Advance Care Planning

The St George Perspective

Goals of ACP in ESRD

- Enhance understanding about illness and end of life issues
- Define patient’s key priorities in end of life issues
- Patient centered care enhancing patient autonomy
- Help patients find hope and meaning in life
- Explore ways to ease emotional and financial burdens

- Most pts support the idea of ACP but not sure of how many are offered the opportunity
- Most pts report never having had a discussion about stopping dialysis
- Many will lack capacity when they move towards death
- Substitute decision makers, guardians, family and health care staff can’t predict patient’s preferences

How can planning be improved?

- Plan in stages
- Involve substitute decision maker in the process
- Specificity to the disease and degree of illness
- Begin by determining pt's understanding and experience of illness
- Focus planning on bad outcomes and benefits/burdens of treatments

Stage of planning in chronic disease

- Early stage – selecting an appropriate person responsible
- When patent has stage III/IV disease, repeated hospital admissions, start to consider goals of care if serious complications result in bad outcomes
- In the very end stage of the disease choices will need to be made about treatment responses to acute episodes. E.g comfort vs survival

The St George Perspective

The motivation

- Literature – APA guidelines on treatment make reference to ACP
- Jean Holley and Sara Davison
- Beginning with the end in mind
- Starting off with a set plan keeping in mind pts preferences
- Enhance communication
- Adopt patient centred approach

The challenges

- Communication
- Documentation
- Logistics
- Wording
- Clinician’s own beliefs, views
- Education

The journey

- Acknowledgement of need
- Identifying responsibility
- Who does this?
- Education
- Trial of process
- Evaluation

The recommendations

1. It is both advisable and appropriate to initiate advance care planning with patients with ESRD
2. Those discussions should be inititated by the Nephrologist. Other members of the renal team may participate.
3. Advance care planning should be initiated in:
    1. All competent patients aged 60 years and above, and
    2. All competent patients, irrespective of age, who furfill one or more of the following criteria:

The recommendations

- The “12 month surprise Question”
- Significant co-morbidities i.e. Charlson Co-morbidity Score=8 and above
- Poor functional status Karnovsky Performance status (KPS) less than or equal to 40

The recommendations

    - Poor QOL

4. The decision on the timing of these discussions lies within the discretion of the Nephrologist. Recommended times would be:
    - As soon as the patient is identified with criteria listed in point 3
    - Pre-dialysis discussions
    - Sentinel events
5. Where possible, ACP discussions should include the patient's family or person responsible

The recommendations

6. Where possible, these discussions should also include the renal social worker.
7. The content of the discussion and any other documentation should include:
    - Information on the nature of ESRD, prognosis, QOL
    - Selecting a substitute decision maker
    - Exploring expectations, goals of care and values
    - An indication as to what circumstances the patient would wish that dialysis and all other active treatment cease and a purely palliative approach commence

This process may continue over many conversations

7. That all ACP discussions are documented. That any ACP documentation is universally available through all relevant sites.

Dear Doctor,

In patients with a serious illness an advance care planning process is recommended. Today we initiated an Advance Care Plan for:

Name:

whom we found competent to make this plan.

Date:

Meeting attended by:

Nephrologist:

On Dialysis or Conservative pathway:

If on dialysis the mode of Dialysis:

Plan

If I were to become ill and unable to make medical decisions for myself I would nominate the following person to be my Substitute Decision maker:

If I were to have a serious life-threatening illness and be unable to make medical decisions for myself I would/would not want:

1. Ventilation
2. Inotropes

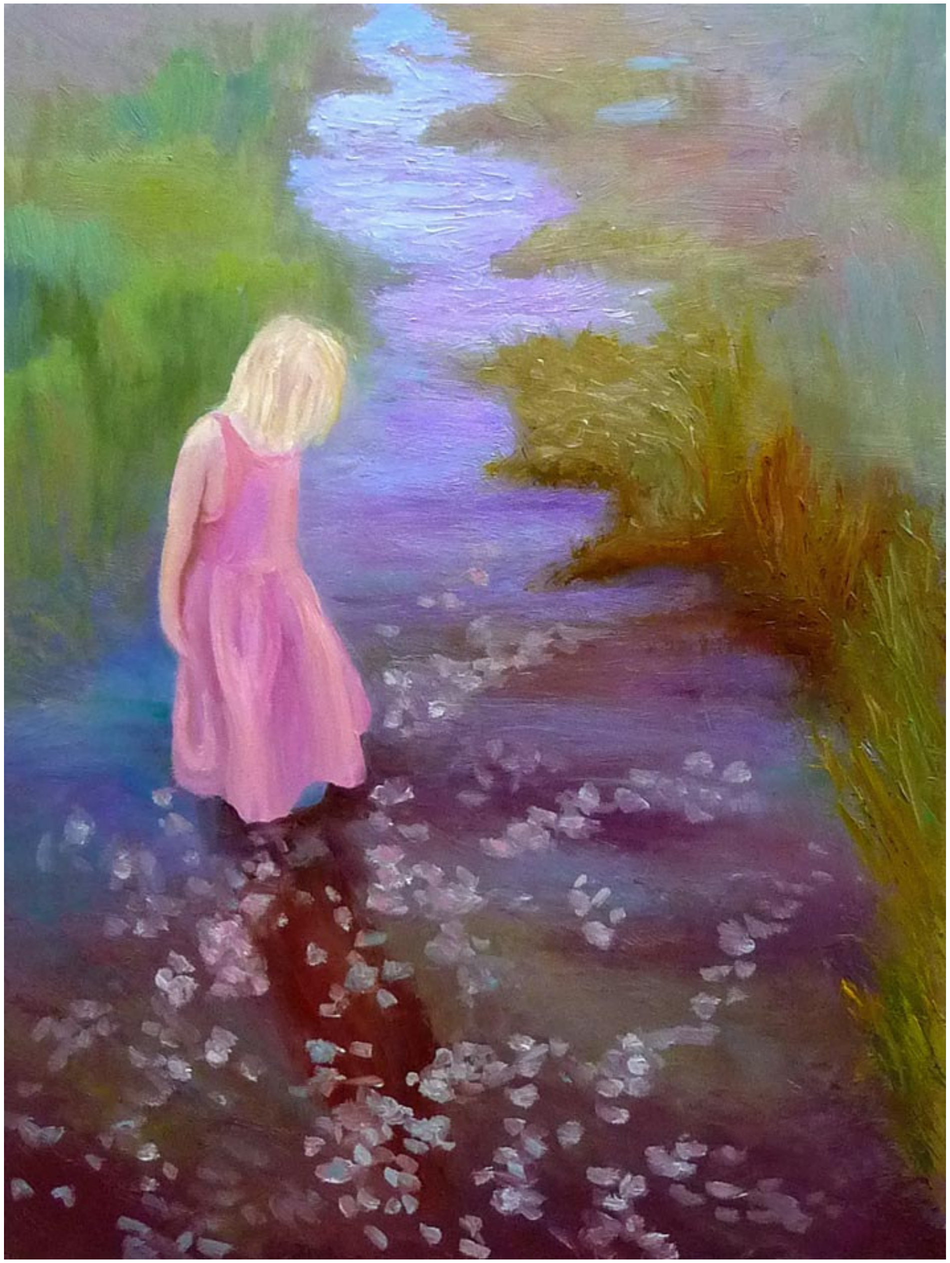
3. Cardio-pulmonary resuscitation
4. Continuation of my dialysis

Signature of patient

Signature of Nephrologist

A copy of this plan will be given to the patient, sent to you, the patient General Practitioner, kept in the patient clinicalfile and be available electronically to all doctors in St George and Sutherland Hospitals. Ideally this Plan shall be reviewed every year.

ACP Patient Experience



Jane’s Story

- Is there such thing as an unacceptable quality of life?

  Where would you draw the line?

Initials & Date: ____________

What makes your life worth living?

Instructions This exercise will help you think about and express what really matters to you. For each row, check (✔) one answer to express how you would feel if this factor by itself described you.

	Life like this would be:			
	difficult, but acceptable	worth living, but just barely	not worth living	can't answer now
a. I can no longer walk but get around in a wheelchair.				
b. I can no longer get outside—I spend all day at home.				
c. I can no longer contribute to my family's well being.				
d. I am in severe pain most of the time.				
e. I have severe discomfort most of the time (such as nausea, diarrhea, or shortness of breath).				
f. I rely on a feeding tube to keep me alive.				
g. I rely on a kidney dialysis machine to keep me alive.				
h. I rely on a breathing machine to keep me alive.				
i. I need someone to help take care of me all of time.				
j. I can no longer control my bladder.				
k. I can no longer control my bowels.				
l. I live in a nursing home.				
m. I can no longer think clearly-I am confused all the time.				
n. I can no longer recognize family/friends				
o. I can no longer talk and be understood by others.				
p. My situation causes severe emotional burden for my family (such as feeling worried or stressed all the time).				
q. I am a severe financial burden on my family.				
r. I cannot seem to "shake the blues."				
s. Other (write in):				

Instructions To help others make sense out of your answers, think about the following questions and be sure to explain your answers to your loved ones and health care providers.

If you checked "worth living, but just barely" for more than one factor, would a combination of these factors make your life "not worth living?" If so, which factors?

If you checked "not worth living," does this mean that you would rather die than be kept alive?

If you checked "can't answer now," what information or people do you need to help you decide?

References

Davison S. Advance care planning in patients with end-stage renal disease. *Progress in Palliative medicine* 2009:17:4: 170 -178

Davison S, Holley J, Seymour J. Advance care planning in patients with end-stage renal disease. In *Supportive care for the renal patient. 2nd ed*. Eds Chambers J et al, 2010, Oxford University Press.

Renal Physicians Association of the USA. *Clinical Practice guideline on Shared decision making in the Appropriate Initiation of and Withdrawal From Dialysis. RPA, Maryland 2010.*

Davison SN, Simpson C. Hope and Advance Care Planning in Patients with End Stage Renal Disease: Qualitative Interview study. British medical Journal 2006; 333 (7574):886.

Pearlman R, Starks H et al. *Your life your choices* http://www.rihlp.org/pubs/Your_life_your_choices.pdf last retrieved August 2011.

Group Discussion topics

Discuss the current processes with ACP in your unit

Has there been an active role? Who has this been initiated by?
What is your role in this?

Are these discussions documented? If so how?

Is there room to start implementing ACP? How?