

1  
00:00:04,450 --> 00:00:08,529

Good afternoon. Hello.

2  
00:00:08,530 --> 00:00:14,709

My name is Bob. I am a part time children's cancer doctor and part time.

3  
00:00:14,710 --> 00:00:22,540

I'm a researcher at the University of York. I have come along to talk a little bit about what it's like working with and a little

4  
00:00:22,540 --> 00:00:28,870

bit about what I've been told about experiences of having cancer when you're little, 18 or younger.

5  
00:00:29,350 --> 00:00:35,920

Now just looking at the audience and being slightly prejudicial about what I'm seeing,

6  
00:00:36,400 --> 00:00:40,990

not a massive chunk of this audience are in my sales pitch

7  
00:00:41,050 --> 00:00:50,370

group, to be honest. So this might be a little bit different than what you've experienced so far.

8  
00:00:51,070 --> 00:00:58,600

I'm going to talk about wiggles, ducks, beads and brutal honesty.

9  
00:01:01,250 --> 00:01:11,060

This is the graph that everybody involved in children's cancer care is obliged by law to show you at some point.

10  
00:01:11,660 --> 00:01:20,800

It's a graph that shows survival, like we've seen with Russell's, over the course of years, as the little lines go up and up and up.

11  
00:01:21,710 --> 00:01:25,550

But unlike the five years, this is ten years out.

12  
00:01:26,270 --> 00:01:36,710

And you can see that for this disease, which is acute lymphoblastic leukaemia in childhood, we've gone from a situation in the seventies where

13  
00:01:37,680 --> 00:01:48,510

virtually nobody survived, to a point where in the early 2000s we were up at the high eighties and we may even be a tad higher than that now.

14

00:01:50,630 --> 00:01:54,240

This is impressive work. This is scientists.

15

00:01:54,260 --> 00:02:04,100

This is patients. This is families. This is an enormous amount of largely not commercial effort bringing up survival,

16

00:02:04,730 --> 00:02:15,620

partly from treating the leukaemia, and partly from meaning the side effects aren't causing the problems that lead to the end of life as well.

17

00:02:16,670 --> 00:02:25,250

How do we do this? Well, we have a variety of things that aid us when we are treating children and young people.

18

00:02:26,000 --> 00:02:31,400

The first of them is a duck. This is chemo duck.

19

00:02:32,060 --> 00:02:40,670

Chemo duck gets chemo. You can see that because you see that the little plastic thing that's dribbling off their foot?

20

00:02:41,660 --> 00:02:44,850

Yeah, yeah, yeah. That is a portacath

21

00:02:44,850 --> 00:02:52,310

needle. It's not a real one. It's a pretend one that if you're little your duck can have a port.

22

00:02:53,720 --> 00:02:58,400

Who here has got a portacath or seen a portacath? I've seen a portacath.

23

00:02:58,400 --> 00:03:04,370

Yeah. So a port a cath is a little lumpy thing that sits underneath your skin,

24

00:03:04,550 --> 00:03:07,650

and instead of fiddling around to try to find a vein to do blood tests,

25

00:03:07,650 --> 00:03:12,440

or put chemo in or anything like that, the little lumpy thing there and somebody highly skilled,

26

00:03:12,560 --> 00:03:18,980

basically not a doctor, takes a special needle and goes \*pop sound\* like that.

27

00:03:19,190 --> 00:03:23,269

They don't always make the noise, in it goes. And then you can do blood tests,

28

00:03:23,270 --> 00:03:30,470

you can put in really, really concentrated chemotherapies. You can do total parental nutrition, you can do all sorts of things, then when it's out,

29

00:03:30,590 --> 00:03:36,140

That's it. You can run around, you can rock climb, you can go swimming, you can go on your bike,

30

00:03:36,290 --> 00:03:41,809

you can go get arrested because you are doing naughty things on Halloween.

31

00:03:41,810 --> 00:03:52,430

and then the police are really nice to you because you've got a portacath. Chemo ducks got it's own wiggles.

32

00:03:53,270 --> 00:03:59,270

And thanks to the effort of a vast number of volunteers in the Yorkshire and the Humber area.

33

00:03:59,810 --> 00:04:01,040

when you come into clinic,

34

00:04:01,040 --> 00:04:10,000

you can get a new chemo duck outfit because people sit at home and they sew and knit and do different outfits for the chemo ducks for our kids.

35

00:04:11,050 --> 00:04:14,290

Chemo duck's brilliant. Because it allows play.

36

00:04:14,440 --> 00:04:21,040

It allows understanding. It allows you to externalise what's happening to you on to somebody else

37

00:04:21,040 --> 00:04:25,150

and you can be the health care professional to your duck.

38

00:04:25,330 --> 00:04:28,960

You can use your duck with your friends, with your siblings, and so on,

39

00:04:29,200 --> 00:04:32,229

to explain what's going on and why chemo duck

40

00:04:32,230 --> 00:04:42,549

has got no hair, and I've, well I've got no hair, but why the patient doesn't have any hair. Superb bits of work that are going on to make things better,

41

00:04:42,550 --> 00:04:48,170

to understand. Understanding, a bit like what I was hearing about just a few minutes ago with

42

00:04:48,170 --> 00:04:55,540

that Watch and Wait stuff, some degree of understanding and control just makes you feel better.

43

00:04:57,320 --> 00:05:07,010

What else can help? Well, the other thing that we've seen is that this goes on for some time, years in some cases.

44

00:05:07,010 --> 00:05:14,020

And many of you will be in the middle of this. What about if you got a bead every time you came to hospital

45

00:05:14,230 --> 00:05:21,910

that said you've had an overnight stay, a different colour one for when you had chemotherapy, a sparkly one for if you had radiotherapy.

46

00:05:23,350 --> 00:05:29,860

A really big shiny one for when you've entered a clinical trial.

47

00:05:31,400 --> 00:05:39,229

What if you had your journey that could be mapped out on an extremely long string that went all the way from

48

00:05:39,230 --> 00:05:46,190

one end to the other and back again and potentially turned around and went back again again the other way.

49

00:05:48,130 --> 00:05:54,970

What if there was a clinical trial where the information sheet wasn't a bit of paper but was a video

50

00:05:56,130 --> 00:06:00,840

of a Lego man animated explaining the study to you.

51

00:06:01,900 --> 00:06:08,080

And then the study, if you were on it, you got a little Lego head went on your beads of courage.

52

00:06:09,490 --> 00:06:12,630

That is how we bribe children into getting on trials.

53

00:06:14,320 --> 00:06:19,780

But we have done that and our clinical trials often have a bead associated with them to go on this bead of courage.

54

00:06:20,170 --> 00:06:22,560

Because then when you're at the end, or even when you're through,

55

00:06:22,870 --> 00:06:29,500

you can look back and you can see, you can visualise, you can understand what is going on.

56

00:06:31,370 --> 00:06:37,290

This is for children and for young people, but why isn't it for grownups?

57

00:06:39,720 --> 00:06:45,780

It isn't for grownups because you lot don't turn around often enough and go, I want a duck.

58

00:06:52,040 --> 00:06:56,390

This is a picture of a young man that finished treatment for Hodgkin's lymphoma.

59

00:06:57,740 --> 00:07:08,680

He hated it. Absolutely hated it. And for years, months afterwards, he would come through and he would grow his hair taller and taller and taller.

60

00:07:09,110 --> 00:07:15,830

And every time he would come in with a hat on, he would pop it off and go, I'm beating you by a long way.

61

00:07:18,750 --> 00:07:25,230

Hodgkins, as we've seen from Russell's data from the network, is one of the commonest one of young people to go through.

62

00:07:25,740 --> 00:07:30,150

And on the far side of Hodgkins treatment, some of you may have experienced this,

63

00:07:30,420 --> 00:07:34,280

the treatment's over. It's gone. But God, I'm knackered.

64

00:07:37,370 --> 00:07:44,270

It's finished, I'm meant to be happy but I am just so exhausted.

65

00:07:45,640 --> 00:07:52,520

And what we don't see in the media is the stories of, you finish your cancer treatment,

66

00:07:53,120 --> 00:07:59,680

if it's on Desperate Housewives or whatever, the next week they're back doing terrible things with the gardener.

67

00:08:00,270 --> 00:08:03,590

No, we don't see that

68

00:08:03,620 --> 00:08:09,890

two years, six months of slowly regaining physical strength.

69

00:08:10,520 --> 00:08:21,230

Why not? Because we don't have enough people writing stories, hassling TV people to say "don't give that crap story".

70

00:08:21,500 --> 00:08:28,680

Give the real story of what happens. Because if you've never seen it and then you experiencing it,

71

00:08:31,530 --> 00:08:35,370

Am I weird? Is it coming back? What's wrong with me?

72

00:08:39,670 --> 00:08:47,729

We need the research like Debs has said, to explain the experience so we can get back out to people and say,

73

00:08:47,730 --> 00:08:53,340

tell the stories properly, give people the knowledge and control that takes things going on.

74

00:08:56,290 --> 00:09:00,910

On the other side. This is a pencil drawing done

75

00:09:01,600 --> 00:09:05,430

by a young man that had just been diagnosed with acute lymphoblastic leukaemia.

76

00:09:06,220 --> 00:09:09,940

Six days in. Couldn't say anything.

77

00:09:11,100 --> 00:09:18,270

But he could draw what it felt like for him and his family to be given a diagnosis

78

00:09:18,870 --> 00:09:26,260

that right at the start of this talk, looked a lot like, Oh my God, look at how good that survival is.

79

00:09:29,390 --> 00:09:35,480

90% survival. 90% survival

80

00:09:36,590 --> 00:09:47,350

means one in 10 dies. That means a primary school class of 30 kids with acute lymphoblastic leukaemia,

81

00:09:48,220 --> 00:09:59,190

three of them won't be alive. And while we as health care professionals often see the 90%,

82

00:10:00,570 --> 00:10:04,240

it doesn't always feel like that when you're on the other side.

83

00:10:04,260 --> 00:10:07,650

And I'm sure that that is also an experience that sits out there.

84

00:10:12,710 --> 00:10:21,620

And then I do a range of cancer types, as you saw with that big graph with the great big lump in grown ups and that tiny little thread,

85

00:10:21,920 --> 00:10:25,940

if we had children's cancer doctors who only dealt with lymphoma,

86

00:10:26,180 --> 00:10:32,080

I mean, it would be brilliant, I'd work one day every three months, but you've got to do more stuff.

87

00:10:32,090 --> 00:10:35,840

So this is another sort of cancer. This is a brain tumour.

88

00:10:37,010 --> 00:10:42,290

Which has an uncolourful version of the same thing that shows virtually no progress

89

00:10:42,290 --> 00:10:49,580

whatsoever over that time period and is still a near universally fatal condition.

90

00:10:51,650 --> 00:10:56,260

Not for want of trying. So what do we do?

91

00:10:56,500 --> 00:11:00,880

Well, the haematologists look down microscopes, and they see things like this.

92

00:11:01,610 --> 00:11:05,830

This, they tell me, shows white cells. Obviously they're purple.

93

00:11:07,890 --> 00:11:16,780

Red cells. Clearly, they're lilac. And also they say, and what don't you see?

94

00:11:17,880 --> 00:11:24,340

Well, I don't see an elephant! There's no rhinoceroses and very few daffodils.

95

00:11:25,510 --> 00:11:29,860

What you don't see apparently are little tiny dots of platelets, which aren't there.

96

00:11:30,920 --> 00:11:38,120

Yeah. Haematologists do this all the time just to try and show just how brilliant they are, and frankly, they are but

97

00:11:38,120 --> 00:11:41,620

it's really annoying. I mean, it could be true.

98

00:11:42,020 --> 00:11:43,610

I'm more used to looking at things like this,

99

00:11:43,610 --> 00:11:49,940

an ultrasound scan, where the put little crosses on and they show things like, you know, a lymph node that's been enlarged.

100

00:11:49,970 --> 00:11:59,150

Yeah. Except this isn't. This is a radar of a hurricane coming in to the coast of Florida.

101

00:11:59,490 --> 00:12:08,010

And I just told you, it's an ultrasound scan. Do not believe people when they just tell you stuff, they might be spinning

102

00:12:08,010 --> 00:12:12,950

you a massive yarn. For example.

103

00:12:12,960 --> 00:12:16,160

No, honestly, Professor told me that was ALL,

104

00:12:16,190 --> 00:12:22,760

so I do believe her. See that's what a white cell should really look like, isn't it?

105

00:12:23,510 --> 00:12:28,820



It's white, it's got big eyes to go round looking for bugs, little arms to hang on to it.

106

00:12:29,180 --> 00:12:32,510

Yeah. What you can't see is that this one has got,

107

00:12:35,440 --> 00:12:39,530

It emits a lot of gas out of its backend. That says "There's a bad thing! Come and eat it!"

108

00:12:42,420 --> 00:12:46,350

Now if you haven't got white cells,

109

00:12:47,100 --> 00:12:53,550

you can't fight bugs, and if you can't fight bugs, then you might die.

110

00:12:54,860 --> 00:12:58,730

And that's really bad. Your leukaemia might be gone,

111

00:13:00,770 --> 00:13:12,390

but you might not be alive. And we know that in ALL in children, in the best risk group, of the kids that die with that condition,

112

00:13:14,060 --> 00:13:17,090

only half of them die of their disease.

113

00:13:18,990 --> 00:13:24,480

The other half die of complications of treatment, a bit like APML thing. When it dropped off

114

00:13:25,050 --> 00:13:37,980

but once we got it treated, it was fine. Our treatments have to include everything, not just looking at getting rid of the cancer itself.

115

00:13:40,740 --> 00:13:45,030

What we do in ALL treatment is variable levels of horribleness.

116

00:13:45,300 --> 00:13:52,590

We start with high levels of horribleness in induction and consolidation, and we go down and then we give you a tiny break off.

117

00:13:53,040 --> 00:13:55,079

And then when the leukaemia isn't looking,

118

00:13:55,080 --> 00:14:03,510

we come back in with a massive sledgehammer again and bash it down and then we spend years drizzling a little bit in.

119

00:14:04,600 --> 00:14:08,950

We drizzle a little bit in because the leukaemia sets up sleeper agents.

120

00:14:09,860 --> 00:14:15,980

And then when they wake up, they think aha! because of the little drizzle of chemotherapy.

121

00:14:17,120 --> 00:14:20,300

There are scency, more explanations but that's really how it works.

122

00:14:21,860 --> 00:14:26,030

And during all of this time, there's variable levels the side effects.

123

00:14:27,340 --> 00:14:36,190

Variable levels of your white cells not being there to fight off infections, variable levels of your lilac cells not being there to give you energy.

124

00:14:41,850 --> 00:14:47,579

Mostly we have no idea why kids develop tumours, why kids develop cancers.

125

00:14:47,580 --> 00:14:54,870

Why kids develop leukaemias, but sometimes we do. This lad came in with a

126

00:14:54,880 --> 00:15:01,930

Burkitt's lymphoma. Said to be one of the rarer sorts when you take the entire population into account. Within children,

127

00:15:02,060 --> 00:15:05,320

it's one of our fairly common sorts of things that came in.

128

00:15:05,320 --> 00:15:09,280

Came in, got hammered with a lot of chemotherapy.

129

00:15:09,520 --> 00:15:16,000

It works really well to get rid of it, including at that time, MabThera, the posh version of Rituximab.

130

00:15:17,740 --> 00:15:20,800

He ended up in intensive care with an infection.

131

00:15:22,000 --> 00:15:25,020

Pretty sick. Came out again.

132

00:15:26,370 --> 00:15:28,170

Now, in grown up land,

133

00:15:28,560 --> 00:15:36,300

you think sending someone to intensive care is quite bad and you should probably do less chemotherapy because they might end up dead afterwards?

134

00:15:37,420 --> 00:15:42,999

In children's land, we are utterly heartless and we go, Oh, you're back!

135

00:15:43,000 --> 00:15:50,460

Great. Have some more chemo. Why? Because that's how we get those really high survival rates.

136

00:15:51,620 --> 00:15:56,320

And they're really uncommon. If you've been to intensive care once, you don't really go again.

137

00:15:56,360 --> 00:16:00,770

It's really pretty unusual. This lad went again on the second cycle

138

00:16:02,350 --> 00:16:07,570

And we thought, this is, this is weird. I mean, once is bad luck, twice,

139

00:16:08,580 --> 00:16:13,080

twice is, did we cock up? Or is there something funny about you?

140

00:16:14,480 --> 00:16:21,470

And actually we then went on and we looked up lots of research and he had an immunodeficiency.

141

00:16:21,830 --> 00:16:29,960

So his body wasn't very good at fighting off things, including fighting off, noticing that it turned into lymphoma.

142

00:16:32,320 --> 00:16:36,700

By doing the researchy things we help to move things forward and helped him.

143

00:16:37,880 --> 00:16:42,470

But it was infections that was going to be the problem for him, not the disease.

144

00:16:45,990 --> 00:16:49,890

An area that we really, really hate is fungus.

145

00:16:51,200 --> 00:16:55,760

Fungus is a massive problem in lots of different ways.

146

00:16:56,580 --> 00:17:01,550

But if you get bread mould growing in your lungs, it ain't good.

147

00:17:03,610 --> 00:17:10,450

And we need to work out better, using data that we're collecting in from this network, using other trials and studies,

148

00:17:10,870 --> 00:17:14,740

who is at highest risk for fungal disease? How can we stop it happening?

149

00:17:15,010 --> 00:17:18,580

How can we predict early? A bit like that early diagnosis idea.

150

00:17:18,910 --> 00:17:22,300

How can we predict early that this is starting to occur?

151

00:17:22,510 --> 00:17:29,190

So we can leap in and clear it out in some way. An area that we need research.

152

00:17:32,180 --> 00:17:40,240

Anybody ever felt sick? Anybody ever been sick and been grateful for being sick to get rid of the feeling of, yeah.

153

00:17:43,430 --> 00:17:46,910

Do you know where most trials of anti-sickness agents get done?

154

00:17:49,460 --> 00:17:55,260

In you lot, in grown ups. Not in children.

155

00:17:56,740 --> 00:18:06,640

And so the kids versions of the drugs when crushed down and made into a smaller dose used in a different group of individuals can take ten years later on.

156

00:18:06,850 --> 00:18:09,890

So the kids are continuing to be sick for a decade beyond.

157

00:18:10,180 --> 00:18:13,450

We're now doing some research to try and look to see how can you draw that

158  
00:18:13,450 --> 00:18:17,440  
information down faster and make it better, to get rid of the sickness that goes.

159  
00:18:17,740 --> 00:18:21,670  
Because if you think about ALL treatment, we're drizzling chemo in for two years.

160  
00:18:21,880 --> 00:18:28,990  
There's going to be periods of time of feeling just crappy because you've got borderline \*groaning sound\* going on a lot of the time.

161  
00:18:30,790 --> 00:18:33,070  
More research is needed in puke.

162  
00:18:34,900 --> 00:18:46,000  
And then Harry wants us to keep showing this photo to show just how bad it is when you've got mucositis, so soreness, mouth ulcers,

163  
00:18:46,330 --> 00:18:55,180  
ulcers through your guts that are at such a level that you cannot swallow your own spit and you are on picas,

164  
00:18:55,180 --> 00:19:03,580  
an intravenous morphine that is at a level twice that you would expect after a major abdominal surgery.

165  
00:19:07,500 --> 00:19:11,310  
Not doing a lot of research on this because it's just sore mouth.

166  
00:19:11,970 --> 00:19:16,800  
That isn't just a sore mouth. More research is needed.

167  
00:19:17,220 --> 00:19:26,580  
Why can't we just take our ideas and split them out and go on in the world and show how wonderful things are and make a difference?

168  
00:19:26,760 --> 00:19:30,440  
Why do we have to do this research over years and years and years?

169  
00:19:30,480 --> 00:19:37,540  
Well. A bit like me showing you the ultrasound scan of the neck

170  
00:19:37,540 --> 00:19:41,060  
node but it wasn't. It was a hurricane. Lots of things

171  
00:19:41,080 --> 00:19:45,830  
have a great idea. They're very plausible and believable, but don't actually work.

172  
00:19:46,490 --> 00:19:54,380  
This is why we do a lot of these randomised trials where half the people get one thing and half the people get another, because there's a brilliant idea,

173  
00:19:54,860 --> 00:19:57,230  
but we don't know if the brilliant idea is right or not.

174  
00:19:57,590 --> 00:20:05,630  
When we look back over time in the children's cancer trials, we find that roughly speaking, half the time, the brilliant idea was right.

175  
00:20:06,720 --> 00:20:08,380  
Half the time it wasn't right.

176  
00:20:08,790 --> 00:20:16,790  
And doing it without would have led to more treatment or more toxic treatment or actually made things worse by doing it.

177  
00:20:18,550 --> 00:20:23,260  
So one of these brilliant ideas was looking at a medicine called Caphosol,

178  
00:20:23,260 --> 00:20:29,350  
that you \*gargline noise\* round when you're going through a bone marrow transplant to try and reduce that really,

179  
00:20:29,350 --> 00:20:33,310  
really horribly sore mouth that you can get after bone marrow transplant.

180  
00:20:34,340 --> 00:20:42,560  
This shows two lines of the amount of pain, the WHO score is the pain of mucositis of the mouth, the amount of pain you get.

181  
00:20:42,740 --> 00:20:49,430  
The black line shows this brilliant new medicine, and the one that's dotted with the white blobs shows

182  
00:20:49,670 --> 00:20:52,940  
if we just gave you slightly salty water.

183

00:20:55,020 --> 00:20:58,550

You don't have to be a massively high powered scientist to see that.

184

00:20:58,560 --> 00:21:08,990

that's virtually copy and paste. Yeah. The Caphosol costs money, makes you feel sick, is really quite gross.

185

00:21:10,020 --> 00:21:14,010

And they were wanting us to just use it because it had been shown in a trial in adults.

186

00:21:14,400 --> 00:21:17,580

And we thought, Yeah, you're selling this too hard.

187

00:21:17,870 --> 00:21:23,190

Sometimes trials are a brilliant idea at showing things don't work.

188

00:21:23,610 --> 00:21:28,170

Because don't work is as important as does work. Another brilliant idea

189

00:21:28,410 --> 00:21:36,910

in children's kidney cancer, we thought do we really need to give them as intensive chemotherapy or could we drop the doxorubicin?

190

00:21:36,930 --> 00:21:41,530

One of the nasty chemotherapy agents. Well, not that there's a nice chemotherapy agent,

191

00:21:41,530 --> 00:21:44,910

but one of ones with loads and loads of side effects.

192

00:21:48,190 --> 00:21:54,010

This shows the difference between some got the doxorubicin and some that didn't.

193

00:21:54,280 --> 00:22:01,380

In red and blue. This one, the brilliant idea worked. You could reduce the chemotherapy, reduce the problems.

194

00:22:05,850 --> 00:22:10,050

And then there's still some stuff that's debated, like, can you eat strawberries?

195

00:22:11,310 --> 00:22:16,410

Not like, Can you eat a strawberry physically? Like, should you be allowed to eat strawberries?

196

00:22:18,410 --> 00:22:21,670

Should you? If you're on treatment?

197

00:22:23,850 --> 00:22:34,290

So there are some people in the world, we call them heartless killjoys or adult haematologists, were firmly of the belief

198

00:22:34,290 --> 00:22:38,430

that strawberries are evil because in the little holes in the strawberries,

199

00:22:39,650 --> 00:22:45,390

nasty bugs hide. And then when you eat them the nasty bug goes \*sinister laughing\*.

200

00:22:49,490 --> 00:23:00,050

There were a number of trials in Children's where the neutropenic diet, including the removal of strawberries, has been done and not neutropenic diet.

201

00:23:00,320 --> 00:23:04,760

Safe diet where yes, you don't eat it if it's going off.

202

00:23:05,120 --> 00:23:09,740

You don't go to McDonald's and have a Mcflurry because if anybody's ever seen that thing where,

203

00:23:10,850 --> 00:23:18,229

have a look on YouTube at the video where they take the front off the ice cream machine in McDonald's and just

204

00:23:18,230 --> 00:23:27,350

look at what's behind it and you will never, even if you've ever had one before, you won't ever have one again. Safe diet versus neutropenic diet.

205

00:23:27,740 --> 00:23:31,700

There was a difference. The kids on neutropenic diet

206

00:23:31,850 --> 00:23:43,160

ate less, didn't get weight gain, felt their life was worse, generally speaking, and took longer to eat food again afterwards.

207

00:23:44,200 --> 00:23:48,010

No difference in infections, no difference in outcomes. We collected over time.

208

00:23:48,340 --> 00:23:57,600

So within children's, excluding the bone marrow transplant population because they're a bit odd, we're now going "no, eat strawberries."



209

00:23:57,840 --> 00:24:02,130

I mean, wash them. If they've got a worm coming out of them, don't eat them.

210

00:24:02,520 --> 00:24:06,620

Not just go eat strawberries, eat other things as well as strawberries, but,

211

00:24:10,990 --> 00:24:16,180

not just research into chemotherapy is important.

212

00:24:18,070 --> 00:24:23,610

So our major message about anything anyone tells you,

213

00:24:24,710 --> 00:24:28,730

particularly when it comes to treatments, is don't just do it.

214

00:24:29,360 --> 00:24:36,380

We need to do the studies to find the answers, and we need those studies to be relevant across the whole of the population,

215

00:24:36,620 --> 00:24:41,600

because sometimes there are really important differences and sometimes there aren't.

216

00:24:41,960 --> 00:24:47,770

But sometimes there are. Brutal honesty.

217

00:24:48,070 --> 00:24:51,610

We do all we can in some cancers to make sure you don't get an amputation.

218

00:24:52,310 --> 00:24:56,720

Sometimes, the patient's been going, "no, I just want that leg off."

219

00:24:56,900 --> 00:25:01,340

Because even though you've done the operation, it hurts, and honestly I'll be better off without it.

220

00:25:01,790 --> 00:25:05,620

And then a few days later, they turn it into a dinosaur for you.

221

00:25:05,630 --> 00:25:12,440

And then sometimes you say, I'm doing some talks.

222

00:25:12,500 --> 00:25:19,069

I need a picture to show after you've been through really intensive treatment on the far side that you

223

00:25:19,070 --> 00:25:27,710

grow up to be like an engaged and active member of society that goes round and does good in the world.

224

00:25:28,070 --> 00:25:38,059

And then your patient sends you this because they just happen to be being in the backing

225

00:25:38,060 --> 00:25:45,160

line for the play/ musical/ burlesque that their mate had done for you.

226

00:25:49,010 --> 00:25:53,280

Working with children and young people has all of that stuff in it.

227

00:25:55,250 --> 00:25:59,810

It has a need to understand what's different about children and grownups.

228

00:25:59,960 --> 00:26:03,980

It has a need to understand that small children are different than middle sized children that are

229

00:26:03,980 --> 00:26:09,020

different than big children that are different than teenagers that are different than young adults.

230

00:26:10,030 --> 00:26:16,660

It has a need to do studies and trials to make things better across the entirety of that spectrum,

231

00:26:16,670 --> 00:26:21,370

not pretend that the average is the same as the extremes,

232

00:26:22,150 --> 00:26:29,229

and it has a need for inclusion within the patient panels and the patient voice, because you can get five,

233

00:26:29,230 --> 00:26:34,960

six, seven year olds telling you about their experience, telling you what research needs to be done,

234

00:26:35,170 --> 00:26:41,140

if you do it in the right way. You can get their voice heard as well as you can

235

00:26:41,350 --> 00:26:47,010

the voice of grown ups if you do it right. All of that

236

00:26:49,490 --> 00:26:53,780

is hugely important and makes a massive difference to what we do.

237

00:26:57,510 --> 00:27:08,100

There is a target from our international organisation that says we should be aiming for no child dying of cancer.

238

00:27:12,660 --> 00:27:24,060

Given that we have deaths from the toxicities and from the other stuff, I do think we should go higher and we should say no child with cancer dies.

239

00:27:25,760 --> 00:27:29,930

And research, like the stuff you're part of, is what's going to help us do that.

240

00:27:31,520 --> 00:27:31,880

Thank you.