# IMPROVING ENVIRONMENTS FOR CARE AT END OF LIFE

Lessons from eight UK pilot sites

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# About the authors

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**Hedley Finn** is design consultant to the Enhancing the Healing Environment Programme and has been a major contributor to the programme since its inception. As well as having undertaken assignments for international clients such as Vodafone and Barclays Bank, he also works as a communications consultant for various NHS trusts and other organisations such as the Camelot Foundation. He is the founder and Chair of Radio Lollipop and was appointed MBE in 1992 for his work for charity.

# Acknowledgements

# Summary

This report presents work to improve the environment of care for those who are dying, bereaved or deceased. Eight projects were undertaken by teams from hospitals and hospices in England and Scotland, and the programme was led by the King's Fund and supported by the charitable trusts associated with each participating organisation.

The work is an adaptation of the King's Fund's Enhancing the Healing Environment (EHE) programme. This programme has already worked with 130 teams from 119 NHS trusts, 2 hospices and 5 of Her Majesty's prisons. More than 1,500 staff and patients have been involved in improving their health care environment.

The programme encourages and enables local teams to work in partnership with service users to improve the environment in which they deliver care. The programme 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 their patient environment. Throughout our work on the environment of care, one theme has remained constant – the need for health care settings that make patients feel cared for and staff feel valued.

Section 1 of this report presents a literature review of the evidence for improving end-of-life environments. Section 2 gives a short description of each project working to improve an environment of care for those who are dying, bereaved or deceased. Section 3 provides an analysis of the lessons learnt across all the sites. Section 4 gives findings from a consensus-building exercise with all the teams and experts in end-of-life care, and Section 5 summarises a number of lessons from this early work and suggests further areas for development and evaluation.

The following are the key recommendations arising from this pilot programme.

*As a result of the literature review and our practical experience we recommend* that the Department of Health and other organisations that fund academic research call for and support further research into how spaces unique to end-of-life care should make people feel; on the use and acceptability of language and signage related to end-of-life care environments; on how best to involve dying people and bereaved relatives in the design and delivery of end-of-life care services; and on the need for designated palliative care facilities in acute hospital settings.

*As a result of our practical experience we recommend* that all the settings within which end-of-life care occurs provide:

- a room where patient and family can be taken for confidential discussions
- the option of single room accommodation designed to engender a feeling of homeliness where patients retain control over their environment
- informal gathering spaces and places where families can meet, confer and talk with care staff
- guest rooms where close family or friends can stay overnight with facilities for catering and internet access
- appropriate places for 'viewing' the deceased.

*Our practical experience also leads us to recommend* that all health service providers include care of the dying, bereaved and deceased in corporate induction programmes for all staff and that professional training for all staff groups should include material on the impact of the environment in end-of-life care.

*As a result of our consultative conference, considering the issues raised by the work, we recommend* the Department of Health should develop national standards for the environment for end-of-life care, significantly increase investment in these environments and ensure that policy and practice development enables everybody to make choices about where they would prefer to die and to revisit that choice as their condition changes.

# Foreword

In 2004 NHS Estates asked their Design Brief Working Group, an interdisciplinary group set up to study subjects related to health care design, to consider the hospital environment where people die. Their report *A Place to Die with Dignity: Creating a supportive environment* (NHS Estates 2005) was relevant for all those involved in end-of-life care.

This report informed us that the places where people die, where families are counselled after bereavement, and where friends and relatives view the bodies of their loved ones are often neglected. Given our experience working to enhance the healing environment across the NHS, this report prompted us to consider a specific pilot programme to learn what might be done to improve the environments for care at the end of life.

In 2005 the King's Fund approached the NHS Charities Association to ask if any of their member charities would be willing to work in partnership with the King's Fund and their NHS trusts to fund a pilot Enhancing the Healing Environment (EHE) programme focusing on environments for care at the end of life (ECEL). In January 2006, in partnership with six NHS trusts, supported by their charities, and two Marie Curie Cancer Care hospices, the pilot programme was formally launched.

The eight projects that came out of this were undertaken by teams from hospitals and hospices in England and Scotland. Half the projects focused on improving mortuary facilities, possibly indicating the generally poor state of these facilities in the NHS. The work at all sites was influenced by a literature review of the evidence base, which identified the characteristics of a good environment for care at end of life. The authors present a summary of this literature review in Section 1.

As the work started, the need to improve end-of-life care has become a matter of intense interest to those who shape policy, as well as to the many clinicians who provide services at the end of life. The development of a Department of Health end-of-life strategy for England (to be published in 2008) and the review of end-of-life services as part of the London health care review exercise commissioned by NHS London and led by Lord Ara Darzi during 2007, are but two examples of the growing recognition of the need to improve end-of-life care.

The Department of Health support for the launch of a national roll-out of this programme to include 20 further end-of-life environments across the country is testimony to the way in which the teams involved in this early work have demonstrated a vital and positive impact on care through their work. Four of the projects in this pilot programme were chosen as case studies where an action research approach was used to identify the early lessons being learnt.

The learning is already important. Given the extension of the programme up and down the country, the forthcoming strategy, and the continued work on end-of-life care as part of the national NHS next stage review, I believe this publication will prove to be a valuable and timely resource.

Sir Cyril Chantler
*Chairman, King's Fund*

# Introduction

The Enhancing the Healing Environment (EHE) programme was launched by HRH The Prince of Wales, President of the King's Fund, in 2000, as part of the King's Fund's activities to mark the millennium. By spring 2008 150 teams from 138 NHS trusts, 2 hospices and 6 of Her Majesty's prisons will have joined the programme and more than 1,500 staff and patients have been involved in improving their health care environment.

The aim of the programme is to encourage and enable local teams to work in partnership with service users to improve the environment in which they deliver care. The underlying ethos is that any changes must promote patient well-being and foster a healing environment.

The programme consists of two main elements:
- development programme for a nurse-led, multidisciplinary trust team
- a grant for the team to undertake a project to improve their patient environment.

The development programme equips teams with the knowledge and skills that they need to undertake their projects, particularly in fostering co-operation and engagement with patients and the public. Team members have the opportunity to explore practical ways in which the health care environment can be improved by the use of colour, light, art and design.

Each trust could choose the area in which it wished to undertake its project provided that: there would be a physical improvement in an area used by patients; they could demonstrate user involvement throughout the project; and their scheme represented high-quality design standards and good value for money.

Two independent evaluations of the programme were published by the Department of Health. The Medical Architecture Research Unit (MARU) was jointly commissioned by NHS Estates and the King's Fund to evaluate the acute and mental heath schemes in London (NHS Estates and King's Fund 2003). Its report highlighted the way in which many projects bring a sense of normality to the hospital environment:
- creating a sense of welcome and reassurance on arrival
- providing garden retreats that give contrast to the pressurised internal space of the hospital
- designing social spaces that provide dignified and comfortable places for meeting relatives and friends away from the clinical environment.

The evaluation, undertaken by the York Health Economics Consortium in partnership with RKW Healthcare Strategists (Department of Health and King's Fund 2006), highlighted the significant benefits for patients, staff and organisations in investing in the EHE model of team-based projects led by clinical staff in partnership with service users.

Without exception, the impact of the EHE programme in the participating trusts has extended beyond the individual projects. The programme has supported the individual development of team members, innovative new approaches to patient involvement and the formation of closer links with local communities, as well as having a major impact on the development of major PFI (Private Finance Initiative) schemes.

## Origins of the ECEL programme

St George's Hospital in London was one of the first trusts to join the EHE programme in 2000. As part of their project the team chose to improve the room used by relatives for viewing the body of a relative or friend who has died on their way to hospital or in the accident and emergency department (A&E). The staff recognised that this room did not create the right atmosphere and wished to improve the room radically using colour, light and stained glass. The redesigned and refurbished room now provides a sensitive, quiet and deliberately non-denominational room for relatives. If the relatives wished, religious artefacts could be placed in the small wall alcoves. The specially designed window allows light into the area, but screens it from the ambulances parked outside and gives privacy to those using the room.



VIEWING ROOM (BEFORE)
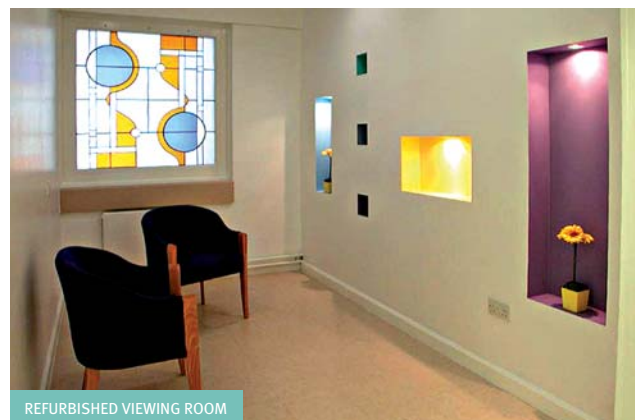
REFURBISHED VIEWING ROOM

As a direct result of the project the clinical staff also reviewed their procedures for caring for those who have died and those who are bereaved in the department. The trust has now gone on to redesign its main viewing facility and has developed a garden for people who have been bereaved next to the mortuary area. The A&E viewing room project, which cost under £5,000, provided an early example of how a relatively small environmental improvement could improve the care given to people who have been bereaved. This small project demonstrated that the EHE approach could improve end-of-life care.

When NHS Estates published their report *A Place to Die with Dignity: Creating a supportive environment* (NHS Estates 2005), it alerted us to a wider need to improve environments for those who are dying, bereaved or deceased. The objectives of this 'pilot' were to test whether the EHE programme could be adapted to these sensitive health care environments and achieve a positive impact, not just on the environments for those who are dying, bereaved or deceased, but also on the individuals and organisations who care for them. While retaining the ethos of the programme, the pilot study adapted the EHE

approach – for example, by including faith leaders in many of the project teams. A mix of team leaders was encouraged, with most teams led by nurses or midwives although team leaders also included bereavement and commissioning officers. Many other professionals and estates representatives were included in the teams.

In 2006, the pilot programme, consisting of a partnership with six NHS trusts, supported by their charities, and two Marie Curie Cancer Care hospices, was formally launched at an event attended by HRH The Prince of Wales, President of the King's Fund, at St James' Palace.

When this work began, there was a weak evidence base. It is hoped that this report will start to build greater understanding of the importance and potential positive role that environment can play in improving end-of-life care. It is part of an ongoing commitment by the King's Fund to ensure a virtual cycle of demonstration and reflection, so that the next stage of this work can substantially add to the currently limited knowledge in this area.

# 1 Literature review

The review that informed the pilot projects sought to identify literature describing the impact of the environment on end-of-life care. The most striking finding was the relative lack of research literature. Nevertheless, there are some significant pointers towards positive therapeutic environments; these include the value of creating home-like environments, incorporating natural light and natural elements in the design, and ways for the patient and carers to control lighting, artwork and noise.

## An ideal environment?

People die in many places, and patients receiving care at the end of their life may be found on any ward or unit (Shipman 2005). End-of-life care is given in all inpatient service areas including critical care environments, accident and emergency departments (A&E), mental health wards, areas dedicated to learning disability services, children's and maternity settings, and ambulances (NHS Estates 2005).

The literature tells us much about those aspects of the environment that are not conducive to end-of-life care including: noise, lack of privacy, crowded rooms, lack of appropriate seating for patients such as electric recliner chairs and lack of amenities for families who are staying (Shipman 2005; Kayser-Jones *et al* 2006). It is widely acknowledged that there may be particular issues in designing a therapeutic environment for children, patients dying from illnesses other than cancer, and people from different cultural and ethnic backgrounds (Secretary of State for Health 2004; Wilson 2004). However, the literature provides few practical and positive examples of good environments from which to learn.

When it comes to providing high-quality end-of-life care, acute general ward areas pose particular difficulties. Nurses on general medical wards report that the physical surroundings reduce the quality of care that they are able to provide to dying patients. These environmental impediments include the lack of private patient rooms, an absence of telephones from patient rooms and drab décor (Thompson *et al* 2006).

### Homeliness

The importance of creating a home-like, peaceful environment for end-of-life care has frequently been emphasised (Furman 2000; Brazil *et al* 2004; Oates 2004; Silver 2004). A home-like feeling can be enabled by allowing patients to bring in personal possessions to 'individualise' their space (Faber-Langendoen and Lanken 2000; Chaudhury *et al* 2003; Lawson *et al* 2003; Finch 2005; NHS Estates 2005; Schweitzer *et al* 2006). The use of art is also thought to humanise the health environment (Coats 2004). As the US Institute for Healthcare Improvement (2006) notes: 'In the past 30 years, hospitals have done a good job in 'de-medicalizing' the childbirth experience. They should aim to do the same for the dying experience.'

## The case for specialist beds

Research has demonstrated that patients in single rooms are more satisfied with the hospital environment, their interactions with staff and overall quality of care. Being looked after in a single room enables greater opportunities to interact with family members and friends. A single room gives patients control over personal information and the opportunity to rest; it reduces noise and embarrassment, increases privacy and the quality of sleep. It also offers the ability to adjust lighting and temperature and enables family members to stay without upsetting others (Chaudhury *et al* 2003; Scottish Association of Community Hospitals and Scottish Partnership for Palliative Care 2003; Ulrich *et al* 2004).

It has also been suggested that a dying patient in a bay or open ward can cause distress to other patients (Brown *et al* 2005; Thompson *et al* 2006). Nurses in a recent study related to end-of-life care on acute medical wards reported that it was distressing for the 'well' patient and family to be privy to an intimate time between the dying person and his or her family (Thompson *et al* 2006). Conversely some sources have commented that some patients prefer the company afforded by sharing (Parker 1998; Kirk 2002) and so patient choice is key. For example, a spokesperson from the Pilgrim's Hospice near Ashford, Kent said: 'There is a move to introduce a national standard for hospices that requires units to provide only single rooms, however at the Pilgrim's Hospice the conscious decision was taken to allow patients to share their space with others if they so wished.' (Parker 2001)

Current Department of Health policy suggests moving a patient to a more private area of the ward or a private room as death approaches (Department of Health 2005). However, it is difficult to anticipate the time of death, particularly in patients dying of illnesses other than cancer, such as heart failure, and this affects decisions about where the patient should be placed and when (Ellershaw and Ward 2003; NHS Confederation 2005; NHS Estates 2005). Furthermore, there is research evidence from Canada to suggest that transitions in the location of care and who provides it can be extremely stressful for individuals facing death and for those close to them, particularly if the transition involves interaction with a new set of health professionals (Burge *et al* 2006).

If specialist end-of-life beds can be made available in hospitals, the literature would suggest that these should consist of large single rooms that are calm and quiet and designed to encourage the presence of family and friends. A 'family zone' with ample space for chairs, a sofa bed, fridge, etc is advocated (Burk *et al* 2003; Centre for Global Partnership 2003; NHS Estates 2003b, 2005; Ulrich *et al* 2004). The space needs to be private and soundproofed and there should be private break-out areas, with refreshment facilities in close proximity (NHS Estates 2005). In particular, the provision of furniture such as a reclining chair for patients is frequently mentioned (Scottish Association of Community Hospitals and Scottish Partnership for Palliative Care 2003; Shipman 2005). The rooms should allow patients to exert some control over their immediate environment such as lighting, television, artwork (Smith 2006).

A specialist end-of-life room can enable the typical requests and needs of individuals in the end-stages of life to be met; these might include open visiting hours, visits from pets, being able to listen to music, and a place for families to prepare favourite foods and eat together (Faber-Langendoen and Lanken 2000; Scottish Association of Community Hospitals and Scottish Partnership for Palliative Care 2003; Gilpin and Schweitzer 2006; InformeDesign 2006; Institute for Healthcare Improvement 2006; Smith 2006). Specialist

rooms would also enable family and friends to find meaningful roles in caring for the patient – for example, assisting with activities of daily living such as eating, washing and dressing, if they so choose (Institute for Healthcare Improvement 2006).

## Views, colours, art and sound

Across all health care environments views of nature and/or gardens are reported to increase levels of positive feelings (Stern *et al* 2003). Access to outside space is also deemed to be extremely valuable for patients, their families and friends (Smith 2006).

Many articles and policy documents recommend the use of soothing colours, although the research-based knowledge available to make informed decisions about colour is limited and conflicting (Tofle *et al* 2006). For example, gender and age differences with regard to preferred colour schemes have been identified, with boys preferring 'cold' colours and girls 'warm' colours; younger children like bold colours and older children more muted tones (NHS Estates 2003a). In addition, natural age-related changes to sight may mean that in general older people experience colours differently from younger people (Dalke *et al* 2004, 2005). Commentators also advise against overuse of one particular colour and emphasise how important it is to think through the effects on appearance and appraisal of skin tone health (Dalke *et al* 2004). If people have a limited degree of control over their environment, exposure to particularly strong or potentially dislikeable colours should be limited (Dalke *et al* 2004).

The findings in relation to art have similar limitations. The research highlights the potential therapeutic impact of art that matches the viewer's taste, but also highlights the dangers of a mismatch with the individual's taste. Get it right and art can reduce stress and anxiety, reduce pain and increase patient satisfaction (Palmer and Nash 1991; Ulrich *et al* 2004). Get it wrong and art can invoke strong negative reactions. Most adults prefer realistic or representational art depicting nature and generally art of this type has been demonstrated to produce positive feelings and be relaxing. However, people who are interested in art tend to like emotionally challenging work using a range of styles (NHS Estates 2003b). Given the potential for the same approach to induce contradictory reactions in different patients it would seem more important to give patients control over the art in their room.

Little has been written about the specific benefits of music and sound in end-of-life care. However, peace and the absence of unwanted sounds are highlighted (Henderson 2004; Brown *et al* 2005). Noise reduction has been demonstrated to reduce stress and heart rate, and improve sleep (NHS Estates 2003b). A reduction in stress, anxiety, blood pressure, respiration rates and pain is regularly asserted as being related to listening to running water, soothing or pleasant sounds, religious music and the sound of people talking. The following have been identified as 'soothing' or 'pleasant' sounds: music, rain, the wind, the sea, songbirds and bees (NHS Estates 2003a). Once again, however, the key appears to be relevance and appropriateness to the individual (Schweitzer *et al* 2006).

## Spirituality

Spirituality is fundamental to discussions around end-of-life issues, yet there appears to be little written about the physical characteristics that make an environment spiritual or about the physical environmental conditions required to successfully meet spiritual care needs. Different religions have specific requirements for end-of-life care, so it would seem

important for the space to be flexible in order to enable appropriate use by the full range of religious groups.

### *Seeking views*

Despite a growing recognition of the importance of capturing, understanding and measuring patients' and carers' experiences of care, research with patients and significant others about end-of-life care is still in its infancy, both nationally and internationally. A variety of research approaches and methods, including interviews, focus groups and questionnaire surveys, has been employed to get a better understanding of good end-of-life care, but little is known about the best ways and most appropriate time to involve dying people and bereaved relatives in such research and service development.

### *Unique features of end-of-life environments*

Concerns regularly raised in the literature that relate uniquely to end-of-life care are the transfer of the body to the mortuary, the relatives' journey to the mortuary, the location of the mortuary, viewing rooms and bereavement rooms/suites, and dealing with the deceased person's belongings. It has been suggested that these dimensions of care not only have an immediate impact but can also influence the subsequent bereavement process (Kennedy 1999; Forte *et al* 2004; NHS Estates 2005). Discussions with team members on the Enhancing the Healing Environment project also raised the issue of managing 'the empty bed'.

## Conclusions

More than 300,00 people die in hospital per year and so the environment for end-of-life care should be of fundamental concern to policy-makers and NHS managers. This review of the literature identifies a number of factors that are repeatedly reported as encouraging well-being and likely to be important to people at the end of their lives. The characteristics of a therapeutic environment at the end of life are: home-like environments, single rooms, facilities for family members, natural light, design that incorporates elements of nature, soothing colours and artwork, windows with views, being able to enjoy pleasant sounds, and having access to outside space and gardens.

In addition there are issues that relate uniquely to the end of life: transfer to the mortuary, relatives' journey to the mortuary, location of the mortuary, viewing rooms and bereavement rooms/suites, and dealing with the deceased person's belongings and managing the empty bed. Patients and family members are increasingly recognised as the 'experts' on the subjective quality of their experience, yet research with patients and significant others about end-of-life care is still in its infancy.

# 2 The pilot projects

## Introducing the projects

This section presents descriptions of each of the eight projects who took part in the programme. The short descriptions and photographs aim to provide an overview of the environments chosen, demonstrate the changes made and summarise some of the early outcomes of the work.

Each participating trust and hospice chose its own project sites, which had to be areas that were to be used by those who were dying and/or their relatives. It was suggested that projects could include offices used for bereavement counselling, quiet and multi-faith rooms, and mortuary viewing areas.

Half of the schemes undertaken by the Environments for Care at End of Life (ECEL) pilot group focused on mortuary viewing facilities. Each was different and had its own specific challenges. However, one area of commonality was the need to ensure that the approach to the viewing suite was in keeping with the refurbished facilities. All too often the corridors leading to the mortuary, typically at the back of the hospital, were used as service corridors and provided storage space for deliveries.

The other four projects focused on redesigning a visitors' room, improvements to a bereavement suite, the creation of palliative care rooms and the redesign of patient rooms in a hospice.

Each team was asked to undertake early and ongoing consultation as part of the work, which needed to be done sensitively. However, the short descriptions illustrate the number of innovative ways of getting patients, families, friends and staff involved, including inclusive launch events, mobile displays, visits to galleries and gardens, and tours of current facilities.

During the course of their project each team examined current working practices in the area in which their scheme was located. Many of the ECEL teams, particularly those that focused on improving mortuary viewing suites, found that bereavement policies were either out of date or poorly communicated. It is noticeable that the revision of these procedures has been one common and important wider benefit of the work.

An important additional outcome of the programme has been the individual development of team members. Many have taken on wider roles or gained promotion as a result of their involvement in the programme. A significant number of team members have used their new-found knowledge and skills to improve environments in other parts of their organisations and are contributing to the planning of new buildings.

The short commentaries and photographs of each of the eight projects are followed by further details in the project directory at the end of the report.

# Birmingham Children's Hospital NHS Foundation Trust

## *Rainbow Suite: refurbishment of viewing suite*

At the Birmingham Children's Hospital it was felt that the viewing suite was difficult to access and not particularly welcoming. The entrance to the suite was a long way from the main hospital entrance and in a corridor leading to the laboratories; access was via a plain, unmarked door.

The viewing suite consisted of the viewing room, which contained both a bed and a Moses' basket, and a small waiting area with facilities for tea/coffee making, a few toys and a toilet. The whole area was well kept but the atmosphere was institutional, as evidenced by the fixtures and fittings used in the viewing room and toilet which were standard hospital sanitary ware.

The team wanted to provide bereaved parents and families of different faiths with an environment that was calming, pleasant, respectful and dignified, an environment where they could spend time with their child. Through the project the team hoped to increase staff awareness, understanding and appreciation of the diverse needs of newly bereaved families.

The team was led by the bereavement care services co-ordinator and included a capital projects manager, a hospital chaplain, a bereavement counsellor and a junior sister. The advisory group set up by the team included the mortuary technician, a pathology services representative, social workers, nurses, the hospital arts co-ordinator and two family representatives.

An interior designer was not appointed by the team, but it was made clear that the design needed to provide appropriate storage for religious artefacts and toys. The refurbished toilet had to include baby-changing facilities, and the whole suite needed to have a more domestic feel through improvement of the general décor and furnishings.
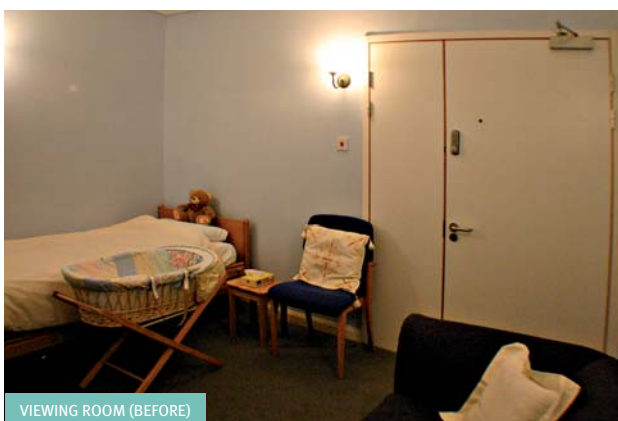


VIEWING ROOM (BEFORE)
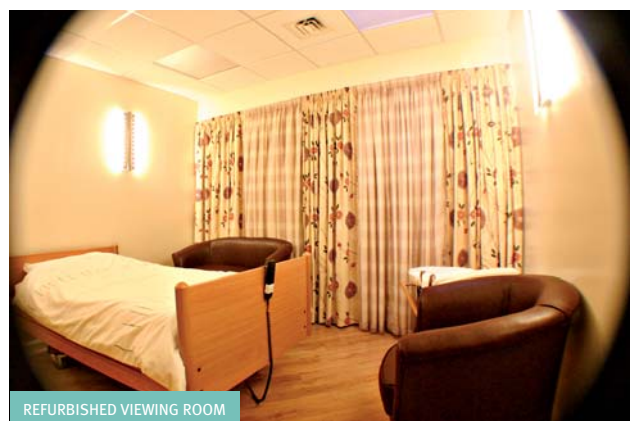


REFURBISHED VIEWING ROOM

The doors to the laboratories were moved further along the corridor, so that a welcome sign to the suite and a wooden door could be incorporated. The entrance was made less intimidating by the use of glass bricks next to the new door. The suite included a larger waiting area, lit by a light well and a large window looking out on the small courtyard garden, created from scratch, with a planted area and a wooden double seat for parents that was specially commissioned.


IMPROVED WAITING AREA

*An amazing transformation – ambience feels exactly right, tastefully and positively supportive for parents.*

*A calm, serene and dignified environment for families to spend time and say their goodbyes.*

TEAM MEMBERS


WOODEN BENCH IN COURTYARD

The viewing room has been re-oriented so that the child's body can be transported more easily from the mortuary. The large mortuary door is behind voile and fabric curtains, chosen to blend in with the overall colour scheme. Care was taken to choose high-quality furniture and fittings, with sofas and chairs throughout the suite. Domestic basins and toilet ware were installed, plus baby-changing facilities, and the whole design complemented with fresh flowers and plants.

# Christie Hospital NHS Foundation Trust

## *Bereavement suite refurbishment*

For this project, a number of areas of Christie Hospital were considered, but eventually the mortuary viewing room and corridor were chosen for refurbishment. The waiting area of the viewing room was drab and dated, with the sloping corridor leading to it at the back of the hospital. This service corridor was often used as storage area. One side of the corridor had clear windows overlooking the kitchen preparation area; bereaved relatives or friends could therefore see and be seen by kitchen staff on their way to and from the suite. In addition the signs were not clear.

Consultation was undertaken by the project team and involved the Patient and Public Involvement (PPI) Forum, Patient Advice and Liaison Service (PALS), mortuary staff and current patients. A number of drop-in sessions were held so that volunteers and staff could learn about the project; information was also given in the trust newsletters and on the trust website. The PPI Forum chose to help finance the project through a strategic health authority (SHA) capital grant.
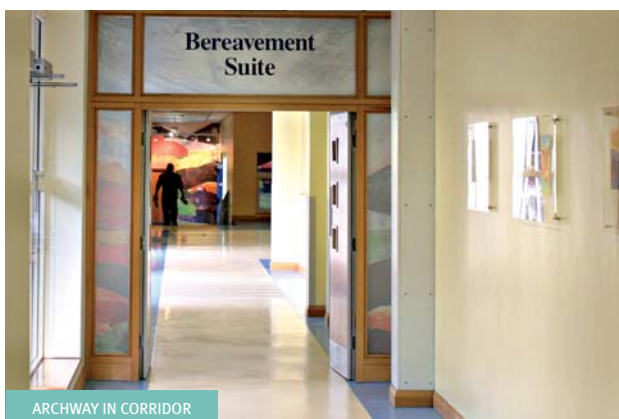

ARCHWAY IN CORRIDOR
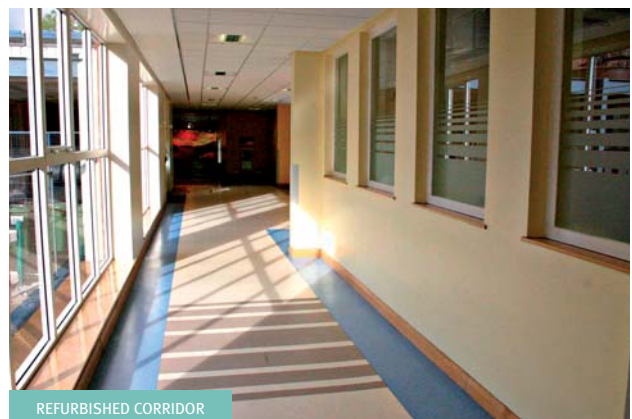

REFURBISHED CORRIDOR

The team was led by a senior nurse/modern matron and included: an estates project manager, the chaplaincy co-ordinator, a clinical services manager and the trust's quality assurance/PPI officer. The team set up a project group within the trust, including patient representatives, an interior designer, the mortuary and catering managers, and a complementary therapist.

An abstract signature image was developed in the workshops held with patients and staff, which were led by the trust's artist in residence. The image was used extensively along the corridor, around the door to the viewing area and over the windows in the waiting room. The original artwork for the image was hung in the corridor, and will be used for all future signs and information relating to bereavement services.

A new 'arch' was built half-way down the corridor, signalling the entrance to the bereavement suite, and the corridor was redecorated and the flooring replaced. Seats were provided for people to rest. The kitchen windows were obscured with opaque film, chosen to match the new flooring design and artwork panels.

Redecoration of the waiting room has created a calm and relaxing atmosphere, with installation of a more flexible lighting system. There is now an office for a bereavement officer and the toilet facilities have been improved.

The viewing area was not part of the original scheme but was also redecorated, with the added purchase of high-backed armchairs. Voile curtains were hung across the window to the viewing area and a heavy curtain hid the mortuary door.

At the start of the project, an audit of use of the viewing area was carried out; although the number of viewings have not increased since the project completed, the length of time spent by relatives in the suite has doubled and repeat viewings have increased.

During the project, the team contributed to the development of the trust's pathway for care of dying people and revision of the policy at end of life. The trust is now considering how to streamline administrative procedures after death.

An aesthetic survey of all public areas within the hospital was subsequently completed by the team. In addition to consideration of how to improve the signs used, the team has contributed to an art, design and environment strategy group that will co-ordinate any capital programme or refurbishment within the trust.



ENTRANCE TO BEREAVEMENT SUITE



REDECORATED WAITING ROOM

*Being involved in the scheme has developed much more than my appreciation of art, understanding of colour and the importance of good design. It has encouraged me to expect more from the environment, given me the opportunity to work as part of a project team, to learn from my team mates and to be involved in something exciting and different.*

TEAM MEMBER

# Guy's and St Thomas' NHS Foundation Trust

## Bereavement centre

When the team joined the ECEL pilot programme, plans were being put in place for the move of the bereavement counselling service from its location in the main hospital alongside the admissions unit to a newly renovated area off the main hospital corridor. These plans were welcomed by staff because the service was located together with the admissions unit; this resulted in a busy and often crowded area.

The area chosen for the new centre was on the second floor of the main building – an area discrete but accessible. The team were able to contribute to the design of three areas, including a waiting room, two interview rooms and an open plan office. The refurbishments were funded through the trust's capital programme.

The team was led by the lead nurse for palliative care and included: the senior bereavement officer, the head of spiritual care, a PALS manager and a capital planning manager. A larger support group was formed at the hospital including representatives from the Guy's and St Thomas' Charity, the mortuary service, and the arts and design group.

One of the key objectives of the team was to increase the amount of natural light in the centre by opening up the old 'arch' windows. There is now a dedicated waiting area and two different size interview rooms to accommodate either single relatives or larger groups.



CORRIDOR (BEFORE)

*This is a fantastic opportunity. It is so important to carry good quality care through when a patient dies, so that the bereaved are well looked after too.*

TEAM MEMBER



OPENED-UP ARCH WINDOW

As a direct result of their participation in the ECEL programme, a successful bid was made to the Friends of St Thomas' for funds to purchase special furniture for the new centre. Further capital was made available by the trust to provide disabled toilet facilities next to the centre.

The team recognised that as a result of their bereavement many relatives and friends found visiting the centre a difficult experience. They wanted to provide an area in the corridor for people to sit either before or after seeing centre staff, so the project focused on improving the corridor next to the new centre, particularly the large window facing the main door to the centre's waiting room. A glass artwork for the large window was commissioned but before eliciting proposals from artists a consultation questionnaire was used to gain patients' views on what colours they would or would not like to see used. Views of relatives were sought at memorial services and those of staff and patients at the trust open day, and via internal newsletters and their intranet. Five artists were short-listed and invited to submit proposals. The project team met with the chosen artist to review the initial design and glass samples, and a final design agreed.

During the project planning phase, the team discovered that the south wing of St Thomas' is grade 2 listed; this led to some delay in planning and installation of the window.


NEW CORRIDOR WINDOW

# King's College Hospital NHS Foundation Trust

## Viewing room refurbishment

Before finalising the ECEL project site for refurbishment, there was wide consultation; a comprehensive communications strategy was developed to ensure that everyone had the opportunity to give their views/opinions. Leaflets were produced and a notice board set up in the main hospital corridor. Articles were written for the trust magazine and the team obtained permission to develop a dedicated section of the trust's website for the project. Presentations were given to many hospital and local groups. The team adopted a signature image – a dandelion – to signpost all bereavement services.

The ECEL team was led by the assistant director of nursing and included: an estates representative, Head of Nursing for Palliative Care, a PPI representative and the hospital chaplain.

As a result of the consultation, the viewing room, which was called the chapel of rest, was chosen as the main focus for the project. Although it was a small area, there was the opportunity to make better use of the space and remove the heavy curtains around the bier, which gave the room a claustrophobic feel. The aim was to bring tranquillity and beauty to the room, improve the lighting and ventilation, and open the space up as much as possible.

The team recognised that the corridor to the viewing room needed to be refurbished, with alternative service corridors being found. Following the team's presentation to the trust's board, it was agreed that there would be capital funding to enable inclusion of the corridor in the project.


ENTRANCE TO VIEWING AREA (BEFORE)


NEW ENTRANCE TO VIEWING AREA

*This project has made a difference and was never just about the environment. The environment drew us in and then turned everything upside down... and I am glad it did!*

TEAM MEMBER
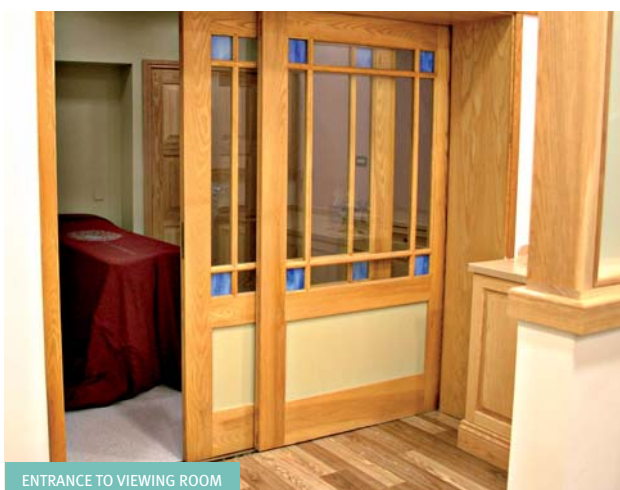
ENTRANCE TO VIEWING ROOM

The main door from the viewing area onto the corridor was replaced and the lock changed to a keypad. A small light box with a dandelion was placed by the door, which is lit when the room is in use. The glass doors dividing the waiting area from the viewing area were retained because this was required by the coroner; the bier was also retained because there was no space for a bed. The old pall was replaced by a specially commissioned one, which was designed to complement the new colour scheme, using an embroidered dandelion. New wooden cupboards were installed. Rather than religious artefacts, different religious symbols can, if relatives wish, be projected onto the wall above the bier by a small projector.

Important features of the new design in the waiting area are the commissioned artwork and light boxes featuring dandelions. The neutral colour scheme, new leather furniture, flooring and wooden cupboards were chosen to blend in with the colours of the chosen images. A small half-screen was placed in the room to obscure the glass doors to the viewing room itself.


USE OF DIFFERENT RELIGIOUS SYMBOLS

During information-gathering at the early stage the team recognised that the trust's bereavement policy needed review. The team leader was instrumental in developing the new policy, which has now been distributed throughout the trust.

The project raised the profile of end-of-life care within the trust. As a direct result the bereavement care policy was revised and care of dying people now forms part of the trust's induction for all staff. A further project to improve the bereavement offices has started with funding from the Nurses' League.

# Royal Brompton and Harefield NHS Trust

## *Royal Brompton Hospital: creation of bereavement office and refurbishment of viewing room*

The Royal Brompton Hospital consists of a number of buildings on a busy road in west London. The 'family room' where relatives saw bereavement staff was located in the Fulham Road building some 5–10 minutes from the mortuary viewing room, which was behind the Sidney Street building. After a viewing most families would need to return to the Fulham Road building to complete the required paperwork; the team were keen to relocate services in a way that avoided this long walk.

The viewing room, located in the basement next to the mortuary, had been refurbished some four years previously, but the décor was tired and dated. The adjoining small waiting area was cramped and had no natural light; the corridor was used to store trolleys and was a main service route for the building. There had been discussion about securing a room for bereaved relatives in the same building as the viewing room for some time. After detailed negotiations, the team acquired a small office near the front hall of the Sidney Street building, next to the PALS office. This provided an opportunity to improve the situation for bereaved relatives.

The team was led by the PALS manager and included: a hospital chaplain, a senior nurse, a business manager from estates and a personal assistant. Many others including mortuary staff played an important part in planning the project.

At the start of the project, staff were invited to participate in a series of 'guided tours' of the viewing room. This raised the profile of the project and the bereavement service within the trust. Participants in the tours were kept informed about the project as it developed: meetings were held with staff, surveys undertaken and information posted on the hospital's website. The tours proved popular and helped to reduce the traffic in the corridor outside the viewing room as people became aware of the need for quiet.
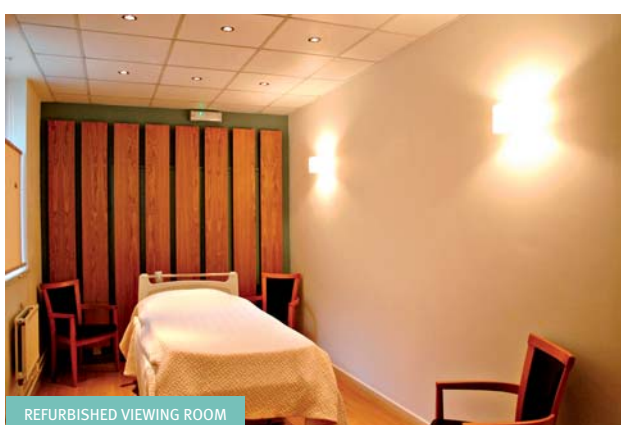


REFURBISHED VIEWING ROOM
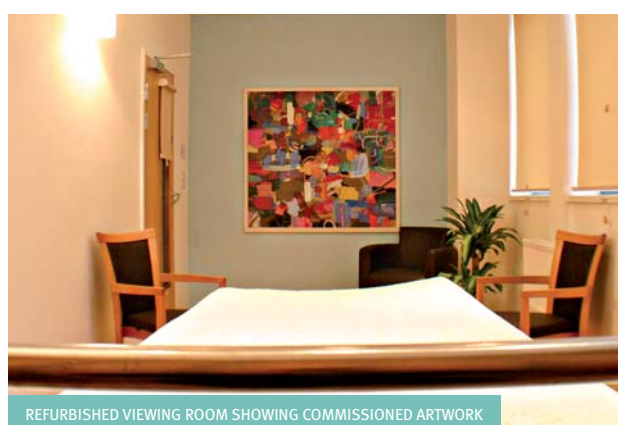


REFURBISHED VIEWING ROOM SHOWING COMMISSIONED ARTWORK

FAMILY ROOM

To link the relocated family room (on the ground floor) with the viewing area and adjacent waiting room (in the basement), the team chose the same colour scheme, fixtures and fittings for both areas. The leather furniture included small sofas and bucket and stackable chairs, chosen to give a warm feel to the place; this was carried through by use of dimmable wall lights and small table lamps. The family room was linked to the courtyard garden that it overlooks by the use of plants; artwork gave added interest. A light box was placed outside the room to indicate when it was in use. The waiting area in the viewing room was extended by knocking out a cupboard. The adjoining toilet was upgraded and now complies with the Disability Discrimination Act. A small glass window was included in the viewing room's door so that family members could glimpse the room before entering or even just view the deceased through the glass. A blind could be drawn if required. The viewing room was repainted with soft blue walls at either end and vertical blinds were put on the windows. Specially designed wood panels hid the mortuary entrance. The bier was replaced with a bed and counterpane. The corridor leading to the viewing room will be refurbished once a major internal project has been completed.



COURTYARD
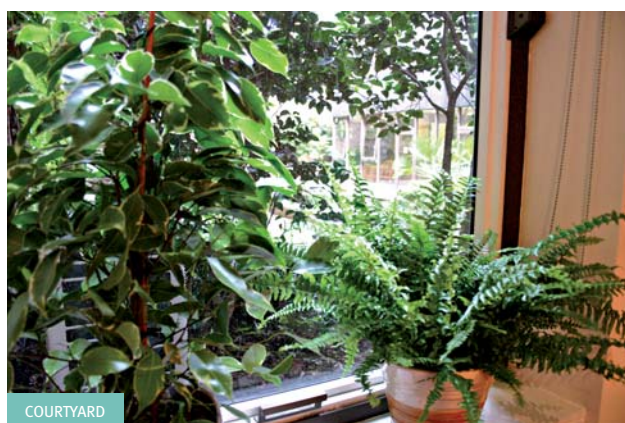
The project, in particular the 'tours', has raised the profile of end-of-life care in the trust. In addition revised guidelines for staff accompanying relatives to the viewing room have been written and circulated throughout the hospital.

*Working on a project like this makes you really want to create something wonderful.*

TEAM MEMBER

# United Bristol Healthcare NHS Trust

## St Michael's Hospital: creation of a palliative care facility

Before starting on the ECEL programme, the Chief Nurse undertook a considerable amount of work to research palliative care needs within the trust. This work had established the need for up to four palliative care beds at any one time and the trust had already agreed to establish a two-bed palliative care facility.

A location was found at St Michael's Hospital, a short way from the main hospital site; it was decided to convert a four-bed bay at the end of a ward into two en-suite rooms specifically designed for patients with palliative care needs. The ward staff already cared for some patients who needed palliative care and the plan was that they, together with the trust's palliative care team, would look after patients in the suite. The aim would be to stabilise patients' treatment, pain and symptom control, and prepare them for discharge to their own homes.

The team was led by the assistant director of nursing/head of midwifery and included: an estates project manager, the head of specialist nursing services, the hospital chaplain and a member of the trust's PPI Forum; the last also represented the Charitable Trust supporting the project. At the start of the project, the team drafted a communications strategy to ensure that all key stakeholders were aware of the proposal to establish a dedicated palliative care suite; this also gave them the opportunity to contribute to project planning for the new service and to the room design.

Initial plans were drawn up to convert the four-bed bay into two en-suite rooms; the views of patients who were under the care of the palliative care team were sought on aspects of design, colour, lighting and feel. The team aimed to create rooms that would be calm, quiet and encourage family and friends to visit. It was decided to use natural materials – wood, leather and fabric – and colours throughout the scheme, and for fixtures and fittings to be to a hotel standard. The team ensured that infection control and hospital standards were met. Both rooms were furnished in the same style, with care taken in choosing furniture; this included leather sofa beds and chairs with fold-down arms, so that visitors could sit close to the bed – close enough to hold the patient's hand. The bed has wooden
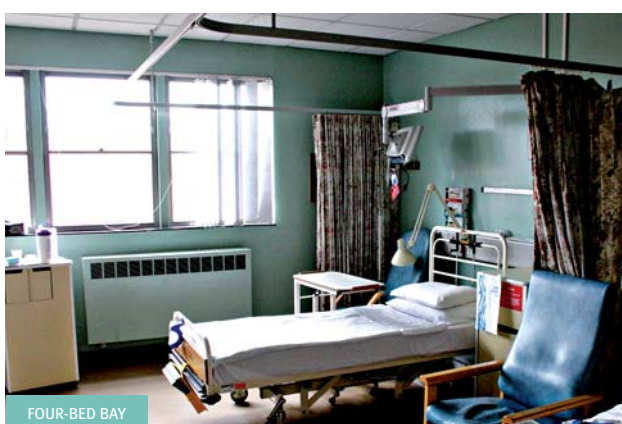


FOUR-BED BAY
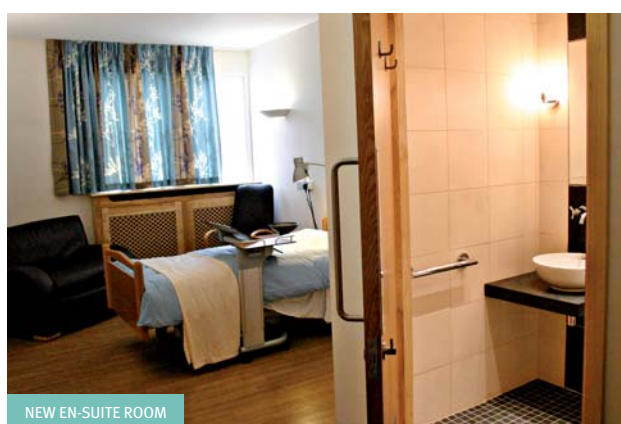


NEW EN-SUITE ROOM

ends, adding to the non-institutional feel of the rooms, and the bed table tilts to make reading easier. Throughout the design process the team wanted to allow patients as much control over the environment as practicable. Lighting is controlled from beside the bed and a coloured light-emitting diode (LED) feature was installed so that patients could choose a different colour lighting scheme for one wall if they wished. The flat-screen TV is also controlled from beside the bed. Temperature of the radiators can be controlled by the patient and/or their visitors.



FRUIT BOWL

As patients requested 'something beautiful', individual designer fruit bowls were purchased. A local bathroom retailer was asked to prepare designs and install the en-suite facilities. The chosen design maximised the space available and included a walk-in shower area with seat. The toilet cistern was hidden behind the tiled walls and a modern basin with slate surround was installed.

The wood theme carried through to the main door, which has an oval window so that staff can unobtrusively check the patient if required. The two rooms are located just inside the main ward door by the entrance to the ward. In addition to creation of the two rooms, additional funding was found to repaint and refurbish the main ward corridor. A local photographer was commissioned to produce a series of photographs of local scenes.

*I learnt so much more than the concept of good art and design.*

TEAM MEMBER

The principles learnt by team members have been used to influence ward refurbishments, the redecoration of the viewing facility and other capital schemes.



BATHROOM

# Marie Curie Hospice, Glasgow

## *Redesign and refurbishment of a relatives' room*

A number of possible projects were considered by staff, and the decision was taken to focus on the relatives' room on the second floor, which was felt to be a manageable project with the potential to improve visitors' facilities. The choice of project site allowed the team to engage with patients and families, to seek their views on what improvements they would like to see; it also demonstrated what could be achieved to staff and potential donors.

When the team joined the ECEL programme, plans were already well advanced for building a new Marie Curie hospice in Glasgow. The team wanted to demonstrate what could be achieved through consultation and good design in order to influence the final design for the new building.

The aim of the project was to transform what was a bland, cold and under-utilised room into a welcoming, user-friendly and flexible space. The room had wonderful views that were obscured by the heavy dark wooden frames on the windows.

The project was led by the Capital Projects Commissioning Officer, who had a nursing background. The team included: the architect for the new building, the hospice manager, practice development nurse and a support services assistant (housekeeper). One of the architects involved in the hospice rebuilding scheme was seconded to the ECEL project team.



RELATIVES' ROOM (BEFORE)

*The entire programme has been a wonderful experience, full of practical information combined with leadership training, practical help on project management and access to a new network of contacts with a shared passion.*

TEAM MEMBER



REFURBISHED RELATIVES' ROOM

The team chose to launch their project with a high-profile breakfast and a presentation for everybody in the hospice to raise awareness and interest. Current usage of the room was audited and questionnaires were prepared for service users and focus groups arranged for staff. In particular relatives were asked how they might like to use the room. As the proposals developed, staff, relatives and members of the hospice bereavement group were engaged to review the design and decisions about final colours and finishes.

The scheme created three distinct spaces within the room, each with its own lighting controls. A new entrance was created from an area previously used for equipment storage. The curved wall of the entrance was enhanced with glass artwork and lighting, and behind it a small area was created for visitors to access the internet or for children to play. A small, screened, kitchen area was provided with a kettle and crockery for making tea and coffee. The window frames in the main seating area were painted white to reduce interference with the view of the surrounding hills. This view provided the inspiration for the commissioned glass artwork at the entrance and around the TV screen. New furniture was purchased, which, together with newly installed radiator covers, voiles and curtains, gives the area a more domestic scale and feel. The room has become a social space for patients to take their visitors. A space that was used infrequently, and only by one family at a time is now regularly used by several simultaneously, which has had the benefit of enabling families to support each other at a difficult time.



NEW ENTRANCE WITH GLASS ARTWORK

*I am so proud of the outcome and even though the space now belongs to one of the ward managers I still pop in regularly to remind me what can be achieved with a little vision, a team well equipped to undertake the task, commitment and drive and a little funding.*

TEAM MEMBER



COMPUTER AND KITCHEN AREAS

A review after the project has shown that visitors find the room comfortable and more welcoming. Families are happy to use the room when patients are receiving care and they also use it when they need some quiet time. The project has raised the profile of user involvement within the hospice. The redesigned room has reinforced the value of good design, art and the use of light and colour; as a result a review of the proposed lighting scheme for the new hospice has been requested. A team member has already used skills and knowledge gained on the programme to refurbish the visitors' room on the first floor.

# Marie Curie Hospice, Hampstead

## Redesign of patient rooms

The plan was to develop a new design for the 20 single rooms used by patients that would set the standard for future refurbishment and redecoration. The rooms had been purpose built when the hospice opened 30 years ago. Initially it was hoped to create up to three 'show rooms', which could be used to show potential donors what could be achieved and support fundraising activities. The project team wanted the rooms to be contemporary but with a homely feel, although with the quality associated with a good hotel rather than a hospital.

The hospice manager, a nurse, led the team, which included managers from the psychosocial team and support services, together with a ward manager and a service user representative. An architect was commissioned and views sought from patients, relatives, volunteers and staff. The team designed a mobile comments board, which was taken around the hospice to various locations so that everybody had a chance to participate.
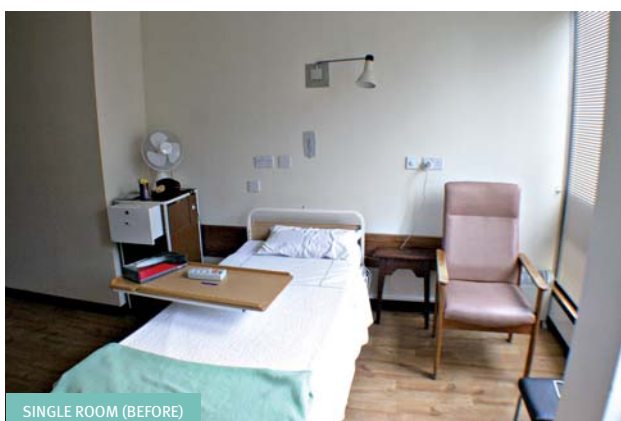


SINGLE ROOM (BEFORE)

*Central to the design has been empowering the patient and maximising their independence as much as possible.*

TEAM MEMBER
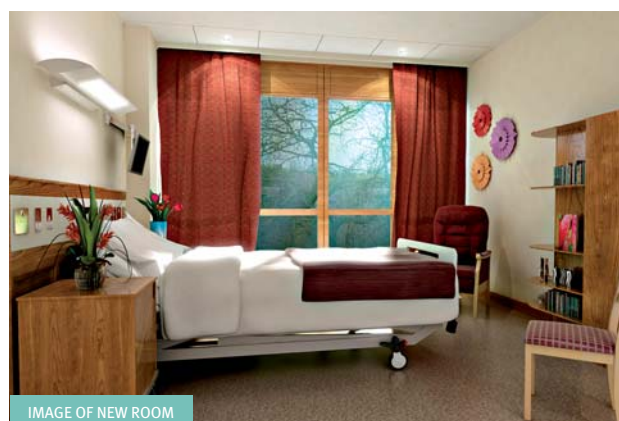


IMAGE OF NEW ROOM

During the early planning phase, it became evident that the planned replacement of all the hospice windows would delay the project and the team had to adjust their timetable accordingly. However, this meant the possibility of refurbishing a larger number of rooms than the team first envisaged.

The designs for the refurbished rooms tried to take into account the needs of both patients who needed specialist palliative care and their relatives and visitors. Central to the design was the wish to empower patients and enable them to maximise their independence as much as possible – for example, to enable patients to alter the level of room lighting from the bed and ensure that it was possible to sit at a basin in a wheelchair. The team were keen to ensure that there was adequate shelving so that patients could bring in items from home; the shelving incorporated a personal safe within its redesign. The design specified that natural materials should be used as much as possible (taking infection control requirements into account) in order to help bring the 'outside in'.

Integral to the project was the proposed commissioning of a series of over 30 artworks for the rooms and corridors. Some of these were paintings although they also included glass and textile artworks. Towards the end of the project design stage, it was decided that the hospice would, in addition to the window replacement, undergo a major refurbishment of its inpatient facilities. The team were therefore in a position to influence the design for the whole refurbishment.


COMMISSIONED ARTWORK (TEXTILE)

Each room was stripped and a number reconfigured to provide more single patient accommodation. A new heating system is being installed together with new lighting and soundproofing systems. The overall design reflects a hotel rather than a medical environment. Rooms include a newly designed bespoke 'cupboard', which includes a wardrobe and space for nursing equipment. A unique feature of the cupboards, placed opposite the beds, is the curved shelf for patients to display photographs, flowers and personal items.


REBURBISHED HYDROTHERAPY POOL

The refurbishment will now extend to day and therapy rooms as well as the corridors within the building. The hydrotherapy pool has been refurbished using the principles that the team learnt during their participation in the programme. The team has been instrumental in ensuring consultation with the users of and stakeholders in this major capital project.

# 3 Lessons from the ECEL programme

## Introducing the action research

An independent action researcher was commissioned to work with the Environments for Care at End of Life (ECEL) teams, interviewing those who participated in the work and their health service colleagues, in order to identify the lessons learnt. This work sought:

- to explore what had been learnt during the programme
- to reflect on the end-of-life care environments that had been created
- to contribute to knowledge about those aspects of the environment that are important to patients, their families and staff involved in their care.

The following thematic analysis derives from the interview data and reflections captured from discussions during the development programme, as well as reports submitted by the team to the King's Fund, locally collected data from questionnaires and focus groups, and site notes from ECEL team visits.

In traditional scientific approaches, a sample is carefully selected to represent the population of interest, so that the findings can be generalised to this wider population. In 'real-world' approaches, such as this ECEL action research, the aim is to gain understanding, so different sampling approaches are acceptable.

This work used two main approaches: first, a minimum data-set was collected from all eight pilot project teams in the form of three staged questionnaire-based reports. This minimum data-set included: existing policies and/or service standards relating to death, dying and bereavement; routinely kept service data such as death rates, viewing room logs/records of use; and comments and complaints about the dying and bereavement services and notes from site visits. This was supplemented by information from local surveys and evaluations, project newsletters, and so on, which provided both useful reference and contextual data, and ensured that all team members felt engaged in the process.

Second, to illustrate the lessons learnt, four case studies were used, each with a different focus:

- the refurbishment of a family viewing room located near the mortuary and creation of an associated garden (Birmingham Children's Hospital NHS Trust)
- the refurbishment of a mortuary viewing room (King's College Hospital NHS Trust)
- establishing a specialist palliative unit (United Bristol Healthcare NHS Trust)
- transforming a relatives' room on an inpatient unit in a hospice (Marie Curie Hospice, Glasgow).

## Findings

### *Engaging and involving the patients and service users*

All teams undertook to seek a broad range of views from patients and service users; all reported positively on the contribution of carers who had used the service that they were working to improve.

The Bristol team, for example, were keen to access the patient and carer perspective in the design of the rooms in their project:

> *User involvement is a hot topic especially in palliative care at the moment. People can be very precious about palliative care patients say… you shouldn't burden them etc… we agreed that user involvement was very important and that the obvious thing was to ask our patients. We chose them carefully, used sensitive wording and designed a questionnaire and gave it to patients and carers. It was very interesting… they wanted an environment that gave them the feelings of quiet and safety etc rather than a particular colour.*

> *They wanted it to be quiet but people to be accessible, privacy, calm, muted colours, much more about the feelings though. It was very powerful playing that back to the group. The power of the patients' voice. They are wanting to feel cared for and safe.*

> *Families sit there for a very long time and are only too happy to do something productive. Only one person said no.*

Overall, patients weren't really concerned about colours; it was more about how the room would make them feel. They wanted:

> *… something beautiful in the room, like a fruit bowl*

and said:

> *… the atmosphere should be of belonging to a kind, caring community with the sanctity of your own room.*

At King's College, the team commented on the usefulness of using staff who were known to dying patients and their relatives when seeking their views. The team found that consultation became a richer and more effective process when the people being consulted knew the person asking the questions:

> *I didn't find it too difficult talking to patients, I've done it over the years, eg, handing out donor cards etc. Renal patients in particular speak openly about death, they're not afraid to discuss it, you don't have to hedge. They appreciated being asked and wanted to be kept informed. I was on familiar ground, it was people that I knew which made it easier.*

Having something to show people was also found to make consultation more meaningful:

*Once we had the photos it made it a lot easier because people said 'that's terrible' and understood why we wanted to change it...*

In Birmingham, the wider team included two parents who had experienced the death of a child at the trust. They found the experience of being involved extremely valuable:

*I enjoyed being part of the team. They were good... they allowed us to express things. Sometimes as a parent you wonder how much power you actually have, how much opportunity to change things there really is because they [the professionals] can always hide behind the regulations at the end of the day 'you're only a parent...'. It's been really good to do it.*

The valuable perspective that people who had actually used the service brought to discussions was emphasised by other team members in Birmingham:

*Relatives notice things we don't, their priorities are different and their awareness is different, they are almost in a state of heightened awareness. They remembered things... details that would not necessarily be obvious to you and I. For example the lighting, it can't be too bright, too bright is too harsh. They [the relatives] were well chosen and didn't need special preparation, they had sufficient distance between them and the death to be able to participate and felt they were contributing.*

However, in the Birmingham project, many of the interviewees felt that more could have been done to access the views from different cultural perspectives. Involvement of this sort does require significant support, as one Birmingham team member commented:

*Not to be entered into lightly but extremely do-able. Both parents self-selected. Perhaps we could've cast the net a bit wider but with the responsibility of supporting and sustaining such a group ... we had to take pragmatic choices. It needs to be explored more – how to recruit and use people appropriately...*

Nevertheless, the importance of such spaces to people who are bereaved emerged very strongly in interviews with parents:

*We remember so clearly those last things... it makes a huge impact those last impressions they feature in your dreams... It's not just the parents but the brothers and sisters too. It has to be nice, not frightening.*

Another important issue in both ethical and practical terms was how to support those parents and service users who had been involved in the project once the project had ended. One of the Birmingham team commented, that the project:

*... raised questions for me about how we end projects, not really sure how we should end projects, needs some thinking through what the next stage is because we've now got these families who've regained their connection with the trust.*

User involvement in its broadest sense had been core to all the projects. All the teams successfully engaged patients and their relatives in the design of their project, demonstrating that patients and their relatives want to be involved in such projects. This involvement has created its own ethical challenges and responsibilities, however, in particular how to support appropriate withdrawal and closure once the project has finished.

## Engaging and involving staff

End-of-life care environments have a huge range of 'users' and stakeholders. For example, most projects required consultation with, as a minimum: mortuary staff, infection control, health and safety, and moving and handling advisers, the trust board or hospice executive team, procurement staff, the Patient and Public Involvement (PPI) Forum, patients and relatives, voluntary services, artists and designers, support services including domestic workers and portering staff, and the spiritual care team.

As well as patients, the Birmingham team also highlighted the huge number of people involved in providing and using these services, alongside the dangers of overlooking any of them in the consultation process:

> *The mortuary technician was really important. The porters… that was interesting, the children's hospital had a session with the Childhood Bereavement Trust which made us realise just how important the porters are. There are so many groups that people usually forget about…*

Similarly, the Marie Curie team in Glasgow recognised the need to take a comprehensive and creative approach to user involvement. Staff were involved during the project through a range of processes. First, the project was launched with a breakfast for staff and volunteers at which their ideas were sought. Structured consultation processes such as interviews, focus groups and questionnaires were used to seek views from a wide range of users, including a group of patients who attended a weekly community drop-in group, people attending a group bereavement session, patients, visitors, hospice staff and volunteers. Early on, focus groups with clinical and support staff were facilitated to determine their views on the current and future use of relatives' rooms on the wards.

However, their experience also highlighted a common problem of managing the different views received during the consultation. One of the team members commented that:

> *… [you] have to be prepared for the answers, it can be quite challenging accepting the diversity of others' views.*

Indeed, in this case, the consultation processes highlighted strong differences between staff views, on the one hand, and patients' and relatives' views, on the other. For example, staff were concerned about whether relatives at different stages in their hospice experience would want to share space with other relatives, whereas the relatives were not concerned about this. Another issue was whether the design should be 'chintzy' or modern and include artwork or not. Once again the staff assumed that relatives would want a chintzy feel, which seemed to be a proxy in their minds for 'homely'. The team opted to give the patients' and relatives' views priority in the final scheme.

Indeed, across many of the projects, the views of staff and of patients and relatives often differed – for example, in rating the importance of artworks. In all these cases, the teams chose to support patients' views, although this sometimes had negative consequences for a team's relationship with the wider staff group during implementation.

Throughout the extensive consultation processes it was clear that many end-of-life environments were hidden away from many of those responsible for the institution. This was noticeable at King's College, where taking the charitable trustees to the viewing room was a powerful factor in helping to secure the funds to support its development:

> *The Trustees hadn't expected the viewing room to be the project chosen but were won over by the arguments. I was very keen that they all went to visit it, it was such an important part of the decision, if they hadn't seen it then they probably wouldn't have been so keen to support the project.*

Extensive consultation was a strong feature in all the projects, and teams spent a lot of time investing in the consultation processes at an early stage. Nevertheless, achieving universal awareness and support from stakeholders after implementation proved challenging at all sites, suggesting that consultation needs to be an ongoing process and that significant investment of time and resources in engaging staff are needed, particularly after implementation.

## Managing language and signs

A constant theme in the reflections of all teams in the programme was the sensitive and appropriate use of language and words such as 'death', those who are 'dying' and 'bereaved', and the naming of places such as the 'mortuary viewing room' and 'chapel of rest'.

At King's College, the dandelion symbol has now been used rather than signs for all bereavement-related services. However, with regard to the viewing room itself:

> *We don't signpost it, we don't want people finding their own way there, they must have an appointment, must go via a member of staff.*

In Bristol, there was also a diversity of views about the signs and name for the palliative care unit because some interviewees were concerned about signalling the purpose of the unit:

> *... we're in a hospital and so I think patients would expect there to be some very poorly people. I would like it to be discreet but say Palliative Care Unit.*

Language and symbolism are extremely important. For example, a recurring issue at our pilot sites was identifying appropriate terminology and/or symbols to use in discussion and on signposts for the mortuary and viewing room areas; there was a strong view across all stakeholders that 'chapel' and 'chapel of rest' were not helpful words. Many of the projects reported that more innovative naming strategies were being considered by their organisations.

## Managing culture change

One of the biggest challenges that some of the teams faced was challenging a prevailing culture of what was acceptable or indeed desirable with regard to environments for end-of-life care. These are some of the reflections from the Bristol team:

> *I've been surprised at the obstacles and strength of feeling about 'tax payers' money' etc. We've even had some nursing staff saying that's a bit posh for patients. We've had to battle a bit too to say hey this is really important. The contractors were brilliant but Estates think they were just flexing their muscles. It caused great difficulties for Estates about us not ordering from their usual suppliers. We had to do all the finding out. We will be presenting these findings as 'lessons learnt'. It's been an enormous challenge for Estates doing it differently. Hopefully now we've done it once it won't be quite so difficult. Was surprised at the negativity...*

Similar challenges arose during the Marie Curie project in Glasgow. To achieve the most benefit for the new family and visitor room, it was important for all staff to understand and adopt a new way of working. The team reported that a key challenge throughout the project was convincing clinical staff that things could be done differently and that they might not necessarily know what is best for patients and their families. In particular, some of the ward nurses who worked in the area of the room felt that they had not been sufficiently engaged in the decision-making about the final design and usage expectations, and were not therefore as positive about the room and its benefits as other staff groups interviewed.

It is crucial to ensure that consultation reaches a very wide group of staff if the team want to ensure subsequent ownership and care for the environment. Indeed, it is noticeable that many projects identified unmet training needs for a wide range of staff who work in these 'special' environments, particularly 'out-of-hours' staff who could need to arrange viewings, cleaning staff and porters, and the vital but often unsung work of the mortuary technicians.

As well as understanding and seeking to manage change in the culture of the institution within which the new environment sits, there was much discussion about understanding and responding to changes in the wider cultural attitudes to death and dying. Teams appreciated the different expectations of various social and cultural groups and the need for discussion about the implications of such expectations on the types of services provided for end-of-life care and where they should be provided:

> *A local Imam was dying in King's several years ago and had 150 visitors a day, we need to have proper open conversations about this sort of thing and the facilities we would hope to, should be providing. We need to keep working on this.*

## Keeping an eye on the impact rather than the design

All the ECEL projects agreed on the importance of keeping an eye on how the new environment would make people feel rather than just focusing on the colour and design as such. Words that were used time and time again in interviews with those on the

programme and in team presentations and reports were 'homely', 'natural', 'comforting', 'practical', 'safe' and 'warm'. Most of the teams were expressly aiming to create beautiful spaces that would make the people using them feel cared for.

The importance of how the new environment makes people feel comes out clearly when we asked those involved to reflect on the impact of their new spaces. The following comments relate to the new viewing area in Birmingham:

*Fantastic, whether you go Scandinavian or are into chintz is neither here nor there to me as long as it looks nice and is practical. Needs to give the message: 'we thought about this and care about you' ...*

*... the space is beautiful, it's perfect, you will never be able to make people feel better but it is comfortable and safe. I remembered from my experience feeling claustrophobic, I just wanted to take her [daughter who had died] out into the fresh air, so when we were talking about the void area I said I would've loved to be able to go out into the fresh air.*

## *The broader impact of the ECEL teams*

Environments of care often encapsulate many of the assumptions made about that care. The fact that many viewing rooms are 'hidden' and located at the back of the hospital tells us something about the relative importance or embarrassment felt about this service. That assumption then becomes embedded physically in the building and tends to continue influencing the practice of those working there.

By a change in the environment, the programme challenges the assumptions that have been embedded in the old facilities and, as a result, the work often creates 'ripples' in the individuals and organisations involved. In this programme we found that the work often led to engagement of the team in subsequent projects within their organisations, either to improve end-of-life care or to influence larger-scale environmental changes.

In Birmingham, the programme has led to a research exercise that aims to explore the psychological, cultural and religious needs of families using the Rainbow Suite (viewing room). In the words of one team member:

*It's already had an impact, I felt the Rainbow Suite had been pushed away, nobody knew where it was, it was only talked about in hushed tones, now it's being talked about. It's raised the profile of the whole issue of bereavement and after death care.*

At King's College Hospital, the project has led to a new trust bereavement policy; indeed, each clinical area now has a bereavement file, which provides guidance on all aspects of bereavement care. In addition, end-of-life care is now discussed during corporate induction and has become part of ongoing practice development workshops. As one of the team commented:

*... it was never just about an environmental project.*

In Bristol the principles learnt by the King's Fund team members have been used in the redecoration of another ward area in the trust and have informed the design of the trust's new cardiac centre. One of the team members was asked to lead a refurbishment of the trust's viewing room and the corridor leading to it, and the director of nursing has set up a group to look at arts and heritage across the trust.

For Marie Curie Hospice in Glasgow, the project has raised the profile of user involvement in service development and enabled the local hospice user involvement committee to explore new ways to capture patient and user perspectives on their services. The lessons learnt and the knowledge gained also inform the plans for a new hospice in 2009. A strong partnership between the project architects and the team members has been forged. A simple example illustrates this effect. Team members report that the programme has provided them with the insight and confidence to ask for the lighting in the new hospice to be redesigned:

> *The lighting of the whole new build has been changed and as a result has gone from utility to ambience.*

It is worth reflecting on how those involved felt that this process occurred. All teams reported gaining a new view on the environment of care. Indeed, the Glasgow team referred to this process as being given 'King's Fund eyes'! Team members saw the combination of expert input and personal and team development, provided as part of the programme, as key to this process and to the new perspective that they are bringing to future work:

> *The programme for me was amazing, it not only opened my eyes (King's Fund eyes) but also my mind to what we can achieve through teamwork, thinking outside the box and even taking some risks if you believe what you are doing will benefit others.*

> *Having been given the knowledge and understanding of the importance of light, colour and the benefit of well-chosen artwork, my confidence has grown and I feel that the choices I will make in the future around the healing environment will be the best it can be.*

ECEL team members are now leading new environmental projects and taking forward work on end-of-life care within their organisations, such as the review of bereavement policies and end-of-life strategies. The programme has informed processes and procedures of user involvement in service development and delivery. Emerging findings from the programme have been shared with key stakeholders throughout and as a consequence have informed the national end-of-life care strategy for England and hospice and day-care projects.

## *Mortuary viewing facilities*

There has been an otherwise undocumented change with regard to the numbers of people who want to use mortuary viewing facilities generally, and the size of groups (up to 20) wishing to view and the number of visits occurring (about 25 per cent visit more than once). Among those interviewed there is a strong perception that this changed hugely over

the last decade, and that some minority ethnic groups are particularly likely to want to visit in large numbers and to stay a long time.

This changing social expectation with regard to viewing, together with the increased use of mortuary viewing facilities, happened at all sites and therefore appears to be a national rather than a local phenomenon. From the figures collected during this work, it is likely that acute trusts will have significant numbers of people using their viewing rooms each year. For example, figures supplied by King's College Hospital suggest that each year more than 3,000 relatives and friends use their viewing room. For many of those viewing this is their only experience of the trust. Even small specialist hospitals such as the Christie in Manchester will have about 15 viewings a month. This apparent social change has tremendous implications with regard to the location, design and maintenance of these facilities for all health care organisations, and the appropriate support of all staff involved.

## Summary

The action research highlighted five key lessons that can inform the next cycle of environmental improvement as well as the growing evidence base for the work.

- All teams found that user involvement had significantly and positively shaped the work. Consultation with users often builds on existing relationships with particular staff or particular services. The consultation was often easier when pictures and plans were sufficiently advanced to enable ideas to be illustrated and discussed. Users often stressed that the 'message' given by the environment was key and that the most important element of that message was that the health care organisation cared for them.

- Extensive consultation with staff was identified as a critical success factor by many teams. However, it was noted that this should not be entered into with an expectation that all staff would hold similar views or that their perspective would concord with that of users. Teams found that they often needed either to give preference to user views or to find ways to resolve different perspectives either by building flexibility into the use of the space or by providing patients or users with a high degree of choice or control over how the environment might work for them.

- All teams found the issue of finding appropriate language, symbols and images difficult. No one involved in the work believed that it was possible to identify a single solution that could be proposed for use across any health care organisation. However, the need to identify the issue as part of the extensive consultation necessary for taking on such work was agreed to be an important first step.

- Many of those involved reflected upon the unanticipated need to manage significant processes of culture change in the way staff thought about end-of-life care. The teams believe that a more public debate about the role of health services in meeting public expectations of end-of-life care would be a significant help in challenging current expectations and shaping future policy and practice. All acknowledge that this debate would need to encompass a much greater understanding of diverse cultural expectations of care at the end of life.

- All teams agreed those settings within which end-of-life care occurs should provide a room where patient and family can be taken for confidential discussions as well as the option of single rooms designed so as to engender a feeling of homeliness where

patients retain bedside control over aspects of their environment such as heating and lighting. The wider environment for care in these settings should also include informal gathering spaces and places where families can meet and confer and talk with care staff. In addition, health care institutions should provide guest rooms where close family or friends can stay overnight with facilities for catering and internet access and ensure that there are appropriate places for viewing the deceased. The teams agreed that further research should be undertaken on the need for designated palliative care facilities in acute hospital settings.

# 4 A consultative conference

## Introduction

This section presents the outcomes of a conference held at the King's Fund (April 2007) that aimed to bring the experience and expertise of the teams involved in the programme to bear on future health policy.

Before the event Environments for Care at End of Life (ECEL) team members developed statements that expressed their beliefs of how health policy could contribute to the future improvement of end-of-life care. These statements were a distillation of what had been found in the literature review and learnt from experience. The conference itself convened more than 100 participants with expertise in end-of-life care from the Department of Health, faith groups, the hospice movement, the Funeral Directors' Association, and a range of health care organisations and professions.

Participants were allocated at random into small groups, and each group was hosted by an ECEL team member. Groups were asked to discuss each of the statements and identify any gaps. Each participant was given 'votes' and asked to use these to indicate the strength of support that they felt for any of the consensus statements. For example, participants could use all of their 'votes' on one statement or distribute them across several. The votes were then collated and presented back to the plenary session. Consent was obtained to record the discussions.

## Results

Although the sample was self-selecting and the process far from a representative or comprehensive consultation, we believe that it is useful to reflect on the current views of many of those with expertise and experience in this area of care. The team members' statements for improving end-of-life care are given in the box overleaf.

## Discussion

The statement that was endorsed most strongly by participants at the conference was the call for national standards on the environment for end-of-life care. Participants suggested that setting a national standard would give staff something to aspire to and encourage all health care organisations to act on this often neglected aspect of care as their performance could then be measured.

The link between the physical environment and how staff worked and the quality of care often lay behind the support for this call for national standards:

**TEAM MEMBERS' STATEMENTS FOR IMPROVING END-OF-LIFE CARE**

**Recognising the centrality of death in life**

- Investment in the environment for care at the end of life should be the same as that for care at the start of life.
- National standards should be developed for the environment for end-of-life care.
- All health care organisations should identify an individual at board level to take responsibility for all facets of the environment for care at the end of life.
- Care of the dying, bereaved and deceased should be included in corporate induction programmes for all staff.

**Care of the dying**

- Every patient should be enabled to make a choice about where they would prefer to die.
- In health care institutions:
  - every patient should have the choice of being in a single or shared room
  - the environment should enable every patient to have both privacy and companionship as required
  - every patient should have access to a space which allows their cultural and spiritual needs to be met
  - the environment should enable patients to make independent choices over environmental features such as heat, lighting, ventilation as well as the display of personal belongings and artefacts including works of art
  - every patient should have the opportunity to have their families closely and appropriately accommodated
  - every patient should have access to the external environment.

**Care of the bereaved**

- The environment should actively demonstrate respect for the bereaved and enable an ethos of support.
- The bereavement suite should be located in an accessible area in the hospital. All staff should be fully aware of its location and purpose and of their individual responsibility to respect the sensitivity of the area.

**Care of the deceased**

- Hospitals should not hide death.
- The mortuary and viewing room should be located in an accessible area in the hospital. The approach should be sensitively signed and decorated, and be free from clutter.
- All staff should be fully aware of the location of the mortuary and viewing room and of their individual responsibility to respect the sensitivity of the area.
- The mortuary environment should enable the individual diversity of each dead person to be respected including culture, religion, and beliefs.
- All staff should be accountable for supporting the essential 'personhood' of the dead in all areas and departments of the health care organisation.

*I think the environment is not only the physical environment, it's about an attitude and a shift in an organisation towards the staff encountering the idea of dying, it means an emotional environment. Maybe the physical environment is something that can be developed in such a way that it helps you with that view, it supports you working in that way.*

*I suppose it's the way you behave, if you go down corridors and taking a family down to a viewing room, you would hurry them, you'd be embarrassed about where you are taking them to... whereas if it is pleasant you will relax a bit because you're proud of what you are going down to, it will be a comfort and care continued from the wards. That makes a difference.*

The statement that received the second largest number of votes related to increasing investment in the environment for care at the end of life; it was suggested that this investment should include factors such as values, energy, intellectual development and ways of working, as well as financial factors.

Many of the statements put patient choice and patient control at the heart of their aspirations for the future. It was noteworthy that the importance of choice over the environment extended beyond death, into how health care staff managed the body of the deceased. The following comments reflected different experiences in relation to the use of single and shared rooms after death:

*My aunt who died last year was actually in a ward and the moment she died she was moved to a side ward, mainly to give us as a family some privacy to sit around. But I also thought they were hiding her away.*

*My dad died in a hospice and I remembered thinking it was all right where he was, there was his bed and I didn't want him moved. These men were his friends and they mourned for him as well, and actually that was quite nice.*

Exploration of difficult issues of choice meant acknowledging that people's preferences change over time and that choices need to be revisited frequently:

*... in fact the choice of where you are may change; if you are in the first stages of your end-of-life journey you may want to be in that room with other people and company, but if you are in your last few hours you may at that point want to have flexibility to move to a single room.*

The need for more flexible spaces was a recurring theme in relation to all aspects of the environment, as was recognition that the physical facilities needed to be designed in a way that enabled choices to be made about fundamental things such as being able to seek companionship or privacy, as well as enabling control over heat, lighting, ventilation and the display of personal belongings:

*... when you talk to patients... they tell you coming into hospital is a complete loss of control and to be able to control things like the light is important... I think the same about choosing the art in your room...*

The following comment illustrates the importance of physical spaces giving the sort of flexibility that can enable appropriate and tailored care, in this case in relation to bereavement offices and mortuary viewing rooms:

*We used to only have the one room, a big room, now we have a dedicated waiting area that takes two families and two individual interview rooms of different sizes, which may be a more discreet and sensitive space for taking the widow, rather than into a large room where they feel alone… we have spaces to allow for options and different types of bereaved families I suppose, and different situations and circumstances. One has to consider whether it's for an individual mourner, families together or a large party of families and friends.*

The next statement with most support, considered by participants as being key to the development of better practice, was 'care of the dying, bereaved and deceased should be included in corporate induction programmes for all staff'. The following comments give a good flavour of the discussion and rationale for such a call:

*… clearly induction for all staff including cleaners, etc covering everyone within the environment, everyone needs to have that sort of induction and support. Actually we tend not to focus on everyone but only on the key personnel within the environment, but it's really relevant to everyone.*

*I think there is certainly a need to train all members of staff appropriately about sensitivity; it's really quite important because there is no point having the right environment, pictures on the walls, etc all coming together physically as an environment for somebody to walk through into another room if members of staff are just cackling and talking about everything as they walk down the corridors completely oblivious to that. Then you've completely undermined what you've achieved in the environment itself.*

Finally, the fifth statement with most support was: 'All staff should be accountable for supporting the essential "personhood" of the dead in all areas and departments of the health care organisation.' This was understood to involve a wide range of issues, including how bodies are collected from wards, how staff behave during postmortem examinations and how bodies are stored in the mortuary, and involved demonstrating care in death as well as in life:

*They [the dead] are human beings who deserve to be treated with dignity and respect even in death.*

*… I don't want to walk down a corridor to see a horrible trolley thing wheeling the body; if it's a lovely trolley it makes some difference.*

*… let's make sure that the respect goes throughout the whole area that includes the autopsy… particularly for a woman in a particular faith, there may be a concept of knowing that she was put naked in the same place as a man. That would be completely against… those who believed when in life that shouldn't happen and why should we be treated any differently in death…*

Concerns were also expressed about how the dead person is moved around the hospital:

*I'd just like to mention the circulation of the dead around the hospital... I could be in a lift with somebody that has just come in to see his wife give birth, there's also the dead arriving, other patients coming in, with neonatal activities in facilities management together with the food and shops, so for dignity it has to be kept somehow separate.*

*... we've recently separated out our Admissions and our Bereavement Offices, as we know from talking to Admissions patients that coming in to book yourself in at the same place as the Bereavement Offices where relatives are coming in to book people out effectively doesn't give you a very good message if you are booking into surgery.*

## Summary

The outcome of the consultative conference was strong support for the following recommendations.

- The Department of Health should develop national standards for the environment for end-of-life care and significantly increase investment in these environments.

- All health service providers should include care of those who are dying, bereaved or deceased in corporate induction programmes for all staff.

- Policy and practice development should aim to enable everybody to make a choice about where they would prefer to die and to revisit that choice as their condition changes.

- Professional training for all staff groups should include material on the impact of the environment in end-of-life care.

- All staff should be accountable for supporting the essential 'personhood' of deceased individuals in all areas and departments of the health care organisation.

- The Department of Health and other organisations that fund academic research should call for and support further research into: how spaces unique to end-of-life care should make people feel; the use and acceptability of language and signs related to end-of-life care environments; how best to involve dying people and bereaved relatives in the design and delivery of end-of-life care services; and the need for dedicated palliative care facilities in acute hospital settings.

# 5 Discussion and recommendations

During the course of this work we have: identified what was already known; learnt lessons about how to improve environments for care at end of life; and identified a strong expert consensus over a small number of recommendations that would improve the policy context for this work and help ensure that it becomes part of a systematic approach to improving end-of-life care in the round.

## The literature

The literature review undertaken at the start of the ECEL pilot programme identified a relative lack of research-based literature on the impact of the environment on end-of-life care. The review did identify a small number of key environmental factors – for example, the need for privacy, lack of noise, homeliness and personalisation, as well as emphasising the importance of nature, natural light, access to outside spaces, and use of natural colours and materials, including artworks, in creating calm and peaceful environments. However, these are factors that could be said to be features of good design for any environment of care. The programme and concurrent action research have sought not only to improve environments radically in eight health care organisations but also to identify themes and issues that require further research.

## Environments for Care at End of Life

Some health care environments are unique to end-of-life care – for example, palliative care units, and bereavement and viewing facilities; the pilot programme provided the opportunity to research the significant impact that environmental improvements in these areas can have on improving care. The critical importance of how an environment both looks and feels has been emphasised.

Half the projects focused on mortuary viewing areas and addressed not only the viewing facilities but also the waiting areas and corridor approaches. These corridors were found to be of particular significance because mortuaries are often situated towards the back of hospital premises and reached via cluttered service corridors.

A number of other environmental and service delivery issues have been identified as a result of the work. Within pressured ward environments, concern has been expressed about how long the bed space should be left empty after a death. This raises issues of dignity and recognition that fellow patients and staff have also been bereaved.

The sensitive care of families and friends after bereavement has been a feature of all the pilot schemes and led to significant improvements in bereavement suites and recognition that administrative procedures need streamlining. For example, office space has been

created to allow for the registrar to be based at the hospital site, rather than asking relatives to make another journey at a time of grief. Work still needs to be undertaken on improving the management and manner of return of the patient's property after death.

## Lessons learnt from the ECEL programme

The project teams learnt much from the practical experience of transforming eight environments for care at end of life. All those involved learnt that user involvement positively shaped their projects and that such engagement was best achieved by building on existing relationships between patients, families and particular staff or particular services. The teams learnt that users often stressed that the 'message' given by the environment was key and that the most important element of that message was that the health care organisation cared for them.

Consultation with staff was also identified as a critical activity, although teams often needed to resolve different user and staff perspectives by providing patients or users with a high degree of choice or control over how the environment might work for them. All teams found the issue of finding appropriate language, symbols and images difficult and learnt that it is important to highlight these issues at the beginning of the work. Finally, the teams learnt about the need to manage significant culture change in the way staff thought about end-of-life care. The teams believe that a more public debate about the role of health services in meeting public expectations of end-of-life care would be a significant help in challenging current expectations and shaping future policy and practice.

Since their projects have been completed, team members have been asked to lead other environmental projects locally, related to both end-of-life care and more general schemes. Involvement in the pilot project has also had other positive consequences – organisations rewriting their end-of-life care strategies, bereavement policies and procedures for mortuary viewing. It has also more generally informed processes and procedures of user involvement in service development, delivery and evaluation.

Those interviewed as part of the action research and expert participants at the consultative conference believed that the numbers of those who die in hospitals were likely to continue to rise. Many of those who die are likely to be older people being cared for in non-specialist areas of the acute hospital, such as general medical, surgical and orthopaedic wards. For these reasons it is thought likely that more acute trusts will wish to consider setting up specialist palliative care units to provide a better service for such patients. These units are likely to provide opportunities for future research and evaluation.

From discussions with the pilot participants on all sites, there seems to have been an otherwise undocumented increase in the number of people wanting to use mortuary viewing facilities generally, the size of groups (up to 20) wishing to view and the number of visits occurring (about 25 per cent visit more than once). There is a strong perception that this pattern has changed markedly over the last decade, and that some groups are particularly likely to want to visit in large numbers and stay longer. This may herald a changing social expectation with regard to viewing those who are deceased, which has implications for the location, design and maintenance of viewing facilities in health care organisations. Should this trend continue, there are also implications for procedures associated with the viewing process and for staff training and support. It is important to recognise that, for many families and friends, a visit to the mortuary may be their only

experience of the trust, so this visit is likely to leave a lasting impression of the quality of care that has been delivered.

## Key points arising from the consultative conference

The consultative conference helped identitfy how the impact of this work could be maximised by creating a systemic approach to improving end-of-life care in the round. We believe the recommendations for national standards; significant investment; corporate induction programmes that include end-of-life care; professional training on the impact of the environment; and a programme of targeted and tailored research, would, if adopted, create a health policy environment in which the new programme could achieve the biggest positive impact for those patients, carers and families who too often currently experience a health system not at its best.

## Recommendations

There is no doubt that the environment plays a critical role in transforming service development and delivery for those at the end of life, and those who are bereaved or deceased. Emerging findings from the pilot and concurrent action research have been shared with key stakeholders throughout the programme, and have informed both the development of the national end-of-life care strategy for England and the support that the King's Fund has given to hospice design projects.

*As a result of the literature review and our practical experience we recommend* that the Department of Health and other organisations that fund academic research call for and support further research into how spaces unique to end-of-life care should make people feel; the use and acceptability of language and signage related to end-of-life care environments, and; how best to involve dying people and bereaved relatives in the design and delivery of end-of-life care services and the need for designated palliative care facilities in acute hospital settings.

*As a result of our practical experience we recommend* that all the settings within which end-of-life care occurs provide:

- a room where patient and family can be taken for confidential discussions
- the option of a single room accommodation designed to engender a feeling of homeliness  where patients retain control over their environment
- informal gathering spaces and places where families can meet, confer and talk with care staff
- guest rooms where close family or friends can stay overnight with facilities for catering and internet access
- appropriate places for 'viewing' the deceased.

*Our practical experience also leads us to recommend* that all health service providers include care of the dying, bereaved and deceased in corporate induction programmes for all staff and that professional training for all staff groups should include material on the impact of the environment in end-of-life care. *We also recommend* that all staff should be made aware of the need to recognise and respect the essential 'personhood' of deceased individuals in all areas and departments of the health care organisation.

*As a result of our consultative conference, considering the issues raised by the work, we developed additional recommendations* that the Department of Health should develop national standards for the environment for end-of-life care, significantly increase investment in these environments and ensure that policy and practice development enables everybody to make choices about where they would prefer to die and to revisit that choice as their condition changes.

# Project directory

| | |
|---|---|
| **Trust** | **Birmingham Children's Hospital NHS Foundation Trust** |
| **Address** | Steelhouse Lane |
| | Birmingham B4 6NH |
| **Project location** | Rainbow Suite (viewing suite) |
| **Project** | Refurbishment of suite including creation of courtyard garden |
| **Funding** | Birmingham Children's Hospital Charities (£20,000) Trust capital funding |
| **Costs** | £55,000 |
| **Artists/designers** | Rita Patel: signage |
| | Frank Tiggs: courtyard bench |

| | |
|---|---|
| **Trust** | **Christie Hospital NHS Foundation Trust** |
| **Address** | Wilmslow Road |
| | Withington |
| | Manchester M20 4BX |
| **Project location** | Viewing suite and corridor |
| **Project** | Refurbishment of access corridor and viewing suite including creation of bereavement office |
| **Funding** | Christie Hospital Charitable Funds (£20,000) |
| | PPI project capital (£20,000) |
| | Greater Manchester SHA (£30,000) |
| | Trust capital funding |
| **Costs** | £91,000 |
| **Artists/designers** | Wendy Short, AFL Architects: design |
| | Pat Mountford: artwork |

| | |
|---|---|
| **Trust** | **Guy's and St Thomas' NHS Foundation Trust** |
| **Address** | St Thomas' Hospital |
| | Westminster Bridge Road |
| | London SE1 7EH |
| **Project location** | South Wing, St Thomas' Hospital |
| **Project** | Commissioned window for bereavement centre |
| **Funding** | Guy's and St Thomas' Charity (£20,000) |
| **Costs** | £20,000 for the artwork |
| **Artists/designers** | Karen Lawrence: glass window |

| | |
|---|---|
| **Trust** | **King's College Hospital NHS Foundation Trust** |
| **Address** | Denmark Hill |
| | London SE5 9RS |
| **Project Location** | King's College Hospital |
| **Project** | Refurbishment of mortuary viewing room |
| **Funding** | King's Charitable Trust (£25,000) |
| | Friends of King's (£20,000) |
| | Patients' amenity fund (£800) |
| | Trust capital funding |
| **Costs** | £72,657 for the mortuary viewing room |
| | Additional £112,745 for the corridor |
| **Artists/designers** | Douglas Reid Associates: architects |
| | Ed Hodgkinson: artworks |

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|---|---|
| **Trust** | **Royal Brompton and Harefield NHS Trust** |
| **Address** | Royal Brompton Hospital |
| | Sydney Street |
| | London SW3 6NP |
| **Project location** | Royal Brompton Hospital |
| **Project** | Refurbishment of viewing rooms and creation of bereavement office |
| **Funding** | The Royal Brompton and Harefield Hospital Charitable Fund (£20,000) |
| | League of Friends (£4,000) |
| | Patient amenities Fund (£7,000) |
| | Paediatric fund (£7,000) |
| **Costs** | £38,000 |
| **Artists/designers** | Alison Wright: designer |
| | David Planner: architect |
| | Jacqueline Hume: artist |

| | |
|---|---|
| **Trust** | **United Bristol Healthcare NHS Trust** |
| **Address** | St Michael's Hospital |
| | Marlborough Street |
| | Bristol BS1 3NU |
| **Project location** | Ward 72 |
| **Project** | Creation of two palliative care rooms |
| **Funding** | The Charitable Trusts for the United Bristol Hospitals |
| | Trust capital programme |
| **Costs** | £128,225 |
| **Artists/designers** | Matt Budd: photographs |
| | Ripples Bathrooms: bathroom design |

| | |
|---|---|
| **Hospice** | **Marie Curie Hospice – Glasgow** |
| **Address** | 1 Belmont Road |
| | Springburn |
| | Glasgow G21 3AY |
| **Project location** | Second floor ward |
| **Project** | Redesign and refurbishment of family room |
| **Funding** | Marie Curie |
| | Donations of flooring, curtains and TV |
| **Costs** | £21,340 (excluding donations) |
| **Artists/designers** | Mura Mullen, Jane Darbyshire and David Kendall Ltd: architects |
| | Gavin Marshall: glass artwork |
| | |
| **Hospice** | **Marie Curie Hospice – Hampstead** |
| **Address** | 11 Lyndhurst Gardens |
| | London NW3 5NS |
| **Project location** | Hampstead Hospice |
| **Project** | Redesign of single rooms |
| **Funding** | Marie Curie |
| **Costs** | Circa £3,500,000 for the hospice refurbishment |
| **Artists/designers** | Tangram: architects and designers |
| | Imogen Luddy: resin artworks |
| | Alison McGill: oil and wax landscapes |
| | Professor Carole Hodgson: cellulose and aluminium sculptures |
| | Till Junkel: multi-media panels |
| | Sine Lewis: woven collage |
| | Carol Andrews: plaster of Paris 'coelenterates' and etched Perspex sculptures |
| | Kara Penn: glass artworks |

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