

The ICGP logo features the letters 'ICGP' in a blue, sans-serif font. To the right of the text is a green circular emblem containing a white stylized tree or human figure with branching limbs.

ICGP

The REDC logo consists of the letters 'REDC' in a bold, sans-serif font. The 'R', 'E', and 'D' are in a dark teal color, while the 'C' is in a bright red color.

REDC

Voluntary  
Assisted  
Dying:  
A report based on  
ICGP membership  
consultation.

September 2023

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# Overview

The ICGP engaged the services of RedC to undertake a qualitative consultation among its membership on the topic of voluntary assisted dying. The Oireachtas Joint Committee on Assisted Dying was formed to consider and make recommendations for legislative and policy change relating to a statutory right to assist a person to end his or her life (assisted dying) and a statutory right to receive such assistance. The Joint Committee identifies six discrete modules for consideration, including legal, ethical, professional issues, potential safeguards, consequences, and operational-policy issues. This consultation will assist the ICGP to prepare its submission and represent its members. The ICGP considers this consultation the first step in what will be a process of consultation and engagement with its members.

- This process consisted of six 90-minute focus groups with GPs.
- The whole membership of the ICGP were invited to join: 101 accepted the invitation and 79 took part in the sessions between 18<sup>th</sup> July and 8<sup>th</sup> August 2023. While a mix of in-person and online groups were planned, due to demand, all were held online, ensuring that we got a very widespread regional representation.
- The sample consisted of a predominance of GPs from non-Dublin, rural areas and those aged over 40 years.
- The format of the discussion was structured around a discussion guide, but left flexibility within this to explore issues of relevance to participants.
- Some quotations have been edited to ensure anonymity and this is indicated using \* where it occurred.



# End of Life

- In terms of understanding the context, there is wide discussion of the Irish culture which is strongly rooted in religion, faith and family – factors that help people cope at end of life. However, there is also recognition that this is changing to a more secular and multi-cultural population over time and that requires less reliance on traditional practice or an assumption that one approach will suit everyone.
- The Irish culture is perceived to be good at dealing with after death, funerals and offering community support to the grieving family. But there is a strong sense that the Irish are not very good at talking about end of life in advance, allowing patients to express their wishes or respecting those wishes. Avoidance of the seriousness of the condition, requests of ‘*don’t tell the patient*’ are quite common.

*“We celebrate it, we embrace the wakes and the funerals and everything but maybe we don't really talk about it. Nobody comes into me and says, 'I want to talk about my end-of-life care,' nobody comes in and asks that, no, so I think we maybe need to have more conversations about it perhaps”.*

*“Culturally and socially, we're very good when somebody dies, and giving support before it. But we're really, really bad at talking about ageing, death, how we want to die. It's all hush-hush, or I don't want Dad to know his diagnosis”.*

*“At times, family members, for all sorts of reasons, mainly good ones, do become very distressed and upset and will significantly try to alter carrying out the expressed wishes of the person who is dying, which are largely paramount”.*

- Many doctors have been at the centre of family feuds over an ailing patient and it's not something they feel well equipped for. However, their relationships with patients over many years means that they recognize their role as a communicator, a support and a trusted face in difficult times. They are also cognisant of the multigenerational relationship and so this can make it challenging to treat the patient alone.
- There is a very positive view of *palliative care services* in Ireland. Specialists are accessible and available in most areas and there is wide recognition that the provision of palliative care has greatly improved in the last five years.
- There is an appreciation that palliative care can greatly ease the pain and suffering that patients and families feel when they're dying. While most counties are well covered for palliative care services, there are perceptions that the level of care depends on where you live. Some counties are better served than others. Ideally, moving forward this would improve.
- However, the provision of palliative and hospice care it is very reliant on the charity sector and is largely underfunded for an aging population. There are also concerns that palliative care is being called upon in conditions where provision of medical care is keeping people alive longer than they would naturally.

*“The funding model for palliative care is heavily based on charitable funding and fundraising, etc., whereas the staffing appears to be funded via the HSE infrastructure, such as the buildings or through charitable donations and I think it probably .... time for the state to step up and have a more active role in creating the infrastructure”.*

*“I think good palliative care covers maybe 95% but both the evidence and our practice when we reflect on it would indicate that there are a small percentage of cases where of itself it is not adequate”.*

- There is a widely shared observation that the COVID pandemic has had an influence on families’ views of end of life. Going into a hospital at that time was such a difficult experience that many doctors feel that families are beginning to look at the quality of end-of-life care, rather than a sense of prolonging life no matter the cost.

*“Families are saying, 'Please don't send them to hospital. Please don't let their dignity and my last abiding memory be of a trolley in A&E-, ' so, yes families are very much wanting comfort and care in the community”.*

- The issue of *advanced care directives* emerged as something that needs to be legalised – many doctors have experience of patient wishes being disregarded by family or even hospitals. More binding and formalised advanced care directives would be one step closer to patient autonomy and giving comfort to the patient towards end of life.

*“People are given NIPPY machines and things to help their breathing that will prolong their life, but there's no clear mechanism very often for stopping those things when somebody has had enough. So, people are kept alive but without quality of life”.*

*“I did have an issue there about 5 years ago where a woman did have an advanced care directive, and it wasn't respected. And even though I advocated for my patient, they still overruled that, and it's terrible how this particular woman is still alive but with no quality of life”.*

- *Terminal sedation* is another issue that arose with some noting that while this is under the umbrella of palliative care, and a realistic part of end-of-life care, it can overlap to some extent with voluntary assisted dying. Supporters point out the reality of assisted dying at present that is well established.

*“If we're going to be involved in keeping them alive so long we have to take responsibility for what that life will look like and what that quality of life and what those symptoms will look like”.*

- In most end-of-life cases palliative care is a huge support; but there are some unavoidable 'awful' deaths that GPs have witnessed. These are primarily unmanaged cancer pain and neurodegenerative conditions. Most doctors agree that there are certain conditions that just cannot be relieved, and they are pained to see the agonising death their patient experiences. The distress can begin in advance as the patient knows what to expect and the family must witness this helplessly. Seeing and understanding this leads many doctors when thinking about their own death to an express desire to avoid such a difficult end to life.

*"I had a patient with advanced cancer in with me this morning, who was very clear what they will do to end their life when the time comes ...and I didn't feel able to further the conversation because I knew what they were saying was that they wanted assisted dying".\**

*"Anyone I've spoken to who deals with motor neurone disease says, off the record, they think there should be assisted dying in motor neurone disease. They can't say it on the record because it's not legal".*





# Voluntary Assisted Dying

- The issue of voluntary assisted dying is recognised as one that needs to be dealt with and that will most probably come into the Irish medical system. Public discussion of the subject is at a relatively early stage and most doctors welcome the idea that a more open conversation around death would take place (whatever their own personal position on voluntary assisted dying).
- There are some who are vehemently opposed and others who are strongly in support of voluntary assisted dying; the majority are conflicted, seeing the merits of it in a minority of cases, but also concerned about their own position in the provision or support of such a service.
- Many find it hard to contemplate, against a lifetime of training in supporting patient's life and health. However, few feel that we can avoid the conversation and there is a desire to have a measured and respectful conversation amongst their professional peers.
- Where doctors are more comfortable about the service is talking about neurodegenerative diseases which are terminal and end of life patients experiencing extreme pain.
- Those in favour of voluntary assisted dying tend to be well informed, having researched the experiences in other countries and are very keen to focus on the fact that this is voluntary. They're aware that only a small percentage of dying people inquire about this and an even smaller percentage actually go ahead with it. They feel that for patients to know that they have the option is enough to give them comfort and peace to deal with their end of life.

Supporters cited a number of key factors to explain their position:

- *Patient autonomy and choice*: giving people choices at times that matter to them and not forcing them to live longer than they want. This allows the patient to say their goodbyes, to get their affairs in order and to leave in a way that is comfortable. It also encourages a more open conversation amongst the patient and their family about end-of-life conditions, something that many doctors feel is avoided at present.
- *Dignity at end of life*: avoidance of extension of life in the face of a terminal diagnosis. Avoidance of certain medical procedures or supportive measures that are not desirable or comfortable. Some terminal conditions are very hard to treat and even with the best palliative care there is an awareness that patients suffer.
- *Relief of pain and fear for those dying*: some have had personal experience of this either through family members or through their own illnesses and know it is not realistic to say that all pain can be managed comfortably. Supporters anticipate that the legalisation of voluntary assisted dying in itself may provide comfort to patients in distress, even if they never themselves avail of the service.

*“I think it is for people who their physical journey is cruel that spiritually and psychologically the way they're not synced is that they're ready to go and their body won't let them go. And I think they are an emerging cohort in the community that we have to listen to, you know? So, people who are in clear consciousness, they have their autonomy, they know what they're doing and they're in these bodies that are just causing immense suffering”.*

- Supporters are very clear about the boundaries that should apply:
  - *Cognitive ability* of the patient to make an informed decision. The issue of cognitive ability is one that can bring the GP into play as they tend to know the patients over the years and feel that they can give an informed opinion. It should be an assessment that has input from someone who knows them well.
  - A process that allows *change of mind*. This is expected to be a relatively slow process over a matter of weeks, if not months. This gives the patient the chance to consider their decision carefully and last-minute checks should be conducted to ensure that they are still committed to their decision.
  - A *medically verified terminal diagnosis* (possibly with the prospect of a difficult death). This is likely to involve more than one medical professional and possibly not the GP at all. This could involve hospital-based specialists who can make this assessment.

Opposition to the concept or practice is evident in those who feel it contravenes everything they trained for - looking after patients and their life and health. Some go so far as to call this murder or suicide, and express concerns that it could send out a general message of devaluing life or countering the progress being made against the rising cases of suicide.

*“I believe in the sacredness of life, and I would believe that it's not ours to give and it's not ours to take. I'd be very frightened by the Canadian system coming in”.*

*“Now I appreciate, of course, that that isn't everybody's lot, and there are situations which cannot be redeemed in that way. But I don't see ending a life as the solution to that, and certainly if it does come in, and I hope it doesn't, I will not be involved in it”.*

- They have concerns about coercion, whether implicit or explicit. ‘*I don't want to be a burden*’ is a commonly quoted patient perspective and some fear that people could be pressurised into thinking that voluntary assisted dying was relieving this burden from the remaining family. As GPs exposed to and involved in the family dynamic at this point, they anticipate that some form of training would be needed in how to recognise coercion and manage this.
- At this end of the spectrum, there can be the use of very emotive language and a tendency to suggest that this option would be extended to or even imposed upon a much wider scope including those suffering dementia and other elderly.

The midground is occupied by the majority of GPs who are interested in the debate. They can see merit in patient autonomy and offering choices to patients in extreme situations. But many concerns are voiced about their own role in this process. They would like to be informed and are keen to hear the views of others and many expressed appreciation for the value of the consultation process by the College.

- Most say they would not like to get personally involved in the process but do expect that they will see it come into the Irish health system at some point in the near future. It is expected to be brought in by legislators but there are concerns about how many professionals will get involved to deliver the service. Reports from New Zealand suggest that patients find this a difficult service to access for this reason. On the other hand, they express regret at the inequity and lack of compassion in making extremely ill people travel to Dignitas in Switzerland.

*“I'm not entirely comfortable with farming out a problem either. That if it's happening, if people are going to extreme measures to try and travel for this treatment to end their lives, are we comfortable with that? It just speaks of a level of indifference that we're happy for that to happen”.*

*“But I think we have to give the patient the choice, and I think we're in the best position, having known the patient for 30 odd years, to be able to either answer the patient's questions, reassure them, maybe put them in a direction of trust and safety from our point-of-view”.*

- It is anticipated that a state system would provide the structure and support, taking the pressure and responsibility off the doctor. Comparative systems are referred to and in particular Canada as one that many have some familiarity with. At least two doctors need to verify the patient's wishes and a multidisciplinary team gets involved so that no one individual is taking the burden of responsibility alone. While Canada is a familiar reference point, those that knew of New Zealand felt more comfortable that it is a country in size similar to Ireland and that the restrictions are very tight at this point.

*“I think the interesting thing is medicine is changing, and it is no longer the doctors deciding really. I think we overestimate our power. It's the public are going to demand this, and I think we have to react to it in a compassionate way”.*



# The Main Concerns

The Main Concerns that GPs have in relation to this concept emerged as:

- *The language* around this is very emotive, potentially divisive, and judgmental. On balance most are happy with Voluntary Assisted Dying or Medical Assistance in Dying. The inclusion of the word *voluntary* is important to avoid any suggestion that this would be imposed on elderly or vulnerable people and medical assistance in dying could be confused with the current situation where terminal sedation is part of palliative care. Moreover, the voluntary aspect needs to include the doctors as well so that there would be no compulsion to be involved. Many who have conflicting feelings would be willing to refer a patient to a provider, but not to be involved themselves.

*“I think this is a societal issue, this is a decision that has to be made by society, but I also think it's very important that doctors should not be compelled to take part in this. I think this should be completely voluntary for everybody involved, it needs to be voluntary for the patient and it needs to be voluntary for the doctors”.*

*“I would help them in any way possible with the medically assisted but I don't know if I would be in a position to be the person there to do it”.*

- There are concerns that *the value of life* may be devalued or challenged unless the conversation is tightly controlled to those who make the choice themselves and are provided with emotional support before they go through with it. Most doctors, even those opposing the concept, are keen to respect the autonomy of dying patients.
- There are concerns about the *potential creeping extension* of it (which has been witnessed in other countries). While it may come in with strict boundaries and respect restrictions, the experience from other countries shows that this is likely to evolve over time. There is a suggestion that people who do not qualify for it may take a legal challenge to argue that they are being discriminated against because they can't access the service. Uncertainty about how the service would develop and evolve is something that holds many back from committing support.

*“That what would start off as a nice, tightly controlled area of treatment, would end up as it has done in other countries, that's well known, has ended up being very much more available than perhaps we would have liked initially. That's what we've to consider”.*

*“So, automatically, as soon as it comes in whoever's excluded from the criteria will be fighting to have it broadened and before we know it it's going to be widespread and it's going to be far beyond what was initially envisaged”.*

- *Potential for abuse or pressure* to be brought on people to avail of this service is voiced. In particular, there is concern about the elderly in nursing homes and those suffering from dementia. It is important that the conversation around voluntary assisted dying makes it clear that neither of these subgroups would be in range for the service.

*“There are cases where it would be the most appropriate. So, I can see a very strong argument for having that legislation, and then I find myself slightly scared that, for some groups, that they will feel a bit pressurised, and that they might end their lives for other reasons, out of a sort of generosity to others”.*

*“People are guilted into dying because their families are paying for them. They feel that they're a burden on society, I think that's a concern”.*

*“I just am worried that it would be abused by people feeling that they had to take on this because they're being a terrible burden to their families..... And I don't think it's necessary in Ireland because I think we have a good palliative care system; I think we do have a form of euthanasia when people are dying. I feel very strongly that it could be open to abuse”.*

- A minority fear that *palliative care could suffer* at a funding level if this was an alternative. Perhaps the state system would anticipate fewer users of palliative care, and this is a concern at a time when this widely appreciated, supportive service is expanding to meet the needs.

*“I think, for a lot of people, they feel that palliative care would be denuded or its value reduced as a consequence to this, which I don't see”.*

*“If you have a very poor hospice service in an area I can imagine that that would contribute to people wanting assisted dying, basically”.*

*“I think they're different choices and I think it would be terrible if we had assisted dying with no palliative care and I think the presence of perfect palliative care does not remove for some people who want to retain control at different points in their life, their desire to seek a medically assisted death”.*

- Concern was expressed about *the relationship* between doctors and their patients and the community.
  - Would a patient's decision be respected by family/community if the doctor got involved?
  - What would the aftermath or fallout of this be?
  - Would it change the doctor's reputation in the area and would it change the trust your patients have, particularly if families disagreed with this?
- In this sense some feel it's probably better if you are not actually directly involved with your patients but can support them access a more anonymised service.

*"I think it would definitely adversely affect our relationships with our patients and with their families, because if families don't agree on management plans, then you'll have half want one thing and half want the other, and how do we deal with that?.... But I agree with X, are we farming out the issue to another country?".\**





# ICGP Role

- *The role of the ICGP* is clearly there to support all the members and therefore, the **college is not expected to take a position for or against** the introduction of the service. GPs want a respectful debate around this, with room to change your mind or your beliefs.

*“I think what the college can do is encourage conversation..... around what's a good death, what do we do when somebody doesn't want to live anymore, and even if we're not a provider of medical assistance in dying, how do we cope with that? How does that affect us emotionally, in our work?”.*

*“The college has really good precedence around protecting GPs professionally (around termination of pregnancy) and I think if the same principles are applied and if the college communicates strongly with the Medical Council, I would be confident none of us would be put into a position that's significantly ethically at odds with our own personal values”.*

- The role of the ICGP is to **inform and educate** doctors about the system that is being discussed, and about the experiences in other countries so that they can have discussions with their patients. It is expected the public discussion and debate will encourage patients to at least discuss their death with GPs. This was observed after abortion was introduced and there are many doctors who appreciate the openness that patients will show them. This in itself would be a positive step forward in encouraging Irish people to consider and discuss their death in advance.

*“Summarising the assisted capacity decisions legislation around capacity would be helpful, and the college is very good at delivering short, educational modules around specific topics such as this”.*

*“We have a duty of care to educate ourselves about the process, about what this is. Because whether we like it or not, it's not our decision whether this is going to come. It's going to be the society's decision, and we need to be educated in order to help our patients”.*

*“I've read around a few of the other countries that have had it, that having that safety there, they may not choose to use it, but knowing it's there gives a certain level of comfort, and they can talk to their relatives then about how they feel because there is a service within healthcare. Whereas if it's not there, they feel scared to talk to their relatives, they feel shame, whatever they might think. At least they can discuss it more openly”.*

*“So, a lot of people .... object to it from their own, personal moral perspective and I think that's very important to respect that and it's important to give them choice, but also there's patients out there who will want to avail of assisted dying and I think it's equally important that we respect their choice”.*

- In summary, **there is more passive acceptance than support or rejection** within the body of GPs interviewed. There are some at each end of the spectrum, but **most in the middle want the opportunity to be able to discuss this with their peers and ultimately with their patients.**



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