CHANGING THE CONVERSATION ON PALLIATIVE CARE

PALLIATIVE CARE: Effective Communication with Family, Caregivers & Providers

Tuesday, September 10, 2024









CHANGING THE CONVERSATION ON PALLIATIVE CARE

Melissa Rosen

Director of National Outreach, Sharsharet

Melissa K. Rosen, Sharsheret's Director of Training and Education, holds a master's degree in Jewish Communal Service from Brandeis University and has been working in the non-profit sector for over 30 years. Her professional experience includes informal education and programming, advocacy, and community outreach. Melissa's work has allowed her to facilitate unique and lasting connections among organizations in the diverse American non-profit community.

Melissa oversees community education throughout the country, training health care professionals, Jewish professionals, and Sharsheret's volunteers. She also manages the Sharsheret's Community Partnerships. Herself a two-time cancer survivor, she is passionate about the Jewish community and cancer support and advocacy.



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WEBINAR AGENDA

- WELCOME & OVERVIEW | Melissa Rosen, Director of Training and Education,
 Sharsheret
- ❖ PATIENT ADVOCATE PERSPECTIVE | Barbara Bigelow, Individual Patient Advocate,
 Metastatic Breast Cancer Alliance
- * KEYNOTE SPEAKER | Caroline Cubbison, M.D., Dana-Farber Cancer Institute
- Q & A | Dr. Cubbison & Barbara Bigelow
- WRAP-UP | Melissa Rosen & All









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BARBARA BIGELOW

PATIENT ADVOCATE, MBC ALLIANCE

Barbara has had breast cancer for over 20 years, the last 8 as metastatic. Initially ER+, she mutated to Triple Negative MBC. A vocal advocate for patient research, she herself was in a clinical trial for immunotherapy that landed her in the hospital for 2 months, relearning how to walk and swallow while undergoing dialysis. Along the way she has also survived lung cancer and melanoma. Today she is the Vice President of Metavivor, committed to raising money to fund metastatic breast cancer research. She also blogs about her experiences using humor to inspire hope for others at The Cancer Chronicles.







FEATURED GUEST

Caroline Cubbison, M.D.

Palliative Medicine, Dana-Farber Cancer Institute

Dr. Caroline Cubbison is a palliative care specialist currently serving at the Dana-Farber Cancer Institute and Harvard Medical School in Boston, Massachusetts. She is committed to enhancing the quality of life for patients with cancer and other serious conditions through expert symptom management, assistance with communication, and coping support. Dr. Cubbison champions a patient-centric ethos, consistently striving to align medical interventions with individual values and goals. Beyond her clinical practice, she is engaged in national and global initiatives to raise awareness and broaden access to palliative care services, thus amplifying her impact on healthcare delivery worldwide.





Palliative Care for People Living with Breast Cancer

Dr. Caroline Cubbison
Palliative Care Physician





"Palliative Care is the umbrella, not the rain".
-Dr. Camilla Zimmerman



Roadmap

Palliative Care in a nutshell

Basics of expert pain management

Communication support

Patient examples

Tools you can access from home



Myth:

 Palliative care is only for people who are nearing the end of life.

Reality:

 More and more studies show that early palliative care improves quality of life for patients and their loved ones regardless of stage of illness.



What is Palliative Care?

Palliate = to alleviate suffering







Tailoring Palliative Care for Breast Cancer

- Younger patients
- Caregivers
- Don't want to burden others
- Active lifestyle



Expert Symptom Management



Expert Symptom Management

Pain

Neuropathy

Muscle and joint pain

Nausea

Anxiety



Myth:

 All patients on receiving palliative care will be prescribed opioids or narcotic medications

Reality:

 Palliative clinicians have expert training that allows them to think outside the box and tailor a pain management plan for an individual person's lifestyle



Expert Pain Management

Adjuvant medications:

Anti-inflammatories, duloxetine, pregabalin, cannabinoids, topical medications and others

Interventions:

Radiation, minimally invasive nerve blocks, steroid injections

Alternative therapies:

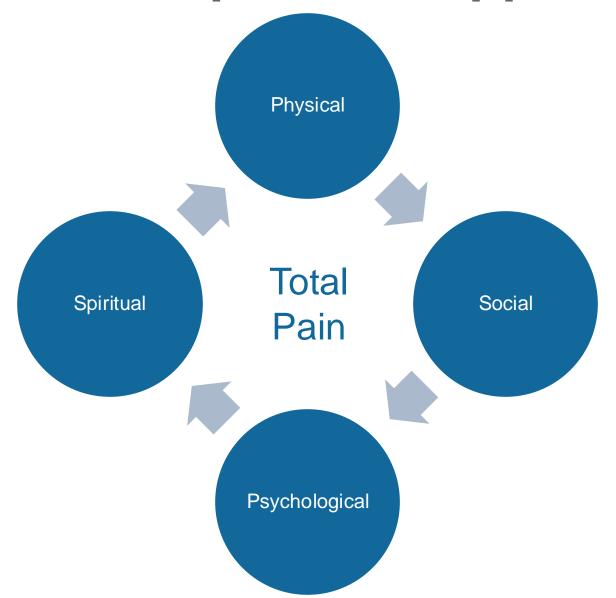
Acupuncture, massage, guided imagery, Reiki

Opioids:

Safely prescribed and closely monitored



Emotional and Spiritual Support





Think and Plan for the Future

Talk about hopes and worries

Think through important documents you can have prepared

Relieve distress around the future, so you can enjoy the present





Communication Support:

What matters most to you?

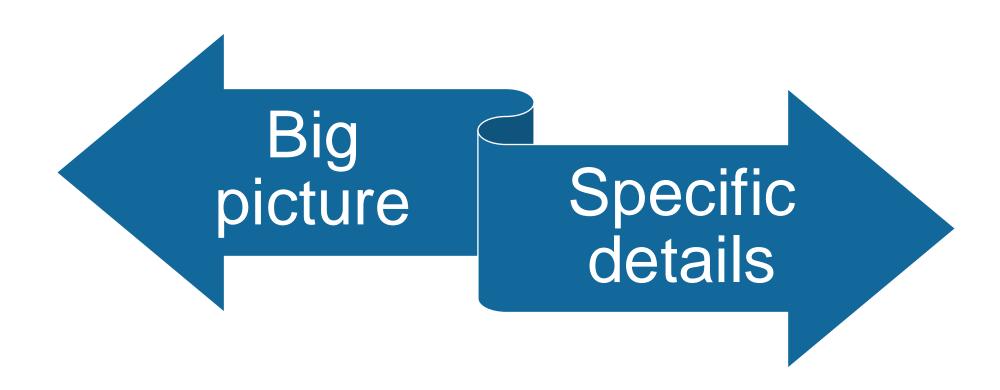


Communication Support

- Understand a person's communication preferences
- Are there other people we should be communicating with?
- Are their differences in how we should be communicating with them?

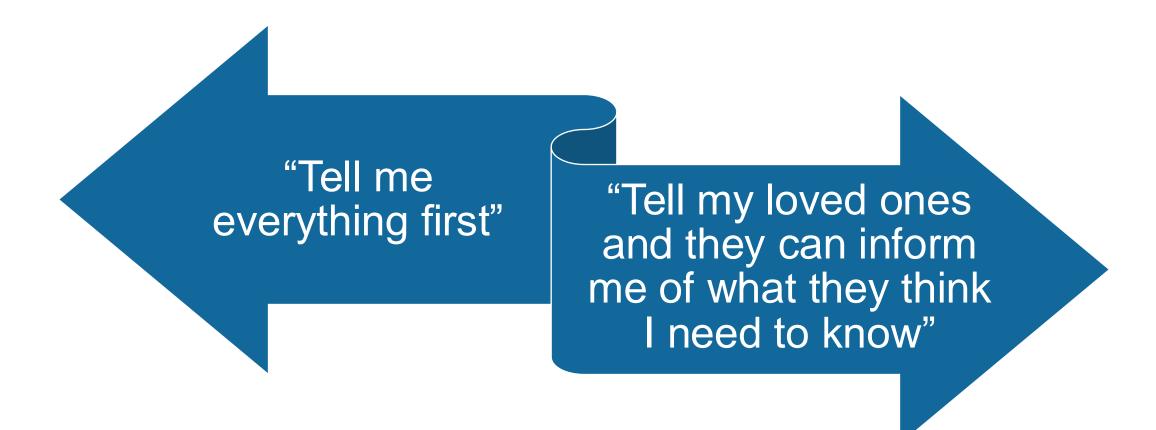


Differences in Communication Preferences



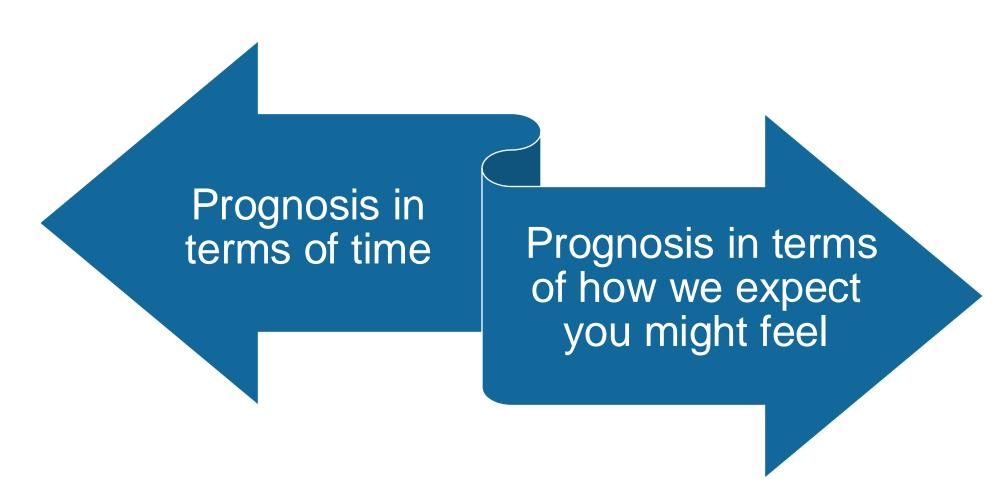


Differences in Communication Preferences





Differences in Communication Preferences





Communication Support

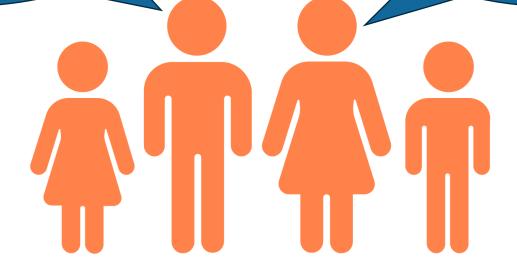
- Do you feel like you understand what is going on?
- Are there questions you want answers to?
- Would you benefit from support in talking to your loved ones about your health?



Supporting Patients and Loved Ones

I would like to know her prognosis, so that I can help prepare our kids and family.

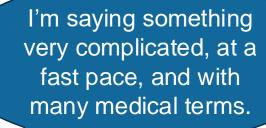
I don't want to know what my prognosis is. That information feels too scary.





Supporting Patients and Medical Teams

I have no idea
what any of this
means, but I'm
afraid to say that.









Communicating During Periods of Uncertainty





Communication Tools

Team Meeting

Family Meeting





Recommended tool you can access from home





the conversation project



What Matters to Me

A Workbook for People with Serious Illness

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			iviy ourc		
•	My Health What is your understanding of your current health situation?		Everyone has their own preferences about the kir receive. Use the scales below to think about what Note: These scales represent a range of feelings; it	t you want at this time.	
			Answer where you are right now. For each scal now. Revisit your answers in the future, as they		
0	How much information about what might be ahead with your illness would you like from your health care team?		 Use your answers as conversation starters. Your answers can be a good starting point to talk with others about why you answered the way you did. 		
		•	As a patient, I'd like to know		
	About Me ·····		Only the basics about my condition and my treatment	All the details about my condition and my treatment	
•	MY GOOD DAYS • What does a good day look like for you?	•	When there is a medical decision to be made, I would like		
	Here are some things I like to do on a good day:		O		
			My health care team to make all the decisions	To have a say in decisions whenever possible	
	EXAMPLES	•	What are your concerns about medical treatments?		
	Get up and dressed • Play with my cat • Make a phone call • Watch TV • Have coffee		O		
	with a friend		I worry that I won't	I worry that I'll get	
0	MY HARD DAYS • What does a hard day look like for you?		get enough care	too much care	
	These are the toughest things for me to deal with on a hard day:	0	How much medical treatment are you willing to go through for the possibility of gaining more time?		
			O		
	EXAMPLES		Nothing: I don't want	Everything: I want to try any	
	Can't get out of bed \cdot In a lot of discomfort \cdot No appetite \cdot Don't feel like talking to anyone		any more medical treatments	medical treatments possible	
	MY GOALS • What are your most important goals if your health	•	If your health situation worsens, where do you want to be?		
	situation worsens?		O		
	These are some things I would like to be able to do in the future:		I strongly prefer to be in a health care facility	I strongly prefer to be at home, if possible	
		0	When it comes to sharing information about my illness with others		
	EXAMPLES		O	•	
	Take my dog for a walk • Attend my child's wedding • Feel well enough to go to church • Talk to my grandchildren when they come to visit		I don't want those close to me to know all the details	I do want those close to	



My Care



Ask your oncologist if meeting with Palliative Care would benefit you.





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Thank you.



SPEAKER SERIES CHANGING THE CONVERSATION ON PALLIATIVE CARE

Q&A



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