

A photograph of two women laughing and embracing outdoors. The woman on the left is older with white hair and glasses, wearing a light blue and white striped shirt. The woman on the right is younger with dark curly hair, wearing a dark green long-sleeved shirt. They are standing in front of a background of trees and foliage, with sunlight filtering through. A blue gradient overlay covers the right side of the image.

# PUSH THE PAUSE BUTTON

Supports for Caregivers





# Our Mission



*We are a relentless ally for anyone who is striving to manage the realities of this disruptive disease. No one can, or should, face cancer alone. While we have witnessed many advances in treating cancer, nothing takes the place of the power, inspiration, companionship, and connection that comes from community because*  
**Community is Stronger than Cancer.**





CANCER SUPPORT  
**COMMUNITY**  
COMMUNITY IS STRONGER THAN CANCER



# REFLECTION

# Overview

- 1** **Becoming a Caregiver**
- 2** **Common Worries and Concerns**
- 3** **Mental Health and Cancer**
- 4** **Role Changes**
- 5** **Benefits of Caregiving**
- 6** **Balancing Caregiving and Work**
- 7** **Emotional Well-Being**
- 8** **Push Pause**



"There are only four kinds of people in the world:  
*those who have been caregivers, those who are  
currently caregivers, those who will be caregivers, and  
those who will need caregivers.*"

**Rosalynn Carter**





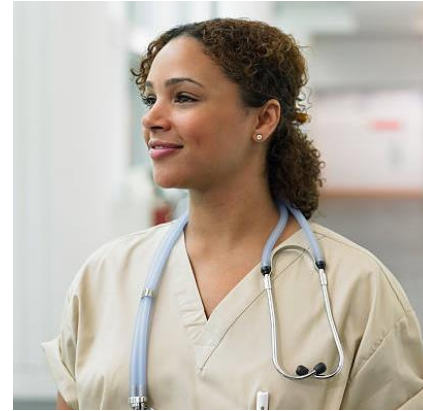
# How Do You Identify?



**care**giver



**care**taker



**carer**



**co**-survivor

# Who Are Caregivers?



“Cancer caregivers have diverse backgrounds and characteristics. Cancer caregivers tend to be women (58%), and most have less than a college degree (60%). They are 53 years old on average (4 years older than non-cancer caregivers). Most cancer caregivers provide care to a relative (88%); six out of ten cancer caregivers provide care to someone age 65 or older.”

Cancer Caregiving in the U.S.: An Intense, Episodic, and Challenging Care Experience.  
Bethesda, Md: National Alliance for Caregiving, 2016

# Becoming a Caregiver

*Cancer Support Community's*  
**Cancer Experience Registry®** found:

- 98%** provided emotional support
- 96%** went with their loved one to medical appointments
- 82%** helped with decision-making
- 79%** coordinated medical care
- 80%** provided transportation
- 74%** helped manage finances





# Common Worries

**Thrust into this role unexpectedly with little preparation**

**Performing caregiver tasks alone**

**Fear of losing someone you love**

**Juggling caregiving duties with other daily activities**

**Feelings of inadequacy**



# Top Concerns

**71%**

Their patient's  
cancer progressing  
or coming back



**67%**

Worrying about  
the future and  
what lies ahead



# Top Concerns

## CAREGIVER REGISTRY: 2020 KEY FINDINGS



### CAREGIVER ROLES

**89%**

were quite a bit/very much  
involved in providing  
emotional support

**80%**

were quite a bit/very much  
involved in going to  
medical appointments with  
the patient

**20%**

spent more than 100 hours  
per week caregiving

**16%**

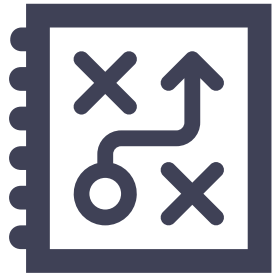
reported having received  
formal caregiving training

**41%**

of those trained wanted  
additional training

# Top Concerns

## CAREGIVER REGISTRY: 2020 KEY FINDINGS



### TREATMENT DECISION MAKING

**39%**

reported making decisions  
together with the patient

**2 out of 3**

were quite a bit/very much  
involved in patients'  
treatment decisions

**29%**

reported that patients  
make decisions after  
considering their opinion



# Top Concerns

## CAREGIVER REGISTRY: 2020 KEY FINDINGS



### PREPARADNESS

**> 1 out of 2**

fell at least pretty well  
prepared to respond to  
and handle patient  
emergencies **(60%)** and  
care for physical needs  
**(58%)**

**58%**

did not feel prepared to  
care for patient's emotional  
needs

**68%**

did not feel prepared to  
handle caregiving stress

# Top Concerns

## CAREGIVER REGISTRY: 2020 KEY FINDINGS



### QUALITY OF LIFE AND DISTRESS

**49%**

reported substantially  
worse anxiety than the  
national average

**34%**

reported substantially  
worse fatigue than the  
national average

**39%**

said their health was  
somewhat or much worse  
than before they began  
their caregiver role



# Top Concerns

## CAREGIVER REGISTRY: 2020 KEY FINDINGS



### CAREGIVER NEEDS

**3 out of 4**

wanted help with  
understanding the patient's  
medical condition and  
treatment

**> 1 out of 2**

wanted help managing  
health benefits and  
financial services

**Nearly 1 out of 2**

reported at least  
sometimes experiencing a  
sense of loss of control  
over their own life



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# Role Changes

# Role Changes



*Caregiving Encompasses a Variety of Duties*

- Multi-Dimensional Job
- Time Consuming

# What Caregivers Do



Physical Caregiving



Practical Caregiving



Emotional Caregiving



# What Caregivers Do



## Physical | Practical | Emotional

- Patient-Health Care Team Liaison
- Coordinate Care
- Personal Shopper
- Give physical care
- Offer emotional support
- Provide Companionship
- Driver
- Housekeeper
- Order and pick up medications
- Handle practical and financial matters
- Insurance advocate
- Other duties as assigned

# Caregiving Resistance



Understand and acknowledge:

- Loss of independence
- Loss of control
- Change and uncertainty

# Caregiving Benefits



Sense of **Purpose and Pride**



Enjoyment of **Role**



Inspired **Advocate**

# Caregiving Benefits



Caregivers' Sentiments About Their Caregiving Duties	Volunteered	Didn't Volunteer
	Strongly/Somewhat Agree (NET)	
Positive		
It's important for me to provide a good quality of life for the care recipient	95%	90%
I like helping the care recipient	93%	76%
I enjoy spending time with the care recipient	93%	75%
Being a caregiver gives me a strong sense of purpose	86%	63%
Being a caregiver has led me to take better care of my own health	73%	55%
Being a caregiver has inspired me to document my own health and legal wishes	68%	61%
Negative		
My own health takes a backseat to the health of my care recipient	53%	66%
My caregiving duties leave me feeling physically exhausted	52%	72%
My caregiving duties leave me feeling emotionally exhausted	51%	70%
I need more help with my caregiving duties	46%	61%
With all of my caregiving duties, I barely have time for anything else	43%	64%
My caregiving duties leave me feeling completely overwhelmed	40%	64%



# Caregiving & Work



## Balancing Caregiving and Work

- 52% of caregivers are employed
- Inform your employer
- Know your legal rights
- Get help and support

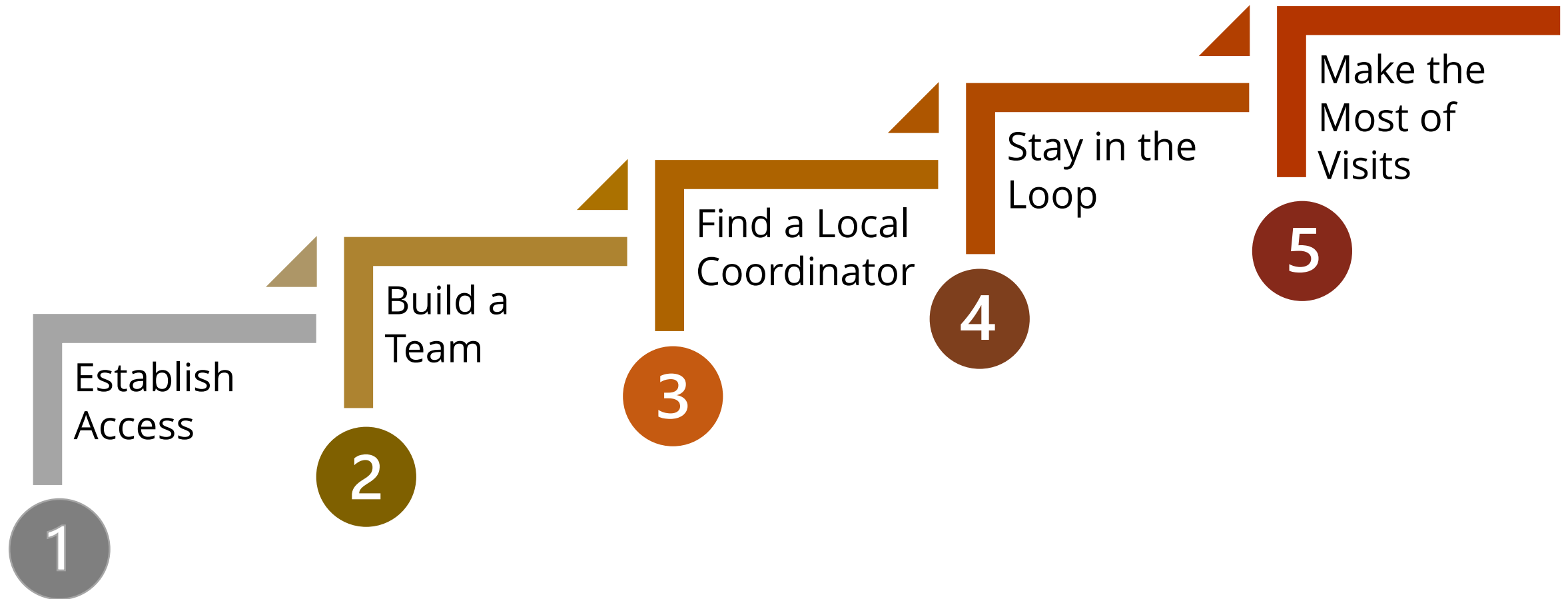


- Who is a long-distance care partner?
- Care-supporting from afar
- Staying connected
- A partner in hope

# Long-Distance Caregiving: 5 Key Steps to Providing Care From Afar

Steady communication and building a trusted team are crucial

AARP, Updated May 15, 2020





# Emotional **Well-Being**



# Uncertainty

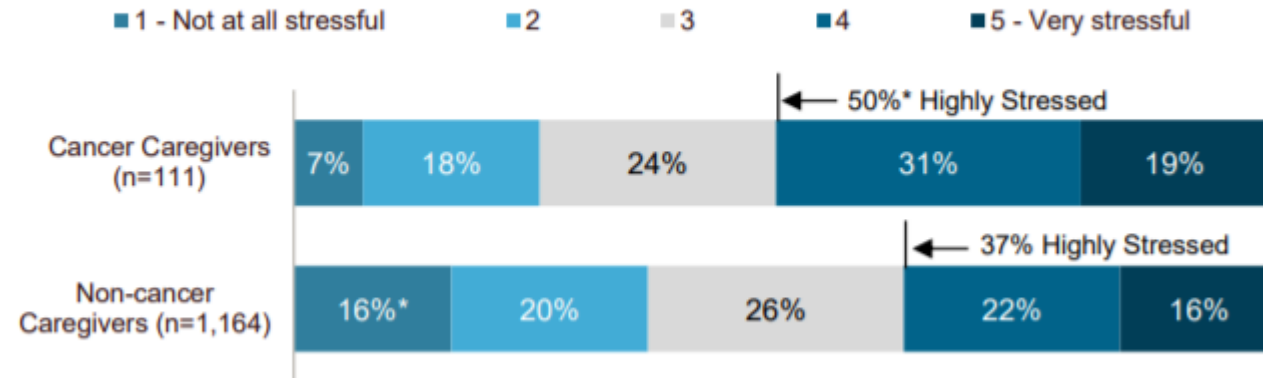


WHAT  
IF ?

# Emotional Stress



**Figure 11: Emotional Stress of Caregiving**





# Mental Health **and Cancer**

# Mental Health



DISTRESS

ANXIETY



DEPRESSION



# Mental Health



## DISTRESS

### The **6<sup>th</sup>** VITAL SIGN

*"If a caregiver experiences high levels of psychological distress, then likely so will the patient (ONS VOICE, 2019)"*



# Mental Health



## DISTRESS


CONSEQUENCES OF STRESS FOR CAREGIVERS

Quality of Life Issues  
Sadness (Worries about position of person)  
Money  
Anxiety  
Chronic  
Social  
Loneliness  
Weight  
Sleep  
Issues



# Mental Health

## ANXIETY



**49%** of caregivers  
reported anxiety levels  
substantially worse than  
the national average.

- Cancer Experience Registry Report

# Mental Health



## DEPRESSION

**34%** of caregivers reported fatigue and depression levels that were substantially worse than national average.

- Cancer Experience Registry Report





# Mental Health



## DEPRESSION

### SEVERE WORRY AND SADNESS

Contact your health care provider for a referral to a **trained psychologist or licensed mental health counselor** if you notice:

- Your worry/sadness is getting in the way of doing the things you need and want to do
- You are worrying or sad most of the day for most days of the week



# Emotional First Aid





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REFLECTION

REFLECTION

# Push The Pause Button



ASSESS NEEDS  
**AND VALUES**



CREATE SIMPLE  
**GOALS**



IDENTIFY  
**ACTIVITIES**



EVALUATE



# Setting Intentions

**1. What is something** I used to like to do?

**2. Can I incorporate it** back into my life?

**3. Do I need to do it differently?** Be creative.

**4. What might get** in the way?

**5. How will I overcome** that obstacle?

**6. Make** a plan.

# The 2 D's



depleters  
*and* **DERAILERS**

# A Little R&R

**REFUEL**



**REPLENISH**

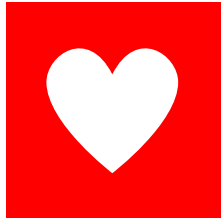


Push Pause



# Summary

## **Make plans** for the future



Make changes that are important to you or your loved one

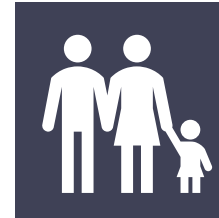


Start a new hobby



Keep moving ahead one step at a time

## **Set new goals** and/or priorities



Spend more time with family/friends




Focus on what really matters



Complete a project (i.e. house project, scrapbook)

# Reach Out



- 
- A close-up photograph of a person's hands held out, palms up, in a gesture of offering or seeking help. The hands are positioned on the left side of the frame, with the fingers slightly spread. The person is wearing a light-colored, long-sleeved shirt. The background is dark and out of focus.
- Trusted Friend/Family
  - Clergy Person
  - Mental Health Professional
  - Doctor
  - Nurse
  - Oncology Social Worker

# Resources





## CONNECT TO THE LLS' INFORMATION SPECIALISTS

Information specialists assist patients and their families with financial and social challenges, and give accurate, up-to-date disease, treatment and support information at every stage of the cancer trajectory.

- **Call:** (800) 955-4572  
Monday to Friday, 9 a.m. to 9 p.m. ET
- **Email:** [infocenter@LLS.org](mailto:infocenter@LLS.org)
- **Leave a message 24/7 and we'll call back.**  
Call (800) 955-4572 to use the automated response system 24 hours a day, seven days a week.





## CAR T Patient & Caregiver Guide



A step-by-step guide for adult CAR T cell therapy patients and their caregivers from referral through treatment and follow-up.



Stock photo.  
Posed by model

For more information call:  
**844-792-6517**

**To best support yourself and your caregivers, contact  
the Cancer Support Community. We can help.**



### Caring for a Loved One

Family members, spouses, partners and friends who take on a caregiving role have a unique relationship to cancer. Caregivers see and experience firsthand how deep and wide cancer's emotional impact can be. They learn how quickly life can become complicated and constrained



### Helping Your Loved One Make Treatment Decisions

Companion to FRANKLY SPEAKING ABOUT CANCER: CAREGIVERS



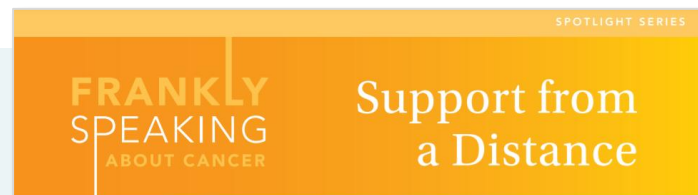
Taking care of someone with cancer is a wide range of feelings, from sadness to joy, even all in one day. Find information as possible in your own words and distress, get support and address your own needs.



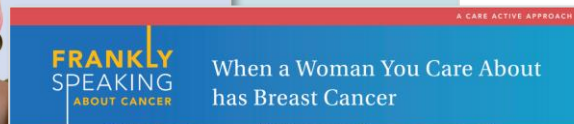
Family members, spouses, partners, and friends who take on a caregiving role feel cancer's deep emotional impact. They learn how quickly life can become overwhelmed by a cancer diagnosis. Your days are suddenly filled with doctor's appointments, scans, lab work, and bills. Your family and friends all want to help, give advice, tell you their stories about people they know or something they read. Helping your loved one make treatment decisions may feel overwhelming. This

booklet has information to help you be an effective caregiver during this time. Additional information can be found in our *Frankly Speaking About Cancer: Caregivers* booklet. For information about reducing stress, finding support, and addressing your own needs, visit

[www.CancerSupportCommunity.org/Caregivers](http://www.CancerSupportCommunity.org/Caregivers).



People who care about someone with cancer can become active participants in enhancing health and wellness for themselves and their loved ones.



People who care about someone with cancer can become active participants in enhancing health and wellness for themselves and their loved ones and nurture their



De Cuidador a Cuidador  
Compartiendo nuestras experiencias durante el cuidado a mujeres con cáncer de seno



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**GILDA'S  
CLUB**





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Q & A

# References

- American Society of Clinical Oncology. (2020). *Advanced cancer care planning*. Alexandria, Virginia; American Society of Clinical Oncology. Retrieved September 14, 2021 from [https://www.cancer.net/sites/cancer.net/files/advanced\\_cancer\\_care\\_planning.pdf](https://www.cancer.net/sites/cancer.net/files/advanced_cancer_care_planning.pdf)
- Bestvina, C. M., & Polite, B. N. (2017). Implementation of Advance Care Planning in Oncology: A Review of the Literature. *Journal of oncology practice*, 13(10), 657–662. <https://doi.org/10.1200/JOP.2017.021246>
- CancerCare (n.d.). *What is a living will*. Retrieved September 14, 2021 from [https://www.cancercare.org/publications/260-what\\_is\\_a\\_living\\_will](https://www.cancercare.org/publications/260-what_is_a_living_will)
- CancerCare (n.d.). *Advance care planning: Be prepared*. Retrieved September 14, 2021 from [https://www.cancercare.org/publications/268-advance\\_care\\_planning\\_be\\_prepared](https://www.cancercare.org/publications/268-advance_care_planning_be_prepared)
- Hamel, Liz., Wu, Bryan., Bordie, Mollyann. (2017, April 27). Views and Experiences with End-of-Life Medical Care in the U.S. *Kaiser Family Foundation*. Retrieved October 19, 2021 from <https://www.kff.org/report-section/views-and-experiences-with-end-of-life-medical-care-in-the-us-findings/>
- Leukemia and Lymphoma Society (2019). *Advance care planning*. Rye Brook, New York; Leukemia and Lymphoma Society. Retrieved September 14, 2021 from [https://www.lls.org/sites/default/files/National/USA/Pdf/Publications/PS94\\_Advance\\_Care\\_Planning2019\\_FINAL.pdf](https://www.lls.org/sites/default/files/National/USA/Pdf/Publications/PS94_Advance_Care_Planning2019_FINAL.pdf)
- National Hospice and Palliative Care Organization. (n.d.). *Planning ahead: Advance directives and end-of-life decisions*. [PowerPoint Slides]. [https://www.nhpco.org/wp-content/uploads/2019/04/Advance-Directives\\_Planning-Ahead.ppt](https://www.nhpco.org/wp-content/uploads/2019/04/Advance-Directives_Planning-Ahead.ppt)
- National Institute on Aging. (2018, January 15). *Advance care planning: Health care directives*. Retrieved September 14, 2021, from <https://www.nia.nih.gov/health/advance-care-planning-health-care-directives>.
- Rietjens, J., Sudore, R. L., Connolly, M., van Delden, J. J., Drickamer, M. A., Droger, M., van der Heide, A., Heyland, D. K., Houttekier, D., Janssen, D., Orsi, L., Payne, S., Seymour, J., Jox, R. J., Korff, I. J., & European Association for Palliative Care (2017). Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. *The Lancet. Oncology*, 18(9), e543–e551. [https://doi.org/10.1016/S1470-2045\(17\)30582-X](https://doi.org/10.1016/S1470-2045(17)30582-X)
- The Conversation Project. (2021). *Get started*. Retrieved October 15, 2021 from <https://theconversationproject.org/get-started>
- UCLA Health. (n.d.). *What is ACP?*. Retrieved September 14, 2021 from <https://www.uclahealth.org/advance-care-planning/what-is-advance-care-planning>
- Johnson, S. B., Butow, P. N., Kerridge, I., & Tattersall, M. (2018). Patient autonomy and advance care planning: a qualitative study of oncologist and palliative care physicians' perspectives. *Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer*, 26(2), 565–574. <https://doi.org/10.1007/s00520-017-3867-5>
- Waller, A., Turon, H., Bryant, J., Zucca, A., Evans, T. J., & Sanson-Fisher, R. (2019). Medical oncology outpatients' preferences and experiences with advanced care planning: a cross-sectional study. *BMC cancer*, 19(1), 63. <https://doi.org/10.1186/s12885-019-5272-6>





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