Fresh eyes approach

Caring to the end: shining a spotlight on bereavement and mortuary services
Acknowledgements

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Award winning programme

We were delighted that our ‘fresh eyes’ programme won the Environment of Care award at the Patient Experience Network National Awards: https://m.youtube.com/watch?v=ghgsUoLoewU

Contact the Clinical Team at Hospice UK

Website: www.hospiceuk.org

Telephone: 020 7520 8200

Email: clinical@hospiceuk.org

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1. Aim

This report summarises Hospice UK’s learning from our ‘fresh eyes’ walkthroughs of bereavement centres and mortuary services in 12 acute hospital trusts across England, taking part in two end of life care hospital improvement programmes supplemented with an analysis of mortality data. A ‘fresh eyes’ walkthrough provides a focused review of a potential family or carers’ journey through and experience of an acute hospital by a small expert team from Hospice UK.

This report focuses on bereavement and mortuary services; other reports describe the methodology and broader learning from the programmes.\textsuperscript{1,2,3,4}

It is crucial that acute hospital trusts see care after death as an essential component of high quality end of life care, value the important role of staff and acknowledge their expertise in providing care for the deceased and supporting their bereaved friends and families.

2. Background

Caring for people who are dying, death, and supporting those who are bereaved is an everyday occurrence in an acute hospital; we have only one chance to get this right. With around 46% of all deaths in England currently occurring in hospital every year\textsuperscript{5} it is important that hospital trusts provide the best possible quality care after death, and support those who are bereaved.

"All remarked positively about any member of staff who responded to them in a caring or empathetic way. These people and their actions were remembered with clarity and described with great warmth" Silvey (1990) experiences of bereaved whose loved ones died in hospital quoted by\textsuperscript{7}.

How bereaved people experience the events around death is an important factor in their long-term well-being\textsuperscript{6}; the journey from pre-death to bereaved is often affected by: poor communication from all staff and between staff internally and to external sources; not being fully involved in the process; staff not aware of relevant policies; problematic environmental factors; a lack of specialised staff for advice and support; and a need for good quality information\textsuperscript{7}. There are bereavement good practice standards for bereavement services\textsuperscript{8}.

Despite this, bereavement and mortuary services are often viewed as an invisible service in acute hospital trusts. Our team – which includes an expert lay-member with lived experience of death of a family member within an acute hospital and professionals with a background in end of life care and quality improvement (who also may have lived experience) – can help to raise the profile of these services, highlighting current good practice and areas for improvement.
3. The services

All the hospital trusts we visited had bereavement and mortuary services.

The types of routine bereavement service included: cause of death certification, information-giving and navigation to other services including what to do after someone has died, and return of any personal belongings. Many also either obtain feedback about the experience of care from the next of kin’s perspective – either routinely by questionnaire or prompted questions during the bereavement meeting or on an ad hoc basis if bereaved people themselves raised any questions or concerns about care. Some of the hospital trusts had a medical examiner who proved invaluable in supporting bereaved people and delivering quality improvement in systems and processes after a death within the hospital. A small number of hospital trusts had a co-located death registration service, which reduces the burden on bereaved people.

The mortuary services provide visiting areas, post mortems and safe and dignified handovers of the deceased person (from wards and then onward to funeral directors) and co-ordination with pathology services as needed. Some of the services provided care for those who died in that hospital trust while other services had a regional remit. Mortuary services are regulated by the Human Tissue Authority, which inspects these services against 42 standards.

“I wanted to visit my husband after he died, as usual. Please don’t invite me to view him.”

Some emergency departments (EDs) / acute assessment units also provide dedicated visiting rooms for bereaved relatives or friends. All hospitals had family rooms for those relatives who are distressed and need a private space away from the busyness of the ward.

All the hospital trusts we visited also had dedicated staff and / or links with local faith groups to provide faith and spiritual care for patients, those who are bereaved, visitors and staff.

Overall, there are highly trained staff and volunteers working in the hospital trusts who work beyond the boundaries of the acute trust – for example with funeral directors, coroners, other providers and statutory bodies.
Throughout our visits we were struck by the professionalism and compassionate care offered by staff working in the mortuary and bereavement services. There are opportunities for hospital trusts to raise the profile of these services with benefits to enabling a trust-wide approach to providing care with compassion and dignity.

The following points are a summary of what the Hospice UK visiting teams felt were important considerations in these services, as a synthesis of good practice and areas for potential improvement seen during the walkthroughs. Examples are illustrated on pages 6 to 10.

The importance of care with compassion – we met compassionate staff who were passionate about their roles, and knowledgeable, skilled leaders who actively sought involvement and feedback from those they support.

Language and terminology are important. Appropriate symbols and labels reflect the wider philosophy of care, and supported by knowledgeable and competent staff.

“"We as mortuary and bereavement staff are often the last healthcare contact families will have with bereaved people, so it is important we get it right."”

Good communication skills and a dignified transfer – staff talked about the importance of communication between teams to ensure that care was seamless, for example between ward, bereavement and mortuary teams. The visiting teams were also concerned with ensuring all deceased persons were transferred with dignity from the ward to mortuary, in line with needs (e.g. bariatric, children/babies, faith) with careful consideration to details such as covers. Also, the type of bag containing the deceased’s belongings often needs consideration.

The infrastructure and resources around staff will help them to provide care with compassion: necessary equipment / information materials and ensuring a responsive timely service. For example, providing junior doctors with a dedicated area, equipment, support and a cup of tea when completing cause of death certificates. Some extra support may help doctors deal with their first / and or more difficult deaths.

The importance of having nice physical environments – as people who are bereaved are likely to experience heightened awareness of their surroundings, so it is possible that poor and inappropriate physical environments may add to their distress. A poor environment maybe interpreted that the service does not care. This is true across all spaces – visiting rooms, waiting areas, meeting / family rooms, corridors, faith / multi-faith areas. Our visit highlighted consistent themes of good lighting, seating, colour schemes, accessibility, quiet, clutter-free calming areas and appropriate furniture all being important. We saw some areas of excellence consistent with ‘enhancing
healing environments’ but alongside areas of excellences we saw known problems that had not been prioritised until our visit. For example, poorly ventilated, stark mortuary visiting rooms. Even hospital trusts with good facilities, were sometimes let down by “unloved corners” and dreary corridors, poor seating and/or inappropriate decorations. We also saw examples of rooms and spaces that had been excellent in the past but standards had not been sustained, for example visiting rooms with stained furniture and the room appearing worn.

“For the bereaved, the memories that they have of a loved one are inextricably linked to the environment in which they last spent time with them”.

**Importance of facilities and spaces** – clear signage, good information provision, easy 24/7 access to refreshments, availability of tissues, water, flowers and wheelchair access within visiting services, easy access to parking and when required dedicated space near the relevant suites. The availability of an appropriate visiting room near ED or acute assessment areas allows bereaved relatives and friends to visit their loved one. Family rooms in these areas and in the wards allow staff to give bad news in privacy.

**Faith and spiritual care** – consider the arrangements and environments to supporting a full range of faiths and those with no faith – generally the Hospice UK team felt that staff and potentially volunteers working in this capacity may need support to understand quality improvement methodologies. We found examples where spaces tried to meet the needs of all, but appeared to miss their overall purpose resulting in not meeting anyone’s needs.

**Innovation** – we met a medical examiner and heard now this new role could improve people’s experience and heard of other developments such as using CT (computed tomography) scans in post-mortems to improve effectiveness of services.

**Sufficient resources and space** are important – space for the deceased to rest in dignity, available and appropriate rooms for private, important conversations and good administrative systems and capacity to ensure there are no unnecessary delays in cause of death certification and pathology turnaround. In our visits in January 2018 to April 2018, a number of mortuary staff highlighted that contingency spaces for the deceased were being used outside of the winter pressures and that things had been extremely challenging during this winter period. We looked at this further, using national data to better understand these pressures.
“The corridor of doom to the mortuary”
The reception staff at the main entrance to the hospital told us they felt bad when directing relatives or friends to bereavement services from the main entrance.

A mortuary visiting room where the bed was too high to sit next to your deceased friend or relative. The room felt a bit ‘unloved’.

Poor signage
The visiting team struggled to find their way around some hospitals. If we had been distressed or anxious, it would have been even more difficult.

Examples of areas for suggested improvement: pictures and comments from the reports where we don’t have pictures

Bereaved relatives had to wait in a busy corridor for their slot in the bereavement office. A family sat in a row looking stunned, at the same time the hospital appeared to rush by.

Delays in death certification potentially causing additional distress. Are junior doctors being supported well enough?
A corner in a multi-faith area
Unclear if the information is for staff or visitors? Will everyone feel welcome? Could ‘enhancing healing environments’ offer a different approach to interior design?

Dignified and showing you care. What is covering the deceased? How are they being transferred to the mortuary? Are bariatric people’s needs met?

Welcoming to all?
Washing facilities inside a multi-faith room.

Visiting teams reflected on use of “cheap plastic bags” feeling someone’s belongings are being “dumped”. The staff couldn’t see this, as it was improvement to what they used before these bags.
The impact of ‘fresh eyes’ and using photos to show and celebrate improvements

From this…

To this…

Relatively simple changes
(use of colour, furniture, decoration) to an existing relatives’ room in ED makes a big difference to the comfort and functionality of an important small space. Many hospital trusts said it was relatively easy to fund these types of changes, including seeking charitable funding. It is important to plan for the maintenance to retain high standards and stocking of disposables (e.g. tissues, drinks).
Examples of areas the visiting team liked: pictures and comments from the reports where we don’t have pictures

Knowledgeable and compassionate staff.

Mortuary visiting
Same site has a dedicated visiting room for children and babies.

Comfortable chairs and resting areas in long corridors. Mobility assistance being available if needed. Pockets of calm.

Quiet, calm space
The relatives’ room in the acute assessment area. A quiet and calm oasis.

Clear feedback loops, and a sense of feedback being listened to and acted on.

Mortuary and bereavement staff’s roles being recognised by the trust.

Mortuary visiting
The waiting area for bereaved people. Natural light, dedicated parking.
**Memory tree**
An elderly care ward in an acute Hospital.

**A visiting room next to ED where a bereaved person can visit their loved one after a sudden death without delay and in privacy with free tea and coffee.**

**Notice board**
Communicates and informs that a space is for all faiths.

**Information leaflets**
How to access religious and spiritual care for all.

**A bereavement space with natural light and a dedicated garden.**

**Visiting Hospice UK team likes**
- Dedicated parking near the relevant bereavement suites
- Tasteful cloth bags to return special items (usually funded through charitable donations)
- Dedicated environment / facilities for a baby or child after death
- Treating the deceased person with the same dignity as in life
- Using the word “visit” rather than the word “view”
5. Service planning over winter and in the future

As highlighted already, during our visits from January 2018 to April 2018, the mortuary staff we met alerted us to how busy their services were during winter pressures. Our visits did coincide and followed a very busy winter period in the NHS. In this time “the NHS has been under sustained pressure over the Christmas period with high levels of respiratory illness, bed occupancy levels giving limited capacity to deal with demand surges, early indications of increasing flu prevalence and some reports suggesting a rise in the severity of illness among patients arriving at A&Es”13.

“We had problems with capacity in the mortuary ... if the funeral directors are also busy, it means it can take longer for the deceased to be transferred ...”

There is seasonal variation in the number of deaths. January 2015, 2017 and 2018 in England and Wales were significantly higher than seen in previous years14 and the potential reasons for this are complex14,15 (and although important are outside of the remit for this report). Our focus is on how mortuary and bereavement services plan and respond to meet these increases, regardless of the underlying causes, to ensure that everyone receives equally dignified and compassionate care regardless of the time of year.

Anecdotally, our conversations with mortuary teams suggest that the service pressures may be greater for regional mortuary services. This could be the case, if all services (pathology, funeral directors, community services) are working at capacity creating additional delays with the result that the deceased stay longer in regional mortuaries. Some mentioned, for example, that funeral directors were either unable or being pressurised by bereaved families to look after the deceased for as short a period as possible. Some mortuary staff we met raised a concern that contingency space for the deceased was being used outside of the winter period.

We analysed data from England and Wales16,17 to understand the current variation and potential future requirements for services (Figures 1 to 3 on the next pages). Figure 1 shows the monthly total number of deaths in England and Wales since 2006 with an underlying yearly average. The seasonal variation is summarised for this time period in Figure 2 of the average and highest and lowest figures for each month. The month of January has the broadest band, indicating there is a greater level of variation as well as more deaths in this month. Figure 3 shows the projected total number of deaths in future years, which will rise.

Mortuary and bereavement services need to plan for an increased number of deaths going forward with potentially greater levels of variability in the traditionally busiest months. The application of methods already used in other parts of the NHS (Statistical Process Control, Process Mapping and Capacity and Demand analysis) could help service planning and resilience. The approach could include understanding if there are any unwanted or unnecessary delays for the deceased person’s journey such as cause of death certification and transfer to funeral directors. The data we used are available for Clinical Commissioning Groups areas. This means that similar analyses can be developed to understand current and future18 requirements in regional mortuary and funeral service capacity. Combining these analyses with existing guidance18 and a focus to improve the experience of bereaved people alongside maintaining the dignity of the deceased would support service transformation.
**Figure 1: Bereavement and mortuary services need to plan for seasonal variation**

![Graph showing seasonal variation in deaths from Jan 2006 to Sept 2018](image)

Source: Office for National Statistics

**Figure 2: A summary of the seasonal variation from Jan 2006 to Sept 2018 showing there are more deaths and greater variation in winter months than other times of the year**

![Graph showing monthly variation in deaths from July 2006 to June 2018](image)

Source: Office for National Statistics
Figure 3: In the future it is projected that more people will be dying as a result of demographic change

Source: Office for National Statistics population projections 2016
6. Summary

The staff we met welcomed us into their services and they were proud of the care they provide to the deceased and to bereaved people. It is important that their work and the services they provide are part of the overall end of life care strategy within the acute trust; that staff are acknowledged, valued and visible. Care after death should be seen as an essential component of end of life care and we observed that often little things – ‘small acts of kindness’ – are the big things and can make all the difference for bereaved people.

Ensuring that the infrastructure and systems exist for staff, including good physical environments, and capacity to meet the needs of those who have died and those who are bereaved is a crucial component of enabling compassionate and dignified services. Taking a ‘fresh eyes’ approach to services, listening to staff concerns and understanding data can highlight the opportunities to improve care.

“The deceased was once a living person and therefore needs to be cared for with dignity. It is helpful if the surrounding environment conveys this respect. This includes the attitudes and behaviour of staff, particularly as bereaved people can experience high levels of anxiety and/or depression”19.
References

1. Hospice UK (2019). Rapid improvement guide for urgent and emergency care in hospitals for people who may be in their last months of life: the lens of acute admissions. 2nd ed.


3. Hospice UK (2019). Impact and learning from eight hospitals using data to understand urgent and emergency care in hospitals for people who may be their last months of life: the lens of acute admissions.


Additional resources

Bereavement Advice Centre. [Online] Available at: www.bereavementadvice.org

UK Government step by step guide on what to do when someone dies: www.gov.uk/when-someone-dies

NHS Education for Scotland. Support for healthcare staff who are working with patients, carers and families before, at, and after death. [Online] Available at: www.sad.scot.nhs.uk
