

## TOOLBOX

# Beyond breaking bad news: how to help patients who suffer

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“He who has a why to live can bear with almost any how.”

—Friedrich Nietzsche

### Expert advice

Despite the fact that clinicians are responsible for delivering bad news, this skill is rarely taught in medical schools or residencies in the United States, and clinicians are generally poor at it.<sup>1-4</sup> Experienced clinicians who have offered recommendations for delivering bad news well agree on many points.<sup>5-8</sup> The box below lists the clinician’s most important goals for the initial breaking of bad news, as cited in the medical literature. The box on the facing page summarizes specific recommendations offered in the literature for delivering bad news, organized into a simple mnemonic (“ABCDE”). Experts also point out that clinicians invariably respond with their own feelings about the bad news.<sup>9</sup>

### Initial goals in delivering bad news

- Allow emotional ventilation
- Achieve a common perception of the problem
- Address basic information needs
- Address immediate medical risks, including suicide
- Respond to immediate discomforts
- Ensure a basic plan for follow-up
- Anticipate what has not been talked about
- Minimize aloneness and isolation (reassure about nonabandonment)

Breaking bad news is sometimes seen as a skill that clinicians can master with attention to the words, setting, and attitude with which they deliver upsetting information. Beyond breaking the bad news, however, clinicians also are called on to help manage its consequences—a task that requires not just expert advice and training, but also attention to patients’ existential and spiritual issues.

### Suffering and meaning

Physician Eric Cassel defined suffering as “the state of severe distress associated with events that threaten the intactness of a person.”<sup>10</sup> In this model, the whole person is a complex integration of many parts, including the physical body, secret inner life, relationships, and sense of underlying meaning in the universe. In challenging one or more of these parts, bad news can cause suffering. For patients, bad news often threatens their identity and challenges their sense of transpersonal meaning. Thus bad news can raise profound spiritual issues.

Clinicians focus often on relieving patients’ bodily pain, less often on their emotional distress, and seldom on their suffering. Indeed, clinicians may view suffering as beyond their professional responsibilities. But by concentrating on physical or emotional pain, clinicians may be ignoring important elements of meaning to the patient as a person, thereby intensifying suffering.

If clinicians feel unable to, or simply do not want to, address the powerful issue of patient suffering, it is appropriate to refer the patient to another professional on the healthcare team who is more comfortable in this arena. Physicians, nurses, psychologists, social workers, and chaplains all have a role in helping patients who suffer and can support each other in providing care to the patient.

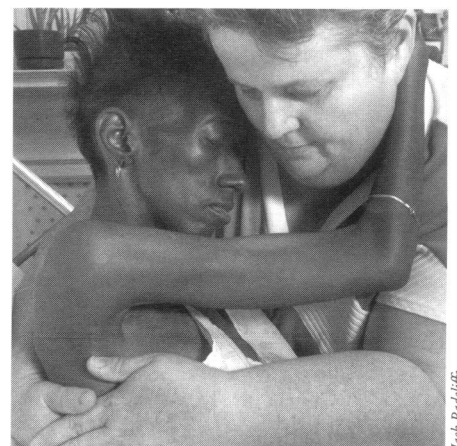
Throughout the process of dealing with suffering, the core task of the clinician must be to understand the patient’s response to the bad news and the meaning ascribed to it. This understanding can come only from a detailed and tolerant exploration of the patient’s unique experience of suffering.<sup>5,10</sup> The clinician’s commitment to nonabandonment and to listening openly to the patient is necessary to being able to accompany the patient through the profound challenges of bad news, especially at the end of life.<sup>11</sup> Indeed, it is the trust possible in the patient-clinician rela-

### Summary points

- Clinicians are rarely taught how to deliver bad news.
- Following published recommendations might help clinicians to deliver bad news well.
- In addition to delivering bad news, clinicians can help patients manage its consequences.
- Important tasks include listening with compassion and understanding the meaning patients ascribe to bad news.
- Clinicians may also offer a number of specific responses to patients to help ameliorate suffering.

tionship that allows clinicians to discover what may be of service to the patient.<sup>12,13</sup>

How can clinicians provide support and how can they help ameliorate suffering? First, clinicians can help simply by listening with compassion. Second, clinicians can provide emotional reflection and validation. Importantly, clinicians also may offer a number of specific responses to patients to help ameliorate suffering. These responses, derived from the work of Cassel and others, are divided into “inquiries” and “prescriptions” that can be offered to help catalyze



Sheila and Georgia

Jack Radcliffe



patients' thinking and gather resources for facing suffering (see box, page 262).

### Finding strength

Patients may be able to bear bad news through personal strength (for example, from previous life experience) or with the strength of others (for example, in bereavement groups). Strength can help hold together the parts of a person threatened with dissolution by bad news.<sup>10</sup>

Clinicians may begin an inquiry into the patient's resources by asking, "When bad things have happened to you before, how did you cope?" Simply asking "What are your sources of strength or support?" will help the clinician identify the patient's need for additional resources. Asking patients "To whom will you turn for support?" may encourage patients to mobilize their own resources.

Based on an understanding of the patient's inner strengths and social supports, clinicians might "prescribe" educational reading material, support groups, and referrals to other professionals, to lend strength to the suffering patient.

### Enhancing growth

The challenge of bad news or illness may be met with personal growth by the patient. The integrity of the whole person may be maintained if the person can compensate for what is lost.<sup>10</sup> Many involved in hospice work report the end of life to be an opportunity for personal growth by patients.<sup>14</sup>

Clinicians might ask, "Even though there are some things you can no longer do, what activities can you still enjoy?" With some patients, the clinician may have to search for an opening: "What about you as a person does this disease *not* affect?"

Reviewing earlier experiences of growth in a patient's life may assist the patient in identifying the processes by which he or she best learns and develops. Research into what has been possible for others at the end of life may challenge the patient's sense of limitation. Volunteer work can help some patients regain a sense of purpose and value.

### Embracing the moment

Bad news often represents a threat to the future, but the resultant suffering may be preempted by embracing the present moment.

## Techniques for delivering bad news well: ABCDE

### Advance preparation

- Ask what the patient already knows and understands. What is his or her coping style?
- Arrange for the presence of a support person and appropriate family
- Arrange a time and place that will be undisturbed (hand off beeper)
- Prepare emotionally
- Decide which words and phrases to use (write down a script)
- Practice delivering the news

### Build a therapeutic environment/relationship

- Arrange a private, quiet place without interruptions
- Provide adequate seating for all
- Sit close enough to touch if appropriate
- Reassure about pain, suffering, abandonment

### Communicate well

- Be direct ("I am sorry, I have bad news")
- Do not use euphemisms, jargon, acronyms
- Say "cancer" or "death"
- Allow for silence
- Use touch appropriately
- Ask patient to repeat his or her understanding of the news
- Arrange additional meetings
- Use repetition and written explanations or reminders

### Deal with patient and family reactions

- Assess patient reaction
  - physiologic responses: flight/fight, conservation/withdrawal
  - cognitive coping strategies: denial, blame, intellectualization, disbelief, acceptance
  - affective responses: anger/rage, fear/terror, anxiety, helplessness, hopelessness, shame, relief, guilt, sadness, anticipatory grief
- Listen actively, explore feelings, express empathy

### Encourage and validate emotions (reflect back emotions)

- Correct distortions
- Offer to tell others on behalf of the patient
- Evaluate the effects of the news
- Explore what the news means to the patient
- Address further needs, determine the patient's immediate and near-term plans, assess suicidality
- Make appropriate referrals for more support
- Provide written materials
- Arrange follow-up
- Process your own feelings

For example, a patient may say, "Although I know I will get very sick from my illness in the days ahead, today I feel well enough to enjoy time with my grandchildren." A patient focused on current feelings, experiences, and meaning may avoid the pain caused by considering a future darkly circumscribed by a bad prognosis. This focus may help dissolve barriers and bring about a sense of intimacy and wholeness.<sup>15</sup>

Clinicians might inquire about patients' desires and current feelings, asking such

things as "What do you feel like doing right now?" Alternatively, asking patients about their hopes and dreams may reveal a desire that the patient might fulfill earlier rather than later: "Is there something you've always wished you could do?" and "What's stopping you from doing it now?"

### Searching for meaning in suffering

The psychiatrist Viktor Frankl wrote that "Man is not destroyed by suffering; he is destroyed by suffering without meaning."<sup>16</sup>



## Strategies for clinicians to help patients who suffer

### 1. Finding strength

- Inquire about the patient's resources:
  - “When bad things have happened to you before, how have you coped?”
  - “To whom will you turn for support?”
- Prescribe resources available to the patient:
  - Regular physician follow-up
  - Psychologist, social worker, chaplain, home-care referral
  - Reading material, videos
  - Specific organizations (e.g., the National Colitis Association)
  - Internet news groups, bulletin boards, chat rooms
  - Support groups

### 2. Enhancing growth

- Inquire about compensatory pleasures and skills:
  - “Even though there are some things you can no longer do, what activities can you still enjoy?”
  - “Are there things about you this disease does not affect?”
- Prescribe steps toward growth:
  - Identify times when the patient has grown in the past
  - Research what has been possible for others
  - Encourage volunteering

### 3. Embracing the moment

- Inquire about current feelings and desires:
  - “What do you feel like doing right now?”
  - “Is there something you've always wished you could do? What is stopping you from doing it?”
- Prescribe a redirection toward current reality:
  - Coordinate disease treatment with personal goals
  - Help set priorities
  - Teach or encourage meditation

### 4. Searching for meaning in suffering

- Inquire about the patient's disease model and meaning of illness:
  - “What does this news mean to you?”
  - “Does this news scare you in any way?”
  - “What do you think caused your illness?”
- Prescribe life examination exercises:
  - Journal writing, autobiography, life review
  - Revisiting the past through photos, people, travel

### 5. Seeking acceptance and reconciliation

- Inquire about personal dissatisfaction and estranged relationships:
  - “Where are you hardest on yourself?”
  - “Do you have any regrets in life?”
  - “Is there anyone you really want to talk to before you die?”
  - “Is there someone you've never been able to forgive?”
- Prescribe steps toward self-acceptance and reconciliation:
  - Advance care planning
  - Distribution of personal possessions
  - Communication by letter, telephone, e-mail
  - Meetings, goodbyes

### 6. Achieving transformation

- Inquire about spiritual and religious beliefs:
  - “Are you a spiritual or religious person?”
  - “Has illness ever changed you in a fundamental way in the past? If so, how?”
  - “Do you know anyone who was transformed in a positive way by illness?”
  - “Where do you think things are headed?”
- Prescribe movement toward transcendence:
  - Spiritual mentor
  - Prayer
  - Letters to loved ones

Searching to understand the meaning underlying bad news or at the end of life can provide solace. “In some way,” Frankl wrote, “suffering ceases to be suffering at the moment it finds a meaning.”<sup>16</sup>

Clinicians must understand the model of disease employed by the patient, as well as the patient's understanding of the meaning of the illness. Asking a patient, “Where do you think your illness came from?” might uncover the patient's beliefs regarding the cause of disease and his or her sense of responsibility for it. Patients often find comfort in learning from their clinicians that the bad news is not their fault. Asking patients, “How are you doing within yourself?” or “What does this news mean to you?” may lead to discussions that help patients begin to grapple with the meaning of their illness, giving them a sense of control.

The sufferer's question, “Why me?,” is a potent one to which clinicians must respond—though not necessarily answer. Clinicians can facilitate the patient's own search for meaning by encouraging the patient to undertake an examination of his or her life and memories. The clinician might offer a prescription to keep a journal, practice meditation, or look through photograph albums.<sup>17,18</sup>

### Seeking acceptance and reconciliation

Philosopher and priest Henri Nouwen wrote about “befriending” one's suffering as the first step toward healing.<sup>19</sup> In accepting suffering, a patient can claim it, become familiar with it, and, potentially, overcome it by embracing it. Consideration of the end of life sometimes prompts patients to forgive or seek forgiveness from loved ones. This forgiveness can provide the patient with an unexpected positive outcome from the experience of illness and has even led some patients to describe their cancer as a gift.<sup>20</sup>

Regret, guilt, and shame act as barriers to self-acceptance. A clinician may gently explore a patient's regrets or personal dissatisfaction with questions such as “Where are you hardest on yourself?” Asking directly about painful or estranged current or past relationships is appropriate for some patients (“Is there someone you really want to talk to before you die?”). Clinicians can offer to assist patients contemplating a reconciliation with an estranged loved one.



An acceptance of bad news allows patients to focus on the tasks of adjusting to their illness or on the tasks of dying, rather than fighting fruitlessly against inevitable mortality. Advance care planning encourages patients to make personal and legal arrangements for the time when they become sick or die. Some patients at the end of life gain a sense of joy and completeness in distributing their possessions to loved ones.

### Achieving transformation

Sometimes, illness and loss may be transformative. Patients can respond to bad news by growing not merely stronger but fundamentally different. In a powerful paradox, such transformation allows patients to discover a passion for life in the face of impending death.<sup>14</sup>

Clinicians can ask, "Are you a spiritual person?" More direct questions include "Has illness ever changed you in a fundamental way in the past? If so, how?" and "Do you know anyone who was transformed in a positive way by his or her illness?"

Although transformation through suffering is an intensely personal event, the clinician has an appropriate role in searching creatively with the patient for how good can come from bad. Clinicians may encourage religious patients to pray or may help them to seek out a spiritual mentor. Sitting with, talking with, or writing letters to loved ones often helps focus patients at the end of life on transcendent issues such as the soul, the meaning of life, and the nature of love.

### Reviving the messenger

In ancient times, the bearer of the news that a battle had been lost was often killed. In a similar fashion, when reacting to bad news, some patients blame their clinicians. This desire to "kill the messenger" seems understandable if clinicians appear merely to deliver prognoses without compassion and to be

locked in battle with death as an adversary rather than acknowledging death as an essential part of life.<sup>21</sup>

Clinicians can deliver bad news well *and* manage its consequences. Clinicians are not responsible for knowing the answers to patients' deeply personal and existential questions; they are called on to be present as witnesses to their patients' suffering and to respect the vulnerability created by the news they bear. Whether simply being present for a patient in shock after the delivery of bad news or accompanying a patient undergoing a spiritual transformation, clinicians can help meet the patient's existential needs. In working to relieve suffering, in helping patients to discover not just *how* to live but *why*, clinicians fulfill an obligation and enjoy a privilege deeply rooted in the healing tradition and sanctified by society at large.

To manage bad news well, the clinician must place his or her relationship with the patient, the strength and reality of their human bond, over the insecurity of disease, the threat of dissolution, and the fear of death. Breaking bad news is not as much a delivery as it is a dialogue between two people, both striving to discover in each other a simple faith in the future and an understanding of meaning beyond themselves.<sup>5</sup>

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