

# It can take a village on rare occasions to achieve end-of-life wishes: “home is where the heart is”

## Abstract

**Aim:** Subjective quality of life wishes are as important at end of life as throughout all of life. In occasional circumstances there is very little time remaining to achieve these wishes and may involve enormous effort by many to accommodate such wishes. Palliative care teams know the true value of this effort, but it is harder to expect other busy services to give up their time to achieve an exceptionally rewarding outcome for patients and their families.

**Methods:** The case reports outlined in this paper hopefully will reflect the true value of extra efforts given by many teams to achieve a wish that lives on with families and truly should help in bereavement. In palliative care end of life wishes are paramount and exceptional circumstances tend live on in all our memories, including other service providers.

**Results:** Therefore, if such a scenario is required in future cases, the response is more immediately positive and engaging. In many countries people live in very isolated, rural areas and getting home for end of life may seem an impossible dream. The west of Ireland has many such rural areas and beautiful small islands only reachable by boat or plane, therefore acquiring use of a helicopter can be invaluable.

**Conclusions:** Use of necessary emergency services is not ideal, therefore thinking laterally of non-emergency services is preferable, patient and family wishes are achieved and there is no concern that other emergency victims are inconvenienced. The words of Dame Cecily Saunders<sup>1</sup> so aptly confer the importance of team work to achieve what may initially seem impossible, ‘you matter because you are you and you matter all the days of your life.’

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## Introduction

All palliative care (PC) focus is on quality of life (QoL), this is a continuum onto end of life (EoL) care, therefore QoL wishes are intuitive to our services. However, for many in healthcare, the biomedical model of ill health is rooted in the belief that ill health is an objective, measurable state and at EoL decisions are made based usually on medical factors, is the patient dying and too ill to move?<sup>2</sup> Illness, on the other hand, refers to a person’s subjective experience of ill health and is indicated by reported symptoms and subjective accounts in terms of distress, discomfort and their wishes.<sup>3</sup> Calman defined QoL in patients as the difference, or gap, at a particular point in time between the hopes and expectations of the individual and that individual’s present experiences.<sup>4</sup> The individual’s own view of their present reality, hopes and expectations can be described only by the individual. If QoL is defined as “*what the patient says it is*”<sup>2</sup> The doctor and the patient arrive at the medical process with different models, the disease model and the ‘illness model’, which must be integrated. There is increasing disillusionment with the purely biomedical model of health assessment, and interest in supplementing such approach with patient-based evaluations has increased. As eloquently put in 1859 by the great existentialist philosopher Soren Kierkegaard:<sup>5</sup> “*If you truly want to help somebody, first you must determine where he is. This is the secret of caring. If you cannot do that, it is only an illusion if you think you can help another human being. Helping somebody implies your understanding more than he does, but first, you must understand what he understands*”.

Very rarely a clinical scenario occurs in which a patient’s EoL wish is to get home/nearer home, but their clinical deterioration of actively dying negates that possibility, for clinical, distance or accessibility

reasons. If on reviewing a dying patient it is clear from them and/or their family, the patient has an overwhelming wish to die at home, it is important to consider this wish. When the view of everyone else involved is that patient is too ill, lives too far away and/or in a very inaccessible place, it can be like a leap of faith to consider, maybe we can achieve the patient’s dying wish. For our services we are used to aiming for the best outcome and acting as strong advocates for our patients, this sometimes means engaging appropriate services, extensive discussions that the right outcome is possible with all teams who are looking after the patient and it can be helpful to quote publications to support a decision that reaffirms the worth of the effort required. Hence, the three cases outlined below reflect on the enormous effort made by all to achieve EoL wishes to get home and confirm the effort was so worthwhile. teamwork matters, ‘*it takes a village*’.

## Case reports

### Patient I

A 96 year old patient had been transferred from Donegal county to Galway University Hospital (GUH), Ireland, for a lung biopsy, as he had two failed biopsies in the local Hospital, Letterkenny General Hospital (LGH). Mesothelioma was suspected and a diagnosis was considered important. He started to die in GUH Intensive Care. PC team were called to address EoL care. On arrival to access, the patient was clearly distressed as he wanted to get back to Donegal. His wife was 94 and he knew the journey would be impossible for her to do and too long to insure she was with him before he passed away. The trip was a 5 to 6 hour journey in very windy, almost ‘rally like’ roads by car. He had never left Donegal in his life and he had never been

away from his wife in decades of marriage. The National Ambulance service (NAS) was contacted, their National Paramedical Co-Ordinator contacted the army, Helicopter Service and the army agreed to air-lift the patient, for free, on humanitarian grounds. We then had to secure a bed in LGH as the local Hospice said they had no bed. The hospital was under enormous bed pressure but another patient agreed to move onto a 'Trolley' to allow this Native of Donegal to get nearer home. On contacting the family they were so stressed that they had begun the journey with their very elderly mun, they were thrilled to be able to turn back circa an hour into their journey. A junior doctor only two weeks in PC, agreed to accompany the patient. He described afterwards, he kept alerting the patient as he feared he would pass away before arrival at his important destination. All the patient's family were in the grounds of LGH to greet their loved one. They cheered with delight when the helicopter landed. He passed away peacefully hours after arrival.

**Patient 2**

A husband/father of three very young children, in his forties was dying of a metastatic cancer that caused a chylothorax that required an indwelling chest drain for symptom control. A chylothorax is the accumulation of lipid-rich lymphatic fluid (chyle) in the pleural space, typically caused by damage to or obstruction of the thoracic duct. This chyle is very viscous or thick and sticky. To go home the chest drain had to be removed, the clinical concern was that he would not survive long enough after the drain was removed to make the four plus hour journey home. His dying wish was to be with his family at home. As above the NAS was contacted, again agreement by the army on humanitarian grounds to air-lift him home. As the helicopter took off they left the door open so the patient could feel the wind, having been so dyspnoeic for so long. The patient commented he had always wanted to see the Eiffel Tower in Paris, so the helicopter took a different route to bring him over some ancient castle remains he had never seen. The whole town came out to greet him home as the helicopter landed in a local football field. His wife contacted a few years later to express to all, especially the army, how vitally important this effort was for her children. What she said was that the enormous effort meant so much to her husband, but most of all to their very young children who felt their dad got such special treatment, their dad 'mattered'. His wife commented, memories and photographs of the whole event helped them so much in bereavement.

**Patient 3**

A 64 year old man from Donegal, who had rarely left Donegal and had never been on an airplane, was referred to PC in GUH dying of advanced cancer. His family were called the evening before due to his significant deterioration, it was felt he would not survive the night. On review as he discussed his home, his eyes lit up, he spoke about his pride of being 'an extra' in two movies filmed in Donegal. He was clear he wanted to go home, as discussions occurred based on previous efforts to get people like him home, he started to brighten up. Again, the army co-operated. Donegal Hospice gave him an urgent bed. The outcome was relief, that was palpable and visible and the patient brightened up and below picture shows a completely different man to the person we meet earlier, this picture is from our national newspaper, The 'Irish Times', his delight is clear in photo.<sup>6</sup> He lived another five days before he passed away with his family around him (Figure 1).

**Other patients**

We have had many patients airlifted to our main islands off the Galway, Mayo coast, these islands made very popular from the movie

'The 'Banshees of Inisherin'.<sup>7</sup> Islanders love their home and enormous efforts have gone into airlifting islanders home. Pictures taken during flights show the beauty patients witness as they know they go home for EoL care. One author is a career long general practitioner on the well known Aran Islands and she as well as all on these Islands have pulled out every stop to insure EoL wishes are accomplished (Figures 2 & 3).



Figure 1 Dying patient brightens up as he heads to his beloved home area.



Figure 2 View patient witnessed as she was flown to her island home.



Figure 3 View patient witnessed as she was flown to her island home.

## Discussion

These cases are very clear, the effort of intense interdisciplinary work done with tight time constraints were so worthwhile. Sometimes, coaxing other teams relegated with the patient's care can be the hardest to bring around to see the value in trying, hence why publication matters as it may help colleagues internationally to achieve a similar outcome. This organisation does demand a lot of intense work, akin to an EoL emergency in many ways and in our experience, everyone reacted with enthusiasm and speed. It is important to engage services that do not take away from emergencies, like the acute hospital helicopters, by asking services not normally involved in emergencies there is a sense that no one loses, 'a win, win'. A factor unknown is in this scenario the non-emergency do require a healthcare worker (HCW) to accompany symptomatic patients and on arrival at the isolated area, that HCW has to make their own way home, often late at night. In our cases we have found word of mouth on the positivity of the outcome helps too, as one team tell another, that was so worthwhile. People involved too showed exquisite kindness and empathy, like the helicopter pilot insuring he brought patient 2 to see a memorable site on his last journey.

### The 'trickle effect' of empathy

It is worth mentioning the 'trickle' effect of other observers also when considered extraordinary issues addressed by multiples of people. Observation of the positive alteration of patients towards joy on addressing issues so close to their heart does impart sometimes on observers and/or students. On one occasion during the Covid-19 pandemic a patient very near EoL was admitted from one of our Islands, Achill, he chatted sadly about home, then we started chatting about the movie, 'The Banshees of Inisherin',<sup>7</sup> it turned out he had never seen it and some of the most dramatic and beautiful scenes are from near his home. He could not go home due to lockdown. The student nurse at the bedside was asked to phone our very cooperative technical department and request a laptop for the patient. She did this and they watched the movie together. A few years later she approached our team and said she is now following a career in PC Nursing and she cited the incident with the movie as having a profound effect on her, she decided, this is what I want to do in my future career.

### The learning from images

An interesting thought is that 98.41% of medical students agreed images and videos would be beneficial for their learning.<sup>8</sup> Therefore, it is hoped the visible joy in a previously dying man, expected to die within hours, helps impart the importance of hard work to address his last wish. Also the beauty of 'home' for many, that that beauty matters. On one occasion it was a struggle to pinpoint the source of as patient's pain and a phone photo her husband happened to show us created a eureka moment and identified pain source immediately.<sup>9</sup> Research showed highly significant reduction in symptom interference in QoL by simply showing their teams a picture of the patient's view of their symptoms in a controlled clinical trial.<sup>10</sup>

### Bereavement

The positive influence of putting enormous efforts into EoL wishes is highly likely to help in bereavement. In the second patient's case such positive feedback was received, but it makes commonsense that putting their loved one first and foremost at such a vulnerable time adds value to good memories. Dame Cecily's quote,<sup>1</sup> is just so empowering and for families left in grief to truly know their now deceased loved one mattered 'all the days of their lives' as their last wish was paramount and achieved.

## Influence of real scenarios on medicolegal decisions

Issues such as EoL decisions create complex medicolegal and ethical webs in which society expects guidance not only from the judiciary but also from the medical and nursing professions. EoL decisions are usually based on concerns that are perceived as QoL concerns. Of interest, a poster presented at a national research forum was later used in a major 'Precedent High Court Capacity Case' in Ireland to educate and explore the value of addressing patient wishes to die at home. It was so visible and explanatory the President of the High Court thanked the educational component of this in his final report.<sup>11</sup> This report is now being taught in a Masters in Ethics course in Ireland, it was a precedent case as major reforms had just been implemented in a new 'Capacity Law', therefore the case received major national attention. The philosophical arguments around patient adaptation and the dynamism of the QoL construct with specific regard to EoL decisions in palliative care populations need further exploration and research.<sup>12</sup>

### Recalibration or response shift

For so many, 'home is where the heart is' and on reflection the more isolated the area sometimes the more beautiful and calming the scenery is. Patient 3 went from actively dying to bright, alert and happy in front of us, as he came to realise his wish could come through. In QoL research, called 'Response Shift' (RS) or recalibration.<sup>13-16</sup> RS is a clinical phenomenon that is visible at the bedside sometimes, creating the space for patients to achieve QoL and EoL wishes could improve the patient's wellbeing. Research should be based on exquisite QoL issues of relevance to patients especially at EoL.<sup>12</sup> The phenomenological perspective acknowledges the dynamic nature of QoL and separates it from any external definition of health. As death approaches, physical deterioration appears with high scientific validation to become relatively less important, and intrapsychic factors are relatively more important.<sup>12,14,15</sup> As palliative care places the QoL of the patient and his or her family as it is 'raison d'être', to accept that there is no way of achieving 'all the layers of EoL, QoL issues' appropriately would not reflect the real enthusiasm of workers in this area.

## Conclusion

Decades ago, immediately after publishing Irish data of improved QoL for patients with impending mortality,<sup>12</sup> one author attended a palliative care meeting in the USA Following a speaker on QoL, expressing words to the effect 'it doesn't take a rocket scientist to know QoL deteriorates as death approaches', the author referred to the publication and its results that QoL can improve as death approaches. This was followed by a silence, then a comment to the effect, 'you are Irish, are you not all very religious over there'? Implication appeared patients don't mind dying. Could it be that, on the one hand, we see and empathize with our patients' experience but, on the other hand, rationalize their reality with our own views in good health? Dr. Jane Poulson,<sup>16</sup> as a PC Physician who develops breast cancer, describes her true paradigm shift in such a worthwhile read for all of us involved in PC, 'Bitter Pills to Swallow': "I found myself transformed from one who orders and administers medication to a terrified recipient. Until then, I had felt that I was a particularly empathetic doctor who listened to and, I thought, heard the stories of my patients. It was a shock, then, to undergo the foreign and surreal experience of becoming a patient". By listening to our patients and families and addressing the 'extra layer' of the true depth of subjective EoL wishes, the extraordinary sometimes can become ordinary. Again, QoL wishes at EoL are as pivotal as throughout the whole palliative care journey

for patients and could impart emotional healing. Michael Kearney writes eloquently on soul pain, death and healing which reminds us of the worth of creating space to promote the patient's sense of personal wholeness.<sup>18</sup> Where there is a will, there is a way! To describe in our very ancient Gaelic language proverb/old saying;

*"Faigheann cos ar siul rud nach bhfaigheann cos ina conai"*

Translation; *"Proactive people reap the benefits of their hard work, while those who wait do not"*.

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## Conflicts of interest

The authors declares that there are no conflicts of interest.

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