

THE COMPETENT NOVICE

Managing sudden death in hospital

Paul J Frost,^{1,2} Stephen Leadbeatter,³ Matt P Wise¹

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RESEARCH, p 1017

¹Critical Care Directorate, University Hospital of Wales, Cardiff CF14 4XW

²Cardiff University School of Medicine, University Hospital of Wales, Cardiff

³Department of Medical Genetics, Pathology and Haematology, University Hospital of Wales, Cardiff CF14 4XW

Correspondence to: P J Frost
Paul.Frost@CardiffandVale.Wales.nhs.uk

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This series aims to help junior doctors in their daily tasks and is based on selected topics from the UK core curriculum for foundation years 1 and 2, the first two years after graduation from medical school.

Junior doctors play an important role in verifying sudden deaths in hospital and communicating with the family of the deceased. This article covers England and Wales; the situation in Scotland and Northern Ireland differs in some respects

Deaths in hospital are common: in 2008-9, 246 525 people died in English NHS institutions alone.¹ Such deaths may be anticipated or sudden and unexpected; they may result from disease or from trauma.² Unexpected, and often premature, deaths can be challenging to manage: the family may have had no time to prepare for the bereavement, and they may not even be aware that the deceased had been admitted to hospital (see cases 1 and 2 scenarios, part 1). Information necessary for the death to be managed sensitively (for example, about the person's cultural and religious beliefs) may be unavailable. A death whose cause is unknown or unnatural will prompt a coroner's inquest and perhaps a criminal investigation. Sudden deaths often occur in acute care areas, such as the emergency department, where clinical pressures conspire to divert the focus of care from the deceased's family. These circumstances increase the potential for suboptimal care, adding to a family's distress.

How best to manage a sudden death?

In the late 1990s, the specialist palliative care team at the Royal Liverpool University Hospitals Trust and the Marie Curie Centre, Liverpool, developed an integrated care pathway for the dying patient, based on their appraisal of available evidence.³ The Liverpool care pathway provides a framework for end of life management, including comprehensive guidance for care after death (case 1 scenario, part

CASE 1 SCENARIO: PART 1

You are called to a general surgical ward to verify the death of a 52 year old man admitted for symptomatic management of advanced oesophageal cancer. On your arrival you hear that the death occurred suddenly, while the patient's wife was out of the hospital. The nurse tells you that his wife has just returned but is unaware that her husband is dead.

CASE 2 SCENARIO: PART 1

You were involved in the management of a 19 year old student who had been stabbed during a brawl and died in the emergency department. The nurses wish to clean the body, and they ask if the chest drains and endotracheal tube can be removed. The police are anxious that the body should not be washed as they fear that forensic evidence may be lost. At this point the receptionist announces that the patient's parents, who are unaware of the death, have arrived.

2). Evidence suggests that adoption of this care pathway has improved the management of death in hospitals when compared with pre-existing standards of care.⁴

However, this care pathway cannot be used fully for unexpected hospital deaths such as the death in case 2. In our experience, the best way for junior doctors to manage such deaths is to proceed in the following stepwise fashion with appropriate support from senior colleagues (figure).

CASE 1 SCENARIO: PART 2

Unfortunately your consultant and registrar cannot come to the ward immediately as they are busy in the outpatient clinic, so you decide to break the bad news yourself. You and a nurse accompany the wife to the relatives' room, where you tell her what has happened. The wife is greatly saddened by the suddenness of the death, although she was aware that her husband was dying and that he had recently been started on the Liverpool care pathway to support his management during the final days of his life.

The pathway also contributed to good care after the death as it describes specific objectives that should be achieved. For the junior doctor in this case these tasks included verifying the death and contacting the deceased's general practitioner. The nurse took responsibility for other tasks, including following the hospital's policy on the laying out procedures; explaining mortuary viewing; entering the patient's death on the hospital computer; giving information on legal tasks; making an appointment with the bereavement office for relatives to collect the death certificate; dealing with the deceased's belongings; and giving general advice and supportive documentation on what to do after death and on bereavement.

KEY POINTS

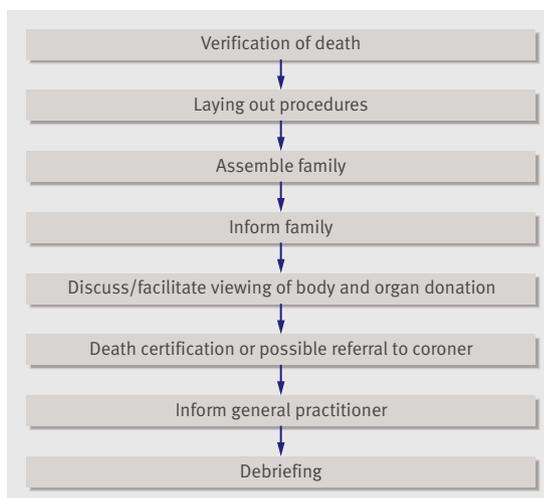
A minimum of five minutes of continuous observation is required to confirm irreversible cardiorespiratory arrest

Families consider that privacy, clarity of message, the ability to answer questions, and a caring attitude are the most important aspects of imparting bad news

Consider organ and tissue donation even when the death is unexpected

Junior doctors must meet legal requirements before completing death certificates and must know when to refer a death to the coroner; if uncertain, they should discuss with a senior colleague

Informal discussion with senior colleagues and peers can help in coping with the emotional impact of dealing with sudden death



Managing sudden deaths in hospital

Step 1: Verification of death

A code of practice for diagnosing and confirming death has recently been published.⁵ To establish death—where the patient is not maintained on life support and where attempted resuscitation has been unsuccessful—there must be no breath sounds audible to auscultation over at least a five minute period and no palpable central pulse during that

time. During this period of observation, if any cardiac or respiratory activity returns spontaneously then you must allow a further five minute period of observation from the next cardiorespiratory arrest. After a continuous period (minimum five minutes) of apnoea and asystole, confirm the absence of the pupillary responses to light, the corneal reflexes, and any motor response to supraorbital pressure, and record the time of death at that point.

Step 2: Procedures for laying out the body

When no suspicious circumstance accompanies the death (box 1), necessary cleaning of the body should proceed, with attention given to any obvious religious or cultural preferences (for example, Muslim or orthodox Jewish relatives may insist that the body is handled only by a person considered appropriate by that religion). The cleaning is done by nursing staff, who might ask junior doctors whether medical devices placed during resuscitation can be removed. When no individual has suggested improper placement and there is incontrovertible documented evidence that a device had been placed correctly (such as end-tidal carbon dioxide monitoring after placement of an endotracheal tube) we recommend removing all devices (unless staff are aware of religious or cultural reasons not to do so) as leaving them in situ may cause the family unnecessary distress. The local coroner could help by

Box 1 | Referral to the coroner

If the answer is yes to any of the following questions, then the death must be referred to the coroner. Discussion is usually with a coroner's officer; the doctor must be clear about the reason for referral, and if uncertainties remain, the doctor should not be dissuaded from further discussion with the coroner in person.

Might injury have played a part?

Injury may have been inflicted by another person or by the deceased himself or herself, or it may have arisen as the consequence of an "accident," at home, at work, in the street, or in hospital.

The delayed complications of injury (such as pneumonia after fractured neck of femur, or pulmonary thromboembolism after surgical repair of any fractured bone) should be regarded as a consequence of injury.

It does not matter when the injury occurred—for example, septicaemia from urinary tract infection in a paraplegic patient after injury to the backbone should be referred to the coroner even if that original injury occurred decades before death. If the death is a consequence of injury it should be referred to the coroner. Scrutiny of all medical records is therefore essential when considering whether a death is to be referred.

Might any toxic substance be involved?

This includes any death that results from the immediate or delayed actions of any drug (including alcohol) or poison, regardless of whether the drug is therapeutic or recreational. The death may result from self poisoning, poisoning by someone else, and unintentionally or by intention. Fatal allergic reactions (for example, anaphylaxis) to therapeutic drugs are included so should be referred to the coroner.

Might there have been something unnatural causing or accelerating the death?

This possibility should be considered carefully when the death is wholly unexpected, albeit from natural causes, and when the possibility exists that someone (or some institution) may be blamed. For example, even if the cause of death is established,

if there are allegations of poor or inappropriate treatment or inappropriate delay before treatment or diagnosis, the death should be referred to the coroner.

Any death that occurs during surgery or before the recovery from an anaesthetic should be referred to the coroner.

If the circumstances leading to death may be regarded as a serious untoward incident, not only must the coroner be informed, but the trust's policy on such incidents must be triggered.

Any death from a disease contracted during the course of employment (in particular, pneumoconiosis) should be referred to the coroner.

Is there evidence that neglect by any person or institution has played a part?

Neglect may be on the part of the deceased person—for example, a person admitted with hypothermia. Alternatively, neglect may be on the part of a carer. For example, an elderly person might be admitted from a nursing home with multiple bed sores and poor nutrition without adequate explanation and may die in hospital while those conditions are being treated. This means that a lengthy interval may have elapsed between admission and death, and the patient may in fact have died from an illness unrelated to the sores and poor nutrition (for example, she might have died from a hospital acquired infection or a pulmonary embolus). It is therefore important to consider the complete history relating to the admission.

Was the deceased in custody at the time of admission or death?

If the person was admitted from prison to hospital the death should be referred to the coroner. If a death seems to arise from an incident after arrest, pursuit, or detention by police officers then that death should be referred to the coroner.

Is there no clinical history or evidence whatsoever that allows you to come to a decision as to cause of death?

Refer the death to the coroner.

producing a policy on how to deal with the removal of medical devices.

Sudden death may be accompanied by soiling and disfigurement of the body. When death is suspected to have been caused by another person, conflict may arise between the desire of nurses not to increase relatives' distress by the sight of a soiled body and the requirement of police to minimise loss or contamination of trace evidence, as in case 2. Junior doctors must refer to senior colleagues to allow informed discussion between senior medical staff, the coroner, and the police. Ideally, such discussion should have taken place before such circumstances arise and a joint policy on how to deal with "forensic circumstances" should have been drawn up.

Step 3: Assembling family

If family members are not already at the hospital they will need to be contacted; the police can be very helpful in contacting next of kin when this information is unknown. A senior clinician should consider whether it is appropriate to disclose the news of the death to the next of kin or other family member by telephone. Relevant considerations include whether the next of kin lives alone, has a medical condition that could be affected by the news, and has ready access to support from family or neighbours; other considerations include distance from the hospital, access to transport, and time of day.

If it is thought that the next of kin would be especially vulnerable to hearing the news of the death by telephone or if the family circumstances are unknown, it may be reasonable to request that the next of kin attend the hospital without disclosing the death.⁶ This approach may be justified by the fact that distressed family members may be better supported at the hospital. Typically a nurse or receptionist makes this call, informing the next of kin of the admission and requesting their urgent attendance at the hospital. Any request for further clinical information can be met with the response that a doctor will speak to them as soon as they arrive. Sometimes—for example, if the next of kin lives overseas—notification of death by telephone is unavoidable; a senior clinician should make this call, but occasionally the task may fall to a junior doctor.

The principles of notification by phone are the same as for a face to face meeting, but the caller cannot see how the person is responding to the news and it is difficult to offer immediate support. None the less, an offer can be made to contact other relatives or friends on their behalf and to meet with them when they arrive at the hospital.

Family and friends usually enter the hospital in small groups, and it is the task of the receptionist to direct individuals to the relatives' room, which should be clean, comfortable, and private (with a "do not disturb" sign displayed). Rarely (usually when the death has been due to violence), it may be necessary to request that security staff are standing by. Any requirement for translator services should be established at this point. The family should be informed that a member of the medical staff will speak to them soon. This is an anxious and distressing time for the family and discussion with them must be prioritised.

Occasionally, relatives and friends may have witnessed the patient's final moments or attempts at resuscitation. In such circumstances these people should generally be taken to the relatives' room and comforted by a senior nurse while awaiting further news.

Step 4: Informing family

The manner in which the circumstances of the death are communicated to the family is crucial and if performed poorly may affect the family adversely for years to come.⁷ A survey of families who had been suddenly bereaved found that the most important aspects of imparting bad news were the ability to answer questions; privacy; clarity of message; and a caring attitude.⁸ Ideally a consultant and a senior nurse should together inform the family of the death. If a junior doctor has been involved in the patient's care he or she must try to attend this meeting as it provides an opportunity for experiential learning and team building. If senior clinicians are unavailable or delayed, a junior doctor may need to break the news to avoid prolonging the family's uncertainty and distress.

Before meeting the family, the informing staff must ensure that they are familiar with all of the clinical history, including interventions undertaken during attempted resuscitation, and when possible provide an explanation of the likely cause of death. They should switch off pagers and mobile phones before entering the room. Ideally staff and family ought to be seated, and the consultant should conduct a brief round of introductions; lengthy preamble is best avoided and handshaking (often a life affirming gesture and occasionally culturally inappropriate) should be considered on a case by case basis.

Remarks should be directed to the next of kin and should open with a warning ("I'm afraid I have some bad news"). Then a clear statement of the fact of death must be given ("I am very sorry to have to tell you that your son has died as a result of his injuries"). Euphemisms for death, such as "passed away," are best avoided. Responses to this news range from overwhelming grief and anger to mute shock; generally at this point families are inconsolable, and often the duty of care is to be a silent empathetic presence.⁹

In our experience, after this disclosure, families are not receptive to detailed information about the death, rather just a brief explanation of the cause. If the doctor can be sure the deceased did not suffer, then he or she should emphasise the absence of suffering. In the rare circumstances when death has occurred after a serious adverse or sentinel event, there should be immediate and honest disclosure with assurance that there will be full and detailed explanation after appropriate investigation under the hospital's governance procedures.¹⁰ If referral to the coroner is necessary, then this should be explained now.

It is appropriate to inquire about the family's religious beliefs and encourage them to discuss with staff any special needs. Staff should ask the family if they wish to view the deceased and also advise on the appearance of the body, particularly if the death has been traumatic. If a forensic examination is necessary then the family should be told not to hold or kiss the body until swabs have been taken from the hands and face (for DNA typing). This can upset the family, but explanation of why it is considered necessary and assurance that the swabbing will be done as quickly as possible may reduce that distress.¹¹ It is reasonable to offer condolences at this time. See case 2 scenario, part 2.

Step 5: Viewing of the deceased and organ or tissue donation

It is important that families have the opportunity to see, touch, and even hold the deceased. Families may

CASE 2 SCENARIO: PART 2

You discuss with your consultant what to do about the nurses' request for removal of the chest drains and endotracheal tube. He is sure that these devices did not contribute to the death and says that the nurses can remove them. After discussion with the police the consultant agrees with them that further handling of the body should be minimised until after proper forensic scrutiny.

You are later present when the consultant breaks the news to the parents in the relatives' room. After the introductions he states that he has very bad news. After a brief pause he says that their son has died as a result of serious stab wounds. The parents react with shock and anguish, and after some minutes the consultant briefly explains that staff were unable to stop the bleeding from wounds to his neck and chest, despite all efforts at resuscitation. He adds that their son was unconscious and not in any distress. He asks if they have any questions. The parents ask if they can see their son. The consultant agrees but warns that his appearance was adversely affected by his injuries and that the police wish to swab his face and hands to maximise opportunities to retrieve evidence that might identify the perpetrator, so they should not touch or kiss their son until the swabbing has been done.

also wish to conduct religious observances and dress the deceased in clothing of their choosing. Every effort should be made to facilitate these wishes provided that they do not hamper any forensic investigation. In the context of unexpected deaths, non-beating heart donation is rarely practicable; if brain stem death has occurred in an intensive care unit, organ donation should be considered.¹² Generally, the responsible intensive care consultant in conjunction

with the local transplant coordinator manages this matter. Junior doctors should take the opportunity to learn by sitting in on these discussions. When a person who has not been receiving life support dies, the opportunity to retrieve tissues such as corneas, heart valves, bone, and skin must not be forgotten. We suggest that junior doctors ought to raise this matter with senior colleagues so that opportunities to donate are not missed. The local transplant coordinator is contacted before the family is approached; the local transplant coordinator is best placed to determine whether any information about the potential donor would render retrieval impossible.

Step 6: Death certification and referral to the coroner

Most death certificates are completed by junior doctors, although concerns have been raised about accuracy and completeness as well as adherence to the statutory requirements (box 2).^{13 14}

Step 7: Notifying general practitioners

A junior doctor should inform the patient's general practitioner of the death: appropriate care can be extended to the family in the community and any appointments that had been made for the deceased cancelled. A telephone

Box 2 | Completion of medical certificate of cause of death*^{15 16}

Consider the following questions before completing the medical certificate of cause of death (MCCD).^{14 15}

Do the circumstances leading to this death indicate the need for referral to the coroner?

If the answer to any of the questions in box 1 is "yes" you should refer the death to the coroner, inform the family of that decision, and not complete an MCCD (although strictly speaking, there is a statutory duty to issue a MCCD in all deaths where the doctor can issue the certificate).

Do you have appropriate registration?

Section 48 of the Medical Act 1983 (as amended) reads: "A certificate required by any enactment . . . from any . . . medical practitioner shall not be valid unless the person signing it is fully registered." However, in NHS institutions, it is common practice for doctors with only provisional registration to issue the MCCD, presumably on the basis of section 15 (3) of the act, which states: "A person provisionally registered under this section shall be deemed to be registered under section 3 above as a fully registered medical practitioner so far as is necessary to enable him to be engaged in employment in a resident medical capacity in one or more approved hospitals, approved institutions or approved medical practices but not further." Whether completion of the MCCD is a necessary component of the role of a foundation year 1 doctor is a moot point—we do not consider it to be necessary.

Were you in attendance during the last illness?

Although there is no definition of "the last illness," the term used on the MCCD, attendance only during a failed attempt at resuscitation would not be regarded as "attendance during the last illness." In practice, if you have not attended the patient for that illness during the two weeks before the death, the registrar of births and deaths will refer the death to the coroner, whether or not you saw the body after death. It is more helpful to relatives if the doctor who has not attended during those two weeks before the death (rather than the registrar of births and deaths) refers the death to the coroner; this avoids delay

and subsequent distress when the death is referred later by the registrar of births and deaths, by which time relatives may have set arrangements in place for a funeral.

Did you see the body after death?

Although there is no statutory obligation for a doctor signing the MCCD to see the body after death, it can only be good sense to do so, to determine identity, the fact of death, and the absence of any external evidence of a reason (for example, injury) to report the death to the coroner.

Do you have sufficient data about the patient and the circumstances of death to make a confident diagnosis of the cause of death?

If you have a clinical diagnosis of a condition that can result in death, and that diagnosis is not a matter for referral to the coroner, you must issue the MCCD. You should consider whether questions remain about that diagnosis that might be resolved by postmortem examination and you should be aware of the Human Tissue Act 2004 and its associated Codes of Practice relating to seeking consent for a hospital postmortem examination.

Can you describe the cause of death in the format required by the MCCD?

Evidence shows that doctors of all grades do not always complete the MCCD in the correct format.¹⁷ Guidance on completion is available in the preliminary pages of the "Book of Certificates" supplied to hospitals.

Are you confident that the registrar of births and deaths will receive the MCCD?

Although in common practice the certificate is handed in a sealed envelope to a family member to take to the registrar of births and deaths, bear in mind that the legal responsibility to transmit the MCCD to the registrar of births and deaths rests with the doctor completing the certificate.

*This is the situation at the time of writing. When the Coroners and Justice Act 2009 becomes law (in 2012) there will be a statutory duty on doctors to refer certain deaths to the coroner, and the MCCD issued by the doctor will be scrutinised by a medical examiner.

CASE 2 SCENARIO: PART 3

After the meeting in which the parents learnt of their son's death, you ask the consultant if tissue retrieval is possible. He says that he will discuss this with the coroner when he reports the death. In the interim you contact the local transplant coordinator, who confirms that the patient was on the donor registry. The coordinator decides to await the coroner's decision before approaching the family.

You telephone the patient's general practitioner and inform her of the death. Later, over a cup of coffee, you discuss the case with your registrar as you wonder whether the death could have been averted. The registrar thinks that the injuries were so severe that death was always going to be inevitable; he suggests that, although staff will always find such deaths difficult to handle, there might at least be some satisfaction in managing the aftermath well.

message may be left with the practice receptionist; if the death occurred outside surgery hours, the phone call will be on the next working day.¹⁸

Step 8: Debriefing

Managing an unexpected hospital death can be professionally and emotionally demanding, especially if the deceased patient was well known to the junior doctor.¹⁹ Emotions such as sadness and guilt are entirely natural. Informal discussion with senior colleagues and peers is a good way of coping with these feelings (case 2 scenario, part 3).²⁰ If negative reactions persist then counselling services are readily available.²¹ If the death was or was suspected to be due to an adverse or sentinel event then the junior doctor must notify the senior responsible clinician as soon as possible. Typically that clinician would arrange to meet with the family; the National Patient Safety Agency has produced guidance to assist with this eventuality.¹⁰

What are the challenges?

Despite the importance of palliative care and end of life concerns, junior doctors have reported insufficient training in how to break bad news, and even senior clinicians do not always feel confident about their ability to inform families of sudden death.^{22,23} Moreover, doctors may be emotionally disturbed by the death of their patients, and in an unsupportive environment this can contribute to burnout.²⁰ These observations suggest the need to improve training in palliative care, including raising awareness of support available for doctors emotionally affected by these matters. Such support is readily available—for example, the British Medical Association provides 24 hour a day access to a confidential counselling service specifically for doctors (www.bma.org.uk/images/d4dpromoflyeraug2009_tcm41-189732.pdf).

Strategies to improve bereavement services such as care pathways for expected and unexpected deaths have been endorsed strongly by England's chief medical officer²⁴; but translation of these proposals into routine clinical practice poses a challenge. The Liverpool care pathway has been criticised as an example of "tick box" medicine, with the potential to produce adverse outcomes; in particular, critics say that adherence to the pathway can hasten death by over-sedation and the inappropriate withdrawal of nutrition and hydration. This may be true if the pathway is followed thoughtlessly and if necessary adjustments to the pathway are not made.²⁵ Junior doctors should be reassured that clinical judgment remains paramount and that deviation from a recommendation in a care pathway is permissible provided that they have a valid reason for doing so. For

example, if a patient starts to improve while on the pathway then clinical matters such as nutritional requirements need to be reassessed.²⁶

Breaking bad news is never easy, and proceedings in the aftermath of unexpected deaths seldom run smoothly even with care pathways.

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A PATIENT'S JOURNEY

Acquired brain injury

Linda Kat,¹ Karen Schipper,¹² Jeroen Knibbe,¹ Tineke A Abma²

¹Reinaerde, Netherlands

²VU Medical Center, Department of Medical Humanities, EMGO Institute, PO Box 7057, 1081 BT Amsterdam, Netherlands

Correspondence to: K Schipper
k.schipper@vumc.nl

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This is one of a series of occasional articles by patients about their experiences that offer lessons to doctors. The *BMJ* welcomes contributions to the series. Please contact Peter Lapsley (plapsley@bmj.com) for guidance.

Linda Kat was 40 when surgery left her with acquired brain injury. She tells of her initial shock, her frustrations, and her need to make her own choices

My problems began eight years ago, when I was 40 years old. I lived with my husband and 2 year old daughter. Because I had problems with my eyes I visited my general practitioner. I suffered diplopia and, after examination, my general practitioner sent me to a neurologist. I had a number of examinations, including magnetic resonance imaging, a scary experience. Shortly afterwards, the neurologist asked me to come to see him immediately as they had found a brain tumour. I was shocked. I had never thought about this possibility. An operation was necessary. I was told I would definitely die without it. But the operation was not without risks. The doctor told me that I would “never be the same again after the operation” and that “my life expectancy wasn’t that high if the tumour proved to be malignant.” I felt, however, that I had no choice and that I understood the risks and consequences. The information didn’t really get through to me. I was just trying to survive. There was no room for doubt.

The shock of having an acquired brain injury

The operation caused severe acquired brain injury. Shortly after the operation I was unable to walk, talk, smile, or eat, and I had problems with my sight. Nowadays I need a wheelchair. My face is also paralysed, so I can’t express my emotions. I can’t laugh or kiss anymore, and I have problems with eating. I also have problems with talking, so I can’t express myself well. As a result, people often fail to understand my conversations. They pretend to understand me. That’s the most awful thing; it makes me feel frustrated and angry when people don’t understand me or pretend they understand me. The only way to express my feelings at these moments is by screaming and yelling, and when I do that people walk away because they find it annoying. Besides these problems, I have cognitive and other impairments. I have problems with my memory and concentration, and I feel terribly tired. I don’t have enough energy to do the things I really want to do.

Struggling against myself and my environment

After being in hospital I went to a rehabilitation centre, where they taught me how to fold up my laundry, and other skills, to make me independent. But for me such things were never the most important in life. After a year in the rehabilitation centre I moved to a nursing home where I lived with old people. It was awful, but as my house wasn’t adapted to my impairments and as my relationship wasn’t stable enough, I couldn’t go home. Gradually I realised that my life had changed dramatically and that I would never be the same again.

My husband decided he wanted a divorce. This felt like rejection and the divorce made me feel miserable. Now

I realise that it was a good decision. Our relationship was already on its last legs before I got the brain tumour. It hurt me tremendously that, initially, my little daughter didn’t want to see me. That felt like another rejection. Thank goodness my friends and family turned out to be loyal. They were a great support to me.

From the nursing home I moved into a home for people with acquired brain injury. My early period in the home can be characterised by fighting. I struggled to become the same person as I was before. I am not and never will be able to take care of myself and my daughter anymore. This makes me very sad as my daughter is the most important thing in the world to me. She makes me feel happy, but her situation makes me sad. I can’t take care of her. When she visits me she gives me energy and hope, but afterwards I am totally exhausted and can’t do anything for a day. Finding a balance between doing something and doing too much is complicated; I have to make choices constantly, depending on my level of energy at that moment. My energy level changes during the course of the day, which is typical of acquired brain injury. One

WHAT CAN MEDICAL PROFESSIONALS DO?

Show empathy. Acquired brain injury often implies radical changes in all the domains of life and in the identity of the patient

Help the patient find a balance in energy levels; inform other healthcare professionals that energy levels may fluctuate daily and that care should be tailored to the daily changing situation of the patient

Pay attention to the feelings and emotions of patients during the chronic phase. After the rehabilitation phase, when the patient is at home, he or she will feel and realise the impact of the brain injury, which may evoke emotions

Give clear information about medical examinations and interventions, checking whether the patient really understands the information and supports the decision making process

Ensure that rehabilitation does not centre just on learning skills. It’s just as important that patients learn to cope with their limitations and the changes in their life, and to discover their strengths

Respect and take notice of the patient’s needs and perspectives without imposing ideas on the patient

Support the expression of emotions and communication with the patient. Not every patient is able to express emotions facially and verbally. Do not pretend to understand the patient. Listen to the patient: be honest and listen carefully

Accept the patient’s identity and values and his or her view on autonomy; not everyone is or wants to be self sufficient and independent all the time

Support the patient in directing his or her life even if this conflicts with the vision of care held by the institution where the patient lives

Give support and information to the patient’s relatives

bmj.com: previous Patient Journey articles

- ▶ Living with lymphangioleiomyomatosis (*BMJ* 2010;340: c848)
- ▶ Recovering from severe brain injury (*BMJ* 2010;340: c839)
- ▶ Dopa responsive dystonia (*BMJ* 2010;340: c668)
- ▶ Cardiomyopathy (*BMJ* 2009;339: b4210)
- ▶ Communication during breast cancer treatment (*BMJ* 2009;339: b4166)

A MEDICAL SPECIALIST'S PERSPECTIVE

Acquired brain injury is damage to the brain that is acquired after birth and can result from traumatic brain injury (caused by, for example, a car crash or a fall) and non-traumatic brain injury (caused by, for example, cerebrovascular events and brain tumours). Acquired brain injury should not be confused with intellectual disability. The damage can be focal or diffuse, and the brain injury can range from mild to severe, leading to mild or more severe symptoms.

Brain injury has extremely varied effects, and no two people can expect the same outcome. Cognitive deficits such as memory problems, concentration problems, and problem solving deficits or perceptual problems can occur, as can motor deficits such as paralysis or spasticity, and communication problems such as aphasia. Patients may also develop problems with understanding and responding in social interactions, and they can become self centred. Most patients report extreme tiredness. Personality changes or neuropsychiatric symptoms such as apathy, emotional lability, irritability, anxiety, and depression can also occur.

Even a mild injury can sometimes result in serious disabilities that will interfere with a person's daily functioning for the rest of their life. Although the outcome of the injury depends largely on the nature and severity of the injury itself, appropriate treatment will play a vital role in determining the level of recovery.

The treatment starts with a period of clinical observation, mostly in a rehabilitation centre. The approach is multidisciplinary. Information about the premorbid physical condition (of the head) and about the patient's personality is important for understanding the patient and his or her behaviour better. The treatment focuses on improvement of physical condition and mobility, teaching the use of aids for daily living (such as an adapted spoon for eating or a walking frame), training in practical skills, cognitive training, reintegration into work or school, and helping the patient to adapt to and "accept" their losses. Linda's story shows, however, that the feelings of loss and sorrow are not resolved during the treatment period. Professionals have to be alert to signals of sorrow during the chronic phase.

Understanding the premorbid factors, neuropsychological profile, and cognitive impairments is necessary for the treatment of neuropsychiatric problems such as apathy, depression, aggression, and anxiety. Many of these problems can be minimised by early intervention based on the neuropsychological profile. Additionally, as patients find it difficult to accept the changes in their life, a system of care involving support, information, and instruction plays a crucial role in patients' rehabilitation and reintegration.

A gradual return into society follows the clinical phase. However, personal factors (such as cognitive impairments and feelings of insecurity) and external factors (such as a lack of facilities and unforgiving environments not suited to people with acquired brain injury) can substantially hinder reintegration. Some patients need professional support for the rest of their lives in the form of specialised nursing homes or day care centres. The medical policy in such places will be focused on the prevention and treatment of chronic problems caused by brain damage, such as decubitus ulcer, retention of the bladder, obstipation (severe and intractable constipation), epilepsy, hypertonía, swallowing problems, infection of the bronchial tubes, becoming overweight, visual problems, cognitive impairments, and neuropsychiatric problems.

Jeroen Knibbe, physician specialising in persons with (intellectual) disabilities and acquired brain injury

day I can do small things, the next day I cannot. This leads to incomprehension.

People don't understand me and sometimes they think I try to mislead them, and then they sometimes respond, "I am not going to help you. I know you are able to do that. Yesterday you did it, so now you have to do it also." Sometimes they say: "We are not going to do that, because you are able to do it by yourself." The staff often say that they are trying to stimulate me to do the things that I can still do myself. However, it is important for me to make my own choices, and these choices can differ from those of the staff. I know myself best, better than anyone knows me, so I want to make my own decisions and stay in control as much as possible. For me it is not that important to wash my own clothes, or always to put my teabag into my mug. For me it is much more important to have a phone call with a friend. I value my friendships highly and the loyalty of my friends. I can't do everything, and I want to choose for myself what is most valuable to me at that particular moment. Sometimes this leads to struggles with my environment. I know people are well intentioned when they try to help, but their kind

of support doesn't always fit my needs. This makes it hard to ask for help, to be responsive to care, and to accept that I am dependent. Yet I realise that I can only continue the life I value when relying on others for support.

Having to change my dreams and having to go on

The brain injury forced me to change radically my perspective and dreams for the future. Most of the things I wanted and did in the past are impossible now. Step by step, I have acknowledged my restrictions and gradually learned to focus on the things I can still do and enjoy. I have also learned to take care of myself and to make more choices of my own. I always say, "the smaller, the better": when you have to live a lazy life, you automatically learn to appreciate small things. I like to listen to music, do some yoga, sit outside my apartment just listening to the birds and looking at the beauty of nature. By focusing on small things, doing the things I want to do, making my own choices, and taking care of myself, I am able to live my life as best I can.

Contributors: LK told her story to KS during two interviews and a series of group training meetings; because of her brain injury LK cannot read or write but can speak in quiet surroundings. KS recorded LK's experiences and used LK's words to draft the article in the first person; KS read the article to LK repeatedly until LK recognised it as her own story. TAA helped KS with the writing process and commented on and edited the text. JK, the doctor at LK's residential home, compiled the two medical boxes. KS translated the article into English, with TAA's help.

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Helping hands during my journey

- Seeing my daughter, talking to friends on the phone, sitting outside watching birds—these are the things in life I have come to value and that make me happy
- The support of friends and family—they helped me to accept my new self and my situation
- Telling my story, and having someone listening to my story patiently in a quiet environment

10 MINUTE CONSULTATION

“My baby keeps bringing up his feeds!”

Jayanta Banerjee,¹ Mita M Roy,² Sheetal Bhojani,¹ Naina Emcy¹¹Southend University Hospital NHS Foundation Trust, Southend SSO 0RY²South West Essex Primary Care Trust, Basildon SS14 3HG

Correspondence to: J Banerjee docjayanta@hotmail.com

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▶ “My baby keeps bringing up his feeds!”

(BMJ 2010;340:c2189)▶ Hoarse voice
(BMJ 2010;340:c522)▶ Sexual health consultation for men who have sex with men
(BMJ 2010;340:c958)▶ Acute cough in adults
(BMJ 2010;340:c574)▶ Female stress urinary incontinence
(BMJ 2010;340:b5533)

A 6 week old baby boy, first child of young white parents, presents with recurrent episodes of vomiting from age 3 weeks. He was born at term after an uneventful pregnancy.

What issues you should cover

This presentation is common and generally falls into one of three categories:

- Those requiring reassurance and parental advice.
- Those with minor problems that can be successfully managed in primary care.
- Those with serious disorders requiring specialist paediatric attention.

Duration and progression of symptoms—thriving babies who vomit after each feed may simply be overfed. Progressive vomiting with faltering growth suggests gastro-oesophageal reflux or milk intolerance. Acute vomiting in a previously thriving baby might be caused by a serious illness such as sepsis.

Character of vomiting—large volumes of projectile vomit within 30 minutes of feeding suggest pyloric stenosis. Alternatively, effortless vomiting might indicate possetts.

Colour or content of vomit—bilious vomiting, particularly in babies, might indicate bowel obstruction, so clarify the meaning of “bilious” with parents by showing colours to compare, for example milk, yellow, bilious, or blood stained.

Type of feed—ask about volume and frequency. Knowing the different types of formula available and their indications is important (see table 1). Vomiting babies not thriving on formula based on cow’s milk protein might be intolerant to it; this can result in secondary lactose intolerance (<http://emedicine.medscape.com/article/187249-overview>).

Amount of feed—a term baby should not be fed more than 120-150 ml/kg a day. Lack of appetite and reduced food intake might suggest a developmental disorder and even heart failure secondary to congenital heart disease.

Associated symptoms

- Ask about abdominal discomfort, diarrhoea, constipation, eczema, skin rash, and cough. Babies that cry intensely after meals may have colic.

Table 1 | Types and indications of formula feeds

Clinical conditions	Types of formula indicated
Healthy baby	Cow’s milk protein based formula, whey based (easy to digest), or casein based (for hungrier babies)
Cow’s milk protein intolerance, eosinophilic oesophagitis, colitis	Hydrolysed (partly or extensively), basic amino acid based formula
Severe atopy, eczema, and strong family history of allergy, eczema, and asthma	Hydrolysed or amino acid based formula
Lactose intolerance	Plant based milk, eg rice, soy, or oat milk
Liver disease, conjugated hyperbilirubinaemia	Medium chain triglyceride based formula
Short gut, major bowel resection	Hydrolysed milk or amino acid based milk
Colic, constipation	Easy digest milk containing partly hydrolysed milk, prebiotics, and nucleotides are being used

IMPORTANT WEBSITES FOR PARENTS**Gastro-oesophageal reflux disease**

NHS Clinical Knowledge Summaries (www.cks.library.nhs.uk/patient_information_leaflet/gastro_oesophageal_reflux_disease)—Information from NHS Direct on gastro-oesophageal reflux disease

NHS Lothian Referral Guidelines (www.refhelp.scot.nhs.uk/dmdocuments/gord_pil.doc)—Patient information leaflet for gastro-oesophageal reflux disease

Pyloric stenosis

Joint website of Great Ormond Street Hospital for Children NHS Trust and University College London Institute of Child Health (www.ich.ucl.ac.uk/gosh_families/information_sheets/pyloric_stenosis/pyloric_stenosis_families.html)—Information on pyloric stenosis

KidsHealth (kidshealth.org/parent/medical/digestive/pyloric_stenosis.html)—Information on pyloric stenosis and links to other medical disorders of the digestive system

Lactose intolerance

Food reactions (www.foodreactions.org/intolerance/lactose/)—Description and terminology of lactose intolerance

Food Standards Agency (www.eatwell.gov.uk/healthissues/foodintolerance/foodintolerancetypes/milkallergy/)—Advice on milk allergy and intolerance

- Discomfort during feeds with back arching might indicate gastro-oesophageal reflux.
- Bronchiolitis can present with bouts of cough followed by vomiting.
- Irritability, lethargy, poor feeding, and fever suggest sepsis.
- Ask if other family members are currently affected by gastroenteritis.
- Child neglect and physical abuse may present with growth faltering and vomiting. Ask about possibility of trauma or head injury.

What you should do**Examination**

- Assess the baby’s hydration status. Sunken eyes and fontanelle, reduced skin turgor, tachycardia, central capillary refill time of more than three seconds, lethargy, poor urine output (less than one wet nappy every six hours), and ketonuria indicate dehydration.
- Look for signs of sepsis: pyrexia or hypothermia, pallor, lethargy, tachycardia, cold peripheries, and petechial rash. Examine for the septic source (for example, meningism) with a systemic examination, ear, nose and throat examination, and a urine dipstick.
- “Test feed” to diagnose pyloric stenosis. A positive test feed in a very hungry baby with vomiting will

Table 2 | Management options for vomiting babies

Conditions	Management options
Acute gastroenteritis with mild dehydration	Start oral rehydration, avoid milk for 24 hours to rest the gut, and reintroduce feeds in small amounts rather than diluted, which can cause electrolyte disturbances
Gastro-oesophageal reflux disease	Consider feed thickeners; sodium alginate and magnesium alginate (Gaviscon) or a trial of anti-reflux medications such as ranitidine and domperidone (doses as advised in <i>BNF for Children</i>). Advise simple measures, such as raising the cot head, sitting baby upright during feeds, and burping afterwards
Cows' milk protein intolerance	Start a trial of hydrolysed milk formulas
Acute bronchiolitis or upper respiratory infections	Provide supportive treatment (eg bronchodilators) and antibiotics for bacterial infections
Uncomplicated urinary tract infections (suggestive on dipsticks and urgent microscopy) and early pneumonia	Antibiotics and follow-up in primary care; follow NICE guidelines (March 2007)
Concerns about non-accidental injury	Involve social services and local primary care trust lead of child safeguarding; if necessary, ask for advice from paediatrician

confirm the diagnosis, but a negative result *does not* exclude it.

- Look for signs of bowel obstruction (abdominal distension and tinkling bowel sounds) and of head injury.
- Atopic eczema, rash, perianal redness, and excoriation suggest cow's milk protein intolerance.

Treatment

The history and examination provide diagnostic direction. Treatment is tailored to severity of dehydration and seriousness of the underlying cause of vomiting.

- Discuss basic bottle feeding techniques—ensure use of appropriate teats (fast, medium, or slow flow) and ensure excessive air is not swallowed.
- Plot growth and development parameters that provide useful information about growth faltering and indicate the seriousness of the condition.

USEFUL READING FOR PROFESSIONALS

- Singh J, Kass DA, Sinert RH. Paediatrics, pyloric stenosis. 2009 (emedicine.medscape.com/article/803489-overview)
- Chung E. Infantile hypertrophic pyloric stenosis: genes and environment. *Arch Dis Child* 2008;93:1003-4
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- Heyman MB; Committee on Nutrition. Lactose intolerance in infants, children, and adolescents. *Pediatrics* 2006;118:1279-86
- British National Formulary for Children 2009*. Section 1.1-1.3

- Refer urgently to paediatric services for: moderate to severe dehydration or suspected sepsis; severe infection (meningitis, severe pneumonia); bowel obstruction or pyloric stenosis (ask parents not to feed further in interim); severe bronchiolitis; any suspicion of head injury.
- Also refer to paediatric services if weight loss has been considerable, for example, a 15% decrease from birth weight, or growth faltering based on weight percentile.
- If not referring the child, provide clear guidance to parents about the next step if symptoms get worse or do not improve, and arrange follow-up.
- For specific treatment of conditions see table 2.

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Understanding self, understanding others

We sat there wanting to hear about other people, but the professor told us to look at ourselves first. That was not what we wanted to hear. We wanted to become competent in working with patients who were culturally or racially different and less fortunate than us, but we wanted it to be easier. We wanted to help them, but did not want to examine ourselves. We were there to learn about them, not us. Some of us became irritated and impatient.

"Please tell me," one audacious student finally asked, "only what I need to know to treat my patients. What do I need to know about minorities or immigrants?"

The look on the professor's face told me he had heard this request before. He calmly told us that we should learn what we can about the experiences of others, but warned us "The best way to understand another is to understand your own experience. Ask yourself, 'What do I know about the trials, tribulations, and

consciousness unique to my indigenous experience that others may not?" Since it is impossible to understand everything about all other cultures, you need to learn what you can about your own group and use it as a basis of understanding others."

I learnt this lesson 30 years ago, and it continues to guide my work in multicultural contexts. I ask myself and my students to seek greater understanding of our own cultural backgrounds, experiences, and world views. We reflect on how we bring all of this to the clinical encounter and how it affects the way we assess and conduct therapy. We engage in self reflection and mindfulness in our work, noticing and modifying our reactions and attitudes towards patients. We try to see that understanding and accepting others is ultimately about understanding and accepting ourselves.

Stephen Murphy-Shigematsu lecturer, Stanford University, Palo Alto, USA smshige@stanford.edu

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