Part 1 will be about my organization, CancerCare.

Part 2 will be How CancerCare can help those with cancer and their loved ones

Part 3 will be General Helpful Information. You work with the caregivers, and you are caregivers yourselves. So, I can share with you some information on caregiving so that you can continue to help others, and help yourselves.

Cancer*Care* was founded in 1944 – 75 years so we are celebrating a big anniversary this year. Clearly, we are an organization of great longevity. We were founded New York City. Our headquarters remains in NYC, but we also have offices in Long Island and as I said, I am in Paramus, NJ. We also have a travelling social worker in Central NJ, and an outreach worker in CT. I like to say that CancerCare is a secret that few know about. And I am happy to spread the word to you, the 90 or so people who are here today.

Cancer*Care* is aleading national organization that provides *free* professional support services and information to help people manage the emotional, practical and financial challenges of cancer. We help those impacted by cancer – and what I say is any age –and any stage. We do work with children who are 4 and up. Those with cancer as well as caregivers, family, friends and bereaved.

We work either by phone or online, or with our grants, in every state and 73% of counties in the US.

We employ over 90 full time employees including 35 masters prepared oncology social workers.

We are a 501(c)(3) nonprofit organization and receive funding from individuals, private foundations, public companies and community organizations.

Our logo is a lantern flame, and we try to be a beacon of hope and light to our clients who are impacted by cancer.

All of our services are free. Free. And if you call our HOPE Line, you will get an oncology social worker. We address the emotional side of cancer.

In fiscal year 2018, our programs and services have helped nearly 187,000 people affected by cancer, and we welcomed 2 million visits to our websites.

Our professional oncology social workers have provided emotional and practical support to 92,300 people thru our Hope line, individual counseling, support groups and community programs

We have provided 41.1 million in financial assistance to 25,500 people to help with treatment related costs such as transportation, home care or child care and copayment assistance.

Leading experts in oncology have led 68 connect education workshops, featuring 211 faculty members and 93 partner organizations drawing nearly 69,000 participants.

We have distributed 1,126,761 print and digital publications to health care professionals, patients and caregivers.

Our comprehensive services include:

- Telephone and face to face counseling (face to face counseling is only available in NY and NJ).
- Support groups which are held over the phone, online and in person (again, only f2f in NY and NJ).
- We have educational workshops where we have a panel of experts discuss specific cancers or topics related in general to all cancer, and these workshops will include the best of the best oncologists as well as a CancerCare social worker to address, again, the medical and the emotional side of cancer.
- Financial grants which are specific and limited

- Literature

(part 2) I'll give you some specifics now on our services.

Our counseling – is offered face to face in our offices in NY, and NJ, but via telephone nationally as well.

The first thing you must know about our counseling services is that we are short term, and cancer focused. We can talk about anything in our counseling sessions – as long as it has something to do with the cancer. We are not a mental health provider. And we conduct a full assessment for our counseling services to make sure they would be beneficial to our clients. Sometimes people need more than we can provide, and in those cases, we do our best to refer to other resources or agencies, or a community mental health center, or the local county mental health board. So, not everyone is appropriate for our services. Generally, sessions are bi to tri weekly. And I will give you a general idea in that face to face clients are offered 12 45 minute sessions. Telephone clients are offered 6 ½ hour sessions. So, again – short term and cancer focused. Of course, if someone is calling for counseling services, we must speak directly to the person requesting counseling. We get calls from other family members or friends who want us to open a record for their - whomever - for counseling services – and we cannot do this.

While we are not an emergency service, we are a place where our clients can talk about their fears and hopes related to their cancer. For example, a Mom in her 40s may not want to put her fears of her cancer dx onto her children, we're there to talk freely and openly about anything that will reduce her anxiety. If you want to reduce anxiety – talking about your fears is a a great way to address them.

BTW, parents often decide to not tell their children about their dx, and I hear that one a lot. And we always think it is NOT the way to go– and we can discuss having everyone in the family on the same page, and addressing the cancer topic with the children openly – where every question is an opportunity to be part of the same story, and to let go of the secrets.   We did a program recently at a nearby hospital and it was entitled, "We're Talking about It." And it was to encourage parents to talk openly about their dx with their children. So we can help parents to have the conversation. What I talk to parents about is that life is really a series of obstacles. And I think it is human nature to want to protect the kids and not discuss the cancer diagnosis with them. But I think that to address obstacles rather than pretend they don't exist can be really helpful and empowering to the kids. And this helps kids to learn to problem solve and recognize that life's path is usually not a clear road.

I'll give you an example. I worked with a woman who had an 8 y o child. She also had children in their late teens and early 20s. She didn't tell her 8 y o about her cancer, but the older children knew. So, I asked if they would abruptly stop discussions when he walked in the room. Yes, they did. Did she think he noticed? Yes she did. And kids tend to make up monsters in their mind.

They feel the energy of something going on, but they cannot define it, and they generally make things to be their responsibility – and from there is acting out – or maybe a decline in grades, or separation anxiety to name a few. She decided to talk to her 8 y o and it was helpful to both her and him. As well as her older daughters.

Then there is the other part – who do you want your children to find out about your cancer from? This is a true story, and I think it speaks volumes. Dad had cancer– but his kids were not told of the dx. So, one day, a child walked up to the person with cancer's child on the playground and said, "My mom told me your dad has cancer." Who do you want your child to learn of your diagnosis from? You – or an outsider?

“And the child was flabbergasted. So, it’s better to have the kids on the same page as the parents and to use the term CANCER.

We can talk to our clients about communicating with their treatment team.

To see themselves as part of the team, discussing with the doctor treatment options. What they are and what can I expect from treatment? What are the side effects? Discussing quality of life issues related to cancer

Encouraging our clients to formulate questions for the doctor ahead of time. To boost their esteem and competence in terms of talking to their MDs and having some ownership in their appts. To remember that the doctor is working for them and with them.

To help with organization, I go with the one notebook concept – where every page is the date and which MD or organization you spoke to and a basic outline of the conversation. Otherwise cancer creates a tremendous paper blob.

First thing I ask clients – is how is their pain management. Everything else emanates from pain management.

Quality of life is all about pain management. Over and over, I hear that doctors – because of the opioid crisis – will really limit discussions about pain management – which is legit, I get it, but there has to be some semblance of pain management discussed and implemented.

We can talk to people about forming a network of support, and we can discuss with our clients – who were often the go to person and the helper of others, to begin to accept help from others and begin to see accepting help from others as a gift that you give to them. Accepting help is a gift you give to others. Accepting help from others is not a sign of weakness, but a symbol of great strength. The adjustment in the transfer of roles in huge. Handing over roles, or taking on new roles if one is a caregiver, the transfers of roles has a multidimensional impact on life. It’s another upheaval.

Important note is that people often think, oh, so and so has cancer. They’ll be fine. How the media depicts cancer is not a true representation of the story. There has been an oversimplification of cancer due, in many respects, to the media. “Look, I had cancer BUT I’m all better now.” Sure, there are innovations and advancements, but no matter what – cancer is tough – on every single element of life.

My analogy about cancer is that it's as though someone took a patient's drawer of life and flipped it over. On the floor is scattered every element of life. Family, friends, work, faith, finances, transportation, healthcare, meals, appetite, and nutrition, hopes, dreams, mood, the body, mobility, independence, exercise,…to name some of the things that cancer impacts. If there are children, there are 100 additional pieces on the floor.

And so, first, the patient tries to make sense of all that is scattered on the floor. And you know what? Nothing will ever,

ever, ever fit together in the drawer in the same way. Ever. It just won’t. Sometimes, friends or relationships are reevaluated, sometimes, the finances are impossible to catch up with – because, unfortunately, cancer can eat up every single dollar that you have.

Cancer can make you poor. Sometimes, it creates a “meaning of life” moment, where people find the diagnosis almost transformative and begin a quest to bring more meaning into their lives. They might take up a hobby they always wanted to, a change the career path. This happens. Cancer is likely to be a crossroads moment.

People tend to speak in platitude with a diagnosis of cancer, or if there is death. It makes them feel better, but it is very DISPARATE FROM THE REALITY OF THE SITUATION.

And as you reassemble that drawer of life that I mentioned, Cancer*Care* is with the client to talk about all these life elements, and what the drawer of life is looking like at this moment.

Friends, who rallied around at the initial time of diagnosis, often forget about the situation by week 3. Then, there are those who think that the entire process is "no big deal," and shy away from the discussion with the person with cancer. And then, there are those who just never discuss the cancer, and their friend of family member's cancer is no big deal. And then, there are the friends and family who completely disappear. This happens all the time.

We do provide bereavement counseling face to face only – not by phone. We also provide online bereavement support

I call cancer "The Brutal Teacher." It teaches you what's important, it can teach family and friends about what to do and not do, and what to say and not say. It increases empathy.

I will explain to you that most of our services start with a phone call to our HOPE LINE. 800.813.4673. This is our national hope line where clients call, often in a state of crisis, that they've just been dx, or that a family member was diagnosed. Either they, or a loved one has cancer. And our goals, as social workers answering the call, is to allow them to tell their story and to hopefully empower them during the course of the call, so that they feel better at the end of the call than they did in the beginning. The Cancer*Care* hope line is open 5 days a week - 9-6 M-Th, and 9-5 on Fridays. . Occasionally, we will be asked a medical question, we explain that we are not doctors or nurses, but we are social workers and then we refer the client back to their oncologist or NIH.

All of us have a working knowledge of cancer that grows over time.

ON this call to our 800 number Hope Line, we will discuss all of our services – our groups, our counseling, our workshops, our literature, other possible helpful resources. Sometimes, we will have someone who is clearly inappropriate for groups or counseling – for example, they may have a thought disorder, or may be paranoid, for example, but we will do our best to help as we can, but won’t delve into our emotional support services with them.

We have limited and small financial grants. And I want to be sure that I am very clear when I tell you about them. Our grants are not available to everyone. Generally, they are based on 250 – 400% of the federal poverty guidelines. Our grants are for transportation, home care or child care. They are one time. Sometimes one time per year, and some other grants are every other year. All grants are open to women. At this time, our grants for men are extremely limited – and are for breast cancer or pancreatic cancer, or if the men live in the NYC 5 boroughs, or NJ, CT or NY Rockland or Westchester counties. So our grants are specific. And men will call us and be angry. Angry. When I explain that there is not grant available for them. And I hear them. The reality is that some grants are often funded by what cancer is meaningful or cause based to the funding.

Mom had breast cancer, so my company is funding a grant for breast cancer. My uncle had pancreatic cancer, so our organization will fund a grant for pancreatic cancer. It's as simple as that. .

A man calls for a grant, often we have to tell him we are sorry, but there is no grant, and we apologize, and maybe there are other resources to offer help. Our social workers will let the client know any organization that we know of, but can never promise that another organization can help, either. All of our other free services are available.

So, if you refer anyone to our line – remember, our grants are small. Might fill up the gas tank a time or two or three.

Most grants are not available to men. So, I always suggest going on our website, cancercare.org, and to manage people's expectations when they call us. Remember, our grants are national. We send out 40 million per annum, so we try to do the most good for the most people. People will sometimes complain about the amount of the grant – okay, they are small, but they might fill up the gas tank a few times, or help pay for child care. We spread ourselves across the nation.

Our website delineates available grants, and I always suggest checking there and signing up for our newsletter. We also will have funding for hurricanes such as Florida or down south, or Puerto Rico.

Our ONLINE and telephone SUPPORT GROUPS – We have support groups for people with cancer and their loved ones – caregivers, friends and bereaved. They are 12-15 weeks. We rotate groups availability. The wonderful thing about our support groups are that someone doesn't have to leave the home to partake. So, when someone is sick from chemo, or needs to be in the home to care for a loved one, or works full time and going to a face to face support group would create the "one more thing to my day" situation, can be part of a group from the comfort of home, or from wherever they are at the time. Groups allow for the understanding, the communality of a situation that others outside the situation generally do not understand. Online support groups are self-registration. Telephone support groups are an assessment process. Groups are not for everyone.

If someone cannot tolerate the stories of others, groups are not a good fit. If they fall apart at the telling of the story – at this time, the group is probably not a good fit. If they eye roll when others tell their story – not a good fit.

Face to face support groups are our only in our NJ/NY offices. We rotate them as well. I do a lot of bereavement groups, because that is what I love to do. But we have groups for kids and groups for those out of treatment and rediscovering life after a cancer dx. We have a very vibrant group rotation.

Our CONNECT EDUCATION WORKSHOPS – we have the oncologist and medical providers at the fore of oncology discuss specific cancers, or topics in general related to all cancers, discuss cancer and treatments, and innovations in treatments, all in an hour. A social worker from CancerCare will also take part in these workshops to address the emotional side of cancer.

We offer helpful literature. And it is really true that knowledge is power. I know that our coping with chemo booklet has been considered the “Go to” booklet by many. Mucositis is mouth sores that often accompany chemo treatment; we have great information on that. But we just have a myriad of helpful information that even includes being a YA with cancer, or caregiving or bereavement.

The program I coordinate is called Healing Hearts, which is a bereavement camp for families with children who have lost a loved one to cancer in the past 2 years. So, while we hope that this is not a program that you will want or need to recommend to the people you work with, just know that it exists in Pennsylvania – so for those in NY, NJ, PA or CT – it's a beautiful program that we put our heart and soul into. And we've had people travel from SC, MA or even Indiana.

Our copay foundation

https://www.cancercare.org/copayfoundation helps with the copays for chemo treatments for specific cancers. It is not available for all cancers, and at this point it is just XXXXXXXXXXX, and this list can change in an hour – in a minute - , so I suggest going onto the website for additional information.

WE’RE In part three – so I’m just going to give you some ideas about cancer and some helpful facts when you are working with someone impacted by cancer.

Medical appts are the best time to communicate with the health care team.

First appointment, to go in the with attitude “I want this to be my team, and we will work together.” But, as much as possible, a second opinion is always a good idea.

Writing down questions for the treatment team is imperative. Taking notes, or better yet, having a caregiver come to appts to take notes is wonderful. Some MDs will allow the appts to be recorded, and of course this is optimum.

What you will see is that at highly emotional or stressful times, your intelligence goes down. Think about that – I love that fact. That’s why, when you’re stressed, we talk about breathing, or walking, or listening to calming music, or coloring. Because you won’t remember things said, or your reactions may not have been what you would have liked as you reflect. I always hear, “I feel like I am in a whirlwind,” or, “I am over whelmed.” When you have those moments, remember, your intelligence decreases. At moments of great upset, your intelligence falls.

Keep everything in one place.

Keep a symptom log. Let your doctor know how you are feeling and any side effects that you may have.

Be sure you understand. I always say that oncology is a whole new language. It’s a language most of us never thought we’d have to speak. And now it’s in our lives or in our jobs, somehow. So, When the doctor says this or that and you are not sure it was understood – suggest something like, “Doctor, is this what I’m hearing?” Or Doctor, I’m not sure I understand what you are saying.

Make friends with the nurses. I am totally into bribery – a bouquet of lollipops or a box of candies will always have them look at you like the person who is thoughtful. And that may, turn out to reflect in some extra time for your questions. It works. You will always be the one who brought the candy in.

Use “I” statements vs “You” statements. “Doctor, I don’t understand what you are saying,” vs. “You’re being unclear, doctor.”

People should know the type of cancer and the stage.

Stage IV is metastatic. What this means is that it has moved from the primary site and has travelled elsewhere in the body. Stage IV, at this time, can be chronic. It can be manageable. But it cannot be cured. It cannot be cured.

They should know what the treatment options.

They should know the possible side fx

They should know what to do if something is “off” and doesn’t seem right.

Often, but not enough, I hear of doctors giving the patients their phone number. But there should be a contact for questions. To know who is the go to person if the doctor is not available in case of emergencies.

What are the benefits of the treatment? What are the risks of the treatment?

There is good info on the web, and there is not good info on the web. Ask the doctor for websites or books that he or she recommends.

Work with a Doctor who is referred by your primary, or your insurance.

You can go to a comprehensive cancer hospital, and you can find that through the national cancer institute's list at cancer.gov.

Agree on treatment goals. This is what I have learned in life. Some people are all about quality of life, and some are about quantity. There is no right, and no wrong. But what I see is that people are one or the other. I meet with people who say, I don't care the side f x of the treatment – to be here one more day – is all I care about. Vs. the people who say, if I can't live the way I want to live, I don't want to have treatment. But there is no right and no wrong and any outlook needs to be honored.

No one needs to tell a cancer patient, how to feel or what to think. We feel how we feel.

There should be a semblance of what the services should cost. This needs to be determined. Sit down with the billing, call the insurance, and find out what your responsibility will be for. Because no one wants to get walloped with a huge bill out of nowhere.

Find out if you need pre authorization.

See if the treatment center allows for payment plans

Do they allow for payment over time? Sliding scale? Forgiving debt?

Find out about the cost of medications. I get those calls all the time.. Meds can run 10,000 dollars a month. Fortunately the VA is here, but we know that veterans will sometimes have treatment outside the VA.

In the case of especially breast cancer or head and neck cancer, ask about plastic surgery options.

Learn about fertility preservation.

Keep a log of the symptoms and how they impact your life – and this is where I say, “listen to your inner voice.” If something is amiss – notify the doctor. Right away. f it’s tolerable, just let the doctor know about the symptoms.

Use the same pharmacy for all your medication.

The pharmacist is also someone you want on your team. You can ask them about contraindications.

Ill answer some questions that Meredith and I discussed –

How do you talk to a caregiver of someone with cancer? First thing I discuss is self-care. CAREGIVERS get sick. They put everything into the care of the others. Seldom do I find that a caregiver carves out time for themselves. It's important to do so. It doesn't have to be an hour here or there. 10 minute snippets can be life changing. Meditating, walking (I call walking the best therapy – and it's wonderful to walk alone and clear your mind. Listen to music. Etc.)

How do you talk to someone who is newly dx?

Listen – don't preach. Ask them the role they want you to play. Counselor, friend, support, cheerleader. And follow that lead.

- Some cancer terms: I say that cancer is a whole new language we never thought we would speak. I’ve told you metastatic means stage IV. Terminal means metastatic. IT all means that the cancer has moved from the primary organ to another location or locations. I can have two primary cancers. I can have breast and lung cancer. But someone with a primary cancer of breast that is metastatic and is in the brain does not have brain cancer. It’s metastatic breast cancer in the brain. You can have metastatic cancer that may go into NED No Evidence of Disease. But, remember that it is going to be considered something, chronic, but manageable. I see that all the time. Where people have Stage IV, but live vibrant and active lives.

- Chemobrain is real. It's difficulty in focusing, remembering, and it often clears up. But it effects can be longer term. What helps is mindfulness techniques, one thing at a time. Focusing on now. Not multitasking. I find that most women are multitaskers, and I'm sorry if I am generalizing, but that's what I find. I think all of us should think about shifting to more of a balance – I like the saying that you can only fit so much perfume in a bag. Right. You can only do what you can do. This quest for perfection in every aspect, and at the same time is elusive. So, mindfulness is important.

Who watched MASH? Charles Emerson Winchester would say, "I do one thing. I do it well. And then I move on." Think about that way of thinking. Do one thing at a time.

Resources we always mention: We get calls every day as to what we can help with and very often, can we help pay the medical bills. I have not found any organization that pays medical bills. Not to say they do not exist, but I do not know of them. When I have a veteran, of course I suggest VA all the way. But sometimes, the travel can be prohibitive for some services. I always say talk to the billing department – pay over time, ask for sliding scale based on income or ask for the bills to be forgiven. You can look this up, but I know that hospitals can write off a certain percentage, and I suggest look that up and ask that percentage to be forgiven. It’s high, btw.

So, when contacting any organizations for services – I always advise clients not to ask for specific things such as “will you pay my bills?’ Ask in what way they do cover. If they cover rent – use them for that. It frees up money for other things.

- I always suggest churches and synagogues to see if they have a good will fund. Will you help me cover the expense of the ride to my radiation treatments – which can be 5 x a week for several weeks. It adds up. Cancer eats the money away. But, do the homework. What is the mileage and what is the general reimbursement rate for mileage. Ask for a specific number.
- 211 - just dialing 211 is the United Way, and they are basically a clearing house for area resources. They usually mention Catholic Charities, Society of St. Vincent de Paul and Salvation Army.
- I love the patient advocate foundation.
- I love family reach – BUT – the treatment center social worker contacts them for the family. Not everyone is eligible.

- Eating well is a priority for the person with cancer and the caregiver. Great website is cookforyourlife.org.
- I love cancerandcareers.org, and they talk about the laws that protect someone with cancer – or their caregivers - in the workplace.
- patient's complaining about a metallic taste in the mouth from chemo? Sour lemon drops, dill pickles, eating with plastic utensils can help.

Clinical trials can be found through clinicaltrials.gov. They are specific, and they have guidelines.

Have the patient see themselves as "consumer."

If it's not working with your doctor or your treatment team, and the communication isn't there ask other patients (that's another reason support groups are wonderful), and ask the nurses for referrals. Nurses are a font of information.

So let's go over quickly some CC info and then I will teach you some mindfulness ideas and techniques:

- All of our services are free.
- We offer small financial grants – to help with transportation, home care and child care. all to women, few to men, so please, manage the expectations on the grant. I suggest you sign up for our emails at Cancercare.org. I also suggest that you sign up on our cancercarecopay foundation for updates. The income is based on 250-400% of the federal poverty guidelines.

- we offer emotional support, short term and cancer focused. With a full assessment. If there is substance abuse – must be in treatment and 1 year of sobriety. Suicidal clients are 5 years out from suicide, because we understand that this populations needs more than we can provide as we are not a mental health agency. That being said, the majority of callers, we can and do help.
- And we have great information. With literature and our workshops.

MINDFULNESS TECHNIQUES

I like coherent breath techniques.

If you are in 20 feet of someone, your heart begins to pick up the electromagnetic field. We are sharing an electromagnetic field right now. You ever notice you're with someone who is highly anxious and you begin to get anxious – you're sharing the field.

So, let's learn ways to calm the field –

First thing I will do is called TAKE FIVE

CancerCare has a great and free app called CancerCare Meditation

There is a great website called "Relax and Sleep Well." That has hypnosis for just about every activity you can imagine. Clients recommended, it is awesome.

I have purchased something called DoDow, to help sleep. It's a light that shines on the ceiling that you breathe with and it lulls you back to sleep. I have found that it works. Sleep is imperative.

Extended breath technique – breathe in for 3 out for 3, in for four out for 4. In for 5 out for five, as high as you can go.

Heart coherent breath: Breath slowly, and aim for an evenly timed inhalation and exhalation. About 5-6 seconds each. Focus on the breath coming in and out of the heart. Doing this for a little as four minutes can bring the heart and mind into coherence.

Remember when you are stressed or upset, your mind and body are not in coherence. Your intelligence is lowered; working on the breathing can help.

And try to remember (Mother Theresa quote)

“Be happy in the moment, that’s enough. Each moment is all we need, not more.”

—Mother Teresa (1910-1997)
Founder Of The Missionaries Of Charity