DRILL A: Perception, invitation, knowledge, emotion

| PERCEPTION / INVITATION |
| --- |
| Clinician ClipartClinician | Patient ClipartPatient |
| What’s your understanding of how your kidneys are doing now? | No one’s really told me anything. |
| Would you like me to share what I know? | Yes, that would be really helpful. |

|  INVITATION / KNOWLEDGE / EMOTION  |
| --- |
| Clinician ClipartClinician | Patient ClipartPatient |
| Is now an okay time to talk about the tests? | I suppose as good as any. What is it? |
| I’m afraid I have serious news. Your kidney function is very poor.  | I thought things were getting better. How can that be?  |
| I know this is quite a shock. | I just can’t believe this. |

Page 1

DRILL B: Respond to emotion

| NAMING EMOTION |
| --- |
| Patient Clipart Patient | Clinician ClipartClinican |
| I’ve just been going to all these doctor appointments and getting all these tests, and I don’t know… | It sounds like you’re feeling overwhelmed.  |
| Yes, exactly, so much is going on and I don't know what to do. |  |

| ACKNOWLEDGING EMOTION |
| --- |
| Patient Clipart Patient | Clinician ClipartClinican |
| No one’s telling me what’s going on. Why can’t I just get a transplant?  | I can’t even imagine how hard this must be. |
| It’s just so scary. I’m really worried.  |  |

| “I WISH” STATEMENT |
| --- |
| Patient Clipart Patient | Clinician ClipartClinican |
| I don’t understand… I’ve done everything right! What aren’t my kidneys getting better?  | I wish you weren’t having to go through this. |
| I know. It’s really hard.  |  |

Page 2

DRILL A: Reassess perception of illness, respond to emotion, reframe, ask permission to proceed

| REASSESS PERCEPTION / RESPOND TO EMOTION |
| --- |
| Clinician ClipartClinician | Patient Clipart Patient |
| Tell me what you understand about your illness. | I’m not getting better with this treatment, but there’s got to be something else out there!  |
| I wish we had a more effective treatment.  |  |

| REFRAME |
| --- |
| Clinician Clipart Clinician | Patient Clipart Patient |
| What’s your sense of where things are?  | I know I’ve got kidney failure, and I’ve been feeling worse and worse. But I’ve had this for quite a while, and I’m hoping it will get better… |
| You’ve been living with kidney disease a long time. And, I think we’re in a different place now.  |  |

Page 1

DRILL A, continued

| RESPOND TO EMOTION / ASK PERMISSION |
| --- |
| Clinician ClipartClinician | Patient ClipartPatient |
| What’s your sense of where things are?  | I know I’m getting worse. I’m afraid I’m just a burden on my kids. |
| This must be hard.  | It is. There’s a lot happening. |
| I hear that. Is it ok if we talk about where we can go from here? |  |

Page 2

DRILL B: Respond to emotion, ask permission to proceed

| EXPECT EMOTION |
| --- |
| Clinician Clipart Clinician | Patient ClipartPatient |
| You’ve been living with kidney disease a long time. And, I think we’re in a different place now. | So, what are you saying – that I’m supposed to give up? |
| I can’t even imagine what it’s like for you to live with an illness that keeps getting worse. |  |

| EXPECT EMOTION |
| --- |
| Clinician Clipart Clinician | Patient ClipartPatient |
| It’s probably a good time to step back and talk about where we go from here. | I’m a fighter. I’m never going to give up. |
| I really admire your spirit and everything you’ve done to fight this illness. |  |

Page 3

DRILL B, continued

| MOVING FORWARD |
| --- |
| Patient Clipart Patient | Clinician ClipartClinician |
| I just kept hoping that someday I would get a transplant.  | I can see how disappointing this is for you. Would it be all right if we talked about where we go from here? |

Page 4

DRILL A: Elicit patient’s values

| MAP (Patient Knows Values) |
| --- |
| Clinician ClipartClinician | Patient ClipartPatient |
| Given this situation, what’s most important?  | It’s important to me that I don’t give up – I don’t want to look back and regret that I didn’t give it everything I had. |
| I admire your fight, and I can see how important it is for you to know that you’re not giving up.  |  |

| MAP (with Surrogate) |
| --- |
| Clinician ClipartClinician | Patient ClipartSurrogate |
| If your dad could understand what’s happening, what would he think?  | He would never want to be hooked up to all of these machines. |
| Tell me more. |  |

Page 1

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Page 2

DRILL B: Elicit patient’s values

| MAP (Patient Not Sure) |
| --- |
| Clinician ClipartClinician | Patient ClipartPatient |
| Given this situation, what’s most important?  | I’m not sure what to tell you. |
| What if you start with what you’re enjoying in your life right now?  |  |

| MAP (Patient Not Ready) |
| --- |
| Clinician ClipartClinician | Patient ClipartPatient |
| Given this situation, what’s most important? | I don’t feel ready to decide. It’s hard…  |
| This is a tough situation for anyone. |   |

Page 3

DRILL B, continued

| MAP (What Patient Wants to Avoid) |
| --- |
| Clinician ClipartClinician | Patient ClipartPatient |
| As you think about the future, is there anything you worry about? | I don’t want to be kept alive if I can’t communicate with my family. I just don’t think life would be worth living.  |
| That helps me better understand what you’re thinking. |  |

Page 4

DRILL A: Align by restating the patient’s values as you heard them

| ALIGN |
| --- |
| Patient Clipart Patient | Clinician ClipartClinican |
| I’m really sick of going into the hospital all the time, and I know this isn’t going to get any better, but I get really scared when my breathing gets worse.  | I’m sure that’s scary. So, what I hear you saying is that you’re tired of going to the hospital, and we need to do a better job of preventing your shortness of breath. |
| Exactly… |  |

| ALIGN (Improvise - Simple) |
| --- |
| Patient Clipart Patient | Clinician ClipartClinican |
| I don’t want to be in pain anymore. And I want to stay at home, spending time with my family.  | (Improvise by aligning with what you heard) |

Page 1

DRILL A, continued

| ALIGN (Improvise - More Complex) |
| --- |
| Patient Clipart Patient | Clinician ClipartClinican |
| I’m scared. I want to live, and I’m worried that I’m not getting better. But I don’t want to prolong anything if it just means being stuck on machines or dependent on my kids. And I don’t want my kids to have to deal with any of these decisions. | (Improvise by aligning with what you heard) |

Page 2

DRILL B: Recommend plan based on patient’s values

| PLAN |
| --- |
| Clinician Clipart Clinican | Patient Clipart Patient |
| Based on what you’re saying, it sounds like we should focus more on your symptoms and keeping you home and out of the hospital.  | Yes, that’s what I want. |
| Managing flare-ups of your chest pain at home instead of in the hospital would help us do that. How does that sound? | That would be a lot better. |

| PLAN |
| --- |
| Clinician ClipartClinican | Patient ClipartPatient |
| Based on what you said is most important, managing your symptoms and keeping you as comfortable as possible, instead of starting dialysis, may be the right plan for you. Does that sound right?  | You’re right. I wouldn’t want to go through all that.  |

Page 3

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Page 4

DRILL A: Exploring Dialysis Options

| Explore Options |
| --- |
| Patient Clipart  Patient | Clinician ClipartClinician |
| I’m so tired of this. | I wish this wasn’t so exhausting, physically and emotionally. |
| I feel like I’m trapped. | Some people decide that dialysis isn’t helping them live the life they want. |
| So what do they do? | Some decide to spend less time on dialysis, or stop altogether. Others decide to keep going anyway. It depends on whether the trade-offs are worth it to them. |
| What happens if someone spends less time on dialysis? | It depends. Some people don’t notice much difference in how they feel, and some experience more symptoms. In your case… *insert patient-specific information here.* |
| What happens if someone stops dialysis altogether? | What information would be helpful to you? |

Page 1

DRILL A, continued

|  |  |
| --- | --- |
| Patient Clipart  Patient | Clinician ClipartClinician |
| How much time would I have left to live? Would that mean I would die? | It must be really tough to think about this? |
| Yeah, it’s scary. How much time do you think I would have? | Most people who stop dialysis have days to weeks to live.  |
| Wow. I didn’t realize things would go downhill so fast!  | It’s a shock to a lot of people.  |
| That sounds really fast. But I guess I knew it, in the back of my mind. | Would it be ok if I shared some information about support that’s available for people who decide to stop dialysis? |
| That would be ok. |  |

Page 2

DRILL B: Introducing Decisions about Other Life-Sustaining Treatments

|  |
| --- |
| Perception, Invitation, Knowledge, Emotion |
| Clinician ClipartClinican | Patient Clipart Patient |
| I want to be sure you get the care that helps achieve what matters most to you. It’s helpful to know in advance whether you would or wouldn’t want certain treatments. | What types of treatments? |
| One of them is CPR. Can you tell me what you know about it? | I’ve seen it on TV, but I don’t know much about it.  |
| Would it be ok if I shared some information with you about CPR? | Sure. |
| CPR can be used when someone’s heart and breathing stop. CPR involves forcefully pushing on the chest, and can also include shocking the heart and putting a tube down the throat to try to get the heart and breathing to start again. | Wow, CPR’s pretty rough.  |
| A lot of people are surprised by that. | I guess you don’t really think about it when you see it on TV.  |

Page 3

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Page 4

DRILL C: When the Patient Wants Information About Outcomes

|  |
| --- |
| ASSESS INFORMATION PATIENT WANTS  |
| Patient ClipartPatient | Clinician Clipart Clinician |
|  | Some people like to know the chances of surviving after CPR, or what life might be like afterward. Other people have spiritual questions related to these decisions. Some people don’t want more information. What about you? |

| STRATEGY 1: SHARE OUTCOMES LINKED TO GOALS† |
| --- |
| Patient ClipartPatient | Clinician Clipart Clinician |
| I don’t want to be in pain or end up stuck on machines. Would CPR help with that?  | I’m concerned that CPR won’t help you live the life you want. There’s a high risk of broken ribs that would cause pain, and a [large chance]\* you’d need more help and wouldn’t be able to live at home. After CPR, you might need the support of breathing machines to keep you alive.  |

† Select the strategy for providing information that best matches the **patient’s preference** for information: potential outcomes directly linked to patient’s stated goals, general information, or specific odds.

\* Customize per the patient’s risk using general terms (e.g., the same, lower, much lower, higher, much higher).

Page 5

DRILL C, continued

|  |
| --- |
| STRATEGY 2: SHARE GENERAL OUTCOMES† |
| Patient ClipartPatient | Clinician Clipart Clinician |
| Doesn’t CPR usually work? | Unfortunately, most adults who receive CPR don’t survive. Young and otherwise healthy people have better chances of surviving, and people with serious health problems have lower chances.  |

|  |
| --- |
| STRATEGY 3: SHARE SPECIFIC ODDS† |
| Patient ClipartPatient | Clinician Clipart Clinician |
| How many people survive after CPR? What are the odds that I’d make it through? | For people on dialysis who get CPR while they’re in the hospital, about 22 out of 100 survive and 78 out of 100 die before they can leave the hospital.One year later, about 7 out of 100 who get CPR in the hospital are still alive, and 93 out of 100 are not.  |
| That doesn’t sound very good. | These are averages for people on dialysis. For people with health problems like yours, the chances of survival are **[higher/lower]**\*. |

† Select the strategy for providing information that best matches the **patient’s preference** for information: potential outcomes directly linked to patient’s stated goals, general information, or specific odds.

\* Customize per the patient’s risk using general terms (e.g., the same, lower, much lower, higher, much higher).

Page 6

DRILL D: Explore Possible Inconsistencies Between Goals & Decisions

|  |  |
| --- | --- |
| Clinician Clipart Clinician | Patient ClipartPatient |
| RECOMMEND A PLAN BASED ON PATIENT’S GOALS |
| Since it’s really important to you to be independent and take care of yourself, I would not recommend CPR if your heart stops. Even if it worked to restart your heart, there’s a risk that you would be too sick afterwards to go home again or take care of yourself.  | I think I would still want to try CPR if my heart stops. |
| EXPLORE POSSIBLE INCONSISTENCIES |
| Tell me what you’re hoping for with CPR. | When it comes right down to it, if there’s any chance I’d get another day with my kids, it would be worth it, even if I end up in pain or in the hospital on machines for a while. I know it might not work, and I might be in terrible shape, but I’d want to give it a try. |
| EXPLORE LIMITS |
| I can see how important your family is to you, and I really respect that. Can you think of a situation when you wouldn’t want CPR? | I want to give CPR a chance. But if you try it and I end up with brain damage, don’t try it again.  |

Page 7

DRILL D, continued

|  |  |
| --- | --- |
| Clinician Clipart Clinician | Patient ClipartPatient |
| EXPLORE LIMITS |
| Tell me what you mean when you say, “brain damage.” | If I get CPR, and afterward I’m not able to take care of myself or make my own decisions, then I wouldn’t want CPR again if my heart stops. I don’t want to be a burden on my family.  |
| Ok. What if you develop those problems before CPR? | Then I wouldn’t want it. |
| SUMMARIZE |
| At this point you would want an attempt at CPR if your heart and breathing stop. If you were ever permanently unable to take care of yourself or make your own decisions, you wouldn’t want CPR. Do I have that right?  | Yes, that’s right. |
| NEXT STEPS |
| Thanks for helping me understand what you want. Your daughter should know about this, too, since you chose her to communicate your decisions if you can’t speak for yourself. Can you bring her with you to your next appointment?  | That would be good. She might have some questions, and I want her to know what I want. |

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