

A Collaborative Program for End-of-Life Care

Presented by
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*Hospice Care, Inc. is an affiliate of
the Visiting Nurse Association of Boston Foundation*

Program Description

A summary of the efforts of Hospice Care, Inc. and the Massachusetts Department of Mental Retardation (DMR) in building a relationship to provide EoL care for underserved individuals.

Goals of the Program

- Describe Hospice Care.
- Describe the tools necessary to develop the relationship.
- Discuss how to overcome regulatory restrictions.
- Discuss a disease trajectory and end-of-life care issues for challenged individuals.
- Discuss how Hospice can help.

What is Hospice Care?

Care that enhances the quality of life, providing comprehensive, multi-disciplinary services to those individuals and families facing the challenges of “life-limiting” illnesses. A health care program for individuals with terminal illness.

Availability of Hospice

Hospice care is available in:

- Individual Homes
- Long Term Care facilities
- Hospitals
- Assisted Living Facilities
- Group Homes/Residences
- Elderly Housing
- Homeless shelters

Availability of Hospice

The Hospice Benefit is available through the federally funded programs of Medicare and Medicaid, as well as most commercial insurance companies. Those with no insurance may qualify for free care.

Eligibility for Hospice

- Goal of care is palliative, not curative.
- All ages.
- All diagnoses.
- Criteria: MD certifies that the patient has a life-limiting illness with a prognosis of 6 months or less, if the disease process runs its normal course.

Hospice: Levels of Care

- Routine Home Care
- Continuous Care
- General Inpatient Care
- Respite Care

What is Covered by Hospice

- All services related to the terminal illness
- On-call, 24/7 triage & visit availability
- All medications related to the terminal diagnosis.
- All DME

DMR relationship building

The step-by-step process

Identification of the need for Hospice services

- Liaison contact
- individual service plan
 - case reviews
 - identification of appropriateness
- identified complexity of training para-professional group home staff

Task Force Development

- DMR representatives
- Pharmacy representative
- Hospice representatives

Task Force Education

- Mutual education regarding services provided by each agency.
 - Several task force meetings
 - DMR services education
 - Hospice services education

Identify Barriers

- Regulations regarding
 - medications
 - physician orders
 - documentation

Identify Barriers

- Level of understanding
 - DMR staff
 - Hospice staff
 - Group Home staff
 - Day Care Provider staff
 - Vendors - CEOs & EDs
 - Guardians

Identify Barriers

- DMR training requirements for
 - House Managers
 - Nursing Staff
 - Direct Caregivers

Identify Barriers

- Additional requirements/policies of vendors
 - specific to program/site/group home
 - DNR orders
 - 3 original DNR forms
 - » guardian consent
 - » renewed annually
 - home death
 - Medication Administration Program (MAP)
 - minimum requirements

Identify Barriers

- Individual beliefs/myths
 - regarding Hospice
 - Hospice hastens death
 - Must be actively dying to seek hospice care
 - Hospice is only for hopeless cases
 - Hospice is only for people with cancer
 - Hospice is only for old people
 - Hospice requires a DNR
 - Hospice is withholding treatment

Identify Barriers

- Individual beliefs/misconceptions
 - regarding DMR
 - people with MR
 - do not have feelings and emotions
 - cannot learn
 - cannot socialize
 - cannot participate in their community
 - are not affected by changes in their environment
 - do not have substance abuse problems
 - cannot have mental illness



Identify Barriers

- Having to work via DMR to introduce the hospice concept to guardians
- Funding for staffing the group home 24/7

Plan

- Develop/provide educational programs for
 - DMR staff
 - hospice: enhancing end-of-life care
 - spirituality in end-of-life care
 - grief and mourning: a normal process
 - final months of life

Plan

- Develop/provide educational programs for
 - Hospice staff
 - Overview of Mental Retardation
 - EoL Care for People with Serious Mental Disorders
 - Medication Administration Program Overview
 - DMR: Questions & Answers program
 - Down's Syndrome & Alzheimer's

Plan

- Develop/Provide educational programs for
 - Vendor CEOs and Executive Directors
 - Hospice informational seminar
 - Group Home Staff
 - Hospice education programs

Plan

- Limit the number of Hospice admissions staff for DMR clients
- DMR staff in attendance at the hospice consult/admission
- Maintain formal & informal communication
 - ongoing

Regulatory Restrictions

- **Documentation**
 - DMR
 - specific/required forms
 - Hospice
 - revisions to accommodate DMR requirements

Regulatory Restrictions

- **Physician orders**
 - must meet specific criteria of MAP
 - issues with prn medications
 - original telephone order must have MD signature within 72 hours

Example of MD Orders

- D/C all previous orders
- In the event of cardiopulmonary arrest, do not resuscitate
- O2 via mask @ 10 L continuous
- Roxanol 5 mg sl q 4 hrs
- Roxanol 5 mg sl q 2 hrs prn for pain as evidenced by attempting to remove O2 or grimacing
- Lorazepam (2mg/ml) 0.5 mg sl q4 hrs prn for anxiety & restlessness as evidenced by frequent position changing
- Levsin 0.125mg/ml, give 1 ml sl q 4 hrs prn for audible congestion
- Acetaminophen 650mg pr q 6 hrs prn for temp > 100

Regulatory Restrictions

• Medication Administration Program

- primary goal
 - ensure safe medication administration to individuals living and working in community programs
- standardized training curriculum
 - minimum 12 hour training
 - MAP approved trainer
 - direct care/support staff
 - certified - adults (18+)
 - medication certification card

Regulatory Restrictions

- Controlled Substances
 - all prescription medications: schedules 2-6
 - countable medications: schedules 2-5
 - MAP policy manual - policy # 10-3
 - » med counts by 2 licensed/certified staff
 - » count at start/end of every shift
 - » 2 person count - minimum every 24 hours
 - » schedule 2-5 meds - must be double locked
 - » any count discrepancy must be reported
 - » count sheets - maintained in bound book
 - » all schedule 2-5 meds - marked as such by pharmacy

Regulatory Restrictions

- PRN Medications
 - specific target signs/symptoms written in orders
 - if unclear, must clarify
 - additional documentation required explaining reason for use and effectiveness
 - MAP policy manual - policy # 06-2
 - » MD orders must have specific target symptoms & instructions for their use
 - » if orders unclear, consultant must be contacted
 - » requires additional documentation

Regulatory Restrictions

- OTC Medications
 - must have MD order
 - administered, stored & documented same as prescription medications
 - must have label same as prescription medications

Regulatory Restrictions

- Four stock medications allowed
 - MOM
 - regular strength acetaminophen
 - Kaopectate
 - Guaifenesin (Robitussin)
- must provide training on use of stock labels

Regulatory Restrictions

- Direct Authorization
 - MAP does not follow a nurse delegation model
 - an RN may not:
 - delegate, supervise, assign or allow certified staff to administer medications to clients "for whose direct care the nurse is responsible"
 - recommend that a medication dose be adjusted, i.e., increased, decreased, omitted or repeated
 - medication certified staff
 - are independent
 - are supervised by a non-nurse

Regulatory Restrictions

- RN role within the Direct Authorization Model
 - serve as MAP consultants
 - serve as trainer and on-going educator
 - provider of technical assistance about medication systems
- MAP consultant
 - RN, Pharmacist, Licensed Practitioner
 - staff must have 24/7 access to
 - must be contacted for all medication occurrences

Regulatory Restrictions

- Packaging/Labeling of medications
- 'starter kit'
 - MD order
 - identify contents
 - specific target symptoms & instructions

Medical Issues

- MR individuals now have a life expectancy approaching 'normal'.
 - due in part to improved living conditions
 - due to improved medical knowledge
 - same risk of diseases & development of medical conditions

Medical Issues

- Mean age of death for persons with MR
 - 1930s 19 years
 - 1970s 59 years
 - 1993 66 years
- Average age for Down syndrome persons
 - 1920s 9 years
 - 1993 56 years

Jamiki, Dalton, Henderson & Davidson, 1999

How We Die, Over the Course of Life

25-35	35-44	45-54	55-64	65+
1. Accidents	1. Cancer 19%	1. Cancer 30%	1. Cancer 37%	1. Heart Disease 34%
2. Suicide	2. Accidents 17%	2. Heart Disease 23%	2. Heart Disease 23%	2. Cancer 22%
3. Homicide	3. Heart Disease 15%	3. Accidents 8%	3. Chronic Lower Respiratory 5%	3. Cerebro- vascular 8%
4. Cancer	4. Suicide	4. Cirrhosis	4. Cerebro- vascular	4. Chronic Lower Respiratory

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Medical Issues

- Medical problems are often difficult to diagnose because of limitations in capacity to communicate
 - frequently communicate by behavior
 - increased irritability
 - impulsivity
 - outbursts of aggression

Medical Issues

- Need consistent support of staff & family to recognize when changes occur

Medical Issues

- Living Longer
 - limited documentation regarding how it might manifest itself in relation to the MR population
 - research opportunities

Medical Issues

- Primary reasons for MR (in order of occurrence)
 - 1 Fetal Alcohol/Drug Syndrome
 - 2 Down Syndrome
 - 3 Fragile X Syndrome

Down Syndrome

- What is Down Syndrome
 - 2nd most common cause of MR
 - accounting for almost 15% of MR
 - associated with genetic anomaly - Trisomy 21
 - different types of Down Syndrome
 - mosaic
 - complete

Down Syndrome & Alzheimer's Disease Trajectory

- Risks of developing Alzheimer's Disease with MR (dual diagnosis)
 - Persons with MR
 - at an increased risk of AD, with incidence rates about 3 times higher than those of the general population
 - Individuals with DS
 - incidence rate - a virtual certainty

AD/DS Comparison

- General Population
 - 1 in 10 over 65
 - > 85, nearly 50%
 - very small percentage in their 40s & 50s
- Down Syndrome
 - All DS individuals exhibit neuropathology of Alzheimer's by the age of 35 !

- Alzheimer's Association, Massachusetts Chapter, www.alzma.org

AD/DS Comparison

- General Population
 - progression of AD
 - average of 8 years
- Down Syndrome
 - small group of DS individuals are dramatically affected by AD
 - following onset of symptoms
 - precipitous decline
 - loss of skills
 - death in 2-3 years

AD/DS Comparison

- General Population
 - average attention span for individuals with AD is about 20 minutes
- Down Syndrome
 - memory loss difficult to detect
 - no clear baseline for short term memory
 - 1st symptoms noticed are likely to be behavioral or personality changes

AD/DS Comparison

- General Population
 - very apparent cognitive decline
- Down Syndrome
 - cognitive decline may be present but not recognized
 - due to limitations in
 - functional ability
 - multiple caregivers

AD/DS Special Considerations

- Diagnosis & Assessment of decline in the individual with AD is complicated by MR
- Common Neurocognitive testing methods are not useful for DS individuals
- Depression can result in pseudo-dementia
- Hypothyroidism, which is observed in almost 30% of DS, may simulate dementia

Other MR aging considerations

- Cardiac Disease
 - O2 at home
 - sleep apnea
- Risk Scale - anyone > 300 lbs
- Antipsychotics: lead to
 - diabetes
 - renal failure

Special Considerations

- Individuals living in a group home identify their housemates as their 'family'.
- Housemates can experience all the grief and sense of loss of a traditional family.
- Caregivers will have to assess the broader impact, particularly on housemates.

Challenges for EoL care

- Staffing
 - layers of staffing - group home - daycare
 - level of education
 - ethnically diverse
 - cultural differences in EoL care
 - culturally illiterate
- Cognitive level
 - patient
 - housemates

Additional Challenges

- Do not understand issues at hand
 - patient & housemates
- Housemates jealous of attention
 - develop attention seeking behavior
 - subtle behavior changes
 - hoarding behavior

Additional Challenges

- Managing Grief
 - Be honest, include & involve
 - listen - be there
 - actively seek out non-verbal rituals
 - respect photos & other mementos
 - minimize change
 - avoid assessment of skills
 - assist searching behavior
 - support observance of anniversaries

Additional Challenges

- People with disabilities have a right to participate fully in the grief and mourning process and in all of society's support systems and rituals associated with those losses.

Additional Challenges

- Concerted effort is needed to offer death education to professionals and caregivers.
 - might include helping caregivers rehearse breaking the news of a death

Benefits of Hospice Referrals

- Fewer crises
- Fewer Emergency Room visits
- Fewer hospitalizations
- Pain and symptoms well managed
- Decreased emotional & spiritual stress
- Increased comfort & dignity
- Increased participation in bereavement services.

Unique Features of Hospice

- Holistic, patient-centered care.
- Patient/family as unit of care.
- Interdisciplinary team approach offering medical, nursing, psychosocial and spiritual care and support.
- Bereavement care.

Unique Features of Hospice

- **“Zero tolerance” of pain and other symptoms.**
 - Updated knowledge of pharmacology.
 - Advanced treatments and interventions.
 - Understanding of underlying disease and its relationship to the dying process.
 - Close monitoring/assessment for change in condition.
 - Careful titrating of medications.

Unique Features of Hospice

Chaplain

- Spiritual assessment & support
- Link to community religious resources
- Funeral planning
- Memorial services
- Spiritual bereavement care

Unique Features of Hospice

Bereavement Coordinator

- 13 months, at no cost
- Counseling, support groups
- Correspondence, & telephone support

Additional Challenges

- Learning politically correct jargon !
 - Hospice jargon
 - DMR jargon
- Learning acronyms

When I Die



- Sometimes life is troubling, sometimes I cry
- Who will be there when I die,
- In and out of hospitals, more and more pills
- Who will protect me, I am mentally ill,
- I am afraid, it is driving me insane
- I want to be comfortable, feel no pain,
- My family is the staff, I am so confused
- Who will stop them if life sustaining treatment
- I can't be a burden or live by machine
- A tube down my throat is not so keen,
- No one seems to listen, their smiles are fake
- I pretend to be sleeping when I am awake
- Why should I wait, the fear I cannot bear
- Back in the hospital, acute care,
- I don't want to die alone with two hour checks
- I want to remain home with dignity and respect.



“You matter to the last moment of your life,
and we will do all we can,
not only to help you die peacefully,
but to live until you die.”

Dame Cicely Saunders



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MA DMR - North East Region

Web Site Resources

- www.
 - thearc.org/faqs
 - state.ma.us/dph/dcp.htm
 - state.ma.us/dmh
 - dmr.state.ma.us
 - hospicefed.org
 - nahc.org
 - nhpc.org

Web Site Resources continued

- www.
 - who.int/mental_health
 - uic.edu/orgs/
 - tigger.uic.edu/~lisab/homepage.htm
 - promotingexcellence.org/mentalillness. Html
 - nami.org
 - opportunitiesunlimited.org/ddinfo.htm
 - omr.state.ny.us/document/hp_faqsdd.jsp

Web Site Resources continued

- www.
 - nofas.org
 - alzheimers.org/pubs/homesafety.htm
 - ds-health.com
 - mhaspectsofdd.com
 - alzstore.com
 - 2.umdj.edu/forumweb/etiopic.htm

Web Site Resources continued

- www.einstein-syndrome.com/health_medical/adults.htm
- zarcrom.com/users/alzheimers/odem/ds7.html
- psychiatry.med.uwo.ca/ddp/bulletins/documents.htm
- angelfire.com/mi4/downs_dementia/CaregivingInfoIndex.html
- geriatric-resources.com/html/behavioral_pain_assessment.html
- geriatric-resources.com/html/nonverbal_behavioral_pain_scal.html

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