Best Practices in Oncology Distress Management: Beyond the Screen

Presenter

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Title

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AdventHealth Cancer Institute

Clinical Health Psychologist and Associate

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Behavioral Health Manager at Florida Cancer

Specialists & Research Institute

Head and Neck Cancer Oncology Social Worker at

the Sylvester Comprehensive Cancer Center at the

University of Miami

Mental Health Professionals in Oncology

Licensed Clinical Social	Complete Master of Social Work degree
Workers (LCSW)	2 years of clinical practice post Masters with supervision by a qualified supervisor
•	Pass the state licensure exam
•	(Optional) Obtain certification in Oncology Social Work (OSW-C)
Licensed Psychologist	Complete doctoral degree, including internship
(PsyD or PhD in Clinical or Counseling Psychology)	Complete 1-2 years of postdoctoral residency
Couriseting r sychology)	Pass national and state licensure exams
	(Optional) Obtain board certification (ABPP-CHP)
Nurse Navigators	Complete degree in Nursing (Associate, BSN, APRN, PhD)
	(Optional) Obtain Oncology Certified Nurse certification; Breast Patient Navigator Certification
Psychiatrist	Complete an MD or DO, including internship, residency, and fellowship
(Medical doctors specializing in managing mental health, including	Obtain licensure
with medications)	Obtain board certification

FIGURE 2. Team Work and Triage²⁴

Department of Supportive Care Medicine (DSCM) Clinical Triage

Social Work	Psychology	Psychiatry	Supportive Medicine	Spiritual Care
 Safety/Risk assessment for abuse, suicide, homicide, AMA Pre-transplant psychosocial assessment Evaluation, support & triage of patient & family coping & distress Counseling for adjustment to illness & changes in medical status Interventions to reduce barriers to care End-of-life & hospice discussions Grief & bereavement support Coordination & facilitation of family meetings Couples counseling & education (cancer-related) School program Advance Directives counseling Assistance with community resources, e.g. financial, mental health, transportation "Aid in Dying" assessment & counseling 	 Psychotherapeutic management of mental health issues impacting treatment Assessment of cognitive & emotional functioning Interventions & treatment planning for high acuity behavioral & adherence issues Psychological techniques for symptom management Individual psychotherapy for severe cancer-related distress, e.g. anxiety, depression 	Assessment & management of altered mental status Pharmacologic treatment of psychiatric disorders Acute management of substance use disorders Assessment of psychiatric stability for treatment Assessment of medical decision-making capacity Acute management of suicide & homicide risk	 Symptom assessment & management Symptom management for patients with substance use concerns Prognostication Initiation of & assistance with goals of care discussions Assistance with hospice evaluation & transition "Aid in Dying" consultation Management of actively dying patients Palliative sedation 	Assessment of spiritual & existential needs & distress Spiritual counseling, including grief & bereavement support Interventions for spiritual & moral distress about treatment & end of life decision-making Spiritual interventions around end of life clinical processes, e.g. DNR, miracle thinking Facilitation of spiritual/religious rituals, sacraments & services

Abbreviations: AMA, against medical advice; DNR, do not resuscitate. Adapted with permission from Schnaitmann et al.²⁵

Distress Screening Tools

Evidence Based Tools Used in Distress Screening

Tool	When to Use	Follow up
PHQ-2	Office / Treatment visit	Watchful waiting
PHQ9	Depression	Supportive Counseling- in house therapy or a community referral (evidence-based)
*COLUMBIA SUICIDE	Suicidal/homicidal statements or behaviors (overt or covert)	Assess, Intervene, Refer, and/or Baker Act / contact law enforcement
GAD-7	Anxiety	Supportive Counseling- in house therapy or a community referral (evidence-based)
DISTRESS THERMOMETER	Office / Treatment visit	Resource referrals; Supportive Counseling- in house therapy or a community referral
PC-PTSD-5 PCL-5	PTSD, trauma	Supportive Counseling- in house therapy or a community referral, (evidence-based)
MY WELLNESS CHECK SURVEY	Office / Treatment visit	Supportive Counseling- in house therapy or a community referral, (evidenced-based)

^{*}Other suicide screening tools are also used based on agency preference

Similarities/Differences by Settings

Academic	Community
Accreditation - NCI Designated Cancer Center, CoC, Breast Accredited, GI Accredited, site specific	Accreditation – Pathology Accredited, Radiology Accredited, Rx-To-Go Accredited, site specific
PHQ-2 / PHQ-9	PHQ-2 / PHQ-9
GAD-7	GAD-7
Distress Thermometer	

PHQ-9 and GAD-7 screening tools

M

Patient Health Questionnaire and General Anxiety Disorder (PHQ-9 and GAD-7)

	Not at	Several	More than half	Nearl every o
doing things.	0	1	2	3
r hopeless.	0	1	2	3
eep, or sleeping too much.	0	1	2	3
energy.	0	1	2	3
	0	1	2	3
	0	1	2	3
yourself or your family down. 7. Trouble concentrating on things, such as reading the newspaper or watching television.			2	3
Moving or speaking so slowly that other people could have noticed. Or the oppositie – being so fidgety or restless that you have been moving around a lot more than usual.			2	3
better off dead, or of hurting	0	1	2	3
Add the score for each column				
Add the score for each column				
	•	•	amn scores):	
Total S	ou to do y	•		at home,
Total S how difficult have these made it for yole one)	Very Dif	our work, t	Extremely D	at home,
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Total S how difficult have these made it for you cle one) Somewhat difficult an have you been bothered by any	Very Dif	fficult flowing productions of the second s	Extremely D bblems? al Over half the days	ifficult Near
	doing things. r hopeless. leep, or sleeping too much. energy. or that you are a failure or have let ings, such as reading the vision. ly that other people could have eing so fidgety or restless that you lot more than usual. better off dead, or of hurting	doing things. doing things. or hopeless. leep, or sleeping too much. energy. or or that you are a failure or have let lings, such as reading the vision. ly that other people could have eing so fidgety or restless that you lot more than usual. better off dead, or of hurting or hopeless. O lot or or that you are a failure or have let lings, such as reading the vision.	Not at all Several days	days the days the days the days doing things. 0

Total Score (add vour column	scores):	

0

0

If you checked off any problems, how difficult have these made it for you to do your work, take care of things at home, or get along with other people? (Circle one)

Add the score for each column

5. Being so restless that it's hard to sit still.

7. Feeling afraid as if something awful might happen.

6. Becoming easily annoyed or irritable.

Not difficult at all Somewhat difficult Very Difficult Extremely Difficult

UHS Rev 4/2020

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Guide for Interpreting PHQ-9 Scores				
Score	Depression Severity	Action		
0-4	None-minimal	Patient may not need depression treatment.		
5-9	Mild	Use clinical judgment about treatment, based on patient's duration of symptoms and functional impairment.		
10-14	Moderate	Use clinical judgment about treatment, based on patient's duration of symptoms and functional impairment.		
15-19	Moderately severe	Treat using antidepressants, psychotherapy or a combination of treatment.		
20 - 27	Severe	Treat using antidepressants with or without psychotherapy.		

AdventHealth Cancer Institute



Normal Distress When Facing Cancer

Distress is a word that has lots of meaning. Here we use "distress" to describe those unpleasant emotions that may arise as you cope with cancer and its treatment. It can affect emotions, thoughts, behaviors and how you interact with others.

Distress is normal when you or a family member has a cancer diagnosis.

AHCI offers this brief Distress Screen. It helps us provide you with ongoing support and the best care.

A Distress Screen is a tool much like a pain scale. A score of 5 or more on the Distress Thermometer indicates moderate to severe distress.

In most cancer centers, the Oncology Social Worker is the first support person you may see when the cancer care team wants to refer you to someone for distress. They are available to you when your distress falls into the area of psychosocial or practical problems. They provide counseling support and assist with referrals to relieve stress related to the problems identified on the distress screen. *

After completing the attached Distress Screen, please indicate your desire to have communication with someone from our Oncology Social Work staff.

Thank you-

Oncology Distress Screening

Distress



Distress is a term used to describe unpleasant feelings or emotions that may interfere with your ability to cope with your cancer diagnosis. It can affect emotions, thoughts, behaviors, and how you interact with others. Distress is normal when you or a family member has a cancer diagnosis. AdventHealth offers this brief Distress Screen. It helps us provide you with ongoing support and the best care.

Please <u>CIRCLE</u> the number that best describes how much distress you have been experiencing in the past week, including today.

Please check if any of the following has been a cause of distress in the past week, including today.

☐ Transportation ☐ Insurance ☐ Financial ☐ Work ☐ School	Depression Anger Anxiety Sadness Worry Fears	☐ Intimacy ☐ Sexuality/Fertility ☐ Relationship with ☐ Relationship with Spiritual/Religious ☐ Relationship with ☐ Loss of faith	children	r Power
Other concerns not listed above: _				
As a result of my Distress Scree Counseling services Education/support groups Spiritual support Advance Directive (Designatio	-			
Patient Signature	Print First and La	ast Name	Date	Time
Qualified Staff / Interpreter Signature	□Phone □Video (Check) Print Qualified	I Staff / Interpreter Name	ID Number	Language Interpreted
Staff Use				
I have reviewed the above information	on with the patient.			
Social Worker Authentication	Print First and La		Date	Time



Patient Label

Sylvester Comprehensive Cancer Center

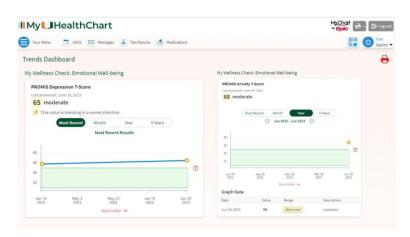
Outpatient Psychosocial Distress Screening:



- EMR integrated assessment and triage
- Delivered prior to ambulatory oncology visits for patients with an ICD-10 cancer DX
- Assessment no more than at one visit in 30 days
- Scored and BPAs triggered in real-time to relevant providers
- Assesses:
 - 5 PROMIS CATs: emotional distress (depression, anxiety), pain, fatigue and physical function
 - Nutrition
 - physical a ctivity
 - practical and psychosocial needs
- Results available to patients and providers in English, Spanish and Creole/French

*All elevated depression and anxiety scores will trigger a BPA to the Social Work team who may administer further screening utilizing the PHQ-9, GAD-7, and Columbia Suicide Severity Rating Scale (C-SSRS).

Best Practice Advisory (BPA) Alert Thresholds			
Domains	Clinician Alert Thresholds		
Anxiety	≥ 65		
Depression	≥ 60		
Pain	≥ 65		
Fatigue	≥ 65		
Physical Function ≤ 40			



MWC Battery:

- 5 PROMIS CATs

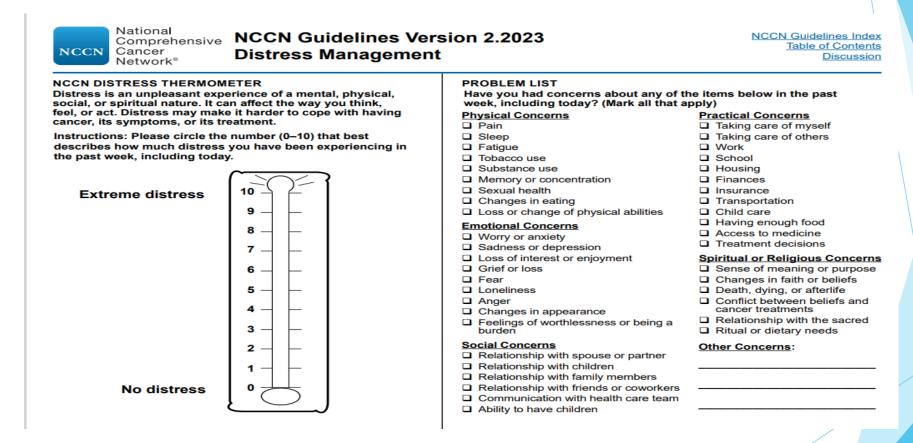
 (Anxiety, Depression,
 Pain, Fatigue,
 Physical Function
- Physical Activity
- Supportive Care Needs
- NutriScore
- FACT-G7 HRQoL.

Implementation of the program and impact on ER visits/hospitalizations publications:

- 1. JAMA Network Open (2023) Implementation of the program
- 2. J Clin Oncology Practice (2022) Impact on ER visits and hospitalizations
- JCO Oncology Practice (2022) Unmet needs associated with ER visits and hospitalizations

Sylvester Comprehensive Cancer Center

Inpatient Distress Screening- (Distress Thermometer) National Comprehensive Cancer Network (NCCN) Distress Thermometer



Source: NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Distress Management Version 2.2023

^{*}All positive scores for depression and anxiety will trigger additional assessments such as the PHQ-9, GAD-7, and Columbia Suicide Severity Rating Scale (C-SSRS).

Florida Cancer Specialists & Research Institute

• PHQ-9 is administered in clinics. Based on findings, referrals to Behavioral Health Therapists and other resources and community referrals are discussed and offered to patient.

The <u>Subjective Units of Distress Scale</u> or SUDS is an easy way to track and let others know how much distress you are having at any given time. The scale ranges from zero to 10.				
SUDS Rating	Level	Description		
10	Extreme Distress	Exploding or Completely Overwhelmed! The most you can imagine. Not able to think, only react.		
9	High to Extreme Distress	Ready to explode! You can't think very clearly. At risk to make very bad choices.		
8	High Distress	High levels of fear, anxiety, sadness, anger, agitation, and/or body tension. These feelings cannot be tolerated for long. Bodily distress is substantial. It is difficult to focus on anything.		
7	Moderately High Distress	Feel agitated and tense. Beginning to feel overwhelmed. It's hard to focus.		
6	Moderate Distress	Most people would describe as a "bad day" but still able to do what you need to do.		
5	Mild to Moderate Distress	Unpleasant, nagging negative mood state (i.e. frustrated, feeling down, or worried) but is not enough to produce many bodily symptoms.		
4	Mild Distress	Mild feelings of tension, mild worry, mild sadness, or annoyance or irritation. Unpleasant but easily tolerated.		
3	"Normal"	Alert (but not distressed). Amount of tension and stress needed to keep your attention from wandering.		
2	Peaceful/Calm	Warm, mellow, contented feeling. Like when relaxing at the beach, or at home in front of a warm fire on a cold, wintery day, or walking peacefully in the woods		
1	Very Relaxed	Awake but very, very relaxed; almost dosing off. Mind wanders and drifts. Drowsy.		
0	Complete Relaxation	No distress at all. Slow, deep breathing. Asleep.		

*Tools available to screen for distress, depression, anxiety, and other mental health disorders.

	'
Name	
$\begin{tabular}{ll} \hline & ACE: Adverse Childhood Experiences Questionnaire \\ \hline \end{tabular}$	
ASRS: Adult ADHD Self-Report Scale-V1.1	
AUDIT: Alcohol Use Disorders Identification Test	
BBGS: Brief Biosocial Gambling Screen	
CAGE-AID: CAGE Adapted to Include Drugs	
C-SSRS: Columbia-Suicide Severity Rating Scale	
DES-B: Adult Brief Dissociative Experiences Scale-M	lodified
EPDS: Edinburgh Postnatal Depression Scale	
GAD-7: Generalized Anxiety Disorder-7	
MDQ: Mood Disorder Questionnaire	
MSI-BPD: McLean Screening Instrument for Borderlin	ne Personality Disorder
PCL-5: PTSD Checklist for DSM-5	
PHQ-9: Patient Health Questionnaire-9	
PHQ-A: Patient Health Questionnaire for Adolescents	į.
SCOFF: SCOFF Questionnaire	
il SIAS: Social Interaction Anxiety Scale	

University of Florida Health Cancer Center



		Distress Thermome	ter Score
		< 7	<u>></u> 7
DUO 2 Casas	< 3	Negative	Positive
PHQ-2 Score	<u>></u> 3	Positive	Positive

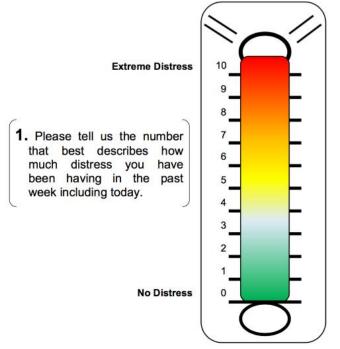
Available in Spanish

Distress is an unpleasant emotional state that may affect how you feel, think, and act. It can include feelings of unease, sadness, worry, anger, helplessness, guilt, and so forth. It is common to feel sad, fearful, and helpless.

Feeling distressed may be a minor problem or it may be more serious. You may be so distressed that you can't do the things you used to do. Serious or not, it is important that your treatment team knows how you feel.

The **Distress Thermometer** (please see below) is a tool that you can use to talk to your health care providers about your distress. It has a scale on which you circle your level of distress. It also asks about the parts of life in which you are having problems. The Distress Thermometer has been tested in many studies and found to work well.

The Distress Thermometer and the other questions below will help your treatment team know if you need supportive services. You may be referred to supportive services at UF or in your community. Supportive services can include help from support groups, chaplains, social workers, mental health counselors, psychologists, or psychiatrists.



2. Please tell us if any of the following areas have been a problem for you in the past week, including today.

Spiritual/Religious

Physical

Physical

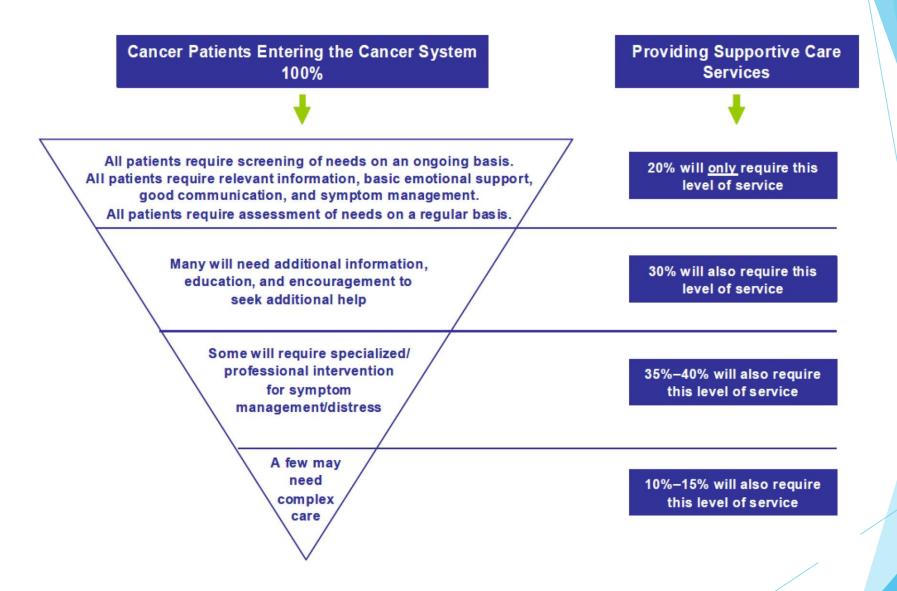
Practical

3. Over the last 2 weeks, how often have you been bothered by any of the following problems?

Family

	Not at all	Several days	More than half the days	Nearly every day
Little interest or pleasure in doing things	0	1	2	3
Feeling down, depressed, or hopeless	0	1	2	3

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Distress Across the Survivorship Spectrum

During work-up for cancer

Upon diagnosis

During active treatment

Upon end of treatment

Upon disease recurrence or progression

Upon experiencing acute treatment side effects and/or long-term treatment effects

During inpatient hospitalization for cancer evaluation, treatment, and/or symptom management

Upon discussion of goals of care and advance directive as end-of-life approaches

At end-of-life and/or during active dying

Mental Health Emergencies in Oncology Settings

- Imminent risk for suicide and/or homicide
 - Baker Act
 - Involuntary psychiatric examination
- Substance use disorder posing imminent danger to self or others
 - Marchman Act
 - Involuntary psychiatric examination
- Delirium
- ► (In some cases) Self-directed discharge from acute care settings

After Distress Screening: Interventions

- Psychosocial education on mental health, coping with cancer, manage acute crisis
 - Validate, normalize, commonalities, problem-solve, plan and strategize
- Individual and/or family therapy
 - Forum to process, communicate, decrease depression/anxiety, feelings of loneliness and grief
 - Evidence based therapy
- Group mutual aid or psychoeducational group forums
 - Connection and support; learning from others' wisdom and tips, instills hope
- Referrals to psychosocial resources: financial, housing, transportation, community services, support groups, psychiatrists, higher level of care/inpatient treatments, nutrition services
 - Supports patients to achieve optimal functioning and independence, maintain/improve well-being
- Referrals and coordination with nurse navigation for DME, home health, palliative and hospice services
 - Ensures access to needed and requested resources; supports quality of life and resilience
- Advance Care Planning and End of Life conversations
 - Facilitates acceptance, awareness, and sense of control; informs care team
- Assessment of suicide and self-harm; safety coordination, Baker Act
 - Protects and supports vulnerable and distressed, coordinates needed care

Beyond the Screen

- > Why is it important to look beyond the screen?
 - > Cancer and suicide are leading causes of death
 - > Greatest risk are among:
 - > Pancreatic
 - > Lung
 - > Colon cancer has increased significantly

Potential Risks when psychosocial issues are left untreated:

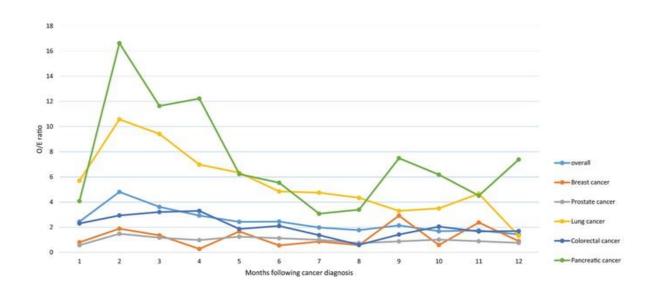
- ➤ Non-compliance with the medical regimen
- > Social and emotional isolation
- Caregiver burden/interference of family roles
- > Development of psychiatric d/o
- Disruption of relationships

Helping the patient cope

- First line of defense in coping, is having a doctor and care team that you feel safe with
- > Remember that you are treating the patient, not just their disease.
- > Caregivers are a strong source of support- so remember to include them in the care plan

Suicidal death within a year of a cancer diagnosis

Suicidal death within a year of a cancer diagnosis: A population-based study



Cancer, Volume: 125, Issue: 6, Pages: 972-979, First published: 07 January 2019, DOI: (10.1002/cncr.31876)

Psychological Issues Related to Cancer

- Anxiety, Panic, stress
- Depression
- Loss and Grief
- Fear of Dying
- Wish to Hasten Death
- Loss of Personal Control/Independence
- Hopelessness/Worthlessness

- Guilt/Anger
- Spiritual Distress
- Intimacy Concerns
- Denial
- Self-Esteem Concerns
- Loss of Dignity
- Irritability and Impatience
- Body Image
- Sexual Problems

Assessing and addressing diverse psychosocial needs



Distress screening is meant to function as an initial step in the more targeted evaluation of the source(s) of the patient's distress.



Distress screening is inherently a clinical function. Assessing for psychosocial problems, such as anxiety, depression, post-traumatic stress, fatigue, and cognitive complaints. The goal of distress screening is to identify and address otherwise unmet biopsychosocial needs.



Screening alone (i.e., without a coherent referral and/or intervention program) is not helpful.



Assessment tools matter



Timing matters (e.g., screening on first visit results in false-positive findings).

Case Scenario

Patient is a 45-year-old female recently diagnosed with thyroid cancer. She will need radiation treatment for several weeks. She is a single mother with two children. She lives 20 miles from the cancer center and doesn't have reliable transportation. She can no longer afford to pay for Marketplace insurance. She has a diagnosis of depression due to past trauma. She only speaks Spanish.

Barriers

WORKLOADS

LACK OF TIME

UNDERSTAFFING

SPACE LIMITATIONS



Questions

Other Supportive Resources

Fertility Preservation

- •Insurance can cover basic fertility (initial consultations and diagnostic exams)
- •In FL, preservation treatment is not usually covered
- •Cost for females is much higher than for males
- •Male Cancer Patients- organization can assist with fertility treatment for the partner if the cancer patient is male

Livestrong.org

- •Helps with the cost of medication for egg/embryo freezing
- •Post cancer: can assist with fresh IVF and Frozen IVF transfers

Stupid Cancer

•Largest non-profit organization that addresses young adult cancer through advocacy, research, support, outreach, and mobile health

Cactus Cancer Society

•cactuscancer.org, provides a safe space where young adults (ages 18-45) facing cancer can connect, cope, and thrive with one another in an online community through creativity and expression.

Cancer Support Community

•cancersupportcommunity.org, Gilda's Club; support and community, experts, resources, education

Mental Health Support:

Psychology Today - psychologytoday.com - directory lists clinical professionals, psychiatrists, and treatment centers providing mental health services.

Brave Health - bebravehealth.com

Che Behavioral Health Services - www.cheservices.com

<u>Yoga</u>

•Free oncology yoga class on Zoom- www.christinaphippsfoundation.com/post/free-oncology-yoga-class-on-zoom

Resources to support patients and family

- Picklesgroup.org- free peer-to-peer support and resources to kids affected by their parent or guardian's cancer
- Cancer.org The American Cancer Society offers programs and services to help you during and after cancer treatment, Lodging During Treatment, patient and caregiver support program, Rides to Treatment, Connecting Cancer Survivors, Hair Loss and Mastectomy Products.
- Triage Cancer- triagecancer.org, provides free one-on-one help in the areas of health insurance, disability insurance, employment, finances, medical decision-making, estate planning, and more
- Westandtogetherinc.org- We Stand Together, 954-667-9336, financial assistance and Scholarship Fund is awarded to Florida High School Seniors and College Undergraduates who has a parent who is battling cancer or has passed away due to cancer diagnosis.
- Cancercare.org- CancerCare, 800-813-4673- counseling support groups, financial and co-pay assistance with co-payments for their prescribed treatments
- Florida Cancer Specialists Foundations (fcsf.org)- 941-677-7181, non-medical financial help with day to day living expenses
- HealthWell Foundation- healthwellfoundation.org, assistance with prescription drugs, counseling services, Cognitive Behavioral Therapy, and transportation needed to manage cancer related behavioral health issues.
- LLS.org- The Leukemia and Lymphoma Society (LLS)-Speak one-on-one with an Information Specialist who can assist with information on cancer treatment, financial and social challenges and give accurate, up-to-date disease, treatment and support information.
- Patient Advocate Foundation- patientadvocate.org, provides case management services and financial aid to Americans with chronic, life threatening and debilitating illnesses.

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- Sophia K. Smith; Matthew Loscalzo; Carole Mayer; Donald L. Rosenstein; American Society of Clinical Oncology Educational Book 38813-821.