# The Art of Living At The End of Life

Circle of Life Hospice



### What is Hospice

- Dr's, Nurses, CNA's, MSW's, Spiritual, Care, Bereavement, Therapies, Dietary, Volunteers.
- Adjunctive therapies; massage, aromatherapy, healing touch, guided imagery and other related techniques.



#### Palliative Care

- Hospice has been the leader in palliative care



Who Are We and Why Did We Do This?

Circle of Life Hospice &
Circle of Life Hospice
Foundation



# Dying today is a stage of Life

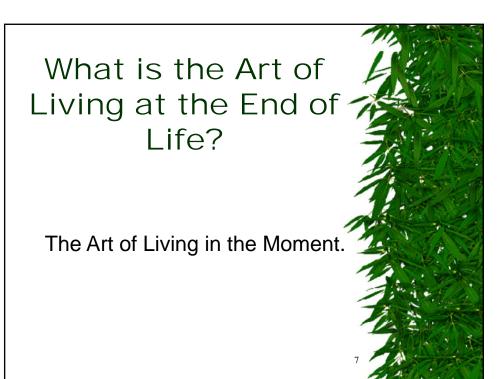
100 years ago death occurred within hours or days. Today dying is a process of many months



# What is a good death

**Peaceful Dying** 





### Kyros Time Versus Chronos Time

We now enter a different time zone, even a different world of time. Suddenly comes the world of slow time that accompanies the grief and moral bewilderment of trying to understand the extinction of the everlasting presence we never questioned.



### Reframing Hope

When I was young when I thought I wanted to die suddenly and hopefully in my sleep. Now I want time to die. There is a lot that I have to do.



#### Reframing Hope

Living at the end of life can be a reflective time, it can be a spiritual journey of meaning and purpose; a journey of hope and personal growth



#### Life Review

The problem of identity is always a problem, not just a problem of youth. The nearest anyone can come to finding themselves at any given age is to find a story that somehow tells them about themselves. Such as the story of your life. A story that honors our lives realistically partly atones for our sufferings, and so instead of leaving us in moral bewilderment, it adds dimensions to our acuteness in watching the universe unfold.



#### Life Review

Stepping Out of The ordinary roles of everyday and into the truth of your true being



#### Life Review

Dying is like any other trip, except this is a Journey that you unpack for



#### Life Review

What is Really Important? RELATIONSHIPS



# Three Types of Relationships

Relationship with self
Relationship with Others
Relationship with our Higher
Power



Spirituality

Meaning and Purpose



### The 5 Things

Please forgive me
I forgive you
Thank you
I Love You
And
Goodbye



Grief and Bereavement

Anticipatory grief



# Grief and Bereavement

Grief is like a stone lodged in your stomach. At first the stone is sharp and it cuts and hurts. But eventually the sharp edges wear down and the stone becomes smooth and doesn't hurt so much. But it is always with you.



# Grief and Bereavement

When you throw a glass of water into the ocean is the water gone? Can you get the water back into the glass.



# Grief and Bereavement

Fear not that which is now, Fear not that which is to come. Life, death & being are as one, it is a circle. There is no beginning and there is no end. For that which is the beginning is the end of the other. Surely the lessons of life are the wisdom of death. Those that live in the knowledge of what the circle truly is have peace beyond measure.



Cultural

and

Institutional

Barriers to

Hospice



#### The Under Utilization of Hospice Services.

- •1992 8% of Medicare Beneficiary Decedents used hospice.
- •1998 19% of Medicare Beneficiary Decedents used hospice.
- •1998 27% of Medicare HMO Medicare Beneficiary Decedents used Hospice.

\*(GAO September 2000 Congressional Report)

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# Hospice is referred to, too late

Half of all Hospice patients are on service less than 2 weeks.



# Decreasing Hospice Lengths of Stay

GAO September 2000 Report to Congress.

- 1993 Average LOS: 76 days. Median LOS: 26 days
- 1998 Average LOS: 59 days. Median LOS: 19 days

Circle of Life Hospice, Reno Nevada.

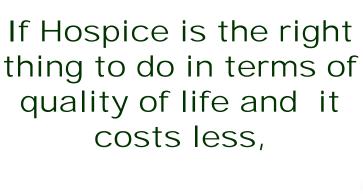
- January 2002 thru April 2002 N= 242.
  - o Average LOS: 37 days.
  - o Median LOS: 12 days.

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#### CMS Paid Advertisement Intended to Promote Hospice Says:

- "First is an understandable reticence to contemplate the end of life."
- "The second perceived barrier is a less than full awareness on the part of patients and practitioners that the covered hospice benefits are both broad and readily available virtually everywhere in the country."

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Then why don't we do what is right?

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### DENIAL

We are a death denying society



Our Health Care System is an Acute Cure Based System

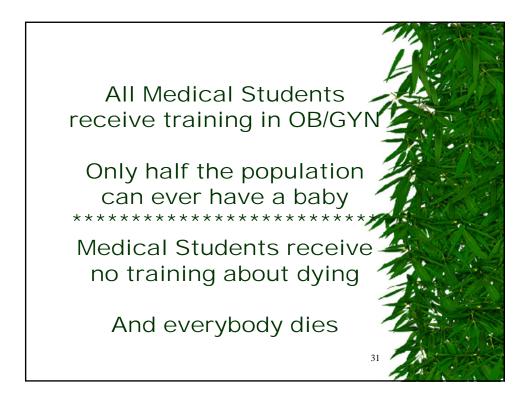
If we can't Cure it
We Don't Know What to do With
It

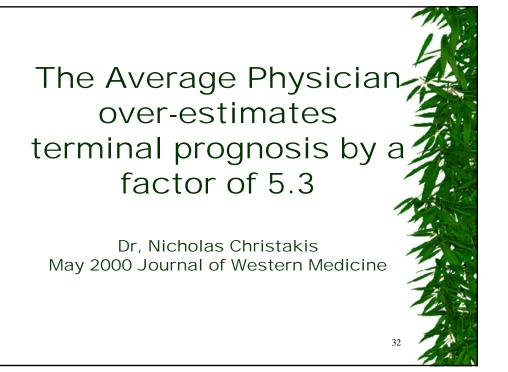


### Physicians see Death as Failure

Medical Students receive virtually no training on death and dying and they don't know how to talk about it.







#### Cured to Death

Most deaths occur in the hospital while receiving life prolonging treatments



# "There is nothing more we can do"

There is a lot more that we can do, we can make you comfortable and we can make this a very meaningful time of life



### The Costs of Being Cured to Death

80% of all healthcare spending occurs at the end of life and most of that is futile care

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### **Hospice Costs Less**

2001 Milliman and Robertson Actuarial Study shows that Hospice is 34% more cost effective



### Koyaanisqatsi

Hopi word meaning"Life out of Balance"
Whenever any system of thinking or doing is not in alignment with reality, the result is pathology.



# So How Do We Fix IT

We do the right thing. We align the system to reality.Reality is what people want.



# What do people want?



#### 1996 Gallup Pole Survey Knowledge and Attitudes Related to Hospice Care

- Home Based Care. Nearly 90% of adults would prefer to be cared for at home if they were terminally ill.
- Patient Control. Americans want to have choice about the services available to them and maintain their freedom and independence to the greatest extent possible.
- Emotional and Spiritual support for patients and families.
   Gaining a sense of closure with family members, not becoming a burden to loved ones, to not be alone and to have bereavement support for survivors.
- Pain control customized to patient's wishes. The prospect of not being able to control pain and other symptoms has been cited as a major source of anxiety for patients confronting a terminal illness.
- Freedom from financial worries. Americans fear impoverishment from the daunting costs of a terminal illness and worry that finances will play a role in the quality of the care they receive.



#### 2002 Harris Poll A Study About End of Life Care

- · Home is where the heart is (86%).
- · Majority consider hospice most knowledgeable.
- Most don't know how end of life care is financed.
- Only three out of five think physicians are truthful about life-limitic conditions.
- Only half believe the health care system adequately explains options.
- 88% believe terminal of patients would benefit from consultations with end of life care specialists.
- Americans who believe that consultation would be beneficial also believe that would give patients and families more control over end of life decisions.
- 81% of Americans believe that terminally ill patients should have consultation when given a life-limiting prognosis of two years or less

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Surveys Represent Americans Values
Desires and Expectations
Of
Quality End of Life Care.

It is what Americans Want!

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Our Attitudes about death and dying need to change

We need to adopt positive healthy attitudes about death and dying.



#### Change the Health Care System

Medical Schools
Social Education
Politicians and Policy Makers



### Two Major Issues



# Circle of Life Hospice Foundation

Think Global Act Local

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### Caregiving

A Crisis of epidemic proportions

The largest single cause of bankruptcies

The Orphaned elders



### Personal Care Attendants

Nevada Medicaid Considers this a duplication of service.

Medicare does not



### Residential Hospice House

Affordable Independent Living for those without Caregivers



**Advanced Illness Planning** 

How It Improves Care
At
The End of Life?



## There Are A Number of Advanced Illness Management Initiatives:

- Demonstration Grants from RWJ, VA and CMS in addition to Insurance Industry initiatives.
  - Improving Care at the End of Life, Tacoma WA.
  - o Group Health of Puget Sound.
  - o BC/BS 11 State Initiatives.
  - o Hospice of the Valley, Phoenix, AZ.

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#### **Identifying The Patient:**

- Review list of Chronically III Patients Seen by Physicians every 60-days.
- "Would You Be Surprised if This Patient Died in the Next 12 to 24 Months?"

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#### **First Contact**

- Physician Informs Patient of follow up call or Nurse Initiates First Call
- Nurse Introduces herself as being from the Physician's Office.
- First Call is about Disease and Medication Teaching.
  - Disease Education Proceeds in Accordance with Patient's Comfort Level.
  - Number and Frequency of Calls Also Proceeds with Patient Comfort Level.
  - o Involvement of Other Disciplines as Appropriate.

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#### The Kitchen Table Discussion

- Assessing patient understanding of disease process, management and prognosis.
- Help patients and caregivers learn "how to live with" versus "dying from" their illness.



#### Bridge to Community Resources Increased by 5X

- Meals on Wheels
- Shuttle Service
- Medical Equipment
- Parish Nurses
- Rx delivery
- Senior Services
- Advanced Directives

- Legal Assistance
- Respite Care
- Home Health Services
- Safety Inspections
- Chore Workers
- Lifeline
- Hospice

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#### **Outcomes**

- Increased Physician Awareness
- Increased Patient and Family Satisfaction
- Increased use of community resources
- · Increased Hospice referrals, LOS, revenue
- Decreased unwanted or unnecessary hospitalizations and ER visits.
- Increased number of patients that died at the location of their choice.

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## Impact on Hospice Referrals (One Clinic)

• Baseline referrals: 9

• First Year: 47

Second Year94



#### **Hospice LOS**

National

o Mean 59

o Median 19

AIP Pts

o Mean 86

o Median 38

58

National data; 1998

#### Costs of End of Life Care

- Hospice accounts for 1% of Medicare spending and .1% of Medicaid Spending
- 2001 Milliman Actuarial Study
  - Hospice 34% more cost effective than nonhospice end of life care
  - o Advanced Directives save
  - o 10-17% during last 6-months of life
  - o 25-40% in the last month of life.



#### Costs of AIP Care

Control Group \$33,167

• AIP Group \$5,458

• Savings \$27,708

• 84% more cost effective.



