
# Honor Individual Goals and Hopes (HIGHway) Curriculum

**Facilitator Guide**

*Version 7/27/23*

**Prepared by**

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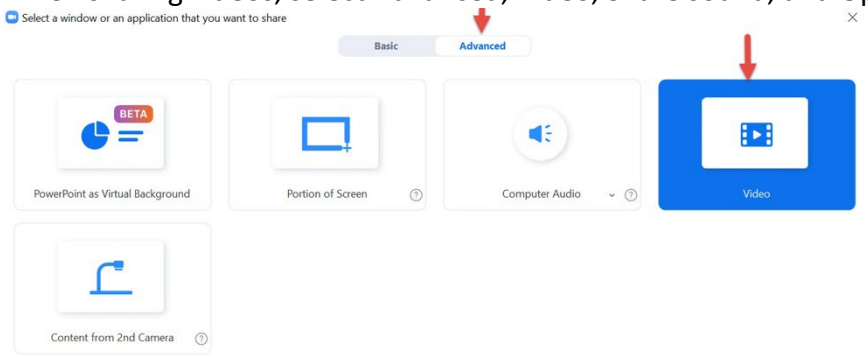
# Introduction

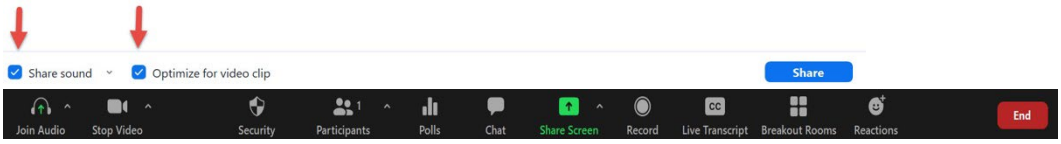
### About this Training

The HIGHway Curriculum consists of three blended learning sessions intended to prepare social workers to facilitate and conduct Advanced Care Planning (ACP) conversations with dialysis patients. Each session includes 120 minutes of planned content and interactions. Each module also includes one or more video presentations to supplement the live sessions. These may be distributed before and/or after the live sessions.

### Preparation Checklist

- ☐ Gather photos and brief bios from participants. Create webpage, document or slide(s) of participants to share during Session 1, prior to Introductions.
- ☐ Familiarize yourself with Zoom's sharing features. See: Sharing Your Screen or Desktop in Zoom
- ☐ When sharing videos, select Advanced, Video, Share sound, and Optimize for video clip.




- ☐ Review modules to identify polling questions and set up polls in advance. Refer to instructions from the polling platform vendor to learn how to set up polls (e.g., Zoom Help Center: Polling for Meetings

## Session 1: Advance Care Planning Conversations

**Agenda**

| Time | Topic | Minutes |
|---|---|---|
| 00:00 – 00:20 | Introduction | 20 |
| 00:20 – 00:30 | Understanding Terms | 10 |
| 00:30 – 00:40 | Poor Demonstration of Advanced Care Planning | 10 |
| 00:40 – 00:50 | HIGHway Roadmap | 10 |
| 00:50 – 00:60 | Motivational Interviewing | 10 |
| 00:60 – 01:30 | Motivational Interviewing Role Play | 30 |
| 01:30 – 01:40 | Giving Control Back to the Patient | 10 |
| 01:40 – 01:50 | Closing | 10 |

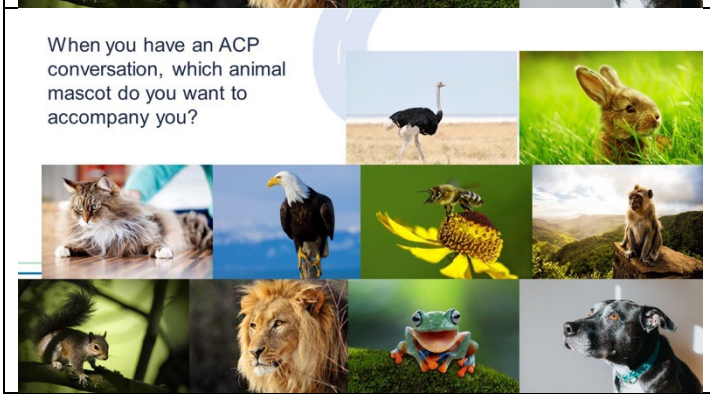
**Learning Objectives:**

- Describe the goals of the PCORI HIGHway grant
- Describe shared decision-making, advance care planning, motivational interviewing and empathy, culture humility, religion and spirituality and how they are constituents of goals of care conversations
- Recognize the trajectory of chronic kidney disease and how the process of advance care planning fits into it
- Apply motivational interviewing techniques to conduct empathetic advance care planning (ACP) conversations to learn what a dialysis patient wants for their future care
- Adapt ACP conversation to the stage of change of the participant

**Supplemental Materials:**

- HIGHWay Project: Implementing Advanced Care Planning for Dialysis Patients
  Recorded presentation (1:32)
- Advanced Care Planning Conversations: Basic Terms & Concepts Recorded presentation (13:33)
- Motivational Interviewing Recorded presentation (29:31)
- Motivational Interviewing Handout (see Appendix A)
- Motivational Interviewing Counts Worksheet (see Appendix B)
- Giving Control Back to the Patient video (3.23)
- Spiritual Dimensions in Advance Care Planning Recorded presentation (17:33)
- Empowering Patients in the ACP Process video (1:21)
- Ensuring Equal Access video (2:27)

**Introduction (20 minutes)**

| Slide | Facilitator Notes |
|---|---|
|  | • Welcome<br>  ○ Welcome participants<br>  ○ Introduce instructors<br>  ○ Introduce other team members |
|  | • Ask participants to share their answers in the chat |
|  | • Ask participants to share their answers in the chat |

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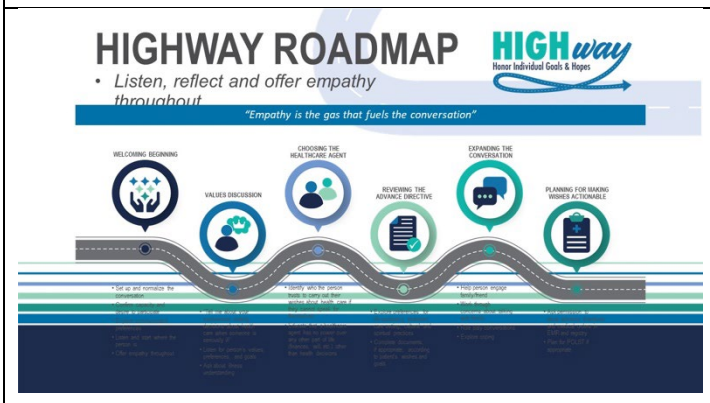
|---|---|
| • Where you are geographically located<br>• How many years as a social worker<br>• How many years at your dialysis organization | • Ask participants to share their answers in the chat |
| Baseline Survey | • Invite participants to complete a survey like this one.<br>• Explain that this survey is designed to measure your current comfort level with advance care planning in the dialysis setting<br>• Note: Survey results are shared in Session 3. |
| QR Code CME | • |
|  | • Introduce the HIGHway project<br>○ The purpose/why<br>○ The schedule<br>○ The to do's<br>○ What happens at each step<br><br>• Play or refer participants to the HIGHWay Project: Implementing Advanced Care Planning for Dialysis Patients video (1:32) |

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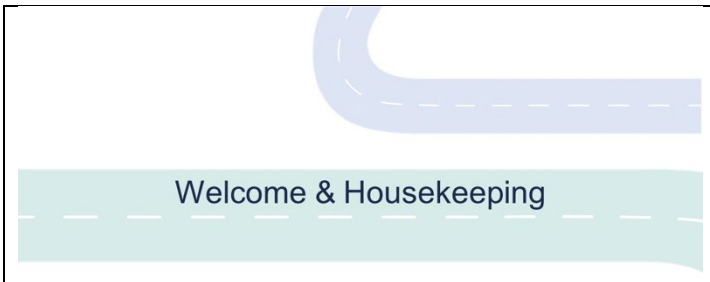
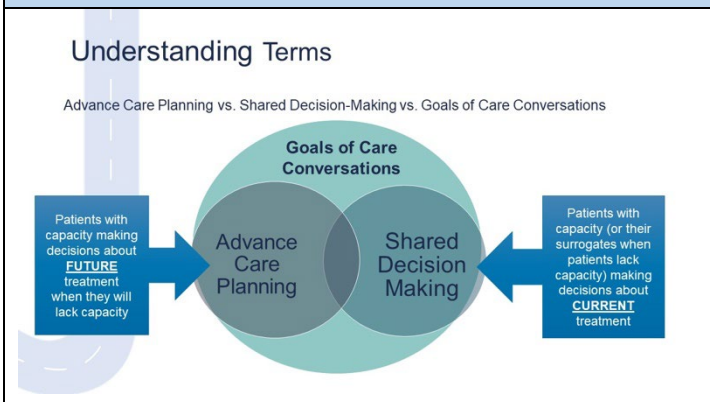
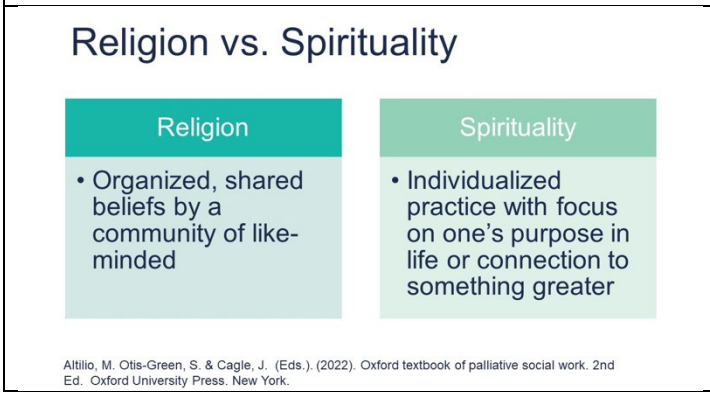
|  | • On-line etiquette<br>  ○ Write out your name<br>  ○ Mute<br>  ○ Camera on<br>• Ground-rules<br>  ○ A safe place for sharing professionally challenging situations<br>  ○ Respect confidentiality<br>• Respect diversity of views |

**Understanding Terms (10 minutes)**

| Slide | Facilitator Notes |
|---|---|
|  | • On the right is shared decision-making: working with a person or their proxy who is participating in the decision<br>• On the left is advanced care planning: enabling people to have their goals and preferences be known and guide their care if they are not able to make decisions for themselves.<br>• Invite participants to ask questions or share thoughts<br>• Refer participants to Advanced Care Planning Conversations: Basic Terms & Concepts recorded presentation to learn more. |
|  | • Conflating these 2 can cause problems- assumptions about community support<br>• Provider discomfort here<br>• Refer participants to the Spiritual Dimensions in Advance Care Planning recorded presentation to learn more. |

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| Cultural Humility<br>Develop understanding of historical, cultural and personal significance of diagnosis<br>  <br><br>Altilio, M. Otis-Green, S. & Cagle, J. (Eds.). (2022). Oxford textbook of palliative social work. 2nd Ed. Oxford University Press. New York. | • |
| ABCDE Model for Cultural Assessment<br>Attitudes of patients and families<br>Beliefs<br>Context<br>Decision-making style<br>Environment<br>Altilio, M. Otis-Green, S. & Cagle, J. (Eds.). (2022). Oxford textbook of palliative social work. 2nd Ed. Oxford University Press. New York. | • |

## Poor Demonstration of Advanced Care Planning (10 minutes)

| Slide | Facilitator Notes |
|---|---|
| Poor Demonstration of Advance Care Planning<br>Tulsky example<br>What could have been done differently?<br>What kind of reaction could this cause?<br>What went poorly? | • Play audio clip, then have participants respond to the following questions via audio or chat:<br>  ○ What could have been done differently<br>  ○ What kind of reaction could this cause<br>• What went poorly Sometimes the conversation is uncomfortable because we don't have a crystal ball<br>• Ask: What would have happened if it were a patient who did want heroic measures?<br>• Take home message – be neutral. Any decision is fine as long as people have the opportunity to understand, think through and make their wishes known. |

## HIGHWay Roadmap (10 minutes)

| Slide | Facilitator Notes |
|---|---|
|  | • Review roadmap as a framework for future sessions<br>• Emphasize importance of adapting with principles of cultural humility and incorporating spirituality |
|  | • It is a windy road that goes off in different directions. |

## Motivational Interviewing Overview (10 minutes)

| Slide | Facilitator Notes |
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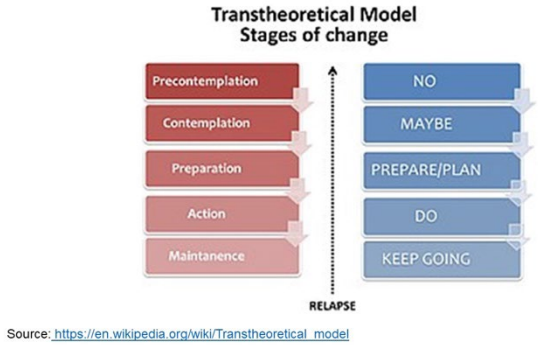
|  <br>Source: https://en.wikipedia.org/wiki/Transtheoretical_model | • We can use this model for all kinds of things (e.g., quit smoking)<br>• Precontemplation: No, I'm not doing this, haven't thought about it (e.g., I love my cigarettes, don't even think about taking them from me)<br>• Contemplation: Ambiguousness, dropping hints, thinking about what are the things that might be positive about this change.<br>• Preparation: Actively planning to do something (e.g., on Tuesday, I'm going to throw my cigarettes away; on call to family about advanced directive, they say they've heard about it, they are on the cusp of doing something about it) |

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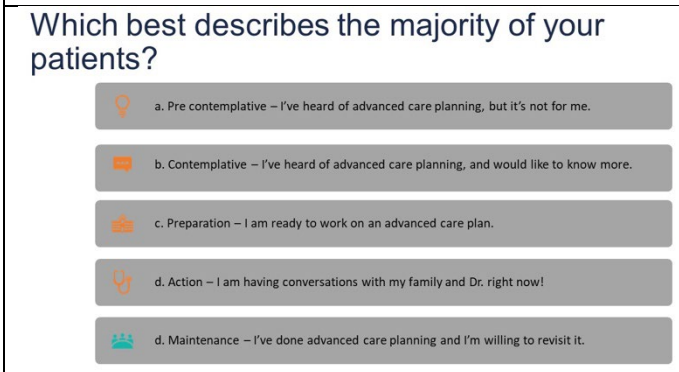
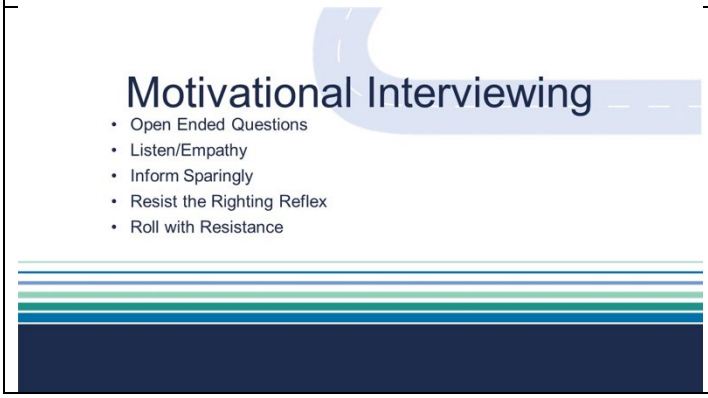
| | • Action: Actively changing. (e.g., I filled out the form, need to get it to my Dr.)<br>• Maintenance: I've made this change, but I may change my mind (e.g., used to want aggressive treatment, now I don't want it).<br>• Relapse: With any behavior change, relapse is a normal part of the process. We don't see relapse as a failure, but as new information that will help us next time. |
|  | • Use polling feature or ask participants to post their answer in the chat. |
|  | • Review MI concepts<br>• Invite participants to ask questions or share thoughts<br>• Refer participants to Motivational Interviewing recorded presentation (29:31) and Motivational Interviewing Handout (Appendix A) to learn more about motivational interviewing. |

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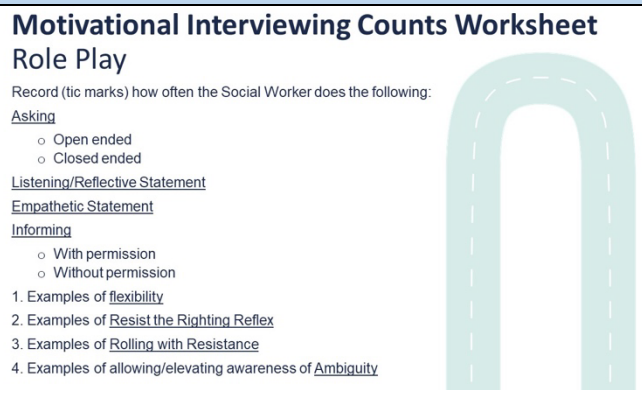
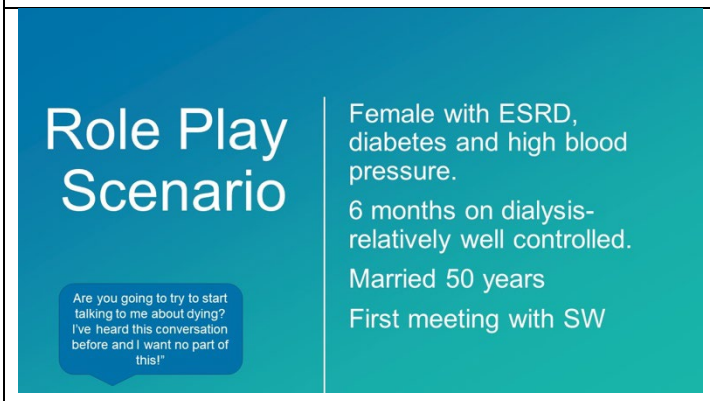
**Motivational Interviewing Role Play (30 minutes)**

| Slide | Facilitator Notes |
|---|---|
|  | • Refer participants to the Motivational Interviewing Counts Worksheet (Appendix B).<br>• Review and explain the worksheet.<br>○ Participants should use it to make note of open/closed questions, listening/reflective statements, empathetic statements, informing with and without permission demonstrated in the role play.<br>○ Note examples of flexibility, resisting the righting reflex, rolling with resistance and allowing/elevating awareness of ambiguity |
|  | • Tell participants you will role-play a conversation based on the scenario.<br>• Facilitators role-play conversation.<br>○ The social worker starts by asking if she was to get really sick and couldn't speak for herself, who would she want to speak for her. Janet responds with responds with... "Are you going to try to start talking to me about dying? I've heard this conversation before and I want no part of this!"<br>• Revisit role-play, switching roles.<br>• Model getting stuck and working through.<br>• Debrief scenario by asking participants to share their observations.<br>• Model debriefing:<br>○ Were you able to use the motivational interviewing skills? Were they helpful?<br>○ What would you differently?<br>○ What would you do next?<br>○ Ask the patient how it felt. |

**Giving Control Back to the Patient (10 minutes)**

| Slide | Facilitator Notes |
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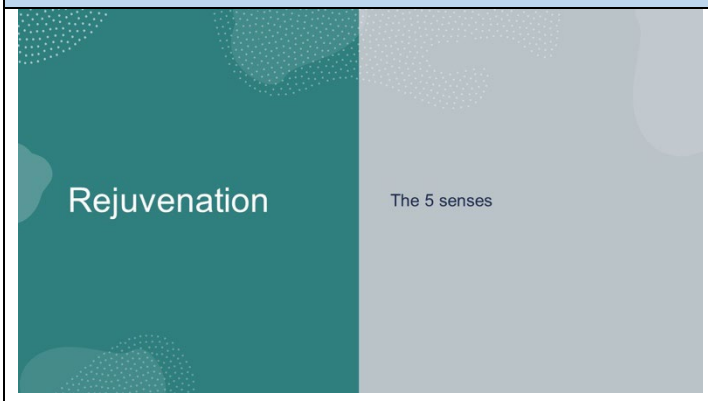
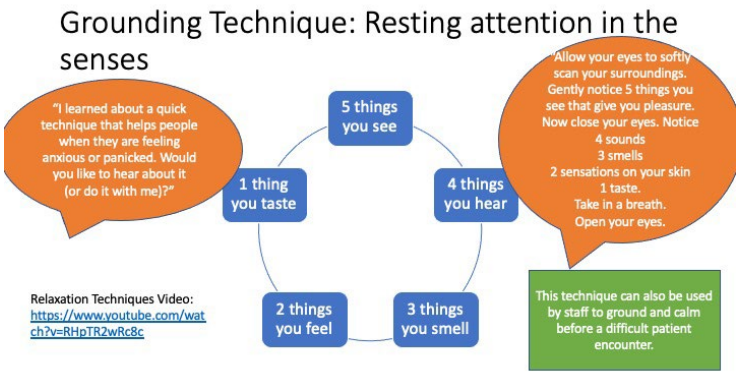
|  | • Play video: John discusses the importance of providers taking the time to give control back to the patient/fully listening to the patient; what it means to be a patient and having to be assertive<br>• We thought this was a good example of what we've discussed today.<br>• Invite participants to share thoughts and reflections. |

**Closing (10 minutes)**

| Slide | Facilitator Notes |
|---|---|
|  <br>  | This technique works by bringing the attention to the sensory experience of this moment. Grounding in present sensory experience – the lived reality of this moment – helps the mind let go of incessant redoing of the past or worry about the future. This technique can also be used by staff to ground and calm before a difficult patient encounter.<br>Relaxation Techniques Video<br><br><u>Facilitator Script</u><br>I learned about a quick technique that helps people when they are feeling anxious or panicked. Would you like to hear about it (or do it with me)?<br>Allow your eyes to softly scan your surroundings.<br>Gently notice 5 things you see that give you pleasure. Now close your eyes.<br>Notice 4 sounds<br>3 smells<br>2 sensations on your skin<br>1 taste.<br>Take in a breath. |

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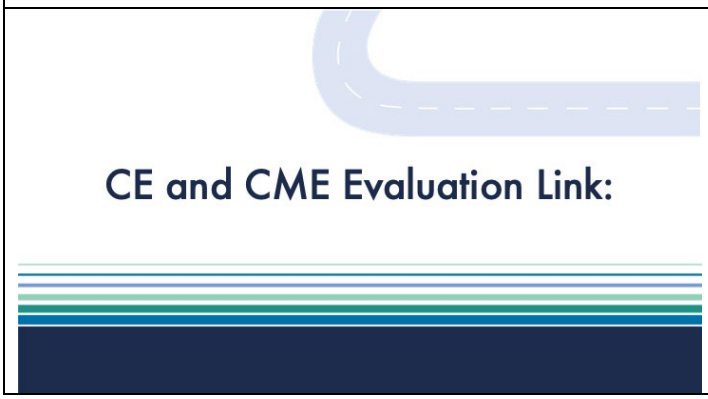
| | Open your eyes. |
|  | • Review homework<br>• Distribute the following question by email or survey to gather examples to weave throughout the training:<br>  ○ Without using any PHI, describe a challenging or difficult situation you have had in doing advance care planning. It can be with a patient, family member, team member, organization, etc.<br>• Refer to supplemental materials<br>• Preview of next session:<br>  ○ More on using empathy as "the gas" to move the conversation<br>  ○ Differing patient perspectives on why ACP is useful – or not |
|  | • Add CE or CME evaluation survey here if approriate |

## Session 2: Advance Care Planning Conversations

**Agenda**

| Time | Topic | Minutes |
|---|---|---|
| 00:00 – 00:13 | Opening/Sharing Experiences | 13 |
| 00:13 – 00:18 | Intersecting Concepts: HIGHway Roadmap & Readiness to Change | 5 |
| 00:18 – 00:30 | ACP Barriers & Facilitators | 12 |
| 00:30 – 00:35 | Tools for Moving the Conversation Forward | 5 |
| 00:35 – 00:45 | Emotion Words | 10 |
| 00:45 – 00:55 | Role Play: Putting Empathy into Words | 10 |
| 05:55 – 01:00 | Additional Practice: Naming Emotions | 5 |
| 01:00 – 01:05 | Break | 5 |
| 01:05 – 01:10 | The Beginning: How Do You Start the Conversation? | 5 |
| 01:10 – 01:15 | The Middle of the Journey | 5 |
| 01:15 – 01:40 | Role Play: Challenging Scenarios | 25 |
| 01:40 – 01:50 | The End of the Journey: Documenting, Communicating to Others | 10 |
| 01:50 – 02:00 | Closing | 10 |

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**Learning Objectives:**

- Apply motivational interviewing techniques to conduct empathetic advance care planning (ACP) conversations to learn what a dialysis patient wants for their future care
- Adapt ACP conversation to the stage of change of the participant
- Reflect on barriers and facilitators experienced while conducting ACP conversations
- Facilitate advance care planning for a patient with chronic kidney disease using the HIGHWay Roadmap framework
- Describe documents used to make patient wishes actionable
- Assist in completion of goals of care, advanced directives and medical orders

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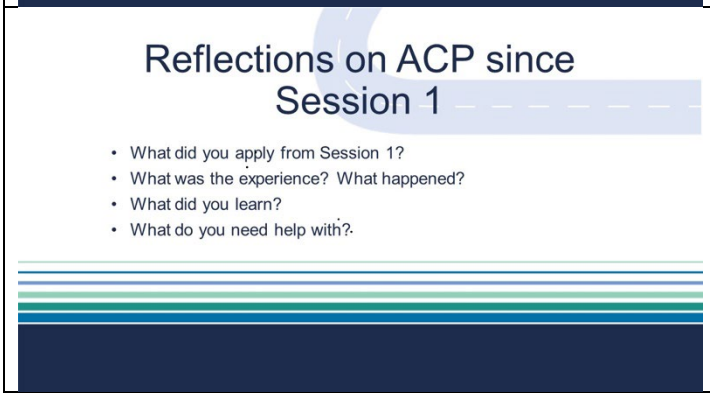
**Supplemental Materials:**

- Principles to Guide the Conversation Recorded presentation (24:41)
- Empathy Word Worksheet (Appendix C)
- Effective Empathetic Communication video (3:23)

**Opening/Sharing Experiences (13 minutes)**

| Slide | Facilitator Notes |
|---|---|
|  | • Review session agenda<br>○ Further empathy skill-building<br>○ Conversations at beginning, middle, end of roadmap |
|  | • Facilitate group discussion related to slide questions. |

**Intersecting Concepts: HIGHway Roadmap & Readiness to Change (5 minutes)**

| Slide | Facilitator Notes |
|---|---|
|  | • Review HIGHway Roadmap<br>○ Beginning, middle and end of ACP are different skills<br>○ At each stage, patient may have different level of readiness to engage<br>○ Empathy helps move from one stage to the next |

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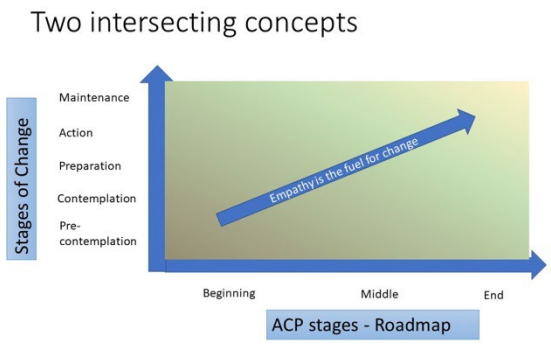
|  | • Applying readiness to change to ACP<br>• Lead discussion of where different patients fit in the space – upper or lower quadrants. E.g. Consider patient who may be ready to discuss a decision-maker, but not ready to fill our advance directive forms – where do they fit on this diagram? They may be high motivation in "middle" roadmap tasks but low motivation for "end" tasks. |

**ACP Barriers & Facilitators (12 minutes)**

| Slide | Facilitator Notes |
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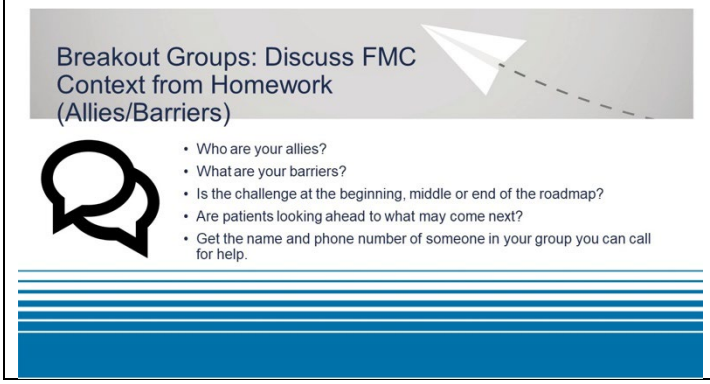
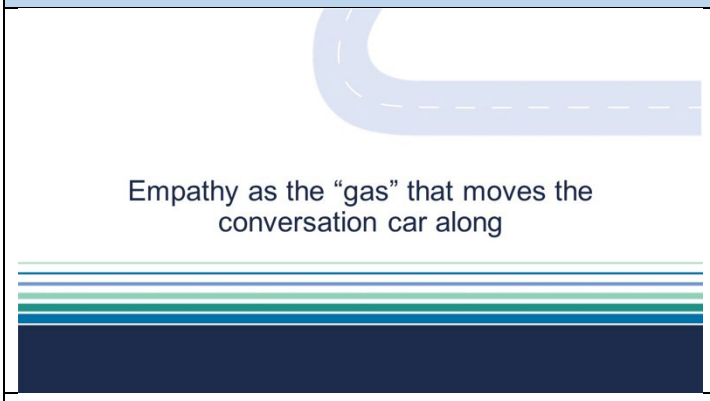
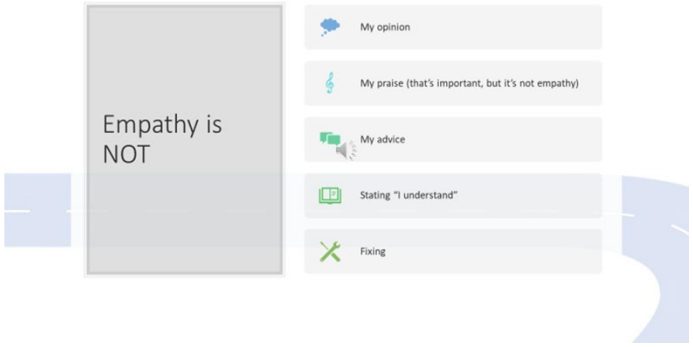
|  | • Facilitate sharing of challenges and strategies<br>○ You are not alone in facing challenges |
|  | • Homework from session 1 was to think about allies and barriers.<br>• Facilitate discussion in breakout groups |

**Tools for Moving the Conversation Forward (5 minutes)**

| Slide | Facilitator Notes |
|---|---|
|  | • Refer participants to Principles to Guide the Conversation recorded presentation (24:41) to learn more about integrating empathy into ACP conversations. |
|  | • Part of skill building related to conversation skills is being able to accurately identify and label what is coming out of our mouth.<br>• What is empathy and what is it not? (These are not all bad things, but they are not empathy)<br>• Empathy is the ability to accurately identify where someone is emotionally.<br>• It is not my opinion. My opinion might be important, but it is not empathy (e.g., Dale, this advanced directive looks great!)<br>• Praise is important, but it is a different skill than empathy (e.g., Dale, I'm really proud of you for XYZ).<br>• Advice may be helpful, but not empathy.<br>• Remove the language of "I understand" – need to be able to articulate what it is you understand.<br>• Fixing – similar to advice – e.g., struggling with my son – hey, why don't I have a phone call with both of you?<br>• Empathy is the ability to resonate and articulate the emotions of someone. |

**Emotion Words (10 minutes)**

| Slide | Facilitator Notes |
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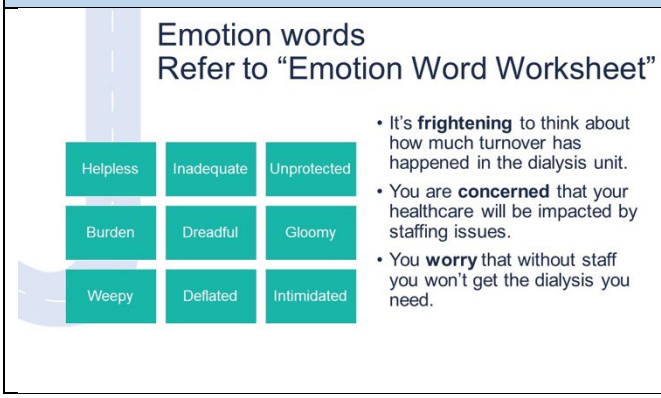
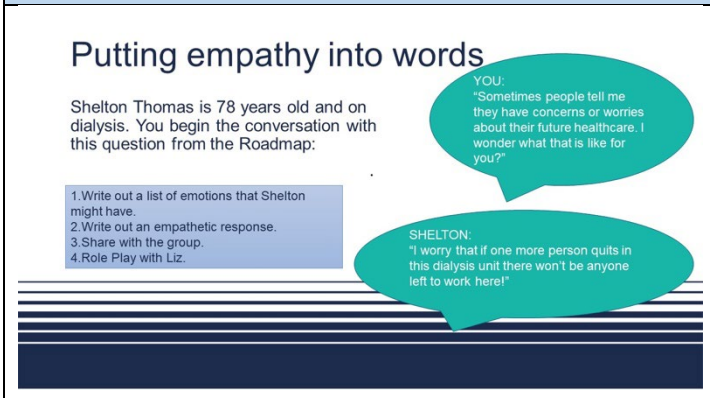
|  | • Refer participants to Emotion Words Reference (Appendix C)<br>• Ask participants to share a scenario appropriate for practicing using emotion words. If participants have nothing to share, refer to scenario in Appendix D.<br>• Elicit participants suggestions for emotion words in response to the scenario |

**Role Play: Putting Empathy Into Words (10 minutes)**

| Slide | Facilitator Notes |
|---|---|
|  | • Review slide with scenario & prompts:<br>  ○ Write out a list of emotions that Shelton might have.<br>  ○ Write out an empathetic response.<br>  ○ Share with the group<br>• Role play scenario<br>• Invite participants to share their perspectives<br>• Examples:<br>  ○ It's frightening to think about how much turnover has happened in the dialysis unit.<br>  ○ You are concerned that your healthcare will be impacted by staffing issues.<br>  ○ You worry that without staff you won't get the dialysis you need.<br>• Explore these statements with the audience. For example, if you respond with "you worry that without the staff you won't get the dialysis you need." How might Shelton respond? How could you refocus to advance care planning? |

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| | • Take-Aways:<br>  ○ Hold off on “fixing” at this point.<br>  ○ Hold space for person to express values. People often give us cues about what they value. |

**Additional Practice: Naming Emotions (5 minutes)**

| Slide | Facilitator Notes |
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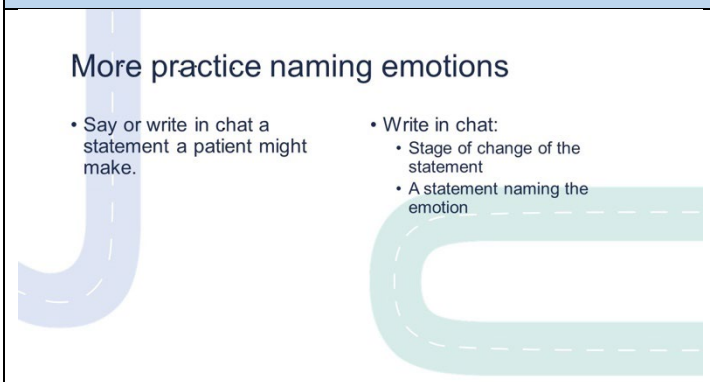
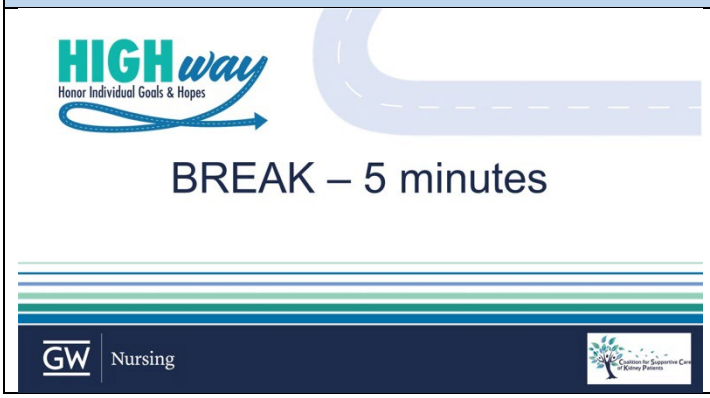
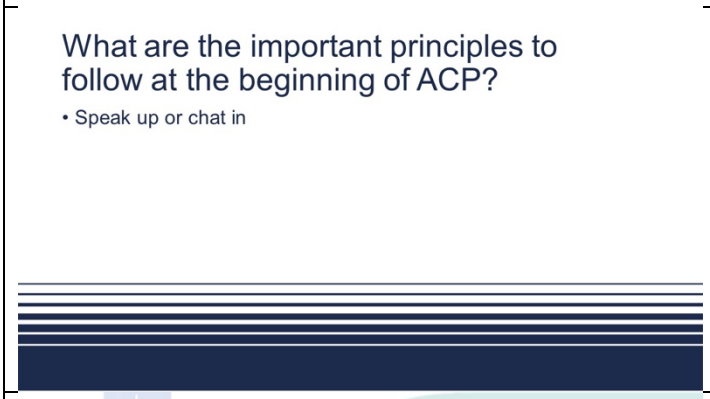
|  | • Ask participants for patient statements that stump them<br>• Participants write out “name the emotion” statements and put in chat |

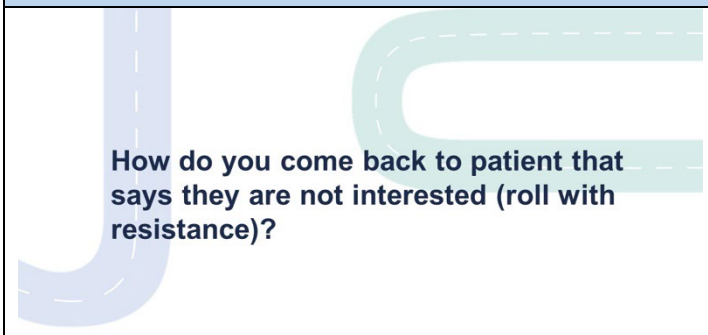
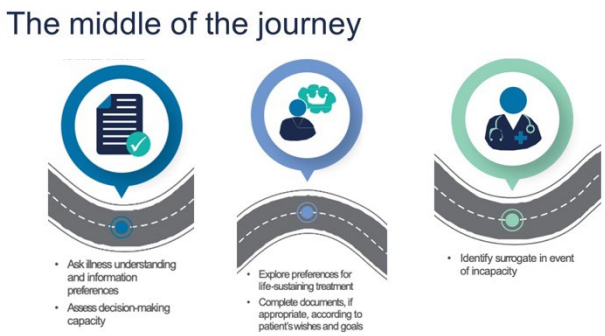
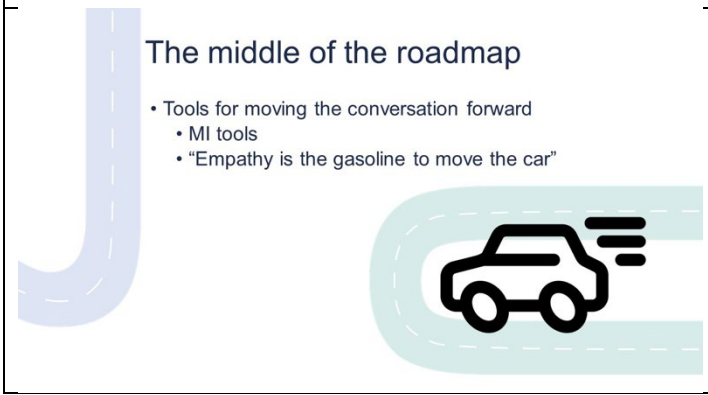
**Break (5 minutes)**

| Slide | Facilitator Notes |
|---|---|
|  | |

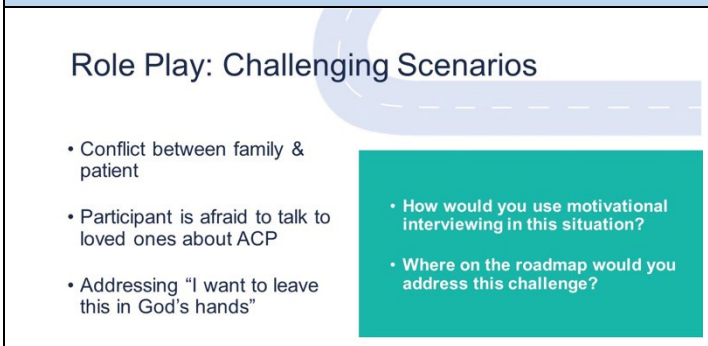
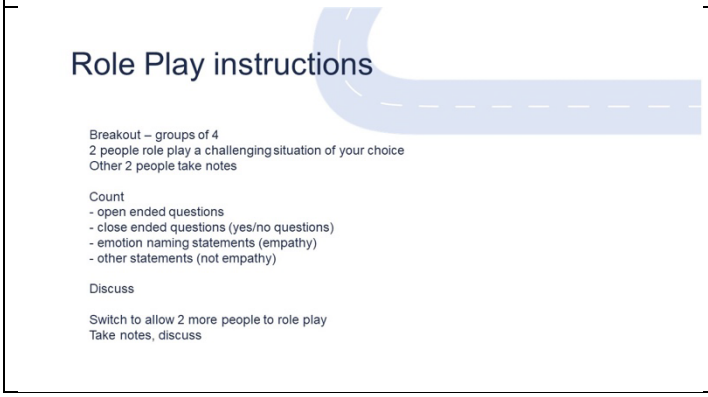
**The Beginning: How Do you Start the Conversation? (5 minutes)**

| Slide | Facilitator Notes |
|---|---|
|  | • Remind participants about Roadmap sections – emphasizing beginning, middle, end<br>• Relate the barriers and facilitators shared in prior discussion with stops on the roadmap.<br>• Relate any specific examples shared of challenging patient situations to where they are on the roadmap |
|  | • Ask participants to share their answers via video/voice or chat. |
|  | • There will be circling back – you will be with patients for years and their goals may change.<br>• Asking is a good place to start: about their wishes; their understanding of their illness; what their preferences are (e.g., Do they like to talk about everything? Do they like family members to handle it?)<br>• Roll with resistance |

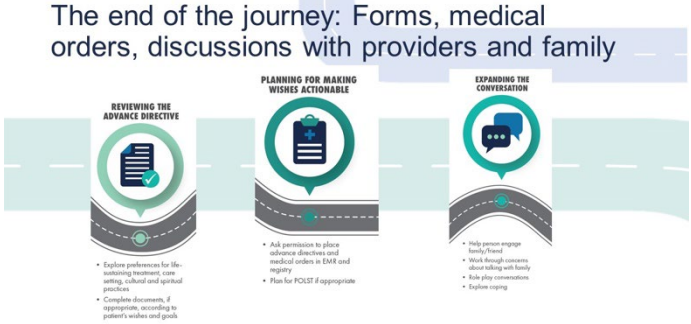
**The Middle of the Journey (5 minutes)**

| Slide | Facilitator Notes |
|---|---|
|  | • Listen for motivations |
|  | • Review these portions of the roadmap related to the middle of the journey<br>• Ask/Discuss:<br>○ When you go in to ask people about their health, what do you hear from patients?<br>○ Do they seem to have a good sense of disease trajectory?<br>○ Are they realistic, unrealistic? |
|  | • History has taught us that asking people about advance directives in a cold/clinical way contributes to resistance |

**Role Play: Challenging Scenarios (25 minutes)**

| Slide | Facilitator Notes |
|---|---|
|  | • Present challenge(s)<br>• Give participants 5 minutes to address the questions on the slides.<br>• Invite participant(s) to share ideas verbally or in the chat |
|  | |

**The End of the Journey: Documenting, Communicating to Others (25 minutes)**

| Slide | Facilitator Notes |
|---|---|
|  | • This has tended to be the starting place for discussions in many dialysis facilities: "do you have an advance directive"? While that is fine as an assessment question, if patient says "no" it's hard to know where to go from there.<br>• Having completion of forms flow from the earlier steps on the roadmap is usually more successful approach. Builds on patient values, makes it easier for patient to articulate what they want and document it in forms. |

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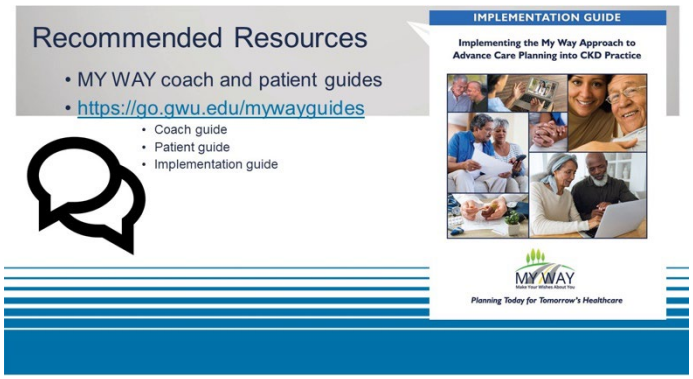
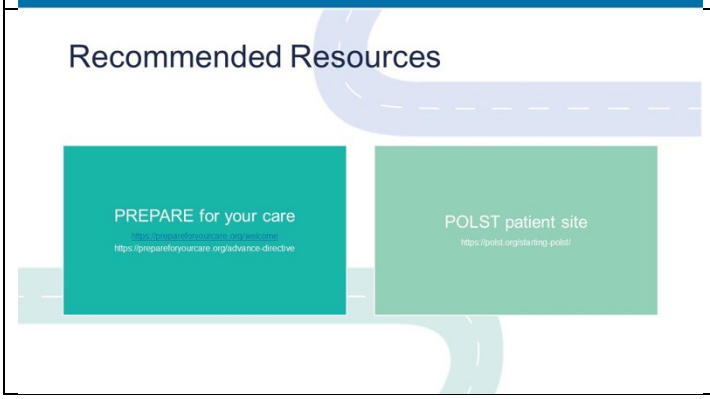
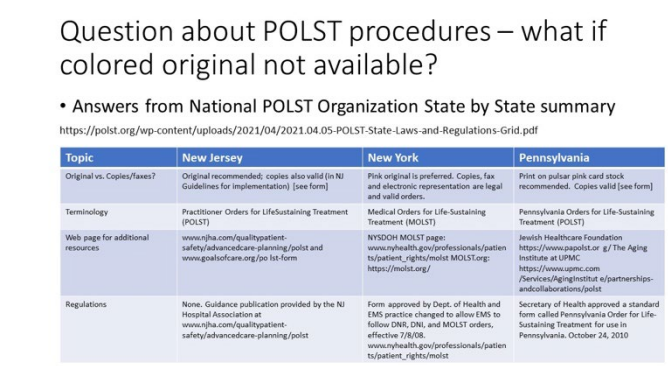
|---|---|
|  | • Describe and refer participants to resources<br>• Three recommended sets of resources:<br>  ○ My Way – develop specifically for patients with kidney disease. Basesd on motivational interviewing. Patient guide and guide for "coach" freely available<br>  ○ PREPARE for your care<br>  ▪ Source for patient friendly forms for every state, multiple languages. Also has patient website that guides patients through filling out forms.<br>  ○ National POLST website – has separate information for patients and professionals |
|  | • My Way summary of steps for implementing more advance care planning |
|  | • Links to PREPARE and POLST<br>• Emphasize that participants should become familiar with PREPARE resources and POLST resources. PREPARE form in particular is much more patient friendly than many state forms. |




- Discuss whether POLST or equivalent forms used in dialysis center. Discuss questions participants have about using such forms. Example question on slide – along with sample answers on POLST website,
- If participants hand POLST to patients directly, emphasize that POLST/MOLST aren't patient friendly forms and should be used in conjunction with patient friendly forms such as PREPARE or My Way patient guide.

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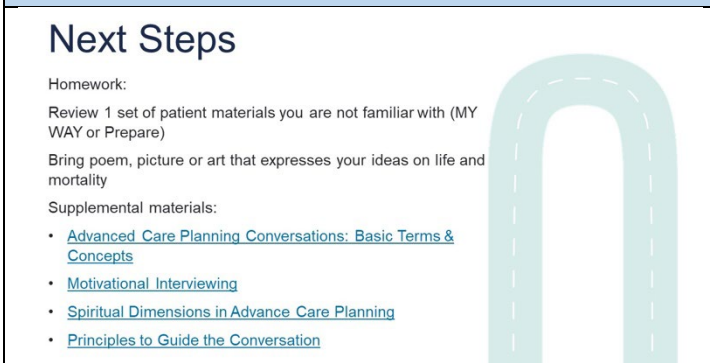
**Closing (10 minutes)**

| Slide | Facilitator Notes |
|---|---|
|  | • Review homework<br>• Refer participants to supplemental materials<br>• See Appendix X for additional guidance regarding art gallery to be shared at the next session. |
|  | • Play video |
| | • CE or CME evaluation as appropriate |

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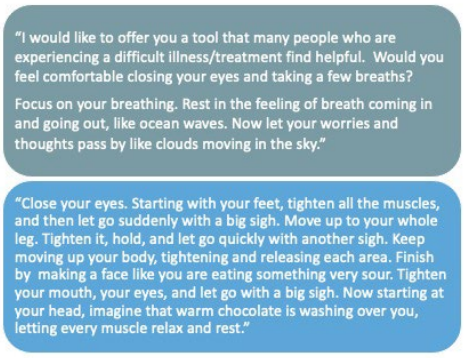
|---|---|
| Guided relaxation exercises<br>  | • Guided meditation for 1 minute<br>○ Use short guided meditation of facilitator's choice to help participants transition back to work duties<br>○ See appendix X for scripts |

## Session 3: Deepening the conversation, including family

| Time | Topic | Minutes |
|---|---|---|
| 00:00 – 00:10 | Opening | 10 |
| 00:10 – 00:20 | Baseline Survey Results | 10 |
| 00:20 – 00:30 | Review Homework | 10 |
| 00:30 – 00:40 | AD Forms & POLST | 10 |
| 00:40 – 00:50 | What motivates people to engage in ACP? | 10 |
| 00:50 – 01:00 | Name the Motivation | 10 |
| 01:00 – 01:05 | Break | 5 |
| 01:05 – 01:15 | Family Involvement | 10 |
| 01:15 – 01:25 | Role Play: Family Involvement | 10 |
| 01:25 – 01:40 | Breakout Groups: Practice Family Involvement | 15 |
| 01:40 – 01:50 | Caregiver Assessment Questions | 10 |
| 01:50 – 01:55 | Art Gallery | 5 |
| 01:55 – 02:00 | Closing | 5 |

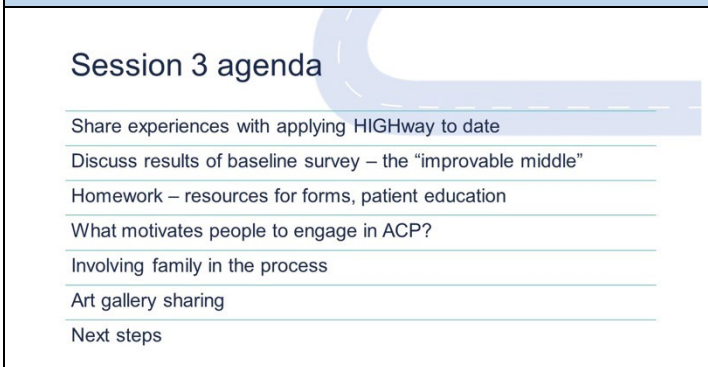
**Learning Objectives:**

- Describe the range of patient perspectives related to ACP
- Describe the social worker's role in leading the care coordination and hand-off process for goals of care conversations for a patient with chronic kidney disease
- Describe strategies to engage family members and resolve conflicts in ACP
- Integrate ACP into the social worker's ongoing workflow
- Describe strategies for leadership and communication of ACP within an interdisciplinary care team

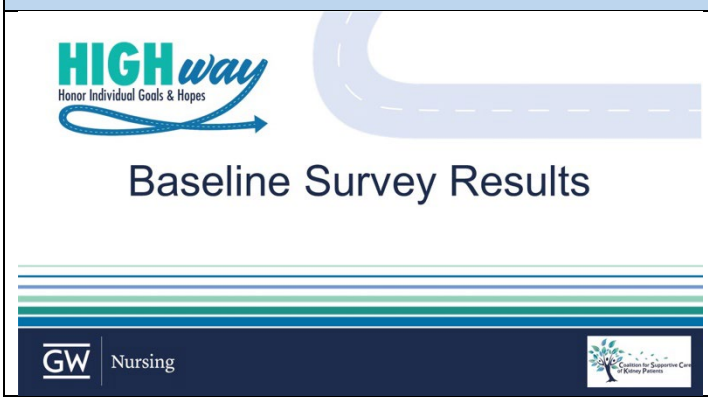
**Supplemental Materials:**

- Key Concepts in ACP: The Patient's Perspective Recorded presentation (17:19)
- Leading ACP in Teams Recorded presentation (5:06)
- Family Involvement in Advanced Directives Recorded presentation (10:31)
- Having the Conversation video (4:00)

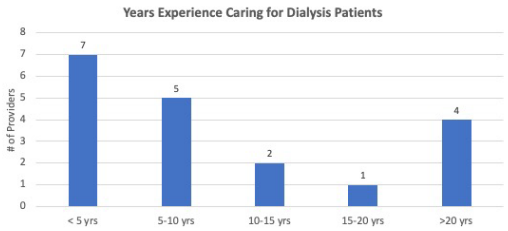
## Opening (10 minutes)

| Slide | Facilitator Notes |
|---|---|
|  | • Review session agenda |
|  | • Share experiences since last session |

## Baseline Survey Results (10 minutes)

| Slide | Facilitator Notes |
|---|---|
|  | • Share results from baseline survey of HIGHway participants in test<br>○ ACP activities that are most, least doable.<br>○ ACP activities that are the "improvable middle" |

19/23 providers in Cohort B completed baseline survey:
12 nurses
7 social workers

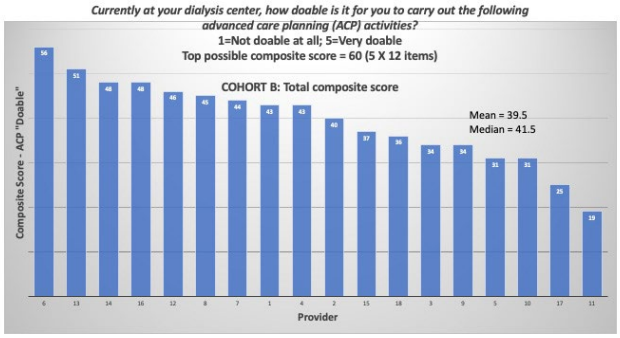



- This slide to be replaced with summary of entire HIGHway project

*Currently at your dialysis center, how doable is it for you to carry out the following advanced care planning (ACP) activities?*

Q1. Introduce ACP to patients
Q2. Have a private, quiet place for goals of care conversations with patients at dialysis center
Q3. Have a private, quiet place for goals of care conversations with patients at dialysis center
Q4. Document patient goals of care in the medical record
Q5. Help patients complete advance directive forms
Q6. Get completed advance directive (AD) forms into the dialysis center medical records
Q7. Help patients enter their advance directives into an available registry or medical record
Q8. Prepare POLST/MOLST forms with patients for further review and signature with their physician
Q9. Know the time to revisit/revise advance care plan and associated documents
Q10. Track where patients are in process of ACP and what is next step
Q11. Work closely and have support of other team members for making ACP a regular part of care
Q12. Use an app or algorithm to help your ACP process

These questions ask how "doable" each step of ACP process is




- This slide to be replaced with summary of entire HIGHway project

## Most and least "doable" ACP activities

Hardest: scored <3 on "doable"

- Help patients complete advance directive forms: mean = 2.8
- Help patients enter their advance directives into an available registry or medical record: mean =2.6
- Prepare POLST/MOLST forms with patients for further review and signature with their physician: mean =2.0

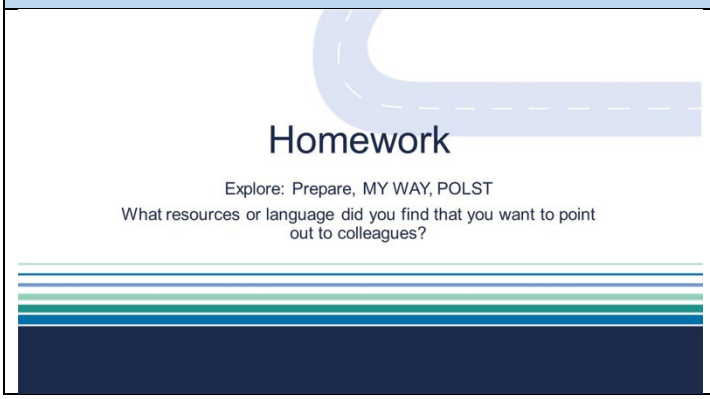
Most doable: >3.5 on doable

- Introduce ACP to patients: mean= 4.1
- Work closely and have support of other team members for making ACP a regular part of care: mean=3.8
- Document patient goals of care in the medical record: mean = 3.8
- Have a private, quiet place for goals of care conversations with patients at dialysis center: mean=3.7

- This slide to be replaced with summary of entire HIGHway project

| | |
|---|---|
| The improvable middle of "doable" ACP activities<br>**Middle scores: 3 to 3.5**<br>• Hold goals of care (GOC) conversations via telehealth: mean = 3.5<br>• Get completed advance directive (AD) forms into the dialysis center medical records: mean =3.4<br>• Track where patients are in process of ACP and what is next step: mean =3.4<br>• Know the time to revisit/revise advance care plan and associated documents: mean=3.2<br>• Use an app or algorithm to help your ACP process: mean =3.2 | • This slide to be replaced with summary of entire HIGHway project<br>• These are places to concentrate improvement activities – since they have room for improvement, but aren't extremely difficult. This is the "low hanging fruit" for change |

**Review Homework (10 minutes)**

| Slide | Facilitator Notes |
|---|---|
|  | • Share homework – what did participants find useful in PREPARE, MY WAY, or POLST?<br>• Note if VYNCA or other advance care planning programs in use, discuss how to help patients engage with those programs |

**AD Forms & POLST (10 minutes)**

| Slide | Facilitator Notes |
|---|---|

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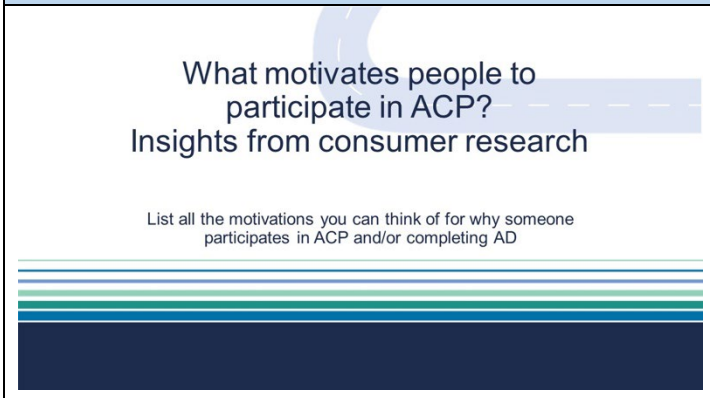
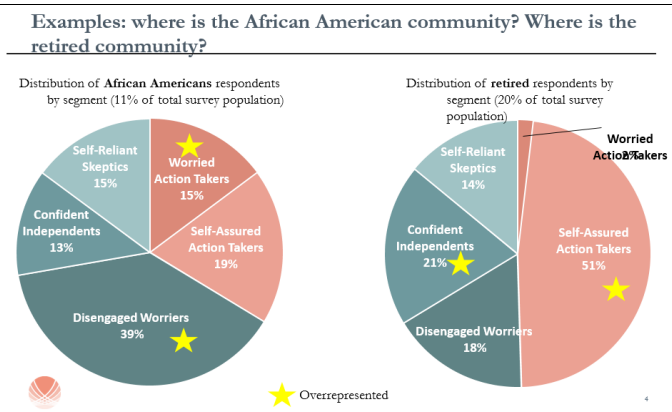
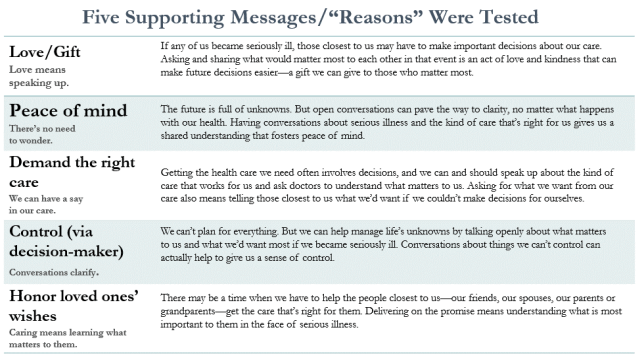
|---|---|
|  | • Review AD forms and POLST<br>• Websites for PREPARE, MY WAY, POLST, VYNCA |

**What motivates patients to engage in ACP? (15 minutes)**

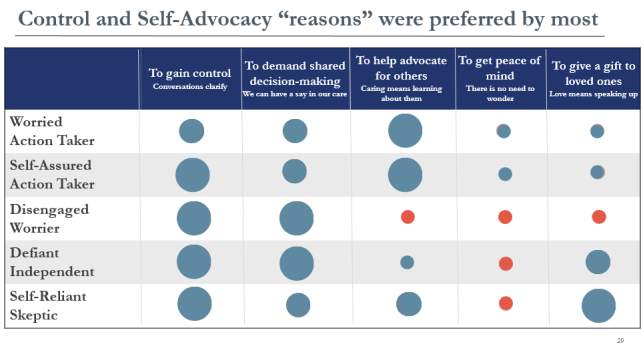
| Slide | Facilitator Notes |
|---|---|
|  | • Write down list of all the motivations can think of for engaging in ACP and/or AD (they can be different motivations)<br>• Explain findings from consumer research from Massachusetts.<br>• Can't tell by demographics what will motivate an individual<br>• Control and advocacy resonated for most groups – but not all individuals |
|  | • Introduce study, who/what they did: Comes from market/consumer research – segmentation.<br>• Titles are alternative to "non-compliant" terminology. Gives the power back to the people and acknowledges they may have good reasons for being where they are |



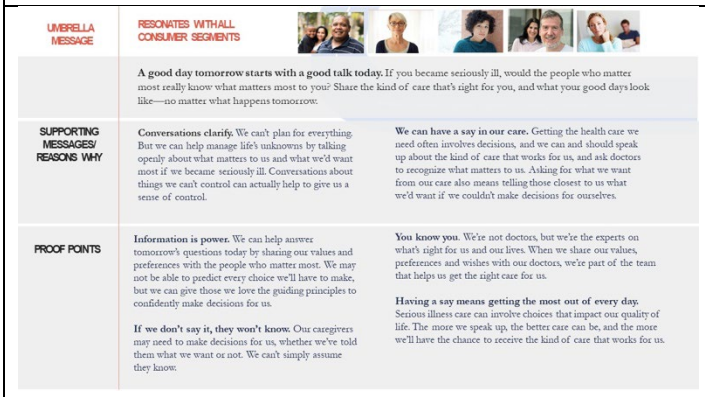

- Looking descriptions, it is coming from their experience with the healthcare system.
- Trust that people come to skepticism/disengagement for valid reasons.
- Demographics are associated with the categories – but you can't assume based on demographics. Have to ask each person and learn their individual view.




- This research tested 5 different messages.




- Different messages resonated differently across the groups. Some people are more interested in doing it for their family; others for themselves
- "Gain control – conversations clarify" resonated for all groups.
- "Peace of mind" not preferred by any group.
- "Give a gift" resonated mostly for "self-reliant skeptics"




- The top message relates to everyone.
- The intent is not to memorize a message for each group, but rather to focus on helping them unpack where they are and why.
- Acknowledge and validate that people have their own reasons for feeling the way they do.
- We are all impacted by factors beyond what we are born with. This

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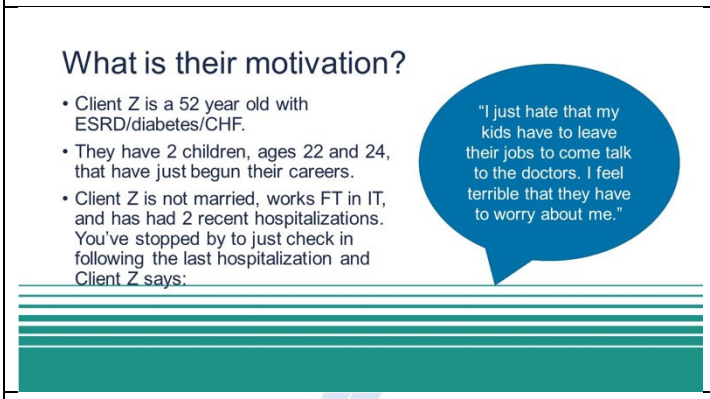
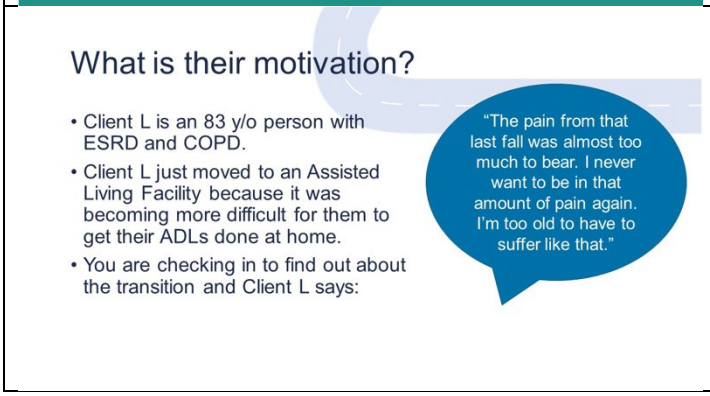
| | study confirms that negative experiences impact people, particularly populations that have historically been ignored or discriminated against in the healthcare system, so they may come with skepticism and we can understand why.<br>• Refer participants to Key Concepts in ACP: The Patient's Perspective Recorded presentation (17:19) for more information and a link to this study. |
|  | • Name the motivation in 2 scenarios<br>• Distinguish naming patient's own motivation from "selling" with a motivation you assume they will relate to<br>• Optional if time – role play a patient whose motive is not apparent |
|  | |

**Break (5 minutes)**

| Slide | Facilitator Notes |
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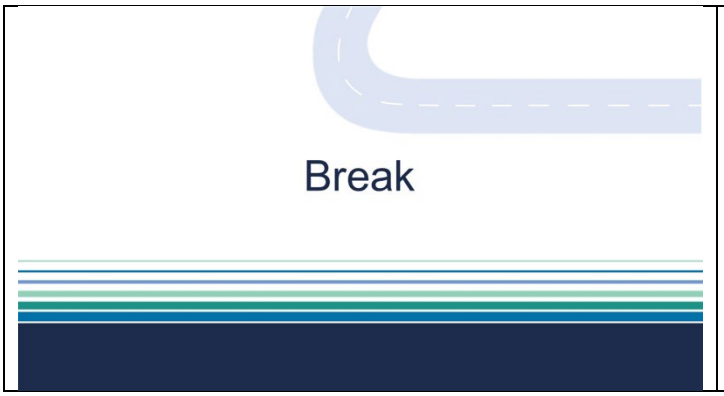
|  | |

**Family Involvement (10 minutes)**

| Slide | Facilitator Notes |
|---|---|
|  | • |
|  | • Ask: What is it like in your dialysis community to partner with family? How does that go for you? Does anyone have a system that is going well?<br>• Reflect on participants responses to reinforce family involvement concepts.<br>• Ask questions to prompt further discussion of participants' experience |

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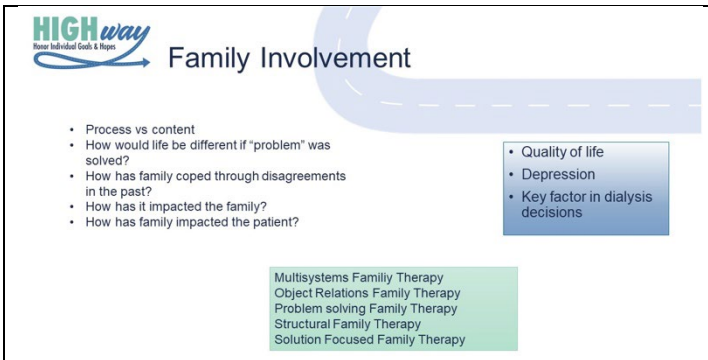
|  | • Family are an underused resource – when we involve family, patients report improved quality of life and less depression. We know that family are key in dialysis decisions. We know it's important to involve them, and yet with don't.<br>• They are also overused: carrying all of the weight (transporting, caregiving, etc.); also may have income lost because demands require them to stop working<br>• Refer participants to Family Involvement in Advanced Directives recorded presentation to learn more. |

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**Family Involvement Role Play (10 minutes)**

| Slide | Facilitator Notes |
|---|---|
|  | • Invite a participant volunteer to engage in a phone call role play where the participant's goals for his/her loved one differ from that of the patient. You are the social worker calling caregiver. You've already met the family.<br>• Step 1: Establish common ground<br>  ○ Tell me how things are going<br>  ○ In honor of transparent conversation, is it OK if I share feedback about what we are seeing here<br>  ○ I know their quality of life is important to you, how can we work together.<br>• See Appendix D for an alternative scenario.<br>• Engage participants in a discussion of strategies to engage & assist caregivers. |

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| | ○ How would you proceed with this family?<br>○ What natural resources exist and can be drawn upon?<br>○ How can the wishes of the client be recognized? |

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**Breakout Groups: Practice Family Involvement (10 minutes)**

| Slide | Facilitator Notes |
|---|---|
| | • Breakout groups to practice involving family member |

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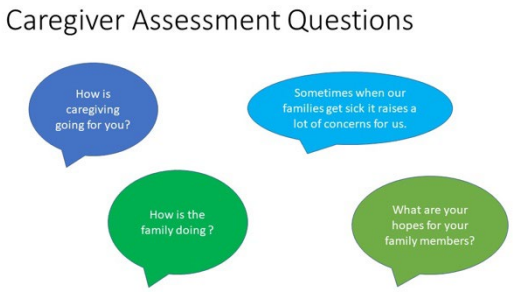
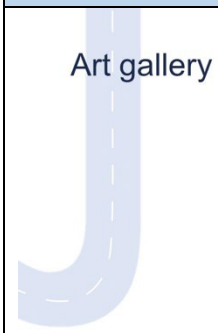
**Caregiver Assessment Questions (10 minutes)**

| Slide | Facilitator Notes |
|---|---|
|  | • These are some options for opening the conversation<br>• Invite participants to share questions/conversation openers they use |

**Closing (10 minutes)**

| Slide | Facilitator Notes |
| --- | --- |
|  | • Invite participants to share thoughts about what they submitted, what it expresses for them<br>• See Appendix X for additional guidance on the art gallery activity. |

# Booster Session 1: Leading Interdisciplinary Teams in ACP

| Time | Topic | Minutes |
|---|---|---|
| 00:00 – 00:10 | Opening | 10 |
| | | |
| | | |

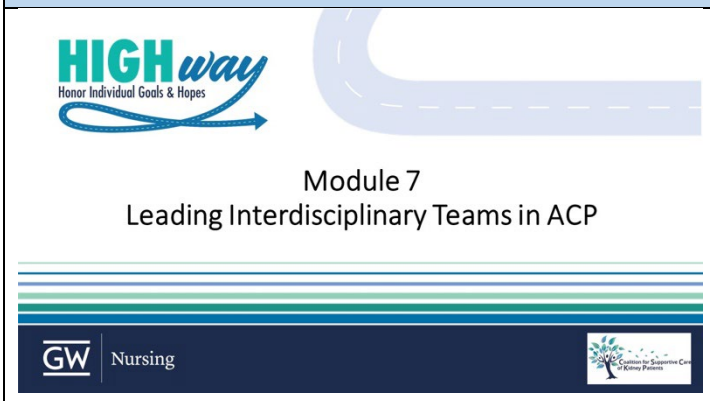
**Learning Objectives:**

- Describe the social worker's role in leading the care coordination and hand-off process for goals of care conversations for a patient with chronic kidney disease
- Integrate ACP into the social worker's ongoing workflow
- Describe strategies for leadership and communication of ACP within an interdisciplinary care team

**Supplemental Materials:**

- Leading ACP in Teams Recorded presentation (5:06)
- Team Planning Worksheet for Advance Care Planning in the Dialysis Unit

**Leading ACP in Interdisciplinary Teams (??)**

| Slide | Facilitator Notes |
|---|---|
|  | • Ask: How do we share with the team the unique value of ACP?<br>• Invite participants to share their approach to leadership in teams when approaching topics such as ACP or other topics.<br>• Refer participants to Leading ACP in Teams recorded presentation (5:06) to learn more. |

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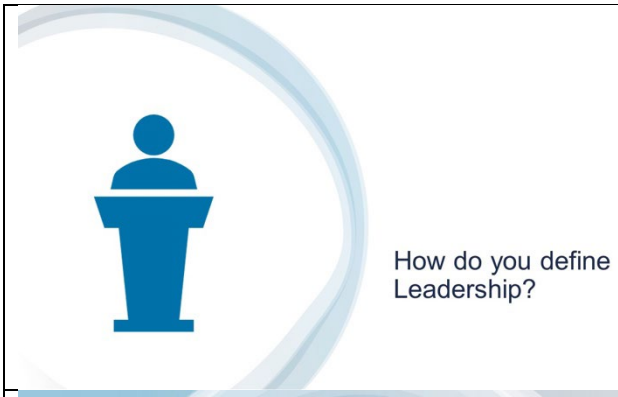
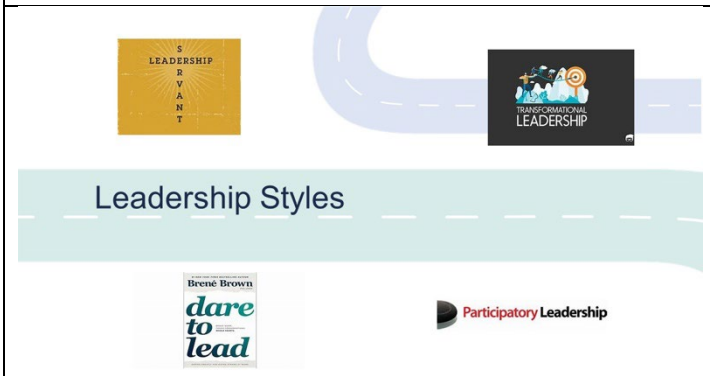
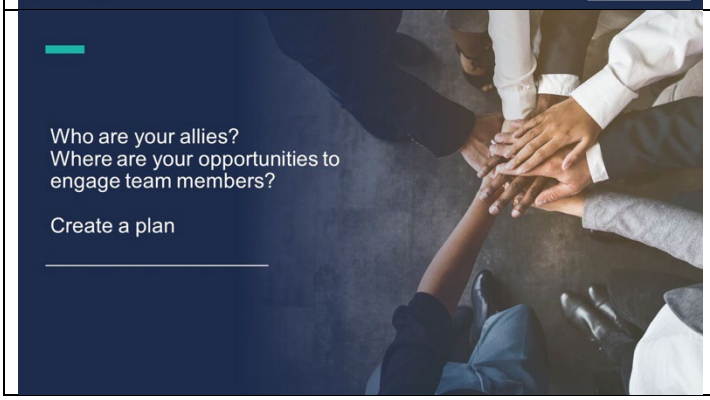
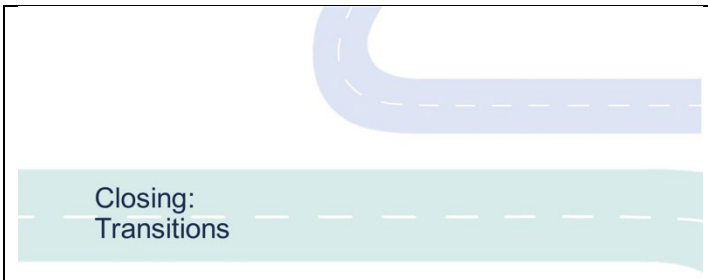
|  | |
|  | There is often a variance of leadership skill sets across disciplines (Klarare et al., 2020) as traditional medical hierarchies can influence interprofessional collaboration negatively (Mertens et al., 2019). This mismatch is both due to training, such as valuing autonomy resulting in a reluctance to delegate authority (Kornacki, 2017) or the opposite of being trained to cede authority to others (Dahlin et al., 2019). Social work leadership describes a client-centered or collective approach (Peters & Hopkins, 2019; Sullivan, 2016) that focuses on the needs of the client and how to improve the conditions, processes, and interventions (Sullivan, 2016 |
|  | |


Introducing
and Supporting
ACP in Teams


Facilitating Team
Communication and
Warm Hand Off


HIGHway
Honor Individual Goals & Hopes
Resolving Conflict in Teams
GW
Nursing


Who are your allies?
Where are your opportunities to
engage team members?
Create a plan


Closing:
Transitions

# Booster Session 2: Implementation Tools

| Time | Topic | Minutes |
|---|---|---|
| 00:00 – 00:05 | Opening | 5 |
| 00:05 – 00:20 | How to Make Things Happen in HIGHway | 15 |
| 00:20 – 00:35 | Cause & Effect Diagram | 15 |
| 00:35 – 00:50 | PDSA & Small Tests of Change | 15 |
| 00:50 – 00:55 | Closing | 5 |

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**Learning Objectives:**

- Facilitate advance care planning for a patient with chronic kidney disease using the HIGHway Roadmap framework
- Describe documents used to make patient wishes actionable
- Assist in completion of goals of care, advanced directives and medical orders

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**Supplemental Materials:**

- Implementation Tools Recorded presentation (16:09)
- Worksheet for Testing Change
- Cause and Effect Handout Progress through Change

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**Opening (5 minutes)**

| Slide | Facilitator Notes |
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**How to Make Things Happen (15 minutes)**

| Slide | Facilitator Notes |
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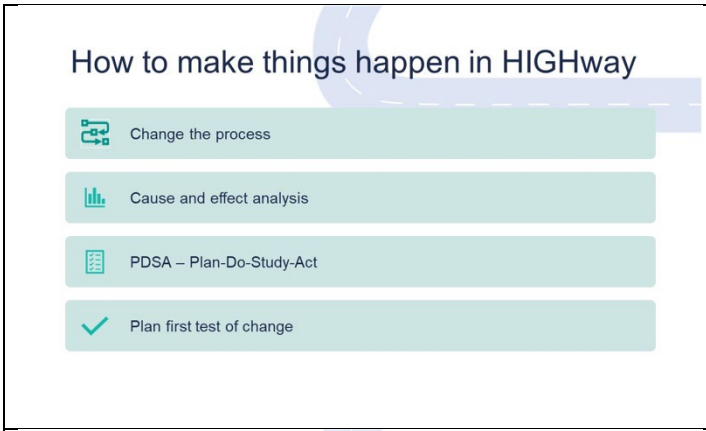
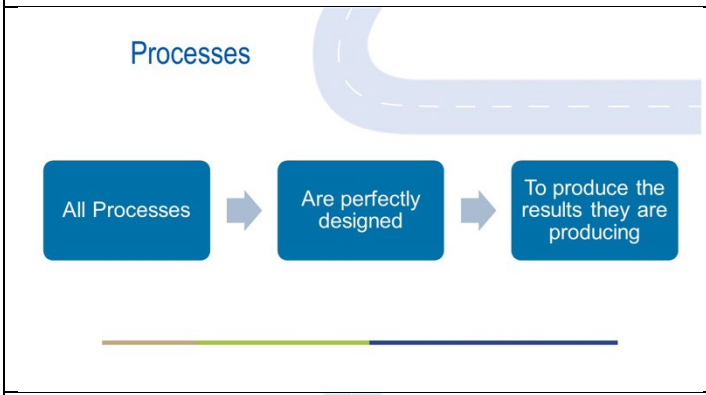
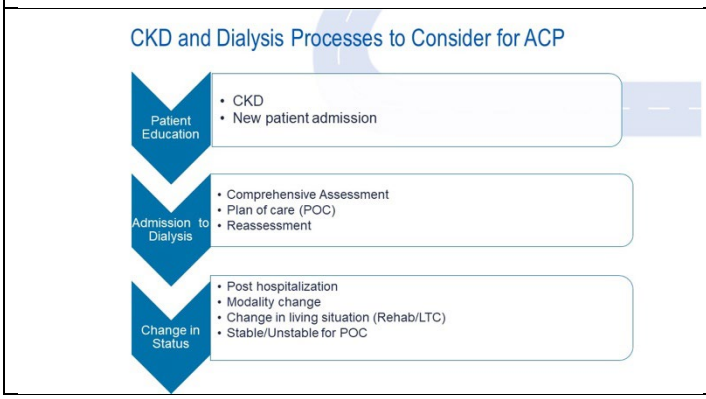
|---|---|
|  | |
|  | |
|  | |

## Cause & Effect Diagram (15 minutes)

| Slide | Facilitator Notes |
|---|---|

## Cause and Effect Diagram

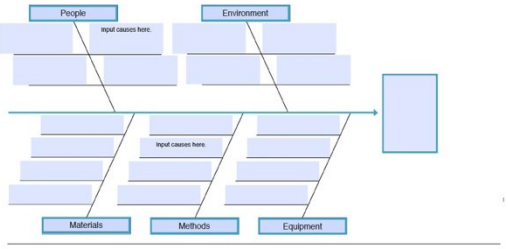
- What causes the problem?
- Materials, Methods, Equipment, Environment, and People.
- 5 Whys- for each cause ask "WHY?" 5 times

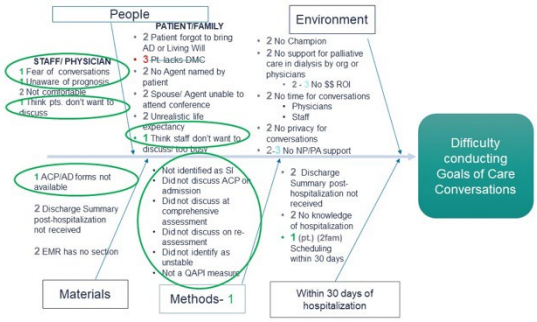
## Example Cause and Effect Diagram for lack of ACP

**Template: Cause and Effect Diagram**

**Team:** **Project:**

1) Input the effect you'd like to influence.
2) Input categories of causes for the effect (or keep the classic five).
3) Input causes within each category.




- First brainstorm everything that could go in that section
- Use 5 whys to generate more items - keep asking "why"
- Then rate each cause – 3= can't control, 2= difficult to control 1= changeable by team -

## Follow up with Cause and Effect Diagram

- Review the Cause and Effect Diagram your team made
- Choose two of the "1's (complete control)
  - Brainstorm how to overcome this barrier
  - Plan how to overcome this barrier - handout
  - This is designing a small test of change

**PDSA & Small Tests of Change (15 minutes)**

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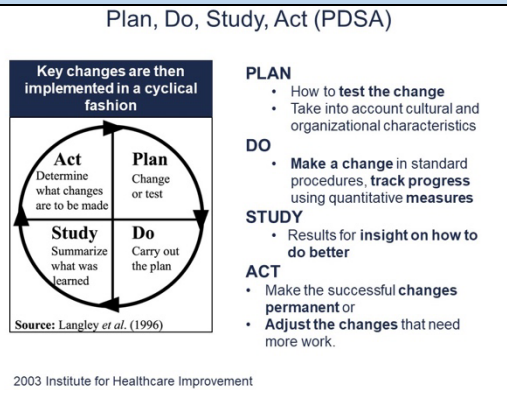
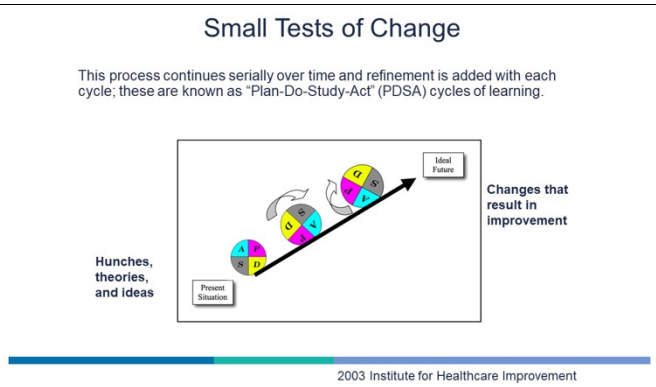
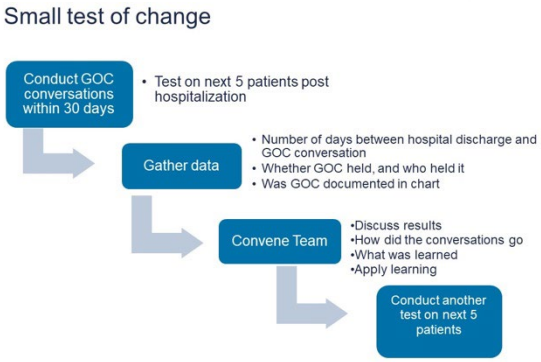
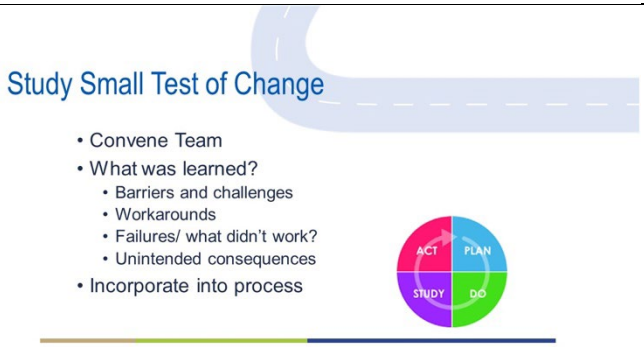
|  | • |
|  | • |
|  | • |
|  | • |

**Worksheet For Testing Change**

**Aim**: (Overall goal you would like to reach)

Every goal will require multiple smaller tests of change

***Plan***

| Describe your first (or next) test of change | Person Responsible | When to be done | Where to be done |
|---|---|---|---|
| | | | |

| List the tasks needed to set up this test of change | Person Responsible | When to be done | Where to be done |
|---|---|---|---|
| 1-<br>2-<br>3-<br>4-<br>5- | | | |

| Predict what will happen when the test is carried out | Measures to determine if prediction succeeds |
|---|---|
| 1-<br>2-<br>3-<br>4- | 1-<br>2-<br>3-<br>4- |

***Do***

**Describe what actually happened when you ran the test**

***Study*** **Describe the measured results and how they compared to the predictions**

***Act*** **Describe what modifications to the plan will be made for the next cycle from what you learned**

●

## Next steps:

- Cause and Effect Diagram (with team?)
- Plan small test of change (keep it small!)
- Test the change on small scale

●

## Narrated powerpoint on implementation

https://vimeopro.com/gwnursing/highwaygrant/video/690941478

●

## Appendix A: Motivational Interviewing Handout

# Understanding Motivational Interviewing

## Summary

Motivational Interviewing (MI) is often recommended as an evidence-based approach to behavior change. However, definitions of MI vary widely, including out of date and inaccurate understandings. This document provides a brief summary of what MI is, what is isn't and where to go next if you are interested in learning more about this approach.

## What is Motivational Interviewing?

*"MI is a collaborative, goal-oriented style of communication with particular attention to the language of change. It is designed to strengthen personal motivation for and commitment to a specific goal by eliciting and exploring the person's own reasons for change within an atmosphere of acceptance and compassion."* (Miller & Rollnick, 2013, p. 29)

The most current version of MI is described in detail in Miller and Rollnick (2013) *Motivational Interviewing: Helping people to change* (3rd edition). Key qualities include:

- MI is a **guiding** style of communication, that sits between **following** (good listening) and **directing** (giving information and advice).
- MI is designed to **empower** people to change by drawing out their own meaning, importance and capacity for change.
- MI is based on a **respectful** and **curious** way of being with people that facilitates the natural process of change and honors client autonomy.

It is important to note that MI requires the clinician to engage with the client as an equal partner and refrain from unsolicited advice, confronting, instructing, directing, or warning. It is not a way to "get people to change" or a set of techniques to impose on the conversation. MI takes time, practice and requires self-awareness and discipline from the clinician. (Miller & Rollnick, 2009)

While the principles and skills of MI are useful in a wide range of conversations, MI is particularly useful to help people examine their situation and options when any of the following are present:

- **Ambivalence is high** and people are stuck in mixed feelings about change
- **Confidence is low** and people doubt their abilities to change
- **Desire is low** and people are uncertain about whether they want to make a change

- **Importance is low** and the benefits of change and disadvantages of the current situation are unclear.

## Core elements of Motivational Interviewing

- MI is practiced with an underlying **spirit** or way of being with people:
    - **Partnership**. MI is a collaborative process. The MI practitioner is an expert in helping people change; people are the experts of their own lives.
    - **Evocation**. People have within themselves resources and skills needed for change. MI draws out the person's priorities, values, and wisdom to explore reasons for change and support success.
    - **Acceptance**. The MI practitioner takes a nonjudgmental stance, seeks to understand the person's perspectives and experiences, expresses empathy, highlights strengths, and respects a person's right to make informed choices about changing or not changing.
    - **Compassion**. The MI practitioner actively promotes and prioritizes clients' welfare and wellbeing in a selfless manner.

- MI has **core skills** of OARS, attending to the language of change and the artful exchange of information:
    - **Open questions** draw out and explore the person's experiences, perspectives, and ideas.

Evocative questions guide the client to reflect on how change may be meaningful or possible. Information is often offered within a structure of open questions (Elicit-Provide- Elicit) that first explores what the person already knows, then seeks permission to offer what the practitioner knows and then explores the person's response.

- **Affirmation** of strengths, efforts, and past successes help to build the person's hope and confidence in their ability to change.
- **Reflections** are based on careful listening and trying to understand what the person is saying, by repeating, rephrasing or offering a deeper guess about what the person is trying to communicate. This is a foundational skill of MI and how we express empathy.
- **Summarizing** ensures shared understanding and reinforces key points made by the client.
- **Attending to the language of change** identifies what is being said against change (sustain talk) and in favor of change (change talk) and, where appropriate, encouraging a movement away from sustain talk toward change talk.
- **Exchange of information** respects that both the clinician and client have expertise. Sharing information is considered a two way street and needs to be responsive to what the client is saying.

- MI has four fundamental **processes**. These processes describe the "flow" of the conversation although we may move back and forth among processes as needed:

- **Engaging**: This is the foundation of MI. The goal is to establish a productive working relationship through careful listening to understand and accurately reflect the person's experience and perspective while affirming strengths and supporting autonomy.
- **Focusing**: In this process an agenda is negotiated that draws on both the client and practitioner expertise to agree on a shared purpose, which gives the clinician permission to move into a directional conversation about change.
- **Evoking**: In this process the clinician gently explores and helps the person to build their own "why" of change through eliciting the client's ideas and motivations. Ambivalence is normalized, explored without judgement and, as a result, may be resolved. This process requires skillful attention to the person's talk about change.
- **Planning**: Planning explores the "how" of change where the MI practitioner supports the person to consolidate commitment to change and develop a plan based on the person's own insights and expertise. This process is optional and may not be required, but if it is the timing and readiness of the client for planning is important.

MI is framed as a method of communication rather than an intervention, sometimes used on its own or combined with other treatment approaches. There are a number of benefits of learning MI amongst other approaches to helping conversations:

- MI has been applied across a broad range of settings (e.g. health, corrections, human services, education), populations (e.g. age, ethnicity, religion, sexuality and gender identities), languages, treatment format (e.g. individual, group, telemedicine) and presenting concerns (e.g. health, fitness, nutrition, risky sex, treatment adherence, medication adherence, substance use, mental health, illegal behaviors, gambling, parenting).
- MI compares well to other evidence-based approaches in formal research studies.
- MI is compatible with the values of many disciplines and evidence-based approaches.
- Although the full framework is a complex skill set that require time and practice, the principles of MI have intuitive or "common sense" appeal and core elements of MI can be readily applied in practice as the clinician learns the approach.
- MI has observable practice behaviors that allow clinicians to receive clear and objective feedback from a trainer, consultant or supervisor.

## Further questions

- What are some ways MI could be helpful in your work?
- What are some reasons you might want to learn more about MI?
- What might be a next step or two? If you are interested in learning more about MI, you might

consider reading the next document in the series: Learning Motivational Interviewing or the core text by Miller and Rollnick (2013).

## References


- Miller, W.R. & T.B. Moyers (2017) Motivational Interviewing and the clinical science of Carl Rogers. *Journal of Consulting and Clinical Psychology, 85*(8), 757-766
- Miller, W.R. & Rollnick, S. (2013) *Motivational Interviewing: Helping people to change* (3rd Edition). Guilford Press.
- Miller & Rollnick (2017) Ten things MI is not Miller, W.R. & Rollnick, S. (2009) Ten things that MI is not. *Behavioural and Cognitive Psychotherapy*, 37, 129-140.

## Appendix B: Motivational Interviewing Counts Worksheet

**Directions:** Record (tic marks) how often the Social Worker does the following:

Asking

- Open ended
- Closed ended

Listening/Reflective Statement

Empathetic Statement

Informing

- With permission
- Without permission

1. Examples of flexibility
2. Examples of Resist the Righting Reflex
3. Examples of Rolling with Resistance
4. Examples of allowing/elevating awareness of Ambiguity

# Appendix C: Emotion Words Worksheet

From: Hepworth, D. H., Rooney, R., & Larsen, J. (2000). *Direct social work practice: Theory and skills.* Pacific Grove, CA.: Brooks.

**Competence, Strength**

| | |
|---|---|
| Convinced you can | confident |
| Sense of mastery | powerful |
| Potent | courageous |
| Resolute | determined |
| Strong | influential |
| Brave | impressive |
| Forceful | inspired |
| Successful | secure |
| In charge | in control |
| Well-equipped | committed |
| Sense of accomplishment | daring |
| Feeling oats | effective |
| Sure | sense of conviction |
| Trust yourself | self-reliant |
| Sharp | able |
| Adequate | firm |
| Capable | on top of it |
| Can cope | important |
| Up to it | ready |
| Equal to it | skillful |

**Happiness, Satisfaction**

| | |
|---|---|
| Elated | superb |
| Ecstatic | on cloud nine |
| On top of the world | organized |
| Fantastic | splendid |
| Exhilarated | jubilant |
| Terrific | euphoric |
| Delighted | marvelous |
| Excited | enthusiastic |
| Thrilled | great |
| Super | in high spirits |
| Joyful | cheerful |
| Elevated | happy |
| Lighthearted | wonderful |
| Glowing | jolly |
| Neat | glad |
| Fine | pleased |
| Good | contented |
| Hopeful | contented |
| Satisfied | gratified |
| Fulfilled | tranquil |
| Serene | calm |
| At ease | |

**Caring, Loving**

| | |
|---|---|
| Adore | loving |
| Infatuated | enamored |
| Cherish | idolize |
| Worship | attached to |
| Devoted to | tenderness towards |
| Affection for | hold dear |
| Prize | caring |
| Fond of | regard |
| Respect | admire |
| Concern for | taken with |
| Turned on | trust |
| Close | esteem |
| Hit it off | value |
| Warm toward | friendly |
| Like | positive towards |
| Accept | |

**Depression, Discouragement**

| | |
|---|---|
| Anguished | in despair |
| Dreadful | miserable |
| Dejected | disheartened |
| Rotten | awful |
| Horrible | terrible |
| Hopeless | gloomy |
| Dismal | bleak |
| Depressed | despondent |
| Grieved | grim |
| Brokenhearted | forlorn |
| Distressed | downcast |
| Sorrowful | demoralized |
| Pessimistic | tearful |
| Weepy | down in the dumps |
| Deflated | blue |
| Lost | melancholy |
| In the doldrums | lousy |
| Kaput | unhappy |
| Down | low |
| Bad | blah |
| Disappointed | sad |
| Below par | |

**Inadequacy, Helplessness**

Utterly
Good for nothing
Powerless
Impotent
Inferior
Useless
Like a failure
Inadequate
Defeated
Incompetent
Inept
Overwhelmed
Like a klutz
Awkward
Unable
Small
Like a wimp
Over the hill
Immobilized
At the mercy of
Insecure
Unsure of self
Weak
Unfit
worthless
washed up
helpless
crippled
emasculated
finished
impaired
whipped
stupid
puny
clumsy
ineffective
lacking
deficient
incapable
insignificant
unimportant
incomplete
like a puppet
inhibited
lacking confidence
uncertain
inefficient

**Anxiety, Tension**

Terrified
Intimidated
Desperate
Terror-stricken
Frantic
Shocked
Afraid
Stage fright
Vulnerable
Apprehensive
shaky
butterflies
defensive
tied in knots
tense
jittery
nervous
unsure
timid
worried
bashful
ill at ease
uncomfortable
insecure
restless
frightened
horrified
panicky
paralyzed
stunned
threatened
scared
dread
fearful
jumpy
distrustful
awkward
uptight
rattled
fidgety
on edge
anxious
hesitant
shy
uneasy
embarrassed
doubtful
self-conscious
alarmed

## Confusion, Troubledness

Bewildered
Tormented by
Perplexed
Trapped
In a dilemma
In a quandry
Going around in circles
Disorganized
Troubled
Lost
Frustrated
Flustered
Disturbed
Stumped
Mixed feelings about
Unsure
Uncomfortable
Uneasy
puzzled
baffled
overwhelmed
confounded
befuddled
at loose ends
mixed-up
in a fog
adrift
disconcerted
floored
in a bind
conflicted
feeling pulled apart
uncertain
bothered
undecided

## Anger, Resentment

Furious
Livid
enraged
seething

## Rejection, Offensiveness

Crushed
Ruined
Wounded
Tortured
Betrayed
Knifed in the back
Belittled
Depreciated
Sensured
Disparaged
Malinged
Ridiculed
Scorned
Scoffed at
Exploited
Slammed
Impugned
Mistreated
Slighted
Overlooked
Let down
Unappreciated
Taken lightly
Degraded
Shot down
destroyed
pained
devastated
cast off
discarded
hurt
abused
criticized
discredited
laughed at
mistreated
devalued
mocked
used
debased
slandered
cheapened
put down
neglected
minimized
disappointed
taken for granted
underestimated
discounted

Could chew nails
Burned up
Bitter
fighting mad
hateful
galled

| | |
|---|---|
| Vengeful | resentful |
| Indignant | irritated |
| Hostile | pissed off |
| Have hackles up | had it with |
| Upset with | bent out of shape |
| Agitated | annoyed |
| Got dander up | had it with |
| Dismayed | uptight |
| Disgusted | bugged |
| Turned off | put out |
| Miffed | ruffled |
| Irked | perturbed |
| Ticked off | teed off |
| Chagrined | griped |
| Cross | impatient |
| Infuriated | violent |

**Loneliness**

| | |
|---|---|
| All alone in the universe | isolated |
| Abandoned | totally alone |
| Forsaken | forlorn |
| Lonely | alienated |
| Estranged | rejected |
| Remote | alone |
| Apart from others | shut out |
| Left out | excluded |
| Lonesome | distant |
| Aloof | cut off |

**Guilt, Embarrassment**

| | |
|---|---|
| Sick at heart | unforgiveable |
| Humiliated | disgraced |
| Degraded | horrible |
| Mortified | exposed |
| Branded | could crawl in a hole |
| Like two cents | ashamed |
| Guilty | remorseful |
| Crummy | real rotten |
| Lost face | demeaned |
| Foolish | ridiculous |
| Silly | stupid |
| Egg on face | regretful |
| Wrong | embarrassed |
| At fault | in error |
| Responsible for | goofed |
| Lament | blew it |

## Appendix D: Case Study for Emotion Words Activity

Terrance is the70 year old caregiver and husband of Mary, a dialysis patient of 3 years in rural Pennsylvania. Terrance requests to meet with the new social worker because he hopes that they can assist in getting better transportation on Weds. During the conversation, the social worker asks him not just how Mary is doing, but how he is holding up. Terrance discloses that in addition to being Mary's only caregiver, waking at 4 AM to get her to dialysis, he has had cancer and he thinks it is re-occurring, but hasn't found a doctor in the community taking new patients. The social worker resists the urge to fix and stays silent, encouraging Terrance to keep talking by nodding her head and avoiding writing or typing. The social worker responds with empathy by stating "You must be exhausted witnessing Mary suffer, and carry the burden of worrying about your own future." Terrance begins to cry and states, "That's not all. Every morning when I wake her up to go to dialysis, she says 'I don't want to go; I'm just going to die anyway. This is just an existence'" The social worker again responds with empathy by leaning in, looking Terrance in the eye, and touching his hand and states, "It's heartbreaking to hear the person you love so much say that." Terrance continuesto quietly cry. The social worker asks, "This is so heavy for you to carry. Who do you have to talk to?" Terrance replies, "no one. I have never talked to anyone about this. This is the longest I've ever talked about Mary's dialysis with anyone."
Terrance is the70 year old caregiver and husband of Mary, a dialysis patient of 3 years in rural Pennsylvania. Terrance requests to meet with the new social worker because he hopes that they can assist in getting better transportation on Weds. During the conversation, the social worker asks him not just how Mary is doing, but how he is holding up. Terrance discloses that in addition to being Mary's only caregiver, waking at 4 AM to get her to dialysis, he has had cancer and he thinks it is re-occurring, but hasn't found a doctor in the community taking new patients. The social worker resists the urge to fix and stays silent, encouraging Terrance to keep talking by nodding her head and avoiding writing or typing. The social worker responds with empathy by stating "You must be exhausted witnessing Mary suffer, and carry the burden of worrying about your own future." Terrance begins to cry and states, "That's not all. Every morning when I wake her up to go to dialysis, she says 'I don't want to go; I'm just going to die anyway.This is just an existence'" The social worker again responds with empathy by leaning in, looking Terrance in the eye, and touching his hand and states, "It's heartbreaking to hear the person you love so much say that." Terrance continues to quietly cry. The social worker asks, "This is so heavy for you to carry. Who do you have to talk to?" Terrance replies, "no one. I have never talked to anyone about this. This is the longest I've ever talked about Mary's dialysis with anyone."

## Appendix E: Case Study for Family Involvement Role Play

- Ada (73) and Ben (76) Folsom were placed together in a nursing home two months ago. Ada presented as alert and fully oriented. Ben has been diagnosed with severe Alzheimer's disease. Ada has ESRD and is currently on dialysis. Ada states that she 'can't stand' dialysis and that it is 'very painful'. Ada reports that she has a lot of cramping, feels very fatigued on a daily basis, low blood pressure, vomiting, headaches, and has been in and out of the emergency room in the past six months. Ada scored a one on her most recent SPMSQ which indicates normal mental functioning. Both must have assistance with all ADLs. Since being in the nursing home, Ada has told workers multiple times that she will convince Ben to take her out of the nursing home and drive them home, as Ada herself cannot drive. The couple has two children, Chris (45) and Kayla (43). Kayla lives with her husband and two children next door to Ben and Ada's home. Kayla is currently unemployed and her husband is a contractor. Chris is recently divorced, lives a three-hour drive away and is a lawyer. No additional family members have been identified.

  During an in-person meeting at the nursing home with Ben and Ada and their two children, Kayla made it very clear that she wants her mother to stay on dialysis. Chris, however, stated that he believes that it is up for his mother to decide, and to 'follow her own [Ada's] wishes'. It was noted that in the past, Ben has also stated that he would like for Ada to stay on dialysis, however, when asked in the current meeting, he stated that he wasn't sure what to think. Ada was tearful in the meeting and told her children she was afraid of being a burden.
- Facilitate a discussion of this case using the following questions:
  - How would you proceed with this family?
  - What natural resources exist and can be drawn upon?
  - How can the wishes of the client be recognized?

## Appendix X: Team Planning Worksheet for Advance Care Planning in the Dialysis Unit

**Goals:**
Set goals that are specific, measurable, attainable, realistic and timely. Goals should answer the question, "Who will do what by when?"
Examples include:

1. I will ask our clinical coordinator to add me to the agenda of the next team meeting to discuss ACP.
2. I will provide a 10 minute overview of the ACP Project to our team during the next team meeting.
3. During the next 5 social work visits, I will begin using the Roadmap.

| **What** (List Steps) | **How** (List Action Items) | **Who** (Assign Someone) | **When** (Date Expected) |
|---|---|---|---|
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |

## Appendix X: Guided Relaxation Exercises

**Facilitator Scripts**

- "I would like to offer you a tool that many people who are experiencing a difficult illness/treatment find helpful. Would you feel comfortable closing your eyes and taking a few breaths? Focus on your breathing. Rest in the feeling of breath coming in and going out, like ocean waves. Now let your worries and thoughts pass by like clouds moving in the sky."
- "Close your eyes. Starting with your feet, tighten all the muscles, and then let go suddenly with a big sigh. Move up to your whole leg. Tighten it, hold, and let go quickly with another sigh. Keep moving up your body, tightening and releasing each area. Finish by making a face like you are eating something very sour. Tighten your mouth, your eyes, and let go with a big sigh. Now starting at your head, imagine that warm chocolate is washing over you, letting every muscle relax and rest."

## Appendix X: Expressing and Cultivating Emotional Understanding of Mortality through Art

Art/Poetry/Music Gallery – You are the Curator.

Through human history and across civilizations, artists have tried to convey their feelings and philosophy about life, mortality, grief. Often, viewing or participating in these artistic works is cathartic and healing in ways that rational expression does not reach. Invite participants to select one personal favorite poem, painting, photograph, song, or any other artwork that expresses some aspect of the illness, dying, death and bereavement experience that is meaningful to them. It can be a work by a famous or popular artist, or something you created yourself, such as a photo, journal entry, or poem. Share these in a gallery during a break or to close a session. Invite participants to share how the artwork is meaningful to them and what it expresses about mortality, living, and dying.