

WEBVTT

NOTE duration:"01:21:21"

NOTE recognizability:0.816

NOTE language:en-us

NOTE Confidence: 0.74489966375

00:00:00.000 --> 00:00:02.256 So hi everybody.

NOTE Confidence: 0.74489966375

00:00:02.256 --> 00:00:06.016 My name is Anna Reisman.

NOTE Confidence: 0.74489966375

00:00:06.020 --> 00:00:07.958 I'm the director of the Program

NOTE Confidence: 0.74489966375

00:00:07.958 --> 00:00:09.536 for Humanities and Medicine and

NOTE Confidence: 0.74489966375

00:00:09.536 --> 00:00:11.336 happy to see so many of you here.

NOTE Confidence: 0.74489966375

00:00:11.340 --> 00:00:14.178 Joining us today for this conversation

NOTE Confidence: 0.74489966375

00:00:14.178 --> 00:00:17.100 between Megan O'Rourke and Lisa Sanders.

NOTE Confidence: 0.74489966375

00:00:17.100 --> 00:00:19.240 Before I introduce the speakers,

NOTE Confidence: 0.74489966375

00:00:19.240 --> 00:00:22.208 I want to acknowledge that this is the

NOTE Confidence: 0.74489966375

00:00:22.208 --> 00:00:24.092 first humanities and medicine event

NOTE Confidence: 0.74489966375

00:00:24.092 --> 00:00:26.591 here since the death of Tom Duffy,

NOTE Confidence: 0.74489966375

00:00:26.600 --> 00:00:28.634 Doctor Thomas Duffy, who was my

NOTE Confidence: 0.74489966375

00:00:28.634 --> 00:00:30.720 predecessor and directed this program for.

NOTE Confidence: 0.74489966375

00:00:30.720 --> 00:00:32.701 Close to 20 years and I have
NOTE Confidence: 0.74489966375

00:00:32.701 --> 00:00:34.710 a lot to say about him,
NOTE Confidence: 0.74489966375

00:00:34.710 --> 00:00:37.134 but I'm going to save it for January
NOTE Confidence: 0.74489966375

00:00:37.134 --> 00:00:39.342 when we have the annual Duffy Lecture.
NOTE Confidence: 0.74489966375

00:00:39.342 --> 00:00:41.832 Just I'll say now that many of us
NOTE Confidence: 0.74489966375

00:00:41.832 --> 00:00:43.736 missed him and his presence even in
NOTE Confidence: 0.74489966375

00:00:43.736 --> 00:00:45.697 this virtual space and looking forward
NOTE Confidence: 0.74489966375

00:00:45.697 --> 00:00:48.275 to having a chance to say more in
NOTE Confidence: 0.74489966375

00:00:48.275 --> 00:00:50.165 January at the Duffy Lecture which
NOTE Confidence: 0.74489966375

00:00:50.165 --> 00:00:52.470 will be given by Doctor Robert Rock.
NOTE Confidence: 0.74489966375

00:00:52.470 --> 00:00:55.380 So more on that to come.
NOTE Confidence: 0.74489966375

00:00:55.380 --> 00:00:58.140 I also want to mention our next event,
NOTE Confidence: 0.74489966375

00:00:58.140 --> 00:01:01.087 which will take place on November 30th.
NOTE Confidence: 0.74489966375

00:01:01.090 --> 00:01:03.190 Which will be a hybrid event,
NOTE Confidence: 0.74489966375

00:01:03.190 --> 00:01:05.650 a panel discussion on racial science
NOTE Confidence: 0.74489966375

00:01:05.650 --> 00:01:08.589 and slavery in US medical schools,

NOTE Confidence: 0.74489966375
00:01:08.590 --> 00:01:10.254 featuring historian of medicine
NOTE Confidence: 0.74489966375
00:01:10.254 --> 00:01:11.086 Chris Willoughby,
NOTE Confidence: 0.74489966375
00:01:11.090 --> 00:01:13.316 author of the New Book Masters
NOTE Confidence: 0.74489966375
00:01:13.316 --> 00:01:15.362 of Health and Conversation with
NOTE Confidence: 0.74489966375
00:01:15.362 --> 00:01:18.110 panelists Leanna DeMarco, Sean Smith.
NOTE Confidence: 0.74489966375
00:01:18.110 --> 00:01:20.670 Carolyn Roberts and medical
NOTE Confidence: 0.74489966375
00:01:20.670 --> 00:01:22.590 student China jilli.
NOTE Confidence: 0.74489966375
00:01:22.590 --> 00:01:24.720 If you're interested in hearing
NOTE Confidence: 0.74489966375
00:01:24.720 --> 00:01:26.970 about these and other future events,
NOTE Confidence: 0.74489966375
00:01:26.970 --> 00:01:28.530 we have a busy spring.
NOTE Confidence: 0.74489966375
00:01:28.530 --> 00:01:29.682 Please sign up for our mailing
NOTE Confidence: 0.74489966375
00:01:29.682 --> 00:01:31.048 list if you're not already on it.
NOTE Confidence: 0.74489966375
00:01:31.050 --> 00:01:31.524 And Karen,
NOTE Confidence: 0.74489966375
00:01:31.524 --> 00:01:32.946 if you could put the address
NOTE Confidence: 0.74489966375
00:01:32.946 --> 00:01:34.419 the e-mail address in the chat,
NOTE Confidence: 0.74489966375

00:01:34.420 --> 00:01:35.000 that would be great.
NOTE Confidence: 0.913185426

00:01:37.440 --> 00:01:39.340 And now for today's presentation.
NOTE Confidence: 0.913185426

00:01:39.340 --> 00:01:41.825 I'm thrilled to have Megan and Lisa
NOTE Confidence: 0.913185426

00:01:41.825 --> 00:01:44.849 here today in this virtual space for
NOTE Confidence: 0.913185426

00:01:44.849 --> 00:01:47.204 the session entitled The Invisible
NOTE Confidence: 0.913185426

00:01:47.204 --> 00:01:49.778 Kingdom Reimagining Chronic Illness.
NOTE Confidence: 0.913185426

00:01:49.780 --> 00:01:52.124 Megan O'Rourke is the author of the New
NOTE Confidence: 0.913185426

00:01:52.124 --> 00:01:54.592 York Times bestseller of the same title,
NOTE Confidence: 0.913185426

00:01:54.592 --> 00:01:55.824 The Invisible Kingdom reimagining
NOTE Confidence: 0.913185426

00:01:55.824 --> 00:01:57.684 Chronic Illness, which was a finalist
NOTE Confidence: 0.913185426

00:01:57.684 --> 00:01:59.239 for the National Book Award.
NOTE Confidence: 0.913185426

00:01:59.240 --> 00:02:01.936 She's also the author of the Long Goodbye,
NOTE Confidence: 0.913185426

00:02:01.940 --> 00:02:04.556 as well as three poetry collections
NOTE Confidence: 0.913185426

00:02:04.560 --> 00:02:05.106 for writing.
NOTE Confidence: 0.913185426

00:02:05.106 --> 00:02:06.744 Has appeared in the Atlantic Monthly,
NOTE Confidence: 0.913185426

00:02:06.750 --> 00:02:08.538 The New Yorker, New York Times,

NOTE Confidence: 0.913185426

00:02:08.540 --> 00:02:09.912 and many other places.

NOTE Confidence: 0.913185426

00:02:09.912 --> 00:02:11.970 She's the recipient of a Guggenheim

NOTE Confidence: 0.913185426

00:02:12.029 --> 00:02:14.024 Fellowship, a Radcliffe Fellowship,

NOTE Confidence: 0.913185426

00:02:14.024 --> 00:02:15.816 and awaiting Nonfiction award.

NOTE Confidence: 0.913185426

00:02:15.820 --> 00:02:17.040 Megan lives in New Haven,

NOTE Confidence: 0.913185426

00:02:17.040 --> 00:02:18.588 where she teaches at Yale and

NOTE Confidence: 0.913185426

00:02:18.588 --> 00:02:19.620 is the editor of.

NOTE Confidence: 0.913185426

00:02:19.620 --> 00:02:21.364 Be wonderful, Yale review.

NOTE Confidence: 0.913185426

00:02:21.364 --> 00:02:22.130 Welcome, Megan.

NOTE Confidence: 0.909429945714286

00:02:24.360 --> 00:02:25.764 My colleague and friend,

NOTE Confidence: 0.909429945714286

00:02:25.764 --> 00:02:26.817 Doctor Lisa Sanders,

NOTE Confidence: 0.909429945714286

00:02:26.820 --> 00:02:29.116 is an internist and associate professor on

NOTE Confidence: 0.909429945714286

00:02:29.116 --> 00:02:31.658 the faculty here of Yale School of Medicine.

NOTE Confidence: 0.909429945714286

00:02:31.660 --> 00:02:33.532 She created and writes the diagnosis

NOTE Confidence: 0.909429945714286

00:02:33.532 --> 00:02:35.980 column for the New York Times magazine,

NOTE Confidence: 0.909429945714286

00:02:35.980 --> 00:02:39.178 the inspiration for the series House, MD.
NOTE Confidence: 0.909429945714286

00:02:39.178 --> 00:02:41.368 She helped create the documentary
NOTE Confidence: 0.909429945714286

00:02:41.368 --> 00:02:43.120 series diagnosis for Netflix,
NOTE Confidence: 0.909429945714286

00:02:43.120 --> 00:02:45.394 which followed a series of patients
NOTE Confidence: 0.909429945714286

00:02:45.394 --> 00:02:47.540 in their search for answers.
NOTE Confidence: 0.909429945714286

00:02:47.540 --> 00:02:49.540 Her most recent book, diagnosis,
NOTE Confidence: 0.909429945714286

00:02:49.540 --> 00:02:51.700 Solving the most baffling medical mysteries,
NOTE Confidence: 0.909429945714286

00:02:51.700 --> 00:02:53.079 is the collection of her New York.
NOTE Confidence: 0.909429945714286

00:02:53.080 --> 00:02:54.991 Times columns Lisa is also the author
NOTE Confidence: 0.909429945714286

00:02:54.991 --> 00:02:56.940 of the New York Times bestseller
NOTE Confidence: 0.909429945714286

00:02:56.940 --> 00:02:58.720 every patient tells a story,
NOTE Confidence: 0.909429945714286

00:02:58.720 --> 00:03:02.476 medical mysteries, and the art diagnosis.
NOTE Confidence: 0.909429945714286

00:03:02.480 --> 00:03:05.318 And very appropriate to today's talk,
NOTE Confidence: 0.909429945714286

00:03:05.320 --> 00:03:06.379 beginning in January,
NOTE Confidence: 0.909429945714286

00:03:06.379 --> 00:03:09.479 doctor Sanders will be taking on a new role.
NOTE Confidence: 0.909429945714286

00:03:09.480 --> 00:03:12.225 She will be at the home of a new

NOTE Confidence: 0.909429945714286
00:03:12.225 --> 00:03:14.605 clinic being created right here at
NOTE Confidence: 0.909429945714286
00:03:14.605 --> 00:03:17.539 Yale that will focus on long COVID.
NOTE Confidence: 0.909429945714286
00:03:17.540 --> 00:03:20.732 We are joined by ASL interpreters Jay and
NOTE Confidence: 0.909429945714286
00:03:20.732 --> 00:03:23.264 Rhonda and closed captioning is available
NOTE Confidence: 0.909429945714286
00:03:23.264 --> 00:03:26.979 and I invite you to put your questions.
NOTE Confidence: 0.909429945714286
00:03:26.980 --> 00:03:28.174 You can use the chat as
NOTE Confidence: 0.909429945714286
00:03:28.174 --> 00:03:29.619 you as as you would like.
NOTE Confidence: 0.909429945714286
00:03:29.620 --> 00:03:31.120 If you have particular questions,
NOTE Confidence: 0.909429945714286
00:03:31.120 --> 00:03:33.760 please use the Q&A.
NOTE Confidence: 0.909429945714286
00:03:33.760 --> 00:03:35.476 Function at the bottom of the
NOTE Confidence: 0.909429945714286
00:03:35.476 --> 00:03:37.692 screen and I will be back later
NOTE Confidence: 0.909429945714286
00:03:37.692 --> 00:03:39.367 for the questions and answers.
NOTE Confidence: 0.909429945714286
00:03:39.370 --> 00:03:40.090 And for now,
NOTE Confidence: 0.909429945714286
00:03:40.090 --> 00:03:42.170 we'll turn it over to Lisa and Macon.
NOTE Confidence: 0.909429945714286
00:03:42.170 --> 00:03:43.470 So welcome everybody again.
NOTE Confidence: 0.884316948181818

00:03:46.910 --> 00:03:48.414 Thank you so much.
NOTE Confidence: 0.884316948181818

00:03:48.414 --> 00:03:50.670 And I think that we're supposed
NOTE Confidence: 0.884316948181818

00:03:50.752 --> 00:03:52.786 to kick off with me reading
NOTE Confidence: 0.884316948181818

00:03:52.786 --> 00:03:54.819 a little bit from my book.
NOTE Confidence: 0.884316948181818

00:03:54.820 --> 00:03:57.538 Thank you everyone for coming tonight.
NOTE Confidence: 0.884316948181818

00:03:57.540 --> 00:04:00.186 It's wonderful to be here in this
NOTE Confidence: 0.884316948181818

00:04:00.186 --> 00:04:02.064 space with you, even if we're
NOTE Confidence: 0.884316948181818

00:04:02.064 --> 00:04:03.552 not together in a physical space.
NOTE Confidence: 0.884316948181818

00:04:03.560 --> 00:04:05.630 And I'm really looking forward to
NOTE Confidence: 0.884316948181818

00:04:05.630 --> 00:04:08.136 talking with Lisa and then talking with
NOTE Confidence: 0.884316948181818

00:04:08.136 --> 00:04:10.600 all of you and hearing your questions.
NOTE Confidence: 0.884316948181818

00:04:10.600 --> 00:04:14.610 I thought, I thought I would read
NOTE Confidence: 0.884316948181818

00:04:14.610 --> 00:04:16.960 just a short section of the book,
NOTE Confidence: 0.884316948181818

00:04:16.960 --> 00:04:18.544 The Invisible Kingdom,
NOTE Confidence: 0.884316948181818

00:04:18.544 --> 00:04:20.656 reimagining Chronic Illness which.
NOTE Confidence: 0.884316948181818

00:04:20.660 --> 00:04:24.580 Began out of my own experience of

NOTE Confidence: 0.884316948181818
00:04:24.580 --> 00:04:27.072 getting mysteriously ill with a
NOTE Confidence: 0.884316948181818
00:04:27.072 --> 00:04:29.487 poorly understood set of conditions
NOTE Confidence: 0.884316948181818
00:04:29.487 --> 00:04:31.699 that turned out and searching
NOTE Confidence: 0.884316948181818
00:04:31.699 --> 00:04:33.754 for years for an answer.
NOTE Confidence: 0.884316948181818
00:04:33.760 --> 00:04:35.860 A search which quickly became
NOTE Confidence: 0.884316948181818
00:04:35.860 --> 00:04:37.960 not only a biographical problem,
NOTE Confidence: 0.884316948181818
00:04:37.960 --> 00:04:39.610 but a kind of intellectual problem
NOTE Confidence: 0.884316948181818
00:04:39.610 --> 00:04:41.170 of kind of writerly problem.
NOTE Confidence: 0.884316948181818
00:04:41.170 --> 00:04:44.194 Which is to say that it set off
NOTE Confidence: 0.884316948181818
00:04:44.194 --> 00:04:46.900 all kinds of questions for me.
NOTE Confidence: 0.884316948181818
00:04:46.900 --> 00:04:48.755 Of the sort that I attended to
NOTE Confidence: 0.884316948181818
00:04:48.755 --> 00:04:51.186 tackle in my work as a journalist
NOTE Confidence: 0.884316948181818
00:04:51.186 --> 00:04:52.758 and nonfiction writer already.
NOTE Confidence: 0.884316948181818
00:04:52.760 --> 00:04:55.316 So a lot of my work as a writer
NOTE Confidence: 0.884316948181818
00:04:55.316 --> 00:04:56.659 has been around.
NOTE Confidence: 0.884316948181818

00:04:56.660 --> 00:04:57.452 You know,
NOTE Confidence: 0.884316948181818

00:04:57.452 --> 00:04:59.828 kind of looking at common experiences
NOTE Confidence: 0.884316948181818

00:04:59.828 --> 00:05:02.424 that that in some ways I think
NOTE Confidence: 0.884316948181818

00:05:02.424 --> 00:05:04.718 we're telling the wrong story about
NOTE Confidence: 0.884316948181818

00:05:04.718 --> 00:05:07.148 where an oversimplified story about.
NOTE Confidence: 0.884316948181818

00:05:07.150 --> 00:05:08.058 And in a way,
NOTE Confidence: 0.884316948181818

00:05:08.058 --> 00:05:09.420 that's what I ended up feeling
NOTE Confidence: 0.884316948181818

00:05:09.478 --> 00:05:11.368 about my own experience of chronic
NOTE Confidence: 0.884316948181818

00:05:11.368 --> 00:05:12.954 illness and realizing that my
NOTE Confidence: 0.884316948181818

00:05:12.954 --> 00:05:14.981 experience stood in for or was at
NOTE Confidence: 0.884316948181818

00:05:14.981 --> 00:05:16.883 least analogous to in certain ways,
NOTE Confidence: 0.884316948181818

00:05:16.890 --> 00:05:18.570 the experience of many others,
NOTE Confidence: 0.884316948181818

00:05:18.570 --> 00:05:22.090 and of course quite distinct in other ways.
NOTE Confidence: 0.884316948181818

00:05:22.090 --> 00:05:25.163 So the book aims to both leave
NOTE Confidence: 0.884316948181818

00:05:25.163 --> 00:05:27.849 quite a lot of research.
NOTE Confidence: 0.884316948181818

00:05:27.850 --> 00:05:29.746 I spent eight years writing it,

NOTE Confidence: 0.884316948181818
00:05:29.750 --> 00:05:32.190 eight years talking to researchers,
NOTE Confidence: 0.884316948181818
00:05:32.190 --> 00:05:33.158 clinicians, patients,
NOTE Confidence: 0.884316948181818
00:05:33.158 --> 00:05:37.070 people with illness, their families.
NOTE Confidence: 0.884316948181818
00:05:37.070 --> 00:05:38.239 One of that research doesn't make it
NOTE Confidence: 0.884316948181818
00:05:38.239 --> 00:05:41.120 into the book, but it's the sort of.
NOTE Confidence: 0.884316948181818
00:05:41.120 --> 00:05:44.000 Substract the book, if you will,
NOTE Confidence: 0.884316948181818
00:05:44.000 --> 00:05:45.561 and then there is a fair amount
NOTE Confidence: 0.884316948181818
00:05:45.561 --> 00:05:46.580 of research in there,
NOTE Confidence: 0.884316948181818
00:05:46.580 --> 00:05:49.420 and that's woven together with my own story,
NOTE Confidence: 0.884316948181818
00:05:49.420 --> 00:05:53.795 and the aim was to illuminate something.
NOTE Confidence: 0.884316948181818
00:05:53.800 --> 00:05:55.448 Very granular, in fact,
NOTE Confidence: 0.884316948181818
00:05:55.448 --> 00:05:57.508 about the lived experience of
NOTE Confidence: 0.884316948181818
00:05:57.508 --> 00:05:59.431 patients with chronic illness
NOTE Confidence: 0.884316948181818
00:05:59.431 --> 00:06:01.347 while also contextualizing that
NOTE Confidence: 0.884316948181818
00:06:01.347 --> 00:06:03.520 experience and sort of social,
NOTE Confidence: 0.884316948181818

00:06:03.520 --> 00:06:04.663 historical, medical history,
NOTE Confidence: 0.884316948181818

00:06:04.663 --> 00:06:06.949 because it seems to me that
NOTE Confidence: 0.884316948181818

00:06:06.949 --> 00:06:08.919 you really can't understand.
NOTE Confidence: 0.884316948181818

00:06:08.920 --> 00:06:11.836 I couldn't even understand my own
NOTE Confidence: 0.884316948181818

00:06:11.836 --> 00:06:14.294 experience without learning a lot
NOTE Confidence: 0.884316948181818

00:06:14.294 --> 00:06:16.479 about the history of medicine.
NOTE Confidence: 0.884316948181818

00:06:16.480 --> 00:06:19.196 And other things to help me think
NOTE Confidence: 0.884316948181818

00:06:19.196 --> 00:06:22.420 about the kinds of problems I was facing.
NOTE Confidence: 0.884316948181818

00:06:22.420 --> 00:06:24.676 So I'm going to read just a few
NOTE Confidence: 0.884316948181818

00:06:24.676 --> 00:06:26.944 paragraphs from a chapter called
NOTE Confidence: 0.884316948181818

00:06:26.944 --> 00:06:30.410 Impersonation, which tries to take on.
NOTE Confidence: 0.884316948181818

00:06:30.410 --> 00:06:33.189 Animating some of the the loneliness really,
NOTE Confidence: 0.884316948181818

00:06:33.190 --> 00:06:36.246 I think of of being ill in a
NOTE Confidence: 0.884316948181818

00:06:36.246 --> 00:06:38.589 way that's not understood.
NOTE Confidence: 0.884316948181818

00:06:38.590 --> 00:06:40.300 So.
NOTE Confidence: 0.884316948181818

00:06:40.300 --> 00:06:41.398 And excuse me,

NOTE Confidence: 0.884316948181818
00:06:41.398 --> 00:06:43.594 I'm getting over a little cold
NOTE Confidence: 0.884316948181818
00:06:43.594 --> 00:06:47.280 so I'm a bit nasal impersonation.
NOTE Confidence: 0.884316948181818
00:06:47.280 --> 00:06:49.219 One of the hardest things about being
NOTE Confidence: 0.884316948181818
00:06:49.219 --> 00:06:51.194 ill with a poorly understood disease
NOTE Confidence: 0.884316948181818
00:06:51.194 --> 00:06:53.707 is that most people find what you're
NOTE Confidence: 0.884316948181818
00:06:53.765 --> 00:06:55.559 going through incomprehensible,
NOTE Confidence: 0.884316948181818
00:06:55.560 --> 00:06:57.510 if they even believe you are
NOTE Confidence: 0.884316948181818
00:06:57.510 --> 00:06:58.485 going through it.
NOTE Confidence: 0.884316948181818
00:06:58.490 --> 00:06:59.834 In your loneliness,
NOTE Confidence: 0.884316948181818
00:06:59.834 --> 00:07:01.626 your preoccupation with an
NOTE Confidence: 0.884316948181818
00:07:01.626 --> 00:07:02.970 enduring new reality,
NOTE Confidence: 0.884316948181818
00:07:02.970 --> 00:07:04.854 you want to be understood in
NOTE Confidence: 0.884316948181818
00:07:04.854 --> 00:07:06.110 a way that you
NOTE Confidence: 0.889386428333333
00:07:06.183 --> 00:07:09.416 can't be. Pain is always new to the sufferer,
NOTE Confidence: 0.889386428333333
00:07:09.420 --> 00:07:11.952 but loses its erect originality for
NOTE Confidence: 0.889386428333333

00:07:11.952 --> 00:07:14.648 those around him, the 19th century
NOTE Confidence: 0.889386428333333

00:07:14.648 --> 00:07:17.028 French writer Alphonse today observes
NOTE Confidence: 0.889386428333333

00:07:17.028 --> 00:07:20.538 in his memoir of Living with late stage
NOTE Confidence: 0.889386428333333

00:07:20.538 --> 00:07:23.976 syphilis in the Land of Pain. He writes.
NOTE Confidence: 0.889386428333333

00:07:23.976 --> 00:07:28.280 Everyone will get used to it except me.
NOTE Confidence: 0.889386428333333

00:07:28.280 --> 00:07:30.752 Worrying that your symptoms are psychosomatic
NOTE Confidence: 0.889386428333333

00:07:30.752 --> 00:07:34.432 or even imagined is part of life for many
NOTE Confidence: 0.889386428333333

00:07:34.432 --> 00:07:36.397 people with poorly understood illnesses.
NOTE Confidence: 0.889386428333333

00:07:36.400 --> 00:07:37.744 Although the experience of
NOTE Confidence: 0.889386428333333

00:07:37.744 --> 00:07:40.140 illness is not just in the head,
NOTE Confidence: 0.889386428333333

00:07:40.140 --> 00:07:42.476 it is also not just in the body.
NOTE Confidence: 0.889386428333333

00:07:42.480 --> 00:07:45.522 The person enduring such an illness
NOTE Confidence: 0.889386428333333

00:07:45.522 --> 00:07:47.960 faces a difficult balancing act.
NOTE Confidence: 0.889386428333333

00:07:47.960 --> 00:07:49.260 On the one hand,
NOTE Confidence: 0.889386428333333

00:07:49.260 --> 00:07:51.717 she must advocate for herself even when
NOTE Confidence: 0.889386428333333

00:07:51.717 --> 00:07:53.897 doctors are indifferent or ignorant,

NOTE Confidence: 0.889386428333333
00:07:53.900 --> 00:07:55.928 and not be deterred when she
NOTE Confidence: 0.889386428333333
00:07:55.928 --> 00:07:57.280 knows something is wrong.
NOTE Confidence: 0.889386428333333
00:07:57.280 --> 00:07:58.117 On the other,
NOTE Confidence: 0.889386428333333
00:07:58.117 --> 00:08:00.503 she also must be willing to ask whether
NOTE Confidence: 0.889386428333333
00:08:00.503 --> 00:08:02.333 an obsessive attention to symptoms
NOTE Confidence: 0.889386428333333
00:08:02.333 --> 00:08:04.920 is going to lead to better health.
NOTE Confidence: 0.889386428333333
00:08:04.920 --> 00:08:06.984 The patient has to hold in
NOTE Confidence: 0.889386428333333
00:08:06.984 --> 00:08:08.360 mind 2 contradictory modes.
NOTE Confidence: 0.889386428333333
00:08:08.360 --> 00:08:09.644 In other words,
NOTE Confidence: 0.889386428333333
00:08:09.644 --> 00:08:13.210 insistence on the reality of the disease and
NOTE Confidence: 0.889386428333333
00:08:13.210 --> 00:08:16.156 resistance to her own catastrophic fears.
NOTE Confidence: 0.889386428333333
00:08:16.160 --> 00:08:18.540 I found it hard that fall and
NOTE Confidence: 0.889386428333333
00:08:18.540 --> 00:08:20.600 winter to strike that balance.
NOTE Confidence: 0.889386428333333
00:08:20.600 --> 00:08:23.208 I was increasingly worried.
NOTE Confidence: 0.889386428333333
00:08:23.210 --> 00:08:24.240 After all,
NOTE Confidence: 0.889386428333333

00:08:24.240 --> 00:08:27.330 a terrible anxiety attends chronic illness.
NOTE Confidence: 0.889386428333333

00:08:27.330 --> 00:08:27.739 Overtime,
NOTE Confidence: 0.889386428333333

00:08:27.739 --> 00:08:30.193 it becomes difficult to untangle the
NOTE Confidence: 0.889386428333333

00:08:30.193 --> 00:08:32.160 suffering from symptoms like pain
NOTE Confidence: 0.889386428333333

00:08:32.160 --> 00:08:34.194 from the suffering inflicted by the
NOTE Confidence: 0.889386428333333

00:08:34.194 --> 00:08:36.192 concern over the possibility of more
NOTE Confidence: 0.889386428333333

00:08:36.192 --> 00:08:38.439 pain and worse outcomes in the future.
NOTE Confidence: 0.889386428333333

00:08:38.439 --> 00:08:40.882 This does not mean that the illness
NOTE Confidence: 0.889386428333333

00:08:40.882 --> 00:08:43.150 is in the mind necessarily.
NOTE Confidence: 0.889386428333333

00:08:43.150 --> 00:08:44.641 Rather, the mind,
NOTE Confidence: 0.889386428333333

00:08:44.641 --> 00:08:47.126 that machine from making meaning,
NOTE Confidence: 0.889386428333333

00:08:47.130 --> 00:08:49.748 makes endless meetings of its new state,
NOTE Confidence: 0.889386428333333

00:08:49.750 --> 00:08:52.242 which may themselves influence
NOTE Confidence: 0.889386428333333

00:08:52.242 --> 00:08:53.488 the experience.
NOTE Confidence: 0.889386428333333

00:08:53.490 --> 00:08:56.530 It was in this recursive hall of mirrors,
NOTE Confidence: 0.889386428333333

00:08:56.530 --> 00:08:59.029 trying to adjust to my body's ailments,

NOTE Confidence: 0.889386428333333
00:08:59.030 --> 00:09:01.340 that I lived.
NOTE Confidence: 0.889386428333333
00:09:01.340 --> 00:09:03.398 There is a loneliness to illness,
NOTE Confidence: 0.889386428333333
00:09:03.400 --> 00:09:07.176 a child's desire to be pitied and seen.
NOTE Confidence: 0.889386428333333
00:09:07.180 --> 00:09:09.360 But it is precisely this
NOTE Confidence: 0.889386428333333
00:09:09.360 --> 00:09:11.104 recognition that is elusive.
NOTE Confidence: 0.889386428333333
00:09:11.110 --> 00:09:13.006 How can you explain and identify
NOTE Confidence: 0.889386428333333
00:09:13.006 --> 00:09:15.084 your condition if no one has any
NOTE Confidence: 0.889386428333333
00:09:15.084 --> 00:09:16.834 grasp of what it is you suffer
NOTE Confidence: 0.889386428333333
00:09:16.901 --> 00:09:18.987 from and the symptoms wax and Wain?
NOTE Confidence: 0.889386428333333
00:09:18.990 --> 00:09:21.540 How do you describe a disease
NOTE Confidence: 0.889386428333333
00:09:21.540 --> 00:09:23.240 that's not always there?
NOTE Confidence: 0.889386428333333
00:09:23.240 --> 00:09:25.669 The hardest thing to convey to doctors
NOTE Confidence: 0.889386428333333
00:09:25.669 --> 00:09:28.419 or friends was the debilitating fatigue,
NOTE Confidence: 0.889386428333333
00:09:28.420 --> 00:09:30.330 which many other patients I
NOTE Confidence: 0.889386428333333
00:09:30.330 --> 00:09:31.858 knew experienced as well.
NOTE Confidence: 0.889386428333333

00:09:31.860 --> 00:09:33.680 Complaining of fatigue sounds like
NOTE Confidence: 0.889386428333333

00:09:33.680 --> 00:09:35.860 moral weakness in New York City.
NOTE Confidence: 0.889386428333333

00:09:35.860 --> 00:09:37.042 Tired is normal.
NOTE Confidence: 0.889386428333333

00:09:37.042 --> 00:09:39.406 But the fatigue of physical dysfunction
NOTE Confidence: 0.889386428333333

00:09:39.406 --> 00:09:42.439 I came to recognize is as different
NOTE Confidence: 0.889386428333333

00:09:42.439 --> 00:09:44.571 from normal sleep deprivation as
NOTE Confidence: 0.889386428333333

00:09:44.571 --> 00:09:46.665 COVID-19 is from the common cold.
NOTE Confidence: 0.889386428333333

00:09:46.670 --> 00:09:48.644 It was not caused by needing sleep,
NOTE Confidence: 0.889386428333333

00:09:48.650 --> 00:09:49.150 I thought.
NOTE Confidence: 0.875522024210526

00:09:51.410 --> 00:09:53.360 But by my body cellular conviction
NOTE Confidence: 0.875522024210526

00:09:53.360 --> 00:09:55.431 that it needed to conserve energy
NOTE Confidence: 0.875522024210526

00:09:55.431 --> 00:09:57.909 in order to fix whatever was wrong,
NOTE Confidence: 0.875522024210526

00:09:57.910 --> 00:10:00.070 the feeling erased my will,
NOTE Confidence: 0.875522024210526

00:10:00.070 --> 00:10:02.926 the sense of identity that drives us.
NOTE Confidence: 0.875522024210526

00:10:02.930 --> 00:10:05.709 The worst part of my fatigue was
NOTE Confidence: 0.875522024210526

00:10:05.709 --> 00:10:09.158 the loss of an intact sense of self.

NOTE Confidence: 0.875522024210526
00:10:09.160 --> 00:10:12.656 It wasn't just that I suffered brain fog.
NOTE Confidence: 0.875522024210526
00:10:12.660 --> 00:10:14.879 It wasn't just the loss of self
NOTE Confidence: 0.875522024210526
00:10:14.879 --> 00:10:16.693 that sociologists talk about in
NOTE Confidence: 0.875522024210526
00:10:16.693 --> 00:10:18.297 connection with chronic illness,
NOTE Confidence: 0.875522024210526
00:10:18.300 --> 00:10:19.770 in which everything you know
NOTE Confidence: 0.875522024210526
00:10:19.770 --> 00:10:21.240 about yourself disappears and you
NOTE Confidence: 0.875522024210526
00:10:21.289 --> 00:10:22.759 have to build a different life,
NOTE Confidence: 0.875522024210526
00:10:22.760 --> 00:10:24.086 a different identity.
NOTE Confidence: 0.875522024210526
00:10:24.086 --> 00:10:27.180 Rather, as I got sicker that winter,
NOTE Confidence: 0.875522024210526
00:10:27.180 --> 00:10:29.660 I no longer had the sense that I
NOTE Confidence: 0.875522024210526
00:10:29.660 --> 00:10:31.670 was a distinct person.
NOTE Confidence: 0.875522024210526
00:10:31.670 --> 00:10:34.342 On most days, I felt like a mechanism
NOTE Confidence: 0.875522024210526
00:10:34.342 --> 00:10:37.029 that moved arduously through the world,
NOTE Confidence: 0.875522024210526
00:10:37.030 --> 00:10:40.078 simply trying to complete its task.
NOTE Confidence: 0.875522024210526
00:10:40.080 --> 00:10:42.280 Sitting upright at my father's
NOTE Confidence: 0.875522024210526

00:10:42.280 --> 00:10:44.989 birthday dinner at a quiet restaurant
NOTE Confidence: 0.875522024210526

00:10:44.989 --> 00:10:47.569 required a huge act of will.
NOTE Confidence: 0.875522024210526

00:10:47.570 --> 00:10:47.976 Normally,
NOTE Confidence: 0.875522024210526

00:10:47.976 --> 00:10:50.818 absorption in a task and immersive flow
NOTE Confidence: 0.875522024210526

00:10:50.818 --> 00:10:54.010 can lead you to forget that you feel pain,
NOTE Confidence: 0.875522024210526

00:10:54.010 --> 00:10:57.666 but my fatigue made such a state impossible.
NOTE Confidence: 0.875522024210526

00:10:57.670 --> 00:10:58.394 I might,
NOTE Confidence: 0.875522024210526

00:10:58.394 --> 00:11:00.566 at the nadir of my illness,
NOTE Confidence: 0.875522024210526

00:11:00.570 --> 00:11:02.502 have been able to write any
NOTE Confidence: 0.875522024210526

00:11:02.502 --> 00:11:03.790 one of these sentences,
NOTE Confidence: 0.875522024210526

00:11:03.790 --> 00:11:06.793 but I would not have been able
NOTE Confidence: 0.875522024210526

00:11:06.793 --> 00:11:08.869 to make paragraphs of them.
NOTE Confidence: 0.875522024210526

00:11:08.870 --> 00:11:10.678 To be sick in this way is to
NOTE Confidence: 0.875522024210526

00:11:10.678 --> 00:11:12.628 have the unpleasant feeling that
NOTE Confidence: 0.875522024210526

00:11:12.628 --> 00:11:14.544 you are impersonating yourself.
NOTE Confidence: 0.875522024210526

00:11:14.550 --> 00:11:15.633 When you're sick,

NOTE Confidence: 0.875522024210526
00:11:15.633 --> 00:11:19.160 the act of living is more act than living.
NOTE Confidence: 0.875522024210526
00:11:19.160 --> 00:11:21.716 Healthy people have the luxury of
NOTE Confidence: 0.875522024210526
00:11:21.716 --> 00:11:23.920 forgetting that their existence depends
NOTE Confidence: 0.875522024210526
00:11:23.920 --> 00:11:26.958 on a cascade of precise cellular interaction.
NOTE Confidence: 0.875522024210526
00:11:26.960 --> 00:11:28.182 Not you.
NOTE Confidence: 0.875522024210526
00:11:28.182 --> 00:11:31.237 Farewell means cherished me now,
NOTE Confidence: 0.875522024210526
00:11:31.240 --> 00:11:33.148 so heavy, so indistinct,
NOTE Confidence: 0.875522024210526
00:11:33.148 --> 00:11:35.533 Dodie writes in his book.
NOTE Confidence: 0.875522024210526
00:11:35.540 --> 00:11:38.960 Align, I know, often thought of.
NOTE Confidence: 0.875522024210526
00:11:38.960 --> 00:11:41.376 My mental sensation of no longer being a
NOTE Confidence: 0.875522024210526
00:11:41.376 --> 00:11:43.999 person had a correlating physical sensation.
NOTE Confidence: 0.875522024210526
00:11:44.000 --> 00:11:45.820 My eyes no longer seemed
NOTE Confidence: 0.875522024210526
00:11:45.820 --> 00:11:47.640 like lenses onto the world.
NOTE Confidence: 0.875522024210526
00:11:47.640 --> 00:11:49.090 They seemed rather to be
NOTE Confidence: 0.875522024210526
00:11:49.090 --> 00:11:50.540 distinct parts of my body,
NOTE Confidence: 0.875522024210526

00:11:50.540 --> 00:11:52.540 as perceptible as fingers,
NOTE Confidence: 0.875522024210526

00:11:52.540 --> 00:11:54.360 ugly, distant, protuberant,
NOTE Confidence: 0.875522024210526

00:11:54.360 --> 00:11:57.000 like old fashioned spectacles.
NOTE Confidence: 0.875522024210526

00:11:57.000 --> 00:11:59.368 My face was a mask I was conscious
NOTE Confidence: 0.875522024210526

00:11:59.368 --> 00:12:00.779 of at all times.
NOTE Confidence: 0.875522024210526

00:12:00.780 --> 00:12:03.276 It made me feel categorically fraudulent.
NOTE Confidence: 0.875522024210526

00:12:03.280 --> 00:12:05.323 I could feel the fat in my cheeks and
NOTE Confidence: 0.875522024210526

00:12:05.323 --> 00:12:07.279 the weight of my bones as I spoke.
NOTE Confidence: 0.875522024210526

00:12:07.280 --> 00:12:09.080 Everything was wrong and that
NOTE Confidence: 0.875522024210526

00:12:09.080 --> 00:12:10.520 wrongness was inside me,
NOTE Confidence: 0.875522024210526

00:12:10.520 --> 00:12:13.144 but I wasn't sure anymore who that me
NOTE Confidence: 0.875522024210526

00:12:13.144 --> 00:12:16.407 was or how to express what was happening.
NOTE Confidence: 0.875522024210526

00:12:16.410 --> 00:12:19.730 As Virginia Woolf testified in on being ill,
NOTE Confidence: 0.875522024210526

00:12:19.730 --> 00:12:20.044 English,
NOTE Confidence: 0.875522024210526

00:12:20.044 --> 00:12:21.928 which can express the thoughts of
NOTE Confidence: 0.875522024210526

00:12:21.928 --> 00:12:23.810 Hamlet and the tragedy of Lear,

NOTE Confidence: 0.875522024210526
00:12:23.810 --> 00:12:26.825 has no words for the sugar and the headache.
NOTE Confidence: 0.875522024210526
00:12:26.830 --> 00:12:27.865 The merest schoolgirl,
NOTE Confidence: 0.875522024210526
00:12:27.865 --> 00:12:29.590 when she falls in love,
NOTE Confidence: 0.875522024210526
00:12:29.590 --> 00:12:31.490 has Shakespeare or kids to
NOTE Confidence: 0.875522024210526
00:12:31.490 --> 00:12:33.390 speak her mind for her.
NOTE Confidence: 0.875522024210526
00:12:33.390 --> 00:12:35.814 But let us suffer or try to describe
NOTE Confidence: 0.875522024210526
00:12:35.814 --> 00:12:38.188 a pain in his head to a doctor,
NOTE Confidence: 0.875522024210526
00:12:38.190 --> 00:12:42.336 and language at once runs dry.
NOTE Confidence: 0.875522024210526
00:12:42.340 --> 00:12:45.497 For me, the hardest part was not
NOTE Confidence: 0.875522024210526
00:12:45.497 --> 00:12:48.020 being comprehended or not believed.
NOTE Confidence: 0.875522024210526
00:12:48.020 --> 00:12:50.030 Physical pain does not simply
NOTE Confidence: 0.875522024210526
00:12:50.030 --> 00:12:50.834 resist language,
NOTE Confidence: 0.875522024210526
00:12:50.840 --> 00:12:53.290 but actively destroys it rights.
NOTE Confidence: 0.875522024210526
00:12:53.290 --> 00:12:56.055 Elaine scary in the body and pain
NOTE Confidence: 0.875522024210526
00:12:56.060 --> 00:12:59.120 to have penis to have certainty.
NOTE Confidence: 0.875522024210526

00:12:59.120 --> 00:13:02.776 To hear about pain is to have doubt.
NOTE Confidence: 0.875522024210526

00:13:02.780 --> 00:13:04.999 The same was true of my symptoms
NOTE Confidence: 0.875522024210526

00:13:04.999 --> 00:13:06.700 of fatigue and brain fog,
NOTE Confidence: 0.908480303333333

00:13:06.700 --> 00:13:08.158 none of which could be seen.
NOTE Confidence: 0.908480303333333

00:13:08.160 --> 00:13:11.168 Indeed, it was true of all my symptoms.
NOTE Confidence: 0.908480303333333

00:13:11.170 --> 00:13:13.347 In those months, I was lonely in
NOTE Confidence: 0.908480303333333

00:13:13.347 --> 00:13:16.077 a way I never had been before.
NOTE Confidence: 0.908480303333333

00:13:16.080 --> 00:13:18.656 I could taste the solitude of the
NOTE Confidence: 0.908480303333333

00:13:18.656 --> 00:13:21.197 human body like brine in my mouth,
NOTE Confidence: 0.908480303333333

00:13:21.200 --> 00:13:24.848 a taste that never left me.
NOTE Confidence: 0.908480303333333

00:13:24.850 --> 00:13:26.834 Maybe I'll stop there.
NOTE Confidence: 0.908480303333333

00:13:26.834 --> 00:13:28.027 And then Lisa,
NOTE Confidence: 0.908480303333333

00:13:28.027 --> 00:13:29.209 if there's other places we think
NOTE Confidence: 0.908480303333333

00:13:29.209 --> 00:13:30.510 of that I could read from,
NOTE Confidence: 0.908480303333333

00:13:30.510 --> 00:13:32.806 I'm happy to read another few pages,
NOTE Confidence: 0.908480303333333

00:13:32.810 --> 00:13:35.294 but to get us at least in the conversation.

NOTE Confidence: 0.897829542105263

00:13:36.920 --> 00:13:39.576 Well, it's great to see you and I'm

NOTE Confidence: 0.897829542105263

00:13:39.576 --> 00:13:41.914 so thrilled that you're a finalist

NOTE Confidence: 0.897829542105263

00:13:41.914 --> 00:13:43.914 for the National Book Award.

NOTE Confidence: 0.897829542105263

00:13:43.920 --> 00:13:46.336 I think that's I'm so excited for you.

NOTE Confidence: 0.897829542105263

00:13:46.340 --> 00:13:49.409 That's really marvelous.

NOTE Confidence: 0.897829542105263

00:13:49.410 --> 00:13:54.250 Right. So you call your book.

NOTE Confidence: 0.897829542105263

00:13:54.250 --> 00:13:55.639 The invisible Kingdom.

NOTE Confidence: 0.9315078783333333

00:13:57.930 --> 00:13:59.238 What do you mean by that?

NOTE Confidence: 0.9315078783333333

00:13:59.240 --> 00:14:01.172 You know, what is this Kingdom and

NOTE Confidence: 0.9315078783333333

00:14:01.172 --> 00:14:03.597 why do you feel like it's invisible?

NOTE Confidence: 0.813099964

00:14:04.460 --> 00:14:06.818 Yeah. So I don't think it's

NOTE Confidence: 0.813099964

00:14:06.818 --> 00:14:09.730 in that exact section, but.

NOTE Confidence: 0.813099964

00:14:09.730 --> 00:14:12.652 So the Invisible Kingdom was an

NOTE Confidence: 0.813099964

00:14:12.652 --> 00:14:16.468 image I came up with to describe.

NOTE Confidence: 0.813099964

00:14:16.470 --> 00:14:18.610 To describe the you know,

NOTE Confidence: 0.813099964

00:14:18.610 --> 00:14:19.934 the book is subtitled
NOTE Confidence: 0.813099964

00:14:19.934 --> 00:14:20.927 reimagining chronic illness,
NOTE Confidence: 0.813099964

00:14:20.930 --> 00:14:23.590 and as I explained in the introduction,
NOTE Confidence: 0.813099964

00:14:23.590 --> 00:14:25.610 I use chronic illness.
NOTE Confidence: 0.813099964

00:14:25.610 --> 00:14:29.220 Sort of interchangeably with two other terms,
NOTE Confidence: 0.813099964

00:14:29.220 --> 00:14:31.422 one of which is poorly understood
NOTE Confidence: 0.813099964

00:14:31.422 --> 00:14:34.505 illness and one of which is infection
NOTE Confidence: 0.813099964

00:14:34.505 --> 00:14:37.712 associated chronic illness or conditions
NOTE Confidence: 0.813099964

00:14:37.712 --> 00:14:40.404 that infection associated illnesses.
NOTE Confidence: 0.813099964

00:14:40.410 --> 00:14:43.178 So in the book there are things I'm
NOTE Confidence: 0.813099964

00:14:43.178 --> 00:14:45.145 writing about that are probably.
NOTE Confidence: 0.813099964

00:14:45.145 --> 00:14:48.320 Relevant to anyone who lives
NOTE Confidence: 0.813099964

00:14:48.320 --> 00:14:51.939 with a condition that that is
NOTE Confidence: 0.813099964

00:14:51.939 --> 00:14:54.359 not doesn't have an end.
NOTE Confidence: 0.813099964

00:14:54.360 --> 00:14:56.726 And then there are things I'm writing
NOTE Confidence: 0.813099964

00:14:56.726 --> 00:14:59.190 about that are really specific to

NOTE Confidence: 0.813099964

00:14:59.190 --> 00:15:01.034 this constellation of conditions

NOTE Confidence: 0.813099964

00:15:01.034 --> 00:15:03.343 that I'm describing as poorly

NOTE Confidence: 0.813099964

00:15:03.343 --> 00:15:05.478 understood that are often entangled.

NOTE Confidence: 0.813099964

00:15:05.480 --> 00:15:06.866 And for whom?

NOTE Confidence: 0.813099964

00:15:06.866 --> 00:15:09.638 The people living with them often

NOTE Confidence: 0.813099964

00:15:09.640 --> 00:15:10.916 don't necessarily look sick,

NOTE Confidence: 0.813099964

00:15:10.916 --> 00:15:13.540 or indeed are so sick that they've almost

NOTE Confidence: 0.813099964

00:15:13.540 --> 00:15:16.140 dropped out of society and are bed bound.

NOTE Confidence: 0.813099964

00:15:16.140 --> 00:15:18.226 And so in various ways they have

NOTE Confidence: 0.813099964

00:15:18.226 --> 00:15:20.280 what's called an invisible illness,

NOTE Confidence: 0.813099964

00:15:20.280 --> 00:15:20.580 right?

NOTE Confidence: 0.813099964

00:15:20.580 --> 00:15:22.680 One of the ways in which they're

NOTE Confidence: 0.813099964

00:15:22.680 --> 00:15:24.384 invisible is the fact that we

NOTE Confidence: 0.813099964

00:15:24.384 --> 00:15:26.735 don't know how to treat them or how

NOTE Confidence: 0.813099964

00:15:26.735 --> 00:15:28.199 to understand these conditions.

NOTE Confidence: 0.813099964

00:15:28.200 --> 00:15:30.132 Another way is that the diseases
NOTE Confidence: 0.813099964

00:15:30.132 --> 00:15:31.420 might relapse and remit.
NOTE Confidence: 0.813099964

00:15:31.420 --> 00:15:33.004 Maybe you have an autoimmune disease
NOTE Confidence: 0.813099964

00:15:33.004 --> 00:15:34.060 that's actually fairly known,
NOTE Confidence: 0.813099964

00:15:34.060 --> 00:15:35.840 but the contours of that.
NOTE Confidence: 0.813099964

00:15:35.840 --> 00:15:36.664 Disease come and go.
NOTE Confidence: 0.813099964

00:15:36.664 --> 00:15:37.900 And so you have periods of
NOTE Confidence: 0.813099964

00:15:37.948 --> 00:15:39.658 functionality and periods where you're,
NOTE Confidence: 0.813099964

00:15:39.660 --> 00:15:40.620 you know, in your bed.
NOTE Confidence: 0.813099964

00:15:40.620 --> 00:15:42.948 And that's a kind of story we don't
NOTE Confidence: 0.813099964

00:15:42.948 --> 00:15:45.710 know how to tell I think as a society.
NOTE Confidence: 0.813099964

00:15:45.710 --> 00:15:47.936 So I became very interested in the
NOTE Confidence: 0.813099964

00:15:47.936 --> 00:15:50.982 fact that as I interviewed about 100
NOTE Confidence: 0.813099964

00:15:50.982 --> 00:15:53.502 patients with different related conditions,
NOTE Confidence: 0.813099964

00:15:53.510 --> 00:15:56.618 all of them expressed this sense
NOTE Confidence: 0.813099964

00:15:56.618 --> 00:15:58.690 of loneliness and invisibility

NOTE Confidence: 0.813099964

00:15:58.772 --> 00:16:01.530 that I just evoked a bit about

NOTE Confidence: 0.813099964

00:16:01.530 --> 00:16:03.130 my own experience and.

NOTE Confidence: 0.813099964

00:16:03.130 --> 00:16:05.714 So I think the book is the attempt

NOTE Confidence: 0.813099964

00:16:05.714 --> 00:16:07.856 to make the case that although

NOTE Confidence: 0.813099964

00:16:07.856 --> 00:16:12.270 each of us as you know, solitary.

NOTE Confidence: 0.813099964

00:16:12.270 --> 00:16:14.860 Individuals undergoing these conditions are,

NOTE Confidence: 0.813099964

00:16:14.860 --> 00:16:15.952 you know, feel invisible,

NOTE Confidence: 0.813099964

00:16:15.952 --> 00:16:16.498 are alone,

NOTE Confidence: 0.813099964

00:16:16.500 --> 00:16:18.320 that together there really is

NOTE Confidence: 0.813099964

00:16:18.320 --> 00:16:20.140 this invisible Kingdom of people.

NOTE Confidence: 0.813099964

00:16:20.140 --> 00:16:21.610 And that through that kind of

NOTE Confidence: 0.813099964

00:16:21.610 --> 00:16:23.118 act of unifying and that sort

NOTE Confidence: 0.813099964

00:16:23.118 --> 00:16:24.298 of poets act of naming,

NOTE Confidence: 0.813099964

00:16:24.300 --> 00:16:26.592 maybe we can help those missing

NOTE Confidence: 0.813099964

00:16:26.592 --> 00:16:28.640 millions be seen and heard.

NOTE Confidence: 0.813099964

00:16:28.640 --> 00:16:31.088 The other reason I call it that is that
NOTE Confidence: 0.813099964

00:16:31.088 --> 00:16:33.776 we are living through a kind of epidemic,
NOTE Confidence: 0.813099964

00:16:33.776 --> 00:16:35.780 as some researchers put it to me,
NOTE Confidence: 0.813099964

00:16:35.780 --> 00:16:37.121 of invisible illness.
NOTE Confidence: 0.813099964

00:16:37.121 --> 00:16:38.462 Autoimmune diseases are
NOTE Confidence: 0.813099964

00:16:38.462 --> 00:16:40.250 dramatically on the rise.
NOTE Confidence: 0.813099964

00:16:40.250 --> 00:16:42.520 And that seems to be not just an issue of.
NOTE Confidence: 0.813099964

00:16:42.520 --> 00:16:43.340 Better diagnostics,
NOTE Confidence: 0.813099964

00:16:43.340 --> 00:16:45.800 but in fact rising rates and
NOTE Confidence: 0.813099964

00:16:45.800 --> 00:16:48.148 as of course we now know,
NOTE Confidence: 0.813099964

00:16:48.150 --> 00:16:50.370 we are living through this really,
NOTE Confidence: 0.813099964

00:16:50.370 --> 00:16:53.138 really troubling and concerning.
NOTE Confidence: 0.82333254625

00:16:55.220 --> 00:16:58.548 Problem of long COVID that is going to.
NOTE Confidence: 0.82333254625

00:16:58.550 --> 00:17:00.632 Be the long after effect of
NOTE Confidence: 0.82333254625

00:17:00.632 --> 00:17:02.416 this pandemic, I'm afraid so.
NOTE Confidence: 0.82333254625

00:17:02.416 --> 00:17:03.864 Those numbers are tremendous.

NOTE Confidence: 0.82333254625

00:17:03.870 --> 00:17:04.922 So, you know, again,

NOTE Confidence: 0.82333254625

00:17:04.922 --> 00:17:07.169 there's sort of this effort to sort of say,

NOTE Confidence: 0.82333254625

00:17:07.170 --> 00:17:09.072 this is not my story, this is,

NOTE Confidence: 0.82333254625

00:17:09.072 --> 00:17:10.680 this is a story of us all that

NOTE Confidence: 0.82333254625

00:17:10.737 --> 00:17:12.389 we all have to pay attention to.

NOTE Confidence: 0.82333254625

00:17:12.390 --> 00:17:14.058 That's a long answer, but yeah.

NOTE Confidence: 0.96183753

00:17:15.460 --> 00:17:20.420 OK, that's, that's a good,

NOTE Confidence: 0.96183753

00:17:20.420 --> 00:17:23.520 that's a good I understand.

NOTE Confidence: 0.96183753

00:17:23.520 --> 00:17:26.072 Times in your book,

NOTE Confidence: 0.96183753

00:17:26.072 --> 00:17:29.576 you're pretty hard on traditional medicine.

NOTE Confidence: 0.96183753

00:17:29.580 --> 00:17:32.292 I felt a little defensive when I was

NOTE Confidence: 0.96183753

00:17:32.292 --> 00:17:34.850 reading it as just a regular doctor.

NOTE Confidence: 0.96183753

00:17:34.850 --> 00:17:37.594 At one point you imagine what a

NOTE Confidence: 0.96183753

00:17:37.594 --> 00:17:39.459 perfect medical encounter would be,

NOTE Confidence: 0.96183753

00:17:39.460 --> 00:17:41.497 and you say that it should be

NOTE Confidence: 0.96183753

00:17:41.497 --> 00:17:43.025 a combination of alternative
NOTE Confidence: 0.96183753

00:17:43.025 --> 00:17:45.357 medicine and traditional medicine.
NOTE Confidence: 0.96183753

00:17:45.360 --> 00:17:48.178 So. What would that look like?
NOTE Confidence: 0.96183753

00:17:48.178 --> 00:17:49.391 I mean, what?
NOTE Confidence: 0.96183753

00:17:49.391 --> 00:17:50.713 What doesn't?
NOTE Confidence: 0.96183753

00:17:50.713 --> 00:17:53.357 Traditional medicine have that
NOTE Confidence: 0.96183753

00:17:53.357 --> 00:17:55.800 alternative can offer you.
NOTE Confidence: 0.838906239375

00:17:57.500 --> 00:18:00.951 Yeah, so the chapter you're referring to
NOTE Confidence: 0.838906239375

00:18:00.951 --> 00:18:04.947 is a chapter where I talk about my own.
NOTE Confidence: 0.838906239375

00:18:04.950 --> 00:18:07.618 Turning to alternative medicine
NOTE Confidence: 0.838906239375

00:18:07.618 --> 00:18:10.017 after traditional medicine really
NOTE Confidence: 0.838906239375

00:18:10.017 --> 00:18:12.002 failed to diagnose me with
NOTE Confidence: 0.838906239375

00:18:12.002 --> 00:18:14.310 anything for more than a decade.
NOTE Confidence: 0.838906239375

00:18:14.310 --> 00:18:17.400 Um, during which I had some
NOTE Confidence: 0.838906239375

00:18:17.400 --> 00:18:18.945 pretty diagnosable conditions.
NOTE Confidence: 0.838906239375

00:18:18.950 --> 00:18:21.524 That was a little further, you know,

NOTE Confidence: 0.838906239375

00:18:21.524 --> 00:18:23.246 research could have probably been found,

NOTE Confidence: 0.838906239375

00:18:23.250 --> 00:18:27.798 presumably including autoimmune thyroiditis.

NOTE Confidence: 0.838906239375

00:18:27.800 --> 00:18:29.004 So in that decade,

NOTE Confidence: 0.838906239375

00:18:29.004 --> 00:18:31.527 I had to really live thrown on my

NOTE Confidence: 0.838906239375

00:18:31.527 --> 00:18:33.453 own resources to figure out how

NOTE Confidence: 0.838906239375

00:18:33.453 --> 00:18:35.556 to function right? I mean, I'm.

NOTE Confidence: 0.838906239375

00:18:35.556 --> 00:18:37.548 I'm always been a very ambitious

NOTE Confidence: 0.838906239375

00:18:37.548 --> 00:18:39.776 and driven person. I was.

NOTE Confidence: 0.838906239375

00:18:39.776 --> 00:18:42.670 Young I was, you know,

NOTE Confidence: 0.838906239375

00:18:42.670 --> 00:18:44.128 2324 when I started getting sick.

NOTE Confidence: 0.838906239375

00:18:44.130 --> 00:18:46.686 I was an editor at The New Yorker magazine.

NOTE Confidence: 0.838906239375

00:18:46.690 --> 00:18:47.566 I had a boyfriend.

NOTE Confidence: 0.838906239375

00:18:47.566 --> 00:18:48.880 I want to have a family,

NOTE Confidence: 0.838906239375

00:18:48.880 --> 00:18:50.746 you know, I wanted to live.

NOTE Confidence: 0.838906239375

00:18:50.750 --> 00:18:54.810 So in the absence of a diagnosis

NOTE Confidence: 0.838906239375

00:18:54.810 --> 00:18:57.669 or much concrete treatment or help
NOTE Confidence: 0.838906239375

00:18:57.669 --> 00:19:00.023 or really interest, I would say.
NOTE Confidence: 0.838906239375

00:19:00.023 --> 00:19:02.489 From the particular set of doctors
NOTE Confidence: 0.838906239375

00:19:02.489 --> 00:19:04.408 I had at that time.
NOTE Confidence: 0.838906239375

00:19:04.410 --> 00:19:06.730 Umm, I, you know,
NOTE Confidence: 0.838906239375

00:19:06.730 --> 00:19:09.630 did turn to alternative medicine
NOTE Confidence: 0.838906239375

00:19:09.630 --> 00:19:11.810 and also just a lot of a lot of
NOTE Confidence: 0.838906239375

00:19:11.810 --> 00:19:14.056 what I'm writing about are kind of
NOTE Confidence: 0.838906239375

00:19:14.056 --> 00:19:15.488 lifestyle management things too,
NOTE Confidence: 0.838906239375

00:19:15.490 --> 00:19:18.610 that I think a lot of autoimmune patients
NOTE Confidence: 0.838906239375

00:19:18.610 --> 00:19:20.850 have way better sleep and better fit,
NOTE Confidence: 0.838906239375

00:19:20.850 --> 00:19:21.942 you know, better food,
NOTE Confidence: 0.838906239375

00:19:21.942 --> 00:19:22.488 all that.
NOTE Confidence: 0.838906239375

00:19:22.490 --> 00:19:22.734 So.
NOTE Confidence: 0.838906239375

00:19:22.734 --> 00:19:24.686 So that led led me in this chapter
NOTE Confidence: 0.838906239375

00:19:24.686 --> 00:19:26.466 to really think about, you know,

NOTE Confidence: 0.838906239375

00:19:26.466 --> 00:19:27.642 what was it that I was from

NOTE Confidence: 0.838906239375

00:19:27.642 --> 00:19:29.029 a very evidence based person.

NOTE Confidence: 0.838906239375

00:19:29.030 --> 00:19:29.810 I like science.

NOTE Confidence: 0.838906239375

00:19:29.810 --> 00:19:32.826 I want, you know, I want science to help me.

NOTE Confidence: 0.838906239375

00:19:32.830 --> 00:19:35.175 Science that's really help me get better.

NOTE Confidence: 0.838906239375

00:19:35.180 --> 00:19:36.892 So what I was trying to get at

NOTE Confidence: 0.838906239375

00:19:36.892 --> 00:19:38.708 in that chapter is actually not

NOTE Confidence: 0.838906239375

00:19:38.708 --> 00:19:40.368 to be prescriptive that there's

NOTE Confidence: 0.838906239375

00:19:40.368 --> 00:19:42.454 any one way that any specific

NOTE Confidence: 0.838906239375

00:19:42.454 --> 00:19:43.806 medical encounter should be,

NOTE Confidence: 0.838906239375

00:19:43.810 --> 00:19:47.570 but more to investigate.

NOTE Confidence: 0.838906239375

00:19:47.570 --> 00:19:51.655 The kinds of stories that conventional

NOTE Confidence: 0.838906239375

00:19:51.655 --> 00:19:55.165 medicine and and and you know,

NOTE Confidence: 0.838906239375

00:19:55.170 --> 00:19:57.288 alternative medicine are telling the patient,

NOTE Confidence: 0.838906239375

00:19:57.290 --> 00:19:59.915 right and to really talk about and

NOTE Confidence: 0.838906239375

00:19:59.915 --> 00:20:02.028 think deeply about for a moment.
NOTE Confidence: 0.838906239375

00:20:02.030 --> 00:20:04.070 What those stories actually do
NOTE Confidence: 0.838906239375

00:20:04.070 --> 00:20:06.396 to and for the patient's right,
NOTE Confidence: 0.838906239375

00:20:06.396 --> 00:20:08.454 we're we're kind of familiar with
NOTE Confidence: 0.838906239375

00:20:08.454 --> 00:20:10.509 telling the story about well you
NOTE Confidence: 0.838906239375

00:20:10.509 --> 00:20:12.144 know alternative medicine you know
NOTE Confidence: 0.838906239375

00:20:12.144 --> 00:20:14.297 may not be effective maybe quackery,
NOTE Confidence: 0.838906239375

00:20:14.300 --> 00:20:15.095 maybe these things.
NOTE Confidence: 0.838906239375

00:20:15.095 --> 00:20:17.257 So you know there's that kind of story
NOTE Confidence: 0.838906239375

00:20:17.257 --> 00:20:19.507 and I I certainly address that in the book.
NOTE Confidence: 0.838906239375

00:20:19.510 --> 00:20:22.471 But what I'm also interested in are
NOTE Confidence: 0.838906239375

00:20:22.471 --> 00:20:24.930 the pretty documented effects of care
NOTE Confidence: 0.838906239375

00:20:24.930 --> 00:20:28.214 and by the way those effects apply also
NOTE Confidence: 0.838906239375

00:20:28.214 --> 00:20:32.660 to traditional conventional medicine and.
NOTE Confidence: 0.838906239375

00:20:32.660 --> 00:20:34.802 You know there's a lot of evidence
NOTE Confidence: 0.838906239375

00:20:34.802 --> 00:20:36.650 that when patients feel cared for,

NOTE Confidence: 0.838906239375

00:20:36.650 --> 00:20:38.820 when they're treated with empathy,

NOTE Confidence: 0.838906239375

00:20:38.820 --> 00:20:40.560 you know the actual level of

NOTE Confidence: 0.838906239375

00:20:40.560 --> 00:20:42.040 medication they need drops down,

NOTE Confidence: 0.838906239375

00:20:42.040 --> 00:20:42.495 right.

NOTE Confidence: 0.838906239375

00:20:42.495 --> 00:20:44.315 The they're symptom reports

NOTE Confidence: 0.838906239375

00:20:44.315 --> 00:20:45.680 drop dramatically down.

NOTE Confidence: 0.838906239375

00:20:45.680 --> 00:20:47.396 So it's really interested in this

NOTE Confidence: 0.838906239375

00:20:47.396 --> 00:20:49.646 like if care is itself that impactful,

NOTE Confidence: 0.838906239375

00:20:49.646 --> 00:20:52.488 why don't we think more about care

NOTE Confidence: 0.838906239375

00:20:52.488 --> 00:20:55.061 and and why don't we make much

NOTE Confidence: 0.838906239375

00:20:55.061 --> 00:20:57.650 more room for our you know medical

NOTE Confidence: 0.838906239375

00:20:57.650 --> 00:21:00.541 system to offer that kind of care

NOTE Confidence: 0.838906239375

00:21:00.541 --> 00:21:01.944 because although I'm critical of.

NOTE Confidence: 0.838906239375

00:21:01.944 --> 00:21:03.626 Doctors in the book, I'm, I'm really,

NOTE Confidence: 0.838906239375

00:21:03.626 --> 00:21:05.250 my focus is really on the system,

NOTE Confidence: 0.8318775

00:21:05.250 --> 00:21:06.558 and it's actually not on doctors.

NOTE Confidence: 0.8318775

00:21:06.560 --> 00:21:07.796 I'm quite sympathetic

NOTE Confidence: 0.8318775

00:21:07.796 --> 00:21:10.900 toward toward the plight.

NOTE Confidence: 0.8318775

00:21:10.900 --> 00:21:12.870 Doctors have saved my life,

NOTE Confidence: 0.8318775

00:21:12.870 --> 00:21:14.330 my my new doctors,

NOTE Confidence: 0.8318775

00:21:14.330 --> 00:21:15.790 so I'm really interested,

NOTE Confidence: 0.8318775

00:21:15.790 --> 00:21:17.536 but I'm also really interested in

NOTE Confidence: 0.8318775

00:21:17.536 --> 00:21:20.207 the fact that so many of the patients

NOTE Confidence: 0.8318775

00:21:20.207 --> 00:21:22.012 I interviewed who had autoimmune

NOTE Confidence: 0.8318775

00:21:22.012 --> 00:21:23.922 diseases felt like they were going

NOTE Confidence: 0.8318775

00:21:23.922 --> 00:21:25.692 through a system that was very

NOTE Confidence: 0.8318775

00:21:25.692 --> 00:21:27.666 siloed and that they would go to,

NOTE Confidence: 0.8318775

00:21:27.670 --> 00:21:28.490 one woman said to me,

NOTE Confidence: 0.8318775

00:21:28.490 --> 00:21:30.527 I went to a rheumatologist and neurologist,

NOTE Confidence: 0.8318775

00:21:30.530 --> 00:21:32.174 a dermatologist say,

NOTE Confidence: 0.8318775

00:21:32.174 --> 00:21:34.306 you know, my GP, my OBGYN,

NOTE Confidence: 0.8318775

00:21:34.306 --> 00:21:36.750 and she said I felt like cardiologist,

NOTE Confidence: 0.8318775

00:21:36.750 --> 00:21:38.983 she said I felt like each one

NOTE Confidence: 0.8318775

00:21:38.983 --> 00:21:40.680 was crossing their organ off.

NOTE Confidence: 0.8318775

00:21:40.680 --> 00:21:42.045 They're like the list and

NOTE Confidence: 0.8318775

00:21:42.045 --> 00:21:43.137 saying not my problem,

NOTE Confidence: 0.8318775

00:21:43.140 --> 00:21:45.580 move you on to the next part of the line.

NOTE Confidence: 0.8318775

00:21:45.580 --> 00:21:45.973 And, she said.

NOTE Confidence: 0.8318775

00:21:45.973 --> 00:21:46.497 And at the end,

NOTE Confidence: 0.8318775

00:21:46.500 --> 00:21:48.668 there I was and all my organs were

NOTE Confidence: 0.8318775

00:21:48.668 --> 00:21:50.998 cleared and I was sick as a dog and

NOTE Confidence: 0.8318775

00:21:50.998 --> 00:21:52.508 couldn't take care of my child.

NOTE Confidence: 0.8318775

00:21:52.510 --> 00:21:53.485 And she had,

NOTE Confidence: 0.8318775

00:21:53.485 --> 00:21:55.760 it turned out she had lupus that

NOTE Confidence: 0.8318775

00:21:55.842 --> 00:21:57.870 just wasn't diagnosable yet.

NOTE Confidence: 0.8318775

00:21:57.870 --> 00:21:59.630 And so one of the things that interested

NOTE Confidence: 0.8318775

00:21:59.630 --> 00:22:01.070 me about alternative medicine,
NOTE Confidence: 0.8318775

00:22:01.070 --> 00:22:03.968 again as a as a kind of cultural critic,
NOTE Confidence: 0.8318775

00:22:03.970 --> 00:22:05.450 thinking of the cultural critic,
NOTE Confidence: 0.8318775

00:22:05.450 --> 00:22:07.410 was that the story alternative
NOTE Confidence: 0.8318775

00:22:07.410 --> 00:22:10.013 medicine tells the patient is one of
NOTE Confidence: 0.8318775

00:22:10.013 --> 00:22:12.309 your body is not a car with different
NOTE Confidence: 0.8318775

00:22:12.381 --> 00:22:14.669 parts that we can take out and fix.
NOTE Confidence: 0.8318775

00:22:14.670 --> 00:22:16.350 Your your body is actually much more,
NOTE Confidence: 0.8318775

00:22:16.350 --> 00:22:18.742 as I say in the book, like a garden, right?
NOTE Confidence: 0.8318775

00:22:18.742 --> 00:22:20.607 That needs tending and it
NOTE Confidence: 0.8318775

00:22:20.607 --> 00:22:22.610 needs this kind of holistic.
NOTE Confidence: 0.8318775

00:22:22.610 --> 00:22:23.496 Overall approach,
NOTE Confidence: 0.8318775

00:22:23.496 --> 00:22:26.597 and I think part of what alternative
NOTE Confidence: 0.8318775

00:22:26.597 --> 00:22:29.575 medicine asks that something I think
NOTE Confidence: 0.8318775

00:22:29.575 --> 00:22:31.543 conventional medicine can probably.
NOTE Confidence: 0.8318775

00:22:31.550 --> 00:22:34.028 Probably do a better job of asking

NOTE Confidence: 0.8318775

00:22:34.028 --> 00:22:35.880 the chronically ill patient is.

NOTE Confidence: 0.8318775

00:22:35.880 --> 00:22:40.490 Given the reality of your condition. What?

NOTE Confidence: 0.8318775

00:22:40.490 --> 00:22:42.926 Given there are things we can't change.

NOTE Confidence: 0.8318775

00:22:42.930 --> 00:22:44.938 What would help you live a better life?

NOTE Confidence: 0.8318775

00:22:44.940 --> 00:22:46.590 What what would help where?

NOTE Confidence: 0.8318775

00:22:46.590 --> 00:22:47.952 Where are the areas that you

NOTE Confidence: 0.8318775

00:22:47.952 --> 00:22:49.160 need help in your life?

NOTE Confidence: 0.8318775

00:22:49.160 --> 00:22:49.505 Right.

NOTE Confidence: 0.8318775

00:22:49.505 --> 00:22:51.920 Which I think my answer to other

NOTE Confidence: 0.8318775

00:22:51.920 --> 00:22:54.052 people's answers to is often not

NOTE Confidence: 0.8318775

00:22:54.052 --> 00:22:55.432 necessarily with even alleviation

NOTE Confidence: 0.8318775

00:22:55.432 --> 00:22:57.898 of the worst seeming symptom, right?

NOTE Confidence: 0.8318775

00:22:57.898 --> 00:23:00.046 That the answer to that question

NOTE Confidence: 0.8318775

00:23:00.046 --> 00:23:01.120 is really complicated.

NOTE Confidence: 0.8318775

00:23:01.120 --> 00:23:02.520 And an analogy for asking

NOTE Confidence: 0.8318775

00:23:02.520 --> 00:23:03.640 that question I think,
NOTE Confidence: 0.8318775

00:23:03.640 --> 00:23:06.316 comes to us from palliative care.
NOTE Confidence: 0.8318775

00:23:06.320 --> 00:23:06.532 So.
NOTE Confidence: 0.8318775

00:23:06.532 --> 00:23:08.016 So that was something I was really,
NOTE Confidence: 0.8318775

00:23:08.020 --> 00:23:08.806 really interested anyway.
NOTE Confidence: 0.8318775

00:23:08.806 --> 00:23:10.378 There's more I could say there,
NOTE Confidence: 0.8318775

00:23:10.380 --> 00:23:13.780 but so I think I was fascinated by the ways.
NOTE Confidence: 0.8318775

00:23:13.780 --> 00:23:16.042 Which both systems had their own
NOTE Confidence: 0.8318775

00:23:16.042 --> 00:23:18.043 scripts and have been positioned
NOTE Confidence: 0.8318775

00:23:18.043 --> 00:23:20.138 as being kind of opposed,
NOTE Confidence: 0.8318775

00:23:20.140 --> 00:23:21.755 but might actually have things
NOTE Confidence: 0.8318775

00:23:21.755 --> 00:23:23.790 if we if we took away.
NOTE Confidence: 0.8318775

00:23:23.790 --> 00:23:26.694 We bracketed certain questions and we
NOTE Confidence: 0.8318775

00:23:26.694 --> 00:23:30.050 looked more at these scripts of care.
NOTE Confidence: 0.8318775

00:23:30.050 --> 00:23:31.390 What? What could we learn?
NOTE Confidence: 0.915965270909091

00:23:33.020 --> 00:23:35.330 Well, I have to say that

NOTE Confidence: 0.915965270909091

00:23:35.330 --> 00:23:37.350 there were several times when.

NOTE Confidence: 0.915965270909091

00:23:37.350 --> 00:23:39.338 I guess the reason I felt defensive

NOTE Confidence: 0.915965270909091

00:23:39.338 --> 00:23:40.907 was because I recognized the

NOTE Confidence: 0.915965270909091

00:23:40.907 --> 00:23:42.863 truth of what you were saying.

NOTE Confidence: 0.915965270909091

00:23:42.870 --> 00:23:45.597 I mean I have also felt as I send

NOTE Confidence: 0.915965270909091

00:23:45.597 --> 00:23:48.360 my patients to cardiologist,

NOTE Confidence: 0.915965270909091

00:23:48.360 --> 00:23:51.990 pulmonologist that they say, well,

NOTE Confidence: 0.915965270909091

00:23:51.990 --> 00:23:56.234 her heart's fine, belongs fine, like no,

NOTE Confidence: 0.915965270909091

00:23:56.234 --> 00:23:59.904 they had a normal stress test, so yes.

NOTE Confidence: 0.915965270909091

00:23:59.904 --> 00:24:02.613 Umm, I I guess that was why

NOTE Confidence: 0.915965270909091

00:24:02.613 --> 00:24:05.440 it was so painful to read.

NOTE Confidence: 0.915965270909091

00:24:05.440 --> 00:24:07.636 You know, I I love the lump.

NOTE Confidence: 0.915965270909091

00:24:07.640 --> 00:24:08.348 Yeah, go ahead.

NOTE Confidence: 0.741934808

00:24:09.790 --> 00:24:11.010 Right. Like I think that's,

NOTE Confidence: 0.741934808

00:24:11.010 --> 00:24:12.735 that's the other thing that

NOTE Confidence: 0.741934808

00:24:12.735 --> 00:24:15.310 I I didn't say is just that.

NOTE Confidence: 0.741934808

00:24:15.310 --> 00:24:18.028 You know, one doctor I interviewed,

NOTE Confidence: 0.741934808

00:24:18.030 --> 00:24:20.655 Jack Cochran, who used to lead the

NOTE Confidence: 0.741934808

00:24:20.655 --> 00:24:22.378 Kaiser Permanente, and he, you know,

NOTE Confidence: 0.741934808

00:24:22.378 --> 00:24:24.160 he talked a lot about this idea

NOTE Confidence: 0.741934808

00:24:24.160 --> 00:24:25.810 of kind of crisis care versus,

NOTE Confidence: 0.741934808

00:24:25.810 --> 00:24:27.394 you know, we talk about prevention

NOTE Confidence: 0.741934808

00:24:27.394 --> 00:24:28.704 and traditional medicine, but maybe.

NOTE Confidence: 0.741934808

00:24:28.704 --> 00:24:30.503 You know, one of the big things

NOTE Confidence: 0.741934808

00:24:30.503 --> 00:24:32.389 that I talk about in the book is

NOTE Confidence: 0.741934808

00:24:32.389 --> 00:24:34.321 the crisis of care for convention

NOTE Confidence: 0.741934808

00:24:34.321 --> 00:24:35.917 time for conventional medicine.

NOTE Confidence: 0.741934808

00:24:35.920 --> 00:24:38.237 That time is so tight and there's

NOTE Confidence: 0.741934808

00:24:38.237 --> 00:24:39.730 so much bureaucracy anyway.

NOTE Confidence: 0.741934808

00:24:39.730 --> 00:24:41.923 So I think that's something that

NOTE Confidence: 0.741934808

00:24:41.923 --> 00:24:43.352 I've heard a lot too, is, you know,

NOTE Confidence: 0.741934808

00:24:43.352 --> 00:24:44.626 how do we really think about, right,

NOTE Confidence: 0.741934808

00:24:44.626 --> 00:24:46.702 that space before you're really sick

NOTE Confidence: 0.741934808

00:24:46.702 --> 00:24:48.715 but you're starting or before your

NOTE Confidence: 0.741934808

00:24:48.715 --> 00:24:50.545 tests show that you're really sick?

NOTE Confidence: 0.741934808

00:24:50.550 --> 00:24:52.210 Let's put it like that,

NOTE Confidence: 0.741934808

00:24:52.210 --> 00:24:52.600 you know,

NOTE Confidence: 0.741934808

00:24:52.600 --> 00:24:54.480 how do we care for people in that space?

NOTE Confidence: 0.860461177142857

00:24:56.380 --> 00:24:59.404 I love the line in your book.

NOTE Confidence: 0.860461177142857

00:24:59.410 --> 00:25:02.788 Where silence, where science is silent,

NOTE Confidence: 0.860461177142857

00:25:02.790 --> 00:25:03.879 narrative creeps in.

NOTE Confidence: 0.860461177142857

00:25:03.879 --> 00:25:06.420 I feel like I have an intuitive

NOTE Confidence: 0.860461177142857

00:25:06.493 --> 00:25:08.028 sense of what that is.

NOTE Confidence: 0.860461177142857

00:25:08.030 --> 00:25:10.366 But what exactly do you mean by that?

NOTE Confidence: 0.860461177142857

00:25:10.370 --> 00:25:11.230 I mean, do you?

NOTE Confidence: 0.860461177142857

00:25:11.230 --> 00:25:12.520 What do you mean by that?

NOTE Confidence: 0.851520461666667

00:25:13.790 --> 00:25:15.146 Yeah, it was a great question.
NOTE Confidence: 0.851520461666667

00:25:15.150 --> 00:25:16.606 I mean, a lot of different things.
NOTE Confidence: 0.851520461666667

00:25:16.610 --> 00:25:17.410 I'm glad you asked that,
NOTE Confidence: 0.851520461666667

00:25:17.410 --> 00:25:18.250 because when I wrote that,
NOTE Confidence: 0.851520461666667

00:25:18.250 --> 00:25:19.612 I was like, I'm not really
NOTE Confidence: 0.851520461666667

00:25:19.612 --> 00:25:21.089 spelling this out for the reader,
NOTE Confidence: 0.851520461666667

00:25:21.090 --> 00:25:22.590 but that's part of the point.
NOTE Confidence: 0.851520461666667

00:25:22.590 --> 00:25:23.655 The line is supposed to
NOTE Confidence: 0.851520461666667

00:25:23.655 --> 00:25:25.080 do for you what it right.
NOTE Confidence: 0.851520461666667

00:25:25.080 --> 00:25:26.886 You're supposed to start to supply
NOTE Confidence: 0.851520461666667

00:25:26.886 --> 00:25:28.370 a narrative. I mean a few things.
NOTE Confidence: 0.851520461666667

00:25:28.370 --> 00:25:31.310 I mean, one is.
NOTE Confidence: 0.851520461666667

00:25:31.310 --> 00:25:31.925 Well, I mean,
NOTE Confidence: 0.851520461666667

00:25:31.925 --> 00:25:33.360 I mean that which is what when
NOTE Confidence: 0.851520461666667

00:25:33.410 --> 00:25:34.670 when we don't have science,
NOTE Confidence: 0.851520461666667

00:25:34.670 --> 00:25:36.450 we don't have frameworks for

NOTE Confidence: 0.851520461666667
00:25:36.450 --> 00:25:38.917 understanding what is going on in the
NOTE Confidence: 0.851520461666667
00:25:38.917 --> 00:25:41.108 body and we don't fully understand long
NOTE Confidence: 0.851520461666667
00:25:41.108 --> 00:25:43.359 COVID when we don't fully understand.
NOTE Confidence: 0.851520461666667
00:25:43.360 --> 00:25:45.894 You know, the rise in food allergies,
NOTE Confidence: 0.851520461666667
00:25:45.900 --> 00:25:46.596 et cetera.
NOTE Confidence: 0.851520461666667
00:25:46.596 --> 00:25:49.380 We as a society start to supply narratives,
NOTE Confidence: 0.851520461666667
00:25:49.380 --> 00:25:52.548 right, we'll say.
NOTE Confidence: 0.851520461666667
00:25:52.550 --> 00:25:55.350 Uh, you know, let's put it this way.
NOTE Confidence: 0.851520461666667
00:25:55.350 --> 00:25:57.095 I have this great aunt
NOTE Confidence: 0.851520461666667
00:25:57.095 --> 00:25:58.840 Gert who was always sick,
NOTE Confidence: 0.851520461666667
00:25:58.840 --> 00:26:00.922 but it was before people really
NOTE Confidence: 0.851520461666667
00:26:00.922 --> 00:26:02.800 understood much about autoimmune disease.
NOTE Confidence: 0.851520461666667
00:26:02.800 --> 00:26:03.197 Before.
NOTE Confidence: 0.851520461666667
00:26:03.197 --> 00:26:03.991 She clearly,
NOTE Confidence: 0.851520461666667
00:26:03.991 --> 00:26:05.976 she probably had some kind
NOTE Confidence: 0.851520461666667

00:26:05.976 --> 00:26:07.360 of autoimmune disease.
NOTE Confidence: 0.851520461666667

00:26:07.360 --> 00:26:09.010 But the narrative of the family
NOTE Confidence: 0.851520461666667

00:26:09.010 --> 00:26:10.710 was like Gert likes attention,
NOTE Confidence: 0.851520461666667

00:26:10.710 --> 00:26:12.005 she likes to be in her bed.
NOTE Confidence: 0.851520461666667

00:26:12.010 --> 00:26:12.727 She's an artist,
NOTE Confidence: 0.851520461666667

00:26:12.727 --> 00:26:14.751 which she was you know and I'm sure
NOTE Confidence: 0.851520461666667

00:26:14.751 --> 00:26:16.788 she did a little bit like attention
NOTE Confidence: 0.851520461666667

00:26:16.788 --> 00:26:18.339 probably because she felt terrible.
NOTE Confidence: 0.851520461666667

00:26:18.340 --> 00:26:20.580 I mean no one visited her but so.
NOTE Confidence: 0.851520461666667

00:26:20.580 --> 00:26:23.835 So when we don't have a framework
NOTE Confidence: 0.851520461666667

00:26:23.835 --> 00:26:26.059 for understanding what you know,
NOTE Confidence: 0.851520461666667

00:26:26.060 --> 00:26:28.700 what an infection associated you know,
NOTE Confidence: 0.851520461666667

00:26:28.700 --> 00:26:29.819 how prevalent infection
NOTE Confidence: 0.851520461666667

00:26:29.819 --> 00:26:30.938 associated diseases are,
NOTE Confidence: 0.851520461666667

00:26:30.940 --> 00:26:31.880 what they might look like,
NOTE Confidence: 0.851520461666667

00:26:31.880 --> 00:26:32.705 who gets them,

NOTE Confidence: 0.851520461666667
00:26:32.705 --> 00:26:34.355 it's really easy for us to
NOTE Confidence: 0.851520461666667
00:26:34.355 --> 00:26:35.750 start to tell a kind of.
NOTE Confidence: 0.851520461666667
00:26:35.750 --> 00:26:37.838 Psychological or cultural story about the
NOTE Confidence: 0.851520461666667
00:26:37.838 --> 00:26:40.510 people who are living with those conditions.
NOTE Confidence: 0.851520461666667
00:26:40.510 --> 00:26:41.798 As a society individually,
NOTE Confidence: 0.851520461666667
00:26:41.798 --> 00:26:43.408 it's also really easy to
NOTE Confidence: 0.851520461666667
00:26:43.408 --> 00:26:44.829 tell ourselves stories.
NOTE Confidence: 0.851520461666667
00:26:44.830 --> 00:26:46.974 So part of that line is about what
NOTE Confidence: 0.851520461666667
00:26:46.974 --> 00:26:49.146 happens to the patient when we lack
NOTE Confidence: 0.851520461666667
00:26:49.146 --> 00:26:51.162 a diagnosis or the diagnosis isn't
NOTE Confidence: 0.851520461666667
00:26:51.162 --> 00:26:53.406 fully illuminating of what's going on.
NOTE Confidence: 0.851520461666667
00:26:53.410 --> 00:26:57.490 And in my case, I felt obscurely that
NOTE Confidence: 0.851520461666667
00:26:57.490 --> 00:26:58.960 something was just wrong with me,
NOTE Confidence: 0.851520461666667
00:26:58.960 --> 00:27:00.036 that I was like,
NOTE Confidence: 0.851520461666667
00:27:00.036 --> 00:27:02.902 not good at being a person, you know?
NOTE Confidence: 0.851520461666667

00:27:02.902 --> 00:27:06.143 And that feeling really warped.

NOTE Confidence: 0.851520461666667

00:27:06.143 --> 00:27:09.808 My entire 20s and 30s,

NOTE Confidence: 0.851520461666667

00:27:09.810 --> 00:27:11.140 first half of my 30s,

NOTE Confidence: 0.851520461666667

00:27:11.140 --> 00:27:13.200 and it's still hard for me to get rid of.

NOTE Confidence: 0.851520461666667

00:27:13.200 --> 00:27:14.565 Like whenever I have a flare now,

NOTE Confidence: 0.851520461666667

00:27:14.570 --> 00:27:15.992 my immediate response is to feel

NOTE Confidence: 0.851520461666667

00:27:15.992 --> 00:27:17.770 that I have done something wrong.

NOTE Confidence: 0.851520461666667

00:27:17.770 --> 00:27:18.938 Like it's my fault,

NOTE Confidence: 0.851520461666667

00:27:18.938 --> 00:27:20.690 something I was supposed to control,

NOTE Confidence: 0.851520461666667

00:27:20.690 --> 00:27:24.100 something and it didn't happen.

NOTE Confidence: 0.851520461666667

00:27:24.100 --> 00:27:25.640 So there's that piece too.

NOTE Confidence: 0.851520461666667

00:27:25.640 --> 00:27:26.652 And then and then,

NOTE Confidence: 0.851520461666667

00:27:26.652 --> 00:27:27.158 you know,

NOTE Confidence: 0.851520461666667

00:27:27.160 --> 00:27:29.728 it extends far outward to thinking

NOTE Confidence: 0.851520461666667

00:27:29.728 --> 00:27:32.262 about things like the rise of

NOTE Confidence: 0.851520461666667

00:27:32.262 --> 00:27:34.466 sort of anti VAX movement, right?

NOTE Confidence: 0.851520461666667
00:27:34.466 --> 00:27:35.158 Like why?
NOTE Confidence: 0.851520461666667
00:27:35.158 --> 00:27:37.580 That's not exactly where science is silent.
NOTE Confidence: 0.851520461666667
00:27:37.580 --> 00:27:40.303 But part of what I'm getting at
NOTE Confidence: 0.851520461666667
00:27:40.303 --> 00:27:43.240 there too is that we do have to.
NOTE Confidence: 0.851520461666667
00:27:43.240 --> 00:27:44.780 This is really challenging.
NOTE Confidence: 0.851520461666667
00:27:44.780 --> 00:27:47.090 Think about the stories people are
NOTE Confidence: 0.851520461666667
00:27:47.159 --> 00:27:49.149 telling themselves and that science
NOTE Confidence: 0.851520461666667
00:27:49.149 --> 00:27:51.557 might have to actually think about
NOTE Confidence: 0.851520461666667
00:27:51.557 --> 00:27:53.687 and engage with and find language.
NOTE Confidence: 0.851520461666667
00:27:53.690 --> 00:27:58.540 For connecting around people's fear too,
NOTE Confidence: 0.851520461666667
00:27:58.540 --> 00:27:59.260 you know.
NOTE Confidence: 0.851520461666667
00:27:59.260 --> 00:28:02.610 Not just the medical piece of the encounter.
NOTE Confidence: 0.81080679
00:28:03.610 --> 00:28:06.706 Right. Well, you know, go ahead.
NOTE Confidence: 0.696537782222222
00:28:07.500 --> 00:28:09.162 Not just fear, but their desire
NOTE Confidence: 0.696537782222222
00:28:09.162 --> 00:28:10.684 is their emotions, but all,
NOTE Confidence: 0.696537782222222

00:28:10.684 --> 00:28:12.052 all of that superstition
NOTE Confidence: 0.6965377822222222

00:28:12.052 --> 00:28:14.260 that we all have. Yeah. Yeah.
NOTE Confidence: 0.86085858

00:28:15.590 --> 00:28:18.443 Well, so. In the face of the kind of
NOTE Confidence: 0.86085858

00:28:18.443 --> 00:28:20.380 persistent pain that you describe,
NOTE Confidence: 0.86085858

00:28:20.380 --> 00:28:22.708 or a recalcitrant illness.
NOTE Confidence: 0.868123774

00:28:25.580 --> 00:28:28.920 People long for something better.
NOTE Confidence: 0.868123774

00:28:28.920 --> 00:28:31.000 You say a better story.
NOTE Confidence: 0.868123774

00:28:31.000 --> 00:28:34.997 Is it the doctor's job to give
NOTE Confidence: 0.868123774

00:28:34.997 --> 00:28:38.419 these patients a better story?
NOTE Confidence: 0.868123774

00:28:38.420 --> 00:28:39.059 Is that useful?
NOTE Confidence: 0.868123774

00:28:39.059 --> 00:28:40.337 Is that part of their job?
NOTE Confidence: 0.868123774

00:28:40.340 --> 00:28:42.560 Or is that I don't know?
NOTE Confidence: 0.868123774

00:28:42.560 --> 00:28:43.988 Where does that story come from?
NOTE Confidence: 0.815435599166667

00:28:45.330 --> 00:28:47.606 You. I think right.
NOTE Confidence: 0.815435599166667

00:28:47.606 --> 00:28:52.027 I don't think it's the doctor's job
NOTE Confidence: 0.815435599166667

00:28:52.027 --> 00:28:56.652 necessarily, but I do think that it

NOTE Confidence: 0.815435599166667
00:28:56.652 --> 00:28:59.148 is probably science's job in part.
NOTE Confidence: 0.815435599166667
00:28:59.148 --> 00:29:02.015 Right. Part of what I'm saying here is.
NOTE Confidence: 0.815435599166667
00:29:02.020 --> 00:29:04.180 We need research, right? The research,
NOTE Confidence: 0.815435599166667
00:29:04.180 --> 00:29:07.300 the absence has to do with the lack of any,
NOTE Confidence: 0.815435599166667
00:29:07.300 --> 00:29:09.256 not lack of knowledge around some
NOTE Confidence: 0.815435599166667
00:29:09.256 --> 00:29:11.460 of the conditions I'm writing about.
NOTE Confidence: 0.815435599166667
00:29:11.460 --> 00:29:14.015 And then I do think that structurally,
NOTE Confidence: 0.815435599166667
00:29:14.020 --> 00:29:15.550 yeah, socially, societally,
NOTE Confidence: 0.815435599166667
00:29:15.550 --> 00:29:20.036 it's our job to think about things like the
NOTE Confidence: 0.815435599166667
00:29:20.036 --> 00:29:23.199 delivery of care and what health is, right?
NOTE Confidence: 0.815435599166667
00:29:23.199 --> 00:29:25.152 I mean, in a way that's the
NOTE Confidence: 0.815435599166667
00:29:25.152 --> 00:29:26.440 function of any polity.
NOTE Confidence: 0.815435599166667
00:29:26.440 --> 00:29:29.632 Democratic polity is to.
NOTE Confidence: 0.815435599166667
00:29:29.632 --> 00:29:32.328 Really be. In some sense,
NOTE Confidence: 0.815435599166667
00:29:32.328 --> 00:29:33.792 constantly thinking about what
NOTE Confidence: 0.815435599166667

00:29:33.792 --> 00:29:35.590 is the right to health.
NOTE Confidence: 0.815435599166667

00:29:35.590 --> 00:29:36.342 What is.
NOTE Confidence: 0.815435599166667

00:29:36.342 --> 00:29:40.020 You know, what are we supplying in a system,
NOTE Confidence: 0.815435599166667

00:29:40.020 --> 00:29:42.680 how has the market affected the system,
NOTE Confidence: 0.815435599166667

00:29:42.680 --> 00:29:44.619 what pressures have been put upon it
NOTE Confidence: 0.815435599166667

00:29:44.619 --> 00:29:46.351 and what pressures are on doctors
NOTE Confidence: 0.815435599166667

00:29:46.351 --> 00:29:48.043 and and patients and the pressures
NOTE Confidence: 0.815435599166667

00:29:48.043 --> 00:29:49.666 really are on doctors too, right?
NOTE Confidence: 0.815435599166667

00:29:49.666 --> 00:29:51.622 I think the critique here is
NOTE Confidence: 0.815435599166667

00:29:51.622 --> 00:29:52.950 not again of any.
NOTE Confidence: 0.815435599166667

00:29:52.950 --> 00:29:54.770 Individual doctors trying to
NOTE Confidence: 0.815435599166667

00:29:54.770 --> 00:29:57.045 labor mightily within this system,
NOTE Confidence: 0.815435599166667

00:29:57.050 --> 00:29:59.174 but really of the structural questions
NOTE Confidence: 0.815435599166667

00:29:59.174 --> 00:30:02.072 that I think we do have to address
NOTE Confidence: 0.815435599166667

00:30:02.072 --> 00:30:04.196 when we're looking at this epidemic
NOTE Confidence: 0.815435599166667

00:30:04.262 --> 00:30:06.253 of chronic illness that exposes,

NOTE Confidence: 0.815435599166667
00:30:06.253 --> 00:30:07.219 I think,
NOTE Confidence: 0.815435599166667
00:30:07.219 --> 00:30:10.117 the weaknesses and the fraught parts
NOTE Confidence: 0.815435599166667
00:30:10.117 --> 00:30:12.853 of the structure of the delivery
NOTE Confidence: 0.815435599166667
00:30:12.853 --> 00:30:15.700 of care in the United States.
NOTE Confidence: 0.815435599166667
00:30:15.700 --> 00:30:18.800 Yeah, so, you know, that's,
NOTE Confidence: 0.815435599166667
00:30:18.800 --> 00:30:20.552 that's that sentence is I think
NOTE Confidence: 0.815435599166667
00:30:20.552 --> 00:30:22.140 a getting at that stuff.
NOTE Confidence: 0.815435599166667
00:30:22.140 --> 00:30:22.802 But also.
NOTE Confidence: 0.815435599166667
00:30:22.802 --> 00:30:23.464 You know,
NOTE Confidence: 0.815435599166667
00:30:23.464 --> 00:30:25.963 getting at a lot of my work
NOTE Confidence: 0.815435599166667
00:30:25.963 --> 00:30:28.519 is about trying to just name
NOTE Confidence: 0.815435599166667
00:30:28.519 --> 00:30:30.749 realities that often go unnamed.
NOTE Confidence: 0.815435599166667
00:30:30.750 --> 00:30:33.400 And the point about story
NOTE Confidence: 0.815435599166667
00:30:33.400 --> 00:30:36.760 there too is to say like.
NOTE Confidence: 0.815435599166667
00:30:36.760 --> 00:30:40.547 The patients, the it's really the person.
NOTE Confidence: 0.815435599166667

00:30:40.550 --> 00:30:42.322 The person living with
NOTE Confidence: 0.815435599166667

00:30:42.322 --> 00:30:44.980 disease is not just a patient,
NOTE Confidence: 0.815435599166667

00:30:44.980 --> 00:30:47.280 they're a person whose life
NOTE Confidence: 0.815435599166667

00:30:47.280 --> 00:30:49.920 happens to have been shaped by.
NOTE Confidence: 0.815435599166667

00:30:49.920 --> 00:30:52.314 The bad luck of or the whatever,
NOTE Confidence: 0.815435599166667

00:30:52.320 --> 00:30:54.707 it is often bad luck of having
NOTE Confidence: 0.815435599166667

00:30:54.707 --> 00:30:57.033 this illness that they now have to
NOTE Confidence: 0.815435599166667

00:30:57.033 --> 00:30:59.339 either now have to or have always
NOTE Confidence: 0.815435599166667

00:30:59.339 --> 00:31:01.715 had to shape their lives around.
NOTE Confidence: 0.815435599166667

00:31:01.720 --> 00:31:03.880 And as Joan Didion said,
NOTE Confidence: 0.815435599166667

00:31:03.880 --> 00:31:04.894 that great essayist,
NOTE Confidence: 0.815435599166667

00:31:04.894 --> 00:31:07.260 we tell ourselves stories in order to
NOTE Confidence: 0.815435599166667

00:31:07.327 --> 00:31:09.115 live that line is possibly couldn't
NOTE Confidence: 0.815435599166667

00:31:09.115 --> 00:31:11.416 be more true of any group but
NOTE Confidence: 0.815435599166667

00:31:11.416 --> 00:31:13.076 patient people with illness, right?
NOTE Confidence: 0.815435599166667

00:31:13.076 --> 00:31:14.100 As someone with illness,

NOTE Confidence: 0.815435599166667
00:31:14.100 --> 00:31:16.080 you're struggling in a way that
NOTE Confidence: 0.815435599166667
00:31:16.080 --> 00:31:17.865 healthy people are not just
NOTE Confidence: 0.815435599166667
00:31:17.865 --> 00:31:19.477 to survive their day-to-day.
NOTE Confidence: 0.815435599166667
00:31:19.480 --> 00:31:20.600 And so for me that.
NOTE Confidence: 0.815435599166667
00:31:20.600 --> 00:31:20.895 Active,
NOTE Confidence: 0.815435599166667
00:31:20.895 --> 00:31:22.665 kind of telling myself a story
NOTE Confidence: 0.815435599166667
00:31:22.665 --> 00:31:23.950 to keep myself going.
NOTE Confidence: 0.815435599166667
00:31:23.950 --> 00:31:26.155 Like what really shaped my
NOTE Confidence: 0.815435599166667
00:31:26.155 --> 00:31:27.324 day-to-day experience, right.
NOTE Confidence: 0.815435599166667
00:31:27.324 --> 00:31:30.230 And so part of that line too is to say,
NOTE Confidence: 0.815435599166667
00:31:30.230 --> 00:31:31.760 you know.
NOTE Confidence: 0.815435599166667
00:31:31.760 --> 00:31:36.769 The story that you are just a bunch
NOTE Confidence: 0.815435599166667
00:31:36.769 --> 00:31:40.290 of organs that are not functioning if
NOTE Confidence: 0.815435599166667
00:31:40.396 --> 00:31:43.819 that's your life and your life is.
NOTE Confidence: 0.815435599166667
00:31:43.820 --> 00:31:45.185 Constricting and contracting
NOTE Confidence: 0.815435599166667

00:31:45.185 --> 00:31:47.915 day after day and you're 27.
NOTE Confidence: 0.815435599166667

00:31:47.920 --> 00:31:51.084 It's not the world's most satisfying story.
NOTE Confidence: 0.815435599166667

00:31:51.090 --> 00:31:53.298 You want your life to have a little
NOTE Confidence: 0.815435599166667

00:31:53.298 --> 00:31:55.177 more meaning and dignity than that.
NOTE Confidence: 0.815435599166667

00:31:55.180 --> 00:31:56.899 And so that's part of what I'm getting at,
NOTE Confidence: 0.815435599166667

00:31:56.900 --> 00:32:01.695 too. It's like. We who are?
NOTE Confidence: 0.815435599166667

00:32:01.695 --> 00:32:02.670 Impacted.
NOTE Confidence: 0.882830281818182

00:32:04.740 --> 00:32:06.777 Have to find a way to make
NOTE Confidence: 0.882830281818182

00:32:06.777 --> 00:32:08.787 meaning of the suffering, right.
NOTE Confidence: 0.882830281818182

00:32:08.787 --> 00:32:10.522 And and and and doctors
NOTE Confidence: 0.882830281818182

00:32:10.522 --> 00:32:12.430 are part of that right.
NOTE Confidence: 0.882830281818182

00:32:12.430 --> 00:32:14.460 The encounters we have with the medical
NOTE Confidence: 0.882830281818182

00:32:14.460 --> 00:32:16.039 medical system are part of that.
NOTE Confidence: 0.882830281818182

00:32:16.040 --> 00:32:17.768 And I know a lot of people who
NOTE Confidence: 0.882830281818182

00:32:17.768 --> 00:32:19.486 work in medicine and and sort
NOTE Confidence: 0.882830281818182

00:32:19.486 --> 00:32:21.328 of are academics who think about

NOTE Confidence: 0.882830281818182
00:32:21.386 --> 00:32:23.318 medicine and like that's not tech.
NOTE Confidence: 0.882830281818182
00:32:23.320 --> 00:32:24.696 Is that really necessary
NOTE Confidence: 0.882830281818182
00:32:24.696 --> 00:32:26.416 part of what medicine does?
NOTE Confidence: 0.882830281818182
00:32:26.420 --> 00:32:29.309 And I do think the challenge here is not
NOTE Confidence: 0.882830281818182
00:32:29.309 --> 00:32:32.275 only a medical challenge to societal one,
NOTE Confidence: 0.882830281818182
00:32:32.280 --> 00:32:35.318 but I don't see a way around.
NOTE Confidence: 0.882830281818182
00:32:35.320 --> 00:32:37.380 I don't see, you know,
NOTE Confidence: 0.882830281818182
00:32:37.380 --> 00:32:38.212 doctors like.
NOTE Confidence: 0.882830281818182
00:32:38.212 --> 00:32:40.708 Occupy so much mental space in
NOTE Confidence: 0.882830281818182
00:32:40.708 --> 00:32:42.921 patients minds and and you're larger
NOTE Confidence: 0.882830281818182
00:32:42.921 --> 00:32:45.337 than life to us really even when
NOTE Confidence: 0.882830281818182
00:32:45.337 --> 00:32:47.920 we're critical you know and and so
NOTE Confidence: 0.882830281818182
00:32:47.998 --> 00:32:50.390 I think I don't see a way around.
NOTE Confidence: 0.882830281818182
00:32:50.390 --> 00:32:53.721 That problem of how do we, how do we,
NOTE Confidence: 0.882830281818182
00:32:53.721 --> 00:32:57.890 how do we make room for medicine to offer?
NOTE Confidence: 0.882830281818182

00:32:57.890 --> 00:33:00.368 Care so people who really need it,
NOTE Confidence: 0.882830281818182

00:33:00.370 --> 00:33:01.050 yeah.
NOTE Confidence: 0.870609879166667

00:33:02.230 --> 00:33:03.959 You know, maybe this is an unfair
NOTE Confidence: 0.870609879166667

00:33:03.959 --> 00:33:05.269 question because I don't know.
NOTE Confidence: 0.870609879166667

00:33:05.270 --> 00:33:06.854 I don't know that you've thought
NOTE Confidence: 0.870609879166667

00:33:06.854 --> 00:33:08.440 about it or researched it at all,
NOTE Confidence: 0.870609879166667

00:33:08.440 --> 00:33:09.984 but are there places?
NOTE Confidence: 0.870609879166667

00:33:09.984 --> 00:33:11.528 Outside of the United
NOTE Confidence: 0.870609879166667

00:33:11.528 --> 00:33:13.429 States that do this better.
NOTE Confidence: 0.863046540909091

00:33:14.290 --> 00:33:15.683 You know, someone asked me that the
NOTE Confidence: 0.863046540909091

00:33:15.683 --> 00:33:17.341 other day and I don't have a great
NOTE Confidence: 0.863046540909091

00:33:17.341 --> 00:33:18.769 answer because I haven't gone to every.
NOTE Confidence: 0.863046540909091

00:33:18.770 --> 00:33:20.258 I just don't know enough about.
NOTE Confidence: 0.863046540909091

00:33:20.260 --> 00:33:21.625 I mean I have a good sense
NOTE Confidence: 0.863046540909091

00:33:21.625 --> 00:33:22.210 of European healthcare.
NOTE Confidence: 0.863046540909091

00:33:22.210 --> 00:33:23.582 I don't have a great sense of

NOTE Confidence: 0.863046540909091
00:33:23.582 --> 00:33:24.869 healthcare in Asia or other places.
NOTE Confidence: 0.863046540909091
00:33:24.870 --> 00:33:28.054 So I don't believe there is,
NOTE Confidence: 0.863046540909091
00:33:28.054 --> 00:33:29.306 you know, you know,
NOTE Confidence: 0.863046540909091
00:33:29.306 --> 00:33:31.112 I think in China there is like
NOTE Confidence: 0.863046540909091
00:33:31.112 --> 00:33:32.756 a they use acupuncture more
NOTE Confidence: 0.863046540909091
00:33:32.756 --> 00:33:34.742 than we do things like that.
NOTE Confidence: 0.863046540909091
00:33:34.750 --> 00:33:36.964 But I don't know enough about and I should,
NOTE Confidence: 0.863046540909091
00:33:36.970 --> 00:33:38.560 I should, I should learn more
NOTE Confidence: 0.863046540909091
00:33:38.560 --> 00:33:40.070 about the global systems as well.
NOTE Confidence: 0.863046540909091
00:33:40.070 --> 00:33:40.390 Yeah.
NOTE Confidence: 0.886909479230769
00:33:41.700 --> 00:33:43.443 You know, I mean, because so much
NOTE Confidence: 0.886909479230769
00:33:43.443 --> 00:33:45.058 of what's wrong with our system.
NOTE Confidence: 0.886909479230769
00:33:45.060 --> 00:33:48.540 System feels very specific to where we are.
NOTE Confidence: 0.886909479230769
00:33:48.540 --> 00:33:50.572 But I don't know that anybody's fully
NOTE Confidence: 0.886909479230769
00:33:50.572 --> 00:33:52.750 gotten it right. Maybe there are.
NOTE Confidence: 0.94828001

00:33:55.390 --> 00:33:59.256 You know. You're somebody who
NOTE Confidence: 0.94828001

00:33:59.256 --> 00:34:05.270 cares a lot about words, I know.
NOTE Confidence: 0.94828001

00:34:05.270 --> 00:34:07.797 And I really am bothered by the
NOTE Confidence: 0.94828001

00:34:07.797 --> 00:34:10.505 fact that you call this group
NOTE Confidence: 0.94828001

00:34:10.505 --> 00:34:12.565 of illnesses chronic illness.
NOTE Confidence: 0.94828001

00:34:12.570 --> 00:34:15.858 You know, there's so many chronic
NOTE Confidence: 0.94828001

00:34:15.858 --> 00:34:19.945 diseases that makes up the the the main,
NOTE Confidence: 0.94828001

00:34:19.950 --> 00:34:23.230 the main type of disease that I treat.
NOTE Confidence: 0.94828001

00:34:23.230 --> 00:34:24.690 You know, as an internist.
NOTE Confidence: 0.94828001

00:34:24.690 --> 00:34:26.804 You know, there are people who have
NOTE Confidence: 0.94828001

00:34:26.804 --> 00:34:29.162 diabetes and high blood pressure and end
NOTE Confidence: 0.94828001

00:34:29.162 --> 00:34:31.250 stage renal disease and heart disease.
NOTE Confidence: 0.94828001

00:34:31.250 --> 00:34:33.776 All these other things that are
NOTE Confidence: 0.94828001

00:34:33.776 --> 00:34:36.290 actually are what I consider.
NOTE Confidence: 0.94828001

00:34:36.290 --> 00:34:38.020 Chronic illnesses.
NOTE Confidence: 0.886400190833333

00:34:40.800 --> 00:34:42.893 What I know you might have touched

NOTE Confidence: 0.886400190833333
00:34:42.893 --> 00:34:44.860 on this in another answer,
NOTE Confidence: 0.886400190833333
00:34:44.860 --> 00:34:48.132 but can you describe what you mean by
NOTE Confidence: 0.886400190833333
00:34:48.132 --> 00:34:50.885 chronic illness and can we come up with
NOTE Confidence: 0.886400190833333
00:34:50.885 --> 00:34:53.818 a better rate is a better description.
NOTE Confidence: 0.886400190833333
00:34:53.820 --> 00:34:54.919 I know that if you could have
NOTE Confidence: 0.886400190833333
00:34:54.919 --> 00:34:56.420 found one, you would have, but
NOTE Confidence: 0.83484805
00:34:57.240 --> 00:34:59.760 I mean look, you know it.
NOTE Confidence: 0.83484805
00:34:59.760 --> 00:35:00.750 Problems of language,
NOTE Confidence: 0.83484805
00:35:00.750 --> 00:35:01.740 languages and material.
NOTE Confidence: 0.83484805
00:35:01.740 --> 00:35:03.819 Like anything else that has its limitations.
NOTE Confidence: 0.83484805
00:35:03.820 --> 00:35:05.800 I I'm pretty clear in the
NOTE Confidence: 0.83484805
00:35:05.800 --> 00:35:08.230 introduction that I try to use the
NOTE Confidence: 0.83484805
00:35:08.230 --> 00:35:10.300 chronic illness is is the umbrella.
NOTE Confidence: 0.83484805
00:35:10.300 --> 00:35:12.715 Right. That I'm parts of the book
NOTE Confidence: 0.83484805
00:35:12.715 --> 00:35:15.020 will be touch on aspects of the
NOTE Confidence: 0.83484805

00:35:15.020 --> 00:35:16.308 experience of chronic illness,
NOTE Confidence: 0.83484805

00:35:16.310 --> 00:35:17.858 which is to say knowing that
NOTE Confidence: 0.83484805

00:35:17.858 --> 00:35:19.536 you're going to be living with
NOTE Confidence: 0.83484805

00:35:19.536 --> 00:35:21.587 something for the rest of your life.
NOTE Confidence: 0.83484805

00:35:21.590 --> 00:35:22.714 My brother has epilepsy.
NOTE Confidence: 0.83484805

00:35:22.714 --> 00:35:25.420 He in some sense has a chronic illness.
NOTE Confidence: 0.83484805

00:35:25.420 --> 00:35:26.995 There are things in my book that
NOTE Confidence: 0.83484805

00:35:26.995 --> 00:35:28.600 apply to his experience, right.
NOTE Confidence: 0.83484805

00:35:28.600 --> 00:35:30.910 But then within that I am speaking
NOTE Confidence: 0.83484805

00:35:30.910 --> 00:35:32.799 much more specifically about the
NOTE Confidence: 0.83484805

00:35:32.799 --> 00:35:35.127 kinds of illnesses that I have,
NOTE Confidence: 0.83484805

00:35:35.130 --> 00:35:37.490 which are these what I call sort of
NOTE Confidence: 0.83484805

00:35:37.490 --> 00:35:38.935 again slightly initially because
NOTE Confidence: 0.83484805

00:35:38.935 --> 00:35:40.915 again there's no great words.
NOTE Confidence: 0.83484805

00:35:40.920 --> 00:35:42.820 Poorly understood illnesses and
NOTE Confidence: 0.83484805

00:35:42.820 --> 00:35:44.720 then also infection associated.

NOTE Confidence: 0.83484805

00:35:44.720 --> 00:35:45.670 Chronic illnesses.

NOTE Confidence: 0.894288858571429

00:35:47.700 --> 00:35:49.668 You know, so I thought about not using

NOTE Confidence: 0.894288858571429

00:35:49.668 --> 00:35:51.419 the term chronic illness at all,

NOTE Confidence: 0.894288858571429

00:35:51.420 --> 00:35:54.556 but that just seemed too technical and

NOTE Confidence: 0.894288858571429

00:35:54.556 --> 00:35:58.375 I do think part of the book is about.

NOTE Confidence: 0.894288858571429

00:35:58.380 --> 00:36:01.700 The adjustments that come with.

NOTE Confidence: 0.894288858571429

00:36:01.700 --> 00:36:03.758 Moving from a you know what?

NOTE Confidence: 0.894288858571429

00:36:03.760 --> 00:36:05.880 What's Susan Sontag called?

NOTE Confidence: 0.894288858571429

00:36:05.880 --> 00:36:08.599 You know, moving to the ninth side of life,

NOTE Confidence: 0.894288858571429

00:36:08.600 --> 00:36:10.440 as Susan Sontag called illness,

NOTE Confidence: 0.894288858571429

00:36:10.440 --> 00:36:11.668 and knowing that you're

NOTE Confidence: 0.894288858571429

00:36:11.668 --> 00:36:12.589 not there temporarily,

NOTE Confidence: 0.894288858571429

00:36:12.590 --> 00:36:13.844 you're there permanently,

NOTE Confidence: 0.894288858571429

00:36:13.844 --> 00:36:16.770 you now have a passport to the

NOTE Confidence: 0.894288858571429

00:36:16.848 --> 00:36:18.786 to the land of being sick.

NOTE Confidence: 0.894288858571429

00:36:18.790 --> 00:36:20.710 It's not a passport you wanted to have.

NOTE Confidence: 0.894288858571429

00:36:20.710 --> 00:36:24.625 So you know I appreciate that

NOTE Confidence: 0.894288858571429

00:36:24.625 --> 00:36:26.206 that imprecisions there.

NOTE Confidence: 0.894288858571429

00:36:26.210 --> 00:36:28.532 I try to be very consistent in the book

NOTE Confidence: 0.894288858571429

00:36:28.532 --> 00:36:30.575 when I use the term chronic illness

NOTE Confidence: 0.894288858571429

00:36:30.575 --> 00:36:34.340 I'm trying to talk broadly about.

NOTE Confidence: 0.894288858571429

00:36:34.340 --> 00:36:35.724 Something about chronicity that

NOTE Confidence: 0.894288858571429

00:36:35.724 --> 00:36:37.800 I think might apply to others.

NOTE Confidence: 0.894288858571429

00:36:37.800 --> 00:36:38.547 And of course,

NOTE Confidence: 0.894288858571429

00:36:38.547 --> 00:36:40.290 always when I use a term or

NOTE Confidence: 0.894288858571429

00:36:40.352 --> 00:36:41.480 think about things,

NOTE Confidence: 0.894288858571429

00:36:41.480 --> 00:36:43.106 I know that my experience may

NOTE Confidence: 0.894288858571429

00:36:43.106 --> 00:36:44.650 not be relevant to others.

NOTE Confidence: 0.894288858571429

00:36:44.650 --> 00:36:47.116 And then I try to use the other terms,

NOTE Confidence: 0.894288858571429

00:36:47.120 --> 00:36:48.760 poorly understood illness or infection,

NOTE Confidence: 0.894288858571429

00:36:48.760 --> 00:36:50.540 associated illness much more specifically.

NOTE Confidence: 0.894288858571429
00:36:50.540 --> 00:36:52.090 What I'm really digging into
NOTE Confidence: 0.894288858571429
00:36:52.090 --> 00:36:53.640 those kinds of histories and
NOTE Confidence: 0.894288858571429
00:36:53.698 --> 00:36:55.438 disorders or autoimmune disease.
NOTE Confidence: 0.894288858571429
00:36:55.440 --> 00:36:56.040 I mean, you know,
NOTE Confidence: 0.894288858571429
00:36:56.040 --> 00:36:56.790 there's a lot of different
NOTE Confidence: 0.894288858571429
00:36:56.790 --> 00:36:57.468 things brought in there.
NOTE Confidence: 0.894288858571429
00:36:57.470 --> 00:36:59.339 So not everything I'm talking about is
NOTE Confidence: 0.894288858571429
00:36:59.339 --> 00:37:01.180 even an infectious infection associated.
NOTE Confidence: 0.894288858571429
00:37:01.180 --> 00:37:02.930 A lot of autoimmune diseases
NOTE Confidence: 0.894288858571429
00:37:02.930 --> 00:37:04.680 may not be infection associated.
NOTE Confidence: 0.894288858571429
00:37:04.680 --> 00:37:08.010 So there's a certain necessarily necessary.
NOTE Confidence: 0.894288858571429
00:37:08.010 --> 00:37:10.395 There is a certain necessary
NOTE Confidence: 0.894288858571429
00:37:10.395 --> 00:37:12.303 fungibility to the terms,
NOTE Confidence: 0.894288858571429
00:37:12.310 --> 00:37:14.438 because to have become as I was
NOTE Confidence: 0.894288858571429
00:37:14.438 --> 00:37:16.918 for a period very fixated on that
NOTE Confidence: 0.894288858571429

00:37:16.918 --> 00:37:19.156 would have limited my capacity to
NOTE Confidence: 0.894288858571429

00:37:19.234 --> 00:37:21.379 write such a wide-ranging book,
NOTE Confidence: 0.894288858571429

00:37:21.380 --> 00:37:23.390 which I ended up feeling was
NOTE Confidence: 0.894288858571429

00:37:23.390 --> 00:37:24.730 much more important than.
NOTE Confidence: 0.894288858571429

00:37:24.730 --> 00:37:26.258 Writing a more technical,
NOTE Confidence: 0.894288858571429

00:37:26.258 --> 00:37:28.168 but perhaps more limited book.
NOTE Confidence: 0.8620091375

00:37:30.060 --> 00:37:33.788 OK. I buy that.
NOTE Confidence: 0.8620091375

00:37:33.790 --> 00:37:39.326 I love that quote from today about pain,
NOTE Confidence: 0.8620091375

00:37:39.330 --> 00:37:41.028 you know, you said, he said.
NOTE Confidence: 0.8620091375

00:37:41.030 --> 00:37:44.446 Everyone gets used to it except me.
NOTE Confidence: 0.8620091375

00:37:44.450 --> 00:37:46.760 You've lived on.
NOTE Confidence: 0.8620091375

00:37:46.760 --> 00:37:48.678 On and off with paint for years.
NOTE Confidence: 0.8620091375

00:37:48.680 --> 00:37:51.904 How was it for you, a writer,
NOTE Confidence: 0.8620091375

00:37:51.904 --> 00:37:54.676 an observer, but also a sharer,
NOTE Confidence: 0.8620091375

00:37:54.680 --> 00:37:57.410 to feel like so much of what
NOTE Confidence: 0.8620091375

00:37:57.410 --> 00:37:59.429 you lived through and felt?

NOTE Confidence: 0.8620091375

00:37:59.430 --> 00:38:02.148 Might not be interesting to others.

NOTE Confidence: 0.8620091375

00:38:02.150 --> 00:38:03.218 Did that scare you?

NOTE Confidence: 0.830705758181818

00:38:04.250 --> 00:38:05.906 You mean in terms of writing

NOTE Confidence: 0.830705758181818

00:38:05.906 --> 00:38:07.470 the book or or living

NOTE Confidence: 0.7348633725

00:38:07.750 --> 00:38:09.178 or telling your story?

NOTE Confidence: 0.32906938

00:38:10.210 --> 00:38:15.810 Um. Yeah. I mean, yeah. Yeah.

NOTE Confidence: 0.32906938

00:38:15.810 --> 00:38:18.816 I felt like this felt like a very high

NOTE Confidence: 0.32906938

00:38:18.816 --> 00:38:22.024 risk book to be writing in numerous ways.

NOTE Confidence: 0.32906938

00:38:22.030 --> 00:38:23.515 And absolutely one of those

NOTE Confidence: 0.32906938

00:38:23.515 --> 00:38:25.018 was I thought, oh, God,

NOTE Confidence: 0.32906938

00:38:25.018 --> 00:38:27.544 this is like when you wake up, you know,

NOTE Confidence: 0.32906938

00:38:27.544 --> 00:38:29.120 you're on like a trip with some friends.

NOTE Confidence: 0.32906938

00:38:29.120 --> 00:38:30.170 And one of your friends is like,

NOTE Confidence: 0.32906938

00:38:30.170 --> 00:38:33.020 let me tell you about the dream I had last

NOTE Confidence: 0.32906938

00:38:33.020 --> 00:38:35.526 that it takes over the entire conversation.

NOTE Confidence: 0.32906938

00:38:35.526 --> 00:38:38.006 Right. So I was very,
NOTE Confidence: 0.32906938

00:38:38.010 --> 00:38:41.209 very highly conscious of the fact that.
NOTE Confidence: 0.32906938

00:38:41.210 --> 00:38:43.303 Hey, no one wants to hear you
NOTE Confidence: 0.32906938

00:38:43.303 --> 00:38:44.960 talk about your, you know,
NOTE Confidence: 0.32906938

00:38:44.960 --> 00:38:46.100 funny health stuff.
NOTE Confidence: 0.32906938

00:38:46.100 --> 00:38:48.820 I mean no one.
NOTE Confidence: 0.32906938

00:38:48.820 --> 00:38:52.892 And B1 of the sort of real writerly problems
NOTE Confidence: 0.32906938

00:38:52.892 --> 00:38:56.874 I had was that in a sense my condition,
NOTE Confidence: 0.32906938

00:38:56.880 --> 00:38:59.757 my experience would look very anti dramatic,
NOTE Confidence: 0.32906938

00:38:59.760 --> 00:39:00.860 right? It took year.
NOTE Confidence: 0.32906938

00:39:00.860 --> 00:39:02.420 It sort of slowly built,
NOTE Confidence: 0.32906938

00:39:02.420 --> 00:39:04.530 I would say in the book I got sick the
NOTE Confidence: 0.32906938

00:39:04.587 --> 00:39:06.876 way Hemingway says you go broke gradually
NOTE Confidence: 0.32906938

00:39:06.876 --> 00:39:08.919 and then suddenly it's not dramatic.
NOTE Confidence: 0.32906938

00:39:08.920 --> 00:39:10.600 I don't know when I got sick.
NOTE Confidence: 0.32906938

00:39:10.600 --> 00:39:13.088 I don't know exactly what's wrong with me.

NOTE Confidence: 0.32906938

00:39:13.090 --> 00:39:16.026 Even still, I have now I have some

NOTE Confidence: 0.32906938

00:39:16.026 --> 00:39:18.119 diagnosis that are pretty clear.

NOTE Confidence: 0.32906938

00:39:18.120 --> 00:39:21.669 I, uh, there's no like big reveal.

NOTE Confidence: 0.32906938

00:39:21.670 --> 00:39:23.536 It's sort of a slow accretion.

NOTE Confidence: 0.32906938

00:39:23.540 --> 00:39:24.620 And my, you know,

NOTE Confidence: 0.32906938

00:39:24.620 --> 00:39:26.240 my symptoms were things like fatigue

NOTE Confidence: 0.32906938

00:39:26.290 --> 00:39:28.138 and brain fog and they came and went.

NOTE Confidence: 0.32906938

00:39:28.140 --> 00:39:31.059 So it's like a nightmare from a

NOTE Confidence: 0.32906938

00:39:31.059 --> 00:39:32.624 narrative perspective, someone who's,

NOTE Confidence: 0.32906938

00:39:32.624 --> 00:39:34.796 like trained to deal with narratives.

NOTE Confidence: 0.32906938

00:39:34.800 --> 00:39:36.536 So I had to spend a lot of

NOTE Confidence: 0.32906938

00:39:36.536 --> 00:39:37.879 time just thinking very,

NOTE Confidence: 0.32906938

00:39:37.880 --> 00:39:40.290 very deeply about what am

NOTE Confidence: 0.32906938

00:39:40.290 --> 00:39:42.218 I trying to communicate?

NOTE Confidence: 0.32906938

00:39:42.220 --> 00:39:43.844 What would make this,

NOTE Confidence: 0.32906938

00:39:43.844 --> 00:39:47.080 the thinking of the book feel dramatic,
NOTE Confidence: 0.32906938

00:39:47.080 --> 00:39:48.583 even if the.
NOTE Confidence: 0.32906938

00:39:48.583 --> 00:39:50.086 The condition itself,
NOTE Confidence: 0.32906938

00:39:50.090 --> 00:39:50.508 manifestation,
NOTE Confidence: 0.32906938

00:39:50.508 --> 00:39:51.344 isn't dramatic,
NOTE Confidence: 0.32906938

00:39:51.344 --> 00:39:55.020 and so I think the real shape of the
NOTE Confidence: 0.32906938

00:39:55.020 --> 00:39:57.054 book is actually a narrative of.
NOTE Confidence: 0.32906938

00:39:57.060 --> 00:40:00.160 Reflection and deepening understanding
NOTE Confidence: 0.32906938

00:40:00.160 --> 00:40:05.258 of everything from mortality to why I
NOTE Confidence: 0.32906938

00:40:05.258 --> 00:40:07.490 was sick to how I think about meeting
NOTE Confidence: 0.32906938

00:40:07.490 --> 00:40:09.837 and how I think about care and all of that.
NOTE Confidence: 0.32906938

00:40:09.840 --> 00:40:11.892 And that that's really the drama of the book.
NOTE Confidence: 0.32906938

00:40:11.900 --> 00:40:13.372 And I had to sort of create a
NOTE Confidence: 0.32906938

00:40:13.372 --> 00:40:14.759 drama of thought in the book.
NOTE Confidence: 0.32906938

00:40:14.760 --> 00:40:15.513 But yeah, absolutely,
NOTE Confidence: 0.32906938

00:40:15.513 --> 00:40:17.019 I was terrified of of that.

NOTE Confidence: 0.32906938

00:40:17.020 --> 00:40:18.908 And to the day, you know, it came out.

NOTE Confidence: 0.32906938

00:40:18.908 --> 00:40:21.440 I mean, even until recently I was,

NOTE Confidence: 0.32906938

00:40:21.440 --> 00:40:24.728 it took a while to really.

NOTE Confidence: 0.32906938

00:40:24.730 --> 00:40:25.272 You know,

NOTE Confidence: 0.32906938

00:40:25.272 --> 00:40:26.627 I think readers responded pretty

NOTE Confidence: 0.32906938

00:40:26.627 --> 00:40:28.408 intensely to the book pretty quickly,

NOTE Confidence: 0.32906938

00:40:28.410 --> 00:40:29.509 but I did not know that that

NOTE Confidence: 0.32906938

00:40:29.509 --> 00:40:30.290 was going to happen.

NOTE Confidence: 0.856159340588236

00:40:33.700 --> 00:40:35.344 It must have been hard at

NOTE Confidence: 0.856159340588236

00:40:35.344 --> 00:40:37.078 times when you wondered as as

NOTE Confidence: 0.856159340588236

00:40:37.078 --> 00:40:38.518 you acknowledged that you did,

NOTE Confidence: 0.856159340588236

00:40:38.520 --> 00:40:41.360 that it might be all in your head.

NOTE Confidence: 0.856159340588236

00:40:41.360 --> 00:40:42.740 I don't think that happened very.

NOTE Confidence: 0.856159340588236

00:40:42.740 --> 00:40:44.354 Did that, did that happen often

NOTE Confidence: 0.856159340588236

00:40:44.354 --> 00:40:46.120 and and when it did happen,

NOTE Confidence: 0.856159340588236

00:40:46.120 --> 00:40:47.800 how did you manage that?
NOTE Confidence: 0.856159340588236

00:40:47.800 --> 00:40:51.034 Because that's just seems to me
NOTE Confidence: 0.856159340588236

00:40:51.034 --> 00:40:54.270 like death to your sense of.
NOTE Confidence: 0.856159340588236

00:40:54.270 --> 00:40:55.220 Getting better,
NOTE Confidence: 0.82012197

00:40:55.370 --> 00:40:57.908 yeah. I mean I so when I I talk
NOTE Confidence: 0.82012197

00:40:57.908 --> 00:41:00.670 a lot in the book about again.
NOTE Confidence: 0.82012197

00:41:00.670 --> 00:41:02.511 So as I just said I got
NOTE Confidence: 0.82012197

00:41:02.511 --> 00:41:04.249 sick in this gradual way.
NOTE Confidence: 0.82012197

00:41:04.250 --> 00:41:07.076 I describe it as being like.
NOTE Confidence: 0.82012197

00:41:07.080 --> 00:41:09.072 You know when you're at the beach and
NOTE Confidence: 0.82012197

00:41:09.072 --> 00:41:10.732 you're walking and sort of slowly
NOTE Confidence: 0.82012197

00:41:10.732 --> 00:41:12.400 getting deeper and then sometimes it'll
NOTE Confidence: 0.82012197

00:41:12.449 --> 00:41:14.267 just be this drop off and you kind of.
NOTE Confidence: 0.82012197

00:41:14.270 --> 00:41:15.896 You know, suddenly are in deep
NOTE Confidence: 0.82012197

00:41:15.896 --> 00:41:17.470 water and the waves are big.
NOTE Confidence: 0.82012197

00:41:17.470 --> 00:41:18.410 That's what it was like.

NOTE Confidence: 0.82012197

00:41:18.410 --> 00:41:20.642 So I started getting sick in my early 20s.

NOTE Confidence: 0.82012197

00:41:20.650 --> 00:41:21.868 But in retrospect,

NOTE Confidence: 0.82012197

00:41:21.868 --> 00:41:25.190 it's very clear that I was quite sick.

NOTE Confidence: 0.82012197

00:41:25.190 --> 00:41:26.198 And I should have,

NOTE Confidence: 0.82012197

00:41:26.198 --> 00:41:28.349 should have been a lot of red flags,

NOTE Confidence: 0.82012197

00:41:28.350 --> 00:41:30.138 but for whatever reason,

NOTE Confidence: 0.82012197

00:41:30.138 --> 00:41:33.200 I think I was not great at.

NOTE Confidence: 0.82012197

00:41:33.200 --> 00:41:35.300 Realizing it was happening.

NOTE Confidence: 0.82012197

00:41:35.300 --> 00:41:38.092 And I also probably just had

NOTE Confidence: 0.82012197

00:41:38.092 --> 00:41:40.516 doctors who were a little too

NOTE Confidence: 0.82012197

00:41:40.516 --> 00:41:43.126 quick to think that I was anxious,

NOTE Confidence: 0.82012197

00:41:43.130 --> 00:41:45.573 or quite a lot too quick perhaps

NOTE Confidence: 0.82012197

00:41:45.573 --> 00:41:48.152 to think that I was anxious. But.

NOTE Confidence: 0.82012197

00:41:48.152 --> 00:41:51.208 And so I spent a decade thinking that

NOTE Confidence: 0.82012197

00:41:51.208 --> 00:41:54.725 I just was doing a bad job of living.

NOTE Confidence: 0.82012197

00:41:54.730 --> 00:41:56.128 As I said before, I mean,
NOTE Confidence: 0.82012197

00:41:56.130 --> 00:41:57.118 and also, you know,
NOTE Confidence: 0.82012197

00:41:57.118 --> 00:41:59.445 I think if you're a young woman and you
NOTE Confidence: 0.82012197

00:41:59.445 --> 00:42:01.840 have any history of kind of eating disorder,
NOTE Confidence: 0.82012197

00:42:01.840 --> 00:42:03.847 I'm not that I had one much of 1,
NOTE Confidence: 0.82012197

00:42:03.850 --> 00:42:07.450 but just I kept thinking.
NOTE Confidence: 0.82012197

00:42:07.450 --> 00:42:09.274 I said I'm eating the wrong
NOTE Confidence: 0.82012197

00:42:09.274 --> 00:42:11.139 food and that's why I'm sick.
NOTE Confidence: 0.82012197

00:42:11.140 --> 00:42:11.860 Which, you know,
NOTE Confidence: 0.82012197

00:42:11.860 --> 00:42:13.300 I was having drenching night sweats.
NOTE Confidence: 0.82012197

00:42:13.300 --> 00:42:14.600 I had hives every day.
NOTE Confidence: 0.82012197

00:42:14.600 --> 00:42:16.340 I had roaming joint pain.
NOTE Confidence: 0.82012197

00:42:16.340 --> 00:42:19.310 I had Vertigo suddenly and dizziness.
NOTE Confidence: 0.82012197

00:42:19.310 --> 00:42:21.514 I painted it all the time, you know,
NOTE Confidence: 0.82012197

00:42:21.514 --> 00:42:23.383 my hands turned white in the cold.
NOTE Confidence: 0.82012197

00:42:23.390 --> 00:42:25.334 I mean, just a whole host of things.

NOTE Confidence: 0.82012197

00:42:25.340 --> 00:42:27.622 I could be functional for weeks and

NOTE Confidence: 0.82012197

00:42:27.622 --> 00:42:29.731 then suddenly be enervated and find

NOTE Confidence: 0.82012197

00:42:29.731 --> 00:42:32.160 it difficult to walk around the block.

NOTE Confidence: 0.82012197

00:42:32.160 --> 00:42:34.200 But because everything was a little

NOTE Confidence: 0.82012197

00:42:34.265 --> 00:42:36.317 vague and it did come and go a bit,

NOTE Confidence: 0.82012197

00:42:36.320 --> 00:42:38.200 it was very easy to feel that again.

NOTE Confidence: 0.82012197

00:42:38.200 --> 00:42:41.208 It was my fault for not managing things.

NOTE Confidence: 0.82012197

00:42:41.210 --> 00:42:42.975 Correctly.

NOTE Confidence: 0.82012197

00:42:42.975 --> 00:42:44.740 And.

NOTE Confidence: 0.82012197

00:42:44.740 --> 00:42:45.420 Yeah,

NOTE Confidence: 0.82012197

00:42:45.420 --> 00:42:50.180 it really distorted my sense of reality.

NOTE Confidence: 0.82012197

00:42:50.180 --> 00:42:51.492 100% being that sick,

NOTE Confidence: 0.82012197

00:42:51.492 --> 00:42:53.460 having drenching night sweats every night,

NOTE Confidence: 0.82012197

00:42:53.460 --> 00:42:54.790 having to change my clothes,

NOTE Confidence: 0.82012197

00:42:54.790 --> 00:42:57.184 going to doctors and having them

NOTE Confidence: 0.82012197

00:42:57.184 --> 00:42:59.978 be like maybe you work too much.
NOTE Confidence: 0.82012197

00:42:59.980 --> 00:43:01.128 Absolutely distorted my sense
NOTE Confidence: 0.82012197

00:43:01.128 --> 00:43:02.850 of reality in ways that I'm
NOTE Confidence: 0.82012197

00:43:02.900 --> 00:43:04.360 still trying to recover from,
NOTE Confidence: 0.82012197

00:43:04.360 --> 00:43:06.300 and that's something I heard
NOTE Confidence: 0.82012197

00:43:06.300 --> 00:43:08.240 from a lot of people.
NOTE Confidence: 0.82012197

00:43:08.240 --> 00:43:10.280 The way I finally realized there was very
NOTE Confidence: 0.82012197

00:43:10.280 --> 00:43:12.637 sick was when my husband basically was like,
NOTE Confidence: 0.82012197

00:43:12.640 --> 00:43:13.736 you don't seem OK,
NOTE Confidence: 0.82012197

00:43:13.736 --> 00:43:15.730 or someone in your 20s who's like,
NOTE Confidence: 0.82012197

00:43:15.730 --> 00:43:17.455 very fit and eats well
NOTE Confidence: 0.82012197

00:43:17.455 --> 00:43:19.180 and sleeps well and like,
NOTE Confidence: 0.82012197

00:43:19.180 --> 00:43:20.572 this doesn't seem typical.
NOTE Confidence: 0.82012197

00:43:20.572 --> 00:43:23.163 And one day I was driving a
NOTE Confidence: 0.82012197

00:43:23.163 --> 00:43:24.879 colleague home from Princeton,
NOTE Confidence: 0.82012197

00:43:24.880 --> 00:43:26.998 where I taught at the time,

NOTE Confidence: 0.82012197

00:43:27.000 --> 00:43:28.840 and I had actually been doing pretty well.

NOTE Confidence: 0.82012197

00:43:28.840 --> 00:43:31.840 And I looked at him and I realized

NOTE Confidence: 0.82012197

00:43:31.840 --> 00:43:34.220 I had no idea who he was.

NOTE Confidence: 0.82012197

00:43:34.220 --> 00:43:36.076 And like, I knew that I knew him.

NOTE Confidence: 0.82012197

00:43:36.080 --> 00:43:37.316 I've known him for 15 years.

NOTE Confidence: 0.82012197

00:43:37.320 --> 00:43:38.240 He's a very famous.

NOTE Confidence: 0.82012197

00:43:38.240 --> 00:43:40.169 Writer who I've known for a long time.

NOTE Confidence: 0.82012197

00:43:40.170 --> 00:43:41.370 It's a friend of mine.

NOTE Confidence: 0.8508975

00:43:41.370 --> 00:43:42.910 I knew I knew him.

NOTE Confidence: 0.8508975

00:43:42.910 --> 00:43:43.705 I couldn't remember.

NOTE Confidence: 0.8508975

00:43:43.705 --> 00:43:44.765 He was my colleague.

NOTE Confidence: 0.8508975

00:43:44.770 --> 00:43:46.993 I didn't know why he was in my car.

NOTE Confidence: 0.8508975

00:43:47.000 --> 00:43:48.580 I didn't know his name.

NOTE Confidence: 0.8508975

00:43:48.580 --> 00:43:50.660 All I knew was like, I know, I know him.

NOTE Confidence: 0.8508975

00:43:50.660 --> 00:43:52.590 It was like waking into, you know,

NOTE Confidence: 0.8508975

00:43:52.590 --> 00:43:54.300 like a sci-fi movie or something.

NOTE Confidence: 0.8508975

00:43:54.300 --> 00:43:56.004 And I had to spend the rest of

NOTE Confidence: 0.8508975

00:43:56.004 --> 00:43:57.912 the Dr pretending that I knew him

NOTE Confidence: 0.8508975

00:43:57.912 --> 00:43:59.850 so that I didn't freak him out.

NOTE Confidence: 0.8508975

00:43:59.850 --> 00:44:00.438 That was driving.

NOTE Confidence: 0.8508975

00:44:00.438 --> 00:44:02.160 I should have stopped the car and be like,

NOTE Confidence: 0.8508975

00:44:02.160 --> 00:44:02.934 could you drive?

NOTE Confidence: 0.8508975

00:44:02.934 --> 00:44:04.482 And I thought maybe I'm having

NOTE Confidence: 0.8508975

00:44:04.482 --> 00:44:06.258 a stroke or something, you know?

NOTE Confidence: 0.8508975

00:44:06.258 --> 00:44:07.482 So I remember coming home to

NOTE Confidence: 0.8508975

00:44:07.482 --> 00:44:08.648 my husband and explain that.

NOTE Confidence: 0.8508975

00:44:08.650 --> 00:44:10.970 And he was like, this is not normal.

NOTE Confidence: 0.8508975

00:44:10.970 --> 00:44:11.780 Something's really wrong.

NOTE Confidence: 0.8508975

00:44:11.780 --> 00:44:13.670 And that's where we kind of got

NOTE Confidence: 0.8508975

00:44:13.727 --> 00:44:15.387 very serious about finding answers.

NOTE Confidence: 0.8508975

00:44:15.390 --> 00:44:17.168 Yeah. And so from that point on,

NOTE Confidence: 0.8508975

00:44:17.170 --> 00:44:18.910 I think I never questioned that.

NOTE Confidence: 0.8508975

00:44:18.910 --> 00:44:20.610 I was very, very sick.

NOTE Confidence: 0.8508975

00:44:20.610 --> 00:44:21.938 But that first decade

NOTE Confidence: 0.8508975

00:44:21.938 --> 00:44:23.266 was one of questioning.

NOTE Confidence: 0.812278014285714

00:44:24.010 --> 00:44:28.749 What a terrible line. That first decade.

NOTE Confidence: 0.812278014285714

00:44:28.750 --> 00:44:32.040 I know, right? Terrible line.

NOTE Confidence: 0.841380330666667

00:44:34.780 --> 00:44:38.268 In the when you the waxing and waning

NOTE Confidence: 0.841380330666667

00:44:38.268 --> 00:44:41.226 well first before I go into that.

NOTE Confidence: 0.841380330666667

00:44:41.230 --> 00:44:43.570 You think the fact that you're

NOTE Confidence: 0.841380330666667

00:44:43.570 --> 00:44:45.690 a woman made anxiety come

NOTE Confidence: 0.841380330666667

00:44:45.690 --> 00:44:47.590 to people's brains faster?

NOTE Confidence: 0.841380330666667

00:44:47.590 --> 00:44:49.042 I mean this always.

NOTE Confidence: 0.841380330666667

00:44:49.042 --> 00:44:50.494 Somebody always writes this.

NOTE Confidence: 0.841380330666667

00:44:50.500 --> 00:44:52.264 Every time I write about a woman,

NOTE Confidence: 0.841380330666667

00:44:52.270 --> 00:44:53.970 somebody in the comments goes,

NOTE Confidence: 0.841380330666667

00:44:53.970 --> 00:44:55.440 she would have been diagnosed a
NOTE Confidence: 0.841380330666667

00:44:55.440 --> 00:44:56.999 lot faster if she'd been a man.
NOTE Confidence: 0.919940313333333

00:44:58.830 --> 00:45:00.797 You know, I spent a long time
NOTE Confidence: 0.919940313333333

00:45:00.797 --> 00:45:02.830 trying to kind of quantify as much
NOTE Confidence: 0.919940313333333

00:45:02.830 --> 00:45:04.566 as I could what Bender played.
NOTE Confidence: 0.919940313333333

00:45:04.566 --> 00:45:06.106 I mean, it's very clear.
NOTE Confidence: 0.919940313333333

00:45:06.110 --> 00:45:07.950 I have a chapter called the woman problem.
NOTE Confidence: 0.919940313333333

00:45:07.950 --> 00:45:10.010 It's very clear that women,
NOTE Confidence: 0.919940313333333

00:45:10.010 --> 00:45:12.120 there's a lot of data.
NOTE Confidence: 0.919940313333333

00:45:12.120 --> 00:45:13.919 And also a lot of subjective reports,
NOTE Confidence: 0.919940313333333

00:45:13.920 --> 00:45:16.552 and I did a lot of reporting that
NOTE Confidence: 0.919940313333333

00:45:16.552 --> 00:45:19.178 suggested to me that women are treated
NOTE Confidence: 0.919940313333333

00:45:19.178 --> 00:45:22.219 differently than men in the medical system.
NOTE Confidence: 0.919940313333333

00:45:22.220 --> 00:45:24.612 Most of the women I interviewed have been
NOTE Confidence: 0.919940313333333

00:45:24.612 --> 00:45:27.318 told they were hypochondriacs or had anxiety.
NOTE Confidence: 0.919940313333333

00:45:27.320 --> 00:45:31.208 They all had within 18 months of being

NOTE Confidence: 0.919940313333333
00:45:31.208 --> 00:45:35.100 told hypochondriac usually and or anxiety,
NOTE Confidence: 0.919940313333333
00:45:35.100 --> 00:45:36.855 a very clear clinical diagnosis
NOTE Confidence: 0.919940313333333
00:45:36.855 --> 00:45:38.259 of something like lupus,
NOTE Confidence: 0.919940313333333
00:45:38.260 --> 00:45:39.784 rheumatoid arthritis, etcetera, etcetera,
NOTE Confidence: 0.919940313333333
00:45:39.784 --> 00:45:42.778 but just hadn't shown up yet on the test.
NOTE Confidence: 0.919940313333333
00:45:42.780 --> 00:45:45.340 So they were in these kind of incipient
NOTE Confidence: 0.919940313333333
00:45:45.340 --> 00:45:47.580 stage of developing the illness,
NOTE Confidence: 0.919940313333333
00:45:47.580 --> 00:45:49.436 but they were getting tests that you know,
NOTE Confidence: 0.919940313333333
00:45:49.440 --> 00:45:51.024 we know the odd tests for a lot
NOTE Confidence: 0.919940313333333
00:45:51.024 --> 00:45:52.169 of autoimmune diseases aren't.
NOTE Confidence: 0.919940313333333
00:45:52.170 --> 00:45:53.847 Great early on.
NOTE Confidence: 0.919940313333333
00:45:53.847 --> 00:45:58.680 So I do think being a young woman.
NOTE Confidence: 0.889665053333333
00:46:01.030 --> 00:46:02.020 You know, as I try to,
NOTE Confidence: 0.889665053333333
00:46:02.020 --> 00:46:04.964 I try to trace the history of the
NOTE Confidence: 0.889665053333333
00:46:04.964 --> 00:46:07.800 concept of hysteria pretty closely.
NOTE Confidence: 0.889665053333333

00:46:07.800 --> 00:46:09.634 And I do think that when you
NOTE Confidence: 0.8896650533333333

00:46:09.634 --> 00:46:11.299 have these vague or subjective,
NOTE Confidence: 0.8896650533333333

00:46:11.300 --> 00:46:13.220 seemingly subjective symptoms
NOTE Confidence: 0.8896650533333333

00:46:13.220 --> 00:46:15.366 like fatigue, brain fog.
NOTE Confidence: 0.8896650533333333

00:46:15.366 --> 00:46:18.830 Uh, it's just very easy to have a
NOTE Confidence: 0.8896650533333333

00:46:18.933 --> 00:46:23.203 kind of history of not taking women's
NOTE Confidence: 0.8896650533333333

00:46:23.203 --> 00:46:26.074 testimony seriously come into the
NOTE Confidence: 0.8896650533333333

00:46:26.074 --> 00:46:28.190 room right for the patient as well.
NOTE Confidence: 0.8896650533333333

00:46:28.190 --> 00:46:30.304 I mean, I think I internalized some
NOTE Confidence: 0.8896650533333333

00:46:30.304 --> 00:46:33.544 of that so we don't have to be
NOTE Confidence: 0.8896650533333333

00:46:33.544 --> 00:46:37.036 freudians to sort of just have absorbed
NOTE Confidence: 0.8896650533333333

00:46:37.036 --> 00:46:40.830 the idea that the body is telling.
NOTE Confidence: 0.8896650533333333

00:46:40.830 --> 00:46:42.286 A deeper psychological truth
NOTE Confidence: 0.8896650533333333

00:46:42.286 --> 00:46:44.470 when we don't have an answer,
NOTE Confidence: 0.8896650533333333

00:46:44.470 --> 00:46:46.228 and that's one of the concepts
NOTE Confidence: 0.8896650533333333

00:46:46.228 --> 00:46:47.929 I try to scrutinize as well.

NOTE Confidence: 0.889665053333333
00:46:47.930 --> 00:46:50.086 One of the body is telling the
NOTE Confidence: 0.889665053333333
00:46:50.086 --> 00:46:51.795 physical truth that we just
NOTE Confidence: 0.889665053333333
00:46:51.795 --> 00:46:53.282 don't understand yet, right?
NOTE Confidence: 0.889665053333333
00:46:53.282 --> 00:46:54.518 What happens then?
NOTE Confidence: 0.889665053333333
00:46:54.518 --> 00:46:57.467 Because I don't think we asked that
NOTE Confidence: 0.889665053333333
00:46:57.467 --> 00:47:00.239 question nearly as often as we should.
NOTE Confidence: 0.889665053333333
00:47:00.240 --> 00:47:01.491 But what I will say is I also talked
NOTE Confidence: 0.889665053333333
00:47:01.491 --> 00:47:03.130 to a lot of men and then we're having
NOTE Confidence: 0.889665053333333
00:47:03.130 --> 00:47:04.040 problems getting diagnosed too.
NOTE Confidence: 0.889665053333333
00:47:04.040 --> 00:47:05.920 You know, it just looked a little different.
NOTE Confidence: 0.889665053333333
00:47:05.920 --> 00:47:07.996 For one thing, men on average,
NOTE Confidence: 0.889665053333333
00:47:08.000 --> 00:47:09.056 we do have good data saying,
NOTE Confidence: 0.889665053333333
00:47:09.060 --> 00:47:10.264 like with autoimmune diseases,
NOTE Confidence: 0.889665053333333
00:47:10.264 --> 00:47:12.070 I think it's something like they
NOTE Confidence: 0.889665053333333
00:47:12.125 --> 00:47:13.630 go to the doctor for the first
NOTE Confidence: 0.889665053333333

00:47:13.630 --> 00:47:15.189 time about two or three years
NOTE Confidence: 0.8896650533333333

00:47:15.189 --> 00:47:16.337 further into their illness.
NOTE Confidence: 0.8896650533333333

00:47:16.340 --> 00:47:18.098 So I think a particular structural
NOTE Confidence: 0.8896650533333333

00:47:18.098 --> 00:47:20.543 problem we have is that women are trying
NOTE Confidence: 0.8896650533333333

00:47:20.543 --> 00:47:22.690 to be responsible agents on their own
NOTE Confidence: 0.8896650533333333

00:47:22.690 --> 00:47:24.545 behalf of their health and they go
NOTE Confidence: 0.8896650533333333

00:47:24.545 --> 00:47:26.700 early and they say I'm not feeling well,
NOTE Confidence: 0.8896650533333333

00:47:26.700 --> 00:47:28.695 but we don't yet or maybe we're
NOTE Confidence: 0.8896650533333333

00:47:28.695 --> 00:47:30.400 starting to now have I think.
NOTE Confidence: 0.8896650533333333

00:47:30.400 --> 00:47:32.128 Some of these better diagnostic tools,
NOTE Confidence: 0.8896650533333333

00:47:32.130 --> 00:47:36.786 um, women overwhelmingly are, you know.
NOTE Confidence: 0.8896650533333333

00:47:36.790 --> 00:47:38.840 Autoimmune disease is something like
NOTE Confidence: 0.8896650533333333

00:47:38.840 --> 00:47:40.765 75% of women experience autoimmune
NOTE Confidence: 0.8896650533333333

00:47:40.765 --> 00:47:43.812 disease versus 25% men long COVID we
NOTE Confidence: 0.8896650533333333

00:47:43.812 --> 00:47:47.130 see is impacting women more than men.
NOTE Confidence: 0.8896650533333333

00:47:47.130 --> 00:47:49.944 I believe MCFS or myalgia can cephalon

NOTE Confidence: 0.889665053333333
00:47:49.944 --> 00:47:51.295 myelitis, chronic fatigue syndrome,
NOTE Confidence: 0.889665053333333
00:47:51.295 --> 00:47:53.185 which are also right about also
NOTE Confidence: 0.889665053333333
00:47:53.185 --> 00:47:54.489 impacting women more than men.
NOTE Confidence: 0.889665053333333
00:47:54.490 --> 00:47:56.855 So there's this particular problem
NOTE Confidence: 0.889665053333333
00:47:56.855 --> 00:48:00.075 that we have a knowledge gap around
NOTE Confidence: 0.889665053333333
00:48:00.075 --> 00:48:02.770 these diseases and we have a habit
NOTE Confidence: 0.889665053333333
00:48:02.770 --> 00:48:04.800 of dismissing women's testimony
NOTE Confidence: 0.889665053333333
00:48:04.800 --> 00:48:07.882 when they come and are, you know,
NOTE Confidence: 0.889665053333333
00:48:07.882 --> 00:48:09.534 testifying on behalf of their own bodies.
NOTE Confidence: 0.889665053333333
00:48:09.540 --> 00:48:11.106 And that we know from studying
NOTE Confidence: 0.889665053333333
00:48:11.106 --> 00:48:12.590 how cancer patients are treated,
NOTE Confidence: 0.889665053333333
00:48:12.590 --> 00:48:13.084 for example,
NOTE Confidence: 0.889665053333333
00:48:13.084 --> 00:48:14.566 when they ask for pain medication,
NOTE Confidence: 0.889665053333333
00:48:14.570 --> 00:48:17.060 women are more often given sedatives.
NOTE Confidence: 0.889665053333333
00:48:17.060 --> 00:48:18.484 Um payment, you know,
NOTE Confidence: 0.889665053333333

00:48:18.484 --> 00:48:20.620 compared to men and pain medication,
NOTE Confidence: 0.8896650533333333

00:48:20.620 --> 00:48:21.832 etcetera, etcetera.
NOTE Confidence: 0.8896650533333333

00:48:21.832 --> 00:48:22.438 Yeah,
NOTE Confidence: 0.876420237647059

00:48:22.510 --> 00:48:25.366 yeah. I mean, the there's a
NOTE Confidence: 0.876420237647059

00:48:25.366 --> 00:48:28.327 phrase in medicine that we used
NOTE Confidence: 0.876420237647059

00:48:28.327 --> 00:48:30.727 to describe people like you.
NOTE Confidence: 0.876420237647059

00:48:30.730 --> 00:48:34.610 Medically unexplored, like you back
NOTE Confidence: 0.876420237647059

00:48:34.610 --> 00:48:37.372 right before you had some answers.
NOTE Confidence: 0.876420237647059

00:48:37.372 --> 00:48:38.986 Medically unexplained symptoms.
NOTE Confidence: 0.876420237647059

00:48:38.990 --> 00:48:42.131 And of course we never add the two words
NOTE Confidence: 0.876420237647059

00:48:42.131 --> 00:48:45.048 that are so essential to that phrase.
NOTE Confidence: 0.876420237647059

00:48:45.050 --> 00:48:48.230 They are medically unexplained to me.
NOTE Confidence: 0.876420237647059

00:48:48.230 --> 00:48:49.450 I haven't figured it out.
NOTE Confidence: 0.876420237647059

00:48:49.450 --> 00:48:52.355 Doesn't mean they there is no answer.
NOTE Confidence: 0.850860003529412

00:48:54.400 --> 00:48:57.669 Right. Or or yet to be medically
NOTE Confidence: 0.850860003529412

00:48:57.669 --> 00:48:59.927 explained symptoms might be another

NOTE Confidence: 0.850860003529412
00:48:59.927 --> 00:49:02.256 way to think about it, right.
NOTE Confidence: 0.850860003529412
00:49:02.256 --> 00:49:04.660 And that's I think, you know,
NOTE Confidence: 0.850860003529412
00:49:04.660 --> 00:49:07.530 I think one of the real intellectual
NOTE Confidence: 0.850860003529412
00:49:07.530 --> 00:49:10.120 questions in my book that I'm sure many
NOTE Confidence: 0.850860003529412
00:49:10.120 --> 00:49:13.080 of you here tonight think about too is.
NOTE Confidence: 0.850860003529412
00:49:13.080 --> 00:49:18.336 It's a real question is what does science do?
NOTE Confidence: 0.850860003529412
00:49:18.340 --> 00:49:20.572 What does medical science do with
NOTE Confidence: 0.850860003529412
00:49:20.572 --> 00:49:22.759 people whose bodies live at the
NOTE Confidence: 0.850860003529412
00:49:22.759 --> 00:49:24.329 edge of medical knowledge and
NOTE Confidence: 0.850860003529412
00:49:24.329 --> 00:49:26.499 early in the book I talk about?
NOTE Confidence: 0.850860003529412
00:49:26.500 --> 00:49:28.030 Basically, this is the story of
NOTE Confidence: 0.850860003529412
00:49:28.030 --> 00:49:29.949 realizing that I was in a body that
NOTE Confidence: 0.850860003529412
00:49:29.949 --> 00:49:31.760 lived at the edge of medical knowledge.
NOTE Confidence: 0.850860003529412
00:49:31.760 --> 00:49:33.112 And as a result,
NOTE Confidence: 0.850860003529412
00:49:33.112 --> 00:49:35.440 all kinds of things happen to me.
NOTE Confidence: 0.850860003529412

00:49:35.440 --> 00:49:37.064 And I'm able to describe those things

NOTE Confidence: 0.850860003529412

00:49:37.064 --> 00:49:39.184 as a way of reflecting certain kinds

NOTE Confidence: 0.850860003529412

00:49:39.184 --> 00:49:40.899 of cultural and scientific narratives

NOTE Confidence: 0.850860003529412

00:49:40.899 --> 00:49:42.704 or medical narratives that we tend

NOTE Confidence: 0.850860003529412

00:49:42.704 --> 00:49:44.440 to tell because I'm just because

NOTE Confidence: 0.850860003529412

00:49:44.440 --> 00:49:47.000 of where I happen to fall in the

NOTE Confidence: 0.850860003529412

00:49:47.000 --> 00:49:49.062 spectrum of knowledge, you know?

NOTE Confidence: 0.850860003529412

00:49:49.062 --> 00:49:51.117 And that's actually really interesting

NOTE Confidence: 0.850860003529412

00:49:51.117 --> 00:49:54.950 to step back from it, right?

NOTE Confidence: 0.850860003529412

00:49:54.950 --> 00:49:58.499 It's a real problem because medical science

NOTE Confidence: 0.850860003529412

00:49:58.499 --> 00:50:01.330 relies on measurements and objectivity,

NOTE Confidence: 0.850860003529412

00:50:01.330 --> 00:50:03.130 and that measurement and that

NOTE Confidence: 0.850860003529412

00:50:03.130 --> 00:50:05.330 objectivity has brought us longer lives,

NOTE Confidence: 0.850860003529412

00:50:05.330 --> 00:50:06.050 better care,

NOTE Confidence: 0.850860003529412

00:50:06.050 --> 00:50:07.974 more accurate care, you know,

NOTE Confidence: 0.850860003529412

00:50:07.974 --> 00:50:11.350 all kinds of ethical practices that we need,

NOTE Confidence: 0.850860003529412
00:50:11.350 --> 00:50:15.250 but it doesn't know there's.
NOTE Confidence: 0.850860003529412
00:50:15.250 --> 00:50:17.546 I think we need to theorize and
NOTE Confidence: 0.850860003529412
00:50:17.546 --> 00:50:19.590 think through the fact that all
NOTE Confidence: 0.850860003529412
00:50:19.590 --> 00:50:21.886 these people live at the margins of
NOTE Confidence: 0.850860003529412
00:50:21.962 --> 00:50:24.104 what we know now more than ever,
NOTE Confidence: 0.850860003529412
00:50:24.110 --> 00:50:25.040 and we need to have.
NOTE Confidence: 0.850860003529412
00:50:25.040 --> 00:50:27.413 Systems of of thinking about that that
NOTE Confidence: 0.850860003529412
00:50:27.413 --> 00:50:29.568 are better than what we have now.
NOTE Confidence: 0.815977516666667
00:50:31.490 --> 00:50:34.910 I agree. When you, oh sorry,
NOTE Confidence: 0.815977516666667
00:50:34.910 --> 00:50:37.148 can I ask one last question?
NOTE Confidence: 0.815977516666667
00:50:37.150 --> 00:50:39.992 When you have these waxing and waning
NOTE Confidence: 0.815977516666667
00:50:39.992 --> 00:50:42.100 symptoms that are so characteristic
NOTE Confidence: 0.815977516666667
00:50:42.100 --> 00:50:44.536 of so many of the diseases
NOTE Confidence: 0.9213610625
00:50:44.550 --> 00:50:45.698 that you talk about,
NOTE Confidence: 0.911531277142857
00:50:46.550 --> 00:50:49.756 how do? How do you explain them?
NOTE Confidence: 0.911531277142857

00:50:49.760 --> 00:50:51.993 How do people who have these symptoms

NOTE Confidence: 0.911531277142857

00:50:51.993 --> 00:50:54.310 explain them to themselves or to their

NOTE Confidence: 0.911531277142857

00:50:54.310 --> 00:50:56.635 families so that it makes sense because

NOTE Confidence: 0.911531277142857

00:50:56.635 --> 00:50:59.147 of it probably makes sense in some way?

NOTE Confidence: 0.82194474

00:50:59.930 --> 00:51:02.670 Yeah. That's a great question.

NOTE Confidence: 0.82194474

00:51:02.670 --> 00:51:04.907 I don't know that it know

NOTE Confidence: 0.82194474

00:51:04.907 --> 00:51:07.295 that I've ever successfully

NOTE Confidence: 0.82194474

00:51:07.295 --> 00:51:10.280 explained except in my book.

NOTE Confidence: 0.82194474

00:51:10.280 --> 00:51:11.834 You know, there's this way in

NOTE Confidence: 0.82194474

00:51:11.834 --> 00:51:13.180 which the writing the book.

NOTE Confidence: 0.82194474

00:51:13.180 --> 00:51:14.602 When the book came out, I was like,

NOTE Confidence: 0.82194474

00:51:14.602 --> 00:51:16.066 oh, now I finally explained it.

NOTE Confidence: 0.875213196

00:51:18.030 --> 00:51:19.560 Now you finally understand it.

NOTE Confidence: 0.57300056

00:51:19.650 --> 00:51:23.050 Yeah, I do, actually. Often.

NOTE Confidence: 0.57300056

00:51:23.050 --> 00:51:24.805 I often suggest to people

NOTE Confidence: 0.57300056

00:51:24.805 --> 00:51:26.560 that they send an e-mail.

NOTE Confidence: 0.57300056

00:51:26.560 --> 00:51:30.296 To people, I do think something about putting

NOTE Confidence: 0.57300056

00:51:30.296 --> 00:51:34.036 things in words on a page or virtual page.

NOTE Confidence: 0.57300056

00:51:34.040 --> 00:51:35.588 Allows the encounter,

NOTE Confidence: 0.57300056

00:51:35.588 --> 00:51:38.684 like the people in the other,

NOTE Confidence: 0.57300056

00:51:38.690 --> 00:51:40.618 to absorb it and take it without feeling

NOTE Confidence: 0.57300056

00:51:40.618 --> 00:51:42.339 the pressure of responding immediately.

NOTE Confidence: 0.57300056

00:51:42.340 --> 00:51:45.460 I think there's a lot of anxiety around

NOTE Confidence: 0.57300056

00:51:45.460 --> 00:51:47.380 how to treat chronically ill people.

NOTE Confidence: 0.57300056

00:51:47.380 --> 00:51:48.908 I I think people want to do well,

NOTE Confidence: 0.57300056

00:51:48.910 --> 00:51:50.814 and then the pressure actually kind of

NOTE Confidence: 0.57300056

00:51:50.814 --> 00:51:52.737 makes them shut off in a certain way.

NOTE Confidence: 0.57300056

00:51:52.740 --> 00:51:54.621 But the last thing I'll say is I think

NOTE Confidence: 0.57300056

00:51:54.621 --> 00:51:56.377 there's a bit also of Alfonso de problem.

NOTE Confidence: 0.57300056

00:51:56.380 --> 00:51:57.592 That great quote where he's like

NOTE Confidence: 0.57300056

00:51:57.592 --> 00:51:59.078 pain is always new to the sufferer,

NOTE Confidence: 0.57300056

00:51:59.080 --> 00:52:00.438 but everyone else gets used to it.
NOTE Confidence: 0.57300056

00:52:00.440 --> 00:52:01.456 Which is to say,
NOTE Confidence: 0.57300056

00:52:01.456 --> 00:52:02.980 like everyone in my family husband,
NOTE Confidence: 0.57300056

00:52:02.980 --> 00:52:05.380 my brothers are used to my health problems.
NOTE Confidence: 0.57300056

00:52:05.380 --> 00:52:07.060 But like, when I'm having a flare,
NOTE Confidence: 0.57300056

00:52:07.060 --> 00:52:08.580 it feels entirely new, right?
NOTE Confidence: 0.57300056

00:52:08.580 --> 00:52:11.114 Or it's almost as bad as ever.
NOTE Confidence: 0.57300056

00:52:11.120 --> 00:52:13.122 So I think explaining that is sometimes
NOTE Confidence: 0.57300056

00:52:13.122 --> 00:52:15.527 you just have to stop and put things into
NOTE Confidence: 0.57300056

00:52:15.527 --> 00:52:17.659 word and say today is a really bad day.
NOTE Confidence: 0.57300056

00:52:17.660 --> 00:52:18.800 This is what's going on.
NOTE Confidence: 0.57300056

00:52:18.800 --> 00:52:21.113 I'm not going to be able to do XYZ.
NOTE Confidence: 0.57300056

00:52:21.120 --> 00:52:23.976 I found that just being very concrete,
NOTE Confidence: 0.57300056

00:52:23.980 --> 00:52:25.022 more concrete.
NOTE Confidence: 0.57300056

00:52:25.022 --> 00:52:27.627 I am about my like.
NOTE Confidence: 0.57300056

00:52:27.630 --> 00:52:29.694 Energy limits and my possible like

NOTE Confidence: 0.57300056

00:52:29.694 --> 00:52:32.600 I just and not to be resentful that

NOTE Confidence: 0.57300056

00:52:32.600 --> 00:52:34.790 no one else understands and and

NOTE Confidence: 0.57300056

00:52:34.860 --> 00:52:37.317 looks out for that has been really

NOTE Confidence: 0.57300056

00:52:37.317 --> 00:52:39.261 important to my own personal life.

NOTE Confidence: 0.57300056

00:52:39.261 --> 00:52:39.558 Yeah,

NOTE Confidence: 0.57300056

00:52:39.558 --> 00:52:42.190 but I think something we all struggle with.

NOTE Confidence: 0.57300056

00:52:42.190 --> 00:52:43.614 I hear this from people all the time.

NOTE Confidence: 0.807508468

00:52:47.570 --> 00:52:48.610 Yeah. Did you want to,

NOTE Confidence: 0.807508468

00:52:48.610 --> 00:52:49.918 did you want to interrupt us?

NOTE Confidence: 0.893381073636364

00:52:50.030 --> 00:52:51.626 I didn't want to,

NOTE Confidence: 0.893381073636364

00:52:51.626 --> 00:52:54.820 but I just felt like I should.

NOTE Confidence: 0.893381073636364

00:52:54.820 --> 00:52:56.848 Just to kind of keep things

NOTE Confidence: 0.893381073636364

00:52:56.848 --> 00:52:58.200 moving if people are,

NOTE Confidence: 0.893381073636364

00:52:58.200 --> 00:52:59.478 I don't know people are going

NOTE Confidence: 0.893381073636364

00:52:59.478 --> 00:53:01.020 to say much beyond 6:15 and I

NOTE Confidence: 0.893381073636364

00:53:01.020 --> 00:53:02.292 want to have time for questions.
NOTE Confidence: 0.893381073636364

00:53:02.300 --> 00:53:04.160 But this has been really,
NOTE Confidence: 0.893381073636364

00:53:04.160 --> 00:53:05.462 really fascinating and.
NOTE Confidence: 0.893381073636364

00:53:05.462 --> 00:53:08.580 I have a question for you, Megan.
NOTE Confidence: 0.828558306666667

00:53:11.160 --> 00:53:14.488 I keep thinking. I keep wondering.
NOTE Confidence: 0.880518995

00:53:16.720 --> 00:53:18.514 I know you said it's not
NOTE Confidence: 0.880518995

00:53:18.514 --> 00:53:19.710 like there were doctors.
NOTE Confidence: 0.880518995

00:53:19.710 --> 00:53:22.770 To blame along the way who are not helpful,
NOTE Confidence: 0.880518995

00:53:22.770 --> 00:53:25.587 but as you said, it's also just the system.
NOTE Confidence: 0.880518995

00:53:25.590 --> 00:53:28.191 But at the same time I'm just want I
NOTE Confidence: 0.880518995

00:53:28.191 --> 00:53:30.601 keep wondering how different would this
NOTE Confidence: 0.880518995

00:53:30.601 --> 00:53:33.570 book have been if you'd encountered?
NOTE Confidence: 0.880518995

00:53:33.570 --> 00:53:35.730 Better doctors early on.
NOTE Confidence: 0.880518995

00:53:35.730 --> 00:53:39.979 And by better I mean somebody who said.
NOTE Confidence: 0.880518995

00:53:39.980 --> 00:53:41.258 I don't know what's going on.
NOTE Confidence: 0.880518995

00:53:41.260 --> 00:53:43.090 It sounds like it's really

NOTE Confidence: 0.880518995

00:53:43.090 --> 00:53:44.920 troubling you and bothering you.

NOTE Confidence: 0.880518995

00:53:44.920 --> 00:53:47.307 It may take time to play out.

NOTE Confidence: 0.880518995

00:53:47.310 --> 00:53:49.068 Doesn't fit into our usual patterns,

NOTE Confidence: 0.880518995

00:53:49.070 --> 00:53:49.736 blah blah blah.

NOTE Confidence: 0.880518995

00:53:49.736 --> 00:53:51.068 Like it doesn't fit the narrative.

NOTE Confidence: 0.880518995

00:53:51.070 --> 00:53:51.830 But I'm here for you.

NOTE Confidence: 0.880518995

00:53:51.830 --> 00:53:52.970 Like, what if you know what?

NOTE Confidence: 0.880518995

00:53:52.970 --> 00:53:54.305 If you had encountered people

NOTE Confidence: 0.880518995

00:53:54.305 --> 00:53:55.850 like that from the get go,

NOTE Confidence: 0.880518995

00:53:55.850 --> 00:53:58.083 you would still be living with everything

NOTE Confidence: 0.880518995

00:53:58.083 --> 00:54:00.632 and all of the suffering and the waves

NOTE Confidence: 0.880518995

00:54:00.632 --> 00:54:02.497 as you described it so articulately.

NOTE Confidence: 0.880518995

00:54:02.497 --> 00:54:03.478 But yeah, but.

NOTE Confidence: 0.880518995

00:54:03.478 --> 00:54:06.030 I think that's such a great question.

NOTE Confidence: 0.880518995

00:54:06.030 --> 00:54:09.009 I, I talk in the book about having this

NOTE Confidence: 0.880518995

00:54:09.009 --> 00:54:11.549 neurologist who I she's still my neurologist.

NOTE Confidence: 0.880518995

00:54:11.550 --> 00:54:12.216 She's amazing.

NOTE Confidence: 0.880518995

00:54:12.216 --> 00:54:14.880 She pretty early on because I was having

NOTE Confidence: 0.880518995

00:54:14.944 --> 00:54:17.548 these horrible basically it was neuropathy,

NOTE Confidence: 0.880518995

00:54:17.550 --> 00:54:19.370 strange form of neuropathy.

NOTE Confidence: 0.880518995

00:54:19.370 --> 00:54:21.645 And she just was like,

NOTE Confidence: 0.880518995

00:54:21.650 --> 00:54:23.785 we don't know why this is happening.

NOTE Confidence: 0.880518995

00:54:23.790 --> 00:54:25.610 I'm probably not going to be able

NOTE Confidence: 0.880518995

00:54:25.610 --> 00:54:27.782 to help you, but I believe you.

NOTE Confidence: 0.880518995

00:54:27.782 --> 00:54:30.299 You're not the only patient I've seen

NOTE Confidence: 0.880518995

00:54:30.299 --> 00:54:32.805 with this often they are young women.

NOTE Confidence: 0.880518995

00:54:32.810 --> 00:54:34.682 I believe you're all telling me

NOTE Confidence: 0.880518995

00:54:34.682 --> 00:54:36.450 the truth and we're doing research.

NOTE Confidence: 0.880518995

00:54:36.450 --> 00:54:39.168 If you want to be part of the research,

NOTE Confidence: 0.880518995

00:54:39.170 --> 00:54:40.310 this is what you can do.

NOTE Confidence: 0.880518995

00:54:40.310 --> 00:54:41.006 It's probably, again,

NOTE Confidence: 0.880518995

00:54:41.006 --> 00:54:42.630 not going to help you anytime soon,

NOTE Confidence: 0.880518995

00:54:42.630 --> 00:54:45.192 but it just was such an important

NOTE Confidence: 0.880518995

00:54:45.192 --> 00:54:48.002 encounter because I felt, you know,

NOTE Confidence: 0.880518995

00:54:48.002 --> 00:54:49.940 talking about invisibility.

NOTE Confidence: 0.880518995

00:54:49.940 --> 00:54:52.028 I felt that my suffering might

NOTE Confidence: 0.880518995

00:54:52.028 --> 00:54:54.100 contribute to some greater knowledge,

NOTE Confidence: 0.880518995

00:54:54.100 --> 00:54:56.356 which was deeply important to me.

NOTE Confidence: 0.880518995

00:54:56.360 --> 00:54:56.888 I just.

NOTE Confidence: 0.880518995

00:54:56.888 --> 00:54:59.391 I wanted to be seen because I didn't want

NOTE Confidence: 0.880518995

00:54:59.391 --> 00:55:01.959 my life and my suffering to be meaningless.

NOTE Confidence: 0.880518995

00:55:01.960 --> 00:55:05.768 I wanted intellectual curiosity.

NOTE Confidence: 0.880518995

00:55:05.770 --> 00:55:07.754 I wanted my plate to go to the,

NOTE Confidence: 0.880518995

00:55:07.760 --> 00:55:08.402 you know,

NOTE Confidence: 0.880518995

00:55:08.402 --> 00:55:10.649 to to to the the pie of

NOTE Confidence: 0.880518995

00:55:10.649 --> 00:55:12.517 intellectual grasp that was going

NOTE Confidence: 0.880518995

00:55:12.517 --> 00:55:14.731 to lead to answers for somebody.

NOTE Confidence: 0.880518995

00:55:14.740 --> 00:55:16.756 But I also think, you know,

NOTE Confidence: 0.880518995

00:55:16.760 --> 00:55:18.755 your question raises a really material point,

NOTE Confidence: 0.880518995

00:55:18.760 --> 00:55:19.456 which is,

NOTE Confidence: 0.880518995

00:55:19.456 --> 00:55:21.892 I think that someone who had made

NOTE Confidence: 0.880518995

00:55:21.892 --> 00:55:24.639 more space for what they didn't know.

NOTE Confidence: 0.880518995

00:55:24.640 --> 00:55:26.579 But while articulating their belief in me,

NOTE Confidence: 0.880518995

00:55:26.580 --> 00:55:29.172 I probably would have been more

NOTE Confidence: 0.880518995

00:55:29.172 --> 00:55:31.730 forthcoming with and started to speak

NOTE Confidence: 0.880518995

00:55:31.730 --> 00:55:34.355 a little bit more firmly and honestly

NOTE Confidence: 0.880518995

00:55:34.355 --> 00:55:37.039 about how extensive my symptoms were.

NOTE Confidence: 0.880518995

00:55:37.040 --> 00:55:39.490 Because I think one thing that I

NOTE Confidence: 0.880518995

00:55:39.490 --> 00:55:41.620 heard from every single person,

NOTE Confidence: 0.880518995

00:55:41.620 --> 00:55:43.636 every single person that I interviewed,

NOTE Confidence: 0.880518995

00:55:43.640 --> 00:55:46.456 and then I have done myself and I

NOTE Confidence: 0.880518995

00:55:46.456 --> 00:55:52.178 still do it this that we hide symptoms.

NOTE Confidence: 0.880518995

00:55:52.180 --> 00:55:54.448 And we hide symptoms because we're

NOTE Confidence: 0.880518995

00:55:54.448 --> 00:55:56.716 met with disbelief or skepticism or

NOTE Confidence: 0.880518995

00:55:56.716 --> 00:55:59.468 we see the face of the doctor change.

NOTE Confidence: 0.880518995

00:55:59.470 --> 00:56:00.480 I have seen it happen.

NOTE Confidence: 0.880518995

00:56:00.480 --> 00:56:02.544 I've just seen my doctor's faces

NOTE Confidence: 0.880518995

00:56:02.544 --> 00:56:04.520 change and start to be like,

NOTE Confidence: 0.880518995

00:56:04.520 --> 00:56:06.564 this can't be true.

NOTE Confidence: 0.880518995

00:56:06.564 --> 00:56:09.119 And so I think the,

NOTE Confidence: 0.880518995

00:56:09.120 --> 00:56:10.800 the person who had been like,

NOTE Confidence: 0.880518995

00:56:10.800 --> 00:56:11.595 I'm your partner,

NOTE Confidence: 0.880518995

00:56:11.595 --> 00:56:12.920 come back in two months.

NOTE Confidence: 0.832320018

00:56:12.920 --> 00:56:13.840 Let's see how it's going.

NOTE Confidence: 0.832320018

00:56:13.840 --> 00:56:15.020 Let's work on, you know,

NOTE Confidence: 0.832320018

00:56:15.020 --> 00:56:17.420 maybe we can work on your energy levels.

NOTE Confidence: 0.832320018

00:56:17.420 --> 00:56:20.018 Maybe, you know.

NOTE Confidence: 0.832320018

00:56:20.020 --> 00:56:21.358 Probably would have given me better
NOTE Confidence: 0.832320018

00:56:21.358 --> 00:56:22.939 quality of life and might over time.
NOTE Confidence: 0.832320018

00:56:22.940 --> 00:56:24.116 I might have said I have
NOTE Confidence: 0.832320018

00:56:24.116 --> 00:56:24.900 these drenching night sweats.
NOTE Confidence: 0.832320018

00:56:24.900 --> 00:56:25.740 I might have said, oh,
NOTE Confidence: 0.832320018

00:56:25.740 --> 00:56:28.155 this started after I was in Connecticut.
NOTE Confidence: 0.832320018

00:56:28.160 --> 00:56:29.917 I was in the being diagnosed with
NOTE Confidence: 0.832320018

00:56:29.917 --> 00:56:31.254 tick borne illness and treated
NOTE Confidence: 0.832320018

00:56:31.254 --> 00:56:32.594 for it getting much better.
NOTE Confidence: 0.832320018

00:56:32.600 --> 00:56:34.076 No one ever asks, you know,
NOTE Confidence: 0.832320018

00:56:34.080 --> 00:56:37.265 like they're just things that never came
NOTE Confidence: 0.832320018

00:56:37.265 --> 00:56:40.616 out because of the kind of very quick.
NOTE Confidence: 0.832320018

00:56:40.620 --> 00:56:42.400 Your cholesterol looks great,
NOTE Confidence: 0.832320018

00:56:42.400 --> 00:56:44.562 you run, you're probably anxious to
NOTE Confidence: 0.832320018

00:56:44.562 --> 00:56:47.019 try to try to meditate and do yoga.
NOTE Confidence: 0.832320018

00:56:47.020 --> 00:56:50.460 And it was like every single time what I got.

NOTE Confidence: 0.832320018

00:56:50.460 --> 00:56:51.471 Yeah, I'm, I'm.

NOTE Confidence: 0.832320018

00:56:51.471 --> 00:56:54.520 So on behalf of all of these doctors,

NOTE Confidence: 0.832320018

00:56:54.520 --> 00:56:55.948 they were nice doctors.

NOTE Confidence: 0.832320018

00:56:55.948 --> 00:56:57.376 They were terrible people.

NOTE Confidence: 0.832320018

00:56:57.380 --> 00:57:00.020 I actually feel warmly towards some of them.

NOTE Confidence: 0.832320018

00:57:00.020 --> 00:57:01.920 They just, we just did.

NOTE Confidence: 0.832320018

00:57:01.920 --> 00:57:02.426 Yeah,

NOTE Confidence: 0.832320018

00:57:02.426 --> 00:57:05.968 framework for offering this kind of care.

NOTE Confidence: 0.89260235

00:57:07.160 --> 00:57:11.990 So you've spent 20 years plus?

NOTE Confidence: 0.89260235

00:57:11.990 --> 00:57:13.385 Pretending to be well,

NOTE Confidence: 0.89260235

00:57:13.385 --> 00:57:15.035 to the best of your ability.

NOTE Confidence: 0.9150930675

00:57:18.110 --> 00:57:23.004 You look wonderful now. Here, you know,

NOTE Confidence: 0.9150930675

00:57:23.004 --> 00:57:25.650 on the spectrum of pretty sick to

NOTE Confidence: 0.9150930675

00:57:25.736 --> 00:57:28.139 feeling fabulous, where are you?

NOTE Confidence: 0.9150930675

00:57:28.139 --> 00:57:30.680 Because we can't tell you've perfected this.

NOTE Confidence: 0.819087485

00:57:33.070 --> 00:57:35.410 Well, it's interesting you ask Lisa,
NOTE Confidence: 0.819087485

00:57:35.410 --> 00:57:37.390 because when I last saw you,
NOTE Confidence: 0.819087485

00:57:37.390 --> 00:57:41.070 I think I said I'm doing really well.
NOTE Confidence: 0.819087485

00:57:41.070 --> 00:57:42.729 And I was, I was doing better.
NOTE Confidence: 0.819087485

00:57:42.730 --> 00:57:44.458 I felt better than I had
NOTE Confidence: 0.819087485

00:57:44.458 --> 00:57:46.389 felt as a 22 year old.
NOTE Confidence: 0.819087485

00:57:46.390 --> 00:57:49.054 And then I got COVID twice this summer
NOTE Confidence: 0.819087485

00:57:49.054 --> 00:57:52.570 through strange circumstances. But.
NOTE Confidence: 0.819087485

00:57:52.570 --> 00:57:54.716 And I'm pretty sick again, right?
NOTE Confidence: 0.819087485

00:57:54.716 --> 00:57:58.118 And it's pretty clear that for me,
NOTE Confidence: 0.819087485

00:57:58.120 --> 00:58:00.969 things like a virus, viruses in particular,
NOTE Confidence: 0.819087485

00:58:00.970 --> 00:58:02.770 always trigger not all viruses,
NOTE Confidence: 0.819087485

00:58:02.770 --> 00:58:04.750 but things like mono. Yeah,
NOTE Confidence: 0.819087485

00:58:04.750 --> 00:58:07.225 I have a lot of the long COVID symptoms.
NOTE Confidence: 0.819087485

00:58:07.230 --> 00:58:08.446 I'm doing much better.
NOTE Confidence: 0.819087485

00:58:08.446 --> 00:58:11.189 I was really sick in August and September.

NOTE Confidence: 0.819087485

00:58:11.190 --> 00:58:12.415 Like, just not thought I

NOTE Confidence: 0.819087485

00:58:12.415 --> 00:58:13.395 would take medical leave,

NOTE Confidence: 0.819087485

00:58:13.400 --> 00:58:15.670 which I've actually never done,

NOTE Confidence: 0.819087485

00:58:15.670 --> 00:58:16.930 and slowly kind of climbing

NOTE Confidence: 0.819087485

00:58:16.930 --> 00:58:18.190 back out of the hole.

NOTE Confidence: 0.819087485

00:58:18.190 --> 00:58:22.334 But, you know, I'm probably at like.

NOTE Confidence: 0.819087485

00:58:22.340 --> 00:58:25.349 60% and I probably have been at like 85%.

NOTE Confidence: 0.819087485

00:58:25.349 --> 00:58:30.220 Fifty to 85 being of my of my imagined one.

NOTE Confidence: 0.819087485

00:58:30.220 --> 00:58:33.775 I don't really know what it's like to feel.

NOTE Confidence: 0.819087485

00:58:33.780 --> 00:58:34.972 Like my husband clearly

NOTE Confidence: 0.819087485

00:58:34.972 --> 00:58:36.462 feels like he just doesn't.

NOTE Confidence: 0.835503785714286

00:58:38.720 --> 00:58:40.169 You could just move through the world.

NOTE Confidence: 0.835503785714286

00:58:40.170 --> 00:58:40.994 Something good doesn't have

NOTE Confidence: 0.835503785714286

00:58:40.994 --> 00:58:42.582 to sleep that much, you know?

NOTE Confidence: 0.835503785714286

00:58:42.582 --> 00:58:44.106 Can you share cereal?

NOTE Confidence: 0.835503785714286

00:58:44.110 --> 00:58:46.110 But I would say, like, you know,
NOTE Confidence: 0.835503785714286

00:58:46.110 --> 00:58:47.850 I have to go. I have my life.
NOTE Confidence: 0.835503785714286

00:58:47.850 --> 00:58:50.289 I I'm able to be here functioning with
NOTE Confidence: 0.835503785714286

00:58:50.289 --> 00:58:52.766 you because I'm very vigilant about
NOTE Confidence: 0.835503785714286

00:58:52.766 --> 00:58:56.012 my sleep and my diet and my things.
NOTE Confidence: 0.835503785714286

00:58:56.012 --> 00:58:59.330 I know support my particular body. Yeah.
NOTE Confidence: 0.936726591666667

00:59:00.060 --> 00:59:01.776 Well, thank you for telling me
NOTE Confidence: 0.936726591666667

00:59:01.780 --> 00:59:03.028 something's telling all of us something
NOTE Confidence: 0.936726591666667

00:59:03.028 --> 00:59:04.340 that's clearly none of our business,
NOTE Confidence: 0.936726591666667

00:59:04.340 --> 00:59:06.713 but I just wanted to acknowledge that
NOTE Confidence: 0.936726591666667

00:59:06.713 --> 00:59:09.127 you have been faking it for years.
NOTE Confidence: 0.759862865

00:59:10.540 --> 00:59:11.820 Happened. And, you know,
NOTE Confidence: 0.759862865

00:59:11.820 --> 00:59:13.740 The thing is that's really complicated
NOTE Confidence: 0.759862865

00:59:13.791 --> 00:59:15.666 and this merits another conversation,
NOTE Confidence: 0.759862865

00:59:15.670 --> 00:59:18.629 another time. But. You know, I,
NOTE Confidence: 0.759862865

00:59:18.629 --> 00:59:21.443 I they're aspects of faking it

NOTE Confidence: 0.759862865

00:59:21.443 --> 00:59:24.290 that I wouldn't say faking it.

NOTE Confidence: 0.759862865

00:59:24.290 --> 00:59:26.650 They're aspects of leading into

NOTE Confidence: 0.759862865

00:59:26.650 --> 00:59:29.510 what's possible for you and brings

NOTE Confidence: 0.759862865

00:59:29.510 --> 00:59:32.422 you joy and meaning that even if

NOTE Confidence: 0.759862865

00:59:32.422 --> 00:59:35.258 they deplete you slightly physically,

NOTE Confidence: 0.759862865

00:59:35.260 --> 00:59:36.770 I think are very important

NOTE Confidence: 0.759862865

00:59:36.770 --> 00:59:37.978 right when you can.

NOTE Confidence: 0.759862865

00:59:37.980 --> 00:59:39.348 There are times in my life

NOTE Confidence: 0.759862865

00:59:39.348 --> 00:59:40.580 where I can't do that.

NOTE Confidence: 0.759862865

00:59:40.580 --> 00:59:42.524 And I think one of the challenges with

NOTE Confidence: 0.759862865

00:59:42.524 --> 00:59:44.226 that disease like long COVID that I'm

NOTE Confidence: 0.759862865

00:59:44.226 --> 00:59:46.019 so excited to hear about your center,

NOTE Confidence: 0.759862865

00:59:46.020 --> 00:59:48.449 I think one of the major challenges.

NOTE Confidence: 0.759862865

00:59:48.450 --> 00:59:50.115 With these energy limiting diseases

NOTE Confidence: 0.759862865

00:59:50.115 --> 00:59:52.394 is that our impulses to be like

NOTE Confidence: 0.759862865

00:59:52.394 --> 00:59:54.326 exercise and do the things you love.
NOTE Confidence: 0.759862865

00:59:54.330 --> 00:59:57.102 And actually that often when I was
NOTE Confidence: 0.759862865

00:59:57.102 --> 00:59:58.920 sickest with something like ME,
NOTE Confidence: 0.759862865

00:59:58.920 --> 01:00:01.566 CFS like made me much sicker.
NOTE Confidence: 0.759862865

01:00:01.570 --> 01:00:04.050 And when I first was getting over COVID,
NOTE Confidence: 0.759862865

01:00:04.050 --> 01:00:07.445 I really had to like not stimulate
NOTE Confidence: 0.759862865

01:00:07.445 --> 01:00:09.430 my brain at all.
NOTE Confidence: 0.759862865

01:00:09.430 --> 01:00:11.750 And that is a special kind of health,
NOTE Confidence: 0.759862865

01:00:11.750 --> 01:00:12.276 you know,
NOTE Confidence: 0.759862865

01:00:12.276 --> 01:00:14.746 for the for the patient and I think it's
NOTE Confidence: 0.759862865

01:00:14.746 --> 01:00:17.186 something that we're all going to have to.
NOTE Confidence: 0.759862865

01:00:17.190 --> 01:00:20.966 Learn how to support because it's very hard
NOTE Confidence: 0.759862865

01:00:20.970 --> 01:00:26.410 to really rest in this really deep way.
NOTE Confidence: 0.759862865

01:00:26.410 --> 01:00:26.620 Anyway,
NOTE Confidence: 0.759862865

01:00:26.620 --> 01:00:28.090 that's going to go as far afield,
NOTE Confidence: 0.759862865

01:00:28.090 --> 01:00:28.810 but yeah.

NOTE Confidence: 0.759862865

01:00:28.810 --> 01:00:32.660 Can I jump into a couple of the questions?

NOTE Confidence: 0.759862865

01:00:32.660 --> 01:00:33.087 Absolutely.

NOTE Confidence: 0.759862865

01:00:33.087 --> 01:00:36.503 OK, so here is 1 from Adam Merring

NOTE Confidence: 0.759862865

01:00:36.503 --> 01:00:39.620 patient advocacy groups and social media.

NOTE Confidence: 0.759862865

01:00:39.620 --> 01:00:41.175 Facebook groups in particular were

NOTE Confidence: 0.759862865

01:00:41.175 --> 01:00:43.115 so crucial to learning more about

NOTE Confidence: 0.759862865

01:00:43.115 --> 01:00:45.071 my illness and covering leads and

NOTE Confidence: 0.759862865

01:00:45.071 --> 01:00:46.360 finding competent medical care.

NOTE Confidence: 0.759862865

01:00:46.360 --> 01:00:47.920 Was this part of your journey?

NOTE Confidence: 0.759862865

01:00:47.920 --> 01:00:50.160 Did you explore these groups and their

NOTE Confidence: 0.759862865

01:00:50.160 --> 01:00:51.804 role in deciphering the Invisible

NOTE Confidence: 0.759862865

01:00:51.804 --> 01:00:53.670 Kingdom as you wrote your book?

NOTE Confidence: 0.759862865

01:00:53.670 --> 01:00:55.788 This is about patient advocacy groups.

NOTE Confidence: 0.759862865

01:00:55.790 --> 01:00:59.960 Yeah. Yeah, absolutely.

NOTE Confidence: 0.759862865

01:00:59.960 --> 01:01:00.448 Absolutely.

NOTE Confidence: 0.759862865

01:01:00.448 --> 01:01:01.424 I mean,
NOTE Confidence: 0.759862865

01:01:01.424 --> 01:01:05.312 I think we absolutely have to
NOTE Confidence: 0.759862865

01:01:05.312 --> 01:01:07.680 center the voices of people living
NOTE Confidence: 0.759862865

01:01:07.680 --> 01:01:09.320 with poorly understood illness and
NOTE Confidence: 0.759862865

01:01:09.379 --> 01:01:11.335 probably have all kinds of illnesses.
NOTE Confidence: 0.759862865

01:01:11.340 --> 01:01:13.340 I think there's so much.
NOTE Confidence: 0.759862865

01:01:13.340 --> 01:01:16.404 I learned from other people every day
NOTE Confidence: 0.759862865

01:01:16.404 --> 01:01:18.500 and some of it is about questions about
NOTE Confidence: 0.759862865

01:01:18.554 --> 01:01:20.634 how to live with and manage my illness.
NOTE Confidence: 0.759862865

01:01:20.640 --> 01:01:22.720 And and to leave this question about you,
NOTE Confidence: 0.759862865

01:01:22.720 --> 01:01:24.076 why use chronic illness?
NOTE Confidence: 0.759862865

01:01:24.076 --> 01:01:26.718 It's because part of life for a person
NOTE Confidence: 0.759862865

01:01:26.718 --> 01:01:28.600 with chronic illness is about management.
NOTE Confidence: 0.759862865

01:01:28.600 --> 01:01:30.928 And one of the things that I'm interested
NOTE Confidence: 0.759862865

01:01:30.928 --> 01:01:33.505 in is how the stories we tell affect
NOTE Confidence: 0.759862865

01:01:33.505 --> 01:01:35.599 our ability to manage our disease.

NOTE Confidence: 0.759862865

01:01:35.600 --> 01:01:37.616 And I think that the ways in which

NOTE Confidence: 0.759862865

01:01:37.616 --> 01:01:39.118 patients have been treated as a.

NOTE Confidence: 0.885313836

01:01:41.190 --> 01:01:43.702 Almost kind of like children, right?

NOTE Confidence: 0.885313836

01:01:43.702 --> 01:01:45.746 Like we're we're treated a little bit

NOTE Confidence: 0.885313836

01:01:45.746 --> 01:01:47.682 like we don't really know our own

NOTE Confidence: 0.885313836

01:01:47.682 --> 01:01:49.879 good and we can't be relied on that,

NOTE Confidence: 0.885313836

01:01:49.880 --> 01:01:52.267 you know, the illness is going to

NOTE Confidence: 0.885313836

01:01:52.267 --> 01:01:54.279 make us irrational and emotional.

NOTE Confidence: 0.885313836

01:01:54.280 --> 01:01:56.296 And of course, in any group you're

NOTE Confidence: 0.885313836

01:01:56.296 --> 01:01:58.720 going to find a plurality of responses,

NOTE Confidence: 0.885313836

01:01:58.720 --> 01:02:01.220 but I would say.

NOTE Confidence: 0.885313836

01:02:01.220 --> 01:02:03.556 Some of the people I've met who are

NOTE Confidence: 0.885313836

01:02:03.556 --> 01:02:05.409 patient advocates are the most informed,

NOTE Confidence: 0.885313836

01:02:05.410 --> 01:02:06.457 the most rational,

NOTE Confidence: 0.885313836

01:02:06.457 --> 01:02:08.900 the the least willing to jump to

NOTE Confidence: 0.885313836

01:02:08.977 --> 01:02:12.092 conclusions because who's more invested?

NOTE Confidence: 0.885313836

01:02:12.092 --> 01:02:14.164 So absolutely, those groups have been,

NOTE Confidence: 0.885313836

01:02:14.164 --> 01:02:15.744 I think, also a really crucial

NOTE Confidence: 0.885313836

01:02:15.744 --> 01:02:17.174 sense of community for me.

NOTE Confidence: 0.885313836

01:02:17.180 --> 01:02:17.604 You know,

NOTE Confidence: 0.885313836

01:02:17.604 --> 01:02:19.540 just like you were having a bad day and,

NOTE Confidence: 0.885313836

01:02:19.540 --> 01:02:20.316 you know,

NOTE Confidence: 0.885313836

01:02:20.316 --> 01:02:23.420 I did join some Facebook groups that in

NOTE Confidence: 0.885313836

01:02:23.506 --> 01:02:26.600 the end I laughed because sometimes it.

NOTE Confidence: 0.885313836

01:02:26.600 --> 01:02:28.072 You know, it just felt like there was

NOTE Confidence: 0.885313836

01:02:28.072 --> 01:02:29.778 also a lot of misinformation in there.

NOTE Confidence: 0.885313836

01:02:29.780 --> 01:02:33.940 So I think finding a way for these groups to,

NOTE Confidence: 0.885313836

01:02:33.940 --> 01:02:35.776 you know, finding the right group for you is,

NOTE Confidence: 0.885313836

01:02:35.780 --> 01:02:37.718 is really important.

NOTE Confidence: 0.885313836

01:02:37.720 --> 01:02:39.981 So kind of related is a question

NOTE Confidence: 0.885313836

01:02:39.981 --> 01:02:40.950 from Tyler Nelson.

NOTE Confidence: 0.846032769545454
01:02:44.230 --> 01:02:45.157 To two questions.
NOTE Confidence: 0.846032769545454
01:02:45.157 --> 01:02:46.702 What Nuggets of advice would
NOTE Confidence: 0.846032769545454
01:02:46.702 --> 01:02:48.807 you offer to partners of people
NOTE Confidence: 0.846032769545454
01:02:48.807 --> 01:02:50.239 facing chronic health conditions
NOTE Confidence: 0.846032769545454
01:02:50.239 --> 01:02:52.009 or chronic health challenges?
NOTE Confidence: 0.846032769545454
01:02:52.010 --> 01:02:53.410 And on a similar note,
NOTE Confidence: 0.846032769545454
01:02:53.410 --> 01:02:55.251 did trends of any kind of rise
NOTE Confidence: 0.846032769545454
01:02:55.251 --> 01:02:56.585 in responses from interviewees
NOTE Confidence: 0.846032769545454
01:02:56.585 --> 01:02:58.517 read their close relationships?
NOTE Confidence: 0.45523566
01:03:02.030 --> 01:03:04.045 That's those are two great questions
NOTE Confidence: 0.45523566
01:03:04.045 --> 01:03:05.940 and actually an area of follow
NOTE Confidence: 0.45523566
01:03:05.940 --> 01:03:08.108 up I really wanted to work on and
NOTE Confidence: 0.45523566
01:03:08.108 --> 01:03:10.070 might maybe I will do this right
NOTE Confidence: 0.45523566
01:03:10.070 --> 01:03:12.066 now is talking more to partners.
NOTE Confidence: 0.45523566
01:03:12.066 --> 01:03:14.331 I interviewed my husband for
NOTE Confidence: 0.45523566

01:03:14.331 --> 01:03:16.954 the book and I asked him, OK,
NOTE Confidence: 0.45523566

01:03:16.954 --> 01:03:18.520 so tell me what this is like for you
NOTE Confidence: 0.45523566

01:03:18.569 --> 01:03:20.137 because as I talk about in the book,
NOTE Confidence: 0.45523566

01:03:20.140 --> 01:03:21.612 it put a lot of strain on our
NOTE Confidence: 0.45523566

01:03:21.612 --> 01:03:22.466 relationship and there were
NOTE Confidence: 0.45523566

01:03:22.466 --> 01:03:24.006 times when I needed him to really
NOTE Confidence: 0.45523566

01:03:24.006 --> 01:03:25.134 understand what was going on with
NOTE Confidence: 0.45523566

01:03:25.134 --> 01:03:27.509 me and I didn't feel he did. Umm.
NOTE Confidence: 0.45523566

01:03:27.509 --> 01:03:30.024 So I think that's fundamental
NOTE Confidence: 0.45523566

01:03:30.024 --> 01:03:32.808 piece of advice I have is,
NOTE Confidence: 0.45523566

01:03:32.810 --> 01:03:35.134 is related to the reading I did
NOTE Confidence: 0.45523566

01:03:35.134 --> 01:03:37.359 today which is to remember that
NOTE Confidence: 0.45523566

01:03:37.360 --> 01:03:39.516 though we get good at managing it.
NOTE Confidence: 0.8955879

01:03:42.060 --> 01:03:42.770 Sometimes.
NOTE Confidence: 0.860220687222222

01:03:44.930 --> 01:03:46.880 It's never fully resolved and it's
NOTE Confidence: 0.860220687222222

01:03:46.880 --> 01:03:49.024 not static like my relationship to

NOTE Confidence: 0.860220687222222
01:03:49.024 --> 01:03:51.370 being sick and the sickness itself.
NOTE Confidence: 0.860220687222222
01:03:51.370 --> 01:03:53.070 Neither of those things are
NOTE Confidence: 0.860220687222222
01:03:53.070 --> 01:03:55.190 static age all of the time.
NOTE Confidence: 0.860220687222222
01:03:55.190 --> 01:03:57.728 And sometimes I really need comfort,
NOTE Confidence: 0.860220687222222
01:03:57.730 --> 01:04:00.328 you know, after being totally fine.
NOTE Confidence: 0.860220687222222
01:04:00.330 --> 01:04:01.810 And it might come out of the blue
NOTE Confidence: 0.860220687222222
01:04:01.810 --> 01:04:03.513 and it might be like a small thing
NOTE Confidence: 0.860220687222222
01:04:03.513 --> 01:04:05.069 goes wrong and I'm beside myself.
NOTE Confidence: 0.860220687222222
01:04:05.070 --> 01:04:07.045 So it can look unpredictable
NOTE Confidence: 0.860220687222222
01:04:07.045 --> 01:04:08.230 or good irrational,
NOTE Confidence: 0.860220687222222
01:04:08.230 --> 01:04:09.874 but it's just about like the
NOTE Confidence: 0.860220687222222
01:04:09.874 --> 01:04:11.380 moment in which your threshold
NOTE Confidence: 0.860220687222222
01:04:11.380 --> 01:04:13.105 just can't take it anymore.
NOTE Confidence: 0.860220687222222
01:04:13.110 --> 01:04:14.990 So I think being very.
NOTE Confidence: 0.860220687222222
01:04:14.990 --> 01:04:17.645 Alert to that and open to that and maybe
NOTE Confidence: 0.860220687222222

01:04:17.645 --> 01:04:19.566 inviting conversation around that could
NOTE Confidence: 0.860220687222222

01:04:19.566 --> 01:04:22.280 be really helpful and also knowing that.
NOTE Confidence: 0.860220687222222

01:04:22.280 --> 01:04:24.050 The person has to take the
NOTE Confidence: 0.860220687222222

01:04:24.050 --> 01:04:25.620 lead and and you're here.
NOTE Confidence: 0.860220687222222

01:04:25.620 --> 01:04:28.404 I think mirroring is one of
NOTE Confidence: 0.860220687222222

01:04:28.404 --> 01:04:30.260 the most important things.
NOTE Confidence: 0.860220687222222

01:04:30.260 --> 01:04:32.414 Another thing that one friend of
NOTE Confidence: 0.860220687222222

01:04:32.414 --> 01:04:34.705 mine has long done that's just
NOTE Confidence: 0.860220687222222

01:04:34.705 --> 01:04:36.645 been incredible is she doesn't
NOTE Confidence: 0.860220687222222

01:04:36.645 --> 01:04:39.009 try to solve problems for me.
NOTE Confidence: 0.860220687222222

01:04:39.010 --> 01:04:41.019 I feel like initially my husband was
NOTE Confidence: 0.860220687222222

01:04:41.019 --> 01:04:43.428 trying to solve everything for me, you know,
NOTE Confidence: 0.860220687222222

01:04:43.428 --> 01:04:45.380 he wanted to get the answers he wanted.
NOTE Confidence: 0.860220687222222

01:04:45.380 --> 01:04:46.690 He would be reading studies.
NOTE Confidence: 0.860220687222222

01:04:46.690 --> 01:04:48.346 And, and I did appreciate that
NOTE Confidence: 0.860220687222222

01:04:48.346 --> 01:04:50.388 that did make me feel cared for.

NOTE Confidence: 0.860220687222222
01:04:50.390 --> 01:04:52.121 But at a certain point I had to say, like,
NOTE Confidence: 0.860220687222222
01:04:52.121 --> 01:04:54.129 I don't know if you could solve this,
NOTE Confidence: 0.860220687222222
01:04:54.130 --> 01:04:56.440 and sometimes it makes me
NOTE Confidence: 0.860220687222222
01:04:56.440 --> 01:04:57.826 anxious and stressed,
NOTE Confidence: 0.860220687222222
01:04:57.830 --> 01:05:00.286 but you're trying to solve it so just.
NOTE Confidence: 0.860220687222222
01:05:00.290 --> 01:05:02.070 Being there and saying I
NOTE Confidence: 0.860220687222222
01:05:02.070 --> 01:05:03.494 see that you're suffering.
NOTE Confidence: 0.860220687222222
01:05:03.500 --> 01:05:04.658 I'm so sorry.
NOTE Confidence: 0.860220687222222
01:05:04.658 --> 01:05:07.790 I wish I could do something for you.
NOTE Confidence: 0.860220687222222
01:05:07.790 --> 01:05:08.790 Standing in the hot sun,
NOTE Confidence: 0.860220687222222
01:05:08.790 --> 01:05:10.158 let's go stand on the shady side of
NOTE Confidence: 0.860220687222222
01:05:10.158 --> 01:05:11.507 the street or let me get you a chair.
NOTE Confidence: 0.860220687222222
01:05:11.510 --> 01:05:12.470 Let me get you a glass of water.
NOTE Confidence: 0.860220687222222
01:05:12.470 --> 01:05:14.702 It's funny how these tiny things like let
NOTE Confidence: 0.860220687222222
01:05:14.702 --> 01:05:17.246 me get you water or your favorite drink,
NOTE Confidence: 0.860220687222222

01:05:17.250 --> 01:05:19.410 it just needs so much, you know?
NOTE Confidence: 0.860220687222222

01:05:19.410 --> 01:05:21.010 It really, they really do.
NOTE Confidence: 0.860220687222222

01:05:21.010 --> 01:05:22.520 So I think just remembering
NOTE Confidence: 0.860220687222222

01:05:22.520 --> 01:05:24.030 the power of small things.
NOTE Confidence: 0.860220687222222

01:05:24.030 --> 01:05:25.774 But what I was gonna say quickly I'll
NOTE Confidence: 0.860220687222222

01:05:25.774 --> 01:05:27.447 pay when I interviewed my husband,
NOTE Confidence: 0.860220687222222

01:05:27.450 --> 01:05:28.350 he said.
NOTE Confidence: 0.860220687222222

01:05:28.350 --> 01:05:31.950 Which he had never said to me before.
NOTE Confidence: 0.860220687222222

01:05:31.950 --> 01:05:35.289 I don't think you know how hard it is,
NOTE Confidence: 0.860220687222222

01:05:35.290 --> 01:05:37.901 how frustrating it is to care so
NOTE Confidence: 0.860220687222222

01:05:37.901 --> 01:05:41.008 much for you and to be so powerless.
NOTE Confidence: 0.860220687222222

01:05:41.010 --> 01:05:41.556 You know,
NOTE Confidence: 0.860220687222222

01:05:41.556 --> 01:05:43.970 and ever since he said that directly to me,
NOTE Confidence: 0.860220687222222

01:05:43.970 --> 01:05:45.905 it's really helped me understand
NOTE Confidence: 0.860220687222222

01:05:45.905 --> 01:05:48.233 his own reactions to this and
NOTE Confidence: 0.860220687222222

01:05:48.233 --> 01:05:50.195 especially when I've been sicker or

NOTE Confidence: 0.860220687222222
01:05:50.195 --> 01:05:54.290 had to go to the hospital. Yeah.
NOTE Confidence: 0.860220687222222
01:05:54.290 --> 01:05:57.200 The second part of that question.
NOTE Confidence: 0.860220687222222
01:05:57.200 --> 01:06:01.169 Or did try any kind of rise?
NOTE Confidence: 0.860220687222222
01:06:01.170 --> 01:06:01.660 You know,
NOTE Confidence: 0.860220687222222
01:06:01.660 --> 01:06:04.068 I do think a lot of people felt like
NOTE Confidence: 0.860220687222222
01:06:04.068 --> 01:06:06.008 partners wanted to solve problems.
NOTE Confidence: 0.860220687222222
01:06:06.010 --> 01:06:10.184 Yeah, yeah. Sometimes that wasn't.
NOTE Confidence: 0.860220687222222
01:06:10.184 --> 01:06:11.936 Always what they needed,
NOTE Confidence: 0.860220687222222
01:06:11.940 --> 01:06:14.789 but there was a lot of variety
NOTE Confidence: 0.860220687222222
01:06:14.789 --> 01:06:16.810 actually in the answers.
NOTE Confidence: 0.860220687222222
01:06:16.810 --> 01:06:17.432 Thank you.
NOTE Confidence: 0.860220687222222
01:06:17.432 --> 01:06:20.690 This I do want to come to this question.
NOTE Confidence: 0.860220687222222
01:06:20.690 --> 01:06:23.108 There's a question about long COVID
NOTE Confidence: 0.860220687222222
01:06:23.110 --> 01:06:25.000 and Lisa invite you to answer this
NOTE Confidence: 0.860220687222222
01:06:25.000 --> 01:06:27.396 as well and James Wright asks to what
NOTE Confidence: 0.860220687222222

01:06:27.396 --> 01:06:29.630 degree do you believe that long COVID?
NOTE Confidence: 0.860220687222222

01:06:29.630 --> 01:06:31.274 Is going to be an inflection
NOTE Confidence: 0.860220687222222

01:06:31.274 --> 01:06:32.370 point and bringing about
NOTE Confidence: 0.829102432380952

01:06:32.431 --> 01:06:34.036 systematic and structural change from
NOTE Confidence: 0.829102432380952

01:06:34.036 --> 01:06:36.270 a medical and a societal standpoint.
NOTE Confidence: 0.829102432380952

01:06:36.270 --> 01:06:38.844 Do you think that the woeful ME CFS
NOTE Confidence: 0.829102432380952

01:06:38.844 --> 01:06:40.729 funding chronic fatigue will improve
NOTE Confidence: 0.829102432380952

01:06:40.729 --> 01:06:43.187 as a result of long COVID will?
NOTE Confidence: 0.829102432380952

01:06:43.187 --> 01:06:45.329 And I guess more most importantly,
NOTE Confidence: 0.829102432380952

01:06:45.330 --> 01:06:47.454 do we feel that overall compassion
NOTE Confidence: 0.829102432380952

01:06:47.454 --> 01:06:49.330 for those suffering from complex
NOTE Confidence: 0.829102432380952

01:06:49.330 --> 01:06:51.694 chronic conditions will begin to grow?
NOTE Confidence: 0.714487772

01:06:54.570 --> 01:06:58.198 I I do think, sorry, I'm going over this.
NOTE Confidence: 0.70483374

01:07:00.550 --> 01:07:04.246 I ohh I have so many feelings and
NOTE Confidence: 0.70483374

01:07:04.246 --> 01:07:07.942 thoughts being yeah, woeful, woeful.
NOTE Confidence: 0.70483374

01:07:07.942 --> 01:07:12.620 MCFS funding yes. I am.

NOTE Confidence: 0.70483374

01:07:12.620 --> 01:07:16.708 I I cycle between being cautiously

NOTE Confidence: 0.70483374

01:07:16.708 --> 01:07:19.140 optimistic and, you know,

NOTE Confidence: 0.70483374

01:07:19.140 --> 01:07:22.728 frustrated that not more has happened.

NOTE Confidence: 0.70483374

01:07:22.730 --> 01:07:24.826 That said, I am in the middle of

NOTE Confidence: 0.70483374

01:07:24.826 --> 01:07:26.609 reporting a long piece about long

NOTE Confidence: 0.70483374

01:07:26.609 --> 01:07:28.803 COVID for the New York Times magazine

NOTE Confidence: 0.70483374

01:07:28.803 --> 01:07:30.849 that is focused on the science.

NOTE Confidence: 0.70483374

01:07:30.850 --> 01:07:33.145 And I can say that the science is incredible.

NOTE Confidence: 0.70483374

01:07:33.150 --> 01:07:35.544 What is happening, the research being done,

NOTE Confidence: 0.70483374

01:07:35.550 --> 01:07:37.530 the speed at which is happening,

NOTE Confidence: 0.70483374

01:07:37.530 --> 01:07:41.760 the way in which. You know.

NOTE Confidence: 0.70483374

01:07:41.760 --> 01:07:44.478 The influx of money from tech,

NOTE Confidence: 0.70483374

01:07:44.480 --> 01:07:47.282 it's extraordinary and like real insights

NOTE Confidence: 0.70483374

01:07:47.282 --> 01:07:50.672 are accumulating in a way at a speed that

NOTE Confidence: 0.70483374

01:07:50.672 --> 01:07:53.378 I did not think was going to happen.

NOTE Confidence: 0.70483374

01:07:53.380 --> 01:07:55.630 So whether those are translatable,
NOTE Confidence: 0.70483374

01:07:55.630 --> 01:07:57.952 whether that research gets translated into
NOTE Confidence: 0.70483374

01:07:57.952 --> 01:08:00.209 therapeutics and the health for people
NOTE Confidence: 0.70483374

01:08:00.209 --> 01:08:02.159 with long COVID is another question,
NOTE Confidence: 0.70483374

01:08:02.160 --> 01:08:04.056 and that's where my concerns enter.
NOTE Confidence: 0.70483374

01:08:04.060 --> 01:08:06.268 How do we translate the science is there.
NOTE Confidence: 0.70483374

01:08:06.270 --> 01:08:08.854 I think we're going to have some answers.
NOTE Confidence: 0.70483374

01:08:08.860 --> 01:08:10.379 Fuller Story is going to take time,
NOTE Confidence: 0.70483374

01:08:10.380 --> 01:08:12.250 but we are going to have things we can offer.
NOTE Confidence: 0.70483374

01:08:12.250 --> 01:08:13.710 People, the question is,
NOTE Confidence: 0.70483374

01:08:13.710 --> 01:08:16.325 do we act with alacrity and speed
NOTE Confidence: 0.70483374

01:08:16.325 --> 01:08:18.782 and agility to offer them and to
NOTE Confidence: 0.70483374

01:08:18.782 --> 01:08:21.044 realize how needed they are to
NOTE Confidence: 0.70483374

01:08:21.044 --> 01:08:23.276 keep people's hope alive and their
NOTE Confidence: 0.70483374

01:08:23.280 --> 01:08:25.520 possibility of their lives going.
NOTE Confidence: 0.70483374

01:08:25.520 --> 01:08:27.180 So I do think we,

NOTE Confidence: 0.70483374

01:08:27.180 --> 01:08:28.590 we really do.

NOTE Confidence: 0.70483374

01:08:28.590 --> 01:08:31.880 We are at an inflection point where

NOTE Confidence: 0.70483374

01:08:31.977 --> 01:08:35.368 we have to talk about urgency and we

NOTE Confidence: 0.70483374

01:08:35.368 --> 01:08:37.800 have to think about harm in a really

NOTE Confidence: 0.70483374

01:08:37.876 --> 01:08:40.744 complicated way that doesn't get mired

NOTE Confidence: 0.70483374

01:08:40.744 --> 01:08:42.952 in bureaucracy, which is to say.

NOTE Confidence: 0.70483374

01:08:42.952 --> 01:08:45.280 And I just watched all of this.

NOTE Confidence: 0.70483374

01:08:45.280 --> 01:08:46.780 I've been reading deeply into the

NOTE Confidence: 0.70483374

01:08:46.780 --> 01:08:48.527 history of HIV AIDS activism and

NOTE Confidence: 0.70483374

01:08:48.527 --> 01:08:50.277 thinking differently about that moment.

NOTE Confidence: 0.70483374

01:08:50.280 --> 01:08:51.918 Because there's that moment where AZT

NOTE Confidence: 0.70483374

01:08:51.918 --> 01:08:53.918 gets rushed out and then it turns out,

NOTE Confidence: 0.70483374

01:08:53.920 --> 01:08:56.020 you know, maybe it's not that beneficial,

NOTE Confidence: 0.70483374

01:08:56.020 --> 01:08:57.320 but it helps some people.

NOTE Confidence: 0.70483374

01:08:57.320 --> 01:08:58.274 It's really harmful.

NOTE Confidence: 0.70483374

01:08:58.274 --> 01:09:00.901 And I think we have to accept that
NOTE Confidence: 0.70483374

01:09:00.901 --> 01:09:02.917 sometimes when we are in crisis,
NOTE Confidence: 0.70483374

01:09:02.920 --> 01:09:05.860 we try things, but, you know,
NOTE Confidence: 0.70483374

01:09:05.860 --> 01:09:07.252 sooner than we might.
NOTE Confidence: 0.70483374

01:09:07.252 --> 01:09:09.140 But why do we carve out that exception?
NOTE Confidence: 0.70483374

01:09:09.140 --> 01:09:10.519 When do we carve out that exception?
NOTE Confidence: 0.70483374

01:09:10.520 --> 01:09:12.740 For what? Drugs, for what interventions.
NOTE Confidence: 0.70483374

01:09:12.740 --> 01:09:14.150 These are conversations we should.
NOTE Confidence: 0.70483374

01:09:14.150 --> 01:09:15.158 Really be actively happening.
NOTE Confidence: 0.70483374

01:09:15.158 --> 01:09:17.114 I think places like Yale is a great
NOTE Confidence: 0.70483374

01:09:17.114 --> 01:09:18.981 place to have them, which are what,
NOTE Confidence: 0.70483374

01:09:18.981 --> 01:09:21.480 what is the harm of not acting
NOTE Confidence: 0.70483374

01:09:21.561 --> 01:09:23.576 versus the harm of acting?
NOTE Confidence: 0.70483374

01:09:23.580 --> 01:09:26.220 What kinds of exceptions are necessary?
NOTE Confidence: 0.70483374

01:09:26.220 --> 01:09:28.026 One way I think about everything
NOTE Confidence: 0.70483374

01:09:28.026 --> 01:09:30.574 is like if things are low risk but

NOTE Confidence: 0.70483374

01:09:30.574 --> 01:09:32.179 the evidence is still accruing,

NOTE Confidence: 0.70483374

01:09:32.180 --> 01:09:34.130 like that's an easier kind of

NOTE Confidence: 0.70483374

01:09:34.130 --> 01:09:36.079 intervention to make than high risk,

NOTE Confidence: 0.70483374

01:09:36.080 --> 01:09:36.620 low evidence,

NOTE Confidence: 0.70483374

01:09:36.620 --> 01:09:36.890 right.

NOTE Confidence: 0.70483374

01:09:36.890 --> 01:09:39.513 But so I I think we're at that inflection

NOTE Confidence: 0.70483374

01:09:39.513 --> 01:09:41.858 point where we need to start having

NOTE Confidence: 0.70483374

01:09:41.858 --> 01:09:44.310 those conversations and I and I do think.

NOTE Confidence: 0.70483374

01:09:44.310 --> 01:09:45.486 The question there is

NOTE Confidence: 0.70483374

01:09:45.486 --> 01:09:46.956 going to be trickle down.

NOTE Confidence: 0.70483374

01:09:46.960 --> 01:09:50.016 It might be limited to some specific centers,

NOTE Confidence: 0.70483374

01:09:50.020 --> 01:09:52.380 but I think some of what we're learning

NOTE Confidence: 0.70483374

01:09:52.380 --> 01:09:54.954 some of the what I'm seeing researchers

NOTE Confidence: 0.70483374

01:09:54.954 --> 01:09:57.380 do right now has implications for ME,

NOTE Confidence: 0.70483374

01:09:57.380 --> 01:09:58.816 CFS, EDS,

NOTE Confidence: 0.70483374

01:09:58.816 --> 01:10:00.970 possibly Lyme disease.
NOTE Confidence: 0.774307225

01:10:03.880 --> 01:10:05.996 I think that actually we are
NOTE Confidence: 0.774307225

01:10:05.996 --> 01:10:08.840 going to see some improvement in
NOTE Confidence: 0.85241206

01:10:08.840 --> 01:10:12.680 in dealing with these these illnesses
NOTE Confidence: 0.85241206

01:10:12.680 --> 01:10:16.936 MCFS because they're part of long COVID,
NOTE Confidence: 0.85241206

01:10:16.940 --> 01:10:18.991 you know so many of these things
NOTE Confidence: 0.85241206

01:10:18.991 --> 01:10:21.368 are going to get attention because.
NOTE Confidence: 0.85241206

01:10:21.370 --> 01:10:24.028 Unfortunately, for better or for worse,
NOTE Confidence: 0.85241206

01:10:24.030 --> 01:10:26.014 there are now lots and lots and lots
NOTE Confidence: 0.85241206

01:10:26.014 --> 01:10:27.868 of people who have these problems,
NOTE Confidence: 0.85241206

01:10:27.870 --> 01:10:29.508 and I think that's going to force.
NOTE Confidence: 0.85241206

01:10:29.510 --> 01:10:32.604 And some of those people are men.
NOTE Confidence: 0.85241206

01:10:32.610 --> 01:10:35.190 And that's going to force.
NOTE Confidence: 0.85241206

01:10:35.190 --> 01:10:39.166 Medicine to take this much more seriously.
NOTE Confidence: 0.85241206

01:10:39.170 --> 01:10:41.255 So I I I'm optimistic
NOTE Confidence: 0.85241206

01:10:41.255 --> 01:10:42.923 because that's my nature.

NOTE Confidence: 0.85241206

01:10:42.930 --> 01:10:45.228 But I also think that having,

NOTE Confidence: 0.85241206

01:10:45.230 --> 01:10:47.660 you know, thousands and thousands

NOTE Confidence: 0.85241206

01:10:47.660 --> 01:10:50.090 of people who have these.

NOTE Confidence: 0.85241206

01:10:50.090 --> 01:10:55.130 Diseases as part of this other long COVID.

NOTE Confidence: 0.85241206

01:10:55.130 --> 01:10:56.222 It's going to be,

NOTE Confidence: 0.85241206

01:10:56.222 --> 01:10:58.610 I think it's going to take us further.

NOTE Confidence: 0.501302596

01:10:59.630 --> 01:11:02.010 Yeah, that's absolutely the other.

NOTE Confidence: 0.501302596

01:11:02.010 --> 01:11:04.251 Just to add to that too like some of

NOTE Confidence: 0.501302596

01:11:04.251 --> 01:11:06.401 the people I've been interviewing with

NOTE Confidence: 0.501302596

01:11:06.401 --> 01:11:08.626 long COVID from my first Atlantic

NOTE Confidence: 0.501302596

01:11:08.626 --> 01:11:11.098 piece back in like March of 2021,

NOTE Confidence: 0.501302596

01:11:11.098 --> 01:11:14.386 our doctors who have long COVID.

NOTE Confidence: 0.501302596

01:11:14.390 --> 01:11:16.870 And you know one of my sources is

NOTE Confidence: 0.501302596

01:11:16.870 --> 01:11:19.428 she's still at work but a couple of

NOTE Confidence: 0.501302596

01:11:19.428 --> 01:11:21.591 her friends have gone on disability

NOTE Confidence: 0.501302596

01:11:21.591 --> 01:11:24.129 doctors who can't work anymore and.
NOTE Confidence: 0.501302596

01:11:24.130 --> 01:11:27.154 You know, she feels like that's she,
NOTE Confidence: 0.501302596

01:11:27.160 --> 01:11:29.264 she's like the structure is still not there,
NOTE Confidence: 0.501302596

01:11:29.270 --> 01:11:31.316 the structure still pushing against some
NOTE Confidence: 0.501302596

01:11:31.316 --> 01:11:34.128 of this, but she's like there's a lot of
NOTE Confidence: 0.501302596

01:11:34.128 --> 01:11:36.549 us who have long COVID and are working.
NOTE Confidence: 0.501302596

01:11:36.549 --> 01:11:38.600 And that is, I think she said to me,
NOTE Confidence: 0.501302596

01:11:38.600 --> 01:11:40.600 it's totally changed how I think about Pops.
NOTE Confidence: 0.501302596

01:11:40.600 --> 01:11:42.454 I used to be a little bit tough on
NOTE Confidence: 0.501302596

01:11:42.454 --> 01:11:44.824 my patients and now I'm like, oh,
NOTE Confidence: 0.501302596

01:11:44.824 --> 01:11:47.608 I see what you're going through.
NOTE Confidence: 0.89980876

01:11:50.070 --> 01:11:55.564 Yeah. I'm going to take this question
NOTE Confidence: 0.89980876

01:11:55.564 --> 01:11:58.270 that was submitted anonymously that.
NOTE Confidence: 0.89980876

01:11:58.270 --> 01:12:00.275 Talks about how medical science
NOTE Confidence: 0.89980876

01:12:00.275 --> 01:12:02.708 relies on objectivity and how that
NOTE Confidence: 0.89980876

01:12:02.708 --> 01:12:05.240 limits Medicine's ability to see more

NOTE Confidence: 0.89980876

01:12:05.240 --> 01:12:07.410 subjective or not measurable symptoms.

NOTE Confidence: 0.89980876

01:12:07.410 --> 01:12:09.265 Can you speak on how that poses

NOTE Confidence: 0.89980876

01:12:09.265 --> 01:12:10.991 a barrier to HealthEquity and

NOTE Confidence: 0.89980876

01:12:10.991 --> 01:12:13.146 what systemic changes are needed?

NOTE Confidence: 0.89980876

01:12:13.150 --> 01:12:14.974 Yeah, I mean that's those are

NOTE Confidence: 0.89980876

01:12:14.974 --> 01:12:16.748 two questions that I'm not going

NOTE Confidence: 0.89980876

01:12:16.748 --> 01:12:18.477 to be able to do justice to.

NOTE Confidence: 0.853580786875

01:12:21.810 --> 01:12:25.114 You know, I think a barrier to HealthEquity

NOTE Confidence: 0.853580786875

01:12:25.114 --> 01:12:29.089 we see definitely in the gendered aspect of.

NOTE Confidence: 0.853580786875

01:12:29.090 --> 01:12:30.470 These illnesses, as we've said,

NOTE Confidence: 0.853580786875

01:12:30.470 --> 01:12:32.730 they're poorly funded, poorly researched,

NOTE Confidence: 0.853580786875

01:12:32.730 --> 01:12:36.384 and we have a lot of women who have,

NOTE Confidence: 0.853580786875

01:12:36.390 --> 01:12:38.490 you know, even something like

NOTE Confidence: 0.853580786875

01:12:38.490 --> 01:12:40.170 autoimmune diseases where there's

NOTE Confidence: 0.853580786875

01:12:40.170 --> 01:12:42.540 still a lot of research to do and so.

NOTE Confidence: 0.853580786875

01:12:42.540 --> 01:12:44.820 There's this kind of perfect storm
NOTE Confidence: 0.853580786875

01:12:44.820 --> 01:12:47.478 of things meeting that I do think
NOTE Confidence: 0.853580786875

01:12:47.478 --> 01:12:49.602 often women are getting worse care
NOTE Confidence: 0.853580786875

01:12:49.602 --> 01:12:51.760 because we know less and we've
NOTE Confidence: 0.853580786875

01:12:51.760 --> 01:12:55.070 invested less and we distrust women.
NOTE Confidence: 0.853580786875

01:12:55.070 --> 01:12:56.546 We certainly know, too,
NOTE Confidence: 0.853580786875

01:12:56.546 --> 01:12:59.850 that we do a bad job of delivering
NOTE Confidence: 0.853580786875

01:12:59.850 --> 01:13:02.868 equitable care to people of color.
NOTE Confidence: 0.853580786875

01:13:02.870 --> 01:13:04.949 And some of my research suggested that
NOTE Confidence: 0.853580786875

01:13:04.949 --> 01:13:06.968 women of color in particular were,
NOTE Confidence: 0.853580786875

01:13:06.970 --> 01:13:10.218 you know, and we see this in studies of,
NOTE Confidence: 0.853580786875

01:13:10.218 --> 01:13:11.970 like, cardiovascular interventions.
NOTE Confidence: 0.853580786875

01:13:11.970 --> 01:13:14.812 But that my subjective research so far
NOTE Confidence: 0.853580786875

01:13:14.812 --> 01:13:17.956 suggests that women of color were getting
NOTE Confidence: 0.853580786875

01:13:17.956 --> 01:13:20.266 diagnosed much later with autoimmune
NOTE Confidence: 0.853580786875

01:13:20.266 --> 01:13:22.672 disease than white women were, you know.

NOTE Confidence: 0.853580786875

01:13:22.672 --> 01:13:24.210 So if the problem is there for white women,

NOTE Confidence: 0.853580786875

01:13:24.210 --> 01:13:25.386 it's even worse.

NOTE Confidence: 0.853580786875

01:13:25.386 --> 01:13:26.954 For women of color,

NOTE Confidence: 0.853580786875

01:13:26.960 --> 01:13:30.336 I'm really hoping some people are doing some

NOTE Confidence: 0.853580786875

01:13:30.336 --> 01:13:33.928 granular database research into this because.

NOTE Confidence: 0.853580786875

01:13:33.930 --> 01:13:35.760 I'm concerned there's a lot of

NOTE Confidence: 0.853580786875

01:13:35.760 --> 01:13:37.610 people just not getting diagnosed.

NOTE Confidence: 0.853580786875

01:13:37.610 --> 01:13:38.138 You know,

NOTE Confidence: 0.853580786875

01:13:38.138 --> 01:13:40.617 they go and they say this and that and

NOTE Confidence: 0.853580786875

01:13:40.617 --> 01:13:42.717 they just get dismissed and then there's

NOTE Confidence: 0.853580786875

01:13:42.717 --> 01:13:45.130 not a lot of follow up necessarily.

NOTE Confidence: 0.853580786875

01:13:45.130 --> 01:13:48.590 So I think we need.

NOTE Confidence: 0.853580786875

01:13:48.590 --> 01:13:53.560 We need that only to be more.

NOTE Confidence: 0.853580786875

01:13:53.560 --> 01:13:55.798 We need to have different frameworks,

NOTE Confidence: 0.853580786875

01:13:55.800 --> 01:13:56.107 right?

NOTE Confidence: 0.853580786875

01:13:56.107 --> 01:13:58.256 And we need to have a framework
NOTE Confidence: 0.853580786875

01:13:58.256 --> 01:13:59.660 of understanding that Women's
NOTE Confidence: 0.853580786875

01:13:59.660 --> 01:14:01.700 Health is very complicated,
NOTE Confidence: 0.853580786875

01:14:01.700 --> 01:14:04.718 that problems in Women's Health can
NOTE Confidence: 0.853580786875

01:14:04.718 --> 01:14:08.330 start young even when you look healthy.
NOTE Confidence: 0.853580786875

01:14:08.330 --> 01:14:08.738 You know,
NOTE Confidence: 0.853580786875

01:14:08.738 --> 01:14:10.166 there's a lot we need to understand,
NOTE Confidence: 0.853580786875

01:14:10.170 --> 01:14:11.748 I think about the interaction of
NOTE Confidence: 0.853580786875

01:14:11.748 --> 01:14:13.572 hormones and the immune system and all
NOTE Confidence: 0.853580786875

01:14:13.572 --> 01:14:15.557 of these things and I'm hoping again that
NOTE Confidence: 0.853580786875

01:14:15.557 --> 01:14:17.363 long proven research brings some of it.
NOTE Confidence: 0.853580786875

01:14:17.370 --> 01:14:19.320 But yeah, we.
NOTE Confidence: 0.853580786875

01:14:19.320 --> 01:14:20.484 Your question is an important one
NOTE Confidence: 0.853580786875

01:14:20.484 --> 01:14:21.899 that I can't do justice to you,
NOTE Confidence: 0.853580786875

01:14:21.900 --> 01:14:24.969 except to say I think these are issues we
NOTE Confidence: 0.853580786875

01:14:24.969 --> 01:14:28.055 need to think deeply about and needed to.

NOTE Confidence: 0.853580786875
01:14:28.060 --> 01:14:28.930 If you're up for it,
NOTE Confidence: 0.853580786875
01:14:28.930 --> 01:14:31.034 I'm going to give you 2 more questions
NOTE Confidence: 0.853580786875
01:14:31.034 --> 01:14:33.244 and then we'll call it a night.
NOTE Confidence: 0.853580786875
01:14:33.244 --> 01:14:35.948 OK, so one question that's.
NOTE Confidence: 0.853580786875
01:14:35.950 --> 01:14:38.169 Kind of different from the the ones
NOTE Confidence: 0.853580786875
01:14:38.169 --> 01:14:40.707 that have been tossing your way so far.
NOTE Confidence: 0.853580786875
01:14:40.710 --> 01:14:42.310 It's just about medical records.
NOTE Confidence: 0.853580786875
01:14:42.310 --> 01:14:44.622 And how did you keep your records straight
NOTE Confidence: 0.853580786875
01:14:44.622 --> 01:14:47.125 when you were going from Doctor to Doctor?
NOTE Confidence: 0.853580786875
01:14:47.130 --> 01:14:47.435 Yeah.
NOTE Confidence: 0.853580786875
01:14:47.435 --> 01:14:49.570 If they're not in the same system.
NOTE Confidence: 0.853580786875
01:14:49.570 --> 01:14:50.810 Like,
NOTE Confidence: 0.853580786875
01:14:50.810 --> 01:14:52.050 yeah.
NOTE Confidence: 0.853580786875
01:14:52.050 --> 01:14:52.380 Well,
NOTE Confidence: 0.853580786875
01:14:52.380 --> 01:14:54.360 they were often paper because it
NOTE Confidence: 0.853580786875

01:14:54.360 --> 01:14:55.954 was before electronic medical when
NOTE Confidence: 0.853580786875

01:14:55.954 --> 01:14:58.114 I was really going to doctor and the
NOTE Confidence: 0.853580786875

01:14:58.171 --> 01:15:00.228 doctor from doctor to doctor, sorry,
NOTE Confidence: 0.853580786875

01:15:00.228 --> 01:15:03.110 I was offered getting printouts would
NOTE Confidence: 0.853580786875

01:15:03.110 --> 01:15:07.450 have been like between 2005 and you know,
NOTE Confidence: 0.853580786875

01:15:07.450 --> 01:15:08.440 2000 and.
NOTE Confidence: 0.853580786875

01:15:08.440 --> 01:15:11.890 14 or something.
NOTE Confidence: 0.853580786875

01:15:11.890 --> 01:15:14.060 So I had printouts of everything that
NOTE Confidence: 0.853580786875

01:15:14.060 --> 01:15:16.229 I had organized and all these files,
NOTE Confidence: 0.853580786875

01:15:16.230 --> 01:15:17.520 and I would, you know,
NOTE Confidence: 0.853580786875

01:15:17.520 --> 01:15:19.608 and I xeroxed all of them.
NOTE Confidence: 0.853580786875

01:15:19.610 --> 01:15:21.850 If I were bringing them to a doctor,
NOTE Confidence: 0.853580786875

01:15:21.850 --> 01:15:22.670 I didn't lose them.
NOTE Confidence: 0.853580786875

01:15:22.670 --> 01:15:23.490 Although once I did,
NOTE Confidence: 0.853580786875

01:15:23.490 --> 01:15:23.821 like,
NOTE Confidence: 0.853580786875

01:15:23.821 --> 01:15:26.469 I had to see a infectious disease doctor.

NOTE Confidence: 0.855938696521739

01:15:26.470 --> 01:15:28.190 And I just was addled and I left

NOTE Confidence: 0.855938696521739

01:15:28.190 --> 01:15:30.196 a whole bunch of records and now I

NOTE Confidence: 0.855938696521739

01:15:30.196 --> 01:15:32.069 just don't even know where they are.

NOTE Confidence: 0.855938696521739

01:15:32.070 --> 01:15:34.730 So yeah, I would print.

NOTE Confidence: 0.855938696521739

01:15:34.730 --> 01:15:36.158 I would have, you know, the offices would

NOTE Confidence: 0.855938696521739

01:15:36.158 --> 01:15:39.638 print things out for me, or I would.

NOTE Confidence: 0.855938696521739

01:15:39.640 --> 01:15:41.902 I guess if they were in, yeah, I've only.

NOTE Confidence: 0.855938696521739

01:15:41.902 --> 01:15:45.316 These days I haven't had to like move

NOTE Confidence: 0.855938696521739

01:15:45.316 --> 01:15:47.972 medical records from one, you know,

NOTE Confidence: 0.855938696521739

01:15:47.972 --> 01:15:49.316 electronic system to another.

NOTE Confidence: 0.855938696521739

01:15:49.320 --> 01:15:51.093 So I guess you could print those out too,

NOTE Confidence: 0.855938696521739

01:15:51.100 --> 01:15:53.718 right? But I will say this has

NOTE Confidence: 0.855938696521739

01:15:53.718 --> 01:15:55.840 changed because of legislature.

NOTE Confidence: 0.855938696521739

01:15:55.840 --> 01:15:57.541 I mean I had doctors who would

NOTE Confidence: 0.855938696521739

01:15:57.541 --> 01:15:59.438 not give me my medical records,

NOTE Confidence: 0.855938696521739

01:15:59.440 --> 01:16:00.668 one of them said.
NOTE Confidence: 0.851665834285714

01:16:02.780 --> 01:16:04.733 Well, I don't think you're going to
NOTE Confidence: 0.851665834285714

01:16:04.733 --> 01:16:06.667 understand very much about what's in them.
NOTE Confidence: 0.851665834285714

01:16:06.670 --> 01:16:08.978 That I would say.
NOTE Confidence: 0.851665834285714

01:16:08.980 --> 01:16:11.080 Went to Yale University and
NOTE Confidence: 0.851665834285714

01:16:11.080 --> 01:16:13.414 graduated Magna a little snippy.
NOTE Confidence: 0.851665834285714

01:16:13.414 --> 01:16:14.983 That's like, I'm pretty good,
NOTE Confidence: 0.851665834285714

01:16:14.983 --> 01:16:16.370 I'm a journalist, I'm pretty good.
NOTE Confidence: 0.851665834285714

01:16:16.370 --> 01:16:17.450 I'm in. Another was like,
NOTE Confidence: 0.851665834285714

01:16:17.450 --> 01:16:19.050 this is just going to make you anxious,
NOTE Confidence: 0.851665834285714

01:16:19.050 --> 01:16:22.018 so I'm not getting them to you.
NOTE Confidence: 0.851665834285714

01:16:22.020 --> 01:16:24.183 So about the diagnosis was I had
NOTE Confidence: 0.851665834285714

01:16:24.183 --> 01:16:26.500 anxiety and then you know or you know,
NOTE Confidence: 0.851665834285714

01:16:26.500 --> 01:16:28.556 then it was like if you read this,
NOTE Confidence: 0.851665834285714

01:16:28.560 --> 01:16:31.150 this was actually someone who thought there
NOTE Confidence: 0.851665834285714

01:16:31.150 --> 01:16:33.239 was something physically going on with me.

NOTE Confidence: 0.851665834285714
01:16:33.240 --> 01:16:34.938 So I think that's, you know,
NOTE Confidence: 0.851665834285714
01:16:34.940 --> 01:16:36.677 at least something that now we all have a
NOTE Confidence: 0.851665834285714
01:16:36.677 --> 01:16:38.592 right to our medical records, thank goodness.
NOTE Confidence: 0.851665834285714
01:16:38.592 --> 01:16:40.422 But organizing they'll be keeping
NOTE Confidence: 0.851665834285714
01:16:40.422 --> 01:16:42.140 track is really important.
NOTE Confidence: 0.851665834285714
01:16:42.140 --> 01:16:43.320 So I don't have great,
NOTE Confidence: 0.851665834285714
01:16:43.320 --> 01:16:45.574 I don't have great solutions to that
NOTE Confidence: 0.851665834285714
01:16:45.574 --> 01:16:49.251 medical electronic problem, sorry. OK.
NOTE Confidence: 0.851665834285714
01:16:49.251 --> 01:16:51.419 And so we'll just do one more question.
NOTE Confidence: 0.851665834285714
01:16:51.420 --> 01:16:53.180 Umm, thank you everybody who
NOTE Confidence: 0.851665834285714
01:16:53.180 --> 01:16:55.620 stuck with us and thank you Lisa.
NOTE Confidence: 0.851665834285714
01:16:55.620 --> 01:16:56.336 And Megan.
NOTE Confidence: 0.851665834285714
01:16:56.336 --> 01:16:58.842 This is a question from Zoe Adams,
NOTE Confidence: 0.851665834285714
01:16:58.850 --> 01:17:00.830 who is a graduate from this
NOTE Confidence: 0.851665834285714
01:17:00.830 --> 01:17:02.899 school and a resident right now,
NOTE Confidence: 0.851665834285714

01:17:02.900 --> 01:17:05.042 actually an intern and she says
NOTE Confidence: 0.851665834285714

01:17:05.042 --> 01:17:07.499 she's a doctor early in her career.
NOTE Confidence: 0.851665834285714

01:17:07.500 --> 01:17:09.156 She really relates to what you've
NOTE Confidence: 0.851665834285714

01:17:09.156 --> 01:17:10.260 said about patients shutting
NOTE Confidence: 0.851665834285714

01:17:10.312 --> 01:17:11.737 down and masking their symptoms.
NOTE Confidence: 0.851665834285714

01:17:11.740 --> 01:17:13.654 Do you have any suggestions about
NOTE Confidence: 0.851665834285714

01:17:13.654 --> 01:17:15.725 how to best communicate early on in
NOTE Confidence: 0.851665834285714

01:17:15.725 --> 01:17:17.150 the patient doctor relationship that
NOTE Confidence: 0.851665834285714

01:17:17.150 --> 01:17:18.938 you're open to hearing them out and?
NOTE Confidence: 0.851665834285714

01:17:18.940 --> 01:17:21.154 Building trust in the system that
NOTE Confidence: 0.851665834285714

01:17:21.154 --> 01:17:22.630 has traditionally wronged them.
NOTE Confidence: 0.851665834285714

01:17:22.630 --> 01:17:24.838 So it's such a great question.
NOTE Confidence: 0.851665834285714

01:17:24.840 --> 01:17:25.396 I mean,
NOTE Confidence: 0.851665834285714

01:17:25.396 --> 01:17:27.342 I think being really direct the way
NOTE Confidence: 0.851665834285714

01:17:27.342 --> 01:17:29.277 you just were would be amazing.
NOTE Confidence: 0.851665834285714

01:17:29.280 --> 01:17:31.800 I would say my neurologist and

NOTE Confidence: 0.851665834285714
01:17:31.800 --> 01:17:32.640 my rheumatologist,
NOTE Confidence: 0.851665834285714
01:17:32.640 --> 01:17:34.908 my neurologist was to see me
NOTE Confidence: 0.851665834285714
01:17:34.908 --> 01:17:36.801 since I was like 2425.
NOTE Confidence: 0.851665834285714
01:17:36.801 --> 01:17:39.087 They both are just very open.
NOTE Confidence: 0.851665834285714
01:17:39.090 --> 01:17:42.065 They just speak it really clear that.
NOTE Confidence: 0.851665834285714
01:17:42.070 --> 01:17:45.076 They understand.
NOTE Confidence: 0.851665834285714
01:17:45.076 --> 01:17:46.579 That.
NOTE Confidence: 0.851665834285714
01:17:46.580 --> 01:17:47.350 You know,
NOTE Confidence: 0.851665834285714
01:17:47.350 --> 01:17:49.275 there are still things medicine
NOTE Confidence: 0.851665834285714
01:17:49.275 --> 01:17:51.478 is learning about the human body.
NOTE Confidence: 0.851665834285714
01:17:51.480 --> 01:17:53.656 And that their job is to care for
NOTE Confidence: 0.851665834285714
01:17:53.656 --> 01:17:55.832 me and help me figure out how
NOTE Confidence: 0.851665834285714
01:17:55.832 --> 01:17:57.684 to manage my symptoms and that
NOTE Confidence: 0.851665834285714
01:17:57.684 --> 01:17:59.520 they're open to helping me manage.
NOTE Confidence: 0.851665834285714
01:17:59.520 --> 01:18:02.520 And so my rheumatologist will always be like,
NOTE Confidence: 0.851665834285714

01:18:02.520 --> 01:18:04.872 is anything else going on that you
NOTE Confidence: 0.851665834285714

01:18:04.872 --> 01:18:07.117 forgot to tell me about or that,
NOTE Confidence: 0.851665834285714

01:18:07.120 --> 01:18:10.680 you know, doesn't seem like a top priority,
NOTE Confidence: 0.851665834285714

01:18:10.680 --> 01:18:12.440 but just you want to let me know
NOTE Confidence: 0.851665834285714

01:18:12.440 --> 01:18:14.353 so we can keep an eye on it or
NOTE Confidence: 0.851665834285714

01:18:14.353 --> 01:18:15.718 I can help you with it.
NOTE Confidence: 0.851665834285714

01:18:15.720 --> 01:18:17.890 But I think also just being really
NOTE Confidence: 0.851665834285714

01:18:17.890 --> 01:18:19.256 direct that looks sometimes
NOTE Confidence: 0.851665834285714

01:18:19.256 --> 01:18:21.458 patients feel they can't tell us.
NOTE Confidence: 0.851665834285714

01:18:21.460 --> 01:18:23.049 Everything. And I really want you to.
NOTE Confidence: 0.851665834285714

01:18:23.050 --> 01:18:25.948 I'm here to help you. And then just.
NOTE Confidence: 0.851665834285714

01:18:25.950 --> 01:18:27.350 I think that open,
NOTE Confidence: 0.851665834285714

01:18:27.350 --> 01:18:29.450 empathetic warm goes a long way.
NOTE Confidence: 0.851665834285714

01:18:29.450 --> 01:18:30.192 I mean,
NOTE Confidence: 0.851665834285714

01:18:30.192 --> 01:18:32.047 sometimes my rheumatologist and I
NOTE Confidence: 0.851665834285714

01:18:32.047 --> 01:18:35.090 have a lot of weird autoimmune stuff.

NOTE Confidence: 0.851665834285714
01:18:35.090 --> 01:18:36.946 And we're not medicating a lot of it,
NOTE Confidence: 0.851665834285714
01:18:36.950 --> 01:18:39.710 but she'll just be like, how's it going and.
NOTE Confidence: 0.851665834285714
01:18:39.710 --> 01:18:41.806 She'll say, look, here's the plan.
NOTE Confidence: 0.851665834285714
01:18:41.806 --> 01:18:44.490 As soon as it starts bothering you enough,
NOTE Confidence: 0.851665834285714
01:18:44.490 --> 01:18:46.534 you call me, we'll write the prescription.
NOTE Confidence: 0.851665834285714
01:18:46.540 --> 01:18:47.268 This is the plan.
NOTE Confidence: 0.851665834285714
01:18:47.268 --> 01:18:48.360 But we don't have to do
NOTE Confidence: 0.8840556075
01:18:48.409 --> 01:18:50.960 it now, you know. So she's just.
NOTE Confidence: 0.8840556075
01:18:50.960 --> 01:18:53.862 Conditions like, I'm so sorry, just I
NOTE Confidence: 0.8840556075
01:18:53.862 --> 01:18:56.529 think creating that war builds that trust.
NOTE Confidence: 0.8840556075
01:18:56.530 --> 01:18:58.658 And a sense that there's a different plan,
NOTE Confidence: 0.8840556075
01:18:58.660 --> 01:19:00.706 that it doesn't involve medication from
NOTE Confidence: 0.8840556075
01:19:00.706 --> 01:19:03.190 day one, but it doesn't involve having
NOTE Confidence: 0.8840556075
01:19:03.190 --> 01:19:05.491 to have three more doctors appointments
NOTE Confidence: 0.8840556075
01:19:05.491 --> 01:19:08.480 before you get relief might also elicit.
NOTE Confidence: 0.8840556075

01:19:08.480 --> 01:19:10.286 It's really nice when you said that,
NOTE Confidence: 0.8840556075

01:19:10.290 --> 01:19:12.146 looking straight at the eye of the camera,
NOTE Confidence: 0.8840556075

01:19:12.150 --> 01:19:14.850 like I felt like it was me as the patient.
NOTE Confidence: 0.8840556075

01:19:14.850 --> 01:19:16.523 You were the doctor and I felt
NOTE Confidence: 0.8840556075

01:19:16.523 --> 01:19:18.169 taken care of and cared about.
NOTE Confidence: 0.8840556075

01:19:18.170 --> 01:19:21.538 So that's really nice.
NOTE Confidence: 0.8840556075

01:19:21.540 --> 01:19:23.444 I like how much just someone saying,
NOTE Confidence: 0.8840556075

01:19:23.450 --> 01:19:26.136 like, I'm so sorry and yeah, like,
NOTE Confidence: 0.8840556075

01:19:26.136 --> 01:19:28.904 you know, I feel like I could really
NOTE Confidence: 0.8840556075

01:19:28.904 --> 01:19:31.734 go to her and tell her things, OK.
NOTE Confidence: 0.8840556075

01:19:31.734 --> 01:19:34.326 I don't feel she's going to judge me,
NOTE Confidence: 0.8840556075

01:19:34.330 --> 01:19:34.980 you know?
NOTE Confidence: 0.76458591

01:19:37.680 --> 01:19:40.520 Yeah. Yeah. Thank you. Lisa,
NOTE Confidence: 0.76458591

01:19:40.520 --> 01:19:42.482 do you want to say anything
NOTE Confidence: 0.76458591

01:19:42.482 --> 01:19:44.330 as we bring this to an end?
NOTE Confidence: 0.64239544

01:19:47.860 --> 01:19:51.180 Umm. Gosh, you know, Megan,

NOTE Confidence: 0.64239544

01:19:51.180 --> 01:19:54.984 you have thought so deeply and

NOTE Confidence: 0.64239544

01:19:54.984 --> 01:19:57.520 wonderfully about these complicated

NOTE Confidence: 0.64239544

01:19:57.520 --> 01:19:59.500 issues that I'm just about to,

NOTE Confidence: 0.64239544

01:19:59.500 --> 01:20:05.590 you know, jump into. Mountain I.

NOTE Confidence: 0.64239544

01:20:05.590 --> 01:20:08.705 I'm I'm really grateful for your book,

NOTE Confidence: 0.64239544

01:20:08.710 --> 01:20:11.664 and I'm really grateful that you're around.

NOTE Confidence: 0.64239544

01:20:11.670 --> 01:20:14.197 And I'm really going to totally pick

NOTE Confidence: 0.64239544

01:20:14.197 --> 01:20:16.663 your brain about the science of long

NOTE Confidence: 0.64239544

01:20:16.663 --> 01:20:19.640 COVID so we usually can just be prepared.

NOTE Confidence: 0.7554800633333333

01:20:21.190 --> 01:20:23.150 Over here, for that I it's I was

NOTE Confidence: 0.7554800633333333

01:20:23.150 --> 01:20:25.412 saying to my husband, I was like.

NOTE Confidence: 0.7554800633333333

01:20:25.412 --> 01:20:27.890 The strange thing is I might have

NOTE Confidence: 0.7554800633333333

01:20:27.971 --> 01:20:30.136 talked like to more researchers

NOTE Confidence: 0.7554800633333333

01:20:30.136 --> 01:20:33.010 than anyone else in the country.

NOTE Confidence: 0.7554800633333333

01:20:33.010 --> 01:20:34.090 I've gotta feel like, hey,

NOTE Confidence: 0.7554800633333333

01:20:34.090 --> 01:20:37.050 this is what they're saying.

NOTE Confidence: 0.755480063333333

01:20:37.050 --> 01:20:39.130 But yeah, I'm at Lisa.

NOTE Confidence: 0.755480063333333

01:20:39.130 --> 01:20:41.762 Thank you for being just the world's

NOTE Confidence: 0.755480063333333

01:20:41.762 --> 01:20:42.890 most incredible interlocutor.

NOTE Confidence: 0.755480063333333

01:20:42.890 --> 01:20:44.626 You have now done this twice for me,

NOTE Confidence: 0.755480063333333

01:20:44.630 --> 01:20:45.635 so thank you.

NOTE Confidence: 0.755480063333333

01:20:45.635 --> 01:20:47.310 It's always ramifying for me

NOTE Confidence: 0.755480063333333

01:20:47.310 --> 01:20:49.400 to have these conversations,

NOTE Confidence: 0.755480063333333

01:20:49.400 --> 01:20:50.355 but it's just an honor

NOTE Confidence: 0.755480063333333

01:20:50.355 --> 01:20:51.310 and pleasure to be here.

NOTE Confidence: 0.755480063333333

01:20:51.310 --> 01:20:54.414 I this is what matters most to me.

NOTE Confidence: 0.755480063333333

01:20:54.420 --> 01:20:56.460 To be thinking with other

NOTE Confidence: 0.755480063333333

01:20:56.460 --> 01:20:58.092 minds about these problems.

NOTE Confidence: 0.755480063333333

01:20:58.100 --> 01:21:01.033 So I'm really grateful for everyone for

NOTE Confidence: 0.755480063333333

01:21:01.033 --> 01:21:04.699 coming out and and for having me the program.

NOTE Confidence: 0.755480063333333

01:21:04.700 --> 01:21:05.985 And he's in medicine with

NOTE Confidence: 0.755480063333333

01:21:05.985 --> 01:21:06.756 some wonderful program.

NOTE Confidence: 0.755480063333333

01:21:06.760 --> 01:21:09.434 Thank you for letting me come speak.

NOTE Confidence: 0.755480063333333

01:21:09.440 --> 01:21:11.060 Thank you both so, so much.

NOTE Confidence: 0.755480063333333

01:21:11.060 --> 01:21:13.492 Thank you ASL interpreters

NOTE Confidence: 0.755480063333333

01:21:13.492 --> 01:21:15.924 and Karen and Duncan.

NOTE Confidence: 0.755480063333333

01:21:15.930 --> 01:21:17.190 We'll see you next time.

NOTE Confidence: 0.755480063333333

01:21:17.190 --> 01:21:18.714 Take care,

NOTE Confidence: 0.755480063333333

01:21:18.714 --> 01:21:19.476 everybody.

NOTE Confidence: 0.755480063333333

01:21:19.476 --> 01:21:21.000 Thanks everyone.