

07 | BITE-SIZE GUIDE TO PATIENT INSIGHT:

SEEKING **FEEDBACK** IN
DISTRESSING OR HIGHLY
EMOTIONAL SITUATIONS

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The NHS is there for all of us and is often part of some of the most significant milestones of our lives; from the birth of a child to the passing of a loved one. Patients, along with the staff who care for them, will experience both the highs and lows of life and the acute emotions that can go with them.

In the world of insight and feedback, these are factors that must be taken into account and responded to in a way that is ethical and compassionate but which considers the need for listening and learning across all areas of patient and staff experience, including those that are highly emotive.

This guide explains why it is important that feedback is sought in most of these situations and shows how a considered approach can achieve an accurate, balanced and honest picture of what happened.

There are particular circumstances that can increase patient anxiety, pain or distress, such as when a person:

- ▶ Gets bad or worrying news;
- ▶ Learns of the death or serious illness of someone close to them;
- ▶ Experiences relationship issues, an overload of work or family pressures, or financial worries;
- ▶ Finds someone else's behaviour unacceptable or frustrating, perhaps because they feel their views are being disrespected or ignored;

- ▶ Feels that there has been an insensitive approach which does not recognise someone's cultural or religious views;
- ▶ Is in an environment that they find bewildering or frustrating, perhaps because they don't understand what's happening or what is being said; or
- ▶ Doesn't have enough information to understand a situation.

The context could be the death of a relative or friend, the birth of a seriously ill baby or the diagnosis of a terminal or life changing illness. Sometimes anxiety can be a reaction to the environment, such as when someone is admitted to A&E or for surgery; sometimes it can be about patients themselves, such as when someone is experiencing an episode of acute mental ill health, or under the influence of alcohol. It could be a combination of these factors.

Of course, everyone accepts that all patients should be treated with dignity and respect and an important factor is the need to understand and respect cultural and religious perspectives. Communication with patients not only needs to be clear but should also be consistent with guidance on accessibility for different groups of disabled people, BME groups and faith groups.

Staff in the NHS can also frequently find themselves in distressing situations, for example, due to a particularly emotional patient case, needing to refer a child or adult case to social services as a safeguarding concern, or a staff grievance.

Thankfully, not all distressing cases involve deaths but, where they do, it is particularly important that loved ones are involved in the right way so that lessons can be learned. NHS England worked with families, carers and others to produce guidance, in July 2018, to help trusts do this better. We recommend reading the guidance – called [Learning from Deaths](#) - alongside this bite-size guide.

What are the challenges of collecting feedback in sensitive or distressing situations?

The first challenge of collecting feedback in these situations is deciding to do so in the first place. Sometimes it appears ethically challenging: might asking for feedback cause further distress? Will it impact negatively on care or treatment? On the other hand, it could be considered unethical to exclude people from the opportunity to feed back just because they are distressed or have experienced a distressing situation – their views count just as much as anybody else's.

“You could almost say it's unethical...Obviously, some people could construe all sorts of barriers like you could upset people by asking them. You cause much more upset if they go away and they have got something really niggling them and they don't actually get a chance to talk about it.” **Clinician working in Palliative Medicine**, as part of NHS England research into End of Life Care¹

Other challenges can relate to the staff members who are collecting the feedback. There are challenges around resourcing, whereby the collection of feedback could be a burden that hinders other clinical priorities. There is often the concern among staff that collecting feedback in the wrong way could actually make the situation worse. It is important that staff are prepared or trained for these situations and feel supported when they ask for feedback.

“If it was done badly, without rigour and without thinking it could do more harm than good” **Academic**, as part of NHS England research into End of Life Care²

1 Ipsos MORI and NHS England, 'Feedback on the Quality of End of Life Care' (unpublished, 2016)

2 *ibid*

There can be further challenges due to the patient's circumstances. In situations where patients are suffering from complex conditions, it may be that they lack the cognitive capacity to accurately give feedback on their experience. People who experience distress may become quiet and reserved, or on the other hand might become angry and confrontational, and these scenarios can make communication a challenge.

In distressing situations, people sometimes fear the consequences of giving negative feedback about their clinicians or caregivers. We also know that many people have a propensity to be so grateful for the care they have received that they feel reluctant to criticise people who have helped them. In these situations, people might not be completely honest or even comment at all.

Why is capturing this feedback important?

Despite the challenges, many people who have experienced distress are not just willing to feed back on their experiences, but want to. They feel that sharing their experience can help improve the experience for others.

“We want to give praise where it is due, and to help make improvements where needed for the benefit of other families” **Participant in research into bereavement in maternity**, undertaken by NHS England³

Sometimes distressing situations can be eased or avoided, and the only way of identifying how to do this is through patient or staff feedback. In some situations, the opportunity to provide feedback can be a way of intervening before frustrations boil over, or can form part of the healing process. Positive feedback passed onto staff during difficult times can have a significant impact on staff morale. In other situations, feedback can be used to make immediate changes to care, delivering direct benefits.

Feedback in these situations is a way of creating a humanising

3 NHS England, 'Gathering Feedback from Families Following the Death of Their Baby' (June 2017)

atmosphere and improving relationships between everyone involved.

“It makes them [patients] feel more like they’re connected with what’s going on and have an influence still.” Hospice staff, as part of NHS England research into End of Life Care⁴

When should feedback be collected?

Timing is critical, and deciding when to collect feedback will have a big impact on other factors such as the type of feedback exercise you decide to conduct. In general there are three timeframes that apply to when feedback can be collected:

- › Straight away;
- › Shortly after; and
- › A lot later.

Feedback asked for straight away or in real time should be carefully thought through. If the person giving feedback is in receipt of care, then fears about reprisal and anonymity may be heightened. The intense emotions experienced in the heat of the moment might mean that the person would tell the story differently if asked at a later time. Asking for feedback ‘in the moment’ might also exclude certain people – such as those who do not have the capacity to take part or those whose immediate care needs are too complex. For this reason real-time feedback should not be used to make comparisons or conclusions that claim to be representative.

But real time feedback can provide a unique perspective, and can also be easier to action. In moments of distress, using real-time feedback to make interventions on time-critical issues can have an immediate impact on patient outcomes. It is often the case that, after experiencing distress, people are less likely to open up about the experience or cannot recall what happened in great detail, and so real-time feedback may well provide richer and more detailed insight. In some instances, asking in the moment will be the only time to capture the experience from the

perspective of the patient – such as when someone is nearing the end of life or is not willing to disclose contact details.

“You’re getting it [feedback] here and now, so you’re more likely to be able to respond more quickly and make that difference to those particular people.” Hospice staff, as part of NHS England research into End of Life Care⁵

Ordinarily, asking for feedback shortly after an experience is considered the most suitable time: it allows people to recall events without obstructing the provision of care, and to reflect on them rationally. However, when someone has experienced distress this might not be the case. Distressful situations have a longer emotional impact than typical healthcare interactions and requests for feedback during a period of grieving, recovery or remorse, for instance, can bring back unwanted memories. For this reason, any feedback exercise that is conducted shortly after a difficult experience should be made as personal and considerate as possible and should start with a conversation to explain why feedback is being sought and why it is important.

Asking for feedback a lot later negates some of these challenges. If the feedback exercise is conducted at an appropriate time after the event or journey, then some of the sensitivities around burdening staff or intruding on the personal experience of the patient or their family and friends are softened. There is still a risk of bringing back difficult memories and so any requests for feedback should be worded carefully and make clear that participation is voluntary.

Asking at this later stage also tends to suit a quantitative survey methodology and there is evidence that respondents are more inclined to give free text comments then, adding to the richness of the research: this gives structure to the feedback and can make it easier for the person to think about and reflect on their experience. However it is important to consider the length and complexity of the survey, and make completing it as easy as possible.

“I want to be part of the survey, but I don’t want it to take too long or be too complicated” Participant in research into bereavement in Maternity, undertaken by NHS England⁶

Who should you ask, and who should ask?

“Sick people if they physically can’t do it, they can’t do it, but if they’re able and even with help they can give you huge information about what their experience is.” Clinician in palliative medicine, as part of NHS England research into End of Life Care⁷

Where possible, getting feedback from the patient or staff member who has experienced the distressful situation should be the objective. However there may be some instances where this is not possible, such as when the patient lacks cognitive capacity due to their condition; when they have died or can no longer be contacted; or quite simply when they do not want to speak directly to the organisation. In such cases, feedback from friends and relatives, carers or other advocates can be sought. Feedback in these instances will be proxy measures of the quality of care, but will still have value.

Whilst it is important that the voice of the patient is not outweighed, in many instances seeking feedback from someone close to them will add an important layer of detail or raise different issues. The NHS has legal duties relating to these groups too, such as ensuring friends and family are kept informed when a patient is nearing the end of life or ensuring that carers are well supported, and feedback highlights how well this is working.

When seeking feedback in distressing situations, it is important that it should not feel remote or impersonal so, where it is practical, a face-to-face session is better than just leaving someone a form. In many cases, it is better that this is done by someone who is not directly involved in the provision of care, as the patient can be more open without fearing consequences. In as many cases as possible this should be someone who is trusted and has established a positive relationship with the patient. If the setting permits it, you may want to enlist a third party, such as involving volunteers, the

6 NHS England, Feedback from Families

7 NHS England, Feedback on End of Life care

chaplains service, or patient liaison staff.

“We are allocated time to sit with bereaved parents and go through the questionnaire with them which translates to changes in our practice... face to face discussions are offered to the families in order to clarify their concerns and the changes they would like to see.” Participant in research into bereavement in Maternity, undertaken by NHS England⁸

However some people can feel under pressure when discussing something in the presence of someone else or be worried about privacy issues. Self-completion methods avoid this, but any survey should be sent out with clear messaging as to who it is from. Having someone senior and responsible for the services put their name to survey letters is important: this emphasises that you are taking the situation seriously and will act on the findings.

Where should the conversation be held?

Consideration of where to hold a feedback conversation is important. It needs a thoughtful approach about what is practical and convenient and what is the most comfortable and reassuring option for the person from whom feedback is being invited.

Willingness to feed back about a distressing situation may depend on the care setting or environment that they are feeding back in. It is important to be mindful of this, and to ensure the setting works for both participants and be practical, comfortable and private. In some cases, that conversation might work best if it takes place in the person’s home.

There also may be reluctance to feed back in a setting where the patient is more likely to have built a long-term relationship with staff, such as in a GP practice where damaging this relationship or jeopardising the quality of future interactions is a real fear. In a GP practice, patients are more likely to be acutely aware of pressures on staff. Extra care should be taken to reassure the patient about these issues, and the value of feedback more generally. In other settings, the relationships between the patient and their

8 NHS England, Feedback from Families

healthcare team may be more transactional, and so patients can be more willing to leave honest feedback. On the other hand, ongoing care can stand in the way of this, as at the end of a particularly lengthy episode of care the majority of patients simply want to get home, and so are unwilling to extend their stay by answering a few questions.

There are sometimes other logistical barriers, too. The process can involve a chain of events – some good, some bad – and there are many healthcare professionals who might have input. As a result, the patient can be unsure about who to give feedback to and when.

“I’m not sure PALS is the right place to go” Participant in NHS England research⁹

How should feedback be collected?

Often people have concerns that giving feedback will result in poorer treatment in the short or long term. Being transparent about who will see their feedback, how it will be used, and giving them the choice to feedback confidentially if they would like to, is important. It is important to remember, though, that where a patient wants to see immediate improvements to their care, concerns about confidentiality may not be an issue.

For people experiencing distress, it may be that they need to be given extra encouragement to report on their experiences. Helping people to understand that giving feedback is a positive opportunity to improve services is crucial. It is especially important to demonstrate how feedback has resulted in positive action or immediate resolution.

“They should be more transparent about what feedback they did and what they did with it” Participant in NHS England research¹⁰

The type of feedback being collected will dictate the appropriate channel to use, but it is always important to ensure that the patient has the opportunity to leave free text comments. For people who have experienced distress, free text can allow them to describe what was unique about their situation.

⁹ NHS England, The Culture of Feedback
¹⁰ ibid

Collecting feedback from people who have undergone a distressing experience can be made easier with the right approach, and by creating a supportive environment whereby patients feel confident giving feedback and staff feel supported to act on it.

A key part of this is offering patients reassurance, choice and encouragement.

CONTACT US

This guide is part of a short series intended to help healthcare providers and commissioners to make greater use of patient insight: <http://www.england.nhs.uk/ourwork/insight/insight-resources>

The work is overseen by the Insight & Feedback team.

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