Improving the patient experience

A place to die with dignity: Creating a supportive environment

NHS Estates

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A place to die with dignity: Creating a supportive environment

Contributing to the Debate

Design Brief Working Group, NHS Estates

For information only
for NHS Trusts
and NHS Foundation Trusts

Contents

'I know death hath ten thousand doors. For men [and women] to take their exits.'
John Webster, 1580?–1625

Foreword

This consultation document sets out the work to date of the Design Brief Working Group (DBWG)[1] on 'A place to die with dignity: Creating a supportive environment'. The document is not definitive, but is intended to outline the key issues, to bring about new thinking and to generate an agenda for good practice around the subject.

For most of us, dying is not a subject that we wish to address; we put it to the back of our minds. This is possibly the reason that, in terms of the design of healthcare environments, "death" and "dying" have not received consistent attention. Recently, there is evidence of an increasing interest in providing places that support a dignified death. Given that 60% of deaths occur in a hospital environment, this is an important subject.

The design of the hospital environment needs to reflect changes in healthcare, but there is also an increased understanding that the quality of the design of healthcare environments impacts significantly on patients, staff and relatives. NHS Estates commissioned the DBWG to produce a paper as one of a number of occasional papers in a series considering the humanisation of the healthcare environment.

1 DBWG is an interdisciplinary group set up by NHS Estates to study subjects related to briefing in healthcare design

It considers how the design of the hospital environment might positively impact on death and dying.

We recognise that it is a first priority that managers develop arrangements to treat and manage patients and their families with dignity and respect. We suggest that staff include palliative care arrangements in patients' care plans. In terms of the hospital environment, our conclusion is clear: the objective must be to design a supportive environment for patients, relatives and staff. In this document we describe in broad terms what might be the requirements of such an environment before and after death.

Our definition of a "supportive environment" is one in which physical, operational and

emotional requirements have been addressed appropriately to create spaces that provide a quality of life, for as long as is required, in which people are comfortable – a sensitively designed space suitable for a diverse community.

Based on the views of religious and charitable establishments, the main focus of the development of contemporary healthcare buildings is that they should become "people-centred therapeutic centres". 'A place to die with dignity' fits within this context. It is intended as a consultation document for all those involved in creating and working in healthcare facilities. It is aimed at NHS trusts and NHS Foundation Trusts, but will be of interest to commissioners and those providing services outside the NHS. Their expertise is acknowledged, and we very much welcome experiences from these sectors.

Using study methods of interview and consultation, literature search and group discussion, this consultation document was developed by taking evidence from key people whose experience is specifically related to the care of the dying.[2]

As the work progressed, it became clearer and clearer that this is a neglected area. There is more relevant information and examples of good practice for us to consider, and we know that there are many with a key contribution to make whom we were not able to reach in the time available. Given the wide range of people with relevant expertise and experience, it was agreed that rather than attempt to produce a finalised document, we would instead share our current thinking and identify what we think are the key questions.

Richard Burton CBE
Chair, Design Brief Working Group

'It is already bad enough; you can either make it a lot worse or a lot better.'

Barry Albin

2 The evidence givers were: Barry Albin, Albin & Sons, Funeral Directors; Molly Cook, Paediatric Counsellor, Guy's and St Thomas's Hospital; Simon Henderson, Chief Architect, Macmillan Cancer Trust; Pauline Kingston, Chair of the Council of Palliative Nurses; and Reverend Robert Mitchell, Chaplain, Royal Free Hospital, London

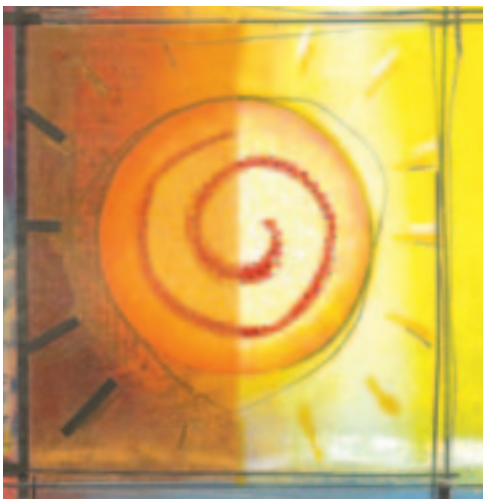
1. Context and purpose of this document

The medical profession is experienced at diagnosing dying; this is generally carried out in hospital by a clinical team. But anticipating time of death is difficult and affects decisions about where the patient should be placed, and when. Further difficulties are met, for example, since the single rooms traditionally used for dying patients are often utilised for other clinical purposes. Thus the question: where do people die when in hospital? – so that we can verify that we are designing for the right areas.

The total number of deaths in England and Wales in 2002 was 533,527,[3] with the majority of people dying in hospital (57% in hospital, over 4% in hospices and 18% at home).[4]

It may be assumed that people die on a hospital ward, but there are many different places where death takes place throughout the hospital, including a multi-bed ward, a single room, a Critical Care area, an A&E department or in an ambulance.

The palliative care nurses consulted for this document had the aura of caring, efficient



people whose job is certainly one of the very keys to "dying with dignity" and helping to deal with the processes that follow. They expressed various needs including:

- office space (for the administrative functions that follow death);
- areas for the grieving relatives, including dedicated areas for bereavement counselling;
- quiet rooms for staff;
- provision for religious and cultural needs.

A sensitive approach is required to the feel of the places where death and dying (and their associated processes) take place. The relationship of these spaces to the main health buildings, including access and

3 Mortality Statistics: general, Series DH1 no 35, Review of the Registrar General on deaths in England and Wales 2002, London: Office for National Statistics

4 *ibid.* (The remaining percentage dies in other establishments, residential or nursing homes.)

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ingress and so on, is another important consideration. The environment needs to be sufficiently flexible to enable the nurses and other healthcare professionals to work effectively.

The Hospice movement has affected all death services, **placing the emphasis on *quality of life* before death**; at present, only just over 4% (22,891 in 2002) of deaths occur within a hospice environment.[5] Dying at home is favoured by many; a survey conducted by Marie Curie Cancer Care indicated that 75% of people seriously ill with cancer would prefer to die at home.[6]

Responding to such a survey needs to take into account the suitability of people's homes for the period before death, as well as how people's views can change once in a caring hospital environment, where they become familiar with staff and have a wide range of equipment and skills at hand, as well as pain relief. Many say initially that they would like to die at home but then change their minds as their condition progresses. More research is probably required in these two areas, but the objective of enabling more people to die in their preferred environment remains valid.

One palliative care nurse interviewed by the DBWG, having experienced patients changing their minds once in hospital, suggested making the environment of the hospital more homely. This has been one of the leads to the idea of a supportive environment, which includes art and design in the immediate surroundings.

In our study, we learnt from the funeral director interviewed what a complicated process follows death, which suggests that the need for a re-examination of post-death arrangements in large medical institutions is pressing.[7]

We can assume that, together with other initiatives, death has taken its place as an important subject in contemporary thinking about caring; for example, the British Medical Journal devoted an issue to the overall subject of death.[8]

These matters create an agenda of issues that need to be reflected in the briefs.

The rest of this document therefore sets out for consultation:

1. What are the key issues that trusts should consider in shaping the environment? (see Section 2)
2. What are the strategic objectives (the Strategic Brief) that trusts should aim to deliver? (see Section 3)
3. How might trusts specify this in the project design brief? (see Sections 4 and 5)

Key issues for consultation are included in each section.

Two annexes are also included. The first gives specific thanks and acknowledgement to those involved in the production of this discussion document. The second lists those documents and research papers of which we are aware at present, and invites further suggestions.

'Death is nothing at all … I have only slipped away into the next room.'

Canon Henry Scott Holland, 1847–1918

5 Mortality Statistics: general, Series DH1 no 35, Review of the Registrar General on deaths in England and Wales 2002, London: Office for National Statistics

6 http://www.mariecurie.org.uk/nursing

7 For example, the number of different locations a bereaved family member has to visit in order to deal with administration after death can be high; bringing together all these requirements in one location would make these responsibilities easier to carry out at a particularly emotional time

8 Death and Dying, special issue of the *British Medical Journal*, 26 July 2003

2. Recommendations and key issues

What are the key general issues for the NHS?

The following sets out ideas for the key general issues that the NHS should seek to address in relation to death and dying in the hospital environment:

- Endeavour to raise expectations, standards and aspirations amongst key stakeholders and decision-makers in this context.
- Increase knowledge of where patients die within the hospital, in order to understand more clearly what spaces and facilities are required, and where.
- Simplify the bureaucracy and processes surrounding death; for example, bring all post-death bureaucracy together, in one building, or in closer proximity to the hospital.
- Undertake research into the issues raised in Section 1 concerning the choice between dying at home or in hospital.

What are they key specific issues for NHS trusts?

The following sets out ideas for the key issues that NHS trusts should seek to address in providing an appropriate place to die with dignity:

- Create a supportive environment for patients, staff and relatives.
- Embed within all NHS trusts strategic thinking on the relationship between the design of the hospital environment and the ways in which death and dying are dealt with.
- Consider the design, location and management of facilities (mortuary, viewing rooms, bereavement counselling etc) and other functions.[9]

9 See also HBN 20 'facilities for mortuary and post-mortem services', The Stationery Office, 2005 and DH guidance on 'Bereavement' (htttp://www.dh.gov.uk/PolicyandGuidance/HealthAndSocialCareTopics/Bereavement/ts/en)

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- Examine the responsibility within the trust for dealing with death, developing a clear system of administration and designating a lead person to oversee issues relating to death.
- Focus on efficient care, but also remember the personal and social issues that arise.[10]
- Support the chaplaincy and spiritual healthcare workforce in the context of the design of healthcare environments (see *NHS Chaplaincy guidance*[11]).
- Do not assume sets of behaviour common to all situations (see *NHS Chaplaincy guidance*[12]).

'Visitors need to be with patients rather than simply visiting.'

Reverend Robert Mitchell

10 For example, whilst it may not be cost-effective to provide 24-hour care at home, the personal benefit to the patient of the supportive quality of the home environment may be greater

11 *NHS Chaplaincy: Meeting the religious and spiritual needs of patients and staff*, Guidance for managers and those involved in the provision of chaplaincy-spiritual care, Department of Health, 2003

12 *ibid.*

3. Designing a supportive environment: Creating a strategic brief

The objectives should cover the quality of an environment that is supportive not only to the patient and family but also to the staff. In a large institution, the journey to the mortuary and the viewing rooms and access for relatives (both entrance and egress) should be carefully considered. The cultural, religious and social needs of patients, visitors and staff should be included in this consideration, with the objective being to provide appropriate and adequate accommodation for religious and spiritual care for all who require it, including those with spiritual beliefs without a specific religious affiliation. Consideration should also be given to the impact of the dying patients on others – *caring for the carers*, for instance.

In this document, issues for consideration by trusts and their designers have been layered according to *building* (shell and services), *fit-out* (scenery) and the fine-tuning of the environment to create the appropriate *settings*. Allowing staff to respond to the personal needs of patients and the diverse needs of families can be supported by the design team through the thoughtful planning and design of the building shell and services to support the flexible layout and management of the interior.

Building

At the level of the design of the *building* (shell and services), we suggest special consideration be given to the configuration of the building to allow for:

- a clear pattern of circulation that separates the movement of facilities and staff from processes (for example the movement of bodies). The position of an entrance to the mortuary and viewing rooms is a key issue;
- a choice of routes: consider the emotional impact of dedicated circulation systems in relation to cost;
- adaptability for spaces to be used for a variety of functions at different times of the day, so providing greater flexibility and potential intensification of usage.

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Fit-out

At the level of *fit-out* (scenery), we would recommend consideration of the allocation and design of spaces to allow for:

- adaptable usage; for example, single rooms becoming a double with interconnecting doors, providing generous space allowance to meet a variety of cultural, religious and social requirements;
- finishes that can be personalised by lighting and personal possessions.

Settings

At the level of *settings* (fine-tuning), we recommend the following be considered:

- ways of adjusting the impact of sight, sound, smell, touch and taste (for example, consider how to control smell in certain circumstances);
- the discreet storage and positioning of equipment (for example, reference to solutions developed for maternity wards may offer possibilities in this context).

4. Design Brief (designing a supportive environment for patients, family/visitors and staff)

Key considerations before death

- The scope and objectives relating to death and dying within a hospital environment, including the operational policies, need to be clear, agreed and understood by those staff involved.
- Effective clinical care and support by staff is the key to *dying with dignity*. The environment should in no way interfere with these requirements and, indeed, should be supportive so that the patient space becomes a part of the process of *dying with dignity*. The environment should also be supportive of relatives and staff.
- The space, preferably a single room, should be calm and quiet, of adequate size to accommodate family members over 24-hour periods, and should be designed for good communication and observation by staff. Staff are likely to want family members and visitors to leave the space at times, so there should be private break-out areas, with refreshment facilities, in close proximity. This will also help, psychologically, to mitigate the effects of long periods with the sick patient and give the family somewhere to talk amongst themselves, to medical staff and others out of hearing of the patient.

- It is essential that the patient space can be private and soundproofed so that other patients are not disturbed.
- The opportunity to bring familiar items from home should be considered – photographs and small objects placed within easy view of the patient.
- The space should ensure privacy and allow some patient control of the environment, and should include a view from the windows and an area to hang suitable works of art. It is hoped that the patient is not moved around the hospital at this stage.
- Large numbers of family and visitors for the patient can be very disturbing for other patients and staff, thus

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consideration should be given to the adjacencies and the position of the patient space without sacrificing staff observation.

- The patient space should be able to adapt to differing cultural and religious practices. One way of approaching this would be to consider carefully any use of religious symbolism, deliberate or inadvertent, to ensure that spaces remain appropriate to all users. This may mean flexibility of furnishings, so the design of spaces is not faith-specific but can be altered to suit (see *NHS Chaplaincy guidance*[13]).
- Staff needs should also be taken into account; for instance, a good staff rest space is essential.
- Living wills need to be acknowledged.
- Consideration needs to be given to issues surrounding the possibility of organ transplantation.

All the above assumes death on the ward. Death in a Critical care area or A&E department will require a different approach, with due consideration given to the family and provision of adequate waiting areas.

'The next best thing to home.'

Pauline Kingston

13 *NHS Chaplaincy: Meeting the religious and spiritual needs of patients and staff*, Guidance for managers and those involved in the provision of chaplaincy-spiritual care, Department of Health, 2003

5. Design Brief (designing a supportive environment for patients, family/visitors and staff)

Key considerations after death

- Again, the scope and objectives relating to death and dying within a hospital environment, including the operational policies, must be clear, agreed and understood by those staff involved.
- It is important to cater for emotional and spiritual needs – with provision of special areas for peace, privacy and quiet. For example, dedicated areas for those who want to grieve, either alone or in a family group, and to meet with bereavement counsellors will be key. The body may remain where death takes place for several hours, and therefore privacy is important.
- Consideration should be given to all approaches, adjacencies and routes (entrances and departures), for example the journey for the bereaved from the place of death to the mortuary.
- Spatial requirements should be considered, for example the mortuary area and viewing room,[14] pathology and chaplaincy. Also, consideration should be given to providing space adjacent to the patient space to allow for large numbers of visitors.
- Cultural, religious, spiritual and social conventions should be respected. For example, the viewing room and its approaches should be considered as a neutral or multi-faith space and treated accordingly in art and design terms.[15]
- Transit/equipment should be considered, for example a well-designed bier to be used to transport the body from the place of death.

'Death must be distinguished from dying, with which it is often confused.'

Reverend Sydney Smith, 1771–1845

14 *Facilities for mortuary and post-mortem room services*, Health Building Note 20, London: The Stationery Office, 2004

15 Some geographical locations have a known local religious population that may mean that it is possible to create specific spaces for that group, but not at the exclusion of smaller groups. Other locations may have a more diverse community. Local populations can change over the lifetime of a hospital building

Appendix 1 – Acknowledgements

Consultation

The Design Brief Working Group would like to thank the following for their valuable contribution to this paper:

Barry Albin, Albin & Sons, Funeral Directors

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'It hath been often said that it is not death, but dying which is terrible.'

Henry Fielding, 1707–1754

Appendix 2 – Selected bibliography and references

We wish to include as many relevant references as possible, and would welcome any further suggestions for inclusion.

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