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Sr. Mello F.C.C., Chairman

Dr. R. Nanjunda Rao, President

From the editors desk

“When we arrive in this world, we are guided in, looked after and physically helped by an expert, a midwife. But there is no equivalent person to gently lead us out of this world, to hold you when we are departing and to make us feel safe when we crossover from Life to Death”. [Trea McNally]

As of date 2657 patients have died in Jeevodaya and we have always strived, insofar as it is possible, to ensure that they have had a pain free, peaceful and dignified ending. One of the most important need of a patient who is dying – who is leaving the world is to make them feel that they are surrounded by love and kindness. This is what we do in

this Hospice and this is that which make our patients die peacefully.

In this issue our Medical Director explores the various methods that we can practice to help not only the patient but also the family to live through and make sense of the last days and hours of the patient’s life and thereafter.

We are happy that the response to IAPC certificate courses have been tremendous, to say the least and would like to acknowledge the role of our old students who have given a tremendous feedback. Thank you!

After the terrible heat of this summer, let us all look forward to some cool and peaceful days both externally and internally.

With warm regards,

Sr. Lalitha Teresa, FCC

MANAGEMENT OF TERMINAL PHASE OF LIFE

Dr. Manjula Krishnaswamy,
Hon. Medical Director, Jeevodaya

About two decades ago ‘Terminal Care’ was loosely used to refer to care of patients whose disease was incurable. When we use the term ‘Terminal’ today, it is more specific. We mean that the end is apparent and imminent – “The patient’s condition leave no room for doubt that death will occur in a matter of days or hours”.

The memory of the last moments of a loved one remains permanently etched in the minds of the near and dear. So, it becomes imperative that wherever and whenever possible, especially in the case of anticipated death, the nurses and doctors ensure that the patient’s death is both peaceful and dignified.

In order to achieve what we term a ‘Good’ death (though some will argue whether any death can be ‘good’), at least in anticipated death, the preparation should ideally be started some time before the patient’s condition becomes critical and he/she is still in a position to comprehend and take decisions – a process which we term ‘Advance Care Planning’. The process essentially involves resetting goals in the present context and exploring the patient’s and the family’s preferences, should the patient’s condition deteriorate and also at the time of death and thereafter. In order to facilitate this, it is imperative that the professional team establish a good rapport with the patient and the family which obviously will take time. The doctor’s experience and intuition should guide him in selecting the appropriate time and place to discuss such delicate and sensitive issues and also be aware that several sittings may be needed. It is ideal for the treating physician to have a colleague and a nurse with him during these interviews with the patient and whosoever the patient nominates, so that there are no controversies at a later date.

SETTING GOALS

“When a person faces a fatal disease that is likely incurable, he or she faces specific decisions not only about medical treatment but also about broader, existential issues concerning the best way in which to spend his or her remaining time.”(Hammes, Bottner et al. 1998) Some examples of areas to be explored are the level of understanding of his illness and his expectation from the treatment, his fears and hopes, things that he generally enjoys in life, his hopes and plans for his family, special events he is looking forward to, his religious and spiritual beliefs. At some later date, if and when the patient and the family have accepted the inevitable, it is time to explore further and get an insight into their preferences such as place of death, continuing treatments to prolong life vs futility, DNR (do not resuscitate orders), nominating a proxy in the event of the patient losing consciousness, religious procedures to be followed if any, funeral arrangements and organ donation. Some call this a ‘living will’ though it is not a legal document. The purpose of this exercise is not only to make sure, as far as it is possible, to honour the patient’s wishes but also to make sure that there is no conflict among the parties concerned.

WHEN DEATH IS IMMINENT

The patient is

- ◆ Profoundly weak
- ◆ Essentially bed bound
- ◆ Drowsy for extended periods
- ◆ Disoriented to time with severely limited attention span
- ◆ Increasingly uninterested in food and fluid
- ◆ Finding it difficult to swallow medicine

AT THIS TIME

Goals have to be redefined

Discontinue certain treatments and initiate new measures for existing symptoms may worsen or new symptoms may arise

MANAGEMENT is the SAME

whatever the cause of the terminal illness.

ENSURE that the DIGNITY of the patient is maintained at all times

TELLING THE PATIENT

- ◆ Seldom necessary (the patient knows)
- ◆ When will it be over? (the long suffering patient)
- ◆ It is all right to let go (the fighting patient)

TELLING THE RELATIVES

- ◆ Even when apparent, relatives have to be informed
- ◆ Allows all those important to stay near
- ◆ Prepares them for death
- ◆ Gives them the opportunity to say farewell

Since it is not possible to predict exact time of death, relatively wide time limits have to be given. ***“Anything can happen at any time”***

SUPPORTING THE FAMILY

“The patient needs the family, the family needs us”

The family

- ◆ Must be told of the importance of their contribution to the care
- ◆ Must be made to feel they are helping and not intruding (even in a hospital)
- ◆ Must be encouraged to stay with the patient
- ◆ Must be encouraged to talk to the patient (even if unconscious)
- ◆ Must be encouraged to hold the patient
- ◆ If they find it too painful – reassurance that it is all right to leave
- ◆ The family remembers the last days and the last hours very vividly” hence it is important

To give explanation (to avoid misunderstanding or misinterpretation) e.g. noisy breathing is difficult breathing, Grunting does not imply distress

- ◆ They should be allowed to interact with the staff and give vent to their feelings
- ◆ They should be given support & offer of help in making arrangements

We have **NO RIGHT OR DUTY, LEGAL OR ETHICAL** to prescribe a **LINGERING DEATH**

“The therapeutic triad”

- ◆ Empathy
- ◆ Warmth
- ◆ Genuineness

“Patients expect this from family and professional carers, the family from the carers”

MANAGEMENT OF TERMINAL EVENTS

Requires

- ◆ Anticipation
- ◆ Preparation
- ◆ Facing the event
- ◆ Bereavement
- ◆ Assessment and management of the patho-physiologic changes of dying

WEAKNESS / FATIGUE

- ◆ Decreased ability to move
- ◆ Joint position fatigue
- ◆ Increased risk of pressure ulcers
- ◆ Increased need for care - activities of daily living, turning, movement, massage

DECREASING APPETITE / FOOD INTAKE

- ◆ Fears of the family: “giving in,” starvation
- ◆ Reminders
 - It must be explained to the family that
 - food may be nauseating
 - anorexia may be protective
 - there is a risk of aspiration
 - clenched teeth express desires, control
- ◆ Help family find alternative ways to care

DECREASING FLUID INTAKE

- ◆ Fears of family: dehydration, thirst
- ◆ Remind families, caregivers
 - dehydration does not cause distress
- ◆ Dehydration may be protective

“Decreased pulmonary secretions - less coughing, congestion, choking

“Decreased GI secretions – less vomiting,

- ◆ Decreased tumour oedema – less pain,
- ◆ Parenteral fluids may be harmful because it can cause
 - fluid overload, breathlessness, cough, secretions
 - IV line tends to act as a barrier between patient and family

PAIN

- ◆ Fear of increased pain – both by patient and family
- ◆ Assessment of the unconscious patient

- persistent vs fleeting expression
- grimace or physiologic signs
- incident vs rest pain
- distinction from terminal delirium
- Management
 - Analgesic requirement may **increase, decrease or remain the same**
 - Do not discontinue morphine even if unconscious - “Reduce to 1/3rd dose (to prevent withdrawal symptoms)
 - **When no urine output** -stop routine dosing, infusions of morphine and introduce breakthrough dosing as needed (prn)
 - Limit to essential medications
 - Choose less invasive route of administration buccal mucosal or oral first, then consider rectal, subcutaneous, intravenous rarely, intramuscular- almost never

NEUROLOGIC DYSFUNCTION

- ◆ Decreasing level of consciousness
- ◆ Terminal delirium
- ◆ Changes in respiration
- ◆ Loss of ability to swallow, *sphincter control*

COMMUNICATION WITH THE UNCONSCIOUS PATIENT

Assume patient can hear everything

- ◆ Create familiar environment
- ◆ Include in conversations
- ◆ Give permission to die
- ◆ Assure of presence, safety

TOUCH - THE MOST IMPORTANT TOOL RESTLESSNESS

Common causes

- Physical discomfort – e.g. unrelieved pain,
- distended bladder or rectum, dyspnoea, nausea, pruritis, cerebral anoxia, drug (benzodiazepines) withdrawal, steroids
- Calming presence of relatives, holding hands, talking will help in calming down the patient
- midazolam drug of choice

CHANGES IN RESPIRATION

Altered breathing patterns

- diminishing tidal volume
- apnea
- Cheyne-Stokes respirations
- accessory muscle use
- last reflex breaths

Fears

- suffocation

Management

- family support
- oxygen may prolong dying process
- Breathlessness
- Loss of gag reflex
- Buildup of saliva, secretions (death rattle)

Management

- scopolamine to dry secretions
- postural drainage
- positioning suctioning

TERMINAL DELIRIUM

- The difficult road to death
- Medical management
- Benzodiazepines, lorazepam, midazolam, neuroleptics, haloperidol, chlorpromaz
- Family needs support, education

WHEN EXPECTED DEATH OCCURS

- ◆ Care shifts from patient to family / caregivers
- ◆ Different loss for everyone
- ◆ Invite those not present to bedside Take time to witness what has happened
- ◆ Create a peaceful, accessible environment
- ◆ Assess acute grief reactions
- ◆ Prepare the body
- ◆ Help with choice of funeral service providers
- ◆ Help with shifting the body
- ◆ Ensure family presence and involvement


- ◆ Notify other physicians, caregivers of the death
- ◆ Secure valuables with executor
- ◆ Dispose of medications, biologic wastes

BEREAVEMENT CARE

- ◆ Attendance at funeral
- ◆ Follow up to assess grief reactions, provide support
- ◆ Assistance with practical matters
- ◆ redeem insurance
- ◆ will, financial obligations, estate closure

BE AWARE OF CULTURAL AND RELIGIOUS BELIEFS IN MATTERS CONCERNING DEATH.

“Death, according to the dictionary, is the end of life, the permanent paralysis of the body’s vital functions, like breathing, brain activity, blood flow to and from the heart. The definition changes when it comes to religions: for some, death means moving to a higher state, while others believe that it is merely a temporary condition and that the soul inhabiting the body will return later on, either to pay for its sins or to enjoy in the next life the blessings denied it during the present incarnation”. (Paulo Coelho)



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