



BEREAVEMENT

A PRACTICAL GUIDE FOR NHS MANAGERS

INCLUDING '101 QUESTIONS'

JULES LEWIS, ROY LILLEY, JULES LOCK

BASED ON AN ORIGINAL COLLABORATION WITH PROF ANNE FAULKNER

WITH A CONTRIBUTION FROM THE ANNE ROBINSON TRUST



This book has been published with the support of an educational grant from

[IMS-Maxims](#)

In association with

[The IHM](#)



[The Academy of Fabulous Stuff](#)



No one dies unless we stop remembering them. How we remember them in death is as important as how we remember them in life.

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Anne wrote extensively about bereavement and dying. There is an impressive bibliography of her books, articles and academic papers. This Guide is based on her work.

LIZ PRIOR

Who writes on behalf of, *Butterfly Volunteers*, The Anne Robinson Trust.

“We cannot take away the whole hard thing that is happening, but we can help to bring the burden into manageable proportions”

“How people die remains in the memory of those who live on.”

Dame Cicely Saunders

THE MAN DIED IN THE CARE OF THE WORLD'S BEST HEALTH SERVICE.

As the dawn painted a cold, grey watercolour wash of day onto the curtain-less windows, the relatives stood hunched around the bed.

All night they had counted the syncopated breaths as the frail man, exhausted by his struggle, let-go his hold on life. Each rise and fall of his chest accompanied by the haunting sound of guardsmen marching on gravel. A countdown to the end.

He had prostate cancer. Common in working men. Diagnosed too late. Common in working men. A fruitless operation later, the silent assassin crept its way around his body and slowly, squeezed the life from it.

His cancer had metastasised and given him excruciating backache. Inexplicably, he was admitted to an orthopaedic ward, amongst the motorcyclists and hip replacements.

No one told the cancer team he was there. In any event, they said; *'he was lucky to get a bed'*.

No one seemed to know what to do. It was left to an ill-prepared, obviously distressed young doctor to say to the bemused relatives, *"It's up to him now"*.

Up to him? Like he had any say in his survival.

The rhythmic rasping stopped. The audience, in the beds on the other side of the flimsy curtain, held its collective breath and willed him to breathe just once more. His wife clutched his lifeless hand. Speechless in grief, she watched her tears splash onto the blanket stretched, tight, across his scarecrow frame.

His time had come.

Amongst the tubes a machine went beep. A green line that once made its way across a black screen, in the blinking of an eye, switched from the Himalayas to the flat lands of the parched Serengeti.

Technology pronounced the man dead.

The rest of the patients in the ward knew, his family knew. His God knew. Unfortunately the young nurse who came to see if "Everything was OK and did anyone want a cup of tea", did not know. She burst into tears.

The next day the man's son was given his few belongings in a black bin-liner.

This is my story. The story of my family. My Dad...

It was this story that made me curious about end-of-life care and ask, could we do it better...

I found Anne Faulkner and told her about my experiences and from those conversations the first edition of this book came.

I'm no expert but Anne was. I think our little book might have made a difference? Certainly Anne's workshops did; made people and the organisations they work for, stop and think.

Now, years later, I have met new experts and things can be very different. I know that.

But we must still train and support staff, be mindful of the families and take the greatest possible care...

We only get one chance

Roy Lilley

INTRODUCTION

This text is taken from the original publication, and to all of us involved in this update, it seems to hold as good today as it did over twenty years ago

This guide is aimed at helping everyone who comes into contact with bereaved relatives, carers and friends to understand what is required of them and the organisations they work in.

A growing area of concern is the care, or lack of care, given to those who are bereaved - either as a result of a terminal illness or of sudden death. Events surrounding the death of patients are some of the most difficult to deal with. Bereavement can be a harrowing experience for both relatives and the staff who have been involved in the care of dying patients.

Wherever you work, in the NHS you are likely, at some stage, to come into contact with a recently bereaved person. How that situation is handled, the training and support given to staff, is a reflection on your organisation's commitment in striving for excellence in bereavement care.

It is an absolute privilege for staff to support relatives at their time of greatest need.

Compassion, respect and dignity must be at the forethought of the care you provide, as you only have one chance to get it right.

Ann Faulkner
Roy Lilley
January 1996

Jules Lewis
Jules Lock
May 2019

THIS IS A WORKBOOK

There's plenty of white space
for notes, doodles, thoughts,
ideas and things to do!

If you are reading
electronically, download the
pages you want, share them and
use them as a learning aid.

If you have a hard copy... what
are you waiting for!

BEREAVEMENT REVIEW

In order to improve services, there is a need to reflect on your current practice and the services you provide.

Complaints tell us something about when people are dissatisfied but in order to gain a complete picture, we need to ask both those who use a service and those who provide it, to comment on current practice.

Many health professionals worry about asking bereaved individuals to comment on services, in case they become upset.

This means that we generally only hear from those who do not feel that they were adequately cared for. Many organisations are now asking relatives for feedback through bereavement surveys. The results can be utilised by health care professionals, to initiate change, which will ultimately improve the service you provide.

A sensitive approach is vital when speaking to a bereaved person, it is important to listen to their needs and enough time must be given to these appointments.

Some departments or wards may already have an approach to dealing with death and bereavement and there may be a Bereavement or End of Life Care Service within the Trust, with good practices to build on and good ideas to share, such as a symbol to represent End of Life & Bereavement Care, a swan or other symbol.

There are many excellent examples of ideas, innovation and best practice to be found at the Academy of Fabulous Stuff, web-site. [Click here](#).

The purpose of this review is to understand what is in place and what is not – a place to start from and how to take this work forward.

WHERE ARE YOU NOW AND WHERE DO YOU WANT TO BE?

NOTES

- Who takes overall responsibility, at present, for care of bereaved individuals?

- What policies and practices exist already?

- Do you have a symbol to represent End of Life & Bereavement Care such as the Swan Symbol?

- Do you have the Swan Scheme (Signs, Words, Actions and Needs) & Swan Rooms or similar for End of Life & Bereavement Care?

- Do you give the family handwritten sympathy cards and Forget-Me-Not seeds, or a memory box?

- Do you offer the family free car parking?

- Do you have a bereavement survey?

- Are current policies and practices adequate to provide high standards of care?

- Is there appropriate training available for all staff and who in the organisation is responsible for delivering this?

- What indicators are used to highlight the future training needs of your staff?

- Are communications skills assessed?

- What are the needs of staff for future training?

- Are relatives given the opportunity to make an informed choice about visiting the deceased person?

- Are the customs and wishes of each bereaved individual known and respected?

- Are the arrangements for Chaplaincy services available at all times?

- Is relevant written bereavement information available? Are they printed in languages other than English?

- What follow-up support is available to relatives carers and friends?

- Who is responsible for such support?

- How are staff supported?

- Do some departments, because of the nature of their work, need more help?

EVALUATING SERVICES

You may find you have to rethink the current services you offer. The review should be seen as a first step.

From the review will come the policy and the implementation strategy.

There are a number of management techniques that can be applied to service planning. It will vary from organisation to organisation. Whichever approach you use there are three fundamentals to consider.

TIMELINESS

Ensuring good policies are in place, is the essence of good management. Recognising the issues, the need to respond to them and being prepared is at the centre of what management does.

It is also the most difficult.

Staff may not be able to see the need for a policy. They may have experienced death in their own lives and families and may consider themselves well able to be sympathetic without the need for training.

However, if all your staff have been involved in the review and the subsequent policy development, they will have ownership of it.

... and they will view change in a positive light rather than it being directed from above.

EVERYONE PLAYS A PART IN BEREAVEMENT CARE

- the switchboard operator will take calls from anxious relatives who fear the worst;
- the car-park attendant who may have to deal, sensitively, with a recently bereaved relative who has overstayed their parking time and has, perhaps been clamped or given a ticket, or simply does not have enough money with them to pay an unexpectedly high parking fee;
- the receptionists who will direct bewildered people around the hospital;
- the domestic staff who will come face to face with grieving visitors on wards;
- the mortuary and chaplaincy service, bereavement, patient advice and liaison service administrators who are there to explain next steps, insuring all documentation is issued and any personal belongings are returned
- managers and Board Members whose job it is to deal with and monitor complaints
- ... and of course the doctors, nurses and allied health professionals who are at the inevitable front line, having those important conversations with relatives either face to face or on the telephone.

POLICIES THAT RESULT IN IMPROVED PRACTICE CAN EASE THE ANGUISH OF BEREAVEMENT.

Following an assessment of your needs, the timely implementation of your policies is crucial. Improved practice through sound policies, will ensure that relatives have the support they need at the hardest of times.

ATTAINABLE

The death of a patient whilst in the care of the NHS can be complex and the circumstances vary enormously.

Death can range from the expected to the unexpected and these bring different challenges.

For some it can be a welcome relief from suffering. Other deaths can be fiercely contested or disputed, with accusations and controversy. These can seriously challenge medical competency and your organisations integrity.

Assumptions should not be made as to how a person might react to the death of a loved one. Indeed, we cannot assume that the dead person *was* a loved one - albeit that they were a partner, child or relative.

All that we can assume is that reactions to death are individual and do not necessarily follow a pre-ordained pattern.

Relatives may be grief stricken and paralysed with loss and unable to cope with what is next; others may be relieved that their loved one is now at peace.

The policies must be thoughtful, knowledgeable, flexible and above all appropriate to the needs of the bereaved. The staff must fully endorse the policies and initiate them with empathy, dignity and respect for all.

MEASURABLE

The policies must be robust enough to deliver the expectations we have of them.

Will they work at three in the morning, in a community home, miles from anywhere?

They must work for everyone.

They must work in a busy A&E, flooded with casualties or a busy, bustling general ward.

The policies must work for new, bank or agency staff, unfamiliar with the organisation and they must work for relatives who have travelled from overseas to be with their loved one in the final hours... and who have to face the immediate prospect of a long journey home.

They must work when the deceased is an internationally known celebrity who met their end in a motorway pile up near your A&E and for good measure, the world's press descends on you.

They must work at weekends, Christmas, Ramadan and Hanukah.

Will the policies be helpful and welcomed by the staff.

Will those who are the deliverers be able, or want, to deliver them?

REDUCING COMPLAINTS

People who complain are usually those who feel that they have not been heard. This is especially true at the time of death when strong emotions of ANGER, GUILT and BLAME come to the surface.

The ANGER may be present for a number of reasons - the apparent senselessness of the situation, the event itself or even with the *God* who 'allowed the death to happen'.

If the individual is encouraged to talk through these feelings, that anger is likely to be diffused. If the anger is ignored it may be deflected onto you or onto your organisation and may result in a formal complaint.

Similarly with GUILT and BLAME. If the individual is not encouraged to talk through these emotions they may fester. GUILT is an uncomfortable emotion and may be discharged by turning it into BLAME. That BLAME may then be directed at you and your organisation.

For example:

Mr B who wanted to die at home, died a week after discharge from hospital. His son, who had been out of the house, returned home to find his father semiconscious in the bathroom. He called an ambulance but his father died on arrival at the hospital.

At first Mr B's son was full of remorse for leaving his father alone in the house. While he was left waiting for news of his father, as time moved on, he began to blame the hospital for discharging his father, for not giving him relevant information and for being uncaring.

When a nurse finally arrived to talk to him, he was angry and abusive.

To avoid complaints, follow the DO's and DON'Ts and observe principles of good practice.

THE DO'S AND DON'TS OF SUDDEN OR UNEXPECTED DEATH

DO'S

DO give a warning that the news is not good.

DO give information at the recipient's pace.

DO give time for information to be absorbed.

DO be sensitive to other's feelings.

DO give individuals time to express feelings.

DO allow individuals to make informed choice on seeing the deceased person.

DO offer relevant information if required.

DO try to meet individual needs.

DO offer appropriate support.

DO offer a follow-up appointment if it is needed to discuss events further with you or another health care professional.

DON'TS

Don't make assumptions.

Don't be judgmental.

Don't break bad news in an insensitive way.

Don't hurry the individual.

Don't insist the individual sees the deceased person.

Don't discourage individuals from seeing the deceased person.

Don't 'normalise' the event.

Don't distance yourself from the feelings of others.

Don't allow an individual to leave without assessing their emotional state.

Don't be surprised or over-react to strong emotional reactions such as anger, guilt and blame.

Don't make comparisons by saying; 'I know how you feel'... you don't. All loss is unique.

PREGNANCY LOSS AND THE DEATH OF A BABY.

The experience of loss is not uncommon in the women's health and maternity services.

It is experienced by women and their partners and families, in many different forms including loss through miscarriage, ectopic pregnancy, stillbirth, neonatal death, termination of pregnancy, selective feticide and infertility.

Caring for those who experience loss is an integral and unavoidable part of the work of all individuals involved in women's health and maternity care.

CHILD DEATH REVIEW

STATUTORY AND OPERATIONAL GUIDANCE

This guidance, to be found [here](#), sets out key features of what a good child death review process should look like. This process combines best practice with statutory requirements that must be followed.

The purpose of setting out key features of a robust child death review process in one document is to ensure that the outputs from reviews are standardised as far as possible and of a uniform quality.

This will enable effective thematic learning from reviews, i.e. a local review may be able to identify specific learning but trends analysis at a national level may identify modifiable factors that could be altered to prevent future deaths.

This requires a degree of standardisation that this document aims to outline; however, clinical commissioning groups (CCGs) and local authorities (the child death review partners) are able to make arrangements for child death reviews as they see fit in order to meet the statutory requirements under the Children Act 2004 (the Act).

The process set out in this document runs from the moment of a child's death to the completion of the review by the Child Death Overview Panel (CDOP) or any equivalent arrangements put in place by child death review partners.

This includes the immediate actions that should be taken after a child's death; the local review of a child's death by those who interacted with the child during life, and with the investigation after the child's death; through to the final stage of the child death review process which is the statutory review arranged by child death review partners.

The process is designed to capture the expertise and thoughts of all individuals who have interacted with the case in order to identify changes that could save the lives of children.

TEN GOOD PRACTICE PRINCIPLES

- Parents should be able to feel in control and be supported in making their own decisions about what happens to them and their baby.
- The care given to parents should be responsive to their individual feelings and needs.
- Parents need information.
- Communication should be clear, sensitive and honest.
- Parents should be treated with dignity and kindness, offered a memory box, hand or foot prints, hair lock & photographs as appropriate.
- Parents' loss should be recognised and acknowledged, their experience and feelings validated.
- Parents need to be given time.
- All those who care for families after the loss of a pregnancy or a baby's death should be well informed.
- All those who care for families after the loss of a pregnancy or a baby's death should have access to support for themselves.
- All those who care for families after the loss of a pregnancy or a baby's death should be given the opportunity to develop their own knowledge, understanding, skills and given support.

5 STEPS FOR GOOD PRACTICE

- Tell the relative their loved one has died sensitively and at the recipient's pace
- Listen
- Do not pre-judge reactions to death
- Follow the bereaved individual's agenda in respect of seeing the deceased person
- Be prepared to give time and offer support in an unhurried way and in the right environment

CHOOSING THE RIGHT WORDS

There is no easy way to tell someone that a loved person will die shortly or has died since they were last seen. The task is often left to junior staff who feel that they have personally failed the relatives by not being able to cure or resuscitate the patient.

Although there are no magic words to use, there is a formula which allows the news to be broken in a sensitive way and at a pace that will be absorbed by the recipient.

WHAT DOES THE RELATIVE KNOW OR SUSPECT?

Asking the relative for their perspective is a vital aid in 'getting it right' ... often they are aware of the reality of the news.

Mrs M was with her husband when he was admitted to hospital following a coronary attack:

Nurse: How does your husband seem to you?

Mrs M: It's his heart isn't it? He had a small attack a while ago but this was worse - is he going to die?

GIVE A CLEAR WARNING

It is essential to give a warning that the news is bad, for this prepares the relative:

Nurse: We are doing all we can but the situation is very serious.

BREAK THE NEWS IN MANAGEABLE CHUNKS

Mrs M was aware that her husband's heart condition was very serious. The nurse was confirming her worst fears and her main task was to support Mrs M during the uncertain time that the team were fighting to save Mr M's life.

CHOOSING THE RIGHT WORDS

Other relatives may have little idea of what is happening. Breaking the news badly may leave painful lasting memories, whereas a more sensitive approach helps the relative absorb the information.

Mr J's son was dead on arrival at A&E following an accident on his motorcycle. Consider the following conversations:

Example 1:

Mr J: I'm Mr J. The police told me my son is here.

Doctor: Yes, I'm afraid he was dead on arrival. (Breaking bad news).

Example 2:

Mr J: I'm Mr J, the police told me my son was here.

Doctor: Yes, what did the police tell you (checking relative's awareness).

Mr J: Just that Colin had had an accident and was sent here in an ambulance

Doctor: I'm afraid there is very bad news for you (warning).

Mr J: It's serious then?

Doctor: Very serious - Mr J...

Mr J: He's dead? - Oh my God!

Doctor: I'm afraid he was dead on arrival - do you want me to explain? (Breaking news at the relative's pace).

Mr J: Not now, oh God, what will his mother say?

In Example 1, Mr J had no time to prepare for the shock of the news, but in the Example 2, the doctor responded to cues from Mr J. The news was no less shocking but Mr J would feel that he was more in control of the situation than in the first scenario.

THE NEED FOR SPACE

There is a big temptation to follow bad news with explanation and information when what is required is space and time to absorb the news. Mr J was in shock on hearing of his son's death and would not have remembered much of any explanation the doctor offered. Even if death is expected, there is still some level of shock once it is realised that a miracle will not happen.

If possible someone should stay with the relative until they feel the need to talk. This may be a matter of only minutes but can be very important.

Pick up the pieces

Rather than give information after bad news is broken, it is important to encourage the expression of feelings and reactions to bad news.

Doctor: This has been a big shock for you.

Mr J: Yes - well I was always on at him to be more careful - told him he'd kill himself - but I really didn't believe - silly young fool - where is he doctor? Can I see him?

Mr J began to express anger towards his son but then spontaneously asked to see him.

BREAKING BAD NEWS FIVE THINGS TO REMEMBER

- Check awareness
- Give a warning
- Break bad news at recipient's pace
- Give space and support
- Pick up the pieces

This is a link to [The Good Grief Trust](#), it is run by the bereaved, for the bereaved and is a valuable resource. Have a look and widen your understanding and learning and consider occasions when it might be appropriate to pass on to relatives, carers and friends.

ORGAN DONATION

By donating organs after you die, you will help save and transform lives of others. However, the act of donation comes at a time when relatives will be at their most vulnerable and health professionals must exercise great care in coming to the issue. Handled well donors wishes can be respected and a person helped into a healthier happier future. Handled badly, all that is lost.

FIRST SOME BASICS

(Based on the content of the very helpful NHS Blood and Transplant website, [here](#))

WHAT IS ORGAN DONATION?

Organ donation happens when organs are taken from dead or living people and given to others whose lives are severely affected by a failed organ. Organs that would otherwise go to waste when a person has died can be given to seriously ill people to dramatically improve and save their lives.

Organ donation usually occurs after death, but an increasing number of people are also donating their organs (for example, one of their two kidneys, or part of their liver) as a “living donor”.

As an organ donor you can choose to donate some or all of your organs or tissue: kidneys, heart, liver, lungs, pancreas and the small bowel can all be transplanted, whilst as a tissue donor you can donate skin, tendons, bone, heart valves, cartilage and eyes to repair or rebuild the bodies, faces and lives of thousands of severely injured people.

WHAT IS THE ORGAN DONOR REGISTER?

The NHS Organ Donor Register is a confidential, computerised database which holds the details of those who have decided that, after their death, they want to donate their organs and/or tissue to others. Sixteen million people are currently signed up.

In the UK organs and tissue from a potential donor will only be used if that is their known wish. Putting your name on the NHS Organ Donor Register makes it easier for the NHS to establish your decision and for those closest to you to support it.

If your decision is not clear, next of kin will be asked what they think you would have wanted, so it is important that you make sure they are aware of your views on organ donation.

WHAT WILL HAPPEN IF RELATIVES DON'T SUPPORT THE DEAD PERSON'S DECISION?

We know that in most cases families will agree to donation if they know that was their loved one's wish. If the family, or those closest to the person who has died, object to the donation even when their loved one has given their explicit permission (either by telling relatives, friends or clinical staff, by joining the Register or by carrying a donor card) healthcare professionals should discuss the matter sensitively with the family.

They should be encouraged to accept their loved one's decision. Strictly speaking relatives do not have the right to veto or overrule that decision. Nevertheless, there will be cases where it would be inappropriate for donation to go ahead if donation would cause distress to the family.

Relatives may have questions such as; *'Will doctors not try everything to save my relative if they think they are a donor.'*

The answer is; health professionals have a duty of care to try and save life first. If, despite their efforts, the patient dies, death is confirmed by doctors at consultant level who are entirely independent of the transplant team. Death is confirmed in exactly the same way for people who donate organs as for those who do not. Once death is confirmed, the donation and transplant specialists would be called in.

Relatives may have misapprehensions about organ donations. They may believe that the organs will be removed *prior* to death or that the need for the organs is more important than their loved one's life to the doctor. Be prepared to explain organs are only taken after a death is certified.

A common objection is; 'I don't want my loved on cut up or disfigured'

Organs and tissue are always removed with the greatest of care and respect under sterile conditions by specialist healthcare professionals. Afterwards the surgical incision is carefully closed and covered by a dressing in the normal way. Only those organs and tissue specified by the donor or their family will be removed and donors are treated with the utmost respect and dignity.

There may be other concerns; 'I don't want to delay the funeral as we have relatives coming from abroad...'

The donation operation is performed as soon as possible after death.

Families should be given the opportunity to spend time with their loved one after the operation if they wish and this is facilitated by the specialist nurse, usually from the transplant team. Arrangements for visiting the deceased person after donation are the same as after any death.

THINGS TO THINK ABOUT

- If the potential donor *does* carry a card, check that the relative is aware of this;
- If the request is made prior to, or immediately after the death, remember these two key points:
 - Relatives' perceptions and priorities may be different from those of the health professional.
 - That the major concern of the relative may be more with the loved one than with a stranger whose life may be saved as a result of the patient's death.

Relatives may regard donation as an opportunity to honour the wishes and memory of a loved one, or... as an unwelcome intrusion at a crucial time. Over time, the joy of knowing another person is living a fuller, happier life, because of the selfless donation of transplanted organs, can outweigh the anxiety and grief of decisions that have to be made swiftly and at the most pressured and difficult of times.

The law makes clear the right of a person to donate their organs after death, unfettered by the wishes of even the closest relative. However, in the practicality, it is important to weigh the impact and distress of relatives and loved ones. Great judgement is required, and no little experience of dealing with relatives and others when they may be at their lowest.

A new option, added to the NHS Organ Donor Register has been developed to give reassurance about how organ donation can go ahead in line with the person's faith or beliefs. [More details are here](#). The new arrangements include access to a faith specific donor card.

It is unlikely a transplant would go ahead in the face of outright opposition from a close relative.

There are proposals for changes in the law in England to a 'presumed consent' model. There are [more details here](#). The [law in Wales](#) is different, Scotland's approach is described [here](#).

In the UK in 2017, 411 people died before the right donor was found, and more than 5,000 people are currently on the waiting list in England.

This is a difficult topic and there is more helpful guidance and explanations of the NHD ODT Clinical website, [here](#).

101 QUESTIONS ABOUT BEREAVEMENT FOR MANAGERS

Here are some questions to use as prompts for workshops, planning and reviewing services.

They are designed to promote discussions and to challenge managers and organisations to ask questions about the services they offer, the way they are organised and to test their fitness for purpose.

We hope you find them useful.

Remember, this is a workbook; you can use the pages to write on and brainstorm... we've made sure there's plenty of room!

STAFF AND COLLEAGUES

1. Who breaks bad news?
2. Is breaking bad news left to chance; or to the person who happens to be on duty?

3. Are all staff trained to have important conversations and break bad news sensitively?

4. Are all staff able to use easily understood language?

5. Are staff available to relatives in the aftermath of the first shock of bereavement?

6. If not; are the relatives referred on to someone who can help them?

7. Is there support for junior staff who are unused to death?

8. How is a staff member's 'first death' handled?

9. Can someone else 'cover' for junior staff who are upset?

10. Is the death the result of an error of judgement, misdiagnosis or mistake? How is staff performance monitored?

11. Do staff recognise that they might be 'blamed' for the death and can they cope with emotional reactions to death?

12. Are doctors and nurses involved in breaking bad news?

13. Are trainee doctors and nurses involved in bereavement work?

14. Are staff rotas arranged to give a mix of experience in bereavement work?

15. If staff numbers are down, is there a system of 'sharing' staff from other wards/departments?

16. Is there a role for trained volunteers?

17. Does this role include 'sitting' with bereaved relatives?

18. Would volunteers be able to recognise severe shock?

19. What support is available for staff who are upset by the death of a long-stay patient of whom they have become fond?

20. Because of the nature of the services, are some staff more exposed to this risk than others?

21. If this is the case does some special action have to be taken?

22. How are staff trained in the management of bereavement issues?

23. How is it up-dated and its effectiveness measured?

24. Where will a relative be taken to recover?

25. If there is a room available, is it 'Sister's Office', where there is a likelihood of interruptions or can it be a room set aside for the purpose?

26. Will the relative have un-restricted access to a telephone other than a pay-phone?

27. What are the arrangements for the relatives to visit the deceased person on the ward?

28. Can the deceased person be made ready for visiting in a timely manner; is there a comb and other toiletries or other needed equipment available for care after death?

29. Will all evidence of medical care such as drips and monitors be taken away?

30. Will the question of organ donation be routinely raised?

31. Who will do it?

32. Will a Doctor or nurse be able to prescribe for a deeply shocked, unstable and possibly elderly relative?

PRACTICAL HELP FOR RELATIVES

33. Is there a Bereavement Office?

34. Is it easy to access for the elderly and disabled, is it easy to find but not advertised to all and sundry?

35. Have the staff had special training?

36. When was the training updated?

37. What objectives have been set for the staff and manager?

38. Is it necessary that they speak more than English?

39. Do they have access to translation services?

40. Does it have user friendly opening hours, such as evenings and weekends?

41. Do they have leaflets/booklets to explain how to register a death and where?

42. Is there a list of useful telephone numbers, such as: CRUSE, Samaritans, bereavement support groups?

43. If required, who will explain about the need for a Coroner's inquest?

44. Is there advice on arranging a funeral?

45. Is there a follow-up bereavement phone call made routinely?

46. Who can give advice on moving a deceased person out of England?

47. How are the deceased's personal effects handed back to relatives?

48. Are soiled clothes laundered before they are returned, or are they disposed of?

49. Are items of clothing and personal belongings carefully packed?

50. How are valuables dealt with?

51. Are relatives provided with a complete list of local undertakers?

52. What is the organisation's policy on dealing with gifts from grateful relatives; both to the organisation and to individuals? The organisation may have an end of life and bereavement care fund, if so, how easy is it to find out more information and donate?

POLICY

53. Are there 'do not attempt resuscitation policies'?

54. Has the Board agreed them?

55. Are they universally applied throughout the organisation, by all the clinical teams?

56. Who deals with disputes about such policies?

57. Are they reviewed, regularly, in the light of advancements in medical technology?

58. Are they explained to relatives?

59. What happens if a relative disagrees with the policy?

60. Is there a policy on requests for organ donation?

61. Do all staff understand the policies and agree with them?

CHAPLAINCY, PRIESTS AND COMMUNITY LEADERS

62. Is there easy access to a Chaplain or spiritual leader?

63. Do the Chaplaincy arrangements reflect the ethnic mix of the area?

64. Is there a list of telephone numbers of priests and leaders from non-Christian religions available and up-to-date and does everyone know where to access it?

65. Are they available out-of-hours?

66. How often is the information up-dated?

67. Are patients and relatives routinely offered the services of the Chaplain or equivalent?

68. Is there a multi-faith Chapel?

69. Is it open at all times?

70. Is it warm?

71. Is there easy access to the key?

72. Does everyone know where to locate the light switches?

73. Is the Chapel regularly cleaned and decorated?

74. Who checks it?

75. Is there a budget for flowers and tissues?

76. Where is the Chaplain in the organisation's management hierarchy and should it include access to the Board?

77. Does the death of a child trigger different policies?

78. What is the policy on the burial of stillborn children after the 24th week of pregnancy?

79. Does it vary from a stillborn child younger than 24 weeks?

80. How will the parents wishes be established?

81. Is the Board ever represented at the funeral of a patient who has died whilst in their Trust's care?

82. Are floral tributes sent?

83. Who organises it and is there a budget?

84. If staff attend patient's funerals are they expected to do so in their own time or are they considered to be 'on duty'?

COMPLAINTS

85. How does the organisation deal with complaints surrounding the death of a patient whilst in the care of the organisation?

86. Are they dealt with routinely or differently from other complaints?

87. Is the Board made aware of such complaints?

88. How are they monitored?

89. What time scales are set down for the resolution of these type of complaints?

90. How fast is a complaint acknowledged?

91. How is it monitored?

92. If a response is required from a clinician, will it be in plain language?

93. Will it delay the process?

94. What role does the Medical Director have?

95. Would the personal visit of the Medical Director to a complainant ever be considered?

96. Is the process of responding to complaints 'legally driven'?

97. Should it be?

98. Does it have to be?

ADMINISTRATION

99. How long will a relative have to wait for the Medical Certificate of Cause of Death?

100. Do the Medics understand any delay can cause anxiety and add to the grief of a relative?

MEDIA

101. Who deals with press enquiries about the death of a patient, have they had training and are they available 24hrs a day?

... and just a couple more

A good service improvement in hospital bereavement services is having a registrar based in the hospital to register the death to allow the bereaved relative to collect the MCCD & register the death at the same visit... are you able to register the death in your hospital?

Have you thought about the role of the [Medical Examiner](#)? There is a lot to be learned from all deaths and relatives are often very willing to take part, particularly if they have concerns over the death of a loved one.

...and, the most difficult question of all

Is your organisation a 'good place' in which to die?

LOOKING FOR IDEAS, BEST PRACTICE?

The Academy of Fabulous Stuff was started to provide a repository of best practice, ideas and innovation-that-works to avoid the costs and time delays of organisations re-inventing the wheel.

There are thousands of ‘shares’ posted by enthusiasts who believe, if you show people what good looks like... they will get on and do it better.

The Academy provides a resource for end-of-life-care and may be accessed, free, [here](#).

SUICIDE

SUICIDE IS COMPLEX...

... it takes courage to know this will be your last step, swallow, jump... and because it is in despair when all hope is gone.

A person without hope is without aspiration, desire and will.

So often a suicide will leave behind people in despair, asking the question why. Why... not of the lost loved one but 'why' of themselves... why didn't I do more? Why didn't I realise?

- In 2017, 5,821 suicides were recorded in Great Britain. Of these, 75% were male and 25% were female.
- Between 2003 and 2013, 18,220 people with mental health problems took their own life in the UK.
- Suicide is the most common cause of death for men aged 20-49 years in England and Wales.

How can we support someone who has been bereaved and affected by suicide?

24% of people bereaved by suicide said they received no support after their loss. Yet, only 1% said they preferred to cope without support. Of those who did get support, 84% said it came from family and friends.

Suicide is a unique loss, often leaving those behind in a unique place of confusion, loneliness, anger, sadness, anxiety or just hollowed-out and you might add to that, stigmatisation. Friends avoid them... and then follows guilt.

Unlike other deaths, suicides often attract publicity, prurience and curiosity. Hitherto hidden elements of a person's life will become public. It is a huge amount to cope with that few of us can be prepared for.

The research seems to indicate that a person bereaved by suicide is likely to have difficulties coping at work or school, or university and often suicide leads... to suicide. That's why bereavement support is very important.

THE SCENARIO WILL BE FAMILIAR.

A suicide will be discovered, an ambulance summoned, too late, or despite the best efforts of the paramedics and A&E, the person will not survive.

What we must remember;

There is never one cause of suicide; it is the combinations of relationship breakdowns, financial concerns, work and sometimes we may never really know.

Suicide is the act that people take to end unendurable emotional pain. We must never judge them.

For the bereaved person, there is often no end in sight. They will want to keep churning what happened, over and over in their minds, seeking an answer. We might have to listen to their story, over and over again. It can be therapeutic for the bereaved person.

Speculation about blame or causes seldom helps.

As in all death, grief doesn't stop, it changes and like the tide, it comes in waves. People sometimes describe grief as a black hole. It never goes away but people find a way around it.

NINE IMPORTANT 'AVOIDS';

1. Avoid assuming someone is getting support or help. Let them know you can help if that is what they want. Be available.
2. Avoid assuming families will support each other. Suicide can invite divisions and family schisms. Neutral help can be valuable.
3. Avoid thinking it's too late to help. It may take days, weeks, months or years before a bereaved person might ask.
4. Avoid assuming other members of the family will know what the cause of death was. It is not uncommon for relatives to try and conceal the actual facts.
5. Avoid, avoiding the subject or the bereaved. Suicide brings chaos into the lives of the people who remain. Time is dislocated and routine destroyed. Helping to maintain a normality might help. Encouraging them to seek the help of a councillor or The Samaritans may be even more helpful.
6. Avoid being curious and don't push for facts about the suicide, notes or the when and the how. That is in the past. Our job is to help the people bereaved by suicide cope. If they want to tell you, that's fine. Don't ask and avoid sounding judgemental.
7. Avoid speculation about the reasons for the suicide. They may focus on disagreements or arguments and anyway, there is never one reason. Suicide is complex, unravels relationships and invites blame. It has no place in managing bereavement.
8. Avoid assuming responses to death by suicide will be broadly the same... they are not. We are familiar with anger, guilt and blame but we can add shame and embarrassment to the complex cocktail of emotions.
9. Avoid pushing for details of the relationship. Colleague, boss, ex-partner, lover, creditor, secret person. It doesn't matter to us.

WHAT DO WE SAY AND WHAT CAN WE DO?

The temptation is to say nothing, that won't help. Acknowledge the loss and try to be helpful. Practical is often the best route.

Think about how the bereaved person wants to be contacted.

As we move into a world of electronic communication the assured privacy of WhatsApp might be appropriate. Texting, as casual as it may seem, is now the preferred communication vehicle for most of the world. Yet, a personal conversation has no parallels.

Staying in touch is a good thing...

... but don't expect instant answers or a call to be returned straight away... people need time and it's enough to know you are there and they have a contact.

Active listening is something we are all familiar with...

... but in the complex environment of suicide, listening for clues is very important. Where do you start? How about asking; 'What is your happiest memory?' Or, 'When did they make you laugh?'
Opening a conversation...

Be patient, it will take time.

Grief is a variety of emotions and there are no ‘solutions’ to ‘ordinary’ grief and there are certainly no ‘solutions’ to the complexity of grieving suicide.

Be available and mean it...

... and if you can't be, that's fine, but define the boundaries. Birthdays, anniversaries will be very painful, if you can find out when they are, make a note in the diary... reach out.

Accept there might be press interest in a death by suicide.

The location, notes left by the deceased, the means. There are [reporting guidelines](#) published by the Samaritans about which you might want to remind a curious reporter.

The right words...

Finding the right words is a skill.

When talking about suicide it's ok to use; ‘died by suicide’ or ‘took her own life’.

The common phrase; ‘committed suicide’ goes back to the time when suicide was a crime and it no longer is and the phrase is no longer relevant. Don't use it.

For more help

[The Samaritans
Help is at Hand, an excellent and helpful small book.](#)

SUPPLEMENT

The next pages come from Liz Prior at the [Anne Robinson Trust](#) a voluntary organisation whose volunteers provide friendship, comfort, compassion and a presence for people facing the end of their lives, ensuring they are not alone and support for their families and friends.

The Trust were winners of an Academy of Fabulous Stuff Award in 2018 and runners up in the Directory of Social Change 2018 Awards in the Every Day Impact category.

No one knows how many volunteers there are in the NHS. The Department of Health and Social Care estimates there are 3 million in health and care, while a 2016 British Social Attitudes survey said there were about 1.7 million.

What we do know is that services are enriched by the help and commitment that volunteers bring to the day-to-day of the NHS. Many of them give their time based on experiences they have had, whilst they, or their relatives have been in the care of the NHS.

OTHER OPTIONS...

Have you ever considered how much impact a team of specially trained end of life care volunteers would have in your organisation?

The Anne Robson Trust is a charity that works to support NHS Trusts to do just that.

They work in partnership with hospitals, to create, equip and sustain teams of Butterfly Volunteers to support hospital patients in the last days and hours of their life.

In their first year of operation at their pilot site, The Princess Alexandra Hospital NHS Trust in Harlow, Butterfly Volunteers supported nearly 500 patients, and their families, made 1300 visits and spend just over 700 hours by the bedside.

Volunteers not only support patients but their loved ones too, this has a positive impact for the clinical staff who are caring for the patient. Feedback about the service from both clinicians and relatives is unanimously positive.

Four new hospital partners are launching schemes in 2019.

HOW DOES IT WORK....

ART works in partnership with NHS Trusts to help them embed teams of Butterfly Volunteers in their organisation, delivering maximum impact in minimum time.

The charity does this by *hand-holding* Trusts through the set up process, providing expertise in structuring and running the service. Critically this includes recruitment of both the volunteer Coordinator and volunteers themselves into the Partner NHS Trust.

ART provides detailed and well-researched training as well as the necessary marketing materials and branded equipment to ensure the smooth running of the scheme.

Once the service is up and running the charity provides ongoing support and guidance to the coordinator as well as monitoring and evaluation to enable continuous refinement and improvement.

Butterfly Volunteers are inducted and DBS checked by the Partner NHS Trust as Trust volunteers and they are supported by a Coordinator who is employed by the Partner NHS Trust.

– this innovative charity is keen to expand their work in order to support more patients at the end of life.

WHAT THEY SAY ABOUT THE ANNE ROBINSON TRUST

“It was so wonderful to have a chat with the Butterfly Volunteer. We had been sitting by Dad’s bed for hours, and she was so kind. A fantastic, much needed service. Thank you”

Ms R, Patient’s daughter, Harlow

“Patients and staff agreed that having volunteers who could support dying patients and their families alongside our clinical staff would be on their “wish list”. We are delighted that we are able to fulfil this wish as the Trust is now working with the Anne Robson Trust to train and support Butterfly Volunteers at PAH.”

Julie Rodgers & Gill Robertson, Lead Clinicians for Palliative Care, Princess Alexandra Hospital NHS Trust, Harlow

“I was so touched by how gently the Butterfly Volunteer spoke to my wife, I was very tired and appreciated some time out, knowing she was being looked after. A wonderful service by a much needed charity”

R Jones, Patient’s husband, Harlow

The Anne Robinson Trust team is more than happy to provide advice to anyone interested in setting up a team of end of life care volunteers. They have different packages to suit different organisations. To hear more about these options, or to have an informal chat....

Contact Liz Pryor on 0203 3286 5494

Email: liz@annerobsontrust.org.uk

Web: www.annerobsontrust.org.uk

MORE INFORMATION

You might want to look at 'The Grief Recovery Method'.

There are full [details here](#).

WHAT GOOD LOOKS LIKE

The room was painted in calm colours. There was a lovely picture on the wall. I remember thinking Mum would like that. A mood light sat on the locker & changed colour. The staff commented how lovely the room looked. It did... a cd player sat beside the mood-light, playing Mum's favourite music, the room was tranquil, no machines, no panic.

The Doctor told us Mum was dying he used the words 'I am sorry there is no more we can do for her, I believe your Mum is going to die in the few next few hours or perhaps, days'. He was kind, we knew she was dying and we needed to hear it from the Doctor. We trusted him, he had been so kind to us.

The nurses came in every couple of hours, to turn & check on Mum, asking did we need anything? They gave us cups of tea, biscuits and sandwiches. They looked after us all... not just Mum.

The specialist nurse visited regularly. She asked us about Mum; what does Mum like and dislike. We told her all about Mum. She arranged for the Chaplain to visit. We'd told her Mum was religious CofE & would like a visit.

Mum was unable to take anything orally now and the specialist nurse did mouth

care and explained to us how we could do it if wished. She did it with Mum's favourite flavour and showed us how. Taste for pleasure she called it.

We felt useful being able to contribute.

Mum responded well. They gave us vouchers to go to the nearby café; a hot drink and a slice of cake and more importantly time away from the bedside to look after ourselves.

The day before Mum died the specialist nurse arranged for a volunteer to sit with Mum so we could go for lunch together.

Me and my sister; a much needed break as we were staying most of the day and taking it in turns at night. We slept on a recliner chair, wrapped in the blankets we were given, to keep us warm.

There was no rush, no panic just clam... we sat and chatted and said our goodbyes.

We had been given a memory box and in it, useful items; tissues, pen, paper, property bag, jewellery bag, lip balm, forget-me-not seeds, café vouchers, a letter & information leaflet about what to expect, changes in breathing, changes in the way Mum looked, diminished need for food and drink.

A swan symbol was explained and placed on the side room door.

Even our car registrations were taken off the system allowing us free parking and open visiting.

On the day Mum died her breathing & colour changed. We had read the leaflet as well as had this explained, we knew what this meant it was confirmed it was likely Mum would die in the coming few hours.

The specialist nurse stayed with us, we each in turn said good-bye, Mum took one big breath in and slipped away, the colour faded, not a wrinkle on her face, it was beautiful, she died in her own nightie, her own pillow and blanket with her family by her side.

We held a hair lock in our hands and kissed her goodbye. The nurse stayed silent in the

room and then spoke with a tear in her eye that was beautiful, checking we were ok she said she would just give us a few moments and slipped out of the room.

She returned with tea, like she always did, this time it felt different. There was no rush, no panic... just calm we sat and chatted and said our goodbyes.

By now it was early evening and the Doctor was still on duty. He knocked on the door and came in. He said how sorry he was. The Health Care Assistant followed and then we had some time alone with Mum.

The next day we collected the death certificate as we were keen to start arranging the funeral. It would need to be on a Saturday as Mum was so popular in the village, so many would be attending.

We returned to the ward with cards and chocolates for the wonderful staff. We will never forget the kindness shown to Mum and us as a family.

My brother said to the staff; when you're having a bad day at work, never forget the difference you make every day. I will never forget what he said.

We have one chance to get it right, for every person, every time.

By Jules Lewis

'This my reflection of the story of a family I was privileged to support, with their Mum's end of life care.'

THE FINAL WORD...

Assessing the bereavement needs of your organisation is the first step and thank you for taking part in this.

The transition from end of life care to bereavement care should be a seamless process. The effort you put in to providing high quality bereavement care will ensure that relatives are able to cope, much more, with the situation they find themselves in.

**We only have one chance to get it right for
every person left behind, and those who grieve
for the loss of a loved one.**