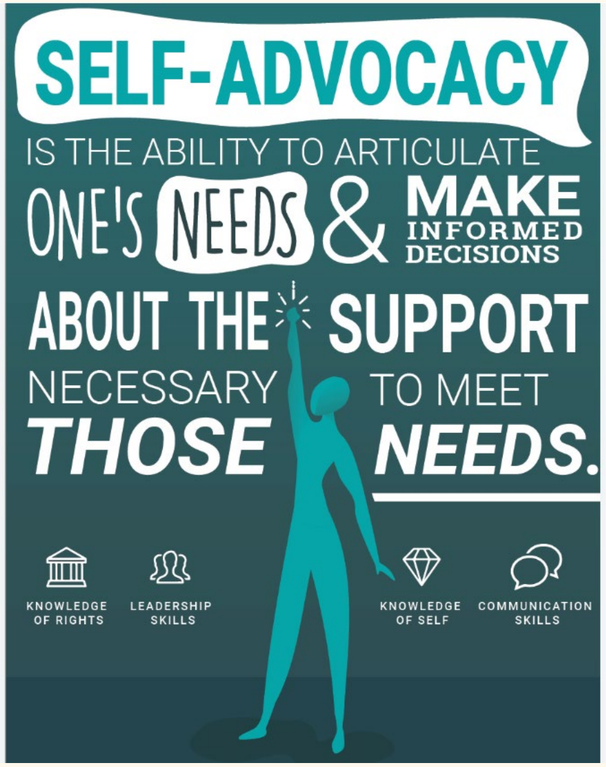
SELF-ADVOCACY AND CANCER SURVIVORSHIP



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DEFINITIONS

CANCER SURVIVOR:

Anyone diagnosed with cancer - whether just diagnosed, in treatment, completed treatment or beyond.

CANCER Co-SURVIVOR:

Anyone who provides support to a person with cancer during their diagnosis, treatment or beyond.

SELF-ADVOCACY

Speaking up for yourself or others, asking questions, and making sure your needs, concerns and goals are heard and met during and after cancer treatment.

SURVIVOR ADVOCACY:

Friends, family, community that support a loved one to make sure their wants, needs and goals are heard by the healthcare team.

Empowered Patients Make Strong Choices

AMIDST THE

Fear Fatigue Isolation Sadness Pain

YOU CAN FIND

RESILIENCE

GRIT

POWER

CONTROL

STRENGTH

SELF ADVOCACY IN ACTION

Asking questions about your health and treatments

Saying what you need to feel safe and supported

Working with both doctors and traditional healers

Making decisions that feel right for you

Taking care of your mind, body and spirit

EASIER SAID THAN DONE

WHY SELF-ADVOCACY MATTERS

1. Improves Communication & Care Quality
Survivors who self-advocate ask more questions, receive clearer answers, and report better care.

2. Leads to Better Health & Symptom Management
Associated with improved treatment adherence, symptom control, and use of survivorship support.

3. Increases Empowerment & Mental Well-Being
Reduces anxiety and increases confidence during the post-treatment phase.

4. Promotes Equity in Diverse Communities
Helps marginalized survivors navigate systemic barriers and request culturally relevant care.

Jernigan VB, et al. (2015), Journal of Cancer Education
Ussher JM, et al. (2017), Psycho-Oncology
Hagan TL, et al. (2018), Journal of Advanced Nursing
Hagan TL, et al. (2020), Journal of Psychosocial Oncology

SELF and SURVIVOR ADVOCACY
SIX PILLARS

1) KNOWLEDGE

2) COMMUNICATION

3) DECISION-MAKING POWER

4) SUPPORT SYSTEMS

5) DOCUMENTATION & ORGANIZATION

6) HONOR TRADITIONS

KNOWLEDGE

LEARN AND UNDERSTAND:

- Your cancer
- Your diagnosis, treatment options, and possible outcomes.
- How lifestyle, traditional practices can support your physical, emotional, spiritual health
- Why it can be important to seek out a second opinion

TRUSTWORTHY ONLINE SOURCES:

American Indian Cancer Foundation®

American Cancer Society®

NIH NATIONAL CANCER INSTITUTE

COMMUNICATION

BE ASSERTIVE: Speak clearly and confidently with healthcare providers

USE "I" MESSAGES: "I think" or "I feel" rather than "you should".

ACTIVELY LISTEN: Listen carefully

CHECK YOUR UNDERSTANDING: Say back what you heard

EXPRESS YOURSELF: Let others know what you are thinking and feeling

MOST IMPORTANTLY….

Ask questions

Don’t hesitate to say, “I don’t understand” OR “Can you explain that another way?”

DECISION MAKING POWER

WHAT THIS MEANS….

- Be an equal partner in your healthcare team
- Make informed choices that align with your values and lifestyle
- Know your rights, including the right to refuse or delay treatment
- Honor your decision-making style

WHAT IS YOUR DECISION-MAKING STYLE?

I PREFER…

1) To leave all decisions about my cancer treatment to my doctor.

2) My doctor makes the final decision about which cancer treatment will be used, but they first seriously consider my opinion.

3) My doctor and I share responsibility for deciding which cancer treatment is best for me.

4) To make the final selection of my cancer treatment after seriously considering my doctor’s opinion.

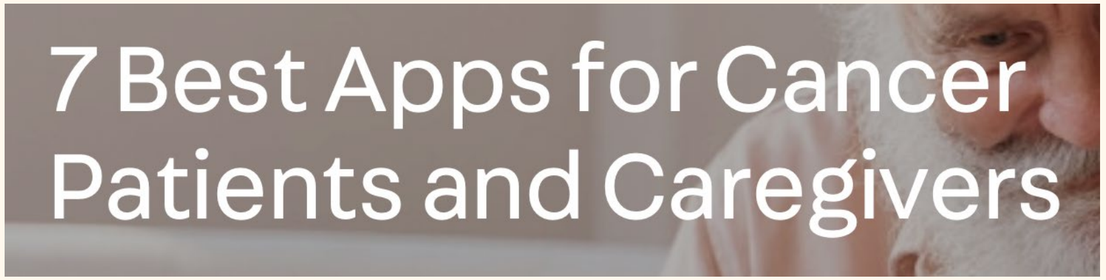
5) To make the final selection about which cancer treatment I will receive.

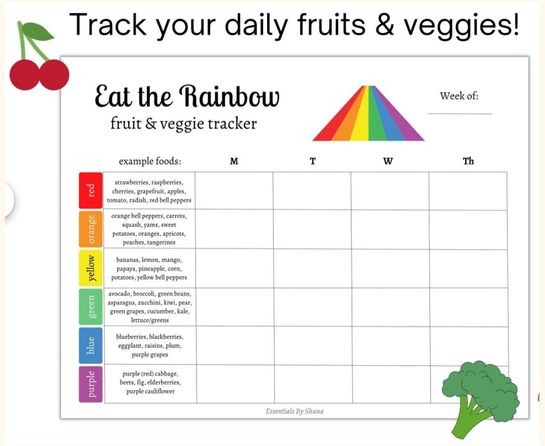
SUPPORT SYSTEMS

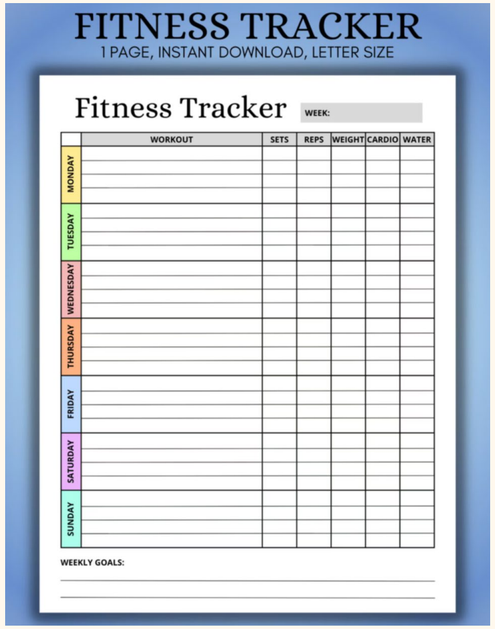
- Build a network of advocates – family, friends, peer groups, patient navigators
- Bring someone to appointments to help take notes or ask questions
- Connect with others who have similar health experiences

DOCUMENTATION & ORGANIZATION

- Keep a personal health record (appointments, medications, test results, etc)
- Track symptoms and side effects to share during visits (what helps, what doesn’t)
- Use tools like journals, apps, or binders to stay organized and prepared







HONORING TRADITIONS

:

- Stay connected to community
- Use both Native healing practices and modern medicine to stay strong
- Share cultural values and priorities with healthcare team
- Expect culturally respectful care

WHAT DOES THIS LOOK LIKE?
Survivor and Caregiver

BEFORE VISIT:	Write down concerns and questions
	Think about what is most important to you
	Let staff know your preferred method of communication
	Explore using the electronic health record system or get assistance to do so
DURING VISIT:	Bring someone with you
	Consider recording visit on your smart phone
	Ask medical team to explain things slowly and clearly
	Say back what you were told to confirm you understood

AFTER VISIT:	Reflect on your feelings about the appointment
	Note any questions or concerns you have about your care plan
	Seek a second opinion
	Review all provided resources and paperwork
Between Visits:	Take care of yourself (eat well, move, sleep)
	Let others take care of you
	Keep track of side effects - what helps and what doesn't

From Patient Advocacy Foundation

WHAT DOES THIS LOOK LIKE?

Healthcare System/Community

- **Culturally Competent Care**
- **Community-Based Navigation and Support**
- **Flexible Communication and Language Access**
- **Improve Access to Care**
- **Family-Centered and Holistic Approach**
- **Collaborate with Tribal and Urban Indian Health Programs**
- **Respect Historical Context and Build Trust**

WHAT DOES THIS LOOK LIKE- Lifestyle

Be active

- Avoid inactivity and return to normal daily activities as soon as possible after diagnosis.
- Work up to getting moderate activity that raises your heart rate for about 30 minutes a day
- Include strength training exercises

Eat a variety of healthy foods from plant sources

- Limit processed meat red meat
- Eat 2½ cups or more of vegetables and fruits each day
- Choose whole grains rather than refined grain products.

Get to or stay at a healthy weight

- If you have overweight or obesity, limit how much you eat of high calorie foods and beverages and increase physical activity to promote weight loss.

REAL WORLD ADVOCACY EXAMPLES

Challenge	Self-Advocacy in Action
Not getting clear info from doctor	“Can you explain that in simpler terms?”
Need for nutrition help	“Can I see a dietitian who understands cancer recovery?”
Feeling overwhelmed or anxious	“Are there mental health or spiritual supports available?”
Wanting traditional healing	“Can I include my tribal healer or spiritual leader in my care?”

REAL WORLD ADVOCACY EXAMPLES

Lifestyle

Communicate Your Goals

"I'm focusing on healthy habits to feel stronger after treatment. Your support means a lot."

Set Boundaries Respectfully

"I'm choosing water over soda. Let's have both at the table?"

Ask for Specific Support

"Would you go for a walk with me once a week?"

Adapt Family Favorites, Don't Cancel Them

"Let's try baking our favorite dish instead of frying it."

Share Information Casually

"Even small changes, like walking 15 minutes a day, help lower risk."

Stay Calm if There's Pushback

"I'm not asking you to change—just to support me while I do."

THE A, B, Cs of MAKING CHANGES

A = Add

What can I **add** at this time, on this day to improve my health?

B = Better

What **better** choice could I make?

C = Change

What **change** could I make to be healthier?

What do I want or need to do to act on this?

From Cancer Clear and Simple

ADVOCACY IN ACTION

A = Add

What can I **add** at this time, on this day to be more self or survivor advocating?

B = Better

What **better** choice could I make to be more self or survivor advocating?

C = Change

What **change** could I make to be more self or survivor advocating?

What do I want or need to do to act on this?

1) Work with others
2) Choose 1-2 pillars
3) Brainstorm something you could Add, Better or Change to be more self or survivor advocating?
4) Identify what would be needed to act on this?
5) If you finish, choose another pillar

THANK YOU