PALLIATIVE CARE

Palliative care and 'end of life' decisions

Early in 2001, the British Medical Journal (BMJ) published an editorial entitled '*A Good Death'.* More recently (July 2003) a whole issue of the Journal has focused on the theme '*What is a good death?'.* Both pointed out that most people state they would wish to die in their own homes, surrounded by family and friends, with dignity and without pain.

The reality is often quite different – many people die in hospital, surrounded by technology and strangers, often with unnecessary discomfort, and with precious little dignity. The original BMJ editorial commented: '*a soulless death in intensive care is the most modern of deaths'.*

In an earlier age of larger families, with higher rates of infant and child mortality, and with people generally choosing to remain close to their roots, death was never far from most people's lives. With smaller families, and greater job and social mobility, contact with death and the dying has become a rare event many people.

The charity 'Age Concern' has commented (1999) '*Death has now been medicalised, professionalised, and sanitised to such an extent that it is alien to most people's lives.'*

These perceptions are compounded by the media prominence given to those who wish to foreshorten their terminal suffering.

Mrs Diane Pretty who subsequently died from advanced motor neurone disease, had been unable to obtain an undertaking from the Director of Public Prosecutions not to consent to prosecution of her husband for aiding and abetting suicide should he assist her to die. In 2001/2002 the courts held that the DPP had no such power and that this was not inconsistent with respect for Mrs Pretty's human rights.

In January 2003, Reginald Crew (also suffering from motor neurone disease) ended his life in a 'voluntary euthanasia' clinic in Switzerland where there is legal provision for this. His widow Mrs Win Crew stated afterwards '*If they had a referendum (for euthanasia in terminal illness), I believe most people would support the change in the law.'*

If unfamiliarity and fear of a painful and an undignified death are helping to drive the euthanasia debate, at least amongst many members of the public, then the quality and availability of palliative care locally must be one essential consideration when advising on whether any change in local law is desirable?

What is palliative care?

The availability of palliative care in Guernsey was reviewed in some detail in the '*Guernsey Cancer Strategy'* which was accepted by the Board of Health in June 2001.

The Report quoted from the Southampton University Hospitals NHS Trust Palliative Care Guide, defining palliative care;

'*Many patients develop illnesses which cannot be cured and which we also know are ultimately fatal. For such patients the focus of care is not cure, but relief or palliation of physical or emotional distress. The aim of palliative care 'is to minimise the constraints of suffering and disability which fatal illness impose on patients, so that they can gain the greatest potential benefit from their remaining lives.*

Such care includes consideration of the families' needs before and after the patient's death. This 'palliative care' approach can and should be employed by every doctor and nurse caring for a patient nearing the end of a chronic illness, and is an integral part of all clinical practice.'

The Guernsey Cancer Strategy went on to point out that palliative care in Guernsey was available from:

- Family practitioners, both in the community and to provide 'continuity of care' by continuing to manage their patients admitted to Les Bourgs Hospice
- The medical oncologist
- An anaesthetist with special interest and training in acute and chronic pain control
- A seven day a week community palliative care nursing team
- A network of palliative care 'link nurses' on acute wards and elsewhere

16

Recommendations of the *Guernsey Cancer Strategy*

The *Guernsey Cancer Strategy* has a total of twenty nine recommendations of which eight relate fully or in part to palliative care. Following acceptance by the Board of Health they are being progressively implemented as follows;

New nursing posts

R20 A specialist cancer nurse post should be created to provide professional leadership in the provision of expert cancer nursing.

The post of specialist cancer 'lead nurse' has recently been advertised, and it is hoped to make an appointment within the next few months.

R21 A specialist palliative care nurse post should be created to provide professional leadership in the provision of palliative care nursing.

A lead specialist palliative care nurse position has been agreed under the 'policy planning process' and should be appointed in the next 1-3 years.

Les Bourgs Hospice – proposed developments

R22 Les Bourgs Hospice should continue to develop with support 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.

Les Bourgs was established as a Charitable Trust in 1991 with a Management Committee reporting to a Board of Governors/Trustees.

Additionally, it has a Medical Advisory Committee with representation from both specialists and family practitioners with interest and expertise in the field of palliative care.

'Andrew Mitchell House' a five bedded unit for patients with *'cancer related disease'* was opened in **June 1991**. According to most recent information, it four main care streams include:

	2002	
Reason for admission	**Males**	**Females**
• Pain and symptom control	19	17
• Respite care	10	8
• Rehabilitation/convalescence	2	3
• Terminal care	7	11

Average length of stay varied between **7** and **21** days plus depending on the mix of cases being cared for.

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 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.

Workload over the past four years has varied as follows:

	1999		**2000**		**2001**		**2002**	
	M	**F**	**M**	**F**	**M**	**F**	**M**	**F**
Admissions	38	37	31	37	35	25	24	26
Re-admissions	15	28	10	23	23	12	17	14
Totals	**53**	**65**	**41**	**60**	**58**	**37**	**41**	**40**

Running costs are said to currently exceed £400,000 per annum and fundraising is co-ordinated by '*The Friends of Les Bourgs'*. Funds are raised principally through membership, donations, bequests, and special fund raising events such '*Roque to Rock'* bike ride and the '*Les Bourgs Ball*'.

Advocate Richard Collas has been chairman of the Board of Governors of Les Bourgs since 1998. He advises that in keeping with **R22** the Management Committee are considering a substantial rebuilding and refurbishment programme which would increase the number of beds available to seven, with additional day care facilities.

This would allow a greater number and wider range of patients to be accepted, and more treatment modalities to be offered.

Who should pay for 'Les Bourgs'?

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.

It has been the experience of the Hospice movement in several parts of Britain that once part government subsidies are accepted, the level of public donations and support tends to decline. It is therefore the view of the current Les Bourgs Management Committee that 'Les Bourgs' should be seen to remain outside States subsidy and support.

The Board of Health and other States Departments should therefore concentrate on funding earlier parts of the 'cancer patient's journey', e.g. outpatient chemotherapy, and community palliative nursing care, and in ensuring 'joined up treatment' in line with **R27** of the '*Guernsey Cancer Strategy*' Report.

Should 'Les Bourgs' offer palliative care services to a wider range of patients?

When it was established in **1991**, 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 it's willingness and ability to offer its full range of services to all who might benefit, irrespective of their underlying condition.

The need for a 'lead' medical clinician for palliative care

R23 Appointment of a lead medical clinician for palliative care who would work in primary care, the hospitals and the hospice. The lead clinician will need strong links to the UK palliative care centre for educational development and to ensure maintenance of clinical skills.

UK figures suggest an area population of 60-80,000 can support the appointment of a palliative care specialist.

The need for the appointment of a palliative care specialist was considered during negotiations for the new Medical Specialist Group contract

At that time, the MSG wrote '*the case for a palliative care specialist as you describe has not been fully proven and that the preferred way forward was for a primary care doctor with a particular interest in this area of medicine to be involved'*.

Preference was given to other specialist appointments including a further anaesthetist, obstetrician, and aged care specialist. The appointment of a palliative care clinician is not seen as a priority by the MSG during the next few years.

Nonetheless, there is support from the Hospice's Medical Advisory Committee, who would give consideration to pump priming such an appointment, i.e. they would fund and employ 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? (see below)

Community Palliative care nursing

R24 Home care should be developed between community palliative care nurses and hospice nurses. The post-bereavement service should also be maintained by the hospice.

Specialist palliative care team

At the time of the '*Guernsey Cancer Strategy'* Report, a full time seven day a week service was provided by a three nurse community palliative care team. There are only two nurses in post at present, and the service has therefore had to be reduced to five days only. Once a third nurse is recruited, a full seven day service will be offered once again, whilst the appointment of a specialist palliative care 'lead' nurse will further enhance the range of services offered.

Role of the District Nurses

As well as specialist palliative care nursing input, a more general role is undertaken by the District Nurses based at Lukis House. These comprise twenty two trained staff (including six qualified District Nurses) and twenty untrained staff, organised into four teams each with a team leader.

There is also a *'twilight/night team'* who are thus able to provide a twenty four hour/seven day service.

During the three months December 2002 – February 2003, the District Nurses made **667** visits (356 working hours) for patients classified as requiring '*terminal or personal care'*. These comprise **6-7%** of all patients seen, and covered the whole spectrum of diseases.

Post bereavement service

The post bereavement service continues to be offered by the Hospice and **83** sessions totalling over **42** hours were offered during 2002.

Changing role of Bulstrode House

R26 The current day services should be combined to meet not only phyisical needs and to provide respite for carers, but to allow patients to have a '*day off from cancer*'.

The *Guernsey Society for Cancer Relief* was established in **1983**, and quickly identified a need for a day hospice facility. Firm plans were drawn up some four years later, and after a period of fundraising, Bulstrode House, located on the Princess Elizabeth Hospital site, was opened in **1993**.

Although capital costs were raised by the *Guernsey Society for Cancer Relief*, who also provides volunteers, 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 in **March 2000**, the number of out patient oncology clinics held locally has increased to three per week, with two additional visiting clinics per month.

There are also three separate outpatient oncology clinics held weekly (Tuesday, Wednesday, Thursday), although occasionally five day treatments are given.

The unit is also participating in five multicentre cancer trials, all of which have been duly approved by the local Medical Research Ethics Committee. Unfortunately a cancer research nurse has recently left, but submissions for participation in additional clinical trials will be submitted to the Ethics Committee once this position has been replaced.

In addition, a number of multidisciplinary teams have been established in breast and colorectal cancers, with plans for additional lung and pancreas multidisciplinary teams in due course.

Strong links are maintained with the Wessex Cancer Centre in Southampton and the medical oncologist intends to spend two days there every month.

This changing role is reflected in an ongoing refurbishment which is being undertaken at Bulstrode House in line with **R26** of the Guernsey Cancer Strategy Report, thus developing a far clearer delineation between the medical interventions performed at the Bulstrode House Oncology Unit, thus allowing Les Bourgs to focus on the range of services detailed above.

The *Guernsey Society for Cancer Relief* continues to fund a wide range of complementary therapies provided within the Unit by qualified therapists and assists with the ongoing refurbishment of Bulstrode House and various additional items as required.

Specialist training for other therapists

R25 Specialist training in palliative care for other specialists should be considered e.g. physiotherapist, occupational therapist, social worker, speech and language therapist.

Although good progress has been made in implementing many of the recommendations of the '*Guernsey Cancer Strategy'* Report, rapid turnover of allied health professionals in Guernsey has meant that there has been little opportunity for implementing **R25.**

The *Guernsey Cancer Strategy Report*, limited numbers of allied professionals in Guernsey has meant that there has been little formal opportunity for implementing **R25.**

However, a number of AHP's employed locally have had previous experience in contributing to a 'team approach' towards palliative care, and this is felt to be a model which should be further developed (see below).

Integrated care pathways

R27 The introduction of policies, procedures and guidelines on clinical management should be developed to ensure patients have seamless journeys across and between different services.

In line with the move towards more '*evidence based*' healthcare, and '*clinical governance*' more generally, there has been increasing interest in the development and implementation of '*integrated care pathways*'. The intention is to ensure that only '*evidence based best care*' is given for any particular cancer, and that there is a '*seamless journey*' for the patient across and between services as suggested in **R27** above.

The Guernsey Cheshire Homes

Group Captain Leonard Cheshire dedicated his post-war energy to helping people with disabilities. Out of his vision was borne the Cheshire Home Movement – *dedicated to helping the physically disabled lead a life as closely as possible to a normal family life'.*

In **1981** a local Steering Committee was formed with the object of creating a Cheshire Home in Guernsey and by **1985** sufficient funds had been raised to purchase a small private hotel which became the '*Guernsey Cheshire Home'.* The first resident was admitted in late **1987** and the Home was officially opened in **March 1988** by Leonard Cheshire himself.

Aims and objectives of the Guernsey Cheshire Home

The Guernsey Cheshire Home 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.

They add:

'*The lives of some of our clients lead may not be as physically or mentally active as other groups of society. This may lead to a perception by people who do not know them that their quality of life is less 'valuable' particularly if they have communication difficulties. This could be a major area of concern.'*

'Any consultation (on planning for their future) should include the main carer as well as next of kin.'

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.

Adequate palliative care is thus both subscribed to and practiced at the Guernsey Cheshire Home.

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

More recent developments in palliative care in Guernsey

Historically, both in Guernsey and elsewhere, the early palliative care movement was closely aligned with care for cancer suffers and their families. It is a measure of how far understanding has progressed in the five years since the '*Guernsey Cancer Strategy*' was formulated, that a far broader perspective is now taken.

This broader perspective is reflected in the NHS '*National Cancer Plan'*, other specialist publications and most recently in a discussion document from NICE (National Institute of Clinical Excellence) entitled '*Improving supportive and palliative care for adults with cancer'*.

This steady evolution to a more broadly based and inclusive approach is well summarised in this following series of quotations.

'*Purchasers are asked to ensure that provision of palliative care with a palliative approach is included in all contracts of service for those with cancer and other life threatening illnesses, including AIDS, neurological conditions, and cardiac and respiratory failure'*. NHS Executive 1996

'*It is the right of every person with a life-threatening illness to receive palliative care wherever they are. It is the responsibility of every health care professional to practice the palliative care approach and to call in specialist palliative care colleagues if the need arises, as an integral component of clinical practice, whatever the illness or it's stage.'* The National Council for Hospice and Specialist Palliative Care Services 1997

'*The active total care of patients with progressive far advanced illnesses and limited prognosis, and their families, requires a multi-professional team who have undergone recognised specialist palliative care training. It provides physical, psychological, social and spiritual support and will involve practitioners with a broad mix of skills including:*

- *Consultant with palliative medicine*

- *Senior nursing staff*
- *Social worker*
- *Chaplain*
- *Physiotherapist*
- *Occupational therapist*
- *Pharmacist*
- *Specialist psychiatric/psychologist intervention*
- *Dietician*

The National Council for Hospice and Specialist Palliative Care Services 1999

In the Guernsey context, it would appear that the lack of a full time or substantially full time palliative care physician and adequate supporting multidisciplinary team is the greatest barrier to providing more widely available palliative care to all who might benefit.

Palliative care services in Jersey

When seeking to implement **R23** for a lead medical clinician in palliative care, consideration was given to a joint appointment between Guernsey and Jersey. This has been discussed with the Jersey Consultant in Public Health, and with the newly appointed Chairman of Jersey *Hospice Care Advisory and Management Committee,* who is also the consultant in pain management at the St Helier General Hospital.

The origins of palliative care in Jersey are somewhat different from the Hospice development in Guernsey, although during recent years they have pursued increasingly parallel courses.

Jersey Hospice Care was founded in **1981**, and originally comprised a home care service - providing this support 24 hours a day, seven days a week.

By **1984**, a need had been identified for a hospice building, and following successful public fundraising, Clarkson House in St Helier was purchased and opened in **1985**.

Strong links were maintained with the Countess Mountbatten Hospice in Southampton, and a palliative care specialist visited regularly.

A bereavement service was established in the 1980's, a lymphoedema clinic was opened in **1997**, and a physiotherapist appointed in **2000**. A range of art and other complementary therapies are also offered.

Jersey Hospice Care is unusual in being a 'nurse lead' organisation, which '*works hard at providing integrated care for all patients who are living with cancer'*. According to their Annual Report, *Jersey Hospice Care* now employs 65 staff, of whom 18 are full time, and has *daily* running costs of around £4,600.

The service continues to be generously supported by the Jersey public, and raised over £2.5m in 2002. Legacies provided a very important source of funding. Staff training has been identified as an important area for future development.

The Jersey consultant in pain management points out the increasing range and complexity of cases being accepted at the Clarkson House Hospice. He does not have specific palliative care training himself, and is therefore broadly supportive of specific specialist palliative care expertise being available to the Channel Islands.

A joint appointment of a palliative care consultant between Guernsey and Jersey would be one way of supplying this expertise and should be explored further.

Conclusions

- Much public support for the greater availability of euthanasia and 'physician assisted suicide' appears to derive from concern about inadequate pain relief and consequent 'loss of dignity' in many hospital deaths. This is compounded by media publicity for people with terminal degenerative conditions who have sought an early end to life through the Courts or by visiting jurisdictions where this is not illegal.

- Demonstration of high quality and readily available palliative care in Guernsey would go a long way to reassuring Guernsey residents that such fears are ill-founded in the local context, and that adequate and accessible palliative care is readily available locally.

- Palliative care was identified as a major theme of the '*Guernsey Cancer Strategy'* Report which was accepted by the Board of Health in June 2001 and which is now being progressively implemented.

- In particular, it can be demonstrated that –

    - Close links are maintained with the Wessex Cancer Centre in Southampton and other off island centres of cancer treatment.

    - A wider range of cancer treatments, including participation in multi centre clinical trials are now available locally. These have a beneficial effect on the quality of care given.

    - There are a range of palliative care services at the Princess Elizabeth Hospital site, through family practitioners, and the community palliative care team, and through the services offered by Les Bourgs Hospice and other community based organisations.

    - There is now a far clearer delineation between those services offered by the Board of Health, and those available through primary care and community based organisations such as Les Bourgs.

- However, despite the steady improvements of recent years, it is felt that some aspects of palliative care need to further addressed;

Desirable future developments

- There appears to be a public perception that the services of Les Bourgs are largely directed towards cancer (and to a lesser extent) HIV sufferers. The Management Committee of Les Bourgs are currently considering a major refurbishment with an increase in available facilities. It is intended to fund these through major public fundraising.

- It is therefore important that the public understand that the facilities and services offered by Les Bourgs are available to all who might benefit from them, and are not restricted to cancer or other specific disease sufferers. The proposed expansion and refurbishment should ensure that Les Bourgs has the capacity to meet this expectation.

- The Guernsey Cheshire Homes also provide a valuable additional resource for patients with other life long conditions, particularly physical disabilities.

- However, in the light of current knowledge, palliative care should be considered the norm for all those whose illness is no longer responsive to curative treatment. The goal will be the achievement of the best quality of life for all such patient and their families.

- At present it is estimated that only 5% of non cancer terminal care patients receive adequate palliative care input. For their families, there is frequently a similar lack of support '*it is sometimes worse to watch someone else die than to die yourself*'.

- It is felt that much of the lack of current palliative care provision could be addressed through the appointment of a full time or substantially part time palliative care physician and the development of a palliative care multidisciplinary team as recommended in the draft NICE guidelines.

- Despite the perception that people with other conditions may suffer unnecessary pain and loss of dignity at the end of life, local medical opinion would suggest that such cases are in fact extremely rare.

- Nonetheless, palliative care is a growing speciality with its own special skills and an increasing scope. For medicolegal and '*clinical governance*' reasons, a growing case can be made for the provision of specific specialist palliative care medical skills locally.

- Although such an appointment could be supported for Guernsey alone, there may be merit in further investigating a joint Channel Island appointment between Guernsey and Jersey.

Dr David Jeffs **26 August 2003**
Director of Public Health
States of Guernsey Board of Health

Acknowledgements

The Director of Public Health, Dr David Jeffs wishes to acknowledge the co-operation and assistance he received from the following whilst researching this report.

Advocate Richard Collas, Chairman, Les Bourgs Hospice Trust

Dr Callum McClymont and Dr Nick King – Medical Advisors, Les Bourgs Hospice

Mrs Anne Martin, Director of Nursing, Les Bourgs Hospice

Dr Peter Gomes, Medical Oncologist, Bulstrode House

Mrs Liz Dorey, Mrs Cathy Gibbs – Palliative Care Nurses, Bulstrode House

Mrs Sue Bourne, Clinical Nurse Manager, District Nurses

Mrs Marlene Place, Head of Home, Guernsey Cheshire Home

Miss Nancy Moore, *Guernsey Society for Cancer Relief*

Dr Duncan Nicholson, Consultant in Public Health, Jersey Health and Social Services Committee

Dr Gari Purcell Jones, Consultant in Pain Control, Chairman Jersey Hospice Care