



BILLET D'ÉTAT

WEDNESDAY, 27th OCTOBER, 2004

POLICY COUNCIL

VOLUNTARY EUTHANASIA
(DEATH WITH DIGNITY)

XVI
2004

B I L L E T D ' É T A T

TO THE MEMBERS OF THE STATES OF THE ISLAND OF GUERNSEY

I have the honour to inform you that a Meeting of the States of Deliberation will be held at **THE ROYAL COURT HOUSE, on WEDNESDAY, the 27th OCTOBER, 2004**, at 9.30am, to consider the item contained in this Billet d'État which has been submitted for debate by the Policy Council.

DE V. G. CAREY
Bailiff and Presiding Officer

The Royal Court House
Guernsey
16th September 2004

POLICY COUNCIL

VOLUNTARY EUTHANASIA (DEATH WITH DIGNITY)

1. Introduction

At the September 2002 States meeting a Requête entitled Death With Dignity, placed by the then Deputy Patricia Mellor and signed by thirteen other Members of the House, received majority support. Consequent to the States' resolution, the then Advisory and Finance Committee was instructed: -

'..to carry out appropriate investigations and consultations with whomever it deems fit, and thereafter, but at the earliest opportunity, to bring a report to the States of Deliberation, on the implications of allowing Doctor Assisted Death or some other similar Death With Dignity Legislation to be implemented within Guernsey, and containing the Committee's recommendations in connection with this matter.'

In order to carry out this research the Advisory and Finance Committee established the Death With Dignity Working Party under the independent chairmanship of a member of the Guernsey Bar and containing the professional expertise necessary to consider the social, legal, medical, ethical and spiritual issues that arise from this complex subject. The Working Party's report, which has been passed to the Policy Council as the successor to the Advisory and Finance Committee, is appended in full.

The Policy Council wishes to record its thanks to the Chairman, Advocate Gill Dinning and Members of the Death With Dignity Working Party for the considerable work that has gone into producing a professionally researched document.

2. Research

It is essential that a subject of this importance takes into account all available experience and expertise. The Policy Council is satisfied that Working Party's research has been thorough and extensive in its scope.

Much information has been gathered from two of the three territories where legislation to facilitate voluntary euthanasia, (to use the generic term which will be used from here onwards), is in place, that is, the Netherlands and Oregon USA. Voluntary euthanasia also became legalised in Belgium in May 2002. The position in territories where voluntary euthanasia was legalised and subsequently withdrawn was also examined.

The Working Party also consulted with, and ascertained the current views of relevant professional bodies representing the medical and nursing professions in the UK. Members were also greatly assisted by having access to Professor Baroness Ilora Finlay and Lord Joel Joffe, two of the most prominent protagonists of the voluntary euthanasia

debate in the UK, who were able to provide insight into the subject from two opposing perspectives.

The opinion of the Guernsey Medical Ethics Committee was sought and a consultation exercise was carried out in February 2004 with a substantial proportion of the local medical and nursing professions.

Probably most importantly, in June and July 2003 Members of the Guernsey public were provided with an open invitation to submit their views to the Working Party on the subject of voluntary euthanasia. In total 296 submissions were made, many of which were extremely well researched and detailed.

The Policy Council would also like to express its gratitude for the input provided to the Working Party by all consultees and research sources.

3. Majority Recommendations of the Death With Dignity Working Party

The Death With Dignity Working Party's report contains a majority view and also a minority report produced by Deputy Peter Roffey and also endorsed by Deputies Hunter Adam and Francis Quin.

The majority view expressed by the Working Party recommends that: -

- There should be no change to the present legal position on any form of euthanasia, and

in support of maintaining the status quo, that: -

- Guernsey should designate a lead clinician in palliative care and provide a management support structure to ensure palliative care of the highest standard,
- law and practice in Guernsey be clarified to achieve greater certainty about advance directives, both for their makers and for the medical professionals considering their applicability, and
- the fact that proper prescribing of pain relief under the double effect principal is legal should be clarified and included as part of any future legislation on end of life decisions.

4. Minority Report

The minority report recommends that Guernsey should legislate to facilitate voluntary euthanasia, utilising a system with scope similar to that in force in Oregon USA. Should the States resolve that euthanasia, in whatever form, is made available in Guernsey, there would be constitutional and legal issues that would require further research before

work could begin on drafting the legislation required. Investigation of these issues has not been carried out by the Working Party as it was not within its mandate so to do.

Deputy Roffey has, however, stated that he intends to place an Amendment to give States Members the opportunity to support the minority report.

In addition, although the necessary legislation is not yet in place to enable a referendum, Deputy Trott and Deputy Jones have stated that, in the event that the States decide to support the minority report, then the States' decision should be the subject of an island-wide referendum. However, the majority of the Policy Council disagrees with this view.

5. Recommendation of the Policy Council

The Policy Council recognises that voluntary euthanasia is a complex and highly emotive issue on which States Members can be expected to vote according to individual views or conscience.

However, after careful consideration of the Working Party's report, the Policy Council, by a majority supports and recommends the Working Party's majority view i.e. that there should be no change to the present legal position in order to support euthanasia in any form.

The Policy Council further recommends that the Health and Social Services Department be directed to progress the Working Party's recommendations on the three associated issues detailed above, i.e.

- the provision of palliative care,
- clarification of the position on advance directives, and
- clarification of the position on the proper use of double effect medication.

B M Flouquet
Deputy Chief Minister

13th August 2004

Death With Dignity Working Party

**Report to the Advisory and Finance Committee in response to the
Requête of 28 June 2002 entitled Death with Dignity.**

24 May 2004

Report to the Advisory and Finance Committee in response to the Requête of 28 June 2002 entitled Death With Dignity.

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1. **Executive Summary**

1. The Working Party was convened to consider the implications of changing the law in Guernsey to allow Guernsey residents assistance to end their life. This also entailed consideration of the related issues of double effect medication, palliative care and living wills or advance directives.
2. Having reviewed the situation in those jurisdictions where a form of assisted death is permitted, the majority of the Working Party considered that the potential benefit of alleviating the suffering of a very small minority of Guernsey residents by means of assisted death would be outweighed by the disadvantages such legislation would entail. The majority of the Working Party were concerned that the legislation would place pressure on the vulnerable such as the elderly, disabled and emotionally suggestible to end their life because they feared being a burden (financially and emotionally) to their families.
3. There was also genuine concern that the process of judging a person's quality of life would lead to the same sections of society being viewed as second class and, perhaps, society becoming more accepting of non-voluntary assisted death for disabled people or people with chronic health problems, whatever the reality of an individual's situation.
4. The evidence reviewed suggests that the vast majority of patients should be able to have their physical pain relieved by responsible palliative care. Good quality palliative care should also ameliorate mental suffering but the Working Party recognised that some patients might still prefer to die at a time of their choosing. It was felt that, whatever sympathy there might be for an individual patient, the good of society as a whole in Guernsey over-rode such people's right to choose, however unpalatable that might be to them.
5. In reaching such a decision, the majority of members took comfort from the fact that they had arrived at the same conclusion as such bodies as the General Medical Council ("GMC"), the British Medical Association ("BMA") and the Royal College of Nursing ("RCN").

6. The majority of the Working Party do not recommend that the law be changed to allow any form of assisted death but do consider that the position of a medical professional administering double effect medication should be clarified and that some guidance be given as to the proper use of advance directives or living wills. All members of the Working Party agreed that further education was needed to enable people to access appropriate palliative care and more resources were needed to expand the service in Guernsey.
7. Some members of the Working Party do believe that there should be a change to the legislation and Deputy Peter Roffey produced a minority report which can be found at Section 13.

2. **Introduction**

1. At the States meeting of September 2002 Members voted by a majority in favour of a Requête on Death With Dignity which was led by Deputy Pat Mellor and signed by thirteen other Members of the States of Deliberation (Appendix 1). The Requête sought to instruct the Advisory and Finance Committee: -

“i) to carry out appropriate investigations and consultations with whomever it deems fit, and thereafter...

ii) to bring a report to the States of Deliberation on the implications of allowing Doctor Assisted Death or some other Death With Dignity Legislation to be implemented within Guernsey, and containing the Committee’s recommendations in connection with this matter.”

In the Committee’s letter of comment on the Requête it stated that: -

“...Should the Requête succeed, then with regard to the first part of the Requête the Committee will consult further with the Board of Health and the Committee for Home Affairs, and take legal advice before reporting back to the States on how the necessary research could best be taken forward and to seek confirmation of the proposed approach.

After that, the Committee would progress the production of the report referred to in the second part of the Requête...”

2. Following the States’ approval of the Requête, the Advisory and Finance Committee assembled a Working Party comprised of political and senior staff level representatives of the Board of Health, Committee for Home Affairs and of the Committee itself. The medical professions and Guernsey Council of Churches were also represented and a successful approach was made to the Guernsey Bar for one of its Members to take the Chairmanship of the Working Party. The Working Party has also received advice from H.M. Comptroller.

The purpose of seeking representatives from these areas was to ensure the availability of knowledge of all those aspects of the subject that might arise during the Working Party's life. A full list of Working Party Members is appended (Appendix 2).

3. The purpose of the Working Party's report is to allow informed debate of the issue later this year by the States of Guernsey.
4. The Working Party has been unable to reach a consensus on whether voluntary euthanasia should be legalised in Guernsey and for that reason there is a majority and a minority conclusion for that issue at the end of this report (see Sections 12 and 13). There is no doubt that the issue divides opinion and this was reflected in the views of the individuals on the Working Party. However, whatever point of view each member held, all members of the Working Party recognised that the issues of euthanasia and palliative care need to be considered by the States and an education programme put in place so that people gain a greater understanding of a very difficult area.
5. This report addresses the social, legal, ethical and medical aspects surrounding euthanasia since it was felt that even if the majority of the Working Party did not feel able to recommend euthanasia to the Advisory & Finance Committee, it was proper to consider how any such legislation could be enacted since the ultimate decision lies with the States of Guernsey, subject to the Royal Sanction.
6. The amount of material available on euthanasia is voluminous and in order to keep this report to a manageable length, much of the material that has been reviewed will not be cited or appended, but Section 3 discusses the methodology and who was consulted during the process. The report is structured so that it considers and reviews the experience of euthanasia legislation worldwide, reviews the legal situation and medical perspective, comments on the public consultation that took place, and then sets out the majority and minority conclusions which the Working Party reached.

3. **Methodology and Consultation**

1. The Working Party decided at its initial meeting on 8 May 2003 to endeavour to produce a final report to the Advisory & Finance Committee within 12 months. In order to achieve this deadline, areas of research were divided up to specific individuals and then those individuals would report at the monthly meetings, usually in writing.
2. The Working Party met on a total of 13 occasions. Each Member of the Working Party who produced research used both their own resources and the resources provided by the Advisory & Finance Committee in terms of sourcing material. In addition to the input provided by the Working Party Members listed at Appendix 2, support was gratefully received from the staff of Carey Olsen and staff of the Advisory & Finance Committee Policy and Research Unit.
3. In addition, the Working Party invited two of the United Kingdom's leading protagonists in the euthanasia debate to come to Guernsey to give a presentation. Baroness Finlay of Llandaff put forward the view that legislation to legalise euthanasia was undesirable and Lord Joffe spoke in favour of euthanasia. The Working Party is grateful that they could spare the time to explain their respective positions to us.

Consultation and Sources of Evidence

4. The Working Party considered evidence collected from a variety of sources. These included:-

Oral Evidence (by invitation)

Dr Callum McClymont, Consultant Anaesthetist, Medical Specialist Group
 Lord Joel Joffe,
 Baroness Ilora Finlay
 The Director of Nursing, Les Bourgs Hospice
 The Board of Governors, Les Bourgs Hospice
 The Clinical Nurse Specialists in Palliative Care

Written Evidence (by invitation)

The Board of Health's Ethical Committee

The Board of Health (re palliative care)
 The Department of Health (The Advisory and Finance Committee wrote to the Lord Chancellor's Department)
 The Scottish Executive (as per the Department of Health)

Public Consultation

An invitation to the general public and interest groups to make written submissions (see Section 10 and Appendix 18) was advertised in the Guernsey Press. In all, written submissions were received from 276 Individuals and 20 Groups and Organisations.

Documents Reviewed (including existing data and published sources)

References – see Appendix 3
 Further reading / bibliography – see Appendix 3

Verbal Liaison

GSSA
 Jersey's International Relations and Policy Officer, Policy and Resources Committee
 Clerk of Tynwald's Office, Isle of Man
 Royal Netherlands Embassy, London
 Department of Health, Welfare and Sport, Netherlands
 United States Embassy, London
 Ministry of Social Affairs, Public Health and the Environment, Belgium
 BMA Medical Ethics Department

Miscellaneous

One member of the working party attended, and took notes, at a meeting of the Palliative Care Section of the Royal Society of Medicine entitled "*Looking Back, Taking Stock, Looking Forward – A History of Palliative Care*". This was held on Thursday 13 November 2003.

A Letter from the GMC, Chair of Standards Committee (sent in by the Voluntary Euthanasia Society).

Survey of local doctors;
 Survey of local nurses;
 Both were superseded by a joint survey of the medical profession – March 2004 (see Section 9)

A list of documents reviewed is attached at Appendix 3.

4. **Definitions and Explanations**

The Working Party agreed that the best definitions in this area were those given by the British Medical Association (“BMA”)¹, some of which are set out below (in italics), together with further explanations where appropriate.

(i) **Basic Care**

“Basic Care means those procedures essential to keep an individual comfortable such as pain and symptom relief.”

The administration of medication or the performance of any procedure which is solely or primarily designed to provide comfort to the patient or alleviate that person’s pain, symptoms or distress are facets of Basic Care. The BMA Code of Practice provides that as a matter of public policy, people should not be able to refuse Basic Care in advance or instruct others to refuse on their behalf.

(ii) **Capacity**

The BMA answers the question. “What is capacity?” as follows:

“An assessment of capacity is not based upon the test, “would a rational person decide as this person has decided?” It is not the decision itself but the thought process which lies behind the decision which is relevant to the question of capacity. Individuals who have mental capacity may make decisions which are apparently completely irrational and the law allows them to do so. There is a presumption both that a person has capacity until the contrary is proven and that a person who legally lacks capacity remains in that state until the contrary is proven. Since the presumption of capacity must be the starting point of any assessment, lack of cooperation or apathy with respect to an assessment of capacity should not lead to a conclusion that the

¹ Taken from British Medical Association website: www.bma.org.uk – location – ethics/physician assisted suicide/terminology

person lacks capacity. For example, the eccentric recluse must not lose legal autonomy simply because of non-cooperation with an assessment”.

The English case law definition of mental capacity to refuse or consent to medical treatment is as follows:

“the person has capacity if he or she can understand and retain information relevant to the decision in question, can believe that information and can weigh that information in the balance to arrive at a choice.”²

(iii) Terminal Illness

“The illness is inevitably progressive and will result in death. The treatments available may be able to slow down the progression, or may alleviate the symptoms, but a cure cannot be provided.”

(iv) Double Effect Medication

“The principle of double effect provides the justification for the provision of medical treatment which has bad effects where the intention is to provide an overall good effect. The principle permits an act which foreseeably has both good and bad effects provided that the good effect is the reason for acting (and is not caused by the bad). A common example is the provision of essential pain relieving drugs in terminal care at the risk of shortening life. Pain relief is the intention and outweighs the risks of shortening life.”

(v) Euthanasia

“A deliberate act or omission whose primary intention is to end another’s life. Literally, it only means a gentle or easy death but has come to signify a deliberate intervention with the intention to kill someone, often described as the ‘mercy killing’ of people in pain with terminal illness.

² In Re C (Adult: Refusal of Treatment) (1994) 1 WLR 290

- *Voluntary – Death is brought about by the patient’s request*
- *Non-voluntary - Killing of a patient who does not have the capacity to request or consent to it, for example, someone in a coma.*
- *Involuntary – When competent people are killed against their will or without their consent.”*

(vi) Physician-assisted suicide

“This involves a doctor intentionally giving a person advice or the means to commit suicide. It describes situations where competent people want to kill themselves but lack either the means or the ability. Death can only be by assisted suicide if the patient acts him or herself. If the patient is unable to act, for example if he or she cannot inject or cause medication to be swallowed, the patient lacks the ability to commit suicide and the act is one of euthanasia.”

(vii) Advance Statements / Advance Directives

“An expression of views, by competent individuals, concerning treatment options likely to arise later when their decision making capacity has been lost. Advance directives, or refusals, are a subset of advance statements, in which treatments are refused in advance. Competently made advance directives, applicable to the circumstances, are legally binding upon clinicians.”

1. People who understand the implications of their choices can state in advance how they wish to be treated if they suffer loss of mental capacity through illness or accident. Just as adults must be consulted about treatment options, young people under the age of minority (aged 18) are entitled to have their views taken into account but are not binding. An advance statement can be of various types:-

- (1) A requesting statement reflecting an individual’s aspirations and preferences. These can help health professionals identify how the

person would like to be treated without binding them to that course of action if it conflicts with professional judgement.

- (2) A statement of general beliefs and aspects of life which an individual values. This provides a summary of individual responses to a list of questions about a person's past and present wishes and future desires. It makes no specific request or refusal but attempts to give a biological portrait of the individual as an aid to deciding what he or she would want.
 - (3) A statement which names another person who should be consulted at the time a decision has to be made. The views expressed by that named person should reflect what the patient would want (in the USA this document is called a 'durable medical power of attorney' and the designated person a 'health care agent').
 - (4) A clear instruction refusing some or all medical procedures.
 - (5) A statement which, rather than refusing any particular treatment, specifies a degree of irreversible deterioration (such as persistent vegetative state) after which no life sustaining treatment should be given. For adults, this again can have legal force.
 - (6) A combination of the above.
2. The fundamental aim of the advance statement is to provide a means for the patient to continue to exercise autonomy and shape the end of his or her life. The principle is not new. Patients who are aware of approaching death have often discussed with their doctors how they wish to be treated. The advance statement registers these views in a more formal way and can be seen as part of a broader willingness to discuss death openly and to deal with the anxieties patients have about what might happen to them if they become mentally incapacitated. An advance statement can be a written document, a witnessed oral statement, a signed printed card, a smart card or a note of a particular discussion recorded in the

patient's notes. Some organisations, e.g. The Alzheimer's Society, have produced templates for advance statements for their members.

3. Since no one can demand a particular medical treatment be given, statements purporting to direct health care professionals are usually refusals. Competent, informed adults have an established legal right to refuse medical procedures in advance. An unambiguous and informed advance refusal is as valid as a contemporaneous decision. Health professionals are bound to comply when the refusal specifically addresses the situation which has arisen. Patients may not however under the current code refuse Basic Care i.e. those procedures essential to keep a patient comfortable such as administration of medication or medical procedures designed to alleviate the patient's pain or other symptoms of distress. In addition patients should not be able to instruct others to refuse Basic Care on their behalf.
4. In the United States, Congress passed the Patient Self Determination Act (PSDA)³, which became effective in 1991. The Act requires all health care institutions that receive Medicare or Medicaid funds to provide patients with written information about their right under State law to execute advance directives, but it does not require States to adopt or change any substantive laws. The written information must clearly state the institution's policies on withholding or withdrawing life-sustaining treatment.
5. All 50 States of America now have legislation and have specimen Advance Statements available from health care facilities or to download from the internet. Examples are attached from the State of Delaware, Rhode Island and the Alzheimer's Society (as Appendix 4).
6. One fortunate consequence of this requirement is that health care institutions in the USA have had to examine or develop policies dealing with termination of life-sustaining treatment. The PSDA also requires facilities to document in each patient's medical record whether an advance directive has been executed, to

³ <http://thomas.loc.gov> – Follow: Bill Text/101st Congress/and search for Patient Self Determination Act/(HR 5067 IH)

educate staff and the public about the right to forgo treatment, and to ensure institutional compliance with State law. Violation of the Act can lead to loss of federal funding.

7. Advance directives in the United States usually comprise two documents:-

(i) A Living Will

A living will puts into writing a patient's wishes for medical treatment in the event of becoming very seriously ill or nearing the end of life. Amongst other things it sets out how he would like his pain managed and whether he would want to be at home or in a hospital. The purpose of a living will is for a patient to describe his general philosophy about how he wants to be treated if he is unable to speak for himself.

(ii) A Health Care/Durable Power of Attorney

A health care power of attorney is a document which gives someone the power to be a patient's lobbyist or advocate if they cannot speak for themselves. The health care power of attorney is a document that names this person. Such a person is sometimes called a health care proxy or a health care agent.

8. According to the individual States further optional documents may be presented concerning:-

- (i) Mental Health Treatments e.g. Electroconvulsive Therapy
- (ii) Organ donation
- (iii) Cardiopulmonary Resuscitation/Do Not Resuscitate Order
- (iv) Religious and spiritual requests (see Rhode Island Specimen Advance Directive appended at 4)

9. The statements usually require two qualified witnesses or one notary public to sign the 'durable power of attorney for health care' form at the same time the

patient signs the document. The witnesses must be adults and must not be any of the following:

- a person designated as the agent or alternate agent;
- a health care provider;
- an employee of a health care provider;
- the operator of a community care facility; or
- an employee of an operator of a community care facility.

(iii) Palliative Care

The World Health Organisation⁴ defines palliative care as:

“An approach that 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, psychosocial and spiritual.”

10. 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

⁴ Taken from World Health Organisation website: www.who.int/en - location - WHO sites/cancer home/palliative care

- 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

The National Institute for Clinical Excellence (NICE)⁵ has published a set of guidelines to establish best practice in the area of palliative care and they are summarised at (Appendix 5).

⁵ Found at www.nice.org.uk and the manual entitled Improving Supportive and Palliative Care for Adults with Cancer can be found at – www.nice.org.uk/pdf/csgspmanual.pdf

5. **The Palliative Care Movement**

1. The modern hospice movement is associated with the name of Dame Cicely Saunders and started in the United Kingdom in 1967 with St. Christopher's Hospice. Cicely Saunders was trained as a nurse and then as a social worker. During her work in a hospital she became aware of the psychological and spiritual needs of dying people, who often felt isolated and alone. She also became interested in the medical treatment for cancer, especially the treatment for pain control.
2. For that reason, she decided to qualify as a doctor. Listening carefully to her patients, their stories of illness and suffering she created the concept of "total pain" which she defined as "an immense physical suffering compounded by psychosocial distress". During her work as a volunteer at a hospice she had the opportunity to use strong opioids and to see that "constant pain needs constant control", that is that analgesics should be given regularly to prevent pain, not on demand to alleviate it.
3. Using her experiences as a nurse, a social worker and a doctor, she integrated all her skills and opened the first modern hospice in London. This hospice combined the tradition of the middle ages hospices with all the modern achievements of medicine, in order to relieve the suffering of terminally ill patients and their families.
4. The hospice model of care developed in the UK is now espoused as a model of clinical excellence and has led to a worldwide movement aspiring to deliver care to dying patients. Britain is leading the way in the practice of Palliative Care.
5. The Working Party was able to meet with Baroness Finlay of Llandaff during the course of their work. Baroness Finlay is a Palliative Care specialist who practices at the Holme Towers Marie Curie Cancer Care Hospice in Wales. She is widely seen as a successor to Dame Cicely Saunders in the development of Palliative Care. In addition to her duties as a practising physician Baroness Finlay is Vice Dean and Professor of Palliative Medicine at the University of Wales College of

Medicine and teaches part of the only course in the United Kingdom for doctors who wish to study the practise of Palliative Care. The Working Party is indebted to Baroness Finlay for the time she spent explaining her experiences as a physician in this field.

6. One of the more interesting aspects of Baroness Finlay's talk was that Palliative Care is not centred purely on the patient's symptoms. Good Palliative Care will look to support the whole family of the patient, consider the needs of any children of the family and in general aim to take both the physical and emotional suffering away from the situation as much as that may be done.
7. It is important to emphasise that Palliative Care services not only deliver direct care to patients and their families, but have an important advisory and educational role to influence quality of care both in hospitals and the community. This will in turn affect society's view of the quality of life available to the terminally ill.

6. **The Process of Dying**

1. It is generally agreed that two different dynamic stages are at work as a person enters the final stages of dying – the first is physical and the second covers the emotional/spiritual/psychosocial⁶.
2. The first stage progresses as the body begins to shut down and death is finally said to occur when all physical systems cease to function. The second stage involves the person coming to terms with their situation and thus could find them expressing a wish to resolve unfinished business, reconcile relationships and even seemingly withdraw from family members. The most appropriate response to this should be one of acceptance, understanding and support.
3. There are many models which hope to make some kind of order out of the stages patients go through, from the symptoms of illness to the moment of death. One such model is The Disease Continuum⁷, which is used in mapping the condition of cancer patients and separates this into nine stages: symptoms, diagnosis, treatment, disease free, cure, survival, reoccurrence, advanced disease and dying.
4. It has been noted with regard to this model that the need for Palliative Care should be identified as early as possible but in reality the interface between acute and palliative care occurs at the time of reoccurrence when the patient realises that the treatment is not going to cure them and the disease is terminal. However, if a patient is diagnosed late in the course of their disease they are usually offered input from a palliative care team from that time on.
5. The Living-Dying Phase Theory⁸ works from the moment a patient is told they cannot be cured to the moment of death, dividing that time into three main sections and identifying the main needs of the patient throughout. The first phase is called the acute crisis phase and begins when a patient is told they cannot be

⁶ See Process of Dying by Alexander Peralta: www.nhpco.org/files/public/CTC_2004_9E_H1.pdf

⁷ See The Scope of Cancer Nursing by Corner, J. (1995)

⁸ See The Experience of Dying by Pattison, E.M. (1977)

cured. It states that the carer's main task during this time is to deal with the patient's reactions in order to prevent their life from disintegrating into chaos.

6. The next phase is known as the chronic living-dying phase and involves the carer supporting the patient's coping mechanisms and helping them and their family adapt and achieve the best quality of life possible through physical, psychological, social and spiritual means.
7. The final phase is terminal and is seen to begin when the dying person starts to withdraw from the outside world. During this time the carer needs to support the patient and their family, providing reassurance and giving information about the final stages of death as well as timely symptom control.
8. Of course it is realised that no one unified model will be able to predict the progression towards death for all terminally ill people as it remains a very personal experience and as such individual reactions will differ greatly. This is of the utmost importance when considering the prospect of euthanasia or assisted suicide as, in the early stages of being diagnosed with terminal illness, patients may express a wish to die immediately due to their fear of living with a lower quality of life. However, after this initial shock and coming to terms with their situation many continue to live with the same standard of life for years and no longer feel the need for it to be cut short.
9. Trying to build a model of the processes of death means carers can be better prepared and more aware of their patient's potential needs and the appropriate times for introducing palliative care can be recognised, making the progression easier and more comfortable for all involved.

7. **Euthanasia – The Worldwide Perspective**

1. Legislation is in place to legalize Euthanasia in several jurisdictions, others are considering proposals, and some have had legalisation, only to have it subsequently withdrawn. The debate everywhere is highly controversial and high-profile, with very passionate and active campaigners on both sides. Statistics published from the countries differ enormously depending on the literature read, so it is difficult to be sure of the reliability of the data. As a result of this, limited statistics will be reported here.

I. Jurisdictions in which a form of Euthanasia is legal

(i) Oregon, USA

2. Oregon was the first place in the world to legalize ‘Physician Assisted Suicide.’ The Oregon Death With Dignity Act (ODWDA)⁹ came into effect in November 1997, allowing doctors to prescribe lethal drugs to patients who are terminally ill, but it is the patient who must physically perform the final act. There are various safeguards in place to ensure that the patient is competent (Appendix 6). There is a notable omission in the law, in that there is no punishment for doctors failing to report an assisted suicide.
3. Attorney General John Ashcroft of the US Department of Justice challenged the right of the legislature of Oregon to pass the law. He said the ODWDA was contrary to a federal law, the Controlled Substances Act, claiming that the use of the lethal prescription was not a legitimate medical use of these federally controlled substances. Since federal laws overrule state laws, in theory this should ensure the repeal of the ODWDA. Ashcroft has so far been unsuccessful in overturning the law, but he is appealing against the decision which allows Oregon the freedom to define the federal law as it wishes.

⁹ A full copy and further information can be found on the Oregon Department of Human Services website – www.chd.hr.state.or.us/chs/pas/pas.cfm

4. Public opinion in Oregon is mixed, as expected, but the law was passed as a result of a favourable public referendum. The inescapable conclusion of that is that the majority of those Oregon residents who voted are in favour of the legislation.

5. In the United States, there is no universally available system of public health care. People are expected to have health insurance and for those who are too poor to do so, there is the state system of health insurance (Medicaid). There has been some comment and anecdotal evidence to the effect that certain health insurance firms have been keen to pay for lethal prescriptions as it is of course much cheaper in the long run for the company than to pay for often intensive nursing and Palliative Care services. The authorities, sensitive to the fact that the Palliative Care service in Oregon is not as extensive as necessary, are making efforts to ensure that there is good quality Palliative Care available to all. It is however, because of the way the data is gathered, impossible to tell how many of the people who have chosen to die under the ODWDA have had financial motivation for doing so. Interestingly enough, these financial pressures could be a middle class phenomenon on the grounds that the rich can afford to pay for Palliative Care services, the poor should get them provided (although the quality is questionable) and those whose health services depend on their insurance company may find that they are not covered for the amount of Palliative Care that may well be necessary. Some insurance companies for example will only pay for six months Palliative Care.

6. The State of Oregon issues a report each year giving statistics on numbers of Physician-Assisted death and prescriptions written in the preceding years. The last report was published on 10 March 2004 and shows that there were 42 such deaths reported in 2003, compared with 38 in 2002. There is no punishment prescribed in the ODWDA for failing to report an assisted suicide and therefore it is difficult to assess the accuracy of the figures. However, what the statistics do show is that in 2003 there were actually 67 prescriptions written and of these 67 people, only 39 used their prescription, most of the remainder had died naturally and 10 people were still alive at the end of the

year. Interestingly, this total of 42 includes 2 patients who had received prescriptions in 2002 and one patient who received a prescription in 2001.

7. The 2003 report also reported that one half of those who chose to die by euthanasia did so within 20 minutes of ingesting the prescribed lethal medication; the range time from ingestion to medication was 5 minutes to 48 hours. Additionally, complications arising from regurgitation were reported in three cases. Given these reported facts it does raise the question whether a system, even as well regulated as that in Oregon would appear to be, can unfailingly offer the 'Death With Dignity' that some seek.
8. Additionally the statistics suggest that those who chose Euthanasia are better educated than average, in the main older and cancer sufferers. It is believed that *reported* assisted deaths accounted for 0.0014% of deaths in Oregon in 2003.

(ii) The Netherlands

9. Holland followed Oregon, by passing a law in April 2001¹⁰ to ensure that physicians would not be liable for prosecution if they observe the regulations set out for assisting suicide. Laws were passed earlier than this date (in 1993 and 1999) to prevent prosecution under certain conditions, but they were too ambiguous to ensure regulation was effective.
10. The Dutch legislation permits a doctor to assist a patient when that person is suffering intolerable pain with no prospect of improvement so the patient may or may not be suffering from a Terminal Illness. The pain can be either physical or emotional and there is a provision that states that Euthanasia is the last resort after all other treatments have not succeeded. It is still proving difficult to determine who is eligible for Euthanasia, for example, a doctor was recently put on trial for assisting a man who was 'tired of life.' The doctor escaped punishment, but was warned that the law had not been intended for

¹⁰ Further information and a copy of the law can be found at "Welcome to the Netherlands" at www.minbuza.nl

such situations. The United Nations Human Rights Committee criticised the lack of safeguards in place in the Netherlands – this can be seen in their observations, appended at 7.

11. An alarming aspect of the system in the Netherlands is the until recently almost total lack of progress in developing alternatives to Euthanasia, due to the undeveloped state of the country's hospice system. This raises the question of whether patients have had access to sufficient other treatments for Euthanasia to be a true last resort.
12. Reports from the country have been mixed, but the latest official figures from the Rummelink Report¹¹ suggest that only 54% of deaths are reported, and that 1 in 4 Euthanasia cases were involuntary.
13. The Rummelink Reports show that the percentage of deaths being reported is increasing but is still indicative of a worrying trend, that until the third year of the reports the vast majority of cases of Euthanasia had not been reported and just over half are now. If a case of Euthanasia is not reported, then it is impossible to check whether the safeguards laid down in legislation have been adhered to and it brings into disrepute the whole structure of the legalised Euthanasia system itself.
14. Equally, the prevalence of involuntary Euthanasia raised concern. One of the main reasons for adopting Euthanasia legislation in the Netherlands was the prevalence of doctors performing involuntary Euthanasia. The latest figures however show that the existence of Euthanasia legislation has made no difference to this practice, with it still accounting for 0.7% of all deaths in 2001, a decrease of 0.1% since 1990¹². In the same period, however, reported deaths from Euthanasia rose from 1.7% of all deaths to 2.6% of all deaths. There has, therefore, been an overall increase in the number of people assisted to die since the legislation was introduced. A copy of the Lancet synopsis of

¹¹ www.nvve.nl – Follow: News/Third Rummelink Report

¹² Euthanasia and other end of life decisions in the Netherlands in 1990, 1995 and 2001 – The Lancet, Vol 362, 2 August 2003 – www.thelancet.com

the third Remmelink Report, referenced on the preceding page and is also appended at 8.

(iii) Belgium

15. The third jurisdiction to legalize Euthanasia was Belgium, which it did in September 2002¹³. The background to the legislation is interesting in that a large-scale research group had discovered that although it was not legal, Euthanasia accounted for more than 1 in 10 of all deaths, and most of these deaths were non-voluntary. In passing a law, it was hoped that the safeguards put in place would prevent abuse of the vulnerable. The bill was twinned with legislation aimed at raising awareness of Palliative Care, to give real alternatives to the dying. One of the problems with this law, which applies equally to other Euthanasia legislation, is that it requires an examination after death to check that the doctor has fulfilled the necessary requirements, so there is no protection given *before* the patient has died.

16. The Federal Ministry for Public Health reported in November 2003 that 203 cases of Euthanasia occurred in the first year of their legislation, with the minister noting that both patients and doctors needed to be given more information about Euthanasia¹⁴. It is anticipated that the first report will be published in June 2004.

(iv) Switzerland

17. The case of Reginald Crew, who became the first British citizen to travel to Switzerland in order to take advantage of the legislation there allowing assisted death, brought Switzerland's legal situation to public attention in January 2003. Assisted suicide (which encompasses Euthanasia) has actually been legal in Switzerland since 1937 and does not require the involvement of a physician, or that the person be terminally ill. There are no safeguards in

¹³ An informal translation of Belgium's Euthanasia Law can be found at www.ruleuren.ac.be/cbmer/viewpic.php?LAN=E&TABLE=DOCS&ID=23

¹⁴ Internet Newspaper Report – www.expatica.com – 25.11.03

place at all to protect the people and no necessity that a person be mentally competent. This means that regulation is virtually impossible, and in practice many hospitals have barred assisted suicide from their premises and many doctors are opposed to it.

18. Many are concerned about the increasing trend of ‘suicide tourism’, as more and more people travel to Switzerland to take advantage of the fact that the law does not require the patient to be resident there.
19. There was uproar in the British press last year after a couple (Robert and Jennifer Stokes) travelled to Zurich and were helped to end their lives by voluntary Euthanasia by a charity called Dignitas on 1 April 2003. Mr Stokes had epilepsy and his wife was diabetic and also had a back condition but they were not terminally ill in any medical definition. One of the particularly tragic aspects of this case was that Mr and Mrs Stokes did not inform their family of their decision and the family was clearly very shocked and angry at what had been allowed to happen.
20. There are no official statistics which analyse how many of the suicides which take place in Switzerland each year are “assisted”.

II Jurisdictions where Euthanasia has been legalised and then withdrawn

(v) Australia

In the Northern Territory of Australia, the Rights of the Terminally Ill Act (“ROTI”) came into affect in July 1996. There then followed several high profile deaths, largely supported by Dr Philip Nitschke, Australia’s primary campaigner for assisted suicide. The Australian Senate repealed the legislation after it had been in place for 9 months, on the grounds that the Northern Territory was a territory and not a state, so could not override the federal law. During that period it was reported that 4 people died using the rights under the Act. A summary of the provisions of ROTI is set out in Appendix 9.

(vi) Colombia

In Colombia an attempt to make the law stricter regarding Euthanasia initially backfired. A lawsuit was brought by an anti-Euthanasia campaigner to challenge the section of the Criminal Code concerning ‘mercy killing’, because he considered it to be too lenient. It stated: *mercy killing – the person who kills someone else for mercy, to end the acute suffering caused by a bodily injury or serious or incurable disease, will be sentenced to imprisonment between 6 months and 3 years.* The campaigner was seeking a stiffer penalty and better protection against the killing of the elderly and infirm. In May 1997, the lawsuit back-fired, as the court stated that “no person can be held criminally responsible for taking the life of a terminally ill patient who has given authorization to do so”. Their ruling made Colombia the only country in the Western Hemisphere whose Supreme Court permitted the practice of active Euthanasia, but it also left the boundaries unclear. After 18 months, the Colombian Senate finally considered the Constitutional Court’s decrees, and rejected the court’s interpretation. This means that a legal penalty for performing Euthanasia is once again in place. It has been reported that no lives were lost during this period.

(vii) Other Jurisdictions

Several other countries have attempted to introduce bills but these have been refused. The proposed legislation in Luxembourg was the only one considered which required that the doctor, having obtained a second medical opinion, address a request for Euthanasia to a special committee, before the assisted suicide was carried out. This system would provide clear control over those patients requesting death, to protect them from external pressures and ensure that doctors followed all of the guidelines. Despite this safeguard, the proposal was still rejected. Canada and France have had several high-profile cases which have gone to court, but without a change in the law. South Africa, Hawaii, Hungary and New Zealand have had their attempts refused, even though there has been much active campaigning in support of a change in the law.

21. A comparison of territories where legislation for Euthanasia was enacted and subsequently repealed and another comparing territories where legislation is currently in force are annexed respectively at Appendices 9 and 10.

III. **The Position in the United Kingdom and Crown Dependencies**

(viii) England and Wales

22. There is no specific legislation in England and Wales or Scotland which deals with Euthanasia or the administration of Double Effect Medication. The legal position on these issues in England and Wales is the same as that in Guernsey (see section 8).
23. There has been a Private Members' Bill to legalise Euthanasia in England – the Patient (Assisted Dying) Bill proposed by Lord Joffe¹⁵. The Working Party is grateful to Lord Joffe for sparing the time to explain the proposed Bill to us and his reasons for supporting the legalisation of Euthanasia
24. On 6th June 2003, the Patient (Assisted Dying) Bill, received its second reading in the House of Lords. The debate lasted for 7 hours, and more than 50 people addressed the issue. In his opening address to the House, Lord Joffe said that the Bill would enable, “a competent adult who is suffering unbearably as a result of a terminal or a serious, incurable and progressive physical illness to receive medical help to die, at his own considered and persistent request.” He was quick to point out that it, “does not cover assisted dying by relatives or friends, nor does it apply to incompetent individuals.” The current law in the UK is such that helping someone to die is a crime under the Suicide Act 1961, making the offence punishable by up to 14 years imprisonment. Lord Joffe explained why he considered this law to be defective, as, “it results in grievous, prolonged and unnecessary suffering to a significant number of patients, who are denied the right to remain in control of

¹⁵ Can be found on the UK Parliament website: www.parliament.uk / Bills before Parliament/Public Bills before Parliament/Assisted Dying for the Terminally Ill Bill

their lives until their death, and of the right, as they see it, to die with dignity. It is ignored by many caring doctors who, moved by compassion, assist their patients to die, which results in grave risks to those doctors' careers, reputations and possibly freedom." He also points out that under the current situation, people with progressive physical diseases are forced to end their lives prematurely, at a time when they are still physically capable of committing suicide. Others are forced to leave the UK to die lonely deaths abroad in unfamiliar surroundings with no safeguards in place.

25. The initial safeguards outlined were that the patient is:

- over the age of 18;
- competent; and
- suffering unbearably from a Terminal Illness.

Additionally the doctor in charge would discuss the diagnosis, the prognosis, and the alternatives, such as palliative and hospice care, and satisfy himself that the patient's request was not the result of external pressure. The patient, with persistent requests, would be referred to a consultant physician who would independently go through the same process as the previous doctor. In the case of there being doubts about the competence of the patient, he must be referred to a psychiatrist. A written statement must be signed in the presence of two witnesses, one of whom must be a solicitor, and this statement can be withdrawn at any time by the patient. There are two waiting periods of fourteen days each which have to be adhered to, where the patient has time to reflect on his decision. Following the assisted death, the doctor must then document the process and send all the medical records to a special monitoring commission set up by the Secretary of State. Lord Joffe ended his opening speech by saying, "the purpose of this Bill is to change the law in the interests of patients, doctors and society as a whole".

26. After a lengthy debate, the House was divided in opinion. Lord Joffe has produced a revised bill which includes several changes and which may eventually be debated when the issue of Euthanasia has been scrutinised by a

Select Committee. Lord Joffe produced a comparison of his Bill (with the relevant changes) with the legislation in Oregon and the Netherlands, which is attached as Appendix 11.

27. In 1993 a Select Committee on Medical Ethics was set up which extensively examined the issue of Euthanasia. Its report was presented to Parliament¹⁶ and concluded in 1994 that “the issue of Euthanasia is one in which the interest of the individual cannot be separated from the interests of society as a whole.” They recommended that there was no need for a change in the current law, which “protects each of us impartially, embodying the belief that all are equal.” They also concluded that “it would not be possible to frame adequate safeguards against non-voluntary Euthanasia if voluntary Euthanasia were to be legalised. It would be next to impossible to frame adequate safeguards to ensure that all acts of Euthanasia were truly voluntary and that any liberalisation of the law was not abused.”
28. The British Medical Association was consulted by the Select Committee and remains concerned that the doctors would “acquire an additional role alien to the traditional one of healer. Furthermore, the psychological context within which health care is delivered would also change, bringing about a fundamental shift in social attitudes to those who suffer long-term illness or disability and who require substantial health resources.”
29. One of the concerns expressed by members of the Working Party was that the Select Committee reported some ten years ago and some members have publicly changed their minds on the conclusions reached. There is therefore a worry that people are being influenced by findings that are out of date. Both the BMA’s view and that of the Select Committee were certainly discussed during the House of Lords’ debate on Lord Joffe’s original bill and may well have significantly influenced those Members of Parliament who voted against the Bill.

¹⁶ House of Lords Session 1993-94 (printed 31/01/94) Report of the Select Committee on Medical Ethics (Volume 1 – Report) HMSO, London

30. The Advisory and Finance Committee wrote to the UK Department of Health (via the then Lord Chancellor's Department) requesting information and the Government's view on Euthanasia. The reply was given that the Government continued to share the views of the Select Committee and could not support the practice of Euthanasia, the letter is appended at Appendix 12.

(ix) Scotland

31. There is no specific legislation in Scotland regulating Euthanasia or the use of Double Effect Medication. Broadly speaking the situation is the same as that in Guernsey, i.e. that Euthanasia would be regarded under the criminal law as murder.
32. The Advisory and Finance Committee wrote to the Scottish Executive (via the then Lord Chancellor's Department) requesting a summary of its present policy on Euthanasia. The response was that there is no present intention to change the law as it may have undesirable consequences for the vulnerable in society. There is however draft legislation before the Scottish Parliament permitting those who lack mental capacity to make a form of Advance Statement which is not binding but rather informative of an individual's views. The letter is appended at Appendix 13.

(x) Isle of Man

33. The Isle of Man also has no specific legislation dealing with Euthanasia or Double Effect Medication. There has recently been a bill proposed to the Manx Parliament in favour of legalizing voluntary Euthanasia. Members of the House of Keys (MHKs) voted 15 to 4 in favour of a Select Committee of 5 members taking evidence on the subject matter of the Bill, and reporting back to the House. The Bill was first proposed by MHKs John Rimmington and Quinton Gill after they heard of a local man, Patrick Kneen, 74, who suffered from prostate cancer. Mr Kneen was diagnosed in February 2002, and told he had between 2 and 10 years to live. He founded the Manx 4 Death with Dignity (M4DWD) campaign.

34. Extensive public consultation has now taken place and is on-going. The Select Committee anticipates producing a report to the House of Keys by Christmas 2004.

(xi) Jersey

35. Jersey has the same legal position on Euthanasia as Guernsey. The Working Party has made enquiries of the States of Jersey as to whether there are any moves to legalise Euthanasia in Jersey. The response was that the States of Jersey has no present intention of reviewing the law.

(xii) Northern Ireland

36. The legal position in Northern Ireland is similar to that in England and Wales, with assisting suicide being a criminal offence under the Criminal Justice Act (Northern Ireland) 1966¹⁷. The Working Party has made enquiries (via the then Lord Chancellor's Department) as to whether there are any moves to legalise Euthanasia in Northern Ireland. There has been no response.

¹⁷ www.northernireland-legislation.hmso.co.uk

8. Euthanasia – The Guernsey Legal Perspective

I Present Position

1. At present, there is no specific legislation in Guernsey which regulates Euthanasia, Double Effect Medication or Advance Statements. We are therefore left with what is known as the common law (i.e. the body of law which has been developed through the courts as opposed to legislation which is approved by the legislature and then enacted by Her Majesty in Council).
2. It is illegal to commit (or to assist someone to commit) suicide (D'Homicide de soy-mesme) in Guernsey under the common law whether the person assisting is a medical professional or a friend/relative of the person who commits suicide. There is no equivalent of the English Suicide Act.
3. A medical practitioner cannot therefore assist, by the provision of medication, advice or direct action, any patient to die if the primary purpose of prescribing that medication or giving that assistance is to bring about the death of the patient. Put simply, such acts would be categorised as homicide.
4. Equally if a medical practitioner prescribes or administers medication to a patient (under the double effect principle) with the primary purpose of providing pain relief to that patient, then since the primary motivation was to provide pain relief and not to bring about death, the medical practitioner will not be guilty of any offence. The law is clear even if the consequence of the medication may well be that the patient's life is shortened. This of course presupposes that the doctor is acting at all times in the manner that a responsible doctor would act.
5. For example, if a doctor gave a patient an excessive dose of opioids, then the doctor would perhaps be liable to prosecution if it could be proved that no other doctor acting properly and professionally would have prescribed such a dose. Additionally, the doctor would almost certainly face proceedings before the General Medical Council.

6. In the same way, if a doctor considers that it would be in the best interests of the patient to withhold or withdraw further treatment, because such treatment will cause further trauma and suffering in a situation where someone is terminally ill (i.e. refusing to resuscitate someone whose heart had failed), then on the basis that the doctor is acting properly, responsibly and in accordance with accepted medical practice, it would not be an offence.
7. A patient who is mentally competent is also able legally to decide that he does not wish to receive any further medical treatment. If a patient has made a decision that he does not want to receive further treatment, even if such refusal may result in their death, then a doctor must respect that refusal or potentially be liable to a charge of assault.
8. The legal position is exactly the same if a doctor is aware of a written Advance Statement made by a patient when he was mentally competent and which the patient has not revoked. A doctor must respect the contents of the Advance Statement (see Section 4 paragraph vii) or render himself potentially liable to a charge of assault.
9. It should be noted however that the BMA's current guidelines on Advance Statement do not permit a doctor to withdraw Basic Care (see Section 4 paragraph i) either as a result of a patient's request or his own professional judgment.
10. There was concern from members of the medical community on the Working Party that a patient may have made an Advance Statement but that it may for a variety of reasons not be available when the need for it arises; for example someone arriving in the Accident and Emergency Department unconscious after a car crash may have an Advance Statement but it could be impossible given the time constraints that the doctors are working under to identify whether one exists and therefore the doctors could through no fault of their own end up acting contrary to the patient's wishes. In such a case, a doctor

would not be liable to be charged with battery since he would be unaware that the patient did not consent to the treatment.

11. A medical professional who is reckless as to whether a patient has consented, ie does not make any attempt to establish what the patient requires does or does not consent to treatment or whether there is an Advance Directive in place may well be liable to a charge of assault.
12. There is no doubt from a legal perspective that there is no pressing need for legislation to clarify a medical professional's position in respect of Double Effect Medication and Advanced Statements. However, both through the medical survey (see section 9 I) and anecdotally, the Working Party is aware that members of the medical community in Guernsey are uncomfortable with the practical aspects of the situation and would if possible like some legal clarification of their position, given that the situations they find themselves in can be understandably very fraught and that society is becoming increasingly litigious.
13. Finally, many people take out various forms of life insurance and it was queried whether the insurance companies would pay out on the policies of those who had been assisted to die. Soundings have been taken from various professional bodies and life companies to the effect that companies would agree to pay out in cases of Euthanasia unless the policy had been purchased very close to the date of death. The position of Guernsey's Social Security Authority is that it would pay bereavement benefits in cases of Euthanasia, should the law be changed. Lord Joffe has attempted to clarify this approach in his Assisted Dying for the Terminally Ill Bill and it might be possible to take a similar approach in a Guernsey legislation.

II Capacity

14. If the Bailiwick of Guernsey is to have legislation for Euthanasia or Advance Directives, then it is imperative to include a definition of Capacity and inCapacity.

15. In Section 4 (ii), of this report, the English case law definition of the Capacity necessary to consent to and refuse medical treatment is set out, together with the BMA explanation of Capacity. Legally however there are many different types of Capacity, such as Capacity to conduct one's own affairs, Capacity to make a gift, Capacity to marry, Capacity to make a will, Capacity to consent to sexual relations etc.
16. In England, there is presently a Draft Mental Incapacity Bill, which was presented to parliament on 27 June 2003¹⁸ and has been proposed as a result of findings by the Law Commission. In 1989 the Law Commission of England and Wales was commissioned by the then Lord Chancellor to examine the issues surrounding lack of mental Capacity. The Law Commission produced a final report in March 1995¹⁹, recommending that "there should be a single comprehensive piece of legislation for making new provision for people who lack mental Capacity".
17. The draft legislation includes a new statutory definition of mental incapacity:

1. *Persons who lack Capacity*

- (1) *For the purposes of this Act, a person lacks Capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of or a disturbance in the functioning of the mind or brain.*

- (2) *It does not matter whether the impairment or disturbance is permanent or temporary.*

2. *Inability to make decisions*

¹⁸ www.parliament.uk – location – Bills before Parliament/Draft Bills before Parliament/Draft Bills 2002-03/Draft Mental Incapacity Bill

¹⁹ www.lawcom.gov.uk – location – Publications/View list of Reports/231 – 01 March 1995, Mental Incapacity (HC 189) (0 10 218995 1) – For a copy call TSO on number at the top of page.

(1) *For the purposes of section 1, a person is unable to make a decision for himself if-*

- (a) *he is unable to understand the information relevant to the decision;*
- (b) *he is unable to retain the information relevant to the decision;*
- (c) *he is unable to use the information relevant to the decision as part of the process of making the decision;*
or
- (d) *he is unable to communicate the decision (whether by talking, using sign language or any other means).*

(2) *A person is not to be treated as unable to make a decision merely because he makes an unwise decision.*

(3) *A person is not to be treated as unable to make a decision unless all practicable steps to help him do so have been taken without success.*

(4) *The fact that a person is able to retain the information relevant to a decision for a short period only does not prevent him from being regarded as able to make the decision.*

(5) *The information relevant to a decision includes information about the reasonably foreseeable consequences of:-*

- (a) *deciding one way or another; or*
- (b) *failing to make the decision.*

3. *Presumption against lack of Capacity*

(1) *For the purposes of this Act, a person must be assumed to have Capacity unless it is established that he lacks Capacity.*

(2) *Any question in any proceedings, under this or any other Act, whether a person lacks Capacity within the meaning of this Act must be decided on the balance of probabilities.*

18. The Law Commission also recommended that people who have Capacity should be able to make advance decisions concerning what medical treatment they might undergo if in future they lacked the Capacity to express their own decisions.
19. The issue of mental Capacity is one that concerns every member of society, since it not only affects those who lose their mental Capacity through obvious forms of illness, such as dementia or Alzheimer's, but also it should be remembered that one can lose one's mental Capacity temporarily simply by becoming unconscious.
20. A paper which explored all areas of mental Capacity in depth would be several times the length of this report but it is worth noting that a patient may have the Capacity to make decisions about his treatment and at the same time be unable to manage his own affairs or have the Capacity to make a will. It is also worth remembering that there is a legal presumption of Capacity, i.e. one presumes that a patient has Capacity unless there is evidence to the contrary. The fact that a patient makes an unwise or foolish choice is not necessarily an indication that someone lacks Capacity, paraphrasing a famous English judge, it is not only the mad who lack wisdom.
21. The issue of mental Capacity is obviously pertinent to the making of a request for Euthanasia or a binding Advance Statement. However, given that medical knowledge moves so swiftly these days, it seems inappropriate that an Advance Directive should endure beyond a set period (5 years at the most) and there is a very real concern for many people that at the end of this set period they could lack the mental Capacity to make a new Advance Directive. One should therefore include in any new legislation for Advance Directives the

ability to ratify an otherwise expired Advance Statement in these circumstances.

22. Equally, some people who are otherwise mentally incompetent have long periods of lucidity or fluctuate between the two states. Provision should be made to allow such people the ability to indicate some choice in respect of their future treatment.
23. Those who are interested in the format of existing Advance Statements used elsewhere should look at Appendix 4.

III Difficulties in legislating for Euthanasia and/or Advance Statements

24. If the States of Guernsey decides that it is appropriate to legalise a form of Euthanasia, then it would certainly be possible to frame such legislation, but the difficulties in so doing should not be underestimated. Those jurisdictions which have legalised Euthanasia, such as the Netherlands, are certainly not free from controversy arising out of the interpretation of their legislation.
25. The Working Party considered that the difficulty which all legalised Euthanasia systems have is how to properly protect people both from their own vulnerabilities and other peoples' machinations. The existing legislation in other jurisdictions tries to do this by means of ensuring that there is a proper reporting system in place and to ensure that the patient has mental Capacity.
26. The first hurdle which arises is therefore whether the patient who it is proposed will end his life by Euthanasia has the mental Capacity to make that decision.
27. At present there is no statutory definition of mental Capacity in Guernsey, in practice it is accepted that the various definitions of mental Capacity in Guernsey follows the definitions provided by English case law, see Section 4.

28. Whilst that definition is a legal one, it will in practice be left to a doctor to assess whether a patient has Capacity or not, with the courts only becoming involved in case of dispute.
29. Once the patient has passed the hurdle of mental competence, there is then the issue of carefully defining the stage at which he is permitted to request Euthanasia. The difficulty of defining through legislation such terms as “unbearable suffering” or “poor quality of life” is obvious.
30. If such terms are to be avoided in favour of the diagnosis of a Terminal Illness with the prognosis of 6 months or less to live, then the problem is easier from the legal draftsman’s point of view but that puts the difficulty squarely back with the medical profession. Perhaps, that is where it should be? The fact is however that doctors are not infallible, the title of a paper “Patients with Terminal Cancer who neither have Terminal Illness nor Cancer”²⁰ underlines this point.
31. The third area of regulation is to decide how all cases of Euthanasia are to be reported. All of the existing legislation has a post event system of reporting which could be thought to permit abuse of the system and under-reporting.
32. Since it is undesirable to allow under-reporting, one method of discouraging it may be to make the penalties for doing so exemplary. It might however be more effective to look at a system of prior reporting so that there is the possibility of checks being made before the patient is assisted to die. This would also entail the setting up of a supervisory body to regulate the process of ending life through Euthanasia.
33. Finally, should the law be amended to allow any form of assisted death, the Working Party considered that the legislation should be framed to ensure that it only applies to residents of Guernsey.

²⁰ Rees, W et al. (1987) 'Patients with Terminal Cancer' who neither have terminal illness nor cancer. BMJ (295) pp318-319.

9. The Guernsey Medical Perspective on Care for the Dying

1. The Working Party received assistance from those members of the Working Party who hold medical qualifications and also other medical professionals working in the area of long term and Palliative Care. The anecdotal material which was brought to the meetings was one of the reasons that a further medical survey was commissioned. The review of existing local Palliative Care (see Section II below) which was undertaken also helped to put together the picture of how Guernsey takes care of its terminally ill. Whilst all this material is interesting when considering the needs of the patient with a Terminal Illness, the medical profession were very aware that there are people who do not have a Terminal Illness who have expressed a wish to use some form of Euthanasia.
2. The views of the Board of Health's Ethical Committee were also sought in May 2003. The Committee responded that its consensus view was that the introduction of legislation to facilitate voluntary euthanasia would be morally and ethically incorrect and cited five key issues (see correspondence and the Ethical Committee's report at Appendix 14). The Committee did, however, give positive support to the provision of a well staffed palliative care service and for the concept of Advance Statements, developed within the context of Guernsey health care, as is current practice in the United Kingdom.

I The Medical Survey

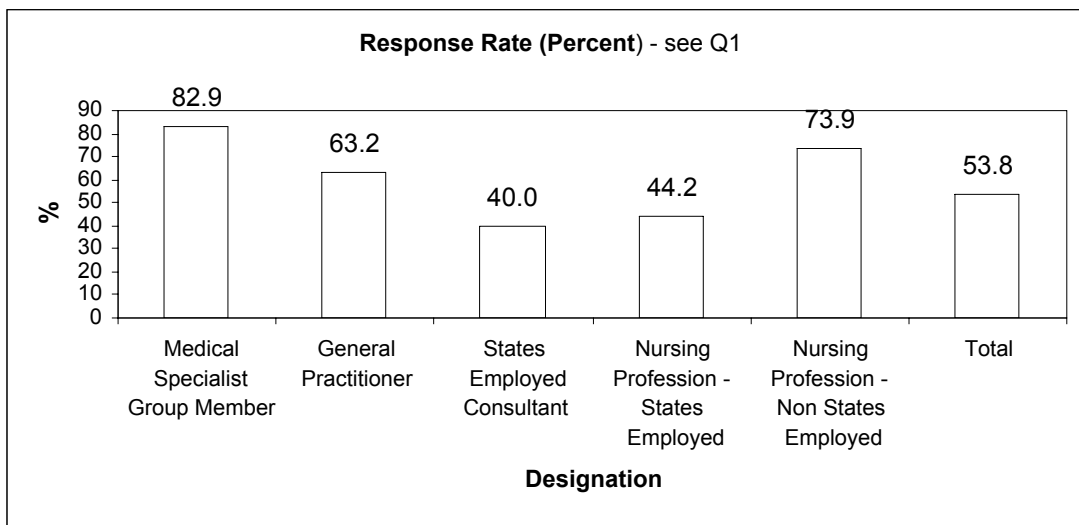
3. At an early stage in the life of the working party two separate surveys were carried out to gauge opinions amongst health care professionals. One covered nursing, the other GPs and Medical Specialists.
4. As the Working Party's knowledge of this complex matter increased and also as production of the report to the Advisory and Finance committee developed, members decided it would be useful to run a more detailed and extensive survey across all branches of the medical and nursing professions using the same questionnaire.

5. The 'Death with Dignity-Survey of Medical and Nursing Professions' was carried out in February/March 2004.
6. All practising Doctors in Guernsey and Alderney were given the opportunity to contribute. This included all Guernsey and Alderney General Practitioners, all members of the Medical Specialist Group and all States Employed Doctors.
7. A large representative and random sample of nurses (222) in both the States and non States employed sectors was canvassed.
8. Although the survey was anonymous, those people making submissions were asked to declare their designation in one of 5 categories:-
 - MSG member
 - GP
 - States employed Consultant
 - Nursing Profession-States Employed
 - Nursing Profession-Non-States Employed

A sample of the questionnaire, (which has been annotated to show the personal comments and observations added to the questionnaires by respondents), and the detailed survey outputs are provided at Appendix 15. The results are also summarized below:

(i) Response

A total of 329 questionnaires were sent out and 177 returned, a total response rate of **54%**.

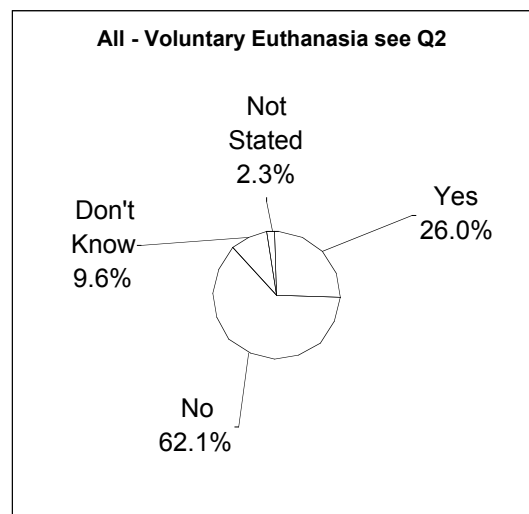


The percentage response was highest amongst doctors with **83%** of medical specialists responding and **66%** of doctors overall.

44% of States nurses responded, **74%** of non states nurses responded giving an overall nurse response rate of **47%**.

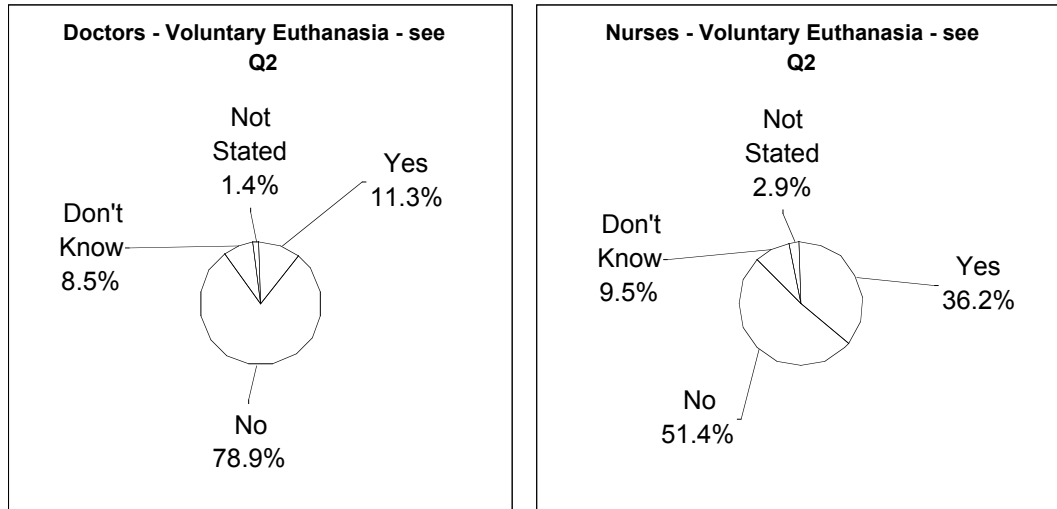
(ii) Voluntary Euthanasia

62% of all respondents felt that no change to the current legislation on voluntary Euthanasia was required.



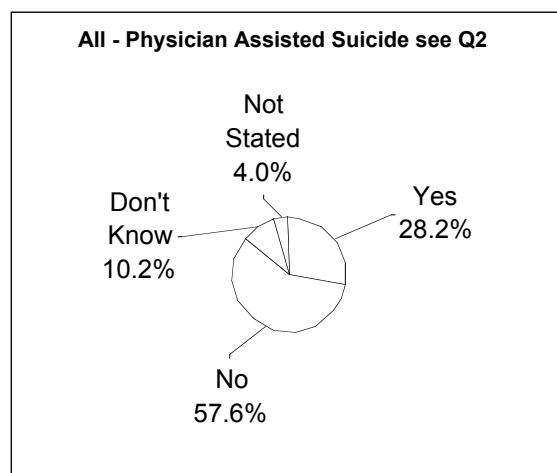
79% of doctors and **51%** of nurses were against any change in current voluntary Euthanasia legislation.

11% of doctors and **36%** of nurses believed The States of Guernsey should move to legalise Voluntary Euthanasia.

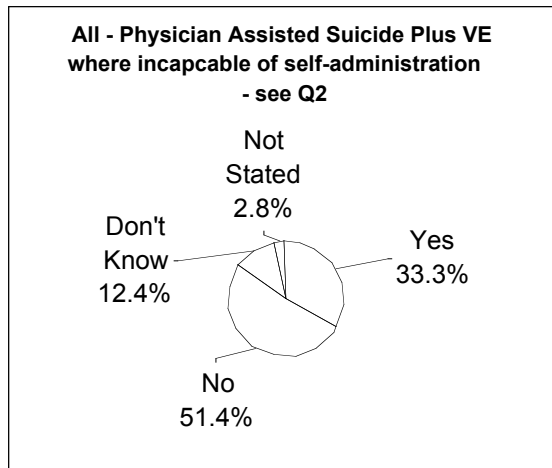


(iii) Physician Assisted Suicide

58% of all respondents were against any change in the law to introduce Physician Assisted Suicide.

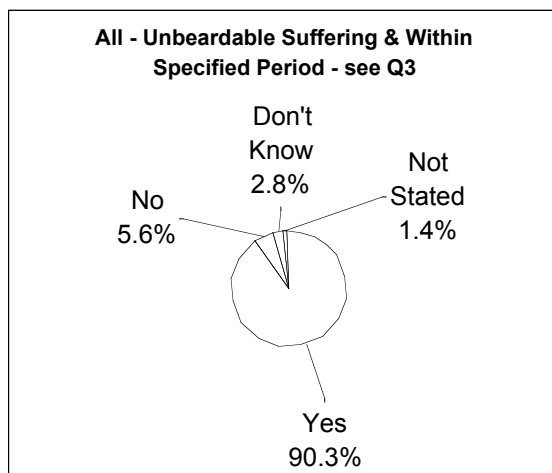


51% of all respondents were against Physician Assisted Suicide with a voluntary Euthanasia provision for those persons incapable of self administering medication for the purpose of ending life.

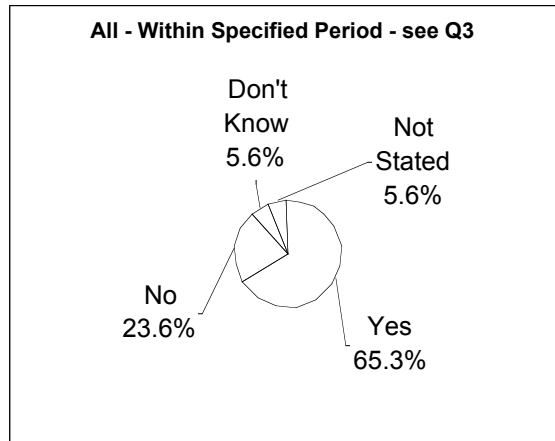


(iv) Breakdown of Opinions of those in favour of legalising Voluntary Euthanasia

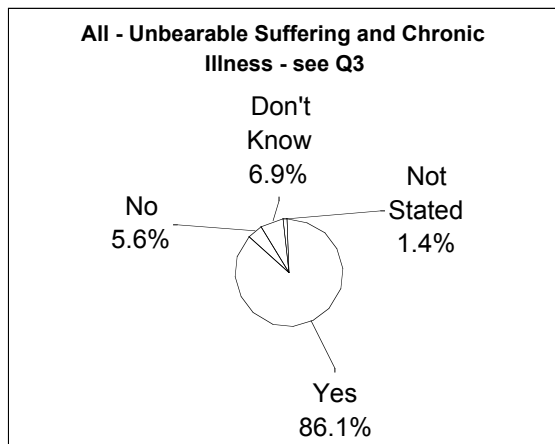
90% of those seeking to legalise Euthanasia wish it to apply to patients with a Terminal Illness and unbearable suffering where it can be reasonably expected that death will occur within a period specified by law.



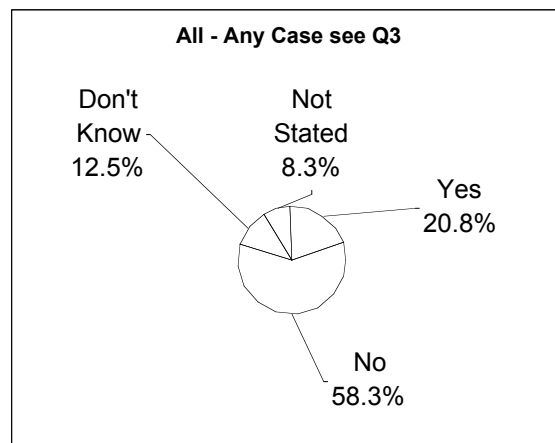
65% of those seeking to legalise Euthanasia wish it to apply to patients with Terminal Illness where it can be reasonably expected that death will occur within a period specified by law.



86% of those seeking to legalise Euthanasia wish it to apply to those with chronic illness with distress and unbearable suffering with no prospect of improvement.

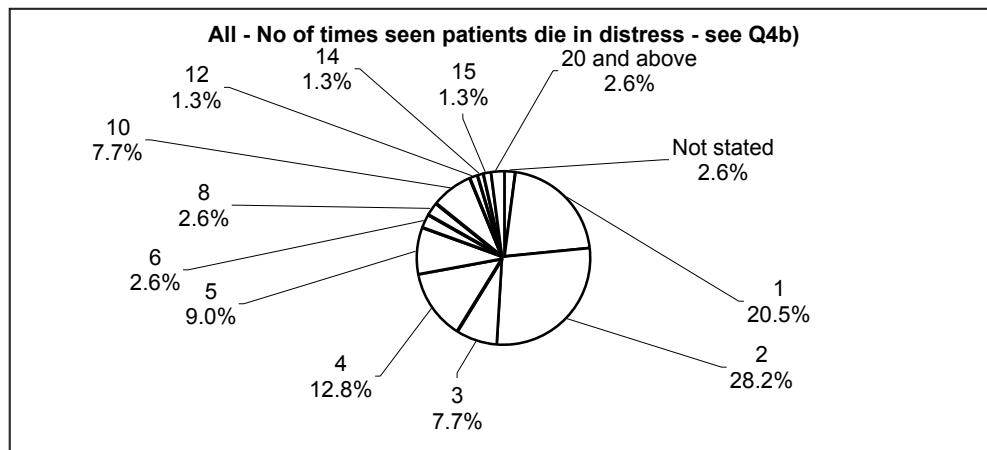


21% of those seeking to legalise Euthanasia wish it to apply to a request from *any* competent patient.

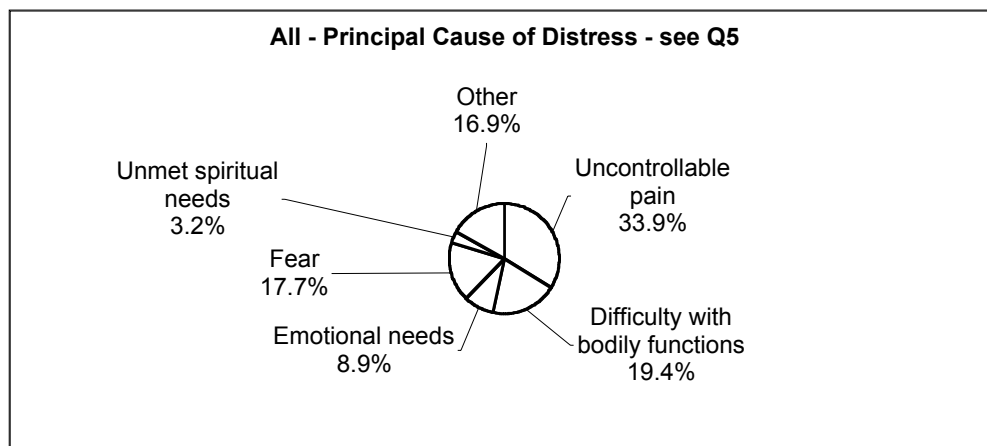


(v) Patients dying in distress

44% of all respondents (**49%** of nurses) had witnessed a patient dying in distress in the previous 2 years. When those who had witnessed patients dying in distress were asked how often this had occurred, **49%** stated that they had seen it in 1 or 2 patients in the past 2 years, **49%** stated they had seen a greater number and others did not answer this question.



The principal cause stated for patients dying in distress was uncontrollable pain. [NB Some respondents ticked more than one box.]



(vi) Advance Statements

97% of all respondents felt that written Advance Statements were ‘Important and must be complied with’ or represented an ‘Important Guideline’. However opinion was split as to whether specific legislation should be introduced to clearly make Advance Statements legally binding (**43%** for specific legislation, **42%** against).

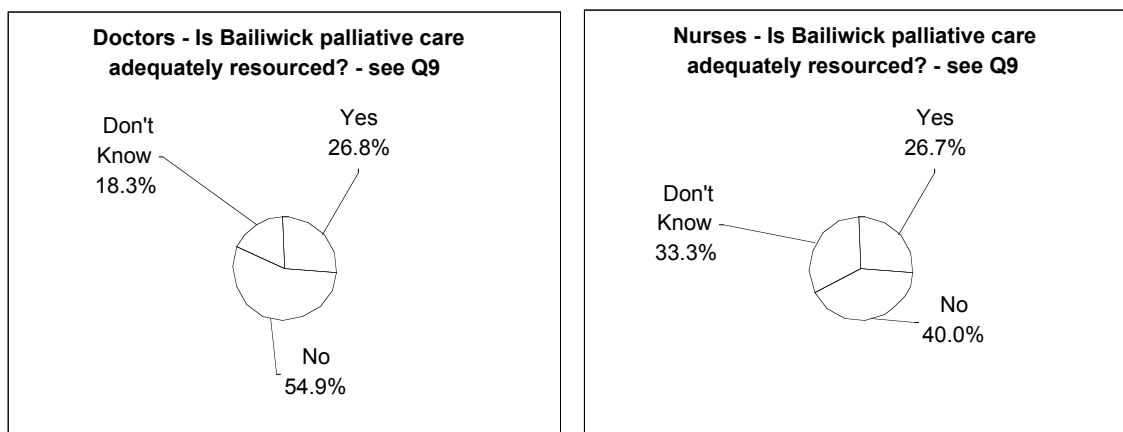
(vii) Double Effect Medication

A majority of both Doctors and Nurses (**64%**) wish to see specific legislation to protect health care professionals in any case of possible ‘double effect’ as a result of administration of medication or other treatments to alleviate suffering.

(viii) Palliative Care Provision

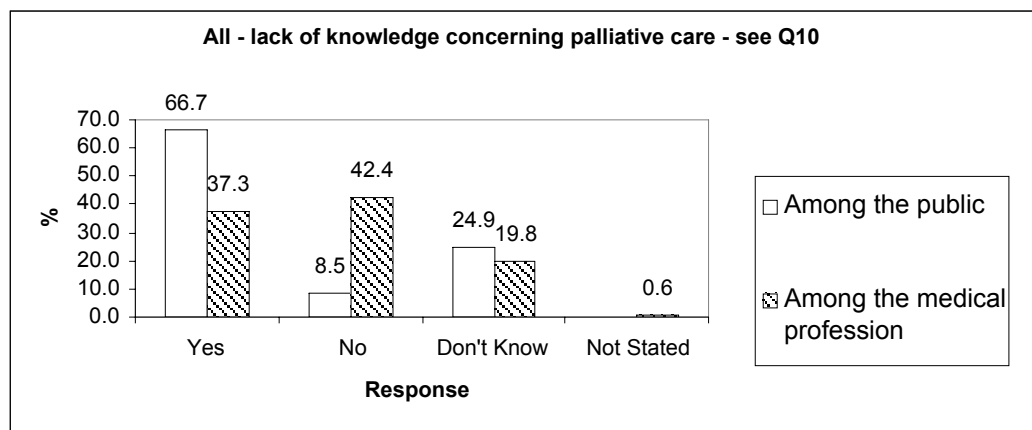
46% of all respondents felt that Palliative Care was not adequately resourced. (**55%** of Doctors and **40%** of nurses).

27% of doctors and **27%** of nurses felt that Palliative Care was adequately resourced.

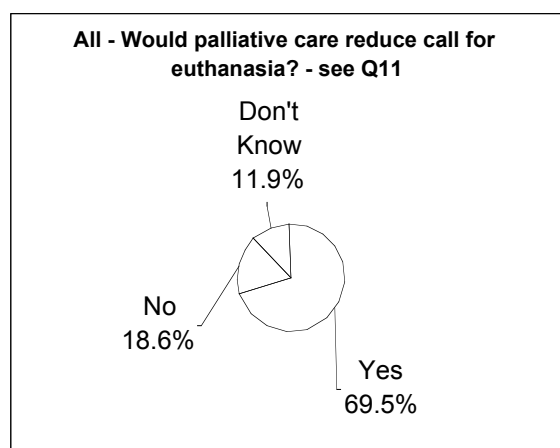


A large group of nurses (**33%**) replied 'don't know' to this question possibly suggesting that this was an area outside their expertise.

In relation to the public awareness of the availability of Palliative Care Services, **67%** of respondents stated that there was a lack of knowledge or clarity among the public about the availability of and access to local Palliative Care services.

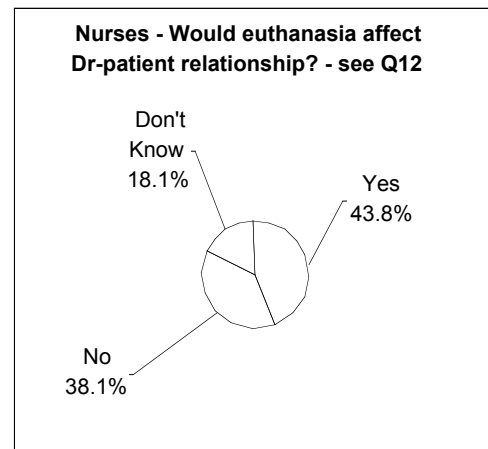
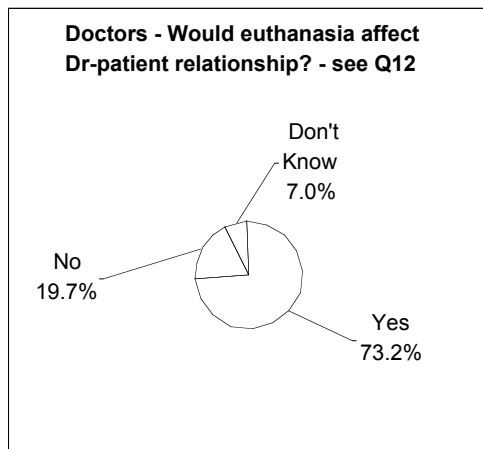
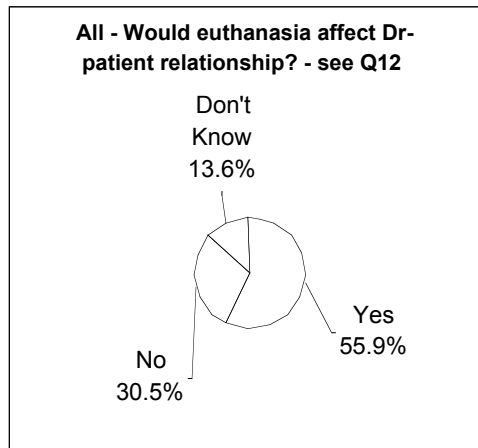


70% stated that there would be a reduction in calls for Doctor Assisted Death with the provision of high quality Palliative Care along with a greater public and medical awareness of the availability of such services.



(ix) The Doctor Patient Relationship

56% (**73%** of Doctors) of respondents felt that the Doctor patient relationship would be adversely affected by the introduction of Voluntary Euthanasia. **44%** of nurses felt that the doctor patient relationship would be adversely affected with **18%** of nurses answering 'don't know'.



II Palliative Care Provision in Guernsey

1. Whilst other aspects of medical care can be successfully carried out in UK or elsewhere, it is imperative that Palliative Care is carried out in Guernsey so that patients can remain near their family and friends at such a traumatic and vulnerable time.
2. In many areas Guernsey is achieving best practice and is offering Palliative Care to people with many Terminal Illnesses, not just cancer. However, since

cancer is numerically the leading cause of premature death in Guernsey, there have been more resources dedicated to cancer care. This led to a Guernsey Cancer Strategy Report being accepted by the Board of Health in 2001 (extracts from which are included in a report by Dr David Jeffs, Director of Public Health, appended at 16, in which he gives an overview of those sections of the Guernsey Cancer Strategy relevant to Palliative Care and detailed recommendations for improvement in its quality and scope), and of its 29 recommendations 8 are relevant to general Palliative Care. These are currently being implemented by the Board of Health.

3. The Working Party acknowledges that Palliative Care provision is currently being provided by:

- (i) Family practitioners, both in the community and to provide ‘continuity of care’ by continuing to manage their patients admitted to Les Bourgs Hospice. Patients have commented how they appreciate the ability of their general practitioner to treat and ‘follow them’ into the hospice.

However very few of the general practitioners have any further specialist training in Palliative Care. Visits (usually daily) by the general practitioner attract a fee. According to the Palliative Care nurses there is a wide variation in the use of Palliative Care services between general practitioners which may suggest that some doctors’ patients are not gaining access to the local Palliative Care services. There is also no formal link with medical specialist level Palliative Care units elsewhere for effective audit of the standards of medical care given in the hospice.

- (ii) The medical oncologist (Dr Peter Gomes). Dr Gomes was appointed to the position of medical oncologist in March 2000 and is a member of the Guernsey Medical Specialist Group. His responsibilities to patients lie in the treatment of malignant disease and are complementary to but distinct from Palliative Care. Medical interventions such as chemotherapy are carried out at Bulstrode House which now houses

the oncology unit (see below). In accordance with recommendation 20 of the Guernsey Cancer Strategy, a specialist cancer nurse post has recently been appointed to co-ordinate a team of expert cancer nurses.

- (iii) An anaesthetist with special interest and training in acute and chronic pain control (Dr Callum McClymont). Dr McClymont is a consultant anaesthetist and is a member of the Guernsey Medical Specialist Group. Sitting on the Board of Governors of Les Bourgs Hospice, he is also available on a non contractual basis for ad hoc advice to GPs on difficult pain control situations and is skilled in invasive pain control techniques. He runs a general pain clinic at Alexandra House in addition to his general anaesthetic workload.
- (iv) A community Palliative Care nursing team. There are currently three full time Palliative Care nurses employed by the Board of Health who have all undergone specialist Palliative Care training. In addition to their duties attending patients, the Palliative Care nurses act as a liaison and consultancy service for other medical professionals and organisations involved in Palliative Care. The nurses also develop policies about Palliative Care and educate other nurses about Palliative Care issues.
- (v) Les Bourgs Hospice. We have a centre of excellence in Les Bourgs Hospice, which was opened in 1991. It has a Medical Advisory Committee with representation from both specialists and family practitioners with interest and practical experience in the field of Palliative Care.

Les Bourgs Hospice also offers day hospice facilities, a range of complementary therapies and a bereavement telephone service. This last is a '*listening service*' only, but those who ask can be referred to a counsellor where appropriate. The day care facilities are recognised as being inadequate and it is hoped that they would be extended by refurbishment shortly. Day care offers important respite for carers of

those patients being looked after at home. The change in role of Bulstrode House from a day hospice to a day oncology unit, (see page 58), has highlighted the shortcoming in the current provision.

When Les Bourgs was established, the focus was on '*cancer related disease*'. When HIV and Aids related disease became more common in Guernsey, patients with these conditions were also accepted. More recently it has broadened its criteria to include '*care for people with advanced Terminal Illness*'. However, review of admissions for the years 2000, 2001 and 2002 show that care given is still very heavily weighted towards cancer patients and those with cancer related disease.

Given the apparent widespread public anxiety about the availability of Palliative Care for those with other conditions, particularly chronic neurological conditions such as motor neurone disease, it would seem desirable that Les Bourgs should emphasise and publicise its willingness and ability to offer its full range of services to all who might benefit, irrespective of their underlying condition.

Running costs are said to currently exceed £400,000 per annum. Funds are raised principally through membership, donations, bequests, and special fund raising events. However, the Management Committee is considering a substantial rebuilding and refurbishment programme which would increase the number of beds available to seven, with additional day care facilities, which would allow a greater number and wider range of patients to be accepted, and more methods of treatment to be offered.

From its inception, Les Bourgs has been one of the most successful Guernsey charities in enlisting the support of the public, raising the not inconsiderable sums required for daily running costs and ensuring that treatments are available to both patients and their families totally free of charge, although attending family practitioners may (and do) charge for their services. Although charities may sometimes contribute

towards these costs, many see these aspects as a potential barrier to adequate terminal care for some people.

Although Les Bourgs Hospice is classified as a nursing home for the purposes of the Long Term Care Insurance (Guernsey) Law, as it does not charge for in-patient stays, it is not eligible to receive Long Term Care Benefit from the Social Security Authority. In addition, no funding is received from the Board of Health.

Medical Advisors to Les Bourgs Hospice can only recall a limited number of cases (perhaps 2-3) who have been admitted to the Hospice and where there have been difficulties in relieving their pain or distress completely.

- (vi) Bulstrode House was originally built with voluntary donations as a day hospice in 1993, although operational costs have been met by the Board of Health. Following the '*Guernsey Cancer Strategy*' Report, the decision was taken that Bulstrode House should be developed as an oncology unit, where day treatments could be given.

With the appointment of a medical oncologist, Dr Peter Gomes, in March 2000, the number of out patient oncology clinics held locally has increased to three per week, with two additional visiting oncologist clinics per month. The unit is also participating in five multicentre cancer trials, all of which have been duly approved by the local Medical Research Ethics Committee.

- (vii) The Cheshire Home. The Guernsey Cheshire Home opened in 1987. It states its aims and objectives are 'to provide a home for residents of the Bailiwick who are suffering from serious physical disabilities such as multiple sclerosis, spinal injury, stroke, motor neurone disease, arthritis, and past accidents. Many of those using the home may require care for the rest of their lives. In most cases their physical

disabilities are such that assistance is required in all aspects of their daily life to ensure that they are able to live as full a life as they wish.’

Care is provided in an atmosphere as close as possible to that of a family home, with the aim of achieving maximum independence for the residents.

There are currently eleven bedrooms, nine of which are occupied by permanent residents, and two of which are available for respite care. Day care is additionally available.

The present case mix of clients includes those suffering with motor neurone disease, multiple sclerosis, muscular dystrophy, cerebral palsy, spina bifida, post traumatic spinal injury, as well as rarer neurodegenerative disorders.

The Guernsey Cheshire Home has four qualified staff, plus care assistants. It differs from the Hospice, in that it describes itself as a *‘registered as a residential home, but staffed as a nursing home’* - its aim is to be a ‘home for life’.

Given the life limiting characteristics of most of the conditions treated, the Guernsey Cheshire Homes is successful in maintaining the majority of patients through until their death. Only rarely is it necessary to transfer the occasional patient to Les Bourgs Hospice or the Princess Elizabeth Hospital for terminal care.

Palliative Care is thus both subscribed to and practised at the Guernsey Cheshire Home.

Although a certain amount of funding comes through the long-term care scheme recently established by the States, the Guernsey Cheshire Home is still very dependent on voluntary fund raising, donations and bequests. Total costs are well in excess of £600,000 annually.

III Where Guernsey falls short of best practice

1. The most important resources in which we fall short of the NICE guidelines (Appendix 5) are agreed by the majority of the Working Party to be:

- (1) The absence of a Palliative Care specialist

UK figures suggest an area population of 60-80,000 can support the appointment of a Palliative Care specialist. Guernsey's population is *62,101 (as at 29 April 2001) and therefore the provision of a Palliative Care specialist would be appropriate. (*NB: For the purposes of a discussion on Palliative Care, includes Alderney's population of 2,294).

There is support from Les Bours' Medical Advisory Committee for the appointment of a Palliative Care specialist. They would give consideration to funding and employing such a clinician for the first 2-3 years providing the Board of Health or some other body agreed to accept responsibility from then on. Consideration has also been given to whether such an appointment might be shared with the Palliative Care services in Jersey but it is not felt that this would be a workable solution.

The Board of Health currently has no plans to appoint a Palliative Care specialist but is planning to assist local GPs at the three largest primary care practices to gain qualifications in Palliative Care. It is hoped that these "specialist" GPs will be able to assist and support their colleagues in the latest Palliative Care techniques.

- (2) Lack of comprehensive management for the various Palliative Care services in Guernsey which has responsibility to administer the service and to ensure efficient communication and dissemination of information to all stakeholders in the service.
- (3) Under provision of inpatient and day patient hospice provision

The Guernsey Cancer Strategy recommends (R22) that Les Bourgs Hospice should continue to develop with support (other than direct financial) from the Board of Health and increase the number of beds provided by one or two together with an expansion of its day care facilities.'

Detailed plans of prospective developments were discussed with the Working Party members who visited Les Bourgs. These will include an expansion in bed numbers and extended day patient facilities. This will assist the provision of Palliative Care to non-cancer patients. Additional secretarial space and nursing accommodation will also be built. This will be funded by voluntary donation.

- (4) Core education objectives for all involved in the care of the dying
- 2. There is an acknowledged need to transfer the best practice in Palliative Care to all areas including the hospitals, elderly care facilities such as nursing and residential homes, and the community.
- 3. A more detailed summary of the current provision of Palliative Care services in Guernsey and the background to their development is provided in two appended reports.
 - (1) Dr David Jeffs, Director of Public Health, gives an overview of those sections of the Guernsey Cancer Strategy relevant to Palliative Care and detailed recommendations for improvement in the quality and scope of Palliative Care. (See Appendix 16).
 - (2) Mrs Jacqui Gallienne, Senior Manager of Children's Nursing Services, gives a detailed breakdown of how the nursing service is delivered, the ages and numbers of patients seen and the types of symptoms requiring treatment. There is also an analysis of the place of death of deceased clients. (Appendix 17).

IV Advance Statements and Directives - The Implications for Guernsey

1. As the most recent medical survey showed, doctors in Guernsey are seeing small numbers of patients who have Advance Statements. The Working Party heard directly from medical professionals who had experienced patients bringing with them ready drafted Advance Statements and also from professionals who had themselves assisted patients to draft an Advance Statement. Concern was expressed that Advance Statements had been reviewed with patients which failed to address the issues that the patient was actually concerned about and showed a worrying lack of medical knowledge. There was concern that even with the best of intentions, people with no knowledge of medical procedure were assisting in the drafting of Advance Statements, which were ultimately of no benefit, or even potential harm to the patient concerned. In practice, even well written Advance Statements can be unhelpful as, at the time of writing them, the exact set of future circumstances cannot be predicted and hence, they can rarely be directly relevant to the situation the patient subsequently finds himself in. It was also felt by some sections of the medical community that, if as a consequence of this report, more and more people were encouraged to sign up to Advance Statements that did not ultimately achieve their aim, then this would be very worrying to the medical community as a whole but especially for those involved in the field of intensive care.

2. The law on Advance Statements and directives is clear, i.e. that these documents are binding and medical professionals must respect a patient's wishes. Additionally, health care professionals in Guernsey have clear professional codes of practice on the issue of Advance Statements as they follow the codes laid down by their professional bodies, such as the GMC²¹, RCN²² and BMA²³.

²¹ Website: www.gmc-uk.org follow: Ethical Guidance > Guidance > Withholding and Withdrawing Life-prolonging Treatment.

²² Further information can be found on website: www.rcn.org.uk

²³ Website: www.bma.org.uk / ethics/publications/guidance/Advance Statements/Advance Statements – code of practice

3. The use of Advance Statements reflects the shift of power away from ‘doctor knows best’ to increasing patient autonomy and shared decision making. This is to be welcomed but it is also an issue which brings with it difficulties, due to the problems of poorly drafted Advance Statements. It is important that Advance Statements do not hinder rather than assist the doctor. The Working Party agreed that Guernsey needs to prepare for the inevitable increase in patients with Advance Statements to ensure that patients benefit from their proper use.

4. However, the Working Party was concerned that the wider community was unaware of the limitations of Advance Statements, including:-
 - (i) Advance Statements are frequently but mistakenly regarded as requests for Euthanasia. An Advance Statement can only extend the *legally available* options into future situations under circumstances in which the patient has lost Capacity. Patients cannot demand or refuse anything in advance that they cannot legitimately demand or refuse when conscious and competent.

 - (ii) Decisions relating to treatment and care are often complex. Interpretation of the patient’s true wishes and intentions may be difficult and an overly simplistic Advance Statement may not assist this process.

 - (iii) Medicine can be an uncertain and imprecise science. There is always the possibility of a mistaken diagnosis.

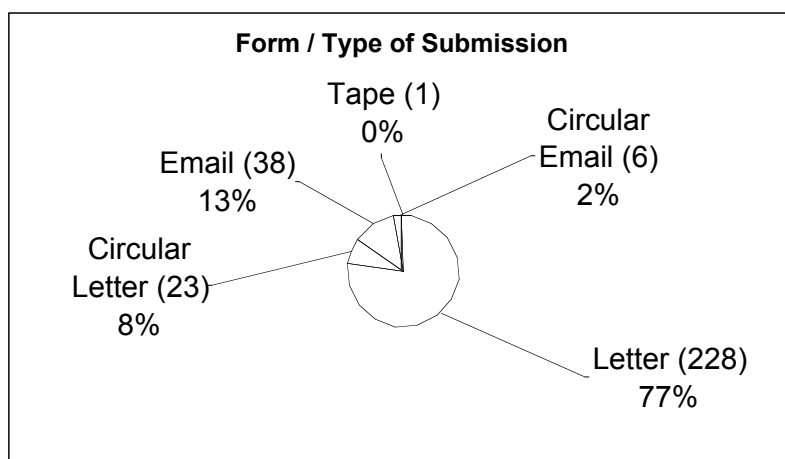
 - (iv) Best Practice is constantly evolving and new treatments are being introduced which can change the prognosis of the patient’s condition. No-one signing an Advance Statement or Directive while well could possibly foresee all future situations or ways in which new medical treatments could affect those situations in years to come. It is often argued that documents could be updated regularly, but this depends on the human ability to remember to do so.

- (v) Patients on the 'verge' of Capacity e.g. early Alzheimer's disease or receiving sedative or analgesic medication and patients with fluctuating Capacity may be adversely influenced by parties with a vested interest.
5. There is also the question of timing and when Advance Statements should be implemented. There would have to be a clearly identifiable 'trigger event' - either the onset of incompetence or the occurrence of another event in the already incompetent. It may not be possible for all those involved to agree. Incompetence is not always permanent so if it is, there needs to be a specified period after which the advance directive is implemented. As a further complication, many medical conditions are readily reversible.
 6. Probably the biggest single problem is that people may well change their minds. The healthy do not choose in the same way as the sick. When people become unwell their attitudes to what they want or find tolerable often change.
 7. The fear which drives many to sign Advance Statements seems to be of losing control, and becoming a member of a disadvantaged group such as the severely disabled, the confused elderly or the terminally ill. However, these are the very groups whose treatment needs a positive approach, and the existence of Advance Statements further stigmatising these conditions would reinforce a negative approach.
 8. When approached by a patient wishing to formulate an Advance Statement, health care professionals need to take all necessary steps to inform and guide the patient about treatment options and their implications. This will necessitate health professionals being given the resources and training to do this.
 9. The Working Party agreed that Guernsey needs to have a protocol for registration, storage and retrieval of Advance Statements. This will require debate with all the stakeholders (patients, health care professionals and lawyers).

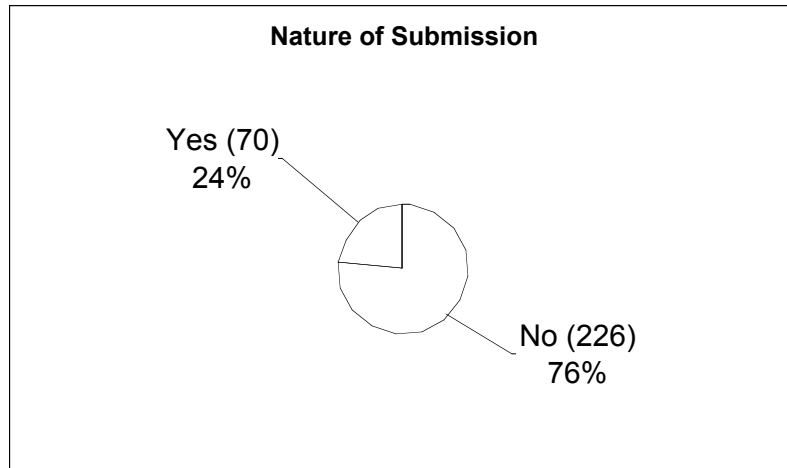
10. There is also the question of how to educate and inform the general public so as to encourage debate about this issue. The Working Party agreed that it is vital for people wishing to make an Advance Statement to have sufficient knowledge to do so properly and, perhaps as importantly, to know when to do so.

10. The Guernsey Public's Response to the Working Party's Consultation Process

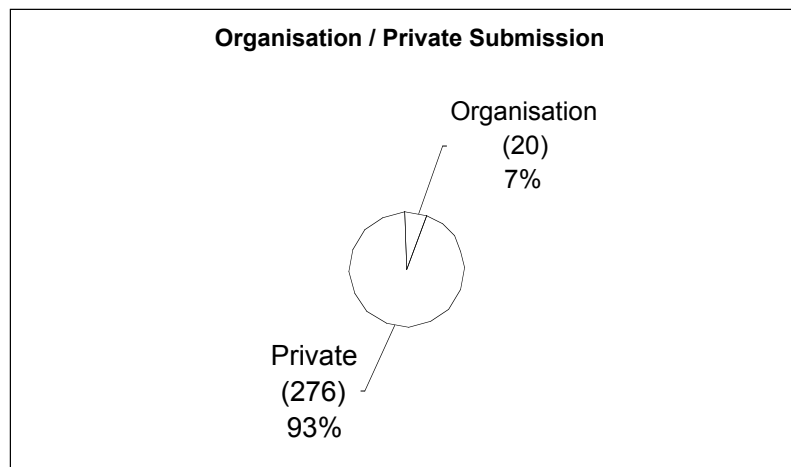
1. There has been understandable interest in the progress of the Working Party amongst the community in Guernsey, with a strong indication that many people wished to be able to express their views to the Working Party and have them taken into account.
2. In June 2002, two advertisements were, therefore, placed in the Guernsey Press inviting submissions from the public and interest groups with a closing date of 14 July 2003. The consultation invitation was also published on the States of Guernsey website.
3. In total, 296 submissions were made, 252 of those being by letter (85%) and 44 by e-mail (15%). Included in the written submissions were 23 copies of a circular letter and a tape recording of a presentation made by Wesley J Smith on 23 June 2003, which was against the legalisation of Euthanasia.

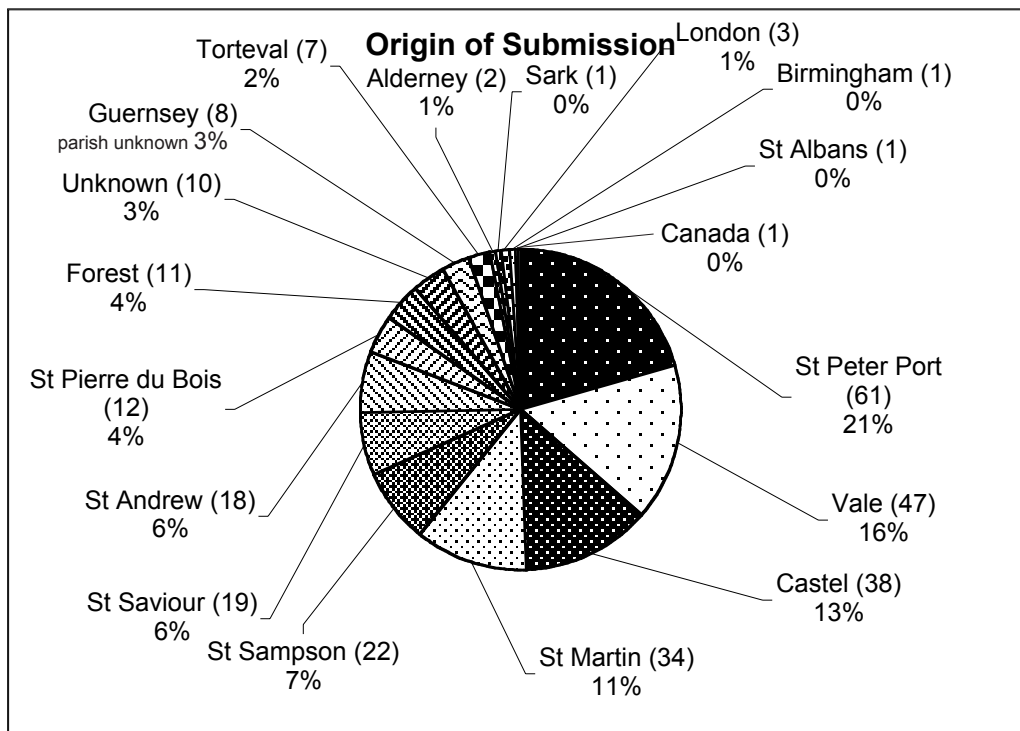


4. All submissions were read in full and analysed. 76% of those who made submissions were opposed to any change in the law to allow Euthanasia/death with dignity and 24% were in favour. It was clear however that there was confusion over the meaning of the term “death with dignity”. It should be noted here that submissions signed by a number of people have been counted only once.



5. Of the submissions, 93% were made by individuals and 7% were made by interest groups. The submissions have been analysed for origin with at least 95% emanating from within the Bailiwick of Guernsey, 1% from London and 3% of unknown origin.





6. It is always notoriously difficult to conclude from submissions of this type the view of the majority of the population. What one can say with certainty is that an overwhelming majority of those who were prepared to take the time to make a submission to the Working Party were opposed to any change in the law.

7. Many people who made submissions were clearly drawing on personal experience and, therefore, it would seem that some people die in situations which their family and friends feel is unacceptable. Equally there is much public confusion between Double Effect Medication and Euthanasia which underlines the need for better public education. There was, however, enthusiasm for good quality pain control and Palliative Care in general, even if that phrase was not used.

8. It does appear from reading the submissions that certain people were very concerned as to the effect any legalisation of Euthanasia would have on Guernsey's society in general and on family life in particular. This is particularly so in a society where most adults now work full-time in order to

pay for housing and it can often appear to elderly members of the family that other people have little time for them. There was a clear concern that elderly people or disabled people could be made to feel a burden quite unintentionally.

9. A fuller analysis of the submissions is attached at Appendix 18. The submissions themselves are not appended as most participants wished to maintain their confidentiality.

11. **The Working Party's Debate and Summary of Key Issues**

1. The ways in which people are able to live and die are fundamental to society and highly emotive. Euthanasia (and the related issues) divides public opinion sharply and is a subject that people are rarely indifferent to. Indeed it became clear that the members of the Working Party reflected these divisions in society.
2. It is worth noting that those who espouse the more extreme arguments for either side tend to end up damaging their own position and obscuring the unpalatable fact that we need to acknowledge that whichever decision is taken cannot be a perfect solution. We have summarised below the main arguments in the end of life debate and have endeavoured to do so in as balanced a fashion as possible.
3. There has clearly been campaigning on both sides of this debate in Guernsey. Guernsey4DAD commissioned a poll by NOP of the Guernsey public's views on Euthanasia. The majority of the Working Party were concerned that the questions used in the NOP poll were confusing and that people may not have understood the questions clearly. Additionally, the results of the public consultation which the Working Party undertook were very different to the NOP survey, with the majority of those who made a submission not in favour of any change to the legislation and, in the submissions, able to explain exactly what they meant.
4. Those in favour of Euthanasia often say that society is moving to the position where an individual's rights are more readily recognised and they acknowledge that this may appear to involve a reduction of what could be described as conservative values in society. They emphasise that there is nothing more personal than the choice of when and how to die.
5. Additionally, pro-Euthanasia activists sometimes seek to characterise anti-Euthanasia campaigners as being religiously motivated, as if it is (unthinking) dogma alone which fuels such opposition. They point out that they are not

forcing people to act contrary to their religious beliefs, just to let people die in accordance with their own views.

6. Such characterisation is inaccurate. There are a great many anti-Euthanasia activists who are not motivated by religious belief. In any event, those whose opposition to Euthanasia is founded on religious belief cannot fairly be accused of lack of thought.
7. However, those who do not agree with any form of assisted death are less likely to espouse the rights of the individual and talk more of the effects such legislation would have on society as a whole.
8. Members of the elderly community have expressed their fear at the possibility of legislation for voluntary Euthanasia with the many subtle pressures that can be brought to bear on them and the worry that they may end up having no choice. It is worth noting that the latest Oregon report (see Appendix 6) noted that 38% of people who were assisted to die felt a burden on family friends and care givers. It is also fair to say that others in the elderly community are supportive of the proposal to legalise voluntary Euthanasia which would allow them to choose the manner and timings of their own death.
9. In the same way, the disabled community is split between those who fear the legislation because it would encourage people to make value judgments on the quality of life led by disabled people and those, indeed some motor neurone and multiple sclerosis sufferers, who would welcome the legislation because of the fears their own conditions bring. The Disabled Rights Commission has recently produced a powerful paper which discusses the views taken by each side in the disabled community, which is exhibited at Appendix 19. It concludes that “in the current climate of discrimination against disabled people, where a lack of access to Palliative Care and social support means that free choice does not really exist. The threat to the lives of disabled people posed by such legislation is real and significant. We, therefore, cannot currently support legislation of Euthanasia.”

10. It seemed to the Working Party however that the most pertinent questions for Guernsey were:

(i) Whether there is need for Euthanasia in Guernsey?

(ii) How one defines that need?

And that these issues should be fully investigated before moving on to the third question.

(iii) Is society in Guernsey ready to accept legislation to allow assisted death and in what circumstances?

11. In seeking to answer the question whether there was a real need for Euthanasia, the Working Party considered how one could define that need. From the perspective of the medical community, there was agreement that the sort of headline attracting cases, such as that of Diane Pretty, were extremely rare and the vast majority of those dying in Guernsey should be able to have their needs for pain relief and symptom control met successfully. Extrapolating the latest figures from Oregon, it was calculated that if Guernsey were to pass similar legislation then in the order of one death every sixteen months in Guernsey might qualify for assistance.

12. It is perhaps useful to consider the situation that Diane Pretty found herself in. Mrs Pretty suffered from motor neurone disease which is a Terminal Illness affecting a sufferer's ability to use his muscles. As well as the more obvious manifestations of the disease, such as not being able to use one's arms and legs, one of the more distressing aspects is that because a sufferer cannot use his throat muscles, they eventually lose the power to breathe. Many motor neurone sufferers are very frightened by this prospect. Mrs Pretty did not wish to die in this way and sought the court's agreement that her husband could to assist her to commit suicide without fear of prosecution. When she failed in the English courts, Mrs Pretty appealed to the European Court of Human Rights on the basis that the UK government and courts by refusing to allow her to end her life in a way she wanted were in breach of her human rights. Mrs Pretty's case failed and she died shortly afterwards.

13. It seemed to the Working Party that it was impossible not to have sympathy with the situation that motor neurone sufferers such as Diane Pretty find themselves in. Other diseases have equally distressing symptoms and consequences. The advice from the medical representatives on the Working Party was however that these cases were rare and that the majority of people who die in Guernsey do not have to suffer such unpleasant symptoms since good quality Palliative Care can ameliorate their symptoms.
14. The majority of the Working Party considered that there were not sufficient numbers of people dying in such extreme circumstances as to justify a change in the law. In trying to define the “need”, there was, however, disagreement amongst the Working Party members as to whether only one person suffering in this way merited a change in the law and whether there had to be such severe symptoms and circumstances in order for there to be a need for a change in legislation.
15. The real heart of the issue therefore is not death but how people wish to live. This led to consideration of issues such as general physical inCapacity, mental inCapacity, tolerance of pain, incontinence, depression and the search for what seemed an elusive definition of a dignified manner of life.
16. For some people in the Island, the present state of law means that they are unable to die when they feel ready to do so and are therefore unable to avoid living what they consider or fear to be a painful, frightening and undignified life, notwithstanding the fact they are not suffering from a Terminal Illness. They consider that they have no quality of life.
17. The Working Party then had to grapple with the issue of whether someone should be forced to live in a situation which is intolerable to them because of their health. Since people’s perceptions of pain and their ability to tolerate symptoms of illness vary, it is reasonable to suppose that it is impossible to clearly define what is “intolerable” to everyone.

18. It is at this point it seems that the real division arises.
19. Should a person legally be able to put an end to his life voluntarily if to him his quality of life has become unbearable? In theory of course, an able bodied person is capable of committing suicide, so in denying that choice to those unable to do so through illness, there is an argument that we as a society are discriminating against those people. Further, by forcing people to commit suicide whilst they are still physically able to, it could be argued that people's lives are being unduly shortened by dying in what is often a desperate and violent way. It could also be argued that we are encouraging Guernsey residents to travel abroad to obtain assistance to die.
20. However, if one supports the principle of individual choice, then the logical extension of that belief would allow assisted suicide on demand whatever one's state of health, which we would believe to be unpalatable for the vast majority of people in Guernsey and was certainly beyond what was considered acceptable by this Working Party. Incidentally, assisted suicide is legal in Switzerland but there is no data to show the numbers of people who are assisted to die or the effects on Swiss society of the law.
21. If one is prepared to accept that Euthanasia may only be acceptable in certain circumstances, then one needs to examine what those circumstances are, which is what the Working Party has tried to do in the body of the report.
22. The difficulty is further highlighted by the fact that good quality medical and social care should be able to ameliorate both physical pain and mental distress that can come with any long term Terminal Illness and in those circumstances should a person who could have all his pain relieved and symptoms controlled, but feel he has no quality of life, still be able to chose Euthanasia?
23. Research into the area of Palliative Care led the Working Party to question what Palliative Care was being provided in Guernsey and what Palliative Care *should* be provided to the people in Guernsey. There is of course the pertinent concern that should Euthanasia be legalised, there would effectively be no

choice for those people who were unable to access good quality Palliative Care either through being unaware of what Palliative Care could provide or inability to afford it.

24. The Working Party felt that more resources should be devoted to Palliative Care by the Island. There is a certain need for more education in this area.

25. The next issue to be balanced in the equation is whether any part of society could be prejudiced by the introduction of legislation for Euthanasia. The Working Party therefore had to consider how the elderly and vulnerable could be protected should legislation be passed. Master Denzel Lush heads the Court of Protection which is the body set up to look after the affairs of those who are no longer mentally competent in England and Wales. He wrote recently of the need not to underestimate the pressure to which the vulnerable are under and the numerous ways in which they are taken advantage of financially. (Appendix 20).

26. There can be no denying that certain sections of society are vulnerable to overt abuse and pressure of a more insidious kind. In a sense, the overt abuse is often easier to counter once discovered. In the DRC report (para 9, page 73 above), there is discussion of cases where disabled people in England have found themselves labelled “Do not resuscitate” whilst in hospital because of illnesses which would not be considered so serious in a “normal” healthy person. Presuming that the doctors attending were responsible members of the medical profession who believed that they were acting ethically and responsibly, these cases tend to show that it has become acceptable to treat disabled people differently (ie less favourably) than non-disabled people. This cannot be acceptable in a civilised society and such examples are used to show that the fears of some parts of the disabled community are justified. The Board of Health has a written policy which sets out guidelines for the use of “Do not resuscitate” notices (Appendix 21) which expressly forbids such practices. One wonders, however, whether the English hospitals concerned had similar policies.

27. One of the recurrent themes in the material reviewed relating to Palliative Care and Advance Directives was that the normal healthy person suddenly afflicted by ill health will make a very different choice as to his future care to the person who already has some illness or disability because of the perception of the quality of life of the disabled. Indeed Baroness Finlay during the course of her presentation to the Working Party emphasised how vulnerable a patient can be at the time of diagnosis/accident. She expressed the view that in her experience it was not uncommon to see a patient diagnosed with Terminal Illness request Euthanasia but experience a change of mind later.

28. The Working Party also considered how Euthanasia legislation was working in practice in Holland and an American State, Oregon. Two issues were particularly interesting:-
 - (i) In both Oregon and Holland there is not a well developed system of Palliative Care equivalent to the British system, although steps are being taken to address this issue in both jurisdictions.
 - (ii) The reporting system in both only necessitates reporting after death, which may allow for abuse and there can be no certainty of each death being reported.
 - (iii) The sixth annual report on Oregon's Death With Dignity Act (2003), which is appended at 6, states that the period between the first discussion of and implementation of assisted death was 36 days for 2003, falling from a median of 43 in 2002.

29. Members of the Working Party considered the so-called "slippery slope" argument in the light of the experiences of those jurisdictions. The argument is that once Euthanasia has been legalised, whatever safeguards have been put in place will gradually be eroded and society's view as to what is an acceptable quality of life will change, leading to greater use of the Euthanasia

legislation and even more relaxation of the safeguards. The inadequacy of the statistics produced by both Oregon and the Netherlands (a direct result of the post event reporting system) allows both sides to claim that the statistics support their view.

30. In the Netherlands, the percentage of involuntary Euthanasia deaths has remained constant, since the legislation was introduced but the number of voluntary Euthanasia deaths has risen which suggest that the law is not addressing one of the problems it was seeking to correct, i.e. the prevalence of involuntary Euthanasia which would be categorised as homicide under Guernsey law. Such statistics also gives support to the “slippery slope” argument, particularly when one sees examples of people using the Euthanasia legislation when they are suffering from depression (see articles appended at 23).
31. Some anti-Euthanasia campaigners compare Euthanasia with abortion noting that for many people abortion has become a choice rather than a procedure carried out for medical reasons. The National Office of Statistics released figures this week to show 175,600 terminations took place in 2002 which represents 1 in 5 pregnancies²⁴. This is a significant increase from the figures when the legislation was first enacted in the United Kingdom in 1967. During 1967/8 23,641 abortions are recorded as having taken place. Those who endorse the “slippery slope” argument would say that this increase in the abortion statistics supports their view.
32. The Working Party spent some time considering the position of the medical profession. The GMC, BMA and RCN are publicly opposed to any change in legislation. The most comprehensive of the BMA statements/press releases on the subject are exhibited at Appendix 24. Locally, the Board of Health’s Ethical Committee also expressed strong opposition to change, see Appendix14.

²⁴ Taken from article in The Telegraph, filed 31.03.04 – Or visit National Office of Statistics at: www.statistics.gov.uk

33. Concerns have been expressed amongst the general public that a change in legislation could irreparably damage the relationship between patient and doctor. Others put forward the argument that doctors are unofficially assisting people to die and that legislation would regulate this practice in everyone's interests.
34. One of the reasons for introducing the Euthanasia legislation into the Netherlands was the apparent prevalence of Euthanasia which was unregulated. Those who support the introduction of Euthanasia in other jurisdictions would assert that Euthanasia is effectively being carried out on both a voluntary and non-voluntary basis by doctors who prescribe pain relief under the double effect principle.
35. It is of course notoriously difficult to assess the situation in a jurisdiction where Euthanasia is illegal because any statistics provided will be affected by the fact that few doctors wish to admit to a practice which is illegal. The confusing of the practice of prescribing pain relief under the double effect principle and providing drugs to hasten death however can be refuted. Professional medical associations, such as the GMC, BMA and RCN, have guidelines under which a professional may prescribe or administer medication under the double effect basis. The medical professional acting properly in accordance with those guidelines cannot reasonably or sensibly be accused of assisting a patient to die. In any event, the confusion over the effect is based on ignorance since the correct administration of opioids itself will not cause death. Baroness Finlay gave a presentation to the Working Party which was absolutely clear on this point but noted that even in the medical community, there was a great deal of confusion on the issue. Doctors are not simply killing their patients in a non-regulated fashion in Guernsey and such fanciful allegations cannot be used to support the argument for the introduction of Euthanasia.
36. Section 9 sets out the view of the Guernsey medical profession on Advance Statements. Whilst the Working Party members acknowledge the difficulties that Advance Directives may bring, they are very conscious that the use of

Advance Statements may increase and lead to even greater problems if there is no attempt to regulate the format. The Working Party members do however acknowledge that an Advance Directive is not an adequate or proper substitute for communication between doctor and patient.

12. **Conclusions and Recommendations**

I Palliative Care

(i) Conclusions

1. The Working Party has heard evidence from both health care professionals and members of the public stating that some patients are continuing to die in pain or distress. Some people are suffering protracted painful and undignified deaths.
2. The Working Party agreed that the first response to the perceived burden of apparently unalleviated suffering and the associated demand for a change in the laws governing Euthanasia is this further review of our current Palliative Care provision and other services for those patients with serious progressive and terminal disease.
3. The Working Party recognises the wide range of services currently provided and the high standards being achieved in many areas, but considers the current resources allocated to Palliative Care insufficient.

(ii) Recommendations

4. It would appear that many of the pieces of the jigsaw are now in place. The Working Party considered that Guernsey now requires the designation of a lead clinician in Palliative Care and a management support structure to ensure Palliative Care of the highest standard.
5. The review of the current Palliative Care services highlighted how fragmented the Palliative Care resources are and the need to ensure greater focus to improve delivery. The review also highlighted the cost to the patient of Palliative Care being provided by GPs and the Working Party agreed that Palliative Care should be available for all patients, regardless of income.

II Advance Statements and Directives

(i) Conclusions

6. The case for changing the legislation to **clarify the use and format** of living wills or Advance Statements/Directives is a compelling one. It should be emphasised, however, that the Working Party are not recommending the use of Advance Statements or Directives for everyone.
7. Some members of the medical profession felt strongly that some people who were bringing an Advance Statement to them had no understanding of what they were asking for and that the documents themselves were often sufficiently badly drafted to only lead to confusion and also failed to anticipate problems that may arise. If that is indeed the case, then since an Advance Statement is legally binding on a doctor who has notice of it, the Working Party concluded that it was imperative to try to ensure that any Advance Directive which a doctor was presented with in future would help rather than hinder the doctor in performance of their duties.
8. The Working Party recommend that more resources be devoted to educating both the medical and wider community of the benefits and disadvantages of Advance Statements with the aim of ensuring they are drafted properly and used appropriately.

(ii) Recommendations

9. We therefore recommend that the law and practice in Guernsey should be clarified to achieve greater certainty about Advance Directives (both for their makers and for medical professionals considering their applicability and effect). In particular we recommend that, in the absence of any instruction to disregard the law or medical ethics, or actual knowledge that a patient's wishes have subsequently changed, an applicable Advance Directive should be

presumed by statute to be binding on medical professionals where the following criteria are met:

- (1) The person must be mentally competent with mental competence to be defined by new legislation.
- (2) The patient must have discussed the issues surrounding the use of Advance Directives with a general practitioner, whom it is to be hoped would receive proper training for this role.
- (3) All such Advance Statements should be witnessed by the patient's own general practitioner and one other person who will not receive any financial or other benefit from his death.
- (4) All such Advance Directives should be kept on the patient's notes with his general practitioner, hospital or nursing home.
- (5) Advance Directives should remain in force for a period of 5 years only from the date of signing at which point they would need reviewing, to ensure that any advances in medicine could be considered by the patient on a regular basis.
- (6) Advance Directives should ideally be in a prescribed format, albeit one which is sufficiently flexible for each person to express his own views, but in all cases must be in terms which are clear and unambiguous to both patients and doctors.
- (7) Provision should be made to include the possibility of people who have periods of lucidity and competency being able to make an Advance Directive and the possibility of those people who lose their Capacity being able to extend an existing Advance Directive.

- (8) Provision should be made in the Advance Directive format to allow a patient to indicate whether he is prepared for his organs to be donated after death.

III Double Effect Medication

(i) Conclusions

10. There is some dispute as to whether medication given under the double effect principle can actually cause or hasten death even amongst the medical community. Those who care for terminally ill patients point out that responsible use of pain relief does not cause death and very, very rarely hastens it. There is a clear need for education of both the medical community and general public on this subject. Further the prescribing of strong pain relief on the double effect principle may leave some doctors feeling vulnerable to litigation or criminal prosecution and this may inhibit them offering strong pain relief to patients.
11. The Working Party considers it important to emphasise that the prescribing of Double Effect Medication is a proper and responsible use of medication and not simply a way for doctors to carry out Euthanasia in a secret and unregulated fashion.

(ii) Recommendations

12. The fact that proper prescribing of pain relief under the double effect principle is legal should be clarified and included as part of any future legislation on end of life decisions.

IV Euthanasia

(i) Majority Conclusion

13. For the majority of the members of the Working Party, there was no compelling need to legislate for Euthanasia in Guernsey at the present time. Inevitably, people reach the same conclusion via different routes due to their religious beliefs, medical knowledge, life experiences, ethical views and their general concept of morality. The concerns that emerged were as follows:-

- (1) There is insufficient awareness and provision of Palliative Care and social care in Guernsey to ensure that everyone who needs palliative or social care within the community is receiving the best possible care. Until that situation is achieved, then any moves to legalise voluntary Euthanasia are premature.
- (2) Legalisation of Euthanasia could encourage people to view anyone whose quality of life differed from the norm as suffering from an unacceptable quality of life and that could impact on the way in which such people were treated by society and ultimately on the care that was provided to those people.
- (3) The “slippery slope argument” although denied by those in favour of Euthanasia is compelling.
- (4) The very real difficulty in protecting the weak and vulnerable in society if a system were established to cater for the small number whose needs cannot be addressed through good quality palliative care and who would choose a doctor assisted death.
- (5) The impact that Euthanasia would have on a society which is already unhappily preoccupied with physical perfection.

- (6) The effect that Euthanasia would have on the relatives of those who had been allowed to seek the “solution”.

- (ii) Recommendation

The majority of the Working Party therefore recommend that there is no change to the present legal position on any form of Euthanasia.

13. Minority Report – Submitted by Deputy Peter Roffey

1. The majority of the Death With Dignity Working Party has concluded that there should be no change to the present law to allow assisted suicide under any circumstances. I disagree and wish to present the following minority report to Advisory and Finance.

2. My report will first deal with the general ethical issues and then go on to deal with some of the other questions raised by the debate and my conclusions thereon. I will also attach a number of appendices in support of my conclusions.

(i) Summary – the case for a very limited and strictly proscribed system of assisted suicide/voluntary Euthanasia in Guernsey.

1. I believe most people have considerable sympathy for those requesting Voluntary Euthanasia in order to avoid suffering during the latter stages of a Terminal Illness. The central ethical case made against permitting such action is that “it is always wrong to deliberately take a life” and that “life is sacred and once that principle is breached we are on a slippery slope”. With respect I have to dismiss such contentions as too simplistic and two-dimensional. While it is attractively neat and uncomplicated to view the issues involved in such black and white terms it also avoids tackling many of the real and appalling dilemmas surrounding suffering at the end of life.

2. While it might sound brutish to some ears, having considered these issues over many months I have concluded that:-

(i) It is not always morally wrong to deliberately take a life because:-

Life should not always be regarded as sacred no matter what the circumstances. I agree that the sanctity of life should always be society’s presumption, no matter what the perceived quality of that life. However I

believe that the final judgement on the sanctity or otherwise of any life should lie with the person whose life it is.

(ii) For the avoidance of doubt I am only talking about allowing assisted suicide in the following strictly proscribed circumstances:-

- Where the individual requesting it is in the latter stages of a terminal condition, **and**
 - Where the individual concerned regards the period of life remaining to him/her as an intolerable burden, **and**
 - Where the individual has genuinely and repeatedly requested release from that intolerable end of life experience through Euthanasia, **and**
 - Where that request has been made in a situation demonstratively free from any undue pressure, **and**
 - Where two medical practitioners agree that the basis for that request is rational and is being made because of a genuine wish to avoid suffering from a condition where there is no realistic hope of recovery.
3. Equally for the avoidance of doubt I am **not** suggesting that anybody – the medical profession, relatives or anybody else – be empowered to make third party value judgements about people’s quality of life or carry out non-voluntary Euthanasia. Nor am I suggesting that the lives of those born with or acquiring either a mental or physical incapacity should be regarded as having any lesser value than anybody else’s.
4. In short I believe the issue to be largely one of “self-autonomy” and the ability to make decisions about one’s own destiny at all stages of life including the final stages of a Terminal Illness. I fully accept that for many that choice will be to “fight to the end no matter what the circumstances”. For others having

the control to decide to be released from an intolerable end of life experience at a time of their choosing would be an empowering rather than diminishing provision.

5. Finally I accept that controls will be required to make sure that such self-autonomy is exercised in a way which is totally free from any external pressures or any climate where one is expected “not to be a burden” and that this may prove a challenging task.
6. It is a matter of regret to me that the direction of the working party has meant that such practical issues have not been examined in as much depth as I would like. Much time – understandably – has been spent on the central ethical and medical issues. Then the majority decision to recommend against any change to the law has detracted from the need to look in detail at how a Voluntary Euthanasia law would be drafted. However I believe that once the States voted for an investigation into this matter detailed proposals should have been drawn up on how such a law would best be drafted and operated if the States so decide, even though the recommendation is not to do so.
7. I will give my views on what form any law on Assisted Suicide/Voluntary Euthanasia should take later in this report. Now I want to turn to a few of the specific issues raised during the investigation.

(ii) Palliative Care

1. All of the Working Party were agreed on the importance of good Palliative Care. I support that view and welcome the strides that have been made in this area in recent years. I also support future strengthening of Palliative Care provision whilst recognising that limited resources will always proscribe what can be provided in Guernsey. Indeed the working party is aware that the Board of Health is working with the three GP practices to improve the provision of Palliative Care in Guernsey. I do not, however, regard good Palliative Care as an alternative to the sort of very limited voluntary Euthanasia described above. Rather I regard them as complementary.

2. It has been said by many campaigning against any change in the law that with modern Palliative Care there is no need for anybody to suffer unduly in the final stages of life. This is demonstratively untrue. Many letters to the Working Party have outlined extreme suffering which has been experienced in specific cases and it seems highly unlikely that even the best Palliative Care could have prevented suffering in all these cases. Perhaps even more telling a survey of nurses in Guernsey has revealed that many of them have seen patients die “in distress” over the last two years. This was quite evenly split between uncontrollable pain and other forms of distress. These health professionals are on the front line and great regard should be given to their experiences.

(iii) Reasons for requesting Euthanasia

1. It has been assumed by some that release from great pain is the overwhelming, or perhaps only, reason for individuals requesting an intervention to end their lives in the latter stages of a Terminal Illness. Therefore if only proper pain relief could be achieved the issue would go away. That is simply not true.
2. In reality most of those who have indicated a wish for voluntary Euthanasia have been motivated by other reasons. Extreme indignity, loss of bodily functions, a totally non-participatory existence, the desire to die at home amongst friends rather than in a clinical setting can all be reasons to wish to shorten the experience of living through a Terminal Illness.
3. These are also the main reasons for people actually taking the option of assisted suicide where it is legal – for instance in Oregon.
4. To some these arguments may seem flimsy or even weak willed but we return to the issue of self-autonomy. Each individual is different and what constitutes “an intolerable burden” varies from person to person. Why should others have the right to insist that an individual continues living a few more

days/weeks in circumstances which they regard intolerable and wish to be released from?

5. In coming to my conclusion in regard to the case in support of those requesting an intervention to end their lives in the latter stages of a Terminal Illness, I have been strongly influenced by the arguments contained in a submission made to the Working Party by the local Branch of the Motor Neurone Disease Association.

(iv) The “Slippery Slope” and the Importance of Controls

1. Those opposed to any legislation of this nature suggest that it will inevitably be a “slippery slope” and that the criteria for Euthanasia will creep and numbers increase. This has not been the experience in either Oregon or Holland. The most recently produced reports on both laws have been added to the appendices relating to the Working Party’s main report and are respectively at 6 and 8.
2. In the case of Oregon the numbers and reasons seem to be consistent and requests for assistance under the Death with Dignity Act made on a rational and considered basis. Holland is more difficult as there was a long medical tradition of mercy killing even before it was formalised by law. The best interpretation of what has happened since the law was introduced is that numbers have remained the same but that now progressively fewer cases of Euthanasia are going unreported and outside the controls laid out in that legislation.
3. This brings us to the situation in the British Isles. It is almost certain that Euthanasia does go on although possibly in far smaller numbers than in Holland prior to the legislation there. It has been suggested that many mercy killings are carried out under the guise of Double Effect Medication although having heard the expert evidence over opiate tolerance this seems unlikely. Nevertheless however frequent or infrequent such unlawful acts of Voluntary Euthanasia may be the patients concerned must be at greater risk because

however well motivated and compassionate the doctors may be they are acting outside a statutory framework of control.

(v) The Effect on Others

1. It has been suggested that the argument in favour of Euthanasia on the basis of personal autonomy is undermined by the fact that other people are also affected by an individual's death. While this is quite true nearly all of the many letters received from relatives of those who have died in distress suggest that friends and family are far more affected by the lack of choice in these matters, and the suffering which their loved one has to go through as a result, than they would be from a relative's decision to avail themselves of a controlled death. Anyway, although it is a difficult area, I believe the autonomy of the individual must transcend the effect on third parties. The idea that we have the right to insist that others carry on living in distress, against their wishes, because their death may upset others seems to me to be disproportionate and perverse.

(vi) The Effect on Doctors

1. One argument against Voluntary Euthanasia is that it will undermine the doctor patient relationship. I don't believe this would be the case if the law was properly framed. I have no evidence to suggest that such a breakdown in trust has happened in other countries that have legislated in this area. Of course I do believe it is vital for doctors to have the right not to have anything to do with voluntary Euthanasia on moral grounds. In this context it is interesting to note that a survey of local doctors and specialists carried out in June 2003, (which brought a response of 68 out of a possible 101), showed that, 36% of those that responded stated that they **would** wish the law to be changed to allow Doctor Assisted Death in cases of debilitating Terminal Illness.

(vii) Chronic Illness

1. It can be claimed that the doctrine of personal autonomy should mean that Euthanasia is permitted to those who want to die because they are suffering from a chronic condition rather than a terminal condition. I accept that a coherent case can be made along these lines but I think the situation is quite different. In one case someone who is going to die very soon simply chooses to avoid distress during the later stages of illness by choosing the time of what is in any case an inevitable death. In the case of chronic illness very different issues arise which impact on the broader question of the morality of suicide in general. I would not support legalising Euthanasia for cases of chronic, non-Terminal Illness.
2. If this seems morally or logically inconsistent I would argue that society is constantly having to make moral judgements over the point at which a type of action becomes unacceptable. Often this involves instinct or “feel”. To me intervention to prevent the suffering of an individual near death is instinctively correct but mercy killing in other circumstances raises far more concerns. This is inevitably a subjective judgement. It is the one that lies at the heart of this whole debate which is why there is no right or wrong answer to the issue of voluntary Euthanasia. It is a process of personal opinion and morality coming together to form the mores of society. I believe society is moving towards a more permissive view as laid out above.

(viii) The Miracle Recovery

1. Some would point out that a law which restricts voluntary Euthanasia to those in the latter stages of a Terminal Illness is undermined by the possibility of a “miracle recovery” by those who the medical profession was convinced were beyond hope. Indeed such an anecdote was used to great effect by Baroness Finlay in her presentation to the working party in opposition to Euthanasia. I can’t deny the possibility that a very few people may choose an easy death who against all expectation would have recovered had the law not existed.

Against this has to be set the far greater numbers who will be consigned to suffer in their last weeks and months, against their wishes, and for who there is genuinely no hope.

(ix) Should We Act Ahead of the UK?

1. I think this raises difficulties for Guernsey. However I made quite clear what those difficulties were at the time of the Mellor Requête. I warned members only to vote for an investigation if they were willing to act in isolation ahead of the UK. The size of the vote in favour of an investigation clearly shows that the States were willing for Guernsey to be in the vanguard on this issue however hard that may be for a small territory.

(x) What Form Should the Law Take?

1. I greatly prefer the Oregon model to that in Holland. I believe it is easier for all concerned to empower the individual to end their own life wherever possible rather than relying on another person to carry out the act. However there are some cases where this is not physically practical – the Diane Pretty case springs to mind – where outside intervention is correct. I believe Lord Joffe's revised Bill is very close to what is required both in terms of limitations and process. However I believe that if the States backs legislation along these lines further work will be required on the detailed proposals.
2. It is interesting to note that if Guernsey was to follow closely the legislation in Oregon then the numbers involved would be tiny. It has been calculated that if behaviour in Guernsey mirrored that in Oregon then the frequency of assisted suicide would be about one person every sixteen months. So I am not suggesting the opening of any Euthanasia floodgates. It has been argued that the small numbers involved mean there is no reason for complex legislation. I would counter that by saying that these infrequent cases will tend to be extreme circumstances where the suffering of even an isolated patient should be a matter of concern. It could equally be claimed that murder is very

infrequent in Guernsey but no-one would suggest that this means we don't need a homicide law.

3. Finally I believe the experience of intelligent people who actually go through the experience of watching loved ones end their lives in either suffering or indignity can be quite telling. Many of the letters from local people who have been through these circumstances affected me greatly. I don't think it is right that these should be put into the public arena so instead I attach two articles by well known people from the UK – John Humpries and Baroness Warnock see Appendices 25 and 26. I believe the feelings they express sum up the views of very many people.
4. I believe it is vital that Guernsey's legislators, whilst listening to the informed views of medical and legal experts realise that these moral issues are ones where we need to reflect the views of the whole community and call on our own ethical values.
5. I hope these thoughts are of some use and would ask that you attach this minority report to any Billet on this subject to be laid before the States.

Please Note: This minority submission is also supported By Deputies Francis Quin and Hunter Adam.

Appendices

App. No.	Description
1	Deputy Mellor's Requête 28 June 2002
2	List of Working Party Members
3	List of references and bibliography
4	Specimen Advance Statements from the State of Delaware, Rhode Island and the Alzheimer's Society
5	Summary of NICE Guidelines on Palliative Care
6	Sixth Annual Report on Oregon's Death with Dignity Act (2003)
7	The United Nations Human Rights Committee observations of the Netherlands
8	Lancet synopsis of 2001 Remmelink (Van der Wal/Van der Maas) Report on end of life decisions in the Netherlands
9	Comparison of jurisdictions where Euthanasia has been legalised and then withdrawn
10	Comparison of jurisdictions with some form of Euthanasia

11	Lord Joffe's comparison of his 2004 'Assisted Dying for the Terminally Ill' Bill with legislation in Oregon and the Netherlands
12	Letter to the Advisory and Finance Committee detailing UK Government's position on Euthanasia
13	Letter to the Advisory and Finance Committee detailing Scottish Executive's position on Euthanasia
14	Correspondence With and Report From Board of Health Ethical Committee
15	Sample of Medical Questionnaire (annotated) and Survey Outputs
16	Report by Dr David Jeffs (Guernsey Director of Public Health) on Palliative Care in Guernsey
17	Report by Mrs Jacqui Gallienne (Senior Manager of Children's Nursing Services) on Palliative Care Services Provided by the States of Guernsey Board of Health
18	Guernsey Public Consultation – Summary of Responses
18A	Working Party's Advertisement Inviting Public Submissions
18B	Acknowledgement Letter Issued to Public Consultation Respondents

19	Disabled Rights Commission Paper – Policy Statement on Voluntary Euthanasia and Assisted Suicide
20	Denzel Lush (Master of the Court of Protection) – Comments on the Mental Incapacity Bill
21	States of Guernsey Board of Health – Policy Guidelines on Do Not Resuscitate
22	Van der Wal/Van der Maas Report on Physician Assisted Suicide in the Netherlands (1990-95) (NB: 2001 Report is appended at 8)
23	BMJ and Radio Netherlands articles (2) giving examples of Netherlands people using euthanasia when suffering from depression
24	Latest BMA releases: (c) Comments following Second Reading of Lord Joffe's Assisted Dying for the Terminally Ill Bill (10 March 2004) (d) Extract from 'Medical Ethics Today' – Euthanasia and Physician Assisted Suicide
25	Sunday Times Article by John Humphrys – 24 August 2003
26	Times OnLine Article by Baroness Warnock – 14 December 2003

IN THE STATES OF THE ISLAND OF GUERNSEY

ON THE 27TH DAY OF OCTOBER, 2004

The States resolved as follows concerning
Billet d'État No. XVI dated 16th September, 2004

POLICY COUNCIL

VOLUNTARY EUTHANASIA (DEATH WITH DIGNITY)

After consideration of the Report dated 13th August, 2004, of the Policy Council:-

1. That there shall be no change to the present legal position in order to support euthanasia in any form.
2. To direct the Health and Social Services Department to report back to the States on
 - (a) the provision of palliative care;
 - (b) the position on advance directives; and
 - (c) the position on the proper use of double effect medication.

K. H. TOUGH
HER MAJESTY'S GREFFIER