

Linda Magann, Amy Waters, & Kelly Li

## ACP IS A PROCESS

Involves communication, reflection, and understanding

Conversation between patient, family, healthcare staff

- Establishes individualised values and goals, and individual approaches to end of life decisions
- In the context of the patient's age, culture, and medical condition



# ACP IS NOT ABOUT

- An NFR order
- Right to refuse treatment
- Advance care directive (legal document)



# DESIRED OUTCOMES

- Enhance patient and family understanding about illness and end of life issues, prognosis, and alternative treatments
- Define individual priorities and address these
- Enhance autonomy and planning healthcare around individual preferences
- Help patients to live well, and receive good care at end of life
- Help patients to find hope and meaning in life, strengthen relationships, and ease emotional and financial burdens



# WHAT ARE THE BARRIERS

- Patient factors
  - Lack of understanding of disease and prognosis
  - Varied expectations from treatment
- Nephrologist factors
  - Lack of training
  - Lack of time
  - Inability to deal with strong emotions, not wanting to upset patients
  - Too much uncertainty in predicting prognosis







### TRIGGERS

- Choosing a conservative non-dialysis pathway
- "no" to the surprise question
  - Clinician response of "no, I would not be surprised if this patient died within the next 12 months"
- Worsening symptom burden
- Multiple hospital admissions or prolonged hospitalisation; sentinel events eg falls
- Functional decline
- Inability to tolerate dialysis eg hypotension, or failing access
- Patient and family request (need to pick up this)
- Request from patient to withdrawing treatment



# WHO IS INVOLVED?

- LOTS OF PEOPLE
- Nephrologist
- Social workers
- Renal nurses
- Palliative care physicians
- Conversations need to occur over multiple sessions
- Set aside time (outside clinic)





### CONTENT

(MANDEL ET AL. SERIOUS ILLNESS CONVERSATIONS IN ESRD. CJASN 2017)

- Explore understanding
- Information preference
- Share prognosis
- Goals, fears and worries, tradeoffs, family
- Make a recommendation
- Reassurance of your ongoing commitment
- Document (copies to EMR, GP, other specialist, patient)



### HOW TO SET UP

"You just went through quite an ordeal. I've noticed that things have been getting more difficult for you. In light of this, this may be a good time to discuss what is most important to you if you are getting sicker"



# CHECKING PERCEPTION/ INFORMATION PREFERENCES

"What is your understanding of what lies ahead with your dialysis and overall health?"

"Would you like me to share what lies ahead?"

"Some patients on dialysis think about how long they might have. Is that something you want to talk about?"



# DISCUSSING PROGNOSIS

"We can't fully predict what is ahead, and there is a good amount of uncertainty. Base on your health status and the best available information, I would say about several months to a year/a year or 2/a few years. It could be longer or shorter"



### FUNCTIONAL DECLINE

"I wish I could tell you that you will get better, but I think we may need to prepare for the real possibility that how you have been feeling may be as good as it will get. It's also possible that more hospitalisations may worsen your quality of life."



### EMOTION

- When a patient is upset, we often feel we have to 'solve' the problem
- It is important to remember that they are emotional because of the news and you don't have to 'fix' it
- Validating and responding to emotion is much more important (and often the emotion dissipates once you have done this)





### HOW CAN WE RESPOND TO EMOTION?

Nonverbal skills?

• Verbal skills?



# **RESPONDING TO EMOTION**

#### Nonverbal skills

- Silence (you don't have to say anything)
- o Touch
- o Posture
- Verbal skills
  - Empathic statements



# ENPATHIC STATEMENTS

- Name the emotion
- Understanding
- Respect
- Support
- Explore

### NAME THE EMOTION

- Useful if the patient is not naming their own emotion ('I'm feeling really scared')
- A suggestion, rather than telling someone how they feel
  - 'You seem a bit anxious'
- Try and <u>understate</u> the emotion, particularly if they are angry
  - o 'Sounds like it's been frustrating'





### SHOW UNDERSTANDING

- This is a really useful strategy in all sorts of situations and even if you are quite uncomfortable talking about emotion to a patient, it is easy to say...
- 'It sounds like you have had a difficult few weeks'
- 'This is a difficult thing to talk about'
- 'This has all happened really quickly, hasn't it'





# SHOW RESPECT-FOR PATIENTS AND CARERS

- 'You have done a great job looking after your mother at home'
  - (NB this can be really useful if care at home has become unmanageable as often the carers feel that they've failed or done something wrong)
- 'I'm impressed you've managed to keep on working up until now'





# SHOW SUPPORT - FOR PATIENTS AND CARERS

- People may feel abandoned as they get more unwell, particularly when 'active' treatments such as dialysis have been ceased
- Showing support can help address this
- 'Our team will do everything we can to support you through this'
- NB make sure you do not promise something that is not going to happen!



### EXPLORE

- Can be particularly useful if you feel you haven't got all the information yet
- 'Tell me more about that'
- 'What is the hardest thing for you?'
- 'What worries you the most about all this?'





### SUMMARY / STRATEGY

 At the end of your conversation summarize where you got to with strategy, plan, goal etc



### LINDA IS A 55 YEAR OLD LADY CURRENTLY ON IN-CENTRE HAEMODIALYSIS

She received a renal transplant at age 38, which failed 10 years later. She has been on haemodialysis ever since and could not be re-transplanted due to co-morbidities.

These include type 2 diabetes, hypertension, coronary artery disease (multiple stents), TIAs/CVAs (no residual deficits), osteomyelitis, and several minimal trauma fractures (wrist, lumbar spine, ankle).

She had multiple hospital admissions this year, and now comes to clinic for follow up after another admission for NSTEMI (not suitable for further stenting).

