

1

00:00:04,200 --> 00:00:05,900
Yeah, it's not like you record great.

2

00:00:07,900 --> 00:00:10,600
Okay, so hi everybody and

3

00:00:10,600 --> 00:00:13,300
my name is Caroline Williams and

4

00:00:13,300 --> 00:00:16,800
I'm artistic associate activist. I'm

5

00:00:16,800 --> 00:00:20,200
also a freelance director who navigates an

6

00:00:19,200 --> 00:00:22,600
invisible disability and I'm

7

00:00:22,600 --> 00:00:25,200
here with Steph. Do you want to just say a little

8

00:00:25,200 --> 00:00:28,600
bit but who you are? Hello. Hi, I'm Steph kempson. I'm

9

00:00:28,600 --> 00:00:31,800
a disabled director dramaturg and

10

00:00:31,800 --> 00:00:35,100
writer who I work a lot in Bristol

11

00:00:34,100 --> 00:00:37,300
and I've got my disability is

12

00:00:37,300 --> 00:00:38,400
also an invisible one.

13

00:00:39,600 --> 00:00:42,400
That's not so and yes, Steph

14

00:00:42,400 --> 00:00:45,100
and I are going to spend the next 20 or so

15

00:00:45,100 --> 00:00:47,700

minutes. Just having a chat about what?

16

00:00:51,300 --> 00:00:54,700

With this kind of disability specifically

17

00:00:54,700 --> 00:00:58,000

invisible disability and to

18

00:00:57,300 --> 00:01:00,100

start with myself. I deal a lot with

19

00:01:00,100 --> 00:01:05,100

fatigue and pain. So that's part of my experience and Steph.

20

00:01:03,100 --> 00:01:06,100

What what's your

21

00:01:06,100 --> 00:01:09,700

load? I have mecfs I've

22

00:01:09,700 --> 00:01:12,900

had for a while and then more recently. I've got

23

00:01:12,900 --> 00:01:15,000

a long covid in the form

24

00:01:15,100 --> 00:01:19,800

of pots, which is quite a different condition to mecfs and

25

00:01:19,800 --> 00:01:23,300

same but different so lots of

26

00:01:22,300 --> 00:01:25,200

fatigue-based stuff

27

00:01:25,200 --> 00:01:28,300

and kind of like your body just layering up about lots of

28

00:01:28,300 --> 00:01:31,500

different things. So we usually call it an energy impairment

29

00:01:31,500 --> 00:01:34,800

and I'm not often that pain-based but I am

30

00:01:34,800 --> 00:01:35,200
today,

31

00:01:36,600 --> 00:01:40,400
All right wearing very

32

00:01:40,400 --> 00:01:41,800
similar clothes by mistake.

33

00:01:42,300 --> 00:01:43,600
So you will enjoy that.

34

00:01:45,600 --> 00:01:48,400
Really? Yeah, I'm just gonna launch right in if

35

00:01:48,400 --> 00:01:51,100
that's all right. And with my first question and I think

36

00:01:51,100 --> 00:01:52,000
it's a question that

37

00:01:53,500 --> 00:01:56,300
is sort of the first Port of Call

38

00:01:56,300 --> 00:01:59,100
really when you're navigating a chronic illness and you want to go back
to

39

00:01:59,100 --> 00:02:02,600
work or you know, our work

40

00:02:02,600 --> 00:02:05,900
is that that moment of I suppose

41

00:02:05,900 --> 00:02:08,200
disclosure where you want to

42

00:02:08,200 --> 00:02:11,400
approach new projects or

43

00:02:11,400 --> 00:02:14,100
people or an organization who might not know about

44

00:02:14,100 --> 00:02:17,100
your condition and I wondered if you could just talk

45
00:02:17,100 --> 00:02:20,300
to us about how you have approached that and

46
00:02:20,300 --> 00:02:23,900
whether you've been on a bit of a journey with that or not and just

47
00:02:23,900 --> 00:02:24,600
share a bit about

48
00:02:25,500 --> 00:02:28,500
For those of us with chronic illness they are there things that you've
discovered

49
00:02:28,500 --> 00:02:30,000
that have been helpful with doing that.

50
00:02:30,800 --> 00:02:32,100
yeah, I mean I've had

51
00:02:33,300 --> 00:02:36,200
Kind of three big thumps of chronic illness

52
00:02:36,200 --> 00:02:39,900
and recoveries. So kind of like three times reentering

53
00:02:39,900 --> 00:02:43,300
the workforce during that time. So the

54
00:02:42,300 --> 00:02:45,600
first time I didn't know I had I didn't

55
00:02:45,600 --> 00:02:48,700
understand it and I found it very hard to be open because I

56
00:02:48,700 --> 00:02:51,500
was putting a lot of pressure on myself to just continue to

57
00:02:51,500 --> 00:02:54,300
perform but doing a lot

58
00:02:54,300 --> 00:02:57,300

of my work from home, but that was when I did a lot more kind

59

00:02:57,300 --> 00:03:01,000

of computer work then necessarily creative rehearsal

60

00:03:00,200 --> 00:03:04,300

room work and but I do remember being open

61

00:03:03,300 --> 00:03:06,400

with people that I really knew and trusted

62

00:03:06,400 --> 00:03:10,600

that I had something going on and but finding

63

00:03:09,600 --> 00:03:12,300

really hard to know how

64

00:03:12,300 --> 00:03:15,300

to communicate about it because I didn't understand I hadn't been

65

00:03:15,300 --> 00:03:18,600

diagnosed by a doctor and I wasn't getting any support basically

66

00:03:18,600 --> 00:03:21,600

so that was quite a challenge and I think that fed

67

00:03:21,600 --> 00:03:24,700

in quite a lot more into how I've and work

68

00:03:24,700 --> 00:03:27,300

since then I think my second recovery, I was

69

00:03:27,300 --> 00:03:30,300

lucky that was working with lots of people that I knew and had known me

70

00:03:30,300 --> 00:03:32,800

for a while so they kind of had an understanding of

71

00:03:33,300 --> 00:03:36,200

What was going on? So it felt like I could be quite open

72

00:03:36,200 --> 00:03:39,200

with them, but I didn't necessarily have to

73

00:03:39,200 --> 00:03:42,300

be so open with people that I didn't understand and I

74

00:03:42,300 --> 00:03:45,600

think now I've moved into my like seventh year

75

00:03:45,600 --> 00:03:48,300

of being ill and my third

76

00:03:48,300 --> 00:03:48,800

recovery.

77

00:03:49,600 --> 00:03:52,900

I have very much

78

00:03:52,900 --> 00:03:55,300

like just started putting in my signature. I try

79

00:03:55,300 --> 00:03:59,000

and bring it into the conversation as early as possible and I

80

00:03:58,300 --> 00:04:01,100

just try and make sure that it's there

81

00:04:01,100 --> 00:04:05,000

and it's upfront so I can talk to people about it and and

82

00:04:04,900 --> 00:04:07,700

make it clear because mine.

83

00:04:08,600 --> 00:04:12,200

Does affect a little bit my kind of like executive function kind

84

00:04:11,200 --> 00:04:14,200

of throughout the day so it's just

85

00:04:14,200 --> 00:04:17,500

it is quite obvious if you spend a whole day with me how much my

86

00:04:17,500 --> 00:04:20,500

energy changes and my behavior

87

00:04:20,500 --> 00:04:24,500

has to change a bit with that energy. So and yeah,

88

00:04:23,500 --> 00:04:26,700

I think because I've experienced my

89

00:04:26,700 --> 00:04:29,300

chronic illness that various different levels over that

90

00:04:29,300 --> 00:04:32,700

seven years, and I've had to have always be

91

00:04:32,700 --> 00:04:33,200

very

92

00:04:34,600 --> 00:04:37,600

Clear that it fluctuates and they will

93

00:04:37,600 --> 00:04:40,500

change all the time. And so I

94

00:04:40,500 --> 00:04:43,500

just have to keep that conversation going because once I

95

00:04:43,500 --> 00:04:45,800

get overwhelmed or tired with my condition.

96

00:04:47,300 --> 00:04:47,800

it becomes

97

00:04:48,600 --> 00:04:51,700

really hard to have easy conversations about

98

00:04:51,700 --> 00:04:51,900

it.

99

00:04:53,100 --> 00:04:54,700

and does it because I feel like

100

00:04:59,200 --> 00:05:01,500

oh, sorry, your microphone dropped out a little bit there.

101

00:05:05,300 --> 00:05:07,500

Like there's a bit of a culture shift in general around.

102

00:05:08,400 --> 00:05:11,800

Access Riders and like I

103

00:05:11,800 --> 00:05:14,800

feel like maybe even even it's

104

00:05:14,800 --> 00:05:17,600

like five years ago. It was it was quite unusual to

105

00:05:17,600 --> 00:05:21,400

be handed a group of access Riders

106

00:05:20,400 --> 00:05:23,600

depending on who you're working with and now

107

00:05:23,600 --> 00:05:26,300

I think actually just before covid it

108

00:05:26,300 --> 00:05:29,900

felt like much more best practice that you would end

109

00:05:29,900 --> 00:05:32,500

up, you know, before you even began to

110

00:05:32,500 --> 00:05:36,500

work with somebody before they ended the room. I guess.

111

00:05:36,500 --> 00:05:39,600

I'm talking to the context of a director who gathered

112

00:05:39,600 --> 00:05:42,400

a team so wanted to understand who those people were but equally

113

00:05:42,400 --> 00:05:45,900

with an organization, you know going through people's

114

00:05:45,900 --> 00:05:48,300

access Riders whether those were any kind

115

00:05:48,300 --> 00:05:52,200

of health conditions or well-being or care and it

116

00:05:51,200 --> 00:05:54,900

does feel like there's there's a shift

117

00:05:54,900 --> 00:05:57,200

around whether that's appropriate and I suppose

118

00:05:57,200 --> 00:05:57,600

I would

119

00:05:58,200 --> 00:06:01,200

I think you'd agree that like there is permission to

120

00:06:01,200 --> 00:06:01,500

do that.

121

00:06:02,300 --> 00:06:05,500

And that people need be brave and in

122

00:06:05,500 --> 00:06:08,000

there and you know

123

00:06:08,600 --> 00:06:11,300

hold that position with pride that it is professional and appropriate

124

00:06:11,300 --> 00:06:14,400

to access writer and to yeah.

125

00:06:15,700 --> 00:06:18,300

And I definitely I feel quite

126

00:06:18,300 --> 00:06:21,400

lucky in that a lot of my access Rider feels like

127

00:06:21,400 --> 00:06:24,300

relatively achievable. Like I always

128

00:06:24,300 --> 00:06:27,200

ask for like a good chair one with

129

00:06:27,200 --> 00:06:31,100

a high back that I can put my head against and with with arms. So

130

00:06:30,100 --> 00:06:33,500

one of I mean, I do have this like mortifying

131

00:06:33,500 --> 00:06:36,700

moment where I go into rehearsal room and I'm like the throne

132

00:06:36,700 --> 00:06:40,400

chair is mine and they can

133

00:06:40,400 --> 00:06:43,400

end up like spiking a lot of conversations. And so I

134

00:06:43,400 --> 00:06:46,300

feel I feel lucky that I have some My Access

135

00:06:46,300 --> 00:06:47,900

needs are like quite easy like

136

00:06:48,500 --> 00:06:51,400

and and like needing a taxi sometimes

137

00:06:51,400 --> 00:06:54,400

to rehearsal or like just needing flexibility on

138

00:06:55,200 --> 00:06:59,000

times of arrival because sometimes I just cannot force

139

00:06:58,300 --> 00:07:01,700

myself to rush in the morning to get somewhere and

140

00:07:01,700 --> 00:07:02,700

so

141

00:07:04,100 --> 00:07:07,100

I definitely think it's a lot easier when you're getting in on

142

00:07:07,100 --> 00:07:10,100

a project early. So if you're getting in

143

00:07:10,100 --> 00:07:13,400

when the Arts Council bid is getting written is so much easier

144

00:07:13,400 --> 00:07:16,100

to manage that in the process. Whereas if

145

00:07:16,100 --> 00:07:19,600

you're someone that's being brought on much later. It becomes really

146

00:07:19,600 --> 00:07:22,300

hard to negotiate that stuff and that can

147

00:07:22,300 --> 00:07:26,000

be really like depending on what role you're in a

148

00:07:25,300 --> 00:07:28,900

creative team on that can be really difficult because sometimes

149

00:07:28,900 --> 00:07:31,800

you might be an actor who really gets called in

150

00:07:31,800 --> 00:07:34,700

auditions after the money is found and

151

00:07:34,700 --> 00:07:38,400

there's not that access and obviously generally

152

00:07:37,400 --> 00:07:41,600

that all goes in at the beginning with the

153

00:07:41,600 --> 00:07:44,300

bid and I part of me does one day if there

154

00:07:44,300 --> 00:07:47,200

needs to be a kind of system of like, can you go back

155

00:07:47,200 --> 00:07:48,900

and be like, actually we need more

156

00:07:49,800 --> 00:07:52,200

We need a bit more access money because we want to

157

00:07:52,200 --> 00:07:55,300

work with this person, but we can't we can't manage

158

00:07:55,300 --> 00:07:58,500

that within the bid that we've got. And so it

159

00:07:58,500 --> 00:08:01,400

definitely as a director. You're quite lucky that a

160

00:08:01,400 --> 00:08:04,200

lot of the time you do. Come on. Yes, really?

161

00:08:04,900 --> 00:08:07,500

And like a contingency pot, you

162

00:08:07,500 --> 00:08:09,000

know essentially around disability.

163

00:08:09,900 --> 00:08:13,200

Would be like really wonderful depending

164

00:08:12,200 --> 00:08:16,100

you know, what the context was in order.

165

00:08:15,100 --> 00:08:18,400

There were no barriers to working with people who

166

00:08:18,400 --> 00:08:22,100

needed certain things. Yeah, and definitely like

167

00:08:21,100 --> 00:08:24,200

I've also been a director

168

00:08:24,200 --> 00:08:27,300

that's coming and like taking over a project where someone shifted and then I've

169

00:08:27,300 --> 00:08:30,000

inherited the process without any access and then it's

170

00:08:30,800 --> 00:08:33,900

Like that's when I'm talking about working with like large organizations

171

00:08:33,900 --> 00:08:36,700

and some organizations are really good at

172

00:08:36,700 --> 00:08:39,500

shifting and they've got that contingency budget within their

173

00:08:39,500 --> 00:08:42,800

building which they can do stuff with and others

174

00:08:42,800 --> 00:08:45,400
are less able to

175
00:08:45,400 --> 00:08:46,200
do that. So

176
00:08:47,300 --> 00:08:50,500
the nature of the work we do is sometimes quite

177
00:08:50,500 --> 00:08:53,500
far like last minute coming into. Yeah. I

178
00:08:53,500 --> 00:08:56,600
can be really hard with your access writer because you just feel quite unreasonable

179
00:08:56,600 --> 00:08:59,800
because you're like, I know you're you're really stretched

180
00:08:59,800 --> 00:09:02,100
and everything is really hard. I also need you

181
00:09:02,100 --> 00:09:05,200
to do this. It can feel that you will strip your access right

182
00:09:05,200 --> 00:09:08,800
back to just what you need to get by which isn't necessarily

183
00:09:08,800 --> 00:09:12,600
like a kind of thriving situation. So it's

184
00:09:11,600 --> 00:09:14,600
about kind of finding the confidence to

185
00:09:14,600 --> 00:09:17,300
push that but which I know is really hard under a

186
00:09:17,300 --> 00:09:20,300
Tory government. Essentially. Yes and really hard when

187
00:09:20,300 --> 00:09:22,500
you're just starting out as well. And yeah,

188
00:09:22,800 --> 00:09:25,200

The feeling of you know, you're trying to earn

189

00:09:25,200 --> 00:09:28,600
your stripes whilst also having to essentially be

190

00:09:28,600 --> 00:09:31,300
really firm about what you need. And the really hard

191

00:09:31,300 --> 00:09:35,200
thing is you don't often see that from the front like those

192

00:09:34,200 --> 00:09:37,800
conversations happen behind closed doors

193

00:09:37,800 --> 00:09:40,400
and you don't you don't hear that

194

00:09:40,400 --> 00:09:43,000
they're saying essentially that is ridiculous and we don't

195

00:09:43,200 --> 00:09:46,400
want to provide that for you. But what you do here, is it going

196

00:09:46,400 --> 00:09:49,300
on about other people? So you do hear people saying comments.

197

00:09:50,100 --> 00:09:53,900
Saying oh, we don't want to work with that person. It's just

198

00:09:53,900 --> 00:09:56,100
too much hassle because of this or because of that

199

00:09:56,100 --> 00:10:00,600
and that that's really hard to hear as someone

200

00:10:00,600 --> 00:10:03,200
who has an invincible condition. Basically is that

201

00:10:03,200 --> 00:10:06,500
sometimes you're just hearing things people, you know being dismissed.

202

00:10:07,300 --> 00:10:10,300
And because they don't quite they're not

203

00:10:10,300 --> 00:10:13,600

fitting the access needs and that's I've never really had anyone turn

204

00:10:13,600 --> 00:10:16,300

me down face to face and those conversations go really

205

00:10:16,300 --> 00:10:17,400

well, but I have felt.

206

00:10:18,100 --> 00:10:21,500

I have felt very annoyed on other people's behalf and had to kind

207

00:10:21,500 --> 00:10:21,700

of like

208

00:10:22,500 --> 00:10:25,500

depending on how articular I'm feeling in that moment and how

209

00:10:25,500 --> 00:10:28,300

much energy I have and how comfortable I feel

210

00:10:28,300 --> 00:10:31,200

with the person just kind of call them out on that if

211

00:10:31,200 --> 00:10:34,000

I can but not be too hard on myself if I feel

212

00:10:34,200 --> 00:10:35,200

like I can't in that moment.

213

00:10:36,400 --> 00:10:39,200

yeah, I mean I've heard stories of you know, and

214

00:10:40,200 --> 00:10:43,200

Essentially access Riders then being an impediment to the

215

00:10:43,200 --> 00:10:46,500

job in the job suddenly disappears for various reasons, that's even

216

00:10:46,500 --> 00:10:49,900

bit shady. And I think that this

217

00:10:49,900 --> 00:10:52,200

was actually going to be my final question, but I feel like it's already

218

00:10:52,200 --> 00:10:55,400
in the room. So I'll ask it and which is

219

00:10:55,400 --> 00:10:58,400
you know, in in a situation like that like what level

220

00:10:58,400 --> 00:11:01,600
of advocacy do you feel that there is if somebody feels

221

00:11:01,600 --> 00:11:04,200
like you know that they've had essentially a

222

00:11:04,200 --> 00:11:07,800
kind of inappropriate dismissal or like is there a

223

00:11:07,800 --> 00:11:10,400
sort of fall back and like checks and balances so that

224

00:11:10,400 --> 00:11:13,600
people can find that help outside of essentially, you

225

00:11:13,600 --> 00:11:16,200
know complaining internally which then is dealt by the

226

00:11:16,200 --> 00:11:17,700
people the complaints about normally

227

00:11:18,600 --> 00:11:21,300
Is really to be honest. I found it really hard.

228

00:11:21,300 --> 00:11:22,200
I've not like

229

00:11:23,300 --> 00:11:26,100
I've not experienced a lot of that in any way that

230

00:11:26,100 --> 00:11:29,400
I've really noticed but maybe once or

231

00:11:29,400 --> 00:11:32,400
twice it has felt like it's coming to play a bit

232

00:11:32,400 --> 00:11:33,300

and

233

00:11:36,100 --> 00:11:39,500

it's just really hard to work out like you can't

234

00:11:39,500 --> 00:11:42,500

know and it feels like if you take offense at

235

00:11:42,500 --> 00:11:43,800

some of these it feels like you're

236

00:11:45,300 --> 00:11:48,500

It's can sometimes feel like you're you're making

237

00:11:48,500 --> 00:11:51,300

a fuss out of nothing and that feels really

238

00:11:51,300 --> 00:11:54,600

really hard. This is my experience. I hopefully

239

00:11:54,600 --> 00:11:58,400

other people would don't feel like that. But it I

240

00:11:57,400 --> 00:11:59,600

so I've really struggled to

241

00:12:01,100 --> 00:12:04,700

And to work that out really and I have

242

00:12:04,700 --> 00:12:05,500

lodged.

243

00:12:06,300 --> 00:12:10,300

I definitely started to get Bolder with making complaints and

244

00:12:11,200 --> 00:12:14,700

I was in a workshop last year where I felt like the

245

00:12:15,800 --> 00:12:18,700

the person running the workshop was really amazing

246

00:12:18,700 --> 00:12:21,100

at covering some aspects of kind of

247

00:12:21,100 --> 00:12:24,400
like feeling discriminated against

248

00:12:24,400 --> 00:12:28,300
but was absolutely not understanding

249

00:12:27,300 --> 00:12:30,400
the experience of another group

250

00:12:30,400 --> 00:12:33,700
of people which which I'm part of as a disabled person and that

251

00:12:33,700 --> 00:12:36,000
was a really hard conversation to kind of

252

00:12:36,300 --> 00:12:39,300
bring myself to say but I felt like

253

00:12:39,300 --> 00:12:42,400
the workshop for me bringing me in so much grief and

254

00:12:42,400 --> 00:12:45,500
really span me out for a couple of days. So I

255

00:12:45,500 --> 00:12:45,900
was just really

256

00:12:47,400 --> 00:12:50,400
really upset it made me feel like I didn't belong in the

257

00:12:50,400 --> 00:12:51,500
theater industry and

258

00:12:52,400 --> 00:12:55,800
And I found that really hard so I definitely I

259

00:12:55,800 --> 00:12:58,200
have and thankfully the people

260

00:12:58,200 --> 00:13:01,100
I spoke to were amazing. When I I kind of

261

00:13:01,100 --> 00:13:04,400

raised it with them and they were like look, we we really

262

00:13:04,400 --> 00:13:07,200

agree. We've had some other comments from other people about this not

263

00:13:07,200 --> 00:13:10,300

being appropriate and we we will be talking to that company about

264

00:13:10,300 --> 00:13:13,400

it. And if they don't change we won't be working with them

265

00:13:13,400 --> 00:13:13,600

again.

266

00:13:14,300 --> 00:13:17,300

And that's really good. Yeah, and I guess like the

267

00:13:17,300 --> 00:13:20,200

more that I conversations like this

268

00:13:20,200 --> 00:13:23,500

happen and you know people with invisible disabilities

269

00:13:23,500 --> 00:13:26,400

are able to essentially have a voice like

270

00:13:26,400 --> 00:13:29,600

that becomes more and more important in terms of educating people which

271

00:13:29,600 --> 00:13:32,800

hopefully means that an experience like the one you had wouldn't

272

00:13:32,800 --> 00:13:35,800

happen so often and but it

273

00:13:35,800 --> 00:13:38,000

almost can't write itself without that level of

274

00:13:38,900 --> 00:13:41,600

feedback. Yeah. Well done

275

00:13:41,600 --> 00:13:42,600

for taking that on. I know it.

276

00:13:43,500 --> 00:13:46,300

It's just really hard isn't it? Like this particular

277

00:13:46,300 --> 00:13:49,500

conversation was about like not getting people's names

278

00:13:49,500 --> 00:13:52,300

wrong or not misgendering people and as someone

279

00:13:52,300 --> 00:13:55,400

who can get really like has a

280

00:13:55,400 --> 00:13:56,800

has a problem with their brain.

281

00:13:57,600 --> 00:14:00,400

And basically loses the ability to really

282

00:14:00,400 --> 00:14:03,700

follow the sign-ups is that they're choosing to remember so

283

00:14:03,700 --> 00:14:06,700

they don't have a good memory. It can feel really stressful

284

00:14:06,700 --> 00:14:09,500

the idea that that is going to impact someone else's

285

00:14:09,500 --> 00:14:13,800

well-being. So and managing like

286

00:14:13,800 --> 00:14:16,300

the way that people receive that feels really important

287

00:14:16,300 --> 00:14:17,800

that information that I'm not

288

00:14:18,500 --> 00:14:22,400

Not always perfect, and I'm not doing it. Anyway, Nick

289

00:14:21,400 --> 00:14:23,900

being neglectful. I'm doing it because

290

00:14:25,900 --> 00:14:28,300

I'm my brain

291

00:14:28,300 --> 00:14:31,300

doesn't work probably. So amazing think

292

00:14:31,300 --> 00:14:34,800

of Tourette's hero and how brilliant Jess is at naming

293

00:14:34,800 --> 00:14:35,800

her.

294

00:14:36,800 --> 00:14:39,400

what Tourette's means and what it means for the

295

00:14:39,400 --> 00:14:42,500

people around her and that yeah, I

296

00:14:42,500 --> 00:14:42,700

really

297

00:14:43,700 --> 00:14:46,700

think that level of like of

298

00:14:46,700 --> 00:14:49,700

ownership around understanding your

299

00:14:49,700 --> 00:14:52,900

illness, which is a personal Journey for everyone and that's

300

00:14:52,900 --> 00:14:55,100

part of it and you know, some people might not feel

301

00:14:55,100 --> 00:14:58,400

Readiness really to stand alongside their illness

302

00:14:58,400 --> 00:15:02,200

in that way and others may do and that's that's awesome. Okay,

303

00:15:01,200 --> 00:15:04,400

but I do feel the clarity

304

00:15:04,400 --> 00:15:08,200

is so helpful as always in a work context Clarity

305

00:15:07,200 --> 00:15:11,600
is helpful. Yeah, and also

306

00:15:10,600 --> 00:15:13,200
you might not like you might

307

00:15:13,200 --> 00:15:16,400
be really okay with coming out with it one day and then the next day you
really

308

00:15:16,400 --> 00:15:19,100
are like coming much more from a place of grief.

309

00:15:19,100 --> 00:15:22,300
You're like actually the idea of announcing to the zoom

310

00:15:22,300 --> 00:15:25,300
room of people that I have and a chronic illness

311

00:15:25,300 --> 00:15:27,400
at this moment just feels too much and that

312

00:15:28,200 --> 00:15:31,500
That that does feel like it needs to like something

313

00:15:31,500 --> 00:15:34,400
about that needs to shift. There's something about like having to come
out to a

314

00:15:34,400 --> 00:15:38,400
group like a room of people like how that's managed and just

315

00:15:37,400 --> 00:15:40,500
there needs a little bit more prep work

316

00:15:40,500 --> 00:15:43,400
sometimes in advance for these events. Oh, no,

317

00:15:43,400 --> 00:15:44,700
should I pause this?

318

00:15:47,400 --> 00:15:50,600

Hello everybody. That was it a post break. We're

319
00:15:50,600 --> 00:15:50,800
back.

320
00:15:55,100 --> 00:15:58,500
Yeah and thinking about day. Yeah, navigating your

321
00:15:58,500 --> 00:16:02,200
illness and and when it feels like you want

322
00:16:01,200 --> 00:16:04,300
to hold that as part of your identity and

323
00:16:04,300 --> 00:16:07,200
other times when you actually don't want to have to do

324
00:16:07,200 --> 00:16:11,400
that, and I wanted to draw people's attention to the chronically

325
00:16:11,400 --> 00:16:14,600
ill artist Network and which been

326
00:16:14,600 --> 00:16:18,000
set up by tele Branson and Louise wildish and it's

327
00:16:17,400 --> 00:16:21,500
specifically for this these

328
00:16:20,500 --> 00:16:23,800
kinds of complications and advocacy and

329
00:16:23,800 --> 00:16:26,500
just a brilliant organization to

330
00:16:26,500 --> 00:16:27,100
connect with

331
00:16:29,700 --> 00:16:32,400
which is finding its momentum I think is we're interesting

332
00:16:32,400 --> 00:16:33,600
point where I feel like

333

00:16:35,300 --> 00:16:38,600

people are finding their feet around articulating what's

334

00:16:38,600 --> 00:16:41,600

needed and working in Industry with chronic illness,

335

00:16:41,600 --> 00:16:43,100

which so many people have

336

00:16:46,400 --> 00:16:49,400

Okay, next question Steph if that's all right, and

337

00:16:49,400 --> 00:16:52,400

could you just Inspire us a bit with the time where you felt like

338

00:16:52,400 --> 00:16:56,700

your needs like were really met and like and how

339

00:16:55,700 --> 00:16:58,800

that works out and like just

340

00:16:58,800 --> 00:17:01,800

anything that where you're like, you know what that was really great. So

341

00:17:01,800 --> 00:17:04,400

it could inspire people listening to this. Yeah. I think

342

00:17:04,400 --> 00:17:08,800

I came on late on a project at

343

00:17:07,800 --> 00:17:11,100

the egg theater and obviously

344

00:17:10,100 --> 00:17:13,000

coming on late. There's you know,

345

00:17:13,400 --> 00:17:17,500

you've already missed the planning production times, but they I think

346

00:17:17,500 --> 00:17:22,100

because they will I was working with their students. There

347

00:17:20,100 --> 00:17:23,200

was a sense they were

348

00:17:23,200 --> 00:17:26,900

very much access supporting the ones that needed accessible on

349

00:17:26,900 --> 00:17:30,400

there really well and and therefore they

350

00:17:30,400 --> 00:17:33,600

really once I joined the team they really looked at

351

00:17:33,600 --> 00:17:36,900

how they could help me manage my energy levels and

352

00:17:37,900 --> 00:17:40,500

and they had an

353

00:17:40,500 --> 00:17:42,500

access budget in the building that meant

354

00:17:43,100 --> 00:17:46,100

that they could pay for some of the

355

00:17:46,100 --> 00:17:50,800

fit up to be done over the weekend, which is costly so

356

00:17:49,800 --> 00:17:52,400

that I could have an evening off

357

00:17:52,400 --> 00:17:55,300

in the middle of the week of a tech week. And as we

358

00:17:55,300 --> 00:17:58,100

all know Tech weeks are like the worst week because

359

00:17:58,800 --> 00:18:01,500

as when the highest volume

360

00:18:01,500 --> 00:18:05,000

of work happens when you're on amongst really intense differences

361

00:18:04,200 --> 00:18:07,200

of darkness and lightness, which can give you a headache

362

00:18:07,200 --> 00:18:10,500
and where is really hard to manage

363

00:18:10,500 --> 00:18:13,300
the getting good meals that can make massive a

364

00:18:13,300 --> 00:18:16,500
difference to your body. And so that was actually a

365

00:18:16,500 --> 00:18:19,500
massive. It was so good. It was

366

00:18:19,500 --> 00:18:22,600
such a really Heap to have that and I really

367

00:18:22,600 --> 00:18:25,100
really appreciate that and that made me

368

00:18:25,100 --> 00:18:28,100
feel really really welcome and the fact that

369

00:18:28,100 --> 00:18:31,700
that money was like ring friend especially for working

370

00:18:31,700 --> 00:18:33,600
with disabled artists and managing that

371

00:18:34,200 --> 00:18:37,800
And as a contingency for that was just really inspiring

372

00:18:37,800 --> 00:18:40,700
and really good and makes so much sense. So brilliant

373

00:18:40,700 --> 00:18:42,700
people can come on board right now.

374

00:18:43,700 --> 00:18:43,900
and

375

00:18:44,800 --> 00:18:47,800
and I'm afraid I'm going to have to ask like where

376

00:18:47,800 --> 00:18:49,000

is it going horribly wrong?

377

00:18:50,400 --> 00:18:53,200

And are there any kind of obvious examples and looking back? Was

378

00:18:53,200 --> 00:18:56,500

there anything you feel that you could have done or they could have done to

379

00:18:56,500 --> 00:18:59,600

prevent that having happened when I think

380

00:18:59,600 --> 00:19:00,100

there's

381

00:19:02,500 --> 00:19:05,200

There's kind of I I think the times that it's gone quite horribly wrong

382

00:19:05,200 --> 00:19:06,500

for me is often me.

383

00:19:07,400 --> 00:19:10,700

Because I really like making fear and I'm a greedy

384

00:19:10,700 --> 00:19:11,200

Pig.

385

00:19:14,900 --> 00:19:16,000

I'll be like

386

00:19:16,800 --> 00:19:17,300

No, no and also.

387

00:19:19,100 --> 00:19:22,800

Tired I can become quite hyper

388

00:19:22,800 --> 00:19:25,500

fixated on finishing and the project

389

00:19:25,500 --> 00:19:26,300

and I find that.

390

00:19:27,200 --> 00:19:30,100

Like and the stakes just become a bit too high for

391

00:19:30,100 --> 00:19:34,200
me where I'm like Oh my must finish this so it's

392

00:19:33,200 --> 00:19:36,600
alone as a

393

00:19:36,600 --> 00:19:39,900
kind of in terms of like able-bodied or whoever like

394

00:19:39,900 --> 00:19:42,600
I feel like that's a symptom of our teeth.

395

00:19:42,600 --> 00:19:46,500
Yeah. It's just a lot worse for me like and

396

00:19:45,500 --> 00:19:48,900
everybody ones. They're like method said

397

00:19:48,900 --> 00:19:53,400
for a little while and I'm like, yeah, but

398

00:19:52,400 --> 00:19:56,100
a bit hungry and weak you're like, oh, yeah,

399

00:19:55,100 --> 00:19:58,300
and then I had us. Yeah, I had

400

00:19:58,300 --> 00:20:02,100
heart palpitations and couldn't stand up for three days. And yeah,

401

00:20:01,100 --> 00:20:04,400
so a lot higher around well,

402

00:20:04,400 --> 00:20:07,300
so I think I've got a lot better at that

403

00:20:07,300 --> 00:20:10,300
talking and owning things and putting things in

404

00:20:10,300 --> 00:20:13,200
place and I definitely know when I first started working with

405

00:20:13,200 --> 00:20:16,500
the support worker, I I just would there's definitely

406
00:20:16,500 --> 00:20:19,200
just lying about how I felt to just like

407
00:20:19,200 --> 00:20:22,400
keep everything running along smoothly, especially when it's my project.
I

408
00:20:22,400 --> 00:20:25,500
was like, yeah. No, I'm absolutely fine or like

409
00:20:25,500 --> 00:20:27,100
no I do feel bad, but I

410
00:20:27,100 --> 00:20:30,300
Just keep going. And so I have

411
00:20:30,300 --> 00:20:33,700
I have like started to understand that

412
00:20:33,700 --> 00:20:36,900
and like I've got a lot better calling myself out because

413
00:20:36,900 --> 00:20:40,000
don't really like it when other people call me out on that like so

414
00:20:39,200 --> 00:20:41,900
you have to call yourself out in that. So that's

415
00:20:42,700 --> 00:20:45,500
those are the times when I've overdone it. I have

416
00:20:45,500 --> 00:20:48,200
also clashed heads with people where and

417
00:20:49,500 --> 00:20:50,300
I run things.

418
00:20:51,400 --> 00:20:54,100
Because my illness I'll run. I'll try and

419
00:20:54,100 --> 00:20:57,700

work out how many things can be soft deadlines and hard deadlines. I'm like, where

420

00:20:57,700 --> 00:20:59,800

is this? How can we make this a soft deadline?

421

00:21:00,700 --> 00:21:03,800

And fit into my schedule so that I'm really managing

422

00:21:03,800 --> 00:21:06,400

my time properly and where do

423

00:21:06,400 --> 00:21:09,200

I have to reach something by a deadline? Like the

424

00:21:09,200 --> 00:21:10,700

really hard ones that you're like

425

00:21:11,400 --> 00:21:12,600

the equivalent of like

426

00:21:13,700 --> 00:21:16,400

getting a visa from the US Embassy like

427

00:21:16,400 --> 00:21:19,700

you can't you can't mess around with that deadline. And

428

00:21:19,700 --> 00:21:22,200

so I have a tendency

429

00:21:22,200 --> 00:21:25,200

to qualify those a bit in my head and work those out so that

430

00:21:25,200 --> 00:21:28,300

I know that if I can't do something on a day I can just roll it over.

431

00:21:29,200 --> 00:21:29,600

and

432

00:21:31,400 --> 00:21:34,200

and sometimes I think other people don't like

433

00:21:35,300 --> 00:21:38,200

they can also get that sense of hyper fixating and meeting

434

00:21:38,200 --> 00:21:39,800
a deadline and they

435

00:21:40,700 --> 00:21:43,400
They don't necessarily do the are you

436

00:21:43,400 --> 00:21:46,600
they're not as used to the negotiation around like your body

437

00:21:46,600 --> 00:21:50,400
and even if they're really understanding at the beginning sometimes once

438

00:21:49,400 --> 00:21:52,500
they get to the most stressful place they can become.

439

00:21:53,500 --> 00:21:54,900
quite dismissive or

440

00:21:57,600 --> 00:21:58,600
frustrated and

441

00:21:59,900 --> 00:22:02,300
having to take on there frustration. It can

442

00:22:02,300 --> 00:22:05,300
be really unpleasant in that moment and

443

00:22:06,200 --> 00:22:09,400
And I having a support worker like can sort

444

00:22:09,400 --> 00:22:12,500
of deflect that a bit. Like is it easier if it's

445

00:22:12,500 --> 00:22:15,300
through someone else? I wonder yeah, I

446

00:22:15,300 --> 00:22:15,400
think.

447

00:22:16,500 --> 00:22:16,800
I think

448

00:22:18,400 --> 00:22:21,400
it's nice to just have someone to talk through about it because

449
00:22:21,400 --> 00:22:24,600
sometimes when you're really tired it can really you can

450
00:22:24,600 --> 00:22:26,600
get a bit anxious and it can be really hard to work out.

451
00:22:27,500 --> 00:22:30,300
What your boundaries are when you're when you're

452
00:22:30,300 --> 00:22:33,900
flagging quite badly. And yeah, and

453
00:22:33,900 --> 00:22:36,100
if it feels like this level of like

454
00:22:36,900 --> 00:22:39,800
Perspective is something that as an

455
00:22:39,800 --> 00:22:41,000
industry like we do.

456
00:22:42,200 --> 00:22:46,000
Strip, like systemically lose Under Pressure. Yeah,

457
00:22:45,300 --> 00:22:49,500
and the, you know actually like

458
00:22:48,500 --> 00:22:51,600
taking myself for example, like, you

459
00:22:51,600 --> 00:22:51,600
know.

460
00:22:53,500 --> 00:22:56,500
Equally like the stakes of me being tired or

461
00:22:56,500 --> 00:22:57,200
too high.

462
00:22:57,800 --> 00:23:00,300
To allow me to work 16 hours a

463

00:23:00,300 --> 00:23:03,200
day for Non-Stop. It's like it's just not going

464

00:23:03,200 --> 00:23:03,400
to happen.

465

00:23:04,200 --> 00:23:08,200
But the truth is and I think that's where I

466

00:23:07,200 --> 00:23:10,300
feel like this work is useful and relevant to everyone

467

00:23:10,300 --> 00:23:12,700
is that you know, if I really follow

468

00:23:14,300 --> 00:23:17,300
A nourishing process. That's also going to nourish everyone

469

00:23:17,300 --> 00:23:18,000
that I work with.

470

00:23:18,800 --> 00:23:21,300
yeah, and and for me that feels like a

471

00:23:21,300 --> 00:23:24,500
gift to everyone and it

472

00:23:24,500 --> 00:23:27,500
feels like you know at the moment we were discussing earlier

473

00:23:27,500 --> 00:23:29,600
before we started recording and

474

00:23:30,900 --> 00:23:33,200
like well what

475

00:23:33,200 --> 00:23:36,800
two things and that I've that I found really helpful

476

00:23:36,800 --> 00:23:40,300
and is a support worker

477

00:23:39,300 --> 00:23:42,400
and specifically and I was looking at

478
00:23:42,400 --> 00:23:45,800
the artist well-being network

479
00:23:45,800 --> 00:23:48,400
with the rich Lou plats

480
00:23:48,400 --> 00:23:51,400
started up which you know again, like it's about bringing

481
00:23:51,400 --> 00:23:54,600
in the level of quite early

482
00:23:54,600 --> 00:23:57,100
on in relation to the process but like

483
00:23:57,100 --> 00:24:00,400
ensuring that there is something like that there and that it does feel as

484
00:24:00,400 --> 00:24:01,900
an industry again because of

485
00:24:03,700 --> 00:24:06,900
recent situations and specifically the

486
00:24:06,900 --> 00:24:09,600
industry reeling from what's happened

487
00:24:09,600 --> 00:24:12,300
in relation to the passing of Chris

488
00:24:12,300 --> 00:24:15,100
good and what appears to

489
00:24:15,100 --> 00:24:18,400
have been going on there around abuse and how again like that

490
00:24:18,400 --> 00:24:21,700
that ability to

491
00:24:24,600 --> 00:24:27,500
Have things in place that allow for a little

492

00:24:27,500 --> 00:24:30,600

bit of pressure to come out of the cooking pot. You know,

493

00:24:30,600 --> 00:24:33,600

whatever those Stakes might be that might be around. You know,

494

00:24:33,600 --> 00:24:36,500

someone doesn't feel that they're being treated appropriately or it

495

00:24:36,500 --> 00:24:40,000

might be that someone's you know, Health needs aren't being met. And

496

00:24:39,200 --> 00:24:42,100

if there's a lot of work that I

497

00:24:42,100 --> 00:24:45,200

think I'd like to sign piece signpost people too

498

00:24:45,200 --> 00:24:48,700

specifically Lucy ellenson. I really recommend following

499

00:24:48,700 --> 00:24:52,100

her on Twitter and she's trying to get her head around all of

500

00:24:52,100 --> 00:24:55,500

this and think about it. Is there the scope

501

00:24:55,500 --> 00:24:59,300

for an industry-wide body that specifically in place

502

00:24:58,300 --> 00:25:00,400

around well-being.

503

00:25:01,300 --> 00:25:04,000

And I do feel like we you know

504

00:25:04,200 --> 00:25:07,000

that as somebody with an invisible disability and ask them with a

505

00:25:07,300 --> 00:25:10,300

chronic illness and stuff. I'd I wouldn't speak for you. But I do feel like

506

00:25:10,300 --> 00:25:13,300
the fact that it's so binary and black

507

00:25:13,300 --> 00:25:16,300
and white for us around like we just we

508

00:25:16,300 --> 00:25:19,400
just can't do these things. I think

509

00:25:19,400 --> 00:25:22,200
is a sort of wonderful example because I think a lot of people push
through

510

00:25:22,200 --> 00:25:24,100
when they maybe shouldn't do

511

00:25:24,800 --> 00:25:27,600
well, I think I would entirely agree

512

00:25:27,600 --> 00:25:28,700
like I

513

00:25:30,100 --> 00:25:33,800
I couldn't say that it like I don't know but like

514

00:25:33,800 --> 00:25:35,200
my my

515

00:25:36,500 --> 00:25:39,500
My illness died with a period of quite severe burnout

516

00:25:39,500 --> 00:25:42,800
from work. So I am I think I would

517

00:25:42,800 --> 00:25:45,300
very committed to giving everything that I could to

518

00:25:45,300 --> 00:25:47,100
work because I felt like I didn't belong there.

519

00:25:48,200 --> 00:25:51,500
So I felt like I had to prove myself so I was pushing

520

00:25:51,500 --> 00:25:54,000
myself really hard to matter.

521
00:25:55,200 --> 00:25:58,600
through working really hard and giving everything

522
00:25:58,600 --> 00:26:01,900
to projects and what I did was I massively burned

523
00:26:01,900 --> 00:26:04,300
out got a virus at the same time and have ended

524
00:26:04,300 --> 00:26:06,700
up unwell, and I think during

525
00:26:07,800 --> 00:26:10,400
those periods of not being able to do very much at all

526
00:26:10,400 --> 00:26:14,100
and really like knowing

527
00:26:13,100 --> 00:26:15,900
that I matter in lots of different ways, but

528
00:26:17,400 --> 00:26:20,400
the main place I place a lot of self-worth

529
00:26:20,400 --> 00:26:23,400
worth was through my work because it really mattered to

530
00:26:23,400 --> 00:26:26,600
me and I think that's the true of a lot of people in the industry and

531
00:26:27,700 --> 00:26:30,800
And I definitely have had to like forcibly extricate that

532
00:26:30,800 --> 00:26:33,300
through therapy away from that

533
00:26:33,300 --> 00:26:33,700
to like.

534
00:26:35,100 --> 00:26:38,300
And and I do I agree with you that is a bit of

535

00:26:38,300 --> 00:26:42,300
a like it is a really important thing that

536

00:26:41,300 --> 00:26:44,100
people need to do as artists because

537

00:26:44,100 --> 00:26:47,600
I think that's where a lot of abusive behaviors come

538

00:26:47,600 --> 00:26:49,700
from is where people start putting the work.

539

00:26:50,500 --> 00:26:53,900
and their own like art view

540

00:26:53,900 --> 00:26:55,800
above the well-being of others and I

541

00:26:56,600 --> 00:26:59,100
I don't think I

542

00:27:00,500 --> 00:27:03,600
necessarily did that too much before but I

543

00:27:03,600 --> 00:27:07,400
definitely did it to myself before and I

544

00:27:06,400 --> 00:27:09,700
don't need to yeah, I

545

00:27:09,700 --> 00:27:13,400
mean, I feel I always felt a lot of guilt about adding

546

00:27:12,400 --> 00:27:15,400
extra work to people's levels or making them

547

00:27:15,400 --> 00:27:18,200
work hard. So I absorbed a lot of things that I

548

00:27:18,200 --> 00:27:21,900
couldn't absorb and I think I generally was just like pulling a

549

00:27:21,900 --> 00:27:24,300
horrible Maggie Thatcher Vibe of only

550
00:27:24,300 --> 00:27:27,500
sleeping like four hours a night or five hours and and just

551
00:27:27,500 --> 00:27:31,400
functionally like that for quite a long time, which was just not good and

552
00:27:30,400 --> 00:27:33,200
I was normal and that's what was

553
00:27:33,200 --> 00:27:36,200
expected. Yeah. Well, I just was I trying to

554
00:27:37,300 --> 00:27:40,100
you know, I'm I'm middle class and I have

555
00:27:40,100 --> 00:27:43,700
have a family that I can go back to but I was trying to live off

556
00:27:43,700 --> 00:27:46,600
a fair wage while not living

557
00:27:46,600 --> 00:27:49,500
at home with my parents in Bristol, which is not London, but it's

558
00:27:49,500 --> 00:27:50,900
still expensive and

559
00:27:51,800 --> 00:27:54,300
Trying to prove to myself that I can make this work

560
00:27:54,300 --> 00:27:57,200
financially and was one of

561
00:27:57,200 --> 00:27:59,800
the main reasons that I kind of, you know, really?

562
00:28:00,900 --> 00:28:03,600
Really struggled and I know people starting

563
00:28:03,600 --> 00:28:06,900
out now with chronic illnesses. They're gonna start it's gonna

564

00:28:06,900 --> 00:28:09,700

be really hard. But in some ways you are going to start you value

565

00:28:09,700 --> 00:28:11,200

your time so much more.

566

00:28:12,400 --> 00:28:16,300

And then other people do and also let

567

00:28:15,300 --> 00:28:19,100

it be a lesson to avoid burnout. Yeah,

568

00:28:18,100 --> 00:28:21,100

so sometimes I like to

569

00:28:21,100 --> 00:28:24,600

scare people with that. Yeah. I got

570

00:28:24,600 --> 00:28:28,600

this through working too hard. Yeah. I'm

571

00:28:27,600 --> 00:28:30,100

thank you Steph. It's really

572

00:28:30,100 --> 00:28:33,300

wonderful to talk to you and I hope people found that

573

00:28:33,300 --> 00:28:36,300

useful and interesting and if there's

574

00:28:36,300 --> 00:28:39,600

anything that is brought up that people want to talk through

575

00:28:39,600 --> 00:28:42,200

more or you can always contact me

576

00:28:42,200 --> 00:28:46,000

at theater to Bristol and I'm hoping

577

00:28:45,400 --> 00:28:48,200

that we'll have another session like this in the

578

00:28:48,200 --> 00:28:51,400
future where we can all gather and be there in person. My

579
00:28:51,400 --> 00:28:54,400
my dream is that we might end up with a little Network

580
00:28:54,400 --> 00:28:57,400
in Bristol that we're you know is a

581
00:28:57,400 --> 00:29:00,200
sort of micro chronic ill artist

582
00:29:00,200 --> 00:29:02,900
network, but just for Bristol something that be really nice.

583
00:29:03,600 --> 00:29:06,200
And all right very well.

584
00:29:06,200 --> 00:29:07,800
Thank you. Bye.