

Challenging Conversations at the end of life Communication Skills

2-day course at St Christopher's Education Centre
St Christopher's Hospice, Sydenham, London SE22
www.stchristophers.org.uk

Reflective Review - *recounting what I learnt that will change my practice*
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Course Attendee, 29-30th March 2017

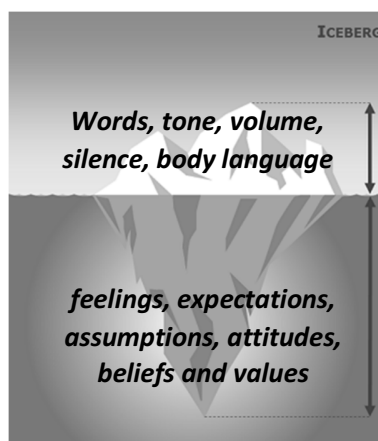
This is just an overview. The course included much more (including role play)

The illustrations below are adapted from internet; they are not course material.

Introduction

There is more to two-way communication than just the words. Many in the caring professions are aware that the tone of voice and body language are also part of communication.

Yet this course has helped me consider more carefully ***the inner response arising from the feelings, expectations, assumptions, attitudes, beliefs and values*** of the patient or their relative when we give them bad news or enquire about ill health.



This response is often not spoken out directly. Or if it is, we often do not know how to interpret and respond to the words (or silence) that result from the information (or question) that we have just given. We even jump to wrong or unkind conclusions about uncomfortable or angry responses, especially when accusing of us or colleagues.

Our problem, as communicators, is that the biggest part of the picture is hidden from our view. What we see or hear is just like an iceberg jutting up above the sea waves. There is much more than what we see, because it is arising from a huge unseen mass below the surface. The use of ice in this analogy has an unfortunate aspect: ice is cold and seems unfeeling. We could also use the picture of a volcano, or a hot spring.

The point of the illustration is as follows: When our patient or their relative receives dramatic, life changing information, the transfer of this information triggers a response from an unseen world below the surface. The response may be massive or subdued, immediate or delayed. Fear is often present. If we are feeling an emotion as we talk to the patient, we need to recognise this in ourselves. We can ask "Is what I am feeling being picked up from the person's unspoken communication to me through their tone, volume and body language". The unspoken part of their communication is telling us what is actually going on inside them.

Protecting oneself and what is valuable

Those hard to grasp feelings come from that inside realisation of important things that need protecting. The patient or relative will often feel the rush of adrenaline and the agitation that comes with it. And those feelings may be deeper than what is said if the patient is requesting further facts from us:

The question *“How long have I got”* may be arising from a deeper unspoken question such as, *“Who is going to look after my children when I die?”* Or if the patient has been permanently disabled, then the question *“Will I ever be able to drive again?”* may only be the surface question of the deeper fear: *“Will I be isolated from friends and family?”* or *“Will I be able to work again and support my family?”*.

The Inner Response to Difficult Circumstances

It is this emotional response to the facts that make conversations at the end of life so challenging.



Whether the feelings are openly expressed or suppressed, we have not finished our communication until we have begun a first step in helping the patient cope with this inner chain reaction that our communication of facts has just started.

A Framework for Challenging Conversations at the end of life

St Christopher’s Education, led by Director Liz Bryan, have distilled important conversations in the care situation down to 5 constituent parts, the 5Ps ©. These are 5 principles that make up a framework to watch for and profit from in every challenging conversation about end of life care:



Person(s), Purpose, Preparation, Process, Product (outcome)

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Short Summary on the 5Ps ©

Suffice it to say that we need to know the **purpose** of the conversation and with that, the desired outcome (**product**). We then need to **prepare** ourselves with information and forethought. If we feel emotionally unprepared, it may be appropriate to ask a colleague to come with you or take your place.

As we begin the conversation, we need to understand who it is we are talking to (the **person**) and this includes observation. But you too are a **person** – so you need to recognise and face what is going on in you before, during and after the event. Consider a short debrief from a colleague or senior after a difficult conversation.

As for **process** – this begins with establishing where they are at, then giving the information and then responding to the patient’s response, that is, responding to their feelings. The first reactions on receiving bad news is only the beginning of a longer **process**.

Active Listening

Active Listening has a clear, attentive opening and closing – no drifting in or out of the conversation. Active Listening includes the skills of picking up cues, gently probing (questioning), checking/ clarifying, reflecting, responding, giving information, paraphrasing, summarising, agreeing to next moves.

It sometimes helps to name a feeling heard during active listening, using a non-threatening tone: “*You sound angry/ frustrated*”. Acknowledging the presence of the feeling can be a start to a more constructive conversation: from that moment on, the patient or relative is no longer wondering if the doctor is “getting” how they feel inside.

Don't keep offering solutions

“Above all, resist the urge to leap in with solutions (or answers to problems) when it starts to feel uncomfortable”. Especially a) because you probably don't yet really understand what the patient is struggling with. b) the patient has to live with the answer, so it is best when it comes from them.

Breaking Bad News

Giving bad news is a process, not an event. The patient or relative will begin processing the news for some time. They often receive more bad news as part of that ongoing process, like onion layers being peeled – the same “onion” but it is raw and freshly painful each time.

Giving bad news involves

- Understanding where someone is at - *including who they are and what they are aware of so far.*
- Giving the news – *precede with a warning sentence.*
- Checking their understanding
- Checking how it affects them - *most importantly: “Respond to the feeling” present.*
- Plans and Support

Palliative care setting: Making longer term plans; Providing long term support.

ED Setting: Making short term plans; Providing short term support
(*e.g. bringing in an ED Senior Nurse to explain arrangements*)

Empathy

Palliative Care Consultant Dr Victor Pace assured us that there is ‘no technique’ that one can use when it comes to communicating bad news.



*How would you like it feel
if the mouse did that to you?*

The key element is summed up in one word: **Empathy**. To empathise is a choice to understand how the patient **FEELS**. Life experience, if applied thoughtfully, promotes empathy.

Empathy described in colloquial terms is: “*understanding where the patient (or relative) is at*”. Use of open questions [that can't be answered by yes or no] allows the person space to express themselves to you from where they are right now.

Empathy continues when your communication after breaking the news still connects with “*where they are coming from*”.

When you get stuck

If you can't think where to go next, Dr Pace advised to recapitulate, empathise with feelings and reflect to yourself about how the situation is making you feel - it may give a clue as to how the patient is feeling (angry, anxious, helpless). You may be unconsciously mirroring that feeling inside you. If so, express this feeling for them e.g. "This has really thrown you hasn't it..." (more silence).

Documenting

Don't forget to document your conversation and communicate outcomes with other staff as necessary.



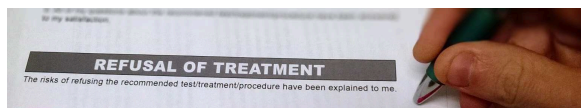
Advance Care Planning

ACP is a voluntary process that aims to initiate conversations between individuals and their care providers. It is an editable document with changing content, forming a story with time. It is usually held by a professional team, but if initiated by the patient years before, a relative may have a copy. An ACP document is about how the patient wants to live, not just about dying. The DoH 2008 'End of Life Care Strategy' encourages us to assess Patient **needs** and **preferences** and document Care Planning.

Such a document is not an Advance Directive and/or an Advance Statement. These must be changed by the patient.

Advanced Decision/ Advanced Directive (ADRT)

Allows a patient to record their wish to refuse certain types of medical treatment. It is binding on the people providing the care if the patient has lost the capacity to make the decision at the relevant time.



To be valid, the person must be over 18 and have capacity at the time of making the decision. They must specify the treatment to be refused and the

circumstances in which this refusal would apply. They must not have made the ADRT under the influence or harassment of anyone else. The document must not have been modified verbally or in writing since it was made.

A **doctor** might not act in line with an ADRT if

- the person has done anything clearly inconsistent with the advance decision that affects its validity.
- the current circumstances would not have been anticipated by the patient and would have affected the decision (e.g. new advances in treatment).
- It is not clear what should happen
- The person is being treated under the Mental Health Act
- Can treat if there is doubt about (or a dispute about) the validity of an advanced decision.

A **person** cannot use an ADRT to

- Ask for their life to be ended
- Force doctors to act against their professional judgment
- Refuse basic nursing care required to keep a person comfortable e.g. warmth and hygiene.

Further Resources:

- **Ambitions for Palliative and End of Life Care** National Framework for local action 2015-2020
<http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/A-Presentation-of-the-Ambitions-for-Palliative-and-End-of-Life-Care1.pdf>
- **ReSPECT**
Recommended Summary Plan for Emergency Care and Treatment
<https://www.resus.org.uk/respect/> Supported by Resus Council, RCEM, RCP, RCGP, RCN & others.
ReSPECT is a process that creates personalised recommendations for a person's clinical care in a future emergency in which they are unable to make or express choices.
Please note: People should not expect to use the ReSPECT process until it has been established in their locality.
- **Advance Directive / Advanced Decision** (ADRT, previously "living will")
<https://www.nursingtimes.net/roles/mental-health-nurses/the-mental-capacity-act-1-advance-decisions/1902489.article>
- **Advance Statement**
<http://www.nhs.uk/Planners/end-of-life-care/Pages/advance-statement.aspx>
Allows the patient to record their personal wishes, preferences and view. It can related to any part of their life and include values and beliefs. It must be taken into account when making "best interest" decisions, but is not legally binding.

And finally:

DNACPR

The presumption is in favour of patient involvement. Do not avoid discussion about dying and CPR to try to spare the patient distress, unless there is a good reason to believe that such distress will cause them harm.

Remember:

Discussion does not mean ASKING the patient (or relative) to decide yes or no if CPR will not succeed!!

CPR is a medical treatment and needs a medical decision (inform of decision appropriately).

It is not effective in advanced progressive incurable disease.

It is not effective in patients who are Cheyne-Stoking.

It is not always necessary to discuss or consider 'now'

English law does not allow demands for treatment – no one can demand a futile treatment.

At best we are only offering an ATTEMPT to save life.

The following page outlines key sections of 2016 guidance and provides link for full pdf download:
<https://www.resus.org.uk/dnacpr/decisions-relating-to-cpr/> It includes the following algorithm.

DNACRP Decision-making framework

