

Transition Planning

A three part series for direct support professional's to help meet the complex needs related to transition planning.



Day 3: Aging Transitions

Thursday March 2, 2017



ConnectABILITY.ca

PARTICIPANTS GUIDE

Introduction

OVERVIEW

The Toronto Networks of Specialized Care in partnership with the DSTO Shared Learning Forum and ConnectABILITY.ca will develop a 3 part Certificate Series for direct support professional's to help meet the complex needs related to Transition Planning. It will be 3 training modules (Day 1: youth; Day 2: adult; Day 3 aging) that will cover a 3 month period and will include DS sector agencies as well as our community partners from Health, Education and Justice. The presentations will be available on video and access to the videos and supporting resources can be found on ConnectABILITY.

LEARNING OUTCOMES

With respect to transitions across the lifespan and sectors, this 3-day event will help participants to:

1. Identify effective strategies to improve system access and navigation for clients and families
2. Use effective planning and decision-making to improve client wellbeing
3. Support client needs relating to their rights and lifestyles
4. Construct a network of individuals who can provide expertise and support

AGENDA

Time	Activity
8:30 am	Breakfast, Registration
9:00 am	Welcome and Introductions
9:30 am	Opening Activity
10:00 am	Presentation G
11:00 am	Break
11:15 am	Presentation H
12:15 pm	Lunch
1:00 pm	Review of Case Study
1:30 pm	Break
1:45 pm	Presentation I
2:45 pm	Closing Activity

WORKING AGREEMENT

In order to ensure all participants have a safe and enjoyable learning experience, it is important that everyone agrees to some basic working principles for the next two days, including:

- Confidentiality will be respected; what is said in the room stays in the room.
- Diversity will be respected; everyone has different levels of knowledge and experience and is entitled to their point of view.
- Everyone will work to create a safe environment so people can feel comfortable sharing their thoughts; disrespectful language or actions will not be tolerated.
- We acknowledge that one approach often does not fit all and that the diversity that both informal and formal helpers bring to a situation can be a strength and an asset.
- Active participation will help to ensure an effective learning experience; however, individuals have the right to decline providing feedback if they are uncomfortable.
- Everyone will make every effort to arrive on time, return from breaks/lunch on time, and to stay until the end of the session.
- Everyone will turn mobile devices off or set on vibrate throughout the day; any calls that must be answered will be taken outside the room.

SESSION EVALUATION AND KNOWLEDGE TRANSFER

- Your feedback is critical to help ensure the continued quality and effectiveness of this session. At the end of the day, please complete the evaluation form provided.
- Around three to six months after the course has been completed, we will e-mail you a brief online survey asking for your feedback about how you have applied the knowledge you acquired from the course and how you are doing on your personal commitments

Welcoming Activity

SELF-REFLECTION

What do you hope to get out of this session?

If you were to describe to a fellow participant the work you do in two to three sentences, so that they could understand what kind of help or assistance you could give them in the future, what would you say?

TABLE DISCUSSION

At your tables, take turns introducing yourself (name, title, agency); briefly mention the kind of work you do and/or services you provide and share what you hope to get out of the session.

Day 3 – Case Study



Margaret

Margaret is 57. She has Down's syndrome and early onset dementia. She lives with a roommate in a SIL apartment. She and her roommate have lived together for 16 years but recently both have increased health needs. Margaret requires more daily supports to manage her care and support changes to her independence is feeding and personal care.

She has refused staff entry into her apartment at times and does not want to leave her roommate. Her roommate will be moving to a palliative care home soon. Margaret often forgets this and becomes upset when she is told. She does not want to lose her roommate and feels like she is 'next'.

What are the next steps for supporting and planning for Margaret and her increased needs? What are some ways to support and mitigate her fears? What resources could you access to help with this transition? What are some ways your agencies current programs and services could assist Margaret?

Approaching our work through the Lens of Equity and Diversity (day 3)

Presented by

Ilaneet Goren, Harmony Movement

Opening Activity



Harmony Movement
Be the Change

Approaching our Work through the Lens of Equity and Diversity

PART 3

Presentation by
Harmony Movement

Ilaneet Goren,
BSW, MSW, RSW, Life Skills (Cert.)





About Harmony Movement

Harmony Movement is a leading provider of equity, diversity and inclusion training and leadership development in Ontario.

We work with a diverse range of clients in the public, private and government sectors.



Visit us at: harmony.ca





- Responsibility to develop Diversity, Equity and Inclusion awareness and analysis (a lens)
- Ensure that *all* individuals and families receiving services feel respected, included, and have an equal opportunity to achieve their best possible outcomes





Opening Activity

 **The Airplane Game**





 **Was this who you were envisioning?**





 **How can we overcome bias?**

STEP 1	Recognize we all have bias because we are human, but we can gain control over it by learning and “unlearning.”
STEP 2	Reflect on your own biases and consider your sources of information: how do you learn about people who you perceive as “different” from you? Where do your ideas come from?
STEP 3	Practice noticing when a biased thought or image comes up in your mind, and check if it’s based on generalization, stereotypes or misinformation (e.g. “Boxers are...”)




Opening Activity

 **Food for Thought:** 

- How do biases show up in our work?
- How do assumptions and pre-conceived ideas about different ethnocultural groups hinder inclusivity? How about our ideas on sexual and gender diversity, and what we consider as “right” or “wrong”?
- **What can help us widen our radius of awareness to include more of the human diversity around us?**

Harmony Movement Be the Change


 **Your Equity Ch**


Google:

Harvard Implicit Association Test

Test your bias!

Harmony Movement Be the Change

 **Harmony Movement**
Be the Change



Questions? Comments?
Connect with us:

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Check out our resource for educators: www.harmony.ca/resources

Harmony Movement Be the Change

Long-Term Care: Reframing the Conversation

Presented by:

Cindy Dodd

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Notes

Phase 1: Is this a good idea?

Phase 2: How do you get the right information to effectively complete the assessment?

Phase 3: How does the home look at the application and make a decision if they can take the person?

Phase 4: Once the person is accepted to the home, what could happen to make transition better?

Aging and Primary Care

Presented by

Shara Ally, Healthcare Coordinator
(Transitions), Surrey Place


Presentation H

Transition Series: How Primary Care Providers Can Anticipate and Participate in Improving Aging for People with Intellectual and Developmental Disabilities and Comorbidities




Shara Ally, Advanced Practice Nurse
BScN, RN, MN, MBA (c)

Objectives



- Review the purpose of the Developmental Disabilities Primary Care Program (DDPCP)
- Examine the purpose of advanced care planning
- Analyze & synthesize the role of primary care providers providing support to people with IDD/comorbidities who are transitioning into older adulthood



Aim of DDPCP



Presentation H



Item	Price
Referrals (e.g., medical, day programs, etc.)	\$1.00
Crisis Management	\$2.00
Power of Attorney	\$2.00
Health Education/Management	\$4.00
Medication Education/Management	\$3.00
Legal Education/Management	\$2.00
Financial Education/Management	\$3.00
Housing Education/Management	\$4.00



Presentation H



Case Study

Patient ID:
Patient Name: Margaret
Age: 50 years old
Gender: Female
Medical Diagnoses: Down's syndrome, early onset of dementia; history of epilepsy; has health passport
Housing: Currently lives with parents
Power of Attorney: Parents
Finances: Managed by parents
Communication: Family health team communicate mostly with parents vs. with Margaret
Reason for visit: Parents are aging and are working with the family health team, Margaret and other family members/caregivers to make decisions about Margaret's future; topics discussed:

1. Parents making important decisions around next steps with Margaret's current living situation; Margaret has a sister, however is unable to provide her with housing because she does not have the capacity to support Margaret and her own family.
2. Margaret's sister will be taking over power of attorney when parents are no longer able to do so
3. Medical: (a) Margaret is aware of the above changes and is beginning to have more seizures; (parents believe she is anxious about future changes) causing caregiver stress and burnout. (b) Janey needs to see a specialist for cervical cancer screening due to abnormal cells detected from her recent PAP smear
4. ER visits: Margaret has had 2 ER visits within the last 3 weeks due to aggressive behaviour


Case Resolution: Anticipating and participating to prepare in advance for Margaret's transition to aging adulthood

- Explore Margaret's concerns/fears
- Discuss Margaret's future goals
- Consider appropriate referrals
- Review goals of family/caregivers
- Determine effective communication technique with Margaret
- Assess for consent and capacity
- Determine power of attorney, housing options, financial aid

- Review medical needs and referrals (e.g., cancer, epilepsy)
- Review reasons for ER visits; create or innovate crisis management plan


Presentation H

Conclusion & Recommendations



Consider barriers

Implications



Acknowledgements:
DDPCP: Dr. Bill Sullivan (MD, PhD) & Dr. Heidi Diepra (PhD)
DDPCP colloquium members: National members
Surrey Place Centre: Dr. Terri Hewitt (PhD) & colleagues



Want more information?

Visit the following website:

<http://www.surreyplace.on.ca/resources-publications/primary-care/tools-for-primary-care-providers/>

Shara Ally: shara.ally@surreyplace.on.ca



Presentation H

Guideline 2: Communication

Background	Action
<p>Communication is considered essential to good healthcare by both healthcare providers and patients with IDD (Baumbush, 2014; Lennox, 2007; Wilkinson, 2013). People with IDD may present with a variety of difficulties in language comprehension, expression or social interaction (Espinoza 2016; Iacono, 2004).</p>	<p>Communicate directly with adults with IDD by themselves. When including their family or caregiver in discussions do so in a way that respects their wishes and abilities (Olney, 2001; Wullink, 2009; Forster, 2016).</p> <p>Be attentive to both verbal and nonverbal cues, learn about the individual's preferred communication method, slow down, and use adapted tools to ensure the person is able to make their perspectives, needs and preferences understood and can understand what is being communicated (e.g., DDPCI Communicating effectively; Books Beyond Words).</p>

Guideline 3: Capacity for voluntary and informed consent

Background	Action
<p>Capacity for voluntary and informed consent varies with the complexity and circumstances of decision making. The limited range of life experiences of some adults with IDD, level of intellectual and adaptive functioning, learned helplessness, and mental health issues might impair capacity to give voluntary or informed consent (Heng, 2014; Sullivan, 2014).</p>	<p>Assess capacity for consent when proposing investigations or treatments for which consent is required, using an adapted tool (DDPCI, 2011). When the primary care provider cannot determine capacity for consent, refer to a psychologist, psychiatrist or other professional trained to conduct such capacity assessments (CRPD, Article 12; Heng, 2011).</p>
<p>Communicating appropriately with adults with IDD is necessary for assessing their capacity to consent and for seeking this consent (O'Dell, 2012).</p>	<p>Adapt communication to the patient's intellectual and adaptive functioning. Involve family or other caregivers to facilitate communication with, and understanding of, the patient with IDD, but be attentive to inappropriate taking over of decision making (Heng, 2011; CRPD Article 2).</p>
<p>A family member or guardian (but not an accompanying volunteer, paid caregiver or support worker) normally has the legal authority to consent on behalf of an adult with IDD who is assessed to be incapable of providing voluntary or informed consent (Sullivan, 2011). Such patients might still be able to convey, through verbal or other means, perspectives that can inform the judgment of a substitute decision maker and primary care provider (Heng, 2014; Sullivan, 2014).</p>	<p>In pursuing or forgoing any health care intervention for an adult with IDD assessed to be incapable of providing voluntary or informed consent, support whatever decision-making capacity is possible in this person. Support substitute decision makers in determining the patient's best interest, guided by knowledge of the kind of person the patient is (Heng, 2011; CRPD Amended Article 12).</p>

Presentation H

Guideline 4: Care of family and caregivers

Background	Action
<p>Families and caregivers of people with IDD often experience significant mental, physical or economic stress in balancing the person with IDD's support needs with other responsibilities (Williamson, 2014; Dawson, 2016).</p> <p>An increase or change in needs or a negative life event can lead to a crisis situation (James 2013; McKenzie, 2016; Ryan 2016).</p> <p>Mindfulness practice, mutual care, and receiving supports for self-care and coping can improve the experience of family and other caregivers, and lead to better quality of care (Hwang, 2014; HD add reference supports evidence).</p>	<p>Proactively attend to the emotional, informational and practical support needs of caregivers (Perkins, 2016; Taggart, 2012).</p> <p>When family or caregiver concerns arise, assess and monitor family/caregiver stress ? <i>respite here?</i> (e.g., Brief Family Distress Scale, Weiss, 2011).</p> <p>Provide resources on self-care and coping strategies to family and other caregivers (e.g., Positive Behaviour Supports, mindfulness <i>explore and discuss respite care? - Karen</i>) (Lunsky, 2016; Perkins, 2016).</p>

Guideline 23: Epilepsy

Background	Action
<p>Epilepsy occurs in about 1 in 5 individuals with an IDD compared with 1 in 100 people without an IDD (Robertson, 2015b). It contributes to early mortality (Robertson, 2015a). It can be difficult to diagnose (NICE, 2016, Chapman, 2011). Choice of treatment and importance of regular monitoring are the same as for the general population (NICE, 2016).</p>	<p>For people with IDD and epilepsy, make a comprehensive epilepsy care plan (NICE, 2016), involving patients, family and other caregivers, and review at least annually (Branford, 2015). The review could include assessing seizure control, adverse effects of drugs including cognitive and behavioural effects, adherence, consideration of misdiagnosis, psychosocial issues, acute seizure management plans, reducing risk for injuries and death, caregiver burden, fertility regulation and follow-up by epilepsy specialist. In addition, review anti-epileptic drugs regularly, e.g., every three months (Devinsky, 2015).</p> <p>Consult epilepsy guidelines and use tools for periodic reviews, diagnosis and management (Branford, 2015; DDPIC seizure tools; NICE, 2016; Whitten, 2007).</p>

Presentation H

Guideline 26: Cancer screening

Background	Action
<p>People with IDD are less likely than the general population to be included in preventive cancer screening programs including cervical, breast, and colorectal cancer screening (Cobigo, 2013, Ouellette-Kuntz, 2015ab). Factors include lack of knowledge of family history to appropriately inform screening intervals, logistic challenges with performing tests, lack of adapted patient education tools and family member reluctance and fears (Greenwood, 2014; Merten, 2015).</p>	<p>Proactively obtain information on family history of cancer for patients with IDD and repeat annually if indicated (Canadian Task Force, 2016)</p> <p>Utilize clinical tools for adults with IDD to promote education and uptake of cancer screening tests. Discuss concerns regarding cancer and symptom management with family and other caregivers and provide information regarding treatment and palliative care (Greenwood, 2014).</p>
<p>People with IDD are less likely to be able to self-monitor and report symptoms and signs of cancer. Consequently, people with IDD who develop cancer often have more advanced cancer at the time of presentation than the general population (Satge, 2014).</p>	<p>Perform a complete skin survey as well as breast examination in adult women and testicular examination in adult men with IDD during periodic health assessments.</p> <p>Proactively instruct patients on natural self-monitoring, as would be considered routine in the general population (e.g, being breast aware, reporting gross hematuria, changes in moles) (Canadian Breast Cancer Foundation).</p> <p>Instruct family and other caregivers regarding observable signs and symptoms of cancer to seek prompt medical attention (Canadian Breast Cancer Foundation, Canadian Cancer Society).</p>

Presentation H

Guideline 31: Behavioural crises

Background	Action
<p><i>Behavioural crises</i> may arise from a variety of circumstances and in response to stressors. When behaviours can no longer be managed safely in the current environment, a situation can escalate to crisis and require assessment and management in an emergency department.</p>	<p>When psychotropic medications are used to ensure safety during a behavioural crisis, ideally such use should be temporary and stopped after 72 hours of usage (Glover, 2014).</p>
<p>A subgroup of people with IDD who visit the emergency department for mental health or behavioural reasons do not have any follow-up with primary care or psychiatry within 30 days of their visit (Balogh, 2013).</p> <p>Follow-up is crucial to continuity of care, prevention of recurrence, and the need to review any medication prescribed to manage the crisis.</p>	<p>Debrief with the patient and caregivers as soon as possible after the emergency department visit in order to minimize the likelihood of recurrence. This should include a review of crisis events and responses (e.g., medication, de-escalation measures), and identification of the possible triggers and underlying causes of the behavioural crisis (Bradley, 2005; Deb, 2009)</p>
<p>Crisis plans are considered helpful to hospital staff and people with IDD and caregivers (Bell, 2012; Hemmings, 2013)</p> <p>People with IDD with primary care involvement and care or crisis plans are less likely to visit the emergency department when a crisis arises (Lunsky, 2012).</p>	<p>If the patient is at risk of recurrent behavioural crises, involve key stakeholders, including local emergency department staff, to develop a proactive, integrated crisis plan which should be available in the emergency department, and regularly updated .</p>

Presentation H

Guideline 33: Dementia

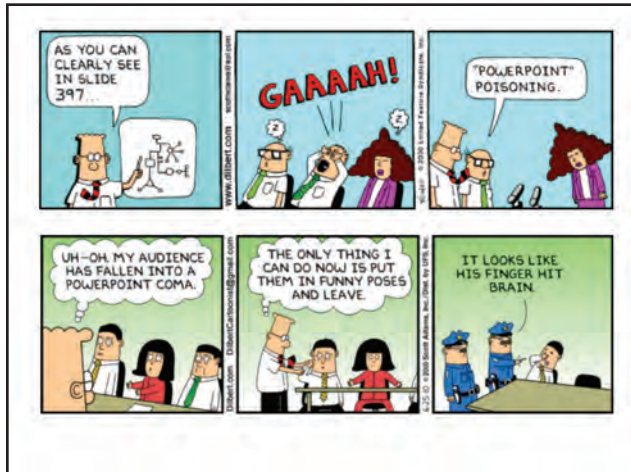
Background	Action
Adults with IDD are at increased risk for developing dementia compared to the general population (age of onset 60-65 years), with a significant increased risk in adults with Down syndrome and at an earlier age (50-55 years) (Dodd, 2015; Prasher, 2014).	Recognize possible early warning signs of dementia such as forgetfulness, new incontinence, loss of personal skills, changes in sleep patterns and in personality and behaviour.
Diagnosis might be missed because changes in emotion, social behaviour, or motivation can be gradual and subtle. A baseline of functioning against which to measure changes is needed (Dodd, 2015).	<p>Refer individuals who are known to be at risk of dementia to a psychologist for a baseline assessment of cognitive, adaptive and communicative functioning after age 40 and at age 30 in individuals with Down syndrome (Dodd, 2015).</p> <p>Monitor with tools designed for people with IDD and dementia (e.g., NTG-Early Detection Screen for Dementia)[hyperlink] (Jokinen, 2013; National Task Group on Intellectual Disabilities and Dementia Practice, 2013; Sheehan, 2014).</p> <p>Educate family and other care providers about early signs of dementia and dementia care (Herron, 2014; Sheehan, 2014). [hyperlink Herron, 2014]</p>
Differentiating dementia from depression and delirium can be especially challenging in adults with IDD (Gangadharam, 2015).	<p>Apply the differential diagnosis criteria for dementia and delirium as in the general population using the HELP framework to review signs and symptoms of concern (Alvarez 2015). After addressing any medical findings and precipitating life events, consider the possibility of depression: A trial of antidepressant might lead to resolution of symptoms and aid clinical diagnosis (Prasher, 2014).</p> <p>When signs of dementia are present, investigate for potential reversible causes including infections, thyroid disorder, hearing impairments, nutritional deficiencies; cardiovascular disease (Alvarez, 2015).</p> <p>Refer to the appropriate specialist (e.g., psychiatrist, geriatrician, neurologist) if it is unclear whether symptoms and behaviour are due to emotional disturbance, psychiatric disorder, or dementia.</p>

Palliative Care Across the Lifespan

Presented by

Tracey Human

Presentation I





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Ensuring Quality of Life



SLF TRANSITIONS CONFERENCE

PALLIATIVE CARE
Session

Presentation I

Conflict of Interest Declaration

- None to declare

Learning Objectives

- Identify effective strategies to improve system access and navigation for clients and families
- Use effective planning and decision-making to improve client wellbeing
- Support client needs relating to their rights and lifestyles
- Construct a network of individuals who can provide expertise and support

Improving System Access & Navigation

Starts with:

- Sharing Common Language
- Shared Understanding of Palliative Care
- Shared Readiness & Collaboration
- Shared strengthening intersection between Ministry of Community & Social Services programs and MOHLTC services & programs



Presentation I

Definition of Transition

Youth

- Transition is a process involving the purposeful, planned movement of youth with developmental disabilities from child-centred to adult-oriented care. Transition can be contrasted with a Transfer. Transfer is a one-time event in which the responsibility of care for a young person with a developmental disability moves from child-centred care to adult-oriented care.

Older

- **Transition between chronic progressive illness stages (disease progression)**
 - Established disease
 - Controlled Chronic disease
 - Advanced Chronic disease
 - End-stage disease
- **Transition to end of life**
 - Indicated by general indicators of decline
 - Specific clinical indicators related to specific illness diagnoses
 - Life expectancy of less than 12 months; 6 months; 3 months (then hours to days; days to weeks)
- **Transition between health care settings**
 - Hospital to home; to residential hospice; to PCU's

Palliative Care



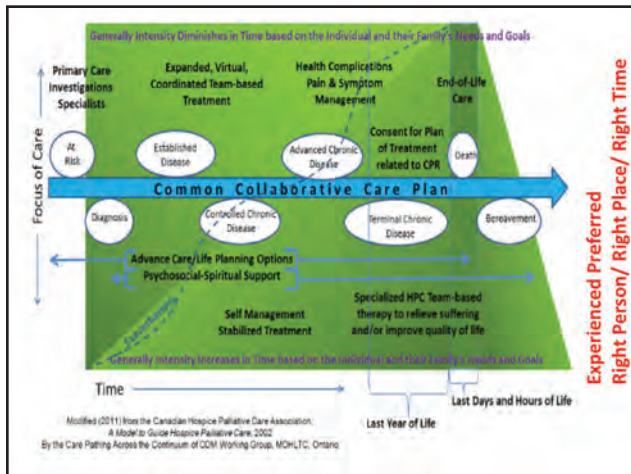
Palliative Care

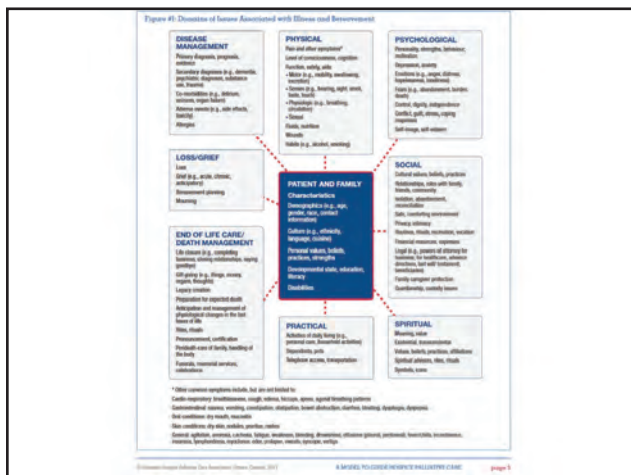
"an approach that improves the quality of life of individuals and their families facing the problems associated with life-limiting illness, through the prevention and relief of suffering by means of early identification, impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual"

CHPCA, 2013

- **quality and consistency of care depends to a great extent on the *knowledge and skills* of formal care providers and *how effective they work as a team***
- The focus is on anticipating needs for the ***right care at the right time delivered by the right team*** that aligns with medically expected outcome & matching informed goals of care

Presentation I





Unidentified Need = Unnecessary Suffering

- Erratic and traumatic transitions
- Missed opportunity for effective care planning that aligns with preference and wishes
- Crisis clinical presentation for individual/family & care burden/exhaustion (physical & emotional)

Just as there are developmental landmarks and tasks described for other points along life's journey, there are developmental landmarks and tasks for end of life

Presentation I

Life closure landmarks

Dr. Ira Byock
Palliative medicine specialist
Professor at Dartmouth
Medical School

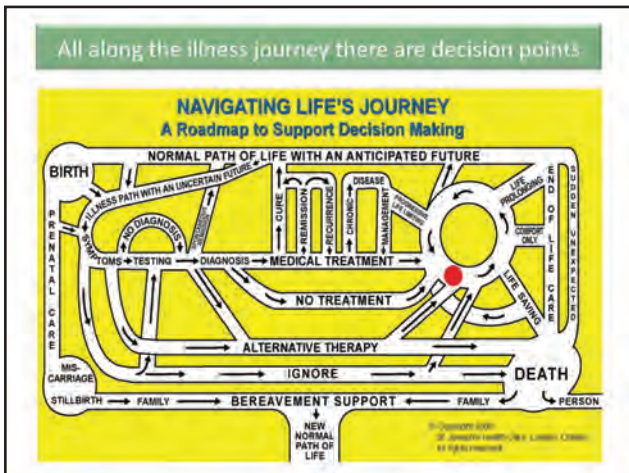
[Dying Well: Peace and Possibilities at the End of Life \(1997\)](#)

Landmarks	Tasks
Sense of completion with worldly affairs	Transfer of financial, legal, and formal social responsibilities
Sense of completion in relationships with community	Choice of suitable social administration (employment, community, organizational, coverage benefit). Components include: expressions of regret, expressions of forgiveness, acceptance of gratitude and appreciation. Leave taking, the saying of goodbye.
Sense of meaning about one's individual life	Life review: the telling of "one's stories"; Transmission of knowledge and wisdom
Expressed love of self	Self-acknowledgment; Self-forgiveness.
Expressed love of others	Acceptance of weakness.
Sense of completion in relationship with family and friends	Reconciliation, release of communication and closure in each of one's important relationships. Component tasks include: expressions of regret, expressions of forgiveness and acceptance, expressions of gratitude and appreciation, acceptance of gratitude and appreciation, expressions of affection. Leave taking, the saying of goodbye.
Acceptance of the reality of the end of one's existence as an individual	Acknowledgment of the totality of personal loss represented by one's dying and experience of personal pain of existential loss. Expression of the depth of personal tragedy that dying represents. Emotional withdrawal from worldly affairs and existential connection with an enduring context. Acceptance of dependency.
Sense of a new self (personhood) beyond personal loss	Developing self-assessments in the present.
Sense of meaning about life in general	Achieving a sense of awe, recognition of a transcendent order; Developing/behaving a sense of conduct with others.
Transition to the "transcendent," to the unknown: "letting go?"	In pursuit of this landmark, the "door" and "threshold" are seen. How: like neurons of the eye except the vision to survive.

Readiness & Collaboration

Navigation Starts with:

- Early ID & Warning signs of health status change
- Decision Points for Clinical Planning
- ACP; Goals of Care; Preferred location for end -of-life care; Care planning
- Awareness and linking to appropriate network of chronic progressive illness experts; palliative care experts; healthcare providers & resources



Presentation I

Early ID is Key to Support Needs/Rights


- **Seamless transitions**
- **Care in right place; at the right time; by right team**
- ID Change in Condition/ be aware of those at risk
- ID need, understand what it can mean so can move to action
- Connect the circle of care



The collage includes a patient in a hospital bed, a patient in a home care setting, and a group of hands forming a circle with the word 'YES' in the center. The word 'NO' is also visible in the top right of the collage.

How Do We ID Early

- **Team approach**
- **Functional decline - 1st ID**
- **Correlated to illness trajectory – 2nd ID**
 - Steady decline
 - Sudden erratic decline (urgent; emergent)
- *These individuals benefit from additional assessment, management, monitoring & support in-house*
- *For the opportunity to deliver optimal care*
 - Transitional & end-of-life
 - Well controlled pain & symptoms
 - Meeting psycho-social, emotional & spiritual needs



Functional Decline Correlates to estimating Survival

There are several functional assessments used

- PRFS (Patient Reported Functional Status)
- ECOG (Performance Status)
- Barthel Index
- FAST
- Others

Gold Standard in Palliative/EOL care

- Gold Standard Framework
- PPS
- PPI

↓ Function
↑ Disease progression
↑ Symptom Burden
= Closer to End Of Life

Therefore need planning and coordination

Links to expert teams

ACP; goals of care; location of care; Health care consent considerations

Presentation I

Palliative Performance Scale (PPSV2) version 2 (developed by Victoria Hospice Society)

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level	
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full	Stable 70-100%
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full	
80%	Full	Normal activity with Effort Some evidence of disease	Full	Normal or reduced	Full	
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full	Transitional 40-60%
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion	
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion	
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly 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	End-of-Life 0-30%
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	-	-	-	-	

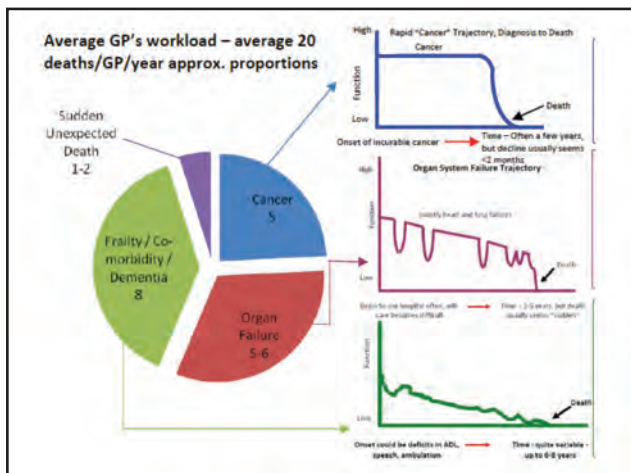
gold standard framework
4th Edition
October 2011

The GSF Prognostic Indicator Guidance
The National GSF Centre's guidance for clinicians to support earlier recognition of patients nearing the end of life

- Predicting needs rather than exact prognostication
- The focus is on anticipating likely needs so that the right care can be provided at the right time
- This is more important than working out the exact time remaining and leads to better proactive care in alignment with preferences

Three triggers that suggest that patients are nearing the end of life are:

1. The Surprise Question: 'Would you be surprised if this patient were to die in the next few months, weeks, days'?
2. General indicators of decline - deterioration, increasing need or choice for no further active care.
3. Specific clinical indicators related to certain conditions.



Presentation I

ID the Change

Something is Changing & Requires Attention

- Behaviours/ Habit changes (social; depression; anxiety)
- Cognition
- Functional ability
 - Motor (mobility; swallowing)
 - Senses (hearing; vision: smell; taste; touch)
 - Physiological (breathing; circulation; bladder & bowel)
 - Sexual
 - Practical (iADLS; ADLs)
- Pain & symptoms
- Fluid/Nutrition

Stop and Watch Early Warning Tool

If you have identified a change while caring for or observing a resident, please circle the change and notify a nurse. Either give the nurse a copy of this tool or review it with her/him as soon as you can.

S	Seems different than usual
T	Talks or communicates less
O	Overall needs more help
P	Pain – new or worsening; Participated less in activities
a	Ate less
n	No bowel movement in 3 days or diarrhea
d	Drank less
W	Weight change
A	Agitated or nervous more than usual
T	Tired, weak, confused, or drowsy
C	Change in skin color or condition
H	Help with walking, transferring, toileting more than usual

☐ Check box if no change noted on the corresponding part of the scale

- Changes from the resident's "normal" can be a signal of medical change

Normal baseline

Change(s) (New "normal")

- *Why are they changing?*
- *Distressed? Why?*

Detecting Change Tools

<p>Early ID Tools</p> <ul style="list-style-type: none"> • Stop & Watch (Early Warning Tool) • ISAR Tool • Dis DAT <ul style="list-style-type: none"> – Disability distress tool • PAINAD <ul style="list-style-type: none"> – For identifying pain in non-verbal or cognitively impaired individuals • DOLOPLUS <ul style="list-style-type: none"> – Identifying behaviour changes (not just elderly) 	<p>Clinical Assessment Tools</p> <ul style="list-style-type: none"> • Gold Standard Framework • PPS <ul style="list-style-type: none"> – Palliative Performance Scale • ESAS <ul style="list-style-type: none"> – Edmonton Symptom Assessment Tool • Many other function change assessment tools (physical and cognitive)
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Presentation I

Early Warning Signs

- **Chronic progressive illness(s)**
 - Associated Signs & Symptoms
 - Worsening or new symptoms
- **Functional decline**
 - Is there slow deterioration (steady)
 - Are the changes happening quickly (unstable)
- **Increasing medical appointments & specialists**
 - Increasing medication changes; medications not working; new medications
- **Recent hospitalizations/ ER visits in last year**

Distressed? Why?

Examples:

- Is it new or worsening pain or other symptom?
- Just a fall? a break? or functional decline warning of illness progression?
- Just indigestion or H. Pylori? Or stomach or intestine cancer?
- Just aches or lymphoma
- Just a fever or pneumonia? Or Leukemia?
- Just weight gain or heart failure?

Always ask WHY
As you know Behaviors are Language!

Building Networks of Experts

Stable	Transitioning	End of Life
Family Physician Chronic Disease Specialists	Family Physician Chronic Disease Specialists Acute Care PCUs for symptom exacerbation management & return home Palliative Navigators PPSMC(staff training/ consultation/ linking to palliative resources) CCAC Rapid Response Nurses Home visiting teams PSW, Nursing Community Hospice Teams Volunteers Psycho-social Spiritual Grief & Bereavement	Family Physician shared care with Palliative Physicians Tertiary Palliative Physicians (Hospital/PCUs) Home visiting Palliative physician teams PCUs for symptom exacerbation & return home Palliative Navigators PPSMC (staff training/ consultation/ linking to palliative resources) CCAC Home visiting teams Palliative Nurse Practitioners PSW, Nursing End of Life Residential Hospices

Presentation I

When To Connect

- When health changes
 - Speed up
 - More health events coming closer together
 - ER trips for symptoms
 - Hospitalized and transitioning back home
 - When seem to be destabilizing
 - When medical management seems to no longer be working
 - When cognitive impairment appears or worsens
 - Advancing chronic disease burden
 - New or worsening pain & symptoms
 - Falls
 - Decreasing mobility
 - Consistently decreasing appetite/wt loss or wt gain
 - Fatigue
 - When care needs exceed what can be delivered in current location
 - Caregiver exhaustion

Margaret

Age 57 with Down's syndrome; Hypothyroidism anemia (low iron in the blood); Congenital Heart ; Pulmonary Hypertension; Cardiomegaly; Cardia arrhythmia (atrium and ventricle); High cholesterol; Cataracts vision; Transmission hearing loss "Glue Ear"; GERD; DA; Degenerative changes upper spine; Early menopause; Early onset Dementia

She has lived with a roommate in a 511 apartment for 15 years. Margaret has been needing more supports to manage living independently and with her personal care. Where she once loved visitors and social activities she no longer likes to leave the apartment. She has refused staff entry into her apartment at times and does not want to leave her roommate. Her roommate will be moving to a palliative care home soon. Margaret often forgets this and becomes upset when she is told.

She watched her roommate go in and out of hospital and is afraid she will have to go to the hospital again too. She remembers vividly her experience admitted to hospital 1 year ago for pneumonia. She was started on CPAP there and has it at home too but is now forgetting to put it on. She has had recurrent bladder and middle ear infections for which she had to see her family doctor each of the last 3 months. She is not telling her support team about the changes she is experiencing.

This morning she lets you in to her apartment. She has lost weight, when she walks you notice her gait seems unstable and she admits she fell earlier "but I didn't hurt myself", when she speaks you notice word finding is a challenge at times; she is withdrawn and sad. You arrange to bring her some of her favorite foods tomorrow afternoon to check in on her again.

You arrive about 2 PM in the afternoon. She is still in same pajamas from yesterday; has swelling in both feet to above her ankles. She looks worn out, more than just tired. She thinks it is because she has not been sleeping well, "It is too hard to breathe when I go to bed". "I think someone is coming into our apartment at night too. I hear things. I see things in my room so I am afraid at night". Over the time spent together you notice when you are talking together she is slow to respond; although she has lost weight her abdomen is rounder; she declines any food; she got dizzy when she stood to go to the bathroom and had to sit down again; You assisted her to the washroom and she was short of breath but it settled again when she sat down for a while; she tells you "my heart was really thumping there for a bit. I'm OK now"; she looks pale and you feel very uneasy about leaving.

What are the changes? What could they mean? Who do you ask?
What's your action? Who do you want to connect with for transition support?

ID the Change <i>Right Time</i>	What's Your Action <i>Right Care; Right Place</i>	Connect <i>Right Team</i>
What are the warning signs	Decision making point What is the need	Who has the expertise
<i>What could it mean?</i>	<i>Does the situation require clinical assessment?</i> <i>What needs to be done that aligns with preferences, wishes, medically expected outcomes?</i>	<i>How will you connect and contact them?</i>

Presentation I

Recap

- To improve access and seamless system navigation for high quality individualized whole person centred care
- Decision making points to Plan effectively
- Early ID of functional decline and Early warning signs of change
- Move to action to ensure autonomy to "Right Care Right Place; Right Time. Plan in advance.
- Integrate your teams with Palliative Experts who can provide expertise and support

Collaborative
Trans-disciplinary Circle of Care

Layer Skills to avoid missing any signs of change

identify

Early ID of change

assess


Early clinical assessment by right team to meet current & future needs

plan

ACP; Goals of Care; Location; HCC

}

High Quality Care
Quality of Life
Autonomy
Dignity



“You matter because you are you, and you matter to the last moment of your life. We will do all we can, not only to help you die peacefully, but also live until you die.”

Dame Cicely Saunders
Nurse, Doctor, Social Worker and Writer
Founder of the Hospice Movement (1918-2005)


Presentation I

*Where do we go from here?
Is this all you need to know?*

How will you practice differently tomorrow?

How will you work as a team?

*Who will you connect to proactively join
the circle of care?*



Palliative Resources

Linking to Palliative Service Providers & Functional Decline Tools

Palliative Pain & Symptom Management Consultants (PPSMC)
Consultant contact - Listed by service area
• <http://www.pccnetwork.ca/contact-us/>

Community Care Access Centres (CCAC)
In home care for PSW, Nursing; Rapid Response Nurses; Palliative Nurse Practitioners; Referrals to Palliative Physicians - and more
• <http://healthcareathome.ca/torontocentral/en/Getting-Care/getting-started>
• <http://healthcareathome.ca/torontocentral/en/Partners/Healthcare-Providers/Physicians-and-Nurse-Practitioners>

Canadian Virtual Hospice
Links to palliative services & programs by area
• http://www.cvhq.org/hospice-care_10/2009/05/16/what-is-the-connection-between-home-support-resources/programs-and-services/available-in-ontario.aspx#sthash=K3h3

Canadian Hospice Palliative Care Association (CHPCA)
Directory of services search by province
• <http://www.chpca.org/2013/03/26/Directory-of-Services.aspx>

List of In-Patient Palliative Care Units (PCUs) & End of life Residential Hospices Toronto
• http://www.uhn.ca/PrincipalsManagement/Principals/Quality/Supporting_Program_Services/Pages/inpatient_hospice_palliative_care_directory.aspx

Functional Decline Tools

There are several functional assessments used

- PRFS (Patient Reported Functional Status)
- ECOG (Performance Status)
- Barthel Index
- FAST
- Others

Gold Standard in Palliative/EOL care

- Gold Standard Framework
- PPS
- PPI

Presentation I

Various Tools Scores

average life expectancy less than 3 - 6 months	Scores indicating marked illness burden disability and declining health status
PPS 50 % or 40%	Individual is destabilizing ; transitioning towards end of life
Clinical Frailty 7 Scale	<ul style="list-style-type: none"> ▪ Time for clinical assessment by palliative expert ▪ Proactive care planning required
ECOG 3	
PSRF 3	
FAST 6C	
Barthel Index 3/20	

Patient Reported Functional Status (PRFS)

0	normal with no limitations
1	not my normal self, but able to be up and about with fairly normal activities
2	not feeling up to most things, but in bed or chair less than half the day
3	able to do little activity & spend most of the day in bed or chair
4	pretty much bedridden, rarely out of bed

ECOG Performance Status

These scales and criteria are used by doctors and researchers to assess how a patient's disease is progressing, assess how the disease affects the daily living abilities of the patient, and determine appropriate treatment and prognosis. They are included here for health care professionals to access.

ECOG PERFORMANCE STATUS*	
Grade	ECOG
0	Fully active, able to carry on all pre-disease performance without restriction
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work
2	Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours
3	Capable of only limited selfcare, confined to bed or chair more than 50% of waking hours
4	Completely disabled. Cannot carry on any selfcare. Totally confined to bed or chair
5	Dead

* As published in Am. J. Clin. Oncol.; Oken, M.M., Creech, R.H., Tormey, D.C., Horton, J., Davis, T.E., McFadden, E.T., Carbone, P.P.: Toxicity And Response Criteria Of The Eastern Cooperative Oncology Group. Am J Clin Oncol 5:649-655, 1982.

Presentation I

Barthel Index of Activities of Daily Living

Instructions: Choose the scoring point for the statement that most closely corresponds to the patient's current level of ability for each of the following 10 items. Record actual, not potential, functioning. Information can be obtained from the patient's self-report from a caregiver party who is familiar with the patient's activities such as a relative, or from observation. Refer to the Guidelines section on the following page for detailed information on scoring and interpretation.

The Barthel Index

<p>Feeding</p> <p>0 = incontinent or needs to be given enteral 1 = occasional accident (spill, mess) 2 = confident Patient's Score _____</p> <p>Grooming</p> <p>0 = incontinent, or cathected and unable to manage 1 = occasional accident (rash, odor per 24 hours) 2 = confident (for over 7 days) Patient's Score _____</p> <p>Transferring</p> <p>0 = needs help with personal care 1 = independent from help but using implements Patient's Score _____</p> <p>Toilet use</p> <p>0 = incontinent 1 = needs some help, but can do something alone 2 = independent (on and off, dressing, wiping) Patient's Score _____</p> <p>Walking</p> <p>0 = unable 1 = needs help using, grasping handle, etc. 2 = independent (hand provided with reach) Patient's Score _____</p> <p><small>Collin et al., 1988</small></p>	<p>Transfer</p> <p>0 = unable - no sitting balance 1 = minor help (one or two people, physical, rail or 2 = minor help (verbal or physical) 3 = independent Patient's Score _____</p> <p>Staircase</p> <p>0 = wheelchair 1 = wheelchair independent, including corners, etc. 2 = walks with help of one person (verbal or physical) 3 = independent (but may use any aid, e.g., stick) Patient's Score _____</p> <p>Communication</p> <p>0 = dependent 1 = needs help, but can do about half unaided 2 = independent (including buttons, dials, keys, etc.) Patient's Score _____</p> <p>Shopping</p> <p>0 = unable 1 = needs help (verbal, physical carrying aid) 2 = independent up and down Patient's Score _____</p> <p>Hygiene</p> <p>0 = dependent 1 = independent (or in shower) Patient's Score _____</p> <p style="text-align: right;">Total Score _____</p>
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Scoring: Sum the patient's scores for each item. Total possible scores range from 0-20, with lower scores indicating increased disability. It is used to measure improvement after rehabilitation. Changes of more than two points of the total score reflect a probable genuine change, and change of one item from fully dependent to independent is also likely to be reliable.

Reprints:

- Collin C, Wade DT, Davies S, Howe T. The Barthel ADL Index: a reliability study. *Int Disabil Stud*. 1988;10(2):61-65.
- Mahoney FI, Barthel DW. Functional evaluation of the Barthel Index. *Med Care*. 1965;3:93-98.
- Wade DT, Collin C. The Barthel ADL Index: a standard measure of physical disability? *Int Disabil Stud*. 1988;10(2):68-67.

FAST (Functional Assessment Staging Tool)

- No difficulties.
- Complains of forgetting location of objects, subjective word finding difficulties only.
- ↓ job functioning evident to coworkers; difficulty traveling to new locations.
- ↓ ability to perform complex tasks (planning dinner for guests, handling finances, marketing).
- Requires assistance in choosing proper clothing for the season or occasion.
- Difficulty putting clothing on properly.
 - Unable to bathe properly may develop fear of bathing. Requires assistance adjusting bath water temperatures.
 - ↓ inability to handle mechanics of toileting (forgets to flush, etc.).
 - Urinary incontinence, occasional or more frequent.
 - Fecal incontinence, occasional or more frequent.
- Ability to speak limited to about half a dozen words in an average day.
 - Intelligible vocabulary limited to a single word in an average day.
 - ↓ non-ambulatory (unable to walk without assistance).
 - Unable to sit up independently.
 - Unable to smile.
 - Unable to hold up head.

Stage	Stage Name	Characteristic	Expected Untreated AD Duration (months)	Mental Age (years)	MMSE (score)
1	Normal Aging	No deficits whatsoever	—	Adult	29-30
2	Possible Mild Cognitive Impairment	Subjective functional deficit	—		28-29
3	Mild Cognitive Impairment	Objective functional deficit interferes with a person's most complex tasks	84	12+	24-28
4	Mild Dementia	IADLs become affected, such as bill paying, cooking, cleaning, traveling	24	8-12	19-20
5	Moderate Dementia	Needs help selecting proper attire	18	5-7	15
6a	Moderately Severe Dementia	Needs help putting on clothes	4.8	5	9
6b	Moderately Severe Dementia	Needs help bathing	4.8	4	8
6c	Moderately Severe Dementia	Needs help toileting	4.8	4	5
6d	Moderately Severe Dementia	Urinary incontinence	3.6	3-4	3
6e	Moderately Severe Dementia	Fecal incontinence	9.6	2-3	1
7a	Severe Dementia	Speaks 5-6 words during day	12	1.25	0
7b	Severe Dementia	Speaks only 1 word clearly	18	1	0
7c	Severe Dementia	Can no longer walk	12	1	0
7d	Severe Dementia	Can no longer sit up	12	0.5-0.8	0
7e	Severe Dementia	Can no longer smile	18	0.2-0.4	0
7f	Severe Dementia	Can no longer hold up head	12+	0-0.2	0

Presentation I

Clinical Pain & Symptom Assessment Tools

- For individuals who can self report or mild to moderate cognitive impairment
 - ESAS
 - 4 Point Scale
- Distress or Pain assessments in non-verbal or cognitively impaired individuals
 - DIS DAT
 - PAINAD
 - ABBEY
 - DOLOPLUS

Wrap up

EVALUATION/FEEDBACK

Please take a few minutes to complete the feedback form if you haven't already done so.

PERSONAL COMMITMENT ACTIVITY:

Self-Reflection

Based on what you have learned today, identify two or three things that you are going to make a personal commitment to do or try in the next three to four months.

What supports will you need to help enable you to be successful in achieving your commitments?

Table Discussion

What are some things you are already doing well regarding supporting people through transitions?

What are some "quick wins" around transitions that would be manageable with the current resources you and/or your agency have?

We hope you have found the day useful and enjoyable.

Thank you for attending!

Self Reflection

We encourage you to use this page to keep track of key points, action items, and connections you make at today's event and hope that you will refer to it once you are back on the job to help reinforce your learning.

KEY POINTS: Use the space below to make note of key points, insights, or take-aways that stand out for you during the day

CONNECTIONS: Use the space below make note of any new people you meet today that you may want to connect with in the future

ACTION ITEMS:

a) Use the space below to make note of key actions you want to take to apply what you learned once you are back at your job

b) What are some of the challenges you anticipate in trying to carry out your action items? How might you address these?

Transition Planning

A three part series for direct support professional's to help meet the complex needs related to transition planning.



SESSION EVALUATION

Day 3: Aging Transitions – Thursday March 2nd, 2017

1. Overall, I found today's session to be:

1 2 3 4 5
Poor Average Excellent

Please explain why you chose that number:

2. The overall relevance of today's session to my practice was:

1 2 3 4 5
Poor Average Excellent

Please explain why you chose that number:

3. What will you do to apply your learning in your work?

4. What I found most useful about the session:

5. One message to the organizers:

6. Other comments?

Thanks for your participation! Your comments will be collated.



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