



Royal College
of Nursing

Breaking bad news: supporting parents when they are told of their child's diagnosis

RCN guidance for nurses, midwives and health visitors





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1

Introduction

This evidence-based guidance replaces an earlier Royal College of Nursing (RCN) publication: *Supporting parents when they are told of their child's health disorder or disability – guidance for nurses, midwives and health visitors* (RCN, 1999).

This new guidance identifies effective strategies to use when communicating with or supporting parents and carers receiving bad news and signposts practitioners to quality resources that will support them in their practice (DHSSPS, 2003a; ACT, 2011). It sets out the key considerations that should be followed in all settings and recommends that nurses should apply the *RCN Principles of nursing practice* (RCN, 2010) when undertaking this particularly complex and challenging aspect of care (see Figure 1).

Figure 1: Applying the Principles of nursing practice (RCN, 2010)

Applying the RCN Principles of nursing practice when breaking bad news

Principle A – nurses and nursing staff who have to break bad news should treat everyone in their care with dignity and humanity. They should understand individual needs, have compassion and sensitivity, and provide care in a way that respects all people equally.

Principle B – nurses and nursing staff should take responsibility for the information they provide and understand that they have to answer for their own judgments and actions. When breaking bad news they should seek to work in a way that is agreed with patients, families and carers and which meets the requirements of their professional bodies and the law.

Principle C – nurses and nursing staff who break bad news appreciate that there is risk involved and take steps to manage that. They are vigilant about risk and seek to keep everyone safe.

Principle D – nurses and nursing staff who break bad news seek to do so in such a way that puts people at the centre. They will involve patients, service users, their families and carers in making decisions and enable informed choices about treatment and care.

Principle E – nurses and nursing staff are at the heart of the communication process: when breaking bad news they record and report on the way the information was received. They handle information sensitively and confidentially and, where applicable, deal with complaints effectively. They are conscientious in reporting to others the things they are concerned about.

Principle F – nurses and nursing staff who have to break bad news understand that they must have up-to-date knowledge, skills, and work intelligently with insight and understanding to meet the needs of each individual in their care.

Principle G – nurses and nursing staff work closely with their own team and with other professionals. They seek to make sure that the process of breaking bad news to patients and families is coordinated, is of a high standard and has the best possible outcome.

Principle H – nurses and nursing staff lead by example, and develop themselves and other staff. They seek to influence the way care is given and how significant information – such as bad news – is imparted, in a manner that is open and responds to individual needs.

The expression breaking bad news is used in this document to describe the process of imparting and receiving ‘bad, sad or difficult’ information (Fallowfield and Jenkins, 2004); bad news may relate “to a child’s diagnosis, condition or prognosis across the range of health and social care settings” (Morton et al., 2000).

Since the expression has such negative connotations and the fact that bad news is defined primarily from the perspective of the recipient, it has been suggested an alternative term such as significant information should be used. However, as breaking bad news is the expression used most commonly in the literature and by health professionals in their day-to-day practice, it is used throughout this document.

Nurses are often in the frontline of supporting children and their families following receipt of bad news. In many cases they may be the health professional best placed to deliver such information.

This guidance document is intended to help the nurse develop an awareness of a range of communication frameworks. Section 3 sets out the key considerations which should be followed in all settings and additional guidance is provided in section 5 for those working in child and adolescent mental health services (CAMHS) and emergency department (ED) settings where it is recognised that there are specific issues to address.

Document scope

Although this guidance is aimed specifically at nurses, midwives and health visitors, it may be of value to all members of the multidisciplinary team and relevant across a range of health and social care settings.

In some cases a nurse will be the professional who delivers bad news; in others they will be providing support to parents and medical colleagues during and following a medical consultation.

While the primary focus of this document is on the delivery of support to parents, this guidance recognises the role that other family members and significant others may play in the lives of children and young people. For this reason the term ‘parent’, as used throughout this document, should be taken to encompass legal guardians and other primary carers.

The principles and considerations outlined in this document also apply to communication directly with children and young people, and the guidance outlines strategies to support parents and carers when talking to their child – whether that child is a patient or sibling. Further reflection is provided into the ethical framework that should support practice.

Background

According to the Department of Health (DH, 2003a, p.17):

“The way in which health professionals present bad news is an important factor in how it is received, understood and dealt with.”

A review of literature has revealed considerable variation in practice in the way in which parents are first given bad news about their child’s health (Smyth, 2004; Rodriguez and King, 2009; Brown, 2011). Evidence shows that while many parents feel well supported when they are given difficult or distressing information, there are many other situations where parents feel confused and let down by the way such information is communicated to them (Contro et al., 2004; Bower, 2009).

The ways in which families are first given the news that their child has a life-threatening illness or diagnosis of disability are words they will never forget (see the Informing Families project resources available at www.informingfamilies.ie); parents can feel very isolated and can struggle emotionally to cope. Potentially bad news plunges children, young people and their families into a confusing and previously unknown world, where professional people will speak in medical jargon and patients may be subjected to various interventions and uncertainty.

It may be difficult to know how a parent or family will react to the news being imparted and so it can be difficult to prepare for the encounter. Disclosing unwelcome information is a complex communication challenge requiring expert verbal and non-verbal skills and is one of the most difficult tasks faced by health care professionals. Studies consistently show that the way a doctor or other health or social care professional delivers bad news places an indelible mark on the doctor/professional-patient relationship (Renty and Roeyners, 2006; Graungaad and

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Defining the issues

Skov, 2007). Should bad or uncertain news be given in a manner which lacks sensitivity and/or is in an environment which is inappropriate, it is likely to cause additional stress to all involved (Davies, 2002).

Nurses and other health care professionals are encouraged to advance their skills in communicating bad news to children, young people and their families, both within the hospital and community setting (ACT, 2011). Such skills are fundamental to health care practice, especially in the case of a serious diagnosis, as it is from that point onward that the parents will enter into a partnership with the health care team (ACT/RCPCH, 2009).

What is bad news?

Bad news can mean different things to different people (DHSSPS, 2003a). There are situations which would be universally recognised as delivering bad news – the adverse results of pre-natal or genetic tests, diagnosis of a serious illness or condition, the progression of an illness when cure is no longer possible, serious road traffic accident and injury, suicide or sudden death.

Other situations are more complex, such as the lack of a diagnosis when a child has an obvious but unexplained impairment, the uncertainty of mental illness, a change in prognosis or expectation, or when raising the issue of palliative care and resuscitation decisions.

It is recognised that use of the term breaking bad news may be viewed as contentious, and yet it is a phrase in regular use by both professionals and the public. In the care of children, these situations are usually transmitted through the feelings of parents. Within literature the definitions include:

'Situations where there is either a feeling of no hope, a threat to a person's mental or physical wellbeing, risk of upsetting an established lifestyle, or where a message is given which conveys to an individual fewer choices in his or her life.'

Bor et al., 1993

'...any information which adversely and seriously affects an individual's view of his or her future'

Buckman, 1992

'...any information that is not welcome'

Arber and Gallagher, 2003

'...[an] uncomfortable experience for both the giver and the receiver'

Aitini and Aleotti, 2006.

The common denominator is that bad news is a message which has the potential to disrupt normal routines; dreams can be shattered and relationships turned upside-down, leading to very different lifestyles and choices. However, over

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Key considerations and practice implications

a period of time and under the watchful care of professionals and family, it is possible for all to adjust to what is happening and, in many cases, to maintain a sense of hope for the future.

The role of the nurse in breaking bad news

In traditional health care practice the expectation has been that it is the responsibility of the doctor, and most often the patient's consultant, to be the primary bearer of bad news to their patient or their family. Much of the earlier literature on breaking bad news is therefore focused on the role of medical staff, with little reference to the role of the nurse when bad news is being given (Taylor, 1988; Miyaji, 1993).

It remains the case that the nursing role is central in providing support to families at a time when bad news is given or reinforcing information delivery following such medical consultations. A study by McCulloch (2004) found that 90 per cent of patients singled out the clinical nurse specialist as the most useful contact; a key responsibility of the nurse specialist role is to provide follow-up to the patient after bad news has been delivered, provide continuity of care and offer emotional support.

The landscape of health care is changing. The continued development of nurse-led services means that nurses in a range of posts – including clinical nurse specialist, ward manager, nurse consultant and community children's nurse – may be the professionals best suited, by virtue of both their skill and knowledge base, to be the bearer of bad news. In many circumstances a specialist nurse may be the lead professional discussing and co-ordinating care packages for children with complex needs – such as palliative support or other services caring for children and families within their home (Corkin and Chambers, 2007).

The role of the nurse is multifaceted and includes that of facilitator, supporter, counsellor, educator, teacher and advocate for the child and family as well as being an instrumental member of the multi-professional care team (Price et al., 2006).

Nurses bring core organisational and observational skills in being able to effectively communicate bad news to parents and their children, and continue to play a valuable role in supporting parents after bad news has been given, whatever its source.

The breaking of bad news

Literature suggests that the manner in which parents are told about their child's diagnosis affects both the way in which they adjust to the situation and the wellbeing of their child (McNeilly et al., 2006; Brown 2007). Parents are often able to vividly recall the time when they were told of their child's diagnosis (Craig, 2006).

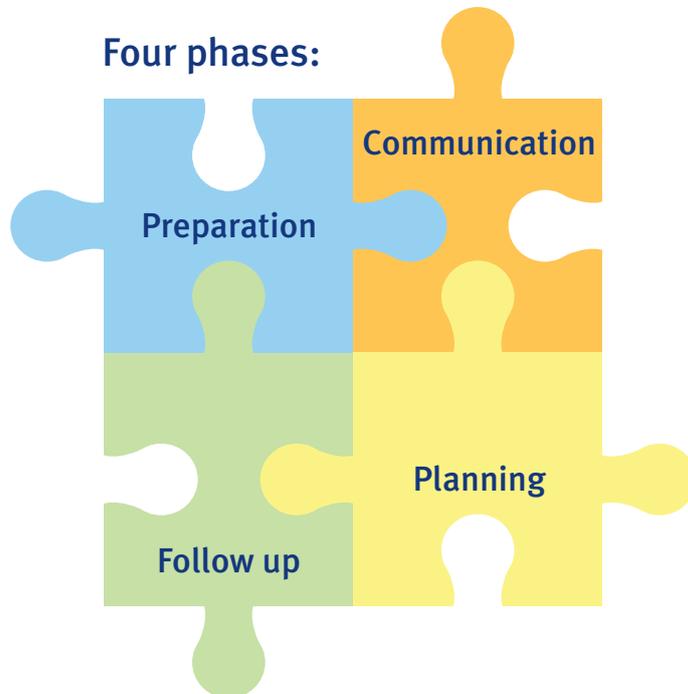
Every recipient of bad news should have access to timely, up to date, accurate and consistent information, in a format and language which is appropriate and consistent to their needs and their particular circumstances and preferences.

Information can be given at different stages of working with a family, as a child's presentation may change or develop over the course of being seen by the nurse. If the family is already known to the nurse this could have a bearing on how the nurse delivers the information; having knowledge of the family and how it works and operates will inform what approach may suit them, adapting to individual styles and needs.

The Kaye (1996) 10 step approach, the SPIKES protocol (Baile et al., 2000), and the ABCDE mnemonic used to assess the acutely ill child (Rabow and McPhee, 2000), all offer sound advice and have been developed to provide structure to the process of communicating bad news (see [appendix](#) on page 17). These frameworks are flexible and allow the health care professional to use their clinical judgement, as the breaking of bad news can take many forms, happen in many settings and cover a range of situations.

These frameworks can be distilled into four phases to aid the process of communicating bad news and can be simply followed in daily practice:

- **preparation** – of self, of recipient, of environment
- **communication** – delivery of the information
- **planning** – agreeing what happens next
- **follow-up** – documentation, provision of written information, liaison with other agencies.

Figure 2: The four phases of communicating bad news

Preparation

The professional role

- Take responsibility – organise and co-ordinate, time is not going to change what has to be said or done, so there is no benefit to the recipient/s or the professional to delay giving unpleasant news.
- Adequate planning and preparation of self (nurse/ doctor) should be undertaken.
- Agree who is to deliver the news and if any other practitioner will accompany and support the information giver and parents, family or carer.
- Know who is to be informed – be aware of who the parent(s), carers and legal guardians are, and establish who will be present during the consultation.
- Sometimes it is impossible to avoid giving bad news to one parent alone because the parents may be separated or one may be working abroad. Ask whether the lone parent would like a friend or relative with them and offer to see both parents together as soon as possible if appropriate.
- If parents are separated, establish which parent has parental responsibility, and agree how to handle the needs of both parents for information, which may need to be met individually.
- Familiarise yourself with the child's background, medical history and test results. Ensure you have all the required information readily to hand.
- Decide what is to be disclosed – how much information, and in what order.
- Ensure you are fully informed of the choices and options in the future management of the child or young person's condition.
- It is helpful to mentally rehearse the disclosure, possible questions you will be asked, the parents' emotional reactions and potential responses.
- Practice speaking phrases and sentences in advance. Do not just think them, actually practice saying them. This will give you the confidence you need in order to speak to the family.
- Turn off beeps and mobile phones – if you are awaiting important calls or are on call ensure a colleague can answer calls on your behalf.

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Recipient needs

- Every recipient of bad news should receive the disclosure in a face-to-face discussion in privacy and should be treated with respect, honesty and sensitivity.
- While it is important to remember that the bad news may be very sad for the child and family, the information that you will be giving will be important in allowing planning for the future.
- Consider any additional requirements parents may have in relation to assistance with communication. This may be the need for an interpreter for parents who cannot fully understand the English language or a signer, braille information or other support for those who have hearing, visual or other impairments such as a learning disability.
- Be aware of the ethnic, cultural and, if relevant, faith background of the family and familiarise yourself with any additional requirements or considerations.
- If the child or young person is going to be present consider their developmental level and any additional support required.
- If the child is not to be present, ensure someone is delegated to be with the child in the absence of parent/s.
- If you suspect that different family members have different levels of knowledge or are approaching the situation very differently, it might be appropriate to see them separately; differences in understanding can lead to tensions and conflict.

Environmental factors

- Try to find a suitable environment – a private, tidy and comfortable room where your conversation cannot be overheard.
- Put a 'do not disturb' warning notice on the door.
- Ensure that distressed parents do not have to walk through a busy area where it can be difficult and embarrassing to be seen by others.
- Allow family time in the room and support as needed after the consultation.
- Ensure a box of tissues and glass of water are available.

Communication

- If you do not know the family, introduce yourself to them and check out who is in the room.
- Sit down, as sitting down will help relax the parents/ carers and try not to have barriers between you and the parents like a large table or irrelevant information around like magazines.
- Ensure adequate time is allocated, as the appointment should not be rushed.
- Try to make a connection with parents and maintain eye contact, as this will show parents that you care and are engaged. Touching their arm or holding a hand can be powerful, but only if they are comfortable with this.
- Be courteous; provide an appropriate welcome and thanks for their attention. If you have a student or a junior with you, introduce them to the family and explain they are working with you today, and seek permission for them to stay and learn from this experience.
- Explore what is known by the parents already.
- Give information honestly, but with sensitivity.
- Try to use simple language and avoid medical jargon where possible.
- Aim to be flexible, responsive and listen to what the family has to say and be intuitive as to body language which indicates how the recipients of the information are feeling.
- Break the news using small chunks or bite size pieces of information with regular checks of understanding and try not to overload parents with information; more than one meeting will usually be required.
- Be comfortable with silence and prepare yourself for possible reaction.
- Check back by asking what has been understood and correct or reinforce.
- Answer questions honestly and in the best interests of the child.

Planning

- Following the communication of bad news parents should be offered time to be on their own, recognising that they may want a nurse to be present for support.
- Plan the next steps; if the consultation has taken place in an outpatient or community setting make sure the family is able to make contact with you or a colleague over the next few days and follow through any management plan agreed.
- If the child is an inpatient make sure the family know that they can revisit the information given and how to contact you or a colleague and follow through any management plan agreed.
- Recommend sources of support and start negotiating care for the various problems and issues that have been identified. Give parents sufficient time to make any decisions.
- Offer to speak to relatives such as grandparents, while remembering to maintain confidentiality, only giving the information which parents are happy to share.
- Arrange a review appointment or a follow-up consultation relatively soon – a series of review appointments/consultations may be needed.
- Ensure the family is aware of who to contact if they have any questions – for example, the specialist nurse.
- Make sure parents are aware if any further test results are expected and how they will receive the results.

Follow-up

- Provide written information or a summary of the discussion.
- Give details of appropriate supportive organisations such as for life-limiting diagnosis at www.togetherforshortlives.org.uk (formally ACT) and Contact a family at www.cafamily.org.uk
- Suggest that parents write down any questions as soon as they think of them, before the next meeting.
- If the child is an inpatient, this is when a nurse may play a crucial role, especially if present when the doctor delivered the news; providing ongoing support and reinforcing information as necessary.
- It is important to build up and maintain a good relationship because there may be ongoing news to communicate.
- Parents may be concerned about how to break the news to their child and what to tell siblings and wider family members. Provide details of local and national support agencies, such as educational psychology services or children's hospice staff.
- Keep and maintain accurate records of the conversation and the information and details exchanged within the multidisciplinary team.
- Psychological support for both children and families can be arranged.

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Barriers to communication

The complexity of the situation can create serious miscommunications, such as the patient misunderstanding the prognosis of the illness or purpose of care (Davis, 1991).

The bearer of bad news can experience strong emotions such as anxiety, a burden of responsibility for the news and fear of a negative response. This stress can result in a reluctance to deliver bad news. According to Maguire (1985) when health care staff are uncomfortable breaking bad news they can avoid discussing distressing information such as a poor prognosis, or convey unwarranted optimism to the patient or family. Clinicians may be uncomfortable discussing prognosis and possible treatment options if the information is unfavourable. Taylor (1988) and Miyaji (1993) suggest that this is due to a number of reasons including:

- uncertainty about the patient's expectations
- destroying the patient's hope
- fear of own inadequacy in the face of uncontrollable disease
- not feeling prepared to manage the patients anticipated emotional reactions
- embarrassment at having painted too optimistic a picture for the patient.

Doctors and other clinicians may be poorly trained and emotionally unequipped to deal with the delivery of bad news (Buckman, 2005; Schildmann et al., 2005). A number of factors can affect the ability to impart bad news sensitively including fatigue, pressure of work and prior clinical experience (Ben Natan et al., 2009).

Inadequate, confusing or uncaring communication will result in dissatisfaction for all involved. When bad news is delivered poorly the experience of receiving bad news will stay with the receiver long after the initial shock has been dealt with (Fallowfield, 1993).

Where English is not the family's first language, staff should use appropriate interpreting services. When patients, parents or carers have additional needs such as sensory impairment, learning or physical disabilities, staff should ensure that the appropriate support mechanisms are available.

Legal and professional issues

When preparing to inform parents of bad news it is very important to establish who has parental responsibility for the child/young person. Parental responsibility is defined as all the rights, duties, powers, responsibility and authority by which, by law, a parent has in relation to the child (Children Act 1989, section 2).

These rights exist in order to allow those with parental responsibility to exercise their duty of care towards the child/young person. This is a dynamic process as the child and young person develops their own identity and autonomy, and becomes competent to make their own decisions.

Dunlop (2008) states that professionals must work within UK law in relation to parental responsibility and within an ethical framework of children's rights. This framework recognises that as a child's sense of autonomy evolves, children and young people have a right to have their opinion taken into account when decisions are being made that directly affect them (Lansdowne, 1998). As a consequence current practice indicates that maturity, capacity and consent are inextricably linked to decision making when considering a child's ability to be involved in the process of breaking bad news. This should include the opportunity for them to meet separately with health care professionals, as well as being involved in discussions with parents.

Consent and competency when disclosing bad news

Decision making with or on behalf of children who are seriously ill or have life-limiting illnesses can present a range of challenges for both the family and health care professionals involved. Families and professionals in all settings which care for children and young people regularly face decision-making dilemmas. These are usually worked out in a considered and constructive way between the various parties involved, namely the clinicians, the children and their families (Wright et al., 2009).

Whenever a child or young person is faced with a serious medical problem, key people may have different points of view about the correct course of action. The clinician may believe it is right or wrong to proceed with a particular clinical treatment. Each of the parents may have a different view. Most importantly, the child will have thoughts and feelings about the treatment, whether or not they are judged to have capacity (Wright et al., 2009).

Within children's palliative care, every family should receive the disclosure of their child's prognosis in a face-to-face discussion in privacy and should be treated with respect, honesty and sensitivity (ACT, 2004). The initial meeting is usually with the parents, although some older children and young people may be present at this meeting, dependent on the individual child or young person and their family.

There are differing views as to whether children should be present during the breaking of bad news meeting. There is a distinct lack of evidence to support practice around this challenging question. Many health professionals choose not to include the child in the initial discussion, giving parents time to assimilate their feelings and vent their emotions before talking to their child (Price et al., 2006).

Lyon et al., (2004) argue that the parents use of defence mechanisms such as avoidance, coping or denial may lead adults to misconstrue the child's behaviour, feeling that it is selfish to expose children to possible fear, sadness, or alienation associated with the truth of dying (Tanvetyanon, 2005). Wolfe (2004) suggests that many children who have lived with a life-limiting or threatening condition have witnessed and heard about other children's deterioration and death, and most dying children will be aware of their impending death.

When a truthful atmosphere surrounds the child, he or she can express grief, discuss preferences and achieve goals (Lyon et al., 2004). Medical guidance (BMA, 2001) highlights that if professionals wish to develop relationships with children and young people based on trust and respect then:

'Lies should not be told in response to clear questions.'

'Information should not be withheld if the child seems willing to know it'.

Higgs (2007) states that the majority of health care professionals would undoubtedly like to be thought of as truthful in talking to dying children about their impending death, however the absoluteness of truth is put into question.

Rigorous formalised communication systems and negotiation within the interdisciplinary team should ensure that there is agreement regarding ethical issues at the end of the life phase of a child's illness (Jassal and Sims, 2006). Staff should be guided by their organisation's policies and procedures regarding consent which includes guidance that advocates that young people with the capacity to decide independently should be involved in making decisions about end of life choices (ACT, 2004; DHSSPSNI, 2003b).

Not all children ask direct questions about their situation and may instead talk around the subject (Dunlop, 2008). During sensitive discussions, the child may reveal that they are aware of their impending death, yet may not want to discuss this further.

Regardless of age, the child may wish their parents to hear on their behalf, therefore shifting responsibility for difficult decision making (Kelsey et al., 2007). However it must be remembered that children continue to develop and it is important to re-evaluate beliefs about the child's understanding, maturity and awareness as time progresses (Wright et al., 2009). Most children will need repeated opportunities for them to raise questions about what is happening to them and planned times for them to explore their concerns.

Supporting parents/carers talking to children, siblings and grandparents

Although the structure of family groups can vary, the central purpose of the family is to create and nurture a common culture that encourages the wellbeing of those people concerned, providing physical and emotional support. Many parents view their children as their common life-project (Brown, 2007). Anything that affects one member will affect the family as a whole. When the stability of family life is threatened, families may lose their sense of purpose and direction (Matthews, 2006; Brown, 2011). Every family is unique in how they react to such news.

5

Specialty-specific considerations

Breaking bad news in the emergency department

Bad news may be very difficult and sad for parents but for some the information may be important in allowing them to plan for the future. However, parents who are coming to terms with bad news may also have the added stress of how to discuss this with their child or with other family members close to their child such as siblings. Parents need to be given relevant and age appropriate material to use in speaking to their child or others.

Parents and carers may need help and encouragement to consider the following points:

- tell your child when you are feeling strong enough
- choose a familiar place where you both feel comfortable
- choose a place where there will be no interruptions
- expect tears/crying and a hug may be required
- give plenty of time for asking of questions
- have information available that is age appropriate with child friendly or teenage friendly (services help provide this)
- discuss what can help – interventions or treatment
- discuss future – what they want and what happens next
- discuss separately with siblings and, if appropriate with the child – but also try to talk to both together
- consider if meeting other children or young people with the same condition or disorder would be beneficial – both for the affected child and for siblings
- consider sharing information with peers and teachers at school.

Bad or distressing news can be defined by the impact it will have on the child and family (Baile et al., 2000). In an emergency department (ED) this can range from the sudden unexpected death of a child, to the diagnosis of a fracture at the beginning of the holidays.

The challenge in the ED is meeting the needs of the child and family in conveying this news when circumstances and the work environment can make this difficult to achieve, compared to other health care or community settings. Breaking bad news must be managed sensitively, honestly and clearly in the ED, meeting the unique challenges that this setting presents (RCPCH, 2012).

The way distressing news is conveyed is important in how it is received and understood, and so consideration of the individuals involved – both staff and family – the environment and the nature of the consultation is required to ensure the most effective and supportive communication possible in these challenging circumstances.

Due to the nature of the ED clinical setting there may be no background relationship with the child and family. This presents different challenges and may contribute to a barrier being established when trying to connect with families (Baile et al., 2000). In contrast to other settings, the suddenness of an event may make it difficult to develop an understanding of the family dynamic, and predict responses and coping mechanisms when preparing to support families when communicating bad news.

Emergency care is associated with stress and the breaking of bad news is an inevitable aspect of that work (Donnelly, 2012). When the news being delivered to families is that of a child death, prolonged resuscitation attempts will have often preceded this and will clearly have an impact on those staff involved. Indeed, paediatric deaths are frequently personalised by ED staff (Reynolds, 2006; Donnelly, 2012).

The ED does usually have the advantage of consistent availability of senior staff, as in most cases consultants are used to being on shift clinically, which provides experience and support and possibly direct involvement in breaking bad news. Within emergency care, nurses are frequently involved in delivering bad news and have a key role in ensuring the most supportive circumstances to communicate this news and provide support afterwards (Farrell et al., 2001).

Advanced practice roles such as advanced nurse practitioner or nurse consultant mean that nurses may take the principal role in leading care for a child and family. Wherever children are treated, it is important to have paediatric trained staff (RCPCH, 2012).

There are key aspects of communicating bad news that must be met within an ED setting to ensure bad news is delivered in a way that minimises negative outcomes. The ED must have a room where the most serious of bad news can be delivered most appropriately and sensitively; ideally this location should also be close to the resuscitation room (RCPCH, 2012). This may not always be possible and breaking bad news will inevitably on occasion occur outside this room, in the main ED for example, when the decision is made to stop resuscitation attempts. Family-witnessed resuscitation, although outside the scope of this document, should be supported within the ED with appropriately trained and supported staff (Baskett et al., 2005).

When breaking bad news occurs within the ED itself, in a semi-public area, this should be delivered in such a way as to make this as private and dignified as possible, protecting the family and making the best environment given the circumstances. The department must be flexible and adaptable, making the physical environment less clinical where this is possible. In sudden death scenarios, remove equipment from around the child (monitoring leads, intravenous fluids and so forth) where this is possible (being mindful of and sensitive to the need for any additional investigation into such a death).

Staff must be mindful of the wide range of reactions to distressing news that families may show. The nature of attendance in the ED makes it more likely that the news will be unexpected; staff must therefore be able to manage and support families in how they react, in an effective and safe manner. Because a relationship is not likely to have been established prior to attendance at the ED it is often best to

ask families what they need. This may allow recognition of cultural, spiritual and family beliefs that are so important in support and coping mechanisms (RCPCH, 2012).

Having broken bad news, staff must also support families and help them deal with the circumstances of the news and its impact, identifying any problems that may arise. This may include, for example, practicalities around the transfer of a child to another hospital.

Resources must be available and in place for families in terms of outside agencies and support services and knowing how to support wider family members in the communicating of bad news to them (RCPCH, 2012). Sign-posting families to useful resources is a key role in supporting them, therefore staff are required to have knowledge and understanding of such resources through education, ongoing training and organisational support. This requires a good working relationship with other specialties as well as local and regional referral centres such as specialist burns, oncology and retrieval services, and other agencies.

Sharing information with the family about a child's mental health disorder

This section of the guidance will focus on the area of child and adolescent mental health. The Health Advisory Service (1995) sets out the way in which professionals work with children in a variety of settings and at different levels of severity. Workers in universal services such as health visitors and community children's nursing teams will often make referrals to Child and Adolescent Mental Health Services (CAMHS) for assessment of children and young people presenting with signs of mental health difficulties or disorders. Professionals working in universal services (tier 1) also offer much input to children with mental health difficulties who may never attend CAMHS at tiers 2/3/4 (RCN, 2009). They too are involved in promoting mental health and supporting children and young people with mental health difficulties.

The primary function of the specialist CAMHS is to develop and deliver services for those children and young people (and their families and carers) who are experiencing the most serious mental health problems (Scottish Executive,

2005). Nurses working in this setting should have post-qualifying experience and training specifically in this field and bring to their practice both clinical and therapeutic skills.

The National Service Framework Standards for the mental health and psychological wellbeing of children and young people (DH, 2004) describes key elements in a CAMH service that works, including making links with existing services both inside and outside of CAMHS such as the education and the voluntary sectors. Services working closely together are necessary for delivering a high quality of care.

There are many things to consider in sharing information with families regarding a child or young person's mental health difficulty. According to Cleary et al., (2009) communication research and investigations into the delivery of bad news is uncommon in psychiatry as compared to other medical specialities. Much of the literature focuses on breaking bad news in the context of physical health problems. However, the delivery of bad news in mental health has been described as being more complex than a 'good or bad news' paradigm.

The SPIKES (Baile et al., 2000) six step protocol for the delivery of bad news is a well-recognised approach in cancer care (see appendix 1 on page 17). As it requires consideration of setting, perception, invitation, knowledge, and a requirement to empathise and summarise, the nurse working in CAMHS may also find these steps relevant and transferable. The Scottish Intercollegiate Guidelines Network (SIGN, 2007) guide on autism spectrum disorders provides a helpful checklist which sets out three stages required in providing access to services and information.

This guidance echoes the phased approach identified in [Section 3](#) of this document, recognising three broad stages when delivering/sharing information with families:

- before assessment
- at the assessment appointment (where information is given about a child/young person's mental health difficulty or disorder)
- feedback appointments (where further information is being shared about a child/young person's mental health difficulty or disorder).

The assumption should not be made that families will always view the news or details of their child/young person's mental health diagnosis as bad news. In fact it can sometimes be a source of relief that there is an explanation for their child presenting with difficulties. It may also give the young person comfort to know that they are not the only person experiencing particular problems and promote understanding in those caring for them.

Parents may, however, respond in varying degrees including anger, relief, guilt, blame or denial. There may also be implications for the parent if their own mental health is questioned or if there are similarities in a family such as the presence of anxiety difficulties through several generations or an undiagnosed autistic spectrum disorder which may be recognised in a parent of a child being diagnosed.

In the CAMHS setting a nurse is part of the multidisciplinary team where assessments are carried out by individuals, jointly with colleagues or in teams. From the point of referral they start to form a therapeutic relationship with the families they work with and who may benefit from seeing the same person for follow-up appointments.

6

Education and training

This section of the guidance reflects on situational skills (RCN, 2010) and examines the implications for pre-registration education in developing and maintaining those skills.

Developing skills in managing communication which has the capacity to be distressing is an intrinsic component of the children's nurses role and is commensurate with the competences nurses require to enter the register (NMC, 2010) and also to uphold the standards as required in the code (NMC, 2008).

Specifically for Domain 2 (NMC, 2010) the entrant to the register is required to have communication skills which are "safe, effective, compassionate and respectful". Nurses must "build partnerships and therapeutic relationships through safe, effective and non-discriminatory communication". They must "take account of individual differences, capabilities and needs" as well as "recognise when people are anxious, in distress and respond effectively". Nowhere are these skills going to be more needed than when dealing with the breaking of bad news.

Introducing and developing the skills of the pre-registrant student to the points of competence outlined above is challenging. Themed lectures and theory sessions, frameworks and principles of communication all have their place but are insufficient alone to equip the emerging professional and additional learning perspectives are required.

For this reason it is important to expose the emerging professional to a clinical area where bad news is going to be given and not be a rare event. Exposure to a range of settings such as ED, community palliative care teams, hospices and child development centres can assist the student to witness at first-hand how clinical experts deliver this information. A log book or reflection activity to critically evaluate, set as a formative but mandatory assessment, should ensure the nursing student focuses on the importance of such events.

There has been an avid interest in educational initiatives such as scenario workshops and role play to help prepare health care professionals (Breier-Mackie, 2001). In many instances student midwives, nurses, social workers and health visitors have limited experience and are often not exposed to how it is done until after they qualify. Consequently, there is potential for poor practice when communicating bad news.

Dealing with difficult conversations and developing health care skills through simulation is currently being highlighted within the university setting (Turner, 2012). The communication of bad news during simulated inter-professional education activities with third year pre-registration nursing and fourth year medical students enables strategies to be analysed by small groups of students during debriefing sessions (Corkin and Morrow, 2011). When studying at post-graduate level in areas such as a paediatric palliative care or care of the critically ill child, students should have the opportunity to explore this important communication skill.

Maintaining workforce skills

Professionals may encounter situations where families are experiencing particularly adverse circumstances. Whether supporting such families is a frequent or infrequent occurrence, professionals will need to possess the skills that enable them to meet individual family needs.

Adopting a strategy of critical awareness and an ability to reflect on and monitor performance can be a useful tool in keeping one's intuition sharp. Advanced communications skills training for frontline staff is mandated in children's cancer care, but required across the range of health and social care settings.

Retention of the appropriate skill set is vital as this cadre of frontline professionals are the role models best placed to pass on their skills to students and new staff. The Knowledge and Skills Framework (NHS, 2004) quite rightly identified communication as a core skill; breaking bad news is included in performance level 3 which aims to develop and maintain communication with people about difficult matters and/or in difficult situations.

7

Supervision and mentoring others

The need for a highly-skilled nursing workforce has been well recognised by health care commissioners, educators and service users. Clinical supervision should be a priority in view of the importance of practitioners being able to effectively work with families, especially in relation to discussing complexity, care planning and ensuring safe practice as well as providing ongoing support.

Literature contains several definitions and perspectives with regards to mentoring, supportive clinical supervision and precepting (Morton-Cooper and Palmer, 2000; Ohrling and Ingalill, 2000; Myrick, 2002). Many of these are transferable to the mentoring and support of staff who need to engage in the process of breaking bad news.

Health care professionals who need to learn to break bad news require secure mentoring, support and supervision to begin with and must be under no illusion as to the level of responsibility, commitment, amount of time, emotional involvement and investment in building trust and relationships that this entails.

Mentoring and clinical supervision require a high level of commitment from each participant for the relationship to be established (Mills et al., 2005). Both can be conducted over long periods and the differences between these relationships lie in the focus of discussions between the participants. Mentoring allows for a more comprehensive review of a nurses skills and abilities, which might range from the management of the scene to the detail and the language used to disclose the information. Clinical supervision, by contrast, may be confined to a particular case or situation that the nurse being supervised has found difficult or troubling.

Supporting staff

Supporting those involved in breaking bad news is fundamental to that news being delivered effectively by staff who feel they can do so with confidence and competence. Education and training promotes this, but beyond that staff will require support in their role.

Communicating bad news is stressful and those involved may experience anxiety and potentially a reluctance to deliver bad news. The process of breaking bad news can sometimes have a short-term and even a prolonged adverse effect on individual staff involved (DHSSPS, 2003a; Farrell et al., 2001). This is particularly evident when the doctor is inexperienced, the patient is young, or there are limited options for treatment (Ptacek and Eberhardt, 1996).

Breaking bad news is an important part of a professional's job and an aspect of practice that adds to the emotional and mental stress that can impact on how nurses function, both professionally and personally (Burbeck et al., 2002).

The emotional impact of communicating a diagnosis of developmental disability (Bartolo, 2002) cancer (Clarke et al., 2002) or diabetes (Lowes, 2011) can produce mixed emotions and prolonged anxiety. Personal emotional support is important for those who find themselves in repeated situations of delivering bad news and dealing with distressed children, young people and their families.

Exposure to traumatic events is distressing and can lead to disabling reactions (RCN, 2006). In both the short and long term, wellbeing and performance can be affected. While this normally resolves with appropriate support it is important to recognise a prolonged effect can develop, potentially leading to post-traumatic stress disorder (RCN, 2006). Compassion fatigue is a gradual lessening of compassion over time due to chronic exposure to traumatic events which has a detrimental effects on individuals, both professionally and personally (Moya del Pino, 2012).

Individuals and the wider team must keep mindful of signs and symptoms of acute stress, such as poor concentration, irritability and low confidence and be able to identify this in themselves and others (Donnelly 2012). A normal response to either a single stressful event such as communicating bad news or the cumulative stress of the working environment,

can be distinguished from that which may lead to a deteriorating performance and professional function. Professionals need to develop an awareness of the risks, learn how to handle stressors and know when to seek help, alongside an understanding of the type of workplace stress and how this impacts on self and function (Donnelly, 2012).

Support agents can be both professional and personal. The individual has a responsibility to identify a need, and access support when appropriate. Health care organisations have a responsibility to provide access to effective professional support (DH, 2000b; BSUH, 2012; RCPCH, 2012).

The RCN (2006) provides guidance on supporting staff through counselling services and details the resources that should be available. Professional support agents include the provision of counselling services which may include occupational health and a chaplaincy service. Personal support agents can include peer support as well as an individual's social support network, though confidentiality and professional boundaries must be adhered to (NMC, 2008).

Debriefing

Following breaking bad news it is important for all health care professionals involved to debrief. Debriefing is an intervention that enables people to talk through an experience and receive support on normal coping mechanisms and reactions. It can either take a professional or personal approach, looking back at the event chronologically and exploring what happened and why, or, on the emotions experienced. This can be an informal conversation between those involved, around how it went and any issues that arose. It is good practice to share experiences as well as promoting a supportive working environment within a team. A more formal aspect of debriefing may sometimes be required through either personal or group reflection (Price et al., 2006).

Debriefing has often focused on the needs of medical staff, but other professionals – most frequently nurses – are now equally involved in this encounter (Farrell et al., 2001).

Common features of formal debriefing include a structured format and formal approach, and should ideally occur within 72 hours of the event (Kinchin, 2007). Talking through events and reactions allows individuals to come to

terms with the experience (DH, 2000b). Discussing in teams helps everyone to understand the roles and contributions of individuals and the team as a whole, value each other, and can add to the overall cohesion within a clinical team as well as wider organisational working culture and learning environment.

Breaking bad news is a complex communication task that requires mutual support within the team for those individuals involved (Baile et al., 2000). Reviving the messenger is a discussion theme that appears in breaking bad news literature; there is a strong emphasis on the support required by individuals who *bear* and *break* bad news, using a whole-team approach (Rabow and McPhee, 2000).

This allows for sharing the burden of bad news. Bearing bad news is how individuals can feel when involved in communicating bad news. The burden of truth, and responsibility carried by those involved – for example in knowing a new diagnosis prior to the family being informed – can be difficult to manage and deal with (DHSSPS, 2003a).

Spending time with a family and knowing what the likely outcome of investigations will be, and dealing with this is an aspect of communicating bad news that demonstrates the complexity of bearing bad news. For this reason the support of staff goes beyond those directly involved in actually communicating bad news. Those involved in any aspects of the child and family's care, must be considered when supporting staff in their roles. This includes those at the peripheries of care, for example, nursing students, HCAs and hospital support staff.

8

Conclusion

Breaking bad news is a difficult undertaking for any health care professional. It can often change the lives of children, young people, their parents and families irrevocably.

The quality of information provided to families depends on the education and training of the health care professionals who deliver the bad news. Nurses can gain the appropriate knowledge and skills to enable them deliver unpleasant and upsetting information in a caring manner, and as clearly and sensitively as possible.

This guidance document has identified some evidence which underpins practice, however further research is needed to support optimal care of children and families (Dunlop, 2008).

Appropriate signposting to existing communication frameworks and additional information has been highlighted throughout this document to enable practitioners to be aware of, and promote access to, additional material relating to this important, complex and sensitive area of care (DHSSPS, 2003a; ACT, 2011).

Literature suggests that the issue of breaking bad news to children and young people is dependent on the age and competency of the child and on the wishes of parents in relation to the delivery of such news. Maintaining open communication and the ongoing provision of information is essential to ensure that the parents and the child/young person have the necessary platform for decision making. Giving opportunities for young people or families to reassess their beliefs, needs and wishes and to discuss these is essential.

Promoting an effective supportive service to staff is vital, ensuring that individuals involved in the emotional labour of nursing do not suffer any adverse reactions. Such support may involve both informal and formal debriefing, clinical supervision, specific training and a learning culture which promotes self care and reflection.

9

Appendix: Protocols and frameworks

SPIKES – a six-step protocol for breaking bad news

Step 1 – SETTING up the interview

Step 2 – Assessing the patient's (parent's) PERCEPTION

Step 3 – Obtaining the patient's (parent's) INVITATION

Step 4 – Giving KNOWLEDGE and information

Step 5 – Addressing the patient's (parent's) EMOTIONS with empathy

Step 6 – STRATEGY and summary

Modified from Baile W, Buckman R, Lenzi R, Glober G, Beale E and Kudleka A (2000) SPIKES – a six-step protocol for delivering bad news: application to the patient with cancer, *Oncologist*, 5, pp.302-311.

The ABCDE mnemonic for breaking bad news

Advance preparation

Build a therapeutic environment/relationship

Communicate well

Deal with patient and family reactions

Encourage and validate emotions

Adapted from Rabow MW and McPhee SJ (1999) Beyond breaking bad news: how to help patients who suffer, *Western Journal of Medicine*, 171, pp.260-263.

10

Kaye's 10 step model

Step 1 – Preparation

Step 2 – What does the patient (parent) know?

Step 3 – Is more information wanted?

Step 4 – Give a warning shot

Step 5 – Allow denial

Step 6 – Explain if requested

Step 7 – Listen to concerns

Step 8 – Encourage ventilation of feelings

Step 9 – Summarise

Step 10 – Offer further help

Modified from Kaye P (1996) *Breaking bad news: a 10 step approach*, Northampton: EPL.

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Additional resources

Together for Short Lives

A UK charity for all children with life-threatening and life-limiting conditions. Please visit www.togetherforshortlives.org.uk

Contact a Family

National charity that supports families of disabled children. Please visit www.cafamily.org.uk



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