

Patients who are dying to go home

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Madeleine Brindley, The Western Mail

A generation ago, people would die at home rather than in hospital - but without the modern nursing, support and pain control techniques we now have at our disposal. Today the majority of terminally ill patients die in the sterile, impersonal environment of the hospital ward, often against their wishes. As Marie Curie Cancer Care campaigns for people to be given the choice to die at home, Health Editor Madeleine Brindley examines the issue

QUALITY of life is one of the watchwords of the all-new caring and sharing health and social care services in Wales. A huge emphasis and resources are placed on helping people to maintain their independence in the face of illness. And new cancer drugs, while not curing the disease, offer patients better quality and extended life in the face of death.

But what about quality of death?

Few people like to think of their own mortality and yet, to borrow an old maxim, there are only two certainties in life - death and taxes.

It is a sad fact that in Wales people die sooner than in other parts of the UK - on average two to three years earlier. The nation has some of the highest rates of heart disease, stroke and cancer in Europe, due in part to the lifestyles of so many people living in the shadow of high levels of deprivation.

Very few people will have spared more than a thought about their own death. We may have mused on the subject of funerals and the merits and disadvantages of cremation, but very few of us will have thought about where we want to die until we are faced with that eventuality, or confronted by the impending death of a loved one.

New research, commissioned by Marie Curie Cancer Care, which yesterday launched a campaign to enable terminally patients to make a choice about where they want to die, suggests that there is a choice gap around the issue of the place of death in Wales.

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A supporting survey by YouGov found that 73% of respondents experienced the cancer-related death of a family member or friend - 53% of whom died in hospital, the highest proportion in the UK. Only 34% were able to choose to die at home.

But when asked if they would prefer to die at home if they were terminally ill, 55% of Welsh interviewees said yes.

And of the quarter who said they had some regrets about where their friend or loved one died, only 2% said they would have preferred them to die in hospital.

Marie Curie Cancer Care's caring services manager for Wales, Viv Cooper, said, "The choice element is the most important thing, although it is not for everyone.

"Research over many years and the research today clearly shows that people would like to make the choice and most people would like to be in their own homes. It's about family, family support and familiarity in your own surroundings - there is no place quite like your own home."

Baroness Ilora Finlay, who is professor of palliative medicine at Velindre NHS Trust and is backing the Marie Curie campaign, added, "There is a big gap between what people feel they want and what happens.

"People who are very sick tend to be in hospital, but for many who know they are dying and want to go home, they do not want to remain in hospital but they need to have everything set up first and they need to know that they will get the care they need at home."

To die at home, a patient needs about 55 hours of nursing support, particularly at night, from qualified nurses and carers. Relatives, family and friends also need to know their loved ones are being properly cared for, as they would be if they were in hospital.

There are currently more than 200 Marie Curie nurses working in Wales as part of the large network of professional and personal support, providing each patient in the community with an average of 63 hours of free one-on-one care.

But if Wales is to redress the imbalance between those wanting to die at home, and those who actually do, while also relieving some of the pressure, significant investment is needed in not only ensuring that the network of support is in place but also to inform patients of their choices.

Prof Finlay added, "This campaign is about quality in death and allowing natural death to occur when it was meant to with good symptomatic control and with people in control so

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they are not dying in despair."

To support Marie Curie Cancer Care call its Daffodil campaign number on 0845 601 3107