

WEBVTT

NOTE duration:"00:19:11.6400000"

NOTE language:en-us

NOTE Confidence: 0.0720590204000473

00:00:00.080 --> 00:00:04.170 He.

NOTE Confidence: 0.925995707511902

00:00:05.040 --> 00:00:35.910 OK, so Haley is our social worker. Hopefully you guys have had a chance to interact with Haley. I just want to put in a plug for our support group, I've said many times our support group is really the Crown jewel of the program and the threats can cology program. And it is what we put into it. So if you or somebody that you that you know, or care about as lung cancer. I really encourage you to be involved in our support group.

NOTE Confidence: 0.940298616886139

00:00:35.910 --> 00:00:43.240 And if there's ways to make it better let Haley are I know 'cause I think it's a critical part of our program.

NOTE Confidence: 0.827898025512695

00:00:43.830 --> 00:00:52.580 So Emily are you going to, she's so Haley cannot be here her children are not feeling well so.

NOTE Confidence: 0.768023133277893

00:00:53.200 --> 00:00:55.820 I Emily is going to step in.

NOTE Confidence: 0.709457695484161

00:00:56.540 --> 00:00:58.830 OK, thank you.

NOTE Confidence: 0.912437200546265

00:00:59.450 --> 00:01:24.160 So we're going to do a brief session on coping with cancer and kind of what that means and I think more than anything else talking about patients from a patient perspective is really important. So we actually have one of our patients that volunteered to talk about her experience a little bit with you and so will start off the session with that and so invite Don to come down.

NOTE Confidence: 0.91875821352005

00:01:25.020 --> 00:01:35.030 And and give a little bit of that perspective and then I'll fill in with some of the information in terms of what we really work on and focus on with patients here it's Milo.

NOTE Confidence: 0.819289445877075

00:01:35.530 --> 00:01:44.940 So thank you. Thank you thank you.

NOTE Confidence: 0.874593615531921

00:01:45.680 --> 00:02:11.940 Pretty evening, I'm done, I'm actually a two time lung cancer survivor an over 10 years ago, I was not living in Connecticut. I wasn't in New Haven. I was in the Boston area and they found my lung cancer by accident. I had a cold. Everyone said it's the Monia. They did the X Ray and the doctor came in and he said to me.

NOTE Confidence: 0.902875483036041

00:02:12.460 --> 00:02:14.060 You don't have no monia.

NOTE Confidence: 0.88556694984436

00:02:14.630 --> 00:02:24.140 But I am seeing uhm what I believe is cancer and I went through treatment cancer free moved back to New Haven.

NOTE Confidence: 0.907163083553314

00:02:24.690 --> 00:02:55.160 And it was recommended that I see Doctor Guettinger and so I began. My annual cat scan visits to see Doctor Guettinger. One of the first few times. I saw him he said to Maine. We're shooting for that 5 year. Mark that 5 year. Mark is what we want to achieve so I counted my years and I got to the 5th year and I walked in and he came in, he said. Everything looks great. I said, Do we break up now and he goes dawn?

NOTE Confidence: 0.907961964607239

00:02:55.160 --> 00:02:56.850 We never break up.

NOTE Confidence: 0.770574688911438

00:02:58.160 --> 00:03:00.510 Um, I'm glad we didn't.

NOTE Confidence: 0.914403796195984

00:03:01.060 --> 00:03:10.270 Because we found cancer again. It was a different cancer, but again in the long and that was in July of 2018.

NOTE Confidence: 0.906282007694244

00:03:13.180 --> 00:03:19.200 At that time I got involved with the lung Cancer Support group.

NOTE Confidence: 0.746071457862854

00:03:19.960 --> 00:03:20.820 And.

NOTE Confidence: 0.95704460144043

00:03:21.440 --> 00:03:24.120 It was one of the best choices I've made.

NOTE Confidence: 0.93403285741806

00:03:24.930 --> 00:03:37.070 The lung Cancer Support group is a group of people. We meet the 1st and 3rd Tuesdays of the month and it's a place where you can go and you can talk about your disease.

NOTE Confidence: 0.890020728111267

00:03:37.590 --> 00:03:44.590 And it's OK to cry when you hear those words you have cancer.

NOTE Confidence: 0.959011077880859

00:03:45.380 --> 00:03:49.860 Everything changes everything changes.

NOTE Confidence: 0.899039924144745

00:03:51.240 --> 00:04:09.410 You can throw a pity party. We have pity parties often at our lung Cancer Support group. We talk about the uncertainty of cancer? Is it going to show up? What are the chances it's coming back and just living with that uncertainty day today?

NOTE Confidence: 0.801027953624725

00:04:10.250 --> 00:04:16.600 We talk about scan ritis that annual scan skin. I dishan we all get it.

NOTE Confidence: 0.931155443191528

00:04:18.920 --> 00:04:32.150 We talk about the resources available at smile. Oh, and also in the greater community and there are so many resources at smile. I think that's one of the ways we're very lucky.

NOTE Confidence: 0.933781743049622

00:04:33.360 --> 00:04:41.430 And we talk about the agony of choosing between longevity and quality of life.

NOTE Confidence: 0.935218811035156

00:04:44.080 --> 00:04:53.760 But the one thing that I've taken from this group is I sat in that room with some of the most courageous people I've ever met.

NOTE Confidence: 0.916585385799408

00:04:54.920 --> 00:05:00.190 And their courage has inspired me to get up each day.

NOTE Confidence: 0.84791374206543

00:05:00.840 --> 00:05:04.370 And to do the best that I can.

NOTE Confidence: 0.920818030834198

00:05:06.070 --> 00:05:13.370 It's just a very wonderful wonderful group of people today I'm a cancer survivor.

NOTE Confidence: 0.903988778591156

00:05:13.870 --> 00:05:18.380 And I see so many of my friends here.

NOTE Confidence: 0.935683250427246

00:05:18.880 --> 00:05:20.660 Today we are survivors.

NOTE Confidence: 0.916209399700165

00:05:21.250 --> 00:05:29.550 And I am so happy to have an opportunity to thank you and all of you professionals from smile Oh.

NOTE Confidence: 0.906955182552338

00:05:30.050 --> 00:05:40.120 You are an exceptional team. I don't care if you're in the Top 20 in my mind, you are the Top you are the best and it's not just.

NOTE Confidence: 0.861985802650452

00:05:40.880 --> 00:05:52.720 Your professional qualifications that you bring each day. It's your person your Personhood. I think Leo Biscaya talks about Personhood.

NOTE Confidence: 0.885086178779602

00:05:53.450 --> 00:05:58.070 And there isn't a person that's on my team that I don't.

NOTE Confidence: 0.866469621658325

00:05:59.070 --> 00:06:07.100 Cherish I have an awesome team. I'm standing here today cancer free so.

NOTE Confidence: 0.765174090862274

00:06:11.250 --> 00:06:15.880 Thank you smile, Oh thanks so much.

NOTE Confidence: 0.873973190784454

00:06:18.240 --> 00:06:31.260 That's a little bit of a tough act to follow but thank you so much for sharing that and a little little insight into your experience going through this.

NOTE Confidence: 0.928835809230804

00:06:33.920 --> 00:07:04.550 So as we think about coping with cancer. I think it's important to recognize people really will cope with cancer in very different ways. And it's going to be an individual process for each and every patient going through this and even different strategies throughout the course of the process from diagnosis to treatment and then survivorship sort of end beyond I think it's critical for people as you as you go through the process to really think about maintaining what's important to you. Whether that's relationships different activities that you enjoy participating in.

NOTE Confidence: 0.913361132144928

00:07:04.550 --> 00:07:15.360 Hobbies and if possible, and meaningful continuing to work and we really try and support that as much as possible for those patients that want to keep working through their treatment.

NOTE Confidence: 0.936278283596039

00:07:16.010 --> 00:07:42.850 And I think as as Don mentioned really trying to shift the focus and I think everybody. That's diagnosed with cancer is a survivor. You're living with your cancer regardless of where you are in this journey and we really want to help you if we can identify and figure out ways to live life to the fullest and maintain the best possible quality of life as you go through the whole spectrum of what it means to have a cancer diagnosis.

NOTE Confidence: 0.92628139257431

00:07:44.810 --> 00:08:15.490 One critical thing that I think is important because when you hear you have cancer is you automatically feel out of control and figuring out ways that you can regain that control and feel like you're not just kind of lost in this onslaught of appointment after appointment and scans and biopsies and meetings with different positions, but really learning about the diagnosis and treatment. If you want to you know for some people that's a component of taking back control, not everybody wants to know everything possible.

NOTE Confidence: 0.901173651218414

00:08:15.490 --> 00:08:39.000 You know about their diagnosis, but taking an active role in your treatment planning sharing with the team taking care of you? What's really important. You are there certain days of the week that are better for you to come into treatment? Are you trying to work treatment appointments around to work schedule or around family commitments, maybe, as a patient you're not driving but when's a family member available to drive you?

NOTE Confidence: 0.908825874328613

00:08:39.530 --> 00:09:11.880 Um and as you focus on what you can control remembering that it's normal to feel sad stressed uncertain. I mean, the anxiety and depression are real and sort of admitting those and working through those feelings with whether it's friends, relatives. You know talking to a counselor a social worker. If you don't want to feel like you're burdening family members with some of the emotions talking to trusted religious figures or even doing more private mechanisms like art therapy, drawing or keeping a private Journal.

NOTE Confidence: 0.923830151557922

00:09:11.880 --> 00:09:26.550 Just ways to kind of let those emotions be processed and get them out of you because if you can move through some of those negative emotions. It really will free up energy to be able to focus on important sort of positive aspects of life as you go forward.

NOTE Confidence: 0.887640655040741

00:09:27.360 --> 00:09:40.690 I think it's also really critical to remember take care of yourself and put yourself first you're sort of the Nexus of this whole operation as the patient.

NOTE Confidence: 0.908358871936798

00:09:41.190 --> 00:09:56.950 And it's OK to say. No, you know, everybody has stresses and demands on them. But this is a big deal, and you know sort of make this journey? What you want trying to carve out time every day to do something that's important to you.

NOTE Confidence: 0.926607489585876

00:09:57.570 --> 00:10:29.980 I think maintaining relationships outside of cancer. It's really easy when you have a circle of friends and family that cares about you. They're calling and checking in and wanting to know well? How are things going kind of what's the latest news but really trying hard to not have cancer be the center of every conversation because it gets really easy when everybody is calling and once that update before you know it. All you're doing is talking about cancer and trying to kind of shift that focus and you know, maybe a brief word or 2 and then but what's going on with you and let's you know, let's talk about something else.

NOTE Confidence: 0.909639596939087

00:10:30.000 --> 00:11:02.490 Certainly exercise is beneficial there's plenty of research that shows as you go through cancer treatment. Exercise has multiple different benefits so as long as you have the energy and there's not sort of a physical limitation. That's certainly something that's recommended for physical and mental benefits and don't be afraid to ask for help. You know whether that's for us from friends or family really trying to kind of create the circle of support where if coming to support group is the right thing for you.

NOTE Confidence: 0.89845871925354

00:11:02.490 --> 00:11:09.590 Finding that safe place to share your fears in your hopes and really celebrate the triumphs as you go through treatment as well.

NOTE Confidence: 0.904788076877594

00:11:12.160 --> 00:11:42.830 And I think it's really important also to recognize the importance of caregivers because for every patient. There is generally a village of caregivers around them and sometimes a lot of that strain and stress. Does fall to one person and recognizing sort of. It is a big commitment and caregivers typically aren't trained for that caregiver role. So it's a whole new world for them. Just as much as it is for the patient, but these caregivers really are a lifeline for patients.

NOTE Confidence: 0.899770975112915

00:11:42.830 --> 00:11:59.150 And we have a lot of resources to help so don't be afraid to reach out, both if patient needs assistance or for caregivers that were here and can kind of help help offer some guidance to support really this whole village and family around the patient.

NOTE Confidence: 0.904414474964142

00:12:01.480 --> 00:12:31.750 And then you know looking at it from a more granular level. There are really day-to-day challenges of going through this cancer process. Getting to accepting the diagnosis is nonlinear. It's you know, there's going to be good days. There's going to be bad days, and it's OK to have some bad days, and not every day. He has to be Mister and Mrs positive. I'm going to beat. This left those negative emotions kind of washed through you and process them and work through this.

NOTE Confidence: 0.918998777866364

00:12:31.750 --> 00:12:42.290 Constant adaptive process, sometimes it's isolating you know, nobody else is walking in your shoes as the patient diagnosed with cancer and that's a hard thing.

NOTE Confidence: 0.908220887184143

00:12:42.930 --> 00:13:14.660 I think another really hard thing is there is still a fair amount of stigma associated with lung cancer diagnosis. There's still this feeling that well if you smoked. You kind of did this to yourself and like doctor doctor doctor deck was just mentioning that may not really be true and we certainly see patients that have certain targetable mutations that may have had some early smoking history. You know years ago. But when we find these mutations. We really have a pretty good confidence level that they're smoking had nothing to do with the lung cancer that they got diagnosed with.

NOTE Confidence: 0.910805821418762

00:13:14.660 --> 00:13:15.550 Down the road.

NOTE Confidence: 0.368554919958115

00:13:16.290 --> 00:13:17.290 Hum.

NOTE Confidence: 0.919923424720764

00:13:17.850 --> 00:13:31.580 Other changes include coping with physical and cognitive challenges. I think chemo brain really is real and can cause some lasting deficits. That's hard for patients to deal with, and kind of work into their daily life.

NOTE Confidence: 0.897007048130035

00:13:32.100 --> 00:14:03.960 Um certainly with this caregiver and patient relationship. There can be rules changes an role strain often you know children are caring for patients and that flip of who's really the caregiver can be difficult. and I think you know financial and insurance concerns, adding another layer of

stress that we want to give everybody the best treatment possible but it does come at a cost and thinking about and recognizing What is this?

NOTE Confidence: 0.908801734447479

00:14:03.960 --> 00:14:27.020 Financial toxicity that we have that can be associated with treatment and be up front with your caregivers. You know, we have mechanisms to support that, but we don't know what you're getting billed so if there are challenges or issues with with the financial peace absolutely bring them to us discuss it in clinic and we can put into place a bunch of different supports when needed.

NOTE Confidence: 0.852279424667358

00:14:29.170 --> 00:14:35.850 And in many cases, you know, Don mentioned really you know.

NOTE Confidence: 0.913631558418274

00:14:36.600 --> 00:15:07.930 Having a positive way of positive experience in going to support group and meeting some of the people and I think I'm constantly amazed by the grace of patients coming in you know going through treatment fighting. This fight everyday but cancer really does help sort of distilled down? What is important you know what are the most critical things that are meaningful to us in our lives and as much as possible remaining positive that's not always an easy thing.

NOTE Confidence: 0.905699133872986

00:15:07.930 --> 00:15:26.080 But having goals staying engaged in in things that you enjoy doing responsive. You know, recognizing and identifying really what is your authentic self? What is important to you? What do you want to accomplish in in the course of your life?

NOTE Confidence: 0.907670497894287

00:15:26.620 --> 00:15:44.160 And then recognizing the limitations of life. We all you know are at some point, not going to be here. Unfortunately, but how do we transcend that limitation and how? Can we make? Whatever time we have left have the most sort of quality and importance that we can give it.

NOTE Confidence: 0.906710684299469

00:15:46.990 --> 00:16:07.940 So there's a whole bunch of layers of support that we offer through through smilow programs. There's meaning centered and either group or individual psychotherapy available certainly are lung Cancer Support group is a great Ave for many of our patients. We also have a caregiver support group that's available.

NOTE Confidence: 0.89857143163681

00:16:10.000 --> 00:16:40.600 And in terms of symptom control. We have nutritionists that are available to meet with patients. The Integrative Medicine

Clinic is really growing and kind of gaining steam to be able to provide some of the more complementary and alternative. Medison peace to our patients. We have a pact program for parents with young children who are learning to sort of cope with the diagnosis and changes that go with cancer. The palliative care group certainly is fantastic in terms of.

NOTE Confidence: 0.926526844501495

00:16:40.600 --> 00:16:57.370 Improving quality of life, helping us to manage symptoms. They specialize in pain management and they also have an interdisciplinary team of Physicians nurse practitioners, a social worker, Chaplin and psychologists so another really nice layer of support that we can add in.

NOTE Confidence: 0.899072408676147

00:16:58.040 --> 00:17:30.090 Miss survivorship clinic has been fantastic. I think now we thankfully are having really great treatments and we're getting more and more patients. Even with the stage 4 lung cancer diagnosis out beyond that, 5 year mark where you know what do we call it? Are you in remission? Is it potentially you know there's the C word for cancer. But there's also the C word for cure and once we get you past that plane. You know what do we call it and it creates almost this existential crisis in patients where it's like?

NOTE Confidence: 0.90385115146637

00:17:30.090 --> 00:18:01.960 Well, I have stage 4 lung cancer. I'm out 5 years. What do I do now, um and how do you kind of rap your head around that it's great news but it's still anxiety, provoking 'cause you're waiting for the other shoe to drop and when am I going to get the bad news so working with those survivorship clinic thinking about you know are there. Other medical things that should be done in terms of ongoing preventive care that maybe aren't as important when you're newly diagnosed but you get out 5 years and there are different things that we need to evaluate.

NOTE Confidence: 0.888620913028717

00:18:01.960 --> 00:18:11.870 Um we mentioned earlier smoking cessation services also are really important as you go through the treatment journey for those who still are smoking.

NOTE Confidence: 0.909354686737061

00:18:13.590 --> 00:18:44.100 Uhm and then just a list of other community resources certainly for going to the Internet and looking for information, making sure you're going to reputable websites American Cancer Society American Lung Association. There's online support groups patient advocacy foundations. Various research initiatives couple of things for patients to live strong program is run through the why and can really help with focused exercise patients for cancer patients and survivors looking to improve.

NOTE Confidence: 0.891806364059448

00:18:44.100 --> 00:19:06.150 Their functional status, those resources for children for of patients with cancer. Various avenues for financial grants and also just a plug for visiting nursing can support services or people will actually come into your home and help monitor you as you go through treatment and really partner with us in clinic to make sure that we're giving you the best care that we can.

NOTE Confidence: 0.910439133644104

00:19:06.810 --> 00:19:11.640 So with that I'll stop and take take a minute or 2 for any questions and then.