

# Cabrini Health: Shared Decision Making

Based On:  
'WHEN ENOUGH IS ENOUGH'  
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***'It is much more important to know what sort of patient has a  
disease, than what sort of disease a patient has'***

Sir William Osler (1849 - 1919)

Seven steps for effective shared decision making conversations

**Ask**  
**Explain**  
**Explore**  
**Options**  
**Advise**  
**Agree**  
**Communicate**

## **Summary**

Major life threatening illness in elderly patients with end-stage chronic disease poses increasing problems for patients, doctors and the health system.

In the face of advanced age and progressive chronic illness the chance of continued invasive treatment being successful is reduced. Prolonged treatment may be distressing for patients and their families and the chance of complications is increased. The dilemma of what treatment to offer in these circumstances is a constant and increasing problem for practicing clinicians.

While it is very important that we do not deny intensive treatments to those who may benefit from them, and are prepared to accept them, it is also important to avoid putting those who do not stand to benefit or who do not desire such treatment through potentially very arduous therapy.

Many doctors have difficulty discussing treatment options with patients who are nearing the end of their lives. Currently it appears that many doctors do not attempt to ascertain the patient's views but simply try to convey the seriousness of the clinical situation and to outline the interventional treatment option. It is left to the patient (or their family) to suggest that treatment is unwanted. However, such is the respect for medical authority that patients and relatives very rarely express these feelings in a crisis situation unless they are specifically invited to do so.

This program is specifically designed to illustrate how effective patient-doctor communication leads to appropriate clinical decisions. The program will teach a simple approach which permits the patient (with their relatives) to outline their situation and wishes. An understanding of the patient's situation and wishes allows the doctor to make a thoughtful treatment recommendation which is more likely to reflect the patient's best interests than that where the doctor understands little (or nothing) about the patient.

Adoption of a communication style that helps to match treatment to patients' wishes must result in better quality medical treatment.

## Introduction

In our 'acute care' health system, doctors often hastily apply the medical and surgical interventions that we perceive our patients and community 'demand', and we fear litigation requires.

However, many frail and sick patients, given the opportunity to express their feelings, acknowledge far greater fear of the intrusion of technology, or of incapacitated survival, than of their own mortality.

Unfortunately, western society has lost the art of talking about, and dealing with, the natural end of our lives. This has in turn affected the way doctors interact with patients at the end of their life, and we have lost touch with our role to recognise and ease the approach of death for patients and their families. Technology seems to offer solutions to all problems. Many doctors find it hard to accept death, unless every piece of technology has been brought to bear - and even then we see the death as a 'medical failure', a statement of our inability.

At the same time many doctors view with concern the increasing debility of patients undergoing medical interventions and lament an inability to influence what they perceive as an unrealistic demand for high technology solutions from these patients and their relatives.

We need to balance an enthusiasm and skill to cure with an acceptance that death is an absolutely natural end-point of all life. A peaceful death in the face of an acute medical crisis is a legitimate treatment option that must be presented as such to our patients

Perhaps we need to rediscover the compassion that enriched the lives of previous generations and allowed open and honest discussion about dying.

There comes a time, for all of us, when comfort and compassion, words and gentleness of touch are the things that matter. As diseases progress, the degenerative changes of age accumulate and the ability to function independently progressively declines, many patients make this transition. We need to ensure that as doctors we are receptive to these thoughts from our patients and able to assist with the transition where appropriate.

**A new approach is required, as outlined below:**

The Traditional Approach (Procedure Orientated)

**Telling**

Focus on medical facts

Fear of litigation

Medical risks and benefits

All treatment options offered

Search for new treatments when previous treatments fail

Survival is the goal

Death is a medical failure

Possible reversibility of this event is central (not in context of life)

**What can be done**

The New Approach (Goal Orientated)

**Listening**

Finding out what patient/relative wants, values and fears

Illness considered in the context of life and aspirations (rather than in isolation)

Death is accepted as an inevitable part of life

Survival is only one of several possible goals

A "Bad Death" is a medical failure

Treatment options determined by patient goals

Medical acceptance where invasive therapy is rejected

**What should be done**

## The Legal Framework

Any consideration of limiting treatment requires an understanding of the legal framework under which medical care operates.

Doctors have a moral obligation not to offer treatments to patients that are of no benefit to them, even if requested by patients or their surrogates. Also, patients have a right to be informed about their treatment options in order to choose whether or not to accept those treatments. Therefore, the process of determining treatment limitations requires two parts: Firstly, doctors may institute treatment limitations if it is felt that they would be non-beneficial for the patient. Secondly, patients may, once informed about a treatment, choose to decline it.

In order to help determine what treatments might be in the patients' best interest (and therefore what treatment options should be offered to the patient) it is important to understand what is important to the patient, and what their current life is like. In order for patients to make informed choices about refusing treatments, it must be explained to them what the treatment involves, what the likely outcomes of that treatment are, and what alternatives are available.

When a patient is unconscious or otherwise incompetent to make a decision regarding their treatment, a **"Person Responsible"** assists with decision making. A valid Refusal of Treatment Certificate completed by the patient prior to losing decision making capacity and which applies to a current condition must be followed. An Advance Care Plan completed by the patient prior to losing decision making capacity should guide health care staff and family members to make decisions in the patient's best interests.

An **Enduring Medical Power of Attorney** who is legally appointed by the patient while they are still competent has the right to either consent to or refuse further treatment provided their decisions are in the best interests of the patient.

The **person responsible** is defined in s.37 of the *Guardianship and Administration Act 1986* (Vic) ("G&A Act"). It sets out a hierarchy that must be followed to identify which person can give consent to medical treatment for an incompetent patient. It is not necessarily the 'next of kin'. The person responsible has the right to consent to treatment on behalf of the patient, but NOT to refuse or direct treatment.

The hierarchy set out in s.37 of the G&A Act to determine who should consent on the patient's behalf is:

- An agent – appointed Enduring Medical POA
- A person appointed by VCAT to make decisions regarding the proposed treatment
- A guardian appointed by VCAT with health care powers
- An enduring guardian appointed with health care powers
- A person appointed in writing by the patient to make medical or dental treatment decisions
- A spouse or domestic partner
- A primary carer (unpaid)
- The nearest relative over 18
  - In order of priority: son or daughter > parent > sibling > grandparent > grandchild > aunt or uncle > niece or nephew
  - When two or more relatives are in the same position the eldest will be the person responsible.

If there is no person responsible available, the doctor can apply to the **Office of the Public Advocate** for consent (a notice is sent under s.42K of the G&A Act).

Doctors are not obligated to provide treatment when:

- A competent patient refuses it
- A properly appointed agent has refused on the patient's behalf (or a parent on behalf of children)
- The treatment is futile
- The treatment is not in the patient's best interests

Both futility and 'best interests' are open to interpretation. Futility is a difficult concept to define but since a treatment which will not work (i.e. futile) is unlikely to be in the patient's best interests the decision may be guided by consideration of whether treatment is, or is not, in the patient's best interests.

In Victoria neither the Agent nor the person responsible (nor the patient themselves) has the right to demand treatment.

From a legal standpoint a doctor is unlikely to fall foul of the law providing he or she is (and on scrutiny is seen to be) acting in the best interests of the patient. It is recognised that these decisions are subjective and an element of 'opinion' is acceptable. It is most important for a doctor to document the reasons for making a treatment decision in the patient's medical file.

Although family members do not have the power to dictate treatment, experience (and court decisions to award costs and even damages when relatives' wishes have been ignored) suggests that it is unwise to ignore them. Where family views differ from medical opinion (and are firmly held) the family's only option is to have the doctor's decision reviewed by the Supreme Court. This is uncommon and can usually be avoided if the treating team takes the time to fully explain their decision to the family. Remember that the final decision on treatment is always made by the doctor in the patient's best interests - which might be different from the views of the family.

In order to document a decision to limit or withdraw treatment it is important to refer to any wishes the patient may have expressed. Quote the views of family members regarding their perception of what the patient would wish (rather than what the family members want) and **state that in your opinion further treatment (or specific treatment) is not in the patient's best interests**. It may be useful to state why you consider it is not in the patient's best interests (discomfort, very unlikely to work, not desired, only likely to prolong death etc.). Where this is documented it is highly unlikely that any subsequent investigation could conclude that the doctor behaved improperly.

Treatment limitations are always best described in terms of what will be done, rather than what will be withheld. For example, a decision to forego surgery and opt for terminal care in the setting of incurable disease should focus on provision of good palliative care and allowing a natural death rather than withholding CPR and surgery.

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## Scientific Background

In the early 1990s the Robert Wood Johnson Foundation funded the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT)<sup>1</sup>. This study sought to improve end-of-life decision making and reduce the frequency of a mechanically supported, painful, and prolonged process of dying.

There was an initial 2-year prospective observational study involving 4301 patients with life-threatening diagnoses. The prospective study documented shortcomings in communication, frequency of aggressive treatment, and the characteristics of hospital death: only 47% of physicians knew when their patients preferred to avoid CPR; 46% of do-not-resuscitate (DNR) orders were written within 2 days of death and **notably 38% of patients who died spent at least 10 days in an intensive care unit (ICU)**. A major conclusion has been that a broad discussion of patients' values and desires is required<sup>2</sup>.

In The SUPPORT study a majority of the patients (58%) who had not discussed preferences for end-of-life care stated that they did not wish to do so. Failure to engage in such discussion makes it likely that these patients would be submitted to unwanted interventions since 87% of those who said that they did not want to talk about prolonged ventilation also indicated that they did not want such treatment<sup>3</sup>.

This finding is consistent with previous research which found that 70% of older patients decided against life sustaining treatments when asked to imagine themselves incompetent with a poor prognosis<sup>4</sup>, or unable to care for themselves after discharge<sup>5</sup>. But at the same time **70% do not wish to make the decision about treatment themselves but want surrogates (family or physicians) to make resuscitation decisions for them**<sup>6</sup>. This raises significant problems (and significant stress) for these surrogate decision makers if the patient has delegated responsibility without giving an indication of the values, which should guide the decision. It also significantly increases the risk that patients will be subjected to intensive medical treatment which they would not want.

Patients and their families appreciate the opportunity to discuss their end of life treatment preferences. Not only are their wishes more likely to be known and followed, but also their satisfaction with their treatment is higher, and their relatives are less likely to suffer anxiety or depression after they die<sup>13</sup>.

In a study to evaluate the accuracy of surrogate's (62% spouses, 29% children) prediction of what an elderly relative or friend would want in a variety of clinical scenarios, predictions were found to be correct less than 70 percent of the time<sup>7</sup>. Surrogates were two to three times as likely to make errors of over treatment as under treatment - that is, **choosing life-sustaining treatment the patient wouldn't have wanted in that circumstance**.

A number of projects are underway to encourage patients (and potential patients) to consider advance care plans and these are to be encouraged. This education program approaches from a very different perspective. It is designed to enhance the skills of doctors who are regularly required to assist patients, and their relatives, confronted by high risk conditions where outcomes are likely to be poor, and often in the absence of any prior directions from the patient.

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## The Program

We need to recognize that patients generally don't talk about their values and wishes, particularly to their doctors, and doctors infrequently raise these topics with patients.

The project aims to encourage doctors to communicate with patients and to suggest language that will assist patients to express their wishes and values. At the same time, it is vital that the attempt to understand values is perceived to be compassionate. **It must not extinguish hope, nor convey a message that treatment is being withheld from those who express clear wishes to undergo intensive medical treatment.**

The program will also alert doctors to the inevitable difficulties which failure to establish wishes and goals with patients while they are competent can subsequently cause both to doctors and to those family members who are left unprepared to make decisions. With such realisation they will become more willing to initiate discussion and minimise subsequent distress.

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## Communication Guidelines

Whenever possible this essential communication needs to occur before a medical crisis arises (when the interaction may prove impossible and a more difficult task will be passed onto both the doctors and the patient's relatives). Failure to plan is a cause of much subsequent dispute and distress. Endeavour never to postpone discussion or leave it to others when a patient is deteriorating – it always seems too early to have these conversations – until it's too late!

Make these discussions a routine and important part of your medical care.

**Principles are outlined and examples of the type of language that might be used are illustrated in *italics*.**

### **General principles of good communication**

There is much recognised and taught about the non-verbal essentials of good communication. These are important. Whilst this program seeks to focus on the verbal approach, a brief summary of important points follows.

- Make time and sit down in a quiet place. A perception of rushing should be avoided (minimizing interruptions is also helpful). Patients are shown to have a perception of better and longer communication if the doctor sits down.
- Make eye contact and be relaxed. Not making eye contact or fidgeting conveys the impression that you can't be trusted.
- Avoid conveying dominance. Things such as standing over patients or sitting behind a desk makes unspoken statements of dominance which can interfere with the balanced roles which are required to find agreed solutions. Uninvited touching can have the same effect.
- It has been observed that most meetings of doctors with patients and their families involve the doctors speaking for almost all of the time. You need to try to change this balance to make more listening time. Aim to make it a 50:50 balance. When people are permitted to speak they perceive that you are interested in them and in their views, this sets a good basis for an effective interaction.
- **Whenever possible try to establish an agreed management plan between the medical team(s) before confronting patients or relatives. Presentation of widely differing perspectives should be avoided since this causes great confusion and distress to patients and families.** Where differing views exist it can be useful to co-ordinate meetings so that representatives of the different medical teams who are involved can meet with the patient and family together. When this occurs, those representatives should meet together before entering the family meeting to plan the interaction. This helps to avoid differing views being presented without balance.
- Involve a non-medical member of the team, either a primary nurse or member of the Allied Health team such as a social worker. This person should not be involved in the delivery of bad news or be required to give their opinions during the meeting; they should instead be an advocate for the patient and their family. They will often obtain useful insights into family dynamics and have the opportunity to address concerns and questions after the doctor has left.

## Explain why planning in advance is important

Take time to explain to patients why leaving end of life decisions to others is not a good idea. Since it is usual for elderly people to want families and/or doctors to decide on medical treatment for them, they should be encouraged to outline their wishes and values to the doctors and relatives so that later decisions are more likely to reflect their wishes. Letting patients postpone discussion until they become unwell and unable to contribute to these discussions is unwise. It will cause stress to their families and medical carers and almost inevitably will result in invasive intervention (such as mechanical ventilation), which they may not desire.

Explain why it is important to discuss difficult issues at this time:

*'I realise that this must be a very difficult time for you and your family and I want to work with you to make sure your care is the best we can give you'*

*'It is important for me to know how you feel about things so that we can be in a better position to plan your care for you if you can't tell me should you become very sick.'*

*'As your doctor, I want to make absolutely sure we are always doing the things that you would want'.*

## Identification of a Surrogate Decision Maker

Getting the patient to identify their chosen surrogate is very important. All families have differing personalities and frequently there will be conflicts between them. Failure to identify a person whom the patient trusts to convey their wishes frequently leads to a range of views being expressed, once the patient becomes incapable. It is then very difficult to judge who is best representing the patient's views and wishes or would have been the patient's preferred surrogate.

In this situation the most interventional view usually prevails.

It is highly desirable that the patient appoints an agent under the **Enduring Power of Attorney (Medical Treatment) Act**. Then their chosen representative will have legal authority to support their decisions. In a number of chronic disease education programs, such as that for chronic dialysis, clinicians suggest the formal appointment of an agent. This practice would usefully be emulated by others in their patient/relative education.

Ideally both the patient and their chosen surrogate (usually their spouse or child) should be present for the planning discussions. Then, when the proxy takes over the role of surrogate decision maker (when the patient is no longer able to contribute) both the doctor and the surrogate have together heard the patient and can interpret the wishes together.

*'If we don't talk about this now while you are able to talk then we will have to ask your family what to do when you become sick. We like to avoid this if we can because we know that families usually find it incredibly difficult and distressing'*

*'I understand that you would like your family to decide for you so it is important that they really know what you want. Do you feel confident that they know what you'd want? Have you talked about this a lot together? Maybe we could ask them to come in and we can talk about the issues together'*

Ask whom they would like to decide for them should they become incapacitated:

*If you became so ill that you were unable to speak for yourself, who would you want to make decisions regarding your medical care?*

This can be very useful in the event of later family dispute if one member is clearly identified (for instance the daughter with whom the patient lives). This question will also identify an agent under the 'Enduring Power of Attorney – Medical Treatment' if one has been appointed (unfortunately this is very rare). If the patient wishes a particular doctor to decide then this will lend authority to this doctor's recommendations in relation to the opinion of others.

It is useful when asking a patient to select a surrogate to suggest that they give their selected representative advice regarding the amount of leeway they want the surrogate to have when interpreting any advance directives. Patients' feelings on this question vary significantly: data suggests that about 1/3 of patients would like their surrogate to have complete leeway when making decisions about life sustaining treatments, while 1/3 would want an advance directive followed closely.

## Seven Steps to effective Shared Decision Making

### Ask, Explain, Explore, Options, Advise, Agree, Communicate

<u>Ask</u>	- patient's understanding of the prognosis and diagnosis
<u>Explain</u>	- explain the medical situation
<u>Explore</u>	- explore functional status, values and attitudes
<u>Options</u>	- outline options (including consequences)
<u>Advise</u>	- give honest advice
<u>Agree</u>	- agree on a plan
<u>Communicate</u>	- write the plan in the notes / explain to relatives

### **ASK what the patient understands of their diagnosis and prognosis**

The discussions that will follow all rely on the patient having a good understanding of their diagnosis and a reasonable knowledge of what to expect with regards to effects of disease progression and life expectancy. Before embarking upon an explanation of these things, it is very useful to ask the patient to summarise for you their understandings. This will elucidate situations in which patients have overly optimistic or pessimistic expectations, and will therefore require more detailed explanations. Where a patient's expectations are far from reality, it may be that discussions about end of life treatment preferences need to be postponed until a more realistic understanding is achieved. It is counter-productive to attempt to reach an agreed plan for management with a patient whose perception is very different to that of the medical team.

Remember that it is common for the clinical situation to have been presented very positively to patients in the interests of generating the maximum of hope. At the same time, a rather more pessimistic (or realistic) appraisal may have been given to relatives. A third, even more pessimistic, prognosis may be conveyed to medical colleagues. All this is liable to result in significant confusion.

Listening to a patient describe their own diagnosis and prognosis can also be a very useful way of identifying how much information the patient is likely to want from you, and also the language that the patient will best receive the information.

## **EXPLAIN medical facts in clearly understandable language**

Should the patient need to make an important decision about their treatment then this can only be valid if they are properly informed about (and understand) their clinical situation. It is necessary to check what the patient and their family understand about the disease. Where patients have been given an unrealistically positive impression, this will need to be addressed (though this often comes as a significant shock). Where there has been a decision by others (treating doctors and family) not to tell a patient bad medical news (e.g. that they have disseminated cancer) this must be questioned where the patient is then expected to make informed choices.

Medical facts need to be explained in clear language, together with their significance.

Misunderstandings will inevitably occur when significance is not understood. A massive intracerebral bleed may be considered to have the significance of a bruise to a patient or family member. Take nothing for granted, a surprising number of people think that brain transplants are both practical and possible!

Be careful to avoid jargon, telling a relative that a patient has a '*Glasgow Coma Score of 3*' or '*cardiomyopathy*' tells them nothing - except to confirm the gulf between you!

Be clear and direct in what you say, avoid vague terminology and un-necessary ambivalence. Focus on facts as much as possible. If you have no idea what the mathematical chances are then it is better not to state absolute numbers rather than just making them up. Using qualitative terms like "very likely" are just as effective for patients.

## **EXPLORE functional level and identify progressive functional decline**

It is important that we spend time exploring before giving options.

Showing interest and trying to understand more about the person's life is an important part of the listening process:

*'I am afraid that I haven't had the opportunity to get to know your mother at all because she was so sick when she came in to hospital. Can you tell me what her day to day life was like before she got sick, say 3 weeks ago?'*

This is a useful lead to explore how much debility is influencing function, and can easily lead to discussion of cognition and motor performance, and consideration of interactions and isolation.

*'What does she enjoy doing now? Are there things which she used to enjoy which she can no longer do?'*

*'Casting your mind back to a year ago, how have things changed for your Mum?'*

Most of us have particular things we like doing. When these stop it can infer a particularly significant change in a person's life situation. It can often be hard to recognise slow changes in functional status, so asking people to reflect back a year or more can often be quite revealing, both to us, and also to them.

It is important to explore functional status carefully – people may be coping well at home only because they have a great deal of assistance. Patients who can't get to the toilet by themselves usually have very significant limitation. Being unable to go to the toilet unaided, or being incontinent, is considered by most people to be an important indicator of dependency and is a major functional loss in the eyes of most people.

All of the above may clarify the extent of a patient's physiological limitation (e.g. due to lung or heart disease). This in turn may assist you to make a treatment recommendation – and the right treatment recommendation – BUT the major point is to try to help the patient (or their family) to tell you how they feel about their life and how it is progressing. **Telling the story will often help the family to appreciate the situation as much as it gives you an idea of the situation.** Sometimes going back many years may be useful.

*'Was he generally looking forward to things, did he have anything planned for the future?'*

*'How would you say she was thinking about her life?'*

*'Are there things you are looking forward to?'*

This can identify those for whom life has little in store and who therefore may not be keen to undergo unpleasant treatments with only a small chance of success. Obviously the role of depression must be considered when patients reduce their interest and interaction with life and begin to look towards death as a solution. You will need to clarify for yourself whether the evidence of physical debility fits with the reported inability. Where lack of interest seems out of proportion to the debility, you may need to try to identify signs of clinical depression and may wish request a psychiatric consultation.

## **EXPLORE values, hopes and fears**

Where a patient has not made their wishes clearly known and is now seriously ill and unable to contribute to the discussion (unfortunately the usual situation), it is useful to try to make the discussion with relatives involve the patient's views by pretending the patient is involved in the discussion:

*'If she were sitting here with us now what do you think she would say about all this'*

This helps to focus the discussion on the patient's perspective and permits their personality and/or approach to life to become a part of the discussion. This simple approach often quickly focuses the discussion when the family respond, 'she'd think it was stupid' or 'she'd say stop it.'

We need to get some understanding of how a patient views the "suffering vs reward" balance of treatment options so that we can try to consider this when making decisions for them in the future:

*'Some people we treat are willing to go through a great deal of discomfort for very long time if there is any chance at all that they might survive, even if they get one problem after another. But for other patients, they only want to try a treatment if it works very well and quickly gets them better. They don't want to go on and on if the treatment doesn't work. Do you think either of these approaches describe the way you feel?'*

This type of question explains that we recognise that people are different and wish to tailor treatment to their wishes. It opens up options for them to consider. They may answer ambivalently but any answer helps you to understand them better.

If it is accepted that resuscitation and other aggressive interventions will not meaningfully extend life, or improve quality, such care will usually not be demanded. Meaningful extension is a subjective concept, which the patient (or surrogate on their behalf) must determine.

People frequently make broad statements about choices in medical care, which don't help guide decisions on specific management options. Indeed, general statements can be dangerously misleading. Ask patients to clarify preferences if they seem too broad. For instance, patients who make statements such as 'I don't want to be kept on a machine' should be asked to clarify whether their wishes would change if their doctor thought the condition might be readily reversible.

Where general statements are made, ask patients/families to explain further:

*'You said that you don't want to suffer, what type of suffering are you talking about?'*

*'You said that you don't want to be a burden to your family, what do you mean by that?'*

*'You said that you don't want to be kept alive as a vegetable, what would that look like for you?'*

*'You said that you don't want to be resuscitated, what sort of things would you include in resuscitation?'*

Most patients believe that, at some point, life-prolonging interventions should be limited. So it is reasonable that this be discussed, particularly in older, chronically deteriorating, and seriously ill patients.

A patient's attitude to life prolonging treatment can be explored by asking:

*'Are there any sorts of treatment that you don't think that you would really want?'*

Discussing death can be a very useful way of helping to understand a patient's perception of values and wishes (obviously this is only appropriate where the patient has already indicated that life is pretty difficult), it is a question we regularly ask patients with psychiatric illness:

*'Have you been thinking about dying?'*

This can permit the patient to tell you that they want to die or to tell you how much they fear, and want to avoid, dying. Either response greatly helps you in your quest to understand how they are feeling. When patients tell us they fear dying, this should be further explored. Are there particular things they are frightened of? This might allow us to focus discussions on what we can do to avoid particular fears around dying, rather than avoid dying altogether.

Discussing CPR (cardio-pulmonary resuscitation) should be simple by this stage:

*'If your heart stops beating, or you stop breathing, we might attempt to bring you back to life by using electric shocks and chest compressions, and putting a tube in the lungs to get you breathing. I know on television that these treatments usually work, but in real life, it is rarely successful unless the person is well to begin with. I'm worried that this treatment will be distressing for you and unlikely to work.'*

*'If you die, I think we should allow you to die naturally at that point rather than trying to re-start your heart with CPR, which I think is very unlikely to help you.'*

It is also useful to understand what a patient hopes to accomplish with the limited amount of time that they have left. Exploring these hopes can frame decision-making regarding medical treatment, and it may become apparent that some of the patients' wishes can be easily fulfilled – offering assistance to achieve these wishes may be far more valuable than offering life-prolonging treatment. For example, a patient might declare that they wish, more than anything, to attend the wedding of a family member. It may be possible to defer, modify or omit an intervention or treatment in order to allow the patient to leave hospital earlier. Without asking the patient, we would not recognise the importance of the family event, and may instead have commenced treatment that prevents the patient from fulfilling their wish.

Often, hope will be layered, and therefore needs to be explored. For example, a patient's primary hope may be to overcome a particular illness and live a long and healthy life. This should be acknowledged, and where this hope is unrealistic, it is worth exploring the next "layer" of hope:

*'I can certainly understand why you would hope to get better from this illness. If that were not possible, what else would you hope to achieve in the time that you have left?'*

Many of these wishes will be as simple to facilitate as being taken outside the hospital to be visited by a pet, completing some important paperwork or meeting with an old friend. It might be reasonable to choose these activities, and hence enrich the patient's remaining time alive, ahead of offering medical treatments that serve only to prolong the patient's remaining time alive.



## **Give OPTIONS for treatment**

It is important for patients (and relatives) to have a clear idea of the possible options together with an understanding of the probable consequences of the different options, in order for informed consent to be valid.

Consequences might include the post-operative course, complications of any interventions, the duration of hospitalisation and rehabilitation, and the eventual change in health circumstances and functional status. Patients can easily perceive that they have a remote chance of getting better (easily) or otherwise they will die during the treatment (or on the operating table). They feel that they have nothing to lose. Unfortunately, for those choosing an interventional option it is rarely like this. Very few patients die on the operating table (a tribute to surgeons and anaesthetists). They are much more likely to return to ICU only to die after a considerable struggle (either in ICU, on the general ward or during convalescence).

Doctors should not present a treatment such as surgery or chemotherapy as “the only option”. Statements such as “*you need an operation, otherwise you will die*” do not present the patient with all of the options that are available to them.

When discussing a non-interventional option (such as palliative treatment of ischaemic bowel), it is always best to discuss it in terms of what **will** be done (analgesia, sedation if required, gathering close family and friends, attending to patient’s end of life rituals) rather than what **will not** be done (surgery, CPR).

**Patients need to understand that they do have something important to lose - that a high risk operation is associated with a substantial risk of causing an unpleasant protracted death, or survival with a reduced quality of life, something which most people strongly desire to avoid. Patients also need to understand that they always have a choice when it comes to potentially life-saving, but also potentially burdensome, treatments.**

## **ADVISE based on the patient's values, fears and wishes**

Doctors may be accused of paternalism when decisions have been made without reference to the patient's views. In response to this criticism many doctors conclude that it is inappropriate to give advice. This is an error. People expect and need professionals to give advice and expect this advice to be good and clear advice. Having taken the time to ascertain the patient's functional state and their values, as above, we are in a position to give advice that is in keeping with the patient's principles.

Not giving clear advice, but just 'listing options', often leads patients and relatives to select treatments that doctors consider to be unrealistic. We, as doctors, have experiences of disease (and its treatment) that the patient does not have. Our patients need the benefit of this knowledge.

Most patients and relatives need and value honest advice. They identify lack of advice from medical staff as a cause of stress. Relatives who have been given clear advice, and have been supported in their decision making, have been found to suffer less subsequent guilt and distress.

However, we must take care to ensure that the patient or relative realise when we change from providing 'medical facts' to giving 'our opinion'. Also, we should first clarify that the patient (or relative) wants our advice, as some will prefer not.

Often it is best to state that you are expressing your opinion. Always remember that what doctors say has great influence, so expressing opinions is a great responsibility. You should always strive to give good, impartial, considered advice.

*'In the light of this situation and your mother's expressed wishes I think it would be appropriate to give full support for 24 hours to see if this is easily reversible, and I think we should plan to meet again tomorrow to re-evaluate the situation.'*

*'If it would help you to know what I think I would do in this circumstance in the light of my experience with this kind of problem, I wouldn't recommend a machine to breath for him because I don't think there is any realistic chance of a good, quick recovery.'*

*'I realise that you want to give him every possible chance to get better, and I also know that you don't want him to suffer through painful procedures that won't be helpful to him. With this in mind I would recommend...'*

We also need to recognise that we can phrase things in a way that predetermines the answer (often without meaning to!). If we avoid this then we can improve the effect of our communication, for instance take the statement:

*'You need an operation'*

This may be stated as a medical fact (i.e. the treatment for this condition is surgical) but the patient is very likely to perceive that you are recommending surgery.

Doctors try to be absolutely honest, which is to be applauded. Sometimes this can lead to problems when we are discussing very poor choices and become focused on the problem of certainty. Almost nothing in medicine is 100% certain so addressing any issue from the perspective of 'is there any chance that this treatment *might work*?' must elicit a positive answer even if the chance is one in a million. If you say there is a chance then it is likely the patient or family will assume that you are advocating treatment (though this may not be your intention). It is better to talk about 'reasonable chance'. This avoids the requirement for absolute mathematical certainty and permits a degree of opinion to enter the discussion.

Examples of undesirable phrasing (which often occurs where surgical 'informed consent' is being obtained) include:

*'If we do nothing he will certainly die, but if we operate there is a chance'*

It may be more honest and helpful to say:

*'He is dying. We could operate, but it is unlikely to change the outcome and would put him through an awful experience without any reasonable chance of recovery. It might be better for us to treat the pain and for you to spend some time with him.'*

or

*'If we were to operate, and your father was lucky enough to survive, he would need a very long period of rehabilitation, and I think it is quite possible that he would never regain the strength that he would need to return home to live. He might then need to go to a nursing home.'*

This still gives patients and relatives the option of opting for intensive operative treatment should they wish. You have not said you won't provide treatment but have simply stated an appraisal of the facts. It is straightforward to revert to an aggressive treatment course should this be requested. This approach also avoids the perception that treatment is being denied (withheld) or has not been considered, both of which can cause anger in patients and their relatives.

When there has been a consensus medical decision that a specific treatment will not be offered to patients on the grounds that it is futile, it is not necessary to describe this option in detail. Instead of saying "there is an operation for this, but we don't think it is a good option", it is preferable to say

*"There are no treatments that can fix this problem. We will instead focus our treatments on..."*

Since understanding of the significance of the medical situation is so important it is useful to invite a response to check that there has been no misinterpretation, for instance by asking

*"It is important that I have explained the medical situation clearly. Can you just tell me, very briefly, what I have just told you so that I can be sure that I've done a good job?"*

Note the difference between "did you understand", which implies that any failure to understand is the patient's fault, and "have I explained this clearly", where we take responsibility for the effective transfer of information.

Identification of any doubts or misunderstandings gives you the opportunity to correct any before proceeding.

**NOTE:** Occasionally you may perceive that you are failing to establish a working relationship with a patient or family. In this case, it is important to withdraw rather than ploughing on. Everyone at sometime will find somebody with whom they are unable to communicate. It is appropriate in this situation to invite a colleague to restart the discussion. Knowing your difficulty, they are likely to approach the discussion very cautiously and frequently encounter surprisingly little barriers.

## AGREE on a plan

Having established the patient's clinical and functional situation and wishes, you are now in a position to formulate a plan together with the patient and/or relatives.

Make a plan which focuses on what the patient has expressed rather than what is technologically possible. Using the patient's own words may be useful:

*'From what you have said, let me suggest the following plan. Please tell me if I am correctly representing your views...'*

Summarise the basis of agreement and finish on a positive note – for instance a guarantee of comfort and avoidance of further discomfort:

*'I think we all agree that treatment up to now has not worked and more aggressive treatment is probably not going to either, and may actually cause her to suffer more. We will keep the antibiotics going and although I think this infection is rather overwhelming they could just work. However, if her breathing fails we won't make her more uncomfortable by putting the breathing tube in her throat, instead we will call you all immediately so that you can be with her, and we'll make sure that she is comfortable and not in distress Does that seem reasonable to you?'*

Explore the possibility that the family may believe that they are causing the patient's death by agreeing to forgo life support and suffer guilt. Focusing on what the patient would want, rather than what the family want, relieves this burden. Strong recommendation by physicians that intensive treatment not be pursued is also highly useful to avoid subsequent guilt:

*'All of the medical team looking after him have discussed the situation together. We are all in agreement that the treatment hasn't worked and that at this stage further treatment won't change the outcome. We are also aware that he has indicated that he has had enough and have taken this into account. I'm afraid he is going to die whatever we do. We are all sorry that things haven't gone the way he'd hoped they would.'*

*"I can see that you all love her so much, and that this hasn't been easy for you. We are confident that the decision to focus on her end of life care now is the right one."*

Almost all families are reasonable if you take the time to talk with them, explain things honestly and share the decision making with them. **Families should not be made to "bear the burden of withholding therapy"**.

You should try to couch the discussion in terms of "obtaining family agreement with a medically determined care plan" rather than "asking family for their permission".

Avoid discussions being focused simply on what you won't do for the patient. Focus on what you will do. For instance, this might include respecting wishes, respecting a desire for fastidiousness or independence which intensive intervention would challenge, or ensuring absence of discomfort, or of a drawn out death.

Remember that everyone is different. **Respect views even if these differ from your opinion.** Just be sure that the decision has been made in full knowledge of the facts and consequences. Some patients express very clear determination to fight and this should be recognised and respected. Providing the approach has been along the lines of the guidelines outlined, it is unlikely that it will be concluded that you do not care.

Sometimes a patient or relative suggests that by enquiring about quality or values you are suggesting that you have a wish to deny treatment. In this situation you should clearly point out that you have made no recommendation but are simply trying to understand your patient's wishes in order that you can advise on a plan of treatment. Make it clear that since they are taking offence it seems that they do want full treatment and that you will plan accordingly, after giving them all of the relevant information.

## **COMMUNICATE the plan**

Document the basis of the discussion in the patient's notes otherwise others who may become involved (often in response to an emergency) will not appreciate what has been decided. It is not sufficient to fill in a "not for CPR" form – the details of the conversations that led to that decision are equally important. It may be useful to read back what you have written to the patient or family.

Should the patient die, then anybody reviewing the case (including the Coroner) will be able to appreciate what has been done and the underlying reasons. Hopefully it will be clear that the decisions have been made in the patient's best interests.

Where decisions have been made with the patient, particularly when a non-interventional plan is agreed, it is important that the relatives are informed of the decision by medical staff. It may be helpful for the patient to be present.

It is not fair, or wise, to leave the patient to explain to their family. Frequently the patient will not be able to give a complete reproduction of the discussions had with medical staff, and the family will not understand and may pressure an older relative to accept an interventional treatment, which they have previously declined. This may reasonably be predicted and can be avoided if the doctor involved with the earlier discussion with the patient meets with the relatives and explains the situation to them. At this meeting it is important to focus the conversation on the patients' interests and wishes and to clearly state that while the family's wishes are important, they are not the focus of the discussion.

Finally, communicate the agreed plan to all other medical teams, nursing staff and other healthcare staff involved in the care of the patient.

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