



An evolving process

**Snapshots of palliative and end of life care in
acute care settings in Scotland**

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Introduction

by the co-chairs of the Living and Dying Well short-life working group on the delivery of palliative care in acute hospitals

Living and Dying Well,¹ Scotland's first national action plan for palliative care, was published in October 2008. *Living and Dying Well: Building on Progress*² followed in 2011, recording the progress made towards achieving the aims of Living and Dying Well and setting out the next phase of actions required by NHS Boards working with stakeholders.

The documents recognised that the progress of a number of illnesses (including, but not restricted to, cancers) can now be predicted. This enables health care teams in hospitals and the community to work with patients, families, social care agencies and the voluntary sector to develop a planned approach to palliative and end of life care that reflects not only evidence-based practice, but also, where possible, the needs and wishes of patients and their families.

Research and our own experience as physicians tells us that given the choice, most people would prefer to die at home. Scotland has very strong palliative care services in community settings that support and enable many people to realise their wish. But for many, and for a variety of reasons, dying at home is not a feasible option. Government statistics³ show that in Scotland, only 23.4% of people die at home. This compares to 58.3% of patients who die in hospital, 15.5% in care home settings and 2.8% in hospice care. Thirty per cent of all acute bed days are used by patients in their last year of life.

This means that much of the need for palliative care will not be situated in the community, where palliative care services are traditionally strong, but in acute hospital settings. We therefore need to strengthen palliative care and end of life approaches in hospitals so that we continually improve the experience for patients and their families. We also need to ensure that through joint working involving hospital, community and voluntary services, appropriate processes are in place to avoid unnecessary hospital admissions for people approaching end of life.

Palliative care, once considered an approach suitable only for people with terminal cancers, is now recognised as being appropriate for anyone with a life-limiting condition, including heart, respiratory and renal disease and dementia, and for people who are old, frail and who may have several co-morbidities. This places a responsibility on doctors and other professionals working within acute care specialties in hospitals to adopt an ethos which accepts that recognising and meeting the needs of patients requiring palliative

¹ Scottish Government (2008) *Living and Dying Well*. Edinburgh: Scottish Government. Access at: www.scotland.gov.uk/Resource/Doc/239823/0066155.pdf

² Scottish Government (2011) *Living and Dying Well: Building on Progress*. Edinburgh: Scottish Government. Access at: www.scotland.gov.uk/Publications/2011/01/27090834/0

³ Information Statistics Division, Scottish Government, 2009.

care and those approaching the end of life, and their families, is part of their core business.

As Living and Dying Well emphasises: “the initial diagnosis of a life-limiting condition, together with critical events and changes in disease progression ... , should be recognised in all care settings [our emphasis] as a trigger for the introduction of a palliative care approach ... based on:

- holistic assessment, with the patient and carer, of their physical, social, emotional, cultural, religious and spiritual care needs and other relevant life circumstances
- planning, coordination and delivery of appropriate care based on the needs identified
- appropriate sharing and communication across all care settings [again, our emphasis] of the needs, and plans identified and actions taken
- regular review and repetition of the assessment and planning cycle.”⁴

This underscores the central message that palliative care is for all who need it, irrespective of their disease state or the care setting in which they find themselves. And, as a recent paper in the New England Journal of Medicine shows⁵, the introduction of palliative care at an early stage of treatment for advanced lung cancer can help patients live longer, as well as improving their mood and quality of life. This emphasises the point that good palliative care can improve outcomes in the same way as other medical interventions.

A number of short-life working groups were established as part of the Living and Dying Well action plan with a remit to develop recommendations in areas highlighted through a national collaborative process as requiring future development work. We were invited to co-chair Short Life Working Group 5, a multi-disciplinary group charged with developing recommendations for palliative care in acute hospitals.

In developing our 10 recommendations, we were conscious as a group that the proportion of hospitalised patients with advanced illness is increasing. With demographic projections predicting significant rises in the numbers of older people in the population and people living with co-morbidities, it seems unlikely that the percentage who need inpatient care in the final years of life will change dramatically.

While every hospital admission of a patient with an advanced illness or who is very old and frail offers an opportunity to assess his or her palliative care needs in advance of moving into the end of life stage, the Short Life Working Group 5 report⁶ highlights the range of challenges hospitals face in delivering high quality palliative care, such as:

⁴ *Living and Dying Well*, page 6, paragraph 14.

⁵ Temel JS, et al. (2010) Early palliative care for patients with metastatic non small cell lung cancer. *N Engl J Med* (363):733–742.

⁶ Living and Dying Well Short Life Working Group 5. Chairs: Dr Pam Levack & Dr Stan Wright
Recommendations on palliative care in acute hospitals. April 2010.
Access at: www.scotland.gov.uk/Resource/Doc/924/0097237.doc

- difficulties for clinical staff in recognising that a patient is actually approaching end of life, particularly when the clinical picture is uncertain or changing
- challenges in delivering specific aspects of palliative care, such as reaching decisions about treatment withdrawal or escalation, providing complex symptom control or communicating bad news
- providing effective education for staff.

This publication aims to help doctors and healthcare teams in hospitals identify and overcome some of the challenges they face by presenting examples – “snapshots” – of good current practice from across Scotland, as described by physicians working in different hospital specialties.

The snapshots illustrate not only the benefits to be accrued from adopting palliative and end of life care principles and tools within acute care practice, but also the challenges doctors and others in acute environments face in assessing and meeting patients’ and families’ needs. They also highlight the significant resources and tools that already exist to help clinical teams to assess, identify and manage patients who require palliative care and those who are approaching the end of life in a humane, caring and effective way. Each snapshot features particular “key issues” that we believe are the central underpinnings of the processes put in place by the featured physicians and their teams.

We hope that this publication will enthuse and inspire all doctors and other health professionals in acute settings in Scotland to look anew at the potential for evidence-informed palliative care and end of life approaches to provide effective, person-centred and appropriate care for patients approaching the end of life and their families. Our grateful thanks go to the physicians whose accounts feature in the publication for their time, their honesty and their commitment to ensuring the best possible palliative and end of life care for their patients.

Dr Pam Levack and Dr Stan Wright

Co-chairs, Living and Dying Well Short Life Working Group 5

Living and dying well in renal services

Around 250 adult patients in Grampian receive regular dialysis treatment through the health board's central and peripheral dialysis units, and about 300 have transplants. There is also a large number of patients with kidney failure who have not yet reached the stage of dialysis or transplantation. The age of patients starting dialysis has been steadily increasing over the years, as **Dr Izhar Khan, consultant in renal medicine in NHS Grampian**, explains.

"The median age of patients commencing dialysis in Scotland has risen from 45 years in 1980–84 to 64 years in 2009," he says. "In the early 1980s, we saw hardly any patients over the age of 65 starting dialysis, but that is not the case now. In Aberdeen, for instance, between the years 2001 and 2009, we started dialysis in around 50 patients aged 80 or over. In the whole of Scotland in 2009, 534 patients over the age of 75 years were receiving renal replacement therapy [dialysis or renal transplantation] out of a total of 4238 patients. It's not that kidney failure is becoming more common, but that people are living longer and that co-morbidities such as vascular disease are being dealt with more effectively."

There is still no research to show that in very old patients in stage 5 renal disease with multiple co-morbidities, renal replacement therapy will offer a better quality of life, or even a longer life, than conservative care. "At this most severe stage, we focus on patients' needs and wishes," Dr Khan says. "Whereas in the past we would have offered these patients dialysis or, rarely, transplantation, we now also offer 'no renal replacement therapy' as an option.

"We stress very much that if the patient doesn't get dialysis, it doesn't mean their treatment stops," he continues. "We don't speak about 'palliative care' as such, but rather refer to the 'conservative' pathway of kidney disease management, which is an active care pathway."

Dr Khan has found that patients often view the conservative management approach as the better option, given the invasive nature of dialysis. Treatment for their kidney disease continues to be offered on this pathway, including the use of erythropoietin and phosphate binders and provision of dietary advice. Patients attend a "low renal clearance" clinic at which management approaches are reviewed and, if necessary, amended.

"We always leave the options open," Dr Khan explains. "For instance, a patient with severe co-morbidity who I feel may not do well on dialysis might nevertheless request to have dialysis. Some of these patients do quite well and will remain on dialysis, but a number will not tolerate it or will come to the conclusion that the benefits it provides are not worth the impositions it places upon them. It is important that the patients have options."

The conservative management approach is about quality of life. Its foundation is a partnership involving the renal team, the general practitioner, the patient's family, the chronic kidney disease nurse, an associate specialist, a social worker and the dietitian. Often, the nurse or associate specialist will visit the patient's home and assess what the needs are, following which a package of support and information is assembled.

The key relationship here is between the renal team and the GP, as Dr Khan explains. "If we are discharging a patient home on the conservative management pathway, we will often speak to the GP before discharge, assuring them that we are there to support. We stress that if there is a major problem, we do not want the patient to be admitted to a medical receiving unit. If we cannot admit to our unit, we will admit them somewhere in the hospital but under our care. Patients and carers can also contact the unit direct to arrange an admission."

The guiding principle of the conservative pathway of kidney disease management is that the death of a person with chronic kidney failure should never be uncomfortable. "What the patients fear most is that their process will be uncomfortable, and while we cannot guarantee how long they will live, we can almost certainly guarantee that their final days will be comfortable," Dr Khan says.

Dr Khan recalls seeking support from specialist palliative care services only once or twice in the last 15 years. "We feel that because the problems patients with end-stage renal failure experience are so specific, we have been able to develop a high degree of expertise in managing their symptoms within the unit," he says.

A few years ago, renal units were very much machine led and were focused on active renal replacement therapy. Now, because of the greater age of patients and their co-morbidities, the renal specialty is becoming more and more conscious of the need for expertise in palliative care management, and many renal units offer the conservative pathway of care as an option.

"We must never think of a patient who is not going to live very long as a patient who is lost," Dr Khan says. "That mindset has changed in nephrology. We dedicate equal skill and time to patients who choose the conservative management pathway as we do to those receiving renal replacement therapy.

"The most important message is that the involvement of the renal team does not stop if the patient is deemed unfit for, or chooses not to undergo, dialysis. While we strive for a good quality of life for our dialysis patients, we equally strive for a good quality of life and, in the final stages, a good quality of death for patients on the conservative management pathway."

KEY ISSUES

Co-morbidities

Shared care

Communication

Quality of life

Teamwork

Choice and partnership in decision making

Living and dying well in cardiology services

Palliative and end of life care needs are now achieving far greater prominence within the specialty of cardiology, **Dr Karen Hogg, consultant cardiologist at Glasgow Royal Infirmary, NHS Greater Glasgow & Clyde**, believes.

“Up until fairly recently in cardiology, we tended not to consider palliative care for our patients until death was imminent,” she says.

“We didn’t consider it for patients with chronic conditions who were deteriorating despite optimal cardiology management. We very much perceived palliative care as being for patients who were dying, most typically for people with cancer. But because cardiology is a very ‘doing’ specialty, not ‘doing’ in this field was alien to our thought processes.”

So things have begun to change, particularly in relation to the large group of patients who have heart failure.

“Many patients do not see heart failure as a terminal condition, despite the fact that its prognosis is worse than that for many forms of cancer,” Dr Hogg explains. “One of the main challenges is that even if the patient has a lot of symptoms, they accept them and don’t see them as terminal. The patient may not think there is much wrong with them. So we have to broach the idea of a palliative care approach very carefully.”

Dr Hogg is involved in the Caring Together programme, a five-year collaboration involving the British Heart Foundation, Marie Curie Cancer Care and NHS Greater Glasgow & Clyde.⁷ Its aims are to improve quality and access to care for local heart failure patients with palliative care needs and to widen patient choice over their place of care. A large component of Caring Together is training, and an education programme on palliative care for heart failure nurses and others is being developed at Glasgow Caledonian University.

The heart failure and supportive care (HFSC) clinic Dr Hogg runs at Glasgow Royal Infirmary is set up more like a palliative care clinic than a bustling cardiology clinic.

“In a traditional cardiology clinic, you see a lot of patients in a short time,” she explains. “In the HFSC clinic, we have fewer patients and more time to see them. We make sure there is nothing else we can offer in terms of treating the heart failure while also focusing on symptom assessment and management, which can include referral to hospice day care. Patients initially may be reluctant about this, but those who have gone have really benefited – it has been a great success. We also look at psychological and spiritual care and care for the carers – these are not things we would normally address, or have the capacity to address, in a standard cardiology clinic.”

⁷ For more information, see: <http://staging.mariecurie.org.uk/en-gb/healthcare-professionals/innovation/caring-together/>

Dr Hogg develops an anticipatory care plan with some patients, focusing on the likelihood of certain circumstances occurring in the future and how they should be dealt with. "For instance, we look at the patient's wishes regarding resuscitation and where he or she wants to be cared for towards the end of life. If it's home, we can specify this in the plan and support the GP to try and facilitate it. The anticipatory care plan is especially helpful if the patient becomes sick at home out of hours and is seen by a doctor they are not familiar with – the plan can help the doctor to make the best assessment for the patient at that time."

The cardiology service is now trying to identify inpatients who may benefit from this approach by putting in place an anticipatory care plan while they are still in hospital. This can then be followed through on discharge, hopefully helping to reduce further admissions to hospital as a result.

"I develop the anticipatory care plans with the patients and whatever family members they want to play a part," Dr Hogg explains. "You need to develop a relationship with the patient and family before broaching some of these issues. They understand why we are doing it, even though some of the reading isn't particularly pleasant for them, and they know it is there to help guide whatever health professional they come into contact with to abide by their wishes. I did some training in palliative care towards the end of my cardiology training, so I'm very comfortable doing the plans. I develop the structure of the plan, then send it to the GP, heart failure nurse and other health professionals involved for comment. I'll then complete it, and it is held by the patient. The plan is reviewed and can of course be changed over time."

There are no palliative care beds in the hospital's coronary care unit, but a new 40-bed cardiology ward is opening in March 2011 and a 12-bed heart failure "pod" will open its doors in October of that year, with provision of single rooms. "My intention is that some of these rooms will be for patients who are receiving palliative care," Dr Hogg says. "We also have access to inpatient beds at the hospice, but what we're trying to do is bring some of the hospice management techniques into the ward – managing patients the way the hospice manages them, but within the hospital."

So is adopting a palliative care approach a difficult "sell" in cardiology? Dr Hogg doesn't think so.

"I was apprehensive about what colleagues would think a couple of years ago, but I am not now," she says. "The reality is that people are quite relieved to have this kind of service in cardiology – patients with advanced heart failure are difficult to manage and present recurring problems because they keep coming back into hospital. So we're offering an appropriate service that people are happy to engage with."

KEY ISSUES

- Advance care planning
- Partnership working
- Holistic care
- Patient choice and education

Like his colleague Dr Karen Hogg in Glasgow, **Dr Martin Denvir, consultant cardiologist in NHS Lothian** is progressing the development of palliative care approaches in cardiology services in Lothian. In collaboration with Dr Kirsty Boyd, a palliative care consultant, and Professor Scott Murray, St Columba's Hospice Chair of Primary Palliative Care at the University of Edinburgh, he and his team are piloting approaches that aim to answer one very simple question – what is the best way to identify people who might be reaching the end of their life on the cardiology ward or in the outpatient clinic setting?

“This sounds relatively straightforward but in fact is very difficult to do, for a variety of reasons,” Dr Denvir explains. “By their nature, cardiologists always feel there is something else that can be done to prolong life. Our practice is based on a critical appraisal of the evidence of what works and what doesn't. Our main aims are to improve the quality of life and to help patients live longer. But when we've exhausted the options to prolong life, we're justified in switching to a way of managing people that can be seen as palliative.”

Dr Denvir is currently looking at the potential of combining largely subjective approaches to assessment that have been used in palliative care settings with more objective measurement methods used in cardiology.

“Palliative care has a number of ways of identifying people approaching the end of life, such as the Gold Standards Framework (GSF),”⁸ he explains. “These define generic and disease-specific criteria, of which heart disease is one, but they are slightly ‘soft’ or subjective criteria. Most cardiologists would find them to be too nonspecific.”

Dr Denvir and his team therefore decided to use GSF criteria to determine whether, on the basis of the criteria, patients coming into the ward with myocardial infarction (MI) or heart failure were reaching the end of life. The scores were compared to more objective clinical prognostic criteria in the Global Registry of Acute Coronary Events (GRACE) score for MI, and the Seattle heart failure (SHF) score, which provides an estimate of one- to three-year survival rates and average years of survival for patients with heart failure.

One hundred and seventy patients with MI were assessed by the GRACE score and the GSF, and 30 with heart failure by the SHF score and the GSF. The results of the pilot suggest that:

- the GRACE score was highly predictive of death of patients with MI (followed up for one year)
- the GSF did not predict death in patients with MI, but did accurately predict the likelihood of readmission over the next year
- the SHF score tended to predict survival better than the GSF, which again was useful in predicting readmission.

Dr Denvir and his team also looked at SHF and GSF scores with 138 patients managed by specialist heart failure nurses in the community, who were followed up for a year.

⁸ For more information, see: www.goldstandardsframework.nhs.uk/

“Again, we found the GSF was a poor predictor of death with these patients,” he reports. “It predicted that 86% of the patients were in their last year of life, while the SHF score suggested less than 5% [6/138] would die in 12 months. In fact, there was mortality of 31% [all-cause mortality].

“Interestingly,” Dr Denvir continues, “patients who were GSF negative – that is, who didn’t meet any of the GSF criteria – were accurately predicted as surviving for at least a year. So being GSF positive was nonspecific, but being GSF negative was actually quite predictive of survival beyond a year. That may be useful.”

Neither system was found to be perfect, but the potential offered by combining them is intriguing. “It is relatively easy to assess patients using the GSF,” Dr Denvir says. “It can be done in your head. In that way, its subjectivity is an advantage – you don’t have to run off and do tests.

“So the approach we’re suggesting is that when you see a patient with severe heart failure, do the GSF in your head and, if it’s negative, you can probably continue treatment with no need to adopt a palliative care approach. But if it’s positive, assess by the more objective criteria of the SHF score and, if the patient is found to be at high risk, it’s time to flag this up to the GP to inform ongoing management. If the SHF score suggests survival of five years or more, keep the patient under review.”

Dr Denvir believes the combination of the GSF with an objective scoring system is probably a positive way forward in trying to identify patients who are approaching end of life. “A combination of subjective and objective measures will support you to discuss the situation with the patient and plan how to make the quality of the patient’s life as high as possible,” he says. “And one of the advantages of the GSF is that it raises consciousness of the palliative care approach among professionals who are using it.

“Our main role is to flag patients who have a high risk of death and/or readmission to hospital to GP services who would then, if they agree with the recommendation, place the patient on the palliative care register,” he continues. “Adopting a combined assessment approach using GSF or other prognostic indicator guidance with numeric clinical parameters incorporated into clinical risk scores could encourage cardiologists to firstly identify and then acknowledge that patients are reaching end of life.”

KEY ISSUES

Assessment
Diagnosing dying
Quality of life
Communication

Living and dying well in services for older people

The early experiences in medicine of **Dr Patricia Cantley, consultant in medicine for the elderly, NHS Lothian**, convinced her that clarity around the aims and aspirations of care for people approaching end of life was crucial.

“So many times as a junior doctor I would be left with vague instructions about ensuring people approaching end of life or who had a terminal illness were ‘kept comfortable’, with little or no explanation of what that meant in terms of what I should be doing for them as a doctor,” she recalls. “The principle of keeping someone with a terrible illness comfortable I could accept, but the detail of how to do it was something else.”

It struck Dr Cantley that many of the really difficult decisions around caring for people who were dying arose out of hours, when senior medical staff were no longer on the premises. With these issues in mind, Dr Cantley has developed a “checklist” for junior medical staff in her department.

“I tried to work out what would have been most helpful for me as a junior doctor to help me give the optimum care to patients,” Dr Cantley explains. “What questions were the most difficult to answer, and what questions would I have liked answered before the senior medical staff left the ward?”

The first item on the list is about making sure that the patient’s diagnosis, prognosis and plan is clear in the notes so that whatever doctor attends the patient at whatever time of day understands what needs to be done.

“This sounds really basic, but it isn’t always clear from the medical notes what the plan is if things deteriorate,” Dr Cantley says. “So the checklist encourages doctors to put things in very clear and simple language in the notes, like: ‘Mrs X is very unwell. She has not responded to treatment of her pneumonia. She may be dying.’ Even by just writing that, you’ve given people permission not to attempt intrusive and uncomfortable interventions if the patient deteriorates further.”

The next part identifies the patient’s symptoms and refers the doctor to the NHS Lothian Palliative Care Guidelines⁹ for advice on management. This section focuses not only on established symptoms but also on those that are predicted, so potential problems can hopefully be addressed early. Resuscitation status and rationalisation of drug therapy also feature here, with decisions taken on how extensive any new treatment efforts should be.

“We need to think about what might happen to a patient with, say, very severe heart failure in the event of a deterioration,” Dr Cantley says. “We might decide that yes, we will treat an infection with antibiotics, and yes, we will treat

⁹ For more information, see: www.palliativecareguidelines.scot.nhs.uk/

if the patient develops a gastrointestinal bleed, but no, we will not transfer the patient to the high-dependency unit.”

Making decisions about moving the patient off site are crucial, Dr Cantley believes. “It’s not an easy decision for a doctor to make. As a consultant, you can get a call at night about a patient you’ve never met, a frail older woman who hasn’t been managing at home and has been admitted to one of the satellite rehabilitation hospitals with pneumonia and deteriorates overnight. And the junior doctor is on the phone to you asking – do you want me to send her to the Royal Infirmary? And to be honest, you really don’t know. But if the action to be taken has been stated clearly in the notes, either that transfer is appropriate or inappropriate, it is so much better. We need to clearly state in the notes how far we will escalate.”

Dr Cantley believes the same rules should apply to less disruptive but nevertheless potentially distressing interventions, such as taking bloods. “We need to be clear about when we are stopping taking daily bloods and doing other tests, such as blood pressures,” she says. “If you find a blood anomaly, what do you do about it? Correcting something like a raised calcium level can be very unpleasant for the patient and might make his or her journey worse. At other times, testing will be appropriate. The important thing is to get it right for each individual patient.”

This section of the checklist also focuses on food and fluids. Discussions on whether to have an intravenous infusion are taken at team level and will be determined according to a range of factors, with the patient’s comfort level being paramount. Actions to manage IV extravasation are also made clear, alongside decisions on invasive feeding techniques.

The third section reinforces the need to review activity and decisions across all these areas at least daily to ensure the plan is still right for the patient. And part 4 emphasises the need to remain constantly in touch with carers and family about what’s happening and why.

There are, of course, other important elements of caring for someone who is very ill or dying that don’t appear on the checklist – issues such as place of care (side room, main ward, or home if possible) and psychological and spiritual issues. Dr Cantley stresses that while these items don’t appear on the checklist, they are very much in the team’s mind.

It’s a very simple checklist, but one which, if followed, makes a big difference to patients and to the team. “You might think that all of these points should be done automatically, but quite often one or two of the steps will be missed,” Dr Cantley says. “Going through the list helps us to focus on what’s most important for the patient.”

KEY ISSUES

- Symptom management
- Resuscitation status
- Advance care planning
- End of life care
- Documentation

Dr Sue Barton, consultant in older age psychiatry at the Royal Cornhill Hospital, NHS Grampian, runs a tertiary unit for older people with dementia who exhibit challenging behaviours, as she explains.

“While the primary focus is on recovery in the sense that most patients move from the unit to community settings in under six months, some of our patients are well on in their journey through dementia and are aggressive or sexually disinhibited in such a way that assessment wards and nursing homes can’t cope. Frequently, we need to make a judgement on where these patients are on their dementia journey, what their quality of life is and, in conjunction with the family, decide how actively we will treat infections and other illnesses. Some, for instance, are found to have tumours, and we wouldn’t propose aggressive and distressing treatments.”

Dr Barton and the ward team have close links with Roxburghe House, the specialist palliative care unit for NHS Grampian, and have accessed support from them in trying to assess the palliative care needs of their patients.

The unit tried two assessment systems that Roxburghe House was piloting: the palliative performance status (PPS), which assesses functional status based on ambulation, the presence and activity of disease, self care, oral intake and level of consciousness, and the palliative performance index (PPI), which assesses the PPS score, oral intake and presence of delirium, dyspnoea at rest and oedema. Staff found, however, that these systems did not work for people with dementia. “All of our patients come out as being close to end of life when scored against them,” Dr Barton says. “They work for patients with cancer and other conditions, but they just don’t work for us.”

The unit is now looking to see if other systems might help and is trialling the Barthel Index on the ward. But decisions on care approaches at the moment are based on discussions involving doctors, nursing staff, occupational therapists, physiotherapists and families.

“We’re really looking at what quality of life patients have and defining what the aims of care should be,” Dr Barton says. “That often involves doing what we can to keep the patients from becoming distressed – many of these patients hallucinate and relive horrible experiences from their past, which is very difficult to treat without using lots of sedation.

“When we discover someone has a tumour or a chest infection, we’ll treat the symptoms, but we won’t order scans or potentially distressing diagnostic interventions. We won’t rush to provide intravenous antibiotics or to transfer patients to the geriatric hospital for further treatment. Instead, we will try to manage their symptoms on the ward.”

Only one of Dr Barton’s current patients would be actively resuscitated in the event of a cardiac arrest. “For the rest of the patients, we’ve discussed the issue with their families and have agreed on no resuscitation,” she says. “These decisions are based on the person’s quality of life and how their lives have changed, and on the futility of resuscitating someone at the end of their dementia journey.”

The foundation of caring for patients who die on the ward is very much working with the families and putting patient comfort first. Good palliative care principles come into play – controlling pain and other symptoms, meeting physical, psychological and spiritual care needs, protecting against avoidable traumas like pressure sores, providing privacy in single rooms and ensuring carers and families have 24-hour access. “There is a mixture of psychiatric and general trained nurses on the ward who are very experienced and very sensitive to families’ needs, understanding the stresses they face,” Dr Barton says. “Good multi-disciplinary team working and planned formal and informal contact with families is the key to our success and in ensuring that patients are treated as we would wish to be ourselves.”

Dementia is a big challenge to health care services now and will become even more so in future. Dr Barton believes that evolving dementia services will have to take account of palliative and end of life care issues and adopt a palliative care ethos much earlier in the illness. “You can’t have a dementia service, particularly in the final stages, without an awareness of palliative and end of life care issues,” she says. “Palliative care services and dementia services working together presents a very positive way forward.”

KEY ISSUES

Accurate assessment
Partnership working
Family involvement
Quality of life

One of the biggest challenges in delivering palliative care to an elderly population is recognising when a person has a terminal prognosis even in the absence of a terminal illness diagnosis. Many people admitted to care of the elderly units may have several ongoing problems, none of which are deemed terminal or life-limiting, but may nevertheless be approaching end of life.

Dr Graham Ellis, consultant in medicine for the elderly, NHS Lanarkshire and his colleagues have adopted a number of means of trying to improve recognition and treatment of dying patients.

“We have an associate specialist with experience in palliative care who has helped us greatly to understand the issues,” he says. “We also have access to local and health board evidence-based guidelines on when to recognise that someone has less than three months to live – these were developed in palliative care settings for use in mainstream settings.

“There is a strong chaplaincy and a carers’ support service that are very helpful in supporting with the stresses families face,” he continues. “And we have guidelines on when to withdraw treatments and manage pathways of decline in different settings that support clinicians to adjust treatments for failing patients appropriately. They also help when explaining to families why their loved one has had his or her medicines stopped or reduced.”

Dr Ellis and his team tend to manage patients requiring palliative care themselves, consulting with specialist palliative care only when complex issues arise, and rarely referring patients to hospice care.

“We are using the Liverpool Care Pathway (LCP)¹⁰ in our wards, which is described as an integrated care pathway that is used at the bedside to drive up sustained quality of care in the last hours and days of life,” he says. “Nursing staff find this particularly helpful in terms of being able to refocus care. The decision to place someone on the LCP is primarily taken only by nursing and medical staff and not the whole multi-disciplinary team. Our understanding of how it should be introduced is that families should be informed that it is our intention to activate the pathway, which involves a face-to-face discussion with them.”

Dr Ellis feels the LCP is used in rather a different way in elderly care than in other services. “I suspect it is rather different from cancer services, where the prognosis and probable pathway may be much clearer than for older people,” he says. “We do sometimes manage to get people home, but more commonly they will die in hospital. We try to exploit whatever options we have in terms of community support, but it is an unusual occurrence.”

Anticipatory care planning is on the agenda for future development in palliative and end of life care in the elderly care setting, as Dr Ellis explains.

“GPs have introduced anticipatory care planning in care homes. We don’t yet have access to these documents in the acute setting to enable us to adjust them for patients and relatives to take with them when they return to the care home, but we’ve been communicating with GPs so they can amend the plans in the light of our advice on what we believe the prognosis is.

“Our aim is to try and reduce the numbers of GP care home admissions of people who are clearly frail and who are at an end of life stage but for whom there hasn’t been a planning process in place specifying, for example, that the person shouldn’t have to undergo a traumatic admission to hospital in the light of his or her condition deteriorating further. But we need to be better at this and start the anticipatory care planning process in the hospital, ensuring that discussions around anticipatory care planning have everyone on board.”

The inclusion of palliative care approaches and thinking in elderly care services in Lanarkshire has reflected a process of evolution rather than revolution, Dr Ellis believes. “There has been a consciousness in care of the elderly for years that a large proportion of our patients will die in our care,” he says. “For instance, there is an 80% mortality at 6 months in our NHS long-stay beds. So there’s always been a recognition that palliative care is part of our core business.

“We’re looking now for ways to standardise the quality of care we deliver,” he continues. “The LCP was an easy sell to many of our staff. They were actively involved in caring for dying people and could see the benefits the framework brings through promoting positive action on relatively simple things – stopping intrusive observations on people who are clearly dying and ceasing medications that may no longer be helping patients or can no longer be taken easily, for instance. But the LCP also helps you to do some of the big stuff as well and supports standardisation of care. It has created a situation in which nurses and others are more confident about speaking about dying with relatives.

¹⁰ For more information, see: www.liv.ac.uk/mcpcil/liverpool-care-pathway/

“The aim is to educate, standardise and improve, and some of the things we’re introducing are helping us to achieve that. But it’s very much a work in progress – we can still do better.”

KEY ISSUES

End of life care
Diagnosing dying
Liverpool Care Pathway
Multi-disciplinary team work
Anticipatory care planning

Living and dying well in intensive therapy services

The intensive therapy unit (ITU) has not traditionally been seen as a palliative care environment, but interest in applying palliative care principles with people who won't survive ITU is growing. **Dr Judith Joss, consultant anaesthetist in ITU at Ninewells Hospital, NHS Tayside**, explains.

"The public perception is that ITU is about saving lives, but around 25% of admissions will die in the unit," she says. "So that means a fairly high percentage of our patients will receive end of life care in the unit."

"Traditionally, we've been seen as a very aggressive, full-on specialty that focuses primarily on cure, but that's changing. We're now trying to integrate palliative care approaches into the normal ICU setting."

The unit has very much adopted a team approach to meeting the needs of patients approaching the end of life. "We're applying the best bits of what we do in ICU to end of life care in the unit – that's about ensuing good communication and strong multi-disciplinary working, creating space for relatives and carers and being on hand 24 hours to answer their questions. All the consultants and nursing staff embrace the idea of employing palliative care principles in the unit, especially around communication."

ICU is an unusual health care environment in that most communication is with surrogates – usually family members – rather than the patient. "The vast majority of our patients don't have competence," Dr Joss explains. "They are either unconscious due to their disease process or their treatment. It is therefore quite uncommon to have patients involved in decision making about care."

There is, however, a group of patients who are referred to ICU from other parts of the hospital who are able to participate in decision making and goal setting. A subgroup of patients will not be considered fit for transfer because they are too unwell or have too many co-morbidities to benefit from intensive care, and Dr Joss and her colleagues are currently looking at decision making in relation to these patients.

"When we are asked to see patients on other wards, there will be a percentage who will not benefit from ICU," Dr Joss explains. "In the past, we've tended to assess these patients, make the decision then have no further part in their management. We're now recognising that while we may not be the right doctors to deal with their ongoing needs, we can look to see if we can identify their palliative care or end of life needs within the acute hospital. It will involve our own staff plus doctors from the palliative care service, and we will be looking to identify how many patients there are, where they are, and how we can improve their end of life care."

Dr Joss and her colleagues have to discuss with these patients and their families the appropriateness, or more accurately the inappropriateness, of transfer to ICU. "These are very difficult conversations to have," she says.

"So we're looking at how we can train junior doctors to manage these kinds of conversation by finding out how experts in other fields, such as consultants in palliative care, teach their junior staff about communication. It's about seeing what cross-expertise we can bring into intensive care."

Most of the junior doctors in the unit are on rotation to learn about critical care and have no aspiration to become intensivists. "Many doctors have had little experience of patient-family communication and have not had to deal with death commonly," Dr Joss says. "We notice a few of our junior staff find it emotionally difficult, and we have to reflect that in our supervision."

Dr Joss recognises that in adopting a palliative care ethos within the ICU, the unit will need to up its game in relation to particular aspects of care, such as bereavement support, relative support and spiritual care.

"When a patient dies, we will write to the GP giving as much detail as we can, describing if the relatives were present when the patient died and how much explanation they had been given," she says. "But we make it clear to relatives that we're happy to see them at any point after the death if they need to discuss something or are struggling to understand the series of events that led up to the death, and a small number of relatives will take this opportunity to return to the unit."

The ICU service of which Dr Joss is a part reflects a developing awareness of palliative care needs in ICUs across Scotland. "I think there is a recognition in Scotland that we need to develop or bring in expertise for the group of patients in our care who are approaching end of life," she says. "We're not unique – we're reflective of most units in Scotland."

KEY ISSUES

End of life care

Multi-disciplinary team work

Communication with patients and relatives

Staff support

Holistic care

Living and dying well in respiratory medicine services

The palliative care work group of the West of Scotland Respiratory Managed Clinical Network, chaired by **Dr Scott Davidson, consultant in respiratory medicine, NHS Greater Glasgow & Clyde**, is looking to improve the care of patients with non-malignant respiratory disease.

One of their projects is about trying to put in place mechanisms to identify patients at risk of dying from their chronic obstructive pulmonary disease (COPD), assess their needs and implement changes that lead to an improvement in their quality of life. "We're trying to improve their lot," Dr Davidson says.

At the moment, a patient-held record is being tested in a small pilot that is focusing on patients with a Medical Research Council (MRC) dyspnoea score of 4 or 5 – those people who are effectively housebound with breathlessness. "The feeling is that no matter if the patient's care is entirely palliative at that stage or not, the patient should have his or her needs assessed," Dr Davidson explains. "If we can help these people to have good quality of life and they live for a number of years, then that's effective palliative care."

The patient-held record has been developed within the palliative care work group and consists of four sections. Section 1 contains the contact details for the professionals involved in the patient's care and a nursing assessment that records data the respiratory nurses routinely collect on issues such as social factors, the home situation and the patient's understanding of their diagnosis. Section 2 is an assessment of the patient's symptoms and is completed regularly by both the patient and the specialist nurses. "We ask them to state whether it has been a good or bad week, as the course of the illness is so variable," Dr Davidson explains. "The nurses also document antibiotic use, weight loss, admission to hospital and the like."

Section 3 is adapted from the *My Future Care Plan* document developed by Dr Boyd and Professor Murray in Lothian and allows the exploration of the patient's thoughts about the future and specific questions about their care. For example, COPD patients who have experienced specific treatments in the past, such as non-invasive ventilation, may discuss their wishes about receiving it again in the future.

Section 4 is an anticipatory care plan that brings together all the information from the first three sections and sets out what patients would wish in the event of a significant deterioration.

Five patients are currently holding the patient-held record. "We're trying to encourage a conversation with patients about the care they want," Dr Davidson explains. "That in itself can be a challenge, because COPD patients tend not to be an empowered population – they may feel responsible for their condition and are not traditionally strong on letting us know what they want."

Dr Davidson says that while respiratory physicians are used to having serious and significant conversations on issues such as these with patients with, for example, lung cancer, COPD patients are a bit different. "COPD patients may not realise just how unwell they are," he says, "so raising the issue of anticipatory planning and palliative care is, I find, very challenging. I don't tend to speak about 'palliative care' per se with them, because I don't want to take away any hope from the patient, and there is always a chance that they may survive five years or more. It's more about focusing on assessing the patient's needs – they have a serious illness, they may not get better, and while it's difficult to predict the future, we want to get the best quality for whatever time remains. It's tailored for each patient, but it can be hard."

Respiratory medicine historically has close links with palliative care and has a natural palliative care focus, Dr Davidson believes. "Much of the general palliative care services for patients are delivered by the respiratory team, but there are close links with specialist palliative care services," he says. "A severe lung disease clinic at the Victoria Infirmary in Glasgow, for example, has a palliative care physician in attendance."

Dr Davidson and his colleagues hope to know more about the impact of their patient-held record and anticipatory care plan pilot at the end of 2011. "We want to know how the patients found it, what hard information was collected, what carers and nurses got from it, and whether it improved lines of communication," he says. "Correspondence between primary and secondary care is always a challenge, so if you have a patient-held record, that may make communication easier."

"The pilot will give us information about whether this is the right way to be going, or whether we need to think again," he continues. "But initial feedback from nurses going out to see the patients is that the patient-held record may be beneficial."

KEY ISSUES

Anticipatory care planning

Assessment

Quality of life

Communication

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