

END-OF-LIFE DECISION MAKING BY GUARDIANS

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END-OF-LIFE

Like birth and taxes, we will all have an “End-of-Life”. The specifics of taxes remain a vagary of incumbent government, and birth usually has a significant period of anticipation prior to the event. In distinction however, in the majority of cases, one’s end-of-life is rarely known with great precision related to how, when and where, unless measured in microseconds.

BACKGROUND

There has been a pendulum shift from the established medical paternalism of the 1950s to a much greater emphasis on patient autonomy, with a patient being much more involved in what happens to their body.

This is addressed through the process or concept of “informed consent”.

Coupled with this, the aging of the “baby-boomer” generation with their affluence and high level of demand, interest in influencing their health interactions and expectation of good outcomes no matter what, has enabled them to live longer, but with a higher level of chronic illness. Some consider that patient expectation has moved even further, causing medical practitioners to adopt a, “whatever you want” approach.

Clinicians have acted to prolong life, but in some circumstances now delay death, including using heroic interventions to support a failing organ system or systems, in a context that cannot be regarded as futile medical treatment. This may arise in a “difficult” clinical setting, where clinical prognosis is guarded, but a fear of potential legal sanction leads to prolonging treatment. In the setting of unknown patient wishes, this conservative approach can be seen as prudent. Such heroic interventions are usually conducted in an intensive care unit (ICU).

Whilst specific units vary, in an adult ICU, some 22% of patients are elective admissions consequent to major surgery, predominantly arising from open heart surgery. The remainder of admissions are “unplanned” in an emergency circumstance from the accident and emergency departments, the operating room or the hospital wards; and any of which can occur at any time of the day. The full spectrum of pre-existing health status, age and cultural expectations is represented. In the order of one third of patients admitted to an ICU do not survive to discharge from that unit, one third are discharged from ICU but do not survive to discharge from hospital, and the remaining one third are discharged home.

Under Victorian law, provisions of the *Medical Treatment Act*¹ provide for a person to refuse medical treatment.

There are many circumstances where a person is unable to determine their own healthcare management. One circumstance, involving adults, who may have previously been able to contribute to their healthcare planning, is within an adult ICU. If the person is unable to participate in their own healthcare decision, there is a requirement for a substitute decision-maker.

Further provisions of the *Medical Treatment Act*² provide for a person to have an Enduring Power of Attorney (Medical Treatment); however, this type of Power of Attorney must be in the proper form as required by that legislation/.

The vast majority of ICU patients acutely lack the mental capacity to undertake rational decision making for themselves. As the majority did not intend to be in the ICU in the first place, not all are pre-prepared with a substitute decision-maker holding an Enduring Power of Attorney (Medical Treatment), particularly those in younger age groups.

Generally, if the patient's wishes regarding their management, should they ever find themselves in the circumstance which have eventuated, are unknown, an appropriate substitute decision-maker acting in the best interests of the patient is available, particularly a spouse or primary biological relative.

It is possible such a substitute decision-maker cannot be identified or does not agree to undertake the role. This may be through uncertainty or conflict, the latter embracing between relatives and the medical team or between different "camps" of relatives with different views. If a suitable and willing substitute decision-maker cannot be obtained, in Victoria, Australia, legislation³ permits an application to be made to the Victorian Civil and Administrative Tribunal to appoint a statutory independent legal guardian.

Relevant provisions of the *Guardianship & Administration Act 1986* (Vic) provides for the exercise of authority by a guardian⁴, and describe⁵ how the guardian must contemplate "best Interests" for a person. This reference to "best interests" broadly requires divining the decision a person would make based on their values, circumstances, and the risks and benefits of any contemplated healthcare intervention. The precise text of section 38(1), dealing with the issue of "best interests", is as follows:

In this Part, for the purposes of determining whether any special procedure or any medical or dental treatment would be in the best interests of the patient, the following matters must be taken into account-

- (a) *the wishes of the patient, so far as they can be ascertained; and*

- (b) *the wishes of any nearest relative or any other family members of the patient; and*
- (c) *the consequences to the patient if the treatment is not carried out; and*
- (d) *any alternative treatment available; and*
- (e) *the nature and degree of any significant risks associated with the treatment or any alternative treatment; and*
- (f) *whether the treatment to be carried out is only to promote and maintain the health and well-being of the patient; and*
- (g) *any other matters prescribed by the regulations.*

Whilst the literature is replete with studies related to substituted decision making, there is none related to how appointed guardians are to undertake their role. The determinations of the guardian typically must be undertaken in a timely manner.

This paper relates to a unique study undertaken in the Office of the Public Advocate (OPA) in Victoria, Australia, from whence many guardians are appointed.

They have a vast experience in decisions related to persons with a disability, particularly around place of domicile, but including significant health-related decisions. Several now have experience related to end-of-life decisions for patients for whom no other suitable guardian could be identified. The research question was to determine:

- (a) what it is that guardians do, and
- (b) how is it different to the managing clinician,

in these end-of-life circumstances when they contemplate an end-of-life decision.

RESEARCH PROTOCOL

Following Human Research Ethics Committee approval, and informed consent of participants, a qualitative study comprising a semi-structured interview lasting 50 to 65 minutes was conducted by the author. The interviews were openly recorded, and transcribed by an independent person experienced with issues of medical terminology and confidentiality. The protocol indicated that each of the OPA guardians involved in the process would be interviewed, despite the possibility of saturation occurring.

RESULTS

Thirteen guardians were invited to participate through OPA and 12 interviews were conducted between March 2008 and April 2009⁶. Relevantly,

- (a) Seven were female,
- (b) One recently retired (but continued in a volunteer capacity); and,
- (c) one retired during the research period (but continued in a volunteer capacity).

Of the eleven guardians who indicated their age, the average age was 51.5 years, with a span of 41 – 61 years of age. The average duration of employment with the OPA was 9.25 years, with a span of 3 – 16 years.

All guardians possessed an interest in people with disability, and three had emigrated from the United Kingdom. There were tertiary qualifications in community work (five), legal (four), disability work (two), allied health (one), archaeology (one) and education (one); of these tertiary qualification, nine were at the Bachelor level, and three at the Masters' level.

The entry to becoming a guardian within OPA had resulted from an internal restructuring for six of the guardians, with four having previously been associated with the Office's Investigator section, one in its Advocacy section, and one in its Guardianship section. Six had applied following noticing newspaper advertisements, with two of these having received personal recommendations once the advertisements had been published. Two further guardians were employed following personal recommendations to apply for a position.

In summary:

- (a) These guardians had participated in the healthcare considerations of 38 patients requiring end-of-life decisions between 1996 and 2009.
- (b) The range for individual guardians was one to seven, with a median of 2.2 decisions.
- (c) The longer a guardian had been employed at the OPA, the more decisions they had undertaken. In part this was a function of an alteration in the process of delegation which evolved over the period from 1996.
- (d) The process by which the guardians made their decisions was considered by each to be an extension of their personal experience related to decisions they made as guardians in the area of suitability of personal accommodation or healthcare matters.

- (e) Each guardian considered they took responsibility for the decisions they made; and,
- (f) Each guardian considered they advocated for the patient's interests, by which they meant the patient's fundamental values.

With respect to the statutory principles of a person's "best Interests", the guardians considered these comprised the least restrictive means to give effect to that person's wishes. They did not contemplate the statutory principles as being a hierarchy.

Ultimately, the guardian derived the decision the guardian believed the person would make if they were able to make reasonable decisions taking into account what matters to them, comprising the person's critical interests and their embedded values.

All guardians considered end-of-life decisions as more significant than accommodation decisions, and all relied heavily on available senior medical opinion. This enabled them to contemplate the distinction between the person's current medical interests and their life interests.

A guardian would refuse medical treatment on behalf of a patient if it was considered to be unduly distressing, or if there were grounds for the guardian to believe the person would not want it. All guardians were aware that people change their mind when confronted with a given set of circumstances that they had only previously ever considered as a matter of conjecture.

The guardians undertook a process to "get to know the person". This involved investigative information gathering. They would contact family members, friends and neighbours in order to determine the patient's presets of faith and culture. They only wanted to focus on relevant issues, including whether the patient's wishes could be regarded as realistic, and the strength of conviction with which the wishes were held.

In addition, they obtained information about current medical status and likely prognosis in order to gain a concept of the type of life they will have with ongoing treatment, particularly with respect to their engagement with others.

The guardians preferred to consider all options related to medical treatment types and extent available, as well as the possibilities life might contain with or without various supportive treatment options.

With respect to an end-of-life decision, guardians expressed a tendency to preserve life, as it is an irreversible process following a decision to withdraw treatment without which life will not continue.

THEMES

Several themes emerged. There were five specific themes, namely:

1. Guardians follow the rules and requirements as provided for in the legislation. Eight of the guardians were specifically asked about this (the others had already spontaneously addressed the question), and indicated that this was “ingrained” in them.
2. Communication is a key tool of the guardians. They enquire to their satisfaction to ensure their decision is right. A pre-existing informal internal communication process within the OPA has now been formalised to ensure the decisions are validated. The medical opinion must be from the most senior consultant involved in the management of the patient. Two-thirds of the guardians would obtain a second opinion from an independent medical consultant if they deemed it necessary.
3. All guardians were passionate with respect to their role and the contribution they are making to the community. They find it internally rewarding. Ninety-seven percent were comfortable with the decisions they had made. One guardian opposed the conclusion of the assessment that that guardian had determined and continued medical treatment, and remains uncertain why that guardian did so.
4. The guardians have no consideration of cost related to decision-making, either in the pure financial sense or the related opportunity cost of use of scarce community resources. That is the economic cost was not a factor in considering the required “best interests” test.
5. Each guardian had one memorable “war story” involving a senior medical practitioner introducing subjective medical paternalism and imposing their impression of the value of a patient’s life.

CONCLUSION

Guardians understand their role, and act according to the legislative requirements demanded of them. They reach their decision once they are satisfied they have all the information necessary to achieve it. The role of the statutory appointed guardian provides a community safeguard for those caught in a most vulnerable situation, but it does retain the human potential for “error”.

As to what do guardians possess or offer that the managing clinician does not, it is clear they possess unfettered authority to reach their decision on a base of significant experience with people suffering a disability. They have investigation resources, and importantly are independent of medical pressure related to the knowledge of another person that might be requiring the resource.

One might ask if the system can be improved? It is unreasonable to attest that the system is perfect, but the “war stories” suggest system is robust as it stands.

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¹ *Medical Treatment Act*, 1988 (Vic); ss. 5 and 5A

² ss. 5AA and 5B

³ *Guardianship & Administration Act* 1986 (Vic)

⁴ s. 28

⁵ s.38

⁶ The remaining invitee declined as that guardian had not undertaken any relevant cases