Autonomy is an important ethical and legal principle. Respect for autonomy is especially important in a hospital setting. A patient is in an inherently vulnerable position; he or she is part of a big and sometimes impersonal institution and is inherently restricted in many of the choices which he or she can make. The view of autonomy taken here is of autonomy as a positive right to make choices about treatment and care as well as a negative right to refuse treatment. This broad view of autonomy is helpful in thinking about decisions at the end of life. As you consider the following case, think about which kind of autonomy right is mainly at risk here, positive or negative.

Re C (An Adult) 1994

Mr C had been detained in a mental hospital for many years. He developed gangrene in one leg and medical advice was that his leg needed to be amputated. Mr C resisted this and said that he would prefer to die with two legs than to live with one. Mr C also offered the view that God would save him and he referred to his own (delusional) belief that he was a world-famous surgeon. The Court held that Mr C had the necessary capacity to refuse the amputation even if the refusal would lead to his death. It was not relevant that Mr C had a mental illness. Everyone must be presumed to have capacity regardless of their underlying circumstances. The test for capacity related to his capacity to make this particular decision and not to his overall situation.

The Court identified three questions as relevant in deciding if Mr C had legal capacity:
1. Could he understand the information relevant to the decision (to refuse the amputation)?
2. Did he believe the information?
3. Could he use this information to make a decision?

The Court found that Mr C understood the information relevant to his decision – including that if he did not have the surgery, he could die. He was also found to believe this information ‘in his own fashion’ and to be able to use this information to reach a decision. Therefore Mr C was permitted to refuse the amputation. (Re C (Adult: Refusal of Medical Treatment) [1994] 1 WLR 290)

Discussion

In Ireland, both government policy and professional guidelines require that health professionals respect patient autonomy in different ways. One of the goals of the Health Service Executive Strategic Plan for 2008-13, is ‘to develop the role of the “expert patient”, especially those with long-term illnesses, in developing their own care plan and in looking after their own condition’ (p.14). Two of the related actions to achieve this goal are; the promotion of patients as ‘partners with health professionals’ and; the education of staff on the ‘importance of patient involvement in their care’ (National Strategy for Service User Involvement in the Irish Health Service 2008-2013). The document defines ‘involvement’ as:

‘A process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing policies, in planning, developing and delivering services and in taking action to achieve change’ (2008, p.6).
In emphasizing the idea of individual patient participation in care planning and self-care, this HSE strategic plan brings Ireland in line with international efforts to change the way in which illness is managed in the 21st century by health professionals and, increasingly, by patients themselves. This focus on patient-directed and patient-centred care is construed as giving expression to patient autonomy and it is also articulated in the Irish Guide to Professional Conduct and Ethics for Registered Medical Practitioners (2009) in relation to the requirement of the informed consent of patients to medical treatment:

‘You should ensure that informed consent has been given by a patient before any medical treatment is carried out. The ethical and legal rationale behind this is to respect the patient’s autonomy and their right to control their own life. The basic idea of personal autonomy is that everyone’s actions and decisions are their own. Therefore, the patient has the right to decide what happens to their own body.’ (Section 33.1, p.34)

The right of autonomy presumes that the person whose right is respected has the capacity to make the decision in question. The case of Re C (An Adult) 1994 above provides an example of the conditions that are required for someone to be seen to have decision-making capacity from a legal point of view. This is based on an English case from 1994. Although the case happened in England, the test for capacity set out in it applies in Ireland as well. (A Bill on Mental Capacity is due to be published in Ireland and this is likely to become law in 2010. The standard for capacity set out in the Bill is likely to be more or less the same as that described in this case).

There are a number of features of the test for capacity as set out in this case which merit further reflection in an end-of-life context.

First, all persons are to be presumed to have capacity. Just because a person is very old, or mentally ill, or intellectually disabled, does not mean that a person can be presumed to lack the capacity to make his or her own decisions. It is especially important to remember this when dealing with older patients or patients with intellectual disabilities. Quinlan and O’Neill note the following view of Irish clinical practice offered by one health professional:

‘I think the most obvious place where patient autonomy falls down is with ageism. If somebody is 30 or 40 or 50 we are much more likely to pay heed to what they’re saying and involve them. If somebody is 70 or 80 or 90 we’re much less likely to do so. As a sweeping statement I think patient autonomy tends to decrease with age and I don’t think there’s a good reason for that but I think that is the practice of what happens’. (Quinlan, C., & O’Neill, C. [2009, p.48] Practitioners’ perspectives on patient autonomy at end of life. Dublin: Irish Hospice Foundation)

A second important aspect of the test for capacity as set out in Re C (An Adult) 1994 is that, in most cases, it will be health professionals who will decide if a patient has capacity or not. As the Irish clinician, Shaun O’Keefe, notes, this presents challenges for many professionals who may be unfamiliar with the test for capacity or who may be unsure of what exactly is required (2008, p.44).

A third point that is clear from this case is that there is a designated standard of autonomy, or capacity, that has to be reached in order for a patient to be considered autonomous from a legal point of view: that they understand relevant information; that they believe the information and that they can use the information in deciding about treatment. This means that the law is not concerned with whether someone is a good decision-maker or not. The law does not ask whether the person is reflective and careful or impulsive and careless. The only matter of interest to the law is whether or not the person reaches the legal standard.

A fourth point about the case is that capacity should be seen, not just as a characteristic which must be assessed, but as a characteristic which must be developed. This view of capacity is consistent with the positive right of autonomy. Research shows that patients’ capacity can often be enhanced by quite simple steps, such as breaking down information into smaller ‘bits’ or making efforts to talk to patients in a way that is meaningful to them and that they will understand. Clearly, this requires effort on the part of health professionals; time and commitment are crucial in deciding what can be achieved in terms of helping a person make autonomous decisions.
A fifth point that Re C (An Adult) 1994 makes is that, when the right of autonomy arises in the context of treatment refusal, it is a very powerful right. It takes priority even when the effect of the refusal is the death of the person.

Finally, it is worth noting that while autonomy is an important principle, it is not absolute. The most commonly recognised justification for interference with autonomy is that respect for the right will cause harm to another person. For example, where a person has a contagious and dangerous disease, say tuberculosis, a degree of interference with his or her autonomous rights (to refuse treatment, to freely interact with others) may be justified on the basis of the harm which would be caused to others who might well become infected with the disease if the person’s right of autonomy were respected.

In addition, there are some who contest the importance that has been placed on autonomy in recent years. Critics argue that the autonomy principle is too individualistic and that it fails to take account of the essential interconnectedness of people or the complexity of the ways in which people make healthcare decisions. Many argue that a broad and more concrete understanding of autonomy is required which places value on solidarity, trust and human relationships.

In light of your reading and understanding of Re C (An Adult) 1994, discuss your response to the following suggestions in relation to professional responsibilities and consider any others that you think should be added.
Suggested Professional Responsibilities

1. **Assume capacity**: Health professionals should presume that patients have decision-making capacity and should assess capacity in a way which is fair and free from prejudices based on age, mental illness or intellectual disability.

2. **Investigate capacity**: If a person, such as Mr C, seeks to refuse treatment, especially life-saving treatment, health professionals should consider whether the person has the capacity to make this decision. It is the responsibility of the professionals involved to investigate capacity. They should familiarise themselves with the legal test for capacity as this is the relevant test to determine whether or not a person is legally entitled to make decisions.

3. **Seek second opinion**: If in doubt in this respect, the professional should seek a second opinion from another professional with expertise in the area of capacity assessment (perhaps a psychiatrist or a geriatrician depending on the circumstances). If doubts remain, legal advice should be sought.

4. **Engage with patient**: Professionals can and should engage with patients who refuse treatment. If professionals believe that it would be in the patient’s best interests to have treatment, they can and should seek to persuade the patient to consent to the treatment. This attempt should be on the basis of dialogue and discussion which should be conducted in a way which is honest and which does not attempt to manipulate the facts.

5. **Distinguish between persuasion and force**: A distinction must be made between honest persuasion and force. While persuasion is legitimate, the use of force is not (unless the person lacks the capacity to make the decision).

6. **Promote and support participation**: Professionals should seek to facilitate people of borderline capacity in making decisions for themselves insofar as this is possible. Ways to facilitate participation include using simple language, speaking at the appropriate volume and speed, using appropriate words and sentence structure, breaking down information into smaller points, and using illustrations and/or photographs to help the person understand the decision to be made. Where a person has communication or cognitive problems, possibilities are offered by the use of picture boards, signing, technological aids. For some people who are restricted to non-verbal methods of communication, their behaviour and, in particular, changes in their behaviour may provide indications of their feelings.

7. **??

Key Terms

**Autonomy**
Autonomy is the capacity of self-determination; it is a person’s ability to make choices about their own life based on their own beliefs and values.

**Principle of Autonomy**
The principle obliges health professionals to respect patient autonomy. In doing so, they recognize and support the unique values, priorities and preferences of patients. The **negative right of autonomy** is a right not to be interfered with. In a healthcare context it is understood as a right to refuse treatment which is protected under the Irish Constitution and the European Convention on
Human Rights. The **positive right** of autonomy requires that necessary efforts are made to ensure that patients are facilitated in taking control of their treatment and care to the maximum extent possible. This can be done, for example, through the early provision of treatment or care plans and open communication with patients and (where appropriate) family members and friends.

**Activities**

1. What actions on the part of health professionals are needed to give effect to a negative right of autonomy? What actions on the part of health professionals are needed to give effect to a positive right of autonomy? Which form of autonomy is easier to deliver? Which form of autonomy is most important? Or are both equally important?

2. Reflect back on the particulars of the case *Re C (An Adult)* 1994. Jot down the requirements for the legal test for capacity. Do these requirements strike you as sensible? Try to imagine yourself applying these requirements to a real patient that you have met in the course of your work?

3. In your view, do professionals in practice make assumptions about capacity in respect of certain categories of patient? If so, which categories? Do you believe that a patient’s capacity can be enhanced? If not, why not? If so, what in your view are the most appropriate ways to enhance patient capacity?

4. Just because a person lacks formal legal capacity does not mean that his or her views and preferences can simply be ignored. Jot down ways in which you think a health professional can take the views of someone who currently lacks capacity into account.

5. The right of autonomy may sometimes be limited because of duties owed to other people. Can you think of circumstances where it might be appropriate to limit someone’s autonomy because of concern for other people or society?

**Key Readings**


Study Session 4

Patient Autonomy in Law and Practice