disaster: "Reality must take precedence over public relations, for nature cannot be fooled."

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How To Do It

Communicate with cancer patients: 2 Handling uncertainty, collusion, and denial

Peter Maguire, Ann Faulkner

Breaking bad news often prompts patients to ask questions about their future like: How long have I got? You then have to help them cope with uncertainty without them becoming demoralised.

Handling uncertainty

When asked: How long have I got? it is tempting to give a finite (Oh, three months) or range (Anything from a month to six months) of time. But such predictions are usually inaccurate, tend to err on the optimistic side, and cause problems for patients and their families. Patients then pace themselves according to the time they believe is left. If they deteriorate earlier than expected and are prevented from achieving planned goals they will feel cheated and bitter. Relatives can find an unexpectedly prolonged survival ("borrowed time") hard to cope with because they have used up their physical and emotional resources. So it is better to acknowledge your uncertainty and the difficulties that this will cause.

Doctor: You asked me how long he has. The trouble is, I don't know. I realise this uncertainty must be difficult for you.
Mrs W: It is. It is terrible knowing that he is going to die but not knowing when. I mean it could be in one month's time or next Christmas.
Doctor: That's the trouble, I just don't know how long it will be.

You should next check if she would like to know the signs and symptoms that would herald further deterioration.
Doctor: What I can do, but only if you would like me to, is tell you what changes would suggest he is beginning to deteriorate further.
Mrs W: Yes, I think that would help me.
Doctor: He will probably complain of feeling breathless, weak, and start going off his food.

You can then encourage her to try to use the intervening time.

Doctor: But as long as there are no signs like that I think you can take it that he is relatively OK. So, you should try to make the most of this time if you can. Is there anything you would particularly like to do?

Later, add that you are prepared to check him regularly, and show a willingness to negotiate the frequency of such check ups.

Doctor: I think it would help if I saw him from time to time to monitor how he is doing. How often would you like me to do that?
Mrs W: Would every month be OK?
Doctor: Yes, fine.

You should explain that if anything unforeseen occurs between these assessments you should be contacted immediately. This gives patients and relatives confidence that they have a "life line."

Doctor: If you are worried at any stage between his appointments you must get in touch with me. I can then assess him and decide what needs to be done.

Few patients or relatives abuse this offer.
When some patients or relatives face uncertainty they show that they do not want any markers.

Doctor: Would you like me to tell you how you might recognise if Peter's health is deteriorating?
Mrs B: No, I'll leave it to you. You're the expert.

Sometimes the uncertainty concerns issues other than "how long." Again you should acknowledge the uncertainty and establish any resulting worries.

Doctor: I sense that this uncertainty is a major problem for you.
Mr J: It is. I feel helpless not knowing what's going to happen or how it's going to happen.
Doctor: What are you worried about in particular?
Mr J: I'm worried about how I'm going to die. I don't want to be a burden on my family, and I'm not sure what to expect after death.
Doctor: Any other concerns?
Mr J: Isn't that enough?
Doctor: Yes, it is, but I just want to make sure I establish all your concerns before we discuss them in detail.

By separating out and exploring each concern the patient begins to see that there is some prospect that they can be tackled.

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Breaking collusion

It is commonly alleged that relatives withhold the truth because they cannot face the pain of what is happening and wish to deny it. More commonly, however, it is an act of love. They cannot bear to cause anguish to their loved one. Approaching collusion from this perspective makes it possible to respect relatives' reasons and work positively with them. The first step is to acknowledge the collusion and then explore and validate the reasons for it.

Doctor: You've told me that you don't feel Richard ought to know what is going on. Why do you feel that?
Mrs P: I'm terrified that if he's told he'll simply fall apart. I wouldn't want that, I couldn't bear it.
Doctor: Well you know him best and you could be right. It could be that if he's told he will fall apart. Have you any other reasons why you feel he shouldn't be told?
Mrs P: I think he'd just give up and turn his face to the wall.
Doctor: Any other reasons?
Mrs P: No.
Doctor: So you have good reason for him not being told.
Mrs P: Yes.

It is then important to establish the emotional cost of the collusion.

Doctor: I now understand why you have kept the information from him, but what effect has this been having on you?
Mrs P: It's been a terrible strain. I'm feeling extremely tense, I'm not sleeping as well as I should, I'm getting nightmares.
Doctor: Would you like to tell me about your nightmares?
Mrs P: He seems to be getting smaller and smaller, he seems to be wasting away.
Doctor: That's, I suppose, what could happen, isn't it, given that he is dying?
Mrs P: (In tears) Yes it is and I'm very worried about it.
Doctor: So it sounds as if you are finding it a strain!
Mrs P: It is. It's a big strain. I worry that he will begin to guess. He's already commented that I seem quieter than usual.
Doctor: Just how tense have you been?
Mrs P: At times I feel at screaming point and I'm taking it out on the children. I feel bad about that, but I just can't see how I can tell him without him falling apart.
Doctor: Are you experiencing any other problems because of not telling him?
Mrs P: Yes, we're not talking together like we used to. I'd like to be extra loving to him, but if I am he'll guess. He says I'm backing off. But I can't explain to him why. It's horrible. Just when I want to be close to him a barrier is growing between us.
Doctor: So, there are two good reasons for trying to consider whether there's some way round this, the strain on you and the effect on your relationship with your husband.
Mrs P: Yes.
Doctor: So would you like me to suggest how we might be able to do something about it?
Mrs P: But you're not going to tell him are you?
Doctor: No, what I'm going to discuss doesn't involve telling him, would you like me to go into it?
Mrs P: Yes, I would.

You should now indicate that you would like to chat with her partner to check whether he has any idea of what is happening to him. You should reinforce that you have no intention of telling him and enter into a contract to this effect.

Doctor: Let me emphasise that I have no intention of telling him. What I'd like to do is to chat to him to see what he's thinking about the present situation. It may be that he will reveal that he knows he has cancer. If that's the case there will be no reason to maintain the pretence.
Mrs P: But you're not going to tell him are you?
Doctor: No I'm not, I will simply check whether he knows. If your hunch that he doesn't have any idea is correct, that's the end of the matter. I won't say anything.
Mrs P: (Reluctantly) All right then.

Your next task is to establish her partner's level of awareness. You should ask an appropriate directive question which elicits his view of what is happening and then explore the cues he gives.

Doctor: I wanted to have a chat to see how you feel things are going.
Mr P: Not very well.
Doctor: Not very well?
Mr P: Isn't it obvious? I'm not having any more treatment. The hospital don't want to see me again but I'm still getting the pain. I'm losing weight and I haven't much energy. I'm in bed all the time now.
Doctor: So what are you making of this?
Mr P: I think it's the end, isn't it?
Doctor: Are there any other reasons why you're beginning to feel it's the end?
Mr P: I've always known that what they've told me was a precancerous ulcer was a cancer. Now what's happening is confirming that I was right. I'm lying here just wondering why no one has levelled with me.
Doctor: It sounds as though you've known for some time what's happening.
Mr P: Yes, I have, but I didn't want to upset my wife. She has enough on her plate with me being ill, and having to run around all the time.

You now should confirm that he is right ("I'm afraid you are right") and then seek permission to convey his awareness to his wife, indicating that she knows the diagnosis. Then negotiate with the couple to see if they are prepared to talk with you to establish their concerns.

As you help the couple talk you may notice that the patient is angry with you. This usually indicates that he feels talking is a waste of time because it will not change the outcome of his disease. If you get this feeling acknowledge it.

Doctor: Would you like to say how this leaves you feeling?
Mr P: What's the point? It's not going to be of much use.
Doctor: It sounds as if you might be feeling that it's no use because it won't make any difference to your situation.
Mr P: That's right; it's not going to stop me dying is it?
Doctor: No you're absolutely right. That's the one thing I can't do and I'm sorry about that. But it may help if we talk about how you're feeling and what you're worried about. It is quite likely there is something I can do to help you both. However, I will understand if you decide not to talk to me.
Mr P: I suppose I've nothing to lose by talking.

Breaking collusion is painful for the doctor because he witnesses the love between a couple and the effects of imminent loss. But it is important to break it as soon as it becomes a problem. Otherwise important

unfinished business will be left unresolved. The patient is then likely to be distressed and may become morbidly anxious and depressed. This mental suffering will lower the threshold at which the patient experiences physical symptoms like pain and sickness and cause problems with symptom relief. Failing to deal with important practical and emotional unfinished business also makes it difficult for relatives to resolve their grief.

Challenging denial

Patients use denial when the truth is too painful to bear. So denial should not be challenged unless it is creating serious problems for the patient or relative. In challenging denial it is important to do it gently so that fragile defences are not disrupted but firmly enough so that any awareness can be explored and developed.

It is first worth asking the patient to give an account of what has happened since his (or her) illness was first discovered and explore how he felt at each key point—for example, when he first developed the symptoms, saw a specialist, was investigated, and was told about his illness. He can then explain what he perceives is wrong, and this may provide glimpses of doubt: "I'm certain it's an ulcer, at least I'm pretty sure it is." By repeating "Pretty sure?" you may prompt him to say, "Well I suppose there could be some doubt." The cue "some doubt" can next be explored to see if he owns up to the possibility that the ulcer could be cancer. It is then important to interpret what is happening by saying, "Part of you prefers to believe that it's an ulcer, but another part of you is willing to consider that it is more serious." The patient can then retreat to denial or develop his awareness further ("I've been trying to kid myself that it's an ulcer, but deep down I realise it's cancer").

If this strategy fails look for and challenge any inconsistencies between the patient's experiences and perceptions.

Doctor: You say you were far bigger in this pregnancy than in your two previous ones. Did you consider why that might be?

Mrs J: I thought it was just one of those things. I didn't think anything more about it.

Doctor: Are you sure?

Mrs J: Yes I am sure it was a normal pregnancy. The reason I'm still feeling so weak is because I didn't take it too well.

The patient had developed ovarian cancer which was so advanced that little treatment could be offered. She preferred to deny this and insisted that her symptoms represented normal sequelae of pregnancy.

If challenging inconsistencies fails to dent denial check if there is "a window." Do this by asking: "I can understand that you feel it is an infection. But is there any time, even a moment, when you consider that it may not be so simple?" The patient may say "No," in which case you have to accept that the patient finds it too painful to look at what is happening. Alternatively, the patient may admit "Yes, there is. Sometimes I feel it could be something much more sinister." Exploring what the patient means by "sinister" may help him acknowledge that he has something much more serious than an ulcer. This then helps him shift from denial into relative or full awareness of his illness or prognosis.

He may then oscillate between denial and awareness. So, do not assume what stance he is going to take but explore it each time by asking: How do you feel things are going?

Conclusion

The best way to validate our guidelines is to try them out in practice. Either they will work and promote confidence or they will prompt you to develop other strategies.

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ANY QUESTIONS

Is there any association between stopping long term beta blockade treatment for hypertension and subsequent myocardial infarction?

Firstly, we must consider the risk of stopping treatment of hypertension and, secondly, the risk per se of stopping beta blockade. The first is easier to address: though hypertension is a risk factor for myocardial infarction, we have no clear evidence that either initiating or stopping treatment influences the likelihood of an attack.

The possibility that withdrawing beta blockers may provoke infarction has often been considered,[1] and could conceivably arise in one of two ways. The first is by withdrawal of a protective effect that may until then have been keeping a heart attack at bay. Beta blockers can be effective in the secondary prevention of heart attacks so an increase in attack rate could perhaps occur after stopping treatment for hypertension at least in subjects who have already had infarcts. The major secondary prevention trials with beta blockade did not address this possible consequence of treatment withdrawal, but any risk is likely to be small. A second mechanism for increase in risk as a result of stopping treatment could follow from induced changes in the beta receptors in the heart. Treatment with beta blockade increases, for example, the number of active receptors capable of responding to circulating adrenaline and other catecholamines. This can be regarded as an adaptive mechanism to overcome the lack of effective sympathetic stimulation and is called "up regulation" in modern jargon. If beta blockers are withdrawn ordinary levels of catecholamines have an exaggerated ("rebound") effect, principally as a result of the enhanced receptor numbers.[2] This effect is seen in hypertensive patients as in others.[3] Excess sympathetic stimulation could then contribute to the provocation of myocardial infarction through various mechanisms that have been reviewed elsewhere.[4] The danger should not be exaggerated, however; in practice beta blockers are often withdrawn suddenly but reduction in the dose over a few days seems a sensible policy.—D A CHAMBERLAIN, *consultant cardiologist, Brighton*

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How hazardous are aluminium cooking utensils? Is there any satisfactory equipment for removing metallic ions from a "cooking solution"?

Aluminium is a normal constituent of the diet and is also used in a wide range of pharmacuetical agents in small doses. Cooking utensils may leak small amounts of the element as a result of action by acidic items such as tomatoes, lemons, vinegar, or fruit juice. No disciplined study, however, has looked at the relative absorption of various types of aluminium in the diet and compared it with the few milligrams that might be extracted from cookware. The amount that comes from aluminium cooking utensils will probably be negligible even in patients with impaired renal function, but a formal study would be valuable.—N P MALLICK, *consultant physician, Manchester*