DRAFT GUIDELINES – WORK IN PROGRESS (version 1)

END-OF-LIFE CARE OF PATIENTS WITH SERIOUS MENTAL ILLNESS

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(The authors invite your comments and ideas regarding these guidelines)

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These draft guidelines (see below) are designed to aid psychiatrists/mental health providers who care for seriously mentally ill patients provide quality end-of-life care to their patients if/when they develop terminal illnesses. The guidelines advocate allowing these patients to die in the setting most familiar to them, if they choose to. These settings can include: state-run mental health institutions, group homes, supported housing, other psychiatric settings such as VA hospitals, etc.

There are two sets of guidelines:

1. **For the care of the seriously mentally ill terminally ill person, and**
2. **For the Institution(s) providing the care.**

You are invited to contact us with comments, suggestions, and questions.

1. Proposed Guidelines for Care of the Seriously Mentally Ill Terminally Ill Person:

1. Psychiatrists/mental health providers in consultation with local hospice/palliative care providers can consider the establishment of an effective interdisciplinary team to care for the severely mentally ill terminally ill (SMITI) patient.

   Hospice/palliative care team members who are comfortable communicating with a seriously mentally ill person are either already experienced with (or may be trained to) identify issues that trigger the need for additional psychiatric involvement. The psychiatric/mental health providers may provide consultation or treatment to manage psychiatric exacerbations and proactively address risks for psychiatric emergencies.

2. Interdisciplinary teams might include the following:
   a. Hospice physician
   b. Internist with expertise in geriatric medicine
   c. Psychiatrist with expertise in geriatric psychiatry
   d. Psychologist with expertise in gerontology
   e. Nursing staff from both the hospice and mental illness treatment settings
   f. Physicians including psychiatric physicians from the community who have either expertise or an interest in the care of terminally ill patients.
   g. Conservators/guardians who act as substitute decision-makers for some seriously mentally ill patients.

h. An on-call ethicist for consultation for special cases.
i. Interfaith spiritual advisors.
j. On-call lawyers who is a specialist in elder law and who has had experience in advising families regarding end-of-life care.
k. Other persons as deemed appropriate because of interest or expertise in the care of the seriously mentally ill and/or in the care of the terminally ill patient. Such persons could come from a hospital, other institutional, community care, or other settings.

3. The team might embrace a common goal of minimizing or eliminating the transfer of SMITI patients out of settings where they have lived for months or years (such as state hospitals, residential care homes, board and care homes, other long term care settings, etc.). The team values allowing the patient (like any other person) to die in a familiar environment surrounded by those persons he/she knows best and who may represent "family" to them

4. Provide training for "in-house" physicians, psychiatrists, fellows, residents, psychologists, nurse practitioners, clinical nurse specialists, other nursing and mental health assistants, as well as other professionals such as pharmacists, social workers, occupational therapists, recreational therapists, hospital volunteers, etc., to improve competence and comfort in caring for the SMITI patient in the setting where the patient resides.

5. Highlight effective pain management and interactions of psychotropic and non-pychotropic medications (including opioids), and other medial/psychiatric developments such as confusion, delirium, depression, suicidal ideation, anxiety, agitation, psychosis, etc.

6. In the institutional or group living setting where other patients with serious psychiatric illness reside, invite all patients to participate in the process. Openly discuss the terminal nature of the patient's illness at community meetings and other patient gatherings. Support patients' wishes to help/support/do things for the dying person while providing opportunity for other patient's to express their feelings, fears, concerning the dying process.

2. General Guidelines for the Institution's providing care for patients with serious mental illness:

1. Consider developing a standing Committee on End-of-Life Care for patients with serious mental illness (see example on this web site).

2. Add in-service trainings on end-of-life care (see example curriculum on this site) for all mental health staff.

3. Develop the knowledge base and confidence among staff to effectively work with conservators, guardians, and other substitute decision makers, to gain support for

allowing the SMITI patient to remain “at home” at the facility if that is his/her expressed wish, or if the patient is unable, because of cognitive impairment, to express a wish, that a thoughtful determination be made that includes allowing the patient to remain in their current setting through the last phase of life is possible.

4. Consider developing instruments (or use materials available on this site) to document preferences for end-of-life care among all psychiatric long-term inpatients early in the course of admission. Preferences may be reviewed with the patient and/or family on a periodic basis. This allows for the patient’s choices to be available in the event that s/he becomes terminally ill.

5. Develop contracts for service provision between the long-term psychiatric facilities and local hospice providers.

6. Encourage administrators and medial directors to embrace quality care at the end of life and to support related initiatives in their respective institutions.