

# Palliative Care for the HIV-infected Inmate in the Correctional Health Care Setting

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Washington, DC



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## Objectives

- Changes in HIV morbidity & mortality in the HAART era.
- Define curative and palliative care
- Care delivery in the correctional setting
- Challenges in the correctional setting



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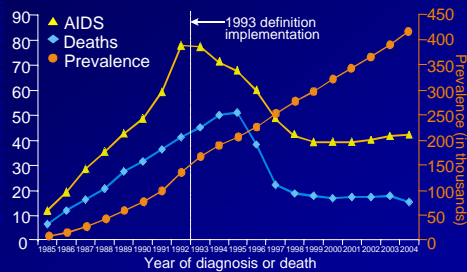
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## Estimated Number of AIDS Cases, Deaths, and Persons Living with AIDS, 1985-2004, United States



Note. Data adjusted for reporting delays.

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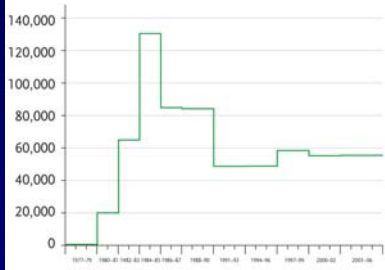
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Estimated New HIV Infections, Extended Back-Calculation Model, 1977–2006, Overall



Note: Estimates are for 2-year intervals during 1980–1987, 3-year intervals during 1977–1979 and 1988–2002, and a 4-year interval for 2003–2006.  
Source: Centers for Disease Control and Prevention

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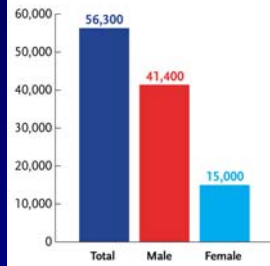
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Estimated New HIV Infections, 2006, Overall and by Gender



Note: Estimates from subgroups do not add to total due to rounding.  
Source: Centers for Disease Control and Prevention

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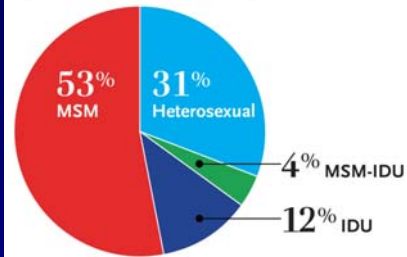
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Estimated New HIV Infections, 2006, by Transmission Category



Source: Centers for Disease Control and Prevention

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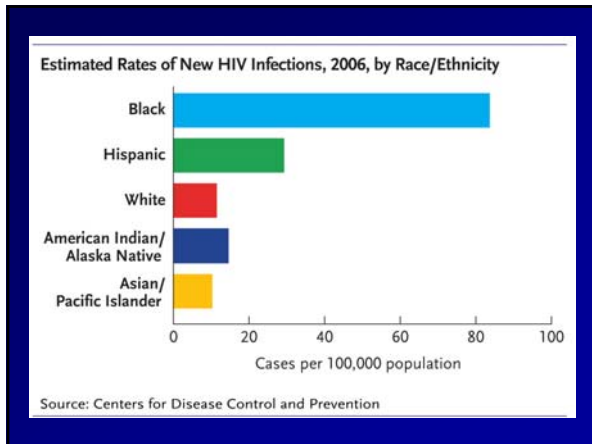
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### HIV/AIDS Epidemiology in U.S. Prisons as of 2005

- As of December 31, 2005, the following numbers of people were infected with HIV or had AIDS:
  - 20,888 State inmates (1.8% of State inmates)
  - 1,592 Federal inmates (1% of Federal inmates)
- This was a slight decrease from 2004 of about 450 inmates

HIV in Prisons, 2005 Bureau of Justice Statistics Bulletin, U.S. Dept of Justice, Office of Justice Programs, Sept. 2007; NCJ 218915.




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### HIV/AIDS in U.S. Prisons: 1999 to 2005

- Since 1999, the number of HIV/AIDS State & Federal inmates has decreased overall.
- 27 States reported a decrease in HIV/AIDS infected inmates, while 18 State & Federal prisons reported an increase.
  - 5 States and District of Colombia either had no change or did not report data

HIV in Prisons, 2005, Bureau of Justice Statistics Bulletin, U.S. Dept of Justice, Office of Justice Programs, Sept. 2007; NCJ 218915.




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## Women versus Men with HIV Infection

- There are a greater percent of females than males with HIV infection in the incarcerated population.
- At year end 2005, an estimated 18,953 males (1.8%) and 1,935 females (2.4%) in State prisons were HIV-infected or had confirmed AIDS.
- The number of cases for both males and females was down from 2004.

*HIV in Prisons, 2005*, Bureau of Justice Statistics Bulletin, U.S. Dept of Justice, Office of Justice Programs, Sept. 2007; NCJ 218915.




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## Concentration of HIV/AIDS-infected Inmates Geographically

- At year end of 2005, half of the HIV/AIDS cases were in the South, nearly a third in the Northeast, and about a tenth in both the Midwest and the West.
- The Northeast reported the highest percentage of HIV/AIDS cases based on its custody population (3.9%).
- At year end of 2005, three states — New York (4,440), Florida (3,396), and Texas (2,400) — housed nearly half (49%) of all HIV/AIDS cases in State prisons.

*HIV in Prisons, 2005*, Bureau of Justice Statistics Bulletin, U.S. Dept of Justice, Office of Justice Programs, Sept. 2007; NCJ 218915.




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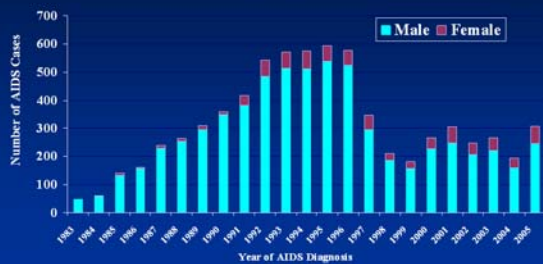
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## AIDS\* in Prisoners by Gender and Year of Diagnosis New York State



\*Data as of February 2007

NYSDOH/BHAE

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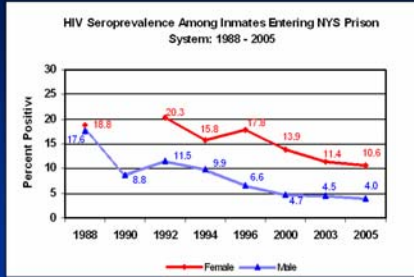
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## Results: HIV Seroprevalence Trends



- HIV seroprevalence rates declined steadily over time for both male and female inmates in the study
- The steady decline has been more pronounced for males (77%) than for females (44%) during the study period

NYSDOH/EHAE

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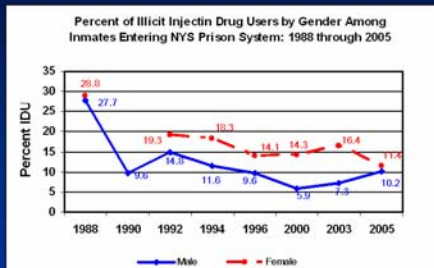
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## Results: Trends in Self-Reported Injection Drug Use (IDU) by Gender



- Self-reported injection drug use (IDU) among incoming inmates shows a downward trend over the years

NYSDOH/EHAE

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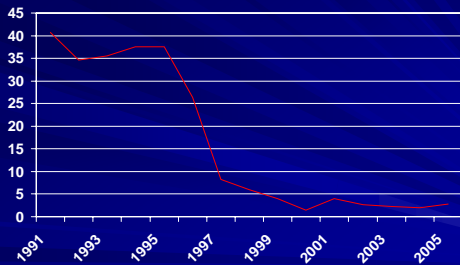
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## HIV-Related Death Rate in New York State DOCS (Rate per 10,000)



Source: NY State Department of Corrections




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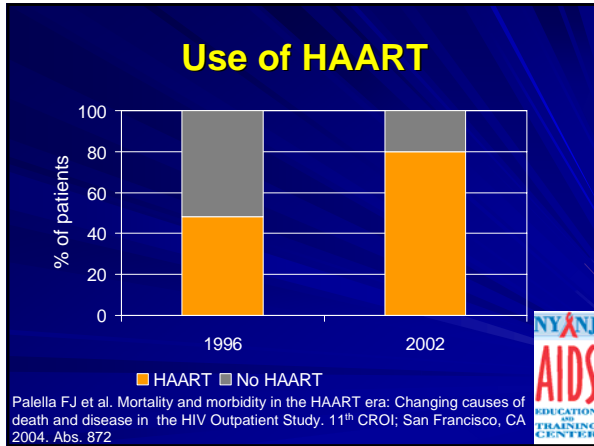
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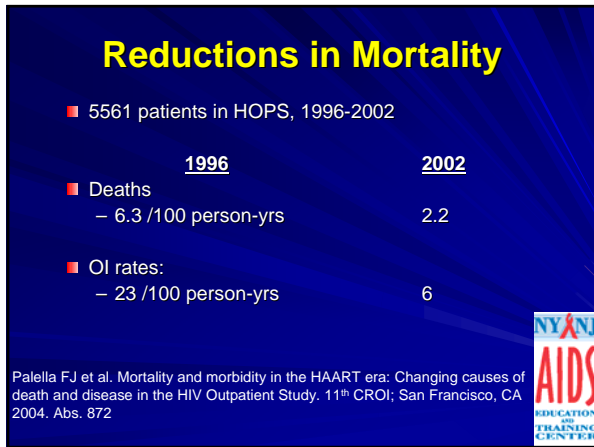
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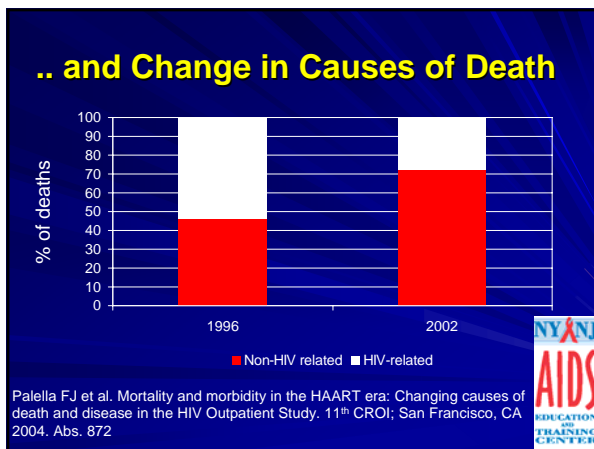
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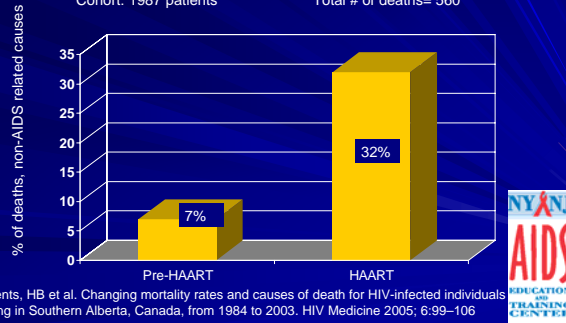
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## Changes in Causes of Death Southern Alberta, Canada, 1984-2003

Cohort: 1987 patients

Total # of deaths= 560




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## Increases in Non-AIDS Related Causes of Death Southern Alberta, Canada, 1984-2003

Causes of Death	1984-96	1997-03
■ Accidental deaths (drug overdose)	2.2%	17%
■ Liver disease	<1	8.4
■ Non-HIV Cancers	<1	7

Krents, HB et al. Changing mortality rates and causes of death for HIV-infected individuals living in Southern Alberta, Canada, from 1984 to 2003. HIV Medicine 2005; 6:99-106




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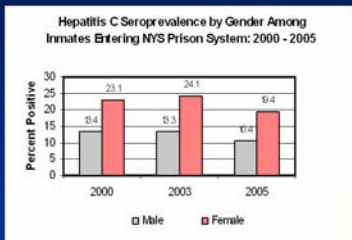
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## Results: Hepatitis C Antibody Status by Gender



- Hepatitis C (HCV) antibody testing was added in 2000. (Not all persons with Hepatitis C antibodies require medical treatment for Hepatitis C.)
- HCV prevalence rates are much higher than HIV prevalence rates in each of the study cohorts
- While some decrease was found in 2005, the decline overall is much smaller compared to declines in HIV prevalence

NYSDOH/SHAE

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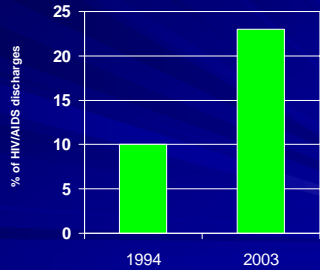
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## PLWHA Are Getting Older...

NY: HIV/AIDS hospital discharges among PLWHA  
50 years of age or older



Source: SPARCS database, NYSDOH

50 yo/older



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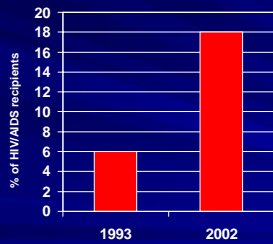
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## PLWHA Are Getting Older...

NY: Medicaid Recipients with HIV/AIDS,  
Age 50+



50 yo/older

Source: Medicaid Claims database



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## Smoking Prevalence among PLWHA

- Prevalence of smoking among people with HIV --- estimated to be **higher** than among the general population
- New England clinics: More than 70% of HIV+ smoke

Niaura R et al. Smoking among HIV-positive persons. *Ann Behav Med* 1999; 21(Suppl):S116

- Swiss HIV Cohort Study
  - 72% are current/former smokers
  - 96% among IDUs

Clifford, GM et al. Cancer risk in the Swiss HIV Cohort Study: Associations with immunodeficiency, smoking and Highly Active Antiretroviral Therapy. *J Natl Cancer Inst* 2005;97:425-432



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## James Readmitted

- In September he was readmitted with persistent fevers to 105 F.
- Liver biopsy and bone marrow consistent with, but not diagnostic for, malignancy.
- Lymph node biopsy confirmed Hodgkin's lymphoma.
- He adamantly declined chemotherapy.
- DNR/DNI order requested by patient.




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## James – Regional Medical Unit

- Transferred to regional prison hospital in Coxsackie, New York




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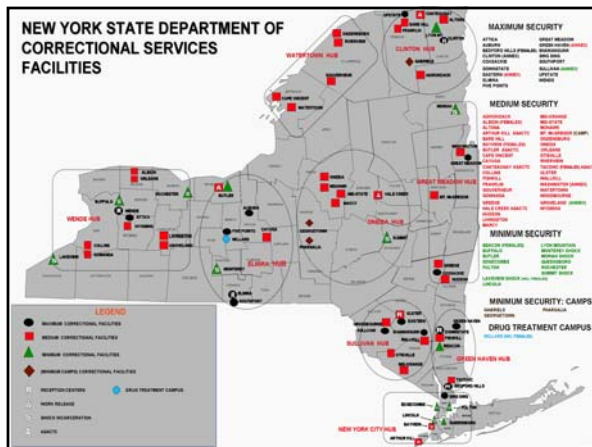
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## Coxsackie Regional Medical Unit

- Established 1996
- Run by vendor contracted with NYSDOCS
- Provides long term and sub-acute care
- 60 bed male facility
- Admit patients from Northeast New York population of 22,000 inmates
- Approximately 70,000 inmates in NY



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## NYS DOCS End of Life Initiative

- Goal was to have Hospice Program in each of the 5 Regional Medical Units (RMU)
  - 4 male facilities (Coxsackie, Wende, Walsh, Fishkill)
  - 1 female facility (Bedford)
  - Total of almost 300 RMU beds at present
  - End of life programs in place in each RMU



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## Terminology

- Curative care
- Palliative care



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## Increased Need for Hospice Care

- Contributing factors
  - Longer sentences
  - Aging inmate population
  - General health
    - Poor to no healthcare before incarceration
    - Destructive patterns of behavior
    - Resistance to access medical care while incarcerated
    - Higher prevalence of communicable disease



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## Coxsackie RMU Hospice Program

- Contractual component between NYSDOCS and vendor providing health care at RMU since 1996
- Community Hospice conducted chart reviews to demonstrate need and cost benefit of End of Life services
- Hospice program implemented in 1997 after development of policies



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## Coxsackie RMU Hospice Program

- 1997 - 1998
  - Focus on education and support services with full-time Hospice RN on site
  - Availability of community-based clergy and social worker
  - Involvement with GRACE Project (Guiding Responsive Action in Corrections at End-of-Life)



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## Selected Enhancements Under GRACE Demonstration Project

- Enhance communication and collaboration within the facility as well as with various agencies such as Community Hospice, CMS, NYSDOCS, specialty providers
- Inmate hospice volunteer program
- Provide further orientation, training and ongoing education for CMS and DOC staff



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## Coxsackie RMU Hospice Program

- 1998 - 2000
  - 16 hour/week Community Hospice RN onsite
  - Participation in patient care conference
  - Hospice availability for consultations and concurrent chart review
  - Director of Nursing and 2 Nurse Practitioners received HPNA certification



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## Coxsackie RMU Hospice Program

- 2000 - present
  - Community Hospice utilized as consultant service for difficult cases and quarterly chart review
  - In-house Case Manager
  - Inmate Hospice Aide Program
  - Incorporated Hospice into employee orientation
  - Cross collaboration between Medical Director and Community Hospice Director



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## Coxsackie RMU Statistics Total (HIV)

	2005	2006	2007
■ Admissions (HIV)	64 (16)	60 (14)	68 (5)
■ Total Discharges	65 (14)	63 (13)	64 (11)
■ Paroled	21 (8)	27 (3)	20 (2)
■ Transferred	22 (2)	16 (2)	22 (4)
■ Expired	22 (4)	20 (8)	22 (5)
■ Hospice Deaths	14 (4)	13 (8)	18 (4)
■ Non-Hospice Deaths	8 (0)	7 (0)	4 (1)
■ % Hospice Deaths	64% (100%)	65% (100%)	82% (50%)

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## Coxsackie RMU Statistics

- 2007 Hospice Diagnoses:
  - Cancer – 15
  - End stage liver disease/Hepatitis C – 5
  - HIV/AIDS – 4 (2 with ESLD, 1 with PML, 1 with Hodgkin’s lymphoma)
  - Other (pulmonary fibrosis, cardiomyopathy, CJD)




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## Challenges Unique to Hospice Behind Bars

- Changing Philosophy
- Acceptance
- Pain Management
- Psycho-Social Support
- Trust Issues
- Visitation
- Consultant Communication
- Advanced Directives
- Comfort Food
- Medical Parole
- Discharge Planning
- Alternative Treatment
- Security Concerns
- Compassion Without Prejudice
- Bereavement




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## Changing Philosophy

- People will die while incarcerated
- Everyone has the right to a “good death”
- Level of health care mirrors that in community
- Inmate vs. patient
- Patient directed care
- It's the right thing to do



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## Acceptance

- Patient acceptance of diagnosis and possibility of dying in prison
- Patient acceptance of care from inmate volunteer
- Patient acceptance of medical care
- Staff acceptance of inmate as a patient
- Security acceptance of compassionate care for an inmate



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## Trust Issues

- Accurate medical information
- Patient with medical staff
- Family with medical staff
- Security with medical staff
- Patient with security
- Patient with other inmates



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## Pain Management

- Trusting patient's pain rating
- Drug seeking vs. drug resistance
- Diversion
- Victimization
- Route of delivery
- Availability of medication
- High doses needed to control pain in IVDU



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## Psychosocial Support

- Isolation
- Family
- "Family"
- Lack of control
- Manipulation as a form of control
- Poor social skills
- Mental health
- Disclosure, confession and forgiveness



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## Visitation

- Distance
- Resources
- Contacting family and friends
- Alienation of patient from family
- Patient reluctance
- Visitor clearance
- Closure and death bed visit



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## Consultant Communication

- Understanding of how DOC works
- Offering treatments not allowed by DOC
- Understanding of RMU capability
- Acceptance of treatment plan
- Adopting Hospice philosophy



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## Advanced Directives

- Reluctance of physicians to discuss
- Addressed with every RMU patient
- Offer patient control over care
- Not required for Hospice care
- Belief that DNR means "no care"
- Attempt to not die in prison
- Availability of Health Care Proxy
- Patient without capacity



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## Comfort Food

- Standardization of meals
- Limited commissary choices
- Family unable to bring in food
- Staff unable to bring in food
- Formalized process established to provide meal requests



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## Medical Parole/FBCR

- Medical parole: for those inmates who have not yet been to their first board appearance
  - \* excludes conviction for murder 1 or 2
  - \* excludes conviction for any sex crime
- Full Board Case Review (FBCR) – for those inmates who have already been to the board once
  - \* have met minimal time requirement

Criteria very stringent  
 Multiple applications  
 Processing period - timing is everything  
 Initiation of process at time of diagnosis  
 Initiate before admission  
 Crime restrictive discharge planning  
 Patient expires during process




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## NYSDOCS: Medical Paroles Requested & Granted

Year	Total		HIV	
	# Requested	# Granted	# Requested	# Granted
1994	255	52	191	45
1995	238	60	179	58
1996	209	44	149	39
1997	98	21	55	16
1998	89	14	44	5
1999	84	17	26	5
2000	82	12	17	3
2001	150	20	34	5
2002	100	14	25	8
2003	119	22	16	4
2004	113	12	16	3
2005	87	12	8	1
2006	79	14	4	2
2007	67	12	5	1

Source: NYSDOCS, November 2007

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## RMU Medical Parole/FBCR

- 2001 to present:
  - 114 patients submitted for RMU MP/FBCR
    - 27 denied (24%)
    - 49 expired (43%)
    - 38 released (33%)
      - 106 released statewide (36% from Coxsackie RMU)
  - 32 HIV patients submitted for MP/FBCR
    - 3 denied (9%)
    - 14 expired (44%)
    - 15 released (47%)
      - 24 released statewide (62% from Coxsackie RMU)




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## Discharge Planning and Follow-Up Care

- Limited choices
- Acceptance of and continuity of treatment plan
- Reliance on parole
- Crime and diagnosis restrictive
- Limited family contact/involvement
- Are they better off in prison?



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## Alternative Treatments

- Very restricted in correctional settings
- Modified touching
- Medical approval to obtain homeopathic treatment



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## Spiritual Support

- Spiritual support limited by religions represented by DOC
- Limited opportunities for fellowship
- Inmate hospice aide and volunteers
- Group effort - not limited to clergy



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## Security Concerns

- Patient manipulation of system
- Distribution of narcotics
- Equipment needed to take care of patients
- Limited understanding of infection control
- Family visits
- In-room vs. visiting room visits
- Body/room search



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## Compassion without Prejudice

- The patient who refuses care for underlying disease
- Seeing the person, not the crime
- Maintaining respect of patient
- Conflicting emotions



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## Bereavement

- Limited family contact
- Reliance on Community Hospice
- Imposed relief time for Inmate Hospice Aide
- Onsite social worker for 1:1 counseling
- Memorial services offered to patients and staff



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## After Death Challenges

- Family not allowed to view body at facility
- DOC autopsy requirements
- Next of kin notification
- Closure obstacles
  - cost of funeral
  - burial on state grounds
  - limited family contact after death



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## James

- RMU evaluation started prior to admission
- Admission evaluation
  - Pain assessment
  - Education level
  - Request to continue DNR
  - Declined chemotherapy/radiation therapy
  - “My T-cells are too low and the chemo will eat them up”
  - Presented with information on Hospice Program



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## James

- Evaluated by:
  - Admitting RN
  - Nurse Practitioner
  - Hospice Coordinator (DON)
  - Physician
  - Social Worker
  - Nutritionist
  - DOC Guidance Counselor
  - Clergy



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## James

- Unplanned family visit the day after admission
- Family given information on Hospice Program
- Patient agreed to and signed for Hospice one week after admission
- Inmate Hospice volunteers scheduled



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## James

- Clinically, James was not able to tolerate medications due to renal involvement
- As his condition declined, treatment medications were stopped
- Palliative medications continued
  - Pain medication
  - Anxiety medication



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## James

- Three days after signing for Hospice, James became confused & obtunded
- End-of-Life orders written
- Family notified of change in condition
- Inmate Hospice Volunteer 24 hour vigil started
- James expired about 3 hours after family visit



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# Federal Bureau of Prisons



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## Federal Bureau of Prisons Hospice Program

- The Federal Bureau of Prisons (BOP) has had hospice programs since the late 1980s.
- The first BOP Hospice Program started at the Medical Center for Federal Prisoners in Springfield, Missouri in 1987.
- Currently the Bureau of Prisons has Hospice/Palliative Care Programs at 5 Federal Medical Centers (FMC): FMC Butner, FMC Carswell, FMC Lexington, FMC Rochester and MCFP Springfield.
  - As of October 2007, 52 inmates were in hospice programs at these locations.

Correspondence with Julia Dunaway, Chief Social Worker at the Federal BOP, November 2007



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## Federal Bureau of Prisons Hospice Program

- An appropriate hospice referral generally includes any patient who has been diagnosed with a terminal illness and given a life expectancy of 1 year or less.
- Patient is eligible to apply for Compassionate Release Procedures for Implementation.

Correspondence with Julia Dunaway, Chief Social Worker at the Federal BOP, November 2007



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## Federal Bureau of Prisons Hospice Program

- A unique characteristic of BOP Hospice/Palliative Care Programs is the use of inmate volunteers.
- Volunteers typically receive training based on national hospice standards, consisting of 30 hours of annual instruction.
- Training is often taught by both BOP staff and community professionals.

Correspondence with Julia Dunaway, Chief Social Worker at the Federal BOP, November 2007



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## The GRACE Project (Guiding Responsive Action in Corrections at End-of-Life)

- Collected information on end-of-life programs in Federal BOP and 14 state DOC systems.
- Analyzed challenges to providing quality end of life care in corrections settings
- Compiled best practice program components

Ratcliff, 2000, Jackie Zalumas, Ph.D., RNC, FNP, Corrections Technical Assistance and Training Project Southeast AETC, 2005

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## Positive Outcomes

Positive outcomes: National Institute of Corrections (NIC) study in 1997

Advantages of hospice approach in the corrections environment:

- Improved quality of life/experience of death
- Improved quality of medical care
- Benefits to staff and inmates
- Benefits to inmates' families and friends
- Cost benefits - decreased trips to outside hospitals
- Decreased security issues
- Good public relations with community

Jackie Zalumas, Ph.D., RNC, FNP, Corrections Technical Assistance and Training Project Southeast AETC, 2005

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## Increase in End-of-life Programs in Corrections

- 30 months after NIC survey, the GRACE Project conducted a new inventory of correctional hospice and palliative care programs.
  - Number of states with end-of-life programs in place or under development doubled.
  - Number of states with at least one hospice program in place increased from 11 to 19.
  - Number of states with an end-of-life program under development had gone from 4 to 14.
  - 9 states with programs in place had plans for additional programs.

Ratcliff, 2000, Jackie Zalumas, Ph.D., RNC, FNP, Corrections Technical Assistance and Training Project Southeast AETC, 2005

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## National Prison Hospice Association

- Provides general guidelines that aim to assist administrators and health care providers in the development and maintenance of prison-based hospice programs.
- Operational guidelines provide a broad outline of:
  - (1) Essential concepts of hospice and palliative care
  - (2) Unique policy issues confronting those who must adapt this approach to the correctional setting
  - (3) Procedures for creating a facility-specific manual for a prison hospice/palliative care program

National Prison Hospice Association, 2007



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## National Prison Hospice Association

- **PO BOX 4623  
BOULDER, CO 80306-4623**
- **303-447-8051**
- [npha@npha.org](mailto:npha@npha.org)



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## Summary

- The face of the AIDS epidemic has changed in the last 27 years.
- Availability of hospice in the prison setting is recognition of the importance of dying with dignity.
- Palliative/hospice care benefits the patient, available family, and the corrections staff.



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## Appreciation

- Alvaro Carrascal, M.D. NY State D.O.H. AIDS Institute
- Julia Dunaway, Chief Social Worker, Federal Bureau of Prisons
- Lou Smith, M.D. NY State Bureau of HIV/AIDS, NY State D.O.H.
- Sarah Walker, M.S. Albany Medical College, Division of HIV Medicine, for her assistance in gathering some of the data.
- Lester Wright, M.D., M.P.H. NY State Dept. of Correctional Services
- Jackie Zalumas, Ph.D., RNC, F.N.P. Southeast AIDS Training and Education Center



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## Thank You!



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