A Journey Of Caring:
Palliative Care And Nephrology

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Objectives

www.bcbswny.com/images/pict_busi_peop_hands.JPG

- Review attitudes towards dying
- Define palliative care
- Share collaboration of Palliative Care and Nephrology

Hello & Goodbye:
Grief & Celebration on Life's Journey

lh5.ggpht.com/.../XvCeW8Tz318/s800/DSC07517.JPG

Doc, Don't Procrastinate… Rehabilitate, Palliate & Advocate

" …assist with the best possible living
or if appropriate,
the best possible death."

"What we need to learn is that it is not about the dying, it is about the living beforehand."

S.V. Jassal

American Journal of Kidney Disease 55 (2), 2010, pp. 209-212

Haemodialysis patients & end-of-life decisions: a theory of personal preservation

media.canada.com/.../seedl.jpg

Personal preservation

- Being responsible
- Taking chances

A. O. Oliver

Journal of Advanced Nursing 2004 46 (5), 558-566

Focus on Living

- Knowing the odds for survival
- Defining individuality
  - Beating the odds
  - Discovering meaning
  - Being optimistic
  - Having faith in a higher force

A. O. Oliver

Journal of Advanced Nursing 2004 46 (5), 558-566

Attitudes towards dying

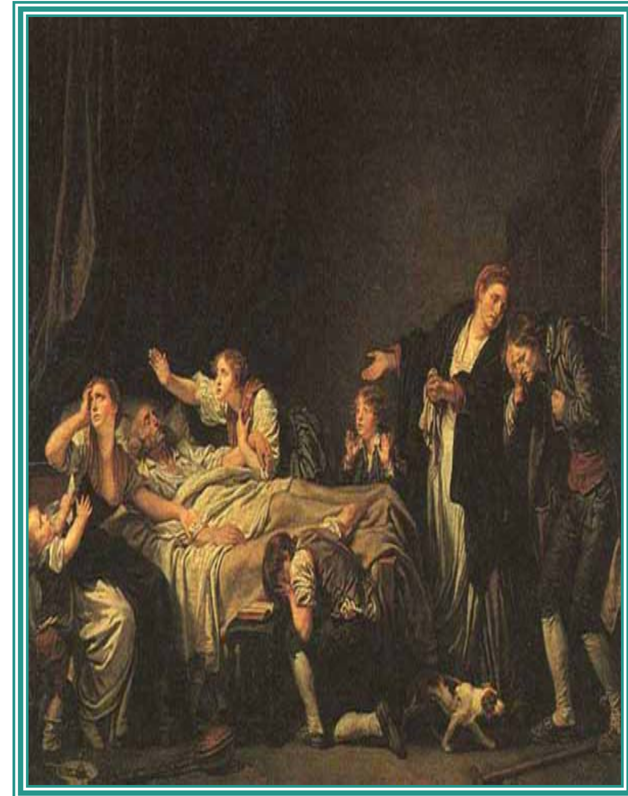
"And you, my father, there on the sad height

Curse, bless, me now with your fierce tears, I pray.

Do not go gentle into that good night.

Rage, rage against the dying of the light."

Dylan Thomas (1914-1953)



www.rjgeib.com/thoughts/lincoln/lincoln.jpg

Attitudes towards dying

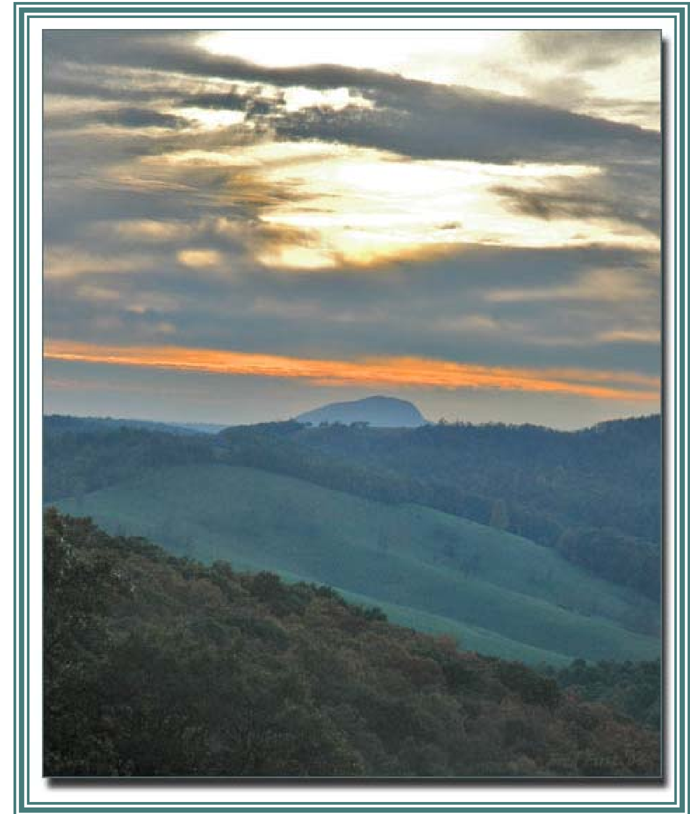
"His are the quiet steeps of dreamland

The waters of no-more-pain,

His ram's bell rings 'neath an arch of stars,

Rest, rest, and rest again."

Walter de la Mare (1873 - 1956)



fragmentsfromfloyd.com/images2/buffalo_oct04.jpg

Decision-Making

"Death is the proverbial 900-pound gorilla in all of our lives".

Most individuals avoid thinking or talking about death.

V. Sweet, 2007 quoted in *Charlotte Szromba*, Palliative Care in Patients with CKD, Nephrology Nursing Journal, September-October 2007, Vol.34, #5

Awareness

Conservative treatment:

Choosing not to start dialysis

The foundation of kidney care.

www.bereavementcare.com.au/.../pics/home_pic.jpg

THE KIDNEY FOUNDATION OF CANADA

Choosing to Stop Dialysis

MAKING THE CHOICES THAT ARE RIGHT FOR YOU

A BROCHURE FOR PATIENTS AND FAMILIES

CANNT Standards

Palliative Care

- Explore understanding of illness trajectory & prognosis
- Identify learning needs
- Explore fears & concerns
- Promote advance care planning
- Respect decisions

www.cannt.ca/images1/logo.gif

Illness trajectory in ESRD

- Progressive decline
- Episodes of acute deterioration
  - Sentinel events
    (i.e. amputation, myocardial infarct)
- Opportunities for advance-care planning
- Improve quality of life
- Plan & improve quality of death

J.L. Holley

Adv Chronic Kidney Dis 2007 Oct:14 (4), 402-8

Risk Factors Leading to Discontinuation of Dialysis

- 76 patients
- 3 ½ years
- Older (66 vs 54 years)
- More likely divorced/widowed
- 2x co-morbidity
- Successive acute problems leading to discontinuation

Bajwa, Szabo & Kjellstrand, 1996

Why end of life care?

Meet Mr. G.

- 87 year old male
  - Admitted for palliative care/no dialysis
- Medical History
  - ESRD 2° Hypertensive Nephropathy
  - Lung cancer with metastases

Why end of life care?

Meet Mr. G. & Family

- Take history
- Assessment
- Goals of Care
  - Palliative Care: YES
  - Code Status: Full Code

This is illogical!!!!

This makes no sense!!!

i29.photobucket.com/.../spock-illogical.png

Why end of life care?

- Meet Nancy
  - 37 years old
  - Hemodialysis x 6 years
  - Cardiac arrest x 2
    - Hypoxic brain injury

Why end of life care?

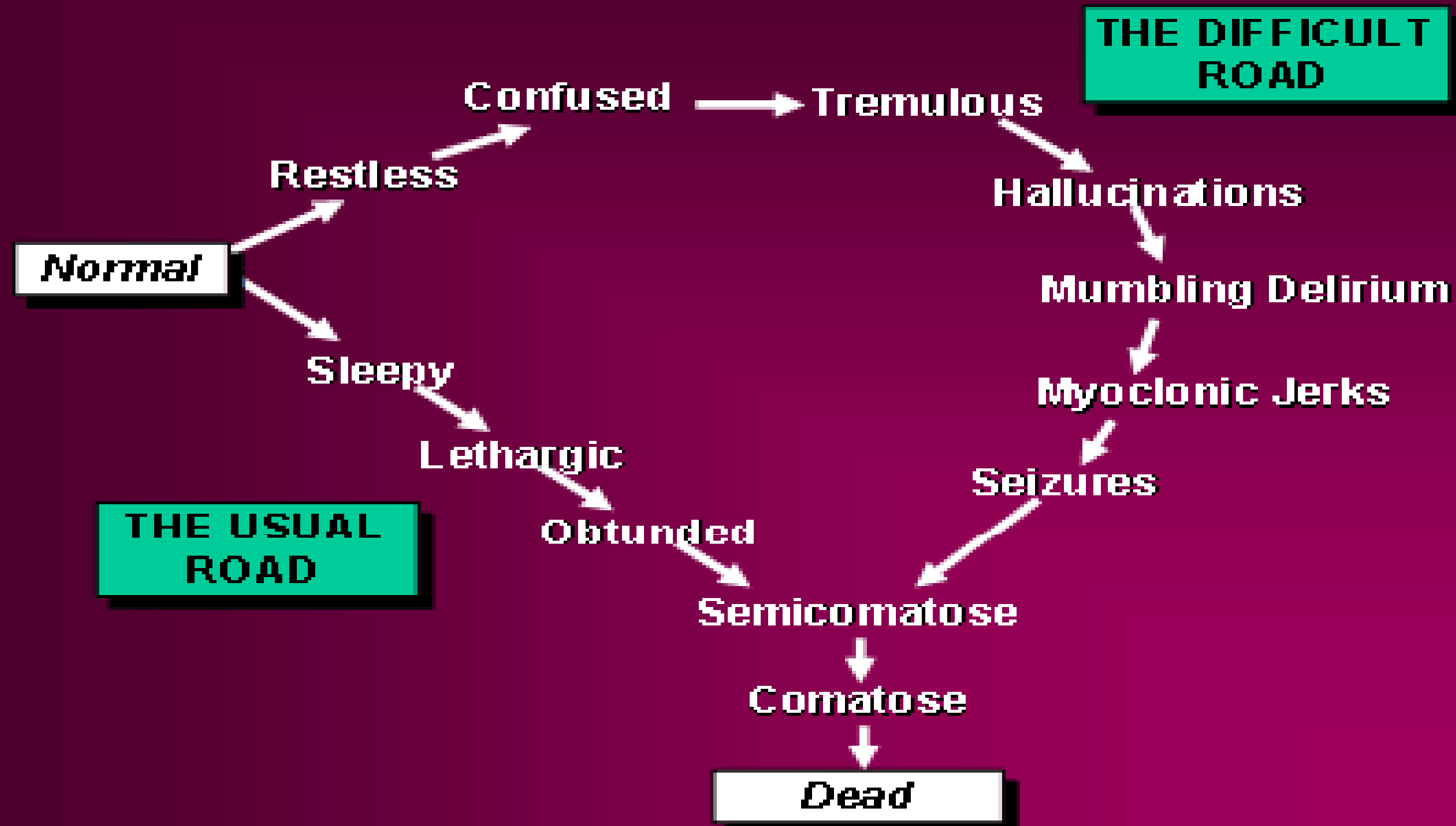
Nancy's Trajectory

- Ward – significant brain injury
- Rehabilitation Centre
- Home
- Nursing Home
- Hospital

images.jupiterimages.com/.../74/58/23265874.jpg

"The task is to help patients successfully negotiate the difficult transitions that accompany life on ESRD treatment."

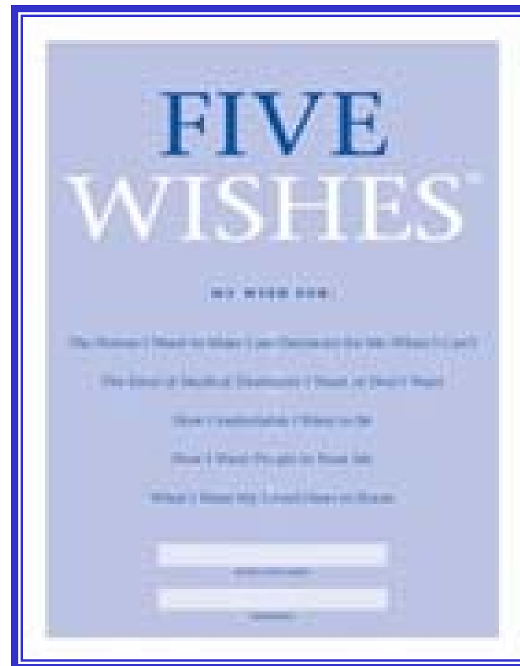
T.A. Hutchinson, 2005



Ferris, von Gunten, Von Roenn

http://www.Medscape.com/viewprogram/5808_pnt

Robert Wood Johnson Foundation



"Five Wishes" (Aging with Dignity)

http://www.rwjf.org

"Five Wishes" (Aging with Dignity)

- What person you want to make healthcare decisions for you when you can't make them
- The kind of medical treatment you want or don't want
- How comfortable you want to be
- How you want people to treat you
- What you want your loved ones to know

http://www.rwjf.org

Cross-Cultural Considerations in Promoting Advance Care Planning in Canada

Prepared for Health Canada by:

Andrea Con, Ph.D.
Research Investigator
CIHR Cross-Cultural Palliative NET
November 2007

Literature review
& focus groups with key informants

http://www.bccancer.bc.ca

Responses from Study

"I think it is whoever on the team has the interest and skill to do so. I think it should be somebody the patient is comfortable with and I really think the patient should be consulted around who they would like to have……"

Con, 2007

Cultural aspects

- Illness & disease
  - patience, meditation & prayer
- Wait until very sick until express wishes
- Generally accepting of death
- Rituals for saying goodbye

Cultural aspects

- Unrealistic to plan for possibilities
  - Sends a wrong message that giving up
  - Quantity or longevity important
- Health system had control

Cultural aspects

- Appointing proxy limited opinion of all family members
  - Impeded collective decision making
  - Many families don't want dying relatives informed of prognosis

Responses from Study

"It would be lovely if there was just a formula

(but no formula)

I think you *get* your opportunities, you have to be able to recognize the opportunities as they arise."

Con, 2007

Quality End-of-Life Care in Dialysis Units

S.Davison

Words of Wisdom

- Unrealistic to do in a week
- Initiate dialogue early and remain open so that we will appreciate what they want from end-of-life care and support them in achieving their goals

S.Davison,Seminars in Dialysis 15 (1), 2001

Palliative Care

www.unxvision.com/images/butterfly_main.jpg

What is end of life care?

Palliative care is an approach to care for people who are living with a life-threatening illness, no matter how old they are.

Health Canada www.hc-sc.gc.ca

pw.vsb.bc.ca/library/media/mapleleaf.gif

What is end of life care?

The focus of care is on achieving comfort and ensuring respect for the person nearing death and maximizing quality of life for the patient, family and loved ones.

Health Canada www.hc-sc.gc.ca

pw.vsb.bc.ca/library/media/mapleleaf.gif

Palliative Care: Core Outcomes

- *Communication & co-ordination* across settings
- *Control of pain* & symptoms, *psychosocial distress, spiritual issues* and practical needs of *patient & family*
- *Preparation* for process of dying & death
- *Sensitive* to changes
  - Values & goals
  - Pros & cons of treatment

Liz Smith, American Family Physician 2006

Palliative Care in End-Stage Renal Disease: Focus on Advance Care Planning, Hospice Referral, and Bereavement

"at best, only 30% of dialysis patients complete advance directives …… yet nearly 80% of patients discuss their wishes for end-of-life care with their families"

J.L. Holley, 2005

Seminars in Dialysis 18 (2) 154-56

Past Experience 1995 - 2004

Toronto General Hospital

UHN

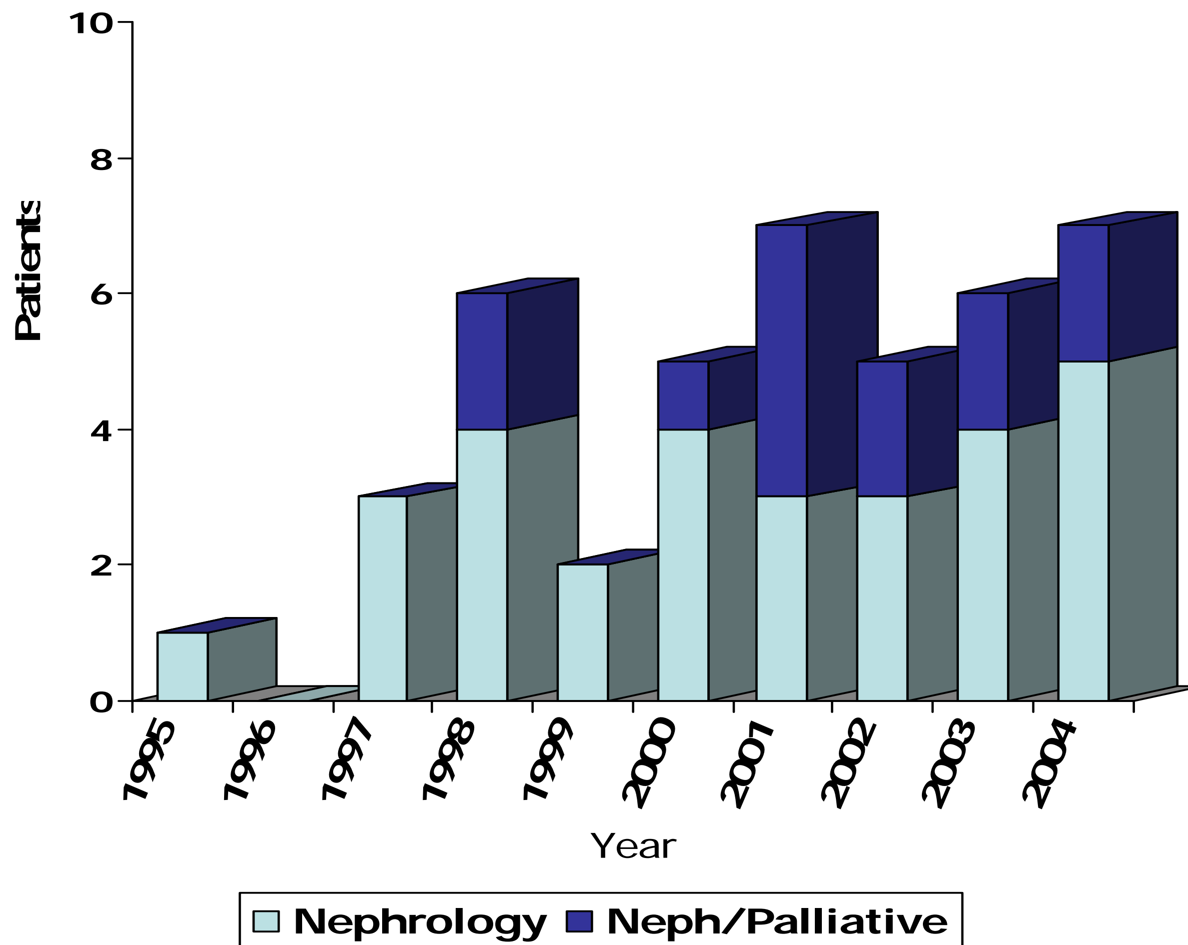
(unpublished data)

Demographics

Chart & Report Review

- N = 42
- Female: 26 (62%)
- Male: 16 (38%)

Palliative Care Per Year



Palliative Care Team

- Decision-making
  - Palliative option
  - Dialysis vs no dialysis
  - Hospice vs hospital vs home
- Counselling
- Symptom management
- Education
- Support

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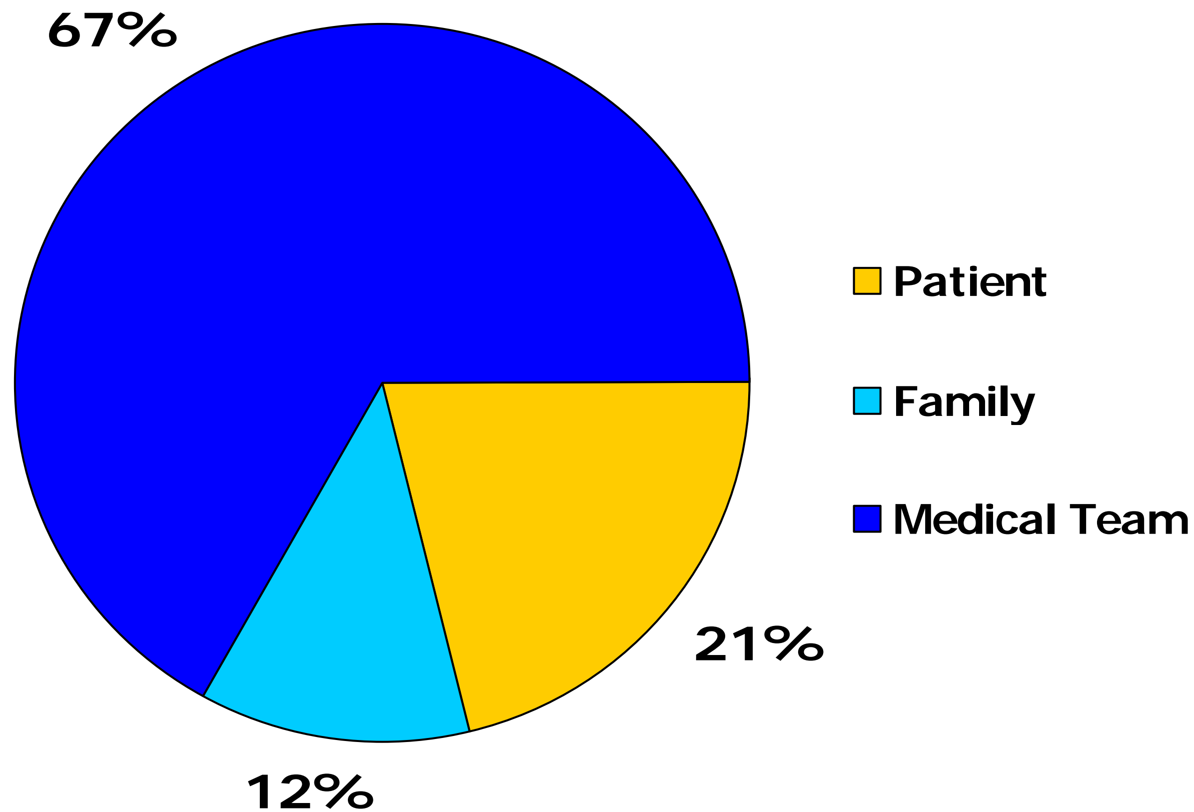
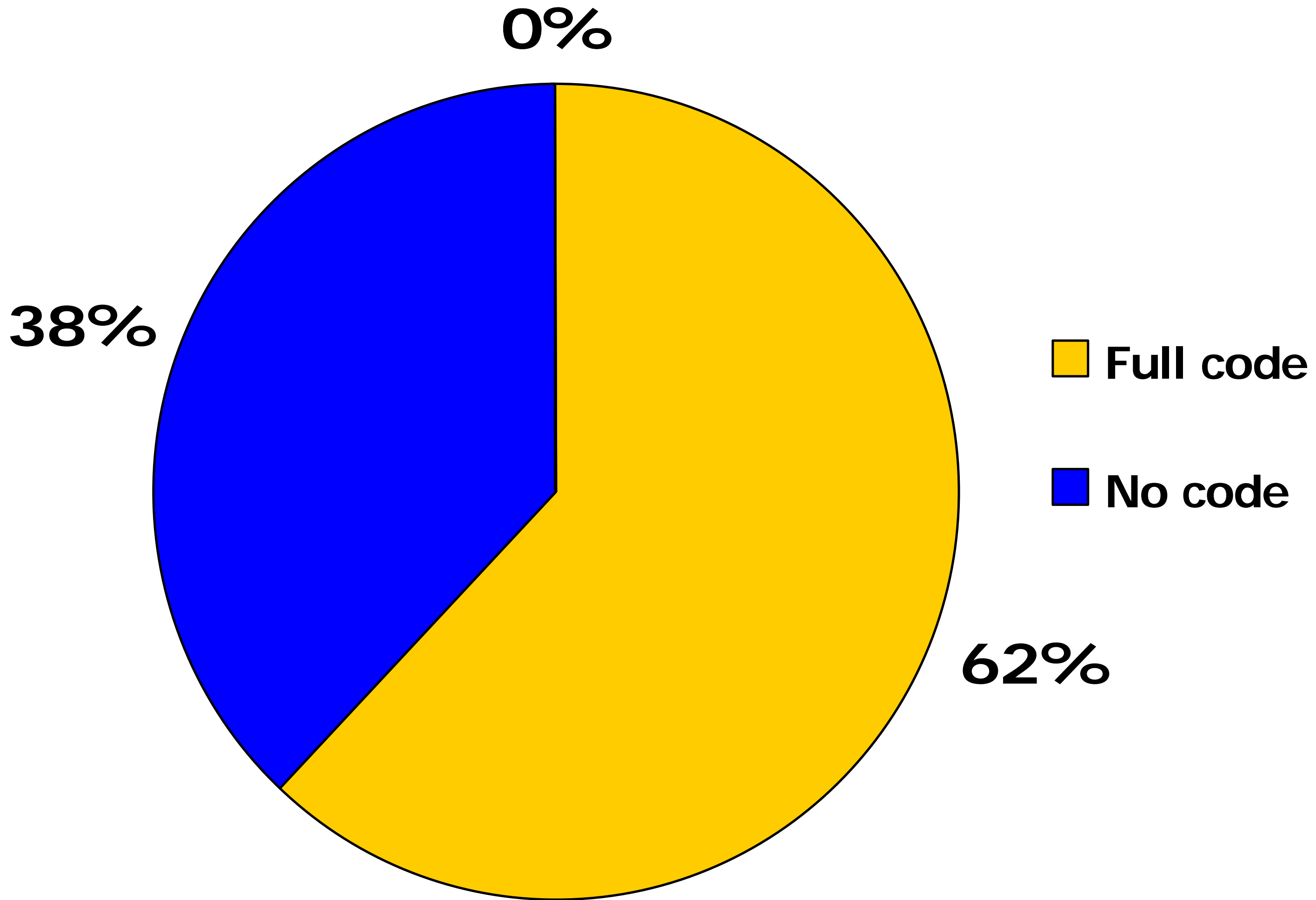
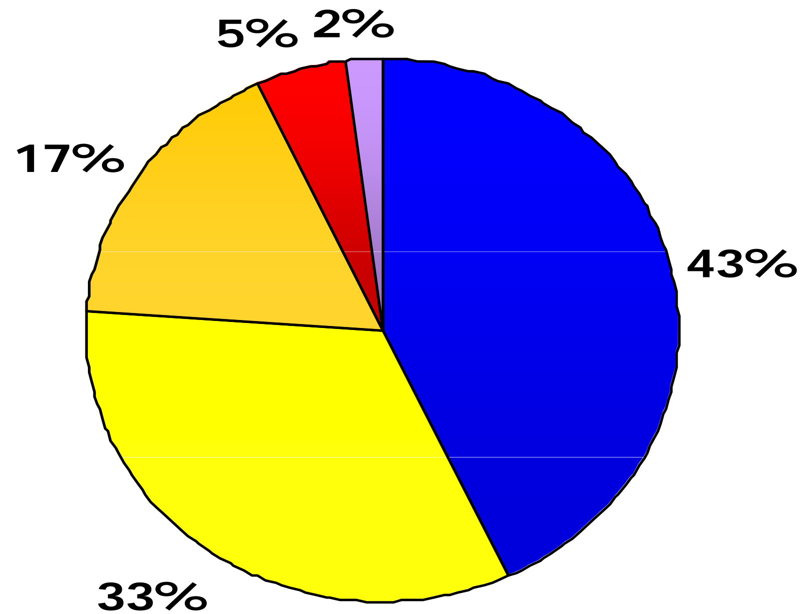
Initiation of Decision-making Process



Code Status Prior to Final Admission



Primary Reason For Palliation



Acute intercurrent disease
Chronic disease
Failure to thrive
Failed access
Failed Trial

Palliation & Dialysis

Decision to withdraw dialysis	Decision to continue dialysis
83%	17%

- Continued dialogue in terms of dialysis continuation
- Hemodynamic stability for continuing treatment potential barrier

Pain management

Pre Decision for Palliation	Post Decision for Palliation
52%	69%

Cancer metastases/myeloma	41%
Ischemic limbs	31%
Ischemic bowel	9%
Calciphylaxis	9%
Myositis	5%
Sickle Cell disease	5%

Dialysis discontinuation and withdrawal of dialysis

Cohen, Germaine,
Poppel, Woods, Pekow & Kjellstrand

Am J Kidney Dis 2000 (36) 140-44

Observational Study

- 8 clinics (Canada & USA)
- 131 deaths in 2 years
- Discontinuation of dialysis
  - 59% women
  - 73% white
  - 22% black
  - 6% Asian or Hispanic
- Mean age
  - 70 yrs (17–89)
- Mean duration of dialysis
  - 34 mos (3– 167)

Cohen, Germain, Poppel, Woods & Kjellstrand, 2000

Observational Study

- Cause of renal failure
  - 46% diabetes
  - 29% hypertension
  - 10% glomerulonephritis
- Most recent dialysis
  - 83% in-centre hemodialysis
  - 16% peritoneal dialysis
  - 2% home hemodialysis
- Pain present in nearly ½ sample

Cohen, Germain, Poppel, Woods & Kjellstrand, 2000

Pain & Symptoms

- 42% of 79 patients available for follow-up in pain last 24 hours of life
  - 5% in severe pain
- Other symptoms
  - Agitation (30%)
  - Dyspnea & myoclonus (28%)
  - Dyspnea (25%)

Pain

Emotional

Spiritual

Physical

Support Measures

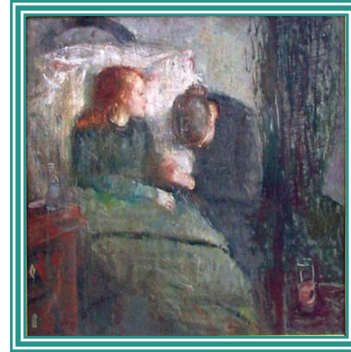
- Non-pharmacological
  - Massage
  - Music therapy
  - Aromatherapy
- Psychological
  - Controlled breathing
  - Imagery
  - Reflection & resolution

massage.fullcoll.edu/newsletter/hands5.jpg

www.picf.org/.../MSSPcansto.hand.kittnT.jpg

Support Measures

- Facilitate family involvement with guidance as needed

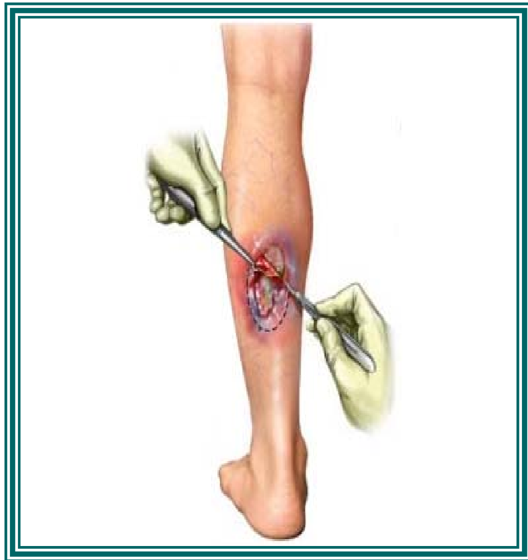


www.departments.bucknell.edu/.../sickchild.jpg

- Referral to chaplaincy for spiritual support as permitted

imgs13.stockmediaserver.com/.../b03615.jpg

Support Measures



www.aurorahealthcare.org/.../exh37231b_ma.jpg

- Prevention
- Position & turning
- Wound care nurse
- Analgesia pre dressings
- Reassess frequency of dressings

Edmonton Symptom Assessment System: Numerical Scale
Regional Palliative Care Program

Please circle the number that best describes:

No pain	0	1	2	3	4	5	6	7	8	9	10	Worst possible pain
Not tired	0	1	2	3	4	5	6	7	8	9	10	Worst possible tiredness
Not nauseated	0	1	2	3	4	5	6	7	8	9	10	Worst possible nausea
Not depressed	0	1	2	3	4	5	6	7	8	9	10	Worst possible depression
Not anxious	0	1	2	3	4	5	6	7	8	9	10	Worst possible anxiety
Not drowsy	0	1	2	3	4	5	6	7	8	9	10	Worst possible drowsiness
Best appetite	0	1	2	3	4	5	6	7	8	9	10	Worst possible appetite
Best feeling of wellbeing	0	1	2	3	4	5	6	7	8	9	10	Worst possible feeling of wellbeing
No shortness of breath	0	1	2	3	4	5	6	7	8	9	10	Worst possible shortness of breath
Other problem	0	1	2	3	4	5	6	7	8	9	10	

Patient's Name ______________________________________

Date ____________________ Time ____________________

Complete by *(check one)*
- ☐ Patient
- ☐ Caregiver
- ☐ Caregiver assisted

BODY DIAGRAM ON REVERSE SIDE

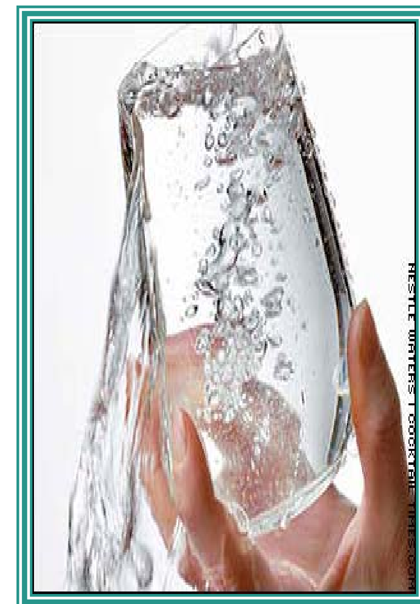
http://www.palliative.org/PC/ClinicalInfo/AssessmentTools/esas.pdf

CH-0202 May 2001

Nutrition & Hydration

images.jupiterimages.com/.../96/01/23220196.jpg

images.inmagine.com/.../izas010/iza103582.jpg



www.cocktailtimes.com/dictionary/top_water2.jpg

Support Measures

- Dehydration
  - Most dying patients stop drinking
  - Last hours, may stimulate endorphin release & sense of well being
- Use of parenteral fluids
  - Considered for reversal of terminal delirium
  - Cumbersome, difficult to maintain
  - Risk of fluid overload
    - Worsen breathlessness, cough & secretions especially with signficant hypoalbuminemia

Ferris, von Gunten, Von Roenn

http://www. Medscape.com/viewprogram/5808_pnt

Support Measures

- Renal failure
  - Liberalize intake per patient's desires
- Loss of appetite
  - Balance risks of aspiration
  - Help families understand
  - Anorexia
    - May result in ketosis which can lead to a sense of well-being & diminish discomfort

Ferris, von Gunten, Von Roenn
The Last Hours of Living: Practical Advice for Clinicians
http://www. Medscape.com/viewprogram/5808_pnt

Pharmacological Options

www.stavros.messinis.com/.../stop-wrist-pain.jpg

WHO guidelines

By the mouth

- Oral unless vomiting or unconscious

By the clock

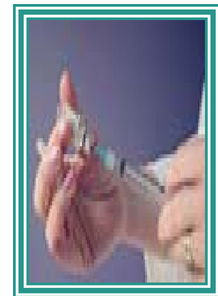
- For persistent pain,
  fixed dose on fixed schedule

By the ladder

- Lowest dose & titrate

For the individual

Attention to detail



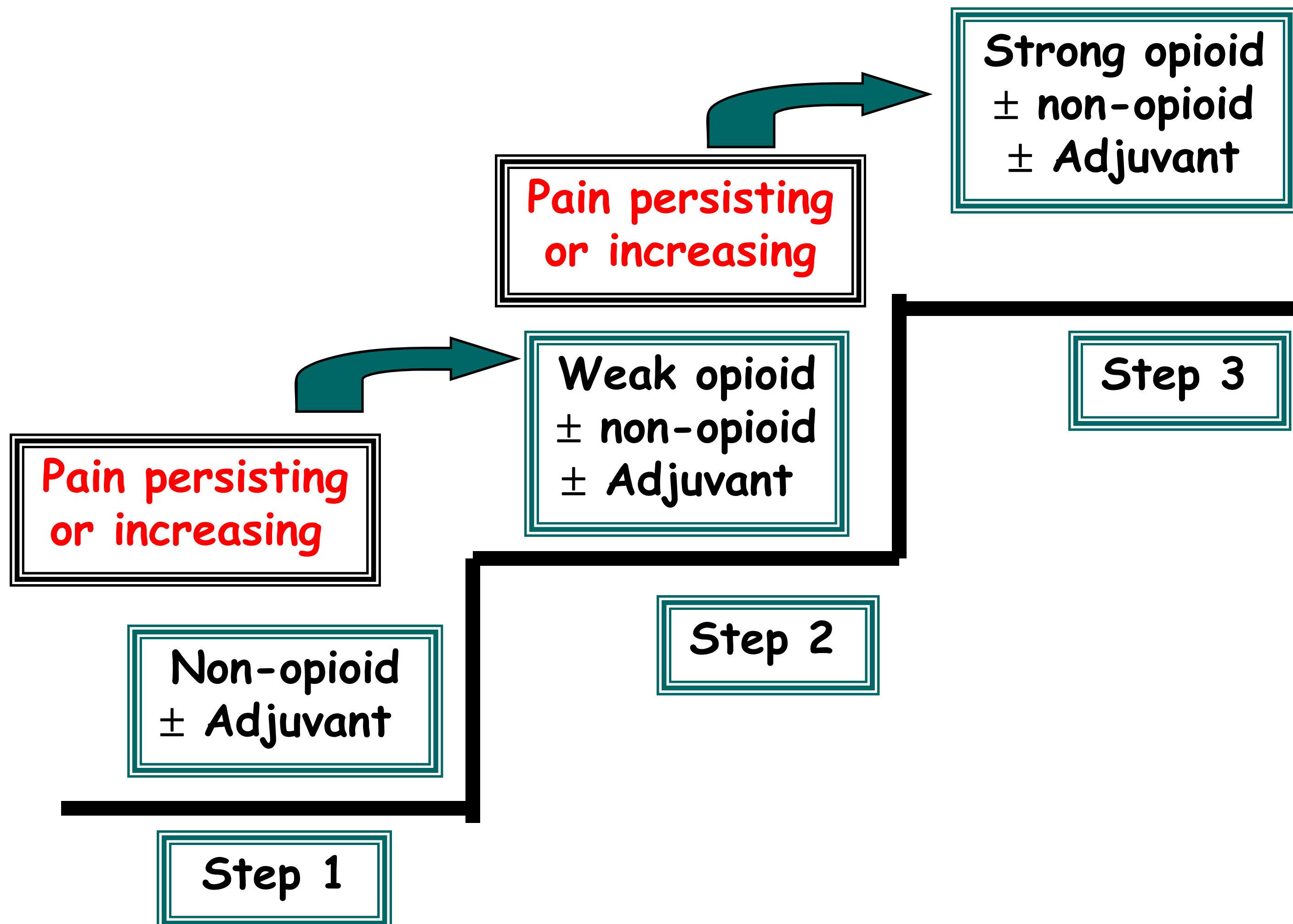
images.acclaimimages.com/_gallery/_TN/0463-06

butterflies-bees-and-evergreen-trees.net/imag...

A. Barnard & E. Gwyther

Pain management in palliative care SA Fam Pract 2006: 48(6) 30-33

The WHO
Three-step Analgesic Ladder



Opioids in Renal Failure & Dialysis Patients

M. Dean

Journal of Pain and Symptom Management

28 (5) 2004, 497-503

Opioids with metabolites

- Morphine
  - Avoid due to metabolites
- Codeine
  - Is metabolized to morphine
- Oxycodone
  - Active metabolites

Options in Renal Disease

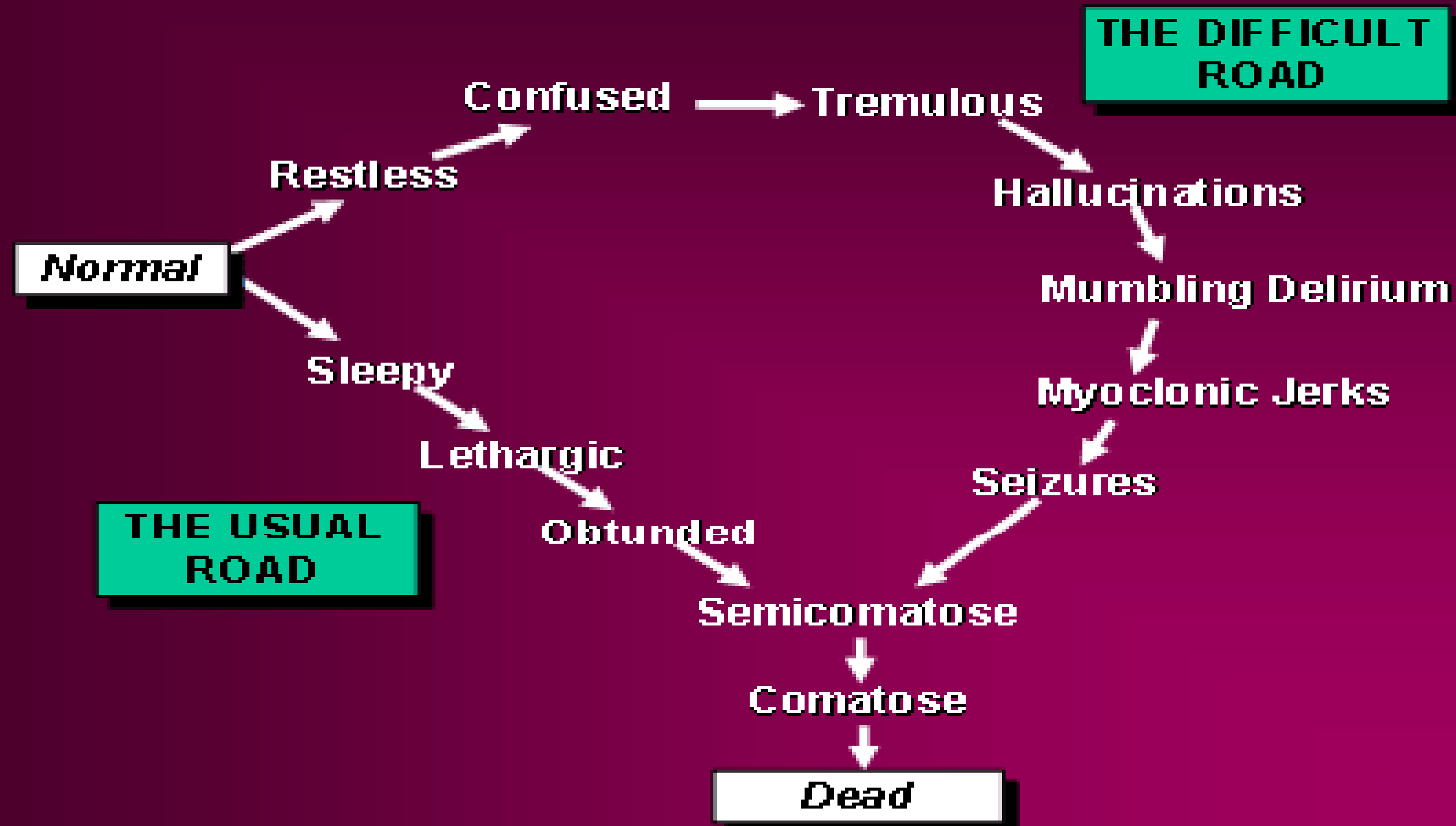
- Hydromorphone
  - Recommend lower start doses
  - Less likely to cause adverse effects in comparison to morphine
  - Careful monitoring
- Methadone
  - In Canada, controlled access
- Fentanyl
  - Availability of transdermal

Non-opioids

- Acetaminophen
  - Oral, suppository
- Antidepressants
  - Burning pain of neuropathy
  - i.e. amitriptyline
- Anticonvulsants
  - Stabbing, shooting pain
  - i.e. gabapentin

A. Ledger

Medication considerations in end-of-life care
CANNT Journal Apr Jun 2004 14 (2) 43-45



Ferris, von Gunten, Von Roenn

http://www.Medscape.com/viewprogram/5808_pnt

Terminal Delirium
("difficult road to death")

Agitated delirium

- Early signs of cognitive failure
- Agitation, restlessness
- Purposeful, repetitious movements
- Moaning, groaning, grimacing

Ferris, von Gunten, Von Roenn

http://www. Medscape.com/viewprogram/5808_pnt

Terminal Delirium

- Potential to misinterpret as pain
- Myth that uncontrollable pain suddenly develops during last hours of life if not present before
- Trial of opioids
  - If not relieved or precipitates myoclonus or seizures, use alternative treatments

Ferris, von Gunten, Von Roenn

http://www. Medscape.com/viewprogram/5808_pnt

Clinical Algorithm & Preferred Medications to Treat Pain in Dialysis Patients

Developed by the Mid-Atlantic Renal Coalition and the Kidney End-of-Life Coalition

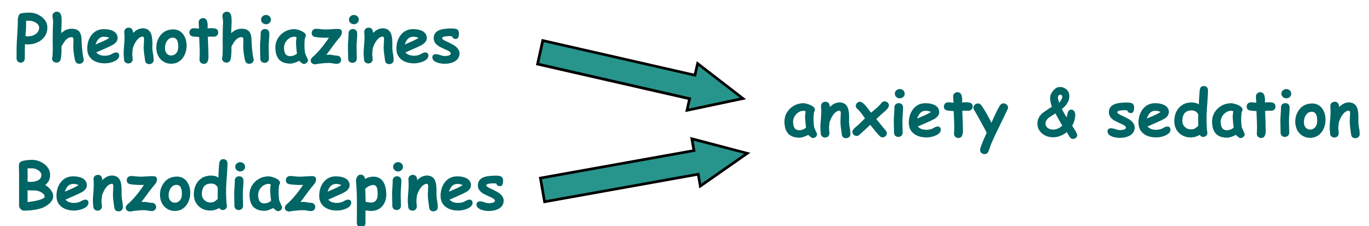
September 2009

http://www.kidneyeol.org/resources.htm

Pharmacological Options

Analgesics	→	regulated times & breakthrough
Antipsychotics	→	nausea & delirium
Laxatives	→	constipation
Antipruritics	→	pruritus

Pharmacological Options



Bereavement

Family

Team

Dialysis Unit

The Palliative Pain & Symptom Management Program

961 Alloy Drive,
Thunder Bay, ON, P7B 5Z8
Phone: 807-343-1625
1-800-319-7246
Fax: 807-344-0944
Website: http://www.ccac-ont.ca/
Please Copy and Share
Drawing by Teresa Trainer
Text by: Marg Nichols, Barb Linkewich & The Long Term Care Committee of Caring Connections
Used with permission from: Preparing for Approaching Death, North Central Florida Hospice
Revised Feb 2008 by Jeff Pruys LUSN

'Til Death Do Us Part...

When Someone You Love Is Dying

Tel: 1-800-319-7246

Is your loved one entering the final stages of life?
Are you seeking ways to prepare yourself for this event?

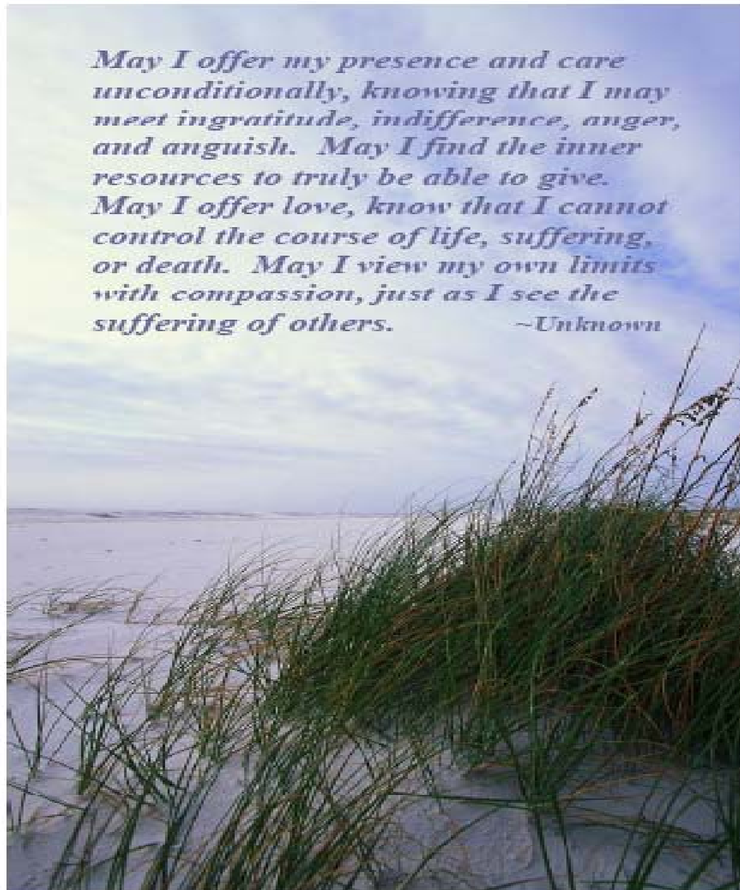
This pamphlet has been designed to assist you with the challenges you will be facing. While the following information may be difficult for you, please know that the intention is to help prepare you for what to expect. Your physical and emotional well being is as important as that of the dying person. Please be aware that not all the described signs of approaching death will be seen in every dying person. If you have questions or concerns about the care of your loved one, please discuss these with your doctor or nurse.

Signs That Death Is Approaching and Helpful Responses

Sleeping: The person may spend an increasing amount of time sleeping, and appear to be uncommunicative or difficult to arouse. This normal change is due in part to the changes in the body's metabolism.
Help by: Sit with your loved one; hold his/her hand, but don't shake it or speak loudly. Speak softly and naturally. Spend time with your loved one at times when he/she is more alert or awake. Avoid speaking about the person in his/her presence. Speak to him/her directly even if there is no response. Never assume that he/she can't hear; hearing is the last sense to be lost.

http://rgps.on.ca/giic/GiiC/giic-contents.html

End-Of-Life Care



SUPPORT FOR CAREGIVERS, FAMILIES AND FRIENDS, CARING FOR A LOVED ONE

TIPS TO REMEMBER

Be a good listener

Ask about their loss

Just sit with them

Remember the loss

Let them feel sad

Make telephone calls

Acknowledge the pain

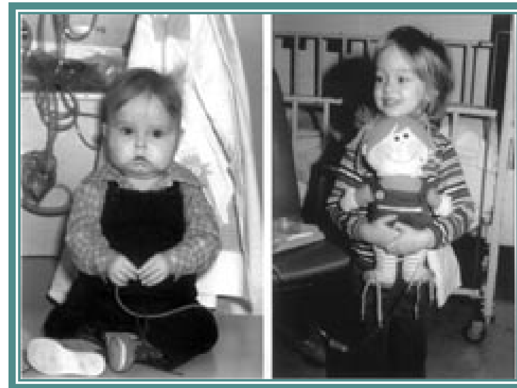
Do not minimize grief

Be available when you can

Ask them about their feelings

http://rgps.on.ca/giic/GiiC/giic-contents.html

What, me grieve?
Grieving & bereavement in daily dialysis practice



"Its by walking the mourner's path that we find our way into the heart and soul of our chosen work. We do it everyday. We just need to wake up to the gifts we've come here to receive."

B.Bartlow *Hemodialysis International* 2006 10:S46-S50

Summary: Collaborative Effort

i98.photobucket.com/albums/l250/armyofdavids/..

- Awareness
- Guidelines
- Education
- Research
- Evaluation

www.tri-events.co.uk/team%20building%20hands.jpg

Lessons Learned

- Family/team meetings
- Early discussion of advance directives beneficial
- Sharing prognosis
- Ongoing translation services
- Determination of goals and expectations

Lessons Learned: Documentation

- Process
- Dialogue
- Reviews
- Transfer of wishes
  - Signed document
  - Orders
  - Follow through between dialysis units, ER & inpatient wards

Lessons Learned

- Pain management to be improved
- Adjunctive medications
- Guidelines for management if concurrent infection
- Liberalize diet with attention to fluid status
- Celebrate life lived – allow good-byes

Geriatrics Interprofessional Interorganizational Collaboration

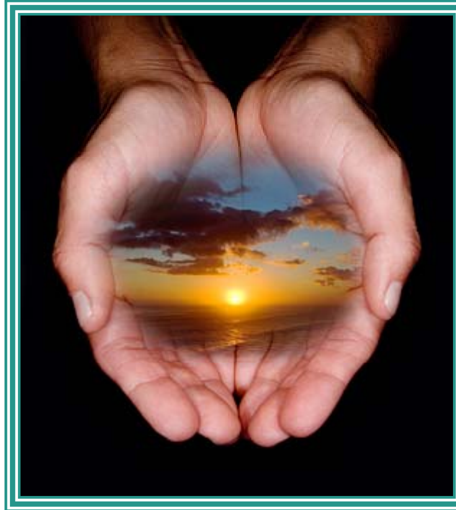
- Advance care planning
- End of life care
- Grieving & Bereavement
- Tools to assist patients & professional

http://rgps.on.ca/giic/GiiC/giic-contents.html

KIDNEY END-OF-LIFE COALITION

- Coalition history
- Advance care planning
- End-of-life decisions in the dialysis unit
- Palliative care & hospice
- Patient & family education
- Physician/clinician education
- Presentations
- Professional Resources

http://www.kidneyeol.org/resources.htm



www.truthbook.com/images/site_images/shutters...

"A good death after dialysis discontinuation should be pain free, peaceful, and brief and need not be an unfocused vision beyond reach."

Cohen et al, 2000