FACING DEATH: DISCOVERING LIFE!

Can we strengthen our response?

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Death affects each of us regardless of who we are and where we live. Yet, we differ in our perception of death, in our observance of the rituals surrounding death and dying and how we interpret the last phase of life. This issue of Contact, looks at the different perspectives about death and dying — in contexts as different as Uganda, India, the United Kingdom and Kenya.

Though death and dying are very sensitive topics that touch our innermost feelings, they are rarely discussed and often dealt with only by our unconscious mind. It is not easy to address “death” in a universally acceptable way, perhaps because it has become a “taboo” topic and we avoid discussing taboos, just as we avoid facing important truths or unpleasant news.

I believe that whoever reads this Contact issue will be truly blessed precisely because he or she is confronted with a taboo. Overcoming this taboo may help us in our professional and private lives. We can grow spiritually by experiencing that God with his healing and loving care is present whenever and wherever we see hopelessness and death.

Few cultures need this healing more urgently than my own. In the western industrialized countries, dying has become an individual and sometimes very lonely affair. People find it difficult to cope with the fact of being mortal and fail to integrate the issue of death into the life of families and communities. Most people are dying in hospitals separated from their families and loved ones. Doctors and nurses are not trained to deal adequately with the fact that life is fragile and finite. That health professionals perceive death as a defeat of their professional effort does not encourage open and honest relationships with patients who are in the last stages of life.

What we urgently need is a new culture that regards dying as a very natural part of life itself and helps health professionals to find a new role in a healing and caring relationship with their patients. Their job does not end when a cure can no longer be hoped for. On the contrary, looking after the needs of dying patients and being with them is one of the essential tasks of a healing profession. This perspective of the interrelationship of life and death is reflected in many biblical stories and the Bible study based on Romans 14 will help us to recognize that both life and death originate from and are directed towards God.

In this issue of Contact, we hear about an excellent example of hospice care in Uganda and we learn about funeral rites in Kenya.

Mary Grenough, in her contribution based on personal experiences with illness and dying in different cultures, challenges us in many ways.

Peter Bellamy who worked closely with the former Christian Medical Commission for many years takes up many of the burning issues, with a particular emphasis on his own country, the United Kingdom. It was here that the modern hospice movement was founded by Dame Cicely Saunders (see Contact No. 122, 1991). From these early days the hospice movement has spread to many countries and helped so many patients all over the world to find a place where their physical, mental and spiritual needs are taken care of and where they can die in dignity and peace. The original concept has been adapted in countless ways but the ultimate goal remains the same and is a challenge to all of us: to come to terms with our own feelings about death and dying and to help those who are about to start their last journey.

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HOPE IN THE FACE OF DEATH

Veronica A Moss, medical director of the Mildmay Centre in Kampala is concerned about improving the quality of life for the dying. She describes the initiatives to allow persons to die with dignity and to support families through the time of bereavement.

Physiotherapy session in progress, at the Noah’s Ark Children’s Centre.

The increasing numbers of individuals dying due to cancer, AIDS and other terminal conditions has brought palliative care into sharp focus. Families may not spend money on someone who is dying. Poverty prevents patients from accessing hospital care. Lack of resources affects hospitals as well as individuals. Patients are often sent home with the instruction, “Take him home. There is nothing more that we can do.” This creates a situation of hopelessness and powerlessness in the patient, family and health care workers. These patients are often left to deteriorate and die with little effort to provide terminal care or family support.

The Mildmay Centre: a practical response

In 1993, the Ugandan Ministry of Health, invited Mildmay International to set up a palliative care service for people with AIDS. Many Ugandans had also experienced the specialist palliative care services offered at the Mildmay Mission Hospital.

Mildmay International immediately convened a local steering committee consisting of representatives of reputable organizations and government bodies already working with people with HIV/AIDS in Uganda. The committee included individuals who were themselves HIV-positive. A joint project between the Ministry of Health, DFID (Department of International Health, UK) and Mildmay International, was developed with an additional grant from the World Bank for equipment.

What does the Mildmay Centre offer?

The Mildmay Centre through its...
What can we do to improve the quality of lives of those who are dying?

Palliative care
The WHO defines palliative care as “the total active care of a person with a progressive illness which is not responsive to curative treatment”. Palliative care emphasizes quality of life and provides care through a multi-disciplinary team that addresses physical, social, emotional and spiritual needs. Palliative care also offers terminal care, with support for the family, both before and after bereavement.

Cost effective palliative care services
Cost effective and compassionate palliative care services would include community-based services and rehabilitation in resource-poor settings to care for those who are chronically ill. Lack of community-based services place greater burdens on the few carers and leaves a growing number of the chronically ill to die without simple interventions that would improve the quality of their lives. The carers’ ability to earn an income will decrease as increasing numbers of individuals become dependant on carers for their daily needs. Community-based care could ensure that many people who are chronically ill could begin to care for themselves or live independently, at least for a period.

Criteria for success
- communities taking responsibility for supporting patients and their families
- practical training for relevant personnel
- sensitizing health care planners at higher levels in the ministries of health

Terminal Care
Terminal care is offered in the final week or weeks of life to provide continuing pain and symptom control, to support the patient and family emotionally and spiritually, and to enable the patient to die with dignity, and in physical and spiritual comfort.

It is often difficult to provide terminal care in a hospital, with staff having little time to give individuals and families. In some countries terminal care for patients with cancer is often provided in hospices, which offer inpatient, day care and home care facilities. In other countries, the emphasis tends to be on home-based care.

Rehabilitation
Health care professionals often give patients with AIDS the feeling that once they have lost a significant amount of weight, or have had a number of serious opportunistic infections, and become weak, there is little that can be done to help them. They are then taken home to their villages, waiting to die while the family or carers look after them. Many of these patients could in fact be enabled, through appropriate symptom control, prophylaxis and management of opportunistic infections, physiotherapy, massage (with or without aromatherapy) nutritional advice and occupational therapy, to regain strength and independence.

Training
Nurses, counsellors, community health workers and doctors, especially in the rural health centres and district hospitals, can be trained to be multi-skilled, to use palliative, wholistic and rehabilitative approach to care. Volunteers and community workers can be trained to recognize and provide care for patients with chronic illness or disability. Family members can be trained to provide basic nursing care, prepare nutritious food for those who have swallowing or eating difficulties, and how to cope with disturbed or difficult behaviour.

Care in the home
Inevitably, much of the care for chronically ill, disabled and dying patients falls on the family members who may be unwell themselves, or may only be children, who should under normal circumstances be at school. Community facilities such as churches can be used to provide cost-effective day care, counselling and pastoral care. Churches and congregations can help and support carers emotionally and physically.
Helping Carers to Cope

Families, partners and friends who care for the sick and the dying need support. Carers may feel reluctant to talk about the problems they are facing and fear being judged an inadequate carer. They may not want to put their needs before those of the patient. They may believe that problems are unavoidable and cannot be resolved. In this situation health workers can:

- teach simple nursing techniques and provide counselling and help carers deal with their feelings of isolation, anxiety or guilt during the care and after death.
- encourage carers to plan their care, keep simple records of medications to share their work with others.
- help carers get enough rest, and nutrition
- help carers talk with a friend, relative or trusted health worker
- start a support group for carers or enable carers to join support groups for their mental and spiritual wellbeing.

Health workers must continue caring for the carer beyond the period of illness and after death, so that the carer can come to terms with his or her own pain, feelings of loss and sometimes, their sense of guilt.

Bereavement support

Families and friends of those who are terminally or chronically ill often have very little social support. They may have become isolated while the person was very sick. Bereavement support should be available before the person dies, and for as long afterwards as families and friends need it.

Different people react to death in different ways, and need different types of support. It can take months or years to come to terms with loss. People’s response may be affected by the way the person died — whether they were alone and in pain, or whether they died peacefully surrounded by those they loved. Those left behind may blame themselves if they feel that things could have been done better.

Bereavement counselling can give people an opportunity to talk about events leading up to the death, about the death itself and rituals immediately after the death.
INTRODUCTION

Churches can provide cost-effective day care, counselling and pastoral care.

The design of Mildmay Centre, is simple, but striking and effective for its purpose of providing outpatient palliative care and rehabilitation services for people with HIV/AIDS-related problems.

Out-patient palliative care services, emphasizes improving the quality of life for all who come to the centre — through treating opportunistic infections, good pain and symptom-control, and rehabilitation. The inter-disciplinary team consists of doctors, nurses, physiotherapist, occupational therapist and nutritional advisor. There are facilities for counselling, pastoral care and a children’s centre.

The Mildmay Centre also offers support to the families and carers, through individual or family counselling, and through workshops for carers. The Mildmay Centre runs monthly workshops for carers where they can meet with others with similar burdens, have some training in basic nursing care and have an opportunity to ask questions, and share with each other or with the facilitators some of their anxieties or frustrations.

Florence: A story of rehabilitation

Florence is 11 years old. When we first saw her, she was too weak to sit up for more than a few minutes at a time. Her hair was thin, her skin was itchy with a widespread rash, and she could not tolerate more than a few mouthfuls of food at a time.

When she first came, Florence was thoroughly assessed by the nursing and medical team, and investigations were started to enable appropriate treatment of possible opportunistic infections to be instituted. Her nutritional status was also assessed, and a gradually increasing feeding plan was started. Found to have tuberculosis, she was started on anti-TB medication. The Centre’s physiotherapist took her through graduated exercises to strengthen her. The staff in The Noah’s Ark Children’s Centre helped her to express some of her feelings around the difficult situation she was in and the bereavements she had experienced in her short life. Being with trained and caring staff who listened to her, with empathy and understanding, enabled her to begin to deal with her losses and the loss of a future.

Conclusion

When the time comes to die, there is much that can be done to relieve suffering and pain, to allow the person to die in comfort and with dignity, and to support and help the family through their time of bereavement.

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DEATH AND DYING IN DIFFERENT CULTURES:
“LIVING ONE’S DYING”

Sr. Mary Grenough, a Maryknoll sister who works with the Council for Health and Development in the Philippines, says that when addressing prolonged sickness and dying, we need to heal, comfort and support when we cannot heal, and always to find its meaning.

Seventeen years ago I was diagnosed with cancer (non-Hodgkin’s malignant lymphoma) and had my own personal “school of dying” through the initial diagnosis, one year of therapy, three years recuperating from the therapy, and the very conscious daily awareness of the disease for about 10 years after the first diagnosis.

In industrialized cultures
In cultures shaped by industrialization, sickness and death are often seen as the enemy. Medical practitioners try to kill supposed causes of sickness. In cases of life-threatening conditions, like cancer and AIDS, the major focus is on becoming a “survivor”. Success is often equated with surviving and the measure of success is usually in terms of “how long one survives” not “how one survives”. People are often made into objects — bodies to be worked on, tumours to be attacked, and workers to be replaced when they can no longer fulfil the corporation’s needs. When patients are in intensive care units or are dying, their family or loved ones cannot stay close to them, touch them or talk to them. Few dare to open conversations that might lead dying persons to ask the really important questions, “What is my situation? Can I recover? Am I dying?”

In a study done in the United States, in 80% of the 9,105 patients the physicians did not understand whether their patients wanted to be resuscitated if their hearts stopped, and failed to routinely monitor patients’ pain. Few are taught how to help patients and their loved ones live their dying. An American Medical Association study (1993-94), reported that only five of the nation’s 126 medical schools offered a separate required course in care of the dying. Medical technologies too often intensify the pain and prolong the dying. When death does occur, too often both the patient and the doctor feel that they have failed in this all important test.

In primal cultures
In indigenous communities and marginalized rural-agrarian groups parents and elders teach children from their earliest years that death is a natural

In every culture and social class, relationships of caring, concern and love help reveal the meaning in life, even in suffering and death.
CULTURE

A woman grieving for her husband who had died of AIDS.

Many strongly believe at the time of serious sickness and death, the ancestors are calling for the person to come and join them. When there is uncertainty about the nature or cause of the sickness, elders or shamans are called to perform rituals to discover the answers. If the indications point to death, the family and whole village gather to pray, to help the person become ready to die. They are not paralysed by unknowing or fear; they have a strong sense of security and continuity of life. If the signs do not indicate that the person will die, they pray for recovery. If signs indicate the cause of the sickness to be that the gods or spirits have been offended then rituals and activities are done to appease the spirits.

Under ordinary circumstances, family and extended family surround the sick and dying. The sick and the dying are rarely left alone. They are stroked, massaged, sung to, talked with and prayed for. Caring and loving connectedness are demonstrated in tangible, creative ways. In some tribes, a “blanket for the journey” is given while the person is dying, so that when she or he dies, the blanket will provide warmth and security for the person after death. Food is offered “for the trip”.

It has been known since ancient times by people who practise therapeutic massage that the body has as much to communicate to the spirit, as the spirit communicates to the body. The healing power of loving massage is only recently being rediscovered by people of advanced technological cultures.

Meaning in life

With the “globalization” of HIV/AIDS and the widening spread of cancer, both the rich and the poor experience prolonged sickness and dying for which even the best and most modern technology has no cure. We need to tap all our human capacities — to heal if we can, to comfort and support when we cannot, and always to find meaning in the experience and to acknowledge our connectedness with and need for each other. All people, whether rich and poor, instinctively crave for meaning. The ultimate danger and suffering is for a person to lose touch with the “meaning of his/her life” — to experience meaninglessness. With meaning, we can endure and cope. Without meaning, we have neither energy nor direction to do either.

Discovering truth beyond the mind

How do we find meaning? The meaning is in life experiences, in death experiences, in the questions that emerge within us through these experiences. For some terminally ill people, their conscious striving to discover their fears, to confront what is holding them back from entering more freely into life’s processes is becoming their best teacher. Facing facts as well as fears, they “awaken” and live more fully as they learn to die, as they learn to let go of their fears and isolation. As their bodies get weaker, they lose the

Death is mysterious and truly sacred. It is probably our best teacher of wholesome spirituality.
illusions that blocked them from experiencing their original nature. They begin to discover truth beyond the intellect. They begin to experience what unites us all as One, and unites us with all of creation.

**Who we are, is all that we have**

Even in suffering and death, relationships of caring, concern and love help reveal meaning in life. We find meaning when we experience love — when we give and receive love.

**How can we do better at helping people die?**

- We need to revere life, in all its stages, including the stage of dying.
- We need to learn to listen to our hearts — to hear one another’s hearts.
- We need to learn compassion and find reasons for hope for ourselves, for our dying loved ones, and for those who are so alone.

To the extent that technological advancement and consumer values have alienated people from their life sources, and life from death — there is need for a cultural revolution around the issue of death and dying. We need to re-invent the experience of death and discover that there are **good ways to die** and bad ways to die. Families and health care practitioners need to recognize that assisting people to die well is a vital goal of good health care.

**The “present” is a gift**

In all cultures, there are people who seem to know and appreciate their past and their history and who have learned to accept and to live their present as gift. Many people learn to live the present as “gift”, only when they discover that their present is challenged by death. Those who live the present as gift, seem to be able to leave room in their unknown future for mystery. Death is mysterious and truly sacred. It is probably our best teacher of wholesome spirituality.

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**Funerals And Development**

Among the Luos, one of the main ethnic groups in Western Kenya, death and the rituals surrounding death are both painful and expensive. The main costs involve food, transport, mortuary charges and other miscellaneous expenses. Often burials are not immediate, and may be delayed for a week, as most funerals are held during the weekends.

As the immediate family can rarely afford the massive expenditure, the deceased person’s clan raises the funds required for the funeral. While committees, such as fundraising committee, advisory committee (to assist in fulfilling customary demands) and funeral committee (to assist in budgeting expenses) reduce the workload on the families of the bereaved, these committees, themselves can be very expensive. Coordination requires meetings, and meetings can be very expensive in terms of food, time and travel over very long distances.

There is no provision made for the family’s expenses following the funeral.

If the deceased is a male who dies without having paid dowry for his wife, or building a small grass thatched hut (*simba*) within the parents’ homestead, then the dowry has to be paid and a house built before the man can be buried. Only when the dowry is paid can the marriage be considered legal. Only a legally married woman can fulfil the cleansing rituals after the funeral. The need to build a *simba* arises as the widow is not allowed to enter anybody’s house before being ritually cleansed.

The widow will have to stay at home for three days after the burial, before the ritual cleansing can take place. Only after her hair is shaved or trimmed can she be remarried to a member of her deceased husband’s family. It is believed that if one does not fulfil these rites, then disastrous repercussions would befall the family and the individuals involved.

Costs can be decreased if people, could form welfare groups and contribute an amount towards an insurance fund within the group. In case of death the money could be used to ease the burden of fund raising.

Cultural rites could be carried out without extravagance.

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Learning to die on a daily basis means that final death will not come as a stranger to be feared. According to Peter Bellamy this life-through death experience is the authentic pattern of reality, the key to existence found in the dying and rising of Christ.

However natural and inevitable it is, our instinct for self-preservation and survival gives us a deep fear of death. Different societies have their own ways of acknowledging and managing the experience of death. In this century in western society, we have increasingly treated death as a taboo area. It has been excluded from society with most deaths occurring in hospitals rather than at home. Children are often "protected" by not being allowed to attend. For most people these services have been minimized to twenty minutes in a crematorium.

**Soul-destroying denial of death.** As people no longer give any outward sign of being in mourning, the society does not “see” those who mourn. It is comparable to the way we treat people of other ethnic backgrounds, people with AIDS, and people who are disabled. We control our inner dis-ease by organizing out of society those groups who evoke anxiety and fear in us. In denying death and the pain surrounding it, we deny life and wholeness to others, and ultimately to ourselves. In our attempt to deny death, we make it seem more powerful than life. The soul-destroying denial of death is more deadly than physical death.

Birth and death are interlinked natural events and death, sexuality and procreation are central to life. We will in our turn need to let go of life, so that that the next generation can explore what it means to be human.

**Life is full of little deaths.** The “letting go” process occurs throughout life — when we discover that we can no longer run as fast as before, when we move to a new home and community to obtain work, when we can no longer have children, or when our parents die and are no longer with us. It is necessary for the seed to fall to the ground and die, in order to give life (John 12.24). Inappropriately clinging to life may increase the quantity of life rather than the quality of life.