2011 Nephrology and Renal Transplant Days
HOSTED BY BC TRANSPLANT AND THE BC RENAL AGENCY
October 6–7
Hyatt Regency
Vancouver
BC TRANSPLANT
An agency of the Provincial Health Services Authority
BC Renal Agency
An agency of the Provincial Health Services Authority

BCPRA EOL Task Group Update
&
New Legislation

Nephrology & Renal Transplant Days

October 6 & 7, 2011

Vancouver, BC

Dr. M. Karim & Wallace Robinson

End of Life (EOL) Framework

The key elements of EOL care, as developed by the EOL task group, for renal patients are :

- Patient Identification
- Advance Care Planning
- Symptom Assessment & Management
- Care of the Dying Patient/ Bereavement

Regional Highlights

- Interior Health
  - Focus has been on Advanced Care Planning with approximately 50 to 60 % of all HD pt complete
  - For the training of staff used the Fraser Health “My Voice” materials
- Northern Health
  - Recent appointment of EOL project lead (all NH)
  - Nephrologists are concentrating on obtaining and/or updating code status for all hemodialysis pt
  - Application of the ESAS in early phase

Regional Highlights

- Fraser Health
  - Reviewing tools for patient identification
  - Building staff capacity for ACP
  - Working with hospice re care of the dying pt, dialysis as part of the symptom management strategy
- Vancouver Island
  - Implementation of ESAS in CKD pts
  - Survey of staff to assess learning needs for ACP
  - Tree of Remembrance

Regional Highlights

- Vancouver Coastal – PHC
  - ESAS quarterly with HD pts embedded into nurses' routine with completion rate of ⩾ 90%
  - Following pain protocol
  - 40% of HD pts have ACP
  - Memorial wall
- Vancouver Coastal - VGH
  - Process for ACP being finalized
  - Use of Pain protocol

Provincial Priorities 2011 - 2013

- Agreement of provincial indicators and subsequent monitoring
- Development of on line educational resources for ESAS
- Development of learning tools (i.e. PowerPoint) to ensure appropriate use of provincial pain algorithms
- Development of provincial algorithms for other symptoms as identified by ESAS - such as pruritis, depression, sleep
- Ensure awareness of Sept 1st Legislation making Advance Directives legally binding
- Continue to build capacity within renal teams

Advance Care Planning: The new legislation in BC & the opportunity for Renal

Advance Care Planning

Wallace Robinson PHC Project Lead – Advance Care Planning

Vancouver CoastalHealth
Promoting wellness. Ensuring care.

Providence HEALTH CARE
How you want to be treated.

Renal and Advance Care Planning

- Dialysis pts have an average higher symptom burden than cancer pts
- ESRD mortality rate ~ cancer
- 20 – 25% dialysis pts die annually
- Dialysis withdrawal = 20 - 25% deaths
- Majority of dialysis patients lack capacity at time decision to withdraw is made
- Conversations about death/dying are commonly avoided until late illness
- Few CKD patients have engaged in ACP

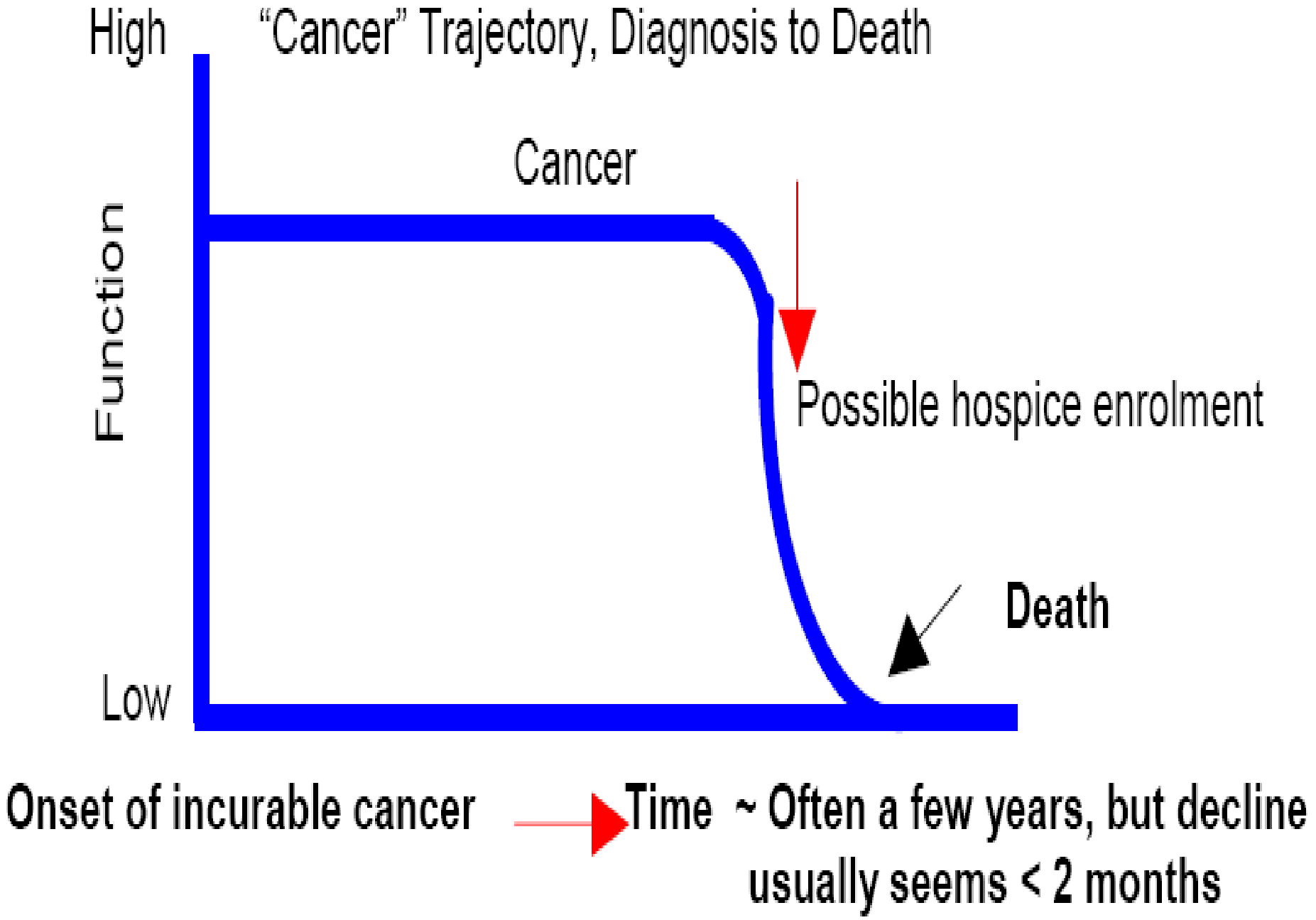
The patients' perspective

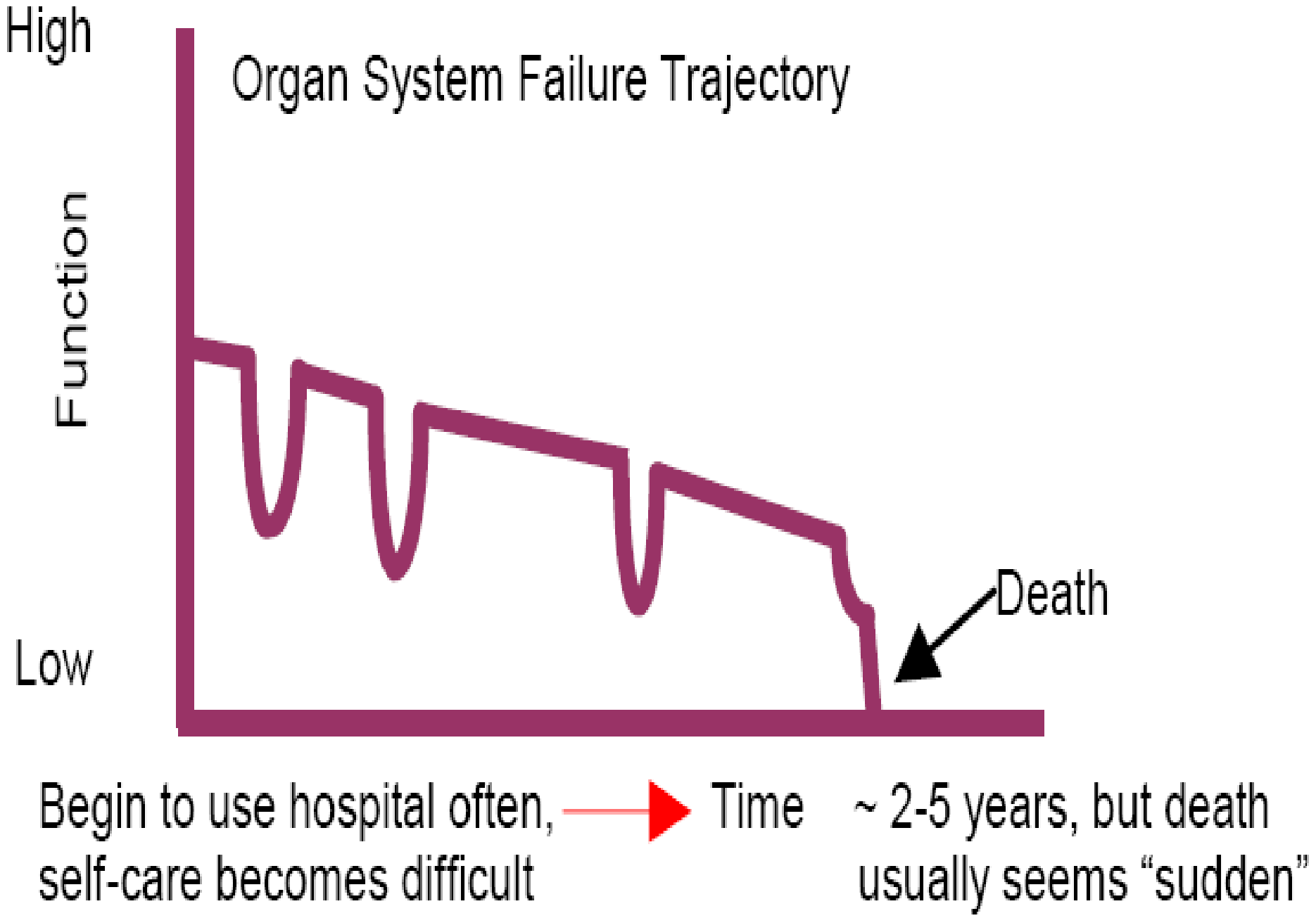
- The majority of patients express that they do not wish to be kept alive by extraordinary means when there is no room for improvement and no quality of life
- 90%+ patients express a desire to talk about ACP but are waiting for the HCP to initiate

Our perspective?

- We believe the patients don't want it
- We believe the conversation will take away hope
- We work tirelessly to make people well, to alleviate symptoms, to improve quality of life
- We see the death of a patient as a failure
- We believe we don't have time
- We believe it is someone else's responsibility
- We are afraid

There is a whole lot of dodging going on


High
"Cancer" Trajectory, Diagnosis to Death
Cancer
Function
Possible hospice enrolment
Death
Low
Onset of incurable cancer
Time ~ Often a few years, but decline usually seems < 2 months


High
Organ System Failure Trajectory
Function
Low
Death
Begin to use hospital often, self-care becomes difficult
Time
~ 2-5 years, but death usually seems "sudden"

A standard provincial approach & the opportunity for Renal

+ Additional options
+ A comprehensive guide for the public
+ Templates for creating RAs & Ads
+ RA witnessing requirements
+ Increased awareness & commitment from MDs, NPs, SW & other HCPs including First Responders
+ Normalizing this planning for the future

— *The terminology & options are confusing*

Elements of Advance Care Planning

Capable adults:

- express their wishes, values, beliefs &/or instructions about which medical interventions to accept or refuse if incapable
- decide 'who decides for me?' in future, if they become incapable
- decide which document is right for them
- share/communicate their decisions and documents

Consent: who decides?

Pre—September 1, 2011

- The **Patient** (if capable or able to contribute)
- **Personal Guardian (Committee of Person)**
- **Representative** as laid out in a Rep Agreement
- **TSDM** (temporary substitute decision maker)

Post—September 1, 2011

- All of the above and/or:
- The directions set out in an **Advance Directive**

Advance Directives - September 1, 2011

- Written instructions made by a capable adult to give or refuse consent for health care directly to the adult's health care provider
- Acted on when adult is incapable
- Must be relevant to the decision required
- No TSDM is sought for the applicable decision in the AD
- If adult also has a representative, then decisions by the representative are based on instructions in AD
- May not bind providers to give treatment that is medically inappropriate

Advance Directive legal requirements

- Two qualified witnesses or one lawyer or Notary Public
- Form within provincial guide but not mandatory
- Must contain statements indicating the capable adult's understanding of the effect of the Advance Directive
- Instructions from previous planning and other jurisdictions may be considered as an Advance Directive if meets these requirements
- If documents are not considered Advance Directives, still always honour expressed wishes to inform SDMs & HCPs

An AD should NOT be followed if:

- there is concern about clarity of capable adult's wishes: vague, contradicts known wishes, AD was not made in good faith (coercion, misrepresentation, incapability)
- if it deals with care on the prescribed list
- not consistent with details within Guide or Health Authority policies

Impact on initiation of treatment

- Consent legislation allows for urgent, emergency care or triage without consent, as previously, unless the health care providers are aware of instructions to the contrary
- Check for instructions: e.g. a Representation Agreement or an Advance Directive; are they valid & if an AD, are directions applicable?
- First responders must comply with known AD wishes
- If wishes/direction becomes known after treatment commenced, should be stopped to be in accord with adult's wishes

Conclusion

It takes courage to face and make these decisions.

It also takes courage for us to open the conversation with people. But if we do it sensitively, from our own place of humanity, as if the patient was our family member, our patients and families will be able to engage in these conversations and we will be giving them a great gift.