CLINICAL COMMUNICATION SKILLS THEME

STAGE/LEVEL 3: 2010-2011

THE DEATH AND DYING COURSE

EL MEDICO DEA PESTE (THE PLAGUE DOCTOR)
ONE OF THE WORST SCOURGES FOR THE CITY OF VENICE WAS WITHOUT ANY DOUBT THE PLAGUE, WHICH STRUCK THE CITY ON SEVERAL OCCASIONS. THE "PLAGUE DOCTOR" WAS A DISGUISE USED BY LOCAL PLAGUE DOCTORS WHO WENT ON VISITS WEARING THIS STRANGE COSTUME TO PEOPLE AFFLICTED WITH PLAGUE.

FACILITATORS' PACK V.17 (29/10/2010)

CCS Stage/Level Co-ordinator:
Sally Quilligan
Lecturer in Clinical Communication Skills

Standard Course Contact Details:
Karen Enright
CCS Administrative Manager
(01223) 769286
ke242@medschl.cam.ac.uk

CGC Course Contact Details:
Jacqueline Keens
Undergraduate Medical Education Assistant
(01284) 712985
jacqueline.keens@wsufftrust.org.uk

Introduction

The Death and Dying course is a two day programme which takes place within the acute care module of stage/level 3 of the school curriculum.

The GMC's Draft Recommendations on Undergraduate Medical Education in 2002 included the following statements:

'During the final year of the curriculum there should be opportunities that help to prepare students for their first PRHO post, and ease the transition between undergraduate education and general clinical training. These should include: consideration of the practical knowledge and skills required of how to deal with the death of a patient and to communicate with bereaved relatives.'

'The individual in society curricular theme should run throughout the curriculum and should cover issues relating to palliation and care of the dying.'

'The medical graduate should have, in addition to the physical, biological and social sciences basic to medicine, a knowledge and understanding of the principles of the amelioration of suffering and the relief of pain and the care of the dying.'

'There should be guidance on the key ethical and legal dilemmas confronting the contemporary practitioner. Students should also have opportunities to consider the ethical and legal dimensions of day to day practice such as the withholding or withdrawing of lifesaving treatment.'

In stage/level 3 of the school curriculum, students rotate through four blocks of senior medicine, senior surgery, senior general practice and acute care. In this final stage/level before graduation, students will have true responsibility for a small number of patients and will be working in one or two students per ward distributed throughout the region. The aim is to prepare students thoroughly for becoming an FY 1 doctor. In this year, students will encounter many aspects of death and dying e.g. breaking bad news, dealing with difficult questions, talking to relatives, sudden death, request for organ donation, palliative care at home and in hospital, 'do not resuscitate' notices and bereavement.

The Death and Dying course has been developed to bring together practical, communication and ethical issues around death and dying. The course has been planned with input from a wide variety of clinicians and from the Clinical Communication Skills, Ethics and Law and Palliative Care vertical themes.

The course aims to be an essential preparation for final year students before they graduate as FY 1s. It will employ a variety of teaching and learning styles including a mix of lectures, discussion groups and experiential teaching with simulated patients (actors) and expert facilitators.

	Teaching style	Title	Covering
Day 1			
9.00	Large group lecture (44)	Introduction	1. Plan of two days 2. Introduce faculty 3. Aim: making students prepared for their FY 1 days 4. Ground-rules: attend all 5. Epidemiology: where die – hospital, home, hospice
9.15	Small groups (6 x 7-8) One facilitator per group	Setting the groups	1. Introduction to the three themed scenarios 2. Learner-centred: actor in with group at the beginning, what issues would group like to cover over the two days, what have they experienced and seen, what has been difficult (knowledge, skills and attitudes / feelings), personally, acknowledge they may get upset, give permission to leave; *nb: facilitators to be prepared and to use student upset positively*
10.00	Small groups (6 x 7-8) One facilitator and one actor per group	First actor session: BBN Case 1: 'expected death' - general medical ward, Advanced Congestive Cardiac Failure	1. Intro: explain setting and recap learning from stage 1 re BBN 2. Transition from disease-modifying Rx to symptom control ('no active Rx') (BBN extended): set objectives and practice 3. Hand out materials: look at BBN grid for SCEE Please note that the structure of the small groups must be flexible depending on the needs of the students in each group: the 'safe' tasks of the session must be able to be put aside at appropriate moments to enable students to look at themselves, their feelings and their own mortality
11.30	Coffee		
11.45	Large group lecture (44)	Palliative care for advanced respiratory disease	Emphasises that most people do not die from cancer, that the biggest problem is that we do not apply the lessons from cancer care to all other deaths - the lessons are fully transferable
1.00	Lunch		

	Teaching style	Title	Covering
Day one			
2.00	Large group lecture (44)	Ethical issues	This session builds on and further enhances knowledge gained in the palliative care module. How to apply ethical principles especially re the issues to be practiced below
3.15	Tea		
3.30	Small groups (6 x 7-8) One facilitator and one actor per group	Second actor session: Ethics in practice Case 1 continued: 'expected death' - the same patient in the morning session has been readmitted later to an acute medical ward with further deterioration of his end stage CCF	1. Intro: discussion re ethical issues from above lecture 2. Patient asking for euthanasia: discuss and practice 3. Resuscitation interview: set objectives and practice Time to be left at the end of this session specifically to explore emotional impact of the day on students Homework to be set for Monday's first large group session – 2-3 scenarios to be handed out with blank death certificates and instructions re filling in – to be completed by next session
5.00	End		Important for facilitators to stay at the end and be available for individual students if needed – 'extra' facilitators may need to help individual students during the day as well

	Teaching style	Title	Covering
Day two			
9.00	Large group lecture (44)	Practicalities re death and dying Legal issues	This session builds on knowledge gained through the stage 2 palliative care module where students were first introduced to death certification but to date will not have experience of certifying a death or completing the forms themselves. This session will cover 2 components (half hour each): 1. filling in certificates, post mortems etc 2. legalities - what to do next, organ donation- etc
10.00	Small groups (6 x 7-8) One facilitator and one actor per group	Third actor session: Sudden death Case 2: unexpected death – A&E setting – aged 21, dying in RTA, brought in alive, but dies in A and E	1. Sudden death – talking to relatives: set objectives and practice (shock or crying) 2. Explanation of need for post-mortem, that coroner's case, that will need to see policeman (coroner's officer) 3. Discuss emotions in doctor/student and coping strategies
11.45	Coffee		
12.00	Large group lecture (44)	Home care	Enabling patients to die at home. This session will cover: 1. Advanced care planning, Preferred Priorities for Care 2. Arranging home care 3. Community and Hospice support

	Teaching style	Title	Covering
Day two			
2.00	Small groups (6 x 7-8) One facilitator and one actor per group	Fourth actor session: Advanced care planning and answering difficult questions. Case 4: As before (CASE 1 & 2). The patient is at home clearly in the terminal stages of heart failure. The GP has been called by the husband/wife saying that he is worse and needs to go to hospital. The patient has previously stated that their Preferred Priorities/Place for Care is home.	1. Difficult questions – relative: practice with set of pre-determined difficult questions A. You'll take him to hospital won't you? B. Is he dying, doctor C. How long has he got? D. What is dying like E. Please don't tell him F. Telephone call from relative from afar, angry 2. Discussion of advanced care planning 3. Discussion of confidentiality and relatives/ who to tell/ ethical and personal issues for pre-reg doctors/students
3.45	Tea		
4.00	Small groups (6 x 7-8) One facilitator	How to cope as a junior doctor around issues of death and dying	Video of FY's discussing personal coping Discussion of own personal coping Small group exercises
5.00	End		Important for facilitators to stay at the end and be available for individual students if needed – 'extra' facilitators may need to help individual students during the day as well

Plan of small group sessions

Location and Timing

The course starts at 9am sharp on Friday morning in one of the two Clinical School lecture theatres (see email from the department administrator to find out which one).

The following statement has been included in the student's pack:
Facilitators have been asked to adhere to strict timekeeping for all CCS sessions. Therefore, you can expect this session to start and finish on time. Please ensure that you arrive at least 5 minutes before the start of the session as students arriving after the initial group introductions may not be allowed to join the group.

Recording equipment will be available in all sessions so, please make sure that any role plays are recorded.

Feedback

Verbal feedback is provided to individual students throughout the session. Students wanting to discuss/request further feedback may wish to speak to the facilitator privately. Similarly, if the facilitator has additional feedback for individuals they may request a meeting at the end of the session. Facilitators will aim to finish 10 minutes before the end of the session to allow time for this and student evaluation/feedback.

The programme includes a session of small group work of approximately 2 hours, each morning and afternoon of the 2 day course. It would be preferable if each small group was facilitated by the same person(s) throughout - there are 6 small groups of 7-8 students each (46 students overall).

The aim of the small group work is to enable students to look in detail at some of the issues that they will face around death and dying when qualified as doctors. Each small group session apart from the first follows a lecture in which specific issues are highlighted and these can form the basis of the group's ensuing work.

It is in the large groups that we introduce subjects and impart knowledge. The small group work will enable feelings, emotions and attitudes to be aired and skills to be practiced experientially.

The structure of the small groups must be flexible depending on the needs of the students in each group: the 'safe' tasks of the session must be able to be put aside at appropriate moments to enable students to look at themselves, their feelings and their own mortality. This means that it is difficult to produce an exact plan of the sessions. The suggestions below therefore focus on the experiential work with actors, practicing skills. However, if appropriate, facilitators must feel free to explore attitudinal issues and feelings within the group and postpone some of the skills issues to later small group work over the 2 days.

We would also like to incorporate some element of learner-centred agenda setting which will again require flexibility to accommodate.

Throughout the course, facilitators should acknowledge that learners may get upset, and give permission for individuals to leave sessions. Facilitators need to be prepared for these

eventualities and to use student upset positively to explore our feelings – it would be a shame if all discussion was at a knowledge or skills level. It is important for facilitators to be available for individual students if needed after sessions – 'extra' facilitators may need to help individual students during the day as well

It may be wise to mention to students upfront that they can miss a session they know will be upsetting – then again they will have to face up to the issue on the wards one day, so may be better to get it over with. But people should at least feel they have a choice.

Day 1

09.00 Large group lecture

09.15 Introduction	**45 mins**

Note: simulated patient will join your group from the beginning of this session and be them self, contributing to exercises and discussions.

Welcome, introduce yourself explain who will be leading this small group through the 2 days if not you for all. Actor to introduce them self.

Round of names (important to do early and encourage an atmosphere of contribution)

Explore the aims of these small group sessions and how the small groups fit into the programme as on previous page (the large groups introduce subjects and impart knowledge. - the small group work will enable discussion about these issues, exploration of our feelings, emotions and attitudes and experiential practice of skills)

Outline timings for the session (really helpful to have the plan of the session on a flipchart so that they can keep a structure in their heads of what happens when)

Learner-centred exercises to discover what issues would the group members like to cover over the two days:

- what have they experienced and seen
- what has been difficult (knowledge, skills and attitudes/feelings),
- what might be difficult personally in the future

Suggestion: use pairs exercises (including the actor) to get the students to think through and explore before coming back to the group.

Ask each group member to contribute what they would like to cover and why.

Explain what we have on offer – the three themed scenarios:

- general medical ward patient with congestive cardiac failure
    - transition to symptom control ('no active treatment') – extension of BBN
    - ethical dilemmas – euthanasia and resuscitation
- accident and emergency unexpected death
    - talking to relatives
    - practicalities re death
- home visit to a terminally ill patient
  Advanced care planning
    - dealing with difficult questions from relatives

Try to set an agenda of sorts

Acknowledge that learners may get upset, and give permission for individuals to leave sessions. Be prepared for these eventualities and use student upset positively to explore that this is a difficult area in practice too

10.00 First simulated patient session	**90 mins**

Introduce first actor session
BBN – broadening the concept - transition from disease-modifying Rx to symptom control ('no active Rx')
Explain setting:

- general medical ward
- patient has end-stage congestive cardiac failure and will soon be able to go home
- you are the FY 2 on the medical firm

Henry Todd is a 60-year-old man with known heart failure. His wife Joan is aged 54, and has given up work as a teacher to look after him. They have three adult children. Henry was admitted seven days ago a medical emergency with worsening heart failure manifesting as increasing shortness of breath and has been stabilised. His medication has been optimised and he is back to where he was several weeks before admission, but is still not good.

The consultant physician has explained to him on a ward round that there's only a certain amount they can do to patch up his worn-out heart rather vaguely. At a recent MDT meeting, it was quite clear that he was moving from active to palliative care but this hasn't been addressed with the patient yet. This morning, as you go round checking your patients, he asks you about his prognosis

Further details of the patient :

60 years old, history of multiple myocardial infarction and previous revascularisation by angioplasty and stents (2 vessels).

Now progressive congestive cardiac failure over the last 12 months with progressive reduction in exercise tolerance to a current position of NYHA stage IV heart failure (= unable to carry out any physical activity without discomfort; symptoms of cardiac insufficiency at rest; if any physical activity is undertaken, discomfort is increased)

Low output cardiac state (BP systolic now 100), echo shows 15% ejection fraction, and progressive renal impairment over the last 6 months - creatinine now 310 micromol / l (eGFR 19msl/min - stage 4 CKD).

PMH:

1. *hypertension*
2. *hypercholesterolaemia*
3. *claudication in the right leg - now not symptomatic because of lack of exercise due to his heart failure*

FH: ischaemic heart disease

SH: Heavy smoker in the past but now stopped

Clinical examination: bi-basal pulmonary oedema, left pleural effusion (moderate), pitting oedema peripherally to the thighs with an elevated JVP +6cm.

Current medication:

1. *aspirin*
2. *statin*
3. *lisinopril 5 mg od*
4. *spironolactone (small dose only because of renal impairment)*
5. *frusemide 250 mg od*
6. *metolazone 5 mg od*
7. *digoxin 62.5 mcg per day*

Diagnosis: end stage ischaemic cardiomyopathy. Not suitable for cardiac transplantation on the grounds of the peripheral vascular disease and renal impairment.

Attempts to reduce the patient's dose of diuretic, ACEI or spironolactone have led to worsening oedema with no improvement in overall ejection fraction or clinical state.

If the above clinical picture were a stable one, then this patient's one year mortality rate would be approximately 60% according to a number of validated scoring systems. Given the relatively rapid and progressive nature of his renal failure and lack of response to alterations in therapy, life expectancy is likely to be considerably shorter; most likely in the region of one to three months.

For more detail please see fact sheet attached to actor role

Facilitator to:

- ensure they understand the specific scenario in enough detail to orientate the group (setting, information already known, notes etc.)
- specifically explain who the learners are and what their role is in the scenario (i.e. medical FY 2)
- provide them with the information that they would know as FY2

Look in general at the difficulties the scenario would pose to them all – how they feel about having to do this task, what emotions it sets up in them. What the difference is between this and telling someone they have heart failure as a new diagnosis (less hope, closer to death, how to offer support and what is on offer)

Think through what their objectives are and the approaches they might need to take. Ask them to relate to what they have learnt already in BBN in stage 1 and in Explanation and Planning in stage 2. Also to what they have seen on the wards

Make a provisional list on the flipchart of skills they wish to practice.

Distribute as you wish any of the three handouts that follow – they will be available on the day. May be better to distribute after the session

Then get started as soon as possible to maximally use the actor. Explain that the first person to go is so helpful as it will give us raw material to work on so we can develop ideas that will help you all

Practice

Explain that this is a chance to practise something difficult before they have to in real life. It is not a judgmental exercise in any way but a golden opportunity – we will provide them with guidance and help.

Encourage one of the students to start the process:

- What would be the particular issues or difficulties for you personally here if you really had to do this
- Set some personal goals for the role-play – what would you like to achieve
- What would be really helpful to practice and refine and get feedback on (try to get the participant to hone them down)
- How can the group help you best
- How and what would you like feedback on

Emphasise to the "doctor" that OK to stop and start whenever. Take time out or start again, as required. Re-play a section or re-play the whole lot, or just stop when help needed.

Chunk this into small aliquots. Although the flow of the interview is truncated this way, you can get many more participants involved and the feedback on communication skills works much better. You can remember what happened in each small bit, give more focused feedback, use the actor's feedback better and do re-rehearsal of different approaches much more. This latter makes the students see the importance of working with the actor - instead of being on trial, they really discover how to find different ways to do the interview.

Stop each person at a pre-determined point. At each stage do good well paced communication skills teaching. When the learner rejoins the group, provide communication skills feedback on the interview so far

Feedback

- Start with the learner –
  - how do you feel?
  - can we go back to the objectives? have they changed?
  - how do you feel in general about the role-play in relation to your objectives?
  - tell us what went well, specifically in relation to the objectives that you defined?
  - what went less well in relation to your specific objectives?
  - or "you obviously have a clear idea of what you would like to try."
  - would you like to have another go?
  - what do you want feedback on?
- Then get descriptive feedback from the group

- If participants make suggestions, ask prime learner if they would like to try this out or if they would like the other group member to have a go. Try to get someone else to role-play a section if they make a suggestion for doing it differently. "Would anyone else like to practise?"
- bring in the actor for insights and further rehearsal: ask actor in role questions that the group has honed down

Remember to:

- look at the micro-skills of communication and the exact words used
- practise and rehearse new techniques after suggestions from the group
- make sure to balance positive and negative feedback
- utilise actor feedback

Please note that we should be prepared to teach. Give the students a good chance to work it out for themselves, but if they can't, be prepared to do limited demonstration, not as a definitive approach but as a suggestion that can also be discussed.

Summarise with one thing learnt by each member of the group and add to flipchart of initial plan

Hand out any sheets left

Collated handouts:

Cambridge Univeristy Hospitals NHS Foundation Trust (2007) Breaking Bad/Significant News Guideline

Framework for breaking bad news

Skills from the CCS BBN – Applying skills with greater depth, intention and intensity

11.30 Coffee	**15 mins**

11.45 Large group lecture	**75 mins**

13.00 Lunch	**60 mins**

14.00 Large group lecture	**75 mins**

15.15 Tea	**15mins**

Day 1

15.30 Second simulated patient session	**90 mins**

Note: same actor will join your group from the beginning of this session and be them self, contributing to exercises and discussions.

Introduce second actor session

Ethics in practice – here we have an opportunity to look at how some of the ethical issues introduced in the previous lecture might arise in practice

Reform group with discussion about some of the issues mentioned:

- what issues have they come across already
- what moral and ethical dilemmas were brought up
- what have they found uncomfortable
- what would they worry about dealing with

Introduce what we have planned – to continue the same case as in the morning but steer towards conversations about euthanasia and resuscitation

Negotiate if that fits their agenda – if not the actor needs to be flexible to adapt to their needs

Explain setting:

- general medical ward (different one from last time)
- the same patient as in the morning session but four weeks months later
- has been readmitted to an acute medical ward with further worsening of his CCF
- patient will suggest euthanasia to the FY

Look in general at the difficulties the scenario would pose to them all – how they feel about having to do this task, what emotions it sets up in them.

- Discuss how they would react
- What should they say or do
- How should they manage the situation
- What are their objectives
- What skills will they try

Make a provisional list on the flipchart of skills they wish to practice.

Then practice as in first session

Steer the students after a while to introduce the issue of resuscitation.
Discuss how this would be a natural thing to discuss here with the patient.

Then move the discussion into difficult waters. Should the doctor bring up issue of resuscitation in discussion?

What would be the advantages and the disadvantages?
Some patients keen to have this discussion – they have written living wills and have no desire to have such indignities. Some though want everything possible and might feel you are being ageist discussing this unless handled well – patients don't want to get the feeling you are trying to bump them off or withdraw their medical treatment. So it is a difficult area to introduce and do well.

Brainstorm approaches and try them out with patient
The current Trust advice re DNR notices will be circulated along with this facilitator pack as well as the BMA/RCN joint statement. Please note that although senior doctors are meant to undertake this task, in practice in the real world, junior doctors do have these conversations and are often caught on the hop without senior cover at weekends etc.

The key here is that the reason for having this conversation is to make sure that we do not play God without reference to the patient or relatives. However, if CPR would be 'futile' or 'confer no benefit', it is deemed unnecessary to discuss this with the patient (a senior doctor could decide alone). The practice in Addenbrooke's Hospital in oncology is that if a patient is actively dying or when CPR would be futile or if the patient has indicated that they do not want any further discussions or have said indirectly that they do not want any more treatment, doctors would not normally discuss CPR and a DNR notice would still be signed.

However, say an elderly patient is poorly, should you not discover if they would <u>not</u> want to be resuscitated? If so, this would probably be addressed in the context of a discussion of their overall care and their feelings. It should be phrased as a question that is routine and asked because although the default position is to resuscitate all, some patients increasingly prefer not to have such extreme measures when the success rate is so low (8%). The difference between active treatment and resuscitation must be made clear. And also the reason for asking it, to make sure we do what the patient wants, not to override their wishes. If you are going to insist on a DNR notice whatever they say because of CPR's futility or conferring no benefit, isn't it cruel to have the discussion? But you should not do it just because of age alone

From previous sessions with junior doctors, lessons appear to include:

- Don't tackle this subject in a rush just because you are under pressure from other staff such as the nurses to get a form signed
- Always do this as part of a much larger discussion about the patient, how they are feeling and how things are going
- General statements along the lines of 'what are your thoughts about how things are going' enable you to pick up on the patient's cues verbally and non-verbally
- Discuss views on dying rather than resuscitation first (if appropriate to situation)
- Introduce the subject carefully:
    - This is something that we increasingly ask people, difficult conversation but important for some patients
    - We need to know your views about some of the things we might do to help you if you were seriously ill
    - So people these days prefer us not to use all the very technical things we can do to them while other people like us to do everything possible

    - The subject that patients differ about a lot is what we call CPR cardio-pulmonary resuscitation – you've probably seen it on the TV – when a patient's heart stops and the team comes along in an emergency to do ventilation and heart massage etc.
    - In the hospital, that is what happens to everyone unless the patient does not want that to happen or of course if they are about to die from something else and that would be futile.
    - We are not discussing here not giving food or fluid or medicines or other active treatment
    - Do you have any strong views – what we want to make sure is that we don't override your wishes
- Make sure that if the patient does not want to discuss this, that you read the signs and back off

Endings

Time needs to be left at the end of this session specifically to explore the emotional impact of the day on students.

Homework also needs to be set for Monday's first large group session – 2-3 scenarios to be handed out with blank death certificates and instructions re filling in – to be completed by next session

17.00 End

Important for facilitators to stay at the end and be available for individual students if needed – 'extra' facilitators may need to help individual students during the day as well

Day 2

09.00 Large group lecture

10.00 Third simulated patient session	**105 mins**

Note: different actor will join your group from the beginning of this session

Introduce third actor session
Practicalities re death and dying – here we have an opportunity to look at how some of the practical issues introduced in the previous lecture might arise in your work

Introduce what we have planned – to look at a new scenario in Accident and Emergency – discussing the unexpected death of a young person with a relative and discussing the necessary practicalities

Negotiate if that fits their agenda – if not the actor needs to be flexible to adapt to their needs

Explain setting:

- A and E in a side-room
- You are the FY 1 on the medical firm who has to see the mother of a 21 year old boy who has just died in the department after a motorcycle crash
- You have just been involved in an unsuccessful resuscitation

The parent has just arrived in the A&E dept at Addenbrooke's hospital. It is 11 pm on a Saturday night. She was phoned from the hospital 30 minutes ago to say that their son Andrew had been involved in an accident and had been brought to casualty. She was told that Andrew was in pain but talking to the doctors. The parent is waiting in the department to see the doctor when the son arrests.
The story is that he overtook a car but did not see another car pulling out from the junction ahead right into his path. He hits the oncoming car full on, smashes into the windscreen and flies off landing 30 metres away. The ambulance arrives within 10 min. He is conscious but complaining of chest and leg pain. Stable throughout the 15 min journey to Addenbrooke's he arrives in A&E with face mask oxygen and a hard neck collar. He knows his Dad will be expecting him and then asks a member of staff to ring and let him know where he is. He is taken into the resuscitation room where he is rapidly assessed. He is talking making normal conversation but is in obvious pain from his chest and legs. He has a high pulse rate, long capillary refill time but normal blood pressure. After the primary survey a chest, neck and pelvic X-rays are performed. It is obvious that Andrew has broken both lower limbs but the chest pain is less easy to diagnose. Two large intravenous lines are started. A more detailed history is being taken from Andrew as the X-rays return. The chest X-ray shows a massively widened mediastinum. The SpR immediately phones Papworth and at this point Andrew loses consciousness. Attempts to resuscitate him are unsuccessful and within 15 min the team decide to stop.

They will have to

- cope with the mother's emotional distress (shock or crying)
- explain the facts about the occurrence in A and E
- explanation of need for post-mortem
- that coroner's case
- that will need to see policeman (coroner's officer)

Look in general at the difficulties the scenario would pose to them all – how they feel about having to do this task, what emotions it sets up in them.

- Discuss how they would react
- What should they say or do
- How should they manage the situation
- What are their objectives
- What skills will they try

Make a provisional list on the flipchart of skills they wish to practice.

Then practice as in first session

Also leave time here to discuss emotions in doctor/student and coping strategies

11.45 Coffee	**15 mins**

12.00 Large group lecture	**60 mins**

13.00 Lunch	**60 mins**

DAY 2

14.00 Fourth simulated patient session	**105 mins**

Note: different actor will join your group from the beginning of this session
The aim of this session is for the student to practice handling difficult questions from family members.
The actor will be the wife of Henry Todd (see actor role). There are a range of questions that could be used after the opening greeting on the doorstop (see list below- select one or two). The key learning for students is to get them to **explore** what is behind the question, the concerns and emotions, **explain** what is happening, reasons, further options etc and **explore** how Mrs Todd feels about this.

If your group reaches this learning early on you can practice handling difficult questions over the telephone (see over page)
Or
Each student to practice handling a difficult question. Brainstorm a list of difficult questions. The actor faces each student in turn and asks a question from the groups list or from list below.

Introduce fourth actor session
Advanced care planning and handling difficult questions

Here we have an opportunity to look at how some of the practical issues introduced in the previous lecture might arise in your work and to give you some life skills to cope with in the real world you will face as a FY – so that you know how to initially handle any difficult question and not get too flustered. We want to offer you a set of generic skills that will help you always.
Facilitator – the key message at the end of this session must be 'explore, explain, explore'

Introduce what we have planned – Advanced care planning and handling difficult questions from a relative of a terminally ill patient.

Negotiate if that fits their agenda – if not the actor needs to be flexible to adapt to their needs

Explain setting
The same patient as per roles 1 & 2 is now in the terminal phase of end-stage cardiac failure. He is now at home. His life expectancy is somewhere between one and three months.

As his GP, you last visited him 2 weeks ago during which he stated that he/she would prefer to die at home. You have been called to the home by his wife She greets you on the doorstep saying "*oh thank goodness you have come doctor, he is so much worse, you will get him into hospital won't you?"*

Then she asks you difficult questions such as:

- *I don't think I can cope with all this – I can't stand it any longer*
- *He is going to get better isn't he doctor?*

- *Are there any other treatments he could try – we'll pay?*
- *Can you go over again with me why this is happening??*
- *Is he dying, doctor?*
- *You won't tell him will you?*
- *How long has he got?*
- *I think there is something terribly wrong but no-one is saying anything*
- *Why him? – He's such a good man*
- *What will it be like at the end?*
- *What more support can you arrange for me at home?*

Facilitators - you can stop the scenario as soon as the question is asked and get the students to brainstorm:

- What is going on?
- What is their immediate gut reaction to the question?
- What would be a platitude?
- What would be a suitable response?

Draw out responses such as:

- Non-verbal empathy
- Verbal empathy
- Acceptance, acknowledgement
- Encouraging the further expression of feelings and thoughts
- Silence
- Attentive listening
- Repetition
- Facilitation especially via paraphrasing of content and feelings
- Picking up cues, checking out our interpretations or assumptions
- Non-judgmental non-defensive response

But overall sell 'explore, explain, explore'

Mention that these always come up in our oncology work with junior doctors – they answer correctly but do not explore the underling issues! Use the book reading analogy for why it is important to look behind the statement – it is not what is said in the quotes in the book that is the key message but what the author writes in the description of the speaker's emotional state and adverbs.

If you have time you may want to practice receiving a telephone call from one of the children:

Her eldest daughter, a nurse, has recently returned to work after having her first child. She lives 20 miles away from her parents, and telephones you to ask if she should give up her job so that she can help care for her mother at home?

- *is he dying, doctor – then please don't tell him – he couldn't cope with it*

Her middle son, who is a teacher, rings on the phone and is angry. He is concerned that the talk is of keeping him/her at home, rather than going into some long-term nursing care home.

This may lead into a discussion of confidentiality and relatives/ who to tell/ ethical and personal issues for pre-reg doctors/students.

This may lead into a discussion of confidentiality and relatives/ who to tell/ ethical and personal issues for pre-reg doctors/students.

15.45 Tea **15 mins**

16.00 Small groups-how to cope as a junior doctor around issues of death & dying 35 mins

The aim of this session is to explore the impact that dealing with death and dying has upon professional carers. More importantly, it is to help the student to recognise and identify sources of support for themselves.

4.00 Introduction: To include aims of the session and the format for the session, i.e. Watch a video, group discussion and exercises, supported by handouts and other resources.

Group discussion
Brief discussion to explore how everyone is feeling so far and to consider the impact of witnessing and caring for the dying and bereaved has for health professional and particularly for self.
Hopefully the group will list the following (feel free to add if they do not)

- Professional get upset too
- People react in different ways – shock, disbelief, tears, sadness, anger, detached
- These reactions are normal
- These reactions often surprise us – may be influenced by how we are feeling at the time, but may bring up memories, thoughts about our own individual experiences or fears around death
- May force us to confront our own mortality

4.10 Introduce Video – approximately 30 minutes. Dr Meera Raithatha interviewing 2 FY2's about their experiences since qualifying of death and dying.

Facilitators please note that the questions from the audience cannot be heard easily. They are as follows:

- Do you have any advice for approaching families for post-mortem?
- How do boys cope?
- Have you been faced with very distraught, angry or upset relatives?
- Do you have any horror stories around breaking bad news? How did you get out of it?
-

4.40 Group discussion (or pairs if you feel this is more appropriate) 10 mins

What are the key points raised in this interview?
Anything else to add

Handout the grief and loss packs to support this discussion. Encourage students to complete the personal history of losses in their own time as a way of identifying and reflecting on own experiences. **There will not be time for them to do this safely in this session**

4.45 Group discussion (or pairs if you feel this is more appropriate) – coping and sources of support 10 mins

The video interview identified talking to others as a means of support what other coping strategies can be used?
Do boys cope differently? What strategies do they use?

4.55 Summary and Evaluation 5 mins

Please leave time at the end of the small group to bring the group to an end. Keep an eye out for students who need to talk afterwards.

5.00 End

Cambridge University Hospitals NHS Foundation Trust

Breaking Bad/Significant News Guideline 2007

Reason for development

a result of proactive risk management

a result of patient feedback

compliance with clinical audit recommendations

to standardise/improve patient care

Scope

Trust Wide

Aim

To ensure that breaking of bad or significant news is imparted in an appropriate environment, is well structured, with appropriate support & in a sensitive manner

Introduction

Breaking bad or significant news is a common occurrence in all areas of the Trust.

How news is discussed can affect an individual's anxiety, comprehension of the information, satisfaction with care, level of hopefulness & subsequent psychological adjustment.

This document outlines recommendations for breaking bad news in a way that would ensure that the standard is achieved.

Ideally breaking bad or significant news should be undertaken by a senior doctor or nurse, i.e. not PRHO or staff nurse

It is recommended that if you are breaking bed news regularly you should have undergone communication skills training as part of CPD.

Recommendations

4.1 Preparation & Environment

- Location should be comfortable, private & quiet
- Convenient time
- Where possible the discussion should be planned & provision made to ensure there are no interruptions
- The news should be given, whenever possible, face to face, i.e. not over the telephone
- Ideally physical barriers such as desks should be avoided.
- Ensure that you have all the appropriate information you require, i.e. test results etc
- Identify member of the clinical team who is able to offer support at the time & afterwards should it be required i.e. specialist nurse

4.2 The people involved

- Identify & have present at the patient's request appropriate significant other
- Ideally there should be minimal clinical staff present i.e. doctor & nurse only, unless agreed with the individual

4.3 Breaking the News

4.3.1 What is said

- Find out what the person already knows and obtain a sense of how they are feeling
- Preparation: give a warning signal
- Break the news
- Acknowledge & explore the individual's reactions & feelings
- Allow for questions, answer openly & honestly
- Check understanding, repeat & clarify as required
- Summarize the discussion, verbally & in writing
- Offer a plan of action, confirm immediate next steps
- Provide as much positive practical support, but not false reassurance
- Convey some measure of hope tempered with realism

4.3.2 How it is said

- Emotional manner (warmth, caring, supportive, respectful)
- Use appropriate non-verbal communication
- Use simple & careful language without euphemisms and avoiding jargon
- Give the news at the individual's pace, allowing time for reaction
- Give information in chunks, checking repeatedly for understanding and feelings
- Read and respond to patient' s non-verbal cues
- Encourage expression of feelings
- Demonstrate empathy by acknowledging patient's reactions and feelings

5.0 Evidence

Referral for Suspected Cancer. A Clinical Practice Guideline.
National Institute for Clinical Excellence. June 2005

Consensus recommendations for breaking bad news
Ptacket & Eberhardt. JAMA Aug 14 1996. Vol 276, No. 6

Guidance from Susie Wilkinson, National Lead for Advance Communication Skills Training program

Kurtz SM, Silverman, JD, Draper, J (2005) Teaching & Learning Communication skills in Medicine 2nd Edition. Radcliffe Publishing, Oxford.

Silverman, JD, Kurtz, SM., Draper, J., (2005) Skills for Communicating with patients 2nd Edition. Radcliffe Publishing, Oxford

WACN Breaking Bad News Audit Report 2003/4

Skills from the C-C guides in BBN **Applying skills with greater depth, intention and intensity**

Initiation	*As in any other interview, success in setting the scene is crucial*
Preparation	How to set up the appointment**:** if the news is serious and complex information needs to be given, preparation requires special thought and planning. When and where should it be done, who should be there, are you as the doctor thoroughly prepared emotionally and factually?
Greet patient Negotiate agenda	Interviewing more than one person at a time: many ill people, or people who know that they are going to be given difficult or complicated information, bring a relative or friend with them to see the doctor. You then have more than one person present with different ideas, concerns and expectations and different agendas. Focusing on the "main" patient is essential. Yet it is also important to take the accompanying friend or relative into consideration. When there is time it is often helpful to agree to see the patient and relatives both separately and together. Note the results of Benson and Britten's study of patients with cancer which showed that most rejected disclosure to others without their consent (1996)
Explanation and Planning	*Breaking bad news is a special case of explanation and planning so it is not surprising that this difficult situation requires particularly masterful use of most of the skills associated with this phase of the interview...*
Chunk and check	**Giving information in manageable chunks and checking for understanding** are key skills here, allowing the physician to calibrate where the patient is at any particular time as this part of the interview proceeds.
Assess the patient's starting point	**Discovering what the patient already knows**, is fearful of and is hoping for is difficult but vital, particularly when the patient is frightened. This may be even more complicated when a relative or friend is present. But there are considerable rewards for obtaining an accurate picture of where the patient and their relative are coming from before giving information such as prognosis or treatment options. This sets the scene for excellent doctor-patient relationships in the future
Assess each person's individual information needs	**Discovering what the patient wants to know** is also critical. Most patients want to know that they have cancer (**Meredith et al 1996)**, including the elderly (**Ajaj et al 2001).** Gauging how much the patient wishes to know requires high levels of skill. Understanding potential cultural influences is helpful here but it is most important to ascertain the needs and preferences of the individual patient or significant other. Various authors make different recommendations about how this task should be accomplished. **Buckman (1994)** suggests a direct preliminary question such as "if this condition turns out to be something serious, are you the type of person who likes to know exactly what is going on?". **Maguire and Faulkner (1988)** suggest a hierarchy of euphemisms for the bad news, pausing after each to gain the patient's reaction. Other authors suggest making a more direct start to giving the news after a warning shot and gauging how to proceed as you go: they argue that patients who wish to use denial mechanisms will still be able to blank out what they do not want to hear.
Use explicit categorization or signposting	**Giving a warning shot** first is a special case of explicit categorization or signposting of information that is about to be given, alerting the patient that all is not as they hoped. It may be useful to give a warning shot near the beginning of the interview, particularly when it is a follow up interview. There are a number of ways to do this: which one might be the best in the circumstance depends on the patient's situation and the doctor's style. For the patient with a terminal illness or the patient with a threatened miscarriage awaiting the result of a scan, it might be *"I'm afraid the news isn't as good as we hoped"* accompanied by appropriate nonverbal behaviour. The doctor can then pause and let the likelihood of the news being difficult for the patient sink in, before continuing the interview. To help patients focus their attention, the usual signposts are also important, e.g. *"There are two important things to remember. 1st…2nd…"*
Relate explanations to patient's perspective	Give hope tempered with realism This is easier for the doctor when the patient has a real hope of recovery or improvement, for example a patient recovering from a road traffic accident, or a patient who is found to have a renal calculus. It is much more difficult to give hope to a patient who has suffered a severe stroke, or in whom chemotherapy has failed. It is important for the doctor to discover the patient's own coping strategies here and to find out how optimistic a person they usually are. Doctors are not gods and they are often mistaken in the prognoses they give. All patients need hope and the key to giving it is to base it realistically on the patient's situation and their feelings about it
Discuss options and opinions	**Discuss treatment options** Again this needs to be introduced when the patient is ready to hear the doctor's recommendations. Make it clear to the patient that they will be involved in decisions about treatment **Give a prognosis** If the patient wants to discuss the future, avoid giving too definite a time scale; however giving a broad framework may help the patient who wishes to plan ahead

Building the relationship	*Throughout the interview continuing to build relationship with the patient and any significant others in attendance is vital. If you do not know the patient or significant other well, laying down foundations for a trusting relationship needs to be done with intention at the very beginning of the interaction.*
Pick up cues, Demonstrate empathy	**Checking out non-verbal cues** allows the doctor to identify points at which the patient wants to ask a question or calibrate the patient's emotional state, and then to express empathy and compassion for the patient's position. It also gives the doctor space to enquire about further concerns and respond to them with feeling. *"I can see that you are very distressed to hear that the results of the tests confirm your worst fears….I am extremely sorry….(pause) …you mentioned your husband is disabled; have you any other concerns you wish to discuss now"*. A special case of picking up cues is associated with the "shutdown" – a point at which the patient (or significant other) who is receiving bad news seems to block out or be unable to take in what you are saying. Acknowledging that the patient does not wish to hear any more requires chunking and checking of your information giving as you proceed and paying particular attention to the patient's verbal cues (for example changing the subject abruptly) or more commonly non-verbal cues (becoming tearful, silent or looking uncomfortable or angry).
Provide support	**Partnership and advocacy** Support for the patient is essential. Overt statements such as, *"we need to work on this together"*, or *"I will speak to the specialist on your behalf ..."*, or *"you will not be left to cope with this on your own.....how can we go forward now?"* may help patients and need to be emphasized.
Demonstrate appropriate non-verbal behaviour	**Doctors not hiding their own distress.** Patients can be upset by doctors who remain unmoved by their distress at being given bad news **(Woolley et al 1989).** Doctors should not fear displaying emotion **(Fallowfield 1993).** But how much of your own distress to share with a patient is a difficult judgement to make and must depend on individual personalities and specific situations. Clearly it is not the patient's task to care for the doctor's distress. On the other hand, it is difficult for doctors not to show anxiety when performing this complex task and patients may pick up the doctor's non-verbal cues here. Retaining the patient's confidence and continuing to build the relationship with the patient is the overall objective here.
Closure	*Time spent on this section of the interview pays dividends; often at this point in the consultation the doctor is able to summarise possible next steps with the patient and give the patient back some control.*
Contract with patient re next steps Safety net	**Clear follow-up plans**, setting an early date for the next appointment, offering to telephone the patient to check that all is well and beginning to plan next steps are seen as supportive and reassuring. Offering to contact significant others when the patient has expressed concern about informing others about a diagnosis or prognosis is often helpful, as is giving time for the patient to absorb bad news and to decide how long he or she needs to consider treatment options. **Document what the patient and the relatives have been told**; this is extremely helpful, particularly when family physician and specialist communicate with each other or in the event that the patient will be working with a team or other health care providers.

A FRAMEWORK FOR BREAKING BAD NEWS

Below is a framework for "breaking bad news" which is based on a number of people's work **(Brod et al, 1986; Maguire and Faulkner, 1988; Sanson-Fisher, 1992, Buckman, 1994; Cushing and Jones 1995)**

SUGGESTIONS FOR BREAKING BAD NEWS

Preparation:

- set up appointment as soon as possible
- allow enough uninterrupted time; ensure no interruptions
- use a comfortable, familiar environment
- encourage patient to invite spouse, relative, friend, as appropriate
- be adequately prepared re clinical situation, records, patient's background
- put aside your own "baggage" and personal feelings wherever possible

Beginning the session / setting the scene

- summarise where things have got to, check with the patient
- discover what has happened since last seen
- calibrate how the patient is thinking/feeling
- negotiate agenda

Sharing the information

- assess the patient's understanding first: what the patient already knows, is thinking or has been told
- gauge how much the patient wishes to know
- give warning first that difficult information is coming e.g. "I'm afraid we have some work to do...." "I'm afraid it looks more serious than we had hoped...."
- give basic information, simply and honestly; repeat important points
- relate your explanation to the patient's perspective
- do not give too much information too early; don't pussyfoot but do not overwhelm
- give information in small "chunks"; verbally categorise information
- watch the pace, check repeatedly for understanding and feelings as you proceed
- use language carefully with regard given to the patient's intelligence, reactions, emotions: avoid jargon
- be aware of your own nonverbal behaviour throughout

Being sensitive to the patient

- read and respond to the patient's non-verbal cues ; face/body language, silences, tears
- allow for "shut down" (when patient turns off and stops listening) and then give time and space: allow possible denial
- keep pausing to give patient opportunity to ask questions
- gauge patient's need for further information as you go and give more information as requested, i.e. listen to the patient's wishes as patients vary greatly and one individual's preferences may vary over time or from one situation to another
- encourage expression of feelings early, i.e. "how does that news leave you feeling", "I'm sorry that was difficult for you", "you seem upset by that"
- respond to patient's feelings and predicament with acceptance, empathy and concern
- check patient's previous knowledge about information just given
- specifically elicit all the patient's concerns
- check understanding of information given ("would you like to run through what are you going to tell your wife?")
- be aware of unshared meanings (i.e. what cancer means for the patient compared with what it means for the physician)
- do not be afraid to show emotion or distress

Planning and support

- having identified all the patient's specific concerns, offer specific help by breaking down overwhelming feelings into manageable concerns, prioritising and distinguishing the fixable from the unfixable
- identify a plan for what is to happen next
- give a broad time frame for what may lie ahead
- give hope tempered with realism ("preparing for the worst and hoping for the best")
- ally yourself with the patient ("we can work on this together ...between us"), i.e., emphasise partnership with the patient, confirm your role as advocate of the patient
- emphasise quality of life

- safety net

Follow up and closing

- summarise and check with patient for understanding, additional questions
- don't rush the patient to treatment
- set up early further appointment, offer telephone calls, etc.
- identify support systems; involve relatives and friends
- offer to see/tell spouse or others
- make written materials available

If the patient attends with a companion, read and respond to the companion's verbal and non-verbal cues, and allow pauses for questions, but remember that the patient is your first concern

Throughout be aware of your own anxieties - re giving information, previous experience, and failure to cure or help

---

Kurtz SM, Silverman JD, Draper J (2005) Teaching and Learning Communication Skills in Medicine 2nd Edition. Radcliffe Publishing (Oxford)

Silverman JD, Kurtz SM, Draper J (2005) Skills for Communicating with Patients 2nd Edition. Radcliffe Publishing (Oxford)

School of Clinical Medicine, University of Cambridge
OSCE Station Mark Scheme

Breaking Bad News

Process grid	*Good Yes (2)*	*Adequate Yes but (1)*	*Not done/ inadequate No (0)*
1. **Greets** patient and obtains patient's name			
2. **Introduces** self, role			
3. Explains **nature** of interview (reason for coming to talk to patient)			
4. Assesses the **patient's starting point**: what patient knows/understands already/is feeling			
5. Gives **clear signposting** that serious important information is to follow			
6. **Chunks and checks**, using patient's response to guide next steps			
7. Discovers what **other information** would help patient, attempts to address patient's info needs *(two marks if attempts to address – student does not need to know answer)*			
8. Gives explanation in an **organised** manner *(2 if uses signposting / summarising)*			
9. Uses clear **language,** avoids jargon and confusing language			
10. Picks up and responds to patient's **non-verbal cues**			
11. Allows patient **time to react** (use of silence, allows for shut-down)			
12. Encourages patient to contribute **reactions, concerns and feelings** *(2 if explores effectively once stated)*			
13. **Acknowledges** patient's concerns and feelings; values, accepts legitimacy			
14. Uses **empathy** to communicate appreciation of the patient's feelings or predicament *(2 if verbal and nonverbal empathy)*			
15. Demonstrates appropriate **non–verbal behaviour** e.g. eye contact, posture & position, movement, facial expression, use of voice (pace, tone)			
16. Provides **support**: e.g. expresses concern, understanding, willingness to help			
17. Makes **appropriate arrangements for follow up** contact			

Notes on exceptional student performance or station design	*Clear Pass:*	*Borderline:*	*Clear Fail:*
	[ ]	**[ ]**	**[ ]**

……

……

Part A

Name: Henry Todd **Age:** 60

Setting
You are on a medical ward and have been for the last seven days following an acute admission with increasing breathlessness. You have heart failure and will soon be able to go home. A junior doctor is doing his rounds and you ask to speak to him

Your wife Joan is aged 54 and has given up work as a teacher to look after you. You have three adult children:
• a 30 year old daughter, Joanna, who lives in America and works as a nurse. She is due to get married next year
• a 28 year old son, Ben, who is working as a teacher
• a 25 year old son, Tom, just qualified as a doctor and working in London.

You were admitted as a medical emergency seven days ago with worsening heart failure manifesting as increasing shortness of breath and you have been stabilised. Your medication has been altered and optimised but really you are only back to where you were several weeks before admission, which is still not very good at all.

The consultant physician has explained to you on a ward round a few days ago that there's only a certain amount they can do to patch up your worn-out heart, which you realise. He seemed sorry that they couldn't do more for you but didn't say anything more. No one has really talked to you about the future but you can see you are deteriorating. You are due to give your daughter away at her wedding in 10 months time. One morning, as a junior doctor goes round checking his/her patients, you ask him/her: “Doctor, can we talk? Do you think I am going to get better enough to visit my daughter in America next year - she wants me to give her away at her wedding next summer?”. You would love to go and really hope the doctor is going to say "yes it'll be fine", but you're beginning to think this is unlikely in the back of your mind and wouldn't be too shocked if that was the answer.

Past medical history
You have had three heart attacks over the last four years and two years ago had angioplasty and stents (2 vessels).

Over the last 12 months you have developed increasing heart failure with progressive reduction in exercise tolerance to a current position whereby you are unable to carry out any physical activity whatsoever without breathlessness which makes you very uncomfortable; even at rest, you now have symptoms; if any physical activity is undertaken, your discomfort is increased.

Your symptoms include:
- ankle swelling which is really severe and now goes right up to your mid thighs
- breathlessness on the slightest exertion
- fatigue all the time
- you cannot lie flat and have to prop yourself up on four or five pillows
- if you fall off the pillows at night, you wake up with really severe shortness of breath and have to get out and have to sit on the edge of the bed for a long time to get your breath
- your appetite is reduced considerably
- weight loss

They have told you that your kidneys are not working very well now as well as your heart

You have also suffered from:
1. High blood pressure for many years
2. High cholesterol which you are receiving treatment for

3. Claudication in the right leg - you were getting a lot of pain in your right leg after walking 50 yards and the leg feels colder and the toes go blue, but now you really don't get much pain because you can't walk very far and therefore the pain doesn't come on because your breathlessness limits how far you can go.

Family history: your father died at about the same age as you after heart attack

Social history: Heavy smoker in the past but now stopped for four years after your first heart attack

Current medication:
1. a small aspirin once daily
2. simvastatin 40 mg daily for your cholesterol
3. lisinopril for BP
4. spironolactone which is a diuretic
5. frusemide which is another diuretic
6. metolazone which is another diuretic
7. digoxin to strengthen the heart

Whenever the doctors have attempted to reduce your medication, you have ended up with much worse swelling. You understand that it's a delicate balance between swelling up or reducing the swelling with diuretics leading to your kidneys being even worse.

In this scenario, you really want to know the answer about going to your daughter. If the doctor palms you off or ask you how much you would want to know if it was bad news, you continue to say "look doctor, I think I really need to know now".

You are a brave person and not prone to breaking down. You are expecting just more of the same and will have to just keep plodding along. In your heart of hearts, you realise that you will not be fit enough to travel to the States for your daughter's wedding. But you haven't realised that the prognosis is in months rather than years. When you find out in a minute that despite all the adjustments the medications are no longer able to keep the heart failure under control and that the prognosis is much more limited, this feels far worse than being told that you had heart failure in the first place – you don't know what to say and feel quite overwhelmed but try to keep your composure as best as you can initially but cannot.

In this situation, your initial response is shock, silence and numbness rather than overt tears or distress. But as the news sinks in that your life expectancy is likely to be just a few months, and that there's nothing they can do about it, you do break down and need a lot of support before you can hear what the doctor is saying.

Part B

Second session: 4 weeks later

Setting
You have been admitted back onto the medical ward over a Bank Holiday weekend. You have suddenly become a lot more breathless, your ankles and stomach are swollen. Your wife is very frightened and distressed. Your GP has told you that your heart failure is causing the worsening of your symptoms and you feel very exhausted.

On admission
You are sitting upright in a chair with an oxygen mask.

Since you have been at home, your breathing and appetite have remained very poor. You have minimised your activities around the home and you now have your bed downstairs as walking upstairs became too difficult. This morning you became extremely breathless. You made light of the situation to your wife who is nevertheless very upset.

Now you feel dreadful again. You wait until your wife goes home to get you some things and then ask to see the ward doctor.

You ask him first:
"Look I can't put my wife through anymore of this. Can't you just give me something - it would be much better for everyone.'

Later, the doctor will ask you about your views about resuscitation – you need to know what he means but you don't want to be mucked about for no reason.

Replays
We may replay this type of scenario again in settings where the doctor wants to bring up this subject from scratch. Say you were an 80-year-old man or woman with a chest infection. You are perfectly acute mentally, but increasingly frail. Doctor brings up issue of resuscitation in discussion. Please think of ways or reacting – some patients keen to have this discussion – they have written living wills and have no desire to have such indignities, some though want everything possible and might feel you are being ageist discussing this unless handled well – you don't want to get the feeling they are trying to bump you off or withdraw your treatment!

Sudden Unexpected Death – A&E setting

Name of relative: **Peter** or **Pam Chamberlain** Age: 54 years

Name of patient: Andrew Chamberlain ***Age 21 years***

Setting

You (Peter/Pam) have just arrived in the A&E dept at Addenbrooke's Hospital. It is 11 pm on a Saturday night. You received a telephone call from the hospital 30 minutes ago to say that your son (Andrew) had been involved in an accident and had been brought to Casualty. You were, at the time, shaken and forgot to ask too many details. The impression you received was that Andrew was in pain but talking to the doctors; so, although you were worried and raced over as fast as you could, you were not expecting any terrible news.

You have just parked on a double yellow line and rushed into A&E. The receptionist has guided you to a seat while she finds the doctor. All of a sudden an alarm sounds; major scuffling of feet and commotion. The receptionist comes back. You are suddenly aware that the problem is to do with your son.

Clinical details

Andrew is a young, fit man; a keen motorcyclist. He went out with his girlfriend to the cinema. She had to work early the next day, so Andrew had dropped her off before returning home.

Travelling on the A10 from Cambridge to Royston he overtakes a car but doesn't see another car pulling out from the junction ahead right into his path. He hits the oncoming car full on, smashes into the windscreen and flies off landing 30 metres away.

The ambulance arrives within 10 minutes. He is conscious but complaining of chest and leg pain. Stable throughout the 15-minute journey to Addenbrooke's, he arrives in A&E with facemask oxygen and a hard neck collar. He knows his Dad/Mum will be expecting him home, so he asks a member of staff to ring and let him/her know where he is.

Andrew is taken into the resuscitation room where he is rapidly assessed. He is talking, making conversation, but is somewhat confused. He is in obvious pain − all over! He has a high pulse rate, long capillary refill time but normal blood pressure.

After the primary survey, chest, neck and pelvic X-rays are performed, it is obvious that Andrew has broken both lower limbs but the chest pain is less easy to diagnose.

Two large intravenous lines are started. A more detailed history is being taken from Andrew as the X-rays return. The chest X-ray shows a massively widened mediastinum. The SpR immediately phones Papworth, and at this point Andrew loses consciousness. Attempts to resuscitate him are unsuccessful; within 15 minutes the team decide to stop.

Social History

Andrew still lives with you. His Mum/Dad died from cancer 4 years ago. Andrew is just coming to the end of his studies at University in London. He was taking a degree in Engineering, heading for a 2:2 and had several job offers that he was debating. He frequently came home at weekends as his girlfriend who he first met over the Xmas holidays lives nearby.
Occupation: You are a teacher at a local comprehensive (in Royston): head of the science department.
Children: You also have a daughter (Joanne) who is 29, is married with two young children. She lives in York.
Type of housing: A 3-bedroomed detached house on the outskirts of Royston – house owner for 20 years.
Background: Went to teaching college straight from school where you met Michael/Mary. Had ambitions to become a head teacher but promotion became difficult in mid-30s – decided to concentrate more on the family, so sacrificed much of your career to be around your family.

Temperament
Pretty stiff upper lip normally. Generally pleasant and easy going. Prone to bottling things up and then bursting unpredictably. Needs to understand exactly what is happening. However, the last few years have taken its toll. You were devastated about losing your partner but felt you had to keep it together as Andrew was in the middle of taking his A Levels. Never really had chance to mourn properly.

Father's/Mother's framework
Ideas and thoughts

- Cannot comprehend that the person you are closest to in the whole world could possibly die in such a way.
- There must be someone to blame – the doctors just didn't do enough; they must have missed something. The ambulance men must have delayed. What about the man who 'caused' the accident in the first place?
- Utter submergence into a desolate place. The loss of your partner is also hitting hard – memories returning of how much you miss her/him.

Concerns – 'How can I cope with being on my own?' 'How can I bring myself to tell my daughter?' Fear of what lies ahead. Anger at those you perceive must have caused your son's death or at least contributed to it in some way.
Practical problems – can't face funeral yet again in so short a time.
Expectations – That the doctors and nursing staff are completely open and candid about all details of what happened. Couldn't bear if anything was hidden.
Feelings – Desolation, very lonely. Angry and an overwhelming feeling of loss. Feel completely out of control.

Behaviour
Very much on the edge. Can hold it together as long as everyone is straight with him/her. Any perceived 'cover up' and you hit the roof, unable to control emotions. Can be calmed down quite easily but the tension is constantly under the surface. Difficulty expressing yourself as too many emotions boiling up inside. Can cope with facts – as long as you feel that it is straight talking.

Possible ways to play out the scenario
You may be asked by the facilitator to play the scenario in different ways, in order to provide the next students with a different and possibly unexpected reaction. Here are some possibilities:

- Denial/non-comprehension that the person you are closest to could possibly be dead (must surely be a mistake).
- Anger: someone to blame – the doctors didn't do enough; they must have missed something. The ambulance men were delayed. What about the person who 'caused' the accident in the first place?
- Self-blame: should never have helped him buy the motorcycle. If only he hadn't wanted to spend so much time with 'her'.
- Switch off/submergence into a desolate place. The loss of your partner is also hitting hard – memories returning of how much you miss her/him, not listening to a word the doctor says.

Footnote
You could ask what the Hospital policy is about letting relatives in to the Resuscitation Room. (At Addenbrooke's it is the policy but everything happened so quickly….)

Death and Dying course: Case 1 – simulated relative role

Name: Joan Todd **Age**: 54

Setting
You are at home. You have called the GP to see your husband urgently at home. You meet the GP on the doorstep saying **"oh thank goodness you have come doctor, he is so much worse. I know he said he wanted to stay at home but he looks so very ill now, you will get him into hospital won't you?"**
The facilitator will guide you as to what other questions you might ask

You are the main carer for your husband Henry. Henry has heart failure, he has been deteriorating gradually over the last few months but particularly so in the last 3 weeks since he was last discharged from hospital. Today as you were attempting to wash him, he became quite intolerant of you, asking you to "stop – let me breathe – you are suffocating me woman". You were very distressed by this as you have always had a very loving relationship. You tried to encourage him to move a little as you know that people who remain in bed for long periods can get bedsores but he got more agitated by this and asked you to leave him alone. To make things even worse, later, he wet the bed as the urinal had slipped from its position. As you were trying to change the bedclothes he became very breathless – you were very frightened and called the surgery immediately (the surgery number is programmed into your telephone as a speed dial number.

Temperament
You are normally an emotional person. Henry is the strong one in the family who you rely upon to remain calm in such situations. When there were concerns for your children's health it was Henry who remained calm and supportive for all. You get very panicky when you see loved ones looking ill, you are not sure how to help and you are scared that you might hurt them or make the situation worse . You can see that Henry is looking very sick. You have not seen anyone look this ill before. You feel very alone and scared about this situation. Your children visit but they have their own responsibilities and problems and so you are keen that they are not involved in providing physical care. You put on a brave face for them and any visitors and you keep very busy cooking and cleaning. You have no previous experience of caring for an ill adult.

Social
Married for 30 years. Enjoyed an active social life until the last 2 years enjoying gardening, (you had an allotment, but this has been too difficult for you to manage on your own) walking (was a member of the local ramblers association), dancing (You and Henry attended the local ceroc classes) unfortunately you have gradually lost contact with these groups. You have found retirement difficult. You enjoyed the company and intellectual stimulation at work. Although ex-colleagues telephone you, there has been little face to face contact.
You have good friends nearby and neighbours who visit you or invite you to dine at their homes but this has not been possible in the last 3 months. You are feeling trapped and at times resentful about the whole situation. You feel guilty about this.

Ideas
You know that your husband is very poorly. The doctors have told you that nothing else can be done to make him better it's now a case of keeping him comfortable. Today he looks worse than you have ever seen him. You were scared earlier that he might be about to die

Concerns
That you are not looking after him properly. You are worried that you are making him worse. You are scared to be dealing with this on your own. You do not know what to do if/when he dies. You do not know what it will be like. You don't want it to happen. You have not seen anyone dead before. You do not know what to do.

Expectations
You know that Henry has expressed a wish to stay at home but if the doctor sees how much he/she has deteriorated he will transfer him/her to hospital. They will be able to care for him better than you.