

Communicating Cancer: Maximizing the Patient Voice

Katie Narvarte Ozuna, LMSW, OSW-C, OPN-CG

1

Presentation Goals

1. Empower AYA patients, caregivers and medical teams to include communication planning as part of the cancer care continuum
2. Identify the benefits and pitfalls various communication outlets for patients and caregivers
3. Provide practical tools for developing communication plans

2

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Why Focus on Communication?

- Better understanding of AYA issues (build trust to learn their specific problems)
- Narrow the gap between AYA disparities (validate potential problems)
- Build trust with healthcare teams (equip them with the tools that help them proactively solve their problems)
- Empathy + Validation + Trust = Empowerment

3

How to Start: Communication Baselines

4

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Assessing Communication Background

1. What do you want to accomplish with your communication?

- Keep family and friends updated
- Keep everyone who asks updated
- Set better boundaries
- Make others around me comfortable
- Answer questions and ease minds
- Connect to others with similar experiences
- Encourage and inspire other others
- I'm not sure

5

5

Assessing Communication Background

2. How concerned are you about your privacy?

- What cancer? Nobody should know
- I will talk about my diagnosis if asked
- I will **not** talk about my diagnosis if asked
- I openly share my diagnosis

3. How do you prefer to communicate?

- Face-to-Face
- Phone
- Text
- E-mail
- Social Media
- Other

6

Assessing Communication Background

4. With what aspects of communication are you the least comfortable?

- Being assertive
- Defining boundaries
- Finding the right balance
- Feeling vulnerable/exposed

4. Do you use social media?

- Yes
- No

7

Lists: Your New Best Friend

1. "The A List" - Make a list of friends and family you want to personally communicate your journey to

2. "The B List" - All friends, family and coworkers not on the "A list" should be OK learning about your diagnosis through your partner, caregiver or friend.



8

Defining Comfort Zones

1. What are you OK talking about?
2. What are you NOT OK talking about?
3. How much do you want to talk about it?
4. What are your communication fears?
5. What are your trigger points?

9

Support Your Supporters

1. Have your own FAQs
2. People are often ready and willing to help before you are ready to receive it.
-Example: "Let me know if there's something I can do..."

10

Step 2

Choose Your Communication Methods

11

Interpersonal Communication: Face-to-Face, Over the Phone

- Advantages: More Personal/Reassuring, Produces a Stronger Emotional Bond, Contextual, Immediate Feedback Loop
- Disadvantages: Mentally/Emotionally Exhausting, Not Scalable, Not Archivable, Time Consuming
- Strategies:
 - Be proactive
 - Set expectations
 - Reinforce what works for you
 - Leverage your assets

12

Hyperpersonal Communication: Computer or Other Proxy

- Advantages: Scalable, Enables Quicker/More Frequent Updates, Less Mentally Taxing, Mediated, Broad Support
- Disadvantages: Limited Privacy, Often Lacks Context, Requires Technology Skills, Delayed Feedback
- Strategies:
 - Using e-mail
 - Finding support on the internet
 - Match your goals with a personalized tactic
 - Secure your privacy settings

13

Match Your Goals with Your Personalized Tactic

Communication Matrix	Interpersonal	Hyperpersonal	Hybrid Model
	Face to Face Phone Calls Individual E-mail	Personal Site Personal Blog Social Media	Facebook Groups Internet Support
Private	Yes	No	Yes
Broadcast	No	Yes	Yes
Support	Yes	No	Yes

14

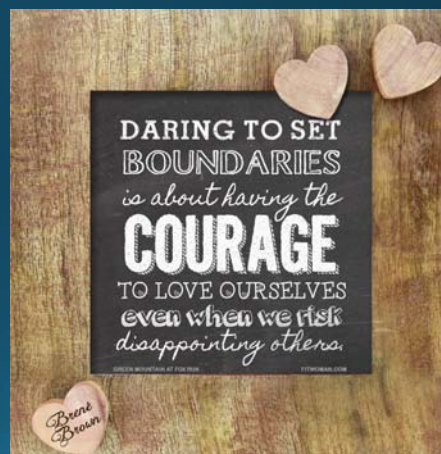
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Step 3 Define Your Boundaries

15

Defining Boundaries

- Be honest
- Use "I feel" statements
- Self-reflect
- Defer, defer, defer



16

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Step 4 Avoid Common Pitfalls

17

Avoid Common Pitfalls

- Don't ignore your own need to talk with someone
- Don't ignore or neglect a friend or relative who may need to open up and talk with you
- Don't protect your loved ones from the negative emotions some days can bring
- Don't expect others to know how to talk about cancer
- Don't feel that there is a perfect way to handle your interactions with others

18

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Step 5 Reevaluate Communication

19

Thank you!

Katie Narvarte Ozuna, LMSW, OSW-C, OPN-CG
Katie.Narvarte@sarahcannon.com

20

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