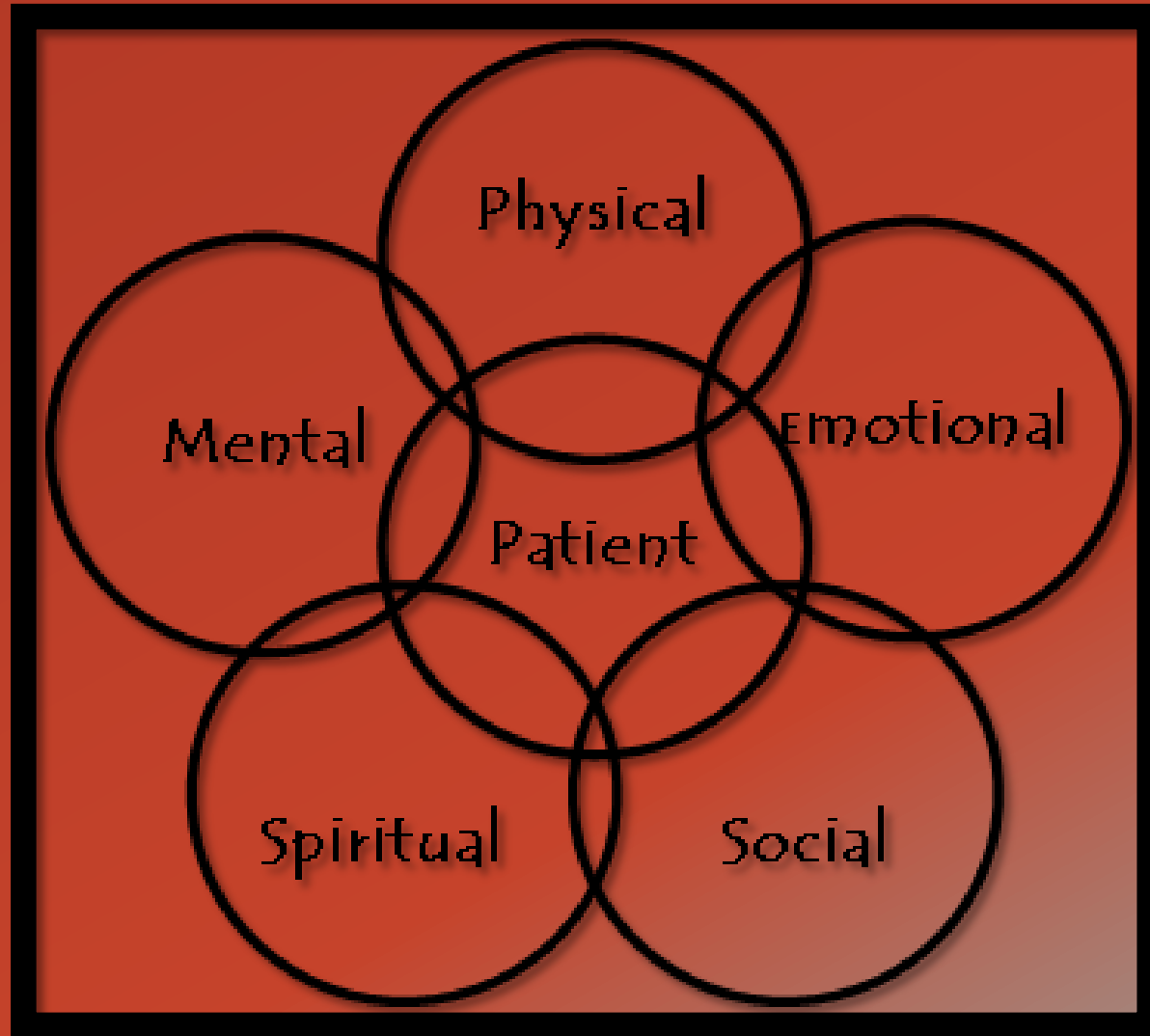


2. Total Pain



2. Total Pain Explanation

- Physical
- Emotional
- Spiritual
- Mental
- Social



3. Assesses for Anxiety & Depression

- We don't diagnose, but listen for signs of these
 - Often guests & families will share these & we would bring this information to the larger care team
- If we are concerned, we will refer to the Team or we will give the client referrals.




4. *PPS Scale – The Psychosocial Model*

- We start with introducing the model of psychosocial using the PPS scale as a structure.
- We start at 100% & describe the psychosocial effects & continue through as the client declines.



4. PPS Scale – The Psychosocial Model

 Palliative Performance Scale (PPS)					
PPS	Ambulation	Activity and Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity and work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity and work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity <i>with effort</i> Some evidence of disease	Full	Normal or Reduced	Full
70%	Reduced	Unable to do normal job/work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/housework Significant disease	Occasional assistance neces.	Normal or reduced	Full or confusion
50%	Mainly sit/lie	Unable to do any work Extensive disease	Considerable assistance req'd	Normal or reduced	Full or confusion
40%	Mainly in bed	Unable to do most activity Extensive disease	Mainly needs assistance	Normal or reduced	Full or drowsy +/- confusion
30%	Totally bed bound	Unable to do any activity Extensive disease	Total care	Normal or reduced	Full or drowsy +/- confusion
20%	Totally bed bound	Unable to do any activity Extensive disease	Total care	Minimal to sips	Full or drowsy +/- confusion
10%	Totally bed bound	Unable to do any activity Extensive disease	Total care	Mouth care only	Drowsy or coma +/- confusion
0%	Death	x	x	x	x

A GPSC Initiative



4. *PPS Scale – The Psychosocial Model*

- Functional assessment tool developed by Victoria Hospice in 2010.
- Based on Karnofsky Performance Scale.
- Karnofsky Performance Scale was developed as a measure of cancer people ability to perform daily tasks.



4. Psychosocial Advice

Beginning the Journey: Early Diagnosis & Treatment

 Palliative Performance Scale (PPS)						
PPS	Ambulation	Activity and Evidence of Disease	Self-Care	Intake	Conscious Level	
100%	Full	Normal activity and work No evidence of disease	Full	Normal	Full	
90%	Full	Normal activity and work Some evidence of disease	Full	Normal	Full	
80%	Full	Normal activity and work Some evidence of disease	Full	Normal	Full	

Most people enter the phase of life-threatening illness looking well but knowing something is not right.



4. *Psychosocial Advice*

What we see..

Physical function is high,
people are often deceived by
apparent good health &
absence of observable signs of
disease.



Grow in grace
- Lilly Oncology, On Canvas



4. *Psychosocial Advice*

Psychosocial Impact

People feel shocked & overwhelmed. Illness & treatment becomes a focal point. Critical health care decisions are made.

- Navigating new systems & unfamiliar territory
- Experiencing the fragility of life
- Feelings of uncertainty can cause a sense of fear & powerlessness
- Physically & emotionally impacted by treatment



4. Psychosocial Advice

The Path Not Chosen: Reoccurrence & Chronic Illness

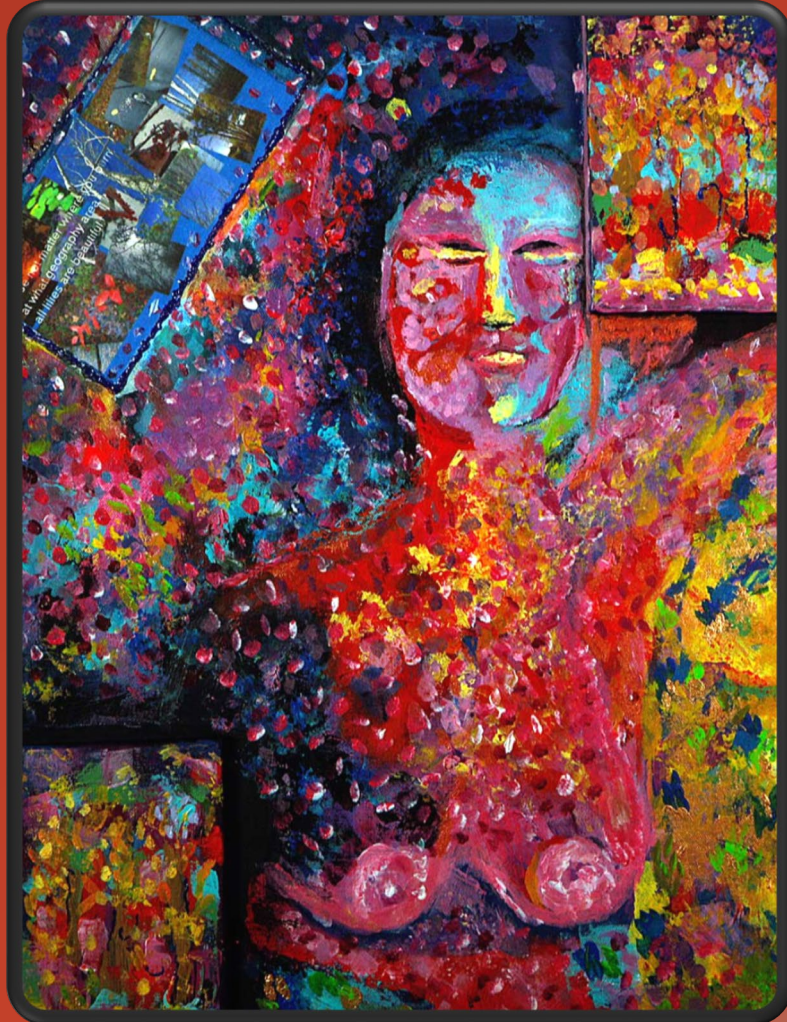
 Palliative Performance Scale (PPS)						
PPS	Ambulation	Activity and Evidence of Disease	Self-Care	Intake	Conscious Level	
80%	Full	Normal activity with effort Some evidence of disease	Full	Normal or Reduced	Full	
70%	Reduced	Unable to do normal job/work Significant disease	Full	Normal or reduced	Full	

Once diagnosed with a life-threatening illness, people live with the possibilities of reoccurrence & disease progression.



4. Psychosocial Advice

What we see..



People may experience remission, recurrence or a gradual progression.

New symptoms develop.

Activities become more difficult, employment may end, household duties & personal interests are impacted.

Colours of Strength
-Lilly Oncology, On Canvas



4. *Psychosocial Advice*

Psychosocial Impact


People often feel vulnerable & betrayed by a prior sense of good health. Priorities are adjusted.

- Dissonance with one's life values can arise from uncertainty & unreliability of one's health
- Feelings of resentment & fear can arise as can feelings of isolation & abandonment



4. Psychosocial Advice

Entering the Unknown: The shift towards palliative care

 Palliative Performance Scale (PPS)						
PPS	Ambulation	Activity and Evidence of Disease	Self-Care	Intake	Conscious Level	
60%	Reduced	Unable hobby/housework Significant disease	Occasional assistance neces.	Normal or reduced	Full or confusion	
50%	Mainly sit/lie	Unable to do any work Extensive disease	Considerable assistance req'd	Normal or reduced	Full or confusion	

A shift towards palliative care involves a change of focus as the disease advances or cure is not possible.



4. *Psychosocial Advice*

What we see...

Disease is not responding to treatment & metastases occur.

Decreased appetite & increased fatigue, reduced mobility.

Further loss of ability to participate in daily activities & personal interests.



What a Nightmare
-Lilly Oncology, On Canvas



4. *Psychosocial Advice*

Psychosocial Impact

This is a period of anxiety & ambiguity. Roles are adjusted & responsibilities shift to accommodate health needs.

- Frequent new losses
- Some feel at a loss for words
- Feelings of hope & despair vacillate
- Fears for the future surface
- Differences in coping abilities arise



4. Psychosocial Advice

A Long & Winding Road: Illness Predominates

 Palliative Performance Scale (PPS)					
PPS	Ambulation	Activity and Evidence of Disease	Self-Care	Intake	Conscious Level
40%	Mainly in bed	Unable to do most activity Extensive disease	Mainly needs assistance	Normal or reduced	Full or drowsy +/- confusion
30%	Totally bed bound	Unable to do any activity Extensive disease	Total care	Normal or reduced	Full or drowsy +/- confusion

Advance stage of disease with little or no chance of improvement. A deeper expression of the grief that has followed people throughout is often experienced.



4. *Psychosocial Advice*

What we see...



Disease is advance.

Increased fatigue & weakness.

Increased drowsiness, intake is limited.

Being Caught
-Lilly Oncology, On Canvas



4. *Psychosocial Advice*

Psychosocial Impact

This is a time of stress & sadness. Care needs intensify.

- Increased physical dependence
- Emotional withdrawal can occur
- Caregivers are often fatigued
- The reality of death is apparent & visible



4. Psychosocial Advice

Watching & Waiting: As death approaches

 Palliative Performance Scale (PPS)					
PPS	Ambulation	Activity and Evidence of Disease	Self-Care	Intake	Conscious Level
20%	Totally bed bound	Unable to do any activity Extensive disease	Total care	Minimal to sips	Full or drowsy +/- confusion
10%	Totally bed bound	Unable to do any activity Extensive disease	Total care	Mouth care only	Drowsy or coma +/- confusion

Life's familiarity is juxtaposed with the unfamiliar closeness of death.



4. *Psychosocial Advice*

What we see...

Cognitive abilities are noticeably affected.

Continuous sleeping or coma.

Restlessness, agitation or delirium may occur.

Significant physical changes in swallowing, breathing, skin tone & temperature.



With a little help from my friends
- Lilly Oncology, On Canvas



4. *Psychosocial Advice*

Psychosocial Impacts


Families search for new ways to communicate & “be present” with people as they become increasingly unresponsive.

- Reduced communication
- Concerns regarding the person’s suffering & restlessness
- Caregivers expectations about dying & death may be challenged



4. *Psychosocial Advice*

Parting of the Ways: The time of death

 Palliative Performance Scale (PPS)					
PPS	Ambulation	Activity and Evidence of Disease	Self-Care	Intake	Conscious Level
0%	Death	x	x	x	A GPSC Initiative x

A time of sorrow & relief; sometimes a sense of unreality.

A new journey begins.



4. *Psychosocial Advice*

What we see...



Death may occur quietly or dramatically depending on disease progression, symptom management & individual characteristics.

Presence

-Lilly Oncology, On Canvas



4. *Psychosocial Advice*

Psychosocial Impact

When people die families may feel shocked, relieved or surprised.

- Family members & care givers will say goodbye in their own way
- Family reactions will vary
- Typically a period of reflection
- After death details & rituals are part of the process



4. *Psychosocial Advice*

Helpful Skills Across the PPS

- Be present
- Discuss experience, remove agenda
- Listen, openly & non-judgementally
- Ask people & families what they need in the given moment; this will change by the week, day & hour
- Review support services available
- Maintain self care



4. *Psychosocial Advice*

Self- Care

- Supporting people may bring up your own past losses
- Its okay to grieve
- Practice mindfulness or grounding techniques
- Seek support as needed



4. *Psychosocial Advice*

Parting Thoughts

- “Death ends a life, not a relationship”
from Mitch Albom, *Tuesday's with Morrie*



4. *Psychosocial Advice*

References

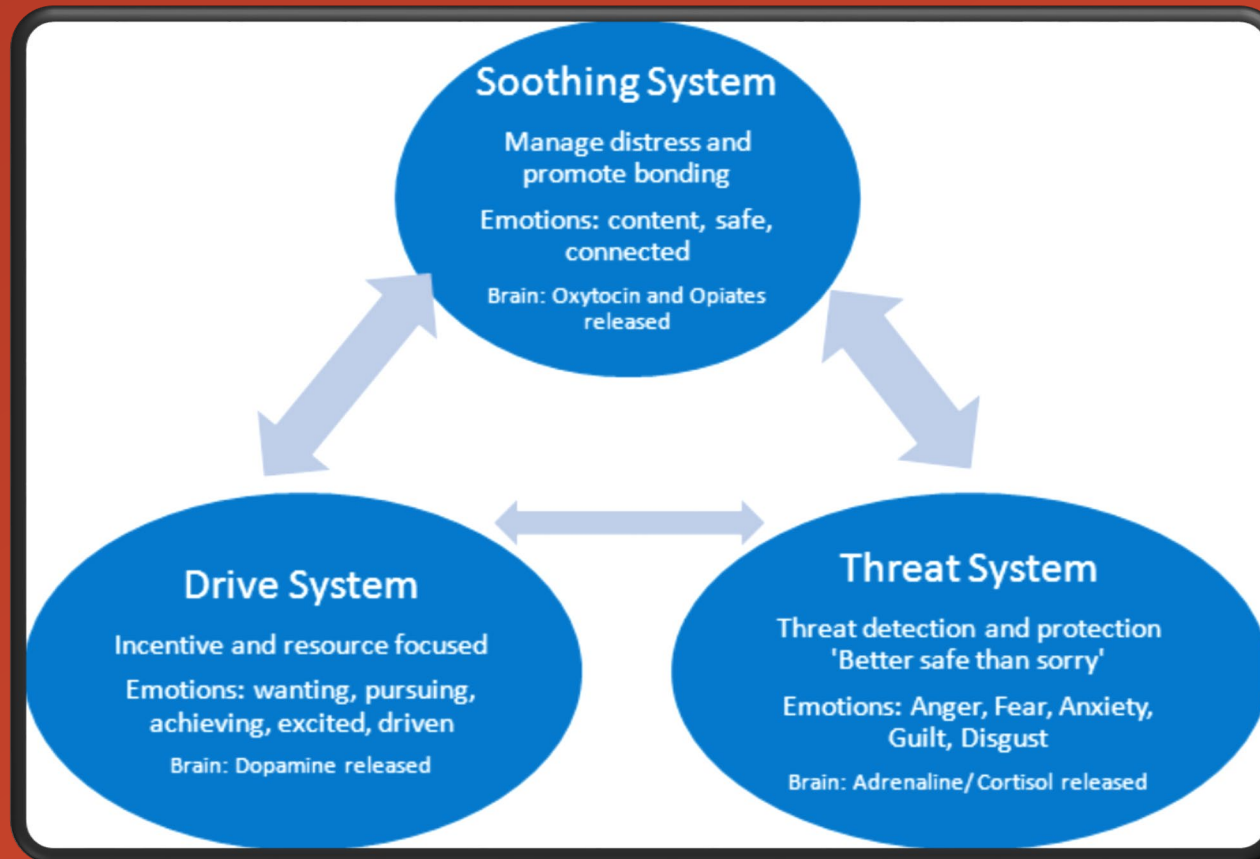
Victoria Hospice Society. *Integrating Care: Framework for understanding the psychosocial impact of physical decline, dying & death*. Infographic.

Victoria Hospice Society. *Palliative Performance Scale*



4. *Psychosocial Advice:* *Compassion Focused Care*

Paul Gilbert's Model of Human States of Being



4. *Psychosocial Advice*

Changes in the PPS

- Every time the PPS changes from a physical point of view, they are changing mentally, emotionally, spiritually & societally
- We are aware of the unit of care, which includes any family/friends.
- Our job is to soothe.



4. *Psychosocial Advice*

How Do We Soothe

- Everyone is unique, so its always different.
- Our first step is to create relationship.
- However there are some common ways



4. *Psychosocial Advice*

Giving Them Their Power Back

- Often they feel helpless or hopeless
- It's not cheerleading, its about giving them simple choices.
- Its about asking them,
- its subtle.



4. *Psychosocial Advice*

Explains Psychosocial Information

- Normalize
- Give information ex:
- Part of our training for our volunteers
- Conversations on pain & suffering as two separate experiences



4. *Psychosocial Advice*

The Jars Model

- The model makes our world bigger to help with our grief
- We think in terms of expanding our capacity to hold our grief.



4. *Psychosocial Advice*

Resistance



- Allowing ourselves to let the grief in
- Its not about getting rid or over it.
- We have to let it change who we are.

