James Valentine, JD, MHS (00:00:00):

(silence).

James Valentine, JD, MHS (00:15:26):

Good morning. My name is James Valentine, and welcome to the externally-led patient- focused drug development meeting on cancer cachexia. I'm here with my cohost Elizabeth Franklin from the Cancer Support Community. And we're coming to you live from the D.C. metropolitan region, actually not too far from where the U.S. Food and Drug Administration headquarters are located. To open today's meeting, it's my pleasure to introduce Elizabeth, who is the president of CSC to provide some opening remarks.

Elizabeth Franklin, PhD, MSW (00:15:55):

Thanks so much, James and good morning, everyone. Welcome to the externally-led patient-focused drug development meeting on cancer cachexia. My name is Elizabeth Franklin and I'm president of the Cancer Support Community.

Elizabeth Franklin, PhD, MSW (00:16:09):

CSC is guided by our mission to ensure that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community. We are focused on the psychosocial wellbeing of patients and look beyond just their physical symptoms to what affects patients, caregivers, and their loved ones, mentally, emotionally, financially, and psychologically. We're the largest professionally led non-profit network of cancer support worldwide with 50 affiliate partners in over 175 locations throughout the country. Specifically, we provide support and deliver a comprehensive menu of personalized and essential services at no charge to anyone diagnosed with any type of cancer and to their loved ones. CSC proudly and boldly uses our three pillars: patient services, insight, and advocacy to serve our community through engagement and public policy and advocacy at both federal and state levels. We have become a leader in advancing the evidence base and promoting patient-centered public policies to ensure that the patient voice is at the center of the national dialogue.

Elizabeth Franklin, PhD, MSW (00:17:26):

Patients are at the core of our work. Therefore, the voice of the person with cancer cachexia is incredibly important and has pushed our advocacy goals forward. We have seen continued advancements in technology and research and know that the patient voice is absolutely critical to innovation.

Elizabeth Franklin, PhD, MSW (00:17:46):

Thank you to the U.S. Food and Drug Administration for permitting us to hold this meeting and to everyone for attending today. Also, we are grateful for the generous contributions of those who have financially supported this meeting, including Pfizer, Roche Diagnostics, and AVEO Oncology. Without you, this meeting could not happen. Moreover, we are pleased to have an attendance more than 150 advocacy and professional organizations, federal agencies and universities, industry stakeholders, and most importantly, patients and caregivers from across the world who support our work on cancer cachexia.

Elizabeth Franklin, PhD, MSW (00:18:28):

Only patient and caregivers can truly help us understand the effects of cancer cachexia. Today, you will hear about the daily reality of living with cancer cachexia from those with varying degrees of the syndrome, using different technologies and strategies to go to school, work, and cope with the often devastating side effects of having cancer.

Elizabeth Franklin, PhD, MSW (00:18:52):

To the people living with cancer cachexia and their loved ones participating today, we invite you to call, to write in during the program. We want to hear as many perspectives as possible. Even if you've only experienced the weight loss or muscle wasting, but you've not received an official diagnosis of cachexia, we want to hear from you.

Elizabeth Franklin, PhD, MSW (00:19:13):

There continues to be a tremendous unmet medical need for people living with cachexia. And we hope this meeting will educate us all. As one of our panelists shared ahead of the meeting, "Cancer cachexia made life as I knew it unrecognizable." So now that you know why this meeting is so incredibly important, let's begin.

Elizabeth Franklin, PhD, MSW (00:19:36):

We are pleased to welcome Dr. Theresa Kehoe from the FDA. Dr. Kehoe is the Director of Division of General Endocrinology in the FDA Center for Drug Evaluation and Research, and she has been at the FDA since 2002. She is in the part of the FDA that reviews new drugs for cancer cachexia. Welcome Dr. Kehoe.

Theresa Kehoe, MD (00:20:01):

Thank you, and good morning. I would like to start by thanking the Cancer Support Community for the invitation to speak to you today. I commend all of the staff involved in planning and carrying out this meeting. Over the last two years, our ongoing public health emergency with the COVID-19 pandemic has raised some unique challenges for meetings such as this. And I'm happy to hear that many patients, caregivers, advocates, and other stakeholders are able to participate today. Thank you all for being part of this meeting and sharing your experiences with us.

Theresa Kehoe, MD (00:20:46):

As you've heard, I'm the Director of the Division of General Endocrinology in the Office of New Drugs in the Center for Drug Evaluation and Research at FDA. I am a board- certified endocrinologist and have been in the Office of New Drugs at FDA since 2002.

Theresa Kehoe, MD (00:21:07):

The Division of General Endocrinology manages the drug development programs for many diseases, including hormonal disorders, growth disorders, and metabolic disorders of the musculoskeletal system associated with cachexia and sarcopenia.

Theresa Kehoe, MD (00:21:28):

Over the years, substantial progress has been made and continues to be made in the arena of oncology with many life-changing therapies becoming available for patients with cancer. These therapies can have great impact on the progression of the cancer and on extending survival for the patients. However, many of the cancers themselves and the therapies used to treat the cancer also have significant impact on a patient's quality of life.

Theresa Kehoe, MD (00:22:08):

Cancer cachexia is defined as involuntary weight loss and muscle wasting. This can negatively influence a patient's physical condition, quality of life, and prognosis. There are many factors that can play a role in the development of cancer cachexia. These include loss of appetite, increased inflammation, and increased energy requirements. It is estimated that as many as half of all patients with cancer may eventually develop cachexia.

Theresa Kehoe, MD (00:22:51):

While FDA plays a critical role in medical product development, we are just one part of the process. These patient-focused drug-development meetings give FDA and other key stakeholders, including medical product developers, academic researchers, healthcare providers, and federal partners, an important opportunity to hear directly from patients, their families, their caregivers, and patient advocates about the symptoms that matter most, the impact of the disease on a patient's daily life, and patients experiences with currently available treatments.

Theresa Kehoe, MD (00:23:39):

Currently, trials for cancer cachexia include endpoints like muscle mass and change in weight. These endpoints may be straightforward to measure, but the changes demonstrated do not tell us whether a patient's symptoms have improved. And without this information, it is difficult to define what is a clinically meaningful change. That is why we continue to work towards defining endpoints that demonstrate a patient's improvement, which would be clinically meaningful and informative to patients and prescribers.

Theresa Kehoe, MD (00:24:23):

We would like to hear what specific things patients look for in an ideal treatment to manage their cancer cachexia. It may be that a therapy would not be able to address all the aspects of cachexia. What symptoms or disabilities associated with cancer cachexia are most important? As you know, many therapies often have significant side effects that can worsen over time. What duration of treatment would you look for? A therapy that you can take for a long period of time, or something only a short course of treatment? These types of discussions will help inform the focus of new drug development and future clinical trials.

Theresa Kehoe, MD (00:25:20):

FDA protects and promotes public health by evaluating the safety, effectiveness, and quality of new products. But we do not develop the medical products and we do not conduct the clinical trials. It is FDA's responsibility to ensure that the benefits of the product outweigh the risks. Therefore, having these types of discussions and dialogue is extremely valuable for us because hearing what patients care about can help us lead the way in figuring out how to best facilitate medical product development for cancer cachexia, and understand how patients view the benefits and risks of the therapies for the treatment of cancer cachexia.

Theresa Kehoe, MD (00:26:12):

We look forward to incorporating what we hear today into the agency's thinking and understanding of how patients view benefits and risks for therapies for cancer cachexia. Your input and perspectives really help us and will also help industry and academia to move the drug development process forward to ensure that new medications meet the needs of people living with cancer cachexia. My colleagues and I are here today to help and hear the voice of the patient. So thank you for your participation. We are grateful for each of you for being here and sharing your personal stories, experiences, and perspectives. Thank you. And back to you, Elizabeth.

Elizabeth Franklin, PhD, MSW (00:27:07):

Thank you so much, Dr. Kehoe. Now we will hear from Dr. Jose M. Garcia, who will provide an overview of cancer cachexia and the current treatment landscape. Dr. Garcia is a professor of medicine at the University of Washington in Seattle and Director of the Clinical Research Unit at the Geriatric Research, Education and Clinical Center at the Puget Sound VA Health Care System. His current research focus includes different wasting conditions in cancer cachexia. His group participates in several human trials in patients with cancer, aiming at characterizing the pathways involved in cancer cachexia, identifying the mechanisms of action of different potential therapies and testing them in clinical trials. Welcome Dr. Garcia.

Jose M. Garcia, MD, PhD (00:27:57):

I want to thank the organizers for the invitation to speak. My name is Jose Garcia and I am a professor medicine at the University of Washington in the Department of Veteran Affairs in Seattle. I've been doing research and providing care in the field of cancer cachexia for over 15 years. I am honored to be here and to speak to a truly diverse audience that encompass key stakeholders in cancer cachexia.

Jose M. Garcia, MD, PhD (00:28:25):

These are my disclosures. Cachexia is defined as an involuntary loss of muscle mass, with or without fat mass loss, caused by a disease such as cancer that is not fully reversible by nutritional support and that leads to progressive functional environment. Although not everybody is familiar with the term cachexia, it is a very common disease that affects many of us, as patients, caregivers, or healthcare providers.

Jose M. Garcia, MD, PhD (00:28:58):

On the picture shown here on the left, you can see the late actor Patrick Swayze before his diagnosis of pancreatic cancer. And on the picture on the center, and on the right, you can see him after his diagnosis when he was suffering from cachexia. You can appreciate how he had lost both muscle and fat in his face and hands. And it only took on his physical function as he leans on post while walking. Cancer is not the only cause of cachexia as this is seen with many other chronic conditions such as lung, heart, renal disease, or simply aging. It's estimated that more than 5 million Americans live with cachexia. How common it is in cancer, depends at least in part on the type of tumor. While cachexia is less common in certain cancers like prostate and breast, it is extremely common with others, such as pancreatic, other gastrointestinal tumors, lung, and head and neck cancers. It is important to remember that because some of these tumors like breast and prostate are very common, a large number of people are living with cachexia due to these tumors.

Jose M. Garcia, MD, PhD (00:30:16):

Cachexia is a disease that is not limited to fat and muscle. It affects many different systems such as the nervous system that controls appetite and the secretion of hormones, liver that plays a role in regulating information, and other systems such as immune and gastrointestinal system.

Jose M. Garcia, MD, PhD (00:30:33):

There are many different factors that contribute to cachexia and several of them are often present at the same time. There are tumor-related factors, such as how aggressive the tumor is and whether it's progressing or causing inflammation. There are factors related to the patient, such as their age or other preexisting conditions, including lung and heart disease, depression, and hormonal issues. And there are also treatment toxicities contribute to cachexia. Surgery, radiation, chemotherapy, and opioids can cause difficulty swallowing, malnutrition, constipation, or poor appetite, for instance. These factors lead to sign and symptoms that can be seen in cachexia, including poor appetite, increased tendons expenditure, low body weight, muscle and fat mass fatigue, low muscle strength and functionality, and poor tolerance to therapy and decreased survival. Not every patient presents with the same combination symptoms. And this is an area where most research is needed to understand different classes of symptoms or phenotypes.

Jose M. Garcia, MD, PhD (00:31:59):

To diagnose cachexia, we look at four different areas. One is mass, which can be assessed by simply weighing the patient in the clinic, or by other more sophisticated methods in research studies, such as a CT scan, an MRI, or a densitometry or DEXA scan. We also look at symptoms, including appetite, fatigue, or quality of life. We do so by asking patients how they feel or in research by using validated questionnaires. Third, we look at strength and physical function. In the clinic we do these by using a clinician-rated score called the Karnofsky score. And in research studies, we can use a number of other tests. Measure grip strength, for instance, what we call stair climbing power, which is essentially having a patient climbing a flight of stairs as fast as they can. A six-minute walk distance test, where essentially you walk for over six minutes, or by using actigrapy-

PART 1 OF 10 ENDS [00:33:04]

Jose M. Garcia, MD, PhD (00:33:03):

Walk for over six minutes or by using Actigraphy. Essentially a device like your phone or your watch that can monitor your physical activity throughout the day. Other measures can complement the first three items. This includes, for instance, Biomarkers, the ones that are used in the clinic today include markers of inflammation, such as CRP or C-Reactive Protein or hormone called Testosterone.

Jose M. Garcia, MD, PhD (00:33:33):

On this slide in yellow, you see the items that are clinically available today and in white are those that are primarily research tools. So oftentimes when a patient comes to the clinic and the provider wants to see whether that patient has cachexia. The only thing that is done today is measurements of body weight and a body mass index, a clinician rated score and assessment of symptoms by just asking the patient, how they are feeling? That's usually the extent of it, even though some of these other tools could be used and are clinically available.

Jose M. Garcia, MD, PhD (00:34:12):

I'll just show you a multitude of tools that can be used to measure the impact of Cachexium patients. But we still have not reached a consensus on which test we should use? This is one of the main barriers in the field. Physical function in the ability to perform activities of daily living are very important to patients, to caregivers and to healthcare providers. However, most studies are focused on mass and not on function, at least in part, because of this lack of consensus on what are the clinically important tools for assessing physical function in its environment.

Jose M. Garcia, MD, PhD (00:34:52):

More research is needed to define validated measures of how a patient feels for instance, their appetite, their fatigue, their quality of life. How patients function, for instance, assessing mobility or activities of daily living, keeping in mind that these endpoints should be assessing the target population in that the magnitude of effect needs to be large enough to be clinically meaningful. So that is if we're for instance, measuring how fast somebody walk, as well as somebody walks now 10 meters or 10 seconds more, is that better than how it was at the beginning? That's what we mean by clinical meaningful.

Jose M. Garcia, MD, PhD (00:35:39):

I want to touch briefly on what is the current management of cachexia. This is an example of the current guidelines on the management of cachexia published recently by American Society of Clinical Oncology. In most cases, a visit with a dietician in nutritional supplements is recommended. In a few settings, a visit with a physical therapist, an exercise regimen are recommended. In my experience, this doesn't happen very often. Now with regards to medications, there are currently no approved medications for the treatment of cachexia. A handful of them are used off label with less than optimal results and often for a very limited period of time. So you can see how this is an area of great need.

Jose M. Garcia, MD, PhD (00:36:31):

So in recent years, our knowledge regarding the pathophysiology cancer cachexia has grown exponentially. Multiple targets have been identified through pre-clinical models and in non-interventional studies in cancer patients. So this is either using rodents for instance, or looking at a group of patients and see what symptoms associate with cachexia. Also what we call proof of concepts or early phase clinical studies have validated some of these targets. Unfortunately, they have all failed in more advanced clinical trials on what we call phase three clinical trials.

Jose M. Garcia, MD, PhD (00:37:25):

Here's the list of the phase three clinical trials that have been reported today. First, you can see that this list is very short and that the criteria to enter patients into the study and to define the success of this study are different between them. Some studies include lung cancer patients while other include collar cancer patients, all included some measures of mass and some included patient report and symptom burden, while none of them included measures of function. With regards to what was considered a successful study, it was defined as a combination of changes in mass and either symptoms or function. Again, this is an example of how much more we need to learn with regards to cachexia.

Jose M. Garcia, MD, PhD (00:38:23):

So a few final thoughts, cancer cachexia will present with different phenotypes based on patient, disease or treatment related factors. We need to recognize that a single agent may not treat all aspects of the disease and that a multi disciplinary approach is needed to address cancer cachexia. So that is not only your doctor, but also include your nurse, your dietician, your physical therapist, your social worker, your psychologist. There are urgent needs in cachexia. This include expanding education among patients, caregivers, and providers about the importance of cachexia. Increasing evidence, resources, and insurance coverage for supportive medical nutrition and physical therapy. These two, I feel are a low hanging fruit. More research is needed to validate animal models and to inform clinical trial design focused on different patient phenotypes, the selection of the target population. That is how do we select which patients will enter a clinical trial and the selection of the clinically meaningful outcomes that will define whether that study was successful.

Jose M. Garcia, MD, PhD (00:39:53):

The last thing very important point is that the funding mechanisms and opportunities need to be aligned with these critical gaps in the knowledge to enable the development and implementation of effective therapies that can help our patients. Ultimately, a successful approach will need input from all key stakeholders, and that's why I'm so happy to be here today and to present to this audience. Patients which are clearly at the center of everything we do, regulatory agencies, researchers, healthcare providers and payers. Research efforts should focus on developing clinical trials in a network that can validate entry criteria, endpoints, outcomes, and methods, and the potential synergistic effects of different drug targets, nutrition and exercise. Clinical meaningfulness should always be taken into account in the design of this trials. Eventually implementation research will be needed to assess the impact of different guidelines and therapies once these are approved.

Jose M. Garcia, MD, PhD (00:41:11):

Once again, I want to thank you for the opportunity to speak. Now back to you in the studio.

Elizabeth Franklin, PhD, MSW (00:41:20):

Thank you so much, Dr. Garcia for that excellent overview.

Elizabeth Franklin, PhD, MSW (00:41:23):

Now I'm excited to turn it back to James Valentine. He Will be our moderator for today. I would like to welcome him and we've gotten to know him over the past several months as he's truly been an excellent leader to help us plan this meeting.

Elizabeth Franklin, PhD, MSW (00:41:36):

James has worked the last 13 years as a champion for the patient voice. He previously worked at the FDA where he was a patient liaison, helping to incorporate the patient voice into medical product review. There James helped to develop and launch the patient focused drug development initiative. In private practice, James has worked with many patient organizations to ensure their community's voices have been heard by decision makers. Relevant to today's meeting, James has been involved in helping plan and moderating three fourths of the over 50 externally led patient focus drug development meetings. So we are in very good hands with James. So it is my pleasure to turn it over to James Valentine.

James Valentine, JD, MHS (00:42:21):

Oh, thank you, Elizabeth, for the introduction. It's wonderful to be here with you all today.

James Valentine, JD, MHS (00:42:26):

Now that we've heard a clinical overview from a disease expert, we get to turn to the core of today's meeting, which is to hear from you individuals living with cancer cachexia as well as the direct caregivers and care partners of those of you living with cancer cachexia or individuals who had lived with cancer cachexia. Patient focused drug development is a more systematic way of gathering patients perspectives on their condition and available treatments.

James Valentine, JD, MHS (00:42:57):

As you heard from FDA's Dr. Theresa Kehoe, your input can help inform the agency's understanding of cancer cachexia, to help inform drug development and review. While FDA has held many of its own patient focused drug development meetings today marks the 53rd externally led PFDD and due to the ongoing COVID 19 pandemic. This is actually the 19th fully virtual ELPFDD of its kind. With thousands of known conditions, this is a truly unique and important opportunity for this community today.

James Valentine, JD, MHS (00:43:33):

So our meeting today, it is interactive. So I want to tell you a little bit about what we'll be asking of you and how today's meeting will be organized, so you know what to expect. First thing in the morning, we'll be exploring the patient and caregiver experience of living with cancer cachexia, and the impact that cancer cachexia has on your daily life. Then we'll build on that discussion and come back in the afternoon for our second topic, which will be to explore various approaches to treatment, including experiences in clinical trials. We'll also be asking you some of those questions that Dr.Kehoe previewed about, for each of our two sessions, we'll first hear from panels of individuals living with cancer cachexia, as well as some care-partners and caregivers, they have prepared statements that will set a good foundation for the broader discussion we'll have with the rest of you who are here live today.

James Valentine, JD, MHS (00:44:27):

Those panelists were selected to reflect a range of experiences with cancer cachexia, but of course, no panel can represent the entire full range of experiences, which is why we'll then in our second way for hearing from all of you, broaden the discussion into a really an interactive discussion that we look forward to having with all of you, our patients and our caregivers who are tuned in. Our goal will be to build on what we've heard from the panel. Hearing either things that maybe compliment or even supplement what the panelists have shared. I'll be asking questions and inviting you to provide your comments. You'll be able to provide your comments in a couple of different ways. We will invite you to dial in by phone and I'll be sharing that number throughout the program. So we can actually have a live dialogue.

James Valentine, JD, MHS (00:45:19):

You can also submit in the comment feature that you'll see under the live stream on the website today, an opportunity to provide written comments, and you can also help answer those discussion questions in writing and Elizabeth will be helping share those throughout the program. You'll also see, we'll be joined by zoom with another panel of some patients and caregivers who will also participate in that live dialogue.

James Valentine, JD, MHS (00:45:45):

The third and final way that we'll hear from you today is through the use of polling questions. So these were our questions where we'll invite our patient and our caregivers to use their phone to respond. If you're following along on your computer, you can also use a tab in your browser, but either way, we want to actually take a moment here to go ahead and get you into our polling system. Once you're in the system, you'll be able to stay on that throughout the entire day, as we progress through new polling questions periodically, it will automatically refresh on the website.

James Valentine, JD, MHS (00:46:18):

So you can go ahead. Now, pull out your phone, open up a browser, go to that new tab in your web browser, and go to PollEV.com/Cachexia. Again, feel free to go there now that's PollEV.com/Cachexia, and we'll be getting to actually some of our first polling questions very soon. These questions they're going to help us broaden the dialogue to everybody who's live today and will help aid in our discussion getting us thinking about some of the topics that we want to explore with you.

James Valentine, JD, MHS (00:46:51):

Whether you're on live today, or perhaps you're viewing this on demand, the live recording of today's meeting, you will be able to provide written comments even after the meeting concludes today. If you walk away feeling that there's something that you forgot, or you didn't have a chance to raise, or maybe it's something that pops into your mind, a week or so from now, we want to encourage you to come back to this same web page. That comment form will be open for an additional 30 days after the meeting. All of the input from today, as well as all of the additional written input that we receive will be summarized in, what's called a voice of the patient report. This is the summary report that reflects what we've heard and learned from all of you today. That report will be provided to the food and drug administration, as well as made available publicly for all stakeholders to use, including our colleagues that are doing drug research and development.

James Valentine, JD, MHS (00:47:50):

So one last administrative thing here to cover is before we get into our first set of polling questions, I want to cover some ground rules that will apply for throughout the discussion today. So we encourage all of you, our individuals that are living with cancer cachexia as well as their family members and care partners to please contribute to the dialogue today.

James Valentine, JD, MHS (00:48:10):

Again, you've can do that through polling, calling in by phone, submitting written comments. We want to hear from as many voices as possible. The discussion today is limited to those individuals with cachexia, as well as their caregivers only. Our other stakeholders who are on from the FDA, from drug development companies, clinicians or researchers. They're all here just to listen. I also want to acknowledge that the views expressed today are going to be inherently personal and the discussion may get emotional at times. So respect for one another is truly paramount. To that end, I do ask that you try to be focused and concise when giving comments. So that way we can hear from as many voices as possible.

James Valentine, JD, MHS (00:48:56):

So without further ado, let's get into our first set of polling questions we have for you today. So you should have just opened up that web browser on your phone, opened up a new tab on your computer browser and go to again, PollEV.com/cachexia. I know that's being displayed right now for you all. So if you haven't already please go to that website and we're going to go ahead and get started with our first polling question for today.

James Valentine, JD, MHS (00:49:26):

This first set of questions, really just to get a sense of who we have in our audience. So we're going to start by ask asking, are you either A, an individual living with cancer cachexia or B the relative or care partner of someone living with cancer cachexia. Again, polling questions are limited to these two stakeholders for today. We encourage everyone else to pay attention to these live results and learn and listen. So we're going to give our audience today some time to make sure we get into the system. We want to capture your responses across the range of questions we have. So while this may be the simplest question of the day, we do want to just give a few moments here, make sure everyone gets into the system can answer these questions. Although as we're seeing, while responses are coming in and we're seeing a little bit of shifting back and forth.

James Valentine, JD, MHS (00:50:26):

It does look like the majority of our audience today are those who are representing patients as relatives or care partners. Then we see about quarter of the audience who are actual individuals living with cancer cachexia. We want to hear from all of you today, both the patient and the care partner perspectives can really help provide a lot of insight into what it is to live with cancer cachexia and how it's treated. So you both are very important.

James Valentine, JD, MHS (00:50:55):

We can move to our next polling question. So here we want to know where you, or if you're a caregiver, we're going to ask that you answer all of the remaining questions today to be about the person for whom you care, living with cancer cachexia. Although for this question, it's probably the same place, but the question here is where do you, or your loved one currently reside? The options here are, for the US, we've divided this into the various time zones. So A US in Pacific time, B US in Mountain time, C the US in Central time, D US Eastern time, E US Alaska time, F US Hawaii time. Then outside of the United States, G Europe, H the Middle East, I Asia, J Canada, K Mexico, or L some other country or region that has not represented in any of the other choices that you're seeing here for this question.

James Valentine, JD, MHS (00:51:58):

So it looks like we got pretty much the bulk of our responses here in while I was reading those responses. Just a moment here in case there's any stragglers in getting their response in. But, it does look like that we're seeing the greatest representation from the US Eastern time zone, but we do see good representation from across the United States participating today, including across Pacific, Mountain and Central times. We do have representation from Europe. So whether you're in the US or outside of the US, we do want to hear your voices today as well.

James Valentine, JD, MHS (00:52:33):

If we can move to our next polling question. So again, just to get a sense of who we have in the audience today here for our third question, we want to know you or the loved one for whom you care that lives with cancer cachexia, are they A female, B male, C non-binary, D if you prefer not to identify or E other. Again, we want to know the, for either yourself or the person that you care for, your loved one with cancer cachexia which response best represents their identity. So again, we'll give you a few more moments to get responses in here. We want to make sure everyone has that chance to answer these early polling questions. As it stands, it looks like we have a little bit more representation from females who are living with cancer cachexia, but pretty close, perhaps also with males. We do not have anyone who has selected any of the other categories.

James Valentine, JD, MHS (00:53:56):

If we can move to our fourth polling question. Here, we want to know how old are you, or again, your loved one that's living with cancer cachexia. If you are the caregiver of someone who has passed away, please select the age at west, which they passed away. The options are A zero to 18 years of age, B 19 to 30 years of age, C 31 to 50 years of age, D 51 to 60 years of age, E 61 to 70 years of age, or F 71 years of age or older. Again, this is the age of the person living with cancer cachexia or who lived with cancer cachexia.

James Valentine, JD, MHS (00:54:50):

So we're seeing quite a spread of ages represented in our audience today, every age category living or having lived with cancer cachexia represented, except for those in childhood years. We're seeing perhaps the biggest category in the 61 to 70 year age range followed by the 71 year age range and older. But we do have representation across all of the other adult age ranges.

James Valentine, JD, MHS (00:55:21):

We go to our fifth polling question, I promise these questions will get more difficult and interesting as we move through the program. Again, we're just getting a sense of who we have in the audience. So our last polling question was asking about current age and so here we want to instead look back and think about at what age did you, or your loved one first have symptoms of cancer cachexia. Again, you can answer these whether or not you or your loved one has been diagnosed with cancer cachexia. Here, we want to know about that first symptom. That first symptom may be different for different people, but whatever that first symptom of cancer cachexia was, did you experience it or your loved one, experience it at A between birth and age 18, B between age 19 and 30, C between age 31 to 50, D between age 51 to 60, E between age 61 to 70 or F that first symptoms of cancer cachexia was experienced at age 71 or older.

James Valentine, JD, MHS (00:56:27):

So while any other results responses are coming in already, what stands out to me is we see that shift earlier, those age of first symptom, of course, coming before current age, but that has actually some of those first symptoms of cancer cachexia did occur in childhood for some as we're seeing here. So we're seeing, would be interested as we get into our discussion today, to understand how the symptoms of cancer cachexia have evolved or changed over time. Is that first symptom, is that something you still have? Has it progressed or gotten more severe? Have you gotten different symptoms of cancer cachexia, over time? We're going to explore some of those topics in our discussion today.

James Valentine, JD, MHS (00:57:16):

So we can move to our six polling question. This will be our final demographic polling question before we move into our first topic. We could just hold on one second. Here we're going to make sure we can get this sixth polling question up. So here we want to know is what type of cancer led to having cachexia for you or your loved one? The options are A lung, B breast, C skin or melanoma, D prostate, E colorectal, F kidney or bladder, G non kins lymphoma, H thyroid eye endometrial, J pancreatic, K leukemia or blood cancer, L co angio carcinoma, or M some other cancer not listed on this slide that again, led to you or your loved one, having cancer cachexia. So we receive responses here still coming in. So we want to give everybody a chance to respond here. We are seeing quite a spread here of different types though. We heard that in our clinical overview presentation, that there is can be quite a range of cancers that can lead to having cachexia. We're glad to see we have representation here today across so many different types, including some that we didn't list on the slide. So we, of course, as you're sharing your perspectives, your experiences, please do share with us also the type of cancer that led to having cachexia. It's always valuable to understand if maybe there are any differences in that experience based off of the type of cancer that led again to having cachexia.

James Valentine, JD, MHS (00:59:19):

So with that, we're going to now shift from these demographic polling questions into that first topic that I had previewed for you, which is really now to understand from you what it is to live with cancer cachexia.

James Valentine, JD, MHS (00:59:34):

If we can pull up our discussion questions for this topic, you'll see some of the types of things we're going to ask you to weigh in on again, through more polling questions, by calling in, by writing in. We want to know of all the symptoms or health effects of your cancer cachexia which one to three of those have had the most significant on you or your loved one's life. We know that there's many different symptoms, different health effects, but what we don't know is perhaps which have our most troublesome for you.

James Valentine, JD, MHS (01:00:04):

We want to know how those symptoms vary? How do they vary from day to day, maybe on a best day versus a worst day of living with the symptoms of cancer cachexia? We also want to know how those symptoms and health effects have changed over time, whether that's from week to week, month to month, or even over the course of different years? We want to know not only what are these different symptoms and health effects that you've had, but also the impacts that they've had on your life activities that are important to you, that maybe you or your loved one can't do at all, or maybe as fully as you would like because of cancer cachexia. Knowing that not all of the experiences of cancer cachexia are ones that have already occurred, but that you'll continue to live with cancer cachexia. We want to think a little bit and hear from you about your concerns, your worries, your fears for the future as you, or your loved one get older living with cancer cachexia.

James Valentine, JD, MHS (01:01:04):

So to get us started on this topic, we are fortunate to have some of your peers, individuals living with cancer cachexia, and care partners who are serving as panelists and are going to be sharing some of their stories. So we have Felicia, Rochelle, Michael, Marianne, and Megan. I'd like to ask Felicia, go ahead and take it away.

Felicia J (01:01:32):

My name is Felicia. I am a third generation breast cancer overcomer. I define overcomer in the following context, I have watched cancer affect 11 women in my maternal family, for more than 30 years. I had a front row seat for each diagnosis and the theme was almost identical. There was a breast cancer diagnosis treatment, side effects, remission, reoccurrence, hospice, and finally death.

Felicia J (01:02:03):

As a caregiver in many of my family's cancer journeys, I was the perfect student learning all cancers nuances. After my cancer diagnosis, cancer seemed surreal. I experienced shock, helplessness, mental and emotional vulnerability. However, my most debilitating cancer foe was something that was unfamiliar to me. Thus, I attribute my significant weight and muscle loss as a part of the cancer experience. Things deteriorated and I was afraid without answers as to what was happening to me. As my treatment progressed, my ability to be independent and ambulatory, decreased progressively. The most significant change was my inability to work full time. My job required physical stamina and I had none. I needed to go on in definite medical leave.

Felicia J (01:03:03):

Next I discovered during my hygiene regimen that I was too weak and I could not lift myself out of the tub. I sat there and tried not to cry. Why did my legs and arms feel like jello? That was not firm. Eventually I mustered up enough strength to get back to my bedroom. There I was sitting on the side of my bed. I had to dress myself by putting on each piece of clothing and resting. I got up and pulled my jeans up around my waist and button them. I was almost proud of myself, but I had a surprise. My jeans fell to the floor as a plus size woman. I should have felt joy at losing weight, but all I felt was dread. I knew that something was wrong and I did not know what it was.

Felicia J (01:04:02):

I scheduled an appointment with my medical oncologist. Hopefully he could give me an answer. During my oncology visit, we discussed as significant weight loss, as crazy as this sounds. He asked me if I were dieting, my doctor suggested that I see a specialist. Now I was afraid that the cancer did spread. I left this office that day feeling as if my body had betrayed me. I had seen weight and muscle loss and other breast cancer family members, and theirs ended in death.

Felicia J (01:04:38):

My son was my primary caregiver. He did everything possible to see that I ate something each day. The emotional stress was awful having my 16 year old son insist that I eat, but I was vomiting everything that I in took. As the weeks of treatment continued, I did not improve. My ambulatory status decreased from independent to needing assistance, walking, standing, and all other physical activities.

Felicia J (01:05:14):

I needed to hold onto something for someone. My favorite activities of walking at the beach and swinging at the playground came to an abrupt halt. I and my caregivers turned into a ball of worry, stress, anxiety, and mental anguish because of an unnamed medical issue. I had no term at all for what was happening. It was emotionally challenging for myself and my son to alleviate some of the medical and emotional stress. I decided that a plus woman like myself, losing weight was beneficial. My friends and coworker commented on how great I looked. That thinking helped me manage the right..

PART 2 OF 10 ENDS [01:06:04]

Felicia J (01:06:03):

Great I looked. Their thinking helped me manage the rising depression, fear and uncertainty about dying and what was happening to me. However, I learned I was blindsided by what was called or related to weight and muscle loss. A term that I had never heard, cachexia, had taken control of my life. I wish there was someone on my medical team that knew about cachexia, that then they could create a patient plan to help me fight it. And it would have relieved myself and my caregivers of unnecessary disease-related stress. Now cachexia is part of my terms in my cancer journal.

Rochelle M (01:06:50):

Hi, my name is Rochelle, and at the age of 48, I was diagnosed with incurable breast cancer. 10 months later, I was informed that I had developed wasting syndrome. Initially I had no clue what that meant, but my doctors and nurses kept stressing the importance of eating whatever I could. Later, I would understand why, because cancer cachexia, as it is medically known has made life as I knew it unrecognizable.

Rochelle M (01:07:19):

After starting treatment, I immediately noticed the desire to eat fading each day. Within three months of starting treatment, I had started to lose weight. The fatigue in the weakness started within just a few weeks of my first treatment. Just to walk my beautiful little pug 10 minutes left me winded. Eating became a chore and making a meal, forget about it. It took every ounce of energy to eat because I was exhausted and nothing tasted normal.

Rochelle M (01:07:48):

I lost about 10 pounds, but not too much at first. By December 2020, most of my clothes did not fit and I realized I had lost more weight. I didn't want to look at the scale, but I knew something was not right. It's just one of the many side effects of cancer treatment, I told myself. When I went to treatment in January, that is when my doctor initially noticed the weight loss and encouraged me to eat, again, whatever I could. I did try, but I couldn't hold my food down, and if I did manage to keep it down, I immediately went to the bathroom after. This became a pattern and I followed up with my doctor. He asked what I was eating, why I couldn't eat and made some suggestions. I tried all of them to include using certain seasonings to help with the taste, which did help for a few weeks.

Rochelle M (01:08:37):

During treatment in February, I was pulled aside and told that I had developed wasting syndrome, AKA cancer cachexia. I have what? At this point I had went from 130 pounds down to 100 pounds between December and February. "Not another thing to think about," I thought. My symptoms started with the loss of appetite. Eating became a chore. Everything about it was hard. Preparing meals, smells, the look of it, tasting it. It felt like I was eating paper.

Rochelle M (01:09:09):

I knew something was drastically wrong because I was a bonafide foodie. When I did eat, I either became nauseous or had diarrhea. Both became my new best friends because they visited often, daily, whether invited or not. Then my throat and chest began to hurt when I ate solid foods, so I was placed on a liquid diet. I began to have issues with my teeth and developed a bad case of GERD. Now, in addition to everything else, I had to see a dentist every three to four months for a specialized cleaning, just so that I don't lose my teeth.

Rochelle M (01:09:48):

All of these particulars that I needed to think of and consider felt like a full time job. How can I do all of this and maintain a regular lifestyle? Needless to say, the idea of eating or should I say not eating has further made me feel isolated and caused significant anxiety and depression. Socially, things are totally different. I've lost friends, the career that I knew and loved, and some of the activities that I love most, which are traveling and community service. I don't have the energy. My immune system is compromised, which makes me at risk for infection, so I've got to be very careful. So we don't go out very much.

Rochelle M (01:10:37):

I feel like I've been forced into the life of someone much older, prematurely. I hit rock bottom in March 2021, when I got down to 94 pounds from 130 pounds in less than four months. When I told my husband, I will never forget the look on his face. He knew I needed to eat or else. We used to love to travel, work out together, visit new restaurants, spend time with family and friends, but not so much anymore. My biggest fear is the impact that cachexia will have on my overall cancer diagnosis. I wonder about having complications to my illness, dying, leaving my husband, my family and friends, but I've realized I can't focus on that. My focus is on healing and ensuring that I eat so that my treatment will work. I refuse to give up and I'm determined to rebuild my new life.

Michael M (01:11:41):

Hi, my name is Mike, and I play the triple role of patient, survivor, and caregiver. I was diagnosed with stage four colon cancer at the age of 42 in 2017. After my first 12 rounds of chemo, I had a recurrence in the fall of 2018 and had to have another surgery. At that point I had no evidence of disease for almost a year and I was in survival mode, until I had another recurrence at the beginning of 2020. I'm currently in active treatment again and my girlfriend Carol, who lives with me, is also a stage four colon cancer survivor, so I play caregiver to her. Prior to my diagnosis, I was working full-time in corporate America and taught a group fitness class twice a week. Once I was diagnosed and had my colon resectioned and a temporary ostomy bag, I began six months of chemotherapy.

Michael M (01:12:34):

At that time I didn't know what cachexia was, but I began to feel the effects right away. I went from being in the gym six to seven days a week to barely being able to walk up and down a flight of stairs. I was struggling to keep up at work. I had difficulty remembering things and multitasking. I would lose focus very easily. Just felt like I was in a fog. I would try to walk to the mailbox and when I got back inside, I felt like I was run over by a bus and I had to lay down and rest. It was a struggle even to just lift a frying pan to cook for myself. Even taking a shower became draining, so I went from showering daily to only showering once a week. These were all the early signs of cachexia that I was experiencing.

Michael M (01:13:15):

I took a leave of absence from work and went on long term disability so I could focus solely on getting through chemo. I tried to eat healthy, but there were many times when I would eat McDonald's or chocolate ice cream, just to keep my weight up. However, I just completely lost the desire to exercise and felt too physically drained to even try. That led to a lot of muscle loss, and all of this combined led to depression. My care team kept encouraging me to at least try to walk when I could and to keep eating anything I could no matter what, just to keep my weight up. In the fall of 2018, I was told I had no evidence of disease and my employer advised they were stopping my disability and I needed to return to work. I knew, however, I didn't have the stamina to work eight to ten hours a day in the office yet.

Michael M (01:14:02):

As I got back into my routine, my energy level started to increase right as I went back to work. I even started pursuing my MBA at night. I was feeling like I was getting back to my old self, even though I was doing maintenance chemo the entire time I returned to work. Then in January of 2020, I had my second recurrence and I had to go back on more aggressive chemo. This time I kept exercising except for three to four days during my treatment weeks. I also kept pursuing my MBA. I kept at this pace for almost two years before it became too much. My performance was slipping at work. I felt like I was letting my team that I managed down because I was struggling mentally again with memory, multitasking, and learning new things. So I made the decision to go on long term disability again, and I stopped pursuing my MBA. Recently, the chemo I was on stopped working and those original cachexia symptoms came roaring right back. I would sleep a lot. I had trouble breathing, so I really struggled to exercise and I would spend most of the day on the couch. I lost the muscle I had just rebuilt over the last couple of years, and it was very frustrating. When I'm dealing with cachexia I have no desire to do one of my favorite outdoor activities, which is hiking. When I'm able to stay active and rebuild my strength, I can hike up a mountain as Caroline and I did together in 2019 when we climbed up Mount Flora in Colorado for an event called A Climb for a Cure. What I fear most is that the chemotherapy I'm on will eventually stop working and the cancer will worsen, and so will the cachexia.

Michael M (01:15:39):

I fear losing my muscle and the weight that I had regained. I fear not being able to be active in doing things outside, like hiking, skiing, and golfing. Being active is how I overcome cachexia, but it's frustrating that I have no control over the cancer or how much chemotherapy my body can handle. I just know that being in the best shape of my life when I was diagnosed allowed me to endure aggressive chemotherapy. Since 2017, I've endured over 70 plus rounds of chemo, but if the cancer won't quit, then neither can I.

Marianne B (01:16:14):

Hello? My name is Marianne and I'm here to share the story of my daughter, Melissa. My daughter was diagnosed with brain cancer at the age of eight. The symptom that affects my daughter the most is the loss of appetite. We are constantly trying new things for her to eat. However, we were told many years ago that the radiation ruined her taste buds, and so this might be what has started the cachexia process a long time ago. She has no interest in food. If left alone, she will never eat. Before we realized that she had cachexia, Melissa was living on her own in Florida. There was a time when we decided that it might be in her best interest to come home to live with us in New York. She had an appointment with her neurologist and when she was checked in, they did her vitals.

Marianne B (01:17:07):

Her heart rate was elevated and her oxygen was very low. They rushed her to the ED in the same hospital. She was admitted with failure to thrive. She had lost 12 pounds and we then learned that she was not eating as well as not drinking. After Melissa was released from the hospital about a week later, she came home to New York. It was then that we realized that something was wrong. In addition to the loss of appetite, Melissa has been anemic for many years. She had gotten very weak and is now in a wheelchair. We suspect that it might be cachexia with a combination of normal pressure hydrocephalus that is responsible for that. Melissa's best days and worst days are not very different from each other. She wakes up at around 10:00 AM and is tired and ready for a nap shortly after lunch at about 2:00 PM. She never has much of an appetite and is a very picky eater.

Marianne B (01:18:08):

Most times she likes something and enjoys it. But within a day or two, she's changed her mind and doesn't like it anymore. I cook very blandly for her. When I put dinner in front of her, she not only takes about an hour to eat a small amount of food, but she also picks apart the food while she searches for something in it that she doesn't like. Melissa's symptoms have been fairly constant for many years. It's me that she has a hard time coping with, because I'm the one who's constantly at her to eat and to drink. It's been a very long time, 35 years since Melissa's original diagnosis. For the most part, she has been able to live a life with purpose and fulfillment. Even though she was on social security disability, she found ways to stay busy and usually volunteered in the local schools as a teacher's aide.

Marianne B (01:19:05):

But after five years of volunteering every single day from 9:00 AM to 2:00 PM, she was handed a letter on the last day of school and asked not to read it until she arrived home. It said that she would not be welcome back the following school year. She continued to decline after that and we knew that we had to bring her back to New York to live with us. Now that she is living in New York, she's homebound. She would no longer be able to volunteer in that or any capacity. At this time, Melissa is reliant on my husband and myself, as well as an agency that provides aides to help us. She is no longer able to drive, shop for herself, or even prepare her own meals. In addition to everything that has gone on, like the rest of the world, we also are affected by COVID.

Marianne B (01:19:59):

We hope that eventually she'll be able to have her aides take her to stores and hope that she can get out of a little bit more. The most important thing that Melissa would like to do and misses the most would be to volunteer as a teacher's aide. She had such self-fulfillment, having a reason to get up in the morning. Now she's always exhausted and doesn't have the energy to even think about it. Melissa is 43 years old and I worry about how much longer my husband and I will be able to take care of her. We are both in our late 60s and it is most definitely getting harder and harder to take care of her.

Marianne B (01:20:36):

The most frustrating thing about her condition is that you would think that surviving cancer would be enough of a hardship, but I've always said that we cured her brain cancer, and now we will spend the rest of our lives, curing the cure. Because of her cancer treatment, she has not developed into a normal adult physically. She has pencil thin legs and arms, but she has a big belly. If she gains weight, it all goes to her belly. In an ideal situation. I wish that there was something that could get Melissa to understand that this is an important part of her illness and effects, but sadly, she's battled so many problems over the years that she doesn't really look for cures. She is suspicious of what is presented to her and she never goes all in.

Megan T (01:21:25):

Hello. My name is Megan. I live in Philadelphia with my husband, our dog, our cat, and two Guinea pigs. I'm a proud aunt to three nieces and two nephews. I'm 35 years old and I am living with a form of bile duct cancer called cholangiocarcinoma. My journey with cancer cachexia unknowingly started months before I was actually diagnosed with cancer. In March of 2020 I started working from home full time because of the pandemic. I started to notice some changes happening. I became more tired and physical exercise became harder and harder. I initially brushed these symptoms off as new working from home pains, but then everything just progressed from there. In my case, I started to tolerate different foods less and less. I stopped having an appetite and I wasn't able to digest certain foods as well as I used to. I made appointments with my family doctors who prescribed prescription heartburn medications.

Megan T (01:22:22):

When those did not work, I switched to new medications and started experimenting with my diet to see if I was having a sudden dairy or gluten allergy. When all that didn't work, my doctor decided that I should go see a GI specialist. Because of the pandemic, it took me a while to get an appointment to see a GI specialist. It was late spring at that point and I had to wait until the summer to get in. I started seeing weight just drop off of weird places where I hadn't previously been able to lose weight. I became really exhausted and I was no longer able to get through a work day without napping through my lunch break. Getting up the stairs with a basket of laundry became a struggle and then getting up the stairs altogether became a struggle, and I wasn't able to keep up with my household chores anymore.

Megan T (01:23:07):

I went from doing three mile daily walks and hikes through the state park to struggling just to keep up with my dog going down the street. I couldn't watch my nieces and nephews anymore without help. And even then I was just exhausted just spending a few hours with them. I knew this wasn't normal for a healthy 34 old woman. I started to think that something was really wrong. I was too young to be this tired all the time. And why was I still losing weight so rapidly, when I was the least active I'd had ever been. Since cancer runs in my family, I did make an appointment to see my OB GYN that summer, just to make sure everything was okay. When I described my symptoms to my doctor, she gave me a high five and congratulated me for losing 60 pounds in such a short amount of time.

Megan T (01:23:51):

When she asked how I did it, I told her that I really wasn't trying to lose that much weight so quickly and I thought that something was wrong, but I received a clean bill of health with that high five and was sent on my way. I still see all of these doctors on a regular basis, even though they missed a serious diagnosis. I just think we have a blind spot when it comes to rapid weight loss, especially in young people. We're just conditioned to always see weight loss as a positive, even if it's a symptom of something much worse. In July of 2020, I finally had my appointment with that GI specialist. I took the first available appointment they had, and when I described the way I was feeling to the nurse practitioner and mentioned my weight loss, she immediately picked up her head and said, well, that's alarming.

Megan T (01:24:38):

She started off by prescribing a huge array of blood tests, which first tipped us off that something serious might be happening. Blood tests turned into ultrasounds, which turned into CT scans and then an MRI. In August of 2020, I received a call from my GI nurse practitioner that I had cancer. I was told to find a good surgical oncologist and in September of 2020, I was officially being treated in the oncology department at a major hospital. After additional CT scans, a biopsy, a chemo port installation followed by a second surgery, I was officially diagnosed with bile duct cancer.

Megan T (01:25:15):

Unfortunately for me, I was diagnosed with an aggressive, fairly rare type of cancer at stage four. My prognosis was not great and I was told that my condition was most likely terminal. We were fighting for a few extra years at that point, at least we hoped. I just kept thinking to myself if I had known something serious was happening when I first started to feel bad earlier in the year, would I still have received such a poor prognosis. Luckily for me, I did respond very well to an aggressive chemotherapy regimen and I started gaining weight and muscle back after a few months of steady treatment. I still do struggle with some symptoms of cachexia. Fatigue, lack of appetite at times, and muscle wasting will probably continue to be part of my life for a long time. But at this point it's hard to know if they're symptoms of cachexia, side effects from the chemotherapy, or symptoms of the cancer itself. I really just think we have a ways to go when it comes to cancer diagnosis, especially in young people. To someone fighting cancer, a few extra months can mean a lifetime. Thanks.

James Valentine, JD, MHS (01:26:23):

Wow. Thank you, Megan and to all of our panelists for being so brave and being willing to share your stories, your experiences, personal experiences living with cancer cachexia or your loved ones. Really important to hear so much of about this and what it has looked like and felt like in your daily lives. And so now we're going to continue on that topic, and it's our first opportunity today to broaden the discussion. To all of you who are following along live virtually here today, and the audience, if you have something would like to share on these topics of the symptoms and health effects and impacts in daily life of living with cancer cachexia, we would encourage you to call in at this time. That number, you can jot this down and call in throughout the program today, is +1 703-844-3231. Again, you can call in, we'll have you live on the program, dial in at +1 703-844-3231.

James Valentine, JD, MHS (01:27:27):

When you call in, you'll just share a little bit of information with our operator and they'll get you into the queue so we can bring you into the live program today. But to get all of us thinking about these same topics, what it is to live with cancer cachexia, what are those symptoms and health effects that you deal with in day to day life, we're going to of go back to a couple of polling questions to get us started. So again, you can open up that web browser on your phone, you can go to that tab that you have open, go to pollev.com/cachexia. Again, keep that open throughout the day to day, we'll be coming back periodically. The questions will automatically update. Our first question for you is we want to know which of the following cancer cachexia-related health concerns do you or your loved one have, or have had in the past.

James Valentine, JD, MHS (01:28:19):

And here you can select all that apply. So some of the symptoms and health concerns might be A, severe weight loss, B, loss of appetite, C, being repelled or disgusted by food, D, nausea, E, a loss of taste, F, diarrhea or upset stomach, G, pain, H, the inability to gain weight even if eating well, I, muscle weakness, J, brain fog or other cognitive impacts, K, fatigue or the feeling of tiredness, L, malnutrition, M, mood changes like depression or anxiety, or N, some other symptom or health concern that you or your loved one have had or have currently as a result of cancer cachexia. And again, please select all that apply. I will point out, this is our first polling question where our participants can select more than one option. So what you're seeing is a percentage of total responses, so that it is not the percentage of people who have selected a particular response. So for purposes of today, whenever we have one of these questions where our respondents can select more than one option view these bars as a kind of ranking, but don't focus too much on the percentage there.

James Valentine, JD, MHS (01:29:44):

So we'll give just a few more moments to allow all of our patients and caregivers to respond to this polling question, although as it stands, we're seeing every one of these symptoms and health concerns represented today. In this kind of relative ranking, we see that loss of appetite, muscle weakness, and the feeling of fatigue or tiredness are the top three, followed closely by of course, severe weight loss and mood changes. We heard a little bit about that from our panelists, but we know that there's not just the physical impacts of living with cancer cachexia, but also the mental and emotional ones. So we're seeing a high impact of that. And then we see, maybe as a third tier, loss of taste and diarrhea or upset stomach as some top symptoms. Although again, everything here has been selected, including others, things that we haven't had listed on this slide. We want to hear about all this wide range of different health concerns.

James Valentine, JD, MHS (01:30:50):

As we heard in our clinical overview presentation, different people will have different kind of constellations or sets of these symptoms. And so we want to know what is the constellation that you're currently living with and has that been different over time? So again, as you're answering these polling questions, we want this really to be just the start of thinking about this. And we want to encourage you to call in, and of course at any time you can see right now under your live stream, there's a comment box, and you can write in with some of your thoughts, share some of your experiences there as well. And we'll be reading those throughout the day. I want to do one more polling question before we brought in the discussion.

James Valentine, JD, MHS (01:31:40):

So in a second polling question, we want to know of those same cancer cachexia-related health concerns, and the last one you told us all of the different ones that you have, or have had, here we want you to think and pick what you think are the top three most troublesome of those various health concerns or symptoms that you have, or have had in the past.

James Valentine, JD, MHS (01:32:06):

I promised earlier that this would get a little trickier, a little more difficult. I know each of these things can have such a large impact on your lives, but for you personally, which up to three of these things have had the greatest burden or caused the most trouble for you in your life? So again, the response options are A, severe weight loss, B, loss of appetite, C, being repelled or disgusted by food, D, nausea, E, loss of taste, F, diarrhea or upset stomach, G, pain, H, inability to gain weight even if you're eating well, I, muscle weakness, J, brain fog or other cognitive impacts, K, fatigue or tiredness, L, malnutrition, M, mood changes like depression or anxiety, or again N, some other health concern or symptom that's not listed on this slide. And again, here we're asking for your top three most troublesome of these various symptoms. So as it stands, it looks like, and again, these are our relative rankings, because our participants can select more than one response. So it looks like the number one is muscle weakness, followed very closely or actually neck and neck with the feeling of tiredness and fatigue. So we want to hear about these things. Saying muscle weakness probably means different things for different people. What has that muscle weakness looked like for you? What has fatigue or tiredness feel like for you? Why did you say it's more troublesome than maybe some of the other things that you experience? We kind of see as other high troublesome symptoms, the loss of appetite, as well as the severe weight loss, but we see a number of other of these health concerns being selected as other individuals' top three, everything except for the being repelled or disgusted by food, nausea or other symptoms.

James Valentine, JD, MHS (01:34:06):

Everything else is in multiple people's top three most troublesome symptoms. So keep your responses in your minds. We're now going to broaden the discussion. We want you to call in, write in, tell us why you picked which of these symptoms to tell us that they're the most troublesome for you. And we're going to start this discussion, broadening it yet again with our Zoom panel. So I'd like to welcome our Zoom panelists, your peers, individuals living with cancer cachexia, and care partners. So I want start here and maybe start with you, Stephanie. As you were looking at those polling questions, particularly the second polling question, and you went from checking off all the different symptoms that were experienced and then had to narrow it down to those that are most troublesome, what did that whittling look like? Did you have a large number of symptoms to pick from, and why did you pick ultimately what you did in the second question?

Stephanie K (01:35:12):

Thank you so much, James. My name is Stephanie Klein-Ahlbrandt, and I am living with stage four, inoperable cholangiocarcinoma or bile duct cancer. I'm based in the New York area, and I was diagnosed early this year in February. Your question is very pertinent, James. I really experienced a large number of all of those symptoms. So rating them was difficult. When I was diagnosed, I have been in excellent health my entire life. My job has required that I travel all over the world and live all over the world. I've been to 80 different countries and really cholangiocarcinoma is a very serious illness, but the effects that I've felt the most, really are from cancer cachexia.

Stephanie K (01:35:56):

I had a 10% loss of body mass and I'm a small person. I'm amazed, I'm very muscular, I've always been an athlete. I've done cycling and running and swimming and yoga. And so I noticed that it wasn't just the weight loss, it was the muscle loss. And then that leads to fatigue, and fatigue so I have a lot of energy and my doctors always think I'm doing so well. And I'm like, but I had 300% more energy before I had this diagnosis. It's the unpredictability about the fatigue as well. So you make a lot of plans, you'll be ready to work and all of a sudden you're hit. The loss of appetite is really surprising. I've been a healthy eater my entire life, very healthy eater. And it's this again, unpredictability, like I'm going to get some ice cream and I'll go choose what looks amazing, and by the time it's in my hand, I have no desire to eat it. And this is kind of the silent killer in cancer.

Stephanie K (01:36:52):

I also was a caregiver to my mother who has cancer cachexia. She has pancreatic cancer, it's a battle to get enough calories in her system so that she can actually thrive with the chemotherapy. We try to explain without food in your body, that's medicine. I've read some of the reports. Cancer patients die as much from this weight loss as from their disease. So it's been a big challenge. It's counterintuitive, but I continue to exercise because I know that that's going to help create the almost minuscule appetite that I have. I continue to eat, even though I'm not hungry. I get hungry maybe once a day if I'm lucky. And I just think, I'm just going through the motions of exercising, just hoping that I don't lose more muscle. So that's just a bit of a small picture, James, of what this disease looks like in my life. Thank you so much.

James Valentine, JD, MHS (01:37:50):

Yeah. No, thank you, Stephanie. I have a couple of follow up questions based off of what you said. Just things that have gotten me thinking. You mentioned that you had the loss of appetite, you've had loss of weight, mainly muscle mass, as well as the feeling of fatigue. Did those, as you're thinking back, did they all happen at once or did you notice some of those first and then later some of the others, did they have a sequence? If you can tell us just a little bit about the onset of those three symptoms.

Stephanie K (01:38:24):

Yeah. So the onset, I think that what I noticed most was almost at the same time, unexplained weight loss. I lost 10% of my body mass, which was a huge amount of weight loss for me. And the fatigue came at around the same time. So I just simply noticed that when I went biking with friends and I'd always be out in front, all of a sudden I was behind. And I was like, "Wow, what's going on?" And so that got me starting to think about what, but also I had turned 50. I thought maybe this is middle age, and no one really prepares you. So it was really both of those at the same time, I think, the unexpected-

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Stephanie K (01:39:03):

... So it was really both of those at the same time, the unexplained weight loss and the fatigue, the onset was really sudden, and then noticing I just don't get hungry anymore. Particularly once you get the diagnosis, it was like I need to now be very clear about what I'm eating, make sure that I'm keeping my weight on because I see the course of this disease. It's a horrible disease, and I'm lucky because I'm still in good shape. But one has to just be eating, even if one's not hungry to eat. That actually has a strange logic as well because if you're not relying on the body signals to eat, you're also out of whack, right? I wonder if that helped answer your question a bit.

James Valentine, JD, MHS (01:39:44):

It really did. The other thing that really struck me in what you said, Stephanie, was the unpredictability. What that tells me is that it's not like this day-to-day very predictable experience. Could you maybe tell me a little bit about what a best day versus a worst day, what some of these symptoms looks like, just so we can see that range of that variability?

Stephanie K (01:40:12):

A best day is I have six Zoom calls, I can get up go to the gym in the morning, get ready for my calls, go through them, maybe half an hour between them do some work in the meantime. By the evening, I feel like I've had a good day of work, and I can be ready to relax a little bit, do something a little bit less high energy. A bad day is just waking up and getting to the gym and realizing I can't, I never go to the gym and can't work out, I go and all of a sudden it's hard to actually get through my workout. Maybe 10 minutes in, I'm like, "Wow." And then I get home, I start getting on these calls, and it manifests in kind of a brain fog as well.

Stephanie K (01:41:01):

The fatigue comes in, and if you have to push through it for calls, you find that you don't have your executive functioning skills at your fingertips. You're not remembering important facts. You're just trying to struggle to get through the day. By the end of the day, it's taking a nap between calls, making an alarm on my phone, waking up and being completely disoriented, "Oh, my gosh, that's right. I have another call."

Stephanie K (01:41:25):

It's that level of variability really. Like I said, if I knew that I was going to be that tired, then one plan's in accordance with that, but you can't stop living your life because you might be exhausted one day. You need to continue to plan. It's really that unpredictability that compounds the other symptoms that we've been talking about.

James Valentine, JD, MHS (01:41:49):

One last question, and I'll let you off the hook here. Thinking about those two different days, that best day versus worst day, thinking to the last week or last month, how many good days do you have versus how many bad days?

Stephanie K (01:42:05):

Let's see. I've got probably three to four good days at least, and then the others being sort of... Between those extremes, I have to say that the good days compared to pre-cachexia life are relative already. Like I said, people still think I'm fully... But I feel myself not having the energy that I had. Bad super fatigue days, two or three, and then you have to go to ground. It's a fatigue that sometimes doesn't necessarily lend itself to, "I'd want to just go to bed for six hours and be able to wake up and be ready to go." It's a different kind of fatigue. Sometimes it's a fatigue where you can't actively participate in your activities, but you're not necessarily in bed at the ER either. It's a sort of a medium. Very difficult to explain.

James Valentine, JD, MHS (01:43:05):

Thank you so much, Stephanie, for sharing all of that. I want to bring Martin into the discussion here. Let's take a step back. Thinking about those maybe polling questions as a way to frame this, again, large list. You can select all that apply, then we make you whittle it down to up to three. What did that look like for you? How did you pick? What symptoms and health effects were most troublesome?

Martin K (01:43:40):

Martin [Kaczynski 01:43:41] and I'm from Austin, Texas. My father had pancreatic cancer for six years and experienced extreme cachexia that progressed throughout the whole illness. We lived in a rural Southern Indiana community where there was a lot of outdoor work, a lot of physical activity. He was a volunteer fireman for 50 years. We chopped our own wood. We had a large property, and so for him, the decline in the muscle strength and the fatigue was just incredibly debilitating to his way of life and all the things that he really enjoyed.

Martin K (01:44:23):

Almost every single thing on that list, he did experience, but those were the ones that really impacted his life the most. There's a secondary effect of that when the things that you love, you're no longer able to do. The mental aspect of that is really also quite a toll, at least it was for him. With the loss of muscle and the increase in fatigue, you also start to lose the things that you love to do, and so that was particularly difficult to have all of that happening at once.

James Valentine, JD, MHS (01:45:02):

And the interrelatedness of those two feeding off of each other, it sounds particularly difficult. Was this onset of cachexia symptoms something that you and the family were able to notice right away? Do you think he was struggling with some of that himself before it was noticeable?

Martin K (01:45:25):

That's a great question. I think that's actually a really important question because it's very hard for a lot of cancer patients to decouple the effects of their treatment and cachexia. Every cancer is different, and every cancer has a different form of treatment.

Martin K (01:45:42):

For my father, he had a Whipple procedure, which is an incredibly invasive reorganization of the pancreas and the small intestines. That was hard in and of itself. Immediately after that, there's a pretty intensive dose of radiation, and then after that he go on chemotherapy. A year later he's gone through so much, it was difficult for us to connect the effects of cachexia with his symptoms because we thought it was just the effects of the treatment. It actually took some years to realize that there was something else going on.

James Valentine, JD, MHS (01:46:25):

As you think about his experience, would you say there was periods of time where maybe his physical strength did get better? Was it all unidirectional downfall?

Martin K (01:46:42):

The general trend was definitely down. It was pretty much down, but I think the rate of decline definitely changed. Those were associated with periods of... There was a remission after a couple years and all the chemo. There were no signs of cancer for some time. That was a period of maybe static-ness. There was no really decline. I don't know if I can say he necessarily was getting a lot better.

Martin K (01:47:18):

He also wasn't nearly as good about doing the exercise and eating well in the first place. We really encouraged that. He might have seen improvements if he had been a little bit more motivated to do some of those recommended lifestyle changes, but I think it was, in general, downhill for most of the time he did have cancer, and then when the cancer would go away, it would stop.

James Valentine, JD, MHS (01:47:51):

I'm sure you had something in mind as you were describing those periods that were more stagnant versus worsening. What's your litmus test for that? Was it his being able to go out and work on the property? How did you notice those different periods?

Martin K (01:48:08):

Definitely he was able to go out and do a little more. We tried to do a lot of traveling after his diagnosis. There were weddings to go to, and people in the family were having babies. He was a very outgoing, sociable person. He had a wide network of friends. When he was feeling like that, visitors would come. He loved to go on road trips, so that was something that he did several times throughout the illness. In those periods of time, he was able to do the things that he really did like to do. It was very meaningful. Sure.

James Valentine, JD, MHS (01:48:44):

Martin, thank you so much for sharing your family and your father's stories here today. I do notice that we have both callers coming in and some written comments. I want to use this opportunity to encourage you to call in if you haven't yet. That number again is 1-7-0-3-8-4-4-3-2-3-1. We'll be getting to some callers shortly, but before we go there, I want to check in with Elizabeth. What are we seeing from some of the written comments?

Elizabeth Franklin, PhD, MSW (01:49:12):

Great comments coming in. I just wanted to touch on one in particular since, Martin, you mentioned the mental impact of cancer cachexia. Carol from Sebastian, Florida said, "It's interesting how the mental impact of cancer cachexia is such a major factor in our health journey. I often don't want to eat because I'm afraid I will have to run to the bathroom, so it's difficult to go out with friends. I have to plan my eating with great care." The quality of life impact that has to be extraordinary. So, Carol, thank you so much for sharing that with us.

James Valentine, JD, MHS (01:49:45):

Thank you, Carol. For others following along, you can write in as well with some of your experiences again in that comment box that's under the live stream here today. But I want to go to the phones. I see we have Martha from Texas. She wants to share some of her husband's experiences with cancer cachexia. We'd like to welcome Martha to the show. Martha, are you with us?

Martha (01:50:15):

I am, and I'm from San Antonio, so I'm just down the road from Martin.

James Valentine, JD, MHS (01:50:25):

Welcome.

Martha (01:50:25):

I wanted to reinforce what some of the other panelists have already said, and then I wanted to add another thought to it. At least two of the panelists have shared how difficult it is to disentangle. Is it the cancer? Is it the chemo? Is it what turns out to be cachexia? Just what is going on?

Martha (01:50:51):

My husband and I also had that same difficulty. While each one of his providers was very caring, there did seem to be a tendency to throw the ball back into another provider's court. It was a little difficult to get a unified approach to what was happening to my husband very quickly in terms of the diagnostic and symptoms of cachexia. My husband's an advanced graduate student ready to start his thesis, and he began having the severe fatigue and some of the mind fog before he ever had a diagnosis. I think perhaps if it weren't for the pandemic, we would've realized sooner how drastic this life change was. But because he was taking his classes online and because he had already had to stop his research assistantship with the university because of COVID, he was living a much more sedentary life than he used to. And so neither one of us really picked up on how much he was changing. But because of his fatigue and his mind fog, he dropped his classes this March of 2021.

James Valentine, JD, MHS (01:52:16):

I'm so sorry.

Martha (01:52:20):

Neither one of us really knew why he was so tired. In April 2021, he was diagnosed with aggressive large cell non-Hodgkin's lymphoma and went into chemo immediately. The chemo was successful. He went into remission in August, but by that time, he had already started losing weight, losing muscle strength, losing balance, which led to falls. He was receiving PT on the times that he was in the hospital. He was receiving PT here at home when he was out of the hospital, but he just kept declining. I end up buying out of my own pocket a lot of equipment, wheelchairs, walkers, and such.

Martha (01:53:23):

But my dear husband just kept getting worse and worse. I had to buy smaller clothes, you name it. He got to the stage where he couldn't even hold up his own cell phone to dial it. He lived with that cell phone in his hand all the time, but he could no longer text. I'm sorry to share this with the group, but it is part of the picture. My husband died three weeks ago in the ICU, and they said it was because of the failure to thrive. That, in addition to the muscle and the other wasting, his heart gave out because it too had become so weak.

Martha (01:54:14):

We maybe come back to this later in the session, I'm sorry, I don't know. I guess I wish that we had realized, and that our providers had told us how serious the cachexia could be. We were all focused on the lymphoma, but it was the cachexia that actually carried him away. So with that, I'll end my sharing.

James Valentine, JD, MHS (01:54:37):

Oh, my goodness. Well, I want to first thank you for being brave and calling in so soon. I'm so sorry for your loss, but also just thank you for sharing such a vivid description of that journey with the cachexia and those impacts that really your husband lived through even before diagnosis and then over time. Just want to thank you so much for sharing.

James Valentine, JD, MHS (01:55:08):

I see we have another phone caller. We have Carol from Florida who wants to share more on some of the mental health impacts of living with cancer cachexia. Carol, welcome to the show. Are you with us?... Carol, are you with us?

Carol M (01:55:34):

Yes, I'm right here. I'm sorry.

James Valentine, JD, MHS (01:55:36):

No worries. Welcome.

Carol M (01:55:37):

Can you hear me?

James Valentine, JD, MHS (01:55:38):

We can hear you. Welcome.

Carol M (01:55:41):

Thank you. I'm the Carol who sent in the mental impact statement that you mentioned a little while ago, I have pretty much every symptom that you mentioned, every issue. I align very much with Rochelle's journey. Pretty much everything that she mentioned was what I was going through as well.

Carol M (01:56:05):

But the mental part is just so difficult for us because we don't really know where to go for help. I don't mean that our oncologists aren't available for us, but this is such a different thing. Do we go to a nutritionist, a naturopath, a physical therapist? It's just very confusing, and it's just one more thing that we struggle with besides our drug treatments, everything else. It's scary. The whole thing is scary. We just don't really know what to do.

James Valentine, JD, MHS (01:56:39):

Not only is it actually experiencing these symptoms. We've heard a lot from the panelists about uncertainty, about the progression, or even day-to-day, but the uncertainty of what to do related to treating or improving the symptoms is what you're saying.

Carol M (01:57:00):

Yeah. I find that sometimes I struggle feeling alone, like I don't know what to do. I'm not sure... I have to be careful about what I eat like Rochelle. I have to be very careful with what I eat. Should I eat now? Am I going to be ill? Can I go out with my friends? Am I declining rapidly now? Is this just a bad day or a week? A lot of it is mental, and I'm just mentioning that because yes, we have our drug protocols. We have all kinds of things from our oncologist, our medical teams, but the mental part is huge.

James Valentine, JD, MHS (01:57:44):

If you don't mind me asking, Carol, this sounds like a tremendous burden mentally that this has. You described the uncertainty of knowing whether you're feeling worse or even feeling physically worse is because of a rapid worsening or is this just a bad day. Can you maybe just share a little bit about what that looks like in your life so we can maybe understand what you're referring to when you talk about that type of moment when you're feeling really bad and you're worrying, is this just a bad day or is this a worsening?

Carol M (01:58:30):

Well, I have more that... You'll be seeing me in the afternoon. I'm part of the afternoon team of patients. But yeah, if I'm having a bad day, that might mean I can barely get out of bed. I'm in pain. I'm just so weak, and I'm so tired. I have to do something to motivate myself to get out of bed. "Okay, Carol, get out of bed and you will get to binge watch this really great show, and go eat some food and just chill out and relax." I have to try to find ways to motivate myself to get up and move forward. Like I said, there are days when I can barely move. And for me, I could care less about eating food, but I know I have to. Food for me right now is not my friend. I don't know. Am I going to be ill? Is it going to make me feel good? It's a struggle.

James Valentine, JD, MHS (01:59:33):

We haven't heard a lot about pain, but you mentioned it. Can you maybe just describe what your experience with that pain in the morning?

Carol M (01:59:44):

I have multiple myeloma, but I'm in a good place. I'm not going to complain. I'm in a very good place. I'm not as ill as some other people with multiple myeloma. I can get up. I am mobile, but I do often have back pain and neck pain and just general weakness. Because I'm very thin, my muscle tone is not there.

Believe me, like some of these other patients that have been speaking, I try to exercise because I know that's really important to survive, get your blood flow going, all of that. I try really hard to motivate myself to do something.

Carol M (02:00:27):

But the mental thing, I'm telling you, it's really difficult to psych yourself up to take that extra step, get out there on the bike, do this or do that because I don't feel like it. I have absolutely no energy. I have pain, but I need to do that, otherwise the next day I will have more pain or less physical ability. So I force myself to keep going and going and going. Luckily I have the mental capacity to do that today, but what will I be like in two months, a year? What will I be like then, and how will I be able to motivate myself then?

James Valentine, JD, MHS (02:01:08):

Carol, thank you so much for calling in and sharing. Again, tremendously important to hear not just about the physical symptoms, but also the mental and emotional ones. So appreciate hearing from you on this.

James Valentine, JD, MHS (02:01:23):

I want to broaden the discussion and we're going to a polling question to help us with that here in a second. But before I do that, I just want to check in with Elizabeth to see if there's anything else we're hearing from the web comments.

Elizabeth Franklin, PhD, MSW (02:01:35):

We had a couple of comments from care partners, caregivers that I thought were really relevant to, especially what Carol was just saying in terms of things that cause fear. Suzanne from Michigan said, "My husband has stopped eating all solid food. It has been 22 days." The fear that must create, especially as a care partner, watching the person that you love, it must cause so much mental anguish. Bringing it back to several of our Zoom panelists have talked about exercise and the importance of exercise like Carol did. Deborah from Cleveland said, "My husband Jeff died from throat cancer and had cachexia as an effect of the cancer. He went from being a pretty athletic man, a runner, a skier, etc., to being very sedentary. He continued to get thinner and thinner and gaunt throughout his entire cancer experience and eventually died."

Elizabeth Franklin, PhD, MSW (02:02:32):

We see those heartbreaking conclusions of what it's like to live with cancer cachexia, watching someone that you love become so thin, become fatigued, to not be able to get out of bed and do the things that they love, and that is really heartbreaking.

James Valentine, JD, MHS (02:02:48):

Thank you, Suzanne and Deborah for writing in with those comments. Again, we want to encourage you, if you have something to share, please call in. Of course, you can write in. Keep submitting those comments in that comment form under the live stream.

James Valentine, JD, MHS (02:03:03):

But now let's broaden this. Of course, we've already started to hear a bit about specific activities that had been impacted, but I want to do a polling question with our audience. Go ahead and again open that browser on your phone, go to that tab, go to PollEV.com/Cachexia. The question I want to ask you right now is, what specific activities of daily life are most important to you that you're either not able to do or you struggle with due to cancer cachexia? We've heard so much about some of these different symptoms and health effects, but now we want to broaden that and understand what is that translating to in terms of impacting your daily life?

James Valentine, JD, MHS (02:03:47):

So the options here, again select the top three. Options are: A, travel and vacationing. B, doing chores, things like cooking and cleaning. C, self-care activities, things like bathing and self-dressing. D, enjoying food or eating. E, going out eat. F, social engagements or social events. G, participating in sports or other recreational activities. H, each attending school or having a job. I, interacting with family members. Finally, J, some other activity of daily life that is important to you that you're not able to do or you struggle with due to your cancer cachexia that you would rate as one of the top three of those activities that are most impacted.

James Valentine, JD, MHS (02:04:36):

Again, we're seeing the percentage of total responses, so view these bars as the responses keep coming in as a general ranking. We'll give you a few moments here to get your responses in. As you're picking these, again, we want to... This is just the start of understanding these impacts on daily life. Any of these impacts will look very different and might be driven by different of those symptoms and health effects. Maybe you can pinpoint one. Maybe it's just kind of everything together. We would like to hear those stories, those experiences from you.

James Valentine, JD, MHS (02:05:17):

As you're thinking about this, please consider calling in, writing in, and sharing your experiences with how cancer cachexia impacts activities in your life. As it stands, it looks like the top item that's impacted is the ability to enjoy food or eating. We've already heard a little bit about this, but it does seem like that impact can be very different or different reason driving why or why not you can enjoy food or eating. We'd love to hear more about that from you.

James Valentine, JD, MHS (02:05:47):

Self-care activities like bathing and dressing is another top choice, followed by the ability to travel and vacation, as well as participating in sports or recreational activities. Perhaps after that, we see doing chores as impacted. But really striking to me is that everything here has been selected by quite a few peoples in their top three, as well as a few other things that we haven't listed.

James Valentine, JD, MHS (02:06:16):

If you're one of those people that picked other, we'd love to hear from you and understand what those things are as well. So again, to get us started on this topic, I'd like to come back to our Zoom panel. While we're talking to them, if you have something to share, please call in. That number again is 1-7-0-3-8-4-4-3-2-3-1.

James Valentine, JD, MHS (02:06:40):

Sandra, let's come to you. As you were thinking about the activities, maybe something that can't be done at all or as fully as you would like. What has been most impacted and why has it been impacted?

Sandra M (02:06:58):

My name is Sandra and I live in Reynoldsburg, Ohio. I'm a nine year pancreatic cancer survivor. In 2012, I had the Whipple procedure. In 2014, the cancer had metastasized to my liver, so I had liver surgery. Sometime after 2018, I began to experience some of these symptom. As James was speaking, I wrote down just about everything he said because it just covered so much of what I've been experiencing over the years, and nobody has diagnosed me with these symptoms. Excuse me for being emotional, but it's been a hard journey. I have not been able to travel a lot. I look at food as being a medicine that I need to do every day, so I eat breakfast, lunch, and dinner, and I have a snack in between. In spite of all that, I still lost muscle tone and lost a lot of weight.

Sandra M (02:08:14):

I shared my concerns with my doctors over the years. Like Megan who spoke earlier, they thought it was a good thing that I had lost weight. I tried to explain to them that the clothes that I had on that they kept complimenting me on was new clothes that I had bought because I lost weight or clothes that I had had altered because they were too big for me. Just about everything that James spoke to, I have the experience except for sleeping a lot. Of course, I haven't done the hiking, but I do suffer from depression, low performance. I live by myself and I have been able to take care of my house and yard and everything else in the past. Bit by bit, I'm not being able to do those things anymore.

Sandra M (02:09:13):

I wonder what the future holds for me. I was reluctant to sit on this panel because I said, "I haven't had that diagnosis. They're not talking about me." But, yes, in fact, you all are talking about me. I will shoot off some emails today to some of my doctors about this because I am very upset about it. I don't know what the future holds for me.

James Valentine, JD, MHS (02:09:39):

Sandra, first off, thank you for participating. It's very important that we hear from individuals who are both diagnosed as well as not diagnosed, but are experiencing these symptoms. And so first off, just thank you. One thing that you mentioned that I wanted to start by asking about is that you said you eat your breakfast, lunch, and dinner, yet you're still experiencing these symptoms. Can you confirm, are you still able to eat the same amount of food that you previously did? Given what you're eating, has that been able to help in terms of, as far as you can tell, the onset and worsening of the weight loss and other symptoms?

Sandra M (02:10:27):

I do eat four meals and have different types of snacks in between my meals. I've been complaining to my regular doctor about this. She prescribed a medication that she thought would increase my appetite, and it made me so dizzy during the day [inaudible 02:10:43], so she told me to take it at night. 12:30, 1:00 at night I might be hungry. I'll get up and get a snack or something, but it still hasn't helped me to put on weight.

James Valentine, JD, MHS (02:11:03):

One of the first things you mentioned was traveling. What symptoms make it hard to travel for you?

Sandra M (02:11:14):

I do have a problem with diarrhea. If you're on a plane, you don't have total control about when you can get up and go to the restroom, if you need to. I have Spyder motorcycle. If I'm riding with a group of people on my motorcycle, and I have to go to the restroom, there may not be a place nearby to do that. And so more and more, I have cut back on some of the travels that I do for that reason.

James Valentine, JD, MHS (02:11:49):

Thank you for sharing. We haven't heard much about the GI and diarrhea problem, so it's good to hear the impact that is having. One last question for you, Sandra. You did mention you live independently. It's getting-

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James Valentine, JD, MHS (02:12:03):

Sandra, you did mention you live independently. It's getting harder to do certain tasks. Can you give us an example of something that's recently gotten harder to do?

Sandra M (02:12:09):

I have a large flower bed around my home and for me, it was like physical therapy to get up early in the morning and go out and do things my gardening. Home repairs have been another challenge. If the smoke detector needed to be changed, I'd bring my ladder into the house and climb up on the ladder. And change the battery. And just this past week, I had to call our fire department and have them come out to change the batteries cause I'm afraid to get up on the ladder. Because I have to reach and I'm afraid of falling.

James Valentine, JD, MHS (02:12:54):

Yeah. Well, Sandra, I really appreciate your sharing all of this. So thank you so much. I want to bring John into the discussion here. John, as you've been thinking about the various symptoms of Cachexia, which of those have, have had impacts on activities in your daily life? What activities have been most impacted?

John M (02:13:16):

Certainly. And thank you for having me on, I appreciate everyone else's time and sharing your stories. Very humbling. My name is John. I'm out in Philadelphia. I am a recent bulky refractory Hodgkin's lymphoma survivor. Battled it for a little over two years and now starting to take a turn. I guess, out of those that you kind of listed, social engagements and events were just a huge thing for me just being... I was diagnosed at like 26 years old. So it's like a vocal point in a lot of males life for social events. So I was having to kind of sit out for that. And I guess, another area that was hard sometimes was kind of letting people know how much you're really struggling. So a lot of Cachexia patients will somewhat isolate how they're feeling or maybe how they're doing, because they don't want their pain to be other people's pain. So there's a lot of internalizing which can get very confusing.

John M (02:14:18):

I guess sports and recreation were a huge thing. I always was a very fit guy. I had lost about 20% of my body weight. I'd gone down from usually about 190. I've recouped it to about 180 now, but I was down to about 150. with just no muscle tone. My skin looked terrible. People saw me, they were just like, "Ah!". Whether or not, it was part the Cachexia, part very aggressive on responsive tumor. But it made also like functioning at my job very tough. You kind of have to have health insurance to treat your cancer. But then oftentimes the work doesn't really coincide with what you're dealing with from the patient perspective. So that was just always a massive struggle. So yeah, it all just resonates with me, with what you're saying so.

James Valentine, JD, MHS (02:15:18):

Yeah. So I'm, I'm curious John, you've listed a couple kind of maybe interrelated impacts in your life, not sure which maybe symptoms are driving which but, could you maybe tell us a little bit about the time course of your symptoms related both to the diagnosis, the treatment, and even now after the treatment. You described that you've been able to put back on some bodyweight, maybe some muscle mass, but is it still a problem for you?

John M (02:15:57):

Certainly. Yeah. So let me, I'll get a little bit more were into it. I had done about 12 rounds maxed dose chemotherapy, which I didn't respond to. So beforehand I had, I guess, what they would call Pre-Cachexia signs. And then after failing chemotherapy, they were going to have me do like a clinical trial, had to see a bunch of different teams.

John M (02:16:19):

And then it was the determined, okay, Cachexia might be more of a part of this because that's when I kind of lost that other 10%. It was basically through a lot of just really, really, really guilt revamping how I look at food. Digestion, I had a lot of stomach slash intestinal issue stemming from probably some of the Cachexia and a lot of just the treatment. So I just did a lot of conditioning and just tried to build on that every day. And that's really difficult. I was very blessed to start to kind of turn a corner with some off-label immunotherapy. So it made me combat a little bit easier, but I just tried to exercise a little bit every day. I just tried to force in as much as I could try to hit like a calorie window if I couldn't I would just try to get back after it the next day so.

James Valentine, JD, MHS (02:17:18):

And the circle back then to something you started talking about, which was the difficulty engaging in social activities. You've mentioned kind of appearance from the weight loss. You've mentioned not wanting to share the burden emotionally with others. You also mentioned things like GI issues. Was it really a combination of all of those things that impacted your know going out and socializing or am I missing something?

John M (02:17:45):

No, you captured a good picture of it. And I think with a lot of the cases, we're kind of hearing there's a lot of layers to it. So it's not as simple as like, "Oh, hey, you're going to be hopefully good in six months or a year, two years". We're kind of past that with everyone here. So kind of describing that to lay people or other people that just maybe don't quite... I guess communication just gets difficult from that perspective, because you are just struggling much more than they have any idea.

James Valentine, JD, MHS (02:18:18):

And would you describe the social impacts more related to going out socially? Or did it impact maybe even relationships and friendships?

John M (02:18:28):

Little bit of both. In terms of going out I wouldn't want to, because I'd be too tired. It'd be like going to see a movie and then it's two hours, but you're falling asleep within 10 minutes. You didn't enjoy that movie cause you fell asleep for all of it. So there'd be that. And then I guess the other part of it was maybe having other people see your pain or kind of just like how they would look at you or just, I guess, give you a lot of that kind of stuff. So it's not all cancer patients necessarily want that level of like look down upon because we try to build ourself up. We have a strong image of ourself and then Cachexia is like an opposite image of that. So just kind of dealing with like a full opposite of what you would ever expect yourself to be in and of itself is kind of a difficulty. So yeah.

James Valentine, JD, MHS (02:19:17):

Well John, thank you for allowing me to kind of ask those questions and really better understand some of those social impacts. So important to hear those as well. I want to just make a pitch. If you have something to share on this topic of what it is to live with cancer, Cachexia. The symptoms and impacts in daily life. Again, you can call in at +1 703-844-3231. Again, that number is +1 703-844-3231. We want to hear it from as many different voices as possible throughout the day today. Try to, as we're seeing already this condition impacts people so differently.

James Valentine, JD, MHS (02:20:02):

And so we'd would love to hear from you even if it's similar symptoms or similar impacts, we know it's very personal still, and we'd love to hear that personal take. I want to check in with Martin here as we've now brought in and talked a little bit more of a focus on important activities that are impacted. Has anything else stood out to you in terms of what's been important that you can't do at all or as fully? Your father, you talked a little bit about some of those impacts, but anything else as you were thinking more broadly about this activities in daily life that were most impacted.

Martin K (02:20:46):

Yeah, I think I focused previously on the physical impact with him. He was also a really passionate cook and cooking is affected in several ways. Obviously, the appetite suppression and the lack of enjoyment of food. You don't really want to cook if you don't really want to eat. And then also cooking's a physical activity. You don't always think about it as a physical activity, but at like standing there at stove and cooking can actually... That was a hard thing. And so, and again, just to touch back on the interplay between that and then the mental health and this impact that not being able to do something that you love has. So I think, I think that was another major area that really affected him.

James Valentine, JD, MHS (02:21:42):

Sure. And was that something that was maybe later in his experience? It seems that maybe the outdoor physical activities would be a little more strenuous or maybe those were first or can you tell us a little bit about that?

Martin K (02:21:59):

Yeah, I think when he had more extreme presentation of Cachexia, there were other things that were happening besides the fatigue and the muscle weakness like sores and the mouth and his hands, there were some effects on his skin. I think John mentioned some effects on his skin that even made it hard to hold a spatula or give somebody a hug. There was a lot of pain associated with touching and physical touch. Those were definitely later symptom. And there was a point where he had some trouble opening his mouth all the way in addition to the sores in the mouth. And so I'll also just say again, that we struggled to understand if those were treatment effects or Cachexia effects. I think they were Cachexia effects, but I'm not sure if anyone even necessarily knows exactly the answer to that question anyway. But yeah, those happened later.

James Valentine, JD, MHS (02:23:11):

Right. I think it makes sense to mention things and it's okay if we don't know if it's the Cachexia or something related or something else because that is something real that people with Cachexia are living with. Ongoing treatment for cancer, perhaps living with the cancer. So you're kind of juggling multiple conditions and side effects at once so even if it is something else, the interplay between the Cachexia and other things is really important to understand too. So thank you so much. Stephanie I know we talked a little bit about some of the exercise and those types of physical activities that were impacted for you. But, what else, as you were thinking through activities in your life that maybe you can't do at all or as fully as a result of the Cachexia?

Stephanie K (02:24:09):

Yeah. Definitely cycling now in New York City. If I'm going to go on a long ride, I have to take one of those electric assisted city bikes instead of the normal city bike. They're really big, heavy bikes. So they're really good for exercise actually, but that's definitely in order just to keep up with like any normal person. Also, I actually have been a scuba diver my whole life, and I didn't do it for a few years because I was very busy and I was traveling and with my diagnosis, I decided something that I really loved doing. So I've actually been doing major scuba diving trips. I was recently in Utila, Honduras, which is a little teeny island off. It's the bay islands in Honduras. I went with my son, he's 20. He's in college, in California, at Claremont McKenna. And he wants to do exciting things.

Stephanie K (02:25:06):

He wanted to do a rec diving course. So we did a rec diving course, but you got to go down 20, 30 meters, 27, 30 meters. And I was out of breath. And the whole thing about scuba diving is you you need to right. I mean, it's obviously something that puts duress on the body for my calculation, given the severity of my illness. I think that my risk profile has changed a little bit. I want to continue to do the things that I love. I'm not willing to just stop everything and be a patient. And so it's important to me to keep doing those types of things. But around me in this scuba diving, a lot of people don't realize that I really have a diagnosis that it's a really small percentage of people that survive this in five years. The average prognosis is really one year. So under that I'd have six months left. I don't listen to any of that. But it affects every part of my life. I have to worry more because I'm not in as robust health. I have to worry about different types infections that I could get through my travel. And even something as simple as meeting a friend to go for a walk in central park, like I said before, on those difficult fatigue days, I will not be able to have like a robust walk and be talking to someone. So we'll sit down on a bench and it's a completely different quality of life. But again, what's really surprised me about this phenomenon is just when I first came across it with my mom, with pancreatic cancer we had all sorts of contraptions to get more calories into her.

Stephanie K (02:26:52):

Right. Like Häagen-Dazs melted. I got [Soylent 02:26:56] and [UL 02:26:57] and all these. We are just trying to pack in the calories to the extent possible. And she just gets full after eating absolutely nothing. And then if her weight dropped, she would be unable to avail herself with chemotherapy. So it was first just seeing her go through it and then seeing it in my own life. My mom is 83 and I'm only 50. And I've had this life of I've worked all over the world for the United Nations and for my government doing human rights and development work. And I never or thought that I'd have to deal with something like this. And so I think it's important for me to have quality of life and not to just descend into the disease. So to the extent possible, I'm just managing it but it takes a major toll on one's life.

Stephanie K (02:27:46):

And really just the mind body relationship changes entire when it's unpredictable what your body might throw up. And the other thing is I am surprised in the medical field that there's not more attention to this. Your oncologist is there to give you the perfect chemo mix. But obviously Cachexia and white blood cells, there's a direct relationship, right? Nutritional status is going to impact anything that you do in your treatment. So this bifurcated approach is unhelpful. And so I am very supportive of the attention being brought and the drive for solutions because, like I said before, the numbers are staggering in terms of, we had one person call in talking about the fact that her husband arguably died from wasting from nutrition loss right in the ER. It wasn't anything else. It was failure to thrive, which is really death by this kind of phenomenon that is more under the table. Yeah.

James Valentine, JD, MHS (02:28:46):

Thank you Stephanie so much. I do see that we've been getting some written comments in. So, I want to check in Elizabeth, what are seeing?

Elizabeth Franklin, PhD, MSW (02:28:53):

Yeah. We've had this ongoing theme of both physical and mental impacts of Cachexia. And so Jerry from Virginia wrote, "I have been racked with leg cramps together with many other symptoms". And Jerry, you didn't mention sort of your lifestyle, but hearing about scuba diving and hearing about motorcycle riding and John's athleticism, those leg cramps can be really significant and can have a huge impact on your life no matter who you are. So it's really important for us to take things like leg cramps very seriously. And that leads to the second comment, which, which reflects something that Stephanie just said too. And it's back to this idea of mental health and Cathy from New London, Pennsylvania, talked about the stress that she and her husband have gone through. She said that, "he is highly stressed and reclusive due to COVID. And at various times I've tried to get appointments with mental health providers, despite his refusal to engage. But they're virtually unavailable. This shortage of psychological support is the only hole we found in the extraordinary care my spouse has received since 2007".

Elizabeth Franklin, PhD, MSW (02:30:02):

And this tacks on to what Stephanie was saying. Webinars like this one today are of valued respite. As a caregiver, I thank you for offering this. And this is why it's so important for the cancer support community and all of our partners to come together to offer something like this, because it is to elevate the voices that you're hearing today. So thank you so much, Cathy, for writing in.

James Valentine, JD, MHS (02:30:24):

Yes. Thank you, Kathy. Thank you, Jerry. It's so important to hear so many of these different symptoms. We haven't heard about leg cramps where we keep piling on. The large range of impacts of living with Cachexia. So I want to look a little bit now towards the future. we've heard so much about what you already have been and are currently living with as a result of the cancer Cachexia. We want to also hear from you all about what it is that might worry you about the future of continuing living with cancer Cachexia. So to get us thinking about this, we have our final polling question for the morning session. So you can open up that browser, go to that tab, go to PollEV.com/Cachexia. If you've kept that open. Our next question for you, we want to know what worries you about your or your loved ones, cancer Cachexia in the future? And we want you to select the top three of those things that worry you. The options here are A, the stress of not knowing how it will progress. B, increased difficulties eating. C, worrying about social impacts. D, GI or stomach issues. E, not having the energy to work and live as you want. F, the impact on your cancer treatment and the healing process. G, the fear of dying. Or H, some other worry that you have about you or your loved ones, cancer, Cachexia in the future that represents a top three worry, concern, fear that you may have.

James Valentine, JD, MHS (02:32:08):

We've already heard a little bit about this today, but I think we've heard such varying experiences of living with cancer, Cachexia. It may or may not be the things you've already experienced that are the things that worry you and so we want to kind of understand what is it that worries you? Why is this the top thing that worries you? It's so important to understand the why in all of these things. So, as it stands in again, these are percentages of total responses, not percentages of people who picked any individual response. So it looks like the top worry for the future is not having the energy to work and live as you want to, or your loved one would want to. Followed by the stress of not knowing how it will progress. So it's very interesting to understand what specific things about not having energy. Is it you're worried that it'll progress or is there certain activities in the future that you're worried about the stress of not knowing how it will progress?

James Valentine, JD, MHS (02:33:19):

Are there certain symptoms that you're worried about in terms of progression? What is it about progression that worries you? We see after that the impact on cancer treatment and the healing process. Always striking is just to see how many different of these impacts are within some number of people's top three. We're seeing everything on this slide, except for some other worries that are in somebody's top three.

James Valentine, JD, MHS (02:33:47):

So to help us maybe start to explore this and worries for the future more, I'm going to come back to our zoom panel, but I want to invite those of you in the audience. If you have something you'd like to share, it can be on something we've already covered. Your current experiences. But if you have also something to share about worries for of the future, please call in. That number is +1 703-844-3231. Again, that's +1 703-844-3231. We'd love to hear your views, your experiences, your perspectives on the future. But to get us started here, maybe John as you're thinking about the future living with cancer, Cachexia. What would you describe as your biggest either concerns or worries for the future?

John M (02:34:40):

The fear of just not knowing simply. We don't really know any like long term effects of it just because it is a relatively new disease. And then all also and this isn't to deter anyone like Stephanie or Sandra or anyone. After you get kind of through maybe part of Cachexia it never really does end. Every day is valiant effort towards eating, exercising, putting the right foot forward. It's exhausting. So the long term effect of mitigating what we may have had happen during our Cachexia time. So, that's my biggest concern.

James Valentine, JD, MHS (02:35:20):

Yeah. And if you're like looking for it and thinking about that worry, are there any kind of specific symptoms that you have in mind or is it really just the whole range of the experience?

John M (02:35:36):

I would say the whole range and then just internally how the organs and all that process, maybe some of those times where we weren't giving ourself proper nourishment and how we were pushing through, and if there's any effects from that.

James Valentine, JD, MHS (02:35:53):

Sure. Well, thank you so much, John. Sandra, I do want to come to you. I know you I've expressed that you do have worries for the future, as you've been thinking about those maybe as you were answering that polling question. Can you share some of those with us?

Sandra M (02:36:13):

The concern is having the energy to take care of myself, maybe having to give up my home and go into maybe assisted living or something. I don't don't know what the future looks like. And another thing that come to mind is I was listening to John is how is it treated and who does the treatment? This is so totally new to me. So, I will add that what I mentioned earlier about even the [inaudible 02:36:45] meals a day, for breakfast, I may pick a day and cook a pound of bacon and a pound of sausage and heat that up for breakfast to make next day and eat off of that for a week or so. And for dinner, I may cook a meal that I can eat off three or four days until I get tired of it. And so cooking is becoming even more challenging for me.

James Valentine, JD, MHS (02:37:15):

Yeah. So one thing I heard lot unclear is the worry about your independence and potentially not being able to do certain activities in your daily life. Cooking, certainly one example of that. But you've talked to us a lot about the different activities you do at home. Is this a near term worry for you? Is this something that you think might be way down the road or can you maybe share with us a little bit about that?

Sandra M (02:37:48):

I'm really worried about it now that a couple girls [cheers 02:37:53] here that came in the mail and I was going to make appointments to go and look at some of these assisted living places just so I can kind of plan my future. And hopefully it's not the near future but just to have some idea what my future looks like because, I feel like I am losing some of my independence.

James Valentine, JD, MHS (02:38:16):

Well, Sandra, I really appreciate you sharing that. Stephanie, I'm going to come to you next, but I want to check in with Elizabeth on if we've been getting any written comments.

Elizabeth Franklin, PhD, MSW (02:38:27):

Yeah. We do have a comment that really aligns with, with something that Sandra has talked about which I think is so incredibly important. And it's when you were never talked to about Cachexia or it was not officially diagnosed. So John from Columbus, Ohio said, "Of all the issues I faced in dealing with colon cancer, multiple surgeries, sepsis, toxicity from chemotherapy, CIPN, extreme weight loss was the most traumatic and caused me hospitalization. Therefore, I'm glad this topic is being studied and addressed so that others can find relief. Cachexia was never referenced during my time in active treatment. And it is helpful in survivorship to know this is a common side effect and not unique to my circumstances". And I know Sandra throughout our conversations with you, this has been something that you've communicated to us that it makes you feel lost. And it adds to that fear because you don't know what the next step is. I just thought it was really important to bring up John's point. So thank you, John.

James Valentine, JD, MHS (02:39:28):

Yeah. Thank you. So Stephanie, coming back to you on this topic of worries and concerns for the future. You've shared so much about what you've already experienced. What are your thoughts about the future?

Stephanie K (02:39:44):

The future of my illness, or just Cachexia and where this is going?

James Valentine, JD, MHS (02:39:48):

For you and your kind of future of living with Cachexia.

Stephanie K (02:39:51):

Yeah. I am right now looking at different holistic medical solutions. So because the oncologist, so I think I have the top oncology care in the world at Memorial Sloan Kettering in New York. But again, it's a very narrow vision. And so I'm looking into... I've used my general practitioner to get different types of blood tests that look at nutrients in the blood that are not actually in the very extensive blood work that is done at MSK to get a sense of that. It's difficult because I am on chemotherapy. And so one has to look at what one can use to supplement. In terms of my journey forward, definitely most people with my disease when I'm on a lot of different Facebook groups, et cetera, it's a disease that you don't see people living with for many years, you see people wasting away very quickly.

Stephanie K (02:40:53):

And so I think it's important to continue to keep up my strength, to do what I can do in that regard. In New York city, trying to find, I've been on a search with my partner for the very best pizza slice in the whole city. And there's a lot that claim to have that. So you play games to sort of get excited about food because this is the new normal. And for me it's a matter of trying to the extent possible, it's keeping my attitude focused on healing and again, healing. And I think that what's happening in medical science is this is being recognized that it's not just a one focused solution where one's looking just at the disease and how to deal with the disease.

Stephanie K (02:41:45):

It's thriving in all of its entirety. And I think that is up to the patient. I will also say that some of the other people here have said that no one spoke to them about Cachexia and it's true. No one raised that to me, there are nutritionists Memorial Sloan Kettering, but no one said as you came in they had all sorts of opportunities to tell you about. You can do this genetic testing, et cetera, but it's just not really on the radar. So I think that that's something that I'd like to see get more attention. If there are nutritionist there that are familiar with what this is, I would love for drug companies to be spending more time on this. There's been a lot of advancement in cancer and also in managing pain, cancer pain, right?

Stephanie K (02:42:34):

The process of suffering cancer is no longer what it was 30 or 40 years ago. And yet with Cachexia, we're still pretty much in the same place. It's really events like this that are raising awareness about it. I do think that we as patients need to take our own holistic healing into our own hands unfortunately at this stage. And just hope that there'll be developments in medical science. In drug development and the rest that can focus a stronger light on this challenge.

James Valentine, JD, MHS (02:43:09):

Yeah. Well, thank you Stephanie so much. I want to check in one last time with Elizabeth. See if we have the final word before we wrap up here this morning session.

Elizabeth Franklin, PhD, MSW (02:43:20):

We do. And Darrell from California wrote in with a word that I think is incredibly important. And he said that, I think that it's important to recognize that the symptoms of Cachexia are long term and even in remission, they still affect your quality of life. Whether physical or emotional, you are just not able to feel as capable of participating in daily activities as your peers. So no matter what the side effect was or what you're dealing with, you can kind of hear that long term ongoing impact of living with Cachexia. And it's not just a today problem. Most of our speakers today have talked about fear of the future or what's coming next. So Darrell, thank you so much for that important comment.

James Valentine, JD, MHS (02:44:00):

Yeah. Yeah. I want to thank Darrell and to everyone, our zoom panelists, everyone that has called in written in, answered a polling question and of course, to our panelists. This has been such an incredible morning of really understanding such a wide range of symptoms and health effects and equally wide range of impacts on daily life. This now is kind of concluding our, our session, which is focused on that. But what we're going to do is we're going to come back after a lunch break and build on this discussion. We want to understand now and what it is that you all do to try to treat and manage and live with these symptoms. Now that we have a better understanding of them. So it's 12:30 PM eastern time right now. We're going to take a 30 minute break return at 1:00 PM Eastern for that discussion on treatments. So we look forward to seeing you back and hearing from you more in the afternoon. So again, thank you.

PART 5 OF 10 ENDS [02:45:04]

James Valentine, JD, MHS (03:14:59):

Good afternoon. And welcome back to the Externally-Led Patient-Focused Drug Development Meeting on Cancer Cachexia. I'm James Valentine, your moderator. And I'm here with Elizabeth, from the Cancer Support Community, as my co-host. We're coming back after a break. We had such a wonderful discussion this morning learning so much from all of you, patients, individuals living with cancer cachexia and caregivers and care partners about what it is to live with cancer cachexia.

James Valentine, JD, MHS (03:15:31):

Now, in this afternoon session, we come back to build on that, to learn from you about the different approaches to treating and managing cancer cachexia as well as to learn a little bit about your preferences for future treatments. So if we can pull up our discussion questions for the afternoon, this will give us a sense of some of the things we'll be asking you to weigh in on.

James Valentine, JD, MHS (03:15:56):

So what you'll see is that we want to hear about the different things that you or your loved one do to try to manage their cancer cachexia symptoms. We learned about so many of these different symptoms. So we would expect that there'll be quite a few different treatment approaches to try to help manage these symptoms. And hearing about what these are, we ... and when we talk about treatments or management strategies, we really are casting a broad net here. We not only want to hear about any potential prescription drugs or other kind of medicines that you might be using as well as medical procedures, but we want to think more holistically. We want to know, are there other types of therapy or nutritional service that you've received? Are there other strategies, maybe nontraditional medicine or diet and exercise that you employ in your daily life?

James Valentine, JD, MHS (03:16:55):

We even would want to hear about lifestyle management techniques. So anything that you might do to modify your daily life to make living with cancer cachexia and its symptoms a little bit easier. So anything counts we want to hear about that. And as you'll see, we want to hear how well those different strategies and treatments help and work in managing the most significant symptoms in health effects of cancer cachexia. Knowing that no treatment particularly drug treatments come without some side effects or downsides, we do want to hear about those as well. So what are the most significant downsides, whether a side effect, the burden of undergoing or maintaining a particular treatment regimen, what are those and how do those downsides affect your daily life?

James Valentine, JD, MHS (03:17:48):

And once we've explored and heard from you about the current strategies that you have, we're going to look towards the future. And we're going to want you to weigh in on short of a complete cure for your, your loved ones, cancer cachexia, what specific things would you look for-

PART 6 OF 10 ENDS [03:18:04]

James Valentine, JD, MHS (03:18:03):

... one's cancer cachexia, what specific things would you look for in an ideal treatment? Maybe another way to think about this is if you were considering a new treatment for your cancer cachexia what factors would be important to you in deciding whether or not to use that new treatment? This morning to get us started on this topic and to provide some experiences and perspectives, we have a panel of patients and caregivers. We have Daryl, Carol, Lisa, Linda, and Melvin, who will be weighing in on this topic. Daryl, take it away.

Daryl R (03:18:40):

Hi, my name is Daryl, and I live in Pleasant Hill, California. I was diagnosed with anal cancer at the age of 66 and developed cancer cachexia as a side effect of the cancer and treatments. The treatments included 16 weeks of radiation and chemotherapy administered simultaneously. At the conclusion of my treatments, I had lost 30 pounds or 20% of my body weight, experienced a significant loss of skeletal mass, and it was coupled with a loss of energy. I was advised by my medical team that I was cured and could resume my regular activities.

Daryl R (03:19:25):

However, that did not turn out to be the case. One year later, I was diagnosed with stage four metastases attached to my lung, chest wall, and ribs. Thoracic surgery was performed to remove the mass, and I was told again that it was successful. But within a month, the surgical site became infected, and it required a secondary surgery to remove the infection.

Daryl R (03:19:57):

As a result of my participation in multiple programs at the Cancer Support Community, I formulated a three-pronged approach to rebuild my body, including dramatic changes in my dietary habits, increased my movement and mind body exercises, and added supplements. This resulted in a 60% improvement in my overall health. I regained muscle strength in my arms and legs, which allowed me to once again perform my daily home care. The knowledge I gained attending nutrition classes at the Cancer Support Community helped cut out most of the foods with empty carbohydrates, bad fats, and sugary and salty foods, and replace them with a mostly plant-based diet, including fresh berries, foods high in omega three, unprocessed seeds and nuts. I supplemented these foods with high protein foods, such as plain Greek yogurt, [Orgain 03:21:07] supplement drink, plant-based, and other high protein foods. I found that a daily glass of Metamucil added regularity to my digestive tract, eliminating swings between constipation and diarrhea caused by my chemotherapy and radiation and pain medications. I also ended up eliminating coffee and wine from my diet and replaced them with a decaffeinated green tea and water cranberry drink. This also helped to further improve my digestive tract and overall body hydration. By the way, none of this was suggested by my medical team. To help build my muscle and skeletal mass, I began a daily routine of yoga and meditation accompanied by a daily four-mile walk. This regime resulted in a slow progression back to a stronger, sturdier body structure and increased my stamina as well.

Daryl R (03:22:17):

Although the progression took about two years to produce positive results, today I am able to perform many of the tasks that I was not able to perform after my cancer diagnosis, the exception being my sense of balance, primarily due to neuropathy in both feet. I was advised by my medical team that it would diminish over time.

Daryl R (03:22:44):

Over the next year and a half, there was a moderate improvement after asking my oncologist to prescribe Gabapentin, and incorporating massage and soaking my feet in a warm Epsom salt bath. Again, none of these was suggested by my medical team. Initially, I began my recovery process with natural and mostly non-prescription medications. They included calcium carbonate, topical steroid ointments, Immodium, stool softener, turmeric capsules with black pepper, and extra strength Tylenol. With moderate improvement after four months, I was able to eliminate all, but the topical steroid ointments and turmeric, and added skin moisturizers to moderate the systemic inflammation throughout my whole body. Again, with the exception of the calcium and the topical steroids, none of these was recommended by my medical professionals.

Daryl R (03:23:53):

The ideal scenario for cancer cachexia would, of course, have been more attention paid to the initial progression and earlier treatment of my symptoms by my medical professionals. I also believe that have my medical team had prescribed Zofran for my bouts with nausea and Gabapentin had been combined with prescription Lyrica in my treatment, the results may have also been more favorable and certainly less painful. Had my cancer cachexia been treated more seriously, I would have had a better and more timely result and maybe, just maybe, been less likely to have metastasized and become infected, thus eliminating additional surgeries, more pain and suffering, and more lengthy recuperation. Thank you for hearing my story.

Carol M (03:24:58):

My name is Carol. I'm 63 and I currently live in Florida and part-time in Connecticut. In 2011, I decided to try skin boarding. It was the best stupid decision I've ever made. I fell, broke my neck, and found out it was due to a tumor which had weakened the bone. The tumor was a plasma cytoma, which is a precursor to multiple myeloma. I was told I had maybe seven years to live, which caused me great trauma for those seven years as I counted down the days. I was treated with chemo pills, then an auto stem cell transplant. After the transplant, I stayed off chemo medication for three years. In 2016, my number spiked, and I was treated once again with chemo drugs. In 2019, I discontinued my chemo meds after my numbers consistently decreased.

Carol M (03:25:45):

I was recently diagnosed with a severe case of small intestinal bacterial overgrowth, SIBO, which is a treatable gut illness that was undiagnosed for four plus years and aligns with cachexia. I cannot gain weight and often feel malnourished and out of sorts. I often don't want to eat because I know there's a good chance I will be ill shortly after eating. My cachexia-related low energy and food issues often manifest into depression or lack of interest in general day-to-day activities, but medical marijuana helps with my nausea and anxiety. I try to exercise more today than in the last 10 years because my muscles are weaker or nonexistent. However, no matter how much I try, I don't feel or appear stronger. Consequently, it's very discouraging.

Carol M (03:26:33):

With the new SIBO diagnosis, I'm taking some medications called Biocidin, a glutamine and GI detox, and I'm following a FODMAP diet. FODMAPS are types of short chain carbohydrates found in certain foods that are indigestible or poorly absorbed. When FODMAPS aren't absorbed correctly in the small intestine, they move through the digestive tract producing an increased volume of liquid and gas in both the small and large intestine. This diet and treatment has definitely helped and made a huge difference in my day-to-day life.

Carol M (03:27:06):

Besides exercise, I'm taking a number of supplements under the guidance of my naturopath and with my oncologist understanding. I also try to eat a low sugar diet, which means no candy, no sugar, and minimal fruits. I meditate, swim, and take regular infrared saunas at home, which help with pain and toxins. I also take a Rick Simpson oil pill each night, which is a highly concentrated cannabis oil extract, which helps with my pain and aids in sleeping. My morning pain is treated with stretching, yoga routines, and sauna. Eating with extreme care helps with my energy level and SIBO symptoms. If I'm able to take a bike ride or do some other physical activity for even 30 minutes, it can make a huge difference in the outcome of my day.

Carol M (03:27:54):

My biggest obstacle is how to motivate my brain to get me to move forward on a bad day. It's easy to give in to the pain and just curl up in bed, which for me is the worst thing I can do. My full-time job is working to stay alive with healthy food choices, physical activity, being mindful, and distracting myself with books or projects and binging TV series, which takes a lot of time out of each day. I try my best to maintain a positive attitude, trying to forget I have cancer throughout as much of the day as possible.

Carol M (03:28:24):

It's difficult to manage all of this, and I often feel like I'm on my own to survive. I have to motivate myself just to get up in the morning due to pain and general malaise. My cachexia has benefited more from physical than drug-related treatments. It would be helpful if there was more guidance provided for patients with exercise suggestions, healthy eating, and information on supplements. More complementary services like yoga, art classes, and massages would help reinforce positive results for our minds and bodies.

Carol M (03:28:55):

Education is also key for the patients, doctors, and caregivers. We don't understand how to navigate cachexia and need guidance. However, most of the cancer seminars I've seen are rather technical and depressing. Occasionally offering a seminar with a lighter topic like the importance of laughter or demoing a class on goat yoga would lighten things up a bit. It might be helpful to give an example of walking through the day in the life of someone who is doing well or demo a great exercise routine specific to our illness. It would be amazing to have a goal setting coach with followups since I'm not always motivated. Having a coach check in would encourage me because I would feel accountable to someone on a regular basis.

Carol M (03:29:37):

I just want to reinforce that I'm unique. What works for me might not work for someone else. Listening to patients communicate fully and without restraint is critical in keeping us on the right path, which is to survive and be happy. This last 10 years has been very hard for me, but I'm blessed that I'm still here three years longer than my original doctor expected and I'm not giving up.

Lisa K (03:30:03):

Hello. My name is Lisa, and I live in Ames, Iowa. My introduction to the term cachexia came late in my husband [Connie's 03:30:11] journey with malignant pleural mesothelioma, a cancer of the lining surrounding the lungs. A pain specialist commented in a written medical record that Connie had a cachetic appearance five days prior to his passing away at 77 years old. This was the first time that cancer cachexia was brought to my attention. Sadly, that report was retrieved following Connie's death on August 1st of 2016. I cannot recall this doctor or any doctor actually telling us about their notice of cancer cachexia symptoms.

Lisa K (03:30:46):

I knew that weight loss and cancer often go hand in hand, and I had to watch my once robust husband waste away, showing early cancer symptoms long before or he was ever diagnosed. I also knew that older people experience muscle mass loss due to natural aging, often accompanied by a general lack of conditioning. What I did not know and what no doctors ever mentioned to us is that weight loss with cancer is not just due to taking in fewer calories or lack of activity. This common misunderstanding created frustration for both Connie and his caregivers leading to misunderstanding about the need to eat more food than was desired and the importance of eating to keep up your strength.

Lisa K (03:31:34):

Connie showed muscle wasting several months prior his diagnosis in October of 2015. I noticed that his buttocks had gotten awfully flabby, mistakenly attributing this to sitting day in and day out for work, not keeping up with his fitness, and being 76 years old. He had gotten a recent clean bill of health from the Mayo Clinic, so cancer never even entered my mind ever. As time went, on the muscles on the back of his arms above his elbows also began to shrivel up. In hindsight, Connie had all of the classic symptoms of a brewing cancer, fatigue, weight loss, loss of appetite and irritability in spite of visits to doctors and no findings of urgent concern.

Lisa K (03:32:25):

While Connie was alive, our symptom management plan consisted of all of the recommendations that cancer patients typically get from cancer brochures and counselors. We tried small and frequent portions, soft and palatable foods, and foods with low fragrance and low spiciness. Many of Connie's favorite foods were off limits, further adding to frustration at meal time. Unfortunately, none of these recommendations proved to be very helpful for Connie. All of our nutrition effort was geared toward weight loss presumed to be due to the side effects of chemotherapy. We did not get any guidance for treating a possible metabolic cancer-related disorder nor were we briefed on some such a disorder.

Lisa K (03:33:11):

In June of 2016, Connie underwent a pain medicine delivery pump implant at the recommendation of Mayo Palliative Care. The after effects of the pump surgery led to another 20-pound weight loss within just a few weeks due to extreme fatigue, poor appetite, having to lie in bed due to poorly controlled pain and possible reactions to the intrathecal morphine he was prescribed for the pump. At the time of his death, Connie weighed just 133 pounds and was 6'1" tall.

Lisa K (03:33:46):

Connie needed good nutrition in order to help heal and maintain his weight and performance status or, at the very least, to not regress. I wish his doctors had done more to ensure that excellent nutrition was available by any means in order to allow healing to happen and to help his mind to function better. I hope that more targeted cancer therapies will be discovered which may reduce nausea and eating difficulties. Regardless, superb nutrition, whether taken orally, intravenously, or through a feeding tube, must always be considered for those facing cancer. It was not always possible for Connie to take in enough calories by mouth during his treatments, and it is critical that the body gets what it needs to function at its best during such a challenging time.

Lisa K (03:34:34):

I wish his doctors had briefed us that no matter how much Connie ate, a syndrome called cancer cachexia likely prevented his weight maintenance. All of this would have helped us navigate more effectively through our cancer journey and could have provided a better overall outcome for Connie. Thank you for listening to our story.

Linda B (03:35:00):

Hi, my name is Linda Bohannon, and I'm coming to you today from Indianapolis, Indiana. I first want to thank the Cancer Support Community for hosting this meeting on what's a very important topic. My experience with cachexia spans nearly a lifetime having spent almost 40 years working in cancer, where I've had the opportunity to watch from the frontline as patients and families spent their precious and limited time together at odds with one another because of the patient's inability to eat, coupled with the caregiver's desire to care for their loved one, both with the best of intentions.

Linda B (03:35:34):

Cachexia became a very personal reality for me in May of 2016. On May 21st, I took my hero, my dad, to lunch for his favorite sausage gravy and biscuits, which he absolutely loved. This day he complained of feeling tired, and he left almost half of his food on his plate completely untouched, which was not normal for him at all and something I had never seen ever. Two days and lab work later, my dad was in the hospital fighting for his life. He had an aggressive form of leukemia called acute myeloid leukemia or AML. The meal that we had together on May 21st was the last regular meal that he would have.

Linda B (03:36:17):

For the next two months, his condition improved a little, declined a lot, improved a little, declined a lot, and I found myself going from daughter to oncology professional and doing all that I could to ensure that if the chemo he was taking decided to work, that the rest of him would be ready to live life on the other side of this experience.

Linda B (03:36:38):

I diligently got him out of bed every day. I bathed him, I washed his hair, I made him walk, and that is where all of this came became very personal to me. On the nights that I didn't stay at the hospital, I would stop on the way in and bring a donut, a milk shake, sausage, gravy, anything I could to really help support him. One day, the nurses had a birthday cake, and one of them brought in a piece and literally just fed it to him. My dad was kind of shy, so telling him no was completely out of the question. I'm thankful that they did just take that step because at least it got calories into him.

Linda B (03:37:13):

The rest of the time, I was relentless in making him drink Ensure milkshakes made with milk, and then instead of water, I replaced that with another high calorie drink, also Ensure clear. Again, if he was sipping on anything or if he was able to ingest anything, I wanted to make sure that it had some sort of calories and nutrients in that.

Linda B (03:37:35):

It was tough. I was convinced that I was forcing him to do this. He hated drinking it. I was making him drink it. I found myself in the same pull-and-tug loop that I'd seen so many of my patients in. It was really devastating for me to watch. My dad, he had a belly. He was a very robust guy. He loved his snacks. He literally disintegrated before my eyes, and his belly, which had been a source of joking and him being jovial, just went away throughout this experience. In some way, I felt that even despite my best effort, I was responsible for not being able to keep him with the nutrition that I would've liked to have been able to.

Linda B (03:38:21):

I was aware of a number of medicines and other tactics that could be tried to stimulate the appetite, and none of them worked particularly well for the patients that I was working with, so we didn't try that with dad. The healthcare team was focused on frankly keeping him alive, so they weren't focused on his nutrition. That was all me. There was even a point in time where I thought about how I could get my hands on marijuana and mix marijuana into his milkshake, but it was illegal in the state of Indiana. It still is illegal in the state of Indiana, and I was sure that I would lose my nursing license. But if I knew I could have gotten a safe supply for him, I probably would've done it anyway.

Linda B (03:38:58):

My dad passed away on July 22 of that year, almost two months to the day of our last meal together. I learned a lot through that experience, and I really wouldn't trade a second of the time that we spent together for anything. But now that I really have experienced the psychosocial impact of that, I just want anyone that I can to know about the experience around that and do everything that you possibly can to eliminate that.

Linda B (03:39:25):

For months after I replayed the scenarios in my head repeatedly. Did I do everything that I could? Did I make him more miserable than I should have? It was truly awful to live through that experience. And then weeks after my dad died, my mom was visited by a Hawk. I was convinced that it was my dad. One day, my friend Josie and I, we were on a road jogging. We stopped for a minute to catch our breath, and I had been talking about how I worried that he was still mad at me for trying to help him make it to the other side and all of the things, walking and feeding and all of that. No sooner did I stop speaking that out of nowhere, a hawk came and it flew down, dipped down, and then just flew away. I knew that that was my dad's message to tell me that it was okay. Thank you so much.

Melvin L (03:40:14):

My name is Melvin. I'm from Houston, Texas. In the first two weeks of May 2018, I visited two clinics undergoing a total of five needle biopsies to a lump on the right side of my neck with no conclusive results, but cancer was a possibility. I went to MD Anderson Center located in Houston, Texas, and with two additional needle biopsies, it was determined on May 15, 2018, that I had metastatic squamous cell carcinoma to the right side of my neck.

Melvin L (03:40:49):

On June 13, 2018, I started my radiation and chemo treatment. My wife was a big help as she drove me daily to and from the treatment center and reminded me about skin care and eating as it was evident I was losing weight, losing muscle definition, and slowly starting to eat less.A side effect of the radiation to the neck and throat area were the difficulties of eating and swallowing food.

Melvin L (03:41:18):

The weekly doctor visits continued to show I was losing weight and my wife was concerned. I recall hoping the nurse did not ask me to take my sneakers off so that the weight count would be higher. I was in denial that I was losing weight. The radiation treatment preparation included taking off my shirt. I can recall seeing that I was losing muscle definition. I became more and more self conscious when taking off my shirt. The emphasis on eating continued to come from the nutritionist when visiting the treatment center. She would kind of warn me that if I did not eat, I would eventually need a feeding tube as if the feeding tube was something bad or was the result of my direct negligence.

Melvin L (03:42:11):

Nevertheless, the treatment to my neck and throat gradually took its toll. I can recall trying to drink water by allowing it to flow down the walls of my mouth into my throat without swallowing because the pain was so bad. Three weeks into my treatment on July 1st, 2018, I started vomiting a dark red, almost purple substance at home. I initially thought it was blueberries that I had eaten moments earlier, but after looking closer, I determined it was blood. My wife rushed me to MD Anderson emergency room, and I was diagnosed with severe protein calorie malnutrition resulting in 14 pounds of weight loss from my original weight of 152.

Melvin L (03:43:07):

The solution for this diagnosis was a surgical insertion of a feeding tube into my stomach. I spent the Fourth of July holiday recovering from a successful surgery. After leaving the hospital, I continued the radiation, chemo, and feeding tube treatment. My radiation and chemo treatment ended on July 25, 2018, as I rung the bell at the Bay Area MD Anderson facility in Houston, Texas. My feeding tube treatment continued for an additional six weeks. Removal of the tube was based on my ability to consume about 2,000 calories per day without using the tube.

Melvin L (03:43:49):

As the weeks passed, healing of the throat from the radiation treatment got better. I can remember the day I tried chicken noodle soup. I cried. Tears of joy rolled down my face as I was able to swallow, and more amazingly, I was able once again to taste food after having no taste at all or food tasting like metal due to the chemo treatment. My ability to return to regular food and wean myself off the feeding tube ended on September 6, 2018. Because of the weight loss, I had to purchase a new wardrobe as my waist size went from 33 to 30, shirts from large to medium, and jacket size from 40 to 38.

Melvin L (03:44:40):

In hindsight, I asked the doctors, mainly the nutritionist, to be more forthcoming and transparent about the likelihood of weight loss, to approach the possibility of a feeding tube from a positive point of view given the radiation treatment to the neck and throat area, and the inevitable when swallowing that would prevent normal consumption of food and eventually weight loss.

James Valentine, JD, MHS (03:45:15):

To Melvin and all of our panelists, thank you so much. Again, we know it's hard to dig deep and think about all of the ranges of different treatments that you underwent as you were navigating living with cancer cachexia.

James Valentine, JD, MHS (03:45:32):

Now we're at the part of the agenda where, for the second time, we get to broaden the discussion to all of you in the live audience, or individuals living with cancer cachexia, and caregivers and care partners. If you have experience to share, recall we're focusing on, first, your current approaches to treatment. Again, when we talk about treatments, we're talking a really broad range of different approaches and strategies, not just medicines or medical procedures that you have tried or are currently doing to help manage living with cancer cachexia symptoms.

James Valentine, JD, MHS (03:46:10):

And so if you have something to share, please dial in. The number is 1-7-0-3-8-4-4-3-2-3-1. Again, that's 1-7-0-3-8-4-4-3-2-3-1. We would love to hear from you. Again, it's important that we hear from as many different voices as possible today. There's a number of different treatment approaches, and even using the same treatment approaches, we know that each person may experience them differently, So we would love to hear from you.

James Valentine, JD, MHS (03:46:42):

To get us thinking about some of these different treatment approaches that exist, we are going to start with a few polling questions. If you've just joined us in this afternoon, we will be going to a number of different polling questions periodically. All you need to do is open a new tab in your browser. Pull out your phone. You can use your web browser on your phone, and you just go to www.PollEV.com/Cachexia. I know that that should be being displayed for you right now. Just go to that website, keep that open for the rest of the afternoon, and we will be working through some polling questions periodically.

James Valentine, JD, MHS (03:47:22):

Our first of a few polling questions I want to start us with this afternoon is focused on the medical treatments. I mentioned when we talk about treatments, we're talking about a wide net. Here we're focused more specifically on the actual medications and medical treatments. We want to know which have you recently used or has your loved one recently used to treat their cancer cachexia, and please select all that apply. If you're a caregiver of someone who has passed that had cancer cachexia, please answer these questions for what they were recently using up until the point that they passed. The options here are: A, megestrol acetate. B, oxandrolone, prednisone, dexamethasone, or other steroid treatments. C, Dronabinol. D, treatments for the gastroesophageal reflux disease or GERD. E, some other appetite stimulant. F, antidepressant or antianxiety medication. G, feeding tube. H, other medications that aren't listed on this slide. Again, we're focusing on actual drug medications or other medical treatments. We'll focus on other approaches in our next question. And then, I, if you have not used medications or medical treatments recently.

James Valentine, JD, MHS (03:48:51):

You can select all that apply. It looks like perhaps the majority of the responses have come in, as I was reading those response options. But again, we're getting a sense here of the different medications and medical treatments that our participants today have utilized recently. We'll remind our audience, since this is our first polling question of the afternoon, where our participants could select more than one option, that the percentages are reflecting a percentage of total responses. When you see a percentage, that does not represent the percentage of people who actually picked that option. As it stands, you can think of these bars as kind of a ranking, and it looks like the most experience by our audience of any particular medication or medical treatment is antidepressant or antianxiety medications. We heard a great deal this morning about the mental health impacts of living with cancer cachexia, and so we certainly want this afternoon to hear about different approaches to treating the mental health aspects. We see that coming up early here in the polling questions.

James Valentine, JD, MHS (03:50:04):

We do see other appetite stimulants and other medications listed here as some other top choices. So certainly we want to hear about what those are even if we didn't list them specifically on the slide. Everything is on the table. We also see that a number of individuals have used different steroid treatments. We also see a number of individuals have not used any medications or medical treatments recently. That doesn't mean that they may not be using other non-medical approaches, and we'll be learning about that shortly. The only thing that has not been used by those in our live audience today is a feeding tube as a medical treatment approach.

James Valentine, JD, MHS (03:50:44):

We're go to do our second polling question. We're going to broaden this and explore things that are beyond traditional medications and treatments. We want to know what are you currently doing to help manage symptoms of cancer cachexia beyond those. So here-

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James Valentine, JD, MHS (03:51:03):

... manage symptoms of cancer cachexia beyond those. Here again, you can select all that apply. The options are: A, using seasoning or spices on your food; B, eating small or more frequent meals; C, using cannabis or CBD; D, taking vitamin B1; E, taking omega-3-fatty acids; F, using bitter herbs; G, exercise; H, stress management techniques; I, acupuncture; J, meditation; K, nutritional supplements other than what have been listed; L, some other management strategy. Again, this is really the catch-all. Anything that maybe you do in your daily life that makes living with cancer cachexia a little bit easier; we want to hear about. Or M, you are not doing anything to manage your symptoms of cancer cachexia. If there's no strategies that you're employing, you can select M.

James Valentine, JD, MHS (03:52:09):

With some final responses trickling in, it looks like the top non-medication treatment strategy is both small and more frequent meals as well as exercise followed closely by cannabis or CBD, and nutritional supplements. We definitely want to hear about these things. How has this helped? In employing these, for example, eating small and more frequent meals, has that made a difference? Have you been able to maintain or prevent the weight loss or muscle wasting? How has that helped or maybe it hasn't? Similarly, with exercise, we want to hear what your exercise regimen is and how it helps if it helps. Really, that applies to each of these things. As we know, it's very personal, the impact that the treatment regimen will have. What we see is almost actually all of these management techniques are being used. No one reports the use of bitter herbs and no one reports that they do not do anything to try to help manage their symptoms.

James Valentine, JD, MHS (03:53:22):

One more polling question before we invite you to weigh in and actually share some more details about your treatment experiences. We want your overall assessment of your current regimen. How well does your current regimen control your cancer cachexia overall or your loved one's cancer cachexia overall? A, not at all; B, very little; C, somewhat; D, to a great extent; or E, not applicable because you're not using anything. This applies to everything that we talked about on the last two slides or the last two questions. How well is that, in totality, controlling you or your loved one's cancer cachexia overall? As it stands, what we're seeing is that about 40% of our participants are saying that their current regimen does not control their cancer cachexia at all. About 30% are saying it helps somewhat; 20%, very little. Just a small minority, 10%, saying that it helps to a great extent. Again, consistent with our last question, no one is reporting that this is not applicable because they're not using anything.

James Valentine, JD, MHS (03:54:51):

I want you to think about the why. Why did you say that it's not helping at all versus helping a little, somewhat, or to a great extent? Everybody, where they are in their journey with cancer cachexia, is different. Maybe even your definition of what very little is or to a great extent might differ. We would love to hear the why. How did you come to the conclusion that you did with this? Again, I'll invite you to call in at +1 703-844-3231 or write in. We have that comment box that has been open underneath the live stream on the webpage today. You can write in with comments to any of these questions throughout the program. Even if I don't call it out, please feel free to write in or call in at any point if you have something to add to the conversation.

James Valentine, JD, MHS (03:55:45):

To get us started though, I'd like to welcome our Zoom panel. We have another panel of your peers, individuals living with cancer cachexia and their caregivers, and care partners who are going to be helping us understand the current and future approaches to treatments. Welcome. I'd like to maybe start Kristen S. with you. As you were thinking about that third question, how well does everything I have at my disposal work to the degree that anything worked? Some people said not at all. You can let us know if that's the case. But if you selected something other than that, what contributed to that? What maybe is helping the most?

Kristen S (03:56:29):

All right. Thank you. Thank you Cancer Support Community for hosting this conversation. It's been a really great day so far. Intense, but really important. I'm glad that we're having these conversations. I'm Kristen Santiago. I live in DC. I'm a caregiver to my mom who lives in Philadelphia who has stage 4 small cell lung cancer. I'm a distant caregiver, but I'm back and forth a bunch and managing from the sidelines, and a lot of times, hands on. I'll say my mom's also a retired nurse. She knows how to work the healthcare system, but it failed her, I would say, in this circumstance. I answered, whatever the first one was, not working at all.

James Valentine, JD, MHS (03:57:20):

Right. Yes.

Kristen S (03:57:22):

Again, for my mom who knows how to navigate, I also in full disclosure work for a Longevity Foundation, which is a lung cancer patient advocacy and research foundation. We know where to go for help, but we're still not getting there. If I were to offer a solution right now, which I don't think that you necessarily ask that, I would recommend that people have access to palliative care because I think they can help get people the emotional, physical, psychosocial support that they need, nutritional support. Having that layer, that's my thing that I've pushed for my mom to get. I'm rambling. I don't know if I answered your question, but [crosstalk 03:58:06]

James Valentine, JD, MHS (03:58:05):

Well, I want to dig in and understand your mom's experience a little bit. You said not at all. That's a big picture question. Maybe can you tell us some of the things that she's tried? Has anything maybe worked even just for a little bit of time? We'll definitely come back and focus in on some of the downsides or things that haven't worked, but maybe just give us a sense of what she's tried. Amongst those, did anything even work even for a short period of time?

Kristen S (03:58:38):

My mom currently is doing some at-home physical therapy, which helps. I think what we've heard earlier, she doesn't have that motivation to exercise, but she loves her physical therapist. With him, she'll go on walks around the living room. I don't mean that in a disrespectful way, but she'll get up and do sit-to-stand exercises. That definitely helps. She has taken anti-nausea medicine to help her eat a little bit more. She hates, but will drink the Ensure and the Ensure Clears, which she hates. But she knows she should. She has tried medical marijuana. In Pennsylvania, it's legal. She didn't like it. I think I heard her-

James Valentine, JD, MHS (03:59:35):

When you talked about the physical therapy, you said it helps. I'm taking your general comment of things aren't helping overall. Meaning it's not stopping the overall disease process. It's not reversing course on what's happened so far, but maybe some things have helped, what I might call, symptomatically. You mentioned the anti-nausea medicine that actually did help some with the nausea, it sounds like. But the PT, you said it helps some. How would you characterize that? How did you notice it? How did your mom notice it if she told you about it?

Kristen S (04:00:17):

I'll say two things. One, she's been in a rehab facility twice to try and build up strength. Both times, they really focus on that a lot as well as nutrition. Each time she's come home from rehab, she's been stronger. Now-

James Valentine, JD, MHS (04:00:40):

Is it really that you notice that? Is it an activity in the house?

Kristen S (04:00:44):

Yeah. She couldn't go to the bathroom or get off the couch by herself or shower. Then she went into a rehab place for a couple weeks and then was able to do that. But it's been up and down. Currently, around the down, but we have someone who comes in a couple times a week. I think we're going to increase that, but she's just tired, right? It hurts her. She doesn't want to do it. Then she feels like crap. Sorry.

James Valentine, JD, MHS (04:01:12):

Oh, no. That's okay.

Kristen S (04:01:13):

We're not being professional, but she doesn't feel well the next day. Then it makes her not want to do it, but in theory it helps build the muscle back.

James Valentine, JD, MHS (04:01:24):

Yeah. Those ups and downs as you described it, is that once a year she's on an up and down? Is it more up and down than that?

Kristen S (04:01:38):

I would guess it depends on the disease, with where she is with lung cancer. She was diagnosed a little over four years ago. The ups and downs have been much closer together right now than they were previously.

James Valentine, JD, MHS (04:01:53):

I see.

Kristen S (04:01:54):

But the muscle wasting has been a lot more intense.

James Valentine, JD, MHS (04:02:01):

Yeah. When you say the muscle wasting has been more intense, it's been a noticeable loss of strength, inability to certain activities again like self bathing, that type of thing?

Kristen S (04:02:12):

Yeah. ADLs are not... We're not checking the boxes there-

James Valentine, JD, MHS (04:02:17):

I see.

Kristen S (04:02:17):

... I would say.

James Valentine, JD, MHS (04:02:18):

Sure. Well, thank you so much, Kristen, for sharing some of your mom's experiences there. I know sometimes it's hard to say what works when there's limited strategies available, but I do want to-

Kristen S (04:02:33):

Can I just add?

James Valentine, JD, MHS (04:02:33):

Yes.

Kristen S (04:02:34):

I'm sorry to interrupt. My parents have access.

James Valentine, JD, MHS (04:02:37):

Yeah.

Kristen S (04:02:38):

Right? It's not like they don't have access. They have the knowledge to navigate, but there's just not resources or a diagnosis, or doctors connecting, which is a common theme, I think, which we've heard. Sorry, James-

James Valentine, JD, MHS (04:02:51):

No. It's okay.

Kristen S (04:02:51):

... for interrupting.

James Valentine, JD, MHS (04:02:54):

Yeah. No, thank you. It's a helpful context. I want to go over to Rick. Rick, on the same topic as we're thinking of the different tools we have in the toolbox, what have people in your life used? What maybe has been most helpful, if anything?

Rick D (04:03:14):

Yeah. Hi. Good afternoon or good morning. Where I am, it's good morning. I'm in Deep Southern Arizona. I've interacted with a lot of folks over the last several years with cachexia. Several of whom have been very close friends and I've been part of their caregiving team. I run an organization that provides support. The simple and most effective solution, believe it or not, have been fast-food shakes. I'm thinking in particular one really dear friend who probably in the last three months of his life, four months of his life, subsisted on heavy chocolate shakes. He could get them down. He liked them. Of course, the irony is with many cancers you want to avoid sugar throughout your treatment. Then there comes a point when you're encouraging people close to you to consume sugar-

James Valentine, JD, MHS (04:04:33):

Right.

Rick D (04:04:34):

... because they can and because they like to. Because at that point in time, quality of life is way more important than survival. Shakes have been huge and ice cream. Ice cream's another big one. Somebody mentioned ice cream before. People feel... It makes them feel good. We've seen them consumed and encouraged, happy doing it, put on weight, feel better. I would say ice cream and shakes, number 1. Number 2-

James Valentine, JD, MHS (04:05:11):

Yeah. Can I ask you something about that, Rick, before we go to number 2?

Rick D (04:05:13):

Yes. Sure.

James Valentine, JD, MHS (04:05:15):

One, I won't ask you to endorse a particular fast food brand or brand of ice cream, but I do want to explore why that's valuable. I think we inherently understand people like sugar, tasty drinks. But with your friend, for example, who was drinking the chocolate shakes, was he ever having aversions to other foods or was his appetite just lower in general? Can you maybe help us understand?

Rick D (04:05:45):

No. Absolutely. I'm trying to be very careful not to endorse any particular shake, by the way. He was having trouble keeping anything down. Didn't want to eat.

James Valentine, JD, MHS (04:06:01):

I see.

Rick D (04:06:01):

Felt nauseous. There were very few foods that were... With this particular guy, he lived on his own. He had a village of five or six of us who would constantly be in and caring for him. We'd stop off at the fast-food place and bring a shake over on the way over to see him. He was very grateful for that. Very often, it's a question we heard this morning; we've heard it since. It's what you can eat. It's what you have a taste for. Your taste change. With cachexia, it impacts your taste buds.

James Valentine, JD, MHS (04:06:58):

Yeah. Absolutely.

Rick D (04:06:59):

Of course, as we know, chemo certainly does that with the old loss of taste. Everything tastes like cardboard when you're...

James Valentine, JD, MHS (04:07:13):

Yeah. Thank you for helping me understand the shakes a little more. I know you had a number 2, if you want to mention that.

Rick D (04:07:21):

Yeah. I had a 2 and a 3. The second thing that I've seen works very well is medical marijuana usually taken through a vape.

James Valentine, JD, MHS (04:07:36):

How would you characterize that? Is that just helping stimulate appetite, to keep food down? Again, is there maybe a particular example you can think of where it helped in a way that you can share that example?

Rick D (04:07:51):

I think it does two things. I think of one particular incidence where I was at a Chinese restaurant at lunchtime with two guys who were pretty close to the end of life and both really good friends. Both of whom I was involved with their caregiving. One of them put a vape on the Lazy Susan. It moved around to the people, to the guys. There was, I think, five or six of us at the table. This was in California. It stimulates appetite, number 1. It also helps immensely with nausea. Both those things. Even if you don't have appetite, if you can suppress the nausea, that's huge. I've seen it and it works. It's easy. Now, not for everybody and you have to get the balance of CBD and THC right. But if you're living in a state where it's legal, you have people that can help you do that.

Rick D (04:09:11):

The third thing I want to mention is something that Kristen mentioned and it's huge. It really wasn't talked about at all this morning, which is the importance of symptom management, palliative care. Palliative care is not end of life. Somebody who wrote in this morning, I recognized who it was. It's, again, a good friend who's going through cachexia right now and who I spoke to at length yesterday. One of the things that I suggested to him, because he doesn't have it, is, "Got to have a palliative care doc on your team. Add them to your team." Why? Because these are the specialists who know how to deal with muscle wasting and with nausea, or with diet and who have access to provide mental health support.

James Valentine, JD, MHS (04:10:09):

Sure.

Rick D (04:10:09):

It is so, so important because we, as caregivers, can help, but we technically don't have the advice. A lot of times, your oncologist is just not up to speed with a lot of the new drugs that are out there. Please add a palliative care doc.

James Valentine, JD, MHS (04:10:29):

Yeah. Well, thank you so much, Rick. Covered a good amount of ground there, but useful to hear those experiences. Just maybe with the show of hand from our other three panelists. Is there something that's worked well or even worked somewhat for you that you would like to share? Kay, Kristin W, or Katherine. Something that you might put in the column of a treatment success even if just a small one. Yeah. Kristin W.

Kristin W (04:10:59):

Hi. Good afternoon. I'm Kristin. I'm in Maryland. My dad was diagnosed with stage 4 lung cancer. Like Kristen, I was not a direct caregiver to my dad because my parents lived in Delaware, but I did do some back and forth. When my dad was diagnosed with cachexia, he lived for about four months after his diagnosis. He was close to the end stages of cachexia by the time he was diagnosed with it. The medications that he took weren't very helpful in managing it. One thing he did do was he continued to exercise. Like Kristen said, the physical therapy for her mom was helpful; the exercise for my dad was helpful. Not from the standpoint of putting on weight and muscle mass, but for his mental health because this is something that he had done for a good part of his life. When he felt good and could do a little bit of it, I think it just made him feel normal.

James Valentine, JD, MHS (04:12:15):

I know you said it didn't maybe help him increase muscle mass, but did he have a sense or did you all, as the family, have a sense that getting in that exercise when he could do it, help him maintain what he had or was it really purely just the normalcy of doing an activity that he enjoyed?

Kristin W (04:12:35):

It was more of the normalcy of doing the activity that he enjoyed. Once he was diagnosed, he went rapidly downhill. Yeah. There wasn't much that we could do that could help him. Also, like Rick and Kristen mentioned, the palliative care doctor, my dad at the end did have a palliative care doctor. She was wonderful. I think that is absolutely important for cancer patients.

James Valentine, JD, MHS (04:13:08):

Absolutely. Thank you, Kristin. I do see that we have some written comments coming in. Elizabeth, what are we seeing anything on treatment successes?

Elizabeth Franklin, PhD, MSW (04:13:18):

We do have a few on treatment successes. Susan from Dover, Delaware put something really interesting into the written comments. She said, "A plate of food can be overwhelming. One idea that worked really well was to place several silicone cupcake holders into a flat food storage container and put a small portion of different foods into each cup. It's like a bento box. Colorful, lightweight, appetizing, and not overwhelming." Just shows the creativity of how folks are handling this.

Elizabeth Franklin, PhD, MSW (04:13:51):

Then I'll also mention and I'm wondering if this is our very own Kay that we have on the screen right now. But Kay, you talked about the importance of what is now the Cancer Support Community and helping you move forward with diet, exercise, education, not feeling alone. I think it really feeds into that palliative care discussion. Right? It's the full package. It's the entire patient experience. It's not just the physical side.

James Valentine, JD, MHS (04:14:17):

Kay, do you want to comment? Well, confirm if that was you, but then either way, comment.

Kay K (04:14:23):

Actually, it was me. Hi. My name is Kay. I'm in Arizona and I am a cancer research having a grant reviewer. But I'm also a pancreatic cancer patient. Yes, all these sessions have been wonderful because I felt the same way as everyone did. Where do I go? What do I do? At that time, it wasn't identified. I found a cancer support community and it did help with the nutrition, with the exercise, with the feeling alone. That is part of your treatment because you do so much to treat your body. You got to remember, you got to treat your mind, too. It helps you. There are days you don't want to eat and it hits every day. Because you wake up and you know whether it's going to be a good or bad day. It's not weekly. It's not monthly, not yearly. It's every day. Some days, like you said, you don't want to eat, but it helped me immensely with the cancer support community.

James Valentine, JD, MHS (04:15:36):

Yeah. Kay, can you tell us then a little bit of what that translated to for you being able to have that support to eat even when you didn't want to? What did that translate for you health-wise?

Kay K (04:15:52):

It gave me hope, let's just say. I deal with pancreatic cancer patients now also. Sometimes, you just say it's too much. It's too much on my plate. I'm just going to give up. They focus you in different areas that you don't have to take the food. You don't have to take everything all at one time and deal with it. I've learned to be patient active and help myself. The doctors were great. They could tell them, but it was me that had to do it.

James Valentine, JD, MHS (04:16:26):

Yeah. Did that help with your nutrition? Keeping weed on, all of that, too?

Kay K (04:16:32):

My nutrition, mainly a lot of my exercise, socializing. You get the fatigue. It's so tired. It's hard to talk on a telephone. I lost friends. These are all things that you have to deal with with the symptoms from this disease.

James Valentine, JD, MHS (04:16:51):

Right. Absolutely. Kristen S., I saw you waved your hand. Did you want to add something to this?

Kristen S (04:16:59):

I was just going to echo the small servings. We make food look fun for my mom. She's like, "Ooh, look how exciting this is." That works in smaller, pretty little plates, and then she's more likely to eat. I agree with that.

James Valentine, JD, MHS (04:17:12):

Oh.

Kristen S (04:17:12):

That's it.

James Valentine, JD, MHS (04:17:13):

No, thank you for echoing that. I do want to broaden the discussion a bit. We have focused on treatment successes. It sounds like a little bit here and there, but not wholesale success. But I do want to understand some of the other side of these treatments that you have available to you. We saw pretty much everything on that medical treatment list being ticked off by our participants as things that they or their loved ones have tried. We know that, again, every medication comes with some downsides, that side effects, the burdens of undergoing the treatment. We want to explore that a little bit as well. To get us started thinking about that, we're going to go back to a polling question. You can pull that phone back out, open up that browser, go to that tab you might have open. If you have it open on your computer, go to PollEV.com/Cachexia.

James Valentine, JD, MHS (04:18:16):

This question we have for you is we want to know what are the biggest drawbacks of your current approaches. This isn't limited to just medications; it's really across all of the different options you have. But we want you to select up to three of what you consider the biggest drawbacks. The options are: A, they're not very effective; B, they have a high cost or co-pay, or they're not covered by insurance; C, they have limited availability or accessibility to you; D, the side effects of those approaches or products; E, the route of administration. For example, if something needs to be injected or infused. F, it requires too much effort and/ or time commitment to keep up with a particular treatment or treatment regimen;

G, some other drawback that we don't have listed here is an option; or H, you can mark this as not applicable because you're not using any treatments.

James Valentine, JD, MHS (04:19:17):

Again, here you can denote what you would view as the three biggest drawbacks to your current approaches, to treatment that can be medical or non-medical treatments. I know it can be hard. Everything has trade offs. There's different trade offs, but please try to select up to three that maybe have the biggest impact on you or your loved one in your daily life. Again, these are percentages of total responses to use the bars as ranking. It looks like the top choice is that they're not very effective. We want to hear about that. What have you tried? What were you hoping it would do? How did you notice that it wasn't very effective or maybe not as effective as you would hope? We want to hear about these things that have been tried even if they haven't worked. It's important to know that.

James Valentine, JD, MHS (04:20:21):

We see that there is a financial burden related to the high cost or lack of insurance coverage as well as tied for three, limited availability or accessibility, which would be interesting to hear what that is then. One example that's been given, it might be medical marijuana, but if there's others, if you don't have access to something, then it isn't a viable treatment option for you. But also we see that it may require too much effort and/or time commitment. This is what I'm really interested to hear about. What of these treatment regimens or treatment approaches are requiring too much effort and/or time commitment? This may apply to traditional medical treatments, but I could see this perhaps maybe applying to some of the non-medical treatments. We want to hear what those are and why you view it as requiring too much effort and/or time commitment. We know that your patients, some of you are still having to balance this with treating cancer plus everything else in your lives. That's a real drawback; one we'd like to learn about.

James Valentine, JD, MHS (04:21:32):

We do have some people reporting side effects to the degree that that maybe impairs your ability to continue on or maybe your quality of life is impacted by continuing taking products that have side effects. We'd like to hear about that as well as any of those other things. One thing that stands out is, of course, that no one mentioned that route of administration, to them, is one of the biggest drawbacks of current treatment approaches. Let's take this back to our Zoom panel. Before we get there, I want to encourage anyone in our live audience that has a treatment downside or something that hasn't worked now that we've broadened the discussion to include those two things. If you would like to call in and share your treatment experience, you can call in at +1 703-844-3231. Again, that's +1 703-844-3231. There's lots of different treatments we know that are out there. We want to know what have you tried. If it didn't work, we want to hear how you noticed or if it did have one of those downsides, what those were. Of course, you can also write in to the comment box as well.

James Valentine, JD, MHS (04:22:49):

Yeah. Katie, can you please tell us a little bit of what you were thinking as you were answering that question of what are the biggest downsides?

Katie G (04:23:04):

Yeah. Hi everyone. Thank you for having us. I am from a suburb of Chicago and I am a former caregiver for my dad, Dave, who was diagnosed with cholangiocarcinoma or bile duct cancer in 2016. He passed away only four months after that. He definitely had cancer cachexia. He had all of the symptoms that we've all already discussed here, but there was never a clear diagnosis with that. Then I'm also here just because it was less than two months ago, my father-in-law was diagnosed with another rare GI cancer called small cell rectal carcinoma. He just passed away two weeks ago. Then he also had cancer cachexia. Again, never received a formal diagnosis of it, but definitely something that we knew that we need...

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Katie G (04:24:03):

... A formal diagnosis of it, but definitely something that we knew that we needed to combat. As far as treatments that we had tried, I was just doing any research that I could and it was not really well perceived, I think by some medical professionals just because it wasn't an official diagnosis. It was just kind of, "That's the cancer." I definitely looked up a lot of stuff about amino acids, but then there's some research that is mixed reviews about that, that, "Yeah. Okay. You can have some positive effects with cancer cachexia, but it can also sometimes drive the cancer." Just because some of that is sugars and we already talked about that's something that cancer patients should try to limit. So that was, I guess, kind of a dead end for us.

Katie G (04:25:06):

What else? Steroids. They were never really given as an option medical marijuana. My dad had tried that before he had passed away. I wouldn't say that it was completely effective for him, but he was so far advanced even at diagnosis that I'm not sure that medical marijuana could have helped. He did eat a little bit when he would take it, but I didn't see any major significant impact with it. But I definitely have talked to some cancer patients that, that has been a good resource for them, that medical marijuana has helped. The small amounts helped, but everything was pretty much a dead end for us.

James Valentine, JD, MHS (04:26:00):

Just maybe to explore medical marijuana because you said that was something that he did try. Some of the other things kind of were things you explored, but ultimately weren't able to or didn't try. You said that was maybe more towards the end, what were the driving symptoms that your dad was having? What were you hoping maybe that the medical marijuana would've been able to help with that it ultimately didn't?

Katie G (04:26:27):

Definitely we were hoping for it to be an appetite stimulant. But, like I said, it didn't really do that. As far as muscle mass and just physical strength, I don't think that we were necessarily looking for medical marijuana to do that. I was kind of assuming that would maybe make him sleep a little bit more. But then with my father-in-law's diagnosis I was trying to look up clinical trials and such. There was a drug called [inaudible 04:27:01] that we had no access to it. It's not something that was in our area or that we could even explore. I'm not sure if I answered your question.

James Valentine, JD, MHS (04:27:18):

No you did. Some of what I'm hearing is part of the downside is either a lack of clear information about the utility of a certain treatment approach or the lack of ability to access what might be a potential treatment approach. That certainly is a real kind of downside to a treatment beyond a side effect or something like that. So, very much helpful Katherine. Kristin W, on this kind of broader topic of either things that have tried that didn't work or maybe whether or not they did they've come with some downside, what sticks out to you?

Kristin W (04:28:02):

Well, with my dad because he was diagnosed so late the medications didn't really help him at all. But I do want to point out the [inaudible 04:28:14] that Katherine mentioned. We actually tried to get emergency use authorization from the FDA for compassionate use for my dad and we did go through the whole requesting from the FDA, which we did through a palliative care doctor because his oncologist wouldn't do the paperwork. I spoke to the drug company to make sure they would provide it for my dad if the FDA approved it, unfortunately the FDA approved it two days after he passed away.

Kristin W (04:28:49):

But it is a very promising drug in terms of increasing muscle mass and quality of life in patients with cachexia. Of the treatments that were currently available that my dad was taking, he was doing the megestrol acetate. The palliative care doctor recommended testosterone for him. And he was doing protein shakes, exercise. In terms of the building muscle mass strength, none of those really worked. But, again, I think it was because his cachexia was diagnosed so late. He was in the refractory stage, so there wasn't much that was going to help him at that point.

James Valentine, JD, MHS (04:29:34):

Right. Right. Nothing helped with quality of life. Maybe not the muscle wasting or the weight, but anything with nausea or pain or anything like that that was related to the cancer cachexia?

Kristin W (04:29:48):

Well, my dad was never nauseous not even with the chemo treatments. So he never took the antiemetics. He liked to eat. He ate up until the day he died. Contrary to a lot of other cachexia patients he never had the loss of appetite. He couldn't eat as much as he was eating before, but he did eat.

James Valentine, JD, MHS (04:30:21):

Well, thank you so much for sharing that Kristin, again about your dad. Want to keep kind of going around here. But, Elizabeth, want to check in with you see if any of our live audience participants have written in anything on treatment experiences.

Elizabeth Franklin, PhD, MSW (04:30:36):

Yeah. In terms of treatment downsides or failures, Christie from Eden Prairie, Minnesota really talked from her experience as a leukemia survivor. She said, "I have always thought nutrition is one of the most lacking disciplines in cancer care." At the Cancer Support Community we hear that from patients all the time that nutrition is something that they want to address and they don't have the resources or the support to do so. It really speaks to a bigger point that [Gesu 04:31:04] from Chester Township talks about when she said, "It seems that the healthcare system is set up from a medical perspective, but not set up to help patient journeys work better. It is just not patient-centric." I think we've heard that in many of the comments today from both our panelists and people who've written in that what they need most they're not getting attended to.

James Valentine, JD, MHS (04:31:27):

Right. Thank you for writing in and want to encourage you if you have other experiences with treatments, we can always go back to other topics if you have treatment success stories, but also these treatment failures or downsides. We want to hear kind of what are your experiences and it might be mixed reviews too. That's okay. But coming back to our Zoom panel here, Kay, as you're thinking about things that been tried that either didn't work and that really stick out to you or maybe had some important downside, again, just what really stands out amongst the different treatments.

Kay K (04:32:10):

Interesting question. Coming from as a patient research advocate I don't see very much on cancer cachexia, which I would like to see. I have seen more lately, probably in the last three months, but it's not looking at more of the quality of life than it is at the science. I see the drugs they're using are maybe more side effects than we have with the cachexia, which is worrisome. We need to figure out the borderline between the cancer and the cachexia. We need to look at patients individually. I have to say as far as the cannabis, I'm a real fan, but as patients remember we don't have that much research on it, which we would love to see more of. But we don't know whether it is promoting the cancer more or helping us with our cachexia. Please make sure that you tell the doctor that you are taking it and watch for the research because you need to know that it's okay to take with the chemo or treatment that you're on.

James Valentine, JD, MHS (04:33:25):

Yeah. Thank you Kay. Continuing on here, Kristen S, treatment downsides, maybe things that haven't worked. Anything we haven't heard about yet, maybe, or a personal take on something that's a little different than what we've heard so far.

Kristen S (04:33:44):

I'll just build a little bit off of what Kay said. I'm all for medical marijuana. I tried to push my mom to take it. I thought it was weird that they would prescribe vape pen for someone with lung cancer and this was before all the issues with vaping. I think that's something that we should look out for and maybe having edibles and [inaudible 04:34:06] and all these other things, but I think that's one thing and I don't have a scientific answer at all. And I don't think that the research is there yet, so we have to fund more research for that type of science. I think that's [crosstalk 04:34:22].

James Valentine, JD, MHS (04:34:22):

Any approaches that were tried that haven't worked, that we maybe haven't focused on so much? I know we've had a lot of talk about different, maybe diets or things that we eat, but we haven't heard a lot about any kind of dietary counseling. I don't know if you've come across that or any of the different medications.

Kristen S (04:34:50):

Yeah. Similar to what others have said, I think my mom met with a nutritionist once or twice, which was crazy to me, again. If you have a palliative care person that's part of your team or there's your quarterback, they can make sure that happens. Again, she's a nurse, she knows what she should be eating. She's also very stubborn woman who says, "Don't tell me what to eat. I'm going to eat what I want to eat." I guess that's when you layer in the psychosocial stuff as well to help get people there. Not a good answer. That's what I have.

James Valentine, JD, MHS (04:35:30):

No, thank you. Rick, you're on this topic of things that those that you've cared for have tried that just didn't work. They were taken to help with either some aspect of the cachexia, some symptom, or again, maybe something, whether or not it worked that had a side effect or a downside, you kind of want to explore this topic with you too.

Rick D (04:36:00):

The one thing that keeps going through my head as we talk about this in terms of access and finding solutions that do work is that it can be really difficult to seek help and to find help. You were just asking about nutrition and counselors. When patients are fortunate enough to be attending an NCI hospital or an NCCN hospital, [inaudible 04:36:33] a National Cancer Institute or National Comprehensive Cancer Network hospital, a lot of these extra bells and whistles are available, easily available. Whether it's diet, in some places exercise... We've actually started an exercise program in one of the NCCN hospitals for people with cancer. But if you are in the middle of the country and you are in a community cancer center, you are really struggling. I've struggled with people that I've cared for to try and get them to find access to diet, to nutrition support, never mind a palliative care doctor. How can we match them up with the registered dietician? I think that for people living with stage III and stage IV cancer, in particular stage IV, we have to do a better job in making sources of information more readily available.

James Valentine, JD, MHS (04:37:52):

Rick, maybe, because I know you interact with a lot of people, when you see someone who goes through one of those programs where they're getting all the bells and whistles versus someone in the community cancer center, in terms of cachexia outcomes, what do you see in terms of differences?

Rick D (04:38:13):

We see a better quality of life with the people that are attending centers of excellence. No question.

James Valentine, JD, MHS (04:38:19):

Is that in terms of the muscle wasting and the weight loss or is this more of the day-to-day how they're feeling and functioning, can you, maybe put some color on that?

Rick D (04:38:33):

Look, I think it's really more in terms of their state of mind and the way that they are handling the symptoms, whether it's the nausea, whether it's the pain. Because a lot of times when cachexia sets in you are almost out of control. The cancer's taken such a grip that it's using so much of your nutrition and there isn't a lot you can do other than to make the patient feel comfortable, which I'm sure some of the other panel members will attest to. If we can help that person feel more comfortable, then they deal better with the cachexia. It may not be physically better. They may not be wasting away slower, but they're handling it. I think there's an obligation on us as caregivers and as advocates to make this end part of the cancer path as smooth as we can and dealing with cachexia is a huge part of doing that.

James Valentine, JD, MHS (04:39:54):

Yeah. I mean that what you're saying really resonates with what we heard in the morning that so much of the experience of living with cancer cachexia or the mental, emotional, social impacts of it. Being able to do things that are... Although we did see the biggest treatment experience reported was anti-anxiety, anti-depression medications, but what I've been hearing from all of you is that it goes way beyond more than just taking a medication for it. It's really all of the support and other types of care that can help with those mental, emotional, social impacts as well. So that really is resonating and kind of connects us well to what we heard in the morning, Rick. I do want to check with Elizabeth, anything on other current treatment experience is good, bad?

Elizabeth Franklin, PhD, MSW (04:40:52):

Yeah. Carol from Sebastian, Florida talked about the importance of staying hopeful and positive. Without that we feel hopeless and the mental part creeps back in and I think that's similar. Rick was talking about how challenging it can be, especially when you have had cancer cachexia creep in. Carol also talked about medical marijuana, which helps with nausea, appetite, and sleeping. And also brought up for the first time naturopaths, which may provide a lot of treatment options that are not available through our medical team and they can test for other conditions that our doctors are familiar with. Again, really filling out that entire cancer care team, the oncologist is incredibly important as is the nurse, the social worker, the palliative care team, but finding the comprehensive team that really works for you.

James Valentine, JD, MHS (04:41:43):

Yeah. Thank you so much for that. I do see we have a phone caller. We have John from Philadelphia who is a former patient, and would love to hear John about some of your experiences with current treatment approaches. John, welcome and are you with us?

John (04:42:07):

Yes. Hi team. I appreciate your time. I spoke at the earlier phase. I just want to kind of thank you all for your experiences. It really resonates with me hearing the importance of being proactive rather than reactive, even though typically we're in a reactive state. My question here is in future oncology social worker. I'm getting my masters now. I have an idea as a survivor what I can do to help mitigate and kind of help patients that come into my ward. But I'm curious to hear from patients, caregivers, doctors, whomever, what your advice could be for someone in my position as a social worker to kind of help with this unknown disease.

James Valentine, JD, MHS (04:42:50):

Yeah. Well, John, as the moderator, I get to be in the position of throwing your own question back at you because both as a former patient and someone who's kind of being trained. I actually want to hear from you on... I don't expect any one person have all of the answers, but what would have helped you in your treatment journey? Whether that's information or maybe it's related to some aspect of... If you had a certain treatment that you could have plugged in that filled a void that you had, what would that have been?

John (04:43:28):

Well, I certainly think having the inform in front of me beforehand would've been helpful because it's sort of you're playing from behind once you find out about cachexia and that is the problem, just not getting it in the forefront. So A, I would put it in the forefront, but then B, in terms of when I see it or maybe if a patient is running into it, I'm giving them an all out [inaudible 04:43:49] on nutrition, exercise. I'm going to be alarming the doctors and just kind of putting it in their ears. Strategy wise, it varies depending on the severity of the case from the patient. That's still kind of things I'm learning to do, but I would kind of do my anecdotal approaches to remedy that situation there.

James Valentine, JD, MHS (04:44:10):

John, actually that, I think compliments some of the things that we've heard from other people including some of our Zoom panelists where you're talking about being able to intervene earlier. If you had information, some of the things that were tried maybe could have helped, but maybe they were tried too late in that cancer cachexia journey. I'm seeing some nodding heads on the panel. I think that's a great insight, John. Thank you so much for sharing it. I want to check one last time any current treatment experiences. I want to be mindful of time that we do want to cover future preferences for future treatments, but, of course, want to make sure we're not missing any comments from the audience.

Elizabeth Franklin, PhD, MSW (04:44:54):

Yeah. The only other comment that has come in, James, is Rochelle who said that... Really focusing on faith and mindfulness, which I think rounds out that comprehensive cancer care experience that if faith is something that's important to you, mindfulness... We had meditation in one of our poll questions. It's really important to tap into what works for you as an individual. Kristen said that cannabis didn't work for her mother, but Rick said that cannabis absolutely worked for his friends and the people he was caregiving for. So, it's finding what's right for you. Rochelle, I think that's such an important point to bring up about if faith is something that keeps you going, that's important to you to bring that into your personal life and the way that you handle cachexia.

James Valentine, JD, MHS (04:45:38):

Yeah. Thank you so much. I said, we're casting the widest net here and absolutely we're... I think a key theme that's certainly sticking out to me is the need to care for the person as they are now and there's lots of different approaches to that. Katherine, I want to make sure that you get to comment on this, treatment downsides things that maybe haven't worked or if you have something to share just on a current treatment approach.

Katie G (04:46:07):

Yeah. Actually the caller kind of said exactly what I was going to say. And that was just that we need a diagnosis early on. We could see so many changes that we haven't seen if this was diagnosed early, but I know our caller just said that. And then also just treating the whole person spiritually, mentally, and physically was what I was going to say.

James Valentine, JD, MHS (04:46:35):

No, it's good to hear if there's that kind of common agreement around some of those things. Rick, I think you had something you wanted to add before we change topics here.

Rick D (04:46:47):

Yeah, very quickly. There's an elephant in the room that we really haven't addressed and I think it's something that the FDA and the medical associations particularly ASCO can do, which is the friction that exists between the oncologist and the palliative care services in a lot of cases. We've seen it where we've suggested to people that we're caregiving for, "Ask your oncologist to line you up with a palliative care doc," and they just don't want to do it because there are control issues. I think we have to do a much better job in making the oncology community, the oncology doctors aware, not just about treatment, not just about the cancer, but about cachexia. I feel they don't really recognize it and they're not necessarily the right doctors to treat it. And when you ask them for help with treatment, they don't always respond. If something comes out of this, it could be that focus.

James Valentine, JD, MHS (04:47:55):

Yeah. Well, thank you Rick. Now we've really talked a lot about current treatments. But as we heard Dr. Theresa Kehoe from FDA talk about earlier, we also want to talk and hear from you about what is that you're looking for from those future treatments. One way to think about this is, if you had a new treatment option put before you, what would be the key factors that would be important to you in making a decision whether or not to try that treatment out? And so, if you have thoughts on this, I would encourage you to call in. We want to hear as many different inputs on this question as well. Just as a reminder, that number is +1 703-844-3231. There's no wrong answers. This could be related to many different aspects of what you might consider or view as important in a next future treatment. To get us thinking about this even more, we have our final polling question of the day.

James Valentine, JD, MHS (04:48:59):

Go ahead and pull those phones back out, open up that browser, the tab in your browser on your computer, go to pollEV.com/Cachexia. Here, we want to kind of get a little bit of a poll of our audience, see where you're at. Of course, importantly, we're going to ask you to follow up and explain why you picked what you picked here. The question here is, which aspects of your condition or your loved ones condition would you rank as most important for a possible new drug today? And we want you, again, to select those top three things that you would view as most important. The options are: A. Stimulating appetite; B. Helping with weight gain or maintaining current weight; C. Providing more energy or strength; D. Decreasing diarrhea or upset stomach; E. Making food taste and smell better; F. Slowing or stopping the progression of the weight loss; G. Living longer; or H. Some other aspect of your condition that you would rank as most important for a possible new drug today that you would select as a top three kind of most important aspect.

James Valentine, JD, MHS (04:50:21):

As you're thinking about this, I want you to think about what would that look like. If a treatment approach could help address one of these things that you view as most important sort of a cure. What would that improvement look like? Stimulating, we see the top one so far, results are still coming in, providing more energy or strength. What would you need to see for it to make a difference in your life? We want to hear from you about that. Living longer. We've heard a little bit about fears around death and dying. And so, what are you looking for? What is it maybe about the cachexia that worries you about living longer that maybe could be helped with?

James Valentine, JD, MHS (04:51:09):

We see next as kind of the third... Next grouping being stimulating appetite. So for stimulating the appetite, what for you personally, for you or your loved one, would you want to see? What type of appetite stimulation, how would, maybe you measure success on that? Then slowing or stopping progression of weight loss. Again, very personal. It would depend on where you or your loved one is in their journey, but what would that look like? What activities would you be able to maintain if that were to happen? These are the kinds of thengs that we want you to help us explore. What stands out is, yet again, with so many different impacts of cancer cachexia we're seeing so many of these aspects rated as a top three for individuals. So nothing is not in somebody's top three here. And so, we want to hear about these. Why did you pick, for those of you who chose making food taste and smell better? What would progress look like for you when it comes to that particular aspect of your condition?

James Valentine, JD, MHS (04:52:15):

One last time, we're going to get this discussion started with our Zoom panel. We're going to come back to our Zoom panel here. Hopefully that polling question kind of helps spark some thinking for all of our Zoom panels here who have been doing a fantastic job. For those of you who are in the live audience, if it's stimulated some thinking for you, please call in. Again, that number is +1 703-844-3231. You could write in as well and we'll make sure to read your comment as part of the meeting today. But here, let's maybe start with Kay. You're looking at the menu of options that we're giving you from that polling question. What aspect... I know it said pick top three, but maybe I'll ask you if you had to even narrow it down to just one or two things, what would they be? And then the follow-up question to that is, and what would actually represent a meaningful benefit on that for you?

Kay K (04:53:23):

Thank you for that question because I would really like to answer this one. What renovated with me was slowing and stopping the progression of the weight loss, which I think is normally would go to the living longer. And that comes with defining your cancer compared to the cachexia. We need to look where hopefully research can find markers or that, because we need to find it earlier. We need to find it early before we need to get to these. That would be my answer because I think it would take care of a lot of those.

James Valentine, JD, MHS (04:54:05):

Yeah. And so, if that treatment now that kind of meets that mark for you were to come along today, what would that mean in your life?

Kay K (04:54:19):

That would mean possibly we could control cancer cachexia. We could control it and possibly, like I said, work with it more in our cancer treatments and live longer.

James Valentine, JD, MHS (04:54:32):

Yeah. Thank you Kay. Kristin W... Everybody beware we're coming around the horn here. Because this is just really important and I do... There's no, again, no right or wrong answer. Actually, they're all right answers. There's no wrong answer. Again, if you had to pick between one or two of those things on the list, what would it be for you?

Kristin W (04:55:00):

I think it would've been providing the energy increase in strength and muscle mass. Also, increase in weight gain. As I think those two things would've improved my dad's quality of life. Also, I'm going to agree with early diagnosis and education and information because my mother was given no information about cachexia when my dad was diagnosed with cancer. It wasn't even mentioned until he was actually diagnosed with it, which at that point was almost too late. Like the caller said we're chasing it instead of preventing it. The weight gain and increasing muscle mass and strength, I think would be important things that would've helped with his quality of life at the end.

James Valentine, JD, MHS (04:56:04):

I want to kind of explore that. I don't want to ignore the second comment about earlier diagnosis. I think that is a real desire and then we should keep on the table, but for this, just in order to understand more, the other part of your comment, which was... Let's take it at that moment where he did get the diagnosis and you were looking then for treatments, you said you would look for something that would help with muscle mass, help with weight, that that would improve his quality of life. Even at that moment, can you think of maybe an example of what would your goal have been for him in that moment in terms of improved quality of life? When you were looking at him as his daughter, what would you have said, "This would make a difference?"

Kristin W (04:56:52):

Well, when he was diagnosed with it and to the time he passed was about four months. So when I saw him, when he was first diagnosed with it, he was walking around, he was-

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Kristin W (04:57:03):

And he was first diagnosed with it, he was walking around, he was doing normal things. Then when I went back and saw him about two months later, he was bone-thin in a wheelchair. Couldn't get up, couldn't walk around. So if he had maintained that muscle mass and strength and could maintain his body weight, I believe that would've helped with that. So his end of life was spent in a wheelchair and in a bed, and that was not my dad at all. So that's kind of where I was coming from with what I picked would be important things for medications to include.

James Valentine, JD, MHS (04:57:46):

Thank you so much. Catherine, coming to you, what did you pick? What would that mean?

Katie G (04:57:57):

If I could have, I would've picked all of them. Of course, out of all the polls, this was the hardest one. I'm like, I would literally pick every single thing because I think this is what we're all hoping for. But I wound up picking for the three, is stimulating the appetite, providing more energy and strength and of course, living longer because of course I want my loved ones to. So the reason why I picked those specifically, like the increased energy and strength and appetite was because doctors at a certain point, they stop treatment when the patient is too weak and cachexia is kind of the face of cancer, and doctors look at it and use it as a judge of can this patient tolerate any more treatment?

Katie G (04:58:57):

So, when the cachexia kind of took over in both my dad and my father-in-law, that was the indicator. It was, they don't have energy, they can't get out of bed. In fact, all of these other treatments for cachexia that we talked about kind of stopped. There was no more PT and OT, right. There was no more chemo, anything because of it. So, I guess if there was some sort of a medication that could stimulate appetite and also provide more energy or strength, ultimately that's my third choice, right? That's going to help them live longer and have a better quality of life, as we heard the other panelists say.

James Valentine, JD, MHS (04:59:42):

Yeah. Thank you, Catherine, Rick, [crosstalk 04:59:45] if you had to whittle it down to one, I know you like your list, but

Rick D (04:59:51):

Whittle it down to one, what's this, I have this strange idea. I'm thinking stimulate appetite because hopefully that will bring in more calories and take care of the energy. And, I'm thinking that maybe we should lean on some of the fast food companies to make shakes available to anybody that has got advanced cancer. It would be a wonderful promotion and it would bring them a lot of goodwill and a lot of happiness to a lot of people.

James Valentine, JD, MHS (05:00:26):

Absolutely. I like that a lot Rick, thank you. And for our zoom panel, last word goes to you, Kristen. S

Kristen S (05:00:32):

Awesome. Thank you. And, and I'm going to like call my parents after this and get my mom some [fat fruit shakes 05:00:37], because I don't think we've tried that yet, but I would say, living longer but only with high quality of life. And I think you get there by increasing the strength. And I know like the eating, it's all intertwined. If I could come up with a magic pill, I think... There're ways to like encourage people to eat-

James Valentine, JD, MHS (05:01:03):

Mm-hmm (affirmative).

Kristen S (05:01:04):

...maybe like trick them to eat, but if there's a pill that can deal with the muscle wasting situation, I think that's where I would focus. That's what we're experiencing in my family. My mom's eating, but she can't stand. So-

James Valentine, JD, MHS (05:01:17):

If something could stop your mom's progression where it's at today, would that be meaningful enough or does it need to actually help reverse?

Kristen S (05:01:27):

Well, reversing would be better-

James Valentine, JD, MHS (05:01:28):

Yes.

Kristen S (05:01:30):

... But if she could like pick up a grand kid, that would be ideal-

James Valentine, JD, MHS (05:01:33):

Yeah.

Kristen S (05:01:33):

...Or just, get up and go to the bathroom. Right. Like these are again like [AVL 00:04:39]. Reversing is better, but, I would maintain.

James Valentine, JD, MHS (05:01:44):

Okay. No, that's helpful to know. So I want to thank our zoom panelists here. We're going to go to a phone caller. We have some written comments that have come in, but I just want to, before we get to those, thank the zoom panel, for everything that they've contributed to the discussion today. It's been a real pleasure, but now let's check in. What are we seeing in terms of written comments that have been trickling in here?

Elizabeth Franklin, PhD, MSW (05:02:07):

Yeah, we have a couple of written comments that are incredibly important and they really kind of set the foundation for some of the challenges facing cachexia patients. So we've heard so much today, but Martha from San Antonio really brings it to this place of, even just standard terminology would aid understanding. Is this condition, cachexia, sarcopenia, adult failure to thrive, or what physicians [in peace 05:02:34] and nutritionist differ on what's causing the syndrome and who is responsible for following it? What is a survivor or caregiver supposed to do? And then we got a follow-along comment from Jay in Woodland Hills who said, I'm an eight year and 10 year pancreatic survivor who lost 60 pounds in four months and he said cachexia is not on my problem list, in his electronic medical record. That seems so simple, like such a small thing, but it's huge because if we can't track it, it's the old, if you can't measure it, you can't improve it. Right. And so I think that those are really important comments that we hadn't quite heard yet, but that could set the stage for how to move forward in helping cachexia patients.

James Valentine, JD, MHS (05:03:14):

Absolutely. So our final words today is going to go to Rochelle from Maryland. Who's calling in and I love this. She had something, that was not on our list of options on the polling, that she would look for from a future treatment. So want to hear about that? Rochelle. Welcome. Are you with us?

Carol M (05:03:32):

Good afternoon. I am.

James Valentine, JD, MHS (05:03:37):

Good Afternoon. Welcome. Very eager to hear what it is you would look for in that next future treatment.

Carol M (05:03:46):

Sure. So as it relates to my particular experience and... Let me pause for a second to just thank everybody. This has been such a phenomenal wealth of information. Just when I thought I knew a nice amount about a cachexia I've learned more, that will help me. So thank you to everyone for sharing... But the one thing that I thought about as it relates, as I said, to my situation, is maybe a drug that would help, not only with the physical aspects of cachexia, but also some of the cycle mental aspects of it. And what I mean by that is sometimes, although I don't have the desire to eat, when I do have the desire to eat, I'm still second guessing what I'm eating. Is this going to make my cancer worse? Is this going to kind of make me, have to go to the bathroom? And so that type of mental, I call it mental gymnastics, is also tough. So that would be an ask that I would have if that's possible.

James Valentine, JD, MHS (05:04:54):

Yeah. So, you're saying, something almost like the anxiety around, and second guessing of eating, not only helps you increase appetite, or reduce, maybe nausea or other issues with ingesting food, but you know, something that actually makes you feel, more confident or maybe more comfortable in eating, is that fair?

Carol M (05:05:23):

Yes. Yes, absolutely.

James Valentine, JD, MHS (05:05:24):

Yeah well Rochelle, thank you so much for sharing that. Yeah, like I said, there is no wrong answer and that is important to round this out because, I think, another thing that really just stands out to me is, how interconnected the physical and the mental aspects of living with cachexia are, and this is just another aspect of that, that we're learning about. So thank you.

James Valentine, JD, MHS (05:05:49):

So now we're at the end of the part of today where we are learning and listening to all of you living with cancer cachexia, and care-partners and caregivers of people living with cancer cachexia. It's been a tremendous day. We've covered a lot of ground from both the morning and afternoon sessions. And as your meeting moderator, I just have to, kind of from the bottom of my heart, thank you for digging deep and exploring what is really a complicated experience. It sounds from so many of you, that it's hard to even know and navigate yourselves, both with the unpredictability of the symptoms and health effects, and so many unanswered questions and unmet needs when it comes to treatments and navigating the healthcare system. Despite all of that unknown and uncertainty, you still shared so many of your stories, and that really has painted a picture of what it is to live with cancer cachexia, this is exactly the kind of information that we all need, the FDA, drug developers, researchers, advocacy organizations. And we even just heard from Rochelle, even your peers. This meeting can be a resource for all of you.

James Valentine, JD, MHS (05:07:13):

And so I just want to thank you for doing that, because it's not an easy thing to focus on some of the negative aspects of, of living with a condition, or not always the things that work, but some of the things that don't. So with that, we're going to move to now part of the agenda where it's really the impossible task of the day, if there was one, which is to try to summarize what we've heard throughout the course of the day. So it's my pleasure to introduce my friend and colleague Larry Bauer. Just to give you a sense of why Larry is probably the best person to try to do this is, as someone listening as an outsider that isn't treating patients, isn't a cancer cachexia patient, Larry has been listening. And Larry draws from his 17 years as a clinical research nurse at the NIH followed by 10 years of working as a regulatory scientist at the FDA, working to try to navigate, some of the issues in drug development that exists for conditions with unmet needs like cancer cachexia. So Larry, welcome to the program. I'll hand it off to you now.

Larry Bauer, RN, MA (05:08:26):

Thank you so much, James. Today has been a really incredible day. I mean cancer cachexia is something I've been aware of, for most of my career. But today has been incredibly educational, and the conversation has been so thoughtful about this topic. So as James said, I will try to give a high level summary of today and what we've heard. I apologize in advance for any important points that might have been missed, but please know these other points will make it into the Voice of the Patient report.

Larry Bauer, RN, MA (05:09:01):

So our meeting today was opened by Elizabeth Franklin who is the President of the Cancer Support Community. This was followed by presentation from Dr. Theresa Kehoe, from the FDA's division of general Endocrinology and Cedar. We were so happy to have Dr. Kehoe with us and she shared how [PFTD 05:09:20] meetings are valuable to the FDA to learn from the experts, people who are living with cancer cachexia and their care-partners. And it's to help facilitate treatment development for cancer cachexia. She said the FDA is trying to find endpoints for clinical trials that are meaningful to patients.

Larry Bauer, RN, MA (05:09:40):

After Dr. Kehoe, we heard a clinical overview of cachexia from Dr. Jose Garcia, from the university of Washington. He taught us that cachexia is an involuntary loss of muscle and fat mass. It's not fully reversible by nutritional support and it's a huge public health problem affecting over five million people in the United States. It's a multi-system disease and there are no good tools for assessing physical function and impairment related to cachexia. This is an area of need in this field. There are several ongoing studies for cachexia treatment. And he said that it may never be that a single agent will treat all aspects of cachexia. So we might need treatments, that approach cachexia from different angles and a multidisciplinary approach is needed for treating people with cachexia.

Larry Bauer, RN, MA (05:10:34):

Then we moved to our first topic of the day, which was the health effects and daily impacts of cachexia. We heard from some wonderful panelists. Felicia started the discussion. She was diagnosed with breast cancer and thought her weight loss was a result of the treatment. She had extreme fatigue, which made her think her cancer was worsening. And her need for assistance and help with the cachexia caused a lot of stress, anxiety and mental anguish. This was a theme we heard throughout the day that cachexia has physical effects as well as a lot of mental and psychological effects.

Larry Bauer, RN, MA (05:11:11):

We also heard from Rochelle, who is diagnosed with incurable breast cancer and developed cachexia within 10 months of diagnosis, she felt exhausted, nothing tasted normal and this caused a 30 pound weight loss within just a few months, so very rapid. And cachexia has had the side effects of also leading to dental issues, to GERD and she worries about what is the impact of cachexia going to be on her cancer diagnosis.

Larry Bauer, RN, MA (05:11:41):

We heard from Michael who was diagnosed with stage four, colon cancer. Michael used to teach fitness classes, was in great shape, but soon after being diagnosed, he could barely walk upstairs. Cachexia and the resulting muscle wasting and fatigue eventually led him to going on long term disability. He fears losing more muscle and the weight that he has tried to gain back.

Larry Bauer, RN, MA (05:12:06):

We also heard from Marianne, who has a daughter named Melissa, who had brain cancer and surgery for that cancer at the age of eight. Melissa has had cachexia and issues with her diet and nutrition ever since. She has a poor appetite and does not like most foods. This has resulted, in her now needing a wheelchair to get around. Melissa would love to be a teacher's aid, but cannot do the work any longer because of her cachexia.

Larry Bauer, RN, MA (05:12:35):

And finally, in the morning, we heard from Megan who had symptoms of cachexia before her diagnosis of Cholangiocarcinoma. She started feeling fatigued, weight loss. It was not connected immediately to having cancer, until months after the symptoms had started. She really wishes that doctors would be more aware that younger people can get cancer too and an earlier diagnosis for her might have helped in the long run.

Larry Bauer, RN, MA (05:13:02):

Over the course of the morning and the discussion, people identified many problems related to eating, poor appetite, weight loss, a variety of stomach issues and almost everyone talked about the muscle loss and weakness. That was one of the top symptoms they had. And the muscle loss leads to severe fatigue. And one person said that cachexia is the silent killer in cancer, I thought that was a very potent statement. And the mental aspects are very challenging. And impacts include not enjoying food and not going out to eat with friends or family. It impacts the ability to travel and not being active, or the ability to participate in sports. And most people reported that dealing with cancer cachexia is a daily battle.

Larry Bauer, RN, MA (05:13:56):

In the afternoon, we shifted gears a little bit into perspectives on cancer cachexia treatments. We heard that treatments often need to come from many different places. One of our first panelists was Daryl, who developed anal cancer at age 66. He has focused a lot on complimentary and alternative therapy, such as dietary changes, mind-body exercises and supplements. These have included yoga and meditation. And he also uses topical steroids and [turmeric 05:14:28]. Support groups, he said, have also been a great help to him.

Larry Bauer, RN, MA (05:14:31):

We heard from Carol who is diagnosed with plasmacytoma at age 63. She said that medical marijuana helps with the nausea and anxiety. We heard several people talk about marijuana related products. She has tried exercise, but says it's an uphill battle. And she says that, trying to treat her cachexia is very time consuming. We heard that from many people, that trying to do all these treatments takes a lot of time out of your life. We heard from Lisa whose husband, [Connie 05:15:03] eventually died from mesothelioma. She said she was not aware he was diagnosed with cachexia until reading doctor's notes after he died. They were never told clear out, that he had cachexia, but she read it several times. Side effects from his treatments caused worsening cachexia and he eventually died weighing only 133 pounds, even though he was six foot three inches tall. And she wishes that she had understood more about cachexia while he was alive.

Larry Bauer, RN, MA (05:15:35):

We heard from Linda whose father was diagnosed with an aggressive leukemia AML. She tried to help him eat, but nothing really helped his lack of appetite, which was so unusual for him. She brought him liquid supplements with high calories and tried everything she could. She shared just how difficult it is for caregivers trying to help people with cachexia.

Larry Bauer, RN, MA (05:15:58):

And finally, we heard in the afternoon from Melvin who had Metastatic Squamous Cell Carcinoma. Melvin developed cachexia and had weight loss to the point of eventually needing G Tube to treat his cachexia. This is the feeding tube placed in his stomach. The feeding tube did help him somewhat and the tube needed to stay in until he could eat around 1500 to 2000 calories on his own per day, which he eventually did.

Larry Bauer, RN, MA (05:16:28):

We heard consistently that there continues to be a great unmet need for people living with cancer cachexia. 65% of people during the polling reported the treatments that exist now, help little or not at all. That's kind of a grim number. Many take medications, or they try to do exercise to treat the anxiety and depression. People have tried small and frequent meals, high calorie shakes, and a variety of cannabis products, where there's very little research on these products, and in some states they are legal and others they are not. It was brought up that having a palliative care doctor on the team can be very beneficial to people. And people overall would be willing, I think, to participate in research and everybody, I think across the board mentioned, they'd like to see more effective treatments. So at this point, I would like to turn the meeting back over to Elizabeth Franklin in the studio, from the Cancer Support Community. And I thank you very much for this opportunity to speak with you today. Elizabeth-

Elizabeth Franklin, PhD, MSW (05:17:35):

Thank you so much, Larry. That was a wonderful summary of today, which has been an incredible day of hearing personal insights to help understand cancer cachexia and its impact on patients and caregivers. Thank you to the FDA for allowing us to hold this important meeting and to the staff who tuned in today. I want to especially thank Shannon Cole with the FDA who guided us throughout this process. Thank you to Dr. Theresa. Kehoe from the FDA, for your perspective on the patient focused drug development meetings and to Dr. Jose Garcia from the university of Washington, for the very interesting and insightful overview of cancer cachexia. Thank you to our friends here at Dudley Digital works media team, who you can't see, but have been kept us going all day long for your assistance with the meeting and to the consultants who helped us plan this, the incredible James Valentine, Larry Bower, who you saw and our friend, [Wendy Zelig 05:18:30]. I am also incredibly grateful for the hard work of the CSC staff. We have an incredibly small but mighty policy team who have been working very hard over the last year to pull this off. So thank you Felicia Woods, [Kim Zuberick 05:18:45], Rachel Solomon, Erin Cop, Leah McPherson, and Andrew Lewis. And also the digital and communications team at CSC. It is a family effort and everyone works so hard and so smart to plan this meeting. Thank you again to our supporters and partner organizations, because this meeting would not be possible without you. And most importantly, a heartfelt thanks to the people living with cancer cachexia and their caregivers. You heard their stories today, their personal experiences. It was an emotional day because this is a very serious syndrome and this is why we held this event today. For those of you who called or wrote in giving your insights, we're so grateful. James, you said many times that it takes courage to reach out and share those types of insights, so thank you so much.

Elizabeth Franklin, PhD, MSW (05:19:36):

And again, this meeting absolutely could not have achieved its goals if it were not for you. So what's next. We will compile all of the information into a report that we call Voice of the Patient, which will be available on CSC's website, along with a recording and transcript of the full meeting. The web link to submit comments for the report will be open for another 30 days. So please consider submitting additional comments, which will be added to the Voice of the Patient report. Until we publish this report, the video from today, along with the list of supporters and partner organizations will be publicly available on this CSC webpage that you're on right now. There will also be a link from the FDA website. So in closing, thank you again, the impact of this meeting will be felt for years to come.

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