Notifying survivors about sudden, unexpected deaths

This article is an edited version of a chapter in the book Grave Words: Notifying Survivors About Sudden, Unexpected Deaths, copyright 1999, by Kenneth V Iserson. Used with permission of Galen Press, Ltd (PO Box 64400, Tucson, AZ 85728-4400; phone: 1-800-442-5369 or 520-577-8363; fax: 520-529-6459; web site: http://www.galenpress.com), and Kenneth V Iserson. A teaching videotape, The Gravest Words, slide sets, and pocket-sized book of protocols are also available from the publisher. Prices and shipping details are on the web site.

THE PROBLEM
Death has replaced sex as the major taboo topic in western culture. Imaginary death—such as the cartoonlike violence portrayed on television and in movies—has replaced reality for most people. When death strikes, as it must, and especially if it strikes suddenly and unexpectedly, we respond with discomfort, distress, and dismay.

A sudden death is one that is unforeseen, unexpected, occurs with little or no warning, and that leaves survivors unprepared for the loss. It comes from an unexpected injury or suicide or from a medical cause such as heart attack, stroke, overwhelming infection, poisoning, or massive bleeding. Death might even result from fear.\(^1,2\)

We have no ingrained cultural responses to tell us how to deal with these crises.

Survivors are victims. Their reactions separate them from life, from reality, and often from caring about themselves, their future, or those around them. When a person learns of the sudden unexpected death of a loved one (bereavement), they experience a sense of being lost and not knowing what to do. Their sense of being suspended from life, inability to concentrate, indifference to immediate needs, disbelief that the deceased is really gone, and feeling that life can never be worth living again hinders their ability to arrange for the funeral and to make plans for other ongoing life needs.\(^3\)

This is grief.

No one likes to deliver the news of a sudden, unexpected death to others; it is an emotional blow, precipitating life crises and forever altering their worlds. Yet, many health, law enforcement, religious, and social service professionals must repeatedly do this as part of their daily work. It can be an emotionally draining and even harrowing experience. This article is designed to help us perform these duties with more skill, aplomb, and assurance.

Perceptive survivors can easily tell which notifiers care and which are only “going through the motions.” It often takes imagination to put oneself in the position of a grieving survivor, especially when wide cultural or age differences exist. Imagination, studying people, advance planning, and learning from experienced mentors is the only way to successfully perform this necessary but tragic task.

Even if you cannot learn to empathize with survivors whose life experience may differ considerably from yours, you can learn to behave appropriately, speak correctly, and assist them in their time of grief. Using death-notification protocols and being accompanied by more experienced partners may be the only way to positively affect these survivors.

WHY SUDDEN, UNEXPECTED DEATH NOTIFICATION IS UNIQUE
Sudden, unexpected deaths severely shock survivors. These deaths strike blows to the very essence of life for those left behind. The decedent’s sudden transition from being alive to being dead shocks all observers, both professionals and lay people alike. The degree of this shock is related to how independent, autonomous, and distinctive the decedent was when he or she died.\(^4\)

Some sudden deaths can even be considered calamitous when victims die unexpectedly of violent, destructive, demeaning, or degrading causes such as murder or suicide. These deaths can profoundly affect the victim’s community, some deaths more than others.\(^4\)

Once a person is dead, the survivors become the victims, the patients—those in need. Sudden deaths often represent major life transitions for the survivors. In an

Summary points
- A sudden, unexpected death leaves survivors unprepared for their loss
- Physicians can learn effective techniques for notifying survivors about such a death
- It is important to use nonmedical language when preparing survivors for bad news
- What survivors want most is a notifier who seems to care that their loved one has died
- Notification protocols can help notifiers prepare for their task and help them understand what to expect

KENNETH V ISERSON
Director
Arizona Bioethics Program
Professor of Surgery
University of Arizona Medical Center
1501 N Campbell Ave
Tucson, AZ 85724
Correspondence to:
Dr Iserson
Competing interests:
None declared
West J Med
2000;173:261-265

Volume 173 October 2000

wjm

261
instant and with no warning, women go from being wives to being widows, children become orphans, and friends survive alone.

In modern societies, people often do not witness the events that bring them grief. Survivors need someone to communicate this news to them. So the primary role of the death notifier is to "break the bad news."

A word must be said here about the commonly used terms, "breaking or delivering bad news." As death educator Kyle Nash says (written communication, April 1999),

These negatively value-laden phrases imply one-sided communication, which should never be the goal of any notifier-survivor relationship. If the communication is thought of in that manner at the outset, notifiers will tend to feel awkward, anxious, and uncomfortable about what they will be or are communicating. When notifiers feel uncomfortable, the type of communication that occurs in these situations does become one-sided.

While it may seem obvious that death notification will indeed be interpreted as negative (that is, bad), I believe that only the survivors can determine what the information means to them. Preferable terms that I use when teaching are "initiating or engaging in difficult conversations." These phrases clearly express 2-way communication and are value neutral.

Survivors’ first reaction when they hear the news is often, “It can’t be true! It can’t be happening!” The professionals around them must give all the support that they can to allow this unfortunate truth to sink in. Family members of those who die suddenly and unexpectedly, either in an emergency department or in a hospital (and also presumably outside the hospital) do much more poorly than those whose deaths are expected. This may be because there is no time for psychological preparation.

EXPECTED VERSUS SUDDEN, UNEXPECTED DEATHS
Most people’s deaths can be anticipated. Those who die are usually elderly people with chronic, often obviously progressive, diseases. Even if the exact day, week, or even month when the death occurs comes as a surprise, no one is surprised when it happens. The differences between these expected deaths and sudden unexpected deaths are illustrated in the table on p 263.

WHO ARE THE NOTIFYERS?
In the United States and Canada, about 70% of deaths occur in health care institutions, so their staff is usually responsible for notifying survivors about the death. In the other 30%, however, this job falls to the police, ambulance or fire department personnel, chaplains, medical examiners or coroners, or coworkers. In nearly all cases, regardless of whether the death occurs in a health care facility, family members and friends of the decedent must then notify others.

NOTIFICATION OF A DEATH DURING A RESUSCITATION ATTEMPT
Importance of nonmedical language
Within most medical facilities, protocols determine who is considered to be the notifier. If a family arrives at the hospital while resuscitation attempts are ongoing, a chaplain, social worker, or nurse may be delegated to inform the family of the patient’s status. These professionals may be more inclined to use nonmedical words to explain what is occurring than would a physician. This is vital because, despite its wide use in the media, the jargon commonly used in hospitals is unfamiliar to most people. To avoid any miscommunication, health care workers who act as notifiers should use “heart attack” rather than “MI,” “injury” rather than “trauma,” and “breathing machine” rather than “ventilator.”

Updating the family
These notifiers should continually update the family about any changes. When things are going badly, the same person, or at least 1 person from the group who initially spoke with them, should progressively inform the family that “things are not looking good.” This alerts them to the grave situation and gives them at least a little time to prepare for the bad news. This psychological preparation for the loss of their loved one is often disparagingly termed “hanging crepe,” but survivors usually view it as “being gentle.” Technically, the strategy is called “presaging” or allowing survivors time for “anticipatory grief.” Some have also referred to these updates as “successive preannouncements” and “preliminary suspicion announcements,” sug-
gesting that it is a gradual build up to what is expected to be tragic news."

In a typical emergency department scenario, a nurse, chaplain, or social worker acts as the liaison between the resuscitation team and the family. They meet family members as they arrive and guide them to a waiting area. Having already been in the resuscitation room, the liaisons have a sense of or have been explicitly told about the patient’s condition and what chance the clinicians think the patient has of making it out of the emergency department and the hospital alive and functional. They in turn deliver this news to the family. Initially, they may say, "We are not sure but after delivering the news in this way, they take the time to sit with and assist the survivors for at least a short time. When these nonverbal or minimally verbal announcements fail, clinicians must fall back on their standard death notification methods.

Occasionally, interactions between the clinician and survivors during resuscitation attempts convey important clinical information. As Dr Bob Orr relates (oral communication, March 1999):

Things weren’t going well during an emergency department resuscitation and I had “hung crepe” a few times with the potential widow. Finally, I told her that we were only continuing with CPR because his pupils had not

### Expected versus sudden, unexpected deaths

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Sudden, unexpected death</th>
<th>Expected death</th>
</tr>
</thead>
<tbody>
<tr>
<td>Approach of death</td>
<td>Immediate or in a short time</td>
<td>Gradual</td>
</tr>
<tr>
<td>Nature of illness or injury</td>
<td>Acute process or acute worsening of a stable chronic illness</td>
<td>Chronic—usually an illness or combination of illnesses</td>
</tr>
<tr>
<td>Causes of death</td>
<td>Disease, suicide, homicide, accidental, disaster, or unknown cause</td>
<td>Usually disease or a result of aging processes</td>
</tr>
<tr>
<td>Age of decedent</td>
<td>Any age, commonly young or middle-aged adults, fetuses, and neonates</td>
<td>Usually elderly but can occur at any age</td>
</tr>
<tr>
<td>Place of death</td>
<td>Usually in public, emergency department/intensive care unit, or at home or work</td>
<td>Usually home, hospital, or nursing home</td>
</tr>
<tr>
<td>When death occurs</td>
<td>At the time of or shortly after the acute event</td>
<td>Months to decades after diagnosis of chronic disease occurring in old age</td>
</tr>
<tr>
<td>Survivor reaction</td>
<td>Disbelief, shock, grief, dismay, disorganization, hostility, and fear</td>
<td>Grief</td>
</tr>
<tr>
<td>Survivor involvement</td>
<td>Usually not present at death; appear gradually at death scene or emergency department</td>
<td>Often present at death or aware of impending death</td>
</tr>
<tr>
<td>Site of last contact with medical personnel</td>
<td>Public space, home, or emergency department</td>
<td>Hospital, home, hospice, or nursing home</td>
</tr>
<tr>
<td>Resuscitation procedures</td>
<td>Often performed</td>
<td>Rarely performed; advance directives often available</td>
</tr>
<tr>
<td>Patient identity</td>
<td>Known or often, at least initially, unknown</td>
<td>Usually known</td>
</tr>
<tr>
<td>Autopsy</td>
<td>Frequent and done by medical examiner or coroner</td>
<td>Rare, and when done, usually by hospital pathologist</td>
</tr>
<tr>
<td>Family’s immediate after-death rituals and requirements</td>
<td>Usually not prearranged</td>
<td>Often prearranged by dying person or family in anticipation of death</td>
</tr>
</tbody>
</table>

**WHAT SHOULD PHYSICIANS DO?**

In some instances, the physicians or surgeons only need to stop, shake their heads, and say “I’m sorry” for survivors to get the news they expect. In these cases, the physicians clearly mean they are sorry for the survivors’ loss as well as for their own inability to change the outcome. It is hoped that after delivering the news in this way, they take the time to sit with and assist the survivors for at least a short time. When these nonverbal or minimally verbal announcements fail, clinicians must fall back on their standard death notification methods.

Occasionally, interactions between the clinician and survivors during resuscitation attempts convey important clinical information. As Dr Bob Orr relates (oral communication, March 1999):

Things weren’t going well during an emergency department resuscitation and I had “hung crepe” a few times with the potential widow. Finally, I told her that we were only continuing with CPR because his pupils had not
THE NOTIFICATION OF DEATH

Once death has occurred, especially in an emergency department, the physician usually has the task of delivering the news, often accompanied by a chaplain, a nurse, or a social worker. Most survivors have no objection if more timely notifications can be made by other professionals, such as a nurse, chaplain, or social worker, as long as they have subsequent contact with the physician. What survivors want most is a notifier who seems to care that their loved one has died—someone who will inform them in a warm, sympathetic tone of voice. As a survivor who did not have that experience said: ‘I could not believe that a death that was so important to me was so unimportant to the people in that emergency room. I left thinking that there must be something wrong with me, that somehow I should not be feeling the way I was feeling. I felt as though I was abnormal.’

Some professionals avoid this responsibility and pass the job to others. This is usually because they have difficulty dealing with one or more aspects of death or the interaction with survivors. This task, however, should never be relegated to the unit assistant, medical or nursing student, or other untrained or partially trained person. The exception to this is when a student or resident, who is in the process of being educated to the death-notification process, is accompanied by an experienced, supervising mentor.

When reluctant notifiers must speak with survivors, they often use a standard, rapid, unconcerned approach as a defense. Others, even those who try to do a good job, just “wing it,” using whatever method seems best. For professionals, these can be career-crippling strategies.

<table>
<thead>
<tr>
<th>Box 1</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Telling survivors about sudden unexpected deaths may be difficult for physicians because they often</strong></td>
</tr>
<tr>
<td>• Lack training and experience</td>
</tr>
<tr>
<td>• Fear being blamed</td>
</tr>
<tr>
<td>• Do not know how to cope with survivors’ reactions</td>
</tr>
<tr>
<td>• Fear expressing their emotions</td>
</tr>
<tr>
<td>• Fear not knowing the “right” answers</td>
</tr>
<tr>
<td>• Fear their own death or disabilities</td>
</tr>
</tbody>
</table>

The dam of restraint can no longer hold back the deluge of tear-filled anguish. The intruders silently, and understandably, wait with patience until the sobbing subsides. After a while, you and your husband look at them as sources of guidance, strength, and information. You ask ‘What happened?’ The intruders, now companions in this sorrow, review the incident with sufficient detail for you to understand what happened. They answer, to your satisfaction, the questions of who was involved, where it happened, how it happened, and where your son’s body is now. They ask if they can contact your own clergy. As you look at your husband, he nods his head and says, ‘Yes, we would appreciate that.’

<table>
<thead>
<tr>
<th>Box 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>This is a survivor’s description of a home notification she endured. It has been modified and used with permission. The survivor was woken in the night by a police officer and a chaplain, who began to ask her questions:</td>
</tr>
</tbody>
</table>

“You start wondering who is in trouble. Your mind begins to race down the checklist of family members: your husband is at work; your son has been staying out too late recently; your daughter is expecting her first child, and she and her husband have been arguing a lot recently.

As this stranger, these ‘intruders,’ continues asking questions, your own questions start flashing though your mind. Your world begins crumbling in on you. You are brought back to the present moment by an insistent voice gently but firmly calling your name. ‘Are you all right?’ You look at the speaker’s face, trying to read what is being said. You hear your own voice, as from a distant point saying, ‘Yes, I’m all right.’ Those probing, intense voices then ask, ‘Is your husband at home?’ You feel yourself beginning to feel faint. The voices urge you to go inside and sit down. As you sit, they ask about your husband again. You take a deep breath, trying to clear some of the cobwebs from your thoughts. Finally, you realize your husband is at home. He traded nights off with a friend and is sleeping. You call him several times before he answers, and you ask him to come downstairs.

Taking the stairs 2 at a time, he hurries to your side. ‘Who are you?’ he asks them, as he puts his arm protectively around your shoulder. You introduce your husband to these strangers who are obviously bringing bad news, although they radiate a calmness and a genuine friendliness that help you feel a little less anxious. Icy fingers of fear clutch your throat as you hear the question, ‘Do you have a son named Tom? He has wavy blond hair and a moustache?’ Your hands move to your throat as though to seek release from that strangehold of fear. The questions continue. ‘Is your son about 18 years old? Does he drive a blue antique pickup truck?’

By the time the news has been delivered, you feel as though you have been in a vacuum—enveloped in a warm, sympathetic tone of voice. As a survivor who did not have that experience said: ‘I could not believe that a death that was so important to me was so unimportant to the people in that emergency room. I left thinking that there must be something wrong with me, that somehow I should not be feeling the way I was feeling. I felt as though I was abnormal.’

| 5 |

Fear the wrong death or disabilities

Fear not knowing the “right” answers

Fear being blamed

Lack training and experience

Don’t know how to cope with survivors’ reactions

Fear expressing their emotions

Fear not knowing the “right” answers

Fear their own death or disabilities

The dam of restraint can no longer hold back the deluge of tear-filled anguish. The intruders silently, and understandably, wait with patience until the sobbing subsides. After a while, you and your husband look at them as sources of guidance, strength, and information. You ask ‘What happened?’ The intruders, now companions in this sorrow, review the incident with sufficient detail for you to understand what happened. They answer, to your satisfaction, the questions of who was involved, where it happened, how it happened, and where your son’s body is now. They ask if they can contact your own clergy. As you look at your husband, he nods his head and says, ‘Yes, we would appreciate that.’”

| 9 |

Fear the wrong death or disabilities

Fear not knowing the “right” answers

Fear being blamed

Lack training and experience

Don’t know how to cope with survivors’ reactions

Fear expressing their emotions

Fear not knowing the “right” answers

Fear their own death or disabilities

The dam of restraint can no longer hold back the deluge of tear-filled anguish. The intruders silently, and understandably, wait with patience until the sobbing subsides. After a while, you and your husband look at them as sources of guidance, strength, and information. You ask ‘What happened?’ The intruders, now companions in this sorrow, review the incident with sufficient detail for you to understand what happened. They answer, to your satisfaction, the questions of who was involved, where it happened, how it happened, and where your son’s body is now. They ask if they can contact your own clergy. As you look at your husband, he nods his head and says, ‘Yes, we would appreciate that.’”
A key psychological response that often diminishes notifiers’ effectiveness is identifying too closely with survivors, thus becoming entangled in their emotions. This may be due to the notifier having experienced a similar event or closely matching the key survivor’s age, cultural background, and social or professional position. There are several reasons why it may be difficult for physicians to tell survivors about sudden unexpected deaths, as shown in box 1.

The qualities of a good communicator are genuineness, warmth and respect for the survivors, active listening, empathy, and openness.

WHY USE PROTOCOLS?
It has been claimed that “effective grief support cannot be reduced simply to a protocol-driven response.” It is true that no protocol can anticipate every eventuality; every notification will differ in some way. Neither can it enable notifiers to break bad news painlessly. It can, however, help notifiers prepare for their task and help them understand what to expect. Protocols combined with staff education have made significant differences in how survivors perceive and respond to sudden-death notifications.

References
1 Harvey WP, Levine SA. Paroxysmal ventricular tachycardia due to emotion: possible mechanism of death from fright. JAMA 1952;150:479-480.