Ninewells Acute Palliative Care & Symptom Control Unit- Report of the 2009-10 pilot

"This initiative has helped patients and their families enormously and has brought together acute surgical practice and palliative practice. This is thoroughly recommended as a model for the future"

Royal College Surgeons of Edinburgh, Dec 2009

Dr Pamela Levack Consultant in Palliative Medicine NHS Tayside

Index

- 1. Background
 - 1.1 What is hospital palliative care
 - 1.2 Tayside Hospital palliative Care Services 1998 2009
 - 1.3 The unit in relation to national & international developments
- 2. Acute Palliative Care & Symptom Control Unit in Ninewells overview
 - 2.1 Dedicated staffing and beds
 - 2.2 Education & ethics programme
 - 2.3 Research programme
- 3. Acute Palliative Care & Symptom Control Unit in Ninewells organisation
 - 3.1 How the beds were organised
 - 3.2 What was different about the unit?
 - 3.3. Improvement measures
- 4. Clinical Results
 - 4.1. Patient population
 - 4.2. Reasons for admission
 - 4.3. Outcome
 - 4.3.1. Pain
 - 4.3.2. Distress
 - 4.3.3. Symptom burden
 - 4.3.4. Length of stay
 - 4.3.5. Place of discharge
 - 4.3.6. Patient and family satisfaction
 - 4.3.7. Staff satisfaction
- 5. Palliative Care Education Programme
 - 5.1. Description
 - 5.2. Benefits to medical staff
 - 5.3. Benefits to nursing staff
 - 5.4. Palliative Care training for seconded nurses
- 6. Summary and recommendations for a permanent unit

Background

Palliative Care in the UK has traditionally been community-focussed. It originated in independent or NHS funded hospice institutions, which are physically separate from acute hospitals. Palliative care services have struggled to keep pace with the increasing need in acute hospitals.

Tayside Health Board approved the development of an acute palliative care unit in 2007. The pilot programme reported here, was possible through a generous endowment from an individual benefactor – on the understanding that NHS Tayside established a permanent unit if it proved to be a success according to specific criteria [Appendix 1.]

This report shows the success of the pilot unit for the first 100 patients and their families admitted from 5.2.09 - 31.12.09. It also reports the benefits to the staff, of the unit education programme.

1.1 What is hospital palliative care?

It is the provision of a service which

- a. Improves symptom control
- b. Helps determine the goals of care and
- c. Assists patients and families plan their future care.

It should be available for all those with advanced disease who need it¹ – not only cancer patients. In addition patients with the most complex needs, for example difficult to-control pain, should have access to a specialist in palliative medicine.

Hospital palliative care can be provided in parallel to "active" treatment for the underlying disease and it should be available *on site*, i.e. in the hospital where the patient is currently being cared for. It is no longer acceptable to exclude patients in need because they are not at home or in a hospice. It needs to support staff

¹ Reference Living and Dying well? WHO

managing difficult problems in advanced illness, as they struggle with the pressures of a busy acute hospital.

60% of patients in Tayside [and the UK] die in hospital and this percentage is unlikely to change in the near to medium future. Furthermore there are continuing reports of considerable unmet needs in patients who die in hospital.

This programme provides a structured approach to the provision of *specialist* palliative care for patients with complex needs plus an on-site programme to increase the confidence of hospital professionals providing *general* palliative care.

1.2. Hospital Palliative Care Service in Tayside 1998-2009

Ninewells Hospital and Perth Royal Infirmary Palliative Care Teams have provided consultative services since 1998. Between the two services, they see a total of 850 patients per annum. Since 1998 the Ninewells service has seen 6000 patients [and most of their families].

In the last 11 years patients have become older [median 71 v 69 years] and frailer. Median performance status has reduced from 50 to 40 out of 100 [Appendix 2]. The needs of patients have become more complex and there are more treatments for more patients with more co-morbidity.

The experience of the Ninewells palliative care service has recently been published by the Royal College of Physicians.² It is the biggest prospective study of palliative care service delivery in an acute hospital. It concluded that the palliative care needs of hospital patients are *different* to those of hospice patients and that in at least one in five patients, these needs are of sufficient complexity to merit a short-stay **dedicated on-site unit**. This is also the recommendation of the World Health Organisation, which estimates that 20-30% of all specialist palliative care beds should be in tertiary centres [cancer centres and major acute hospitals].

-

² Levack P RCPE Audit Scotland Repiort

There are patients with palliative care needs in every hospital ward and speciality; therefore all staff must be confident in the provision of basic palliative care. A structured hospital **education programme** is needed. Finally we believe in a culture of research in hospital palliative care, through a **research programme** linked to the Clinical Research Centre.

1.3. The unit in relation to national and international health strategies.

If all patients who need the service are to access it, seven days a week wherever they are, local and national policies must ensure palliative care is integrated into mainstream healthcare. The development of a hospital unit is included in the Tayside strategy [2006]; supports the national *Living and Dying Well* strategy [2008]; and has attracted attention from the World Health Organisation. As a result Tayside has been designated a WHO Demonstration site for Palliative Care.

2. The pilot Acute Palliative Care & Symptom Control Unit – overview

2.1. Dedicated staffing and beds

Three beds [single rooms] were identified in a surgical ward [ward 9] for the one-year pilot – for patients in the surgical, oncology and haematology wards. Endowment funding provided the following staff:

- a. 7.4 WTE nurses seconded to train in hospital palliative care
- b. A consultant in Palliative Medicine to direct the Education Programme
- A dedicated secretary to provide administrative support for the unit and the hospital palliative care service
- d. Dedicated sessions from physiotherapy, occupational therapy and pharmacy

The chronic and acute pain services, social work and chaplaincy made a commitment to support the pilot without any additional funding.

2.2. Education and ethics programme

The biggest gap in the provision of palliative care identified by the Audit Scotland report ³ was in hospital. It stated that the confidence of all medical and nursing staff to provide general palliative care, needed to be improved, and that all patients should have access to a specialist in palliative medicine if indicated. The pilot addressed this need by establishing an Education Programme for hospital staff led by an experienced Director of Palliative Care Education.

2.3. Research programme

We have the commitment of a strong multidisciplinary group including physicians, anaesthetists, neuroscientists, etc. Only 0.1% of National Cancer Research Funding supports palliative care projects and once the unit is formally established we hope to submit for research grants. A portfolio of clinical research area is being developed to include:

- Patient experience
- Molecular studies in association with opioid analgesia
- Molecular models of neuropathic pain
- Early epidural blockade; ambulatory epidurals: reduced costs and bed days

3. The pilot Acute Palliative Care & Symptom Control Unit – organisation

3.1. How the beds are organised

Nurses were seconded to the unit from a wide variety of wards and shifts organised so that a palliative care nurse was available for the unit 24/7. There was a degree of cross-cover and sharing of skills and knowledge, promoting goodwill within the ward. It also spread palliative care skills, as few nurses in an acute hospital have training in looking after patients with palliative care needs. Inevitably there were times when a shortage of nurses on the surgical floor necessitated nurses being moved - and this impacted on the palliative care nurses. This is the

reality of a non- dedicated facility in an acute hospital and should be less of an issue in a stand-alone unit.

3.2. What was different about the unit

Before admission, patients and their families were informed that the focus of the short stay unit was intensive palliative care. The purpose of admission was explained - improving symptoms, organising getting home etc. Within 48 hours, a family meeting was held to ensure that the goals of care corresponded to the patients and families' understanding.

It was also explained that we worked as a **team** [acute and chronic pain specialists, occupational therapist, social worker, chaplain, physiotherapist pharmacist etc]. We explained that we took a proactive approach in the unit and that, for example, the chaplain would drop in and see all patients – unless any patient preferred otherwise.

3.3. Unit improvement measures - PCU⁶

On admission, an assessment was made as to what speciality input was needed [Appendix 3]. Details were recorded of when this was achieved. Family meeting details were recorded and whether this was achieved within 48 hours. Symptoms were assessed daily using the Edmonton Symptom Assessment Score [Figure 1]. On admission the patient completed this with the doctor's help and on subsequent days the patient with the nurse's assistance did this. For those patients who were too ill to complete it, staff made whatever assessment was possible.

Patients and their families [where appropriate] were asked to comment about what Was good, what could have been better and what suggestions they had for this new service [Appendix 4].

Figure 1 Example of ESAS scoring done on admission and 48 hours later

On admission	48 h	ours	s late	er								
No pain	0	1	2	3	4	5	6	7	8	9	1	Worst possible pain
·											0	
Not tired	0	1	2	3	4	5	6	7	8	9	1	Worst possible
											0	tiredness

0	1	2	3	4	5	6	7	8	9	1	Worst possible nausea
										0	
0	1	2	3	4	5	6	7	8	9	1	Worst possible
										0	depression
0	1	2	3	4	5	6	7	8	9	1	Worst possible anxiety
										0	
0	1	2	3	4	5	6	7	8	9	1	Worst possible
										0	drowsiness
_						_		_	_		
0	1	2	3	4	5	6	7	8	9		Worst possible appetite
										0	
0	1	2	3	4	5	6	7	8	9	1	Worst possible feeling
										0	of well-being
0	1	2	3	4	5	6	7	8	9	1	Worst possible
										0	shortness of breath
0	1	2	3	4	5	6	7	8	9	1	Worst possible distress
										0	
0	1	2	3	4	5	6	7	8	9	1	Constipation
		-		-	_				,	0	
0	1	2	3	4	5	6	7	8	9	1	
										0	
)))))))))))))))))))) 1) 1) 1) 1) 1) 1) 1 2) 1 2) 1 2) 1 2) 1 2) 1 2) 1 2	1 2 3 0 1 2 3	0 1 2 3 4 0 1 2 3 4 0 1 2 3 4 0 1 2 3 4 0 1 2 3 4 0 1 2 3 4 0 1 2 3 4 0 1 2 3 4 0 1 2 3 4 0 1 2 3 4	0 1 2 3 4 5 0 1 2 3 4 5 0 1 2 3 4 5 0 1 2 3 4 5 0 1 2 3 4 5 0 1 2 3 4 5 0 1 2 3 4 5 0 1 2 3 4 5 0 1 2 3 4 5 0 1 2 3 4 5	0 1 2 3 4 5 6 0 1 2 3 4 5 6 0 1 2 3 4 5 6 0 1 2 3 4 5 6 0 1 2 3 4 5 6 0 1 2 3 4 5 6 0 1 2 3 4 5 6 0 1 2 3 4 5 6 0 1 2 3 4 5 6	0 1 2 3 4 5 6 7 0 1 2 3 4 5 6 7 0 1 2 3 4 5 6 7 0 1 2 3 4 5 6 7 0 1 2 3 4 5 6 7 0 1 2 3 4 5 6 7 0 1 2 3 4 5 6 7 0 1 2 3 4 5 6 7 0 1 2 3 4 5 6 7	0 1 2 3 4 5 6 7 8 0 1 2 3 4 5 6 7 8 0 1 2 3 4 5 6 7 8 0 1 2 3 4 5 6 7 8 0 1 2 3 4 5 6 7 8 0 1 2 3 4 5 6 7 8 0 1 2 3 4 5 6 7 8 0 1 2 3 4 5 6 7 8 0 1 2 3 4 5 6 7 8 0 1 2 3 4 5 6 7 8 0 1 2 3 4 5 6 7 8	0 1 2 3 4 5 6 7 8 9 0 1 2 3 4 5 6 7 8 9 0 1 2 3 4 5 6 7 8 9 0 1 2 3 4 5 6 7 8 9 0 1 2 3 4 5 6 7 8 9 0 1 2 3 4 5 6 7 8 9 0 1 2 3 4 5 6 7 8 9 0 1 2 3 4 5 6 7 8 9 0 1 2 3 4 5 6 7 8 9 0 1 2 3 4 5 6 7 8 9 0 1 2 3 4 5 6 7	0 1 2 3 4 5 6 7 8 9 1 0 1 2 3 4 5 6 7 8 9 1 0 1 2 3 4 5 6 7 8 9 1 0 1 2 3 4 5 6 7 8 9 1 0 1 2 3 4 5 6 7 8 9 1 0 1 2 3 4 5 6 7 8 9 1 0 1 2 3 4 5 6 7 8 9 1 0 1 2 3 4 5 6 7 8 9 1 0 1 2 3 4 5 6 7 8 9 1 0 1 2 3 4 5 6 7 8 9

4. Results

4.1 Patient population

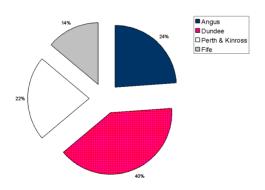
574 patients were referred to the Ninewells Hospital Palliative Care Service 5.2.09 – 31.12.09. 89/100 had cancer; 11 (11%) had conditions other than cancer. Based on the 11-year experience of the hospital palliative care team, it was estimated that 20% of referrals would benefit from admission to a dedicated unit for a more intensive approach. During the pilot 17% [100/574] of patients referred to the service were admitted to the unit. As the pilot was available for patients in the surgical and oncology directorate, 42% of admissions were from oncology, 4% from haematology and 30% from surgical wards high dependency unit. However, it was clear that this percentage would be greater if the unit were available to the medical directorate. In addition, with only three beds, we frequently had a waiting list.

There is a definite population of patients in a busy acute hospital, who benefit from an intensive palliative care approach delivered in a dedicated on-site unit

The median performance status of patients was 50 [Appendix 1] i.e. patients spent 50% of their time in bed as a result of their illness and needed considerable assistance bathing etc. Based on the Palliative Care Prognostic Index [PPI; Appendix 5], in which a PPI of 6 or more predicts a survival of less than 3 weeks; the median PPI of patients was 5. Thus a minority of patients admitted to the unit were considered to be imminently dying [i.e. within a few days or 1-2 weeks]. Some patients however are too frail to transfer to hospice.

Unit patients came from all areas in Tayside [Figure 2]. Less than half [40%] resided in Dundee, 24% in Angus, 21% in Perth & Kinross and 15% in Fife.

Figure 2. Admissions to Unit in relation to place of residence



The unit provides a service for patients with complex palliative care needs for all Tayside

4.2. Reasons for admission to unit.

Pain has been previously identified as the main reason for referral to the specialist palliative care service in Ninewells.² It was therefore no surprise that pain was the main reason for admission in 73% of patients. These patients had already been seen by the HPCT on their parent ward but it had not been possible to improve their pain to a satisfactory level.

51/100 (51%) patients required complex, specialist drug usage such as alfentanyl, ketamine, methadone or epidural analgesia. 22/100 patients' pain necessitated a consultation with an anaesthetic pain specialist or neurosurgeon.

4.3. Outcomes

4.3.1. Pain

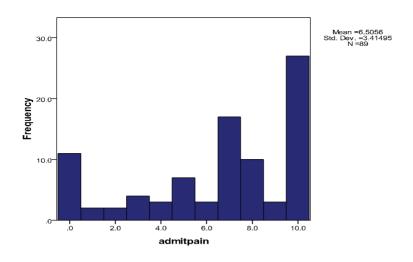
Pain was significantly reduced from 74*to 4 within 48 hours

Pain was the commonest reason for admission [Figure 3]. The median pain score on admission was 7, and one third had pain, which they reported as 10 out of 10. A score of greater than 10 was not recordable but it was our experience that many patients described their pain as "20 out of 10". After 48 hours, median pain score had reduced to 4 [Fig 5]. Of the 69 patients in whom pain was measured on admission *and* 48 hours later, this reduction was highly significant [p<0.001].

Figure 3. Patient pain scores on admission

-

^{4*} out of 10



4.3.2. Distress

Distress was significantly reduced from 7 to 0 within 48 hours

The median distress score on admission was 7 [Fig 4]. 42% had a score of 10/10. Median distress score within 48 hours of admission was 0 [Figure 4]. Of the 57 patients in whom distress was measured on admission and 48 hours later, this reduction was highly significant [p<0.001].

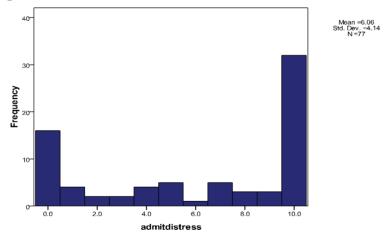


Figure 4. Patient distress scores on admission

4.3.3. Total symptom burden

There was a significant reduction in total symptom burden within 48 hours

Most patients had multiple symptoms [Fig 5]. Nonetheless, most were able to score their symptoms with the help of a nurse or doctor. The score of all 10 symptoms were totalled to give a total symptom burden. The median total symptom burden on admission was 42. Data was not assessable by the unit staff for 9 patients who were too ill. The median symptom burden recorded at 48 hours was 33. For the 70 patients in whom admission and 48 hour measurement was possible, this reduction was highly significant [p<0.001].

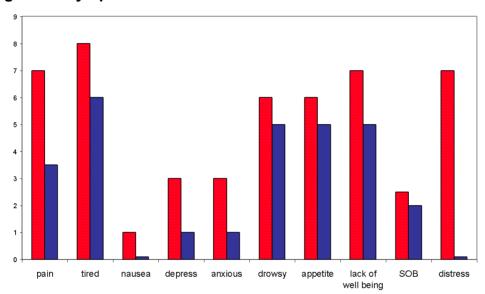


Figure 5. Symptoms on admission to the unit and 48 hours later

ESAS [Edmonton Symptom Assessment Scale] + distress on admission □ after 48 hours ■

4.3.4. Length of stay

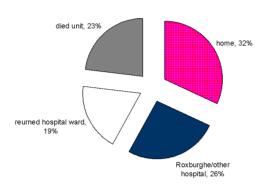
The median length of stay was 5 days. Two thirds of patients were in the unit for one week or less. Patients with the longest length of stay had very complex pain needing anaesthetic or neurosurgery intervention [Appendix 6]. The management of such patients will be researched and streamlined as the unit matures.

4.3.5. . Outcome - place of discharge.

77% patients were discharged from the unit: 32% went home, 26% to a hospice or community hospital. 36% of patients were seen by occupational therapy, all within 2 working days showing the benefits of an intensive team approach.

19% of patients returned to their original ward for active treatment or further consideration of active treatment. 23% died in the unit; this compares with a mortality of 80% in a hospice such as Roxburghe House.





58% patients were discharged from the hospital directly from the unit.

4.3.6. Patient & family satisfaction

Those who were able to were very willing to answer simple patient and/or family satisfaction questions [Appendix 4]. This does not constitute a qualitative satisfaction study, but the answers do provide feedback on the acceptability of this new service. Comments, almost without exception, were very positive. Patients and families valued the personal attention, the quiet, the focus on detail, the speed with which painkillers were available, and the importance put on the patient and family being central to care.

"I woke up and had no pain...the last time I had no pain was 3 months ago"

Patient who got home

"I was able to have time with particular nurses and get to know them"

Patient with severe anxiety & nausea

[&]quot;"You couldnae make it better"

Patient's response to question what could make the service better?

"Best wishes as you press the case for the permanent establishment of your amazing unit"

A relative

4.3.7. Staff satisfaction

"When the symptoms are quickly sorted, we have more time for patients"

Nurse on unit

"I have worked here for eight years and this is the first time I have been regularly asked to see patients such as these"

Hospital chaplain





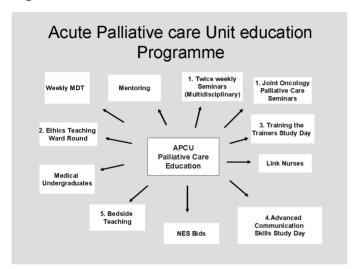
Since the unit opened we have also had a number of sizable cheques from friends and relatives

5. Education Programme

A locum consultant with international experience in palliative care education was appointed for a year in January 2009. A comprehensive programme commenced in March 2009 [Figure 8].

1. **NEW Twice weekly teaching seminars** 48 seminars were held [Appendix 7] – multidisciplinary /jointly with oncology. Attendance was **600 staff** [nurses and nursing students 409, doctors, 93, medical students 20, AHP 78]. Each session was evaluated – and without exception evaluated highly. Dr Jeffrey is a highly skilled teacher⁵ and the only consistent criticism was that participants wanted more time for education.

Figure 8.



- 2. **NEW Ethics teaching ward round.** 6 sessions considered ethical issues raised from a case in the unit: resuscitation, feeding & hydration, sedation, informed consent, rationing. Evaluation was good
- 3. **NEW Training the Trainers in communication skills.** A one-day workshop was held for eight specialist registrars in palliative medicine [Dundee & Aberdeen] at the West Park Conference Centre. The course was well evaluated and all course members have subsequently improved their teaching skills.
- 4. **NEW Advanced communication skills course.** Two three-day courses were delivered. The maximum number [15] completed each course.
- **5. NEW FY1 experience palliative care.** Three FY1 doctors are attached at any one time to ward 9. Over the 12 months 8 FY1's gained practical experience of looking after palliative care patients, and this was highly rated.

6. Summary & recommendations for developing a permanent unit

We made a commitment to provide:

- 1. Short-stay specialist beds for intensive palliative care 24/7
- 2. A dedicated multi-professional team to integrate palliative care into mainstream medical care that was not deferred until the last few days of life
- 3. Safe, rapid discharge for patients who prefer to be in their own homes
- 4. An education resource for the hospital
- 5. Research and audit to demonstrate the benefit of specialist palliative care

The pilot has succeeded. It succeeded because of the commitment of staff in numerous specialities: specialist palliative care [nursing and medical staff], chronic and acute pain, secretarial, chaplaincy, physiotherapy, occupational therapy, social work and pharmacy – who believed that this model of care made a difference not only to the patients [and their families] in this report – but in raising the profile of palliative care in hospital. It succeeded because of senior management support – allowing innovation to flourish and encouraging a model of care that is not only a first in Scotland but for the UK. We have already been asked to present preliminary results at national and international conferences and further publications in clinical and management journals will follow.

NHS Tayside agreed in August 2009 to continue the initiative, expand the number of beds and make the facility available to all hospital patients.

Acknowledgments:

We are very grateful for the generous endowment, which has made the pilot possible and ensured the future development of a dedicated unit in Tayside. The pilot has established the need for high quality palliative care in hospitals – something that Mr Peter Bates, a precious chairman of NHS Tayside, very firmly believed in.

Appendix 1. Submission to Thorntons May 2008

New Ninewells Hospital Symptom Control Unit (SCU)
The development of an innovative, short-stay unit, as a professional and educational resource for Ninewells Teaching Hospital and Cancer Centre.

Background

Hospitals and staff are hard pressed to deliver well-managed, high quality care for those with chronic and life-threatening illnesses, who are often elderly. Too many patients & families have unsatisfactory hospital experiences related to end-of- life care and although hospice care will only ever be appropriate for a minority, many would benefit from access to high quality palliative care. Terminal care is only part of palliative care, and many of the principles of hospice/palliative care can be successfully applied in the acute setting, in parallel with "active" therapy. The transition from curative & more aggressive palliative therapies to a more symptom-based palliative approach is the key to good end of life care.

Ninewells Acute Trust identified a need 10 years ago and determined that palliative care support should be available for those who need it. The Ninewells Hospital Palliative Care Team [HPCT] was appointed in 1998 and has seen over 4500 patients [and their families] since. The team [2.5 WTE nurse specialists and 0.5 Consultant] is part of the specialist palliative care service. After careful evaluation and peer-reviewed publication of the team's clinical experience it is clear that the HPCT model has reached the limit of effectiveness as an isolated advisory service. A more comprehensive palliative care service is needed for such a large, busy cancer centre, to meet the increasingly complex needs of patients & families, support the work of the HPCT and help the clinicians and management deliver coordinated high quality palliative care.

Many patients are in inappropriate care in the acute setting e.g. in an acute surgical ward where the care is good but the organization of the unit is not orientated to the needs of these patients. Patients admitted to the SCU would otherwise have remained in acute units. In the SCU patients will have intensive assessment and rehabilitation in order that they can move to the most appropriate setting preferred by patient and family e.g. home, local cottage hospital, hospice or back to the acute ward for further treatment if their symptoms are controlled and their further treatment is appropriate. The SCU will *not* be a hospice in the acute setting. Patients do not want to have to choose between curative and comfort care, they complement each other.

The SCU will:

- 5. Be short stay [4-5 days] and provide intensive palliative care in a specialised environment.
- 6. Provide dedicated multi-professional input [specialist palliative care nursing and medical staff, chronic and acute pain specialists, physiotherapist, occupational therapist, psychologist, chaplain and pharmacist], which is integrated into mainstream medical care.

7. Provide medical and nursing leadership and an education resource for the hospital

The SCU will benefit professionals, patients and families by providing:

- 8. Specialist advice which is not deferred until the last few days of life;
- 9. Expert intensive control of symptoms and distress on site day or night. Such patients at present need to be transferred to Roxburghe House. For many patients, families and staff this is not appropriate [even if a bed were available which it frequently is not], as they may still be having active anticancer treatment or they are not thinking that their illness is at such an advanced stage.
- 10. A comprehensive plan of care with patient family and professionals, aligning what is medically possible with the patient's aims.
- 11. Safe, rapid discharge for patients who prefer to be in their own homes
- 12. Unique opportunity to carry out research and audit to demonstrate the benefit of specialist palliative care

As an example of a patient who would benefit

29 year old with rapidly progressive cancer and increasing pain no longer responsive to medical management. She needs an epidural, which can currently only be done in Roxburghe House. The patient needs on-going oncology intervention and also knows the medical and nursing staff in Ninewells – she does not want to move. In a teaching hospital & cancer centre, we should be able to provide such intervention on site. Once stabilised in SCU, a decision could be made to transfer the patient to a more appropriate step-down facility e.g. community hospital/home/original ward/place of choice.

SCU as part of NHS Tayside's strategy

The concept was presented to the Strategic Management Group of the Single Operating Unit in May 2005, was subsequently warmly approved by NHST Board on 11 January 2007, and has wide support throughout the clinical staff of Ninewells. Over the last 10 years, many relatives have expressed the wish for a facility like the SCU.

It has attracted interested from the World Health Organisation. The WHO has pioneered a public health strategy to integrate palliative care into existing health systems, to ensure that all those who need palliative care expertise can access it. A group of senior managers and clinicians from Tayside visited the Catalonia WHO Collaborating Centre in 2007 to discuss the proposal with the Director of WHO Public and Palliative Care Health Programme. The Tayside model of care (unique in the UK) has been submitted to the WHO as a potential WHO Demonstration project.

Financial implications

At the Strategic Policy & Resources Committee on 20 March 2008, the SCU development was categorised as very worthy. Funding has not yet been approved, and in the current very tight financial climate, it is unlikely that this service will be funded for at least a year.

The necessary staffing infrastructure of A&C, Allied Health Profession (AHP), medical and nursing staff to support this proposal is complete and fully costed [£490k per annum]. A Business case and operational policy is complete [all papers available].

Appendix 2. Palliative Care Performance Status

Palliative performance status %	Ambulation	Activity and Evidence of Disease	Self-Care	Intake	Conscious Level
100	Full	Normal Activity No Evidence of Disease	Full	Normal	Full
90	Full	Normal Activity Some Evidence of Disease	Full	Normal	Full
80	Full	Normal Activity with Effort Some Evidence of Disease	Full	Normal or Reduced	Full
70	Reduced	Unable Normal Job / Work Some Evidence of Disease	Full	Normal or Reduced	Full
60	Reduced	Unable Hobby / House Work Significant Disease	Occasional Assistance Necessary	Normal or Reduced	Full or Confusion
50	Mainly Sit/Lie	Unable to Do Any Work Extensive Disease	Considerable Assistance Necessary	Normal or Reduced	Full or Confusion
40	Mainly in Bed	As Above	Mainly Assistance	Norma or Reduced	Full or Drowsy or Confusion
30	Totally Bed Bound	As Above	Total Care	Reduced	Full or Drowsy or Confusion
20	As Above	As Above	Total Care	Minimal Sips	Full or Drowsy or Confusion
10	As Above	As Above	Total Care	Mouth Care Only	Drowsy or Coma
0	Death	-	-	-	-

The different areas of activity are assessed as in the example above. The corresponding PPS% is the line, which corresponds most closely to what the patient is able to do - in the example above PPS is 50%

Appendix 3. APCU Improvement Measures - PCU⁶

1. Intensive symptom control and reduction distress

- Admission ESAS % reduction symptoms/48 hours
- Admission distress level and cause
- 48 hours ESAS

Recorded after leaving PCU

• 48 hour distress level and cause

2. Intensive assessment – appropriate disciplines

11 1	consultation < 2WD	
Palliative Medicine		
Palliative care nurse	•	
Palliative medicine consultant	•	
AHP's		
• OT	•	
• Physiotherapist	•	
• Lymphoedema Nurse Specialist	•	0/ achieved/pack
Social/Family	_	% achieved/need
GP Social Services	•	
Social Services	•	
Pharmacy		
 Dedicated Specialist 	•	
Neuroscience/Pain		
• Acute/Chronic Pain Specialist	•	
Neurosurgeon	•	
Emotional support		
Psychologist/psychiatrist	•	
• /Counsellor	•	
3. Family meeting		
Achieved	•	
Achieved in 2 working days	•	
4. Intensive future Planning		
Plan for discharge made	•	%
Discharge as planned achieved	•	%
Discharge as planned achieved withi	n 7 days •	%
Discharged home	•	%
T Care/Died in unit	•	%
5. Satisfaction		
Patient	•	SCORE
Family	•	SCORE
Nurse	•	SCORE
Staff	•	SCORE
Staff 2	•	SCORE
Sui 2		DOM
6. Patient story		
Recorded whilst in PCU	•	
D 1 1 0 1 ' DOTT		

Appendix 4. Relatives Questionnaire

We are currently piloting 3 beds in Ward 9 for patients from Surgery and Oncology and Haematology who require intensive symptom assessment and management, or have complex discharge planning needs.

Can you take time to read the questionnaire and answer the questions as honestly as you can? Please add any comments that you feel might help improve the service we provide in the future.

The questionnaires will remain anonymous. Thank you for your time. Please return your completed questionnaire to Senior Charge Nurse, Ward 9.

			_
	Yes	No	Comments
Were you aware of the reason for your relatives transfer to the unit			
Were your relative's symptoms controlled quickly when they transferred to the Unit?			
Did you feel the setting was appropriate to their needs?			
Were the nurses able to spend time with you?			
Do you feel we could improve the service we provide for patients?			
What did you like?			
What would you change?			
Any suggestions?			

Palliative Performance Scale	10-20	4.0
(PPS)	30-50	2.5
	≥ 60	0
Oral Intake	Severely reduced	2.5
	Moderately reduced	1.0
	Normal	0
Oedema	Present	1.0
	Absent	0
Dyspnoea at rest	Present	3.5
	Absent	0
Delirium	Present	4.0
	Absent	0
	Total	

Appendix 6. The two patients with longest length of stay

Case history 1.

79 year old man with prostate cancer and bone metastases. Uncontrolled pain due to nerve pressure from a tumour mass. Pain score 8 out of 10 at best. Seen by anaesthetic consultant & specialist in chronic pain. Epidural inserted – pain 2 out of 10. Developed unrelated cardiac problems, which delayed insertion intrathecal, pump, and then last minute equipment problems forced further delays. Issues related to extended stay:

Case history 2.

33-year-old man with colorectal cancer, bone, liver and lung metastases. Admitted to the unit because of severe hip pain - due to bone metastases. Multiple opioids and neuropathic agents tried without success.

Situation exacerbated by intense patient and family distress and complex family dynamics. His care involved specialist in chronic pain [consultant anaesthetists], oncology, psychiatry, psychology, occupational therapy, chaplaincy, social work, physiotherapy and palliative medicine.

Reasons for long stay:

- 1. Uncertainty about potential for more oncology treatment
- 2. Difficulty inpatient assessment due to severe low mood
- 3. High family distress
- 4. Need to establish secure environment and establish trust
- 5. Use of epidural and intrathecal requiring intensive management.

Appendix 7. Education Programme:

Topics covered at teaching seminars

Assisted suicide Nerve pain (twice)

Bone pain Neutropenic sepsis

Breathlessness (three)

Non malignant palliative

care

Cancer cachexia Oncology palliative care

interface (twice)

Communication (three) Pain assessment

(twice)

Complex discharge Pain management

Confusion (twice) Palliative emergencies

(twice)

Difficult pain (twice)_ Palliative sedation

End-of-life care (twice) Patient dignity (twice)

Ethics Prescribing (twice)

Ethnic minorities Radiotherapy (twice)

Hydration Talking to relatives

(four)

Intestinal obstruction Team working

Nausea 7 vomiting (three)