Time to Improve Informed Consent for Dialysis: An International Perspective

Frank Brennan,* Cameron Stewart,† Hannah Burgess,* Sara N. Davison,§ Alvin H. Moss,** Fliss E.M. Murtagh,** Michael Germani,¶†† Shelley Tranter,* and Mark Brown*

Abstract
The literature reveals that current nephrology practice in obtaining informed consent for dialysis falls short of ethical and legal requirements. Meeting these requirements represents a significant challenge, especially because the benefits and risks of dialysis have shifted significantly with the growing number of older, comorbid patients. The importance of informed consent for dialysis is heightened by several concerns, including: (1) the proportion of predialysis patients and patients on dialysis who lack capacity in decision making and (2) whether older, comorbid, and frail patients understand their poor prognosis and the full implications to their independence and functional status of being on dialysis. This article outlines the ethical and legal requirements for a valid informed consent to dialysis: (1) the patient was competent, (2) the consent was made voluntarily, and (3) the patient was given sufficient information in an understandable manner to make the decision. It then considers the application of these requirements to practice across different countries. In the process of informed consent, the law requires a discussion by the physician of the material risks associated with dialysis and alternative options. We argue that, legally and ethically, this discussion should include both the anticipated trajectory of the illness and the effect on the life of the patient with particular regard to the outcomes most important to the individual. In addition, a discussion should occur about the option of a conservative, nondialysis pathway. These requirements ensure that the ethical principle of respect for patient autonomy is honored in the context of dialysis. Nephrologists need to be open to, comfortable with, and skillful in communicating this information. From these clear, open, ethically, and legally valid consent discussions, a significant dividend will hopefully flow for patients, families, and nephrologists alike.


Introduction
In the modern era, there has been a significant shift in the demographics of patients with ESRD, with an increase in older and frailer patients who have multiple comorbid conditions. This change has highlighted the imperative of carefully balancing the benefits and risks of dialysis treatment. This balance has medical, ethical, and legal dimensions. Nephrologists, like all physicians, are well aware of the need for and importance of informed consent. There is, however, a major disconnect between that awareness and the reality of adherence to the requirements for informed consent for dialysis (Figure 1, Tables 1 and 2). Too often, patients are told when they will need dialysis and not if they will need dialysis (1), are not informed of the possibility of conservative management (2), and are not adequately informed of the burdens and risks of dialysis. How have we come to this point? As Kaufman et al. (3) stated, “procedures that are relatively low risk . . . [such as] dialysis quickly become standard practice. Actual clinical choice about them is thereby eliminated.”

The suggestion that nephrologists may eliminate actual choice is extraordinary in a discipline that recommends shared decision making for all patients facing dialysis discussions (4).

One context of shared decision making is the process of informed consent leading to the initiation of dialysis. Informed consent is a specific process prescribed by law, and this encompasses several elements. In addition to the perspective that dialysis, as standard practice, does not require a process of informed consent, there are many causes for deficits in practice, including an inadequate understanding of the legal requirements of informed consent; inadequate training or modeling of these conversations; a perception that prognostic data are sufficiently robust to make clear recommendations or if countenanced, a reluctance to disclose such information; a belief that nephrologists have an ethical and/or legal obligation to offer dialysis to all patients and that failure to do so exposes clinicians to possible litigation; and a level of discomfort in having these conversations. Each of these challenges needs to be addressed. None are insuperable. It is by no means clear why dialysis has been somewhat exempted from informed consent in day to day practice, but this presumably stems from days when it was a more immediate life-saving procedure in predominantly young single-disease individuals.

In this paper, we outline the legal requirements for a valid informed consent to dialysis at common
Throughout, dialysis refers to hemodialysis and peritoneal dialysis. Common law jurisdictions are those that are derived from English judge–made law, including England and Wales, Northern Ireland, Eire, Australia, New Zealand, Canada, and the United States. Although there are jurisdictional differences, the basic legal elements of consent are shared across these countries.

Understanding the nature and content of informed consent to dialysis is important medically, ethically, and legally. This process is especially important in light of (1) the common fallacy that informed consent is simply securing the signature of a patient on a form. Nephrologists should realize that informed consent is a process, required by law and ethics, which necessitates a series of steps. Often, however, this is telescoped into a very brief discussion because of inadequate pre-ESRD care or because the patient has crashed. The latter situation is a medical emergency. The law does not require consent in a medical emergency but expects the physician to go ahead and act in the best interests of the patient. Clearly, however, if the patient was already known to a nephrologist before the crash, then an opportunity for informed consent has been missed. Additionally, this process is especially important in light of (2) the rapid growth in the number of older patients commencing dialysis (5), (3) questions surrounding capacity of patients with ESRD (6), (4) literature comparing the survivorship of older, frailer, and more comorbid patients on dialysis with those on a conservative, nondialytic pathway (7), (5) concerns expressed about the levels of information currently given to patients by nephrologists in the process of consent (8,9), and as a result, (6) uncertainty that patients understand the likely trajectory of their illness and the full

Figure 1. | The elements of a legally valid consent for dialysis.

<table>
<thead>
<tr>
<th>CAPACITY</th>
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<tbody>
<tr>
<td><strong>Does the patient have capacity to make an informed consent?</strong></td>
</tr>
<tr>
<td><strong>The nephrologist should check if the patient understands and retains information and employs reasoning</strong></td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>Not Sure</td>
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<tr>
<td>No</td>
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<table>
<thead>
<tr>
<th>VOLUNTARY</th>
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<tbody>
<tr>
<td><strong>Was the decision made freely and voluntarily?</strong></td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
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<table>
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<tr>
<th>SUFFICIENT INFORMATION</th>
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<tr>
<td><strong>Was sufficient information given to the patient in an understandable manner?</strong></td>
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<tr>
<td>Yes</td>
</tr>
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<td>No</td>
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- The role of dialysis
- The logistics of ongoing dialysis treatment
- The benefits and risks of dialysis including the likely trajectory of the disease and the effect on the life of the patient.
- Any risks material to the individual patient
- An explanation of the option and role of conservative care.

<table>
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<th>Consent invalid</th>
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<th>Legally/ Valid Informed Consent</th>
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implications of dialysis on their life, independence, and functional status.

**Elements of Consent**

There are four basic elements of a legally valid informed consent are. 1) The patient must have the decision-making capacity to consent to the treatment. 2) The consent should be an informed one, with information given in an understandable manner. 3) The consent must be made freely and voluntarily. 4) The consent must cover the treatment given.

If any one of the elements is absent, the consent is legally invalid. An exception to this process is where a competent patient waives this right and hands over the process of decision making to other people, usually the family (10). Ethicists have added further elements to the process of informed consent, including the importance of a physician recommendation, a decision in favor of a clinical plan, and authorization of that chosen plan in the signing of a consent form (11). These elements are set out in Table 2. The literature reveals a significant disconnect between these legal and ethical requirements and current nephrology practice (Table 1). Clinicians should realize that informed consent is more than simply securing the signature of a physician on a form. Informed consent is a process, required by law, which necessitates a series of steps set out in Figure 1.

**Capacity**

An 84-year-old man has ESRD secondary to hypertensive nephrosclerosis. During discussions about dialysis, it becomes obvious that the patient has significant short-term memory loss and is struggling to manage at home.

The law presumes that an adult patient has the capacity to consent to medical treatment (12). That presumption, however, is open to challenge. If there are concerns, it is prudent to organize a formal assessment of capacity. That prudence is especially important in view of the contemporary demographic profile of patients on dialysis, because in developed nations, the age cohort of patients on dialysis that has the greatest prevalence is the 65- to 84-year-old age group.

Decision-making capacity has three elements: understanding the information provided, retaining that information, and reasoning to reach a final decision (13). Capacity should be
assessed in relation to the specific decision being made at that time.

There are two common clinical situations where difficulties with capacity may occur. The first is the patient with the uremic symptoms of drowsiness or confusion. The second is the patient with dementia. It is important to note that these conditions per se do not mean that the patient lacks capacity to make an informed consent. The issue is whether the patient understands, retains, and reasons with sufficient capacity at the time that the consent process occurs. If there are concerns about the capacity of the patient, it may be prudent to organize a formal assessment of capacity using specific instruments (14,15). The process for patients who lack capacity is covered later in this article.

**Voluntariness**

A 72-year-old man has polycystic kidney disease. He has had two renal transplants. The second is failing. He informs his family that, after considerable thought, he has chosen not to go back onto dialysis. His nephrologist says to the patient, “I don’t think that is the right decision; in my view you really do not have a choice and you should go back onto dialysis.” One daughter repeatedly says to her father, “You must start. Mum has gone. We can’t lose you too. I couldn’t bear it if you went.” The patient consents to recommencing dialysis.

The law states that, for a medical consent to be valid, it should be made voluntarily and without undue influence (16). Distinguishing clinician recommendation and family opinion from undue influence can be difficult. In the English case of *Re T* (*Adult: Refusal of Treatment*) (17), the court emphasized that patients, by definition, are vulnerable due to their illness and rely on the support of family and carers. The key difference between valid support and undue influence is the undermining of the independence of the patient (17). Lord Donaldson posited the test of undue influence as follows.

> Does the patient really mean what he says or is he merely saying it for a quiet life, to satisfy someone else or because the advice and persuasion to which he has been subjected is such that he can no longer think and decide for himself? In other words “Is it a decision expressed in form only, not in reality?” (17)

Variations on the scenario above are relatively familiar. Inevitably, family members will have and express an opinion on dialysis. That opinion may be on the basis of deep emotions, such as fear and guilt. Equally, patients may make decisions on the basis of the perceived needs and wants of their family. Rarely would such interactions constitute undue influence, such that the will of the patient was overborne. The law is quite strict in its definition. The law will only find involuntariness if the patient who consents to dialysis was not simply influenced but whether that influence was undue, such that his/her will was overborne. If the patient above commences dialysis, the question is not simply whether he was influenced but whether his will was overborne. In the above scenario, the nephrologist is incorrect in both fact and law. The patient does have the choice of conservative kidney management, and common law states that a competent adult has the right to refuse treatment (18).

**Level of Information Required**

A 74-year-old man has ESRD secondary to hypertensive nephrosclerosis. His nephrologist says to him, “we will need to prepare you for dialysis.” He is told he will be referred to a vascular surgeon who will arrange vascular access and that his dialysis will occur three times per week.

The common law states that, to exercise the right to determine what shall be done with his or her own body, a patient needs to be adequately informed by the clinician (19).

Broadly speaking, common law approaches this issue in two ways. (1) The law of battery states that, if a patient has a medical or surgical intervention without that person’s consent, then the clinician has committed a wrong to that person. The information required to ensure consent is advice as to the nature and effects of the intervention (19). (2) The law of negligence. As physicians, nephrologists owe their patients a duty of care. The standard of care is what a nephrologist would reasonably be expected to do in the examination, diagnosis, and treatment of their patients. The latter includes the doctrine of informed consent. This doctrine requires that “the voluntary agreement by an individual to a proposed procedure, given after appropriate and reliable information about the procedure, including the potential risks and benefits has been conveyed to the individual” (20). This doctrine is recognized in common law jurisdictions.

What level of information is required to be given by a nephrologist? In the context of dialysis, it is: (1) the nature of dialysis, (2) relative risks associated with dialysis, and (3) alternatives to dialysis. In many jurisdictions, although courts may refer to the accepted practice of a body of nephrologists, the court is the ultimate judge as to whether that practice meets their standard of care (19). Therefore, it is not sufficient for a nephrologist to simply rely on common practice (“we don’t usually go into too much detail”) regarding consent to dialysis.

In the United States case of *Canterbury v Spence*, the court held that a physician should explain to a patient all of the material risks of the treatment that a reasonable person in the position of the patient would be likely to attach significance (21). Since that case, many courts in the United States have followed the reasonable patient standard (22). In Canada, the Supreme Court in *Reibl v Hughes* agreed with this reasoning (23). In Australia, the High Court in *Rogers v Whitaker* held that, when physicians discuss the relative risks associated with treatment, they have a duty to warn a patient of a material risk inherent in the proposed treatment; a risk is material if, in the circumstances of the particular case, a reasonable person in the patient’s position, if warned of the risk, would be likely to attach significance to it or if the medical practitioner is or should reasonably be aware that the particular patient, if warned of the risk, would be likely to attach significance to it (19).
The Supreme Court of the United Kingdom in Montgomery v Lanarkshire Health Board (24) endorsed the Rogers v Whitaker test of what constitutes a material risk. In Eire, the Supreme Court of Ireland has, in more recent cases, favored a move toward the reasonable patient standard (25). In New Zealand, the requirement to gain informed consent is codified: every patient must be provided with the information that a reasonable patient, in the patient’s circumstances, would expect to receive (26).

The Material Risks Associated with Dialysis

Nephrologists have a duty to warn the patient of any material risk inherent in the process of dialysis. In the context of dialysis, a risk is material if, in circumstances of the particular patient, a reasonable person in the patient’s position, if warned of the risk, would be likely to attach significance to it or if the nephrologist is or should reasonably be aware that the particular patient, if warned of the risk, would be likely to attach significance to it. This might include the nature of ESRD, the role and nature of dialysis, the need for a dialysis routine and regular monitoring, changes in lifestyle and schedule, changes in diet, the known symptom burden of patients on dialysis, and the general complications of dialysis, including postdialysis fatigue, intradialytic hypotension, headaches, cramping, sepsis, and issues of vascular access. The law requires a discussion that includes both general information and how this information relates to the individual patient in their circumstances.

It can be argued that the entire cohort of patients with ESRD might attach significance to a discussion about further material risks when they consider their individual situation, seeking to balance the inevitable imposition of dialysis on their former life against their expected survival and likely quality of life. This is particularly relevant for patients who have characteristics associated with a poor prognosis on dialysis, including frail patients, many older patients, and patients with significant comorbidities, with chronic malnutrition, and for whom the nephrologist estimates a limited prognosis (4). For these patients, nephrologists might conclude that dialysis is likely to cause more harm than good. If the nephrologist reaches this conclusion with regard to a particular patient, ethicists would argue that the nephrologist is obliged to inform the patient and recommend against dialysis (11). A failure to give such a view leaves the patient adrift in decision making, not knowing what their physician thinks. Ultimately, it is the patient’s decision, but to reach that, the law requires that the patient is equipped with information.

In terms of the content of the information given, there are two areas of information that are particularly important: the anticipated trajectory of the disease and the effect of dialysis on the life of the patient. Both aspects should be discussed with an emphasis on the outcomes most important to the patient, recognizing that there are limitations in the currently available tools measuring both.

Trajectory of the Disease and the Effect on the Life of the Patient

Several years ago I asked … a capable and thoughtful nephrologist, “What is the most serious ethical problem in clinical nephrology?” Without hesitation she said, “our failure to inform patients with end stage renal disease of their [statistical] prognosis” (8).

Prognostic information is the single most important piece of information that patients need to make informed choices (27).

For an individual patient, accurate prognostication of a patient’s life expectancy is challenging. Invariably, it involves a complex combination of objective measures and clinical intuition (28). Therein is a challenge for physicians in communicating both clinical prognosis and uncertainty. Doing both is entirely appropriate. Indeed, Michel and Moss (9) saw clear advantage of this combination for patients with ESRD. They stated that “[i]n fact, it is in situations of clinical uncertainty that patients most want to introduce their extramedical values to assist in the decision-making process; thus candor about uncertainty of prognosis may encourage shared decision making” (9). When dialysis is being considered, prognostic information may be presented to the patient in various ways. One is annual mortality data, specifically in age-specific cohorts. Another is to compare the prognosis of patients with ESRD who pursue dialysis with that of those on conservative management. Criteria found to be statistically associated with poor prognosis in patients on dialysis have been listed above. In terms of conservative management, in one study, patients of average age 82 years old with ESRD who chose conservative management survived a median of 16 months, and about one third survived 12 months past a time when dialysis might otherwise have been indicated (eGFR below 10 ml/min) (29). Although prognostic instruments may not be sufficiently sensitive or specific to inform an individual patient of his exact prognosis, they are informative at identifying high-risk patients (30).

From time to time, patients with CKD will have an acute deterioration in renal function (e.g., postcardiac surgery) that precipitates a more urgent decision about dialysis. For this reason, we believe shared decision making about dialysis should be made early in the course of CKD; consent may be obtained at any stage in this process.

Another issue is the effect of dialysis on the life of the patient. A discussion about quality of life alone, as discerned by current instruments, cannot capture the full implication of commencing dialysis on a patient and his/her family (26). Those effects include limitations on independence; time spent in the hospital or dialysis center either on dialysis or with the complications of treatment; interference with usual daily activities, including pastimes; changes in diet; the distance and time of travel to dialysis units, especially in rural and remote areas; problems with mobilizing if frail; and the ubiquity of postdialysis fatigue and other symptoms. In an Australian study, patients approaching ESRD were often willing to trade months of life expectancy to reduce the burdens and restrictions on travel and independence imposed by dialysis (31). Patient groups in the United States and Canada also stated that quality of life is more important than length of life (32,33). A summary of the material risks to be discussed in the
process of informed consent for dialysis is provided in Table 3.

Sharing All Treatment Options

A patient with ESRD has three treatment options: dialysis; a conservative, nondialysis pathway; or renal transplantation. The legal obligation of a physician to explain to a patient other approaches to treatment was recognized in the Canadian case Haughian et al. v Paine (34) and in Australia by Justice Kirby in Rosenberg v Percival (35). To Kirby, the failure to inform the patient of available alternatives means that “[a]ny choice by the patient … is meaningless” (35).

A discussion about alternative options should be specific to the individual patient. For some patients, this may be a choice of modality. For other patients, this should include providing a clear explanation of the concept and content of conservative kidney management. It is important that the patient and family understand that conservative care is not medical abandonment and that the nephrologist will continue to review the patient. Ideally, conservative management should be a combination of excellent renal and palliative medicine (36). Over time, it is hoped a synthesis of these disciplines—kidney supportive care—will be a standard part of the practice of all nephrologists.

Issues of Communication

Nephrologists should be bilingual: they should speak the plain language of their patients and the technical language of their discipline. In terms of providing information and advice, it is critically important that the nephrologist uses language that is clear and understandable to the patient.

Another issue is the nature of the nephrologist-patient relationship. As with all health professionals, this is not a relationship of equals. There is an intrinsic vulnerability in being a patient, both physically and in terms of knowledge. For patients, the relationship with the nephrologist is one on the basis of trust. In terms of informed consent, this places a responsibility on the doctor to be careful in acting on that implied trust. As Beran (37) stated, “[t]he doctor must ensure that the relationship is not used as a ‘blunt instrument’ to achieve a desired outcome but rather should empower patients to decide their fate.” The process of informed consent is an interactive experience between the physician and patient. The clinician provides the information, and the patient decides. That decision, freely made and on the basis of the information given, will be grounded in his/her priorities and values. The law has shifted the onus significantly to include the perspective of the patient and indeed, obliges physicians to know what is relevant to the individual patient to fulfill their responsibility in information giving. Medical information, therefore, combines with and is guided by both practical expertise and patient values. Ideally, this two-way exchange between clinician and patient allows a treatment decision to be reached that is founded on wisdom and respect.

Overarching this discussion of communication is the importance of giving patients time to consider carefully their options, talk to their family, and when necessary, have further discussions with their nephrologist. Importantly, as Miller (8) stated in the context of information giving to patients with ESRD and on dialysis, “I[...]o know what the patient would like to know, we need simply to ask, but having done so, we must then be silent and listen” (Table 4).

A critical concern is the situation where the patient, inadequately prepared in the predialysis setting, deteriorates. Here, there is little time. This situation is compounded if the nephrologist is unaware of his/her legal and ethical obligation to obtain an informed consent or unprepared to participate in this process.

Finally, it is important to acknowledge that the provision of information to patients in a predialysis setting may come from many sources, including senior renal nurses and social workers. Nevertheless, the law holds the physician overseeing dialysis as ultimately responsible to ensure that the patient has made a valid, informed consent to treatment.

At the commencement of the section Level of Information Required above, we set out a scenario. In that scenario, the information provided to the patient was procedural, not contextual. It did not contain any information on the benefits and risks involved in being on dialysis, any explanation of prognosis, or any discussion about quality of life. There was no discussion of the possibility of a conservative kidney management pathway. Finally, the patient was not informed that he had the right to refuse treatment at any time. The process of informed consent described in that case fell short of the standard that we are espousing in this paper.

Cultural and Religious Perspectives

Informed consent to medical treatment is founded on the principle of autonomy. Such a principle is regarded in diverse ways across cultures and religious faiths. For some, autonomy is paramount; for others, it may be a foreign world view (38), whereby the cultural imperative may require that important decisions are made by the head of the family or collectively within families or close knit

<table>
<thead>
<tr>
<th>Table 3. Material risks of dialysis</th>
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<tr>
<td>As part of informed consent process and underpinned by the principle of shared decision making, the following material risks should be discussed</td>
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<tr>
<td>General complications of dialysis, including vascular access, sepsis, intradialytic hypertension and hypotension, fluid overload, and postdialysis fatigue</td>
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<tr>
<td>Prognosis as assessed by available prognostic tools</td>
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<tr>
<td>Anticipated effect on the life of the patient, family, and carers</td>
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groups. This process may include the belief within families that difficult news will result in their loved one losing hope; the primacy of filial obligations favoring the commencement of or rejecting the withdrawal from dialysis; the belief that forgoing dialysis constitutes abandonment, an immoral act, or euthanasia; and finally, a cultural prohibition against mentioning to the patient the trajectory of the illness, prognosis, or death and dying. Recognition of these cultural and religious dimensions by nephrologists is important in all aspects of decision making, including the process of informed consent (39).

Role of Guidelines and Codes of Ethics

In their deliberations, courts view professional guidelines and protocols seriously. Although they may not be necessarily authoritative in those deliberations, courts find these sources of professional recommendations and practice extremely helpful and indeed, may find that they inform the content of the duty of care. The main guidelines in nephrology on informed consent are set out in Table 5. A useful point of reference is recommendation 2 in the Renal Physicians of America guidelines on shared decision making (4).

The Right to Refuse Dialysis

A competent adult may refuse medical treatment, including dialysis, even if that treatment is needed to stay alive (18). It does not matter whether the patient’s reasons for taking this decision are “rational, irrational, unknown or even non-existent” (17).

Emergency Dialysis

An exception to the legal imperative of obtaining consent is a medical emergency (40). Dialysis may be initiated in the context of an acute illness and rapid or unexpected loss of kidney function. After the emergency has resolved, an informed consent process should commence for future dialysis management. The exception to this approach is where the patient, when competent, has expressly stated that he or she does not wish to commence dialysis, even and including in the context of an emergency.

Deciding for the Incompetent Patient

The law states that, if a patient is incompetent, then the physician should examine any advance care plan made by the patient when competent and discuss it with a designated surrogate decision maker. If the patient has not expressed his/her wishes or nominated a surrogate decision maker, the physician should approach whoever is the medical surrogate decision maker under the provisions of the law in the relevant jurisdiction. This decision-making process should be on the basis of what the person would have chosen if competent in combination with the medical recommendations. In the context of dementia, that recommendation should be on the basis of the anticipated clinical trajectory of dementia; the troubling sequelae to the initiation of dialysis in nursing home residents, including patients with dementia (38); and the Renal Physicians Association guidelines, which recommend that “[i]t is appropriate to forgo dialysis for patients with … irreversible, profound neurological impairment” (4).

Another challenging clinical scenario for nephrologists is the highly comorbid patient who has a major irreversible sentinel event leading to ARF and is too unwell to communicate. In this scenario, the decision making around dialysis can be fraught. The family may be entirely unprepared for this deterioration and in this moment of crisis and grief, insist that dialysis is commenced. The nephrologist, possibly seeing the patient for the first time, may recommend against dialysis. The process of dialysis itself becomes the focus of discussion rather than a preparation of the family for the death of the patient.

Resolution of Conflict

One of the great challenges in modern nephrology is the patient and/or family who insists on treatment, including dialysis, contrary to the recommendation of the nephrologist. This places the nephrologist in a difficult position. Legally and ethically, physicians are under no obligation to provide treatment, including dialysis, where they conscientiously feel that this treatment is inappropriate or excessively burdensome to the patient. Strategies here include recommending a cooling off period for the family to consider the matter further, seeking the second opinion of another nephrologist, consulting an ethics committee, and most definitively, bringing the case to a court to resolve the issue (4). In an excellent overview of conflict resolution, Back and Arnold (41) stated that “resolving conflicts between physician and family members often requires that the physician moves from trying to convince the family

### Table 4. Important aspects of communication in the process of informed consent

<table>
<thead>
<tr>
<th>Aspect</th>
<th>Description</th>
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<tbody>
<tr>
<td>The importance of shared decision making as recommended by the Renal Physicians Association (4)</td>
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<tr>
<td>Inviting the family to be part of the discussion</td>
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<tr>
<td>Quiet environment</td>
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<td>Clear understandable language—avoid technical language</td>
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<tr>
<td>Nephrologist-patient relationship—recognize patient vulnerability physically and in terms of knowledge</td>
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<tr>
<td>Allowing patient and family an opportunity to clarify and question information</td>
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<tr>
<td>Information may come from multiple sources—nephrologist, renal nurses, renal social worker</td>
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<tr>
<td>Give patients and families time to consider decisions</td>
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towards seeking to understand why the family holds a particular view."

**Consent to Access Procedures**

This paper has concentrated on the process of informed consent to dialysis. A separate process of informed consent needs to occur before the insertion of vascular or peritoneal dialysis in preparation of commencing hemodialysis or peritoneal dialysis, respectively. As an observation, it seems that consent for these (surgical) procedures remains the norm, whereas consent for dialysis *per se* remains problematic.

**Informed Consent as Best Practice in Nephrology**

The confluence of medicine, law, and ethics strongly indicates that the informed consent of patients before commencing dialysis is best practice. Authoritative nephrology guidelines have expressly endorsed this approach (4). That practice is not fulfilled by simply securing the signature of a patient on a form. It requires a conscientious recognition by the nephrologist of his/her legal and ethical obligations and a clear and adequate discussion with the patient leading to a truly informed consent.

**Conclusions and Next Steps**

To change the current situation, the first and critical step is knowledge. Additionally, the parts of that knowledge are (1) recognition that dialysis requires informed consent and is not exempt from this process, (2) recognition of what the law requires, and (3) recognition that the Renal Physicians Association of America expressly stated that informed consent is a component of and requirement for shared decision making.

There are two common themes to the challenges to nephrologists in informed consent to dialysis: awareness and preparedness. Awareness necessitates knowledge and understanding of the law of consent, which is summarized in Figure 1. Preparedness is the willingness of nephrologists to expand consent conversations beyond the mechanical aspects of dialysis to include topics such as prognosis, quality of life, the aspects of life that matter most to the patient, and the option of conservative kidney management. An important dividend that flows from such an open and transparent approach is that any other discussion about future planning or crisis management becomes easier to initiate and conduct. A consent discussion is foundational. All later discussions will be far more comfortable in its shadow.

**Disclosures**

None.

**References**


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**Table 5. Recognition of and guidelines for informed consent in nephrology**

<table>
<thead>
<tr>
<th><strong>United States</strong></th>
<th>Renal Physicians Association guidelines (4)</th>
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<tr>
<td>CMS Conditions for Coverage state that patients in renal units have a basic right to informed consent that is entrusted to the medical director of the dialysis facility (48)</td>
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<td>The American Society of Nephrology in conjunction with the American Board of Internal Medicine Foundation’s “Choosing Wisely” campaign recommend that nephrologists “not initiate chronic dialysis without ensuring a shared decision-making process between patients, their families, and their physician” (49)</td>
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<td>The American Medical Association (50)</td>
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<tr>
<th><strong>United Kingdom</strong></th>
<th>Department of Health guidelines on informed consent (51)</th>
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<tr>
<td>One of the “key and enabling” competencies of trainees in nephrology is the ability to obtain an informed consent (52)</td>
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<tr>
<th><strong>Australasia</strong></th>
<th>In Australasia, the Caring for Australasians with Renal Impairment guidelines for nephrology practice emphasize the importance of an informed consent to dialysis (53)</th>
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<tr>
<td>In Australia, the National Health and Medical Research Council guidelines on the provision of information to patients (54)</td>
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<td>The Australian and New Zealand Society of Nephrology Renal Supportive Care guidelines 2013 have chapters on prognosis, the law, and the ethics of dialysis (55)</td>
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<td>New Zealand has a statutory regime governing informed consent (26)</td>
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<th><strong>Republic of Ireland</strong></th>
<th>Irish Medical Council guidelines to physicians on informed consent (56)</th>
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CMS, Centers for Medicare and Medicaid Services.
17. Re T (Adult: Refusal of Treatment) [1993] Fam R 95, 1993
20. Australian Health and Medical Research Council: General Guidelines for Medical Practitioners on Providing Information to Patients, Commonwealth of Australia, Canberra, Australia, 2004
21. Australian Health and Medical Research Council: General Guidelines for Medical Practitioners on Providing Information to Patients, Commonwealth of Australia, Canberra, Australia, 2004
22. Royal College of Physicians and Surgeons of Canada: Objectives of Training in Adult and Paediatric Nephrology, Royal College of Physicians and Surgeons of Canada, Ottawa, Canada, 2009
23. Canadian Medical Association: General Guidelines for Medical Practitioners on Providing Information to Patients, Commonwealth of Australia, Canberra, Australia, 2004
24. Australian Health and Medical Research Council: General Guidelines for Medical Practitioners on Providing Information to Patients, Commonwealth of Australia, Canberra, Australia, 2004
25. Australian Health and Medical Research Council: General Guidelines for Medical Practitioners on Providing Information to Patients, Commonwealth of Australia, Canberra, Australia, 2004
26. Royal College of Physicians and Surgeons of Canada: Objectives of Training in Adult and Paediatric Nephrology, Royal College of Physicians and Surgeons of Canada, Ottawa, Canada, 2009
27. Canadian Medical Association: General Guidelines for Medical Practitioners on Providing Information to Patients, Commonwealth of Australia, Canberra, Australia, 2004
28. Australian Health and Medical Research Council: General Guidelines for Medical Practitioners on Providing Information to Patients, Commonwealth of Australia, Canberra, Australia, 2004
29. Australian Health and Medical Research Council: General Guidelines for Medical Practitioners on Providing Information to Patients, Commonwealth of Australia, Canberra, Australia, 2004
30. Australian Health and Medical Research Council: General Guidelines for Medical Practitioners on Providing Information to Patients, Commonwealth of Australia, Canberra, Australia, 2004
31. Australian Health and Medical Research Council: General Guidelines for Medical Practitioners on Providing Information to Patients, Commonwealth of Australia, Canberra, Australia, 2004
32. Australian Health and Medical Research Council: General Guidelines for Medical Practitioners on Providing Information to Patients, Commonwealth of Australia, Canberra, Australia, 2004
33. Australian Health and Medical Research Council: General Guidelines for Medical Practitioners on Providing Information to Patients, Commonwealth of Australia, Canberra, Australia, 2004
34. Australian Health and Medical Research Council: General Guidelines for Medical Practitioners on Providing Information to Patients, Commonwealth of Australia, Canberra, Australia, 2004
35. Australian Health and Medical Research Council: General Guidelines for Medical Practitioners on Providing Information to Patients, Commonwealth of Australia, Canberra, Australia, 2004