

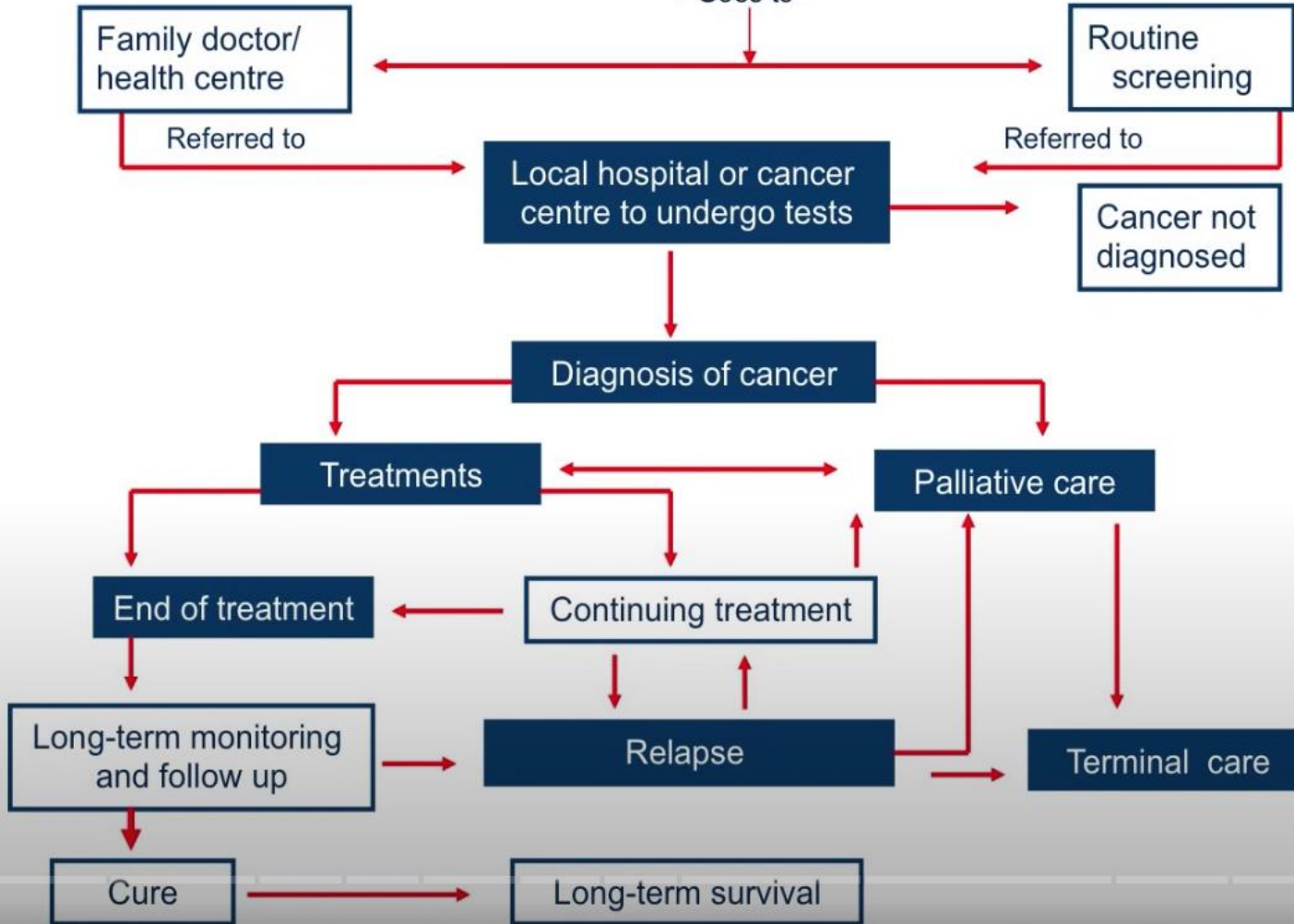
# General Psychological Issues n Palliative Care

KV GANPATHY – PhD & Clinical Psychologist

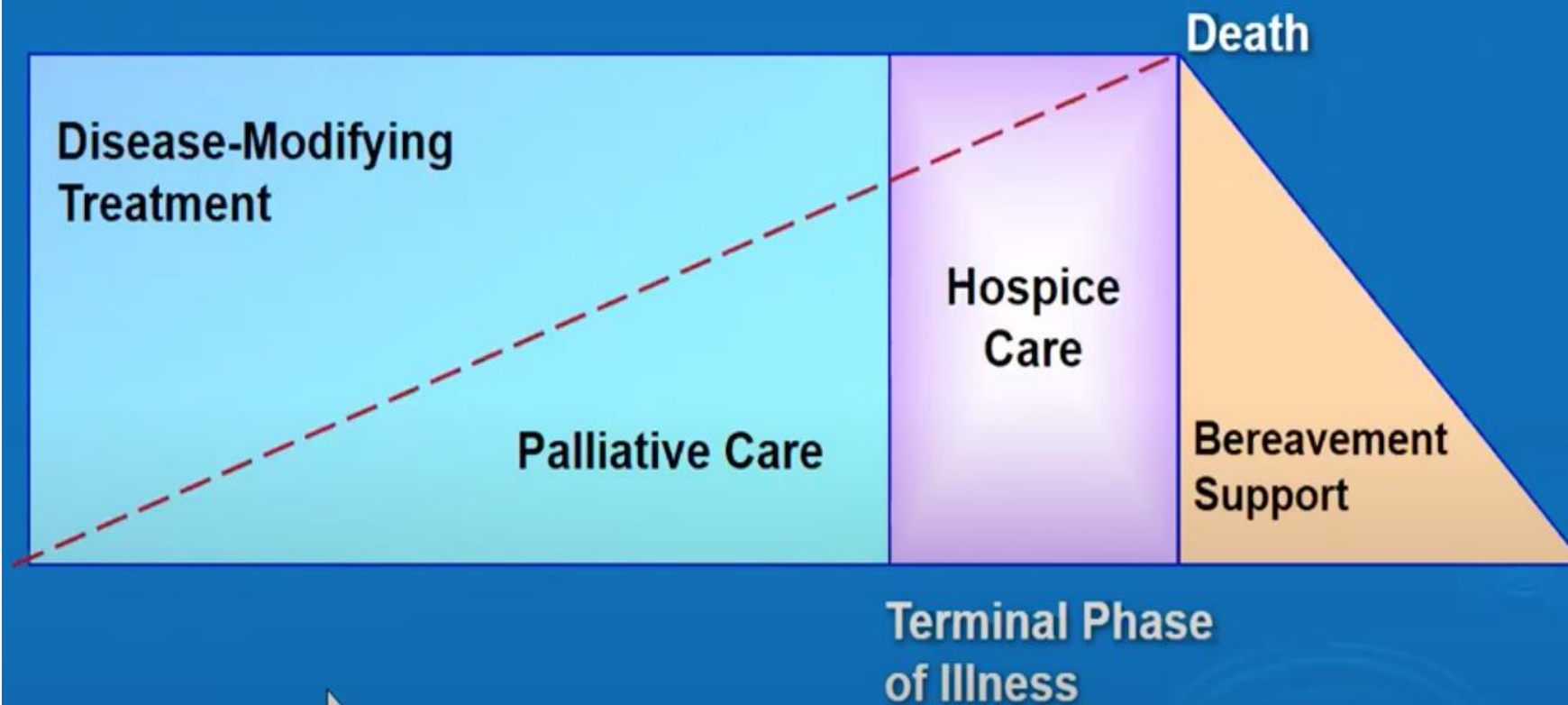
# Map of Patient Pathways



Goes to



# Continuum of care



Where is  
the

# Illness: Times of Transition

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- finding an abnormality
- seeking an opinion/diagnostic testing
- hearing a diagnosis
- starting treatment
- finishing treatment
- getting back to normal (being a survivor)
  
- experiencing a new episode/on-going illness
  
- requiring palliative care
- approaching death (end of life)...death
- grieving the loss

Diagnosis

(hearing the doctor's diagnosis)

# Diagnosis

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D numbness, disbelief, panic

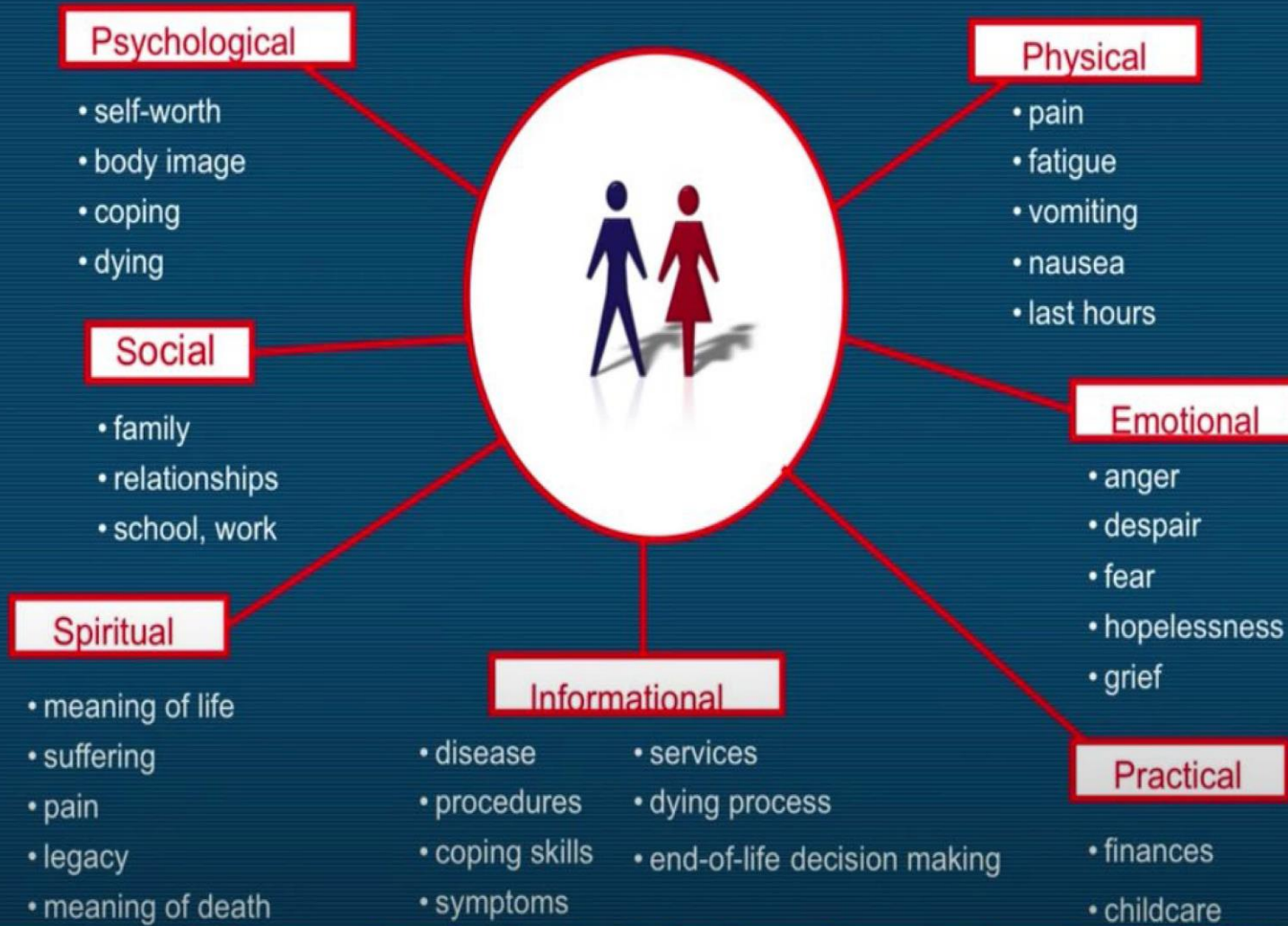
"life is irrevocably changed"

"life is irrevocably changed"

telling others

telling others

# Needs and Examples of Patients with Life-Threatening Illness



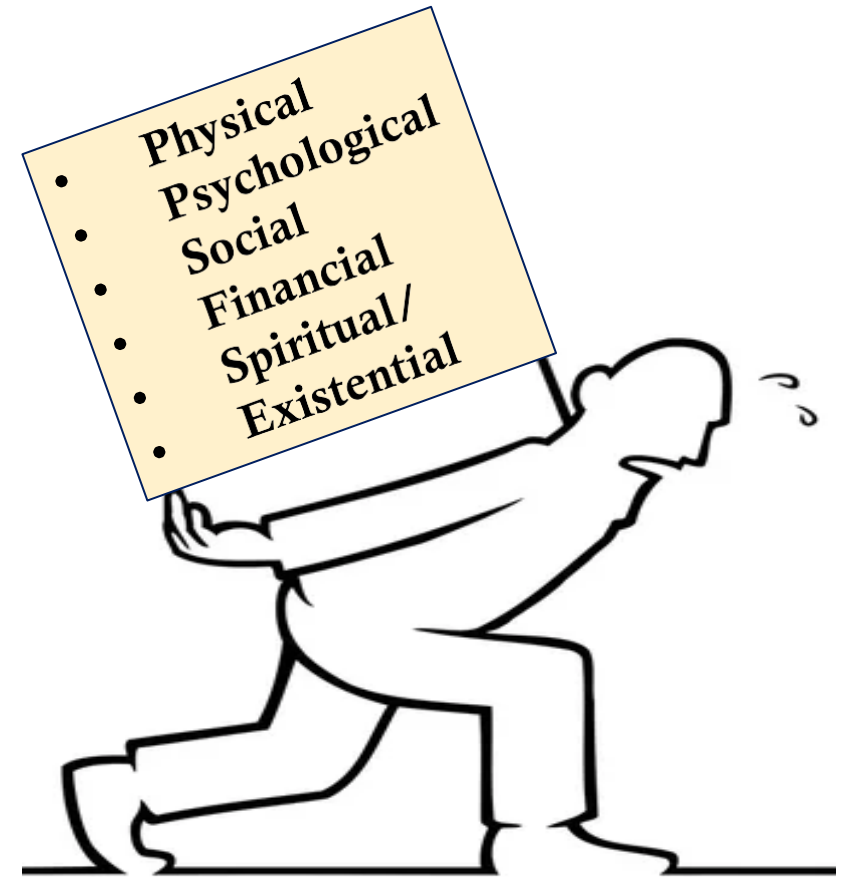
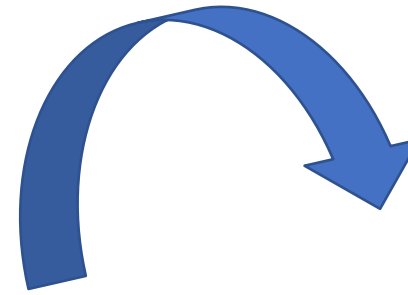
Cancer has more than a physical impact – there are social, emotional, psychological, spiritual, and practical consequences as well.

The changes may be felt at various points throughout the cancer experience.

A diagnosis of  
cancer



Suffering...



# Treatment (multiple side effects)

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- pain, fatigue, difficulty sleeping, difficulty concentrating, menopause, skin changes, anxiety, bowel changes, sexual changes, nausea, vomiting, hair loss, weight change...





# Rehabilitation (after treatment finishes)

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- reflecting on what happened and what is ahead
- dealing with long-term side effects
- re-establishing life/living priorities
- fear of recurrence

Body Image

Roles and Relationships

Feelings of Loss/Grief

Living with Uncertainty

Emotional Distress

# Sense of self

How did the Individual express

*I felt like a broken tea cup. All the pieces were lying on the floor and I know I could glue them back together, but I also knew that the cup would be fragile and never quite the same again.*

# Conceptualizing Psychosocial Distress in Serious Illness

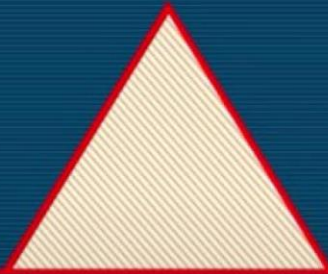
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## Normal Distress



- Fear
- Worries
- Sadness

## Severe Distress



- Depression
- Anxiety
- Family Dysfunction
- Spiritual Anguish

# Normal Worry

# Anxiety Disorder

- Intermittent

- Constant

- Difficulty in concentrating

- Unable to concentrate

- Intermittent preoccupation

- Constant Preoccupation

- Occasional difficulty sleeping

- Continued insomnia

- Crying spells provide relief

- Frequent crying spells interfering with daily activities

- Fear and apprehension connected to a upcoming event

- Free floating fear and apprehension

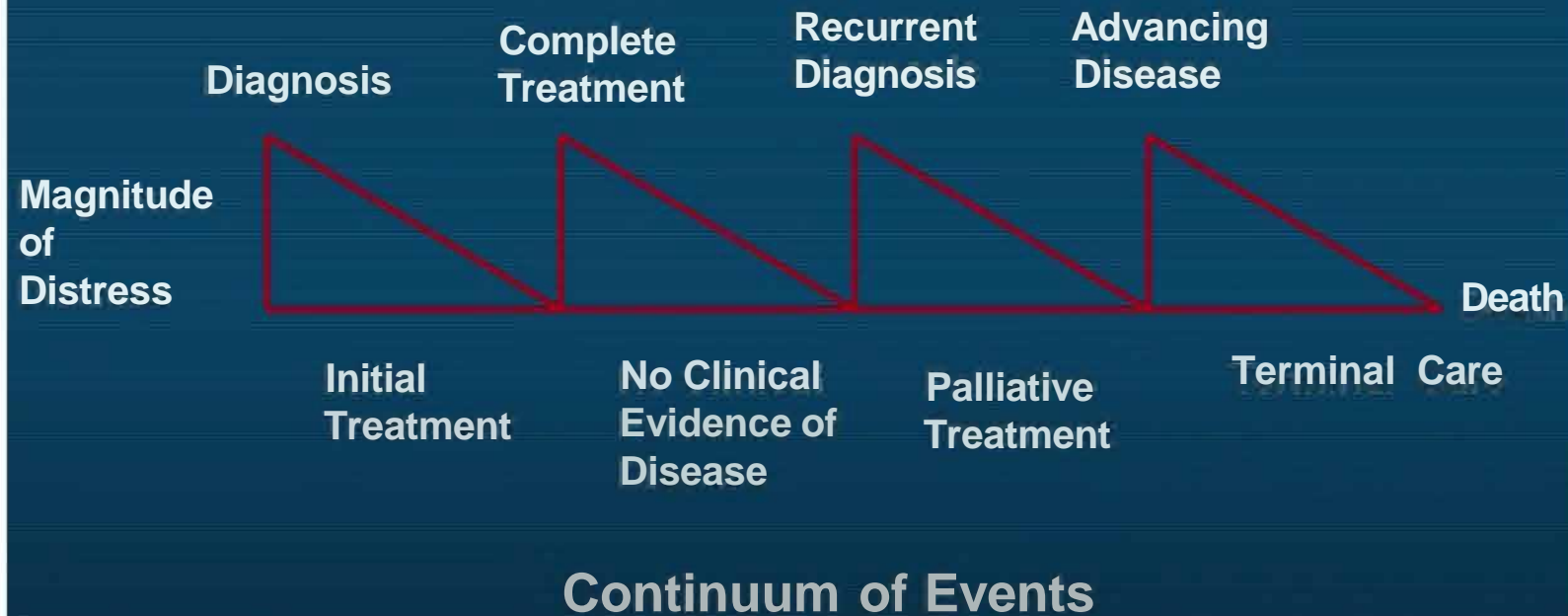
- Few physical symptoms

- Many physical symptoms

- Has ways to reduce anxiety

- Few ways to reduce anxiety

# Conceptualizing Psychosocial Distress in Cancer





Personal  
Feelings



Preferences



Fears



Attitudes



Beliefs and  
Opinion



## Psychological barriers



# Case Scenario- 1

- Mrs. Rani, a 67-year-old, music teacher who is widowed and diagnosed with early-stage breast cancer
- Well-adjusted, with no known past psychiatric history
- Knows her diagnosis and has undergone treatment and is now on hormone therapy
- Expresses sadness and fear because of multiple physical issues after her initiation with hormone therapy, is tearful and frustrated but is accepting of the disease
- Wants to know the details regarding her future health status and what her life will be like especially due to the current complications and loss in independence
- Very supportive surgical team who did her initial treatment and good support from family and friends
- Says she will take it as it comes. “Ready for anything”



# Emotional Distress – 6<sup>th</sup> vital sign

- Multi-factorial, unpleasant emotional experience
- Psychological, social, spiritual, and/or physical
- Interferes with ability to cope effectively with the disease and its treatment
- More acceptable, less stigmatizing



**5 VITAL SIGNS:  
 Temperature, respiration,  
 heart rate, blood pressure,  
 and pain**

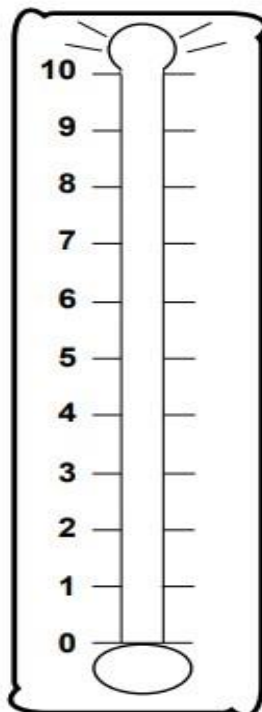


### NCCN DISTRESS THERMOMETER

Distress is an unpleasant experience of a mental, physical, social, or spiritual nature. It can affect the way you think, feel, or act. Distress may make it harder to cope with having cancer, its symptoms, or its treatment.

Instructions: Please circle the number (0–10) that best describes how much distress you have been experiencing in the past week, including today.

Extreme distress



No distress

### PROBLEM LIST

Have you had concerns about any of the items below in the past week, including today? (Mark all that apply)

#### Physical Concerns

- Pain
- Sleep
- Fatigue
- Tobacco use
- Substance use
- Memory or concentration
- Sexual health
- Changes in eating
- Loss or change of physical abilities

#### Emotional Concerns

- Worry or anxiety
- Sadness or depression
- Loss of interest or enjoyment
- Grief or loss
- Fear
- Loneliness
- Anger
- Changes in appearance
- Feelings of worthlessness or being a burden

#### Social Concerns

- Relationship with spouse or partner
- Relationship with children
- Relationship with family members
- Relationship with friends or coworkers
- Communication with health care team
- Ability to have children

#### Practical Concerns

- Taking care of myself
- Taking care of others
- Work
- School
- Housing
- Finances
- Insurance
- Transportation
- Child care
- Having enough food
- Access to medicine
- Treatment decisions

#### Spiritual or Religious Concerns

- Sense of meaning or purpose
- Changes in faith or beliefs
- Death, dying or afterlife
- Conflict between beliefs and cancer treatments
- Relationship with the sacred
- Ritual or dietary needs

#### Other Concerns:

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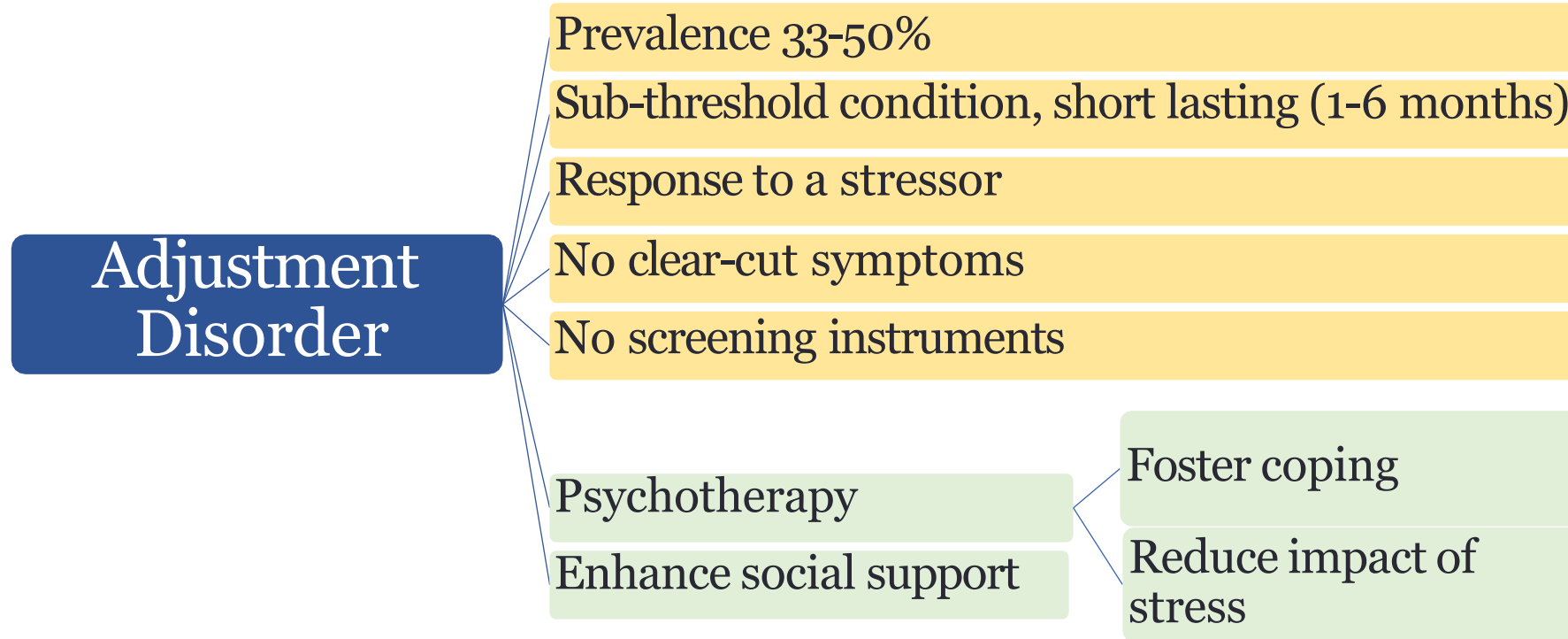
Note: All recommendations are category 2A unless otherwise indicated.  
Clinical Trials: NCCN believes that the best management of any patient with cancer is in a clinical trial. Participation in clinical trials is especially encouraged.

# Distress Continuum



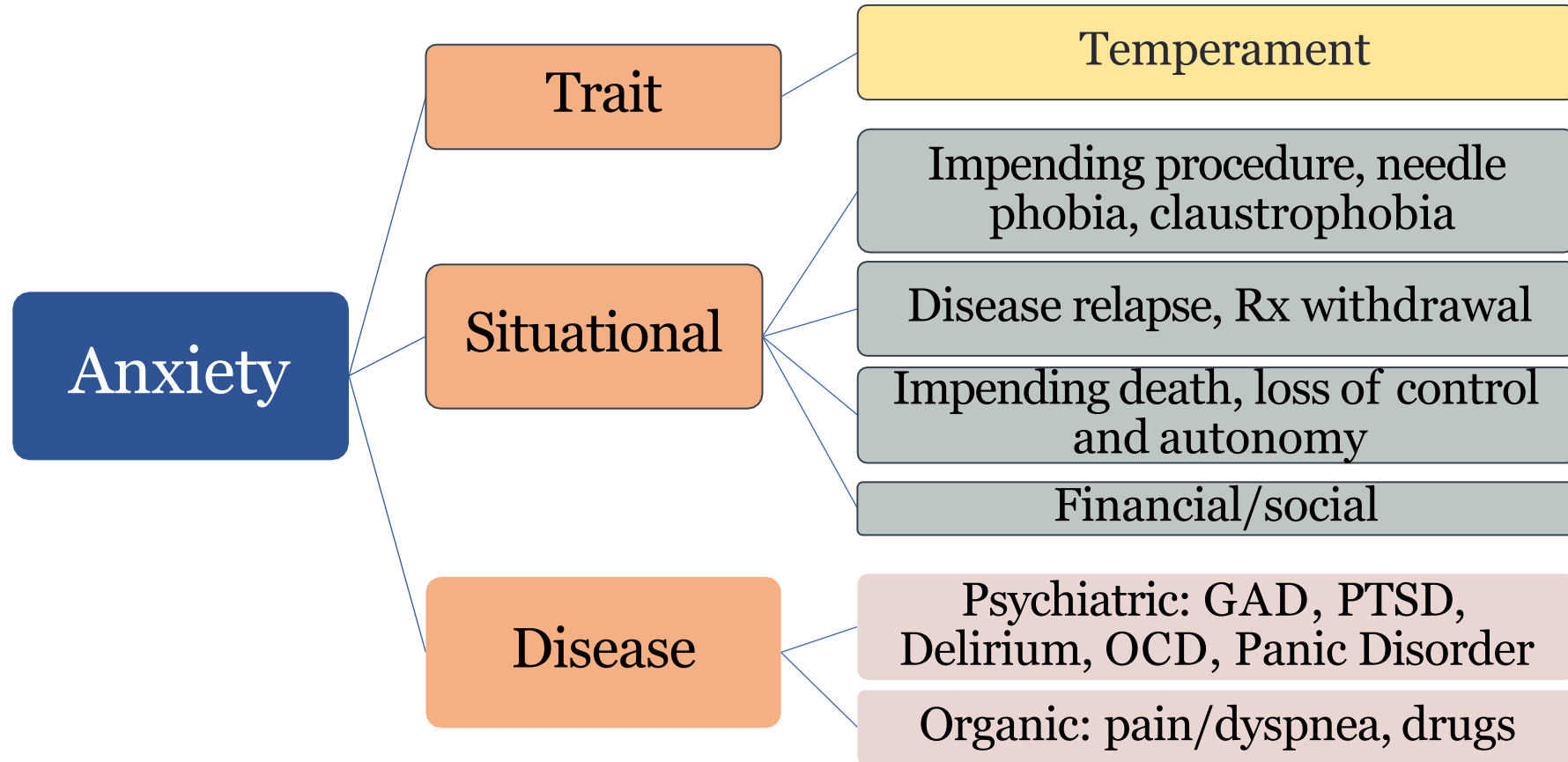
# Case Scenario- 2

- Mr. Siddharth, 23-year-old, IT professional who is unmarried and diagnosed with Non-Hodgkins Lymphoma
- He was a happy go lucky person even during the initial days of his cancer treatment with chemotherapy
- He is aware of his diagnosis and understands he has a long drawn treatment (8 months)
- Even though he started out very resilient, with every passing cycle of chemotherapy he is irritable, anger outbursts with family- especially to his mother, is isolating and has a poor routine.
- Wants to know how fast he can finish his treatment so he can get back to his normal life.
- His family is very worried and is unsure of how to handle him.
- He says “Give me back my old life”



# Case Scenario- 3

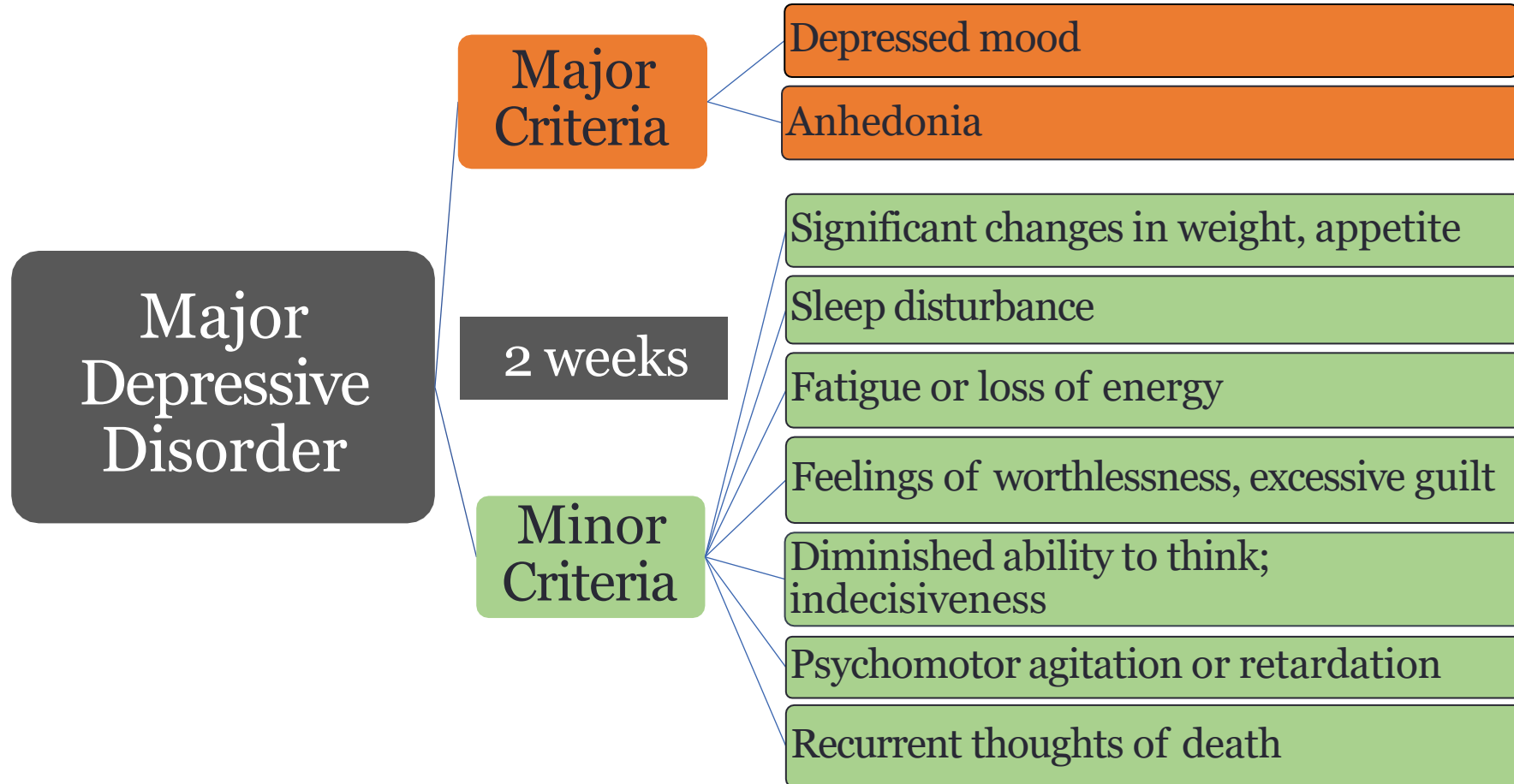
- Mrs. Nandini is a 38-year-old, married, homemaker who is a k/c/o Osteosarcoma which recently metastasized to her lungs
- She underwent an amputation of her right limb and has completed multiple lines of treatment with CTRT for her cancer
- Despite the amputation she is mobile with her prosthetic limb and was able to do most of her activities until the disease spread to her lungs
- Currently dependent on her daughter (10 years old) and husband (only breadwinner) and feels she is a burden to her family
- She doesn't like to be left alone during the day and is unable to sleep at night.
- Wakes up in the night suddenly with palpitations, sweating, and feeling suffocated
- The family reports at times she gets annoyed with them
- Before every hospital visit she becomes extremely tearful
- She says, "The disease has spread, I'm worried... what is going to happen now?"

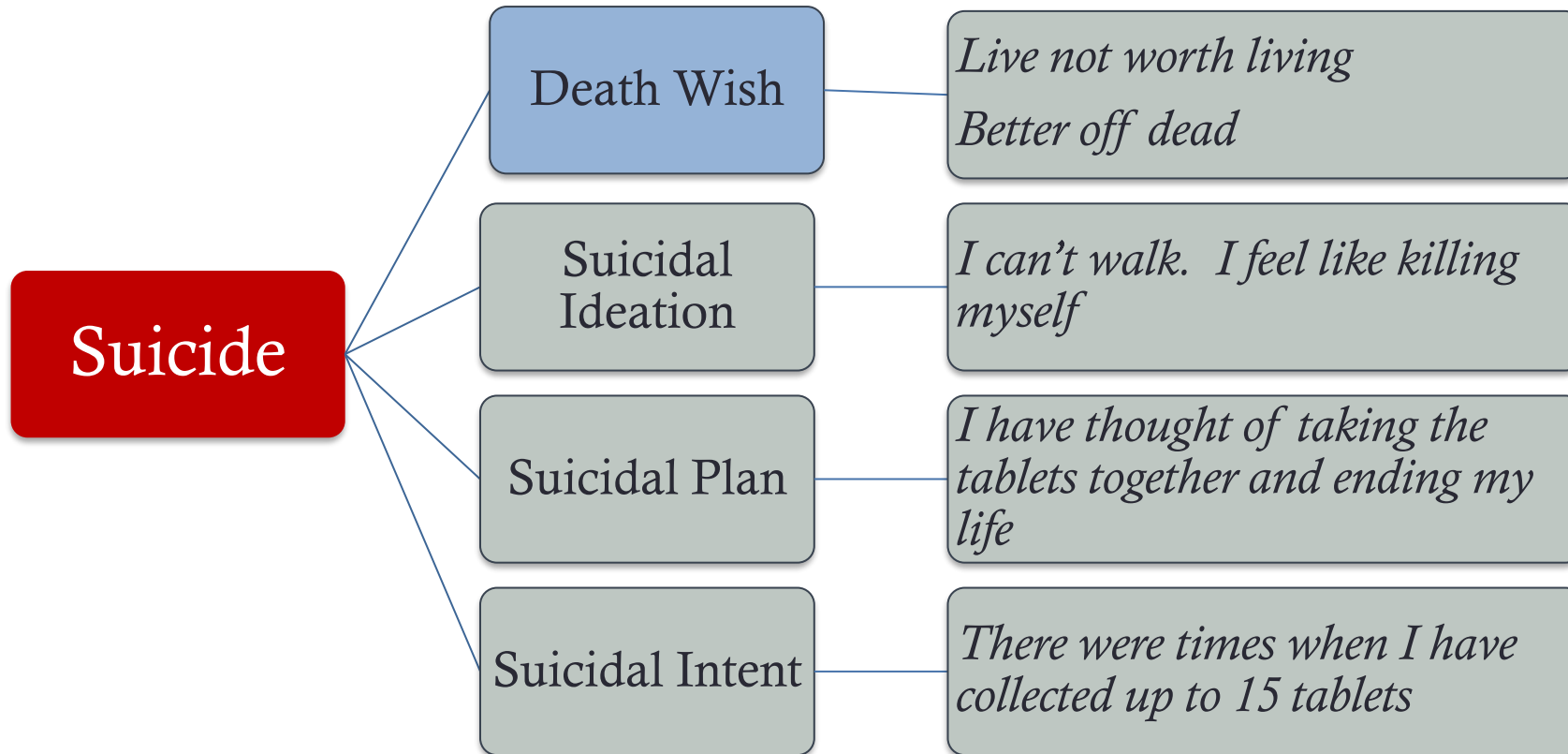


# Case scenario- 4

- Mr. Mani is a 52-year-old gentleman who was a carpenter by profession
- During the pandemic, he was diagnosed with Advanced Ca. Tongue and was suggested CT RT, which he decided against owing to financial difficulties and lack of support.
- Considered going for naturopathy treatment but abandoned it due to lack of funds.
- He separated from his wife over 15 years ago and has 2 daughters (1 married, 1 passed away) which also increased his substance use (Tobacco & Alcohol)
- Due to the increasing symptoms of pain, foul-smelling wound, inability to eat, speak, swallow, and poor sleep his nephew admitted him to the hospice
- He was always altruistic by nature although lived a lonely life due to marital issues but now is having increased low mood and has lost all meaning and purpose in his life
- He is aware of the diagnosis and that his disease is progressive but unsure of the prognosis and future
- He says, “If I can’t eat and drink then I rather not live”.







# Importance of psychosocial support?

- Impairs capacity for pleasure, meaning, connection
- Erodes quality of life
- Impacts adherence to Rx
- Amplifies pain and other symptoms
- Causes anguish and worry in family members and friends
- Risk factor for suicide and requests to hasten death

**Palliative care is incomplete without the psychosocial spiritual domain!!**

van der Maas PJ, van Delden JJM, Pijnenborg L, Looman CWN. Euthanasia and other medical decisions concerning the end of life. Lancet. 1991; 338:669-74

## Key Points...

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- Each one of us is unique.
- We will react and respond (cope) in our own way to stressful situations.
- Our emotions and behaviors are a result of how we “see” the situation (our perspective)

*"The quality of life for patients and the manner of their dying is sometimes more influenced by psychosocial factors than by physical factors" (Tanchel, 2003)*

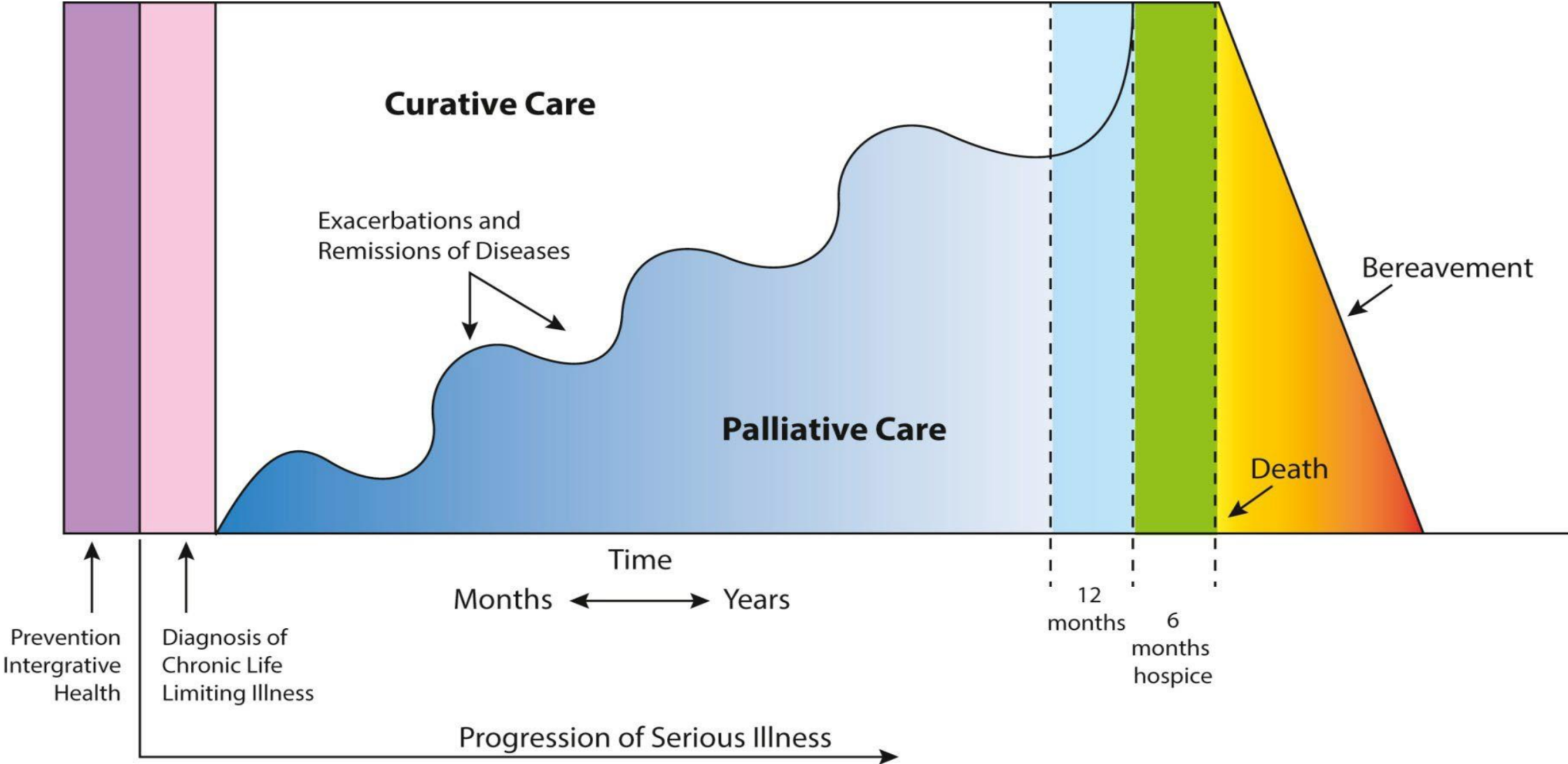


"There is no health without mental health."

David Satcher, MD

16<sup>th</sup> Surgeon General of the United States  
1998-2002

# The trajectory of palliative care...




What do you need to learn in paediatric psycho oncology – ecancer medicalscience, SS Datta et al, March 2019.

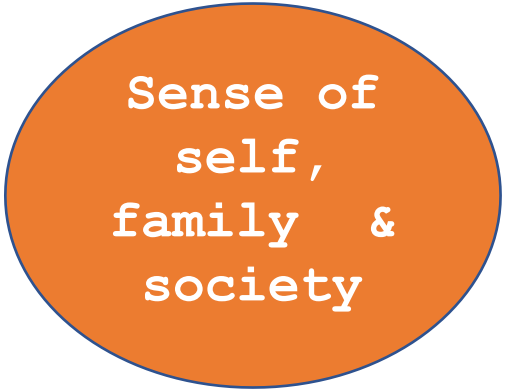
intensity -of cancer's impact depend on a variety of factors - value the patient attributes to the affected body part to assist the patient in his or her psychosocial recovery



Site of  
the  
disease



Sense of  
self &  
body  
integrity



Sense of  
self,  
family &  
society



Transformed  
Sense of  
self, &  
trauma



Communication

Children

Perception of the world

Making sense of the world

Developmental Vs. Chronological world

Adolescents

Experimenting & exploring the world , often against norms set up by adults – disagreements Between parents & adolescent – understand the reason behind disagreement,

# Importance of psychosocial support?

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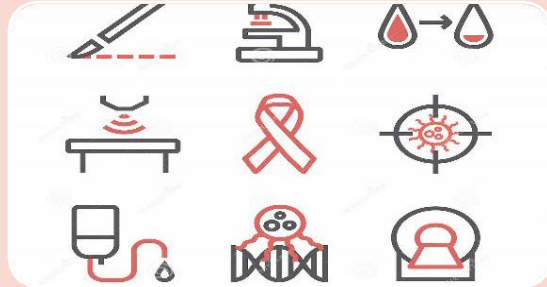
# Normal Adaptation

- Ongoing process
- Regulate emotional distress
- Gain mastery
- Remain active and involved with life
- Interplay of interpersonal and psychosocial factors



# Who requires psychological support in cancer?

(Grassi & Travado, 2008)



## Medical Factors

(Stage of disease, treatment, physical symptoms)

## Individual Factors

(Psychological & Psychiatric issues, personality traits, age)

## Interpersonal & Social Factors

(Poor social support from interpersonal ties and diffuse social support, Concurrent stressful events)

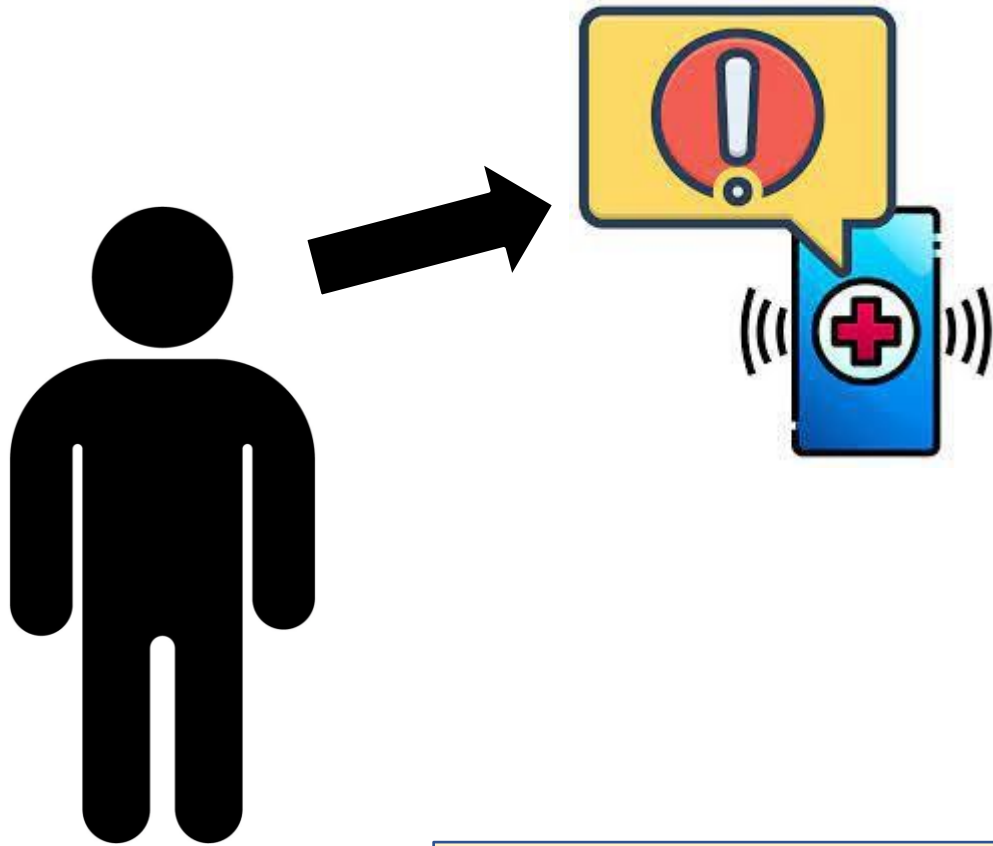


# Cancer: Personality and Illness



“Personality is the dynamic organization, within the person, of psychophysical systems that create the person’s characteristic patterns of behaviour, thoughts, and feelings”. (Allport, 1961)

The word “personality” originates from the Latin word *persona*, which means “mask.”

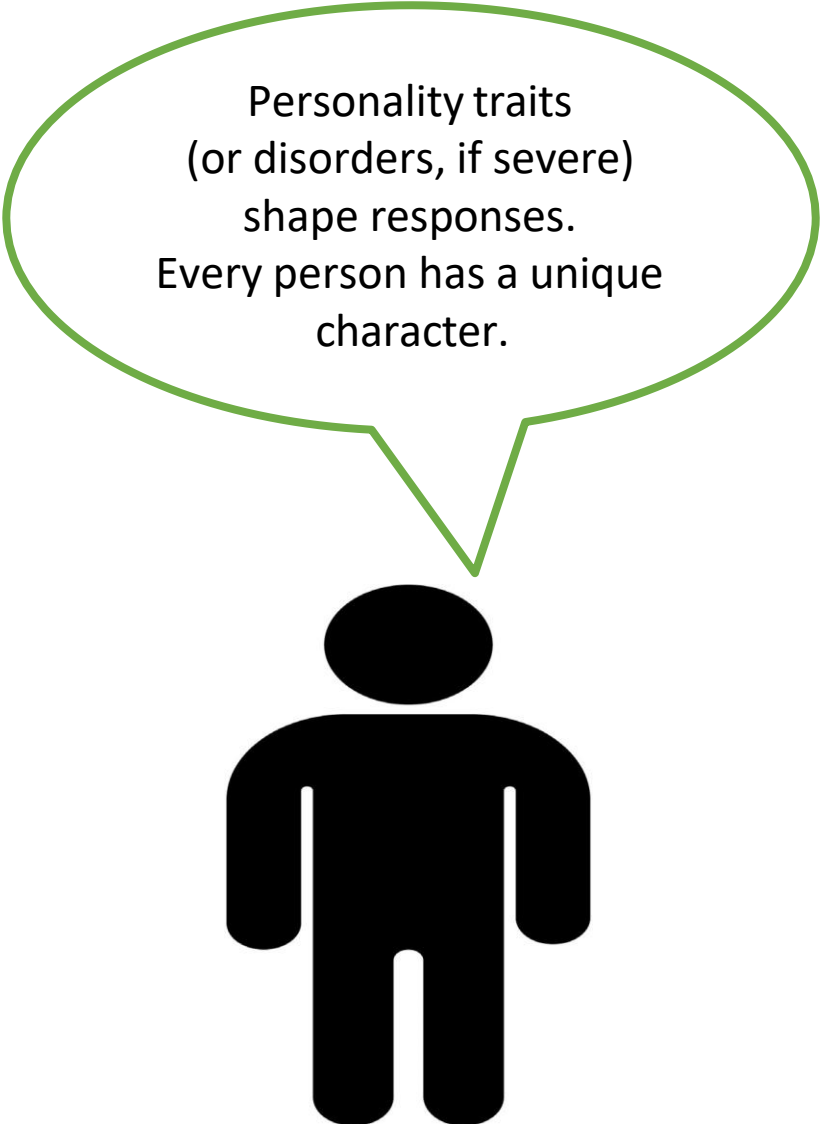


Emotional  
responses

Behavioural  
responses

These are multidetermined.  
The characteristics of the disease, life experience, temperament,  
personality, illness concept, coping styles, and defense  
mechanisms impact eventual responses.





Personality traits  
(or disorders, if severe)  
shape responses.  
Every person has a unique  
character.

There are clusters of behavioural styles which encompass most characters

Stressors (psychosocial and physiological) unmask and highlight personality traits, which are often well camouflaged by social customs and manners.

Ego defence mechanisms (automatic responses that confront threat)  
Unconsciously rearrange mental conflict created for 'peace of mind'.  
A protective illusion which can be adaptive and/or pathological.

Ego defences retain equilibrium, though potentially at the cost of psychological symptoms.

Each individual is different in the ways they respond. Responses are dynamic, fluctuating and changing continually.

Personality traits and disorders exist on a spectrum.

**DISCLAIMER**

It should be noted that the vast majority of uncooperative patients do not have a personality disorder. Personality disorders are pervasive patterns that require understanding a patient's behavior in multiple contexts

# Personality and Illness in Clinical Practice

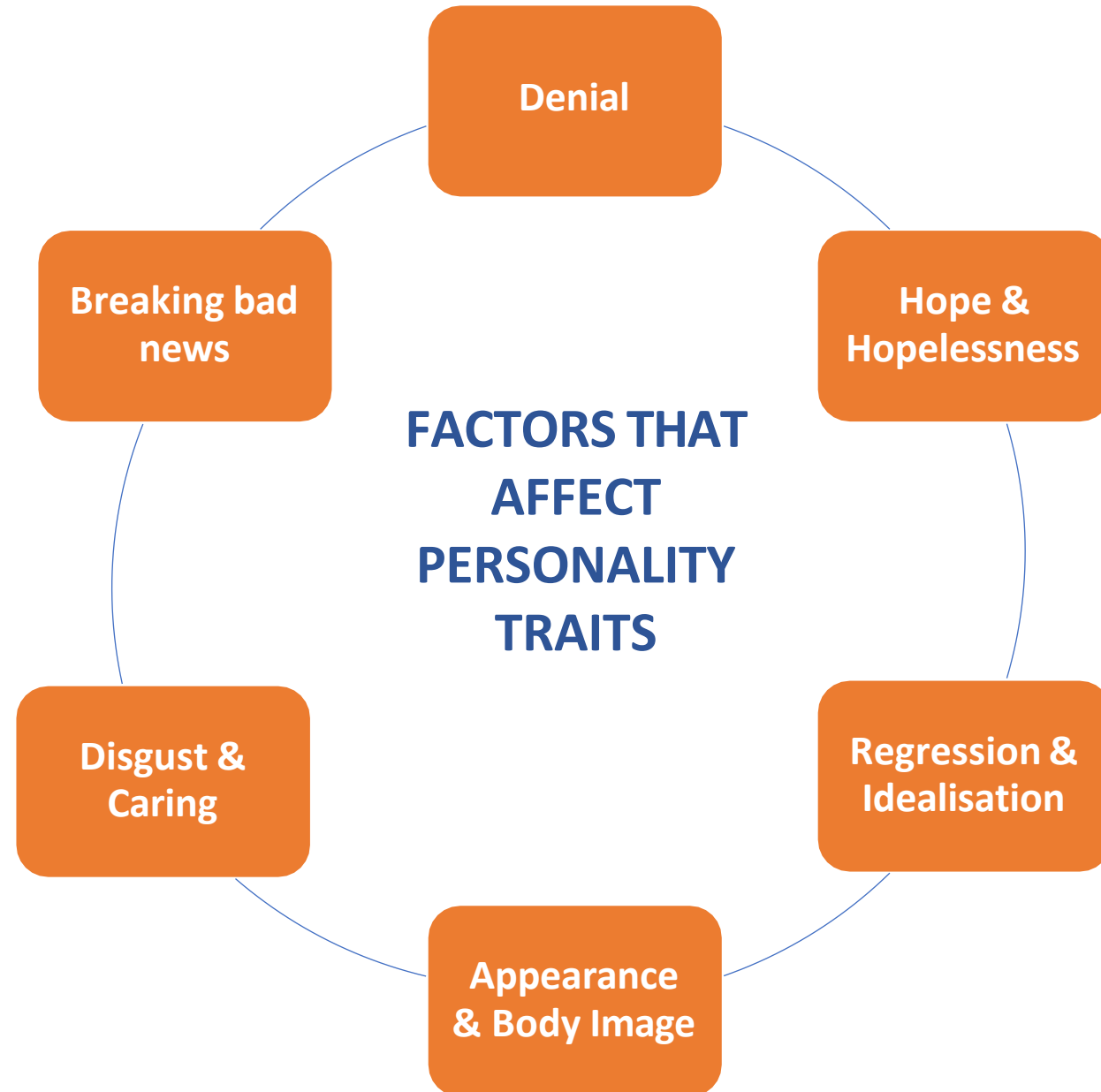
Personality Trait	Personality characteristics	Meaning of illness	What you might feel	Management
<b>Dependent</b>	Needy, self-doubting, helpless, demanding seeking reassurances	Fears abandonment	Flattered initially, overwhelmed, avoidant of patient	Reassure within limits; mobilize others to share dependency; schedule regular, brief consultations
<b>Obsessive/Compulsive</b>	Orderly, meticulous, in control, indecisive, restrictive emotions	Loss of control	Admiration, identification, irritation as time-consuming	Encourage collaboration in care; provide medical information; structure and routine
<b>Histrionic</b>	Melodramatic, flirtatious, seeking attention	Loss of attractiveness	Appeal, pity	Firm, clear boundaries; clarify, not confront

# Personality and Illness in Clinical Practice

Personality Trait	Personality characteristics	Meaning of illness	Countertransference response	Management
<b>Borderline</b>	Impulsive, unstable relationships, identity disturbances, affective instability, self-mutilation	Loss of self	Pity, attraction, saviour	Firm boundaries; shared care; consistency; patience
<b>Narcissistic</b>	Arrogant, entitled, grandiose, vain, indifferent to others, devaluing	Shame at loss of self-concept of perfection and invulnerability	Anger, inferiority, prestige of caring for important patient	Foster and soothe battered self-esteem; don't challenge entitlement; empathize with affective emptiness
<b>Paranoid</b>	Suspicious, litigious, distrustful, moralistic, blames others	Proof that the world is against them and medicine is exploiting them	Anger, medicolegal wary and defensive practice, conservative decision-making	Courtesy, honesty, respect; counterprojective dialogue (acknowledge resulting feelings, not the content of ideations); litigious awareness

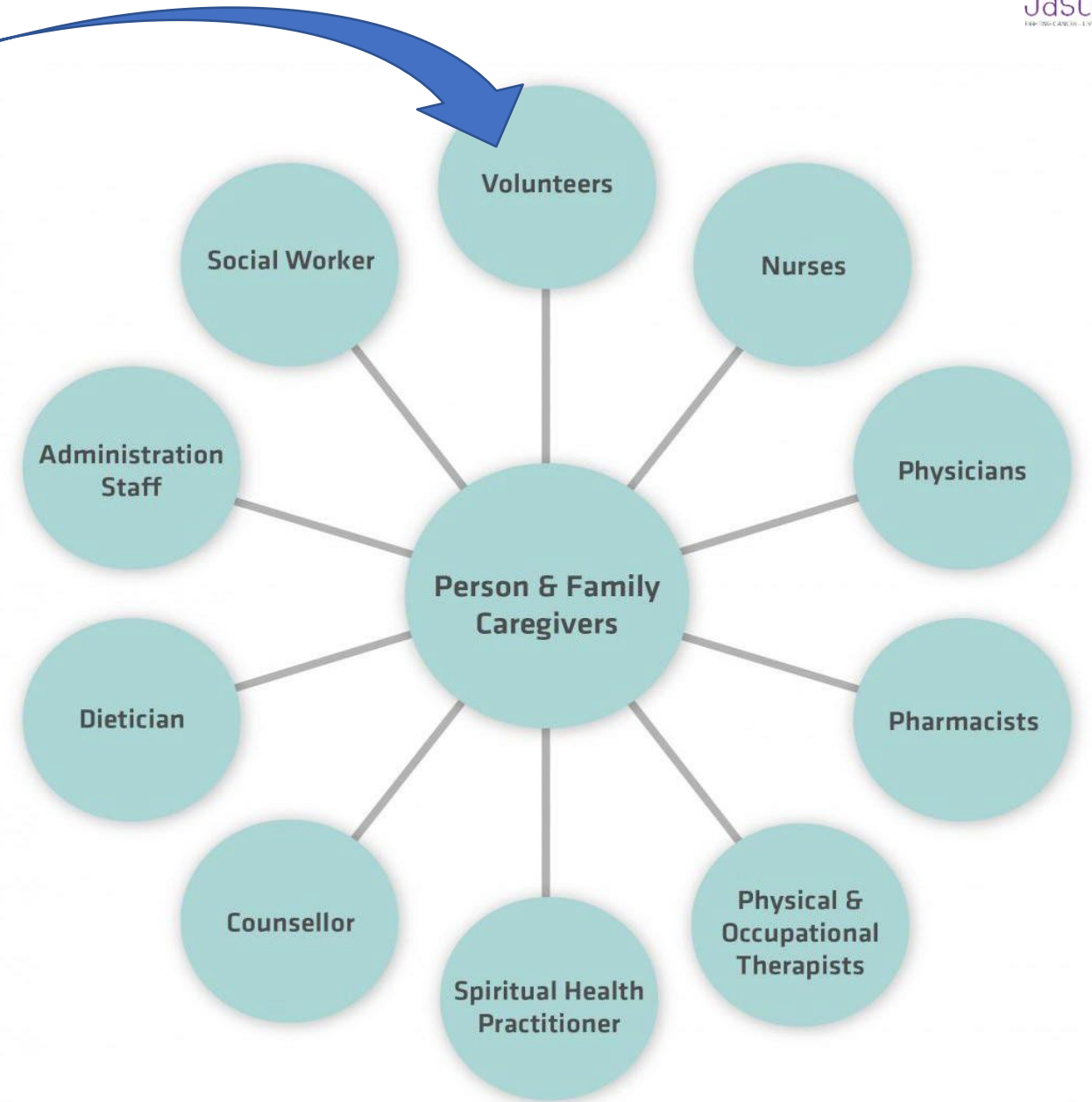
# Personality and Illness in Clinical Practice

Personality Trait	Personality characteristics	Meaning of illness	Countertransference response	Management
<b>Antisocial</b>	History of antisocial behaviours, plausible, exploitative, angry	Loss of status, aloneness	Fear, anger	Firm management guidelines; operate in a safe environment
<b>Schizoid</b>	Aloof, distant, eccentric, isolated, socially awkward	Fear of intrusion, interference	Difficult to engage, abandon	Respect privacy; maintain consistent quiet interest



How can volunteers contribute?

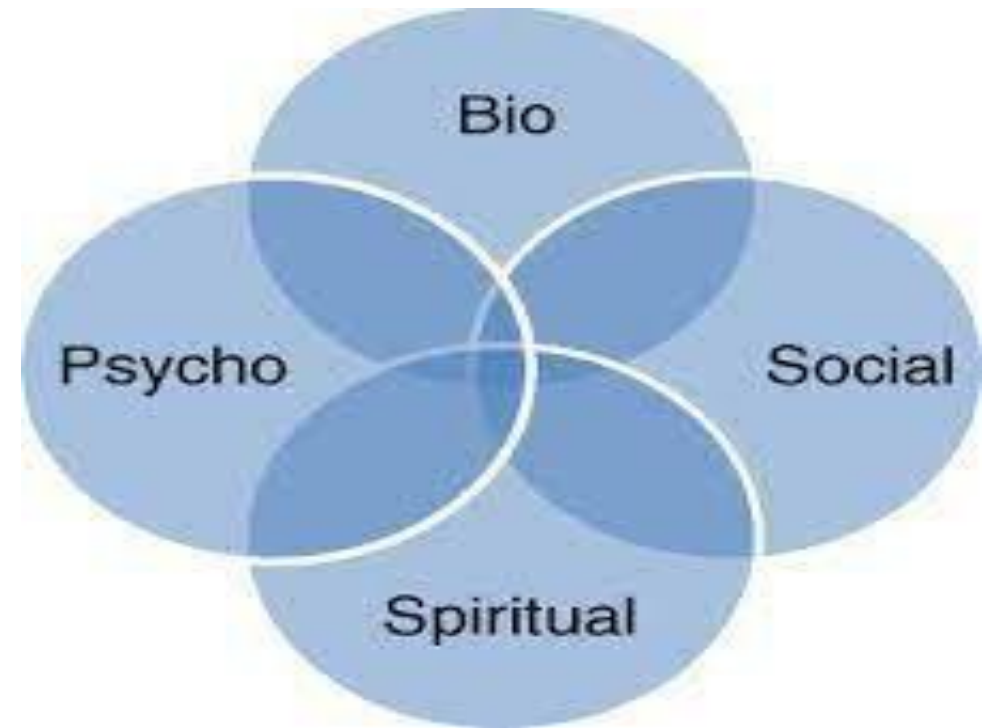
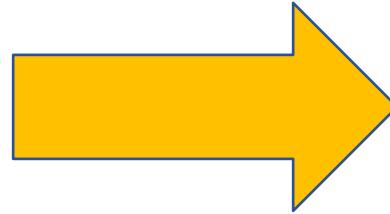
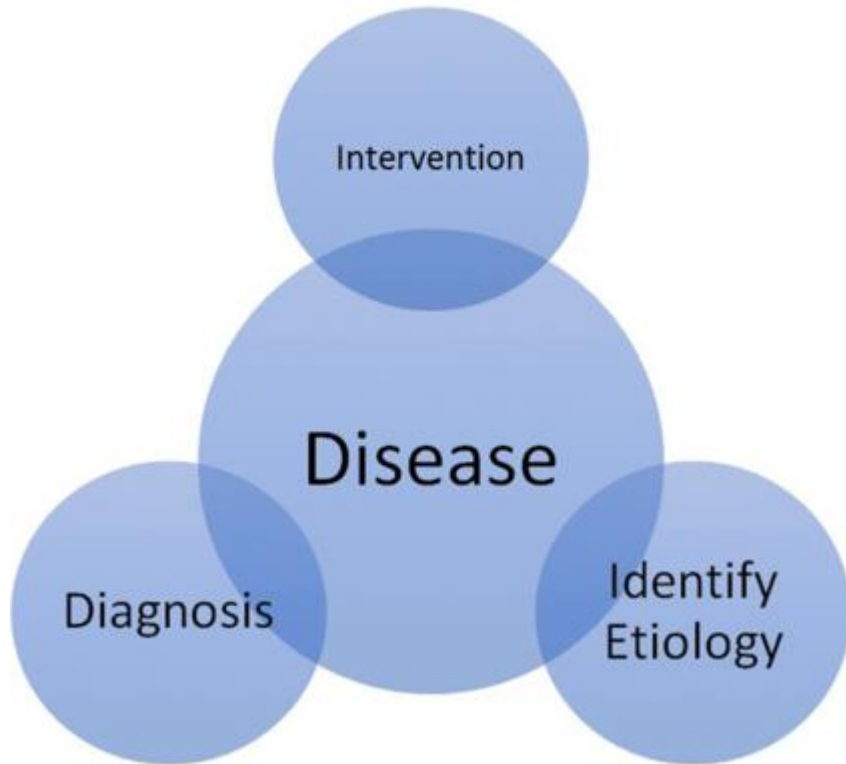
**Important Part of  
the Palliative care  
Team**





# Holistic Management

Biomedical Model



# Tiered Model of Care

**Figure 1:** Tiered Model of Psychosocial Care in Oncology



# Psychosocial Coping in Cancer

- Living with cancer requires the ability to adapt to living with the stressors of unremitting symptoms
- a process of “stability through change”- Allostasis



# Psychosocial Coping responses

## Problem-focused coping

- directing action to resolve or alter the threat
- Planning, problem-solving, restraint, seeking information/instrumental advice and cognitive reappraisal

## Emotion-focused coping

- *which involves management of emotions*
- managing and/or mitigating problematic emotional responses to stress, such as fear and distress, by using strategies like avoidance, denial, venting, disengagement, acceptance, positive reappraisal and emotional support

**Enlisting Support**

# Caring for the caregiver

**PHYSICAL &  
MENTAL HEALTH**



**CAREGIVING CAN  
ALSO BE  
MEANINGFUL**

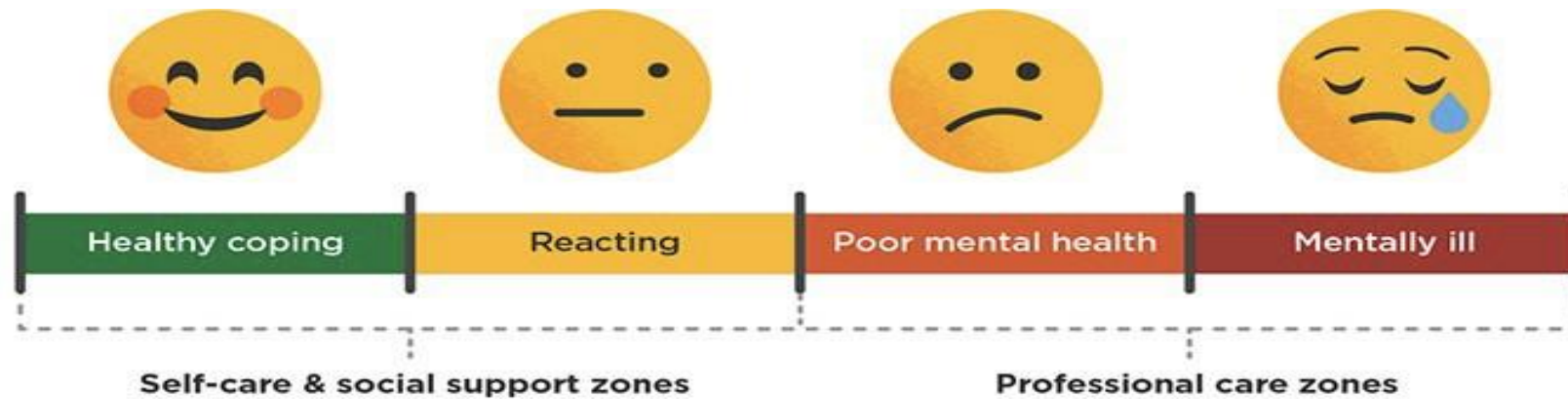
**FOCUS ON  
RELATIONSHIPS**

Patients &  
Families

Volunteers

Healthcare  
Providers

# Referrals to Mental Health Professionals...





**HEALING HEARTS & COMMUNITIES**  
WORLD HOSPICE & PALLIATIVE CARE DAY **8 OCT 2022**

**Thank you!**



# Why addressing Psycho social factors important (Van den Mass et al)

Loss of  
dignity  
57%

Pain  
46%

Unworthy  
dying  
46%

Dependency  
33%

Tired of life  
23%