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The Psychosocial PPS: Recognizing the psychosocial transitions that occur along the illness trajectory

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CONFLICTS OF INTEREST DECLARATION



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- I have no conflicts of interest to declare.

LEARNING OBJECTIVES



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- Introduce the idea of psychosocial transitions (as they relate to the PPS trajectory)
- Consider key considerations for select psychosocial transitions
- Challenge you to apply this information to your work / setting

A little about where I come from:

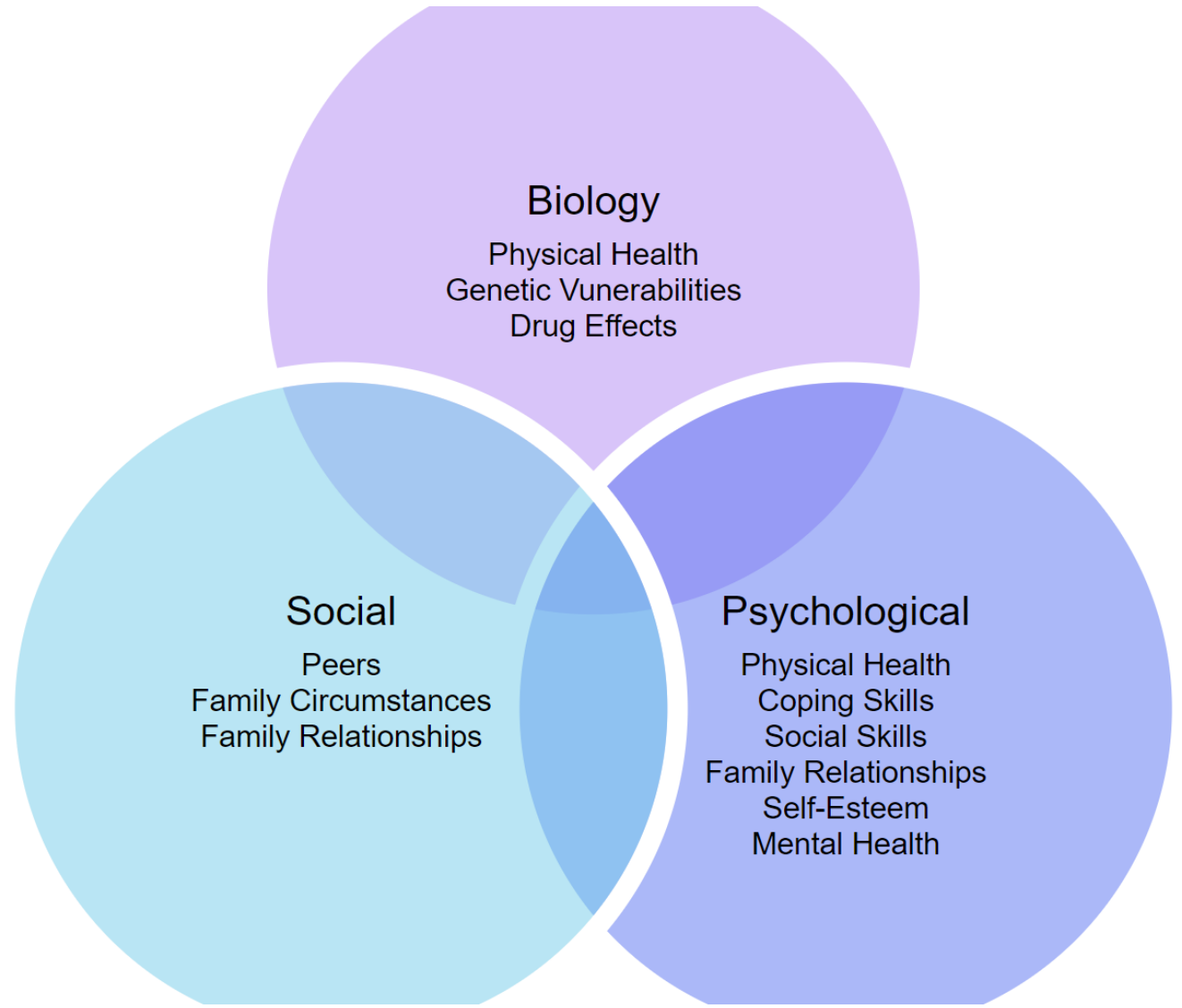
- A comprehensive program of care
- An interdisciplinary team
- A mission to enhance quality of life



Palliative Performance Scale (PPS v2)

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
PPS 100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
PPS 90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
PPS 80%	Full	Normal activity with Effort Some evidence of disease	Full	Normal or reduced	Full
PPS 70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
PPS 60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
PPS 50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
PPS 40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
PPS 30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
PPS 20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
PPS 10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
PPS 0%	Death	-	-	-	-

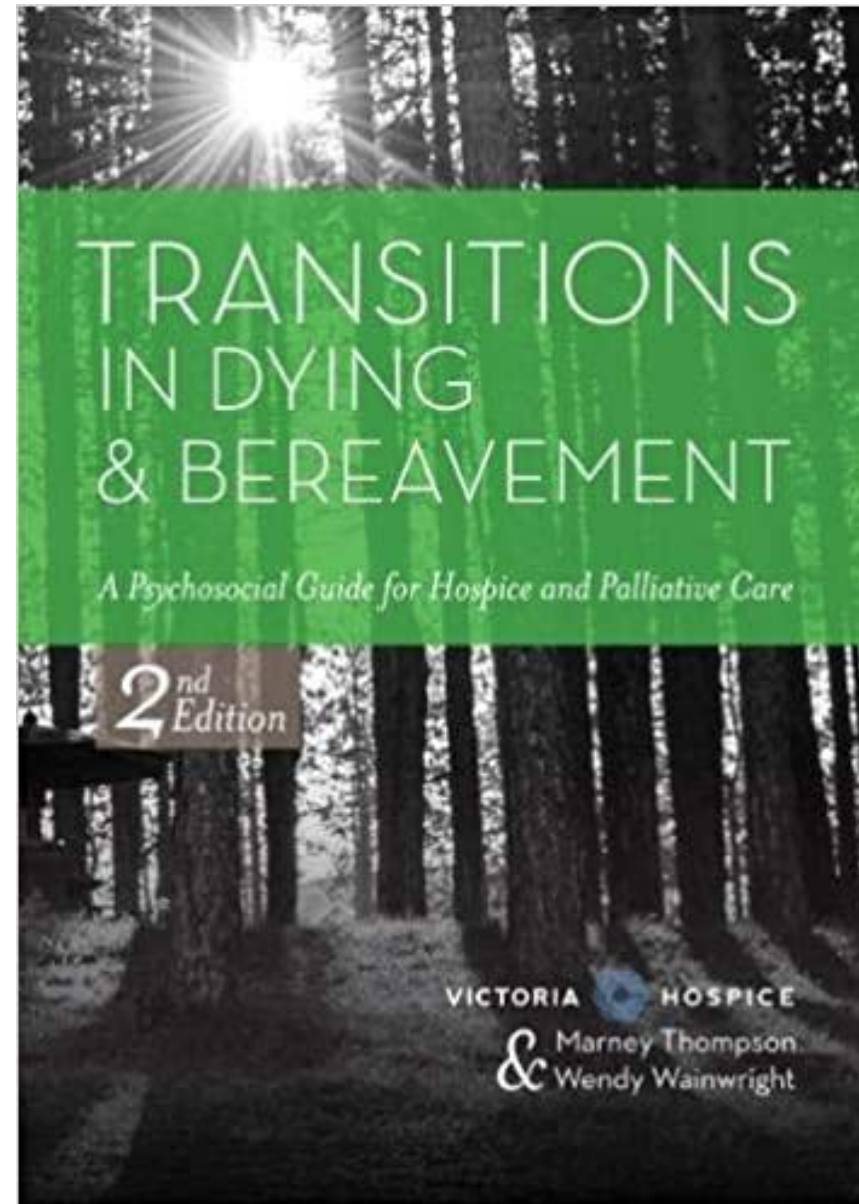
How can we use this widely used communication tool, that is patient centric, and physically focussed, to *introduce a more holistic, patient and family centered approach* to care?



Project: Identify Psychosocial Transitions through Illness & Bereavement

Goals:

- Introduce a holistic model of care that integrates people's physical and psychosocial needs
- Improve communication between people about psychosocial end of life and bereavement needs
- Provide a framework to improve inter-professional, psychosocial, EOL and bereavement education, training, and research



PPS 60/50 - The shift to HPC

PPS 60-50%	Change in Focus	Pt/Family Losses	Emotions	Communication
Patients	<ul style="list-style-type: none"> From managing the disease to managing one's life 	<ul style="list-style-type: none"> Shrinking world Reviewing one's life 	<ul style="list-style-type: none"> Ambivalence: hope/denial Fears re future 	<ul style="list-style-type: none"> Protecting others Loss of words
Families	<ul style="list-style-type: none"> Feeling abandoned New system 	<ul style="list-style-type: none"> Roles alter Reactions vary Resentments arise 	<ul style="list-style-type: none"> Powerlessness Fears re ability to manage 	<ul style="list-style-type: none"> Differences increase Indirect

Opening question: *How might this shift in focus impact your routines and lifestyle?*

Intervention: Explore emotions and support difficult conversations; family differences

PPS 40/30 - Illness Predominates

PPS 40-30%	Change in Mobility	Dependence & Withdrawal	Family Grief	Family Stress & Fatigue
Patients	<ul style="list-style-type: none"> Progression varies, more dependence Increased symptoms 	<ul style="list-style-type: none"> Isolation vs. being a burden Loss of control 	<ul style="list-style-type: none"> Worn out Closure important Guilt 	<ul style="list-style-type: none"> Conserving energy Care plans Thoughts of death
Families	<ul style="list-style-type: none"> Focus on physical care, patient needs Preparing for increased care 	<ul style="list-style-type: none"> Assume decision-making Disengagement vs. attachment 	<ul style="list-style-type: none"> Reality of death apparent 	<ul style="list-style-type: none"> Strengths & struggles intensify New roles, isolation

Opening question: *How are you managing with the changes that you're currently facing?*

Intervention: Facilitate discussions about sources of strength, stress, and support

PPS 20/10 – As Death Approaches

PPS 20-10%	Connection	Decision-making Alone	Expectations of Death	Restlessness and Confusion
Patients	<ul style="list-style-type: none"> • Symbolic communication • Little or no connection with others 	<ul style="list-style-type: none"> • May have expressed wishes or not 	<ul style="list-style-type: none"> • May influence family's decisions, comfort 	<ul style="list-style-type: none"> • Varies from mild to extreme
Families	<ul style="list-style-type: none"> • Sitting vigil • Concerned with changing communication 	<ul style="list-style-type: none"> • Various views & levels of comfort 	<ul style="list-style-type: none"> • Focusing on death • Relief, sadness, &/or anger 	<ul style="list-style-type: none"> • Concerns & questions re causes of sedation, suffering

Opening question: *What are you doing to maintain your connection with each other?*

Intervention: Provide people with simple information about what they may see and hear and do when the person is dying.

PPS 0 – Time of Death

PPS 20-10%	Nature of Death	Reactions	Practical Details	Rituals
Families	<ul style="list-style-type: none">• Questions & concerns about the death; expected, shocking	<ul style="list-style-type: none">• Varying responses range from shock, disbelief to relief	<ul style="list-style-type: none">• Care & removal of the body	<ul style="list-style-type: none">• May have rituals/beliefs or not

Opening question: *What questions or concerns do you have, if any?*

Intervention: Normalize & support the range & depth of people's reactions and needs

Walking the Edges

When death occurs	Grief Reactions	Family Interactions	Support	Practical Matters
Friends & family	<ul style="list-style-type: none">• Autopilot /busy• Emotional /incapacitated	<ul style="list-style-type: none">• Changing roles• Confusion & hurt	<ul style="list-style-type: none">• Most abundant time• Can be welcome or intrusive	<ul style="list-style-type: none">• Much to do: funeral arrangements & planning a service

Opening question: *What sort of help are you receiving from friends and family? How is that for you?*

Intervention: Explore and identify sources of support (both personal and practical/professional)

Entering the Depths

Adjusting to loss	Intense Emotions	Interacting with Others	Living with Grief	Spiritual Questions
Friends & Family	<ul style="list-style-type: none">Shock and numbness recede, loss is 'real'	<ul style="list-style-type: none">Isolation by choice or circumstance	<ul style="list-style-type: none">Less busyJuggling the activities of life with the overlay of grief	<ul style="list-style-type: none">Exploring what happens when we dieWhere is my person?

Opening question: *How is this loss and your grief impacting your life and relationships currently?*

Intervention: Normalize changes in grief and provide information about the grief process

Reconnecting with the World

Mending the heart	Emerging	Ongoing Grief	Remembering	Identity
Friends & Family	<ul style="list-style-type: none">• More energy available for life• Ready for new/novel	<ul style="list-style-type: none">• Recognition that grief is forever• Waves or pangs; bittersweet	<ul style="list-style-type: none">• Connection established• Remembering is OK	<ul style="list-style-type: none">• Who and how am I without this person is forming

Opening question: *Have you found any place or activity or object that helps you to feel connected to... (the person who died)?*

Intervention: Explore / envision and mine personal 'bucket list' –identify projects with value/purpose

Partner chat

1. What point(s) stood out for you from this presentation?
2. What is one thing that you learned in this presentation that you will do differently in your work / setting?
3. Who else in your work/setting would benefit from this learning?



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The 5 Stages of Grief

1. There is no stage
2. There is no stage
3. There is no stage
4. There is no stage
5. There is no stage

@giftsfromgrief



Psychosocial PPS Transitions

PPS transition	60/50 <i>The shift to hospice palliative care</i>	40/30 <i>Illness predominates</i>	20/10 <i>As death approaches</i>	0 <i>Time of death</i>
Key considerations	<ul style="list-style-type: none"> • Change in focus • Patient grief • Emotions • Communication 	<ul style="list-style-type: none"> • Change in mobility • Dependence & withdrawal • Family stress • Family grief • Family fatigue 	<ul style="list-style-type: none"> • Doing to being • One-way communication • Making decisions alone • Death expectations • Restlessness & delirium 	<ul style="list-style-type: none"> • Family reactions • Nature of death • After-death details • Rituals
Sample questions	<i>How has this shift in focus impacted your routines and lifestyle?</i>	<i>What are your needs and priorities right now?</i>	<i>How supported and/or confident are you feeling about the decisions you are making?</i>	<i>Do you have any questions about the dying process or death?</i>

Bereavement Transitions

Transition	<i>Walking the edges</i>	<i>Entering the depths</i>	<i>Reconnecting with the world</i>
Key considerations	<ul style="list-style-type: none">• Grief reactions• Family interactions• Social support• Practical matters• Follow-up	<ul style="list-style-type: none">• Intense emotions• Interacting with others• Living with grief• Spiritual questions	<ul style="list-style-type: none">• Emerging from pain• Ongoing grief• Remembering• Identity
Sample questions	<i>What sort of support are you getting from friends and family? How is that feeling?</i>	<i>How is this loss and your grief impacting your life and relationships currently?</i>	<i>What do you do when you are really missing the person who died? Have you found anything that helps you to feel connected to them?</i>