# **Social Work Assessment Notes**

# A Comprehensive Outcomes-Based Hospice Documentation System

**User's Guide** 



### Introduction

More than just an assessment tool, the Social Work Assessment Notes (SWAN) is a patient-centered comprehensive documentation system that links assessment findings to the hospice plan of care across 9 psychosocial areas for hospice patients and their caregivers. The project to design a new documentation system started in an effort to address the changes in 2008 to the Medicare Hospice Conditions of Participation (COPs)<sup>[1]</sup>. These regulations called for an "outcome-oriented approach to patient care" and described a cycle of care in which assessment data about patient and family needs are incorporated into an individualized, patient-centered plan of care. Hospices were called upon to gather assessment data in a "systematic and retrievable way" in order to facilitate outcomes measurement and use in the organization's quality assessment and performance improvement program. The SWAN was designed for use in our electronic health record but the same concepts could be applied to a paper-based system.

The SWAN incorporates requirements of the Medicare Hospice COPS, psychosocial assessment elements required by the Community Health Accreditation Program (CHAP) and meets Texas regulations for licensed Home and Community Support Services Agencies. It also incorporates quality standards from the National Hospice and Palliative Care Organization and elements from the National Consensus Project Clinical Practice Guidelines for Quality Palliative Care.

Existing assessment tools capture numerical ratings for defined areas but none of them "stand alone" in that all require supplemental documentation to provide a complete picture of the patient and caregiver and to meet regulatory documentation requirements. The SWAN combines a measurable numerical rating with narrative charting to provide complete, compliant, and comprehensive documentation of patient and caregiver needs, preferences, and services provided.

#### Project Team

Development of the SWAN was a true collaborative effort. Over twenty social workers have a fingerprint in this project and much appreciation goes to our entire social work staff for their enthusiasm. The project team included: Angela Hansen, LCSW, ACHP-SW and Social Work Supervisor, Jessica Sather, LMSW, Tina Bollman, LCSW, Alicia Horton, LCSW, Peg Maupin, LCSW, Dede Sparks, LCSW, Christina Perez, LCSW, Jan Bowen, LBSW and University of Texas School of Social Work Professors, Dr. Barbara Jones and Dr. Elizabeth Pomeroy, Co-Directors of the Institute for Grief, Loss and Family Survival.

Ron Matsuda and Donna Harden in the Information Technology department supported this project by entering the SWAN assessment fields, problems, goals, and interventions into the electronic health record and demonstrated unending patience through multiple revisions.

Community support came from the University of Texas School of Social Work MSSW field interns and Dr. Michele Rountree's research students who conducted a literature search in support of this project.

This project was made possible through the backing of members of the Hospice Austin administrative team: including Paige Fletcher, Director of Clinical Services who generously supported the time needed to work on the project; and Ellen Martin, Director of Quality who provided encouragement on outcomes measurement and ensured regulatory and accreditation requirements were met.

# **Background**

Development of the SWAN is described elsewhere<sup>[2]</sup>. Briefly, the project started with an evaluation of existing measures and assessment tools for hospice patients and caregivers to identify key data elements useful in the psychosocial assessment of hospice patients and caregivers<sup>[3,4,5]</sup>.

### **Overview of the SWAN Documentation System**

The SWAN is a two part system with assessment notes that are linked to the plan of care. It includes nine psychosocial areas to assess:

- 1. Care Needs/Safety Concerns
- 2. Financial Needs
- 3. Awareness and Understanding of Prognosis
- 4. Sense of Well Being/Adjustment
- 5. Interpersonal Issues and Level of Social Support
- 6. Coping Related to Loss and Anticipatory Grief
- 7. Suicidal Ideation and Potential for Suicide Risk
- 8. Cultural Values Related to end of Life Care
- 9. Decision Making and Advance Planning

For each psychosocial issue, the social worker identifies which issues the patient and caregiver is willing to work on and addresses them in the assessment notes and in the plan of care. If the patient or caregiver does not want to address an issue, this is noted in the documentation and can be monitored.

In the plan of care: the social worker documents a numerical rating of the severity of the issue for the patient and the caregiver at the beginning of each visit. Interventions are provided during the visit. The social worker also documents a numerical rating for the progress made toward the goal at the end of the visit. The assessment notes have space for narrative documentation on specific patient and caregiver details related to the assessment, problem severity, or progress towards goals.

The numerical ratings are useful to track outcomes for individual patients and caregivers from visit to visit. These can be used in aggregate to measure and track outcomes for groups of patients. These ratings can be used to provide quantitative data useful to quality improvement.

The following pages outline the specifics of:

- Assessing each of the nine psychosocial areas in the assessment notes
- Assigning numerical ratings in the plan of care for outcomes
- Interventions to use for the psychosocial issues/areas

#### Assessment Notes

**Snapshot of the Initial Psychosocial Assessment Note (IPSA):** The Psychosocial Status/GAP (Goal, Assess Current Status & Plan) is a field in all notes across all disciplines. This is used to document a brief synopsis of the plan of care which populates the weekly Interdisciplinary Team (IDT) notes.

The fields on the left side of the assessment form are important to the interdisciplinary team, meet regulatory requirements, or are linked to assessment fields in other disciplines' notes. They include: a description of the Personal History and Current Situation, Primary Diagnosis, Current Mental Status, Preferred Communication Styles for the Patient and the Caregiver, Social Work Contact Frequency, Pain Level (at the start of the visit and at the end of the visit) Volunteer Request, Collaboration, Bereavement Risk Assessment, Resuscitation Code Status and Advance Directives.

The fields on the right side of the forms are the nine psychosocial areas to be assessed and addressed in the assessment notes and the plan of care.

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WAssess	
SW Initial Ps	sychosocial Assessment Note Form ID: 67274
Psychosocial Status/GAP:	٩
·	Care Needs/Safety:
Personal History and Current Situation:	Needs Met/No Safety Concerns <>Unmet Needs/Safety Concerns
Primary diagnosis:	Financial Needs: No Financial Concerns <> Financial Distress
Patient Preferred Style of Communication:	Understanding of Prognosis:
CG Preferred Style of Communication:	Knowledge/Understanding <>Lack of Knowledge/Understanding
SW Frequency/POC:	Well Being/Adjustment: Sense of Well Being/Adjustment <> Lacks Sense of Well Being/Adjustment
	Interpersonal Issues/Support:
Pain Level: Start of Visit:	Emotional/Social Support <> Lack of Emotional/Social Support
Pain Level: End of Visit:	Loss/Anticipatory Grief:
If unable to score 0-10, select 999 and select 999 comment.	Effective Coping/Grieving <> Ineffective Coping/Grieving
999 Comments:	Suicidal Ideation and Risk:
Volunteer Request:	
Collaboration with:	Cultural Values:
Bereavement Risk Assessment:	Congruent <> Incongruent
Resuscitation Code Status:	Decision Making/Planning:
Advance directives:	Knowledge/Understanding <> Lack of Knowledge/Understanding

**Snapshot of the SW Ongoing Assessment Note:** the nine psychosocial assessment fields are continued on the right. There are fewer fields on the left side than in the IPSA and there is a narrative field.

😻 SW Ongoing Assessment Note 2014 [Hospice Care] - DESIGN MODE			
Menu			
Page 1			
SW Ongoing Assessment No	te (FormID:67275)		
Psychosocial Status/GAP:			٩
SW Narrative Note:		Care Needs/Safety:	
		Financial Needs:	
	a Und	derstanding of Prognosis:	
		Well Being/Adjustment:	
		personal Issues/Support:	
SW Frequency/P0C: Pain Level: Start of Visit: If unable to score 0-10, select 999 and select 999 comment.		Loss/Anticipatory Grief:	
Pain Level: End of Visit:	Su	iicidal Ideation and Risk:	
Collaboration with:		Cultural Values:	
Volunteer Request:	De	cision Making/Planning:	
Advance directives:			
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In our electronic health record, psychosocial issues are labeled as "problems, issues, and opportunities" or PIOs. Different systems have different names for the problem list in a plan of care, but the same principles apply. For each psychosocial issue the social worker can indicate the needs and preferences for the patient, caregiver or both separately.

When the social worker documents in any of the nine psychosocial fields in the assessment notes, a box pulls up with the following content to guide them: (shown on next page)

- Extended Description (Help) with a reminder of issues to document in each field
- Pick Choices to indicate whether a PIO/Goal will be opened, continued, discontinued, etc. in the plan of care
- Comments where the narrative story of the situation, interventions and responses can be documented

Snapshot of the Help Box for the Care Needs/Safety Psychosocial Field:

Extended Description (Help)	]
and need for additional reso	<ul> <li>to perform ADLs, obstacles to patient safety purces (caregivers, respite, and alternative f risk or existence of abuse/neglect - results in</li> </ul>
Selection	
PIO/G/I set in POC	
Pick Choices	
PIO/G/Iset in POC	
Continue PIO in POC	
Discontinue PIO in POC	
Declines to address PIO	
No need for PIO/G/Lin PO	С
Not Assessed	
•	4
Comments	
Potential PIO Categories	
Problem (PIO)	
Active	

## **Overview of Content in the Nine Psychosocial Fields:**

For each of the nine psychosocial areas, there are several issues to address and possible questions to ask during an assessment interview. These are summarized below:

#### 1. Care Needs / Safety Concerns

#### **Issues to assess**

- Current and changing care needs
- Ability to perform ADLs
- Obstacles to patient safety
- Need for additional resources or alternative placement
- Current and potential future caregiver limits
- Need for help with planning for future
- Issues of impaired decision making or need for capacity screening
- Risk or existence of abuse/neglect/exploitation
- Need for intervention or referral to APS/CPS

#### **Possible questions**

- Has your illness created any practical problems?
- What kinds of things do you need help with now?
- What do you anticipate needing more assistance with in the future?
- Are you feeling safe? Do you have any safety concerns?

#### 2. Financial Needs

#### **Issues to assess**

- Need for financial assistance
- Referral to agency or community resources

#### **Possible questions**

- Has your illness impacted you financially?
- Are you concerned it may in the future?

#### 3. Awareness and Understanding of Prognosis

#### **Issues to assess**

- Knowledge and understanding of prognosis and disease process
- Issues of denial and acceptance of hospice care and philosophy
- Need/desire for accurate information and EOL education
- Facilitation of open discussion/meeting

#### **Possible questions**

- Can you tell me about the history of your illness?
- What has your physician told you?
- Do you feel you have enough information about what is going on with you?
- How did you hear about hospice?
- How have you handled difficult conversations with loved ones?
- Are you and your family in agreement with hospice care?

#### 4. Sense of Well Being / Adjustment

#### Issues to assess

- Quality of life issues include the ability to enjoy regular activities
- Impact of illness on lifestyle
- Sense of autonomy and control
- Preferred environment to live in and preferred place of death
- Satisfaction with environment and living situation
- Regrets and unfinished business
- Fulfillment of needs/desires for intimacy including sexual expression
- Emotional factors such as intense sadness or depression, anxiety and fear related to: terminal illness, physical decline, loss of independence, need for caregivers or alternative living arrangements, the fear of burdening others, and of impending death
- Current and past coping, any past trauma or loss impacting current situation
- Need for relaxation and anxiety reduction techniques, supportive counseling and EOL education

#### Possible questions

- What is most important to you at this time?
- Do you have any concerns that aren't being addressed? How can we help you with this?
- What do you find yourself thinking about a lot?
- What kinds of physical changes have you been experiencing? Have any of these changes caused you worry? How are you coping with this?
- What do you do with stress or worry?
- Can you think of other past struggles or situations you've had to deal with? How did you get through that time? What was helpful?

#### 5. Interpersonal Issues and Level of Social Support

#### Issues to assess

- Family dynamics/conflict
- Factors that impede healthy communication
- Divergent expectations
- Prior history of mental illness or substance abuse
- Isolation and available emotional support
- Desire for resolution/reconciliation.

#### Possible questions

- Sometimes families don't agree on everything in these kind of situations any areas where this is the case for you?
- What other things are going on in your life right now?
- Are you able to talk with anyone about all of this?
- Have you received counseling in the past? If so, what did you seek help with?
- Who is or are your "go to" people when you need support?
- How is your illness impacting your relationships?
- Is there anyone you are most worried about?
- A serious illness can make us more aware of people most important to us. Have you experienced this?
- Sometimes people may use alcohol or other substances to cope with stress. Is that an issue for you or your family?
- How have relationships changed since you became ill?
- Is there anyone you'd like to work out any past differences with?
- Any situations where you might desire to get or give forgiveness?

#### 6. Coping Related to Loss and Anticipatory Grief

#### Issues to assess

- Emotional factors related to impending death: guilt, anger, unresolved issues, past loss, and past trauma impacting current grief
- For caregivers there is the paradox of holding on and letting go, impending changes to the family system, ability to acknowledge the reality of death and the pain of grief
- Assess coping strategies, need for EOL education, counseling and support

#### **Possible questions**

• How are you and your family doing at communicating with each other during this stressful time?

- This can be a time when you are closest to those you love and also a time of letting go. How are you doing with all this?
- Because of the changes going on you may also be experiencing other losses in your life. What are some of the most important changes for you and how are you handling these changes?
- What do you do with all these changes, stress and worries?
- Sometimes current stress brings up old problems and past losses in unexpected ways. Are you revisiting old hurts?

### 7. Suicidal Ideation and Potential for Suicide Risk

#### Issues to assess

- Identify presence of suicidal ideation and distinguishing between the readiness for life to end and the desire for an end to suffering
- If at risk, complete Suicide Risk Assessment and plan interventions

#### **Possible questions**

- Do you ever think of ending all this?
- If answer is yes, explore further and do suicide risk assessment.

#### 8. Cultural Values

#### Issues to assess

- Identify, seek understanding of, honor, educate, and advocate for needs related to beliefs and cultural values
- May include communication style and preferences, space, role of family members and special traditions
- Address cultural, religious, familial organization/processes and preferences related to plan of care elements such as pain control, decision making, and death

## Possible questions

- How do you make important decisions in your life? Can you share an example of one?
- Who was involved with the decision to seek hospice care?
- How do you like to communicate with your family?
- Any preferences on how we should communicate with you and your family?
- Are there beliefs and traditions you'd like for the care team to know about?
- Are there important religious observations we should be aware of?
- Are there special traditions at the end of life we should honor?

#### 9. Decision Making and Advance Planning

#### Issues to assess

- Need/desire for information, education and assistance with:
- Advance planning and decision making related to healthcare choices
- Advance directives
- Final arrangements
- Other legal issues

#### **Possible questions**

- Do you have advance directives?
- Do you know we all have the right to make and have our healthcare preferences and choices honored?
- Do you know what advance directives are? Do you want information about them?
- Does your family agree with your decisions?
- How do you want us to give you information in order to help with decisions?
- Do you have final arrangements in place?
- Would you like information about different options for making final arrangements?

#### Plan of Care: Problems, Issues, and Opportunities (PIOs), Goals and Interventions

If an issue is assessed and addressed during a visit, a PIO is opened in the plan of care. A numerical rating is assigned for the severity of the PIO at the start of the visit, for progress made toward the goal by the end of the visit and the interventions that were used are selected. For example, if there is a caregiving crisis, then the focus of that visit may be only on the Care Needs & Safety Concerns PIO and no other PIOs on that visit.

#### Snapshot of the Plan of Care:

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	PIO Category					PIO's	$\mathbf{)}$			
Domain	Category	~	Descript	ion Due to		$\sim$				*
Social Work	1. Care/Safety		1. Care/	Safety : due	to Unmet Care	Needs and	l-or Safety Co	oncerns.		
Social Work	2. Financial	-								
Social Work	3. Prognosis	-								
Social Work	4. Well Being/Adjustment									
Social Work	5. Support									-
Social Work	6. Grief		•						Þ	
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			Int	erventions	selected for: 1	L. Care/Saf	ety : due to	Unmet Car	e Needs a	
		_	Туре		Interventions					*
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		-	Assess		Assess caregiv	er limitations	to providing	i care		
		_	Assess		Assess patient's	s decision-m	haking ability			
		-	Collabor	ate	Assist with plac	ement in nu	rsing facility			
		-	Collabor	ate	Assist with resp	ite stay in n	ursing facility			-
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Once a PIO and Goal are selected they are rated. The severity of the PIO is rated and then the outcome or progress made toward the goal is rated. (shown on next page)

# **Snapshot of Severity Rating for PIO:**

		nity Information	_					
E	) omain:	Social Work						
	PIO:	1. Care/Safety : due to U	nmet Care Needs -	and-or Safety Cor	cerns	\$		<u></u>
Set By/Dis	scipline:	Hansen, Angela	Sv	V Start I	Date:	01/15/2015	10:30	Am
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Results/Outco								
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Snapshot of Outcome Rating for Goal: (set for patient, caregiver or both)

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	Start Date:	01/14/15		<u></u>
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Snapshot of Numerical Rating Language for the Severity of the PIO and the Outcome toward the Goal:

Goal Outcome Lookup	X
Level Outcome	*
0 Care needs met - no safety concerns	
1 Most care needs met - no current safety concerns	
2 Some care needs unmet - potential safety concerns	
3 Many care needs unmet - strong safety concerns	
4 Care needs not met - immediate safety concerns	
	Ŧ
Outcome Level Description	
Care needs met - no safety concerns	A
	-
OK Cancel	

## Specific Language for Each of the Nine Psychosocial PIOS and Goals:

Each psychosocial area is assessed on a continuum and rated using a Likert scale from 0 to 4.

#### 1. Care Needs and Safety Issues

Care Needs Met/No Safety Concerns  $\leftarrow \rightarrow$  Unmet Care Needs/Safety Concerns

- 0 Care needs met no safety concerns
- 1 Most care needs met no current safety concerns
- 2 Some care needs unmet potential safety concerns
- 3 Many care needs unmet strong safety concerns
- 4 Care needs not met immediate safety concerns

#### 2. Financial Needs

No Financial Concerns  $\leftarrow \rightarrow$  Financial Distress

- 0 Financial needs met no financial concerns
- 1 Most financial needs met no current concerns
- 2 Some financial needs unmet potential concerns
- 3 Many financial needs unmet financial concerns
- 4 Immediate financial needs unmet significant concerns

#### 3. Awareness and Understanding of Prognosis

Knowledge/Understanding  $\leftarrow \rightarrow$  Lacks Knowledge/Understanding

- 0 High level of knowledge and understanding
- 1 Substantial knowledge and understanding
- 2 Adequate knowledge and understanding
- 3 Minimal knowledge and understanding
- 4 Lack of knowledge and understanding

#### 4. Sense of Well Being/Adjustment

Sense of Well Being/Adjustment  $\leftarrow \rightarrow$  Lacks Sense of Well Being/Adjustment

- 0 High level of adjustment and sense of well being
- 1 Substantial level of adjustment and sense of well being
- 2 Adequate level of adjustment and sense of well being
- 3 Minimal level of adjustment and sense of well being
- 4 Lack of adjustment and sense of well being

#### 5. Interpersonal Issues and Level of Social Support

Emotional/Social Support  $\leftarrow \rightarrow$  Lacks Emotional/Social Support

- 0 High level of emotional and social support
- 1 Substantial emotional and social support
- 2 Adequate emotional and social support
- 3 Minimal emotional or social support
- 4 Lack of emotional or social support

## 6. Coping Related to Loss and Anticipatory Grief

Effective Coping/Grieving  $\leftarrow \rightarrow$  Ineffective Coping/Grieving

- 0 Effective coping with loss and grief
- 1 Substantial coping with loss and grief
- 2 Adequate coping with loss and grief
- 3 Minimal coping with loss and grief
- 4 Ineffective coping with loss and grief

## 7. Suicidal Ideation and Potential Risk

No Suicidal Ideation/Risk  $\leftarrow \rightarrow$  Suicidal Ideation/Risk

- 0 No evident ideation or potential risk
- 1 Some ideation with low potential risk
- 2 Increased ideation with some potential risk
- 3 Frequent ideation and increased potential risk
- 4 High amount of ideation and immediate risk

#### 8. Cultural Values Related to End of Life

Plan of Care Congruent with Values  $\leftarrow \rightarrow$  Plan of Care Incongruent with Values

- 0 High congruence between plan of care and values
- 1 Substantial congruence between plan of care and values
- 2 Adequate congruence between plan of care and values
- 3 Minimal congruence between plan of care and values
- 4 Lack of congruence between plan of care and values

#### 9. Decision Making and Advance Planning

Knowledge/Understanding of Options  $\leftarrow \rightarrow$  Lacks Knowledge/Understanding of Options

- 0 High level of knowledge and understanding of options
- 1 Substantial knowledge and understanding of options
- 2 Adequate knowledge and understanding of options
- 3 Minimal knowledge and understanding of options
- 4 Lack of knowledge and understanding of options

## **Plan of Care Interventions**

The following section shows the list of possible interventions to be selected for each of the nine PIOs/Goals in the plan of care. Interventions may also be customized.

#### 1. Care Needs and Safety Concerns

PIO: Unmet Care Needs and/or Safety Concerns

Goal: Care Needs Met/No Safety concerns

Assess	Explore care needs and identify safety issues.
Assess	Assess caregiver limitations to providing care.
Assess	Assess patient's ability to make decisions.
Assess	Explore existence of plan for current and future care needs.
Collaborate	Collaborate with caregiver, family, facility, and IDT re: plan of care and needs.
Collaborate	Assist with placement in nursing facility.
Collaborate	Assist with respite stay in nursing facility.
Collaborate	Refer to community resources for additional caregiving assistance.
Collaborate	Request hospice volunteer to provide support and respite for caregiver.
Collaborate	Refer to Adult Protective Services or Child Protective Services.
Educate	Advocate for patient self-determination and desire to remain independent.
Educate	Identify possible consequences of decisions or lack of decisions.
Educate	Educate on disease progression and anticipated changes in care needs.
Educate	Educate regarding options/community resources for additional care.
Therapeutic	Encourage expression and validate feelings regarding decision-making.

Therapeutic	Encourage inclusion of significant others in decision making process.
Therapeutic	Encourage formulation of care plan for future needs.
Custom	Add custom intervention.

#### 2. Financial Needs

Goal: Financial Needs Met

### Interventions:

Assess	Assess financial needs.
Collaborate	Refer and collaborate with community resources.
Educate	Provide information re: options for final arrangements.
Educate	Provide information regarding resources for legal assistance.
Therapeutic	Assist with identification of financial needs.
Therapeutic	Assist with application for SSDI/SSI or MAP.
Therapeutic	Encourage utilization of available community resources.
Custom	Add custom intervention.

#### 3. Awareness and Understanding of Prognosis

- PIO: Lacks Knowledge and Understanding of Prognosis
- Goal: Knowledge and Understanding of Prognosis

Assess	Assess understanding of diagnosis and prognosis.
Assess	Explore understanding related to level of developmental/emotional functioning.
Assess	Explore openness to further information and discussion.
Collaborate	Facilitate access to accurate information.
Collaborate	Involve medical staff to provide specific information.
Educate	Provide information regarding disease process as desired.
Educate	Educate about hospice care and philosophy.
Educate	Educate regarding signs and symptoms of impending death.
Educate	Involve members of the IDT in education regarding end of life process.
Educate	Provide guidance and coaching to adults related to talking with children.
Educate	Provide age appropriate education related to the diagnosis, decline and dying process.
Therapeutic	Establish rapport to promote comfort and trust.
Therapeutic	Encourage expression of feelings and thoughts about the prognosis and/or impending death.
Therapeutic	Facilitate discussion regarding prognosis and/or disease process.
Therapeutic	Provide hospice presence, supportive counseling and emotional support.
Therapeutic	Provide active listening, validation and normalization re: feelings expressed.
Custom	Add custom intervention.

# 4. Sense of Well Being and Adjustment

- PIO: Lacks Sense of Well Being or Adjustment
- Goal: Sense of Well Being and Adjustment

Assess	Assess emotional/environmental factors impacted by illness & physical decline.
Assess	Assess need for assistive devices to improve functioning.
Assess	Assess how children's need are being addressed related to coping and adjustment.
Assess	Explore previous history of anxiety and coping patterns.
Assess	Identify, honor and advocate for wishes and desires.
Assess	Assess support system and need for intervention to facilitate effective coping.
Collaborate	Collaborate with caregiver, family, facility, and IDT re: plan of care and needs.
Collaborate	Identify/refer to community resources to help maintain independence.
Collaborate	Request hospice volunteer for emotional support, socialization and to help with specific tasks.
Collaborate	Refer to community resources for additional assistance.
Educate	Advocate for preferences, choices, and right to self-determination.
Educate	Educate and encourage use of healthy coping strategies.
Educate	Provide information/referral to pediatric community resources for additional counseling.
Educate	Provide supportive counseling and end of life education.
Educate	Teach and encourage use of stress reduction and relaxation techniques.
Therapeutic	Brief counseling to strengthen family/caregiver support.
Therapeutic	Identify critical wishes for remainder of life.
Therapeutic	Identify fears and areas where patient/caregiver can maintain control.
Therapeutic	Encourage and support independence and participation in meaningful activities.
Therapeutic	Encourage expression of feelings and desires related to quality of life.
Therapeutic	Encourage use of existing functions and strengths to enhance coping and adjustment.
Therapeutic	Establish rapport to promote comfort and trust.
Therapeutic	Facilitate strengthening of previous and existing coping skills.
Therapeutic	Provide emotional support and counseling related to loss of functioning.
Therapeutic	Provide short term strength based counseling to reduce stress level and facilitate adjustment.
Therapeutic	Encourage active participation in decision-making.
Therapeutic	Strengthen and support problem solving skills.
Therapeutic	Identify and encourage behaviors and activities that increase sense of well being.
Therapeutic	Encourage use of existing functions and personal strengths.
Therapeutic	Provide support related to patient's loss of functioning.
Therapeutic	Provide supportive presence.
Therapeutic	Validate, normalize and encourage expression of feelings.
Custom	Add custom intervention.

- 5. Interpersonal Issues and Level of Social Support
  - PIO: Lack of Emotional or Social Support
  - Goal: Emotional and Social Support

# Interventions:

Assess	Identify strengths, explore communication patterns, and past coping.
Assess	Assess support system and need to increase interventions to facilitate coping.
Assess	Explore impact of illness on roles and relationships.
Assess	Identify substance abuse issues/concerns.
Assess	Assess desire to change substance abuse behaviors.
Collaborate	Collaborate with local and/or long distance family.
Collaborate	Encourage communication with members of children's support network and/or assist with
	contacting school counselors.
Collaborate	Facilitate identification/creation of support system.
Collaborate	Facilitate patient/caregiver family meeting to enhance communication and collaboration.
Collaborate	Refer to and collaborate with community resources.
Collaborate	Request hospice volunteers to provide socialization, support, and to alleviate isolation.
Collaborate	Identify/refer to community resources for substance abuse treatment.
Educate	Identify/encourage self care and healthy coping strategies.
Educate	Offer social work services.
Educate	Teach and encourage use of stress reduction/relaxation techniques.
Therapeutic	Establish rapport to promote comfort and trust.
Therapeutic	Counseling to enhance functioning and/or strengthen support system.
Therapeutic	Encourage effective communication skills and coping mechanisms.
Therapeutic	Encourage verbalization and normalize feelings related to change.
Therapeutic	Encourage life and relationship review.
Therapeutic	Encourage identification and appropriate expression of feelings.
Therapeutic	Encourage the identification of strengths and the ability to problem solve.
Therapeutic	Facilitate communication with support system.
Therapeutic	Provide hospice presence, socialization, and emotional support to alleviate isolation/loneliness.
Custom	Add custom intervention.

# 6. Coping Related to Loss and Anticipatory Grief

- PIO: Ineffective Coping with Loss and Grief
- Goal: Effective coping with Loss and Grief

Explore knowledge of grief process and assess past and present coping with grief and loss.
Explore knowledge of grief process and provide education as patient/caregiver desires.
Explore need for extra support or assistance at time of death.
Identify losses related to change in condition and illness.

Assess	Identify past and present coping with grief and loss.
Collaborate	Involve members of the IDT in education regarding end of life process.
Collaborate	Refer to community resources re: need for additional and/or specialized counseling/support.
Collaborate	Request an 11 <sup>th</sup> hour volunteer.
Educate	Educate, normalize and validate reactions and feelings.
Educate	Educate/reinforce hospice procedures at the time of death.
Educate	Provide age appropriate educational materials.
Educate	Provide guidance and coaching to adults related to talking with children.
Educate	Teach comfort measures to alleviate physical and emotional symptoms.
Therapeutic	Encourage the offering of choices to family members to participate in closure activities.
Therapeutic	Encourage the expression of feelings.
Therapeutic	Encourage and participate in life review.
Therapeutic	Establish rapport to promote comfort and trust.
Therapeutic	Present and encourage healthy coping and expression of grief.
Therapeutic	Promote anticipatory grief work.
Therapeutic	Provide hospice presence, emotional support and unconditional positive regard.
Custom	Add custom intervention.

# 7. Suicidal Ideation and Potential Risk for Suicide

- PIO: Suicidal Ideation and Potential Risk for Suicide
- Goal: Reduced Suicidal Ideation and Potential Risk

Assess	Assess potential risk for suicide.
Assess	Explore sources of emotional pain and hopelessness.
Collaborate	Collaborate with caregiver, interdisciplinary team and physician.
Collaborate	Encourage and participate in development of a safety plan.
Collaborate	Involve other members of IDT to address concerns related to fear of pain and suffering.
Collaborate	Refer to community resources for additional support and crisis care.
Educate	Educate caregiver regarding options and safety measures.
Therapeutic	Establish rapport to promote comfort and trust.
Therapeutic	Explore concerns and fears related to suicidal ideation.
Therapeutic	Identify and encourage the open expression of feelings.
Therapeutic	Assist in the development of healthy coping strategies.
Therapeutic	Provide hospice presence and supportive counseling.
Therapeutic	Monitor the patient situation and need for further intervention.
Custom	Add custom intervention.

#### 8. Cultural Values

## PIO: Lack of Congruence between Plan of Care and Cultural Values

Goal: Plan of Care Congruent with Cultural Values

#### Interventions:

Assess	Explore meaning of relationships and identify cultural issues.
Assess	Assess comfort with expression of grief in relation to cultural values.
Assess	Explore ways the patient/caregiver receives support in relation to cultural support.
Assess	Identify and honor cultural practices, rituals, and traditions.
Assess	Identify cultural customs and issues related to decision-making and end of life rituals.
Collaborate	Seek community resources to support cultural needs.
Educate	Educate and advocate regarding patient/caregiver's cultural norms and needs.
Therapeutic	Establish rapport to promote trust and provide unconditional positive regard.
Therapeutic	Clarify roles and desired communication related to cultural needs.
Therapeutic	Encourage and validate expression of feelings, thoughts, and desires.
Custom	Add custom intervention.

#### 9. Decision Making and Advance Planning

- PIO: Lack of Knowledge and Understanding of Options
- Goal: Knowledge and Understanding of Options

Assess	Assess desire for adequate and accurate information.
Assess	Explore understanding of advance directives and/or other documents.
Collaborate	Involve medical staff to provide more education as needed/desired.
Collaborate	Refer to community resources for assistance with final arrangements.
Collaborate	Refer to community resources for legal assistance.
Educate	Provide information related to options for final arrangements.
Educate	Provide information related to options for advance directives.
Therapeutic	Assist with completion of advance directives.
Therapeutic	Encourage and/or facilitate discussion of end of life wishes.
Therapeutic	Encourage securing legal documents to designate decision makers.
Therapeutic	Facilitate completion of final arrangements as desired.
Custom	Add custom intervention.

# **Case Scenarios:** (Practice Exercises)

The following section has three case scenarios the reader can use to practice choosing PIOs/Goals in the plan of care and rating the severity of the PIOs.

Instructions: Information presented in each case study is obtained during the Initial Psychosocial Assessment visit. Pick two or three Problems, Opportunities, Issues (PIOs) and Goals to initially open in the Plan of Care. Think about what the patients and caregivers identify as their most important needs and goals, as well as immediate issues to address. You may also open a PIO/Goal in the Plan of Care for an issue to be monitored. Once you indicate which of the nine PIO/Goals to open, rate the severity of the issue from 0 to 4. Remember PIOs/Goals can be opened and closed throughout the cycle of care as needed.

## **Case Scenario 1**

## **Home Patient**

John Smith is a 58 year old Caucasian male with a diagnosis of lung cancer with metastasis to the brain and kidneys. He ambulates with use of a cane and has lost a significant amount of weight. He has received chemo and radiation over the past 18 months without success. During the visit, John stated he is at peace with the decision to stop treatment for the cancer but expressed concern about how his family will cope with this decision.

John has been married to Paula for thirty years and they have two adult children. John lives at home with Paula and their 20 year old son. His daughter lives nearby with her husband, their 5 year old daughter, and she is expecting another baby. John and his daughter have a close relationship. He expressed concern for how she is handling his diagnosis/prognosis as well as the impact of this stress on her current pregnancy.

John has a history of loss which includes his father, sister and brother. He acknowledges that he has never really addressed his feelings related to these losses—particularly the complicated death of his brother. A few years ago, John discovered his brother dead and the cause of death was never identified. He shared his belief that he has never coped very well with loss and expressed a desire to begin talking more about his own loss history.

Due to his inability to work over the past several months, John's wife Paula has become the sole income provider. John and Paula have not yet identified a future caregiving plan and currently John is home during the day while Paula works. Both John and Paula are worried about their financial situation due to their restricted income and they are struggling to pay their bills.

Near the end of the visit, Paula disclosed privately that her husband has a history of alcohol addiction and though he has been sober for several years, she worries that he may start drinking again due to all the current stress.

# **Case Scenario 2**

# **Nursing Facility Patient**

Mrs. S. is a 78 year-old Hispanic female with the diagnosis of End Stage Heart disease. Following a fall in her home, she spent one month in rehab on the skilled unit at the nursing facility. Due to her physical decline she has become unable to participate in physical therapy and she was moved to a long term bed in the facility. Her physician made the referral for hospice care.

Prior to her stay in the nursing facility, Mrs. S lived in her long time home with her spouse of 53 years. The daughter reports she has confusion at times and while she was still at home she began having difficulty sleeping at night and was once found wandering in their yard late at night.

Mrs. S insists nothing is wrong with her and she wants to go home. Her husband is considering plans to take her home and states "family should take care of family." While he remains fairly independent (he still drives and manages their finances), he would need help in assisting his wife with her ADLs.

The daughter is married, has three young children (ages 4, 5 and 7) and works in the mornings. The daughter states she worries about her parents and is concerned she will not be able to assist her father as much as they will need. She feels her mother probably needs to remain in the nursing facility and is concerned about her father's health and ability to care for her mother.

During the initial social work visit with the whole family, the spouse and adult daughter struggled to understand that Mrs. S may not get better and were also not in agreement about what type of care would be best. Mrs. S. repeatedly stated that she just wants to go home.

Advance directives are in place and the daughter is the MPOA for both parents. The daughter relayed that she has spoken with her parents and knows what their desires are for final arrangements, but reports that no plans have been put in place.

## **Case Scenario 3**

#### **Pediatric Patient**

Jamie is a 10-month-old African American male infant born with a congenital birth defect. He was not expected to live but was stabilized in the hospital after his birth. Knowing that his prognosis was poor, the parents took Jamie home with hospice care. In the months that followed, the mother experienced severe, untreated post-partum depression. After she made a suicide attempt resulting in an in-patient hospitalization, the parents decided to move closer to family so they would have more support.

Jamie is cared for by his mother and father who recently moved to the area to be closer to the father's family. The maternal grandmother was present during the visit with the parents and is very involved with the caregiving and decision-making. The parents also have a five-year-old son who is healthy.

During the visit the mother and father appeared to be very bonded with the baby. The father reported significant concerns about finances as neither he nor the mother are currently employed. The maternal grandparents are currently paying the rent and utilities at their apartment but they will only be able to assist financially for a limited time. The father stated he would like to see his wife have more emotional support as he has concerns regarding how she is coping with this transition.

The parents have not shared their baby's prognosis with their older son. The parents both state they know their baby will not live long but they are not yet ready to complete an OOH-DNR. The mother is not currently expressing suicidal ideation and she is taking an anti-depressant. She has not yet been able to find a local resource for psychiatric follow up care or counseling.

This section indicates which PIOs were identified and rated for severity by a group of eight social workers who read the case studies using the prior instructions. They referred to the SWAN Psychosocial Assessment Guide, the Plan of Care Assessment Severity Rating Scale and the list of possible interventions for each of the nine psychosocial areas.

*Case Scenario 1 (Plan of Care PIOs opened):* Financial Needs (average severity rating of 3), Interpersonal Issues & Level of Social Support (average severity rating of 2) and Coping Related to Loss & Anticipatory Grief (average severity rating of 3). Possible PIOs to address in the future: Care Needs/Safety Concerns, Sense of Well Being/Adjustment and Decision Making & Advance Planning.

*Case Scenario 2 (Plan of Care PIOs opened):* Care Needs/Safety Concerns (average severity rating of 2), Awareness & Understanding of Prognosis (average severity rating of 3) and Sense of Well Being/Adjustment (average severity rating of 3). Possible PIOs to address in the future: Cultural Values, Decision making and Decision Making & Advance Planning.

*Case Scenario 3 (Plan of Care PIOs opened):* Financial Needs (average severity rating of 3), Suicidal Ideation & Potential Risk (average severity rating of 3) and Interpersonal Issues & Level of Social support (average severity rating of 3). Possible PIOs to address in the future: Awareness & Understanding of Prognosis and Decision Making & Advance Planning.

## **Frequently Asked Questions**

1) What if you have a question about where to document an issue in the assessment notes? For example, what if the issue seems to fit in either Sense of Well Being/Adjustment or Interpersonal Issues & Level of Social Support?

Refer to the SWAN Psychosocial Assessment Guide to find the most appropriate field. Ultimately, the most important thing is to document the issue in the assessment notes and address the issue in the Plan of Care.

- 2) Will this documentation system pass scrutiny from auditors and surveyors? The SWAN documentation system has been in use for several years and in that time has passed two Community Health Accreditation Program (CHAP) site visits and several state surveys. After a routine federal audit, the auditors commented that the social work documentation was the best that they had ever seen.
- 3) If something is changed in the Plan of Care (adding, discontinuing or changing the PIOs, Goals & Interventions) should this also be documented in the assessment notes?

Yes – a change in the Plan of Care should also be addressed in the assessment notes which allows for a narrative explanation of any changes.

4) What if you assess and then resolve an issue during a visit?

You can open a PIO/Goal in the Plan of Care, rate the severity and the outcome, and then discontinue it for the same visit. For example, the severity of the PIO could be a rating of 4 at the start of the visit. Progress made toward the Goal can be rated a 0 if the problem is resolved by the end of the visit.

### Refer to the appendices for the:

- **SWAN Psychosocial Assessment Guide** for clarification on issues to be addressed in the nine areas or fields in the assessment notes.
- SWAN Psychosocial Assessment Areas and Hospice Plan of Care for the numerical ratings for PIOs and Goals in the Plan of Care.

#### References

- 1. Centers for Medicare & Medicaid Services (2008). Hospice Conditions of Participation Final Rule. Retrieved from: https://www.federalregister.gov/articles/2008/06/05/08-1305/medicare-and-medicaid-programs-hospiceconditions-of-participation.
- 2. Hansen, A.G., Martin, E.E., Jones, B.L., & Pomeroy E.C. (in press). Social Work Assessment Notes: An Outcomes-Based Hospice Documentation System. *Health and Social Work*.
- 3. Mularski R.A., Dy, S.M., Shugarman L.R., Wilkinson A.M., Lynn J., Shekelle P.G., Morton S.C., Sun V.C., Hughes R.G., Hilton L.K., Maglione M., Rhodes S.L., Rolon C., & Lorenz K.A. (2007). A Systematic Review of Measures of End-of-Life Care and Its Outcomes. *Health Services Research*, 42 (5), 1848-1870.
- 4. Reese, D. J., Raymer, M., Orloff, S. F., Gerbino, S., Valade, R., Dawson, S., . . . Huber, R. (2006). The Social Work Assessment Tool (SWAT). *Journal of Social Work in End-of-Life & Palliative Care*, 2(2), 65-95.
- 5. Teno J. (2004). Time: Toolkit of Instruments to Measure End-of-Life Care. Accessed January 27, 2010: http://www.chcr.brown.edu/pcoc/indextools.htm.

#### Resources

National Consensus Project Clinical Practice Guidelines for Quality Palliative Care http://www.nationalconsensusproject.org/Guidelines\_Download2.aspx

National Hospice and Palliative Care Organization Quality Standards http://www.nhpco.org/qualitypartners