

Routes to Success

in end of life care – achieving quality environments for care at end of life



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Introduction

“The physical environment of different settings, including hospitals and care homes, can have a direct impact on the experience of care for people at the end of life and on the memories of their carers and families.” (End of Life Care Strategy, Department of Health, 2008)

There is now a great deal of evidence about the critical importance to patients, relatives and staff of the environment of care. It not only supports recovery but is also an indicator of people’s perception of the quality of care. However, until relatively recently there has been little investment in identifying the aspects of the environment that are especially important for those receiving palliative care, their relatives and the bereaved.

This guide identifies a number of key environmental principles to help improve privacy and dignity for patients and relatives and to support the bereaved, whose memories live on once their loved one has died. It is designed to be of use at each stage of the end of life care pathway and across all care environments, including hospitals, hospices and care homes – although the sections on bereavement centres and mortuary viewing rooms are likely to have most relevance to acute hospitals.

It is important that when new buildings or refurbishments are planned we take the opportunity to make changes that will improve service delivery and quality. The aim of the guide is to provide practical support to those charged with delivering end of life care services, showing how patients’ and relatives’ experience can be improved through relatively small scale environmental changes. These can be as simple as de-cluttering corridors and noticeboards or as far-reaching as establishing a hospital bereavement centre, which has wider implications for the organisation of services and support.

One key message is to ensure that patients, their relatives and all the staff who care for them are consulted during the development of any capital schemes. They have much to offer and their input has made a real difference to many of the schemes highlighted in this publication.



1.1 Background

In 2004 NHS Estates asked its Design Brief Working Group to consider the hospital environment where people die. Their report (*A place to die with dignity: Creating a supportive environment*, NHS Estates, May 2005) was a consultation document for all those in health care. It indicated that the places where people die, where families are counselled following bereavement and where friends and relatives view the bodies of their loved ones are often neglected.

A subsequent review of the literature describing the impact of the environment on end of life care (*Improving environments for care at end of life*, The King's Fund, 2008) identified some significant pointers towards positive therapeutic environments. These included the value of creating home-like environments, incorporating natural light and the natural elements in the design and ways for the patient to remain in control of their environment from the bedside. At much the same time the Department of Health's new End of Life Care Strategy laid considerable stress on the importance of the care environment (DH, 2008).



1.2 Enhancing the Healing Environment

"Dying patients and their families deserve dignity and a caring environment. This programme is an important step towards better care for a much neglected group. Improving the environment in which people are cared for can make a huge difference to how they feel."
Niall Dickson, Former Chief Executive, The King's Fund

The King's Fund has, since 2000, been working with health care providers to improve the environment of care through its award-winning Enhancing the Healing Environment (EHE) Programme. The programme encourages and enables local teams to work in partnership with service users to improve the environment in which they deliver care. It consists of two elements: a development programme for a nurse-led, multidisciplinary team and a grant for the team to undertake a project to improve the patient environment. Further information can be found on The King's Fund web site (see resources).

The findings from a pilot programme launched in 2006 by The King's Fund to improve Environments for Care at End of Life (ECEL) influenced the development of the national End of Life Care Strategy. Subsequently in 2008 the Department of Health commissioned and funded The King's Fund to extend the ECEL programme to 20 organisations that provide end of life care (*Improving the patient experience: Environments for Care at End of Life*, The King's Fund, 2011). This programme has been evaluated by the Sue Ryder Care Centre for the study of supportive, palliative and end of life care at the University of Nottingham (*Environments for care at end of life: evaluation of The King's Fund's Enhancing the Healing Environment Programme*, University of Nottingham, 2011). The programme has helped focus attention not only on the acute hospital ward environment but also on rooms for relatives and viewing facilities in accident and emergency departments. The 20 projects also included the provision of end of life care suites for people with dementia and people in prison (see appendix).



The King's Fund has also worked with The Prince's Foundation for the Built Environment to establish principles for hospice design. (*Principles of Hospice Design and associated Environmental Design Audit Tool*, The Prince's Foundation for the Built Environment and The King's Fund, 2010)

The lessons from these strands of work in NHS trusts, hospices and HM prisons have informed this guide, which draws together key themes that are particularly important in end of life care environments.

Throughout The King's Fund's work one theme has remained constant: the need for health care settings that make patients feel welcomed, looked after and cared for, and staff valued.

1.3 End of Life Care Strategy

The End of Life Care Strategy recognises that the physical environment in different settings, including hospitals and care homes, can have a direct impact on the experience of care for people at the end of life and on the memories of their carers and families (DH 2008). Central to this is the importance of providing environments that encourage dignity and respect and recognise the need for:

- Rooms where an individual and their family can go to talk privately
- Informal gathering spaces where families can meet
- Guest rooms where close family and friends can stay overnight, with facilities for catering and communication.

In addition, following death particular attention needs to be given to:

- The transfer of the body to the mortuary
- The location of the mortuary and how it is approached by families, friends and carers
- The viewing room
- Rooms where families, friends and carers can sit quietly and receive the deceased person's property and collect the death certificate.

The importance of these spaces is recognised in the Quality Markers (1.7.2) which require that "All providers have assessed their current environments

for care from the perspective of people at the end of life and their carers and have incorporated plans for improvement into their formal estates strategies." The accompanying measures are through audits of estates strategies and their implementation.

1.4 The Hospice Design competition

In 2007 His Royal Highness The Prince of Wales, President of The King's Fund and The Prince's Foundation for the Built Environment, challenged both organisations to use their combined expertise to develop a set of principles, via an architectural competition, that could be used to inform future hospice design and, more widely, all environments in which care is delivered to people at the end of their lives.

It was agreed that the competition should build on the learning from the ECEL pilot. More specifically it should:

- Raise the profile of the importance of hospice design
- Bring together the expertise of the two organisations and a hospice partner to enable best available research and evidence to be used to inform a set of principles for the future design of hospices
- Engage a number of architectural practices to work up outline designs for hospices through a limited competition
- Provide the hospice partner with an opportunity to contribute to the formative stages of hospice design and to select architects through the competition.

Patients and staff from two hospices helped develop the design principles behind the brief for the competition which was held in February 2009. Five main principles were established for future design:

- The natural environment, natural materials and the elements
- Beauty, arts and crafts
- Dignity and privacy
- Legibility and comfort (including respecting time)
- Robustness and economy.

1.5 Emerging themes in design for end of life care environments

The following overarching themes have emerged from work undertaken to improve the environment of care for people who are dying, their relatives and the bereaved:

Natural environment

- The natural environment and the changing seasons have a profound effect on people, especially those who are dying
- Ideally patients should have access to gardens which provide therapeutic, uplifting, accessible spaces suitable for those who have limited mobility or are in wheelchairs. Planting should appeal to the senses including sight, hearing, smell and touch
- Views of nature from windows and doors should be maximised
- Artworks depicting nature, the use of natural materials, and natural colour schemes all help to bring the outside in
- Good natural light and ventilation, with access to fresh air, makes a real difference. Any artificial ventilation should be unobtrusive and noiseless
- Moving water can be incorporated into interior and exterior design.

First impressions

- The entrance space to the building or unit should create a good, professional first impression and a sense of reassurance, warmth and friendship with a small seating area for those who are waiting
- The function of the reception area should be clear and the area uncluttered, with notices kept to a minimum
- Information should be easily accessible, including access to the internet.

Comfort

- The overall design should be inclusive for all ages, cultures, and abilities and create a sense of welcome
- Colour can be used to enhance comfort and create a homely feel with domestic rather than institutional elements and furnishings where possible. Light levels should be adequate and capable of being adjusted when appropriate
- Elements of craft and carefully placed works of art can lift the spirits and create moments of delight and interest.

Privacy and dignity

- A range of informal spaces and private rooms should be provided for discussions with staff
- Bedrooms should provide privacy and quiet and be designed to allow the patient maximum control over their environment. Bathrooms should be as homely as possible
- Controls for lighting, curtains or blinds, heating/cooling, entertainment, internet access and the nurse call system should be within reach of the patient at all times
- Use of coloured linens or artworks can help personalise rooms and aid orientation.

Spiritual spaces

- There should be open access to a quiet, spiritual space designed to comfort and support those of all faiths and none.





Spaces for relatives and friends

- Designated spaces should be provided for relatives, with drinks on offer and access to toilets and showers
- There should be facilities, not necessarily a bedroom, for relatives to stay overnight if required.

When a death occurs

- There should be appropriate spaces for relatives to sit quietly to receive property and undertake the required administrative procedures
- The approach to the viewing facilities should be dignified
- The viewing area should be designed to be as comfortable as possible.

1.6 Steps to success

The need for a team

"The group and the leader need to have a vision and to be able to stand by that as there are times when it would be easy to give in to differing opinions and water down the quality of the refurbishment and settle for a 'safe option'."

Consultant in Palliative Medicine

Practical tips

At an early stage do something together as a team to learn how each of you see the current environment. Take some photos of the project area and take time as a team to discuss what impression they give you of the care provided.

"The diversity of the team has resulted in a positive approach to projects I have worked on since the completion of the bereavement suite with an open-minded attitude and approach to listening and incorporating many more ideas into project briefs and designs."

Senior Building Officer

Any improvement project requires a team approach. Try to involve clinical staff, estates staff and people who work in the area – for example, mortuary technicians. Select people who are enthusiastic, have a mix of skills and experience and who want to change and improve services. Try to make sure that the team has a senior mentor, preferably at board level, to support the project and help make connections.

De-clutter spaces

"De-cluttering the area, the physical space, is important, not forgetting equipment and noticeboards."

Divisional Manager

"Remove dusty fake flowers, air fresheners and candles."

Clinical Care Outreach Sister

Cluttered noticeboards, corridors and waiting spaces can give a very poor impression to patients and visitors. Many noticeboards are full of notices for staff and perhaps would be better placed away from the public eye while corridors full of unused equipment may not only be a hazard but can create an unprofessional and untidy impression of the ward.

Practical tips

Hire a skip and get everybody involved in a de-cluttering day – you will be amazed at how much can be thrown out!

Consultation and engagement

"Ask the patients and relatives – you may be surprised by the answer. We were told ventilation was the number one priority which was a complete shock. For our current project on the inpatient unit we asked the patients what they would like to improve and again ventilation of the unit and the ability to open a window came back as the main priority."

Consultant in Palliative Medicine

"Give power back to the frontline staff by asking what they would like to change – lots of NHS departments are very hierarchical with staff being too inhibited to voice an opinion."

Consultant

Establishing the needs of patients and carers is an absolute prerequisite to a successful project. They will see the current environment in a very different light to those who use it every day. Although it may seem daunting ask patients and relatives what they would like, their needs may not be complex. It may be, for instance, a reclining chair rather than a bed if they have to stay overnight or the ability to make a drink without disturbing nursing staff.

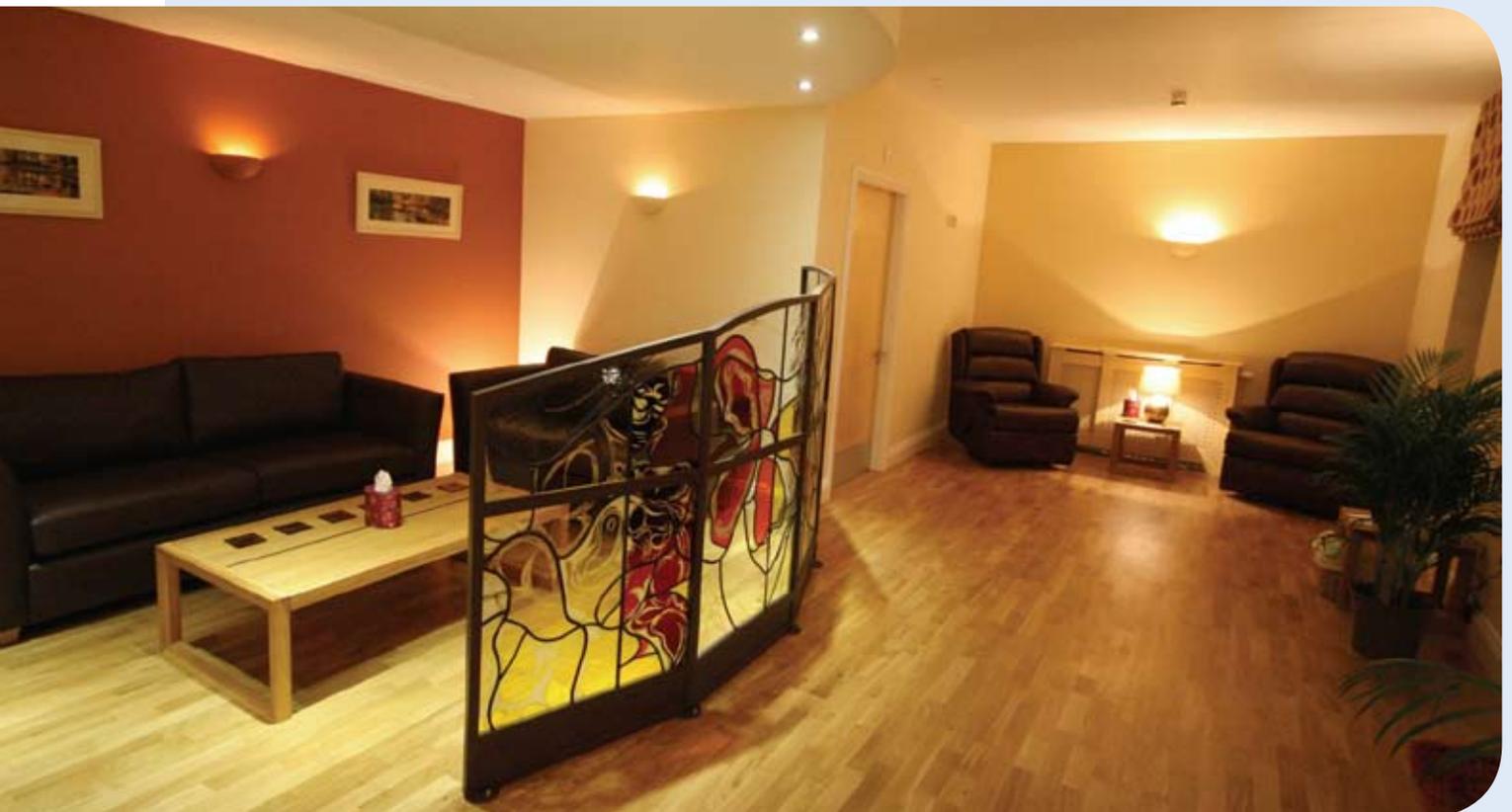
It may be helpful to have a wider group of people to act as a reference group for the project – keep on testing out your ideas with them.

Get key stakeholders, including charities and even funeral directors, involved early – they may help with funding or gifts in kind.

Don't forget to talk to staff. Some of their families may have already used, or will in the future use, end of life care services. But many others may not know about the current service provision, particularly for the bereaved.

Practical tips

If you are looking at refurbishing the mortuary you could have an allocated time when staff could visit – many will not know what is currently provided. Use the event both to publicise the service and your project.





Assuring quality and sustainability

"The quality of the building products used had to fall within the budget but the best affordable was used."

Consultant Nurse Palliative Care

"The whole attitude of the unit changed from 'it is just pretty pictures' to yes, this matters we need to carry on and refurbish the unit."

Palliative Care Consultant

Get the opinion of others not used to the environment – they will bring a fresh pair of eyes. It is often the little touches that make a real difference. Make sure you insist on high quality materials and furnishings – they do not always cost more and will stand the test of time. If you do not feel work is up to standard, say so. It is often better to have less rather than more.

Practical tips

If you cannot afford original artworks think about using large photographs. If the view is non-existent or there is no window, use a light box!

Look to the longer term

"The development of the bereavement suite led to other areas being improved. The corridor leading up to the bereavement suite was dark and dingy and it hadn't been touched for years. The bereavement suite put the corridor to shame and the CEO had it repainted and windows put in to allow light. It looks much better now."

Cancer Lead Nurse/Nurse Consultant

"At Barnet our local Brownies have planted spring bulbs in pots that they will bring in soon. Afterwards we will give them a 'clean hands' session with the glow box plus a certificate and badge. They get to be involved in their community and we can offer them education about hand hygiene, so it's mutually beneficial."

Deputy Director of Patient Experience

Giving staff and patients the opportunity to become involved in an environmental improvement project is likely to have additional benefits both to the individuals and the organisation. Many volunteer schemes and support groups have been set up as the result of projects.

Staff can become more confident about voicing their needs and more open about their patients' needs. Patients and relatives can gain real enjoyment from group activities and art workshops.

Look to future possibilities for linkage to other environmental and service improvements. Plan for the longer term and don't get bogged down.

Practical tips

Remember to maximise the project. Something that starts off as a refurbishment can lead to significant improvements in service delivery with benefits for both patients and staff.

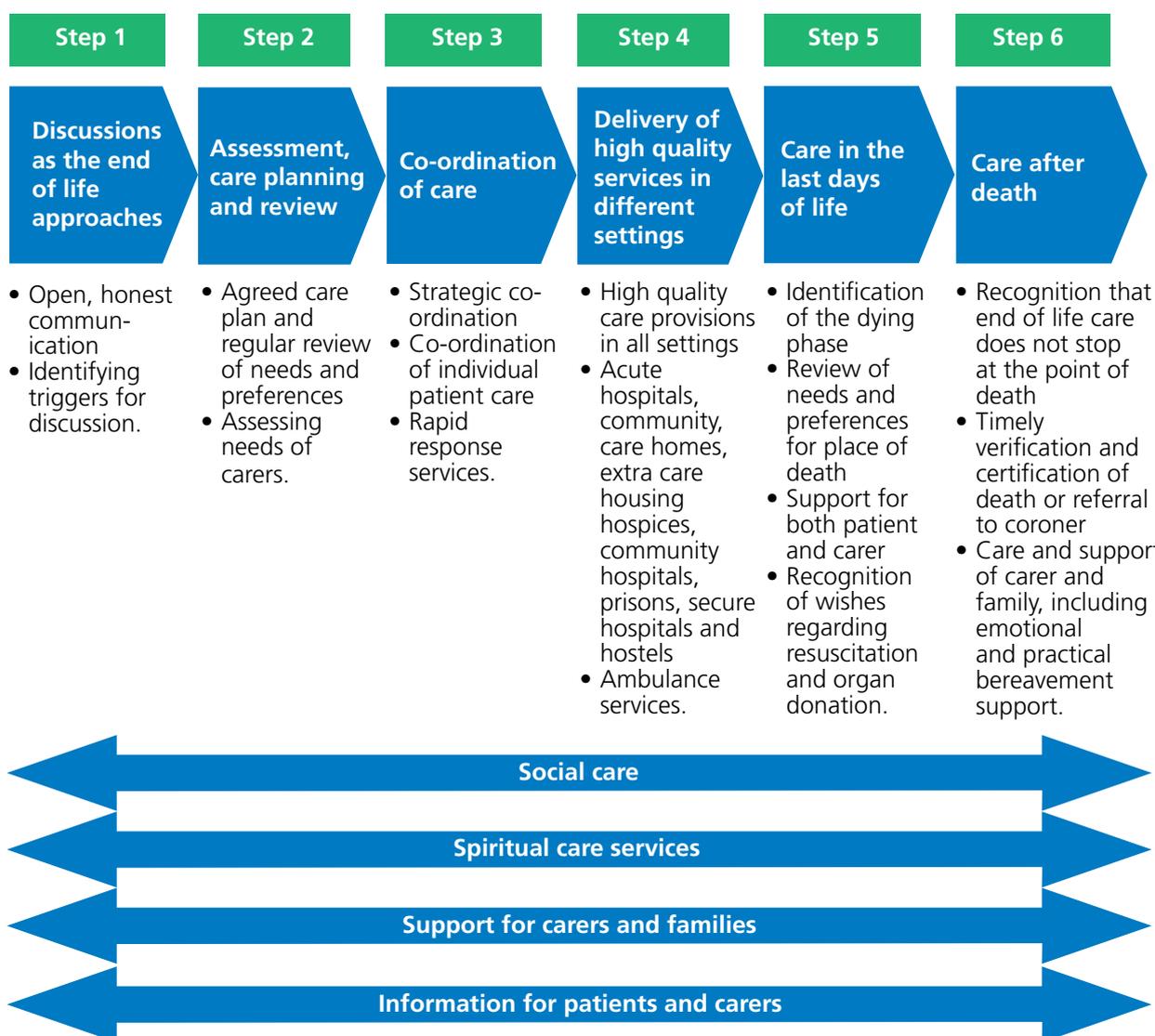
2.1 End of Life Care Pathway

A welcoming and supportive environment is an essential component of good quality care and makes a real difference to patients, relatives and the bereaved. The end of life care pathway describes six stages of care, from discussions as the end of life approaches to care after death. Many of the themes outlined in this publication are applicable to each of the six steps – for example, the need for private spaces for discussions between relatives and staff.

This part of the guide is therefore presented in a slightly different format to other *Routes to Success* publications.

Instead of being divided into six sections according to the six stages of the pathway, it looks at the pathway from an environmental perspective and is separated into four overlapping sections. These are: how environments can be created for relatives, for those receiving palliative care, bereavement centres and mortuary viewing facilities.

Each section outlines the relevant step or steps of the pathway as well as listing questions to ask yourself and top tips on how to get started. Case studies highlighting best practice are also included.



2.2 Provision for relatives

Steps 1 to 5

“Sometimes relatives could be found in their cars as this was the only private space they could find in the hospital.”

Deputy Director of Patient Experience

Relatives and friends may spend a great deal of time at the bedside of people who are receiving palliative care. However, sometimes they need to get away, even for a very short time, to relax and refresh themselves. Often their needs are not complex but provision of private spaces, facilities to make a drink or snack without disturbing staff, to have a shower and perhaps take a short nap can make a profound difference to their well being at a very stressful time.

Towards the very end of life relatives may not want to be far away from the bedside and ideally a room should be set aside for them close to where their relative is being cared for. At other times a communal relatives' facility for patients on the Liverpool Care Pathway may also offer support from other families, access to the internet to check emails and the opportunity to sit outside for a while.

Both relatives and patients should be involved, wherever possible, in discussions about environmental changes – even when they cover an early stage of the pathway.

Ask yourself

- Is there a dedicated, comfortable space for relatives to talk to staff?
- Is there somewhere private for relatives to go away from the bedside?
- Can they make themselves a drink?
- Can they make a telephone call and access the internet?
- Is provision made for them to stay overnight?
- Can they have a shower?
- Do they have access to a dedicated outside space?

Top tips

- Review underused space – for example, bathrooms – to see if they could be converted for use by relatives. Look at larger spaces – for example, dining rooms, courtyards and spiritual spaces – to see if they could be used in part to provide facilities for relatives
- Ask families what they want. Often their needs are not complex



- Think about how families will gain access to the space – for example, by key card
- Provide quiet, private, welcoming spaces, ideally with access to a garden or views of nature, and somewhere for children to play
- Use colour and artworks to provide interest and create a non-institutional feel
- Choose comfortable furniture and fittings, including sofas with footstools or reclining chairs for people to take a nap
- Provide a coffee/tea machine and perhaps a microwave so relatives can make a drink or snack
- If relatives are likely to stay for some time provide a dedicated shower and toilet
- Provide internet and wifi access so people can stay in touch.

You may also want to think about

- Making sure spaces are provided in A&E and outpatients for staff to talk privately to relatives
- Providing 'comfort packs' and herbal pillows for relatives to help relaxation and relieve stress.



Case Study



Barnet and Chase Farm Hospitals NHS Trust

The Garden Room: a private retreat for family and friends of patients receiving palliative care

The need for a dedicated space for relatives of dying patients at Barnet Hospital was brought home to Kay Laurie when three sisters revealed they had been taking it in turn to sleep in their car when they needed a break from their mother's bedside, because there was nowhere else to go.

"Space is at a premium at the hospital," explains Kay, Deputy Director of Patient Experience, "and there was nowhere apart from public spaces for families and friends to retreat for down time when someone was at the end of their life."

Given that an average of 120 patients die at the hospital each month the need for such a facility was clear. What family and friends wanted was not a bedroom – just a private space where they could rest and relax. The next issue was: where were they going to put it?

Given the hospital's space restrictions, the search for a suitable location was always going to be problematic. But eventually the project team secured an under-used hospital courtyard.

To test the water the team held a 'Room for the Day' public event in the courtyard in July 2009 to show what the new facility might look and feel like. When this proved popular it set about finding a permanent solution.

In the end it decided on an eco-friendly, contemporary cedar wood-clad building with 'living roof' and large glass

doors that could fold back to give access to the garden that had been created within the courtyard. The main room has recliner chairs as well as two sofas while an adjoining cafe space – created from the vestibule area next to the lift – houses drink-making facilities, a table and chairs as well as a PC with internet access and web cam.

The Garden Room was officially opened in October 2010 and is already proving very popular with relatives who talk of it as a "godsend" and "'a little bit of peace in the storm". "This has been a place of peace to escape from a bad dream for a few moments," said another family.

Although backed by the trust and part of The King's Fund's Environments for Care at End of Life programme, the £170,000 cost of the project has been largely met by donations from the Hospital Friends, members of the public and grants from local charities. Kay thinks this is a model that may become increasingly common in these financially straitened times.

It also makes sustainability critical. "If the project is to be sustainable we need to keep people engaged in it and the garden is key to that," says Kay. Underlining this point, all the plants in what she calls the 'Garden of Gifts' are donated and planted by volunteers.

The team hopes that the design lessons from the garden room can now be extended to the refurbishment of mortuary viewing facilities at the hospital.

Kay, who has been involved with the project from the start, is immensely proud of what has been achieved. "You live and breathe these projects," she says. "We all did a terrific amount in our own time and actually donated some items for the room ourselves. That means you really have got a stake in it. It was a long journey but it was worth it in the end."

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PART 2 continued

2.3 Delivery of high quality care

Steps 4 & 5

"There were no chairs in the hospital ward so we had to stand by the bed holding my sister's hand until she died."

Relative

Most people still die in general hospitals. Yet in many health care buildings it can be difficult to provide peaceful but fit-for-purpose institutional environments for patients on the Liverpool Care Pathway or receiving palliative care. In addition the challenge of providing well-designed spaces for those dying with dementia, whether in hospital or nursing homes, is increasing.

Studies suggest patients have mixed views about the merits of being nursed in a single room or in a multiple-bedded bay. However, what is not in doubt is that patients should, wherever possible, be offered the choice and that their privacy and dignity should be maintained throughout their care.

Palliative care patients in hospices have been keen to discuss the design features they would like included. For example, they would like suitable shelving so that photographs can be viewed from the bed, access to safes to keep valued possessions and in-room fridges for cooling drinks. The need for access to the internet and a web cam has been an increasing request as extended families may not be able to visit.

Ask yourself

- Can patients exercise control over their environment?
- Can they adjust their bed?
- Do patients have access to a television and the internet?
- Have unwelcome sounds and smells been minimised?
- Can windows be opened to provide natural ventilation?
- Can patients see the natural world from their bed?
- Are comfortable chairs provided for visitors?

Top tips

- Create a peaceful, clinical but non-institutional care environment

- Give patients as much control over their environment as possible. As well as their bed position they should ideally be able to control lighting, heating and to close blinds or curtains
- Maximise any views of gardens or landscape. It may be possible to lengthen windows to floor level or to create Juliette balconies
- Allow patients to personalise the space by providing accessible shelves for photographs and memorabilia
- Use colour and provide special bed linen and furnishings to create a non-institutional feel
- Make sure lighting is adjustable and can be varied through the day
- Give patients and relatives the chance to listen to music
- Choose artworks that will lift the spirit, provide interest and distraction
- Think about redesigning bathrooms and showers to be more inviting so patients feel encouraged to use them
- Provide comfortable seating for relatives who may stay for long periods of time.



You may also want to think about

- Providing a space relatively close to the bedside for relatives to sit while staff are with the patient
- Creating a private garden or terrace area so that the bed can be wheeled outside
- Providing a fridge for drinks.



Case Study



Leicestershire Partnership NHS Trust

A new end of life care suite for dementia patients

The Oak Room at Evington Centre in Leicester is a new purpose built facility that is helping to transform the end of life care experience for people with dementia and their relatives.

The suite, which consists of three adjoining rooms including bedroom, bathroom and lounge, emerged from The King's Fund Enhancing the Healing Environment programme but has been made possible by the contributions of local people as well as the hard work of the project team.

Evington Centre is made up of four wards which provide assessment and care for around 80 patients with dementia, explains project leader Sharon Hames from Leicestershire Partnership Trust. But in recent years the profile of those patients has changed with many more being seen at a later stage of the condition and many ending their days on the ward.

The problem was that the facilities didn't always match these changing needs. "Although nurses were praised for their end of life care there were no special facilities for this. We were nursing these patients in a fairly basic NHS single bed room."

Recognising that their facilities needed to be improved prompted Sharon and her colleagues to approach The King's Fund. In March 2009 they attended the launch of a new part of the Enhancing the Healing Environment programme, specifically focused on environments for dementia care.

It was the start of a very steep learning curve, she admits. "Our project team had never worked with each other before and to be honest we didn't know what on earth we were doing!"

They soon discovered they would also need to raise a significant proportion of the money for the £85,000 new facilities themselves. Although the Department of Health, via The King's Fund and Leicestershire Partnership contributed £30,000 each, that still left £25,000 to be raised through local donations.

They eventually achieved it but it involved feverishly hard work from the three-member project team. "The King's Fund has very high expectations and most of the work had to be done in your own time," she says. "I certainly burnt the midnight oil many times!"

Following exhaustive consultations with users, relatives, staff and the general public a design was finally agreed and in October 2010 the new Oak Room suite was opened. It consists of a large bedroom with patio doors that open out to a small private garden, flanked by a lounge with recliner and kitchen on one side and a bathroom and toilet on the other.

"One of the key challenges for us was thinking differently and moving away from that NHS culture of this is how we've always done it," says Sharon.

After the initial design had been drawn up, the team planned to omit the garden area in order to save money. "But when we consulted relatives that came out top of their list. It just shows that professionals' perspective can be very different from that of relatives and that was an important lesson."

The new suite has been open for six months now and is already having an impact. "One lady said her lasting memory was of a calm and peaceful environment. It allows patients to die with dignity, privacy and respect and the environment is key to that."

It has also been the catalyst for a number of changes in practice, she says. Ward staff now receive training in end of life care from

staff at the local hospice. Some centre staff have also been designated as end of life care advisers and an amended version of the Liverpool Care Pathway has been introduced especially for dementia patients.

The impact of the new facility is currently being evaluated by the National Institute for Health Research and its report is expected next year. But Sharon has no doubt the effort has been well worth it. "It's achieved wonderful things that would never have happened without this. I'm so proud to have been involved."

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Case Study

South Tees Hospitals NHS Trust

Creation of palliative care beds and facilities for relatives in South Tees

Over the last two years James Cook University Hospital in South Tees has transformed a traditional six-bedded side ward into a palliative care area containing four inpatient beds and two adjoining rooms for relatives.

Ward 9 caters for people with chest and respiratory diseases, many of whom receive palliative care. But because of the need to nurse patients with a high infection risk in isolation, patients who were dying sometimes did not have a side room available to them.

“That was difficult for patients, relatives and staff,” says Acute Medicine Divisional Manager Yasmin Scott. “It puts a great deal of stress on nursing staff when they feel they cannot deliver optimum care because they can’t provide side rooms for a dying patient and their family or when there is the possibility they may have to be moved out of one.” At the same time there was no private place for the family to go if they were not at the patient’s bedside.

That was the starting point for a radical rethink of the ward’s facilities at the start of 2008. It was given further momentum by a survey of bereaved families showing that what they wanted was somewhere that was homely and private where they could sit and have a cup of tea or something to eat and remain close to their loved one.

The other factor in what finally emerged was The King’s Fund’s Environments for Care at End of Life programme which the trust joined in March 2008. “We would probably have gone along the lines of doing something nice but traditional,” says Yasmin. “But The King’s Fund presented us with some very different and more radical ideas and we decided ‘yes, we can do this!’ It opened our minds to really look at different things.”

The Fund also pointed the trust towards new ways of attracting money for the project as well as making use of volunteers and publicising the project more effectively through, for instance, articles in the local press. In addition the voluntary services within the hospital funded the purchase of a range of items including soft furnishings, electric beds and pressure relieving mattresses. Further donations from local charities have provided resources on an ongoing basis.

The result is a radical transformation of what was a very traditional hospital bay. The area – now designated the division’s palliative care area – contains four larger, airier



bed areas separated by decorated glass panels rather than curtains. There is also a new ensuite toilet and a relatives’ room with drink-making facilities while an alcove across the corridor has been converted into a sitting area. The palliative care bay is accessed through an electronic pad.

The new facilities opened in August 2010. A formal survey to discover patient and relatives’ views will be completed at a later date but initial feedback has been extremely positive. It has also been welcomed by staff. “It’s so much less stressful when you have a dying patient because you know they can be accommodated in the palliative care ward,” says Yasmin.

In addition it offers greater flexibility, with dying patients from other parts of the hospital also being accommodated in the ward when space allows – as well as non-palliative care patients when the occasion arises.

The radical design has influenced the refurbishment of the rest of Ward 9, which took place at the same time as the palliative care ward, as well as the planned overhaul of the acute medicine wing. It has also attracted interest from a neighbouring trust and has helped to inform plans for a new bereavement suite and mortuary viewing facilities.

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2.4 Bereavement suites

Step 6

"The beautiful environment facilitates the delivery of my role and the feedback from the bereaved has been immediate and very positive."

Bereavement Co-ordinator

For many people the distress of bereavement can be made worse by the need to return to the place where their loved one died to collect the death certificate and any belongings. This is especially so if they have to return to the clinical atmosphere of a ward area. The opportunity to thank staff may be welcomed but the prospect of seeing another patient in the bed where their loved one died will not be.

However, in smaller buildings such as hospices and care homes there is usually a dedicated space for the bereaved so they do not need to revisit bedrooms or wards. But this is not the case in many general hospitals where the bereaved may still have to return to the ward or wait in public corridors near the general office to collect belongings and certificates. Although more hospitals are providing integrated bereavement services, the space provided is not always satisfactory.

Where bereavement suites have been created one unexpected outcome has been that the relatives have started calling in for other things. These might include information about what happens after somebody dies, pre-bereavement counselling or just the opportunity to sit in a peaceful space away from the busy hospital.

Ask yourself

- Is clear information given to people about administrative arrangements following the death of a loved one?
- Is there an appointments system?
- Is dedicated parking provided for the bereaved?
- Do people need to visit more than one area in the building to collect property and certificates?
- What kind of bags do you use for the deceased's property?
- Can deaths be registered on site?

Top tips

- Look at how you can create a clear visual branding – for example, a special logo – for bereavement information and services. This will help relatives to make links between spaces even where they are in a different part of the hospital. Make sure that the bereavement office, suite or centre is well signposted
- Ensure there is a private space, preferably near to an entrance where dedicated car parking is provided, for people to wait
- Choose comfortable and appropriate furnishings to create a welcoming, non- institutional environment. Think about the use of natural materials and colours and artworks
- Provide sufficient space to accommodate more than one family group as well as tea/ coffee-making facilities
- Make sure there is some activity provided for children and younger visitors.



You may also want to think about

- Replacing plastic patients' property bags with a more dignified alternative
- Providing access to, or views of, a private outdoor space or using artworks to offer views of gardens or landscapes
- Working with the local authority to providing registration services on site. Don't forget you will need a separate office and two entrances if both births and deaths are to be registered on site.



Case Study



Southend University Hospital NHS Foundation Trust **How Southend's new bereavement suite is making a real difference**

The new bereavement suite at Southend Hospital has a soothing effect on clients and staff from the moment they walk in, says Palliative Care Lead Nurse Wendy Warner. "It just feels so calm and peaceful as soon as you go in," she says. "It is also south facing so the light alters during the day and can be fantastic."

The new suite was opened in November 2009 and was the culmination of a long battle to improve after death services at the hospital. Until then relatives had to collect their loved one's death certificate and belongings at the general office in the hospital's main entrance. It was not uncommon for visitors to the hospital to walk past weeping relatives.

Everyone at the trust acknowledged that the service was inadequate, says Wendy, but nothing had moved until the launch of The King's Fund's Environments for Care at End of Life programme in 2008. That provided the catalyst not only for a new suite but also for the appointment of a bereavement co-ordinator, funded by the trust.

There were still a number of obstacles to overcome. The chosen accommodation, in the middle of the hospital, had previously been a consultants' rest room. Despite being little used, the change of designation involved a "big cultural shift", says Wendy. Some staff also voiced concerns that visitors to neighbouring wards might be upset by a prominent bereavement area.

However, the overall response to the new accommodation has been very positive – especially from relatives. The suite, which has a local sea design theme, consists of three rooms – a waiting area with comfortable chairs and drink-making facilities as well as two adjoining offices.

One of these offices is a 'one-stop shop' where relatives can complete a range of activities such as registering the death, cancelling benefits and so on. The other is used for appointments with the bereavement co-ordinator who is able to return property and offer advice and support as well as referring a relative on to counselling where necessary.

The role of the co-ordinator has expanded significantly since it was first introduced, says Wendy. In addition to offering help and advice in the immediate aftermath of a death, she is increasingly called in by ward staff for advice to provide support to families before a patient dies.

"When we initially looked at how staff felt about caring for the dying and bereaved they often felt inadequate but this service increases their confidence and helps empower them."

Despite the progress, some issues like collecting notes from the wards and use of office staff still have to be developed, she says. The trust has also had to scale back its plans for a new mortuary because of funding shortages but it is still hoped to update both this and the emergency department viewing room in the near future in line with The King's Fund's design principles.

The new suite has made a big difference to the quality of after care provided to bereaved relatives, says Wendy. Not only is the experience now more private and less bureaucratic, it also makes people feel more valued and appreciated.

"I don't think it's simply an environment change because obviously there needs to be a funded service as well – but the two go hand in glove," she says. "The bereavement suite is right at the heart of the hospital and can't be ignored. End of life now has a higher profile. That's what we wanted."

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2.5 Viewing Rooms

Step 6

“99% of those visiting the facilities now mention how lovely the environment is and those who have visited prior to the refurbishment said how grateful they are that the work has been done.”

Directorate Senior Nurse – Surgery

The surroundings in which people see a loved one for the last time leaves a very powerful memory not only of the person who has died but also of the environment in which they have been cared for.

Although figures suggest that the number of families wishing to view the deceased in hospitals is increasing, mortuary viewing areas are often undervalued and staff can feel embarrassed by the environment they work in. This, together with the reluctance of staff to accompany the bereaved, can mean viewings in the mortuary are sometimes actively discouraged.

The journey to the mortuary, which is often located at the back of the hospital, can give a very negative impression while waiting and viewing rooms can often feel very outdated, airless and unwelcoming. Many ECEL team members who have worked on improving viewing areas have called this their “walk of shame”.

Staff, including board members, may not have visited the mortuary. It may be helpful before the project starts to give them the opportunity to do so. It is also important to ensure that staff, including porters, nursing and mortuary staff, junior doctors and local undertakers, are asked for their views.

The following questions are also important in relation to other areas where viewings take place – for example, in a hospital accident and emergency department or in the hospice room where the patient died. (See also *Environments for Care at End of Life: Newham Case Study* – DVD available from the National End of Life Care Programme).

Ask yourself

- What is it like to walk to your mortuary? Could it be classified as a “walk of shame”?
- Is there a private waiting space where people can have a drink? Are toilet facilities provided?
- How does the viewing room feel? Is it well lit and how does it smell?
- Can you hear noise from the mortuary beyond?
- Is the area outdated, cluttered and depressing? Are there heavy curtains, plastic flowers, air fresheners and half-burnt candles?
- Are there comfortable chairs, particularly for older people?

- Is there suitable artwork?
- Is there somewhere private for people to go to collect their thoughts after the viewing? Can they get a breath of fresh air?

Top tips

- Ensure that the journey to the mortuary, the entrance, the waiting and viewing areas are uncluttered and as unclinical, welcoming, pleasant and private as possible. Ensure there is a separate entrance for undertakers
- Ensure there is appropriate private space for people to wait before viewing and to collect themselves afterwards. Use glass film if you need to obscure windows to aid privacy
- A Disability Discrimination Act-compliant toilet with mirror should be provided. Ideally tea/coffee-making facilities should also be made available



- Consider getting specialist advice about adjustable lighting over the bier or bed in the viewing area. Make sure noises from the mortuary cannot be heard and obscure the mortuary doors

- Furnishings and furniture should be contemporary and in good order and seats with arms should be provided for older people. Artworks should be in place to help distract and lift the spirits

- People may wish to have a sight of the deceased before entering the viewing area to ease the transition. Think about providing a small window in the entrance door with a blind or a partially obscured window



- The viewing room should be culturally sensitive to the community it serves. Appropriate space should be made available for any religious observance following death. If religious artefacts are requested by relatives make sure they can be stored away when not needed.

See also tips for bereavement suites (2.4)

You may also want to think about

- Providing dedicated car parking for the bereaved
- Providing a garden or courtyard space nearby for people to use before or after a viewing
- Providing a card on which people can write messages to leave with the deceased if they wish.



Case Study

Luton & Dunstable Hospital NHS Foundation Trust A redesigned entrance and mortuary viewing suite

Mo Kermack, Practice Development Nurse, Critical Care at Luton and Dunstable Hospital Trust, recalls how one visitor to the hospital's old mortuary viewing room confided that he had found the journey there so harrowing he couldn't bring himself to go in to view his loved one at the end.

"It had been so horrifically bad that he couldn't imagine what the viewing room itself would be like," she says.

That experience was far from unique. It was not only that the waiting and viewing rooms were rather dark and impersonal, the route there was through one of the pathology entrances. People had to pass along a walkway that was a favourite roosting area for the many pigeons that lived on the site and was very difficult to keep clean. It also offered little privacy since visitors could be seen by those using the adjoining café area.

All this helps to explain why when the hospital first approached The King's Fund's Enhancing the Healing Environment programme in May 2008, an overhaul of the mortuary bereavement facilities was very much top of its list.

Initially, recalls Mo, the plan was simply to refurbish the walkway. But once the team – consisting of Mo, the chaplain, the estates manager, the midwifery matron and the mortuary manager – had discussed matters in more detail with The King's Fund they decided they should be more ambitious and take in the viewing facilities as well.

"That's one of the things you get from The King's Fund – to think differently," says Mo. "They convince you that you can do whatever you want to achieve. So we weren't going to take 'no' for an answer!"

But that was also when the hard work began. Initially the team was meeting once a month but as the pace quickened it became every week. The team consulted hospital staff, including nurses, porters and mortuary staff, as well as local funeral directors. It also used the hospital's website and the local radio and press to publicise the project and keep people abreast of developments.

The final result – which has cost £104,000 and was officially unveiled in October 2009 – has if anything surpassed people's expectations, says Mo.



The viewing suite is now accessed via a covered pigeon-free walkway, which has been screened from the café using frosted glass and bamboo planting. A door leads into a small garden with a wooden bench and a small water feature.

Internally, the two main rooms have been reversed. The space that was the viewing room now consists of a comfortable, modern waiting room with commissioned artworks and offering views of the garden beyond. The new viewing room ceiling has been designed to focus the eye on the bier, with an integral, adjustable lighting system.

Both staff and users have responded positively to the changes and it has given those who use it regularly – especially mortuary staff and porters – a renewed sense of ownership and pride, says Mo. "People love it – which may sound strange but it's very peaceful and calm and quiet."

She also hopes that in future parents whose babies have died will be able to view their children here rather than in the delivery ward. The local group of the Stillborn and Neonatal Death Charity (Sands) is supporting the project and has donated a cot and bed linen.

She feels immensely proud of what she and the team have achieved. "In fact," she says, "I still go down there regularly just to check it out. It was definitely worthwhile and I would recommend that process to anyone."

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Case Study

Salisbury NHS Foundation Trust

Centralisation of bereavement services and redesign of mortuary viewing area

Staff at Salisbury District Hospital used to refer to the journey relatives had to make between the bereavement office and the mortuary viewing facilities as the “walk of shame”.

It involved a long, gloomy walk along a basement corridor populated by clinical waste bins with the ever-present possibility of bumping into an undertaker.

Sam Goss, the Bereavement Suite Manager, who has headed a major revamp of the hospital's bereavement and mortuary facilities over the last two years, says staff felt they had to begin the delicate business of tending to distressed friends and family with an apology.

This was not only because of the journey itself but also because of the facilities at either end, from a reception area that was also part of the PALS office, to the stark, institutional viewing room.

“It all made our job a heck of a lot more difficult,” he admits. “It doesn't matter how well someone has been cared for and good a death it was, if we get it wrong at the end then their last memory of their loved one is of that, and that's what they'll talk about in relation to the trust. It can wipe out all the good work that's gone before.”

All that changed when Sam and his colleagues teamed up with The King's Fund's Environments for Care at End of Life programme in 2008. Their first plan was a fairly modest one to redecorate and introduce new furniture, artwork and extra facilities.

But once the Salisbury team started discussing the possibilities in more detail, their thinking became more ambitious, says Sam. They realised this was a chance not only to improve the environment but to integrate bereavement and mortuary services within one building and raise the profile of after death care within the trust.

That would also be a lot more costly. The original plan was to rely on the £30,000 grant from the Department of Health, via The King's Fund, topped up by £10,000 from the trust but now they had to find an extra £100,000.

Sam and his team raised the money from local hospices, charities and other bodies and work on a major revamp of the mortuary building began in August 2009 and was completed by October.

The result is a new purpose-built structure that incorporates the bereavement office, a waiting area and



the viewing room under one roof. A light, airy reception area together with dedicated parking makes the building both welcoming and private. And the other rooms, decorated with original artwork and textiles and simply furnished, give a calm, non-institutional feel.

The changes have transformed the experience of many bereaved relatives and friends. They can attend the bereavement office in pleasant, private surroundings, collect the death certificate and their loved one's belongings and then proceed to the viewing suite if they wish.

“In the past they couldn't relax with the deceased because they felt they had to go in and then leave,” says Sam. “Now they say it's made things so much easier. They can sit down and have a chat with the staff and take some weight off their shoulders. They can have a cup of coffee and if they wish they can see their loved one and spend time with them – it's a cathartic process.”

The revamp is already having an impact elsewhere. The hospital's A&E department has redesigned its viewing area along similar lines and a number of other trusts have expressed interest in the Salisbury model.

The project involved a lot of hard work, says Sam, but it has been worth it. “It's done wonders for me, not only as a manager of a bereavement service but also as an individual. It has helped focus me on what we can do.”

More information:

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1. Useful resources

Documents

A place to die with dignity: Creating a supportive environment
NHS Estates, May 2005

End of life care strategy: quality markers and measures for end of life care, DH (2009). http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_101681

Environments for care at end of life: evaluation of The King's Fund's Enhancing the Healing Environment Programme.

University of Nottingham, 2011

www.nottingham.ac.uk/nmp/research/groups/src/index.aspx

Gold Standards Framework

<http://www.goldstandardsframework.nhs.uk>

Improving environments for care at end of life.

The King's Fund, 2008

<http://www.kingsfund.org.uk/environment>

Improving the patient experience: Environments for Care at End of Life

The King's Fund, 2011

www.kingsfund.org.uk/patientexperience

Liverpool Care Pathway of the Dying patient (LCP)

http://www.mcpcil.org.uk/liverpool_care_pathway

National End of Life Care Strategy, DH (2008). http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277

Principles of Hospice Design and associated Environmental Design Audit Tool

The Prince's Foundation for the Built Environment and The King's Fund, 2010

Websites and other materials

NHS End of Life Care Programme

<http://www.endoflifecareforadults.nhs.uk>

Help the hospices

www.helpthehospices.org.uk

The King's Fund

www.kingsfund.org.uk

Gold Standards Framework

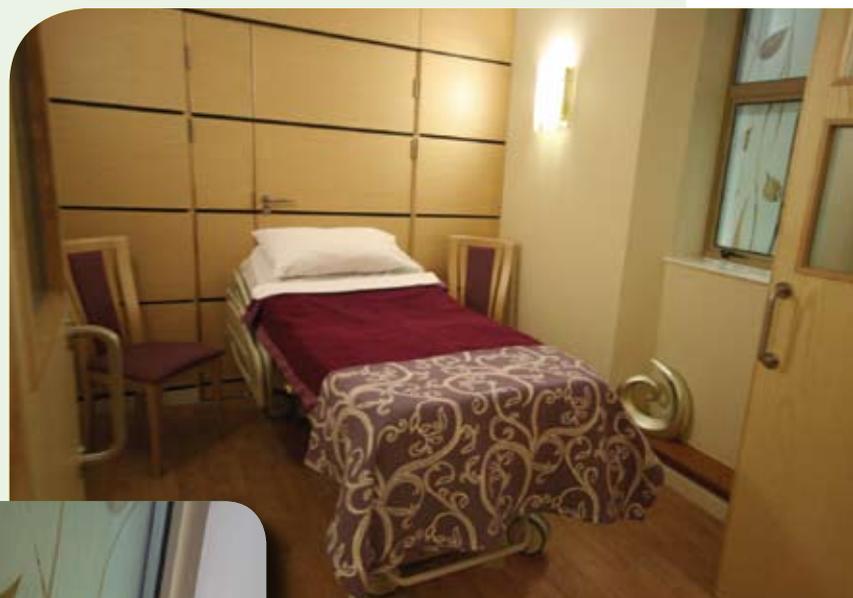
<http://www.goldstandardsframework.nhs.uk>

Liverpool Care Pathway of the Dying patient (LCP)

http://www.mcpcil.org.uk/liverpool_care_pathway

Environments for Care at End of Life: Newham Case Study DVD

Available from National End of Life Care Programme (see above)



2. Recommendations on mortuary design

The University of Nottingham was commissioned by the Department of Health and The King's Fund to undertake an evaluation of the Environments for Care at End of Life Programme (*Environments for care at end of life: evaluation of The King's Fund's Enhancing the Healing Environment Programme*, University of Nottingham, 2011).

As requested by the Department of Health, mortuary viewing facilities were a key focus of the evaluation case studies in order to inform future policy.

As part of its assessment of mortuaries, the evaluation team highlighted some key recommendations for consideration by the Department of Health as part of the review (see the NHS Estates guidance *Facilities for Mortuary and Post-Mortem Room Services*, NHS Estates 2005). These recommendations, which are taken from the University of Nottingham's evaluation report, could equally apply to organisations who may be considering refurbishing their current mortuary viewing rooms.

Advice on future mortuary design

- **Architecturally:** To be successful, a space needs to have a stylish contemporary feel without becoming too self-conscious or overbearing. The best spaces achieve a reassuring atmosphere of calm contemplation that is culturally and religiously neutral, which is highly appropriate for the kind of diverse communities that most hospitals have to serve.
- **Location, entrances and signposting:** Where space allows, create a separate outdoor access point to allow for dedicated car parking and a more private reception area, away from the noise and activity of the main hospital entrance area. Use individual signage, distinct from the standard hospital design, to reduce the institutional feel of the visit.
To maintain the quality of experience for the visitor across the range of end of life services, where possible, avoid separating the bereavement services suite and the mortuary viewing facility. Instead, locate these close together, and make sure they have a consistent standard of decor, lighting and furnishing. (See NHS Estates 2005, paragraphs 4.1 and 5.3.)
- **Outdoor space:** Where possible, include a small 'private' garden area in the entrance to and/or exit from the bereavement facility that can be used by the visitor as a relaxing transitional space.
- **Body viewing suite:** Create a simple sequence of distinct spaces to allow for a suitable transition either side of the body-viewing experience. Where possible, avoid

the need to backtrack through the reception area – for example, by using a one-way circulation route that may involve exiting through a garden or courtyard area, when available. This will avoid the possibility of interrupting another family making their way into the viewing facility. (See NHS Estates 2005, paragraph 5.6.) Make sure that the sequence of spaces from reception to body viewing avoids crossing 'clinical' corridors, such as the staff route to the mortuary, where bodies may be in the process of being moved. This will avoid any disruption to the atmosphere of the viewing sequence by a sudden return to 'standard' hospital decor. High-quality furniture and finishes are recommended, with a broadly light and neutral feel. Give consideration to the use of 'accent' features such as individual art or craft works, coloured or stained-glass windows, and a decorative textile pall.

- **Viewing room:** Use top-lighting, whether natural and/or artificial, to provide a strong sense of focus within the body viewing area. An emphasis on light from above, and from concealed sources, can help create a calm and contemplative atmosphere, as well as a sense of being in an 'in-between' realm – a quality that most visitors find appropriate for this kind of experience. Avoid strong side-lighting and any possible views in or out.
Access doors from the mortuary to the viewing rooms can be subtly disguised within timber panelled walls, curtained, or may be left visible. In each case, high-quality natural finishes, such as solid wood or wood veneers, are preferable. (See NHS Estates 2005, paragraph 5.10)
- **Environmental conditions:** Within the body viewing area, it is important to exclude any extraneous noise from adjacent spaces, such as the body-handling and mortuary areas. However, some low-level background noise, such as from the environmental systems, is generally acceptable.

Use negative air pressure, created by extract ventilation in the body viewing space, to ensure that odours from the mortuary do not escape into the waiting and reception areas. However, take care to ensure that air extracted from the body viewing space is replaced from the waiting and reception areas (in other words, is pre-conditioned) rather than being drawn in directly (and potentially cold or damp) from outside. Good air-seals around the access doors to the body-handling area and any outside doors and windows will help to achieve this.

The temperature and environmental conditions in the body viewing space should be as close as possible to those in the reception and waiting areas.

3. List of participating organisations and projects

Thanks are due to the teams from the 20 organisations who participated in the Environments for Care at End of Life programme who have provided the majority of the information which forms the basis of this guide and the case studies. The programme was commissioned and funded by the Department of Health as part of its work to support implementation of the end of life care strategy in England.

Organisation and project site	Project
Barnet & Chase Farm Hospitals NHS Trust Barnet Hospital	The Garden Room – creation of a relatives room and garden
Cambridge University Hospitals NHS Foundation Trust Addenbrooke's Hospital	The Perry Suite – creation of centralised bereavement suite and refurbishment of relatives room, accident and emergency department
East Kent Hospitals University NHS Foundation Trust Queen Elizabeth the Queen Mother Hospital	The Beresford Suite – provision for relatives of patients at the end of life
Frimley Park Hospital NHS Foundation Trust Frimley Park Hospital	The Time Garden – redesign of courtyard garden for palliative care patients and relatives
Lancashire Care NHS Foundation Trust Frank Gardham House	Thyme and Space Garden – redesign of garden to provide accessible walkways and sensory garden areas
Liverpool Women's Hospital NHS Foundation Trust Liverpool Women's Hospital	The Mulberry Suite – creation of palliative care suite including relatives room
Luton & Dunstable Hospital NHS Foundation Trust Luton and Dunstable Hospital	Refurbishment of entrance to and mortuary viewing facilities including creation of garden
Newham University Hospital NHS Trust Newham General Hospital	Redesign of main mortuary viewing area and redecoration of accident and emergency room used for viewing
North Bristol NHS Trust Frenchay Hospital Southmead Hospital	Redesign of mortuary viewing facilities and creation of gardens on both hospital sites
Northampton General Hospital NHS Trust Northampton General Hospital	The Evelyn Centre – creation of a bereavement centre
Northumbria Healthcare NHS Foundation Trust Wansbeck General Hospital	Wansbeck Oasis – creation of communal relaxation area for relatives and palliative care patients
Nottingham University Hospitals NHS Trust Hayward House	Refurbishment of day care area and conservatory
NHS Portsmouth Jubilee House	Redesign of main entrance and reception and creation of a relatives room
Salisbury NHS Foundation Trust Salisbury District Hospital	Redesign of mortuary areas including creation of bereavement suite
Shropshire County Primary Care Trust Bishop's Castle Community Hospital	Creation of palliative care and adjoining relatives rooms with courtyard garden
South Staffordshire & Shropshire Healthcare NHS Foundation Trust St George's Hospital	Creation of palliative care and relatives suite
South Tees Hospitals NHS Foundation Trust The James Cook University Hospital	Creation of palliative care beds and relatives room
Southend University Hospital NHS Foundation Trust Southend Hospital	Creation of a centralised bereavement services suite
York Teaching Hospitals NHS Foundation Trust York Hospital	Creation of a centralised bereavement services suite
HMP Isle of Wight (formerly HMP Albany)	Creation of two enhanced care/palliative care rooms and garden

www.endoflifecareforadults.nhs.uk

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