

End of Life Issues

Church of Scotland

Church and Society Council

Church and Society Council
Church of Scotland
121 George Street, Edinburgh, EH2 4YN
Phone: 0131 225 5722
www.churchofscotland.org.uk
Charity Number: SC011353



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END OF LIFE ISSUES

1. Introduction

1.1 The aim of this report is to consider many of the issues surrounding the end of life. Some of the areas considered are sensitive and emotive. A significant amount of media coverage in the past year has surrounded decisions by individuals to seek assisted death, or to refuse medical treatment. However, one of the great joys which the Christian church has is the responsibility to proclaim the message that there is more to life than simply this life: as Paul says,

¹ If for this life only we have hoped in Christ, we are of all people most to be pitied

1.2 It is also recognised that the church has the opportunity not only to offer spiritual comfort to those coming towards the end of their lives, but also to ensure that their last days are as fulfilled as possible.

1.3 There is a tendency in much of the public debate on issues surrounding death to infer some ill-defined excellence or worthiness, to refer to “dying with dignity”, when the reality for the carer or onlooker may appear to be the converse. In general by ‘death’ we mean physical death and not spiritual death; in the Old Testament the ideal may be thought of as the death of Abraham, who:

breathed his last and died at a good old age, an old man and full of years²,

in contradistinction to the many murders and massacres which are recorded.

1.4 It must be remembered that ethical decision - making near the end of life:

- 1.4.1 **is not done in a vacuum**. Wrestling with ethical issues around a time of death is done by patients, clinicians, carers and relatives who all bring their own life experience, values, beliefs and feelings to the decision-making process, which itself takes place in a specific context involving a unique patient with a disease or injury presenting itself in a particular way.
- 1.4.2 **is an art not a science**, no matter how many Biblical principles and ethical guidelines are followed.
- 1.4.3 **has pastoral implications** – spiritual (including an impact on beliefs and values, as well as raising ‘why’ questions) and psychological – for patient, relatives and staff. The death itself, the manner of the death, or the continuing survival of a patient and their subsequent quality of life are significant, as is the decision-making process, and by whom decisions are made.

¹ I Cor. 15: 19 (NRSV)

² Gen. 25: 8

1.5 The whole focus of “end of life” should not just be on the moment of physical death, but on the period (days, weeks or months) leading up to that event, with the emphasis on achieving the best quality of life possible. The focus should follow the palliative care model of holistic care – physical, psychological, spiritual, social – with positive objectives which will enhance the remaining days of the patient, and of relatives and carers. This is true “dignity in death”.

2. Definition of terms

2.1 Palliative Care:

2.1.1 Palliative care is an approach which improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems (physical, psychological, social and spiritual). Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient’s illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies which are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

For further information see www.who.int/cancer/palliative/definition/en

2.2 The Liverpool Care Pathway (LCP)

2.2.1 The LCP represents a continuous quality improvement programme for care of the dying. It allows for the transfer of best practice care of the dying in the hospice environment into other care settings. A key feature of the LCP is that it empowers generic healthcare workers to deliver optimum care to dying patients, irrespective of diagnosis.

For further information see www.mcpcil.org.uk/liverpool_care_pathway

2.3 The Gold Standards Framework (GSF)

2.3.1 The GSF is a systematic evidence based approach to optimising the care for patients nearing the end of life in the community. It aims to develop a locally-based system to improve and optimise the organisation and quality of care for patients and their carers, and to help people to live well until the end of life.

For further information see www.goldstandardsframework.nhs.uk

3. Spirituality and Religion

3.1 Spirituality is a well used and recognised term, yet one which lacks a clear definition. However, that lack of definition is a strength since it requires us to engage with people and to discuss spiritual needs rather than assess spirituality against set criteria. End of life care issues regularly lead to the concept of suffering, and a key element of suffering is pain. Spiritual suffering can contribute to physical pain but more often presents as distress rather than as pain. Common areas of distress include fear of dying, and questions such as “why me?”, and “how and when will I die?”. As the end of life draws closer, these concerns for self often change to become focused on others and include concern for family, friends, social and financial needs, and religion³.

3.2 Spirituality is also regularly confused with religion. Religion may be a part of a person’s spirituality but not always. While all family carers and professional carers have the potential to provide spiritual care, in hospitals and hospices there are chaplains who have experience and expertise in spiritual and religious care. Chaplains are appointed to provide spiritual care to all patients, their visitors, and staff.

3.3 In recent years the provision of spiritual and religious care has benefited greatly from multi-faith and multicultural approaches to healthcare and also the move towards professionalisation of healthcare chaplaincy. Religious care, and Christianity in particular, was in danger of being sidelined. However, along with the other world faiths, the spiritual and religious needs of Christians are taken seriously by the Scottish Government and NHS Scotland. NHS Education for Scotland, in partnership with the Scottish Interfaith Council, produced the report: ‘*Religion and Belief Matter*’⁴, which clearly states that spiritual and religious care are essential elements of healthcare.

3.4 The Church and Society Council acknowledges and endorses the Scottish Government definitions of Spiritual and Religious Care published in the Chief Executive Letter (2008) 49 which sets their relationship in context:

The NHS in Scotland recognises that the health care challenges faced by the people it cares for may raise their need for spiritual or religious care and is committed to addressing these needs.

³ Mitchell, D. (2008): *Spiritual and cultural issues at the end of life*. *Medicine* **36**: 109-110.

⁴ SCF, NHS Scotland, *et al.* (2007). *Religion and Belief Matter: A resource for all healthcare staff*. Glasgow, The Scottish Interfaith Council.

Spiritual care is usually given in a one to one relationship, is completely person centred and makes no assumptions about personal conviction or life orientation.

Religious care is given in the context of shared religious beliefs, values, liturgies and lifestyle of a faith community.

Spiritual care is not necessarily religious. Religious care should always be spiritual. Spiritual care might be said to be the umbrella term of which religious care is a part. It is the intention of religious care to meet spiritual need.⁵

3.5 Much of the contemporary discourse around end of life issues focuses primarily on physical illness, particularly when a terminal condition is diagnosed. The debate around mental ill-health and end of life choice is an equally complex area and, whilst not the subject of this report, the Church and Society Council recognise the importance of mental illness and acknowledge the need for appropriate study in this area.

4 Advance Decisions

4.1 An advance decision (AD), known as an ‘advance directive’ (commonly referred to as a ‘living will’), is a document which expresses the wishes of an individual as to their treatment should they become mentally incapacitated in the future and unable to make decisions. Under the *Adults with Incapacity (Scotland) Act 2000* there are two specific Powers of Attorney. The legislation provides for

(1) A "continuing attorney" who has authority to manage financial and property matters, and

(2) A "welfare attorney" who has authority to manage matters relating to personal welfare. These are registered with the Public Guardian in Scotland. The "welfare attorney" would (or should) be aware of any advance directives the patient has made, and has legal authority to be involved in any discussions/decisions relating to the patients medical/ nursing care.

4.2 Why have advance decisions?

4.2.1 It is a growing concern that many people will end up in hospital or in a long stay institution and lose their competence, and thus autonomy, in decision-making. An AD gives them the same right to refuse treatment as a competent patient. The demand for advance decisions is partly driven by fear – of prolonged pain (and suffering), of indignity, and of dependence on others and/or on machines.

⁵ The Scottish Government (2008). Chief Executive Letter 49 *Spiritual Care*. Edinburgh, The Scottish Government Healthcare Policy and Strategy Directorate.

4.3 It has been long recognised that an individual has the right to self determination, and that every person has the right to have his bodily integrity protected against invasion by others:

...the right of the competent individual to refuse treatment is ingrained in both common law and human rights law – and this right persists even though it may result in the patient's death.⁶

4.3.1 It is argued that an adult should be similarly allowed to make decisions about their future treatment should that person lose competence.

4.4 An AD enables the doctor in charge of a patient with impaired decision-making abilities to take into account the individual's wishes. It can transfer some responsibility for difficult decisions from family onto medical professionals. Indeed, it can comfort families to have some 'steer' from the patient. In some cases, the wishes of relatives will not necessarily coincide with those of the patient, and may be biased by financial and other considerations.

4.5 What are some of the problems with advance decisions?

4.5.1 ADs assume that prognosis is a precise art when this is far from being the case. In the real world medical prognosis is frequently right, but often wrong. It is also difficult to draw up a document which clearly defines all possible circumstances and can unambiguously define what is a 'severe' disability or illness.

4.6 ADs indicate the patient's past, rather than their present, attitude to terminal care. Individuals often change their minds on this matter over time. The healthy do not choose in the same way as the sick. In other words, an AD is less conclusive than the current statement of a competent, fully informed person.

4.7 ADs may specify that no fluid or food should be provided by artificial means; however, some doctors do not regard nutrition and hydration, by whatever means provided, as medical treatment. There is concern that food and fluids could be prohibited in cases when it would be clinically appropriate. Changing circumstances may render the AD inappropriate or even obstructive to the best care indicated for new circumstances. If such a decision were to be binding, the best management may be precluded. It is also claimed that ADs are a 'Trojan horse' aimed at the legalisation of euthanasia.⁷ Although they cannot demand that active steps should be taken to end life, ADs have been vigorously supported by pro-euthanasia organisations, such as Dignity in Dying.

4.8 The current position

4.8.1 ADs are legally valid for refusing treatment, but not for expressing treatment preferences, and will in all likelihood remain in use. We appreciate there are some

⁶ Mason, J.K. and Laurie, G.T. (2006): *Mason & McCall Smith's Law and Medical Ethics* 7th ed. Oxford: Oxford University Press, p630.

⁷ Care not Killing: www.carenotkilling.org.uk

benefits for their use but we are concerned that while the theory driving them may be simple, the practice is not. It is difficult to draw up a document which will be definitive in all potential circumstances leaving little room for change of mind during the critical time. We do not support any legal extension of their use or scope. However, the use of a welfare attorney, who has the authority to manage matters relating to personal welfare, who would be closely involved in discussions with health professionals and would be fully aware of the patients' wishes would be an alternative, whether or not the person has an AD.

4.9 A good relationship in which clear communication takes place between trained and experienced healthcare professionals and patient - as is usually the case with palliative care in hospices - is consistently better than an AD.

Previous deliverances by the General Assembly

The subject of Euthanasia has been discussed by the General Assembly of the Church of Scotland on four occasions, with Deliverances as follows :-

Deliverance in **1977**: “ ...[while] *we are aware of no theological difficulty in allowing a patient in extremis to die naturally, [we] disapprove of the deliberate termination of life...* ”

Deliverance in **1981**: “*The General Assembly re-affirms the view consistently held, that the Christian recognises no right to dispose of his own life...* ”

Deliverance in **1994**: (following the submission of a Study Group report on “Euthanasia – A Christian Perspective”⁸). “*..the General Assembly opposes the introduction of legislation on Euthanasia, abhors its practice, and rejects the principles on which it is proposed....* ”

Supplement of **2008**: A review was requested by the General Assembly in 2007 and this was based on the House of Lords Select Committee on Medical Ethics report in 1994 which begins:

There should be no change in the law to permit euthanasia.

This Report contained 21 conclusions and recommendations. The 2008 Supplement reviewed the developments and medical advances over the last decade and was approved by the General Assembly of 2008.

5. Assisted dying

5.1 “Assisted dying” is a relatively new phrase which frequently replaces “physician assisted suicide” (PAS) or euthanasia in literature. Euthanasia has particularly unacceptable connotations, and the move to a less evocative terminology perhaps reflects a changing attitude in society to those who elect to take this route at life’s end. In common with many Christians, the Church of Scotland through the General Assembly

has long opposed euthanasia. However, for those with different, or indeed no religious beliefs, many would claim the right to exercise autonomy in taking this final decision.

5.2 Several factors have influenced this perceived change in attitude. The Kirk's 1995 Report on Euthanasia pointed out that

*suicide is still recognised by most people as a tragedy, but no longer as a sin.*⁸

Legislation now exists in several other countries permitting PAS within certain guidelines. The unsuccessful Bill introduced in 2006 by Lord Joffe sought to achieve this in the UK Parliament, and MSP Margo Macdonald's proposed End of Life Choices (Scotland) Bill to the Scottish Parliament has the same aim. Facilities now exist in Switzerland (Dignitas) enabling other nationals to avail themselves of assisted suicide, and there has been widespread reporting in the media of patients travelling there from the UK. Such reporting has generally been of a sympathetic nature. Concern has also been expressed that, despite great advances in palliative care, resources for end of life care in the UK are less than satisfactory.

5.3 There is some support for permissive legislation, as was demonstrated by patients backing the actions of the Glasgow GP, Dr Kerr, who had to face GMC censure for providing a lethal prescription for a terminally ill patient. For the medical profession, the proposal to allow PAS represents a move away from one of its basic tenets – to preserve life. Despite this, a small on-line survey of 92 doctors in September 2008 showed 35% in favour of legalising PAS⁹.

5.4 It is still difficult to assess whether the legalisation of PAS elsewhere has given rise to increasing numbers choosing to avail themselves of it. There is concern that some might feel themselves under pressure to accept PAS to avoid placing burdens of care on their loved ones. Data from Oregon suggest that in 10 years of legalised assisted dying there has been no rise in the number seeking the option¹⁰ – although this conclusion is disputed in other studies¹¹. There is also concern, however, that legalisation there has undermined, rather than enhanced, other aspects of end of life care. In the Netherlands a fall in assisted dying reporting in fact resulted from an increase in the use of terminal deep sedation (Deep sedation, defined as: “the use of pharmacological intervention intended to induce or maintain sedation (deep sleep) to reduce the palliative patient's awareness of distressing and refractory symptoms”, is NOT equivalent to euthanasia when the intention is not to induce death)¹².

⁸ Board of Social Responsibility, Church of Scotland (1997): *Euthanasia, a Christian perspective*; Church and Society Council, Church of Scotland (2008): *Supplement to Euthanasia, a Christian perspective*.

⁹ Foster, K. (2008): *One in three medics back mercy killing*. Scotsman, 8th Sept.

¹⁰ Quill, T.E. (2008): *Physician assisted death in the United States: Essay - Are the Existing “Last Resorts” Enough?* Hastings Centre Report **38**: 17-22.

¹¹ Hiscox, W.E. (2007): *Physician-assisted suicide in Oregon: the ‘Death with Dignity’ data*. Medical Law International **8**: 197-220.

¹² Rietjens, J. *et al* (2008): *Continuous deep sedation for patients nearing death in the Netherlands: descriptive study*. BMJ **336**: 810-3.

5.5 Assisted dying is usually presented as a “dignified” death. This is not always the case, indeed relatives are frequently discouraged from being present at the point of death. NHS Scotland has produced a plan for improvements in palliative care, “Living and Dying Well”¹³ to address the issue of current deficiencies. Clearly it would be a disgrace if vulnerable patients opted for assisted dying because of a lack of resources to give them an acceptable quality of life in their last months.

6. End of life issues in children

6.1 This subject was dealt with extensively in the 1997 Report on Euthanasia⁸ from the Church of Scotland Board of Social Responsibility, to which readers are referred. The authors of that report included a specialist neonatal paediatrician; the current study group contained no such expertise, and it was felt that no change to the previously established position was required. Some of the main points from the 1997 report are reproduced below:

6.2 Paediatric terminal illness: The conscious child

6.2.1 Most conscious children requiring terminal care are cancer patients; there has been significant recent expansion in the specialised hospice provision for children.

6.3 The emotional aspects of caring for a dying child are difficult for parents and staff to handle, irrespective of the symptoms of the condition. Carers must consider the autonomy of children, as well as considering them as people who have a right and a need to know what is happening to them in terms that they can understand. A child, like an adult, has the right to express wishes, feelings and preferences; this must include the opportunity to accept or refuse treatment: eg further chemotherapy where there may be doubt as to the likelihood of response. It is responsible and necessary to give factual information to a child as much as to an adult, and experience has shown that children may handle the terminal care situation better than many adults.

6.4 Adequate symptom relief, sometimes self-administered and controlled by the child, and support for the family through the time of trauma are essential.

6.5 Involving family (including siblings) in decisions results in easier relationships and management of difficult situations. Counselling of the whole family is often necessary, and involvement of other children in family grief has a healing effect. Long family silence about a dead child, although common, generally has a destructive effect.

6.6 Paediatric terminal illness: The unconscious child

6.6.1 These are usually sufferers from trauma, head injury, and brain lesions of various kinds. The most frequent problem encountered is head injury related to traffic accidents. The criteria and debates for brain death are the same as in adults. ‘Switch-off’ decisions are generally made on the same grounds of negative expectation of recovery; parents

¹³ The Scottish Government (2008): *Living and Dying Well: A National Action Plan for Palliative and End of Life Care in Scotland*. CEL 40.

usually have the veto and often wish to continue life support initially, but may reach a point of acceptance of the futility of this after an opportunity to come to terms with the realities of the situation. Where the life-support requires to be switched off, this is usually done with the parents present, one of them often holding the child in the period after switch-off.

6.7 The Christian response

6.7.1 The Christian response will involve

- Palliative care with appropriate responses and resources.
- Better communication in respect of the child, taking account of the need for counselling and a recognition and respect for the child, equally, as a person formed in the image of God.
- Valid motivation: the phrase ‘compassion mingled with respect’, attributed to Mother Teresa, perhaps sums up the most constructive attitude. The irreducible minimum of care could be defined as: fluid and nutrition, analgesia and tender loving care (TLC).

7. Definition of Cessation of Life

7.1 While it must be recognised that, in many cases, death is a process rather than simply a point in time, “brain death” as a legal definition of the cessation of life emerged in the 1960s as a response to the ability to resuscitate individuals and to mechanically keep the heart and lungs working. In simple terms, brain death is the irreversible end of all brain activity (including involuntary activity necessary to sustain life) following loss of blood flow and oxygenation.

7.2 Traditionally, both the legal and medical communities determined death through the end of certain bodily functions, especially breathing and heart beat. With the increasing ability to resuscitate people with no heart beat, respiration or other signs of life, the need for a better definition of death became obvious. This need gained greater urgency with the widespread use of life support equipment (which can maintain body functions indefinitely), as well as rising capabilities and demand for organ transplantation.

7.3 Today, both the legal and medical communities use brain death as a legal definition of death. Using brain-death criteria, the medical community can declare a person legally dead even if life support equipment keeps the body's metabolic processes working. A brain-dead individual has no clinical evidence of brain function upon physical examination. This includes no response to pain, no cranial nerve reflexes, and no spontaneous respirations. It is important to distinguish between brain death and states which may mimic brain death (eg barbiturate intoxication, hypoglycemia, coma or chronic vegetative states). Some comatose patients can recover, and some patients with severe irreversible neurological dysfunction will nonetheless retain some lower brain functions such as spontaneous respiration, despite the losses of both cortex and brainstem functionality.

7.4 The diagnosis of brain death needs to be rigorous to determine whether the condition is irreversible. Legal criteria vary, but it generally requires neurological examinations by

two independent physicians; these must show complete absence of brain function, and may include two flat-line electro-encephalograms (EEGs) 24 hours apart.

7.5 Despite the adoption of such criteria in the United Kingdom, brain death has been questioned from the beginning. For example, brain dead pregnant women have lived up to 200+ days and given birth to healthy children¹⁴. Others have argued that there is insufficient evidence that the entire brain is dead in a brain dead individual. Some brain dead individuals have continuing EEG activity and others maintain normal or near-normal body temperature, implying continuing hypothalamic function. While it is unlikely that the medical profession will revert to the “heart death” definition of the cessation of life, it should be noted that this area remains controversial.

8. Sedation

8.1 Symptom control should be based on the needs of each individual patient. While deep sedation may not often be used deliberately, sedation can be a side effect of other treatments and must be assessed continuously. Symptoms such as pain, restlessness, obstruction with vomiting, breathlessness, swallowing problems and spiritual pain, can be very distressing not only for the patient but also for their carers and loved ones.

8.2 Pain relief is usually given orally, following the World Health Organisation ‘analgesic ladder’. If the patient cannot tolerate it, or if nausea is the main problem, medication can be given by a syringe pump until symptoms are under control, and patients often manage to revert to oral medication. Assessment should be done in a multi-disciplinary setting, and it is often the nursing staff who will alert the doctors and initiate change in symptom control as they are closest to the patient.

8.3 It is difficult to say at which point it could be argued that some of the drugs used might “hasten death”, as the progression of disease is often relentless and symptoms need to be controlled. Sometimes patients require sedation to allow them to have a good night’s sleep, as they are so anxious and exhausted. After this they can often cope better and are able to face things calmly.

8.4 The wishes of the patient should always be paramount. They may have preconceived fears, which when explained can be resolved. While relatives are closely involved, it is the patient who should decide. Many patients ask not to be allowed to suffer. The 2003 WHO declaration on palliative care states that suffering should be prevented or relieved (See Definition of Terms).

8.5 Many aspects of the physiology of dying are well established, such as withdrawal from the world, declining food, and sleeping. Alleviation of dehydration can be part of the palliative symptom control, such as by intravenous or subcutaneous fluids. Relatives often get alarmed when these things happen, and it is important that staff give adequate explanations. Many Scottish health boards now follow the Liverpool Care Pathway,

¹⁴ Shewmon, D. A. (1998): *Chronic 'brain death': Meta-analysis and conceptual consequences*. *Neurology* **51**: 1538–1545

training medical staff in spiritual aspects of palliative care, such as the concept of spiritual pain and suffering.

8.6 Most patients know they are dying. Many do not fear death itself but are afraid as to how they are going to die. Relatives can either help or hinder a 'good death' as they may refuse to accept the reality, even though the patient has done so. This can prevent the patient from fully opening up as they feel they have to be brave and pretend they are fine. Careful exploration of issues by medical and nursing staff can help.

9. Non- malignant conditions

9.1 More resources are often available to those with a diagnosis of malignancy (cancer) than to those with other, but no less life-threatening, conditions of a non-cancerous nature: a cancer diagnosis often attracts more sympathy and concern in a community, frequently stimulating major fund raising initiatives of great and lasting value. Financial aid, hospice facilities, and nursing support can be harder to access for sufferers from some of these "Cinderella" conditions. Much support for the terminally ill depends on charitable funding rather than the NHS. The hospice movement is one example of this, and support organisations such as Marie Curie Cancer Care, Macmillan Cancer Support, and the Maggie's Centres¹⁵ also rely upon charitable giving. Unfortunately, some of these facilities are provided for cancer sufferers only¹⁶.

9.2 The "*Living and Dying Well*"¹³ action plan for palliative and end of life care in Scotland, produced in 2008 by NHS Scotland, recognises the need to address this problem, and gives a useful classification system for non-cancerous illnesses with poor prognosis.

- 9.2.1 The first category is those with Organ Failure. This includes heart disease (mainly heart failure), chronic lung disease, end-stage kidney failure, and neurological conditions. The three most significant illnesses in the last group are Motor Neurone Disease, Multiple Sclerosis, and Parkinson's disease.
- 9.2.2 The second category comprises patients with frailty (multiple conditions leading to increasing impairment of function), Dementia, and Stroke.

9.3 None of these conditions can be described as curable, and thus sufferers are approaching the end of life, though that point may be months or even years away. The impact of any one of these diagnoses on a patient and their families can be devastating.

¹⁵ Maggie's Centres have been developed with the express purpose of providing a wide range of care and assistance for cancer patients and their relatives. This includes help with information, benefits advice, psychological support both individually and in groups, courses and stress reducing strategies. See <http://www.maggiescentres.org>

¹⁶ Shipman, C. *et al.* (2008): *Improving generalist end of life care: national consultation with practitioners, commissioners, academics, and service user groups*. British Medical Journal **337**:a1720

9.4 Many cancerous conditions are now treatable and some curable. People with organ failure or dementia can only look forward to their health deteriorating at an unpredictable rate. A good example of the problems surrounding this issue is the situation of people with dementia. In addition to living with an incurable condition, those with dementia must live with the knowledge that they will eventually lose control of their lives and actions. Patients with many of these conditions spend considerable periods of time at home with a partner, who is often also in their later years and with physical disabilities, and who may become increasingly worn down and frustrated. People often describe seeing a partner's decline into dementia and ultimate death as a "double bereavement".

9.5 From a subjective point of view, being helpless and in need of care because of dementia might well seem like a great indignity, especially in a society such as ours which puts a premium on autonomy and independence. But this does not mean that persons with dementia have lost their intrinsic human dignity. Philosophers have argued that people with dementia:

...should be retained within a circle of protection, because we remember what they have achieved and we honour their biographical past....Rightly so, for surely (all) those who are ill, dependent and dying remain our fellow humans. As such they never lose their dignity.¹⁷

9.6 To be cared for by others requires trust in the carer. It requires recognition of the carer as caring and of the importance of human community. Decisions should not be influenced by perceived quality of life criteria because every patient, with or without dementia, should be equally valued and provided with the love and support of others.

9.7 Most patients in these categories require frequent hospital admission as time progresses. They cannot enjoy holidays as they may be uninsurable for travel, they are unemployable, and they cannot plan for an uncertain future. In addition, people with chronic lung disease and their families may be locked in legal struggles for compensation over a perceived cause of their illness, with settlements often outstanding at the time of death.

9.8 The main needs are for day-time support, and in the later stages night-time also; for good continuity of nursing and medical care; for adequate respite care; and, ultimately for many, a residential placement which allows partners to visit on a regular basis. Sadly, in much of rural Scotland this last need cannot be met, and many life partners are separated during their final months together. The *Living and Dying Well* plan is to be welcomed, addressing as it does the need to recognise the special requirements of families affected by these conditions. It also sets out to apply good models of practice such as the Gold Standards Framework and the Liverpool Care Pathway to non-cancer patients, ensuring a truly holistic approach. Palliative care practitioners are well aware of these needs and are

¹⁷ Sutton, A. (2008): *Christian Bioethics: A Guide for the Perplexed*, T&T Clark, p54

striving to improve access to hospice beds¹⁸. The recent initiative by Marie Curie Cancer Care and the British Heart Foundation to set up a pilot centre in Glasgow for heart failure patients and their families is also a very welcome development indeed¹⁹.

10. Nutrition and hydration

10.1 This subject is a much wider debate than simply “End of life issues”. Within the euthanasia debate it usually focuses on the withdrawal of artificial feeding, as in the case of Tony Bland who was in a Persistent Vegetative State (see Airedale NHS Trust v. Bland, 1993²⁰). In the Bland case Lord Lowry expressed his view as:

I do not believe that there is a valid distinction between omission to treat a patient and the abandonment of treatment which has been commenced, since to recognise such a distinction could quite illogically confer on a doctor who had refrained from treatment an immunity which did not benefit a doctor who had embarked on treatment in order to see whether it might help the patient and had abandoned the treatment when it was not seen to do so.

10.2 If ‘end of life’ is strictly defined as the last hours or days, then thirst may be appropriately managed by good mouth care and soothing by whatever the patient finds helpful (eg sucking ice or pineapple).

10.3 Artificial nutrition and hydration have been considered as medical treatments by the British Medical Association (BMA) since 1992. Subsequently the BMA ethics committee in 1999 proposed that the withdrawal of artificial nutrition or hydration from incapacitated patients should not only be possible for patients in Persistent Vegetative State but should also be an option for patients who have suffered a “serious stroke or have severe dementia”, states in which patients may continue for months or years. Guidelines have been given by the BMA Ethics Committee.²¹

10.4 Some health professionals regard the provision of artificial nutrition and hydration as basic care which should always be provided unless the patient’s death is inevitable, in which case the benefits may no longer be proportional to the burdens. There has been considerable debate over the last decade on the subject of hydration. The ethical, legal and medical dangers of a regime of sedation without hydration in the dying has been reviewed in a 2005 publication “No water – No life: Hydration in the Dying”.²²

¹⁸ Sugden, C, Consultant Palliative Care Physician, St Andrew’s Hospice, Airdrie: Personal communication

¹⁹ Puttick, H. (2008). *Charities team up to give palliative care to patients with heart disease*: The Herald. Dec. 17th

²⁰ http://www.swarb.co.uk/c/hl/1993airedale_bland.html

²¹ British Medical Association Ethics Committee report (1999): *Withholding or Withdrawing Life-Prolonging Medical Treatment – Guidance for Decision Making*: Section 21.4

²² Craig, G.M. (2005): *No water – No life: Hydration in the Dying*. Fairway Folio

10.5 A serious issue arises in the general care of frail elderly patients where adequate fluid intake may be limited by difficulty in holding a cup or pouring a drink, and where adequate nutrition may be inhibited by inappropriate food or food presented in such a way that the patient cannot feed themselves. If adequate and appropriate nutrition and hydration is medical treatment then it must be supervised by a health care professional. If it is general care, there is a risk that it regarded as the responsibility of the patient and their 'human rights' to take or refuse what is provided.

11. Allocation of resources for end of life care

11.1 Palliative Care: In 2006/2007 in Scotland, £59 million was spent on specialist palliative care, half of which came from the voluntary sector. It is not possible to say how much is spent on non- specialist (generalist) palliative care. Part of the difficulty is in deciding when the end of life period starts. The Scottish Government launched an action plan for palliative care in Scotland in October 2008¹³. It is not clear how much money is pledged to implement this plan. Key elements of this strategy are two systems: the Liverpool Care Pathway and the Gold Standards Framework.

11.2 In terms of place of death, 58% of deaths occur in hospitals, 18% occur at home, 17% in care homes, 3% in hospices, and 3% other²³.

11.2.1 **Hospices:** Most specialist palliative care is focussed in hospices, where the majority of patients have cancer. Hospices care particularly for those who have complex problems such as hard-to-control pain.

11.2.1.1 The majority of people who are dying are therefore cared for by staff who are not specialists in palliative care, either in hospitals, care homes or in their own homes. Not everyone who is dying has complex needs which require a specialist. However, a recent report on palliative care services in Scotland identified that good palliative care is not always available to everyone who needs it. This is particularly true for those dying from non-malignant diseases such as dementia, heart disease and respiratory disease²⁴.

11.2.2 **Care Homes:** Scotland has an ageing population, and the number of people dying in care homes is increasing. There is evidence to suggest that there is suffering among those dying in care homes for various reasons, including:

- lack of access to palliative care education
- high turnover of staff
- low staffing levels

²³ Department of Health (2008): *End of Life Care Strategy – promoting high quality care for all adults at the end of life*, London

²⁴ Audit Scotland (2008): *Review of Palliative Care Services in Scotland*. Edinburgh, August

- an emphasis on rehabilitation which makes dying peripheral, despite the fact that those living in care homes are increasingly frail with complex needs on admission.

11.2.2.1 The majority of care home residents die within two years of admission²⁵. Although care home staff training is largely co-ordinated by the Scottish Commission for the Regulation of Care, maintenance of levels of trained, competent and motivated staff is largely the responsibility of individual care homes. Emphasis in training is usually given to nutrition, hydration and pain control; spiritual care is often considered less important.

11.2.2.2 Changing practice in care homes takes time as it involves a change in the culture of care. This requires adequate resources in terms of practice development projects which are long enough to allow changes to be embedded and sustained. A key recommendation of a recent feasibility study on the use of the Gold Standards Framework in Care Homes was the need for greater availability of palliative care support and more formal links between care homes and providers of specialist palliative care²⁶.

11.2.3 **Hospitals:** Hospital specialist palliative care teams are now well established in larger hospitals. These teams are usually small and have an advisory/educational role. However, most patients are only in hospital for a relatively short period of time (2-3 weeks in most cases).

11.2.3.1 More than half (54%) of all complaints made about the NHS are about deaths in hospitals. Many of these complaints relate to poor communication about death and dying²⁷; with increasing awareness of these issues among hospital staff, it would be hoped that this would improve.

11.2.4 **Home:** Although many people with progressive illness say they would like to die at home, the majority of people continue to die in hospital. The factors which influence where people die are complex but include:

- **Factors related to illness**– clinical changes which occur because of illness
- **Individual factors**– patients’ beliefs, wishes and inner resources to cope with illness, and also carers at home who face increasing burdens with the advancing condition of the patient

²⁵ Hockley, J., B. Dewar and J. Watson (2004): *Developing quality end of life care in eight independent nursing homes through the implementation of an integrated care pathway for the last days of life. Phase 3 of Bridges Initiative*. Copies are available from jwatson@stcolumbospice.org.uk

²⁶ Hockley, J., J. Watson and S. Murray (2008): *The Midlothian ‘Gold Standards Framework in Care Homes’ project*. Copies can be downloaded from the Palliative Care Research Group website at the University of Edinburgh

²⁷ Lowson, S. (2007): *Why families complain about end of life care in the NHS*. End of Life Care 1, No 2

- **Environmental factors**– healthcare input available and social support networks, in addition to layout of the house (for example, when the bathroom is on a different floor to the bedroom), and wheelchair access to and within the house ²⁸

11.2.4.1 In practice, some of the reasons why patients often require admission are symptoms which are difficult to manage at home, fear and anxiety of the patient and/or their family, and carer fatigue.

11.3 There is an opportunity for individual congregations or presbyteries to have a significant role in palliative care, in conjunction with Social Services. With a good organisation, staffed by volunteers alongside professionally trained people, a valuable Christian service can be made available. An example of what can be achieved is provided by the Evergreen Trust²⁹.

11.4 The challenge is to improve the quality of end of life care, wherever people die and whatever their condition or financial circumstances³⁰. Good end of life care depends on appropriate levels of trained and motivated staff, access to palliative care education, access to specialist advice and support in more complex cases, adequate levels of support for staff to avoid burnout and, equally importantly, more intangible resources such as compassion. It is hoped that the national action plan, *Living and Dying Well*, will ensure that adequate and appropriate resources are made available to enable good end of life care to be delivered in all settings.

12. Education of Healthcare Professionals

12.1 Since its inception, palliative care education has used the model of multidisciplinary education. Palliative care is synonymous with holistic care which includes the body, mind, social and spiritual and so healthcare professionals from the disciplines which support these areas of care study and work together. The Scottish Government in its standards for palliative care identified chaplains, doctors, nurses, occupational therapists, pharmacists, physiotherapists and social workers as the key professions of the

²⁸ Gomes, B. and I. Higginson (2006): *Factors influencing death at home in terminally ill patients with cancer: systematic review*. *BMJ* **332**, 515-518.

²⁹ The Evergreen Trust, based in Stamford, Lincolnshire, aims to promote holistic health in individuals and healthy attitudes towards ageing, challenging age discrimination and negative social expectations, and has grown to 26 paid staff and 110 registered volunteers in just 3 years. The Trust is supported by churches and agencies all working together in the community. It seeks the promotion of healthy ageing, working to build self-esteem and to restore social status, improving the circumstances of ageing and vulnerable people. It achieves this through home support services (helping with domestic, shopping and laundry needs) and volunteer services – including a befriending scheme, meal provision, a clean team and a hospital to home support team. See <http://www.evergreencare.org.uk/> for further details.

³⁰ Barclay, S. (2008): *Place of death- how much does it matter?* *British Journal of General Practice*. Editorials, April

multidisciplinary team with additional access to identified specialists in psychological and other services³¹.

12.2 A key and central element in palliative care education is training in communication skills: how to break bad news, dealing with difficult questions, coping with strong emotions, etc. These skills are now recognised and developed in the training of healthcare professionals, and of doctors in particular. The GP training programme offers doctors an opportunity to use these skills in real life situations and is a good example of how community healthcare services can also benefit from this approach.

12.3 Through enhanced communication skills and studying together, healthcare professionals gain an in-depth understanding of each others roles and expertise and therefore have a more informed and holistic approach to care. It is particularly helpful in ethical dilemmas such as assisted dying where the concept of suffering may be central but is rarely about pain alone, where informed decisions require a broader approach than simply understanding the physical needs of the patient.

12.4 The principle of multidisciplinary education is incorporated in the decision of NHS Education for Scotland in their recent commissioning of professional education for Healthcare Chaplaincy; a condition of the contract is that it should be set in the context of a multidisciplinary healthcare education programme.

13. Care for the Carers

13.1 When making an ethical decision in distressing circumstances a key question which must be asked by all those involved in the process is: **whose needs are being met?** Distress, including feelings of helplessness and lack of control, may be felt by the patient, relatives and staff involved. For example, a patient may become agitated and restless near the end of a terminal illness and the relatives may ask the staff involved to increase the amount of sedation the patient is being given. At times such distress may have to be lived with and through in order for the patient's and relative's spiritual and emotional needs to be assessed (is there unfinished business the patient and/or relatives want to deal with?) and, where possible, met. However, staff can only make the offer to help patient, relatives and friends address these issues. Ultimately, it is their choice whether to address such issues or not.

13.2 At times it may be appropriate to sedate a patient heavily to meet the needs of relatives as well as the patient. Often near death, patients become increasingly more concerned about the needs of their loved ones rather than their own and do not wish to additionally burden their family with their own personal distress as well as the anticipatory grief relatives are already experiencing.

13.3 *'Perhaps patients die as they live.'*³² – some die in quiet acceptance, others restless and still wanting more, and others still raging against the world and the incomprehensible

³¹ NHS Quality Improvement Scotland (Formerly the Clinical Standards Board for Scotland) (2002). *Clinical Standards Specialist Palliative Care*. Edinburgh

way God allows injustice and suffering. Relatives and staff often find it difficult when others die in a manner they would not want for themselves.

13.4 It is also hard when the collaborative decision made in any given circumstance is not the one certain persons involved would personally have come to. For example, for staff to continue to treat a patient whose best interests they feel would be served by ceasing all active treatment and be allowed to die when the consultant they work with insists treatment is still beneficial. Staff's emotional and spiritual needs also have to be recognised and attended to, where appropriate, during the process of dying (or not), and also following death(s).

13.5 Rituals, for patients, relatives and staff during the dying process, at death and afterwards, may provide a context, and permission, for the expression of or acting out of feelings and wrestling with issues of understanding and meaning. Other denominations, in Scotland and beyond, historically ritualise dying and bereavement more comprehensively than the Church of Scotland. However, for example, increasingly parish churches as well as healthcare chaplaincies hold regular memorial services or times of remembrance for the bereaved in the months following their bereavement. In our post-modern world, society has become bereft of a common language, symbols and stories to engage with the pain and mysteries of life and death – the majority of people are no longer familiar with the Judeo-Christian narrative. Therefore, utilising gestures and actions within ritual moments may provide a shared means of expressing grief and marking, with dignity, the importance of lives lived and lost: for example, the lighting of candles, the placing of flowers or objects relating to the dead, the planting of shrubs and trees or the sponsoring of lights on a community Christmas tree. Church representatives, as resident ritual 'experts', have much to offer in facilitating such rituals for individuals, families and communities in healthcare, parish and national settings.

14. Christianity and euthanasia

14.1 All faiths offer meaning and explanations for death and dying; all faiths try to find a place for death and dying within human experience. Religions regard understanding death and dying as vital to finding meaning in human life. Dying is a natural process, and is often seen as an occasion for getting powerful spiritual insights, as well as for preparing for the afterlife to come.

14.2 In common with virtually all religions, Christianity would recognise that those who become vulnerable through illness or disability deserve special care and protection, and that proper end of life care is much better than euthanasia. Euthanasia has been opposed for a number of reasons: for example

14.2.1 **God has forbidden it**

The command from God which says 'you must not kill' is usually interpreted as meaning 'you must not murder'. However, a broader interpretation is that you must not take

³² Jeffrey, D. (2000): *Care versus Cure*. In *Ethical Issues in Palliative Care*, ed. P. Webb, 14-42. Manchester: Hochland and Hochland.

human life. This rules out euthanasia (and assisted suicide), as carrying these out would be against God's commandments, and would be an attack on the sovereignty of God.

14.2.2 **Human life is special**

Human beings are made in God's image, therefore they have a special value and dignity. This value doesn't depend on the quality of a particular life, and taking a life violates that special value and dignity, even if that life is full of pain and suffering.

14.2.3 **Human life is sacred**

The sanctity of human lives derives from the fact that God created them; therefore human life should be protected and preserved, whatever happens, and we shouldn't interfere with God's plans by shortening human lives.

14.3 One of the issues which repeatedly comes up in discussions around this issue is the area of personal autonomy: "it's my life, and I can choose how and when to end it". This may be particularly true in the individualistic West, where personal choice pervades all areas of life - including religion. While it must be recognised that personal autonomy is indeed an important issue, as has been argued elsewhere in this document, interpersonal relationships are also important. Life is lived and death experienced as part of community.

14.4 The worth of every human life needs to be emphasised and celebrated; in particular, the deliberate ending of life would be a matter to be deplored if it were to be seen as a means of saving (financial) resources, or that any person was perceived as merely a burden.

15. Pastoral care and end of life care

15.1 Whilst certain aspects of end of life care belong to the multidisciplinary team within the hospital and hospice services, the church remains a powerful source of healing for people as they near death, and for their families. This pastoral task takes on a number of forms. At one level, the church as a community is available as a form of support, encouragement and friendship. By offering important forms of relational and spiritual support, the church community provides an anchor which can help people to cope with the reality of their impending death and to die well. In terms of the issues highlighted in this report, this is no small point. There is evidence to suggest that if a person has their spiritual needs met, if they can find meaning and purpose in the midst of their dying, they are less likely to ask for physician assisted suicide³³. In other words, if palliative care includes good spiritual care then some of the ethical issues surrounding euthanasia and physician assisted suicide may not arise in the first place. It is when such needs are not met that people may feel the need to hasten their deaths. However, the pastoral role of the church has other important and often unnoticed dimensions. Earlier we stated that "*perhaps patients die as they live.*" This is an important point that we need to return to

³³ Breitbart, W. (2002): *Spirituality and meaning in supportive care: Spirituality- and meaning-centered group psychotherapy interventions in advanced cancer*. Supportive Care in Cancer 10: 272- 280.

here. When we discuss the issues surrounding end of life care we tend to think in terms of people's experiences during the last days and months of their lives: when they are dying. However, on reflection, end of life care begins much earlier in a person's life.

15.2 Living with hope, dying with dignity.

15.2.1 There is a good deal of research evidence which indicates that people's spirituality, and in particular their religious spirituality, can be of great help when approaching death³⁴. The Christian tradition provides us with structures of hope, meaning and new possibilities even in the midst of pain and suffering. In a death-denying culture such as our own, Christianity enables us to look at death quite differently from the culture around us, offering us rituals, prayers, scriptures and communities that embody and live out the belief in the resurrection. This in turn provides both life and death with new meaning. This is important. Our beliefs and understandings of the world help us to die well. But our beliefs about life and death don't miraculously appear at the end of our lives. We die in precisely the way that we live. Dying well requires that we live well, not just at the end of our lives but throughout the whole of our lives. In other words, the time to begin to develop the types of beliefs and practices that will be so helpful to us as we face death is not when we are struck by illness, but rather in the practices of everyday life during seasons of illness and health.

15.3 End of life care begins in the day to day life of the Christian community and not simply within the hustle, bustle and technical expertise of the medical ward at the end of a person's life. Our preaching, teaching, and community-building from cradle to the grave changes the meaning of death and dying in important ways, and forms the foundation for effective end of life care. End of life care therefore begins where we are right now. As Christians concentrate on their spiritual formation in the present time, so they begin to prepare themselves for that time when suffering and pain will form the tragic garland that decorates their experience, at least for a while. The church then provides a vital if often overlooked aspect of end of life care which relates both to pastoral care and to the types of ethical dilemmas that have been highlighted in this report.

16. Conclusion

16.1 The Church proclaims that Jesus came to bring "*life in all its fullness*"³⁵. This report seeks to affirm this view, and to encourage all concerned to seek to help those approaching the end of their lives to experience as fulfilled a life as possible. It is recognised that many difficult decisions must be made as the end of life approaches - not least as those most profoundly affected may not be able to fully express their needs or desires. Although a natural process, the finality of death and the "letting go" which that involves for all parties means that the end of life can be a very stressful and emotional period - especially when, as is increasingly the case, this "end of life" period can extend over weeks or months.

³⁴ Sinclair, S., J. Pereira and S. Raffin (2006): *A Thematic Review of the Spirituality Literature within Palliative Care*. *Journal of Palliative Medicine* 9: 464- 479.

³⁵ John 10: 10

16.2 Many areas where improvements can be made could be identified - from a wider understanding of palliative care beyond simply the alleviation of pain, to the need for the provision of appropriate pastoral and spiritual care - including for health care staff and carers. Making such improvements will in many cases require an increase in resources - sometimes financial resources, although it must also be recognised that non-monetary resources (such as compassion) are important parts of the equation. The Church stands resolutely against the idea that human life is made less dignified or worthy by limitations in capacity, and affirms again opposition to legislation which seeks to bring about the deliberate ending of life.

16.3 Despite the inevitable sadness involved in saying farewell to a loved one, the church has a responsibility - and in some ways the privilege - to ensure that all participants in the process experience as fulfilled and comfortable a final journey as possible.

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Proposed practical outcomes

The Church and Society Council would offer the following as some examples of practical responses local churches or Presbyteries could develop:

- “Old age pastors” in congregations
 - Pastoral care
 - Care of carers
 - Practical support for carers
- Utilisation of church resources:
 - Halls for eg friendship clubs
 - “Taxis” to get people to church/ doctor/ hospital visiting
- Legal issues- eg powers of attorney
- Bereavement care

- Continuation and creative development of use of ritual to mark lives and deaths of deceased in local communities eg memorial services, times of remembrance
- Congregational Bereavement Care Teams (Trained and Supervised)
 - Liaising with local healthcare professions. Thus able to support and cross refer those bereaved identified as most isolated and vulnerable in communities by healthcare professionals and/or church.

Resources for End of Life Report

While not an exhaustive list the following are offered as examples of resources which are available for individuals and church groups to draw on.

Bereavement

Cancer Link Aberdeen & North (CLAN) <http://clanhouse.org/cms/>
 Cruse Bereavement Care <http://www.crusebereavementcare.org.uk/>
 Royal College of Psychiatrists
<http://www.rcpsych.ac.uk/mentalhealthinformation/mentalhealthproblems/bereavement.aspx>

Children and Bereavement

Child Bereavement Trust <http://www.childbereavement.org>
 Children's Hospice Association Scotland <http://www.chas.org.uk/>
 Notre Dame Centre <http://www.notredamecentre.org.uk/>
 (for children and families with complex needs)
 Richmond's Hope
<http://www.richmondshope.org.uk/index.htm>
 Winston's Wish <http://www.winstonswish.org.uk/>

Useful websites

Alzheimer Scotland – Action on Dementia <http://www.alzscot.org/>
 CancerBacup <http://www.cancerbacup.org.uk/Home>
 Macmillan Cancer Support <http://www.macmillan.org.uk>
 Maggie's Centres <http://www.maggiescentres.org>
 Marie Curie Cancer Care <http://www.mariecurie.org.uk/>
 Motor Neurone Disease Association <http://www.mndassociation.org/>
 Multiple Sclerosis Society Scotland
<http://www.mssocietyscotland.org.uk/scotland/>
 Patient UK <http://www.patient.co.uk>
 Scottish Motor Neurone Disease Association <http://www.scotmnd.org.uk/>
 Scottish Partnership for Palliative Care <http://www.palliativecarescotland.org.uk/>
 Widowed and Young Foundation <http://www.wayfoundation.org.uk>

For Advice

All hospices offer 24 hour advice service for healthcare professionals. Hospice staff will be aware of what help is available locally.