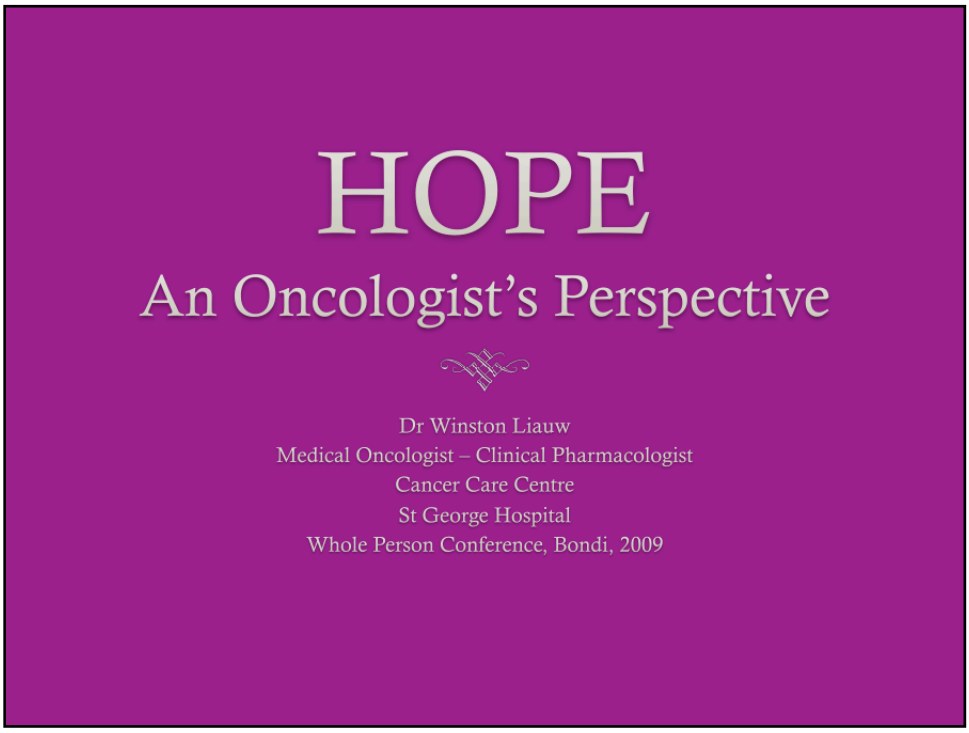
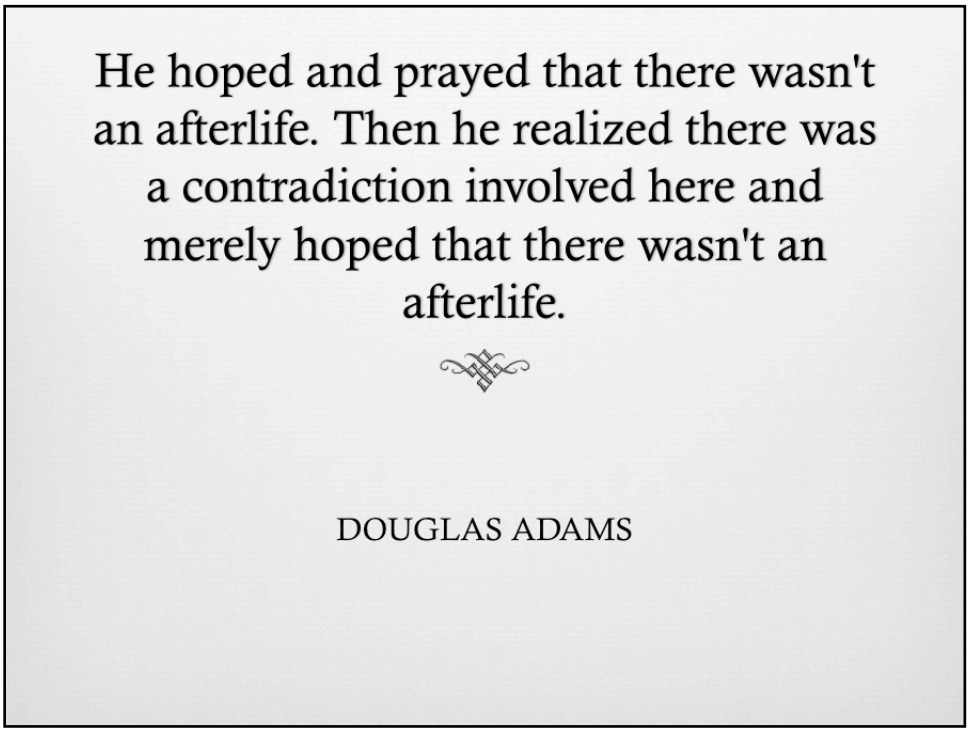
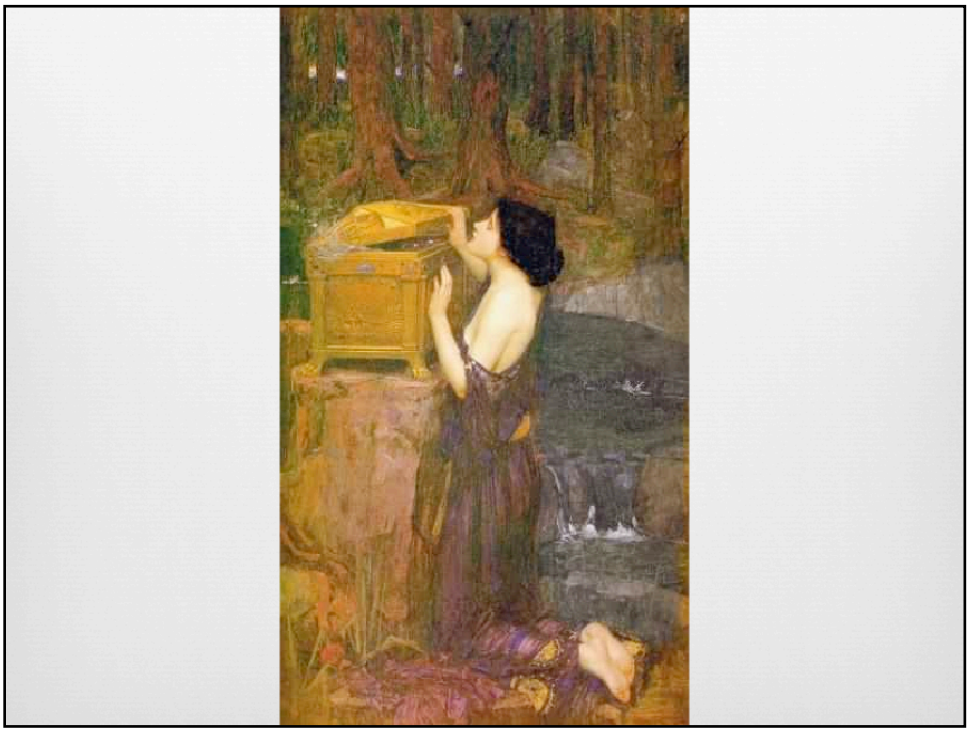


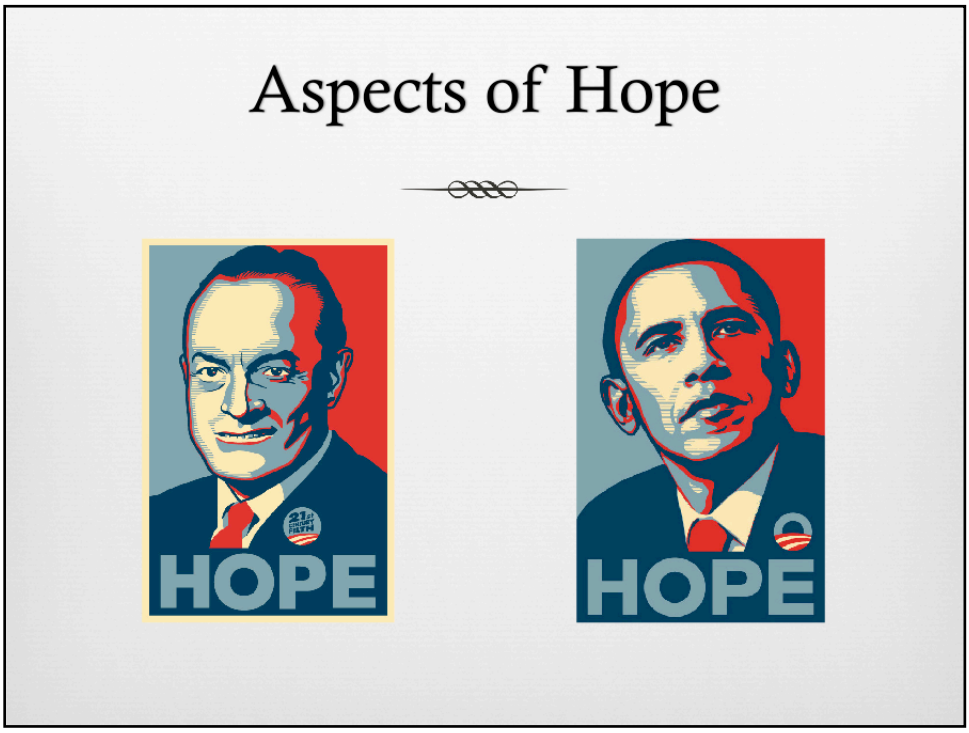
Thank you to the organizing committee for asking me to speak on the topic of HOPE from the perspective of a medical oncologist. An understanding of hope is an important aspect of understanding the whole person and in particular the process of dealing with terminal illness. Research indicates that hope is a substantive issue for almost all patients with cancer.



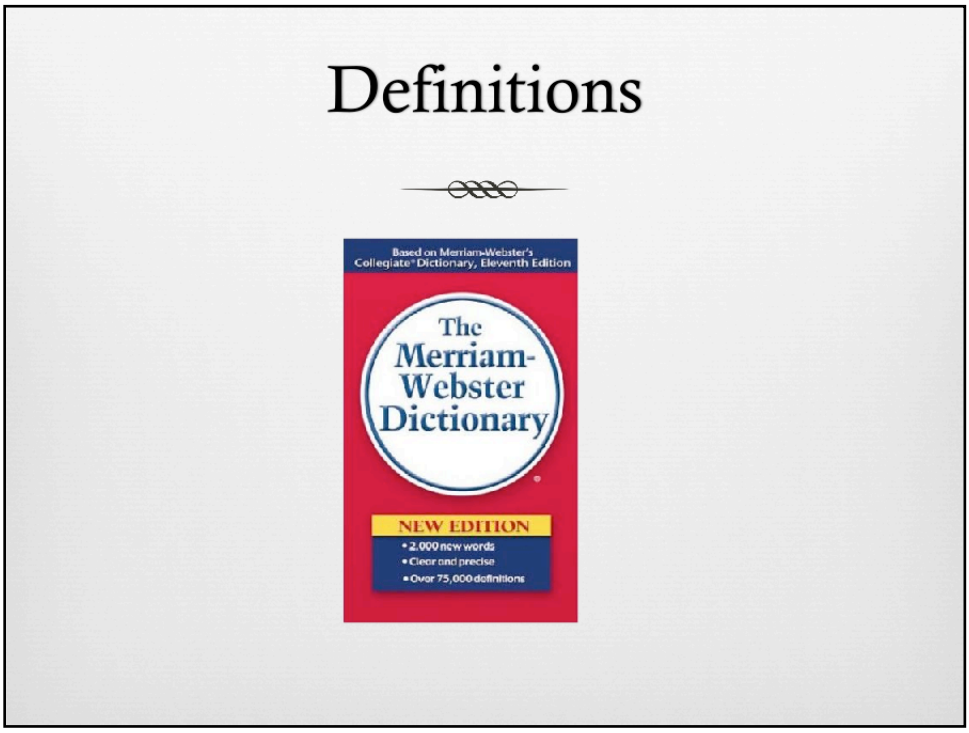
Having said this I must confess that after thinking about this topic for some time I rather hoped that I could escape the commitment. It's my sense is that hope is one of those concepts that everybody intuitively understands and yet finds, terribly difficult to explain.



Not only is hope difficult to explain but researching hope is difficult because it hasn't fit in a box since the time Pandora let it out.

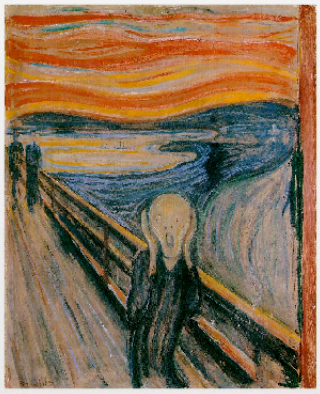


The problem of fitting hope into a box is compounded by the fact that it can be studied from many perspectives including theology, philosophy, psychology, psychiatry, and surely a host of other "ologie"s.

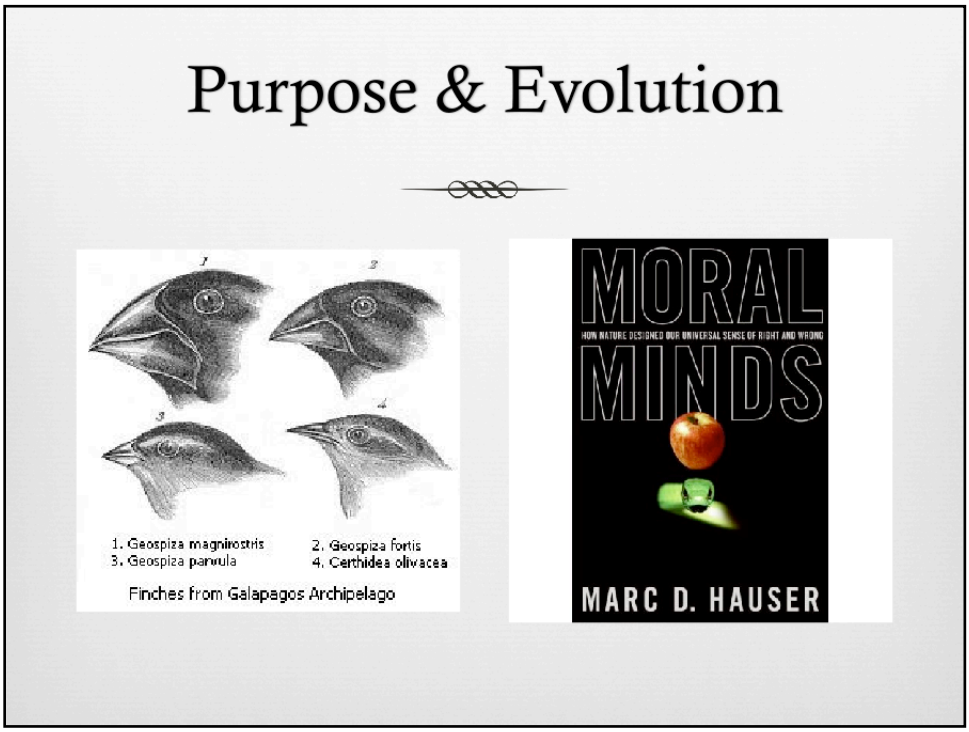


So let me start with a definition. Hope refers to an individual having a wish, expectation or aspiration for something to happen, that would be, from their perspective a good outcome or an improvement of their current situation. I note that one can have personal hopes or hopes for other individuals.

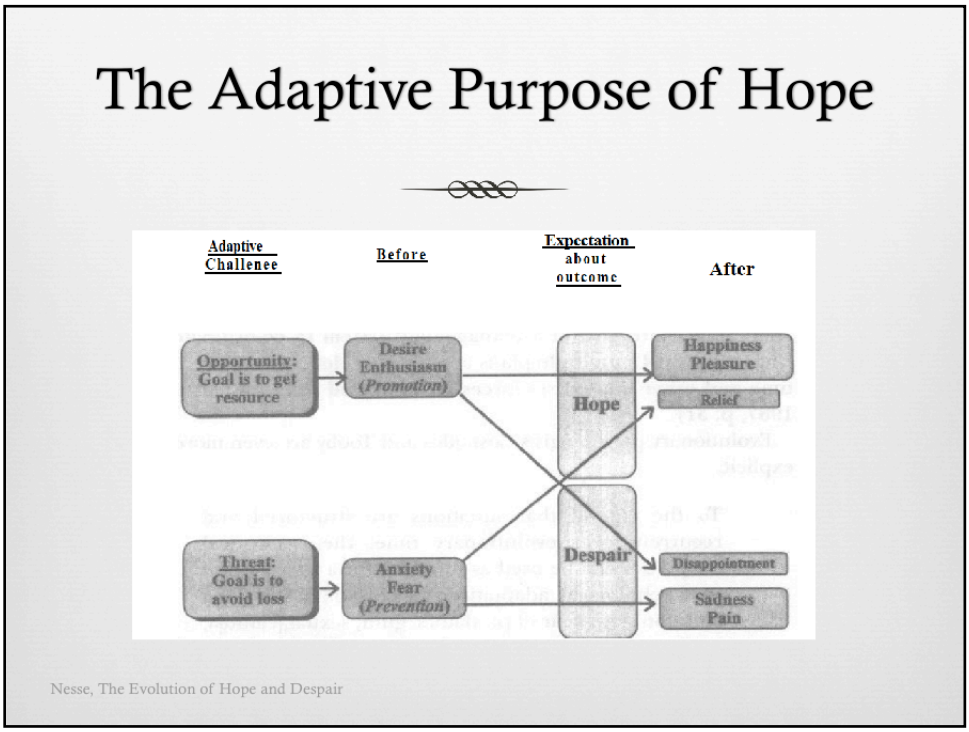
Definitions



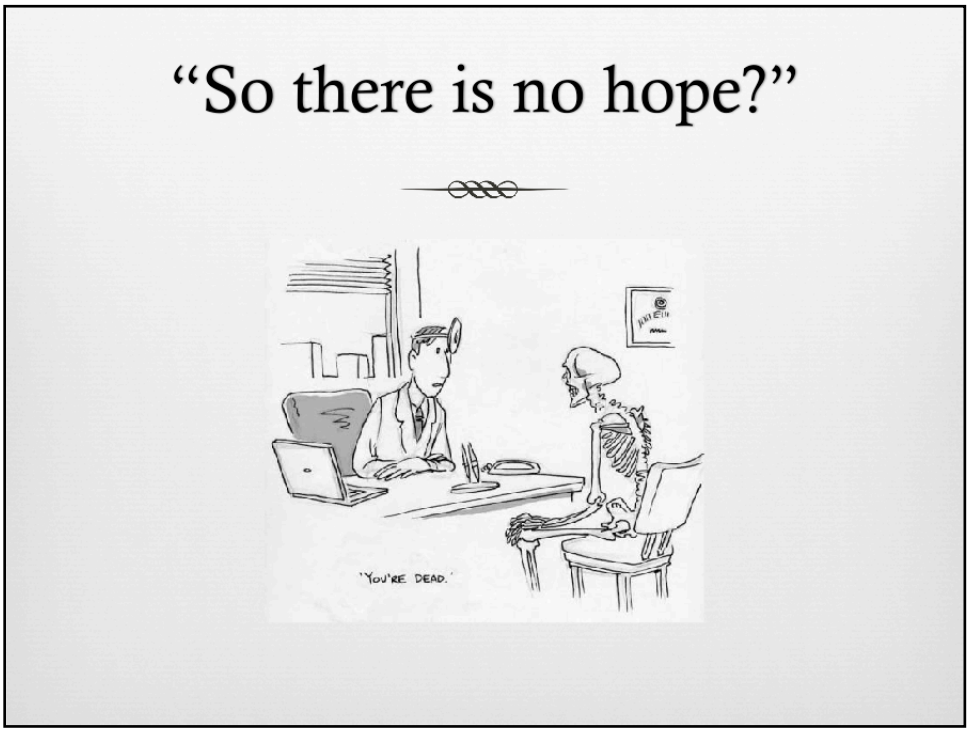
I note that it is not unreasonable for an individual to hope for death, whether or not society would view it as a desirable outcome, and especially when the wish for death is genuinely a hope tempered by a fulfilled life and not due to its' antithesis – despair.



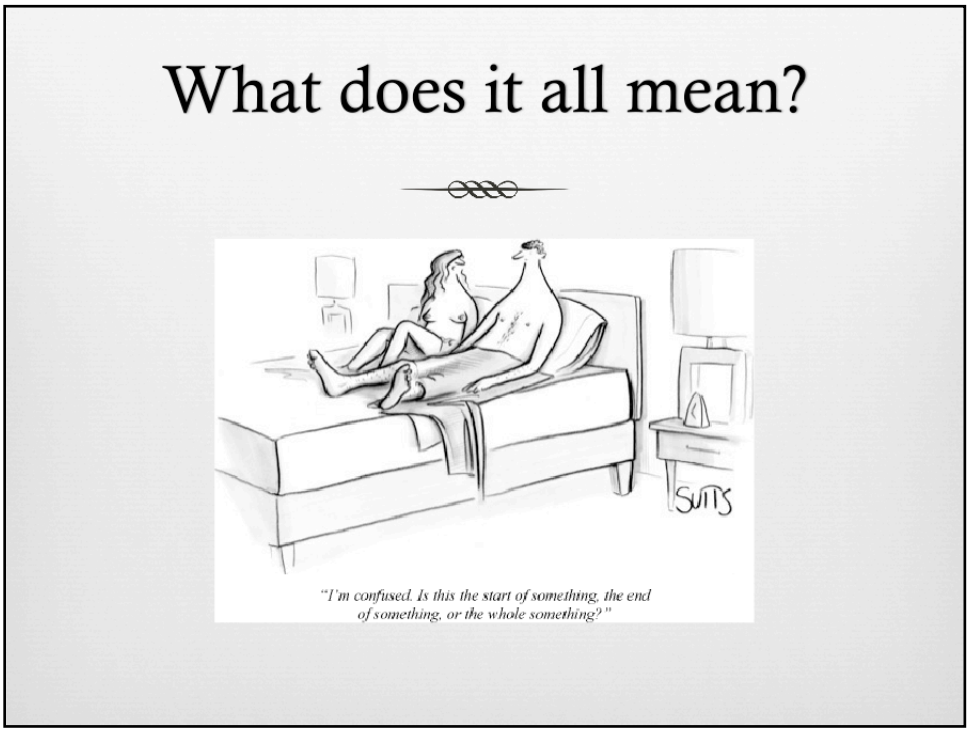
This definition, however, is not entirely satisfactory because it does not address the question of the purpose of hope. If the ability to have a sense of hope is essentially universal then biologically it presumably serves a purpose. Given the increasing evidence that emotions and morality evolved then hope should be no different. From an evolutionary perspective hope is an adaptive strategy that is consistent with the fright-flight reflex.



Nesse described the relationship of hope and despair in the context of individuals having opportunities, or threats to their opportunities, and in terms of the outcomes, happiness or sadness. Hope serves a purpose in helping individuals deal with threats to their wellbeing however it is apparent that hope can be maladaptive, i.e. if the hope is too different from the realistic outcome then despair and sadness is likely to be more intense.



Now let me put to you the scenario that we all deal with on a regular basis. The conscientious physician, having duly attended communications skills training, proceeds to explain to a patient that they have exhausted all treatment options for their cancer. Palliative therapies will continue to be offered but anti-cancer therapy, in particular curative therapy, is not available. The patient asks "So doc, there is no hope?" A similar scenario that I encounter is when a patient attends for a second opinion and says, "The other doctor was very nice but he just didn't give me any hope".

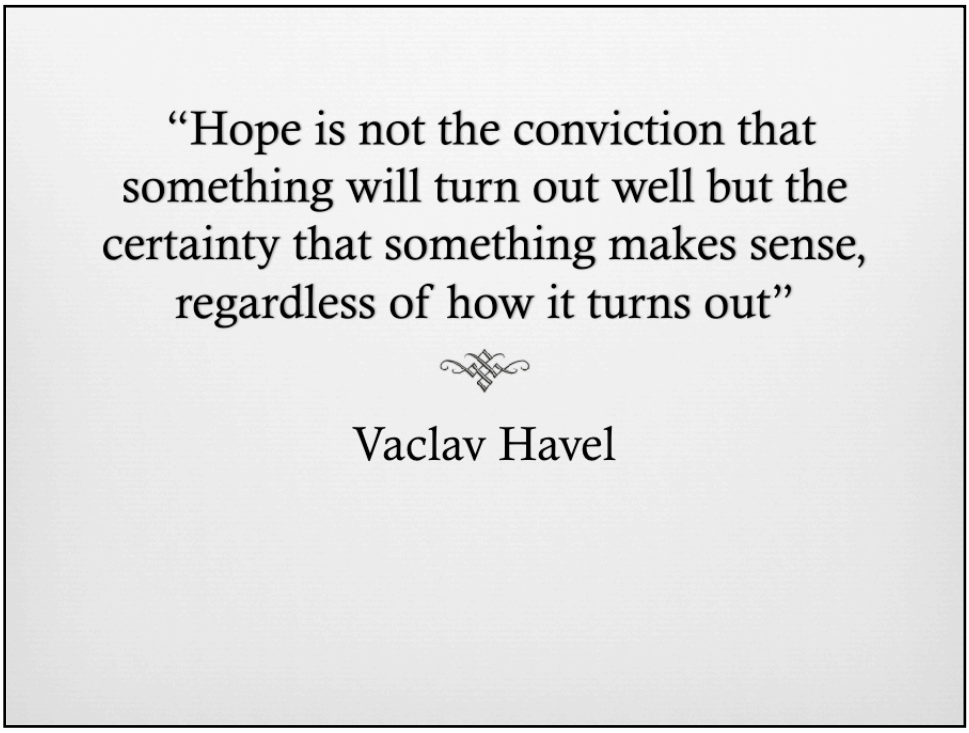


Personally, as a clinician, when confronted by the question "is there any hope?" I'd rather be somewhere else. I think that this "hopen"-ended question is perhaps a trap. Here are some thoughts that might run through your mind after being asked this question:

What does this person mean by hope?
What exactly are they hoping for?
What is their reference point for having the hope?
What is their world view?
If the hope is able to be articulated is it a realistic hope?
If the non-realization of a hope conflicts with their particular worldview will the patient experience despair?

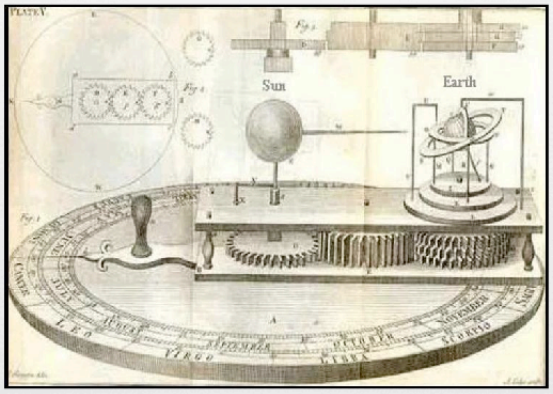
What does an individual mean by hope? Well clearly this will vary from person to person but an immediate observation is that hope is a singularity. My 4-year-old son would like a lot of things: trains, balls, ice cream, lollies, and so on. But I don't think you would really call this hope. I think when people speak of hope then it is a singularity. When pushed they may break it down into components but fundamentally hope is expressed as a singular: **it is the way they would like things to be**. My sense is that hope is an expression that life should turn out in a certain way. That person should live, should be cured, should live a long time, without pain, with certain people around them, and so on.

Any self-respecting social scientist would state that hope is a multi-dimensional concept but I challenge that generalization. Yes, hope can have different aspects but we must be careful to separate out hope from other emotions. For example, in the case of a family that is reluctant to make a decision about resuscitation status – is this family really expressing hope for the recovery of their loved one or are they avoiding guilt associated with the responsibility of decision making.



So now let me propose that hope not only pertains to a singular outcome but an outcome that is concordant with an individuals' world-view – i.e. how things should be. The real problem with the denial of hope, the recognition that a hope will not be realized, is that it fundamentally challenges an individuals' view of the world.

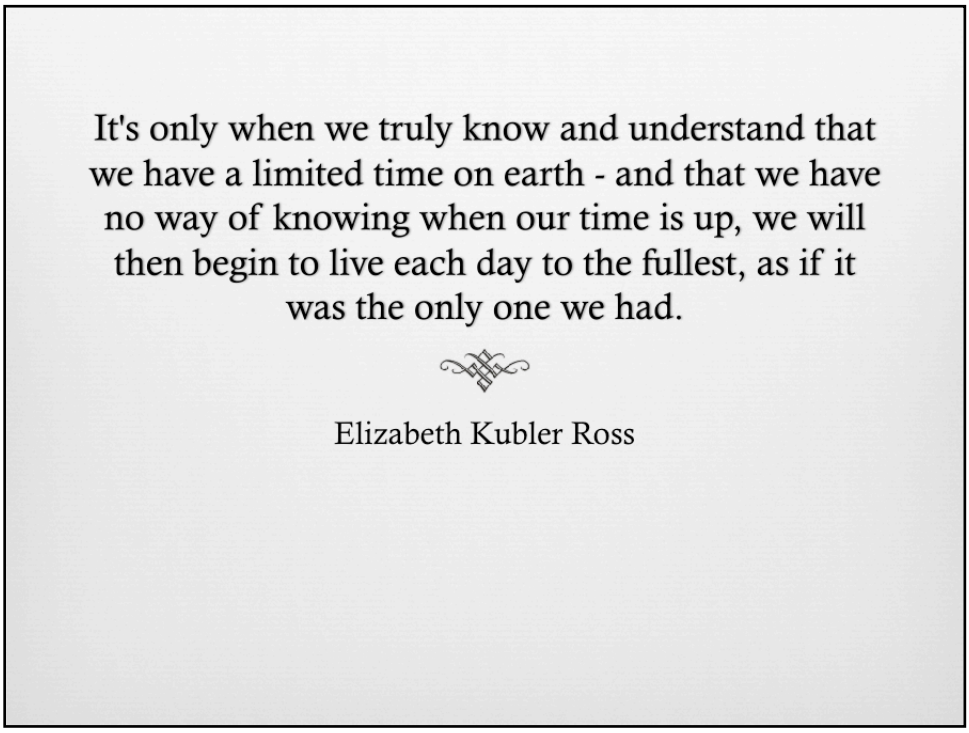
World Views



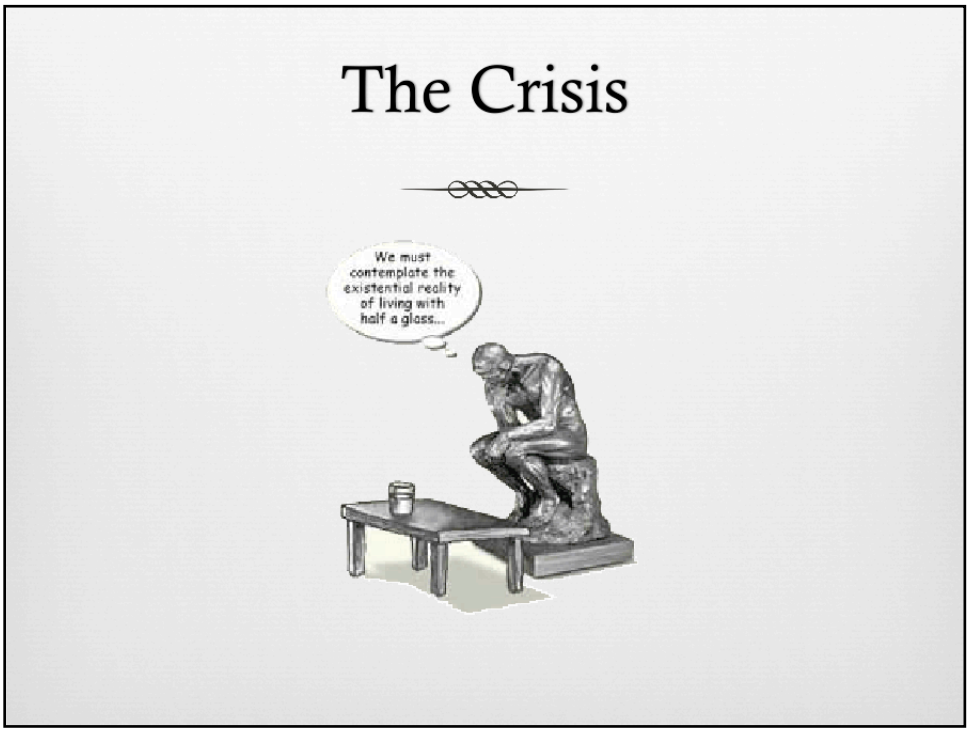
Even in its' simplest form a world-view is powerful stuff. To say to me that 40 is no longer the new 30 but the end of my life would be a cognitive challenge to say the least.

But nothing is ever as simple as this. Personal views of the world, whether unconscious or consciously built, have extra-ordinary depth. World-views are not just about the person but the relationship of the person to the world. When hope is challenged it is a challenge to the relationship of a person with their world.

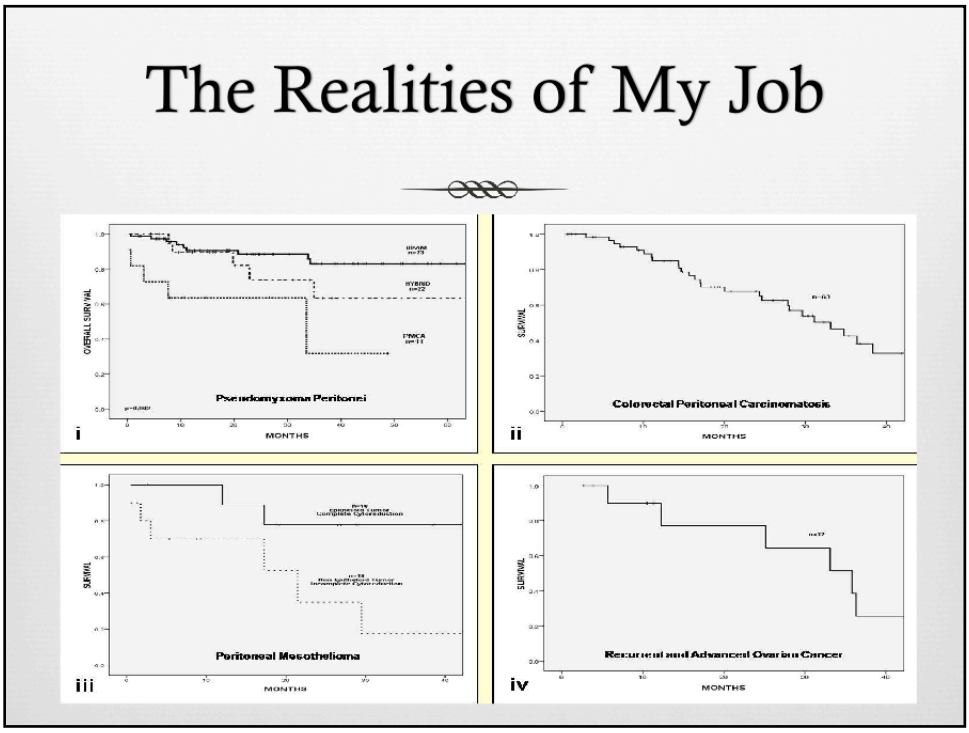
In a sense, it is unavoidable, when considering world-views, that we also discuss religion. This is not easy territory for me as I am clearly unqualified to discuss theology. Certainly I was raised in a Protestant environment but today I identify myself as a bright, a person who fosters a naturalistic world-view, free from the supernatural. Maybe this disqualifies me from having this discussion. Or maybe it doesn't, because an atheist can still have hope.



So where does religion, as a basis for a worldview, fit in the discussion of hope? The interesting thing about religion as the basis of worldview is that the perceived denial of hope can be concordant or discordant with one's world-view. For many people, the transition to death is entirely concordant with their worldview. Now they may not be in a state of nirvana, they may not have accepted death and may still hope for a turnaround in their situation but at least their situation is concordant with their expectations. We must remember death is a natural outcome for all men and there is little else that would suggest otherwise.



Unfortunately the same religious framework can, in my opinion, be detrimental. For some individuals the denial of hope is extremely discordant with their worldview. In fact, the denial of hope may be so discordant that it might lead to such extreme cognitive dissonance that the worldview is actually challenged. We now have questions emerging like “does God really exist?” or “if so, then what is God doing about my situation?”. When hope is denied worldviews can be challenged, for the religious individual faith can be challenged. Or, indeed the converse can occur and for some faith can be acquired.



So let's come back to my patients' question "so there is no hope doc?" Now my immediate thought is that I must be extremely careful what I say because I lack a fundamental piece of information: what is my patient's worldview? In the context of generally brief consultations I suspect there is no entirely satisfactory response to the question.

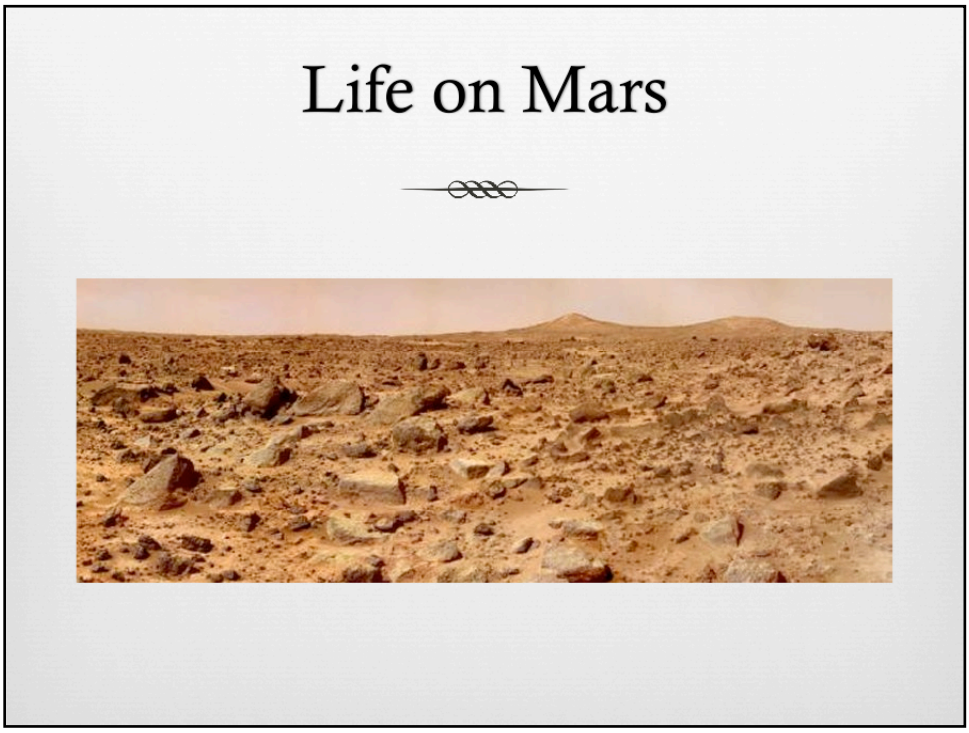
Possible responses could be:
"Well, hope can mean different things. Sometimes, hopes need to be reviewed and seen in the in the context of what is most likely to actually happen. "

or

"Well, if by hope you mean a miracle that will lead to recovery, then I'd have to say that miracles are exceptionally rare. There is a chance, but it is very, very low. If you are a religious person I think you'll find that your religion offers hope even when death occurs. Perhaps you would like to talk to a priest or somebody else about this."

or

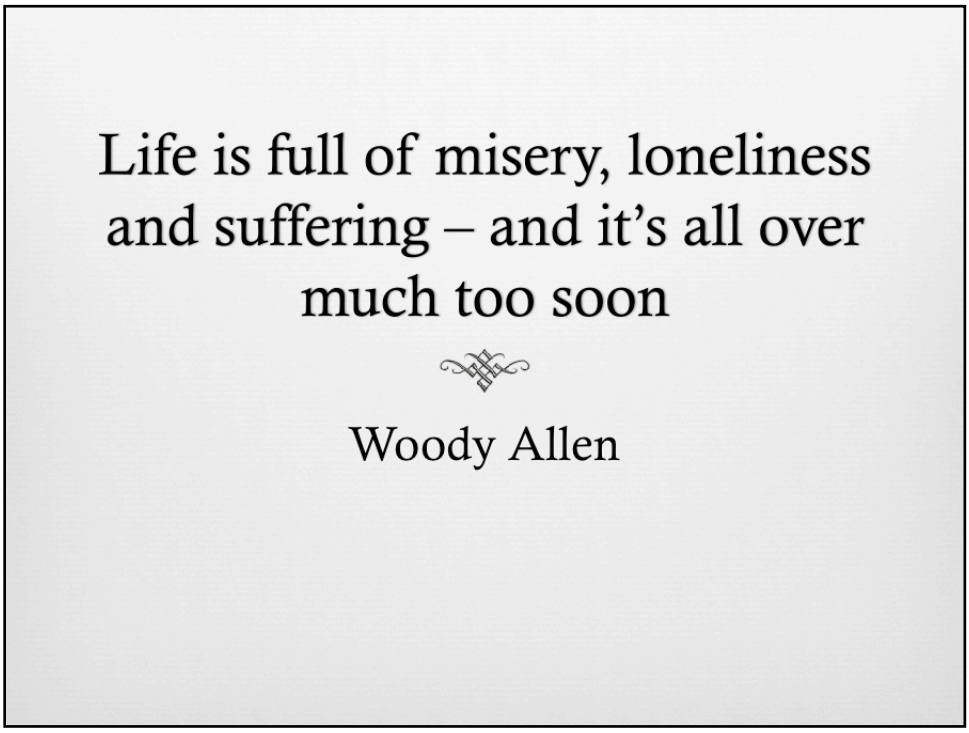
"Tell how you expect things to turn out"



It is commonly said, “where there is life there is hope”. Although this statement could be interpreted in a number of ways, in my experience people who adhere to this aphorism mean “whilst I am alive or my loved one is alive there is a chance that there could be a miracle”. This assumption, even for the religious believer must be incorrect. Even in religious texts the occurrence of miracles is exceptional and uncommon, they are, after-all, miraculous. This means in practice that either the hope is false or the fundamental basis of the hope has been misconstrued. By misconstrued I mean that the statement “where there is life there is hope” is fundamentally a misinterpretation. What should really be stated is that **“despite death, there is hope**”. To me this assertion would be common to many religions.

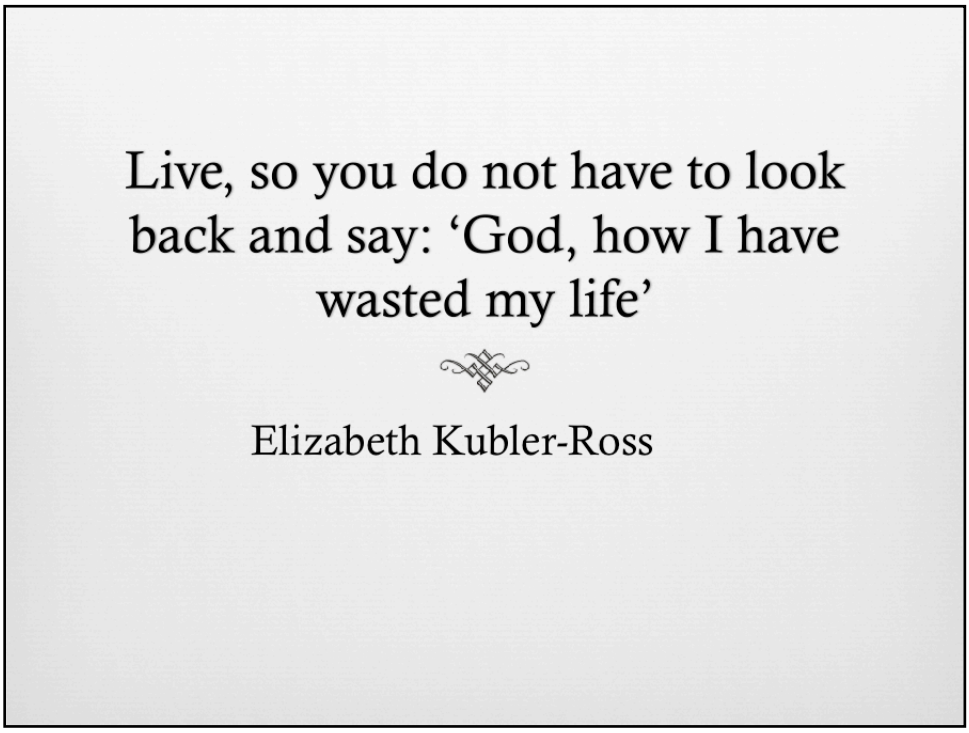
So in situations where a patient or their family has (from our perspective) an unrealistic hope there must be a 2-step process to lead to realistic hope. Firstly, a diagnostic assessment must be performed. The worldview must be appraised. Indeed the worldviews of all of the stakeholders might need to be appraised as frequently problems arise because of variable worldviews between patient and family, or individual family members. Once the worldview is established identifying how that worldview might be discordant with the hope is important or, in the case of my theological example, identifying misunderstandings of the world may be important. Finally, once these diagnostics are carried out then undertaking to re-align the hopes to make them more grounded in reality yet simultaneously concordant with worldview should be he aim. In effect the therapeutic goal is to reduce the discordance between the patient's reality and their hope/worldview by aligning these two concepts.

So in practice what should (do) I do for the patient or family experiencing a reality/ hope discord (crisis). The following steps should be taken:
1. Careful education and communication as to why the situation is the way it is.
2. Reassurance that everything appropriate (but not everything possible) is being done to manage the situation.
3 Counsel to realign hopes. This may require obtaining consultation from the relevant religious member, social worker, etc.
4. Try to align expectations of both patient and family.
5. Reassess expectations



But hang on, isn't this a cop out – here is somebody who is a self-professed atheist giving instruction about theology. I've dealt with the supernatural but not the natural world and surely even those with a naturalistic worldview must have hope.

Well, I think this has to be true but I am not convinced that I have truly observed a secular existential crisis of hope. In my experience, rational explanation trumps unrealistic hope. I think we also need to make a clear distinction between expectations of the individual and expectations of an individuals family and loved ones. For example, a common scenario is that family members insist that everything be done to keep a family member alive. There are multiple reasons why this might be the case: a family member may be central to a person's worldview and so in this circumstance the hope is appropriate. But another aspect of the scenario is the perceived responsibility that a family member might have for their loved one: they don't want the responsibility of making the decision about palliative care, for example.



Now one fundamental problem with the action plan outlined above is that it is more than likely that by the time the crisis of hope is recognized it is actually too late to effectively manage the problem. For this reason, in the context of whole person care, the process of instilling realistic hope must begin with the initial consultations, not at the point where the terminal phase of life has already begun. Being very clear about the possible journeys and their outcomes should start from the beginning of the therapeutic relationship.

Indeed forging realt\istic hope should start much earlier. It is fashionable to support preventative medicine as the panacea for healthcare. If this is the true then it should also be the case that imbuing individuals with a set of values that serve as a framework for a life grounded in realistic hopes is critical to overall life satisfaction. As Vaclav Havel suggests, everything must make sense and of course, we must feel that our life has not been wasted. The most satisfying interactions I have are with the people who can say "I've lived my life well and am happy with what I've done, I am prepared to die"


Thankyou
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