

**Transcript: Oireachtas Committee on Health and Children: 24<sup>th</sup> October 2013.  
Hearings on end-of-life issues. Session 1 – Why is it important to pay attention to end-of-life issues?**

**Chairman:** I welcome everyone to the public session of the meeting. I remind those in attendance that all mobile phones must be switched off as they interfere with the sound and recording system.

**End-of-Life Care: Discussion**

**Chairman:** The meeting is divided into two parts. I ask members to be concise in their contributions as this will assist in the running of the meetings. This is the first meeting in a series which will investigate the arrangements for end-of-life care in Ireland and what measures can be taken to ensure that persons of all ages who are approaching the end of life are enabled to die well and with dignity. End-of-life issues will affect every human being. They encompass the areas of both physical and mental health. Death is a fact of life. Some 29,000 people died in Ireland last year and up 290,000 people were bereaved and are coming to terms with loss.

It is appropriate that the committee turn its attention to the current system of care for those who are dying and how the health services are organised to deal with end-of-life care. I thank the committee members for their involvement in the preparation for these hearings. I thank Senator Marie-Louise O'Donnell for her assistance and Senator John Crown for his expertise.

This country has a long tradition of dealing sympathetically and respectfully with the end of life and bereavement. It is important that those approaching the end of life, as well as their families and friends, are treated with dignity and respect and given proper care and support. A significant part of the health budget is also invested in caring for our dying patients. We need to examine how a high-quality health service can be provided by making proper use of resources. We will all have an end-of-life experience - hopefully, not for a long time to come, although this is not in our hands to decide. It is good policy for the committee to review and plan for the future. I hope this series of meetings will help in the examination of the key issues and lead to the development of a basis for a framework for future planning and further action. Over the course of these hearings we will hear from experts who are delivering end-of-life care in all care settings, be that in hospices, in the community or in nursing homes. We thank those who are attending the committee meetings voluntarily and willingly in order to give us their insights and expertise.

I ask all contributors to be conscious of time, as there are two sessions today. We plan to hold six sessions over the next five meetings. The committee will publish a report which it is hoped will lead to further action.

I welcome Ms Sharon Foley, Ms Patricia Rickard-Clarke, Professor Eamon O'Shea and Dr. Joan McCarthy. I advise the witnesses that, by virtue of section 17(2)(l) of the Defamation Act 2009, they are protected by absolute privilege in respect of their evidence to this committee. If they are directed by the committee to cease giving evidence on a particular matter and they continue to do so, they are entitled thereafter only to qualified privilege in respect of their evidence. They are directed that only evidence connected with the subject matter of these proceedings is to be given. They are asked to respect the parliamentary practice to the effect that, where possible, they should not criticise or make charges against any person or persons or entity by name or in such a way as to make him, her or it identifiable. Members are reminded of the long-standing ruling of the Chair to the effect that they should not comment on, criticise or make charges against a person outside the Houses or any official by name or in such a way as to make him or her identifiable.

I invite Ms Sharon Foley, chief executive officer of the Irish Hospice Foundation, to make her opening remarks.

**Ms Sharon Foley:** I take this opportunity to commend the committee's Chairman and members on their decision to hold a series of hearings into end-of-life care. They are doing the people of Ireland a great service and I welcome the initiative. Reviewing the care of the most vulnerable members of our society is both worthwhile and essential. Every year, 29,000 people die in Ireland, and it is estimated that 290,000 people are left bereaved. It is obvious that death matters in Ireland. While €72 million is budgeted for specialist palliative care, international research suggests that up to €1.3 billion of the national health budget is being expended on end-of-life care. However, this spending is largely unplanned and uncoordinated. No one wins, neither the patient nor the State.

The elements of a good death are truly personal to each and every one of us. There are many elements, personal, communal and societal, which contribute to whether a person has a good death. We cannot promise to be able to influence each of these factors but we do believe that much more can be done by health and social services to ensure better end-of-life care, everywhere. We believe it is possible to secure high-quality care for those facing death which will also ensure the best use of resources. We believe it is the right of every person to die in comfort and dignity, but we believe this must be planned for. The key recommendation of the Irish Hospice Foundation is that we need a national end-of-life and bereavement strategy to plan for the inevitable and to ensure there is no absence of care and no ignorance of need and that end-of-life care is as good as possible.

A national strategy is needed to help us to plan, develop and co-ordinate end-of-life care in hospices, hospitals, homes and communities, as well as addressing the wider economic, legal and administrative issues. This must be a strategy for the entire population, from those who need GP support up to all those who need specialist palliative care to manage their pain and other complex symptoms. This strategy needs to be relevant and supportive of all health care and social care staff who are required to deliver health and social care. The strategy must be relevant to all patients, young and old, to patients all over Ireland and to patients with all conditions, including dementia.

I have three further specific recommendations. We need to develop hospice care. We have plenty of strong national policies around specialist palliative care but we fall down when it comes to putting policy into practice. The result is that some citizens have more access to more services and a choice of care while as many as 2,500 people cannot access an inpatient hospice bed because these do not exist in the regions in which they live. The current number of hospice beds is 155. According to HSE plans this number should be 450. The budget for the national specialist service in 2013 was €72 million - about one third of the cost of running one Dublin hospital for a year. This budget has been cut repeatedly over the past few years. Three regions in the country have no inpatient hospice unit - the north east, the midlands and the south east - as well as the counties of Kerry, Wicklow, Mayo and Roscommon. This inequality between regions and counties is unacceptable. Some people are able to access a full range of services while others with the same needs are denied this access.

The lack of a full range of hospice services has an impact for patients and the health system. Hospital care is expensive. Our research into deaths from cancer shows that fewer sufferers die in hospital if they live in a region which has a hospice, from 52% of deaths in hospital in the north east to 21% in the mid-west. The support of a hospice home care team will mean that a patient is nearly twice as likely to be able to die at home.

Practical ways to support the provision of specialist palliative care are urgently needed. A national end-of-life and bereavement strategy would help us to plan all services, including specialist hospice care. In addition, there must be improved support for acute hospitals to deliver better end-of-life care. Most of us wish to die at home, but 43% of us will die in an acute hospital. A hospital audit we conducted shows that more than 80% of people who died in hospital were admitted via the emergency department, and had the same long wait as everybody else. That is not what people

want for themselves or their loved ones. The audit also estimated that up to one quarter of patients could have died at home if the appropriate community supports had been in place.

A great deal remains to be done. Our hospitals aim to cure, but they must acknowledge and plan for their role in providing end-of-life care. The reality is that people die every day in hospitals. That is not a failure on the part of those facilities; it is a fact of life. We need to support hospitals in delivering the very best end-of-life care which ensures dignity and comfort for the dying patient. There are already examples of excellent practice throughout the country, which should become everyday practice across the board. For example, our hospice-friendly hospitals programme has developed a range of recognised quality standards, staff training programmes and practical resources. If a charity can do that much, one can only imagine what might be done if services are properly planned and funded. There is scope for substantial innovation and enhancement within the estimated €1.3 billion that is allocated to end-of-life care. I urge members to strive for more and work to do better.

Death in hospitals should be considered as part of the national strategy for end-of-life care. While we await that strategy, we have a fantastic opportunity arising from the formation of the new hospital groupings. These groupings should be directed to develop and deliver comprehensive plans for how they will cope with the people who die in their facilities and how they will care for the bereaved. At the same time, we need to help more people to fulfil their wish to die at home. Two thirds of those asked express a preference to die at home, but only 26% actually achieve that preference. While people sometimes change their minds, it is clear that we can do more to help greater numbers to fulfil their wish to die at home. A great deal of good work is already being done through our primary palliative care programme, our nursing for night care services and our funding of children's outreach nurses who support families caring for children at home. However, active planning is needed to develop comprehensive home and community supports which, at the same time, will save resources in the acute hospital setting. Again, we come back to how a national strategy can help us to develop community supports to help people to die at home.

If members take away only one point from today's meeting, I hope it is an awareness of the need for a national end-of-life and bereavement strategy which helps us to plan ahead and ensure people can die well, wherever they are. It is worth remembering that we all have only one chance to get it right in terms of our end of life. I thank the Chairman and members.

**Chairman:** Thank you, Ms Foley. I now invite Ms Patricia Rickard-Clarke who is representing the national council of the Forum on End of Life in Ireland.

**Ms Patricia Rickard-Clarke:** I thank the Chairman and members of the committee for inviting me to speak on behalf of the Forum on End of Life in Ireland. The forum represents the voice of people in Ireland on end-of-life issues surrounding dying, death and bereavement. It is an initiative of the Irish Hospice Foundation and was launched in 2009 by the then President, Mary McAleese, and is chaired by Mrs. Justice Catherine McGuinness. I propose to highlight several areas in which the forum is working in order to enable people to die well in Ireland.

One of the forum's key objectives, as contained in its work plan for 2013 to 2015, which was submitted to the committee, is to advocate for a national end-of-life strategy. Issues arising at end of life are wider than simply health care. Any of us who has had a loved one die knows only too well that there is a myriad of financial, legal, social, cultural and administrative issues related to a person's wishes other than those related directly to health care. For this reason, we need a comprehensive interdepartmental strategy which can address all areas of end of life and ensure the issue is effectively addressed by Government policy.

In short, we must recognise end of life as a natural part of the lifecycle. Government policy addresses the needs of the newborn, of school-going children and of people up to and post retirement age. So too should it address the needs of those at end of life. The forum's work plan addressed some of the issues that should be addressed by an end-of-life strategy, including, for instance, regulation of the funeral industry – one of this country's least regulated industries – and the importance of end-of-life proofing of buildings to enable more people to die well in their own homes and communities.

Another of the forum's objectives is to change policies and practices where this is required. Our systems must be flexible enough to take on board the needs of those at end of life and to change accordingly. Later today I will attend the forum's conference in Dublin Castle - an event that takes place every two years - where 300 members of the public and health professionals who are interested in doing things differently will discuss how we can make Ireland a good place to die. One example of a procedure that needs to be adapted is the forum's recommendation that authority be extended to trained nurses and paramedics to pronounce death. This was raised during the public consultation the forum undertook in 2009 to 2010 as something that needed to happen, both from the perspective of bereaved families and in terms of making effective use of personnel in hospitals and emergency situations.

Advance care planning is another important issue. How many members of this committee have made an up-to-date will that reflects their current circumstances and wishes? If they are anything like the rest of the population, most of them will not have done so. How many members have thought about where they would like to be cared for at the end of their lives? Have they considered whether they would prefer to die at home and whether they would prefer cremation over burial, or *vice versa*? Have they told anyone close to them about these wishes or kept them to themselves? Many of us have made such decisions but without communicating them to another person. Talking about death in Ireland is the final taboo we have to face. People in many other countries make advance directives as a matter of course throughout their lifetime. We need to catch up in this regard.

The Think Ahead project - a major element of the forum's end-of-life work programme - is a public awareness initiative and broad advance planning tool designed to guide members of the public in discussing and recording their preference regarding end of life. It is important that we articulate what we want in preparation for a day where we may not be able to speak for ourselves. Not only is it our right to speak for ourselves; it is also our responsibility to spare our loved ones the burden of having to make decisions on our behalf, not knowing whether they are doing the right thing. The forum is initiating a culture change through Think Ahead which encourages people to think, talk and tell: think about what they would like; talk to their doctor or someone they trust; and tell someone close to them of their wishes in order to ensure they are carried out.

While advance directives are recognised in Irish law and are legally binding, there has as yet been no legislative framework to give clarity to the public and health care professionals. That is set to change. The Minister for Justice and Equality, Deputy Alan Shatter, stated in July 2013 that provision for advance directives will be included on Committee Stage of the Assisted Decision-Making (Capacity) Bill 2013. We hope this will help to ensure that people know their rights and can express their preferences.

Think Ahead was launched by An Taoiseach in 2011 and is currently being rolled out nationwide with the help of community groups and key players, including health professionals, solicitors, accountants and local politicians. The initiative is part of the move in Ireland towards meeting our international obligations under the Hague Convention on the International Protection of Adults of 2000, the 2006 United Nations Convention on the Rights of Persons with Disabilities, and the Council of Europe

recommendation in 2009 regarding powers of attorney and advanced care directives. These international obligations require us to have systems in place to take account of individuals' will and preferences and ensure their respect and dignity are maintained in carrying out their wishes at the end of life.

We have an opportunity here to make real changes that will enable people to die well in Ireland. We must take that opportunity. I thank members for their time.

**Chairman:** Thank you Ms Rickard-Clarke. I now call on Professor Eamon O'Shea from the Irish Centre for Social Gerontology at NUI Galway.

**Professor Eamon O'Shea:** My background is primarily in aging and dementia studies. I possess a particular knowledge of end-of-life care, having done some work in this area during the past five years or so.

Irish people are living longer and this means that more of them are going to reach the stage at which end-of-life care will be necessary. One of the important aspects of the work I do relates to transitioning to death. Many people die outside the home, but transition to end of life is a really interesting concept in long-stay care in particular. People transition into older age; they then transition into some level of dependency, then into perhaps residential care and then into the end-of-life stage. It must be recognised that they undergo a series of transitions and that everything does not happen all at once. We sometimes think of death as coming suddenly, but it often does not do so. To reinforce what previous speakers stated, we must be aware of the need to integrate care structures in order to ensure that the various services work together. I refer in particular to gerontology and palliative care services, which are critical.

The other generic context is that of information flows between living and dying. I spend a great deal of time in nursing homes and residential homes. These are places of living but they are also places of dying. What one notices immediately in these homes is the need to create a culture of understanding of death and of support for those who will be left behind. Information flows between care staff and people who are dying and those who remain living are critical. These are the critical interfaces we sometimes forget when considering palliative care services.

The third generic concept relates to quality-of-life issues. These are serious issues and one of the critical dimensions of the human rights of people who are dying is that they must continue to live until they actually pass away. The sort of personhood associated with dying must be to the forefront in the context of how we care for those who are dying. In this regard and in the context of the work I do in the area of dementia, it must be to the fore when it comes to those who are cognitively impaired. There is a need to support those who cannot communicate in ways which would be considered normal but who can still communicate in some fashion. These are critical aspects which we need to discuss.

Another major issue relates to "mediating differences", as I term it, and communication. Ms Rickard-Clarke referred to communication and advanced directives. There is a need to take on board how we communicate decisions at various times in our lives. For example, decisions we take now might resonate ten, 20 or 30 years' time. There is a need to be aware of this factor and the progress being made towards introducing legislation in this regard is really welcome.

On the locus of decision-making among individuals, health professionals and families, we have all been at the interface at which we feel we want to give and receive information. However, we do not always get the information we require. Information is critical, as is the discourse relating to life and

death. It is difficult for people to discuss death, but this is so necessary if the quality of life and standard of care that are essential are to be achieved.

Issues relating to communication and language barriers and to different cultural ways of dying are arising with increasing frequency. Some of the staff at residential care homes come from different cultures and they may have a different interpretation and understanding of death and dying. Increasing numbers of people from other cultures will be dying in our hospitals and residential care homes and we need to consider the differences to which I refer if we are to meet the requirements of such individuals.

The final aspect of mediating differences relates to education and training. It is critically important that generic staff should be trained to understand end-of-life care issues. This matter cannot be viewed as being one with which palliative care services will deal. All care staff in hospitals and residential care will be obliged to deal with death and dying and they need to be trained to do so.

On facilities and services, we need to think more about the infrastructure of dying - that is, the places in which people die and the privacy, dignity and respect associated with death. It is not always possible to do so but we need to make much better efforts to get the infrastructure right in terms of our approach to dying. The position is similar with regard to the bereavement services required after death. When someone in a residential care home dies, everyone notices. We need to discuss this matter and put in place services for those who are left behind in such homes when a valued member of the community dies. So often, this matter is just passed over.

I wish to make a quick comment on dementia and the need to make cognitive impairment an issue. There is some international evidence to the effect that people with dementia are often subject to unnecessary investigations, receive less pain relief and are the subject of over-prescribing. There is a need to be careful when it comes to those with dementia who are nearing death.

Following a number of years of research, I am of the view that there is a need for greater consultation with individuals for many years before death, as death approaches, when they are transitioning into long-stay care, and right up to the time of death. We need to talk to people but we also need to learn how to talk to them. Dialogue is extremely important. The second element is that we must improve both the physical infrastructure and bereavement services. The third element relates to enhanced education and training for staff, which is really critical. The fourth element relates to the need to make end of life and bereavement major public policy issues. I would encourage movement in that direction.

**Chairman:**   I thank Mr. O'Shea and welcome Dr. Joan McCarthy from the school of nursing and midwifery at UCC.

**Dr. Joan McCarthy:** I thank the Chairman and members for inviting me to attend these important hearings. My background is in ethics, in teaching ethics and in researching ethical topics with health professionals in Cork, Ireland and abroad. I will focus on ethical problems and suggest solutions in respect of some of the core issues and ethical challenges I see arising for people involved in end-of-life care.

When it comes to death and dying, patients, health professionals and families must make decisions in tense, fraught, emotionally demanding and constrained circumstances. In this context, recent research indicates that the general public has little understanding of the basic terminology relating to end-of-life care. People are confused with regard to the processes relating to such care and uncertain about the role of families in the context of information-sharing with patients or in respect

of making decisions for patients. In addition, health professionals are uncertain with regard to patient autonomy rights and can feel pressurised by family members into denying patients relevant information or carrying out treatments they consider futile.

An understanding of the ethical challenges at the end of life is central to good end-of-life care because lack of knowledge, uncertainty about ethical obligations and responsibilities, lack of confidence in expressing nagging doubts and concern with regard to litigation and professional accountability can and do lead to oversight, error and poor practice. As previous speakers indicated, Irish legislative and regulatory bodies are driving reform in this area. This is long overdue and welcome, but if the kinds of reform envisaged in the national consent policy or the Assisted Decision-Making (Capacity) Bill are to be fully realised, then there must be a cultural shift in health care organisations and in practices. Such a shift must also take place among members of the general public. Ultimately, it makes good clinical, social and economic sense to develop educational strategies and support to ensure that clinical practice is ethically and legally sound.

We might live in an age of instant solutions but ethical problems in end-of-life care are not easy to resolve because they involve value-laden opinions, strong personal beliefs and emotional responses. As Professor O'Shea observed, the increasing diversity of the Irish population means that different cultural values must be respected and different religious perspectives understood. There is also a need for greater sensitivity, deeper understanding and more inclusive policies and practices. Increasingly, ethics is everybody's business. We cannot just leave ethics to the ethical experts; nor can we assume that clinical expertise implies ethical expertise. Moreover, recent legal challenges in respect of assisted suicide and euthanasia might have captured the public imagination but clarity and understanding are also required in order to engage with or understand more usual but also very complex and contested decisions and interventions such as those which relate to starting, stopping and de-escalating treatment, sedation, pain management and the provision of nutrition and hydration.

It follows from that kind of complexity and the dense textured challenges that are presented in end-of-life decision making that educational strategies, policies and research need to be put in place. One set of educational resources that has already contributed to demystifying ethical issues that arise in regard to end-of-life care is the document, Ethical Framework for End-of-Life Care. It is the outcome of a unique collaboration between my team in University College Cork, UCC, the Royal College of Surgeons in Ireland, RCSI, and the Irish Hospice Foundation. It is a set of resources for health and allied professionals and the general public. It considers ethically challenging situations in end-of-life care in the context of ethical values, professional codes and laws.

In this presentation, I suggest two important simple, practical and economic initiatives that will consolidate and extend the work and the impact of the ethical framework. The first initiative is a national network of clinical ethics committees. Introducing clinical ethics committees into model one to four hospitals and other health care providers in the community would bring us in line with international practice. In Canada, Australia and the United States they have such multidisciplinary committees, which perform a threefold function: To provide ethics education for health professionals, staff, patients and families; formulation and review of health care policies in the light of ethical considerations and; consultative support to staff with complex and difficult clinical cases.

Some committees already exist, for example, in Beaumont Hospital and the Bon Secours organisation in this country but I suggest that they are introduced across the board and that there is a regional and national network among the clinical ethics committees. In light of budgetary constraints, the cost would be minimal and largely administrative at local level but there is a need for some support at national level to co-ordinate the network and ensure there is translation among

various committees around best practice.

My second suggestion is a national end-of-life health care ethics observatory. That would be a joint initiative of institutes and universities in partnership with hospital education centres and professional bodies in Ireland. Building on the collaboration between UCC and RCSI the observatory would include tasks, such as providing educational support to the general public; to improve the training and continuous professional development of clinicians and health care staff; to develop and update the ethical framework to ensure that it is current and fit for purpose; and to initiate fourth level educational programmes, PhDs and clinical doctorates in clinical ethics and bioethics to support ongoing work. Research would be included in that area. Again, with an eye to budgetary constraints, the observatory could start as a virtual observatory. What is important is that it is national not where it is sited. It could be supported initially by a network of key people and eventually should find accommodation in the longer term in a large hospital.

Finally, when the Liverpool Care Pathway was found wanting in the UK, the reviewers called on the British Government to ensure that "guidance on care for the dying is properly understood and acted upon, and tick-box exercises are confined to the waste paper basket for ever". Drawing on the experience of others, we can see end of life and dying as a complex art. Care of the dying is a complex art that demands a range of many skills, including ethical skills and competencies so that sight is not lost of the fundamental bond between professional and patient. Where ethics support is part of a standard practice of health care organisations, the international evidence indicates that health care staff are more ethically literate leading to improved patient and family outcomes and less moral stress, desensitisation and burnout for health professionals who are struggling at the coalface due to current budgetary constraints. The two initiatives I suggest, namely, the national clinical ethics committee network and the observatory would work together to ensure the development of that kind of ethical literacy. It presents an opportunity for Ireland to take a leadership role internationally in the development of ethically and legally sound clinical practices in end-of-life care.

**Chairman:**   I thank Dr. McCarthy and all the witnesses for their excellent testimony this morning. I apologise on behalf of Deputy Ó Caoláin who had to leave. He is dealing with a Bill later and he had to leave to prepare for it.

**Senator Marc MacSharry:**   I thank the panel for their presentations and their ongoing work. I have two brief questions only because the presentations were very good in terms of recommendations for us to consider. It was said that the potential expenditure each year could be €1.3 billion. Could the witnesses elaborate a little more in that regard? They said it is not in the interests of patients, the health service or anyone. Are we wasting money, doing the wrong things with it or is it purely an issue of general management following on from a strategy? I would welcome more information in that regard.

There was brief reference to the right to die and euthanasia as a policy. Could I get a general view from witnesses on the matter? I do not advocate euthanasia but I am interested in the views of witnesses on the issue because there have been some high profile cases in recent years in the courts and the committee could benefit from hearing the views of professionals in the end-of-life area.

**Deputy Sandra McLellan:**   I welcome the witnesses to the meeting this morning and thank them for their presentations. I echo the Chairman's apology on behalf of Deputy Ó Caoláin who could not attend this morning. I have a few points to make and questions to pose.

With regard to the Irish Hospice Foundation, I am aware that Marymount Hospice in Cork is very well regarded and is the subject of many fund-raising activities. The work of the hospice staff is truly heroic. The point on staffing and resources is well made. Has the Government or HSE indicated at any stage whether additional funding will be made available? Are witnesses aware of whether there are commitments on additional beds?

I have a query on what was said by Ms Patricia Rickard-Clarke on the need for end-of-life proofing of homes. It is an interesting proposal. What would it involve and are there any countries to which we should look as an example in that regard?

Professor O'Shea highlighted the fact that there is a substantial challenge in terms of qualifications and training. He made the point that there are significant gaps in qualifications and education. What courses are available and do additional courses need to be provided or can the shortfall be met by other means?

Dr. McCarthy made some interesting proposals on clinical ethics committees. A point was made in a later presentation about a stand-alone entity. What is her view on such a proposal and could it age with the need for a change in culture which she flagged? Would it aid clinical ethics committees and what form should such an entity take?

**Senator Jillian van Turnhout:**   I am approaching the hearings as a learning exercise in the hope that when we bring together the report that we will be able to add our voice and put together recommendations. I am in no way an expert on the issue. A wealth of experience is evident in this first session.

My question relates to the call for a national strategy. Many of the points could be integrated in a strategy. How realistic is the call at the moment? Wearing my other hat on children's issues, we are close to finalising a strategy. How close is the strategy in this area? I wonder how much we should pin on the strategy as we wait for it.

We have to get down to dealing immediately with some of the component parts of the issues the witnesses have raised with us. The issues I am considering include community care, the timeliness of such care, the care of people in their own homes - the statistics have been given in this regard - and how such care complements the medical health care system. I deliberately use the word "complement" rather than "compete". I am interested to know about the strategy in that regard.  
**Chairman:**   I will come to the other members shortly but I want to go back to the panel of witnesses.

**Ms Sharon Foley:** Some of those questions may have been addressed to me. To answer Senator MacSharry's question, the figure of €1.3 billion is an international estimate based on an assumption that approximately 10% of the national health care budget is spent on end-of-life care. That is being delivered not only by those providing specialist palliative care, which is for those with special and complex needs, but also by the public health nurse, the general practitioner or the general nurse working on the ward. We do not know where all of that funding is spent but we get a sense that much more thought and planning could be put into end-of-life care in all health care settings to ensure we can deliver better end-of-life care. That is from where we take our evidence.

With regard to euthanasia, we in the Irish Hospice Foundation operate to hospice principles, which is neither to hasten nor to postpone death. There is no doubt that there could be a debate on euthanasia but we would believe so much more needs to be done to deliver good palliative care

services throughout the country. That is our position. We must get that right first before we move on to the next debate, and there is a good deal that needs to be done in that regard. I

held up a national strategy to members. That was done in 2001. In 2009 a national implementation plan was developed by the Health Service Executive which identified its priorities. In a way that answers Senator van Turnhout's question as well. There are many commitments in place but we must see those move into action. Some updating and refreshing may need to be done in light of new findings, but we must move that into action.

On the Government commitment, there was some commitment in the 2013 service plan to open the beds in Marymount that were developed as part of the new build in Marymount and also to move towards planning in Waterford and Kerry, but we still do not have an opening date for that. These issues need to move from the pre-planning and discussion stage to actual plans and development. It must be remembered also that each of those developments is hugely supported by volunteers who are out fundraising day after day to support them. Their patience will run out at some point if they are not seeing commitments made. Already, 44 beds that were built remain unopened, approximately 20 of them in the hospice in Blanchardstown. It is simply not good enough to have these facilities developed, supported by the volunteers in line with national policy, and then not delivered upon. Have I answered all my questions?

**Chairman:**   Yes.

**Ms Patricia Rickard-Clarke:** On the issue of euthanasia, Senator MacSharry might know that the Law Reform Commission produced a report in 2009 on the question of the recommendation of legislation for advanced care directives. That was following an issue that had arisen in the public arena about the need to have this legislation. The commission was not looking at that stage at the law on homicide, which includes assisted suicide and euthanasia as criminal offences. It was saying that it had not even got off the blocks in terms of considering people's wishes at the end of life. We need that conversation, and we need the legislation on advance care planning. In the research the commission did it was very clear that if we had a good legal framework in terms of planning for the end of life, the debate would move away from assisted suicide and euthanasia to a later stage, but we have not even started that.

I mentioned the various international obligations. In 2009 the Council of Europe recommended that member states must have facilities in place to allow people the right to self-determination and autonomy, the right to enduring power of attorney and the right to have an advance care directive. We badly need legislation to comply with our international obligations in that regard.

On end-of-life-proofing of buildings, the forum is talking about cases in which people die at home. It is about the adaptation of a room or, in terms of local authorities' development plans, the need to consider having wider doors in particular rooms in buildings or in communities. Many people now are choosing not to be buried in the traditional manner and we must take account of people from other nationalities, etc., living in Ireland. In the community and in the public arena we need buildings and facilities for people if they choose to be buried there. There is also the question of crematoriums and so on, because more people are opting now to be cremated, but we do not have proper facilities in terms of public buildings, or even in our own homes, to deal with such issues.

On the national strategy, I come at that issue from a non-health-care perspective. In the Assisted Decision-Making (Capacity) Bill we have the legislation on capacity but we have not yet got the detail of the Bill on advance care directives. That proves that there is not always the interdepartmental coming together that is required. From a legal perspective, we must have a strategy to allow people

to assign enduring power of attorney so that when people lack capacity we are not into the courts system. Similarly, in terms of their care, we have the advance care directive.

Regarding wills, we all know that not making wills causes great hardship to people and families. When people are ill and dying I am averse to people running in asking them to sign pieces of paper or whatever. If they have not made a will, that is not the time to do that. There must be advance planning in all of those areas. It is vital that all Departments with responsibilities in this area come together to develop an end-of-life strategy. I hope I have answered the questions.

**Chairman:**   How do we compare to Europe or the rest of the world in that regard?

**Ms Patricia Rickard-Clarke:** Badly.

**Chairman:**   Is it a cultural thing or-----

**Ms Patricia Rickard-Clarke:** It is. That is why we hear of the taboo with regard to talking about and planning for death. In Canada, for example, when people get married, take out a mortgage and buy a house, they make their wills to provide for their children. They assign enduring power of attorney and their advance care directives. Those are in place and they continue to update them as their circumstances change; therefore, their wishes are being recorded all the time. Culturally, we are bad at planning for that, but the international research indicates that when planning takes place it is easier for people facing the end of life, and indeed family members.

Another issue is that people might say we do not have court cases on many of these issues. We do not because people who lack capacity do not have money. We do not have free legal aid for these issues, as we see in other jurisdictions where there is a lot of litigation. We must get that planning in place and have a framework.

**Professor Eamon O'Shea:** To take up the question of euthanasia, I have no expertise in that area but I do have expertise in the issue of quality of life and communication about death. That is the first step. That needs to be done first. The emphasis on quality of life and what is a good death requires conversation at a societal level as much as at a staffing level within the services. That is the first stage in this discussion, as my colleagues have stated.

With regard to education and training, there is a paradox, as far as I am concerned, in that dying is an inherently private experience but it is also an incredibly social experience. It is a social experience for care staff and communities and we must think about that in terms of education and training. I am not simply talking about education and training for better care but about attitudes to death. It is about cultural appreciation of death and how to locate death within life - within the living - for the living. That to me is as much part of a holistic approach to death as clinical guidelines or a good policy towards death and dying.

One thing a strategy achieves - this goes back to the first question on expenditure - is to bring together a good deal of information and in that way provide a focus. We know from experience that strategies tend to attract money and that they tend to make us make good decisions on the best approach to the spending of that money. That is one of the good aspects of a strategy.

We definitely must figure out how much we are spending because we need to know that to make good decisions about how to allocate resources. However, there are issues with respect to other strategies. For example, the national dementia strategy is about to be finalised over the next three to six months and within that there must be, for example, some appreciation of dying for people

with dementia. In other words, we also must integrate within such sectoral areas issues in respect of death and dying. It is as important to bring such issues into these various places. For example, this is also really important in respect of other chronic diseases.

**Dr. Joan McCarthy:** On euthanasia, I agree with my colleagues about the importance of a national conversation on death and dying. It is important to welcome and accept that sincere and reasonable people disagree about euthanasia and assisted suicide. It would be good to welcome any kind of conversation about our fears and worries in this regard and not to be afraid of scaremongering to the effect that every discussion we have about death and dying must be or is about suicide, assisted suicide or euthanasia. It would be good if people were not afraid to say what they believed about it, understood it to be and so on. The kind of courageous journey of a citizen such as Marie Fleming is something that will happen repeatedly because people hold strongly to their wish to be in control of how they die and particularly of when they die when they face highly traumatic illnesses and so on.

On the issue of euthanasia and assisted suicide, I also believe it touches on people's underpinning moral values, their religious perspectives and their world views. This of course makes it extremely difficult, profound and emotional. We can honour this and can welcome differences of opinion about it without being obliged to say this commits us to this, that or the other thing. In the meantime, as I stated in my presentation, ordinary and usual things happen in death and dying in respect of breaking bad news, sedation and so on, about which people do not have an understanding. We are just beginning to grasp the importance of recognising and respecting patients' choices regarding ordinary, basic matters, the importance of communicating with patients and so on. Consequently, there are many things we can do but in respect of assisted suicide and euthanasia, one certainly is to not be afraid of embracing the disagreement and the diversity of views pertaining to it - that is, the fact that reasonable and sincere people hold different views on it, the varying levels of evidence extant for the implications of introducing it and so on. The discussion of the issue in the High Court was an example in which reasonable and sincere people discussed evidence in respect of assisted suicide.

I was not sure about the question from Deputy McLellan about the clinical ethics committee being a stand-alone entity. Perhaps I did not express myself clearly, but I am not talking about a stand-alone clinical ethics committee. I am talking about a national network of clinical ethics committees, as well as some support for that national network in the form of a small task force in the HSE, the Department of Health or a large hospital, which would support the translation of ideas among the existing clinical ethics committees. The eighth module of our ethical framework is quite detailed on this issue and was mainly written by Dr. Louise Campbell of NUI Galway, who is a national expert on clinical ethics committees. In addition, Professor David Smith of the Royal College of Surgeons in Ireland has been working closely with clinical ethics committees around the country. Consequently, there is some national expertise in this area and the eighth module of the ethical framework explains what such committees are, how they work internationally and so on, which is helpful for us.

**Chairman:**   As five other speakers have indicated, I will now call on Senators Colm Burke and Crown and then Deputy Catherine Byrne, in that order.

**Senator Colm Burke:**   I thank everyone who made presentations this morning, as they were highly informative. The Marymount hospice has opened in Cork this year and an additional 20 beds are being provided there. I understand the facility is recruiting an additional 36 staff and hopefully they are about to come on-stream, which would be welcome. I am a little concerned about the three areas in the country without hospice facilities or beds and they certainly should not be obliged to wait the 20 years it has taken for the expansion in Cork to take place. This matter must be prioritised. I have a concern regarding the national strategy that pertains to families. On foot of the

number of people who have left the country, many people no longer have children who live in Ireland and there must be careful planning for this issue in that present levels of support may well not be in place in ten or 15 years' time. It is an issue that underpins the importance of putting in place a national strategy in this area.

A number of speakers have touched on the legal issues and as someone who has been practising for more than 25 years, I am a little concerned about the lack of extant knowledge about the legal process. Even simple matters arise, such as people who have made wills failing to advise the executors that they have been made. This is amazing. Similarly, trying to get people to create an enduring power of attorney is extremely difficult and I agree with Ms Patricia Rickard-Clarke's point when she spoke about buying a house and getting all those things in place at the same time. It is something that must be done and this is about disseminating information. I seek the witnesses' views on how they would approach getting across such a message. Should it be a joint approach from a number of Departments and Government agencies, or how do they envisage it happening?

Another issue that concerns me greatly is the level of litigation now arising regarding the administration of estates for which wills are made. I have found an increasing level of litigation where wills exist and one reason for this is the tendency of courts to allow costs for such litigation to be drawn from the estate of the deceased. In cases in which people have a fairly frivolous claim against the estate, they will lose their action but their costs still are paid from out of the estate.

There is a message from this that must be dealt with because, speaking as someone who is operating in a legal capacity, I find amazing the reluctance of the courts to release moneys for the benefit of the person while at the same time, a great deal of those moneys are being used up in litigation afterwards. Perhaps there should be a discussion paper on how restrictive are the courts with regard to releasing moneys where people require care. This must be tackled and there is a present need to disseminate an information package in this regard. As the relevant information is not out there, what are the witnesses' views as to how this should be approached?

**Senator John Crown:**   I thank our colleagues and, as someone who was recently told he was one of the leading referrers of people to the palliative services in the country, I just wish to state what an outstanding job they do. It has been a real pleasure to see this specialty and discipline growing over the two decades in which I have been back in Ireland. I have a couple of quick points to make and will ask a couple of quick questions.

First, I deal with a large number of patients who die and in each week of my career I meet on average two people who definitely will pass away from the illness with which they came to see me, as well as some others who ultimately also will have that outcome, where it might not have been apparent that it was inevitable but where it still has happened. It has dawned on me that there is no real right way to die. It is very different. Some people clearly get phenomenal benefit from the warm embrace of being in a specialised purpose-built hospice, and that is really excellent. Some people - I believe an increasing number - wish to die at home, and I believe we should do everything we can to accommodate them. There also are people who wish to continue their care in a seamless fashion in the institution in which they have been looked after through the potentially curative phase of their illness. However, when that is no longer working and when, sadly, they are in the terminal care phase of their illnesses, for want of a better phrase, they would be quite happy to stay in the same institution in which they had been treated.

There is a real need to have a little flexibility and nimbleness in the way we develop our end-of-life services to accommodate those and facilitate the choice which is critical.

After the very sad conversation with a patient after the active phase of their treatment is over, they very often ask me if we are sending them to a hospice. I tell them we would be delighted to have them go to the hospice if they so wish. However, if they want me to continue being their doctor, we can give them the same care with the expert palliative services which we have in our hospital. It is critically important in developing the strategy that we acknowledge those three elements. Does the delegation believe there should be an emphasis on one direction rather than the other?

The second issue is one of cost. There is no doubt there is a significant amount of waste in the care of people who would not be thought of as formally palliative. Culturally and historically, palliative care has been regarded as cancer-related. That is changing, however. One reason is that the actual post-active treatment/pre-death phase of many cancer patients is quite short. Patients can be quite well, up and about and getting active treatment until that last treatment is no longer available to them. Often that final phase is shorter than expected. There is an increasing recognition that the extraordinary skills built up by palliative medicine doctors and care nurses would be beneficial for other people. I was delighted to hear Professor O'Shea refer to the needs of dementia patients. There are many of them who have been badly disabled by cerebrovascular disease or strokes whose quality of life is miserable, who do not want any more active medical treatment and whose primary concern is the symptomatic quality of their life. There is a real need to focus the energies and skills of the palliative services in directions which have not been thought of as classical palliative services.

With respect to cost, we often have a chat with a patient informing him or her that there is nothing else we can do to make the cancer shrink but we are not giving up and will look after them in a different way. When one does cross that Rubicon, the aspect of the cost of the hospital-based part of the care becomes a lot cheaper. This is apparent when one discourages the young doctors from enthusiastically ordering the extra tests they read about in medical school by asking them whether it will make the patient feel better or worse. It is also important to cost the different methodologies in end-of-life care.

With respect to the euthanasia debate, I always promise my patients that I will be with them as long as they want and I will not let them die in pain. If one takes that philosophy and undertakes to will give whatever level of medication is required to make patients' symptoms go away and will guarantee patients will die comfortably that is not euthanasia.

We must acknowledge that we have developed an extraordinary new national resource with one of the world's true leaders and developers in the field of palliative medicine, Professor Declan Walsh. He has spent a long career in developing the palliative care unit at the Cleveland Clinic in the United States and has come to make his services available to us in Ireland. He is a resource all of us need to tap into in a big way.

**Deputy Catherine Byrne:**  I acknowledge the work of the National Council on the Forum of End of Life in Ireland lead by a woman I admire much, Mrs. Justice Catherine McGuinness, and wish it well in its conference today. Most families want dignity and love for their loved ones when they are passing on. There is a fear when the word "hospice" is mentioned. However, they provide excellent care for the patient and their families. I had the privilege of my mam dying at home with the help of a palliative care team, as well as the unconditional love of my two brothers who lived with her, minding her to the end. For those who want to pass away at home, we should try our best to make it happen. In the case of my mother, we were glad she could be at home surrounded by family and friends but most of all helped by the palliative care team which brought us into a space where we had never been before and made us very comfortable.

I am surprised the report stated there are only 155 hospice beds available. In 2013, the Health Service Executive, HSE, plan stated 92% of all patients referred to a hospice should be admitted in one week. Given the shortage of hospice beds, how near are we to this target?

I have been to several cremations lately. It is like a conveyor belt with people put in one door and shoved out the other. There is no time for people to stay around and sympathise with the family. It seems to be a constant rush by undertakers to get people in and out on time so that someone else can pass through afterwards. This is wrong and needs to be looked at. What is the trend for cremations? Are they becoming more of an option across the country?

The Irish Association of Palliative Care terms palliative care as life-enabling. In what way does one work towards changing the perception of palliative care? When one hears someone is in palliative care, just like the word "hospice", people automatically believe the person in such care will die. This does not necessarily happen and people can live for some time with the right care. How can we change that perception of this type of care?

**Deputy Peter Fitzpatrick:** I wish to put on the record what a wonderful job palliative care teams do as I experienced with my late father and my mother at present. I also want to put on record what a wonderful job the hospices do. Ms Foley stated €73 million is spent on specialist palliative care but it is unplanned and uncoordinated. Will she elaborate on this? It is a service that is doing a fantastic job and I would not like to think there is waste there? She stated 26% of people die in their homes. If one has the support of a hospice home care, one is nearly twice as likely to die at home. Will she expand on that? There are 155 hospice beds but the HSE has stated there should be 450. What is happening to close that gap? Every person has the right to die in comfort and dignity.

**Deputy Dan Neville:** I welcome the delegations for their presentations. We are lucky in the mid-west that we have the Milford Care Centre hospice which has allowed many people to pass away at home. Everyone in the mid-west has had some family member given assistance by this hospice.

A debate will open up shortly on euthanasia and assisted suicide. What are the views of the delegations on this? We can all have closed minds that it cannot happen. However, I believe there is going to be a strong and vigorous debate around this issue.

**Senator Marc MacSharry:** Are there abuses in the funeral industry? Is there a need for some form of regulation?

**Chairman:** I must suspend the sitting. I apologise to our witnesses for this interruption, but we are called to vote in the Dáil as elected Members of our democracy.

*Sitting suspended at 11.10 a.m. and resumed at 11.35 a.m.*

**Chairman:** We resume now in public session and I apologise to our witnesses. There were two divisions in the Dáil and one in the Seanad. Senator MacSharry had to leave us because he is the Fianna Fáil spokesperson on a Private Members' Bill in the Seanad. He sends his apologies.

**Ms Sharon Foley:** Some of my answers will be combined answers to various questions. Senator Burke asked about 92% of patients being referred in one week. If there are no specialist hospice in-patient beds in a region patients cannot be referred. The HSE simply cannot meet that target. Several people talked about legal issues and emigration. I reiterate the point that end-of-life care and our approach to death, dying and bereavement is much wider than health. That is why we are calling for a national end-of-life and bereavement strategy.

To encourage people to deal with the legal matters involves raising the debate about dying, death and bereavement in Irish society. Advance planning then becomes part of one's natural life. One plans for the end of one's life when one is well and gets on with living one's life. It should become an everyday practice.

There are things that can be done now. As we speak, the HSE and the Department of Health are drawing up their service plan for next year. The committee can play an important role. There is a need to protect the budget that is allocated to specialist palliative care, protecting hospice home care.

Somebody asked a question about the impact of a hospice home care team on patients. The team is able to come into the home and provide that care at home. It makes a huge difference to patients at the end of life. If a team has a patient with complex needs who requires a bit more care and they cannot provide that care at home, they have no choice but to transfer that patient to the hospice, if they are lucky enough to have one in the area, or the acute hospital. They play a hugely important role but they need to be supported. We have a concern about hospice home care. Invariably, it is provided by small teams comprised of four to ten nurses, which are easily affected by cuts to budgets. One must deal with sick leave, maternity leave or people leaving, or the team may suddenly be halved after a budget cut. That has an impact on the ability to deliver hospice home care.

I reiterate that one of the things that can be done is for projects that have been earmarked to go ahead is to move from a preplanning to a planning stage. Senator Crown spoke about the choice of care location and promising people a good death. In our larger submission, members will see that we outlined all the elements that contribute to a good death. Some of those are well beyond our control. A good death is in some ways a facet of whether one has had a good life, building up good family and social supports, whether one has a belief system, and how society supports people who are dying, so we cannot promise all of those things. However, there are things we can do now to make things better. What we would like to see in a broad end-of-life strategy is the taking into consideration and pulling together of all of these wider elements to produce a coherent road map for the next five to ten years.

Senator Crown spoke about the need to improve skills in acute hospices. We have been advocating for that for a long time. In the past year, the clinical care programme for palliative care has developed a competency framework which has involved all the partners. That is about increasing the skills of health care staff at all levels of the health care system so they have the requisite skills around palliative care and are able to deliver care. We would like to see that competency framework developed.

My response to Senator Crown's and Deputy Neville's questions about what is being done to plug the gaps in the different areas is "Not enough". In the midlands, we have funded a piece of work to look at what might be the care needs of patients in hospices. It found the equivalent of 18 full-time beds are being used all the time for patients with palliative care needs. In respect of the earlier point about much of the budget being spent on end-of-life care, it is there and is being spent on end-of-life care, but we do not know where it is being spent and it is largely unco-ordinated and unplanned.

My colleague will talk about the regulation of the funeral industry. In terms of trends in cremation and the uses of cremation, we do not have the figures to date but all we know is that demand is rising, it is a very unregulated area and it is something that needs to be developed. In respect of the communication strategy, requiring our staff to have good communication skills around end of life is one thing, and we must provide the training and education. If any member wants to take part in any

of our training and communication courses across all the Irish hospitals, we would be happy to provide the training or even come into Leinster House to provide that training. Communication in respect of staff is also a facet of the general capacity of our society to talk about dying, death and bereavement. There needs to be a better and more open debate in Irish society about the need to plan ahead and to consider and plan for people who are dying.

**Ms Patricia Rickard-Clarke:** In respect of the point made about the level of support that will be available in the future for people whose family members are emigrating, this further emphasises the need for advanced care planning. The Assisted Decision-Making (Capacity) Bill 2013 will contain a provision for the office of public guardian. One of the roles of the public guardian will be to devise codes of practice and a public awareness programme, including leaflets, to inform the public about the need to make wills, allocate enduring power of attorney and prepare advance care directives. It will inform the members of the public about the need to plan ahead for when they lack capacity. That is extremely important. It is also extremely important in that the Bill provides that the public guardian will work with professional groups on codes of practice that will guide these groups. For example, it is terribly important that lawyers have their own practice guidelines on how to deal with these issues.

The tendency of the courts to allow costs to be awarded out of an estate is normal practice, but it is not always the case, depending on the situation. Obviously, that is one of the current rules. Many of the administration cases coming before the courts that are being litigated arise out of people dying in debt, so there are insolvent estates and difficulties arise in how to deal with that. That is one aspect. It is important to note that under the personal insolvency legislation, one of the mandatory requirements for a debtor is to make provision in the case of incapacity or death, so that they will probably draw up a will or allocate enduring power of attorney, which is a very worthwhile provision in that legislation.

I could not emphasise the role of the public guardian strongly enough in respect of public awareness. As I said in my opening statement, the forum is a public awareness initiative, so it is up to all of us in different groups and professions and the forum to promote public awareness of that planning, which is so important. We talked about the training of health care professionals. Many members of the public do not understand that they should go to a specialist lawyer in respect of these issues, which can be complicated and very difficult in particular family situations. It is terribly important that lawyers' skills are improved, and the Law Society of Ireland has a role in that as well. The Law Society of Ireland has issued a number of guidelines, particularly in respect of dealing with older people and vulnerable people, over the past few years, but there is still more to be done in that area.

In respect of the regulation of the funeral industry, there is no bar to entry and no licence provision at the moment. There is no qualification for the embalming of bodies or opening of a crematorium. We need regulation. The council of the forum contains a representative of the Irish Association of Funeral Directors. We have a working group that is looking at these issues and will make detailed proposals in respect of this. We will be making proposals in respect of planning by local authorities for end-of-life situations.

**Chairman:**  Is Ms Rickard-Clarke saying that any person can open an undertaker business with no qualification and no standard?

**Ms Patricia Rickard-Clarke:** Yes. There is no licensing or regulation at the moment. Lots of people undertake training.

**Chairman:**  That is not mandatory but is done voluntarily.

**Ms Patricia Rickard-Clarke:** Yes.

**Chairman:** With regard to crematoria, is planning permission-----

**Ms Patricia Rickard-Clarke:** Planning permission is issued in order to open a crematorium, but we do not have standards.

**Professor Eamon O'Shea:** I will be brief, because my colleagues have covered most of this. One issue that came up was the uniqueness of death and how each death is different. This is critical to maintaining the personhood about which we spoke, particularly with people who have cognitive impairment. Again, I stress that particular groups need special attention in terms of the uniqueness of each death and the need for services to recognise that. In respect of how communities are changing, particularly with regard to age and family structures, a good death requires communities of the living. By that, I mean that we need living and vibrant communities in order for all of us to die well. There must be some public visibility around death and that understanding of death to support the private grief that is associated with it. This is something we need to think about in terms of how we organise health and social care services and how we integrate voluntary, statutory and family views about death. It is critical to keep that community focus on the way we think about a holistic view of health rather than a clinical one all the time. In respect of costs, we need serious scrutiny of how we spend money in the last weeks of life in terms of making good decisions about where best to allocate that money, because we do not know whether some of that expenditure might need to go to other areas that embrace some of these broader social, personhood and holistic elements of life. To make good decisions about where we spend money, we need more information about how we allocate these resources.

**Chairman:** Senator Crown made that point in his remarks. He used the analogy of the young doctor conducting a battery of tests. Professor O'Shea referred to information about dying as a contentious issue. Have we changed in that regard?

**Professor Eamon O'Shea:** It has been five years since we conducted our research. It is interesting that older people, in particular, were willing to speak about death in general but when it came to being specific about their own deaths, there was reluctance on their part and among care staff in residential settings to address this issue. We are learning how to speak openly about these issues but until we get to that point the information deficit will remain. Where we have an information deficit or a vacuum, we can sometimes get bad policy. This is not necessarily because what is going on is wrong but perhaps it is not what people prefer or need at that particular time. That is related to resource allocation. Sometimes we get bad resource allocation decisions because we are not concentrating on what is really important. I do not have extensive expertise in this area but, from an economic point of view, it is important in the last months, weeks and hours of dying. That is what we have to address in terms of the broader strategy if we are to understand these relationships. It is particularly important to get resources to flow to where they can best be utilised.

**Dr. Joan McCarthy:** Further to what my colleagues have said about the uniqueness of every death, it is important not to sanitise death or consider it in terms of dying in the surroundings of one's family. There are patients who will rage against the dying of the light. There are awkward patients and others with imperfect families or no families. Health professionals have to deal with those kinds of situations. Doctors and nurses must, for example, work with families and patients who are in conflict or despair. Advance directives like think ahead and let me decide, which was developed by a colleague in UCC, Professor William Molloy, support health professionals and families because they make clear what the patients want.

In regard to Deputy Catherine Byrne's question on perceptions of palliative care, the palliative care specialists coming before the committee in the next session will be able to speak to that subject more expertly than I can. The European and Irish associations of palliative care have conducted research demonstrating that the use of palliative care does not hasten death. If anything, it makes people more comfortable with the process of dying. Pain management is something that accompanies the journey of the dying person. It does not push him or her towards death. It is a gift to all of us to be able to draw on that support.

On Deputy Neville's question about euthanasia and assisted suicide, those debates are about the processes involved. We are only beginning to understand what it means to respect people's autonomy. What does it mean for us as a culture to accept people's choices, preferences and individual responses to their life projects and what obligations do these place on health professionals? In very ordinary ways, people exercising choice is something that is difficult to promote. For example, I was disoriented when I came to Leinster House today because I am not used to the system. I was somewhat disempowered by the entire process. In the same way, patients and their families are disempowered when they enter a hospital because they do not know what is going on. In a basic way, we are only beginning to think about how we can enable people to believe they can participate and have a role in making decisions.

We need to develop processes that allow us to debate issues like euthanasia and assisted suicide in a reasonable way that allows sincere people to voice their views and consider national and international evidence. We must also think about the impact such debates will have on the goals of medicine and nursing. What are nurses and doctors supposed to be? Important questions arise in regard to solidarity and communal responsibilities, as well as preserving the integrity of doctors and nurses. As the Deputy noted, these issues are going to be a part of our culture but it is important that they do not sabotage the important subjects we need to discuss in the everyday sense of people dying in hospitals, health care settings or, ideally, at home.

**Deputy Mary Mitchell O'Connor:**   I thank the witnesses for their empathetic presentations and, in particular, for their discussion of holistic death compared to clinical death. I acknowledge their concerns about costs. They are being very respectful with their language in this discussion but when the issue emerges into the public domain, the focus for us will probably be on assisted suicide and euthanasia and some of what they said will be forgotten. How can we separate the two issues to make them work for the person who is dying and his or her family so that euthanasia is not the only focus for the media?

Professor O'Shea advised that we need to upskill doctors and somebody else spoke about upskilling lawyers. Is that happening as part of the training programme for young doctors or do we need to retrain them to deal with death properly?

**Chairman:**   I concur with Deputy Mitchell O'Connor that it is important the issues raised by the witnesses are not lost in the external debate. End of life care will affect all of us. Is it fair to say that assisted suicide will affect a minority whereas we should be looking at the majority?

**Deputy Dan Neville:**   It is a major ethical issue. We have followed the debate in the UK and studied the report that was prepared in that country. It is an area we will have to consider carefully rather than allowing it to be sprung on us. We should not leave it to the High Court to decide that we must discuss the issue. I am not being judgmental one way or the other.

**Ms Sharon Foley:** The forum on end of life, which was supported by the Irish Hospice Foundation, conducted a year long consultation on all matters related to death, dying and bereavement, and we

found that the Irish public was willing to engage on all aspects. It is refreshing to see such willingness to get involved in debate not only about bereavement but also the dying process, loss and supporting people at the end of their lives. I have confidence in the committee's capacity to steer that debate and, to reiterate my opening comments, I welcome this initiative as a brave step that is much needed in Irish society.

**Ms Patricia Rickard-Clarke:** Most people want to have a happy death at the end of their lives. We have a lot to do before we get into that debate. I am happy to engage in it and if the public wants a debate I am sure this committee will facilitate one. However, we are way behind most other jurisdictions in planning for our deaths and facilitating families through bereavement. We have not even put legislation in place in this regard. On the question of professional training, culturally we are also lagging. All of our professions need to be trained to recognise the right to autonomy and self-determination. Once the legal framework has been put in place, considerable training will be required to understand the legislation.

**Professor Eamon O'Shea:** The training should be given not only to medical professionals but also everyone engaged in this area. Reference was made to the holistic approach to dying.

If our approach to dying is truly holistic it must broadly move beyond the clinical, medical and caring areas into an understanding of what is needed around death.

This debate should be about the living. The living are living until they die and it is about how we create the quality of life and what we consider to be a just, human-rights-based approach to dying, but it must be emphasised and placed in the context of living and how living takes place right up to death. It is up to us to shape that debate. It incorporates pain relief, counselling and bereavement, but it is about how we constitute the quality of life associated with the living as we approach death.

**Dr. Joan McCarthy:** I reiterate what my colleagues have said. It is very much about the nuts and bolts, the ordinary everyday and acknowledging "death" and "dying" as ordinary words that are not so terrifying. If we take the sting out of those words we will also be less afraid of challenges and debates with regard to assisted suicide and euthanasia.

**Chairman:**   I most sincerely thank our four witnesses for their presentations and the substantive body of work they have submitted as part of their presentation. They are available on the Oireachtas website and will be part of our final report. We have made a very positive start to our series of hearings.

*Sitting suspended at 12.05 p.m. and resumed at 12.10 p.m.*