

Roseanna Cunningham, MSP for Perth

# Proposed Palliative Care (Scotland) Bill

**A proposal for a Member's Bill to require needs-based palliative care to be available on demand**



17 November 2008

## Member's Foreword from Roseanna Cunningham MSP



At the moment, access to palliative care is variable across Scotland and the available care is also variable. Currently, there is no legal requirement that high-quality palliative care be provided to those in need.

This consultation paper sets out my proposal, which aims to place a statutory duty on health boards in Scotland to provide high-quality palliative care to those who need it, and asks for your views. It also provides the relevant background and considers the likely outcome.

Palliative care is care that improves the quality of life for patients and their families facing advanced, incurable, life-threatening or terminal illness. It is intended to include general and specialist palliative care, whether provided in the home, hospital or hospice. But one of the things my consultation paper does is to offer a definition of palliative care and asks you how well it matches your own understanding or views on what it is.

This consultation highlights the uneven access to palliative care in Scotland and says why it should be extended to patients with life-threatening conditions other than cancer. Recent Scottish Government statements and plans for palliative care, referred to in the paper, acknowledge the need for improvements in provision and set out a Government palliative care plan, but my Bill seeks to go a crucial step further to make these improvements a legal obligation on local NHS Boards.

I invite you to consider and respond to this consultation paper. The paper includes a number of questions about the future of palliative care in Scotland, which you might find a useful starting point. This is your opportunity to make a significant contribution to shaping the effective legislation that is needed, and I encourage you to do so.

**Responses must be submitted by 28<sup>th</sup> February 2009**, and should be sent to the following address:

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Alternatively, **e-mail responses** should be addressed to [roseanna.cunningham.msp@scottish.parliament.uk](mailto:roseanna.cunningham.msp@scottish.parliament.uk).

In addition, please feel free to pass on this consultation paper to any other parties that you think may have an interest.

### **Publication of responses**

To help inform debate on the matters covered by this paper and in the interests of openness, please be aware that all responses submitted on this consultation paper will be made public. Names given in responses will also be made public, unless you indicate otherwise. Personal data referring to third parties included in the response will not be accepted without explicit written consent from the third party.

However, if you wish the contents of your response to be treated in confidence and not made public, then please say so. Your request will be respected.

All responses will be included in any summary or statistical analysis, which will not identify individual responses.

Copies of this paper can be made available in Braille, large print or audiocassette on request.

Additional copies of the paper or alternative formats can be requested using the contact details above and calls via Typetalk are welcome. An on-line copy is available on the Scottish Parliament website at:

<http://www.scottish.parliament.uk/s3/bills/MembersBills/index.htm>

A handwritten signature in black ink that reads "Roseanna Cunningham MSP". The signature is written in a cursive style.

**Roseanna Cunningham MSP**  
Scottish Parliament

## Acknowledgement



Roseanna Cunningham MSP acknowledges the support of the directors and staff of St Margaret of Scotland Hospice in working towards the introduction of a Palliative Care Member's Bill in the Scottish Parliament. Key contributors include Patron; Professor the Baroness Finlay of Llandaff; Director and Professor of Palliative Medicine, University of Edinburgh, Marie Fallon; Chief Executive, Sister Rita Dawson; Director of Clinical Services, Elizabeth Thomas; Nurse Lecturer, Jacquie Malcolm and Assistant Administrator, Clare Murphy.

St Margaret of Scotland Hospice is Scotland's first and largest hospice and a leading centre for palliative care in the west of Scotland. The hospice cares for 60 in-patients, 30 needing expert palliative care and 30 with complex medical and nursing needs who need specialist care for the older person. St Margaret of Scotland Hospice is also a leading provider of Community and Day Patient Palliative Care, continuing Medical and Nursing Education and Family Counselling and Bereavement Support.



## CONTENTS

	Page
Member's Foreword	1-2
Aim of the proposed Bill	5
Background	5
Who benefits?	6
Recognised need to improve palliative care services	7-8
Audit Scotland palliative care review	9
High-quality palliative care: general adoption of good practice	10
Funding	11
Accountability	12
Who will be affected by the proposed Bill?	12
Conclusions	13
Consultation questions	14
Annexes	
Case Studies	15-24
List of Consultees	25-26

## Consultation on a Proposal to Introduce a Bill on Palliative Care in the Scottish Parliament

### Aim of the proposed bill

1. The objective of this proposed Bill is to secure access to high-quality palliative care for everyone in Scotland on the basis of need. The proposal aims to secure this by placing local NHS Boards under a statutory obligation to provide that care and set up reporting arrangements so that the quality of care provided can be monitored. Evidence from professionals in the field, as well as the experiences of patients and families, strongly suggests access to palliative care is inequitable across Scotland and its quality is variable. Evidence also strongly suggests that patients with non-cancer and other life-limiting illnesses, who can greatly benefit from palliative care, have less access to it. Five case studies are attached to this paper, which illustrate well the issues surrounding access to, and quality of, palliative care.

2. The population of Scotland is ageing and with that process there will be an increasing incidence of serious, complex, chronic illness towards the end of life. The need for good-quality palliative care for all who need it, therefore, will become all the greater in future years.


3. This paper sets out the background to the proposed Bill and provides a definition of palliative care, indicating what best practice would include. It gives examples of problems with current provision and indicates how this proposal would improve the availability and quality of palliative care. **You are invited to make any points you think would be relevant to the proposal.**

### Background

#### *Defining palliative care*

4. There are various definitions of palliative care, but the following World Health Organisation (WHO) definition is internationally recognised and is proposed for the purposes of the Bill:

*“Palliative care is 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...”*



5. The WHO outlines nine elements of palliative care. It:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor postpone death;
- integrates the psychological and spiritual aspects of patients' 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 bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiotherapy and includes those investigations needed to better understand and manage distressing clinical complications.

**Q1 What are your views on using this definition of palliative care for Scotland in the proposed bill?**

### **Who benefits?**

6. Whilst palliative care is most often associated in the public mind with terminal cancer care, it is also of great benefit to patients with other progressive, life-limiting conditions. They include:

- Cystic Fibrosis
- Dementia
- Heart failure
- HIV/AIDS
- Motor Neurone Disease
- Multiple Sclerosis



- Muscular Dystrophy
- Parkinson's Disease
- Renal Failure and
- Respiratory Failure

**Q2 What are your views on whether all progressive, life-limiting conditions should lead to an entitlement to palliative care?**

*Who provides palliative care?*

7. Specialist palliative care is provided by multi-disciplinary teams whose members have trained specifically in palliative care,. These include for example, consultants in palliative medicine, clinical nurse specialists, chaplains, social workers, pharmacists and other, appropriate health professionals. Specialist palliative care can be provided at home, including care homes; in hospitals or hospices. Care, however, focuses on complex needs such as pain management or psychological, social or spiritual needs.

8. The other category is general palliative care, which is provided during a patient's day-to-day care across all health care settings by his or her usual carers.

*A good death*


9. One of the overall aims of palliative care is to provide the conditions for a good death. Although there are inherently subjective elements in what may be said to constitute a good death, the following have been usefully identified:

- being treated as an individual, with dignity and respect;
- being without pain and other symptoms;
- being in familiar surroundings; and
- being in the company of close family and/or friends.

## **Recognised need to improve palliative care services**

10. In recent years the need to improve palliative care has been recognised widely within and outwith Scotland. The previous administration committed itself to the provision of:

“high-quality palliative care to everyone in Scotland who needs it, on the basis of clinical need not diagnosis and according to established principles of equity and personal dignity”



11. Internationally, the World Health Organisation published two reports reviewing the scientific evidence on palliative care and recommended that policy-makers:

- develop a strategy to meet the care needs of an ageing population at the end of life, particularly those who are living and dying with a range of serious, chronic illnesses;
- ensure palliative care is a core part of health care services and not an add-on;
- acknowledge people's right to high-quality palliative care, including specialist palliative care and choice regarding place of care and death;
- ensure equity of access to palliative care services.

12. In England, Baroness Finlay of Llandaff's Private Member's Bill on Palliative Care, introduced in 2006, has received a third unopposed reading in the House of Lords. This Bill has received widespread public support indicating that in England and Wales provision of palliative care is also an issue.

13. The report *Living and Dying with Advanced Heart Failure* highlighted variations in standards and access to palliative care as a significant challenge faced by patients and carers in cases of advanced heart failure. Moreover, in comparison to those with cancer, patients with advanced heart failure have inadequate symptom relief, a worse prognosis and more limited access to palliative care support, social and financial services. Patients with advanced heart failure are also less knowledgeable about their condition and have less opportunity to address end-of-life issues.

14. The report also stated there were approximately 100,000 people living with heart failure in 2007, but indicated an expected increase in the prevalence of heart failure by as much as 70% by 2010, due to an increasing elderly population.

15. In his preface to the report, Dr Harry Burns, Chief Medical Officer for Scotland, said;

"I fully endorse what I think is one of the most important statements in the report: that the inherent unpredictability of the disease is not sufficient justification for a failure to introduce appropriate palliative care to the ongoing management and support of those with heart failure." [p.4]

16. The report concluded that there should be a wider recognition of heart failure as a terminal condition adversely affecting quality of life in order to facilitate better service provision.

## Audit Scotland palliative care review

17. In August 2008 Audit Scotland published its review of palliative care provision in Scotland. The review confirmed that palliative care is primarily cancer-focused and mostly provided by generalist staff in hospitals, care homes or patients' own homes. However, the report indicated palliative care needs are not always recognised or well supported and suggests support of generalists by specialists would improve palliative care provision for patients and their families.

18. The review states that palliative care needs to be better joined up, particularly at night and weekends, and that support for family and friends who are caring for someone is not widely available.

## Scottish Government palliative care action plan

19. In October 2008, the Scottish Government launched its Palliative Care Action Plan in fulfilment of its commitment made in 2007. The Action Plan aims "to ensure that good palliative and end of life care is available for all patients and families who need it in a consistent, comprehensive, appropriate and equitable manner across all care settings in Scotland". Whilst this is welcome, as is the emphasis on the principles of equality, dignity and quality of care, the Action Plan acknowledges that it:


"... does not yet have all the answers. *Living and Dying Well* identifies some changes which can be made in the short and medium term, and some which will take a little longer and will require further collaborative and developmental work, as well as additional input of time and resources." [p.9]

### *The proposed Bill and current Scottish government proposals*

20. Essentially, what the proposed Bill envisages is a significant addition to the measures proposed by the Scottish Government. The Government's proposals are the result of extensive collaboration with stakeholders, which has produced wide agreement about aims and a shared commitment to them. These are substantial and necessary achievements.

21. The aim of the proposed Bill is entirely consistent with those proposals, but goes a significant step further. The Bill, by placing a statutory duty on NHS Boards to provide high-quality palliative care for all on the basis of need, will raise the priority of palliative care provision and give added focus to efforts to achieve that outcome across Scotland.

22. A statutory obligation will encourage the necessary co-ordination, training and system design changes, as well as the development of funding streams and reporting methods. It would, therefore, greatly increase the care being delivered as envisaged and bring forward the point at which it would become available. The proposal will also have the effect of acting to maintain and protect the provision and



standards of palliative care across Scotland and put in place a greater degree of accountability than is contained in the Government's proposals. These must be worthwhile objectives for an aspect of health service provision that will only grow over time.

### **High-quality palliative care: general adoption of good practice**

23. There are a number of good practice initiatives being used to improve the quality of palliative care; these are principally the Delivering Choice Programme, the Gold Standards Framework – including the entry of patients onto the Palliative Care register – and the Liverpool Care Pathway. The overall objective of these initiatives is to offer patients more choice in relation to their health needs, including improving choice and quality of care at the end of life. Specific objectives are to achieve:

- greater choice for patients, irrespective of their diagnosis, where they wish to live and die;
- a decrease in the numbers of emergency admissions of patients to hospital when they wish to die at home;
- a decrease in the number of patients transferred from a care home to hospital in the last week of life;
- to educate and up-skill generalists across health and social care settings in end of life care delivery.

24. The route to quality care may be different, but by providing some form of measurement it should be possible to monitor care standards across NHS Board areas. It is my intention therefore to specify within the proposed Bill the type of information, which will allow the Government and the Scottish Parliament to determine whether this aspect of my proposal is being achieved. As such I have drawn up a list of data from which it should be possible to identify whether patients have received high-quality palliative care. For each patient in every health board area, the following information should be recorded and reported to provide an indication of whether high-quality care has been provided:

- place and cause of death;
- how well pain and other symptoms have been assessed, documented and managed, based on evidence-based clinical recommendation;
- the number dying in their place of choice as suggested in the Advanced Care Plan;
- number of out-of-hours emergency admissions at end of life to all care settings; and
- the stage at which palliative care was made available.

25. These minimum reporting requirements have been chosen as they are measurable and will provide a basis on which NHS Boards can report their progress in meeting the needs of patients who require high-quality palliative care.

**Q3 A list of indicators of high-quality palliative care has been provided. What other indicators should be included and why?**

## **Funding**

26. The greatest issue for NHS Health Boards and local authorities will be the funding of palliative care for all patients throughout Scotland.

27. In 2006, the Scottish Partnership for Palliative Care (SPPC), the representative body in Scotland for palliative care, published the report of its 3-year research project into the issues around increasing access to palliative care for people with life-limiting conditions other than cancer. The report provided reassurance that the aim of increasing access to palliative care to people with non-malignant conditions is achievable. Consultation responses indicated that much could be achieved “without making hugely unrealistic demands” on budgets. Better co-ordination, service design and relatively small changes to working practices could “achieve significant impact”.<sup>10</sup>

28. According to the Audit Scotland review of palliative care, in 2006/07 £59 million was spent on specialist palliative care in Scotland. Almost half that total came from the voluntary sector. In Audit Scotland’s view, it is not possible to say how much is spent on general palliative care but the review does point out the practical need for NHS Boards and their partners to plan now to meet the predicted increase in demand from an ageing population.

29. It is recognised that funding and implementation of the Liverpool Care Pathway would also be an issue for a variety of Health and Social Care providers beyond NHS Boards.

30. It will be for the Scottish Government, in its adoption and implementation of the National Action Plan to consider the budgetary implications of palliative care for both cancer and non-cancer palliative care.

31. My proposed Bill will underpin the National Action Plan. However, by making it a duty for NHS Boards to provide high-quality palliative care to all who need it, my proposal will have some cost. Although there is an indication that increased access to palliative care could be achieved without substantial demands on budgets, the Government is providing additional funding. It would be helpful to have some indication of where the greatest costs will be incurred.

**Q4 What are the funding implications of this proposal? Please provide detailed costings.**

## **Accountability**

32. The proposed statutory obligation on NHS Boards to provide high-quality palliative care to those in need should be monitored to ensure that the aim of the proposal is being met. Therefore my proposed Bill will have to set out a mechanism to achieve this.

33. It is my intention that NHS Boards should report annually on the implementation of their palliative care plans, including the quality of palliative care provided. In addition, the Government should be required to report annually to the Scottish Parliament on the implementation of its national strategy for palliative care. A matter for consideration is whether this is done separately from, or is included in, existing reporting requirements.

## **Who will be affected by the proposed Bill?**

34. Those who will benefit from the Bill will be patients, their families and carers.

35. Health and Social Care providers will be expected to comply with the Bill to ensure patients receive access to high-quality palliative care, choice of preferred place of care and staff must be trained to the standards required to deliver such care. Health and Social Care professionals at all levels are responsible for the delivery of end-of-life care and ensuring patients receive equity of access to the highest quality of palliative care in their locality.

36. NHS Health Boards in each authority in Scotland will have a responsibility to deliver palliative care to patients with all end-of-life chronic diseases and to implement the National Plan in relation to palliative care introduced in October 2008. This will involve NHS Health Boards working in partnership with the Scottish Government, the Scottish Health Council and Voluntary Organisations to ensure delivery to all people in need of this care throughout Scotland, regardless of diagnosis.

37. The Scottish Government will be affected by supporting the implementation of the National Action Plan by the need to establish the budget requirements to ensure palliative care availability for all conditions, both malignant and non-malignant.

38. The Scottish Health Council will need to measure the patient focus/public involvement aspect of target achievement and the collection of good practice examples.

39. Voluntary organisations will be required to ensure staff are trained in the delivery of palliative care whilst ensuring that patients, their families and carers have access to high-quality palliative care. Voluntary organisations will be expected to work in partnership with the NHS Health Boards and the Scottish Commission for Regulation of Care to ensure that appropriate standards are met.

**Q5 What other organisations etc. will be affected by the proposal and in what ways?**

## **Conclusions**

40. The evidence shows that the needs of people dying with a non-cancer diagnosis and the needs of their families are similar to those with advanced cancer. Nevertheless, only a small minority access specialist palliative care. Indeed, for many people with advanced heart failure, the severity of symptoms exceed those with a cancer diagnosis and their set of needs can be of similar and / or greater complexity.

41. Recommendations from key documents and the positions of past and present Scottish Governments endorse a wider access to palliative care based on need, not diagnosis. They also endorse the reshaping of resources for all life-limiting conditions, the education and training of all health and social care professionals, the setting of measurable targets and the use of evidence-based care models.

42. These are not only sensible and humane objectives but will be seen as increasingly necessary as the Scottish population ages. The time to prepare is now. That is why the proposed Bill places a clear priority to high-quality palliative care provision across Scotland by placing a statutory obligation on NHS Boards to provide it.

**Q6 Please provide any other comments on the Bill's proposal to place a requirement on all Health Boards to provide high-quality palliative care to everyone in need of it.**



## **Consultation Questions**

**Q1 What are your views on using this definition of palliative care for Scotland in the proposed Bill? (See paras 4-5)**

**Q2 What are your views on the whether all progressive, life-limiting conditions should lead to an entitlement to palliative care? (See para 6)**

**Q3 A list of indicators of high-quality palliative care has been provided. What other indicators should be included and why? (See paras 23-25)**

**Q4 What are the funding implications of this proposal? Please provide detailed costings. (See paras 26-31)**

**Q5 What other organisations etc. will be affected by the proposal and in what ways? (See paras 34-39)**

**Q6 Please provide any other comments on the Bill's proposal to place a requirement on all Health Boards to provide high-quality palliative care to everyone in need of it. (See paras 40-42)**



## Case Study A

Annemarie & Ian

Age – Forties

Diagnosis – Heart Failure

Length of care episode – 5 months

Ian was diagnosed with heart failure five months prior to his death. He had been given a prognosis of one year. At the time of diagnosis, Ian had prepared himself for the 'worst'. He arrived at his clinic appointment expecting bad news, however was unprepared for the full impact of being told nothing else could be done. The news was delivered over a 10-minute consultation and Annemarie and Ian were left to make their way home. This was a journey Annemarie described as the journey into despair. No-one had asked what support they had; no-one had explained what would happen next.


Ian's condition deteriorated very quickly. When he entered into the final phase of life it had not been recognised, therefore neither Ian nor Annemarie was prepared. Ian had chosen to die at home, Annemarie did not realise what this would mean for her.

Due to drowsiness and increased symptom issues an Ambulatory Pump was commenced and 'Out of Hours' telephone numbers were written down. Annemarie describes Ian as being 'flagged at GEMS' but didn't know what this involved. She presumed it meant that when help was needed he would be a priority.

Ian died out of hours. Annemarie called GEMS. She was told that there were diabetics in need of care therefore their Insulin injections were a priority. Annemarie describes this as a 'living nightmare'.

### Issues

- Ian was distressed and needed Annemarie to relieve this distress. She had already called those who she had been told to contact and help was not on its way.
- Annemarie knew there was an injection that could be used to relieve Ian's distress at end of life. She recounted the conversation when she was told this. She felt she was trusted to administer all other medications but had been told only doctors or nurses could administer this injection. She felt angry about this.
- Ian's situation had not been co-ordinated despite involvement from a Community Nurse Specialist from the local hospice. Annemarie narrated a conversation involving her being told to be strong for Ian and how difficult it would be to visit often as Ian did not have a cancer diagnosis, although she was encouraged to call if needed. She called often but did not have her calls returned.

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- Annemarie wanted to administer the injection but was afraid. She didn't know what it was or how it would work; she did not want to cause any more suffering for Ian. She wanted to relieve it. Ian was frightened. Annemarie felt completely inadequate.

#### Her Hopes & Her Message

- “Don't let Ian's death be in vain. Don't let anyone else go through what we went through. If people are to die at home, carers need education, training and a lot of support, especially surrounding what to expect and how to cope. Don't think that caring for someone who is dying should have a tick-box attitude attached. You need to really care and spend time.”

## Case Study B

Gordon & Michael

Age – Teens

Diagnosis – Juvenile Huntington’s disease

Length of care episode – 7 years

Michael was diagnosed in his early teens. His mother died as the result of a car accident in 2000, and around that time he began to show some distressing signs: Michael’s motor skills diminished, his speech became slurred, and he had poor balance and was falling.


Michael was seen by a neurologist who diagnosed Juvenile Huntington’s Disease – which his father, Gordon, had “no idea was in the family.” This was a shock for Gordon and the family – “to know your son had a terminal illness almost destroyed us ...we probably mourned for the first year after diagnosis.” The diagnosis brought various seizures and behavioural problems. The seizures were more difficult to diagnose as epilepsy, which was very difficult to manage. Michael’s condition deteriorated following falls and broken bones, eventually using a wheelchair. The most distressing loss was his speech – he could no longer say what he wanted – “he couldn’t get the words out.”

Gordon explained the Scottish Huntington’s Association was great for advice and support on where to go for help and advising on entitlements and benefits. The family would have been lost without them.

Gordon described the length of the day when looking after a relative with a terminal illness – not just a 24 hour day, but a 60-minute hour and a 60-second minute, where Michael could not be left alone.

It was a very difficult time for both Michael, as the patient, and Gordon, as his main carer. Carers who came into their home were great; however due to expense and availability, this service was not always available for longer. Gordon was given a break from 5-7pm each day, which allowed him time to go shopping or for a cup of tea with a friend – “to wind down.” However, this was not a long time and he was always conscious of clock-watching.

Michael was peg fed and received medication up to 6 times per day. He was in extreme pain for the last few months of his life and trying to get medication to help was a struggle. Michael’s consultant was approached and basically said that he should take paracetamol. The neurologist advised morphine and a higher dose Baclofen for Dystonia Myoclonus and muscle spasms which were causing extreme pain until the day he died – “which was torture for Michael.” Up to four weeks later, Michael was still being given paracetamol, which “did not touch the pain.”



Michael had pneumonia six months before he died, which was followed by weekly infections. These were painful for him, eventually leading to a constant infection.

Only after Gordon made contact with the Palliative Care Team (PCT), two days before Michael died, did they become involved. Gordon had understood this contact was being made by the hospital staff, after he had contacted them “for pain relief and just to settle him.” Gordon felt he was “shouting and nobody was listening.”

#### Issues

- Finance over person – the lack of availability of additional carer support
- Michael not receiving the correct medication – ineffective pain management, no evidence of the WHO analgesic ladder, instead repeatedly being given paracetamol for severe pain
- The lack of Palliative Care involvement in the early stage and throughout a troublesome trajectory
- Hospital staff not considering Palliative Care Team involvement. No referral, no evidence of Multi-Disciplinary Team co-ordination
- Carer felt he was “shouting and nobody was listening.”

#### His Hopes & His Message

Families live with this disease for 24 hours, seven days per week. The stress of looking after a relative and the physical condition is sometimes unbearable: “torture for us all and especially for Michael.”

The professionals must listen to the families and understand what they are going through.

## Case Study C

Moyra & Jack

Age – Sixties

Diagnosis – Alzheimer’s Disease; initial diagnosis – “small stroke”

Length of care episode – 7 years


Jack had a changing cognitive function over a period of months. “He would put things away for safe keeping and then forget where”. Jack’s family found this to be a source of frustration. Moyra first noticed a significant change when Jack’s driving became impaired. He lived in Milngavie and worked in Renfrew. Over a period of only a few months he had two accidents. His driving was no longer safe, neither for him nor other motorists.

Alzheimer’s Scotland visited Jack and Moyra to assess support needs. The visitor quickly recognised Jack was unaware of a diagnosis of Alzheimer’s and would become extremely distressed if disclosed. A visiting social worker a few weeks later was not so perceptive. When Alzheimer’s Disease was mentioned Jack became very distressed. The social worker backtracked and stated she was looking at the wrong notes.

Jack was first admitted to a care home for respite to allow Moyra a ten-day visit to her cousin. This was the first time Jack had been admitted to a care setting. Moyra communicated all information to the care home staff, paying particular attention to his medication. Jack’s medication got ‘mixed up’; he was distressed - hitting his head off walls. When Moyra arrived to collect Jack he rejected her. He wouldn’t look at her.

She admitted that whilst respite may help the carer “it doesn’t help the patient, it makes them worse.”

Over time, Jack turned night into day. Moyra recalls one particularly difficult night. Jack was demanding a hot meal in the middle of the night, which was not unusual. Moyra had not slept for many nights. She was tired, distressed and at the end of her human resources. In the morning she called the GP. She was tearful. He visited and prescribed night sedation. He wrote the prescription and handed it to Moyra. It was a cold, snowy December day. She got herself and Jack dressed, and managed to get Jack into the car. Moyra drove to Milngavie, parked the car as close to the Pharmacy as possible, leaving a walk. She got Jack to the Pharmacy and handed the prescription to the assistant, only to be told the medication was out of stock. Moyra explained that the medication was crucial for that evening. She was advised to return one hour later. She couldn’t. She repeated the process of getting Jack to the car, going home, undressing Jack who was completely



disorientated, and eventually bursting into tears. A friend called. Moyra explained what she needed and her friend collected the medication.

Life continued. Jack attended a Day Centre, which he disliked. In his opinion the driver was 'hopeless' and with Radio One blaring in the background. Jack sat with his hands over his ears. His behaviour deteriorated. Eventually it was suggested Moyra consider long-term care. She felt she had let Jack down.

Moyra intuitively knew when Jack was approaching end of life. He lay on top of his bed more often. She requested he be reviewed by the doctor. When the doctor arrived, he spoke to Moyra without looking at Jack. The following statement reduced Moyra to tears:

“You know with this illness – dementia – there is no betterment. It’s something you need to be aware of.”

The doctor left straight afterwards. He had not looked at nor spoken with Jack. Moyra burst into tears and was comforted by nurses.

Moyra had never heard of Palliative Care.

#### Issues

- Moyra expressed concern over the management of respite opportunities and whilst she recognised the need for carer support, she was also cognisant of the impact on the individual
- Moyra and Jack’s family were not prepared for end of life approaching; they did not receive any support or guidance. Moyra had to initiate the doctor's visit
- Communication and person-centeredness were compromised throughout Jack’s illness
- Moyra never received nor expected any support other than respite and Day Care and yet the greatest need was at night time

#### Her Hopes & Her Message

“I don’t know what the answer is. I know they need to go into respite but it’s the worst thing for the person. They come out different people. You lose your husband when he has dementia, but when you see them really suffering like that, you are going through another bereavement. It’s a double loss.”

## Case Study D

Judy and David

Age – Sixties

Diagnosis: Grade IV brain tumour

Length of care episode – 7 months

David, a husband, father of four and “papa” to a grandson, was diagnosed at the age of 61.

David’s appointment with his cardiologist was approaching and Judy, his wife, contacted the cardiologist to let him know she had noticed a change in David: he was not behaving as he usually did. During the appointment, the cardiologist, who knew David very well, realised “something was amiss.” He did other tests instead of the routine checks. David was sent for a brain scan in May 2005, which showed a Grade IV brain tumour. His family realised this was very serious.

Judy recalls that managing David at home was generally very difficult following his diagnosis. He became angry and difficult to control at home – at one stage, he “kind of went for” his wife – which was when the family called for help.


The District Nurse and the Community Hospice Nurse stepped in. Managing David’s moods and communication was incredibly difficult at home. The Hospice made a phenomenal difference and when David was admitted to the Hospice, he was able to regain some of the control which was so important to him and took him away from his illness, through art therapy and by writing stories of his life and travels. Staff recognised the times when he and the family needed extra help ... allowing him to write a letter to his wife the day before he went into a coma.

David had one wish – to go back to his home in Perthshire. He was allowed to do this for a weekend in the country, with the support of the Hospice Team co-ordinating and Marie Curie nurses. The weekend was a wonderful opportunity for the family to talk and share “a lot of truths.” David was quite happy to go back to the Hospice – he had made his peace with the world.

It was not long after the weekend at home when David eventually went into the coma, the family were allowed to be there together – they “moved in” – which was the only place they could imagine this would be allowed to happen.

Judy feels that it really important for the opinion of partners and close family members to be recognised early by GPs – especially where they have noticed a change in behaviour.

At the time of David being told of his diagnosis and prognosis, the professor



responsible for David's care realised David could not make decisions and no longer wished to be in the room. David left the room with two of his children. The family members who remained in the room were informed and agreed there would be "no point in doing the radiotherapy."

There were instances following this where David was consulted on how his treatment should go when his family knew he was no longer able to make a decision – "he was confused because of the tumour and he would have got angry and confused because he could no longer make a decision".

### Issues

- Involvement of the patient's relatives in diagnosis – observing changes in behaviour/well-being
- Listening to and respecting the valuable contribution carers can make
- The importance of communication at end of life – not expecting too much of a patient who is no longer well enough to know how their treatment should go or the consequence of decisions
- Collaborative decision-making – involving close family members who know the patient very well
- Access to hospice care – the importance of patients and their families having access to specialist Palliative Care in the community and also access to in-patient hospice care when the need arises.

### Her Hopes & /Her Message

Judy explained "There is a certain point where the doctor's recognition should be there that the patient cannot be consulted and needs to be left out of the loop. It is better to leave this to those who really care."



## Case Study E

Morag & Fiona

Age – Thirties

Diagnosis – Renal Failure & Retinopathy

Length of care episode – continues

Fiona was diagnosed with diabetes at age 7. Whilst this filled her family with fear and foreboding, they had no idea what was to come. Fiona went on to develop renal failure secondary to diabetes. She then lost the sight in her left eye in 1997 and 3 months later her right eye.

In January 2007 Fiona was admitted to Glasgow Western Infirmary as routine. Whilst being an inpatient, “someone”, Fiona has no idea who, began to review her social circumstances and care package. Prior to admission, Fiona had achieved a successful independent life, despite adversity. On this admission it was deemed inappropriate for her to have care during the night at home.


The Multi-Disciplinary Team involved in Fiona’s care assessed her as deserving of overnight care to ensure safety at home. “The powers that be” said no. Fiona had a seven-month hospital admission and was not allowed discharge home to her own flat. The condition of discharge was that she move into her parents home, who would receive no support.

### Issues

- Fiona has experienced multiple losses in life – her independence is crucial to her. Someone made a decision without explanation, resulting in her loss of independence, and just as importantly, her faith in the team caring for her.
- Fiona’s parents were immediately given full responsibility for her care, without referral to other services for support. Fiona has experienced “respite” at her local Hospice without follow-up or further dates. She believes this may be because she doesn’t have cancer.
- Prior to the involvement of the Palliative Care Team, Fiona’s quality of life was diminishing. She experienced intractable pain, drowsiness, nausea and fatigue. When the team became involved her opiates were switched, achieving better pain relief with fewer side effects including increased alertness, reduction in lethargy and fatigue, thus improving her quality of life and “giving me back the old Fiona.”

### Her Hopes & Her Message

“Put yourself in my shoes and consider how grateful I am that I received palliative care and all the benefits that go with that. Just think if someone in your family was



suffering in some way. Think of how different life could be with the right support and care.”

## List of Consultees

Adult Hospices in Scotland  
 Age Concern Scotland  
 Alzheimer Scotland  
 Asbestos Groups  
 Association for Children's Palliative Care (ACT)  
 Association of Community Health Partnerships  
 Association for the Deaf, Tayside  
 Audit Scotland  
 British Deaf Association Scotland  
 British Heart Foundation  
 British Medical Association  
 Cancer Backup  
 Capability Scotland  
 Care Commission  
 CHAS: Children's Hospice Association Scotland  
 Chest Heart and Stroke  
 Children in Scotland  
 Clinical Leads for All Managed Care Networks  
 Chest Heart and Stroke  
 Churches – All faiths – Christian Alliance  
 Citizens Advice Scotland  
 COSLA  
 Deaf Connections  
 Deafblind Scotland  
 Dr Harry Burns (Chief Medical Officer Scotland)  
 Edinburgh & Lothians Racial Equality Council  
 EHRC  
 End of Life Observatory  
 Engender  
 Equal Opportunity Commission Scotland  
 Equality Network  
 Executive leads for each Health Board in Palliative Care  
 Gaelic Language Promotion Trust  
 Gaelic Society, Inverness  
 General Medical Council  
 Glasgow Women & Social Inclusion Group  
 Glasgow Women's Voluntary Sector Network  
 Grampian Racial Equality Council  
 Help the Hospices  
 Jewish Care Scotland  
 Liverpool Care Pathway Team  
 Local Authorities in Scotland  
 Macmillan Cancer Support  
 Maggie's  
 Marie Curie



MS Society  
National Council for Palliative Care  
National Deaf Children's Society  
NHS Education Scotland (NES)  
NHS Quality Improvement Scotland  
Nicola Sturgeon MSP, Cabinet Secretary for Health & Wellbeing, Scottish  
Government  
North of Scotland Cancer Network (NOSCAN)  
Nursing and Midwifery Council  
Outright Scotland  
Parkinson's Disease Society  
Patient Partnership Forums  
Paul Martin (Chief Nursing Officer)  
Poverty Alliance  
Prof. Elizabeth Ireland, Clinical Lead for Palliative Care, Cancer Care  
Research Centre, Stirling University  
Prof. Nora Kearney, Cancer Care Research Centre, Stirling University  
Regional Cancer Advisory Group (RCAG)  
Richard Simpson MSP, Shadow Minister for Health  
RNID Scotland  
Royal College of Nursing  
Royal College of Physicians  
Royal College of Surgeons  
Royal National Institute of the Blind  
Save the Children  
SAY Women  
Sense Scotland  
Scottish Council on Deafness  
Scottish Health Council  
Scottish Human Rights Centre  
Scottish Interfaith Council  
Scottish MND Association  
Scottish Parliament Cross-Party Group on Palliative Care  
Scottish Partnership for Palliative Care  
Scottish Patients' Association  
Scottish Refugee Council  
Shelter Scotland  
Shona Robison MSP, Minister for Health and Wellbeing  
South East Scotland Cancer Network (SCAN)  
Strathclyde Centre for Disability Research  
The Haven  
The Prince's Trust  
University of Edinburgh  
Waverley Care  
West of Scotland Cancer Network (WOSCAN)  
West of Scotland Deaf Children's Society

