25.209 --> 00:27:27.308 That led to how I ended up writing it. That's the
way it goes. People say a thing, mean a thing,
00:27:27.308 --> 00:27:29.258 and someone else hears it in a
00:27:29.258 --> 00:27:33.308 different way.
00:27:33.308 --> 00:27:37.607 You react off of that and not the reality.
00:27:37.607 --> 00:27:42.457 No one remembers exactly what happened.
00:27:42.457 --> 00:27:49.208 That's how that part came to be.
00:27:49.208 --> 00:27:57.658 One of the chapters I was so happy to
00:27:57.658 --> 00:28:24.959 write was the chapter where I had surgery.
00:28:24.959 --> 00:28:27.359 I h
00:28:27.359 --> 00:28:30.857 ad never experienced a kidney being transplanted
into someone. I felt fortunate that my surgeon . . . I emailed him and told him
I was working on this book.
00:28:30.857 --> 00:28:32.708 I asked him to watch a surgery.
00:28:32.708 --> 00:28:34.707 He said "sure,
00:28:34.707 --> 00:28:36.708 come on in!"
00:28:36.708 --> 00:28:39.157 I got all the scripts.
00:28:39.157 --> 00:28:42.957 I may have gotten to cut something.
00:28:42.957 --> 00:28:44.908 Not tissue.
00:28:44.908 --> 00:28:51.907 I'm no surgeon.
00:28:51.907 --> 00:28:53.958 I watched a donor nephrectomy and
00:28:53.958 --> 00:29:01.507 walked across the hall

00:29:01.507 --> 00:29:05.058 to watch it put into the recipient.
00:29:05.058 --> 00:29:09.858 It was such a gift to see that and
00:29:09.858 --> 00:29:16.508 imagine me in one room and Robert in
00:29:16.508 --> 00:29:19.408 the other and write about it from that standpoint.
00:29:19.408 --> 00:29:23.158 At the same time, it was
00:29:23.158 --> 00:29:30.958 weird.
00:29:30.958 --> 00:29:33.458 Imagine you're that body lying there
00:29:33.458 --> 00:29:36.358 unconscious and people are positioning
00:29:36.358 --> 00:29:38.457 you and doing all sorts of things they
00:29:38.457 --> 00:29:40.457 need to do.
00:29:40.457 --> 00:29:48.107 You have zero awareness.
00:29:48.107 --> 00:29:52.658 I would have had to write it
00:29:52.658 --> 00:29:55.358 differently and with less detail than
00:29:55.358 --> 00:30:01.908 what I was able to thanks to that experience.
00:30:01.908 --> 00:30:07.958 Anna Reisman: Those were really good chapters.
00:30:07.958 --> 00:30:11.007 Can we take a step back and talk
00:30:11.007 --> 00:30:13.458 about when you went through the
00:30:13.458 --> 00:30:15.658 evaluation for the kidney transplant
00:30:15.658 --> 00:30:20.558 and the people you dealt with.
00:30:20.558 --> 00:30:23.509 This is starting a conversation about
00:30:23.509 --> 00:30:32.108 people who are black with kidney disease.
00:30:32.108 --> 00:30:34.360 Dr.
00:30:34.360 --> 00:30:37.408 Vanessa Grubbs: I was thinking about my sur-
geon.
00:30:37.408 --> 00:30:40.957 I gave him a signed copy of the book
00:30:40.957 --> 00:30:44.908 to thank him.
00:30:44.908 --> 00:30:51.158 I mentioned him in the acknowledgements.
00:30:51.158 --> 00:30:57.358 I
00:30:57.358 --> 00:31:00.808 was completely positive about him,
00:31:00.808 --> 00:31:03.108 but not Robert's surgeon.
00:31:03.108 --> 00:31:05.158 It wasn't OK.

00:31:05.158 --> 00:31:12.009 A lot of flks
 00:31:12.009 --> 00:31:14.408 olks take offense when you say anything
 00:31:14.408 --> 00:31:20.158 that's not glowing about
 00:31:20.158 --> 00:31:22.159 them or someone they work with.
 00:31:22.159 --> 00:31:26.357 At the end of the day,
 00:31:26.357 --> 00:31:30.808 I wanted to be able to stand firm and
 00:31:30.808 --> 00:31:32.808 acknowledge that no one could point out
 00:31:32.808 --> 00:31:36.808 a lie in my writing.
 00:31:36.808 --> 00:31:38.908 "This is the truth.
 00:31:38.908 --> 00:31:42.558 This is different."
 00:31:42.558 --> 00:31:48.308 Going back to the day that Robert had
 00:31:48.308 --> 00:31:51.909 his followup transplant evaluation,
 00:31:51.909 --> 00:31:58.059 he had been on the list for several years.
 00:31:58.059 --> 00:32:37.160 It's amazing how ignorant we are in
 00:32:37.160 --> 00:32:38.960 general about what happens in this
 00:32:38.960 --> 00:32:41.659 whole process. I blame the transplant world for
 that. I feel like it leads to more distrust. This gets back to giving people reality
 to prevent them from informing themselves based on movies.
 00:32:41.659 --> 00:32:44.158 We thought he would get a pager and would get
 a page the next day to come back to
 00:32:44.158 --> 00:32:46.409 the hospital and come to the hospital to
 00:32:46.409 --> 00:32:48.259 get a kidney.
 00:32:48.259 --> 00:32:53.359 It's not that way at all.
 00:32:53.359 --> 00:32:55.358 I didn't get everything right in the
 00:32:55.358 --> 00:33:01.909 piece I wrote about that.
 00:33:01.909 --> 00:33:05.059 That was some of the transplant
 00:33:05.059 --> 00:33:09.458 people's criticism.
 00:33:09.458 --> 00:33:14.709 I was a primary care director.
 00:33:14.709 --> 00:33:17.209 If I didn't know better,
 00:33:17.209 --> 00:33:54.312 it was because they didn't talk to us.
 00:33:54.312 --> 00:33:56.909 It was a case in point about
 00:33:56.909 --> 00:34:00.559 how at the county Hospital we were never

00:34:00.559 --> 00:34:03.309 engaged in helping a patient get access to a kidney transplant. That was the point about it being one-sided. Each person came into the room and said

00:34:03.309 --> 00:34:05.460 something specific about him as a black person.

00:34:05.460 --> 00:34:09.359 County Hospital we were never engaged in helping a patient get access to a kidney transplant. That was the point about it being one-sided. Each person came into the room and said something specific about him as a black person.

00:34:09.359 --> 00:34:14.208 The one that was the most ridiculous

00:34:14.208 --> 00:34:17.108 was the transplant nephrologist who

00:34:17.108 --> 00:34:22.308 responded when Robert asked

00:34:22.308 --> 00:34:29.207 [

00:34:29.207 --> 00:34:32.359 vd

00:34:32.359 --> 00:36:10.961 ideo cut.

00:36:10.961 --> 00:36:13.558] [Kicked out of Zoom meeting.

00:36:13.558 --> 00:37:04.311 Rejoining now.

00:37:04.311 --> 00:37:09.459]

00:37:09.459 --> 00:37:13.309 I don't think any of them acknowledged me.

00:37:13.309 --> 00:37:17.459 It was strange to sit there and be cp

00:37:17.459 --> 00:37:19.709 ompletely ignored.

00:37:19.709 --> 00:37:25.158 They said these strange things.

00:37:25.158 --> 00:37:27.661 They were inconsistent.

00:37:27.661 --> 00:37:30.209 You got one presentation to a larger

00:37:30.209 --> 00:37:33.609 group that was invited.

00:37:33.609 --> 00:37:35.909 You got close to the top and had

00:37:35.909 --> 00:37:41.210 these one-on-one meetings.

00:37:41.210 --> 00:37:52.612 They would say something different to Robert.

00:37:52.612 --> 00:37:54.509 I don't think any of them acknowledged me. It was strange to sit there and be completely ignored. They said these strange things. They were inconsistent. You got one presentation to a larger group that was invited. You got close to the top and had these one-on-one meetings. They would say something different to Robert.

00:37:54.509 --> 00:37:59.608 In the clinical setting,

00:37:59.608 --> 00:38:10.861 it's hard to know what others are experiencing.

00:38:10.861 --> 00:38:12.810 If someone without medical training goes to see
00:38:12.810 --> 00:38:16.860 the director,
00:38:16.860 --> 00:38:22.259 they probably assume the director is
00:38:22.259 --> 00:38:25.109 that way with everyone.
00:38:25.109 --> 00:38:34.959 They would have no idea if the person
00:38:34.959 --> 00:38:37.509 is much warmer with someone from a
00:38:37.509 --> 00:38:39.909 different group or if they're taking these ridiculous
00:38:39.909 --> 00:38:42.008 race based algorithms into mind for
00:38:42.008 --> 00:38:50.609 their care.
00:38:50.609 --> 00:38:55.909 Most of what happens is not so blatant.
00:38:55.909 --> 00:38:59.159 We already know that's not the case
00:38:59.159 --> 00:39:07.409 outside the exam room.
00:39:07.409 --> 00:39:09.910 Anna Reisman: I'm glad you brought up
00:39:09.910 --> 00:39:11.959 race-based algorithms.
00:39:11.959 --> 00:39:13.959 I wanted to talk about that.
00:39:13.959 --> 00:39:21.710 You've written about that.
00:39:21.710 --> 00:39:25.710 with the GFR in your book and elsewhere.
00:39:25.710 --> 00:39:30.910 Explain to people what that means and
00:39:30.910 --> 00:39:33.909 how it affected Robert's experience.
00:39:33.909 --> 00:39:36.658 Dr.
00:39:36.658 --> 00:39:38.808 Vanessa Grubbs: I don't know how it
00:39:38.808 --> 00:39:40.759 affected Robert.
00:39:40.759 --> 00:39:44.260 When in medical school,
00:39:44.260 --> 00:39:46.310 these equations didn't exist.
00:39:46.310 --> 00:39:50.559 I'm old.
00:39:50.559 --> 00:39:55.458 My first day of nephrology fellowship,
00:39:55.458 --> 00:40:00.810 our director told us of all things we
00:40:00.810 --> 00:40:04.111 needed to know presented us with these
00:40:04.111 --> 00:40:11.209 equations and where they came from.
00:40:11.209 --> 00:40:13.209 That's where I first saw this "if
00:40:13.209 --> 00:40:19.110 African American,

00:40:19.110 --> 00:40:21.209 " correction.
00:40:21.209 --> 00:40:23.409 At the time,
00:40:23.409 --> 00:40:31.260 it was about muscle mass.
00:40:31.260 --> 00:40:39.360 African Americans had higher muscle mass.
00:40:39.360 --> 00:40:42.458 "What about a frail black woman or
00:40:42.458 --> 00:40:49.960 white body builder?"
00:40:49.960 --> 00:40:51.910 They said it was a good point and flew
00:40:51.910 --> 00:40:56.160 by to the next thing.
00:40:56.160 --> 00:40:58.259 I thought I was by myself in thinking
00:40:58.259 --> 00:41:00.110 it was not OK.
00:41:00.110 --> 00:41:03.909 Really,
00:41:03.909 --> 00:41:11.558 it wasn't until I wrote my book and
00:41:11.558 --> 00:41:15.908 saw Dorothy Roberts TED talk where she
00:41:15.908 --> 00:41:19.459 mentioned her experience with these
00:41:19.459 --> 00:41:24.708 equations of kidney function and lung
00:41:24.708 --> 00:41:26.659 function that I realized I wasn't
00:41:26.659 --> 00:41:38.560 completely insane. Someone else noticed this.
00:41:38.560 --> 00:41:41.009 The EGFR is the estimated glomerular
00:41:41.009 --> 00:41:43.357 filtration rate,
00:41:43.357 --> 00:41:45.308 or how much blood per minute the
00:41:45.308 --> 00:41:50.108 kidneys are filtering.
00:41:50.108 --> 00:41:56.258 If they were not working as well,
00:41:56.258 --> 00:41:59.608 they would not filter blood as quickly.
00:41:59.608 --> 00:42:04.459 This is where these equations come from.
00:42:04.459 --> 00:42:06.458 They use a simple blood test,
00:42:06.458 --> 00:42:08.607 creatinine,
00:42:08.607 --> 00:42:13.907 to start.
00:42:13.907 --> 00:42:15.908 Our bodies produce a steady amount
00:42:15.908 --> 00:42:18.559 each day.
00:42:18.559 --> 00:42:20.558 We should get rid of the same amount
00:42:20.558 --> 00:42:22.408 each day.

00:42:22.408 --> 00:42:29.659 It's an estimate.
 00:42:29.659 --> 00:42:31.808 The creatinine is produced from the
 00:42:31.808 --> 00:42:34.908 breakdown of muscle tissue.
 00:42:34.908 --> 00:42:38.458 What they noticed in this study that
 00:42:38.458 --> 00:42:43.908 was published in 1999 was
 00:42:43.908 --> 00:42:47.458 (it inc
 00:42:47.458 --> 00:42:50.358 luded
 00:42:50.358 --> 00:42:53.158 black and white people)
 00:42:53.158 --> 00:42:58.658 . They noticed that
 00:42:58.658 --> 00:43:04.258 the black people in the study had
 00:43:04.258 --> 00:43:06.708 higher creatinine levels at a given age
 00:43:06.708 --> 00:43:17.158 than the white people did in the study.
 00:43:17.158 --> 00:43:19.310 They believed it was because of muscle mass.
 00:43:19.310 --> 00:43:21.508 In the original paper,
 00:43:21.508 --> 00:43:27.558 they quoted three
 00:43:27.558 --> 00:43:30.958 small studies that didn't prove
 00:43:30.958 --> 00:43:33.258 anything about muscle mass by race.
 00:43:33.258 --> 00:43:35.408 That stuck.
 00:43:35.408 --> 00:43:37.558 No one questioned it.
 00:43:37.558 --> 00:43:43.408 For 20 years,
 00:43:43.408 --> 00:43:46.710 we were using this equation which
 00:43:46.710 --> 00:43:50.558 considered things that affected how
 00:43:50.558 --> 00:43:52.858 much creatinine the body made and how
 00:43:52.858 --> 00:44:01.508 fast the kidneys got rid of it.
 00:44:01.508 --> 00:44:03.358 The ultimate equation includes gender,
 00:44:03.358 --> 00:44:07.308 age,
 00:44:07.308 --> 00:44:12.258 and race (black or not)
 00:44:12.258 --> 00:44:14.309 . That went on to the next generation
 00:44:14.309 --> 00:44:19.807 of the equation.
 00:44:19.807 --> 00:44:23.107 They used race as well even though
 00:44:23.107 --> 00:44:25.808 the study was more diverse.

00:44:25.808 --> 00:44:31.758 There was 5%
00:44:31.758 --> 00:44:34.808 Latin and Asian identifying people.
00:44:34.808 --> 00:44:42.258 There were 10000 participants.
00:44:42.258 --> 00:44:45.658 They decided there to set up their
00:44:45.658 --> 00:44:48.709 analysis as black versus other.
00:44:48.709 --> 00:44:52.609 That's nothing objective.
00:44:52.609 --> 00:44:54.458 Someone's decision to set up an
00:44:54.458 --> 00:45:00.059 analysis
00:45:00.059 --> 00:45:05.709 of these robust statistical values.
00:45:05.709 --> 00:45:11.258 In the original study,
00:45:11.258 --> 00:45:13.158 they never talked about how the black
00:45:13.158 --> 00:45:15.908 people in the study were
00:45:15.908 --> 00:45:18.608 poor,
00:45:18.608 --> 00:45:20.910 had diabetes,
00:45:20.910 --> 00:45:25.908 high blood prssre
00:45:25.908 --> 00:45:30.460 essure compared to the white people.
00:45:30.460 --> 00:45:36.858 These factors are things that we know
00:45:36.858 --> 00:45:39.709 by themselves associated with kidney function.
00:45:39.709 --> 00:45:43.511 Instead of them talking about that aspect,
00:45:43.511 --> 00:45:47.908 they boiled it down to race.
00:45:47.908 --> 00:45:51.259 I had been writing about it,
00:45:51.259 --> 00:45:54.808 talking about it over the years.
00:45:54.808 --> 00:45:57.958 When I started out in medical school,
00:45:57.958 --> 00:46:01.710 this didn't exist.
00:46:01.710 --> 00:46:09.108 Now it's being taught to medical students.
00:46:09.108 --> 00:46:11.209 I respect the blindness of medical
00:46:11.209 --> 00:46:15.510 students in this generation.
00:46:15.510 --> 00:46:18.458 We were raised to believe that race was
00:46:18.458 --> 00:46:22.108 a social construct.
00:46:22.108 --> 00:46:27.258 This racism was not OK.
00:46:27.258 --> 00:46:32.109 They were at the forefront of

00:46:32.109 --> 00:46:34.208 creating a movement to force a
00:46:34.208 --> 00:46:36.159 conversation about these equations.
00:46:36.159 --> 00:46:38.309 Initially,
00:46:38.309 --> 00:46:47.007 I was being blown off.
00:46:47.007 --> 00:46:53.759 I'm a bit surprised that it got to be
00:46:53.759 --> 00:46:56.509 a movement.
00:46:56.509 --> 00:47:04.609 We had a better replacement
00:47:04.609 --> 00:47:07.509 , another blood test that hasn't been
00:47:07.509 --> 00:47:11.059 celebrated across all the labs in the country.
00:47:11.059 --> 00:47:18.510 It's more expensive and takes longer to get.
00:47:18.510 --> 00:47:20.509 This could have been done and had been
00:47:20.509 --> 00:47:26.459 done before.
00:47:26.459 --> 00:47:31.959 We had to engage in this 2-3 year
00:47:31.959 --> 00:47:35.409 battle and a whole taskforce of the two
00:47:35.409 --> 00:47:38.060 major kidney organizations to come to
00:47:38.060 --> 00:47:44.059 the conclusion that race shouldn't be in there.
00:47:44.059 --> 00:47:49.659 They went back to the study for
00:47:49.659 --> 00:47:54.909 the large equation including 10000 people.
00:47:54.909 --> 00:47:56.908 They pulled everyone's data and gave
00:47:56.908 --> 00:47:59.959 us a new equation.
00:47:59.959 --> 00:48:03.711 We could have done that from the beginning.
00:48:03.711 --> 00:48:05.858 Why did we need to fight back and
00:48:05.858 --> 00:48:09.109 forth for years?
00:48:09.109 --> 00:48:13.209 The equation has been changed.
00:48:13.209 --> 00:48:16.109 There's an effort to get people to
00:48:16.109 --> 00:48:20.159 replace that in how labs are reported.
00:48:20.159 --> 00:48:23.858 This notion of race Dr.
00:48:23.858 --> 00:48:29.010 Vanessa Grubbs: Logical meaning is insanity.
00:48:29.010 --> 00:48:31.159 The social scientists in the PhD
00:48:31.159 --> 00:48:35.311 world know that
00:48:35.311 --> 00:48:37.709 this is some shit we made up.

00:48:37.709 --> 00:48:42.410 We made up race.
 00:48:42.410 --> 00:48:44.611 It is not anything that has valid
 00:48:44.611 --> 00:48:46.911 reasons behind it.
 00:48:46.911 --> 00:48:50.659 We keep trying to prove it.
 00:48:50.659 --> 00:48:52.909 Originally,
 00:48:52.909 --> 00:49:00.310 it was to help make people
 00:49:00.310 --> 00:49:02.409 in colonizing other places and
 00:49:02.409 --> 00:49:06.759 slighting
 00:49:06.759 --> 00:49:09.359 making
 00:49:09.359 --> 00:49:14.659 j
 00:49:14.659 --> 00:49:17.512 people thinking there were groups that
 00:49:17.512 --> 00:49:30.261 were inferior and needed to be enslaved.
 00:49:30.261 --> 00:49:33.009 make
 00:49:33.009 --> 00:49:38.808 people think there were groups that were inferior
 and needed to be enslaved.
 00:49:38.808 --> 00:49:42.458 I could go back to the part about
 00:49:42.458 --> 00:49:48.208 Robert unless you wanted to move on to something
 else.
 00:49:48.208 --> 00:49:51.708 Anna Reisman: I appreciate the
 00:49:51.708 --> 00:49:55.509 explanation and baffling fact that
 00:49:55.509 --> 00:50:01.510 there's still such controversy about it.
 00:50:01.510 --> 00:50:05.559 You talked about finishing your renal
 00:50:05.559 --> 00:50:09.209 fellowship and looking for a research position.
 00:50:09.209 --> 00:50:14.811 You've encountered so much resistance.
 00:50:14.811 --> 00:50:26.460 One potential mentor you talked t
 00:50:26.460 --> 00:50:28.359 o rolled their eyes when you said there was racism
 in
 00:50:28.359 --> 00:50:31.209 the system.
 00:50:31.209 --> 00:50:33.607 Did he know the system was racist?
 00:50:33.607 --> 00:50:36.659 Was it too political?
 00:50:36.659 --> 00:50:39.809 Was this real science?
 00:50:39.809 --> 00:50:42.057 Dr.

00:50:42.057 --> 00:50:44.059 Vanessa Grubbs: I can't speak to what
00:50:44.059 --> 00:50:49.758 was in his mind and heart,
00:50:49.758 --> 00:50:52.009 but can go based on what he said and
00:50:52.009 --> 00:50:56.708 my reaction to it.
00:50:56.708 --> 00:51:02.060 My sense is that if it was something
00:51:02.060 --> 00:51:06.809 it was something that was too controversial.
00:51:06.809 --> 00:51:09.559 I was in a tough place because of the
00:51:09.559 --> 00:51:12.059 health affairs piece.
00:51:12.059 --> 00:51:16.459 I stand firm on believing that,
00:51:16.459 --> 00:51:21.058 had that article come out before they
00:51:21.058 --> 00:51:25.058 offered me a fellowship position,
00:51:25.058 --> 00:51:27.010 there would have been a reason why I
00:51:27.010 --> 00:51:30.459 couldn't have come into the fellowship.
00:51:30.459 --> 00:51:34.010 The piece came out after.
00:51:34.010 --> 00:51:36.259 I found out that a lot of people were
00:51:36.259 --> 00:51:38.760 upset by it.
00:51:38.760 --> 00:51:41.110 They thought I was shooting from the
00:51:41.110 --> 00:51:46.260 hip and it wasn't fair.
00:51:46.260 --> 00:51:50.159 I was so naive in thinking the
00:51:50.159 --> 00:51:55.809 transplant community will see that this
00:51:55.809 --> 00:52:01.209 is a director who could see this in our system.
00:52:01.209 --> 00:52:03.359 "No I'm not,
00:52:03.359 --> 00:52:09.508 what are you?"
00:52:09.508 --> 00:52:12.509 When I think about it,
00:52:12.509 --> 00:52:16.609 the whole reason I went into
00:52:16.609 --> 00:52:22.158 nephrology was to do this research on a
00:52:22.158 --> 00:52:27.560 access and disparities.
00:52:27.560 --> 00:52:32.359 Our colleagues wrote down this dsprty
00:52:32.359 --> 00:52:34.059 identify problems,
00:52:34.059 --> 00:52:40.259 but don't come up with solutions.
00:52:40.259 --> 00:52:43.909 We need to be somewhere where we can

00:52:43.909 --> 00:52:45.859 change how things can be canon.
00:52:45.859 --> 00:52:51.010 I've proposed interviews,
00:52:51.010 --> 00:52:53.507 observations behind these closed doors
00:52:53.507 --> 00:52:55.359 that I have no access to.
00:52:55.359 --> 00:53:01.559 I probably never will at this point.
00:53:01.559 --> 00:53:03.659 What was I going to say?
00:53:03.659 --> 00:53:13.009 The ments
00:53:13.009 --> 00:53:14.807 entors refused to support me in this line
00:53:14.807 --> 00:53:18.359 of research.
00:53:18.359 --> 00:53:20.459 Just because a study doesn't exist
00:53:20.459 --> 00:53:30.508 doesn't mean the problem isn't true.
00:53:30.508 --> 00:53:40.910 I bumped up against this with the race
00:53:40.910 --> 00:53:48.658 correction thing.
00:53:48.658 --> 00:53:51.509 I've done a couple little studies.
00:53:51.509 --> 00:53:54.159 They were really hard to get published. No one
can fathom that there are built-in inequities in
00:53:54.159 --> 00:54:04.208 the system. It ended up not being
00:54:04.208 --> 00:54:07.658 almost completely de-railing my career.
00:54:07.658 --> 00:54:09.658 I had to come up with something I was
00:54:09.658 --> 00:54:17.857 interested in that fit my mindset.
00:54:17.857 --> 00:54:20.057 My mindset is still bent towards
00:54:20.057 --> 00:54:22.257 preventative care.
00:54:22.257 --> 00:54:26.558 I looked at periodontal disease as a
00:54:26.558 --> 00:54:32.208 risk factor for chronic kidney disease.
00:54:32.208 --> 00:54:34.858 I did a pilot randomized control trial.
00:54:34.858 --> 00:54:38.359 It was cool,
00:54:38.359 --> 00:54:41.708 but it was a no-brainer.
00:54:41.708 --> 00:54:45.708 We didn't have to do research studies
00:54:45.708 --> 00:54:47.758 to prove that dental care is good for a
00:54:47.758 --> 00:54:54.258 person's overall health.
00:54:54.258 --> 00:55:00.359 Why can't we just help people be healthy?

00:55:00.359 --> 00:55:03.058 Because of the experience of being in
00:55:03.058 --> 00:55:05.209 nephrology and being upset with all the
00:55:05.209 --> 00:55:08.259 things that happened,
00:55:08.259 --> 00:55:19.912 that's how I came to
00:55:19.912 --> 00:55:22.208 be passionate about palliative care and end of
00:55:22.208 --> 00:55:25.460 life and that became my focus.
00:55:25.460 --> 00:55:31.659 I wouldn't have envisioned any of this ever.
00:55:31.659 --> 00:55:33.761 Little girl from North Carolina.
00:55:33.761 --> 00:55:37.059 Here I am.
00:55:37.059 --> 00:55:43.209 This is where I'm supposed to be.
00:55:43.209 --> 00:55:51.810 Anna Reis
00:55:51.810 --> 00:55:59.409 man: One more question about palliative care.
00:55:59.409 --> 00:56:05.009 This phrase stuck with me that you wrote.
00:56:05.009 --> 00:56:08.708 "I was always taught that transplant
00:56:08.708 --> 00:56:13.609 was better than dialysis and that
00:56:13.609 --> 00:56:15.508 dialysis was better than death always."
00:56:15.508 --> 00:56:18.259 Do you agree with that now?
00:56:18.259 --> 00:56:20.309 Dr. Vanessa Grubbs: I do.
00:56:20.309 --> 00:56:24.209 I'm less draconian,
00:56:24.209 --> 00:56:27.707 less rigid about the thinking.
00:56:27.707 --> 00:56:29.708 There's more nuance in the way I think
00:56:29.708 --> 00:56:31.809 about things.
00:56:31.809 --> 00:56:37.759 I believe if there's is
00:56:37.759 --> 00:56:45.259 there's something wrong with
00:56:45.259 --> 00:56:48.508 putting someone who's 50-60 years old
00:56:48.508 --> 00:56:54.508 on dialysis.
00:56:54.508 --> 00:56:56.659 nothing
00:56:56.659 --> 00:57:02.808 wrong with putting someone who's 50-60 years
old on dialysis.
00:57:02.808 --> 00:57:08.658 But I don't think someone who's 80-90
00:57:08.658 --> 00:57:12.910 with many problems should be put on

00:57:12.910 --> 00:57:17.209 dialysis because their kidneys are failing.
00:57:17.209 --> 00:57:20.558 We should manage their symptoms rather
00:57:20.558 --> 00:57:22.558 than put them on dialysis.
00:57:22.558 --> 00:57:25.159 Most of medicine,
00:57:25.159 --> 00:57:29.007 particularly in nephrology,
00:57:29.007 --> 00:57:31.008 the tendency has been to think of life
00:57:31.008 --> 00:57:37.008 or death.
00:57:37.008 --> 00:57:41.959 It does a disservice by considering
00:57:41.959 --> 00:57:45.459 what life is like on dialysis.
00:57:45.459 --> 00:57:49.359 I can't imagine any nephrologist
00:57:49.359 --> 00:57:55.659 taking care of dialysis patients can
00:57:55.659 --> 00:58:01.809 tie up someone who doesn't have an idea
00:58:01.809 --> 00:58:04.458 of where they're at so we can prolong
00:58:04.458 --> 00:58:06.710 their life in this state for a few more
00:58:06.710 --> 00:58:11.559 days.
00:58:11.559 --> 00:58:13.659 There's something wrong with that.
00:58:13.659 --> 00:58:18.508 All those things matter.
00:58:18.508 --> 00:58:20.458 I believe we need to be more
00:58:20.458 --> 00:58:22.610 thoughtful and honest with people about
00:58:22.610 --> 00:58:28.458 what to expect.
00:58:28.458 --> 00:58:31.708 We talk about people being dead in
00:58:31.708 --> 00:58:36.259 two weeks if they don't start dialysis.
00:58:36.259 --> 00:58:38.508 "Here I am six months later!"
00:58:38.508 --> 00:58:42.109 You said I'd be dead!"
00:58:42.109 --> 00:58:44.309 There's a lot that goes into it.
00:58:44.309 --> 00:58:47.809 We stop there for the most part.
00:58:47.809 --> 00:58:50.559 Over the last few yrs
00:58:50.559 --> 00:58:55.358 ears,
00:58:55.358 --> 00:58:58.009 I'm happy to be a part of this movement.
00:58:58.009 --> 00:59:01.709 We have to talk about what dialysis
00:59:01.709 --> 00:59:04.307 is like for people so they can rll

00:59:04.307 --> 00:59:11.059 eally
00:59:11.059 --> 00:59:14.959 and make a recommendation for them.
00:59:14.959 --> 00:59:18.059 Too many of us give them their
00:59:18.059 --> 00:59:20.359 options without providing guidance.
00:59:20.359 --> 00:59:23.059 It's not OK.
00:59:23.059 --> 00:59:25.208 We're supposed to partner with our
00:59:25.208 --> 00:59:28.459 patients and their families,
00:59:28.459 --> 00:59:30.462 not just present a list of things for
00:59:30.462 --> 00:59:35.908 them to choose.
00:59:35.908 --> 00:59:42.008 Anna Reisman: Speaking of that,
00:59:42.008 --> 00:59:47.309 we'll just talk about this before we end
00:59:47.309 --> 00:59:49.258 . I apologize to those with questions.
00:59:49.258 --> 00:59:52.358 They're in the chat.
00:59:52.358 --> 00:59:54.758 Dr.
00:59:54.758 --> 00:59:58.660 Vanessa Grubbs: I don't see them.
00:59:58.660 --> 01:00:02.959 There's a separate Q&A.
01:00:02.959 --> 01:00:06.109 I'm happy to hang on for a few
01:00:06.109 --> 01:00:14.309 minutes for folks who are going to stay on board.
01:00:14.309 --> 01:00:18.108 Anna Reisman: I wanted to use what you
01:00:18.108 --> 01:00:22.009 just said to talk about how we're
01:00:22.009 --> 01:00:23.909 learning about dialysis now through
01:00:23.909 --> 01:00:27.159 your new youtube channel.
01:00:27.159 --> 01:00:29.209 Dr.
01:00:29.209 --> 01:00:31.359 Vanessa Grubbs: I'm working on my
01:00:31.359 --> 01:00:34.959 next one now.
01:00:34.959 --> 01:00:37.309 Hopefully I'll get it up soon.
01:00:37.309 --> 01:00:44.709 I'm getting better.
01:00:44.709 --> 01:00:49.709 Because of the things I've written,
01:00:49.709 --> 01:00:52.108 I have put out a different perspective
01:00:52.108 --> 01:00:56.208 than what people are used to.
01:00:56.208 --> 01:01:02.458 Folks reach out to me asking my advice.

01:01:02.458 --> 01:01:04.359 A lot of them are in states of high stress,
01:01:04.359 --> 01:01:10.059 anxiety, fear.
01:01:10.059 --> 01:01:12.059 I tend to answer them one by one.
01:01:12.059 --> 01:01:19.558 I felt like Dr.
01:01:19.558 --> 01:01:24.709 having a youtube channel would help me reach
more people.
01:01:24.709 --> 01:01:30.109 One of the things I've felt strongly
01:01:30.109 --> 01:01:33.958 about is how we talk about patient education.
01:01:33.958 --> 01:01:39.358 People have to physically be in our
01:01:39.358 --> 01:01:42.810 clinic in order to receive that education.
01:01:42.810 --> 01:01:48.609 When you thinking about kidney failure,
01:01:48.609 --> 01:01:51.409 people don't get symptoms until it is
01:01:51.409 --> 01:01:53.359 time to start dialysis.
01:01:53.359 --> 01:01:57.709 They don't want to accept it.
01:01:57.709 --> 01:02:00.210 They tell us we don't know what we're
01:02:00.210 --> 01:02:03.409 talking about.
01:02:03.409 --> 01:02:06.108 They wouldn't come to the clinic.
01:02:06.108 --> 01:02:09.310 They would run away from it until
01:02:09.310 --> 01:02:12.559 kidney failure caught up with them as
01:02:12.559 --> 01:02:14.759 it always does unless something else
01:02:14.759 --> 01:02:17.159 gets you first.
01:02:17.159 --> 01:02:20.908 Those people aren't looking for information.
01:02:20.908 --> 01:02:24.159 If I put it in a more public platform,
01:02:24.159 --> 01:02:27.258 I thought people would come across it
01:02:27.258 --> 01:02:30.308 even if they weren't looking.
01:02:30.308 --> 01:02:39.759 That's my hope.
01:02:39.759 --> 01:02:44.508 In the intro I just talked about what
01:02:44.508 --> 01:02:47.859 made me move forward in this direction.
01:02:47.859 --> 01:02:49.809 The first one is people
01:02:49.809 --> 01:02:56.710 misinterpreting things I've written.
01:02:56.710 --> 01:02:58.909 When I talk about not thinking

01:02:58.909 --> 01:03:01.908 dialysis is not always better than death,
01:03:01.908 --> 01:03:06.609 I'm talking about frail old people.
01:03:06.609 --> 01:03:11.109 Not a spry 75 year old.
01:03:11.109 --> 01:03:15.809 A small population that will not gain
01:03:15.809 --> 01:03:20.959 benefit in quality and quantity of life.
01:03:20.959 --> 01:03:27.059 I get quite a few younger people.
01:03:27.059 --> 01:03:29.259 My next video is about being driven
01:03:29.259 --> 01:03:32.159 by fear.
01:03:32.159 --> 01:03:35.609 I'll do videos on the earlier things
01:03:35.609 --> 01:03:37.958 to help educate people about some of
01:03:37.958 --> 01:03:44.209 the preventative things.
01:03:44.209 --> 01:03:47.161 Things will be based mostly on emails
01:03:47.161 --> 01:03:52.209 I get from people.
01:03:52.209 --> 01:03:56.958 I hope people start writing to me
01:03:56.958 --> 01:03:59.359 . I can't do anything specific and
01:03:59.359 --> 01:04:04.958 hope I don't get in trouble.
01:04:04.958 --> 01:04:06.861 My hope is to be helpful to as many
01:04:06.861 --> 01:04:10.759 people as possible.
01:04:10.759 --> 01:04:13.209 Anna Reisman: Fantastic.
01:04:13.209 --> 01:04:15.058 Wonderful.
01:04:15.058 --> 01:04:22.658 I will tell patients to utilize this resource.
01:04:22.658 --> 01:04:25.209 Thank you so,
01:04:25.209 --> 01:04:27.158 so much.
01:04:27.158 --> 01:04:31.408 I love talking to you.
01:04:31.408 --> 01:04:35.258 Your book is terrific.
01:04:35.258 --> 01:04:42.058 Anyone who hasn't read it should read it.
01:04:42.058 --> 01:04:46.058 It goes over all the things we talked about.
01:04:46.058 --> 01:04:50.358 It goes into a lot of depth and is
01:04:50.358 --> 01:04:52.608 really good in engaging writers.
01:04:52.608 --> 01:04:56.657 Thank you for being here.
01:04:56.657 --> 01:05:01.209 If we could not close this immediately,

01:05:01.209 --> 01:05:03.558 if anyone wants to ask a question afterwards,

01:05:03.558 --> 01:05:07.358 we are officially done.

01:05:07.358 --> 01:10:39.358 [End of Discussion.