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SEARCH

THINKING

Breaking bad news

For decades, the way bad news was broken was, as one official British report put it, “deeply insensitive”. Now we do it better, thanks to the efforts of one American widow



ONE WINTER EVENING in 1986, a police officer stood outside a home in north London, knowing he had to tell the woman inside that her husband was dead. Just 23, Jason Clauson was the newest recruit at the station, and therefore, by tradition, the one pushed into delivering the “death message”. “They’d say, ‘Come on lad, you’ve got to go and do it.’ If you objected, the governor would have gone, ‘Don’t be so stupid.’”

A few hours earlier, Clauson had been called to a roadside where a man in his late 50s had been found dead at the wheel of his car. It transpired that the man had taken early retirement and was on his way home from his last half-day at work, when he had apparently stopped because he felt unwell. Seconds later, he had a massive heart attack; the engine was still running when he died.

“He was sat there for three hours with the car overheating before someone noticed and started banging on the window, thinking he was asleep,” Clauson remembers. “By the time I got to the house, his wife was panicking because she’d called his office and they’d told her he’d left hours ago. So as soon as she opened the door and saw me, she knew something was wrong and she staggered on the doorstep. I reached out to grab her and her daughter got hold of her and said, ‘What’s wrong?’ And now they’re both saying, ‘What’s up? What’s wrong?’ Just bombarding me with the same question.

“I remember being told, ‘try and get them to sit down because if they faint [while standing up] they’ve got further to fall’, so eventually I got them to sit down. Basically I said, ‘I’m afraid I’ve got some terrible news for you. Your husband has passed away in his car.’ And you could see her world collapse. And you could see her daughter’s world collapse too. And I was sitting with my arm on the shoulder of two ladies thinking, what do I do now?”

Breaking bad news might seem straightforward. “It’s not rocket science,” said one surgeon I spoke to, “you’ve just got to be a half-decent person and give them the facts.” But common sense tells us that those facts are an emotional bomb waiting to go off. And medical thinking now recognises this: receiving bad news, according to the *Western Journal of Medicine*, “results in cognitive, behavioural, or emotional deficit in the person receiving the news that persists for some time after the news is received.” News of a sudden death can prompt intense crying, anger or guilt. Some people appear calm and controlled; others are seized by a need to be busy—faced with overwhelming pain, some of us block it by going and doing the washing-up. But no one in such a predicament can be considered normal. We go into shock, which means we are unbalanced mentally and physically. Distress impairs circulation, makes us cold, disrupts the endocrine, immune and cardiovascular systems, upsets rational thought, disturbs sleep.

Every year, 1.17m people die in road accidents around the world. As of January 2011, 7,066 soldiers from coalition forces had been killed in the wars in Iraq and Afghanistan, along with an estimated 110,000 civilians; in 2007, the last year for which there are full figures, 521,303 people died of cancer in western Europe. Behind all these statistics are families who need to be informed and someone whose job it is to inform them. There is now a widespread belief that the way the news is delivered has a profound effect on the way the dead person is remembered and the way the survivors heal.

There are some textbook examples of what not to do. Putting a note through the letterbox; getting the victim’s name wrong; using euphemisms such as “lost” or “passed on” (confusing at a time when someone is trying hard not to believe it); and turning up in shorts and flip-flops, like the British diplomats who greeted one woman as she arrived in Bahrain

in 2006 after her husband's death in a boat disaster. A vision that has stuck in her mind, rather than anything that was said.

And what of the bearers of bad news? What is it like to knock on a door knowing you are about to instigate the worst moment in someone's life, and then have to confront the ways in which they do or do not deal with the fact that a life has ended? We live in an age where death has been largely exiled offstage. Families used to see it up close, at home; it did not typically involve hospital wards or dual carriageways or a stranger breaking the bad news. And there has been a slow realisation that unless the psychological particulars of that moment are addressed, unless the many challenges of grief and shock are dealt with competently, there can be unwelcome consequences. Which is why a number of fields have begun to wrestle with the problem: how do you break bad news in a good way?

ROB COCKBURN SITS in his office in London, opens his laptop, inserts a DVD and shows me how best to tell someone they're dying. Cockburn manages Connected, a nationwide British programme to train oncologists in "difficult consultations".

Launched in 2008, and funded by the Department of Health, it has so far trained 9,000 clinicians working with cancer on three-day courses using experts, actors and role play. The course is not voluntary: all cancer specialists in Britain are now expected to attend. This is the legacy of a shift in medical thinking. Thirty years ago, doctors believed that the dying didn't want or need to know how ill they were. They disguised the truth in euphemisms ("just a little growth") or restricted it to the patient's family. Telling the patient, they believed, would take away all their hope. Even a decade ago, doctors felt quite anxious about telling people they had cancer and were going to die, so that news was often withheld from them.

In 2000, a report entitled Open Space was published by Macmillan Cancer Relief. "If only the surgeon would talk to me properly," one patient said to the researchers. "They arrived in a group of five round my bed in hospital—and he talked quickly to me—he discussed something with them and moved on—I had no chance to ask questions...the surgeon gave me the impression he was busy big-time in front of his juniors—and not caring about my feelings...he is a clever surgeon but has a bad way with patients."

Also in 2000, the Blair government launched a Cancer Plan to upgrade services and start a new drive informed by an increasing awareness of patients' psychological needs. Some patients, the plan said, were "being given bad news in a deeply insensitive way, being left in the dark about their condition and badly informed about their treatment and care...By 2002 it will be a pre-condition of qualification that they [hospital consultants] are able to demonstrate competence in communication with patients."

The ability to communicate is now seen as an essential clinical skill. The DVD in Cockburn's

laptop is some homework for his trainees. It features Dr Pauline Leonard, a consultant medical oncologist and trainer on the course, who is in her 40s and has long blonde hair, along with two fictional characters—“Sylvia Braithwaite”, a meek woman in her early 50s, suffering from bowel cancer, and her domineering husband “Harry”. The couple are played by actors, but the scenario is based on a real case. Sylvia has had surgery to remove a tumour and part of her bowel, followed by six months of chemotherapy, and she thinks the worst is over. But this is the moment when Dr Leonard has to tell her the treatment hasn’t worked: the cancer has spread to her liver and lungs and she has only 12 to 14 months to live.

Cockburn goes through the DVD, stopping and rewinding to discuss Dr Leonard’s methods. He picks out the way she starts by asking Sylvia how she is: “she’s allowing the patient to express feelings.” The trouble is that Sylvia says she’s feeling a lot better and looking forward to having her colostomy bag removed. She smiles, hopefully. We fast-forward.

Dr Leonard pauses, then takes a deep breath. “There was never a guarantee that six months of chemotherapy would stop the cancer.”

Cockburn points at the screen, “That’s the warning shot,” he says. “ ‘No guarantee’—now if you were hearing that, you would subconsciously or consciously think: hang on a minute, that doesn’t sound so good.”

He presses play: Dr Leonard gives the facts, and then says, “I’m afraid, Sylvia, we’re not able to get it out any more.” Phrases like “I’m afraid” and “I’m sorry” are recommended as they flag up the fact that bad news is coming. Sylvia starts crying. “I’m sorry, this is very sad,” says Dr Leonard, leaning forward to touch her shoulder and hand her a tissue. An “empathy shot”, Cockburn says, which shows the doctor is not just concerned with the cold transmission of facts.

Seven minutes into the consultation and emotions are running high. The domineering husband sprays some irrational anger at Dr Leonard, complaining about spending “half a mortgage” on hospital parking. Sylvia is still crying. But worst of all, it’s clear she hasn’t absorbed either the information, or its outcome. Her focus is not on the “precious time left”, as Dr Leonard calls it, but on her colostomy bag (the least of her worries). She hasn’t grasped the fact that she’s dying at all. “She’s blocking,” says Cockburn. Sylvia may feel that as long as she keeps talking about the colostomy bag, Dr Leonard can’t tell her about the cancer spreading, and she can pretend it never happened.

So Dr Leonard tells her again. In the end she has to tell her a third time. “Chin up, girl,” says Harry, after around ten minutes, “Where there’s life, there’s hope.”

You can see why some consultants bridle at doing this. How much easier to keep quiet, as suggested in Bailey and Love’s “The Short Practice of Surgery”, a key textbook that has been through many editions. “There will, of course, be a small number who really should not be confronted with the realities of fatal illness,” the 1984 edition advised in the section on “What to Tell the Patient”, before highlighting the virtues of a Brompton Cocktail: a prescription of morphine, cocaine, honey, gin and chloroform water.

“We find it really difficult telling people really difficult things,” Dr Leonard tells me later. And she is experienced—in her clinic at the Whittington Hospital in north London, she has to tell two to three patients a week that they are coming to the end of their lives. Even a decade after the Cancer Plan, “we’re not trained to deal with the emotional fallout.”

The immediate fallout tends to be tears, shock, numbness or a sense of unreality. Some people are unnaturally calm, which may not help: “It presents a challenge for working out if they’ve understood what you’ve said,” says one consultant.

Models such as spikes, a six-step protocol for breaking bad news, have caught on quickly in

medical schools because they provide a framework and make a messy situation easier to manage (“set up an interview...assess the patient’s perception”). But in the end the consultation comes down to two people: doctor and patient. And when they sit facing each other in the consulting room, patients can be very influenced by the doctor’s manner. In 1991 the British Medical Journal published a study called “Your Child is Dead” by Ilora Finlay and Doris Dallimore. It asked the parents of children killed in car accidents to comment on the way three groups—the police, nurses and doctors—had delivered the bad news. The police were rated the most sympathetic because it looked as if it mattered to them. “He cared so much he had tears in his eyes,” was one parent’s comment on one officer.

The lesson, says Dr Leonard, is that showing emotion is OK. She recently examined some junior doctors and found them skilled at adopting the bad-news framework, but it failed to benefit the patients, because they were terse and curt. “Of course, don’t reach for the tissues first and start crying. But in medicine we’re trained to be so professional and we come across as cold and actually, if you are a bit choked and you are sad, patients don’t mind, because they see it hurts you too.”

ON DECEMBER 5TH 2001, Alexsis de Raadt-St James was at home in San Francisco, sitting at her desk in her bedroom. Then aged 44, a graduate of Massachusetts Institute of Technology, consultant for high-tech companies and mother of two, she was about to fly to London to meet her husband, Nick de Raadt, who ran a shipping logistics company. It was a normal day, she says. And the normality prevented her from fully believing what happened next. The phone rang. A voice said her husband was dead. He’d had a heart attack. He was in a hospital in France. He was 48. It was unthinkable.

She looked at her six-year-old daughter playing on the floor by her feet. She remembers asking how it happened, but not understanding what was being said. She remembers hanging up, and trying to compose herself; a driver was waiting to take her to the airport. “My first thought was this intense trauma, the second was, how do I tell my children?”

She went through the deep physiological changes that sudden grief brings: a surge of the stress hormone cortisol; shallow breathing (women, in particular, can develop the “freeze” response to extreme trauma); an instinct to try and put a logical framework on an event that is quite illogical by asking questions—how did it happen? did he suffer? what were his last words?—along with an inability to absorb the answers because shock impairs brain function. “You know how you can drive from your home to the store without even thinking,” says Dr Margaret Chesney, a professor at the Osher Centre for Integrative Medicine, San Francisco. “Well, when something like this happens, you don’t do that any more.”

For de Raadt-St James, the death of her husband was part of a cluster. Her father-in-law had died of heart complications eight months earlier, in April 2001; a close friend died of a heart attack in May. Her own father died from a heart attack the following April. In all four cases, a phone call came out of the blue that made her lie awake at night shedding tears, and not just for all the relatives she’d lost. “What happens”, she says, “is you develop post-traumatic stress around the event, around the notification.”

She began to ponder the emotional dynamic of that moment. “I learned the power of saying, ‘Hello, it’s so and so. Is there someone with you right now? May I speak to you for just a moment?’ Just try and ease into it. It’s very important.”

De Raadt-St James is the second generation of her family to wrestle with these questions. Her father was a telegram boy for Western Union, delivering death notifications during the second world war, and then a death notifier in the United States Army. Before he died, her father talked about his experiences. “He said it was the hardest thing he was ever asked to do. He never forgot the look on the face of the person he was notifying. Or the screams from the mothers as they saw him in the doorway. He said he was woefully, woefully undertrained

and completely unprepared emotionally. We realised there had to be a better way of delivering the message.”

Using her own wealth, both earned and inherited, she gave \$2m to the Department of Psychiatry at the University of California, San Francisco, to sort out a new model. The result was the Death Notification & Stress Management Programme (DNP), an online education and training programme for notifiers and survivors, designed to combine practical help with an understanding of the psychological and physiological impact of shock.

Drawing on research on post-traumatic stress by Dr Charles Marmar, chairman of the Department at UCSF, the DNP also contains a “pre-notification cognitive behavioural stress inoculation”: a freephone number with a recorded message designed to act as a balm for notifiers with last-minute nerves.

She offered the DNP to the US Army, and they implemented it in 2004, a year after the invasion of Iraq. Their procedure is that a casualty notification officer delivers the news, and a casualty assistance officer arrives soon after to deal with the fallout—repatriation, burial, benefit. “There was a much greater awareness throughout the army that they needed to improve how death notification was handled,” says de Raadt-St James. Behind this lay a series of damning newspaper stories about families’ bad experiences: notifiers reading robotically from a card; families being told the victim was killed in action, when, in fact, he died in friendly fire; relatives hearing the news on National Public Radio.

In modern warfare, it’s not just the news media that the authorities need to outpace. The bad news has to reach the family before it slips out on mobile phones or is posted on Facebook. “The importance of delivering a DNP message quickly, accurately and compassionately took on a whole new meaning,” says de Raadt-St James.

In Britain, the aim is for the media to report war deaths after the families have been informed. An understanding exists between the media and the armed forces, but it briefly collapsed last July when the Afghan president, Hamid Karzai, apologised for the deaths of three British soldiers from 1st Battalion the Royal Gurkhas, by a rogue Afghan soldier, in Helmand Province, at a press conference. The news sped around the world, reaching the families before the special deputation. The British army failed to achieve a fundamental objective through no fault of its own. The British news reports that followed included an unusual phrase. Not the conventional “The families have been informed”, but “The soldiers’ families are being informed.”

So, why do notifiers need training? Aren’t we as humans sufficiently socialised to know that if we want to break bad news to someone, we simply lower our voices and choose our words carefully? “Forgive me for being so flippant, but it’s very much one statement and it was thought people really didn’t need any training for that,” said one British army insider, “and of course people used to do it with all the consequences of not knowing what they were doing: you can be traumatised; you can break down telling the news, especially if you knew the individual concerned, and actually that is not what somebody wants at that stage. They need someone quite strong and calm and practical—very much a good listener.”

Another common pitfall is to respond to the overwhelming nature of the situation by becoming intensely talkative, and saying too much that is not based on fact, or making promises that can’t be kept.

“Yes, there is a certain common sense to it [notifying],” says Gerard Choucroun, former project manager for the DNP programme, “but knowing they are about to sever someone’s connection to their children or their spouse is hugely, hugely anxiety-provoking. So, asking people to keep their common sense and wits about them while they themselves are highly agitated and highly emotional, and relating to a situation that can be very difficult, well, not

everyone is able to do that.”

The DNP emphasises the need for a calm, measured, soothing voice; a slow delivery with long pauses; not invoking religion, just the facts, as compassionately as possible; avoiding intimate gestures such as hugging; acknowledging the survivors’ grief and allowing space for their emotions; ensuring that they are not left alone; responding honestly if asked where their loved one is and were they in pain, and not being afraid to say “I don’t know.” It recommends using a pen and paper, as they will remember only 12-15% of what they’re told. It introduces ritual to disaster and makes a big difference, Choucroun says. “It puts them [notifiers] on a better footing to remain calm and keep the conversation lucid and reasonable.”

In 2005 the licence for the DNP was transferred free of charge to the Metropolitan Police at Scotland Yard in London; in 2007 it was donated to Britain’s Ministry of Defence for \$1. The MOD acknowledged they needed help. “Around ten years ago, we realised our system wasn’t working very well,” says Colonel Hugh Welby-Everard (RTD), who was responsible for updating it. “It was clear family expectations were getting higher.” There were to be other spurs, notably “the high-profile nature of the operational casualties”—the wars in Iraq and Afghanistan. Deaths were now in the public eye; so there needed to be an eye on public relations. Until 2000, the British army had been using a manual that was a generation out of date, entitled “Casualty Procedures 1974”. The assumption was that one person could do both the job of breaking the news and dealing with the practicalities of benefits and funerals. And training, of course, was non-existent. “It was very much based”, one insider said, “on financial constraints rather than emotional management.”

TODAY, THE CASUALTY notification officer (CNO) and visiting officer (VO) are two distinct people. The CNO delivers the news, stays for two hours or so, and then backs out, never to be seen again (no matter how well-meaning, that person will forever remind the family of the worst day of their lives). He hands over to a VO who takes on the long-term support of the family. There is a new instruction manual: JSP 751, a pan-service document drawn up by the mod in 2007, which outlines strict rules and procedures. Every soldier has to nominate an emergency contact (EC); once this person has been informed of the death, the code EC kinformed is to be used. There is also a funeral grant of £2,500; and “skills courses” in bereavement awareness, listening and role play.

Scotland Yard no longer sends new recruits to deliver the “death message”. The supervisor selects the best person for the job. It has a training DVD, “The Message”, and free-phone numbers for notifiers and bereaved families. “We try to avoid giving the family ‘secondary assaults,’” says Detective Constable Joan Sewell, family liaison adviser, Scotland Yard, who adapted the DNP for the Metropolitan Police: and this model has since been used by the BBC, which has many correspondents in the field, and the Red Cross. Insensitivities used to include handing over personal effects in a plastic bag. Now bereaved families are presented with a white linen box. “Some families want clothes cleaned and repaired, but some want things like a watch as it was: stopped at such and such time when that train crashed or whatever.”

But the biggest change is that the police no longer deliver the bombshell and then walk away. Family liaison officers (FLOS) help with the practicalities of mortuaries and inquests—a result of the 1999 Macpherson report into the racist murder of Stephen Lawrence, an 18-year-old student, in 1993, which highlighted how the police’s failure to keep the family informed exacerbated their pain at the worst possible time. DC Sewell has transformed the FLO service and been awarded an MBE . “You used to come away leaving families in a distressed state. I remember one lady—her husband was killed in a deep-sea-diving accident, and she said, ‘How can I get his car back?’ And you had to say, ‘I’m really sorry, I can’t help’”

IN 1944 OLIVE Warton was a young wife, living in Worcestershire with her in-laws and her

small son, John, while her husband was serving in Normandy. "John ran to the door and picked up the letter," she remembers. "He always used to, you see. He brought the post to me and then he looked at me and said, 'Daddy? Is it from Daddy?'"

Olive opened the letter. "It is my painful duty to inform you", it said, "that a report has been received from the War Office notifying the death of Lance Corporal Lawson George Warton, Herefordshire Regiment, on August 15th 1944. The report is to the effect he was killed in action."

"That was more or less all it told me," says Mrs Warton, now 89. Her husband had already been dead a week. She had to piece together the details of what happened that day by contacting members of his regiment, and finally, 37 years later, by visiting the orchard in Le Theil, Normandy, where her husband received a shot in the neck from a German machinegun. "We were left on our own," she says, "we didn't have any support. It was a very dark time."

Sixty-three years later, another young British woman became a war widow. Private Craig Barber, a tank driver, was killed in Basra, Iraq, on August 6th 2007, aged 20. He was married to Donna, with a son, Bradley, aged three, and had been about to fly home to celebrate his first wedding anniversary. A casualty notification officer knocked on Donna's door in Bridgend, South Wales, within hours of Craig's death, followed the next day by a visiting officer, who has stayed in touch ever since. "Three years on, he's still around if we need him," says Donna, now 24. "He's lovely. He is part of the family, he comes to all our barbecues." While Olive had to fight to get her husband's photographs from Normandy returned, Donna was not only asked if she would like Craig's clothes, but if she'd like them washed. "I found it weird at the time, but then realised something with his smell on would be quite a comfort. I could cooch up in his rugby jersey and go to sleep."

During the second world war, service deaths were processed by the War Office in London, where civil servants typed the notification letters. Since 2005, Britain has had a Joint Casualty and Compassionate Centre (JCCC), an airy modern building on an army base in Gloucester. Its staff of 40 are well rehearsed in the rituals of military death. The call comes in on a secure phone line. Another name is added to the white board along with the cause of the death: KIA (killed in action), DOW (died of wounds), or FF (friendly fire). A casualty notification officer is thoroughly briefed before being dispatched to the family home; if it's the middle of the night, they wait outside, as the policy is to let families sleep while they can. A visiting officer is deployed. PlayStations and watches are retrieved from distant camps. Letters are read and some returned to senders because not all love letters are written by wives (the JCCC know their job too well to be indiscreet). Driving licences are cancelled, headstones discussed.

In some places, the element of compassion has been taken a step further. Madrid now has a team of emergency psychologists who attend incidents alongside the police, the fire service and paramedics. Since 2003, the samur-Protección Civil emergency service has had a team of six psychologists on 24-hour shifts, responsible for breaking bad news to relatives after traffic accidents, large-scale catastrophes or the sudden death of a family member. Teresa Pacheco Tabuenca, one of the psychologists, already has a grimly distinguished CV. She was deployed to the Madrid train bombings in 2004, the ETA terrorist attack on Barajas airport in 2006, and the Madrid plane crash in 2008. "We offer care on the spot to the indirect victims of the incident—relatives, witnesses," she says, "at the same time as the paramedics are carrying out their duties. Our job is not to remove the pain caused by a death, that is impossible, but to help reduce the emotional impact."

This is the unavoidable truth: even when delivered well, bad news is still bad, often devastating. "I still have dreams about trying to go into the room to tell my children they had lost their father," says Alexis de Raadt-St James. And the catch in her voice confirms how it

still weighs on her mind. She wells up with tears. “Having to tell someone else, and give someone that same pain you just felt—it was the most heart-wrenching event of my life.”

Jason Clauson is now a traffic patrol officer, aged 49, based in Chadwell Heath, Essex. In the last 25 years he has visited 100 families to tell them the cold truth that no one wants to hear; and since 2004 he has also been a family liaison officer. A short, muscular man with an open manner, he says that if he’s at a fatal collision, he also likes to be the one knocking on the family’s door. “I don’t want someone else looking at the teleprinter, seeing the message, and thinking, yeah, bloke killed in motorcycle accident, better go and tell the widow. I can answer questions about where it happened and why. I can be a connection to their loved one’s last moments.” Such detail may seem insignificant amid the enormity of a fatal accident, but for bereaved families in deep shock, it can mean a great deal. Three years ago, he was at the scene of an accident where two 19-year-old boys were killed. One was thrown from the car and died outright; the other was trapped in the passenger seat. Clauson held the boy’s hand through the twisted metal and heard his last words: “Tell mum I’m sorry.”

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