

Oncology Lunch & Learn— January 23, 2024



**COMMUNICATING & CONNECTING WITH ADOLESCENTS AND  
YOUNG ADULTS THROUGH THE ONCOLOGIC ILLNESS TRAJECTORY**

**Sima Z. Bedoya, PsyD & Mallorie L. Gordon, PhD**

# OBJECTIVES

**IDENTIFY** DEVELOPMENTAL CONSIDERATIONS AMONG  
AYA ACROSS THE TRAJECTORY OF CANCER CARE

**EMPLOY** EFFECTIVE STRATEGIES IN COMMUNICATING  
AND ESTABLISHING RAPPORT WITH AYAS

**DELINEATE** AYA-PREFERRED RESOURCES ACROSS  
THE TRAJECTORY OF CANCER CARE

# OUTLINE

## AYA DEVELOPMENT

### ENGAGING AYAs + BUILDING RAPPORT

Approach

Communication

Facilitators

## ILLNESS TRAJECTORY

### TIMEPOINT-SPECIFIC COMMUNICATION

Protocol Initiation

Transition to Adult Care

Transition to Outpatient Care


End of Life (EoL)

## RESOURCES FOR AYAs

Format

Development

Preferences

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# ADOLESCENT + YOUNG ADULT DEVELOPMENT



# UNIQUE CHARACTERISTICS OF AYAs WITH CANCER

DEVELOPMENTAL DIFFERENCES

NEEDS + CHALLENGES

RISKY BEHAVIORS + IMPULSIVE DECISIONS

OUTCOME DISPARITIES



# DEVELOPMENTAL DIFFERENCES

IDENTITY FORMATION

SEEKING INDEPENDENCE

EFFORTS TO ESTABLISH AUTONOMY

IMPORTANCE OF PEER RELATIONSHIPS



# **DISTINCT NEEDS & CHALLENGES**

DOCTOR-PATIENT COMMUNICATION

TREATMENT DETAILS

PEER SUPPORT

ROLE IN DECISION MAKING

INFORMATION ABOUT AVAILABLE RESOURCES

SOCIAL OPPORTUNITIES



# **RISKY BEHAVIORS & IMPULSIVE DECISION MAKING**

HIGHER INCIDENCE OF POTENTIALLY  
HARMFUL BEHAVIOR

PEER INFLUENCE

DEVELOPMENT OF PREFRONTAL CORTEX  
+ EXECUTIVE FUNCTION

ROLE OF FEAR OF RECURRENCE AND/OR  
PERCEIVED RISK





# OUTCOME DISPARITIES

SIMILAR SURVIVAL RATES (+ NOTABLE EXCEPTIONS)

HIGHER RISK OF SECONDARY HEALTH PROBLEMS

SIGNIFICANT FINANCIAL BURDEN

WORSE OVERALL PSYCHOSOCIAL FUNCTIONING

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# ENGAGING AYAs + BUILDING RAPPORT



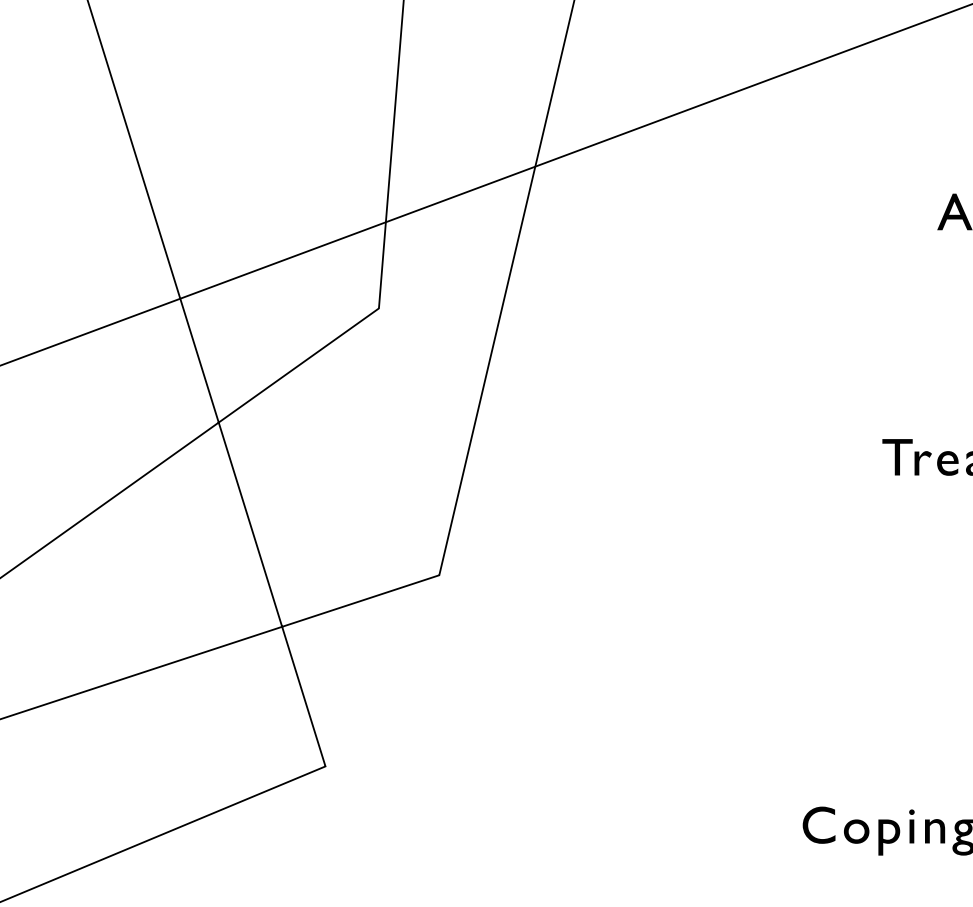
# THERAPEUTIC ALLIANCE

PARTNERING WITH PATIENT + CAREGIVERS TO BUILD RAPPORT

ACKNOWLEDGING PATIENT + CAREGIVERS EXPERTISE

SUBJECTIVITY OF PROVIDER'S PERCEPTIONS

COLLABORATIVE GOAL-SETTING



Adjustment to Diagnosis

Depressive Symptoms

Procedural Distress

Poor Self-Concept

Treatment Non-Adherence

Neurocognitive Deficits

Anticipatory Anxiety

Social Functioning Issues

Pain, Nausea, Fatigue

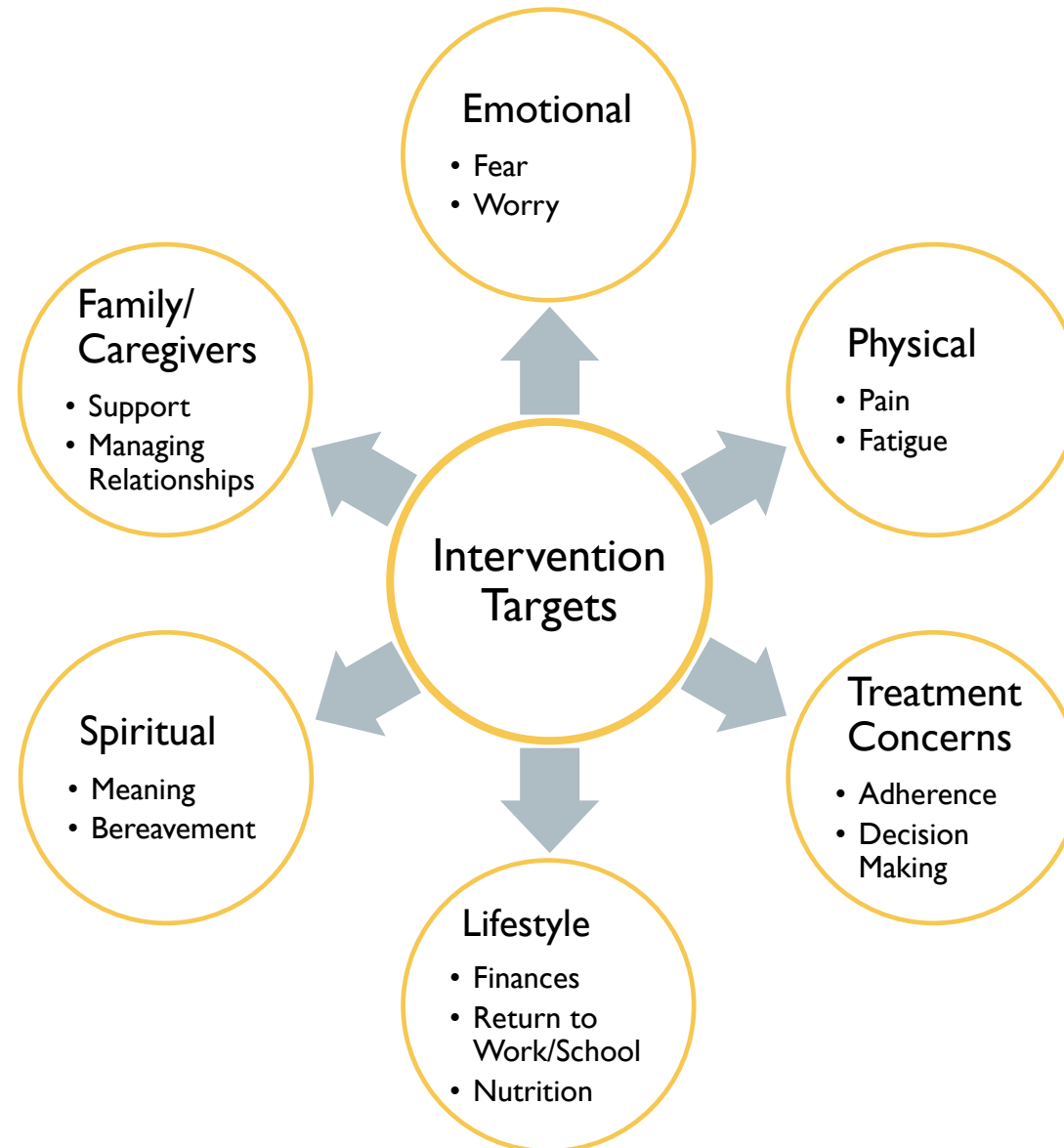
Fertility Concerns

Coping with Illness/Treatment

Mood Diagnoses

## **COMMON PSYCHOSOCIAL CONCERNS**

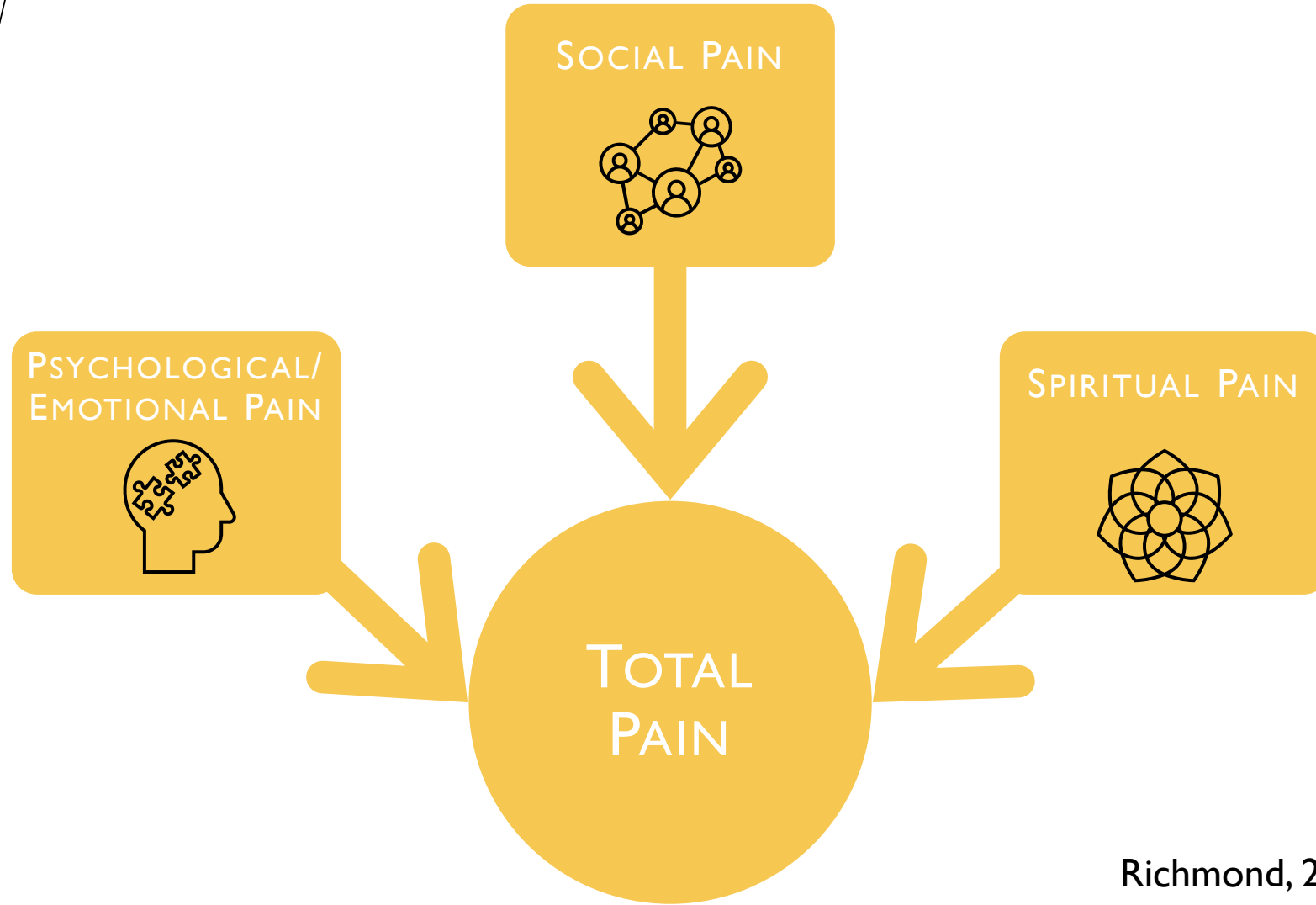
# CLINICAL CONSIDERATIONS IN AYA CANCER



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# ILLNESS TRAJECTORY

# TOTAL PAIN IN THE AYA PATIENT





# EFFECTS OF GRIEF ON SERIOUSLY ILL YOUTH

RELATED TO AWARENESS OF DISEASE STATUS

INFLUENCED BY STAGES OF KNOWLEDGE  
ACQUISITION + UNDERSTANDING

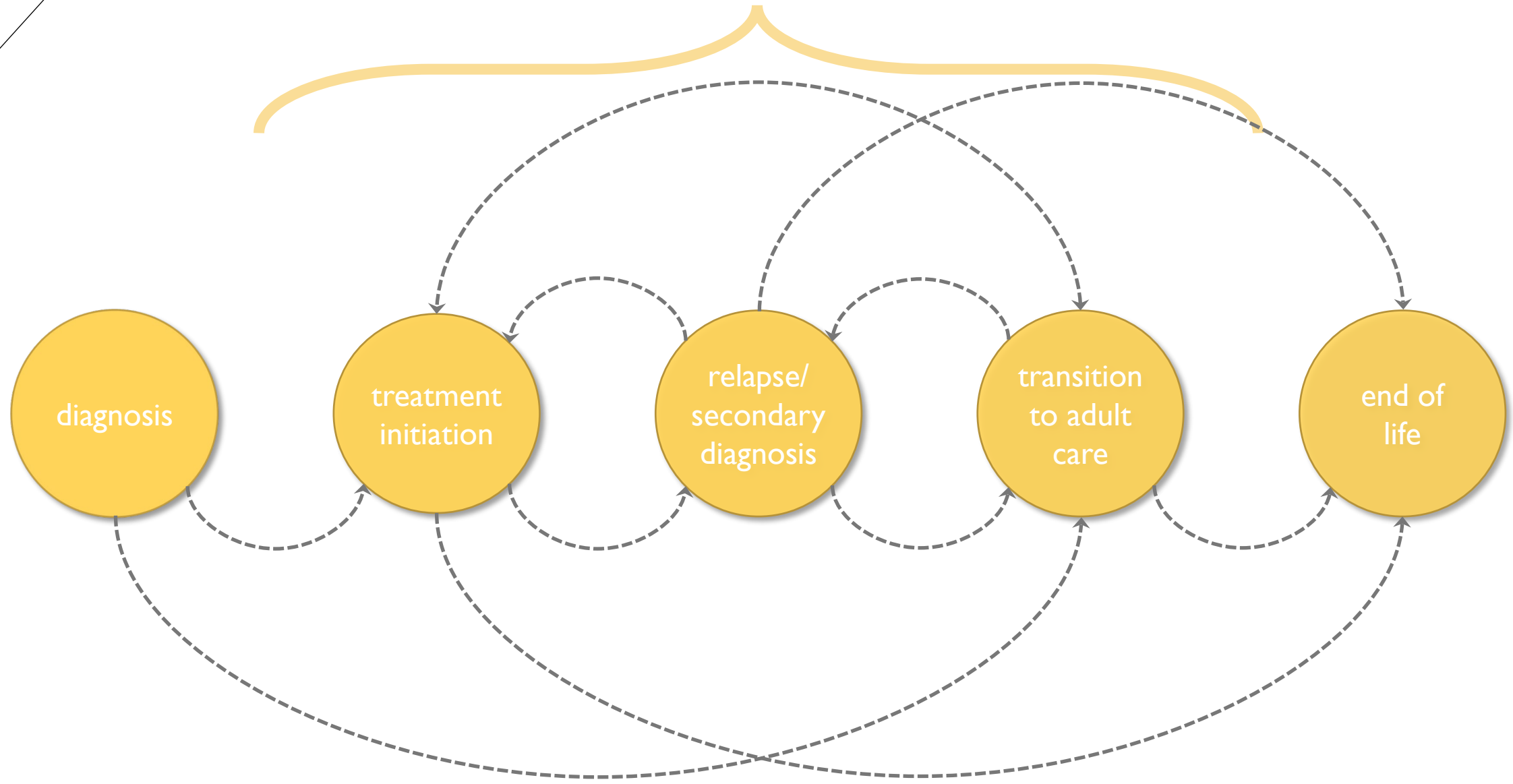
CAPACITY FOR REFLECTIONS REGARDING  
THEIR ILLNESS

MAY ELICIT A WIDE RANGE OF FEELINGS,  
INCLUDING **ANGER**, **SADNESS**, AND **FEAR**



# ILLNESS TRAJECTORY

survivorship



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# TIMEPOINT-SPECIFIC COMMUNICATION CONSIDERATIONS + STRATEGIES

# TIMEPOINT-SPECIFIC CONSIDERATIONS

INITIATION

Health Literacy  
Informational Needs  
“Orientation”

OUTPATIENT

Loss of Certain Structure + Regulation  
Social Supports + Caretaker(s)

ADULT CARE

Waning Supervision + Guidance  
Waxing Responsibility + Control

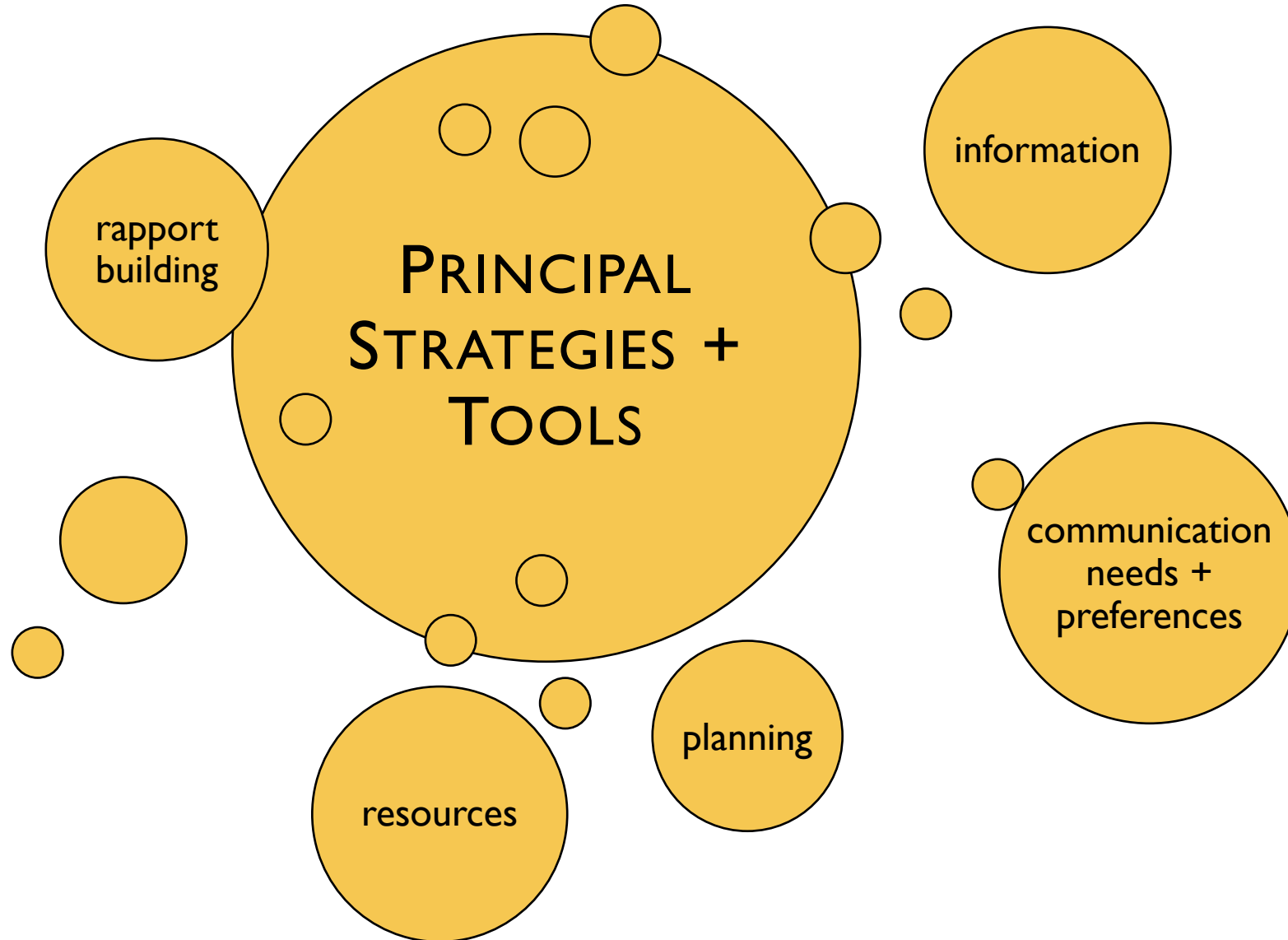
RELAPSE or  
2° DIAGNOSIS

Treatment Options  
Risk Appreciation

END OF LIFE

Premature + Unfamiliar  
Planning  
Fear + Uncertainty

# COMMUNICATION STRATEGIES



# COMMUNICATION STRATEGIES

PRINCIPAL STRATEGIES + TOOLS

anticipatory guidance

OUTPATIENT TREATMENT

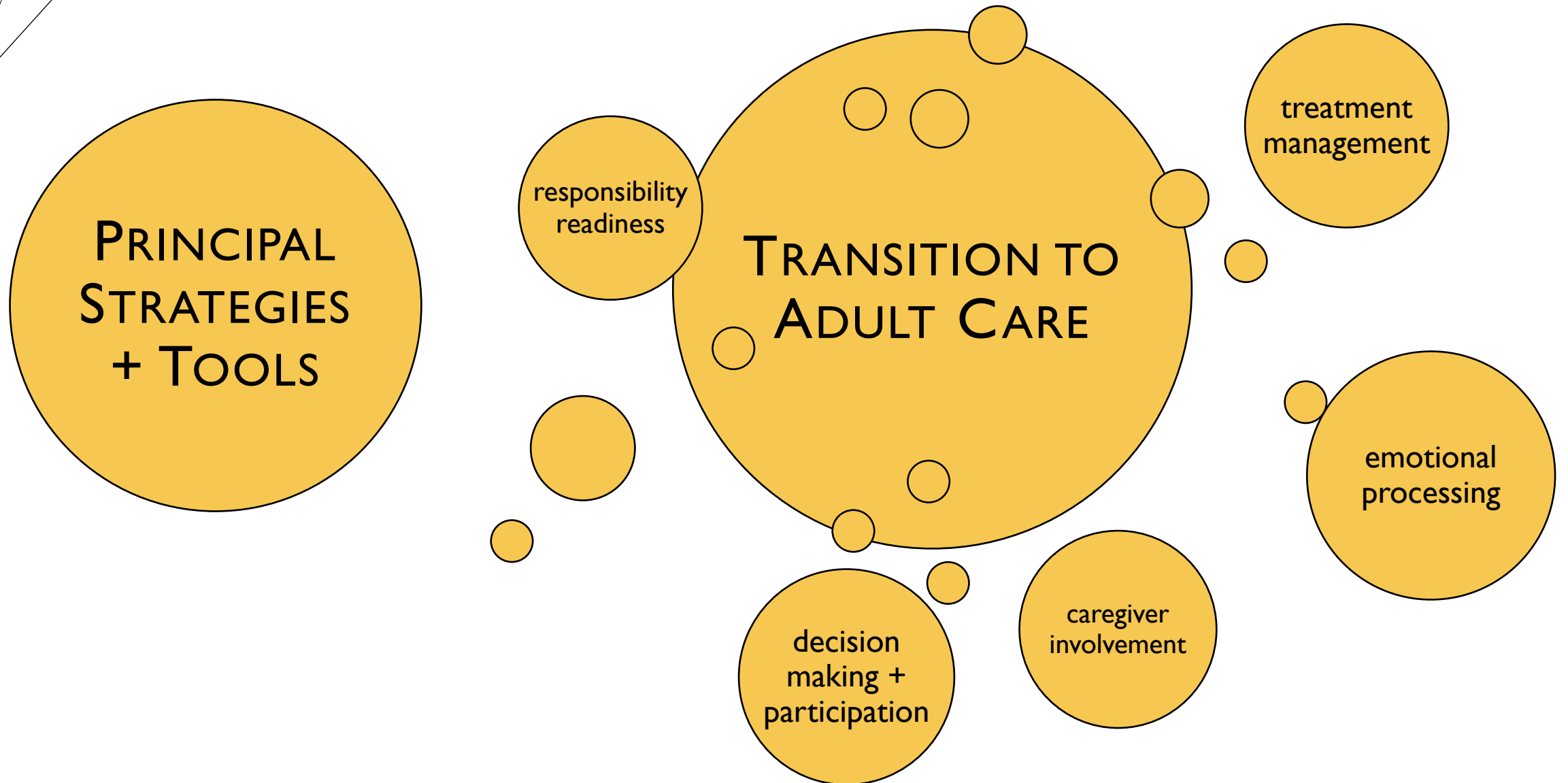
self-efficacy

symptom evaluation + messaging

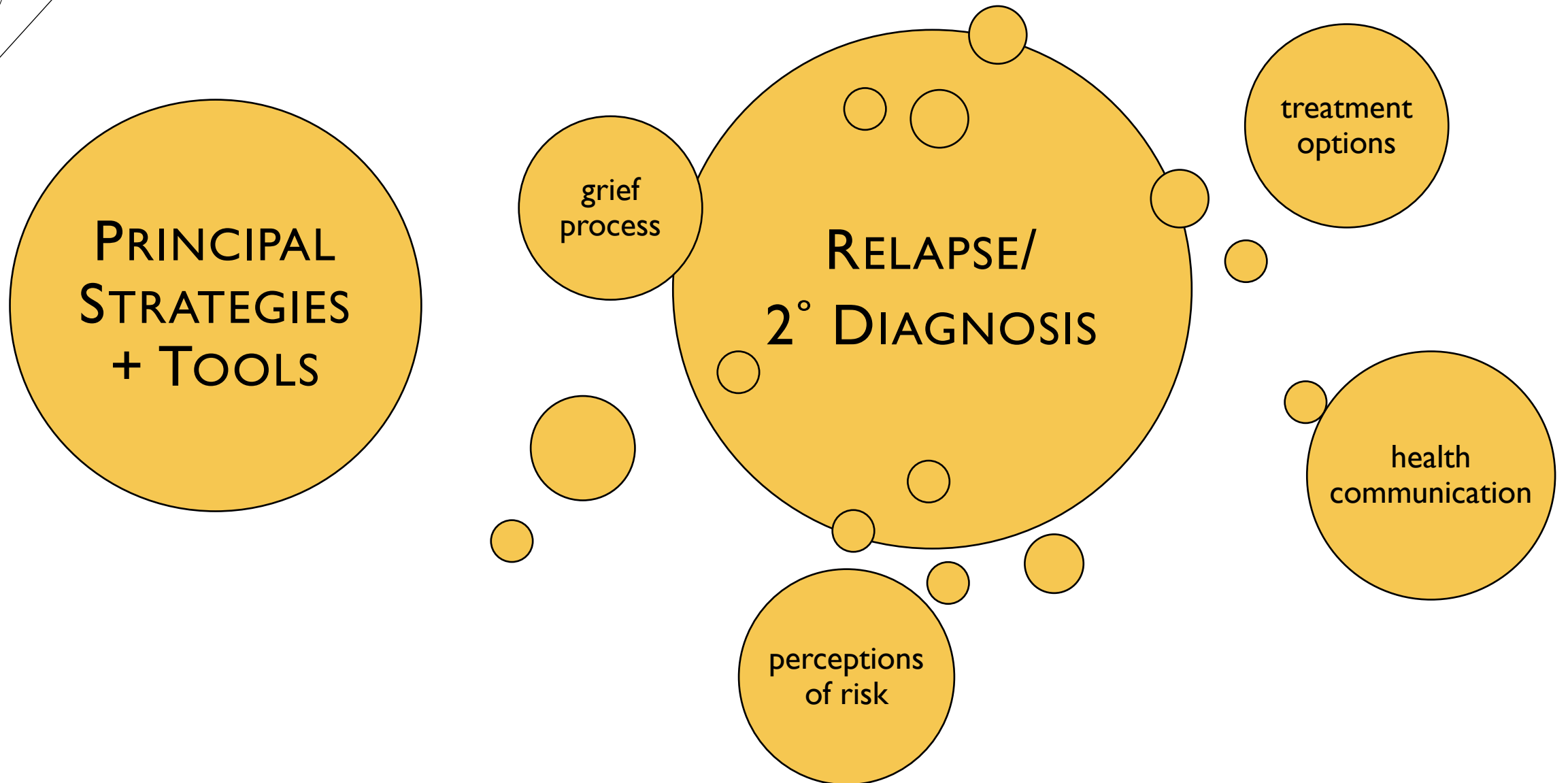
symptom management

navigating care

# COMMUNICATION STRATEGIES



# COMMUNICATION STRATEGIES



# TIMEPOINT-SPECIFIC CONSIDERATIONS

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# END OF LIFE COMMUNICATION STRATEGIES & CONSIDERATIONS



# WHEN TO HAVE DISCUSSIONS

START EARLY (EVEN IF HYPOTHETICAL)

INCLUDE PALLIATIVE CARE TEAM

AVOID CRISIS

REPEAT DISCUSSIONS



# WHO SHOULD BE INVOLVED?

COMFORT + FAMILIARITY WITH END OF LIFE  
CONVERSATIONS

STRONG RAPPORT

ASK!



# HOW TO APPROACH EoL DISCUSSIONS

PRIOR AD DISCUSSION

ASSESS AYA WILLINGNESS + COMFORT

ACKNOWLEDGE CONCERNS

OUTLINE THE WAYS THAT SUCH  
CONVERSATIONS MIGHT BE HELPFUL

EXPLORE HYPOTHETICAL SITUATIONS



# WHAT TO TALK ABOUT

TAILOR CONTENT TO THE INDIVIDUAL PATIENT  
+ THE TIME POINT

KEEP AYAS INFORMED

ASSESS UNDERSTANDING

DISCUSS PRIORITIES

THOUGHTS ON FAMILY, FRIENDS, + LOVED ONES



# CONSIDERATIONS FOR AYA AT EoL

## DEVELOPMENTAL DISADVANTAGE:

SOCIAL, EMOTIONAL, AND COMMUNICATIVE SKILLS

PERSONAL EXPERIENCES WITH DEATH/EoL

FAMILY BACKGROUND + CULTURE

BODY AWARENESS

CONTROL AND INDEPENDENCE

AYA OPINIONS



# WHY CONVERSATIONS ARE IMPORTANT

UNCERTAINTY CAUSES DISTRESS

AVOIDANCE CONVEYS TABOO

POORER OUTCOMES FOR PATIENTS + FAMILIES



# COMMON BARRIERS

PRESERVE HOPE

FOCUS ON CURE/TREATMENT

RESPECT WISHES



# THREE CASE SCENARIOS

CONSIDER:

- ISSUES SPECIFIC TO ILLNESS + TREATMENT
- DEVELOPMENTAL FACTORS
- WHAT TO EXPECT + WHERE TO DIG DEEP



**TREY**  
**CASE EXAMPLE**

15 years of age

Diagnosed with Multiple Endocrine Neoplasia (MEN2B) and Medullary Thyroid Carcinoma (MTC)

Followed by specialized peds and oncology teams throughout childhood + adolescence

Worsening chronic pain and GI concerns over the past year

History of mild cognitive + academic deficits



**HOPE  
CASE EXAMPLE**

21 years of age

Diagnosed with ASPS in 2011

Primarily treated at the NIH, but from Trinidad

Uses social media to document and cope

Disease progression + no longer responsive to treatment



**RILEY  
CASE EXAMPLE**

29 years of age

Diagnosed with Leukemia

Receiving treatment for 4<sup>th</sup> relapse

Has never had an ACP discussion

Recent ICU admission

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# RESOURCE PREFERENCES

# AYA RESOURCE NEEDS

DESIGNATED SUPPORT + SERVICES FOR AYAs ARE OFTEN LIMITED OR UNAVAILABLE

ASSOCIATED WITH REDUCED QUALITY OF LIFE + POOR HEALTH OUTCOMES  
(E.G., NON-ADHERENCE TO MEDICATION, PREVENTABLE MORBIDITY)

SPECIFIC, TAILORED INFORMATIVE + SOCIAL SERVICES:

INFORMATION + GUIDANCE FROM PROVIDERS ON MAJOR LIFE CONCERNS  
(E.G., BRAIN FOG, FERTILITY, FINANCES)

SOCIAL SUPPORT

DEVELOPMENTALLY APPROPRIATE INFORMATION + ACTIVITIES THAT  
ENHANCE SOCIAL CONNECTIONS



# **NIH AYA NEEDS ASSESSMENT**

## **PAST ASSESSMENT:**

**NEED FOR GENERAL HEALTH + MEDICAL  
INFORMATION**

**DESIRE FOR INFORMATION ABOUT PRIMARY  
HEALTH CONDITION**

**DATA SUGGESTS THIS CONSISTENCY ACROSS  
MEDICAL + DEMOGRAPHIC FACTORS**

**POST-COVID ASSESSMENT UPDATE  
FORTHCOMING**



# KEY AYA RESOURCES

TEEN CANCER AMERICA

STUPID CANCER

CANCER + CAREERS

TAKE CHARGE

CANCER FINANCES

[ABP ROADMAP PROJECT]





# **EoL RESOURCES**

CAKE

THE CONVERSATION PROJECT

MY EoL DECISIONS:  
AN ADVANCE PLANNING GUIDE + TOOLKIT

RESPECTING CHOICES

PREPARE FOR YOUR CARE

VOICING MY CHOICES

# VOICING MY CHOICES

## Voicing My CHOICES

A Planning Guide for  
Adolescents & Young Adults

### Voicing My CHOICES™ Table of Contents

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Say What Makes You Feel Supported, Write What Decisions Brings You Peace

Choose What Provides You the Most Comfort, Voice Your Thoughts and Needs

SEPARATE “MODULES”

DECREASES EOL PLANNING ANXIETY

ENHANCES AYA COMMUNICATION WITH  
FAMILY + FRIENDS, BUT NOT WITH  
HEALTH CARE PROVIDERS

# The types of **Life Support Treatment** I Want, or Do Not Want



**If a time comes** when you are very ill and not able to speak for yourself, it will be important for your health care agent to know your preferences on **life-support treatment**.

Life-support treatment means any medical procedure, device or medication used to try to keep you alive. In place of life-support treatment, you may choose to allow a **natural death**, in which life-support measures that prolong the dying process are not used, and care is focused on providing comfort and support. You can opt for a natural death by completing a Do Not Resuscitate order.

A person's decisions about life support are deeply personal, and making these decisions can be emotional. Gather the facts you need to make informed decisions by talking to your health care team. In particular, understand the benefit as well as the burden the treatment may offer you. A treatment may be beneficial if it relieves suffering, restores functioning, or enhances the quality

## Examples of Life Support

**Interventions** to treat life-threatening conditions such as infections or failure of the bone marrow to make blood cells. **Machines or devices** that support injured organs and allow them to recover function:

- Placement of **catheters** to provide treatments or to monitor organ function
- Placement of **tubes** through the nose or mouth into the stomach to provide nutrition
- Placement of tubes to drain **urine** from the bladder or **stool** from the intestine
- Antibiotics to treat **infections**
- Medications to treat **pain and anxiety**
- Transfusion of **blood** or blood products
- Perform **surgery** if needed to help increase survival
- Perform **CPR** if the heart stops
- Machines or devices to support **injured lungs** (oxygen therapy, mechanical ventilators, breathing tubes)
- Machines to replace **kidney** function (dialysis)
- Medications or devices to help injured **heart** functions

## My Choice



1

**If treatments are available that may cure or improve my disease or disorder**

- I would like life support treatments provided to me to help me survive.
- I would not like life support treatments to be provided.

2

**My disease or disorder is not responding to available therapies or cannot be treated** - OR - **I have developed severe permanent brain injury and no recovery is expected** - OR - **I cannot be awakened from coma or cannot recognize or respond to any person or place**

- I would like to focus and limit my care to only those interventions that provide me comfort from physical and emotional distress. Treatments that otherwise only prolong death are unnecessary.
- I would like all treatment to be continued.

3

**If life support is unsuccessful to stabilize or improve a disorder in a reasonable period of time**

- I would like to reassess the goals of my care, or if unable, to have my healthcare agent reassess the goals of my care.
- I would like to continue life support.

\_\_\_\_\_

\_\_\_\_\_

The place I want to be when the end of my life is near is:  at home  at the hospital

Other: \_\_\_\_\_

Other decisions I would like respected:

\_\_\_\_\_

\_\_\_\_\_

I have completed a DNR (Do Not Resuscitate) Order:

- yes, it is located \_\_\_\_\_
- no



## My Choice

- I prefer not to be a part of planning my service.
- I prefer to have my family make choices about my service.
- I prefer to plan my service.
  
- The type of service (s) I would like are:
  - Funeral**
  - Memorial service**
  - Celebration of my life**
  - No service
- I would like: (Please check all that apply)
  - To be **buried**  
This is where I prefer to be buried: \_\_\_\_\_
  - To be **cremated**  
This is where I prefer to have my ashes/remains placed: \_\_\_\_\_
  - An **open casket**
  - A **closed casket**
  - To **donate my body** to scier \_\_\_\_\_
  - To be an **organ donor**, if po: \_\_\_\_\_
  - A limited **autopsy**
  - A standard **autopsy**
  - A research protocol **autopsy**
  - I would like my **healthcare agent** to make the autopsy decision
  - I would like my **healthcare agent** to make the autopsy decision

## My Voice

The clothes that I would like to be wearing (for service/cremation/burial) are:

\_\_\_\_\_

The music I want at my service:

\_\_\_\_\_

The food I want at my service:

\_\_\_\_\_

The people I would like to be present are:

\_\_\_\_\_

I would like these readings at my service:

\_\_\_\_\_

I would like these other arrangements at my service:

\_\_\_\_\_

If my family or friends want to make contributions or donations I would like them to go to:

\_\_\_\_\_

## My Belongings This is How I Would Like To Share My Belongings

Clothes: \_\_\_\_\_ Pets: \_\_\_\_\_

Games: \_\_\_\_\_ Books: \_\_\_\_\_

Art: \_\_\_\_\_ Music: \_\_\_\_\_

Photographs: \_\_\_\_\_ Phone: \_\_\_\_\_

Computer: \_\_\_\_\_ Other electronics: \_\_\_\_\_

Furniture: \_\_\_\_\_ Money/savings: \_\_\_\_\_

Car: \_\_\_\_\_ Other heirlooms or belongings: \_\_\_\_\_

The person I would feel most comfortable going through my belongings is: \_\_\_\_\_

How I would like to be remembered on my birthday:

\_\_\_\_\_  
\_\_\_\_\_

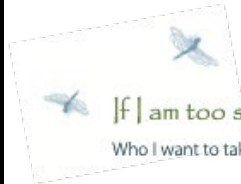
How I would like to be remembered on other important days:

\_\_\_\_\_  
\_\_\_\_\_

Things I would like people to do to keep my memory alive:

\_\_\_\_\_  
\_\_\_\_\_

As a parent, you may worry about how your illness impacts your child(ren)'s life, or how to explain your prognosis to you child(ren) in an age appropriate way. You may also experience anticipatory grief about not being able to raise your child into adulthood. It is important for others to know how you want your child(ren) to be cared for and supported, especially if you become very ill and cannot express your wishes on your own.



## What I Want for My Children

If I am too sick to care for my children:

Who I want to take care of my child(ren) when I am not able:

\_\_\_\_\_

Ways I want my child(ren) to be comforted and supported include:

\_\_\_\_\_

Preferences I have for my child(ren) visiting me:

\_\_\_\_\_

How I want my illness and prognosis to be communicated to my child(ren):

\_\_\_\_\_

If I am very ill or on life support, I want my child(ren):  To be with me  To not be with me  Other:

\_\_\_\_\_

When the end-of-my life is near, I want my children:  To be with me  To not be with me  Other:

### After my death:

Rituals or activities I would like to be continued with my children to keep my memory alive include:

\_\_\_\_\_

I want my child(ren) to remember me as:

\_\_\_\_\_

Wishes I have for my child(ren) include:

I have arranged for the care of my children after my death, my preferences include:

I have arranged for the financial care of my children after my death, my preferences include:

\_\_\_\_\_

Other arrangements I have made or would like made for my child(ren) include:

\_\_\_\_\_

Other things that are important to me are:

\_\_\_\_\_





**CONNECTING WITH AYAs CAN  
CREATE BETTER THERAPEUTIC  
(+ HEALTH-RELATED) EXPERIENCES**

Need a Consult?

Mallorie L. Gordon, Ph.D.

240-551-0772

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