About Dying & Helpful Suggestions to those Visiting the Dying

Presented by:

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GRIEF AND BEREAVEMENT SUPPORT
We should never forget dying is a family affair and if not handled well, can affect members of the family for the rest of their lives.

The dying person asks of us:
• Maintain my hope
• Know what my disease is doing to me
• Know how lonely the journey is and;
• Don’t desert me

About Dying

We all know that eventually each one of us must die. It has been said that each person’s death is uniquely individual, just as each life is different from any other. However, the personal experience of dying is also influenced by factors over which the individual often has little or no control. Causes of death, prevailing social and cultural values that give meaning to life and death and attitudes and behaviour of other people, all have a decisive impact on the dying person.

Personal Needs

The personal needs of dying patients were not widely appreciated until 1969 when Elisabeth Kubler-Ross published On Death and Dying, a book based on her extensive interactions with dying patients.

Dr. Elisabeth Kubler-Ross publicised the dying patient’s need for honest caring communication from both family and staff. She also identified several stages of adjustment through which many patients progress from the time when they learn they are going to die until death occurs. She never suggested that these stages were cut and dry, so to speak. You can see a dying person experiencing denial, anger, bargaining and depression, all in a day’s living. Elisabeth Kubler-Ross wrote of acceptance, “I believe resignation is more the attitude we see as people approach their death”.

The goal of providing personalised, dignified care of the dying is often not easily obtained. Death and dying are topics that until quite recently, people in our society have tended to avoid and deny. Dying people frequently have difficulty in accepting their pending deaths and are additionally burdened by the discomfort of both symptoms and treatment as well as by a range of emotions which include despair, fear and resentment.

Emotions

Family and friends likewise experience many contradictory emotions, a desire to provide care and support is often interwoven with a wish to deny the fact of impending loss. Resentment and guilt are often felt but seldom expressed; concern with the spiritual dimensions of death alternates with anxiety of the financial costs of hospitalisation and loss of earnings.
Often medical practitioners and other health professionals, trained to regard patients in terms of diseases to be cured and death as an enemy to be conquered, experience difficulty in finding a balance between detached professionalism and personalised care.

**Should the dying person be told?**

So often I am confronted with the question as to whether the dying person should be told he/she is dying. Well, I believe, and I think most health professionals caring for the dying believe, that every dying person has both the right and the need to know his/her condition. Unless they know their chances, working through the feelings of denial and anger are denied to them and as a result they are not going to be able to progress towards a peaceful death.

Just because a patient has not been told he/she is dying does not mean he doesn’t know. Many patients possess a peculiar insight, particularly when they are dying, which enables them to assess the reality of their illness. So we only kid ourselves if we believe a patient who is dying does not know what is happening to him. It has been said that patients appreciate the gentle truth. Kubler-Ross said, “Never tell a patient outright that he is drying,” that is very brutal. Rather tell him of the serious nature of the illness and then give hope by telling of the possibility of improving the quality of life and the treatment that will be given to ensure the quality of life for the remaining days.

The main point is, let the dying person bring up the issue of death and dying when he or she is ready. When the dying person does begin to talk of death, don’t play games or try to deny how sick he/she is. Just say what feels right at the moment. Above all, if you show you care, the dying person can see your willingness to help and your humanness and will accept this.

**Loss of Identity**

Human care of the dying is also complicated by the setting in which it occurs; general hospitals may be excellent places for restoring health, saving lives and conducting research but they are often seen as bewildering, mechanical and impersonal by patients and their visitors. The personal needs and preferences of the dying person must fit in to the policies and procedures of a large bureaucratic organisation. People can become numbers on a computer and are often hooked up to feeding tubes, catheters and machines that monitor their vital signs. It is little wonder that they are inclined to feel a loss of individual identity. Moreover, the efforts of the medical staff, particularly the nursing personnel, who attend the patients on eight hour shifts, providing personalised care can be hampered by the exigencies of hospital routine. A heavy work load can preclude spending sufficient time with a dying person to become familiar with his or her individual feelings and fears.
If we are acting as caretakers we also need to be aware that we become the new family to the dying person and must protect ourselves against becoming over involved with a person who will die. As a nurse, to experience too much grief as a result of personal involvement with one particular dying person and his/her family, could impair effective care of others.

Largely as a result of such problems, several alternative settings have emerged for the care of the dying, including the modern hospice. This may be a freestanding model, a palliative care ward in a general hospital with special staff and home care for dying persons, supervised by hospital based medical staff and palliative care nurses.

The whole approach of the modern hospice was born out of (and set to remedy) the negative experience of the typical hospital death. Modern hospice care begins with the question, what does this dying person and the family need, and then, with competence and compassion, endeavours to meet those needs and then give the dying person the control over their dying, allowing them to live until they die. This means maintaining real life as long as possible, ensuring the dying person is alert and comfortable, capable of enjoying family and surroundings, not desensitised by pain and anxiety.

**Pain**

Dr. Cicely Saunders describes the pain of the dying person as total pain and as having five faces: physical, mental, spiritual, interpersonal and financial. Much of this total pain is tied up with the dying person’s family and loved ones, their interactions with each other and their reactions to the approaching death. It is very easy in focusing on the needs of a dying person to overlook those of the person’s family. I know from my involvement with hundreds of terminal cases over the years at Mount Carmel Hospital, many families do less well with loved ones when they are dying than when they were in good health. The toll they subsequently pay in guilt, depression and despair, can be high. Since my day to day work with the terminal patient, I always have my eye on two things, first, the dying person’s comfort; second, how the family is reacting. A dying person needs all the emotional support the family and loved ones can give.

**Expressions of Love**

People who are close to death in terms of being in the terminal stage of their disease are capable of dying at any moment so there must be an expression of care and love as soon and as early as possible. We need sometimes to ask forgiveness or say I forgive you. Dying can be a time of reconciliation between parents and children, a time when families forgive a lifetime of hurts and experience unconditional love, perhaps for the first time in a lifetime of living together.
Anticipatory Grief

The family of the terminal patient may go through the mourning cycle prematurely and write the dying person off before they are dead. Thereafter, they react in a cold and distant fashion because they do not want to reopen a painful chapter that in their minds has been closed. If you see this development, you should caution relatives against burying the patient while he or she is still alive because this person needs their emotional support to the end.

Often relatives when faced with the impending death of a loved one will pretend it is not happening. This denial that a loved one is dying is hard to deal with, but it is important to try because of the immense burden of guilt the survivor will feel later. Friends react in the same way. Rather than risking saying the wrong thing, many friends fail to visit and when they do, can say little or nothing. There are then long silences between old friends and loved ones punctuated by nervous banalities. None of us has been taught what to say to a dying person or how to confront death. Talking about the weather, the football and the TV programs is easier, but we must ask ourselves are we truly meeting the dying person’s needs? Are we trying to control the atmosphere with ordinary conversation about a world they dying person feels less and less a part of? By just “being there”, listening to what a dying person is saying we learn much about death and dying. We learn each person and each death is unique.

What to Say

Talk to the dying person as you would a friend. Relate person to person. Don’t be afraid to show your humorous as well as your serious side.

Hear what the dying person is saying but also what he is not saying. Use your mind, heart, eyes and ears to listen. Recognise that people and families have long standing patterns of communication and means of coping with stress. Attempting to interrupt or change their usual patterns will just increase the stress.

Respond to concerns with compassionate honesty. If you don’t know the answer, just say so. Often people are interested in what you think or feel about a situation.

Appreciate the dying person’s need for privacy. Never force communication. You must develop the ability and sensitivity to know when a silent and noncommunicative person is ready to talk.

Talk about the ‘here and now’ at first. Let the dying person bring up the subject of his dying, the future, or his personal life. They will do this with such statements:

“Why won’t my family talk about my dying?”
“I’m afraid of the unknown – what does happen after death?”
“I’m so tired, I don’t want to live like this.”
“I don’t want to upset my family, but I think my death will be a relief.”
Don’t share your personal problems spontaneously. Be willing to expose some of your uncertainties, fears and vulnerabilities. You will gain insight into your own feelings; in sharing your humanness with a dying person you might better understand what it is like to be dying.

When working with families I advise them to treat the dying person not very much differently than they did before the illness. I advise them to tell them if they make unreasonable demands and even to argue with them. It is even okay to get mad and lose your temper. I tell people to do all the things as far as possible, that they did before the personal was terminally ill. Dying is painful enough without the patient being handled as though they were already dead.

**Loneliness**

There is nothing better for a dying person or his family than involving him in his care. One of the things a patient suffers from most is loneliness and that these feelings of isolation along with the symptoms of insomnia, weakness, agitation and depression that accompany the process of dying, are frequently relieved when a close relative or friend is in close communication. The family needs to be involved in the treatment physically, as well as emotionally. Basic nursing procedures are easily learned and lovingly carried out. Many family members can be taught basic relaxation techniques as well as therapeutic massage and acupressure for the relief of symptoms. This helps with pain and anxiety and is very therapeutic for the relative as well as for the patient.

**A Dying Child**

Special mention should be made of the unique circumstances surrounding the dying child. The death of a child in modern society is tragic and untimely. Since the turn of the century, mortality in infancy and childhood has declined significantly. When a child dies today, either as the result of an accident or a fatal disease, the persons involved are often surprised and shocked as well as hurt although many of the problems involving the dying child are similar to those faced by adults, the dying child faces additional difficulties.

The death of an elderly person at least contains an element of timeliness. The person has lived a long life and death is appropriate and normal. The terminally ill child on the other hand is facing death at a very inappropriate time in life. The untimely death offends our values and sense of meaning. The older person facing death can look back on a lifetime of experience where as the dying child must face the premature termination of a future. The sense of wrongess can create additional anger and resentment both for the child and for those who care for him or her. The dying adult moreover, can understand the nature of the disease and treatments, if the medical staff are open and communicative.
The child however, has a limited ability to make sense of what is happening. It becomes very important that the child be surrounded by people who can make the times to discuss and explain everything possible at their level of comprehension. Family and caregivers must be extremely sensitive to the child’s unspoken needs as well.

What is a Hospice / Palliative Care?

   Not everyone is able to die at home. The cause of the disease and the family situation will make nursing by loved ones at home impossible. At this time the doctor may suggest transfer to a hospice or palliative care unit.

   When cure is no longer the aim, the hospice or palliative care philosophy brings a new dimension of care.

   Hospice begins with the question: What does this dying person and their family need? And then, with competence and compassion, endeavours to meet these needs, and give the dying person control over their dying, allowing them to live until they die.

   Modern hospice, or the palliative care movement, is a recent phenomenon. It is devoted to the care and happiness of dying persons and to the emotional wellbeing of their families. Primarily it is concerned with persons dying with advanced cancer or HIV/AIDS, some children and those in the prime of their life.

   Hospice is the quality of life and for the dying this means maintaining real life as long as possible, ensuring that the patient is alert and comfortable, capable of enjoying family and surroundlings, not desensitised by pain and anxiety. Quality of life includes observing the sunrise from an open window, listening to the birds, smelling the flowers, holding a baby, watching the joy of your family at Christmas, talking walks in the garden with loved ones or alone, reading, creating with mind and/or hands, enjoying the infinite activities of an active life.

    Hospice is love in action,
    A journey of faith and trust.
    Hospice is seeing the invisible
    And doing the impossible.
Effective Ways of Helping the Frail Aged, the Sick and the Terminally Ill Being Cared for at Home

When you want to help someone who is being cared for at home, the following suggestions will help you to be more effective:

• Always telephone before you call in to visit or bring food. Then be punctual about arriving when you said you would. The patient may be waiting for your arrival and departure to bathe, take pain relief medication or to have a meal. Usually a short visit, say 20 minutes is best unless you are asked to sit with them. Also come to listen – don’t bring your own worries.

• Taking food is a wonderful act of love and concern. Usually most caregivers are so busy caring they find that time and energy is in short supply for food preparation.

• Always ask how many will be eating. Bring enough for one or two meals at the most. Ask if there is anything they are not permitted to eat or any foods they do not like.

• Bring your food in disposable containers. It saves the worry of returning dishes and washing up.

• If someone has a large family, share the joy of giving, ask a neighbour or group at church to prepare meals.

• Send flowers while they can be enjoyed. They remain there as an indication of your caring. Rent a video – but take it early in the day so that they can choose when to watch it and then pick it up the next day at a time to ensure no late fees.

• If it is Spring or Autumn – helping to mow the lawn, rake the leaves or weeding flower beds is a big help. If the family are keen gardeners they worry if the garden is not tidy. If someone is terminally ill, take gifts such as aroma oils and candles, luxury soaps and body lotions – just to spoil them. A small beautiful lace pillow or hand-knitted bed socks are especially welcome for aching necks and often cold feet.

• If the illness does lead to death – visits with food, flowers and cards are appreciated after the funeral. Remember the surviving family have plenty of company at the time of the funeral, but mark your calendar for a visit 3-6 weeks following the death. This is when the reality of the loss takes hold and make for a very lonely time.

Pointers of Pain

Acute Pain - Acute pain is pain which occurs suddenly and which is expected to last only a short time. It may be associated with such incidents as acute injury or surgery and is easily and effectively treated with analgesics (pain killers) and by other supportive measures such as rest, immobilisation (bandaging, etc), hot and/or cold packs, elevation and physiotherapy.
**Chronic Pain** - Chronic pain is pain which can occur suddenly or slowly build up over a period of time. It is constantly present but its intensity may vary. Chronic pain can be associated with conditions which are life threatening or not life threatening.

**Chronic Pain in Non Life Threatening Conditions** - Chronic Pain in non life threatening conditions such as arthritis, neuralgia, pancreatitis, back injury and headache is often best treated by multi-disciplinary team in a well resourced Pain Clinic.

The first important aspect of management of chronic pain in this setting is to correctly and specifically identify the cause of the pain. If this cause is ‘curable’ then treatment will be directed that way. If the cause is not curable and the pain is likely to persist, then treatment will be directed towards:

- Control of depression by psychotherapy (talking therapy) and/or medication.
- Behaviour modification which teaches the patient how to enjoy an active and fruitful life.
- Some technology may be employed ie. TNS machine.
- Gentle therapies such as massage, aromatherapy, etc.

**Chronic Pain in Life Threatening Conditions** - Conditions such as cancer, HIV/AIDS and end stage organ failure are associated with chronic pain in less than 50% of cases. When chronic pain does occur, it may vary in character and intensity from time to time due to changes in the disease process.

Many patients will have their symptoms totally and adequately managed by their family medical practitioner. Occasionally the family medical practitioner will enlist the assistance of a multi-disciplinary palliative care team. When this occurs, an individual caring team is created consisting of:

- the patient
- the carers (family and friends)
- the family medical practitioner
- the generalist community nurse
- the clinical nurse, specialist or consultant (palliative care)
- other professionals ie, counsellor, spiritual adviser, pharmacist, physiotherapist, occupational therapist as required.

Ideally, the family medical practitioner should retain overall responsibility for the management of the patient and the co-ordination of the team.

Chronic pain in life threatening conditions can be adequately controlled in most cases and certainly modified in all cases. All the techniques already mentioned for the control of acute pain and chronic pain in non life threatening conditions are employed together with therapies which have been developed specifically for use in the palliative care setting.
Drug therapies include:

- Analgesics including strong drugs such as morphine and simpler drugs such as paracetamol.
- Other drugs which are not primarily analgesics but which impact on pain. Such drugs include steroids, antidepressants, anticonvulsants (epilepsy drugs), cardioactive drugs (heart disease drugs), diuretics (fluid tablets) and antibiotics.
- Drugs to ease other symptoms such as nausea, vomiting, constipation, breathlessness and agitation.

**Spiritual Care for the Dying by Roger Cole, F.R.A.C.P.**

Death today is unpredictable in its timing and impact on people, often without justice or accord for the good heart and nature of those it visits. It seems not to value love, relationships or religion and presents crisis whenever it threatens and apparent finality. In looking at death, there is value in reflecting on the two Chinese characters that comprise the word crisis – one meaning disaster, the other meaning opportunity. Spiritual care for the dying highlights an opportunity to realise truth, yet understands the sense of disaster that people facing death experience at the time. With such understanding ordinary people can offer spiritual support to the dying if their sense of truth offers strength and wisdom to a great extend than their fear generates anxiety. Anyone who can reflect comfortably on their own death and who has a concept of eternal life, without the desire to preach their beliefs, has the qualifications required to offer spiritual support. Anyone who is a relative or friend of someone who is dying, who can truly listen and share honestly in the relationship, will give the dying person an opportunity to release suffering and realise their true nature, with its eternal identity and divine qualities.

Spiritual care for the dying is a form of compassion that extends limited human boundaries beyond the physical relationship into a realm of pure vibrations of love, light and understanding. It facilitates the potential for healing through self-realisation and rediscovery of a connection with the source of divine knowledge, peace and unconditional love. It is, nevertheless, a very simple and practical form of care giving, expressed in truth and self-awareness as support that facilitates the processes of letting go and reconciliation. Let us now consider these aspects in more detail.

**Truth and Self-Awareness**

In this day and age, spiritual care is more a reflection of understanding who we are than the particular beliefs of religion we adopt. Relatively few souls are sustained to the extent of attaining peace and acceptance in dying by formally structured religion alone. This is largely because we have substituted our true spiritual identity to an acquired ‘false’ identity through the physical body. In this, we become attached to others who bring about the experience of love and live our lives with tenuous security, dependent on relationships and material wealth or possessions.
Ultimately the love attachments that bring us our greatest joy result in the deepest of sorrow when death brings about separation and loss. This is the result of body consciousness, which can be looked on as the source of all the problems of worldly relationships today. It represents a form of illusion that binds the mind, intellect and emotions in a continual cycle of temporary happiness giving way to disappointment when the relationship no longer lives up to expectation or to devastation when it ends.

People of the world today consider a lifetime to be the existence of the physical body from birth to death. So it is of little surprise that they sink into despair when faced with the seeming truth of mortality, after hearing about a terminal illness or about the sudden death of someone close to them. The reality that each one is a soul or living, conscious energy, with an eternal existence beyond the physical body is the truth of self-awareness that we have lost. To be effective in caring for the dying we need first to renew our relationship with Truth, breaking the habit of recognising self and others as bodies, limited by birth and death. In recognising soul, or the nature of the mind, one immediately discovers the non-existence of death and understands that separation, loss or suffering result from a false impression that the end of the physical body extinguishes life. This extraordinary recognition can be offered to someone who is dying in a short daily exercise of reflective prayer or meditation as follows:-

Try to sit quietly and practice a short mediation each day, in which you imaging you are separate from the body and gently affirm: “I am a soul, ever present and loving. My original nature is peace. I am living, light and energy and exist eternally beyond the awareness of my physical body”. Spend at least five minutes doing this for yourself. Next, consider the dying person you would like to help spiritually. Picture the face of that person, then remember his or her nature and personality. Imagine that this nature takes on the form of a shimmering light just above the person’s head or face, connected only by a fine thread of radiant light to the centre of the forehead. Move and dissolve all sensations of physical pain and suffering into this healing, loving, pure form of radiant light. Now gently affirm: “you are a soul, ever present and loving. Your original nature is peace. You are living, light energy and exist externally beyond the awareness of your physical body”. Spend at least five minutes doing this for the other person. As you do this fill yourself with compassion and love for that person and finish by imagining your loving feelings as light merging and healing the soul nature or personality of the other one. Sit in this timeless state of loving union for as long as you wish. Have great faith in the benefit of this practice and you will discover a greater depth of relationship with the one you care for, one of the greater easiness about death and one with greater understanding of soul. Whether you do this alone or adapt it to do with the other person, it will be beneficial as it invokes genuine love and compassion for the soul.
Support

To truly support someone who is dying we must first respect and accept them. Respect
their attitudes, views or beliefs and accept their moods or ways of coping. Every person
is unique and behaves according to his or her own nature and personality when facing
death. Someone who has never been open with feelings is likely to feel uncomfortable
about sharing their emotions with others, even when close to dying. This can be very
hard when you love that person, particularly if a barrier is erected that prevents you
saying the things you would like to. Such people, though, will often talk about their
life, the good times and their regrets. Be alert to such opportunities as this is often the
way they begin to open up and share their life with someone else. Talking with you life
this is of benefit to the person facing death and they will appreciate the personal who
has listened to them with a real prospect that they might go on to share deeper feelings
relating to their present situation.

In supporting someone who is dying, we must be sensitive, then, to the type of
person they are, as well as willing to take the journey with them, by listening to them.
Try to be natural, just your normal self, without wearing masks that are either falsely
superficial or excessively sombre. Be balanced, light hearted and humorous yet willing
to seriously enter that person’s deeper fears, loneliness or despair. The person who is
dying really values someone who treats them in a normal way and is more likely to
unburden their anxieties to such a character.

When we truly listen to someone, we are not just listening with our ears. We are
listening with sensitivity to the whole persona of that individual, respecting whether he
or she wishes to share in our company or not. When people who are dying wish to talk,
they offer opportunities to loved ones and may be frustrated by any avoidance of the
subject. For instance, the person may say to you, “The lumps are getting larger every
week.” Or “I’ve really had enough of living like this.” If you are awake, alert and aware
you will realise these are openings and the person wants to talk to you about concerns,
anxieties or hopelessness. The person feels lonely and isolated with these fears and
you have been given the opportunity to really help. If you respond with prompts such
as, “Is it worrying you, that the lumps are getting larger?” or “It must be really awful,
what don’t you like about it?” then your willingness to listen will enable that person to
release the burden. All to often people respond in a way that is emotionally unhelpful,
with platitudes about positive attitude or excessive sympathy, neither of which enable
the person to speak about the things that trouble the mind.

If, through the sharing time you are able to hold an inner sense of spiritual awareness,
reflecting an understanding of the immortality of the person you are with, then you will
be enveloped in a feeling of radiance and peace. The vibrations of this attitude will reach
out and comfort the soul while you listen to the heart. Do not worry though if, through
the closeness and love for that person, you find yourself shedding a few tears together.
Consider them to reflect your relationship and be aware that they can give permission
to the other person to let go. In letting go you can both find healing and peace beyond
the sorrow or frustration you are sharing.
Letting Go

When people attain complete and unadulterated acceptance of death, they convey a natural radiance that others experience as peace. In this condition of acceptance, the soul is also recognising the truth of immortality and gives an example to us of spiritual transcendence. When people are with such an individual, they describe experiencing an atmosphere of complete peace or pure spiritual love, accompanying a feeling of presence that is powerful, influential and divine. Even when the relationship is close, such as husband and wife, the spouse will recognise that the person who is dying is no longer concerned about their relationship, yet is all loving toward it. Furthermore the person now has no concern for any worldly matters, yet exemplifies connection with all true human interests. There is complete detachment from the roles or responsibilities that previously worried or burdened the individual and yet every role and responsibility is being fulfilled in these moments of pure radiance.

In this awareness of death, there is no unfinished business to attend to, as the soul is free from the bondages of relationships, the problems of the world and the burdens of roles or responsibilities. If you are to recognise the spirituality of true acceptance then your spiritual support gives loving freedom to a dying friend or relative by letting them go. If your heart can accept that the soul needs to leave this body and that disease or injury are cleansing opportunities for transition, then you can help by allowing them to ‘die’ or leave their physical relationship with you. Spiritually though you have an eternal connection that you can nurture, even after the passage of someone you loved dearly. All too often, we see relatives and friends urging the person to keep up the fight or to be ‘positive’, which only increases the feeling of responsibility and leads into depression, failure or hopelessness. And all too often relatives and friends feel hurt if someone dying seems to distance him or herself from them when, in reality, the distancing is making the passage more comfortable for the one who is leaving.

If you are sensitive to the letting-go process and are able to let go yourself then a peaceful death may follow. This requires strength, courage and love in the spiritual caregiver, as it is by no means easy to go beyond one’s own feelings of loss or the pain of grief when in the company of the death of a loved one.

Reconciliation

Spiritually is universally recognised as the atmosphere or vibration surrounding someone who embodies purity with loving simplicity, wisdom and humility. Reconciliation is a term that describes the attainment of purity, accompanying transformation of character and realisation of the essential truth of immortality. Faith is the certain knowledge of immortality that stems from the awareness of true self as spirit or soul engaged in human experience through the physical body.
It is through faith that we express the real potential for reconciliation of purity of all souls, before, during or after their physical ‘death’.

Perhaps the deepest spiritual support you can extend to a dying person is the faith held in your heart for reconciliation of the soul. There is no need for you to relate this directly as it is expressed in your natural ability to listen, share and let go in the manner we have already considered. With such an attitude, you will not bind other people to you in love or sorrow but will give them the freedom through a hidden wisdom that lies in your understanding of soul.

In such a stable manner, you bear witness to life in transition rather than death, and your outlook more than your words become an instrument for reconciliation.

**The Dying Person’s Bill of Rights**

- I have the right to be treated as a living human being until I die.
- I have the right to maintain a sense of hopefulness however changing its focus may be.
- I have the right to be cared for by those who can maintain a sense of hopefulness however changing that may be.
- I have the right to express my feelings and emotions about my approaching death in my own way.’
- I have the right to expect continuing medical and nursing attention even though ‘cure’ goals must be changed to ‘comfort’ goals.
- I have the right not to die alone.
- I have the right to be free from pain.
- I have the right to have my questions answered honestly.
- I have the right not to be deceived.
- I have the right to die in peace and dignity.
- I have the right to participate in decisions concerning my care.
- I have the right to have help from and for, my family in accepting my death.
- I have the right to retain my individuality and not be judged for my decisions, which may be contrary to the beliefs of others.
- I have the right to discuss and enlarge my religious and/or spiritual experience these may mean to others.
- I have the right to be cared for by caring sensitive knowledgeable people who will attempt to understand my needs and will be able to gain some satisfaction in helping me face my death.

*Judy Tatelbaum ‘The Courage to Grieve’*
Come the Dawn

After a while you learn the subtle difference
between holding a hand and chaining a soul
And you learn that love doesn’t mean leaning
and company doesn’t mean security.
And you begin to learn that kisses aren’t contracts
And presents aren’t promises.
And you begin to accept your defeats
With your head up and your eyes open.
And learn to build all your roads
On today – because tomorrow’s ground
Is too uncertain for plans and futures have
A way of falling down in mid-flight.
After a while you learn that even sunshine
Burns if you get too much.
So you plant your own garden and decorate
Your own soul – instead of waiting
For someone to bring you flowers.
And you learn that you really can endure
That you really are strong
And you really do have worth.
And you learn and learn…
With every goodbye, you learn