

*A Collaborative Approach to End of Life Care for Individuals with  
Developmental Disabilities*

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## How the Collaborative got started

- In 2003 Northeast Region Area Office nurses of DDS in Massachusetts noticed a large group of individuals were dying without the benefits of Hospice Care.
- As a general rule, most individuals were admitted to the hospital to die
- In the rare instance that individuals were cared for in their group home until they died, staff would provide great physical care, but with some difficulty due to the lack of knowledge of the dying process and lack of supports for housemates, family and staff regarding end of life care.

## Members of the Collaborative

- 5 area office nurses from Region III of DDS.
- Executive Director of a community hospice agency
- The nurse liaison of the community hospice agency
- The CEO/ owner of the Hospice agency's pharmacy, who also had a working knowledge of MAP regulations.
- And hospice clinical staff, which included the chaplain, social worker, and clinical director

## Goals of the Collaborative

- Identification of those individuals who would benefit from hospice care on an ongoing basis
- To ensure that hospice staff are comfortable with the needs of individuals with a developmental disability
- To ensure that DDS and provider staff are familiar and comfortable with hospice care
- To Create a smooth merging of the different regulations that Hospice and DDS must follow
- To standardize a process of transition to hospice care
- To monitor the use of hospice for individuals with a developmental disability and modify procedures as necessary

## Various residential settings

- Their own apartment
- With family members
- Adult foster care
- Shared living
- Group home
- Nursing home

## Video

## Projects: Trainings

- In the past five years there has been a tremendous amount sharing of information between the two agencies!
- Some of the topics included:
  - DDS overview
  - MAP ( Medication administration program)
  - Down syndrome/ aging with individual who have developmental disabilities
  - Death and dying
  - Spirituality

## Projects

- Development of glossary of terms from both hospice and DDS to be available for all agencies and limit potential communication errors (please refer to handouts)
- Example: In DDS primary care is the term used to reference the Doctor, in Hospice it is used to refer to the key care giver
- Development of the Documentation Management System
  - Known in the Northeast Region as the Hospice Book.

## Obstacles

- Fear
  - Staff
  - Family and/ or Guardians
  - Individual
- Reluctance of PCP to order hospice

## Obstacles

- Individuals might have community supports such as a PCA ( personal care attendant). This is a support covered under Medicare, and cannot continue with Hospice admission ( double billing) Their role includes duties such as ADL care, housekeeping, cooking, shopping, doctor's visits.
- Resolved:
  - Individuals with PCA hours and referred to Hospice can continue with the PCA
  - Individuals who are on hospice and apply for PCA hours will be denied

## Obstacles

- Pain Management – ongoing training is needed, usually client specific
  - Identifying unique signs and symptoms of pain; an individual might exhibit severe head banging and rocking, one might conclude that they are in pain, but with our individuals this might be normal behavior when they are happy, pain might be evidenced by nonverbal cues, self isolation into their room with an individual who usually is very social. Many are not able to verbally tell you that they are in pain.

## Obstacles

- Coordination of Care
  - In a group home setting, the provider staff usually is the primary contact with the MD and coordinates care.
  - Resolved
    - when hospice is in place a "point person" is needed to be the conduit for information to be shared with all caregivers.

## Map Policies

- DDS recognized the need to re-evaluate the current policies surrounding medication administration when hospice is involved.
- A focus group was developed in 2006 with members from DDS, DMH, DPH, Hospice, and the Massachusetts Board of Nursing.
- A addendum to the current MAP policies was developed addressing the obstacles of medication administration in a hospice setting.
- The focus group wanted to protect both the non-licensed staff member who is administering the medications as well as the Hospice nurse, ensuring that she was not delegating any nursing skills with her consultations.
- Update as of May 2007:
- Hospice policies have been approved.
  - If you wish to look at Massachusetts MAP policy on Hospice, it can be viewed on the Massachusetts DDS web site at:

[http://www.mass.gov/Eeohhs2/docs/dph/quality/drugcontrol/map\\_policy\\_manual.pdf](http://www.mass.gov/Eeohhs2/docs/dph/quality/drugcontrol/map_policy_manual.pdf)

## Obstacles

- Starter Kits ( Comfort Kits, E-Kits etc.)
- When to bring to the group home
- How to monitor/ count the medications in the kit
- How to store it according to MAP regulations
- Resolved
  - Can be delivered to group home sealed (similar to the Emergency Carts in the hospital)
  - It is counted/checked for the seal, once the seal is broken all medications within will be counted
  - It is to be double locked in the medication closet in the group home

## Comfort Kits – new obstacles

- Doctor's orders
- Kits being delivered to group home before obtaining the MAP doctor's orders.
- Training – Kits opened for training purposes, now Mock kits are available to use for training.
- Clarification of responsibilities regarding the Kit.
- Resolved:
  - In collaboration with the Hospice agency a standard doctor's order sheet was developed which met both agency's regulations.
  - This order sheet is given the MD along with the hospice prescription for the Kit. Both documents are then given to the pharmacy and the Kit along with the doctor's orders are delivered to the group home at the same time.

## Comfort Kit responsibilities

- **Contents of Sealed Comfort Care Kit ( example as the contents are different with the various agencies) :**
  - Morphine Sulfate will be 12 unit doses of 5mg each Morphine sulfate will be 10 unit doses of 10 mg each
  - **Compazine** gel one topical syringe with 6 doses
  - **Haldol** oral solution (total quantity 5ml) **Ativan** oral solution (total quantity 10ml)
  - **Hyoscyamine** oral solution (total quantity 5ml)
  - **Acetaminophen** suppository 650mg (total quantity 2 doses)
  - **Gloves**
- MAP certified staff will receive the kit and store it according to MAP regulations.
  - MAP certified staff need to count the sealed kit q shift while seal is intact.
    - ( if seal is broken then see below)
- Kit should have a name of individual and expiration date on the outside. Each Kit is good for 3 months.
- It is the responsibility of the Hospice Nurse to monitor and replace kit when it expires. The hospice nurse will dispose of the expired kit in the presence of Group Home staff and document according to Hospice Care Inc policies.
- The contents DO NOT need to be refrigerated.

- **Opened Comfort Care Kit**
- Ativan Liquid needs to be placed in count book (has oral calibrated dispenser)
- MS needs to be placed in count book.  
*\*\*\*Please note that all staff (hospice and group home) must document any use of the countable medications in the count book and appropriate medication sheet.*
- MS is the only med that needs to be unit dosed.
- \*\*\*\* ONCE KIT IS OPEN ALL TOPICALS MUST BE KEPT SEPARATE FROM ALL ORAL MEDICATIONS. \*\*\*\*\*

## Orders for Comfort Kit

- Should be reviewed by the admission nurse during initial admission meeting, to insure that all MAP requirements are met for the doctor's order. The Hospice admission nurse will then submit the orders and the prescription to the MD for signature. The MD's office will then forward the signed copies to the specific hospice pharmacy.
- Initial comfort kits will not be sent out to the group homes until the Pharmacy receives the signed doctor's orders. The pharmacy will send the order's with the kit. If the initial kit arrives without orders, the group home should notify the pharmacy and not accept the kit. (Replacement kits for expired kits do not need new orders).
- Once orders are signed, the provider agency is responsible to post and verify the orders on the med sheets.
- **Training for Comfort Care Kits:**
  - Area office nurses and Hospice staff will have available to them mock/dummy comfort kits that can be used for training.
  - **DO NOT** open the comfort kit on arrival or for training/ orientation. The kit is to be opened only for medicating the patient/ individual.

## Obstacle – Hospice Graduation

- Medicare regulations and re-certification of individuals who have been on hospice
- If improvement has been noted how do we continue supports that were originally provided by hospice and no longer meet criteria

## How to identify decline in an individual with a developmental disability

- Functional Assessment tool
- Direct care questionnaire
  - How have they changed?
    - Eating habits
    - Level of support increased
    - Ambulation/ Transfer status
    - Chronic infections
    - Recent hospitalization
    - Wound / skin breakdown.
    - Communication issues
    - Level of endurance

## Direct Care Questionnaire

- **Communication:**
  - Is it taking longer for he/she to express his wants and needs
  - Does direct care have to anticipate what he/she wants
  - Is he/she unable to use any communication tools that they had previously i.e., Communication book, sign language.
  - Are they inappropriately using the tools
  - Are they less interested in interacting with peers/staff?
  - Is there a shortened attention span?
- **Dining:**
  - Is it taking longer for them to eat?
  - Does it appear that they have forgotten how to chew/ swallow?
  - Is staff feeding them
  - Are they resistive to eating?
  - Has the diet been modified
  - Are you using more adaptive equipment to allow them to continue to be independent
  - Can they still drink, or are liquids now being spoon fed.
  - Have you changed to smaller more frequent meals?
  - Are they showing signs of being tired during meal time?
  - Are they on supplements
- **Mobility:**
  - Are they ambulating? With assist of 1 or 2
  - Are you using a gait belt?
  - Are they in a wheelchair? For how long
  - Can they transfer independently?
  - Do they need assist of staff? 1 or 2
  - Do you use a lift or assistive device for transfers?
  - Are they staying in bed longer?
  - Do they appear to be uncomfortable with transfers?

- **Cognition:**
  - Are they more confused then 6 months ago?
  - Do they recognize familiar staff?
  - Do they know what day it is? Did they ever?
  - Do they continue to participate in home activities?
- **Medical:**
  - Have they been sick?
  - Have they had any medication changes?
  - Have they stayed home from program for any reason?
  - Have they been to the hospital for any reason?
- **Sleeping:**
  - How are they sleeping?
  - Do they wake up during the night?
  - Are they sleeping during the day?
  - When are they most awake?
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## Hospice Loose Leaf Notebook

– This is where all information will be kept for an individual who is on Hospice.

- Client Info
- Doctor's orders
- Medication sheets and progress notes
- Medication information/ reference materials
- Resource information ( glossary terms etc.)
- Hospice Staff notes
- DNR information ( blank forms that are required by DDS for a DNR) Blank Health care proxy forms and care and comfort forms

DRAFT HOSPICE SHIFT REPORT Name: \_\_\_\_\_

Date:	7-3	3-11	11-7	Comments
Bowel Chart	NONE SMALL MEDIUM LARGE DIARRHEA	NONE SMALL MEDIUM LARGE DIARRHEA	NONE SMALL MEDIUM LARGE DIARRHEA	
Urine Output	TOILETED INCONTINENT CATHETER	TOILETED INCONTINENT CATHETER	TOILETED INCONTINENT CATHETER	
Mobility Status Position changed Q ____ hour	BEDREST CHAIR HOW LONG AMBULATORY	BEDREST CHAIR HOW LONG AMBULATORY	BEDREST CHAIR HOW LONG AMBULATORY	
Sleep Pattern	# OF HOURS SLEEPING	# OF HOURS SLEEPING	# OF HOURS SLEEPING	
Appetite	DRINKING YES NO EATING YES NO	DRINKING YES NO EATING YES NO	DRINKING YES NO EATING YES NO	
Pain Management	MEDICATED YES NO	MEDICATED YES NO	MEDICATED YES NO	
STAFF SIGNATURE				

## Where are we today in the Northeast Region ?

- 2002: Hospice admissions: 2
- the collaborative was started in November of 2003
- 2003: Hospice admissions: 2
- 2004: Hospice admissions: 4
- 2005: Hospice admissions: 6
- 2006: Hospice admissions : 10
- 2007: Hospice admissions: 32
- 2008: Hospice admissions: 31
- 2009: Hospice admissions: 36
- 2010: As of February 15, 2010 admissions: 5

## Question and Answers

- In Memory of video

## Resource Web Sites

- [www.DDS.state.ma.us](http://www.DDS.state.ma.us)
- [www.angelfire.com/mi4/downs\\_dementia/CaregivingIndex.html](http://www.angelfire.com/mi4/downs_dementia/CaregivingIndex.html)
- [www.denison.edu/collaborations/dsq/health99.html](http://www.denison.edu/collaborations/dsq/health99.html)
- [www.ds-health.com/](http://www.ds-health.com/)
- [www.geriatric-resources.com/html/behavioral\\_pain\\_assessment.html](http://www.geriatric-resources.com/html/behavioral_pain_assessment.html)
- [http://www.mass.gov/Eeohhs2/docs/dph/quality/drugcontrol/map\\_policy\\_manual.pdf](http://www.mass.gov/Eeohhs2/docs/dph/quality/drugcontrol/map_policy_manual.pdf)

## Resource Web Sites

- [www.psychiatry.med.uwo.ca/ddp/bulletins/documents.htm](http://www.psychiatry.med.uwo.ca/ddp/bulletins/documents.htm)
- [www.tigger.uic.edu/~lisab/homepage.htm](http://www.tigger.uic.edu/~lisab/homepage.htm)
- [www.albany.edu/aging/lastpassages/docs.htm](http://www.albany.edu/aging/lastpassages/docs.htm)

Thank You