



Cancer: Keys to Survivorship – Living With, Through, and Beyond Cancer/Communicating with Health Care Providers

- Carson Jacobi:** It's now time for us to talk to one another. It's now time for our panel discussion. I would like our three keynote speakers to come back up to the stage and in addition, I would like to invite three new panelists. Nancy Keen writer, editor, and parent of a child cancer survivor. Andrew Stadnick an acute myelogenous leukemia and bone marrow transplant survivor, and Steven Friedman, a testicular cancer survivor.
- How will this work? We have two microphones in the center of the isles. We also have a hand held microphone if you would like someone to come to you to assist you with your question. You may ask questions of any of the panelists and when we are ready, if anybody has a first question.
- We have another panelist, Carolina Hinistrova, she is a breast cancer survivor, and Susan Leigh will be right with us. Why don't we start with our first question.
- Audience Member:** Hi. This is a wonderful resource for people who are here today to participate in this wonderful forum. But I am wondering what the panelists would recommend in terms of other resources that are available to people and what kinds of information in particular for the newly diagnosed would they recommend?
- Steven Friedman:** I'll answer that question as someone who is a three-year survivor now. When I first got diagnosed, we did a lot of--used the Internet profusely and spoke very frankly with our doctors and two--not to advertise any websites or anything, but two most useful resources we found were the ACOR website, ACOR.org and also, at the time it wasn't really handy for the consumer but now it is really good for patients, is the ClinicalTrials.gov site that NIH runs.
- Those I think are the most excellent--first places to go look and seek out information on what your doctors are telling you, and be able to, as I said back in the '70s, '80s, question authority.
- Carson Jacobi:** Nancy.
- Nancy Keen:** I will throw in one other website recommendation. The Physician Data Query--that's the NIH website. It's updated frequently. It gives the current standard of care for every type of cancer. There is a lay version and there is a health professional version.
- The lay version is just the basic information that you need, and I recommend that if people are going to go read the health professionals' versions, that they do a little self-analysis and find out if they really want citations of the medical literature, do they want to hear about statistics at that point in their treatment, and if so, go ahead and read them.



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- Nancy Keen:** That way, they can verify whether what's been proposed for them is really the current standard of care, because as you know, you know, you aren't always given the best options for care that are currently available. Also, you might look into face-to-face support groups in your area, if that makes you comfortable, or also, the online support groups are wonderful for people who are newly diagnosed, because sometimes you just can't talk about it.
- So ACOR.org. There are currently 99 mailing lists for different types of cancers and you can get on those and hear what other people have said, and just listen if you are not quite ready to talk yet.
- Steven Friedman:** I would like to actually mention that NCCS's own website as a very complete listing of a lot of the resources that were already mentioned plus several others. You can find that at www.canceradvocacy.org [updated link]. It allows you to search at a number of resources and it could help put you in contact with some of those physician provider groups, support groups, as well as just literature resources that you want to review.
- Carolina Hinistrosa:** So try to speak with people that you trust and they may give you a referral to a group of patients and I think that that is really quite important to begin with.
- Carson Jacobi:** Lisa.
- Lisa Stepp:** I also think it's really important that any information that you get from these websites, or from any reading that you do, that you do take that in and discuss it with your health care professional.
- Cancer is a very individual disease. It is personal to each individual patient and when you read about something or you see about a clinical trial, it's really important that you discuss that with the physician or health care professional that's managing your particular case.
- Carson Jacobi:** Yes. Susan.
- Susan Leigh:** I just wanted to mention that the cancer survival toolbox, which Susan Scherr mentioned, has an entire side, wonderful side on how to access information and it's all within, it's a wonderful storybook format. So it's like listening to a book on tape. But it gives, you know, you practical ways of accessing information, how you actually do it and then how to access whether it's good information or not. So it's something else that's free for you.
- Carson Jacobi:** Thank you, panelists. We'll take another question from the audience.



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- Kendra Marsh:** Carson, I want to just add something to that. We all know how we personally process information. Some of us are able to look at a video and process that well. Some people are computer illiterate. Whatever works for you. Just because somebody throws something down on a piece of paper and says, well this is the best thing, go do this-- It may not be the best thing for you.
- So as Lisa said, everything is so very individualized. So is your information and how you process it. If you don't understand the information that you do find, it's not doing you any good and could in fact be detrimental. Make sure that you can process it.
- We also have to realize that we speak many different languages, and some people are not able to understand some of the video things that are out there or print information. So it's important that your health care provider or someone at an organization provides you with the information that you can actually understand yourself. It's no good to you if you can't understand it.
- Carson Jacobi:** Thank you, Kendra. Next question.
- Audience Member:** After completion of your treatment, what are some of the most important resources and issues that you should consider as far as you know, after you finish your regular treatments. What are some of the areas that are most important for you to address?
- Carson Jacobi:** Anyone? Alright.
- Andrew Stadnick:** For me, one of the biggest issues was returning to a certain state of physical and psychological fitness, and that meant, as some of the speakers mentioned before, was regular exercise, healthy diet. I am still guilty of falling into some of those things that are not so healthy from a diet standpoint and I probably don't exercise as much as I should or want to.
- But it's important that you get on that track where you are able to start some flow in that direction, especially after some of the treatment that we have gone through, that can be as physically demanding as they are. It helps you psychologically to build up that mental strength as well as physically.
- Audience Member:** I would like to address one piece of this question that Susan brought up in her presentation, which is knowing what your treatment is and being aware of the likelihood risk for certain late effects.
- So let me tell you a little story. When my daughter finished treatment back in-- she was diagnosed in 1992 and finished treatment in 1994 when she was six



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Audience Member: years old, I went in on her last day of treatment and I said to the fellow who we were seeing, "When would you like me to set up Catherine's echocardiogram?" and she said "Oh, we don't do those here."

I don't argue with people. I go around them. So I went to the director of the clinic and I said, "When do you want me to set up Catherine's echocardiogram?" and she said, "Well we don't do those here." I mean, they do them but they don't do them for the kids at that point who were survivors of leukemia.

I said, can I send you an article from the *Journal of Clinical Oncology* and can you call me and we can talk about it? And she said sure. So I sent her an article that listed the children's cancer groups, cardiology, subcommittees' recommendations for a heart follow-up for children who are treated with anthracyclines, which many of you out there might have taken, because it can damage your heart. The younger you are, the more likely you are to have a late effect to your heart and the dosage, also dosage related, are still not well understood. So information is growing.

I sent her that article and she called me up and she said, you know, I didn't know this. We are so busy clinically. I keep up with the current treatments but we are supposed to have people come back from the meetings and tell us what late effects we are supposed to be watching for.

What that told me was that I needed to be more of an advocate for my daughter than I ever dreamed I was going to have to be, merely because, although treatment of childhood cancer is one of modern medicine's miracles, we have been focused on a cure and we are in that position now with many cancers for children where many--most of the children are not cured and we need to expand our view so that we think about what are the effects of those cures on the next 70 or 80 years of that child's life.

So what you need to do is, I think, is get a list of all the treatments from your physician. You need to know what radiation was given, at what dosage, to what part of the body, by whom it was given. What chemotherapy drugs, the total dose of drugs, at what age, and by whom were they given. You need to go to BMT, how many of them you have, what type, and you need a contact person. You need to know what your treatment was and then you need to have a follow-up plan, and that means you need to go to someplace that has a comprehensive late effects clinic that's going to follow you, and that applies to adults as well.

There were no written materials for kids with cancer, so two medical professionals and I wrote a book, called *Childhood Cancer Survivors, A Practical Guide To*



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Audience Member: *Your Future*, that outlines all that information and how to access it. So I think you need to know what your treatment was and what your follow-up plan is so that you can file it away in the back of your brain, and not worry about it but be aware that if you ever get symptoms of any of those late effects you need to go check them out.

Carson Jacobi: Susan.

Susan Leigh: I think following along on those excellent suggestions, we are such a mobile society now that we switch doctors as we move, you know, to different locations or as physicians change health plans, it is imperative that you keep track of your own medical records.

When you have something done, if you have a surgical procedure, when you have the information about what kind of therapy you had. It may be in a summary letter that the physician writes. It may be something in the chart the physician or nurses take care. Get copies of those. Those are your records. Get copies of them, take them with you, because you absolutely have to have that information so that other physicians, whether it's an oncologist or a primary care physician, or a urologist, or a gynecologist, they may be finding something many years in the future and they may want to know if it has anything to do with your primary therapy and if it was in a field or whatever.

You've got to have that information. So you know, be your own best advocate that way and carry your records. Have a portable system of carrying your records with you.

Carson Jacobi: Yes, Carolina.

Carolina Hinistrosa: Yes, I think another important aspect besides having a file with all this information and all of that is to take care of your mental health. We tend to focus very much on the cancer patient when they are a patient and sometimes we forget about the late effects, psychological late effects often ... in your experience.

So I think it's important to look at your body as a whole and reach out for support and continue to do that. I have found in the group that we formed with Latinos, Latinas, with cancer, that the support of other survivors and the communication with other survivors is extremely important for long-term well-being.

So don't forget that aspect. It doesn't mean that you will be--it's a balcony type of people and not to remind you that you have cancer in a bad way, but it's the support in the uplifting sense you have when you see people around and understand what you have been through. So don't forget the mental health aspect.



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Andrew Stadnick: I think one thing I would like to add to all that besides keeping your records and reaching out to people is, just remember to live life. It's too short. Live it to the best and greatest you can and love everybody you see. Because you've gotten a new ticket on life and use. Sort of the mental side of it and the psychological side of it is a lot of change for people. You look at life very differently and getting that organized, getting your priorities reorganized. I am still working on that.

Carson Jacobi: Thank you, panelists. Another question, please. Sir.

Audience Member: Yes, I would like to say something. You know, people talk about groups, support groups and this is actually the first time I have been able to come to a place where there are other survivors or victims, patients. It's taken me a year to get this far. Some of us can't do that.

We have other resources and I think, you know, ask our family whenever we can. If it wasn't for my wife, my son, I don't know how I could have gotten this far. But that and another thing is to, to look at for individual counseling. You know, those of us who don't participate well in groups, we need to just be able to sit down for an hour and you know, cry, talk, and get through this.

I think that's probably one of the greatest things. Sometimes we kind of say, well, we don't need that. But I really believe that. But your family and a counselor is something that I think for a lot of us, will help most, you know, besides medicine.

But those other individual one-and-one things, okay. So if you have a good wife or a good husband, take advantage of them. Because, you know, if you don't survive, they are going to be left alone. Okay.

Carson Jacobi: Thank you for sharing that. Do any of the panelists have any responses.

Carolina Hinistroso: Yes, I think that I very, very much agree with what he said and I am glad you brought that up. When I was diagnosed with breast cancer the first time, almost seven years ago, I was one of those people who was afraid to share in a group and I looked for individual counseling and that helped me tremendously to get through the surgery and all of that.

Later we formed a support group for Latinas with breast cancer and we found that this concept of the support group was not a very familiar one for Latinas in this community in the Washington area and we came with all the excitement of doing something new and we thought was very necessary.

But we found that women would come to the group the first time and then they



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Carolina Hinistrosa: wouldn't show up again. This was, yes, well I talked to other people about this and why do I need to keep talking about this to other people. This was not, I mean, you don't talk about cancer in a social setting.

We started right off individual counseling, recognizing the difference between us that it's not a one-size-fits-all and that we need to understand--not only that you may not be in a mental state to share with other people, but you may have difficulties fitting schedules and we need more flexibility.

We have found--the support group, that we--the support program that we have at Nueva Vida, which means new life, has three components, has individual counseling, has support groups, and also has peer counseling, recognizing that people sometimes are intimidated to talk with a counselor and they may want to speak with another survivor who has been trained to do this.

So I think it is a responsibility also, of the support programs, to try to understand the differences in survivorship, and the thing is that we are different people and we need to reach out to people and not just feel so good that we formed this support group and that people should come to us and why aren't they coming. They are lazy or they are not grateful that we have this.

No. People are different and people have different needs and we need to recognize those needs.

Carson Jacobi: Thank you, Carolina. Anybody else? Kendra.

Kendra Marsh: One of the things in our support organization, which is BMT Support Online, we are an online support group. We have a great number of gentlemen who join us, who say that they could not possibly go to a face-to-face support group and sit there and discuss some of the issues that they discuss regarding their cancer therapy, because it is difficult to talk about for them. The physical aspects of it as well as the emotional aspect.

We women tend to be a little bit more open about that. So it's a great support. If you cannot get or you do not have access to an online support group, many organizations, *The Leukemia & Lymphoma Society* is one of them that offers "First Connection." Get somebody through the telephone, you can teleconference or telephone call with somebody. They have people who volunteer to do this and they are wonderful.

One of my first connections with somebody was on the phone and she was also a myelodysplastic survivor, so that was very, very important. There is another group of people that we have to remember when it comes to support. Many of



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Kendra Marsh: you probably here today are caregivers. Our caregivers need mental health support to take care of the patients.

Carolina Hinistrosa: We tend to focus on the patients and their needs, and our caregivers are wearing out. They are wearing away. We offer peer support group for caregivers one night a week on Thursday nights, which has been very, very beneficial to family members.

We have spouses, children, parents of people who are going through transplant. Siblings, siblings that have been the donor for the patient. Sometimes the donor for the patient who does not survive and they don't know if it's because of something that wasn't good enough about their marrow--as you know, that is the cause of the person's death--or something. It's very, very important that we support our caregivers.

Many organizations stand alone that offer caregiver support to people who are care giving individuals that have a variety of disease, disorders, or the elderly or something. So it is very important for you caregivers as well. You are angels. We love you and the way you take care of us is second to none. So take care of your mental health as well and physical health.

Carson Jacobi: Nancy.

Nancy Keen: Just make one quick comment about that. There is no one right way to do it and although I think most of us find that different people have different ideas of what we should be doing that we are the only one that knows the best way to get through it for ourselves at that time. I like to say that we are all sort of walking through a jungle but we are finding our own path and each one of those paths is valuable.

The other thing is, I just think we need to be gentle with ourselves and recognize we are doing the best we can and that our needs shift over time and that that's expected. So that's it for that.

Carson Jacobi: Thank you, panelists. Another question, please.

Audience Member: I have so many, I don't know where to start. But my first question is and I think maybe you answered it. My first question is, the thing that's been the most difficult for me with my diagnosis of AML seven months ago, is that I have four teenage children, two sets of twins, and they keep asking me, Mom, when are you going to die? What should we do or how long will you live? You know and should we go the college in California and all over the world wherever they are?



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Audience Member: I don't know how to help them. They want to be with me if I'm going to die in six months. On the other hand, if I'm going to live for ten years, should they go and live, you know, a normal life. I wondered if anybody else had any problems like that and how to deal with them?

Also, I have an elderly father who relies on me. Maybe this is all something I should address in therapy. But I just wondered--this is one of the things that makes me feel very lonely.

Carson Jacobi: You have expressed very clearly what you are experiencing and I would like to ask our panelists if they have any responses.

Susan Leigh: I couldn't even begin to give you, you know, the kind of in-depth answer I think, that, I mean, you have opened up such an array of information and information seeking. But there is a book by one of our fellow survivors, Dr. Wendy Harpham, and she wrote this wonderful book called *When a Parent Has Cancer*.

It deals with all of the issues, no matter whether your child is two years old, 12 years old, or 20 years old. The problems that we have as parents who have these kids who are out there saying, what do I do? Each one of your children is going to be different, too, and they are going to need different kinds of support.

So I just would recommend that this is one way that you could get some support, and then she would help you--help develop your own plan as to how you can, you know, deal with this experience within your own family.

Carson Jacobi: Yes.

Steven Friedman: I would also like to say my children were seven, five and three when I was diagnosed three years ago, and that book that Susan mentioned was fantastic for me to read as well as my wife to read in terms of dealing with the children and the different stages they were at. I mean seven, five and three is very different. I think that my cancer, AML I had, impacted my seven year old daughter the most, and today we are still dealing with, when Daddy goes to the doctor, is he going to come back?--because a lot of time I go to the hospital and not come back for weeks or a month or so.

But the book was excellent in helping give us ideas on how to help the children cope with it and how to deal with it and it does cover the whole age range for children, for parents who have cancer, and I recommend it highly as well.

Carson Jacobi: Thank you. Yes, Kendra.



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Kendra Marsh:

It's going to be impossible for you to tell your children what to do. That's a really difficult answer to give you because we all want to tell you exactly the best way to go about doing this. You've asked a very poignant question or set of questions.

My daughter was eight when I went through my transplant, and she was my rock. She is sitting right there if you want to wave. She was my partner in many ways. She's my partner in faith and in healing. She would kiss the top of my bald head and rub and say, that's good fertilizer for that hair to grow back.

She was wonderful. But your daughters as they are growing into--they are obviously close to adulthood or are adults and having to make their own decisions in their life. Nobody knows. You don't know with your AML exactly what your survival length of time is going to be.

We could be doing this forum in ten years and you would be sitting right here in this seat and you will be talking about how I advised my daughters when I was going through my treatment. So that's difficult. I think if I were facing that situation right now, I would tell them to look straight inside themselves and see exactly what it is that they need to do to live their life fully.

Everybody around your life is not going to stop when you have a cancer diagnosis. If they allow that to happen in their lives, that's a signal for you to allow it to stop in your life. If you make sure that you live your life very fully on a day-to-day basis, insist that they do the same. They may be looking for permission to do that, even.

Give them that permission to live their lives as they need to live them to grow as people, and expect their support, and tell them that you will call on them when you need them. Sometimes they worry that maybe, you know, you just want to say, well, I'll be fine, Honey--just go ahead and do what you need to do.

Assure them, and I have done that with friends: I promise I will call you when I need you, and that really does put people at ease in going about living their lives. I don't know if that helps. I hope it does.

Carson Jacobi:

Thank you, Kendra. Thank you for your question, Ma'am. Another question?

Audience Member:

I am a cancer survivor as well, and this is not my first time to attend a conference like this. I really enjoyed coming here not long ago and learned so much. But I just wanted to comment that sometimes with resource materials, there are taped versions but not a print version for deaf patients.



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Audience Member: There are materials I would like to access and friends of mine as well and there's not written transcripts for us or support groups that include us. So I am wondering if I can get some help on that and if there can be options for both taped and written materials.

Carson Jacobi: Thank you. Kendra.

Kendra Marsh: I would like to address that first. If you find a piece of material that you believe is going to be helpful to you and you cannot process it, that perhaps it is in video form with no audio, or with an audio that you cannot hear or something, ask the people who produced that material, could you please produce this in written format. Ask them that. They are there to serve you and that's why they put that information out.

Call them. Write them a letter saying, could you give this to me in this version? I need this information and this is how I need it. Ask them to do that. I don't know of any of our organizations that wouldn't be happy to do that in a way you can understand. Very important.

Audience Member: Okay, I just want to say that I did do that, and have not gotten follow-up, until I just gave up.

Kendra Marsh: Never give up. Call again.

Carson Jacobi: I just--I really appreciate the difficulty that you are having and I am wondering if we could get a representative from the deaf community to become an advocate for that community and work with some of our national organizations. I would love to get you signed up with NCCS and *The Leukemia & Lymphoma Society* today. So give your number to them.

Audience Member: Okay, that's great. Yes, I am happy to do that. I have done some work in the past—okay, I have done some of that in the past but had some energy problems and wasn't able to sustain it. But and also have held some discussions in the past but plans have not followed through. But thank you.

Carson Jacobi: Thank you.

Steven Friedman: One thing that I would like to point out is that the cancer survival tool box that NCCS and in a collaborative effort with other organizations, has, is that you can download the tapes that are available outside, you can download those transcripts off of the Internet site. So that is available for you in printed format. It's also available in other languages including Spanish and Chinese.

So there is some of that translation available.



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- Audience Member:** That's great. I would like to get a copy of that web address or how I can access that.
- Steven Friedman:** Sure. That web address is [www -](http://www.canceradvocacy.org)
- Audience Member:** Something to write with.
- Steven Friedman:** It's in the packet. It's www.canceradvocacy.org [updated link]. I can give it to you again afterwards if you can't find it.
- Audience Member:** This is where I can get the information in the toolbox resource you are talking about?
- Steven Friedman:** Yes.
- Audience Member:** Thank you very much.
- Steven Friedman:** You're welcome.
- Carson Jacobi:** Thank you. Another question from audience? Please, come forward.
- Audience Member:** My question also to the survivor who asked about teens. There is a program I know in Fairfax Hospital [Inova Fairfax Hospital for Children, in northern Virginia] called "Life With Cancer." They have teen groups and programs for young adults, and I think bringing teens together to talk about some of the questions you've raised and helping them process that can be very helpful to them.
- I'm a health care professional. In the last ten years, we have all seen a lot of changes as a result of managed care. Susan Leigh mentioned that. Physicians that have an increasing number of patients. Physician practices that come together for economies of scale, changes in the composition and the qualifications of the health care team--sometimes they are not really being a health care team.
- Many of those changes have made it difficult for survivors to follow the advice that you are giving today, and I see that more and more as a health care professional. I am wondering what advice you would have for patients for survivors to deal with the impact of managed care.
- I realize it's a very broad question, but so many people come into hospitalization without patient care that are newly diagnosed, really not having an understanding of how the health care system has changed and how difficult it can be to get quality health care.
- Carson Jacobi:** Lisa.



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Lisa Stepp:

I think my first suggestion, and it was listed on the slide as well, be polite and be persistent. It's in health care we are really busy. The practices are really busy. You don't always get to see the same physician each time.

But if you take the time to ask the questions that you need answered, express what you are feeling, express your symptoms, express your concerns--it may seem that one physician maybe doesn't have the kind of bedside manner that you get along with the best: But there is going to be someone on that team that you need to identify as someone that you can speak with, someone that you can communicate with in a manner where you feel like that you are truly getting your questions answered.

I think the other issue with managed care in particular, when we talk about having to switch physicians from time to time, someone doesn't have your insurance, you need a physician that's on that plan, that type thing. Again, you are the one who knows your experience. You are the one who knows how your disease has been and what your course of treatment has been and just keeping that line of communication open with whatever health care professional you see, to make sure that they understand where you are in your treatment and what your needs are so you can get them met.

But I can't stress enough to be persistent. In my own experience, I sometimes am not that way. If I get an answer that's just a half an answer or someone seems busy, I have a tendency to stop asking as well. But this is your life. This is your treatment. This is your experience and you've got to get it across to your health care professional.

Carson Jacobi:

Susan.

Susan Leigh:

I think with the way health care is right now, it's just absolutely imperative that we learn how to be our own best advocate, as has been mentioned today. When somebody comes in and you are, you know, you've got this bombshell that you've got cancer, you kind of don't know where to start.

So if we have the programs in place and if we have the programs like the one at Fairfax Hospital, if we've got these in place where we can start getting people partnered with the people who can help guide them, the navigators, the guides within the system, the earlier the better so that we can learn how to ask the right questions and get the best care that we can get.

But I also think that this is a real plea for those of us who have the energy and the motivation to get involved politically. Because it's going to come from the



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Susan Leigh:

consumer. We are going to have to have a real groundswell from the consumer community to make change and to make sure that our health care system doesn't continue to disintegrate at the rate it really has been disintegrating.

But let's get involved in a political level so that we can help develop the--find the solutions to some of the many problems that we have now. I think a lot of the solutions are going to have to come from the communities.

But that's a tough--that's a really tough question and I don't think there is any easy answer for it, but thanks for bringing it up.

Carson Jacobi:

Carolina.

Carolina Hinistrosa:

I have mentioned that the community in which I work, which is the Latina community here in the Washington metropolitan area, and more than half the women that come to our program are women who feel they are not entitled to asking any questions because they don't have health insurance. They have charity care. They go to the doctor and they feel that should just go and be seen and not speak because they are taken precious time from the doctor.

When I have had the opportunity to come with them to appointments, I am just amazed at how considerate these women are of the time of their physicians. But I do feel that they are patients and they are entitled to asking questions.

So we write down a list of questions before the appointment and I ask them for them because the women that I come with, typically don't speak English. We ask our questions and I think we take the time we need. I have never been cut off by a physician saying, look, I need to go to the next appointment.

I think if you are clear about what you are asking, and they understand that this is really important to the patient, we have--it can be a successful interaction, maybe typically is one. So I think you need to be conscientious about what you are doing and be clear and focused about the questions you are asking.

It is useful to have a survivor actually come with you because they may anticipate questions that you didn't even think about that are relevant to the patient. But, yes, we are living in a rushed world. But the nature of this business is really human life.

So we are just bold and we take the time that we need to take and it works.

Steven Friedman:

I think it's very important for you to be your own advocate when it comes to your insurance rights and your benefit limitations. One of the things that you can--there are certainly many things that you can do. Certainly you can review



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Steven Friedman: the information that was provided to you by the managed care plan when you signed up--understand those benefits.

You can certainly bring that information to a lawyer and have them review the legal implications or the barriers that might be set up by your plan. You can certainly go to your physician's office and talk with the staff person that handles the insurance activities in that office. They deal with it on a daily basis. They certainly have run into all sorts of issues and problems with insurance companies, and they can probably already anticipate the situation that you are in and answer some of those questions.

I certainly think that what you want to do is contact the managed care plan and talk to the customer service rep or the nurse representative that you might be dealing with for your particular situation and get the answers to your questions in writing and get some tangible feedback from them as opposed to just one phone conversation out of 150 that they may have had that day.

Have some back material for you on record. So be your own advocate and understand your own benefits and that will go a long way in helping you deal with some of the issues that people talk about when they deal with the managed care plans.

But I do want to say that not every interaction with the managed care plan is a horror story. I had an HMO when I was diagnosed and I had no problems getting my referrals or my pre-certification for my hospital stay or my surgery. I saw the same physician and the only time that I changed physician is because the physician left to go to another facility and I chose to stay at the community center where I was.

So I've actually had a very good set of interactions with my managed care plan and I know that may sound like a few compared to many of the horror stories that are out there. But there are some good interactions that you can maybe not look forward to, but you can rely upon.

If you have a good plan, if you have a good set of benefits and, certainly again, be your own advocate and rely on the interactions with your physicians to get you through that process.

Carson Jacobi: Thank you, Steven. Nancy.

Nancy Keen: There have been a lot of good suggestions already made and I have three quick ones. One is that--I have always found it helpful to get a case manager. As soon as my daughter was diagnosed, I called the insurance company. I said, you are



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Nancy Keen:

going to get bombarded with bills for the next three years and could you assign me one person so we could expedite this and they won't be confusing for anybody--for you or for me?

They assigned someone. I sent them a picture of my daughter. I called her up. I was polite to her. I always worked well with her and things were very, very smooth. So having a case manager with a complicated medical situation really helps.

Sometimes if you ask, they will give you one because it's in their benefit to do it. Another thing is to appeal. If that is denied through your managed care plan or your HMO, you can appeal that and oftentimes it's overturned and you can get the treatment that you need upon appeal.

The third thing is, to separate medical discussions of medical treatment from how it's going to be paid. I am finding more and more when I talk to people that they are only being given options that are covered by their plan. They are not being given all the options that are available.

One of my relatives is currently being treated for metastatic lung cancer, and he came back with a very ineffective, old ... prescription for ... medication that was contraindicated because of some of the other medical problems he had, and I said, you know, I think they gave you that because it's the cheapest one around. There are a couple really good ones. Let me write them down for you, and I wrote the names of a couple.

I said, why don't you go ask them if they can prescribe these, because I think they are just giving you this prescription because they think you've only got Medicare and they didn't tell you what else was effective.

So he went down there and it turned out, you know, he had supplementary insurance. But even if he didn't, he should know his options, and perhaps he would have been willing to pay for that out of his own pocket. So when he went down, they said, oh, well, we just assumed you were on Medicare and wouldn't you know and this is expensive.

So now he has an appropriate ... he is much more comfortable now. So try to get them to say, well, let's put how we are going to pay for this aside for a moment, but what would you recommend if economics weren't an issue here? What do you think my options are and what would you recommend? And then talk about how you are going to pay for it.



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Carson Jacobi: Thank you, Nancy. Kendra.

Kendra Marsh: I had a bit of a unique circumstance because after my diagnosis initially, I was turned over to hospice. So my insurance said, why would we want to go ahead and pay a quarter of a million dollars for you to have a bone marrow transplant when you are a hospice patient?

So it was very difficult. The appeal process worked for me. I outlined--I had to gather a little bit of my own data actually to support the fact that people with myelodysplastic disorders who were transforming into leukemias had indeed been transplanted and successfully and were living.

So don't take no for an answer. The first time I heard don't take no for an answer from somebody in this community was Susan Stewart at the *Blood and Marrow Transplant Newsletter* and reading their materials and also getting in contact with other people who had appealed and who had successfully appealed their cases.

Again, I am reiterating--case managers. If you can make it personal with a case manager, I think you can go a lot further [than] if you just call and they say no and you say okay well they said no and leave it at that. They are going to leave it at that.

If you don't leave it at that, you will cause them to not leave it at that. So don't leave it at that.

Carson Jacobi: Carolina.

Carolina Hinistroso: I think another aspect that is very important in all this discussion we are having with ideas about what to do and what works and doesn't work is I think it's important to ask your provider, what is the evidence for what you are prescribing for me?

I think that is important both from an individual's point of view so you know what you are getting to and what the expectations--you can create realistic expectations for what is going to happen. But I think from a community point of view, too, because we as patients, of course, we will be doing whatever we can to get the best or increase our chances of survival.

But in terms of the wide community, it's very clear that resources are limited and we don't want to waste our energy, our lives, terrible side effects for something that maybe not work.

So I think it's important--having the evidence behind what is being prescribed is



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Carolina Hinistrosa: important just to really bring this to reality: what is [this] going to do for me and what expectations can I have from this?

I know this may be difficult for me as a patient to deal with. We have said several times, be your own best advocate. Not everyone is in a position to do that. Not everyone feels strong enough to do that, or they are terrified of the answers. Find another advocate for you that you can work with, and maybe sometime later you will be able to face all of that information.

But it is important that someone, if not yourself, someone else is doing that work for you . . .

Steven Friedman: I just want to reiterate what Nancy and Carolina and Kendra said is, we looked at it. We had--I was under a managed care HMO and we had managed care on one part of the triangle, our physicians on the other, and us on the third, and it sort of that balance of triangle and getting the case manager and getting to know them personally and requesting them to come out to the hospital.

I mean they need, look at it this way, it's like you are a contractor for them because they are going to pay the hospital and they want to see the quality of the work they are paying for and we got our case manager to come out almost weekly to visit with us and to meet with the doctors and we had discussions and the more personal relations you can build with them with the managed care people, the more you are going to get out of it and make it work.

Carson Jacobi: Nancy.

Nancy Keen: I'll say one last thing about that. A couple things that I've noticed that are given in scarce supply are civility and appreciation, and this is just both for insurance companies and health care providers. I find, I tell my kids this and I tell people who are newly diagnosed this, that we have a goodwill bank, and if we make a lot of deposits, when we need to make an occasional withdrawal, we are still going to have a balance.

It is amazing to me how many people in insurance companies are never thanked for what they do. If anybody does you a good deed, call them up and thank them or write you a note. I send Christmas cards to everybody, and thank you notes, who do good deeds for me.

It's amazing how frequently they continue to do those if I need some help. It's the same thing with physicians. I can't tell you how many physician friends I have who tell me that they are routinely, they are not seeing us at our best. They are seeing us when we are sick and are scared.



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Nancy Keen:

So if we take the time whenever anything goes well to thank them for that, so when something doesn't go well we can say we have a balance. I have my good friend who is a hematologist, who is a wonderful woman, very, very--she is just a wonderful communicator. She is very warm. She gives people her home number. She is just an amazing physician.

I asked her how many thank you notes she had had since she had been in practice for ten years and she said, I could count them on both hands. I said, how many complaints? She said, you don't want to know.

So these people have a very hard job, and I think a part of our job is to show appreciation for what they do and then point out whenever there is a problem and try and work it out together, and together we are a lot stronger. We will get a lot better care than we [will] if we adopt an adversarial or submissive posture.

So I think if we are civil and we show appreciation, things are going to go better for all of us.

Carson Jacobi:

Well, thank you all. If you can please help me thank our panelists.