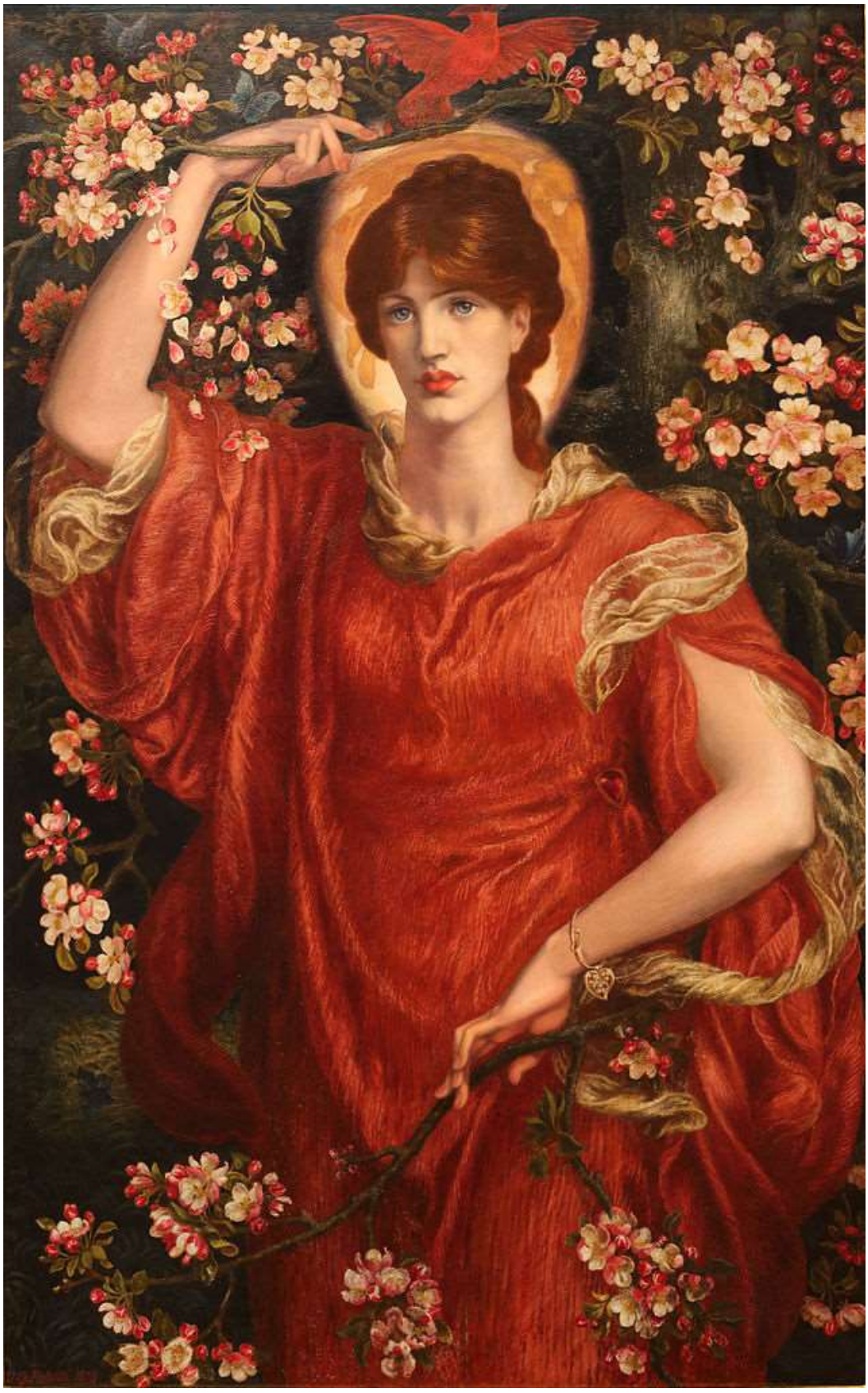
THE NORTHERN HOSPITAL

ADVANCE CARE PLANNING



"A Vision of Fiametta", Dante Gabriel Rossetti, oil on canvas, 1878, private collection.

"...How many valiant men, how many fair ladies, breakfasted with their kinfolk and the same night supped with their ancestors in the next world!...

The condition of the people was pitiable to behold. They sickened by the thousands daily, and died unattended and without help…

Many died in the open street, others dying in their houses, made it known by the stench of their rotting bodies…

Consecrated churchyards did not suffice for the burial of the vast multitude of bodies, which were heaped by the hundreds in vast trenches, like goods in a ship's hold and covered with a little earth."

Giovanni Boccaccio, The Decameron, (1350-53).

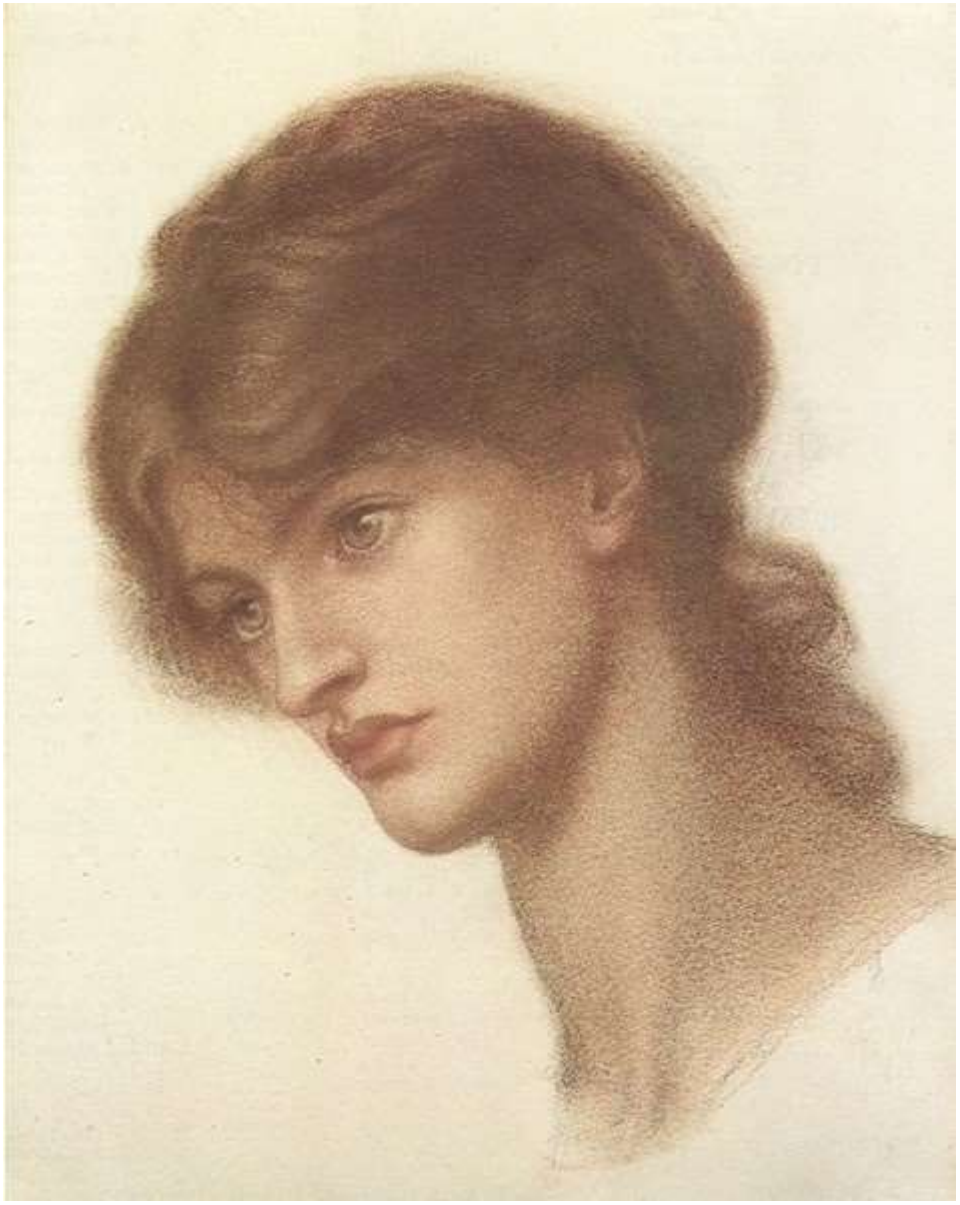
The "Great Pestilence", as it was known to its contemporaries, otherwise known to history as "The Black Death" of 1347-1350, was the greatest biomedical disaster in human history. It swept suddenly through Europe and the Near East and for three years devastated and terrified the population who thought that the vengeance of God had come among them for their sins. Many were convinced that the apocalypse (the end of the world) had come. Conservative estimates have put the death toll at 20-25 million. A later "pestilence", the great influenza pandemic of 1919 would claim more lives in total than this, however in the context of the mid fourteenth century this figure represented 30-40 percent of the entire population. This was a disaster on a scale that had never before been encountered in human history and has not been matched since. There are instances in England of whole villages disappearing from the written record at this time. The Black Death had profound psychological effects on the surviving population. These effects can be seen reverberating through the art and literature of the ensuing 200 years. The popular children's rhyme "Ring around the Rosies" is thought to echo the memory of the Black Death, a subconscious attempt, the psychiatrists tell us, to pacify and repress society's collective memory of an unimaginably terrifying event.

Boccaccio was a direct witness to the Black Death and has left a description of those times for posterity in his book, the Decameron. Written just two years after the event it has become one of the seminal landmarks in Western literature. It is a fictional work set against the backdrop of the plague's visitation to Florence, his hometown that was particularly hard hit by it. His description of the total physical and moral disintegration of society that occurred at this time and the feelings of utter terror and disbelief of the population makes poignant reading indeed. The people of his time had no concept of what was happening to them and could only attribute it to the will of a wrathful God or a malignant alignment of astrological influences. The sense of despair is palpable as he describes the helplessness of the people. Whole families would perish together in their houses within days, with no one left in the city to bury them. He describes how in these circumstances the people on seeing the helplessness of the medical profession to do anything to alleviate the disaster, chose to go their own various ways to combat the "visitation". He describes with horror the vast array of increasingly desperate measures that people tried, from rosewater, bloodletting and prayer to the consumption of all manner of bizarre concoctions, including crushed emeralds, gold and snake skins!

In the Decameron 10 young people of the city, 3 men and 7 women reject all these measures and decide that the only course of action is to escape the desolation and despair of the city, and calmly await the judgment of God. They take up refuge in an abandoned nobleman's country manor set in an idealic "Garden of Eden" just outside Florence. Here

they decide to pass the time by each of them telling a story on each of the following 10 days, whilst the plague rages all around them. One of the young female storytellers is the beautiful Fiametta and it is this character that inspired the stunning "vision" that Dante Gabriel Rossetti would have over five hundred years later.

In the 21st century the Black Death is only a distant memory, yet there comes a time in many individual's lives were they must face their own personal "Black Death". Whilst our forebears of the mid fourteenth century would be amazed at the ease with which medical science can now treat Yersinia Pestis there nonetheless remains many other conditions including cancers, neuro-degenerative disorders and ageing, for which there are still no answers. We can learn from the Decameron that in the face of this powerlessness we must allow patients to make their own choices in how they wish to deal with their situation. It is to be hoped however that these decisions can now be well informed ones. Patients may need to be educated about potentially distressing and ultimately fruitless measures. They may need to be provided with a clear vision of more appropriate measures that will provide a restful and dignified refuge for their last years or hours.



A Study for Fiametta, Dante Gabriel Rossetti

ADVANCE CARE PLANNING

Introduction

Emergency Departments are continually called on to provide emergency treatment for elderly and/ or very unwell patients who may be at the terminal stages of their lives or disease processes or who are dying.

Aggressive invasive and burdensome medical management is frequently not appropriate for many of these patients, and decisions about how far to investigate or to treat can be complex and difficult.

These decisions will often need to be made in conjunction with the patient's own preferences, or where they are unable to make these decisions, with relatives or principal carers. It is important in these situations to identify the correct substitute decision maker and to include them in the decision making process.

Pressured and hurried decisions are not optimal for complex and often emotional situations, and may lead to needless, distressing and even non-beneficial interventions.

Completing an **Advance Care Plan** prior to a crisis presentation to the Emergency Department can help alleviate the distress and uncertainty of decision-making in these circumstances.

It should be stressed that Advance care Plans that aim to limit inappropriate escalation of medical treatment does not equate with *no* treatment!

Advance Care Planning is a way for patients to let their health care providers and significant family and friends know in advance what health care options they want, **should they become too unwell to communicate this.**

They may indicate:

- Who they have appointed to be their Medical Treatment Decision Maker or Person Responsible.

- Preferences and values that they would want taken into account when making medical treatment decisions

Background

A competent patient can consent to or refuse medical treatment.

A patient has decision-making capacity in relation to the proposed decision if:

1. They can understand the information relevant to the decision and the effect of the decision.

2. Retain the information long enough to make the decision.

3. Weigh the information to make a decision.

4. Communicate the decision in some way.

Advances in medical technology have created increasing potential to prolong life through artificial or mechanical means. This can create dilemmas when the underlying medical problem has limited reversibility or when the means for sustaining life are excessively burdensome.

Doctors and family can find themselves having to decide for the patient when to withhold or withdraw life-sustaining treatments when the patient can no longer communicate their own decision.

Advance care planning enables a patient's preferences and values to be taken into account in these decision-making discussions.

Sometimes there will be written documents; more often there will have been a verbal discussion between patient and family.

Both must be taken into account.

The Philosophy of Advance Care Planning

Advance care planning is a process enabling a patient to express preferences about his or her future health care in consultation with their health care providers, family members and other important people in their lives. It is based on the ethical principle of respect for patient autonomy.

An Advance Care Plan offers the competent patient an opportunity to say now who they would want to be their substitute decision-maker in the event they lose competence. It also enables the patient to describe what they would want considered by their substitute decision-maker and doctors when making medical decisions for them.

It may include instructions about specific treatments and/or values and beliefs that they would like to be applied to that decision-making.

Process of Advance Care Planning

The process involves individuals talking with their health care providers, family and significant others about the medical treatments and care they would and wouldn't want if they were unable to speak for themselves.

This should be as well-informed as possible, recognising that it is not always possible to anticipate what future health problems will arise for a patient and what decisions might need to be made.

Some individuals choose to document their preferences in writing - as an **Advance Care Plan**.

A copy of this plan can be kept in the individual's medical record.

The Advance Care Plan should only be applied if the individual is unable to speak for themselves. If the patient is able to speak for themselves, and an Advance Care Plan is available, it can create a starting point for a discussion with that patient about treatment. It

is also an opportunity to check that the Advance Care Plan is still current. A patient with medical decision-making capacity can override their own Advance Care Plan.

Documentation

Advance Care Planning documents may include the following:

Copy of the patient appointment of a **Medical Treatment Decision Maker**. In Victoria, this is usually a **Medical Enduring Power of Attorney**, but they may have appointed an **Enduring Guardian with healthcare powers** or an Enduring Power of Attorney with personal powers that includes health. If multiple appointments have been made, the Medical Enduring Power of Attorney is always the **Medical Treatment Decision Maker** or **Person Responsible**.

- A Refusal of Treatment Certificate, (in the state of **Victoria**). A valid Refusal of Treatment Certificate that applies to the current situation must be followed exactly.

- A statement of information the patient would want to be considered by others when planning medical care, including treatments that they may want withheld.

- A Record of Advance Care Planning Discussions, which may include discussions documented within a doctor's letter.

It is not relevant that the Advance Care Planning document does not have the letterhead of your organisation; the document belongs to the patient and not to the organisation

Patients with Advance Care Plans should have the relevant Legal "Alert" in their medical record.

Role for Emergency Departments

Identification

Patients with Advance Care Plans may present to the Emergency Department.

Patients *who would benefit* from an Advance Care Plan but do not have one may present to the Emergency Department.

Although the patient or their substitute has a responsibility to make their treatment preferences known, it is important that Emergency Department staff **facilitate** this communication by specifically enquiring if the patient has an Advance Care Plan, and specifically asking about the appointment of a substitute medical decision maker.

Process in the ED in Victoria

Note that exact legal procedures will vary from state to state.

In the State of Victoria:

- **The Medical Enduring Power of Attorney** can consent to and refuse treatment on behalf of the patient who lacks capacity to do this for themselves.

The Medical Enduring Power of Attorney may refuse medical treatment if they believe the treatment would cause the patient unreasonable distress, or they reasonably believe that the patient would consider the treatment unwarranted.

- **Other** Persons Responsible, or Medical Treatment Decision Makers, cannot refuse treatment on the patient's behalf, using the Refusal of Treatment Certificate, but the practitioner cannot provide treatment where the Person Responsible withholds consent; doctors must follow the legal process for consent if they seek to provide that treatment.

Referral from the ED

Patients are frequently identified in the ED who may benefit from an Advance Care Plan.

The following steps can be taken:

- Initial discussion with the patient themselves
- The results of this initial discussion should be recorded in the patient's medical record.
- Further discussion may also be necessary with the patient's general practitioner and any relevant specialist practitioners.

Emergency Departments play a key role in identifying patients who may benefit from an Advance Care Plan.

The ED however is clearly not the appropriate place to develop a comprehensive Advance Care Plan for a patient, although a **Goals of Patient Care** form can be completed to communicate the medical treatment plan regarding treatment escalation, and limitations to treatment escalation, while the person is in the Emergency Department.

Currently in most EDs, the best initial line of referral will be via the department's **Care Coordinator, but this will depend on local practice.**

It is important to remember that patients should not be compelled to develop an Advance Care Plan but, rather, should be given the opportunity to consider one.

Resources

Important sources of information on Advance Care Plans include:

1. **Advance Care Planning Australia.**
   - www.advancecareplanning.org.au
2. **Office of the Public Advocate in each state**

   In Victoria:
   - www.publicadvocate.vic.gov.au
3. **Department of Health in each state**

In Victoria:

- http://www.health.vic.gov.au/acp/

References

1. Singer PA, Roberston G, Roy DJ. Bioethics for clinicians: 6. Advance care planning, CMAJ 1996; 15 (12): 1689-1692

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