PROTOCOL FOR CARE OF THE DYING PATIENT

For Catholic Health Professionals

A reference document for specific guidance on required details of holistic, palliative care, UK Association of Catholic Nurses and UK Catholic Medical Association©. December 2021.

Contents

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"Incurable – cannot mean that care has come to an end" (Congregation for the Doctrine of the Faith, 2020).

Introduction

When the health of an individual deteriorates to an irreversible state, palliative care is appropriate for the person. Care for the dying is a special privilege in serving humanity, accompanying people to the natural completion of life.

Treatment and care priorities must include symptom relief as part of individualised, holistic care to allow patients to live as comfortably and as fully as possible.

Palliative Care definitions

The World Health Organisation (WH0) has defined the concept of palliative care in holistic terms as:

"An approach which improves the quality of life for patients and their families facing life threatening illness, through:

- *the prevention,*
- *impeccable assessment and*
- *treatment of pain and other problems, physical, psychosocial and spiritual"* (WHO, 2011).

The UK Palliative Care Bill (2020)

Baroness Ilora Finlay, an expert Professor in Palliative Care, introduced the 'Access to Palliative Care and Treatment of Children Bill' (2020) [HL]. The Bill defines palliative care in holistic terms:

"Care which is delivered to seek to improve the quality of life of persons with life-limiting illness or approaching the end of life, through the prevention and relief of suffering by means of early identification, assessment, treatment and management of pain and other problems whether physical, psychological, social, or spiritual" (Finlay, 2020).

AIM OF PALLIATIVE CARE

One of the primary purposes of care for the dying patient is the relief of pain and suffering. Effective management of pain and other symptoms, in all forms, is therefore, critical in the appropriate treatment and care of the dying. This aim underlines the need for holistic approaches, in maintaining optimum physical and mental well-being. While many individuals may see palliative care as a simple or a straightforward concept, healthcare professionals know that there are individual, ethical, moral, practical, and spiritual elements that are central to ensuring that palliative care is not only person-centred, but effective, dignified, safe and compassionate (Tallo, 2016).

PROGNOSIS

Palliative care should be introduced, based on the patient's needs, rather than relying on prognosis which can be a subjective judgment. This particularly applies, if the patient is suffering from chronic conditions such as heart and lung diseases. Questions about prognosis are to be encouraged from the patient and family members. It is particularly important for all involved in the care to understand that prognosis is accepted as difficult and often can be confounded.

Team working in palliative care

The independent review panel of the *Liverpool Care Pathway (LCP)* recommended that a senior clinician should lead the palliative care team (DH, 2013).

Care assistants and volunteers, with appropriate training and safe monitoring, can be invaluable members of the care team.

Patients need to believe in the skill and dedication of their health team, whether in hospital, hospice, or home, and the good treatments for symptom control. These can allow for a peaceful, natural death, together with the holistic approach to healing of the mind and spirit before death.

Multidisciplinary care

Palliative care is the province of those clinicians with expertise in the specialty. This should not mean the denial to patients of the expertise of other specialist practitioners, who may provide benefit for the patient's particular problems in a perhaps complex case. One example is in controlling unstable Type 1 Diabetes. Such medical problems do not stop because the patient is receiving palliative care.

ETHICAL DECISION-MAKING

Ethical issues in palliative care often arise because of concerns about how much and what kind of care makes sense for someone with a limited life expectancy. The maxim: *'primum non nocere'* (first do no harm) of traditional medical ethics has guided medicine and nursing for centuries. Despite the recent legal and professional developments which consider assisted food and fluids as medical treatment they should be considered as part of humane care, where appropriate.

There are limits to active treatments when prognosis is not hopeful. But due to the treatments for symptom control, no patient should be told that 'there is nothing more that we can do'.

It is well-accepted that caring for patients for whom treatment is withheld or withdrawn, can create significant professional and personal dilemmas. Open discussion, collaborative decision making and consistent review in practice are crucial to avoiding moral distress during treatment cessation.

St Pope John Paul II reminded doctors that education of professionals is required for them to know: *"A substantive moral difference between discontinuing medical procedures that may be burdensome, dangerous, or disproportionate to the expected outcome and the taking away of the ordinary means of preserving life, such as feeding, hydration, and normal medical care and if done, willingly and knowingly, is true and proper euthanasia by omission"* (Saint John Paul II, 2004).

Proportionate treatment and care

Therefore, the Catholic Church teaches that there is no moral obligation to use disproportionate means in care of the dying and that the patient has a right to refuse them. Proportionate means are those that in the judgment of the health team and the patient offer a reasonable hope of benefit and do not entail excessive burden.

Consensus in decision-making is key to minimising ethical discord, and personal beliefs and experience are crucial factors (McLeod, 2014).

However, termination of required hydration, even if nutrition is not possible in palliative care, is unethical, where hydration can be appropriate, tolerated, and safely monitored.

HOLISTIC CARE AND INDIVIDUAL NEEDS ASSESSMENT

Holistic care is an ethical approach to patient needs and part of the duty of care. It does not advocate unnecessary, overreliance on drug therapy. The Nursing and Midwifery Council expects nurses to be able:

> *"In partnership with the person, the carers and their families, to make **holistic**, person centred and systematic assessments of physical, emotional, psychological, social, cultural and spiritual needs, including risk, and develop a comprehensive, personalised plan of nursing care" (NMC, 2010).*

Holistic needs assessments are promoted by the MacMillan Charity.
https://www.macmillan.org.uk/healthcare-professionals/innovation-in-cancer-care/holistic-needs-assessment

THE INDEPENDENT REVIEW OF THE LCP (DH, 2013).

Concerns raised by the findings of the review included:

- poor communication with the dying person and their relatives,
- the issue of consent
- the issue of hydration

Patient communication needs

Effective communication is fundamental to good clinical practice and in line with patients' rights. Health professionals caring for patients in need of palliative care, should provide them with appropriate information to help with understanding of the condition and required treatment. This gives the patient the opportunity to consider and discuss the situation with family members, as wished, unless the patient is lacking capacity.

Issues, such as provision of *effective hydration*, the complexities of *cardiopulmonary resuscitation and advanced directives* need sensitive discussion with patients by the doctors and nurses as part of patients' rights to effective communication.

Practitioner documentation

The LCP review panel (DH, 2013) also recommended that guidance should specify that the **senior clinician** writes in the patient's notes, a record of the face-to-face conversation in which the end-of-life care plan was first discussed with the patient and his/her relatives or carers.

The record of that conversation must include the following:

- The clinician explained that the patient is now dying and when
- How death might be expected to occur, using language, which is clear, direct, and unambiguous.
- If the family or carers do not accept that the patient is dying, the clinician has explained the basis for that judgment.
- The relatives or carers had the opportunity to ask questions (DH, 2013).

Informed consent

Consent is a fundamental patient right and applies in all fields of treatment and care. It is particularly important to ascertain consent in palliative care before the patient may lose capacity, due to deterioration. Therefore, regular communication with dying patients is essential.

PHYSICAL NEEDS: SYMPTOM CONTROL

Patients in the advanced stage of a serious and/or life-threatening illness typically experience multiple symptoms, the most common of which may include pain, depression, anxiety, confusion, fatigue, breathlessness, insomnia, nausea, constipation, diarrhoea, and anorexia. In all circumstances, health professionals must be knowledgeable (as with any other specialty), to provide basic, humane care and relief of all symptoms, (wherever possible), and to prevent other distress such as hunger and thirst.

NUTRITION AND HYDRATION

Nutrition and hydration are separate issues and need to be approached as such.

Nutrition - Oral feeding

Loss of appetite can be a feature of the life of a dying patient. Liaison with the Nutritionist and Speech Therapist can be an example of involving other members of the multidisciplinary team. Measures that may encourage and increase oral intake include:

- Using a flexible approach to feeding needs
- Helping the patient with feeding
- Ensuring easy to swallow foods
- Providing small portions or favourite or strongly flavoured food as desired
- A small amount of a favourite alcoholic drink may stimulate appetite about thirty minutes before meals.

Supportive measures

- Good oral hygiene
- Moistening the mouth with swabs

Clinically assisted nutrition

Those patients who have an existing feeding tube in situ, can be maintained in accordance with the overall aim of comfort and tolerance, in line with individualised safe, monitored care. Some patients who are unable to take oral nutrition can benefit from a central or IV feeding line when the prognosis is unclear.

Hydration

Health professionals should ask:
What are the symptoms caused and/or aggravated by dehydration? (Dalal & Bruera, 2004).

Thirst

Debate about hydration should focus on the concept of thirst in line with planning for quality life for the dying patient. This stance is more humane than concerns about unnecessarily prolonging life. Thirst should not be a compounding symptom for the dying patient. It should be considered as a preventable and treatable problem.

Thirst symptoms

The importance of treating thirst and dehydration in all patients, must be understood. It is especially important not to forget those patients at the end of life, when those particular signs and symptoms may be missed or ignored (Bubna – Kasteliz, 2017).

Patients have reported feeling terrible thirst and other effects when being denied hydration. Additionally, the following dehydration - associated symptoms cannot be dismissed as just unfortunate:

- Delirium, restlessness, agitation.
- Lowering of the pain threshold.
- Diminishing of the analgesic properties of opioids and
- Opioid neurotoxic side effects

Oral fluids - safety aspects

Offering oral fluids may be dangerous as patients can be sedated or confused so that they are less able to drink, if at all. It is salutary to know that dehydration can increase pain by diminishing opioid efficacy. Therefore, where patients are critically dehydrated, they need assisted and monitored hydration.

Mouth care is fundamental to nursing care but cannot always alleviate thirst.

Subcutaneous (s/c) fluids

Life sustaining food and fluids are basic needs of everyone. The benefits and potential disadvantages of assisted hydration should be explained. The subcutaneous route should be considered as an excellent option due to its simplicity, low cost, and feasibility in the home setting (Dalal, & Bruera, 2004).

The subcutaneous (s/c) route may be easy to manage in home care settings. It can have distinct advantages over the intravenous (i/v) route in the elderly confused, and at the end of life. The s/c route is easier to apply when the patient is dehydrated with collapsed or thrombosed veins, or if an intravenous (iv) cannula keeps being pulled out. For instance, a subcutaneous cannula can be kept out of a patient's sight, protected and accessible behind the shoulder. There is no risk from inadvertent air bubbles or delay in replacing empty bags and therefore, particularly useful when rehydrating a patient at home or in a nursing home (Bubna – Kasteliz & Bodagh, 1993).

Clinically assisted hydration at home

Ilora Finlay, Professor of palliative care, and a former President of the Royal Society of Medicine has made it clear that when patients are thought to be dying, that does not mean that fluids become futile. "Subcutaneous fluids can be done at home, (by easy means of gravity, e.g., a picture hook and changed by the District Nurse): patients do not need to be admitted to hospital (Finlay, 2008)."

Nursing 'rapid response teams'

These nurses can also help the patient and family at home with managing s/c hydration and possible symptom control.

Adverse effects of s/c fluids

Several studies of adverse effects from subcutaneous fluid have been found to be infrequent and are easily avoided (Dalal & Bruera, 2004). One infrequent effect, (local oedema) can be managed by reducing the infusion rate or careful use of diuretics.

A clear timeframe for review is required after about 48 hours; by then, the patient may be less able to drink, which may be because the patient is dying. It is also important to make families aware that such fluids will need to be stopped or slowed, if they cause obvious complications such as signs of fluid overload, skin swelling, discomfort, or signs of pulmonary oedema.

Intravenous fluids

When these can be given, then subcutaneous fluids should not be used due to the risk of 'easing' patients into an 'end- of - life' routine and the subcutaneous route can be erratic in absorption.

Hydration should never be withheld or withdrawn, with the sole purpose of causing the death of the patient. Such unlawful and unethical practice was condemned by the panel charged with the independent review of the LCP which was discredited and recommended for withdrawal in 2014.

Competent medical and nursing practitioners, either in the hospital or community settings should be able to manage such simple infusions without difficulty, by regular monitoring, titrating to need, physical signs, and the response of the patient.

Assisted Hydration, when required, absorbable, practicable and carefully monitored, will not harm patients, and should be included as part of fundamental and humane care. The LCP review panel stated that deliberate denial of fluids is unacceptable and unethical, and doctors and nurses should be held to account by their regulatory bodies for such practice. They will monitor and review the fluid rate and volume (DH, 2013).

Staff education – patient hydration needs

The LCP review panel in 2013, recommended that caring for the dying must never again be practised as a tick box exercise and in relation to nutrition and hydration, the importance of staff education was emphasised:

- All staff in contact with patients should be trained in the appropriate use of hydration and nutrition at the end of life and how to discuss this with patients, their relatives, and carers.
- Specialist services, professional associations and the Royal Colleges should run and evaluate programmes of education, training, and audit about how to discuss and decide with patients and relatives or carers how to manage hydration at the end of life (DH, 2013).

A retired Geriatrician and author of books on medical ethics, including the dangers of dehydration notes that "attention to hydration should be part and parcel of good palliative care" (Craig, 2004). As already stated above, hydration should never be withheld or withdrawn, with the sole purpose of causing the death of the patient. Such unlawful and unethical practice was condemned by the panel charged with the independent review of the LCP which was discredited and recommended for withdrawal in 2014.

PAIN RELIEF

Treatments such as morphine and sedatives, may be a cause of earlier death if they are given inappropriately as unethical care in someone who is not symptomatic. It is recognised that opioids given to dehydrated patients are diminished in their analgesic properties.

Opioid toxicity

Long-term use of opioids can lead to accumulation of its toxic metabolites leading to various adverse events, known as opioid toxicity. This condition is often missed and misdiagnosed in clinical practice and hence, seldom managed appropriately (Ostwal, 2017).

Opioid-induced toxicity should be regularly assessed and aggressively treated to improve the quality of life of the patient and to decrease distress in both patient and their caregivers (Ostwal, et al, 2017).

A change and /or rotation of opioids would allow for clearance of metabolites while maintaining or improving pain control in patients on chronic opioid treatment for cancer pain who develop symptoms of toxicity (de Stoutz et al, 1995). The European Association of Palliative Care (EAPC) Research Network has developed recommendations for treating opioid-induced adverse effects (Cherny et al, 2001).

Individualised pain relief

Escalation of analgesic opioid drugs is not always wise when the pain may be neurogenic, that is, not inflammatory or caused by pressure on other organs. Therefore, opioids are not always first line to use for neurogenic pain. The cause for pain needs to be investigated and relevant drugs employed. This can minimise the known complications of opioid drugs. It should be known whether pain relief should be targeting nerve pain or inflammation, to be able to offer the appropriate analgesic agent.

- Amitriptyline is a type of drug called a tricyclic antidepressant (TCA). These drugs were originally developed to treat anxiety and depression, but when taken at the appropriate dose initially and with ongoing dose review, can reduce or stop neurogenic pain. The role of TCAs in the treatment of neuropathic pain is now well established and has the best documented evidence (Saarto & Wiffen, 2007).
- Anticonvulsants have been evaluated and used effectively in neuropathic pain states.

Breathing problems

Shortness of breath or the feeling that breathing is difficult is a common experience at the end of life. Measures to help ease breathing, can be helpful, such as

- raising the patient's position in bed/ chair
- opening a window, without causing a draught
- using a humidifier or using a fan to circulate air in the room.
- a small fan, held about six inches from the central part of the face so that the cooling effect is felt around the sides of the nose and top lip can reduce the sensation of breathlessness The benefit should be felt within a few minutes (Guys and St Thomas NHS Trust, 2015).
- morphine or other pain medications can also help relieve the sense of breathlessness.
- oxygen, if required on a continuing basis, needs nebulisation to prevent drying of the mouth and nasal mucosa.

The elderly person

Due to the older person's particular sensitivity to drugs, it is recommended that evidence for both non-pharmacological and pharmacological interventions is known for symptom management (Palliative Care Clinical Studies Collaborative, 2014).

Many frail older people have died without needing an opiate and often, required no medication at all. Syringe drivers are not always obligatory (Kinley & Hockley, 2010).

Other symptoms

Several antipsychotic drugs are effective for nausea and vomiting in small doses. Nausea, an often-short term side effect of opioid drugs, can be caused by constipation, an associated side effect of long-term opioid drugs.

Constipation

Non-drug treatments, such as increasing fluid and dietary fibre intake can be helpful.

Preventive monotherapy with stool softeners is considered ineffective and use of a scheduled stimulant laxative often is required. Co-prescription is required of either a softener and / or stimulant e.g., magnesium sulphate/senna as cheaper and most efficient rather than psyllium or glycol derivatives which are expensive and require adequate water ingestion (1,000 to 1,500 mL per day) (Swegle & Logemann, 2006).

Other drug support - respiratory agents

Noisy, respiratory secretions which can occur in the dying patient, can be upsetting to the relatives. Careful patient repositioning can be helpful. Compared to atropine, glycopyrrolate has reduced cardiovascular and ocular effects. It diminishes the volume and free acidity of gastric secretions and controls excessive pharyngeal, tracheal, and bronchial secretions. In common with other antimuscarinic drugs, caution is advised in patients with prostatic hypertrophy, paralytic ileus, pyloric stenosis, and closed angle glaucoma. Buscopan can reduce secretions but must be given early to have an effect.

The route of administration for these drugs can be intramuscular or intravenous. Patients will be more comfortable at home by the insertion of an indwelling cannula to the arm so that regular administration is possible by the District Nurse / Rapid response team, day, or night.

Questions to ask

Has the person been taking analgesics orally?

- Are any of their other medicines essential for their comfort?
- Is the person agitated?
- Does the person sound chesty or have retained secretions?

SEDATION

Sedation, as part of required treatment may be needed for patients who are: *terminally agitated, delusional, or psychotic and becoming a danger to themselves or others.* Sedation practice must always be clinically justified, among the team, to the patient and the family.

Palliative care specialists have argued that with careful assessment of reversible factors and alternative management for problems like delirium, some of the need for sedation may be avoided (Thorns & Sykes, 2000). *"The ethical and legal risks of sedation would be greatly reduced if palliative carers took a more active approach to hydration and quite simply provided hydration for a matter of days until life ends naturally"* (Craig, 2002).

Midazolam

This sedative drug is considered a high alert medication because of the risk of respiratory depression and respiratory arrest when used without appropriate resuscitative equipment or qualified personnel for monitoring.

Serious side effects such as slow/shallow breathing, severe drowsiness/dizziness may be increased, if this medication is taken with other drugs that may also cause drowsiness or breathing problems such as opioid drugs. This was a common combination in the use of the LCP.

'Blanket' sedation

Unnecessary sedation drug regimes, without hydration, give patients no chance of return from the point of oblivion. Such practice goes against health professionals' mandate to provide ethical, individualised, and humane, holistic care.

There was significant media coverage surrounding the LCP and relatives' concerns about people dying from dehydration and suffering with distressing symptoms due to inadequate fluid intake. Suspicion was also raised, that fluids were withheld and even denied to dying persons, to hasten death.

Safe practice

Staff must be competent in the use of resuscitation equipment, able to identify serious complications of sedation and opioids and knowledgeable about the appropriate antidotes to reverse them: IV flumazenil for sedative benzodiazepines and naloxone for opioids as part of a safe, care culture.

PALLIATIVE CARE IN ACCIDENT AND EMERGENCY DEPARTMENTS

There is growing literature about ways to best use palliative care services in Accident and Emergency Departments (Quest et al, 2013). The palliative care nurse can provide support for the A & E staff, often overwhelmed by:

- Medical emergencies, sudden deaths,
- Failed efforts at resuscitation,
- Trauma care,
- Victims of crime,
- Increasing population of vulnerable, complex patients, accessing the A & E department as their only source point for care in chronic disease.

The palliative care nurse will be aware of helping to manage oncology emergencies, for example, *Haemorrhage, Bone Marrow Depression, Sepsis, and Spinal Cord Compression.*

The specialist nurse can also assist the A & E staff in giving news of a death:

- Explain what has happened,
- Assess the family members' immediate coping,
- Assess physical, spiritual, and psychological needs,
- Assist in making decisions about care and transition of the body.

PSYCHOLOGICAL/EMOTIONAL/ SOCIAL CARE

Distress

Along with the five vital signs of temperature, respiration, heart rate, blood pressure, and pain, what is now regarded as the sixth vital sign in cancer care, covers 'Distress'. It is important for health professionals to include emotional distress as a factor when assessing the wellbeing of patients with cancer. It could be also useful for assessing the emotional status of patients with non-cancer conditions.

Many patients can experience a feeling of being a burden, either to their family or the carers. This is now established as the top and constant reason for requests for assisted suicide, in countries where assisted suicide is legalised. It is important to understand that those patients, asking for assisted suicide are more commonly in mental pain, rather than physical pain. This fact is a recognised and constant statistic.

Depression in advanced Illness

Up to half of patients with cancer suffer from symptoms of depression (Rosenstein 2011). The elderly, also suffer from high rates of depression and suicide (Brown, Rutherford et al, 2016).

Because depression often manifests somatically (Tylee & Gandhi, 2005), and if patients are not screened, clinicians miss half of all cases of clinical depression (Ansseau et al, 2004). The proponents of holistic care are vindicated by these findings. Where depression and anxiety are suspected, or exhibited, the team members have a duty to seek appropriate help for the patient to allow thorough assessment and appropriate treatment and care.

Unfinished business

The concept of 'unfinished business' is important to be addressed and is a truly relevant concept for many patients who are reaching the end of their life and for their families. The aim of those who care for dying patients, is not to speed them towards death. Contrary to such an ethos, health professionals are very well-placed as companions for the dying patient. Professionals must develop their skills to acknowledge sensitively with patients, the inevitability of death. This allows professionals and patients to concentrate on improving the quality of their lives, to put their affairs in order and, wherever possible, to say goodbye before it is too late.

EMOTIONAL/SOCIAL CARE NEEDS

Unfinished business does not only apply to financial affairs. Does the patient need:

- Emotional/ social/ spiritual support or support in making amends with someone distanced that they need to see again?
- Is the patient in need of reconciliation with the prognosis?
- Is the patient depressed, perhaps about their pet?
- Do social services need to be involved? Preferred place of care? Discussions are important with a realistic mode of discussion for what may or may not be possible

Financial/ practical needs

These can be considered as part of the holistic approach to care and are as important in terms of what may really be worrying the patient.

- Does a will need to be made?
- People with cancer are considered disabled under the Disability Discrimination Act (1998)
- The Equality Act (2010) protects the disabled
- Patients with less than 6 months to live, are eligible for non-means tested benefits.
- The Cinnamon Trust can help elderly patients with arrangements for pets in the planning of care needs

SPIRITUAL CARE

The dying experience is unique for each individual. For many individuals, death is not an end to life. It is simply a passage to another dimension, sometimes called heaven, the spiritual world, another plane of existence, or nirvana.

Florence Nightingale wrote that, "The needs of the spirit are as critical to health as those individual organs which make up the body". Ever since then, spiritual care has been part of nursing (Hutchison, 1988).

Spiritual needs cannot be met if patients are routinely and inappropriately sedated to death. Inappropriate, thus unethical sedation practice will disallow the important issue of spiritual needs to be met by nurses and their ministers of religion as part of patients' holistic care needs. The importance of spiritual care applies whether patients are imminently dying or not. Therefore, there is a need for caution with sedation particularly in line with this spiritual aspect of holistic care required by patients.

Spiritual distress

This is considered to be an approved nursing diagnosis which has been defined as:
"a disruption in the life principle that pervades a person's entire being and that integrates and transcends one's biological and psychological nature" (McFarland and McFarlane, 1997).

Education for spiritual support

As knowledge of issues involved in death and dying increases and positive attitudes are promoted, the spiritual care and support for people who are dying will improve.

The Royal College of Nursing (RCN) commissioned in 2010, an online survey on spirituality and spiritual care in nursing practice. Nurses taking part in the survey considered the following issues to be important:

- education and guidance about spiritual care,
- clarification about personal and professional boundaries and
- support in dealing with spiritual issues. (RCN, 2010)

The role of the Chaplain

Chaplains may be ministers of religion, nurses, or lay people. Definitions of palliative care and 'end of life care' need to be carefully explored and understood. Where such labels are applied to patients, practitioners must always be prepared to question whether they are truly appropriate, mindful of the difficulties in diagnosing 'dying'. The spiritual needs of non- Christian/non-Catholic patients must be accommodated by contacting the Rabbi, Imam, or other denominational minister on their behalf.

Chaplains have an important role within the team and are entitled to ask questions and voice opinions about the general welfare of patients they may minister to, in addition to their spiritual needs. Nurse Chaplains are in a particularly good position to liaise with the team members to build up trust for the patient and family's benefit and understanding of the true situation.

Last rites (the Sacrament of the Sick)

This term is more commonly replaced by the term: 'sacrament of the sick'. This is a comforting sacrament for Roman Catholics who are very ill or near death. Its purpose is sanctification and remission of sins. Catholic teaching is that it enables remission of sins and it should therefore be offered to all Catholics who are dying as an essential source of sanctifying grace as we prepare for our final journey to eternal life.

Hope

Hope is a vital element in healing and can be considered as an important, invisible virtue, even though the possibility of a cure may be remote. Human beings need encouragement in practising this virtue as it is a positive orientation to life rather than despair. Patients need faith and hope in their carers' skills and readiness to always meet any challenge, regarding symptom prevention and control. Hope cannot be seen but can be made visible in the individualised care and attention to each patient.

Spiritual awareness involves care to alert the patient and family to the spiritual dimensions of human life. Health professionals should help patients to prepare for death according to their religious beliefs and strive to put at their disposal the comforting rituals and sacraments of their individual religion.

ADVANCE DIRECTIVES

There are increasing calls for a national database of people's 'Living Wills', instantly accessible by all healthcare practitioners, both in primary care and hospitals and to be accessed also by paramedics and A&E doctors. This sounds very efficient; however, it should be considered unethical for someone to have an Advance Directive without being given an understanding of how the Mental Capacity Act (MCA, 2005), defines 'treatment '. This is defined as: 'any diagnostic or other procedure' and that clinically assisted food and fluid is considered as medical treatment, according to the Act.

Changes in medical guidelines and in law (MCA, 2005), mean that patients may be at risk from decisions to stop giving them food and fluids or to stop giving them medical and nursing care. People, have the right to, and often do, change their mind about their previous wishes and the 'Good Samaritan' practitioner will ensure patient understanding of 'treatment' as defined today.

Patient autonomy vs patient care

Some patients who are very distressed about their prognosis may feel hopeless and may just give up, refusing to accept their limitations, and loss of their independence and privacy and find it difficult to accept offered help in terms of general care.

Developing a relationship is essential as each patient is a unique individual. The most pressing issues, such as a patient refusing medication that is needed or hygiene issues can be addressed with patience and sensitivity and good judgment.

The topic may have to be discussed several times in different ways, actively listening to the patient, trying to understand their fears. By communicating well, it can help patients understand the situation, the benefits of assistance and allow trust to be developed which increases acceptance of care.

Cultural sensitivity

The need for cultural sensitivity is an integral part of the role of the patient advocate - an expectation of the Nursing and Midwifery Council Code of Conduct: standards of practice and behaviour (NMC, 2018). A study of nurses' experiences in caring for culturally different patients, (Boi, 2000), found that they shared similar problems in terms of language barriers, which were worsened by a lack of knowledge of the patient's culture. It is good practice for nurses to have an awareness of cultural flexibility and understand the family's wishes in respect of practices which may differ in the care of patients during their illness and after death.

Audit

Clinical and educational audit should be a regular part of best practice in palliative care. It should involve examining medical treatment, nursing care, spiritual support and any concerns of relatives and carers.

Palliative care promotion

- The duty of health professionals is to lobby for appropriate funding for both training of staff in palliative care and for staffing to be improved.
- Those responsible for medical and nursing curricula need to consider the time allocated for education on this important specialty.
- Palliative care is an issue of great importance within our society with many clinicians and academics alike, arguing that there should be more investment from the Government, Charities, and other bodies to ensure the delivery of safe, effective, and high-quality palliative care, across the United Kingdom.

The imminently dying

The Catholic moral tradition does not tell us that we are obliged to do everything we can to preserve life, whatever the cost. Dying patients requiring palliative care, may not benefit from *burdensome and non-effective treatments*. Even assisted nutrition and hydration, which is not medical treatment but ordinary care, can be withdrawn, for individuals in the clear circumstance of the dying process.

The dying process

Diagnosing death must not ever be a prediction that becomes a self-fulfilling prophecy. The process of dying is to be understood as the result of the body eventually becoming overwhelmed by the burden of the disease.

Though potential thirst can be distressing for relatives to imagine, much comfort can be provided by explanation about the dying process and ensuring understanding of reasonable measures that can still be employed, such as moistening the mouth.

Conclusion

"Good care of the dying is not assisted dying"
(More Care Less Pathway, DH, 2013).
Compassionate care of the dying can be an achievable aim in the UK, where the modern

Hospice movement originated.

Deliberate acceleration of death has no place in good medical and nursing care. Palliative care is a specialty where holistic care is vital to ensure every patient's needs are assessed and met. This ensures a non-'blanket' approach to care of the dying. There is no dispute that the NHS is under strain particularly with the advent of COVID -19. However, rather than defeatist staff attitudes to the challenges of palliative care or a 'tick box' mentality, patients warrant optimum management and care by committed professionals. Overall responsibility for palliative care should not be devolved to unsupervised junior doctors. The responsibility for patient care, generally, is within the province of the Consultant or General practitioner (DH, 2013).

None of us, in the end can stand in the way of death and committed Christians and those of other faiths, believe that death, as well as a sad farewell, is a gateway to a new and promised life. Thus, as we care for the dying, acceptance of that dying is centrally important to the care we give with empathy, compassion, justice, and hope.

Sources of support:

- Anscombe Bioethics Centre www.bioethics.org.uk
- Medical Ethics Alliance: https://medethicsalliance.org.uk/contact/
- Catholic Medical Association UK: https://catholicmedicalassociation.org.uk/
- Association of Catholic Nurses UK: http://www.catholicnurses.org.uk/
- Alliance of Prolife Students www.allianceofprolifestudents.org.uk
- Care Not Killing https://www.carenotkilling.org.uk/
- Help for relatives of loved ones who are being denied fluids: https://dehydrationlifeline.org/

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