BC KIDNEY DAYS

Hosted by BC Transplant and the BC Renal Agency

2016

Conservative Care Pathway: A Client-Centred Approach

Abbotsford Kidney Care Clinic

October 7, 2016

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Goals of Session

1. Introduce the newly developed client-centred BCRA Kidney Care Clinic Conservative Care Pathway

1. Review the spirit and application of the pathway by the interprofessional team with case study examples.

Overview of Session

- Conservative Care
- Patient Centred Practice
- Conservative Care Guideline
- Conservative Care Checklist
- Case Studies
- Q & A

Conservative Care in Chronic Kidney Disease is care without dialysis or transplantation

"I don't want dialysis"
"I don't want to be tied to a machine"

- Without options education this is not an informed decision
- Address comments that are reactive and based on fear, avoidance, or not understanding implications of choices

Life is more than just “Survival”

Table 1. Six commonly articulated goals of care

1. Be cured
2. Live longer
3. Improve or maintain function/quality of life/ independence
4. Be comfortable
5. Achieve life goals
6. Provide support for family/caregiver

Adapted from reference 8, with permission.

Questions Relevant to Patients

Will dialysis prolong my life?

What will dialysis do for me?

Will dialysis improve my quality of life?

How would dialysis impact my daily life?

If I decline, what's next…?

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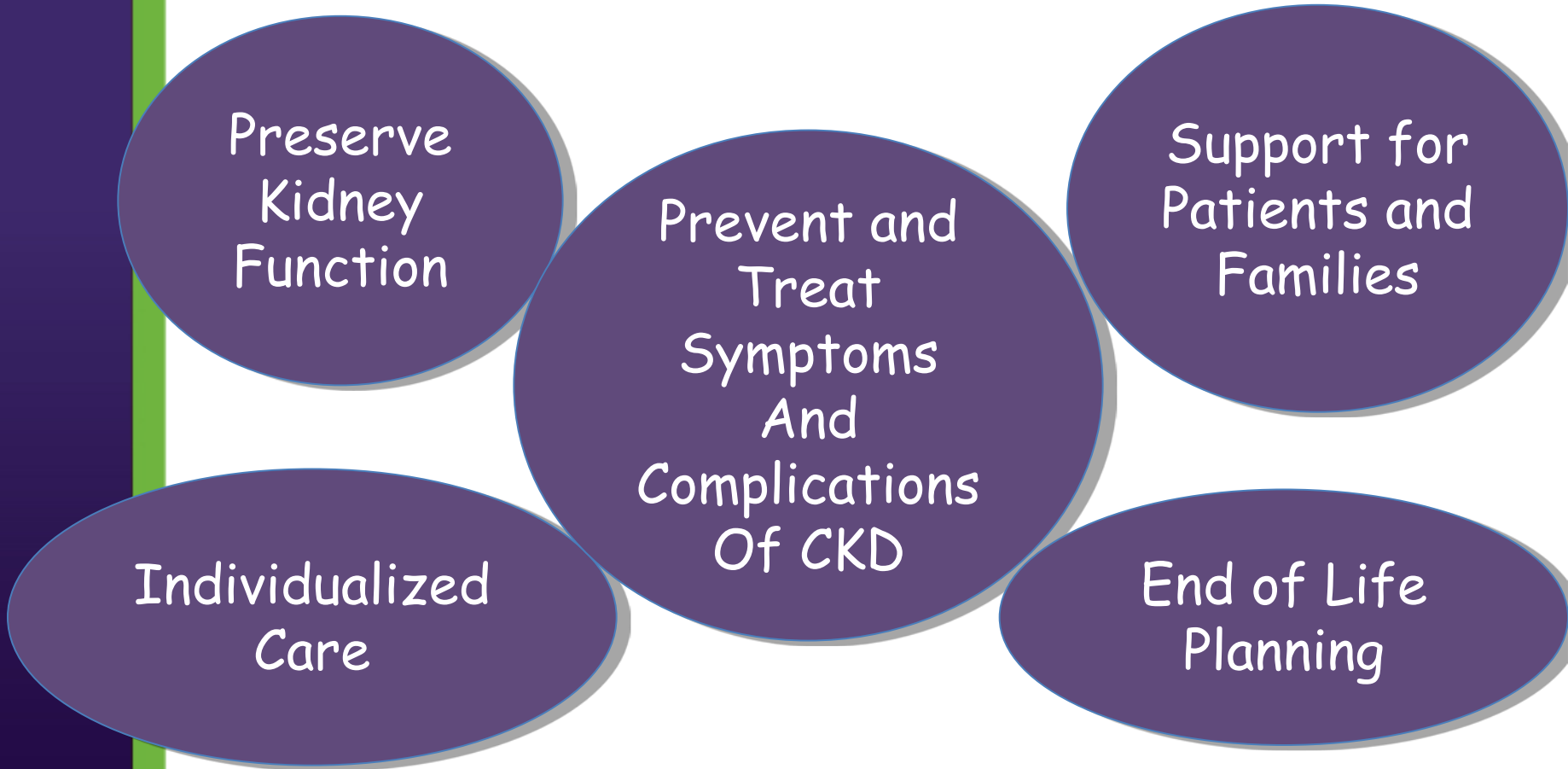
Goals of Conservative Care



Important Considerations

- Anxiety and/or Depression
- Capability for understanding implications
- Values and Beliefs
- Multiple Perspectives
- Potential lack of support for patient's decision

In the event of disagreement, the comfort, dignity, wishes and values of the patient are paramount and should be respected

…a narrow interpretation of beneficence that focuses only on life extension fails to consider that many elderly patients have other goals and priorities that are equally if not more important to them

End-of-Life Care Preferences and Needs: Perceptions of Patients with Chronic Kidney Disease

Sara N. Davison

Department of Medicine, University of Alberta, Edmonton, Alberta, Canada

Background and objectives: Despite high mortality rates, surprisingly little research has been done to study chronic kidney disease (CKD) patients' preferences for end-of-life care. The objective of this study was to evaluate end-of-life care preferences of CKD patients to help identify gaps between current end-of-life care practice and patients' preferences and to help prioritize and guide future innovation in end-of-life care policy.

Design, setting, participants, & measurements: A total of 584 stage 4 and stage 5 CKD patients were surveyed as they presented to dialysis, transplantation, or predialysis clinics in a Canadian, university-based renal program between January and April 2008.

Results: Participants reported relying on the nephrology staff for extensive end-of- life care needs not currently systematically integrated into their renal care, such as pain and symptom management, advance care planning, and psychosocial and spiritual support. Participants also had poor self-reported knowledge of palliative care options and of their illness trajectory. A total of 61% of patients regretted their decision to start dialysis. More patients wanted to die at home (36.1%) or in an inpatient hospice (28.8%) compared with in a hospital (27.4%). Less than 10% of patients reported having had a discussion about end-of-life care issues with their nephrologist in the past 12 months.

Conclusions: Current end-of-life clinical practices do not meet the needs of patients with advanced CKD.

Clin J Am Soc Nephrol 5: 195–204, 2010. doi: 10.2215/CJN.05960809

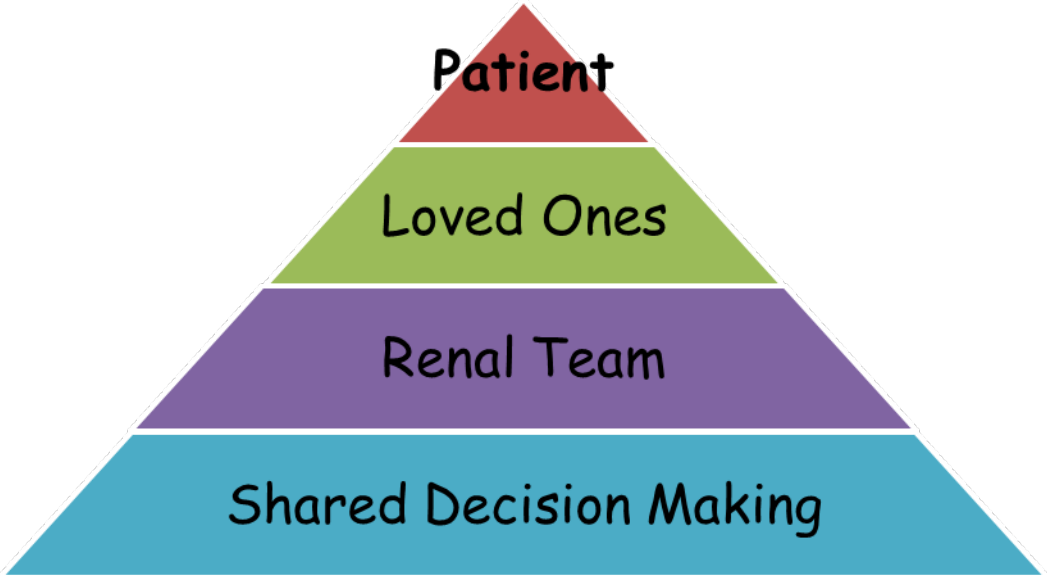
Sara N. Davison, 2010

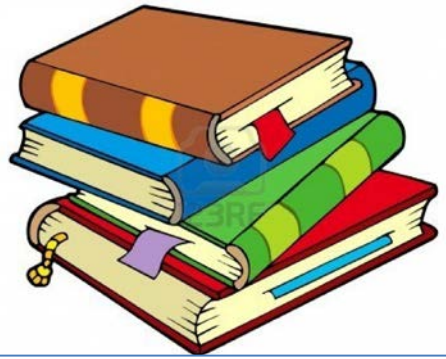
- 60% regretted their decision to start dialysis
- Patients had limited knowledge of their options
- More patients wanted to die at home or in hospice setting
- Less than 10% patients reported having a discussion on EOL issues with their nephrologist in the last 12 months

Dialysis as Default

Risks and Burdens of Treatment

Treatment Options that Fit Patient Goals





Continued Research

Survival in elderly patients with CKD stage 5

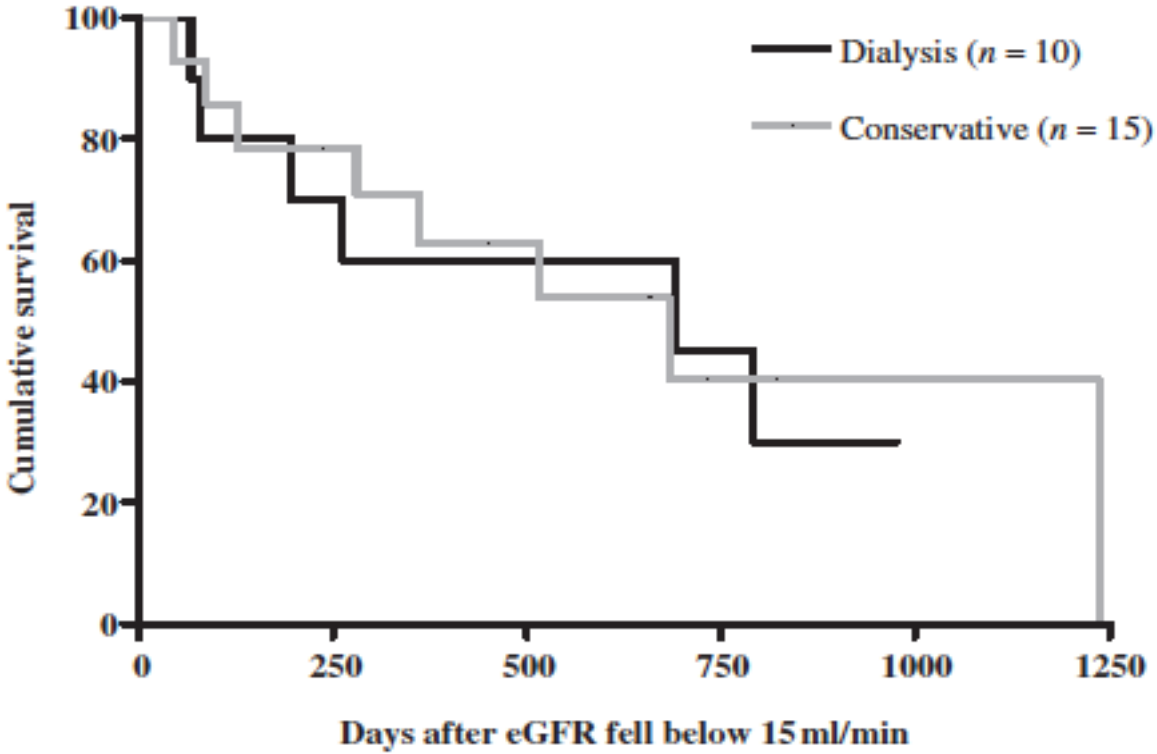
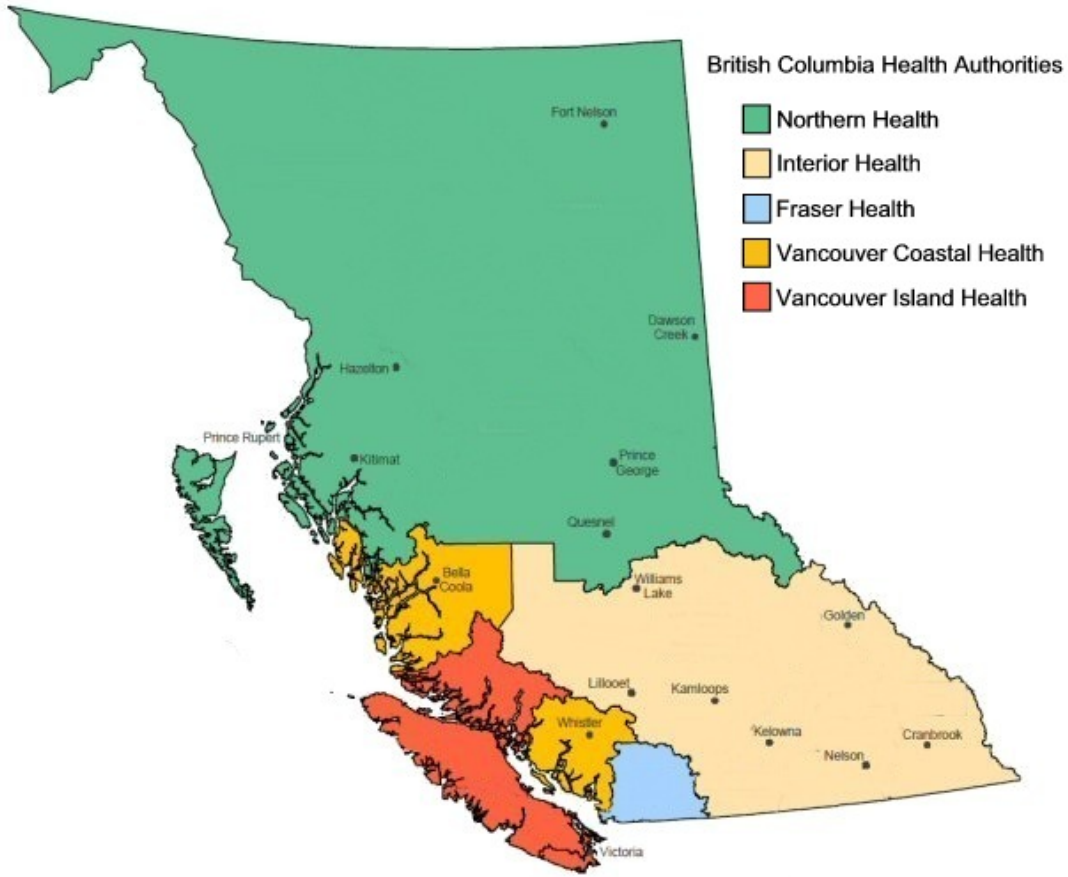
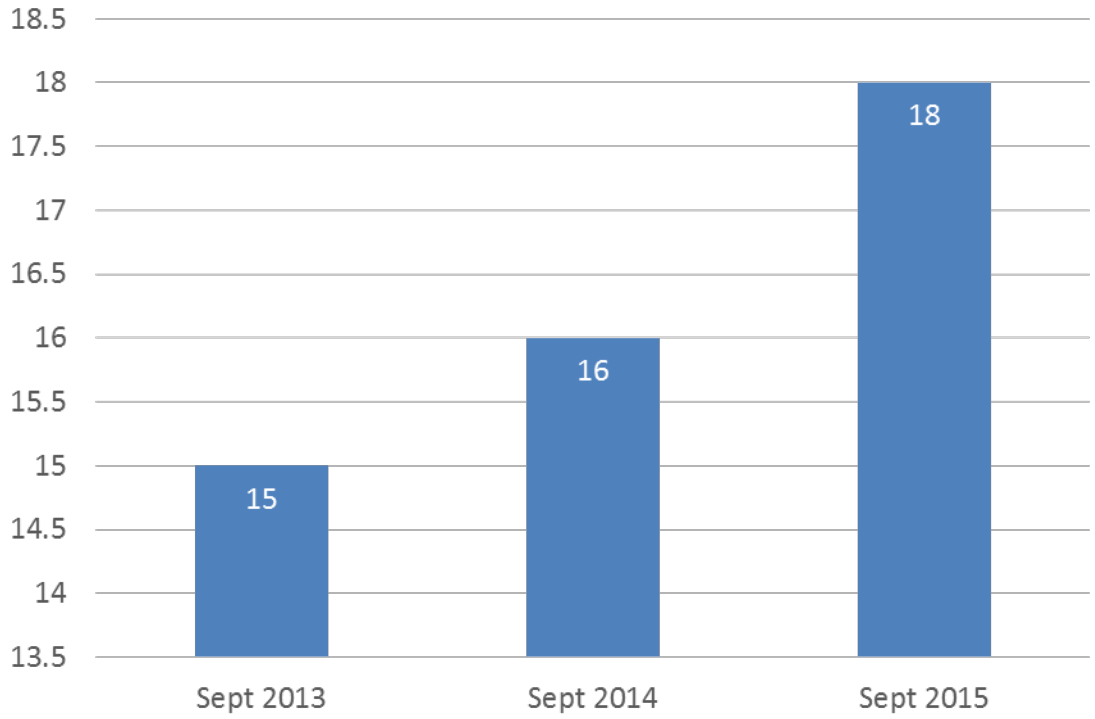


Fig. 3. Kaplan–Meier survival curves for those with high comorbidity (score = 2), comparing dialysis and conservative groups (log rank statistic <0.001, df 1, $P = 0.98$).

13 KCC’s in BC following over 10,000 patients

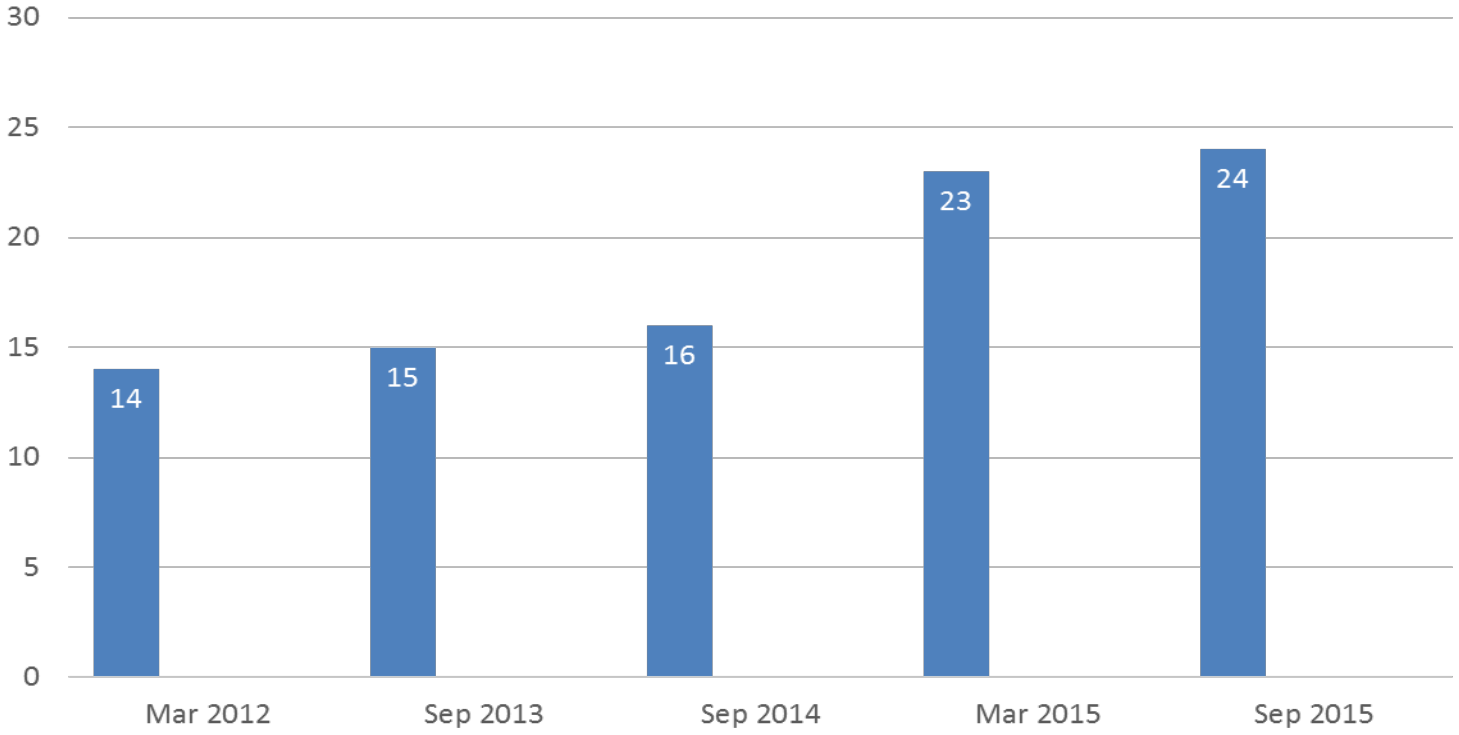


Despite similar age, the % of patients with low GFR increasing



Mean age of patients in KCC
71 +/- 14 y in each cohort

The % of patients choosing conservative care is increasing



BC Kidney Care Committee
Conservative Care Pathway

A compassionate, patient focused option involving an active, organized approach to optimizing care for patients with end stage kidney disease

Conservative Care ≠ Do nothing

Conservative Care Pathway

BCRenal agency

BC Kidney Care Clinic Guideline:
Conservative Care Pathway

DRAFT Mar 16, 2016

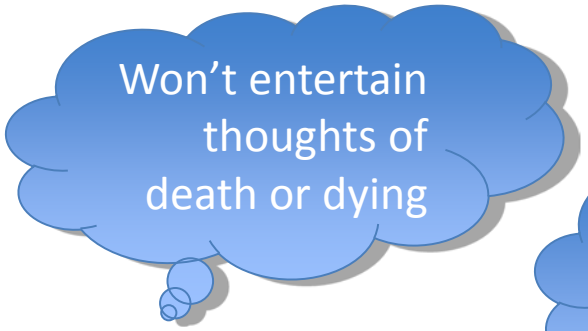
Contents

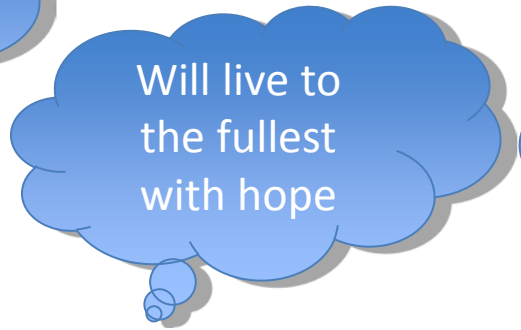
Conservative Care Pathway

Spirit of Conservative Care

- Honours patient's values and goals
- Respects patient's boundaries
- Responds to patient readiness

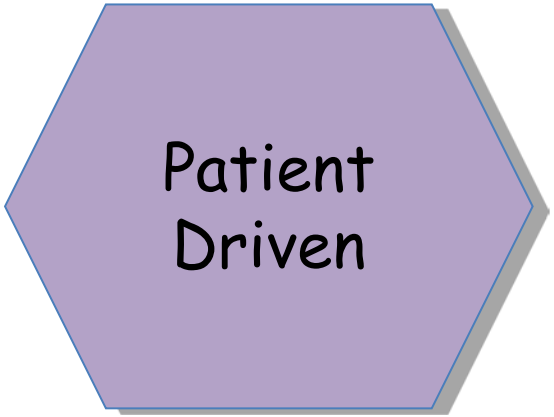
or





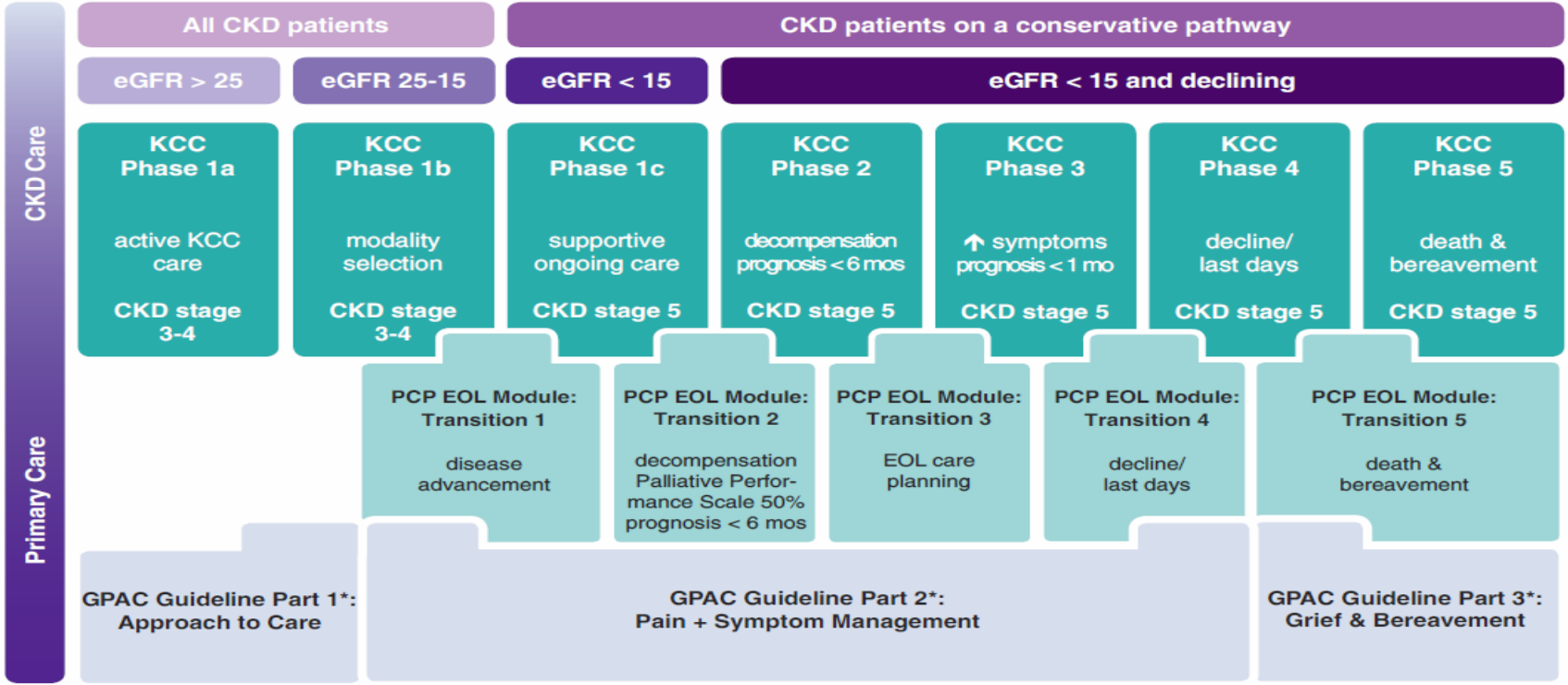
Conservative Care Checklist

- Stays on the Chart
- Is not a "to do" or "task" list
- Lists elements that may be applicable with regards to end of life
- Includes elements that will not be appropriate for any given patient



CONSERVATIVE MANAGEMENT PATHWAY FOR ADVANCED CHRONIC KIDNEY DISEASE IN BC

BCRenal an agency of the Provincial Health Services Authority



*GPAC Guideline on Palliative Care for the Patient with Incurable Cancer or Advanced Disease

CKD= Chronic Kidney Disease
KCC= Kidney Care Clinic
GPSC= General Practice Services Committee
PCP= Practice Support Program
EOL= End-of-life

MY SYMPTOM CHECKLIST

(MODIFIED ESAS*)

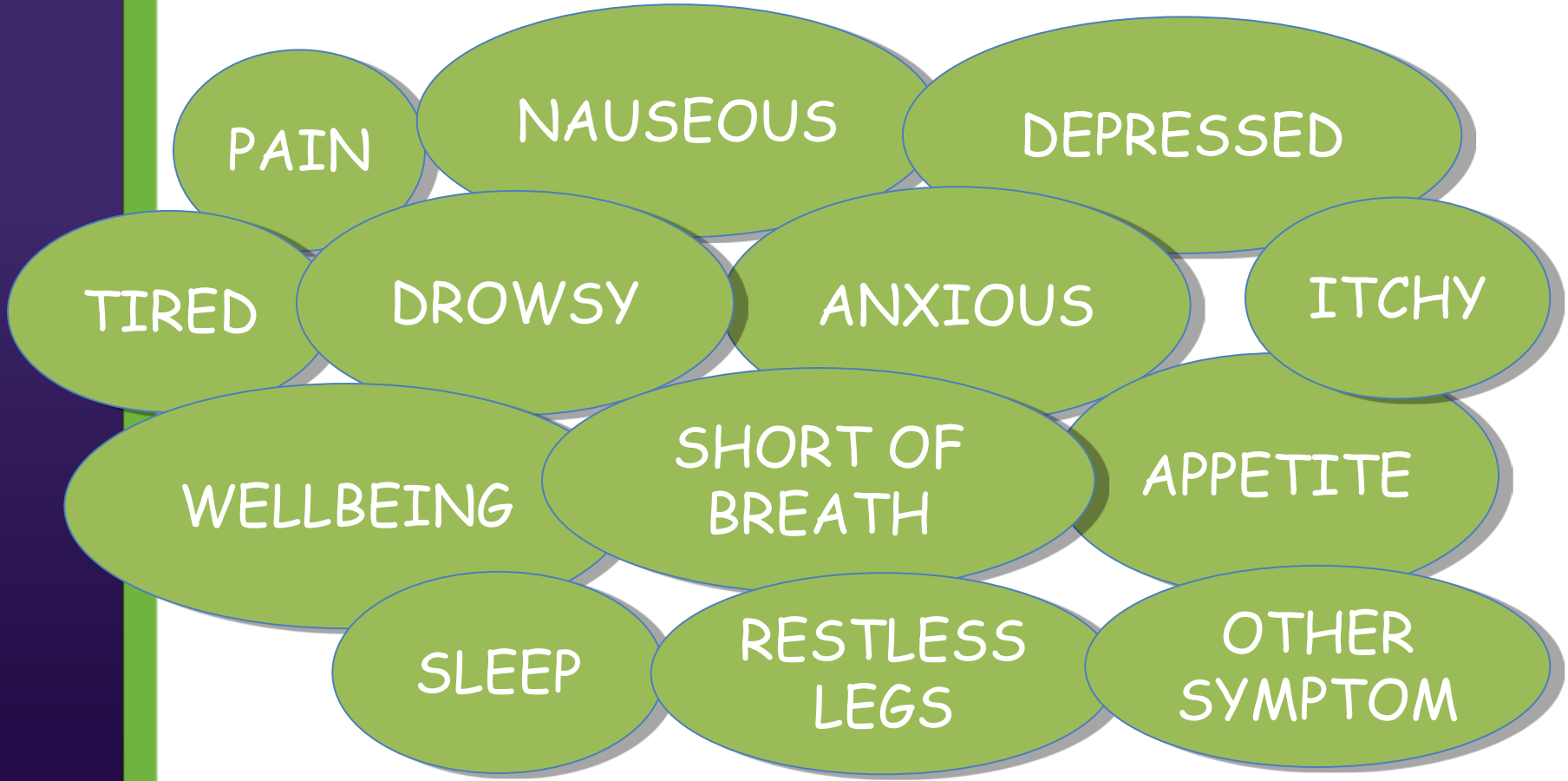
BCRenalAgency.ca

Updated July 2016

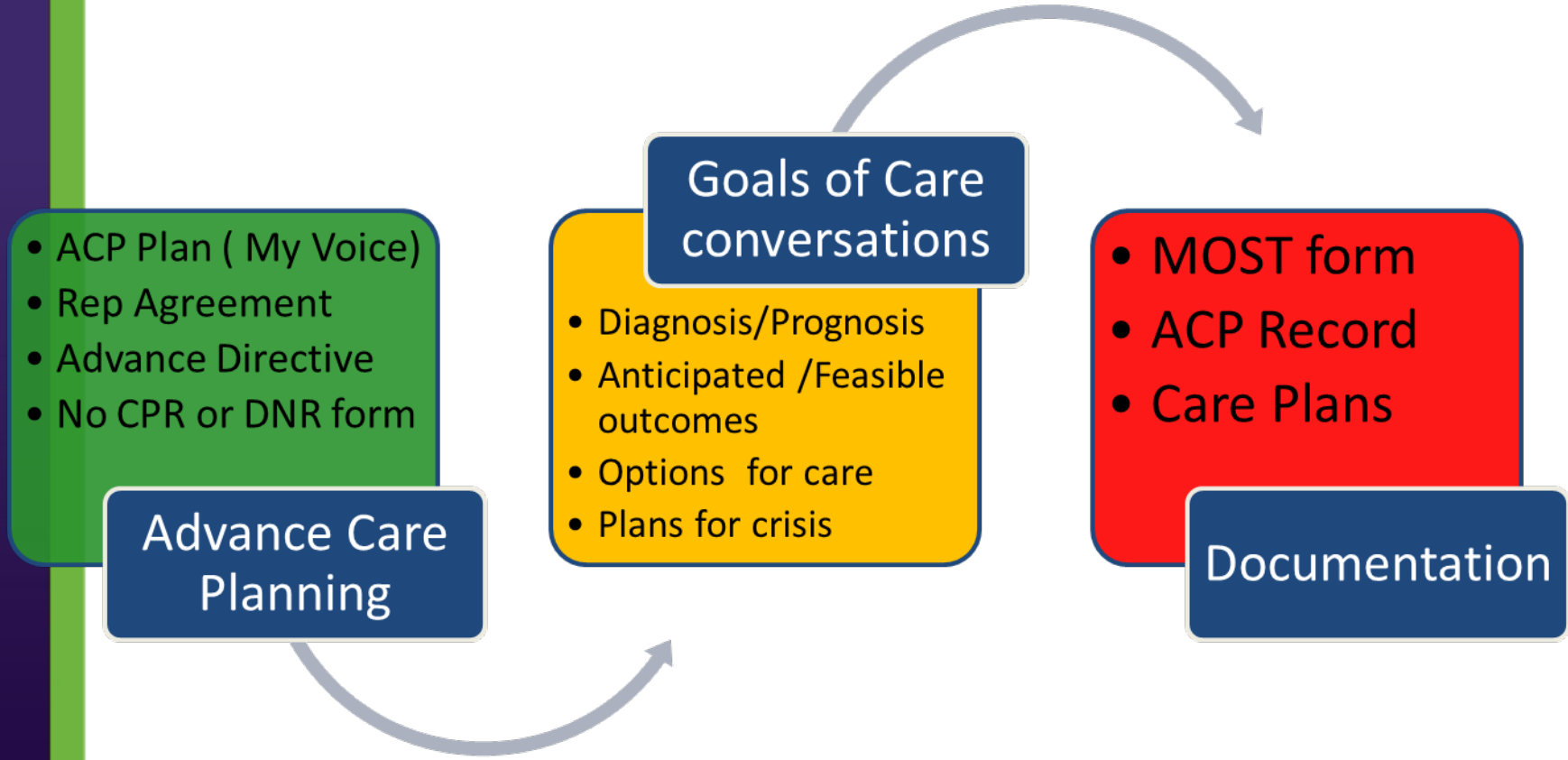
*Adapted from the ESAS developed by the Alberta Capital Health and Caritas Health Group Regional Palliative Care Program

MY SYMPTOM CHECKLIST

MY SYMPTOM CHECKLIST



ADVANCE CARE PLANNING CYCLE



MOST form

SECTION 1: CODE STATUS: *Note: CPR is not attempted on a patient who has suffered an unwitnessed cardiac arrest.*

☐ *Attempt* Cardio Pulmonary Resuscitation (CPR). *Automatically designated as C2. Please initial below.*

☐ *Do Not Attempt* Cardio Pulmonary Resuscitation (DNR)

SECTION 2: MOST DESIGNATION based on documented conversations *(Initial appropriate level)*

Medical treatments excluding Critical Care interventions & Resuscitation

_____ **M1**	**Supportive care, symptom management & comfort measures.** ***Allow natural death.*** *Transfer to higher level of care only if patient's comfort needs not met in current location.*
_____ **M2**	**Medical treatments available within location of care. Current Location:** _____ *Transfer to higher level of care only if patient's comfort needs not met in current location*
_____ **M3**	**Full Medical treatments excluding critical care**

Critical Care Interventions requested. NOTE: Consultation will be required prior to admission.

_____ **C1**	**Critical Care interventions excluding intubation.**
_____ **C2**	**Critical Care interventions including intubation.**

SECTION 3: SPECIFIC INTERVENTIONS *(Optional. Complete Consent Forms as appropriate)*

Blood products ☐ YES ☐ NO Enteral nutrition ☐ YES ☐ NO Dialysis ☐ YES ☐ NO

Non-invasive ventilation ☐ YES ☐ NO

Other Directions:

SURGICAL RESUSCITATION ORDER

☐ WAIVE DNR for duration of procedure and peri-operative period. Attempt CPR as indicated.

☐ Do Not Attempt Resuscitation during procedure.

SECTION 4: MOST ORDER ENTERED AS A RESULT OF *(check all that apply)*

☐ **CONVERSATIONS/CONSENSUS** ☐ Capable Adult	NAME:	DATE: (dd/mm/yr)
☐ Representative	NAME:	DATE:
☐ Temporary Substitute Decision Maker	NAME:	DATE:

☐ **PHYSICIAN ASSESSMENT** and ☐ Adult/SDM Informed and aware ☐ Adult not capable/SDM not available

☐ **SUPPORTING DOCUMENTATION** *(Copies placed in Greensleeve and sent with patient on discharge)*

☐ Previous MOST ☐ Provincial *No CPR*	☐ FH ACP Record ☐ Advance Directive	Representation Agreement ☐ Section 9 ☐ Section 7	☐ Other:

Death & Bereavement

- Bereavement support
- Grief counselling and referrals
- Sympathy card if appropriate
- KCC team reflection

Case Study: DI

"delightful 81 year old living independently"

… she will need to start some form of renal replacement therapy in the near future. Given her extensive cardiac Hx and we primed her for this discussion today and my plan below will outline where we move forward for PD"

- Complex process to choose Conservative

Case Study: VR

- 90 yr old gentleman articulating long held values
- Representation Agreement done by lawyer prior
- Son named Representative and DIL's sister as Alternate SDM as living in VR's community
- Alternate became VR's primary paid caregiver
- She Reframed Conservative Decision as Euthanasia

"We don't agree on his decision regarding dialysis"

- SW rev'd legality & conflict of interest of alt SDM
- Died in Hospice with Safety Plan Related to Representative Agreement

Case Study: SK

- 50 year old woman in MH residential facility
- Long held articulated values and beliefs
- Involved Aunt identified as Representative (Sec 7)
- Care Conferences including professional caregivers
- Conservative Decision
- Hospital Admission
- Complications re Capability
- Case Conference
- Family Care Conference
- Safety Plan for SK and wish for Conservative Care

Case Study: KS

- 88 yr old Male
- Mult co-morbidities
- CKD with a baseline GFR of 20
- Developed rapidly declining kidney function w/ GFR 8-10
  - Associated w/ nephrotic range proteinuria, concern that pt may have developed a glomerulonephritis.
- Met with pt and his daughter, both in agreement to proceed with conservative care.

Case Study: KS

- MOST DNR M1
- Pt's Goal: Comfort measures
- Pt decided he did not want invasive investigations
- ACP completed and identified SDM
- Symptoms: SOB (vol. overload), anorexia, N/V
  - Started on diuretics, Maxeran
- Palliative care referral accepted and made
- GP notified of care plan
- Pt admitted to hospice– passed away there

Case Study: CR

- 87 year old female
- PCKD, progressive declining kidney function over several years
- Pt followed thru KCC at ARH
- SDM: niece
- Pt's sister had been on dialysis and pt felt her sister did not have any QOL
- PT along with her niece, chose conservative care
- MOST DNR M2

Case Study: CR

- Symptoms: anorexia, leg cramps, restless legs, puritis, peripheral neuropathy, nausea
- Started on Atarax and Clonazepam, Stemitil and Gabapentin
- When symptoms worsened, palliative care referral completed
- Pt lived at home up until one week prior to death
- Chose to be admitted to hospice for her final days, where she passed away

Questions