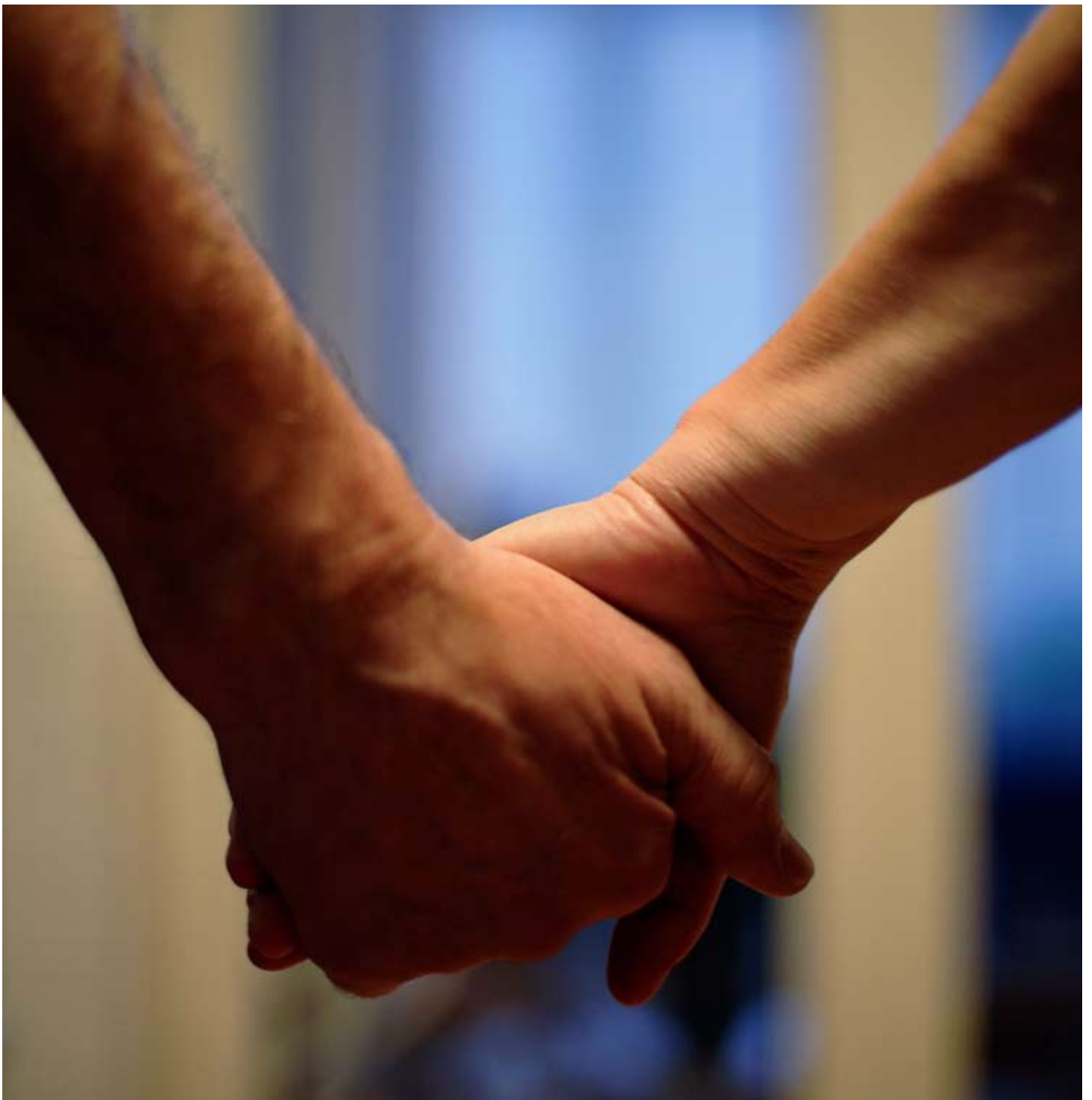


# A Charter for Dignity at the End of Life





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## Foreword

The Rt Hon the Lord Warner

Over 500,000 people die each year in the UK. Whilst some people will die a sudden death, many will die as a result of a terminal or chronic illness. What matters most for these people is the quality of those remaining months or weeks, dignity at the time of death and support for those who care for them.

Impressive medical advances mean, as more of us live longer, there will be more people diagnosed with terminal illnesses whilst the proportion with complex medical conditions will also increase.

As 'consumers' of health care we demand more. Expectations of public services are much higher than previous generations. Now, with the 'baby boomer' generation reaching retirement age, the requirement for health services to respond is greater than ever before.

Choice and personalisation are central to the current debate about the future of the

National Health Service and social care. The Government's first ever End of Life Care Strategy aims to deliver increased choice to all patients about how they want to be treated at the end of life, including the final stages. Government clearly acknowledges that people increasingly want to make their own decisions about treatment and care at the end of their lives.

The Charter for Dignity at the End of Life places choice, access to services and personal control at the heart of improvements to end-of-life care. I hope that its recommendations will be carefully considered by the providers, policy decision-makers and users of our much valued and treasured National Health Service.

*Norman Warner,*



## Introduction

Sarah Wootton, Chief Executive, Dignity in Dying

In a recent survey, having healthcare choices at the end of life is valued more highly than having choices at the time of giving birth. An overwhelming majority of us want more choice about where we die, pain relief, access to quality health care and not to have life prolonged against our wishes. At the end of life, as during it, we want to be treated as individuals, to be respected and for those who care for us to be supported and protected. Basically to be treated with dignity.

But more than half of hospital complaints received regard end-of-life care and there is a serious 'disconnect' between what people expect at death and the services that are currently available. That is why Dignity in Dying is publishing the first ever Charter for Dignity at the End of Life which sets out what needs to be in place if dying with dignity is to be a reality. From diagnosis and access to palliative care to the expectations of care and health services; from how and where people die, to bereavement counselling and support for those we leave behind.

At Dignity in Dying we campaign for terminally ill, mentally competent people to be given the option of an assisted death if they feel their suffering has become unbearable. The Charter includes this call. But we believe that assisted dying forms part of a wider debate around choice at the end of life. Ultimately, each individual decides what they believe is a dignified death. Most people will see their needs met through personalised and good



Principles for Dignity at the End of Life

quality palliative care. But although only a minority of terminally ill people would exercise the right to an assisted death, many will take comfort in having the choice.

Our Charter for Dignity at the End of Life says that a dignified death means having choice about where we die, how we die and who is present. A dignified death means exercising control by planning for the end of life. A dignified death also means having access to expert information on the choices available for end-of-life care, access to high quality palliative care tailored to individual needs, and access to support for carers and family members.

The Charter for Dignity at the End of Life is calling for a fundamental shift in how end-of-life care is managed and delivered. We want to see services that are sensitive, responsive and accessible to all. Choice, control and access need to be at the heart of any end-of-life policy if we are to ensure that all people can have, what they consider to be, a dignified death.

*Sarah Wootton*



## Sue Stapely Having control over treatment

"I have a genetic renal condition and advanced osteo-arthritis.

I made my first Advance Decision many years ago when my two sons (now in their 30s) were in their teens. I talked to them about the kind of death I would want, under what circumstances I would want to refuse medical treatment, my atheism, my preferences for a Humanist funeral or celebration, and my wish that my body should be used for medical research.

My latest Advance Decision, made a year or so ago, is properly registered with my GP and counter-signed by him - fortunately my GP is entirely comfortable with all this - so many aren't. My wishes are known to my executors and my sons, and have

been the subject of further conversations with my family and closest friends. They know where my Advance Decision and all my documents are, and I think it is comforting for them to have some certainty, and not to have to wonder what they should do when the time comes."

## At diagnosis

### Providing access to information

A terminal diagnosis creates significant emotional and psychological issues for patients, their families and friends. It is essential that information about the illness and the options for care are communicated by professionals who have the necessary expertise and training to do so with honesty and sensitivity.

Past initiatives to improve communication skills training have greatly aided both patients and care providers. Every health and social care professional must be fully equipped to have appropriate conversations with their patients and therefore must receive specialised communication skills training.

With the emphasis on choice at the point of diagnosis, patients also require simple, accessible information in order to make fully informed decisions about the type of care they would like to receive during their illness.

### Setting out wishes and needs

A survey commissioned by Dignity in Dying showed that 65% of people think they would be more likely to have a dignified death if they could discuss and record their wishes around care and treatment at the end of their lives. Yet 40% of people have never discussed their wishes for care and treatment at the end of their lives with anyone.<sup>1</sup>

Terminally ill people need to be given the opportunity to communicate and record their needs and wishes related to their future end-of-life care. This could involve setting out issues such as where they wish to be cared for, any requirements related

to beliefs and values, and who should be present at the time of death. This can be set out in a document known as an End-of-Life Care Plan.

In our survey, 67% of people say that an End-of-Life Care Plan is a good idea.<sup>2</sup>

**Dignity in Dying believes that all people diagnosed with a terminal illness should be able to record their wishes and preferences when they are approaching the end of their lives.** Though not legally binding, health professionals have a professional obligation under the Mental Capacity Act to take expressed wishes and preferences into account. However, we want to take this one step further and place a duty on health professionals to seriously engage with End-of-Life Care Plans.

### Having control over treatment

People have the right to refuse treatment, provided they are mentally competent, but they have no right to request a certain type of treatment. Advance Decisions (formerly known as Living Wills) allow people to record their wishes for future treatment, even before they are diagnosed with a condition or illness, in case they lose the capacity to make these decisions. Only Advance Decisions to refuse treatment are legally binding, and must be followed by doctors and other health professionals, having been made statutory since the enactment of the Mental Capacity Act in October 2007.

People can also set out their preferences for certain treatments in their Advance Decision or in their End-of-Life Care Plan, if they wish to do so. Health professionals will have to take these wishes for treatment into account but they are not legally binding.

Some people decide to appoint an attorney to make decisions for them if they lose capacity to do so in the future. The Mental Capacity Act has created a new legal tool called Lasting Powers of Attorney, to replace the current system of Enduring Powers of Attorney, which extends the power of attorneys to making welfare or healthcare decisions.

The use of Advance Decisions is becoming increasingly widespread. Our own survey showed that 1 in 8 people (13%) had an Advance Decision in 2006 up from 8% in 2005 and 2% in 1995.<sup>3</sup> Whilst it is essential that individuals are able to record their wishes, they must also have confidence that they will be carried out. However, health professionals are not always alerted to the fact that an individual has made an Advance Decision.

**That is why we are calling for Advance Decisions to be held as part of a nationwide health records system using a central registration facility.**

Advance Decisions have been a significant step forward in the patient-centred approach to end-of-life care. **However, we believe that far more needs to be done to raise awareness of Advance Decisions among the general public. We believe there should be a national campaign, backed by the Government, to ensure everyone knows their legal right to refuse treatment.**

### Dr E A Macdonald FRCR MA, Consultant Oncologist, Author "Difficult Conversations in Medicine" **Difficult conversations towards the end of life**

"Some of the most challenging conversations for doctors involve the sharing of bad news about a diagnosis with patients and their families. Each person is different and the best communicators among doctors try to respond to the needs of each person individually. Although inevitably some doctors communicate better than others, these skills of empathy, clarity and pace of discussion can be taught.

It is important first to clarify exactly what the patient understands about the situation so far and then to explain clearly in straightforward terms, free of medical jargon, what the diagnosis entails. What is the name of this condition? (writing the diagnosis down can be very helpful) What treatment options are available? What are the potential complications and side-effects of each of these? What is the outlook if the patient decides against treatment or if the treatment does not work?

It is essential that the patient takes away from this discussion at the very least the assurance that symptomatic measures and continuing care are guaranteed to the best of the team's ability.

Often there is too much information for people to take in all at one sitting and an early return visit is preferable. Once the reality of a diagnosis has sunk in is the best time to explore how each patient would like to proceed."



## Rose Marie Kelly Ongoing care

"I was diagnosed with bowel cancer four years ago. The cancer quickly spread to my lungs and since then I have had intensive chemotherapy and four major bouts of surgery.

During the course of my illness I have had very different experiences in two different hospitals. The first hospital I went to was terrible - the pain relief and nursing care were not sufficient and I saw several people die in agony. The second hospital was much better at providing care for the dying, but there clearly aren't enough hospice spaces for everyone who

needs them. I was lucky enough to have family who could look after me at home whilst I was extremely ill from chemotherapy but not everyone has that kind of support. I really feel that there is a postcode lottery of treatment and it simply isn't fair."

# Access to quality care

## Access to palliative care

The current inequalities in accessing palliative care services are unacceptable. In a recent report, the Royal College of Physicians confirmed that access to palliative care services is inadequate and inequitable, with unacceptable variation in care geographically, across demographic groups and across diagnoses.<sup>4</sup>

Palliative care is routinely offered to cancer patients but is not routinely available to those with other terminal conditions such as Motor Neurone Disease or respiratory disease. Recent polling by Dignity in Dying shows that around 9 out of 10 people agree palliative care should be available to those suffering other terminal conditions.<sup>5</sup>

The Government has recognised the need for improvement with its manifesto commitment to double investment in palliative care services. The Royal College of Physicians has confirmed in a recent report that funding of palliative care services is unsatisfactory, with the NHS contributing only about 30% of the costs of specialist palliative care.<sup>6</sup> In addition, there are wide variations in the spending by Primary Care Trusts on palliative care.

**We believe that more resources should be made available and that a more consistent system for the provision of end-of-life care services is needed.** There is a clear need for a fairer and more consistent organisation of the complex array of end-of-life care services, with a more transparent system for commissioning based on local needs and preferences. The National Council for Palliative Care, Marie Curie, the Cicely Saunders Foundation and Help the Hospices - the hospice movement's national charity - all agree. We hope that the new Care Quality Commission will see end-of-life care as a subject for an early review.

## Quality in palliative care

Dying patients have complex needs and research has demonstrated that people do not always get the care they need. Dissatisfaction seems to be particularly high with palliative care delivered in hospitals and is evident from a range of sources.<sup>7</sup> Currently, more than half (54%) of all hospital complaints received by the Healthcare Commission are about end-of-life care.<sup>8</sup>

Under the NHS End-of-Life Care Programme, a great deal of time and effort has been put into designing tools such as the Gold Standards Framework, the Liverpool Care Pathway and Preferred Priorities for Care. Practice shows that these tools have a very positive impact on the quality of end-of-life care services.<sup>9</sup> The challenge is to spread the use of these best practice tools among health professionals and to ensure they are used effectively across different settings.

Studies have also shown that many health professionals continue to harbour misinformed attitudes towards morphine, which can result in patients being left in unnecessary pain.<sup>10</sup> The Royal College of Physicians has recommended better research into treatment for symptom control in a recent report on palliative care.<sup>11</sup>

**Dignity in Dying believes the Government needs to ensure it has an accurate picture of the standard of end-of-life care and that the quality of palliative care services needs to be measured in order to record any progress made in improving service provision.**

## Being treated as an individual

Health and social care staff at all levels should have the necessary knowledge and skills to recognise and respond to the individual needs of terminally ill people.

There is a considerable difference between caring for a person and treating them. Caring for a patient means recognising and where possible responding to a person and understanding what matters to them. At a time when a person's illness can rob them of their dignity and their sense of identity, attention and care given to small but significant personal details can matter a great deal.

Good quality care takes the concerns of both patients and relatives into account and aims to respond to individual needs. As well as providing physical relief, people must be offered the psychological, emotional and spiritual support that they may need.

**Dignity in Dying believes that treating people as individuals must be at the heart of improvements to palliative care services and that training must be routinely offered to health and social care professionals to achieve this.**

## Supporting carers

Unpaid carers provide most of the care for older, disabled or terminally ill people. There are more than half a million carers of terminally ill people in the UK.<sup>12</sup> Nationally it is estimated that unpaid carers save the economy an average of £10,000 per carer - a total of almost £60 billion per year.<sup>13</sup>

Carers take on their role with little or no training or support and often with adverse consequences for their own health and employment. 625,000 carers experience physical or mental ill health as a direct consequence of caring, while one in five carers is forced to give up work because of their caring responsibilities.<sup>14</sup> It is currently possible for an employer to refuse to employ a carer or to dismiss them because of their

caring responsibilities. Unless they can claim sex discrimination the carer is left with no protection. Carers Allowance remains low at just £50 per week and, because it is regarded as income replacement benefit, is not available to those of retirement age.

Since the 1999 Carers' Strategy, Government has made considerable improvements in support for carers. Since April 2007, carers of spouses and family members have had a statutory right to ask for flexible working. A National Carers' Strategy was launched in June 2008, which sets out a vision for providing greater services and support for carers in the next ten years. The actions as set out by the Government to transform this vision into reality cover issues such as more investment into planned breaks for carers, improving financial support, information and advice, the promotion of flexible working, training for the workforce, emotional support and targeted support for young carers.

Dignity in Dying believes that carers should be involved in discussions with the patient around care and treatment and that carers should be made aware of their personal right to have their needs assessed as well as of their entitlements to benefits, quality breaks and other support.

**We support calls for carers to be better rewarded so that anyone providing more than 35 hours of care per week, regardless of age, should receive a carer's benefit in recognition of their caring role. Carers should be given breaks that they would want to take, at times that are convenient for them and respite care should be of good quality so they have peace of mind that their loved one is being well cared for. Carers should also be better protected under law, so they cannot be discriminated against because of their caring responsibilities.**



### Peter Jones Wanting choice over where and when to die

“Just over six years ago, after a year of tests, I was diagnosed with Motor Neurone Disease (MND). Now, I am confined to a wheelchair, I cannot use my arms and I am losing the ability to speak. MND is taking me away from my family a little bit more each day.

Throughout my personal and working life I have evaluated my choices and then made the decisions I knew were right for me. The final decision I want to be able to make for myself is how and when I die, but I am denied this by the current outdated laws in this country.

In order to have that choice I considered going overseas for an assisted death, but I decided against it because I do not want

to die in a strange land, in a strange flat, and most of all, I do not want the threat of prosecution hanging over any family members who accompany me.

I hope that I will die at home in comfortable and familiar surroundings with family around me, but I have no guarantees. A change in the law would make a huge difference to my quality of life, because it would give me the peace of mind of knowing that if my suffering became too much, I could have the peaceful, dignified death that I want.”

## At the time of death

### Choosing where to die

Polls have shown that people want to be able to make choices and want to be given control right until the end of their lives.<sup>15</sup> 57% of people would prefer to die at home, yet the number of home deaths has fallen over the past ten years from 27% to 22%. Only 13% of people would want to die in a hospital, but in reality 6 out of 10 (58%) people spend the last days of their lives in a hospital ward.<sup>16</sup>

The success achieved by the Marie Curie Delivering Choice Programme, which aims to allow palliative care patients to be cared for in the place of their choice, demonstrates that we can enable people to receive care and die in their place of preference.<sup>17</sup>

**Dignity in Dying is urging the Government to take the outcomes of this and other recent initiatives seriously and pay due regard to an individual's preferred place for receiving care at the end of life.**

### Choosing to refuse treatment

In the UK, we have the right to refuse treatment and we now also have a statutory right to refuse treatment in advance, in the event of losing mental capacity. In cases where we depend on life-sustaining treatment to survive, we can decide that we want to have treatment stopped in order not to prolong life needlessly. This marks an important step forward in exercising choice at the end of life.

Thanks to improvements in public health and medical technology, people are living longer lives. 79% of people think it is important to have a choice about when they die and not to have their life prolonged against their wishes.<sup>18</sup>

Dignity in Dying believes that the provisions in the Mental Capacity Act (2005) support patient choice where people depend on life sustaining treatment, but fail those who do not.

### Having a legal right to choose an assisted death

Control and choice are the foundations of a dignified death. 86% of the British public think it is important for people who are terminally ill and reaching the end of their lives to be able to exercise choice about their healthcare.<sup>19</sup>

For some terminally ill, mentally competent people, control and choice at the end of life means having the option of an assisted death at a time and place of their choosing.

The law at present prevents this choice. As a result, many people seek to take control of the manner and timing of their deaths in other ways. While some make an Advance Decision to refuse treatment, or refuse food and water, others take more desperate and dangerous measures such as attempting to commit suicide, asking a loved one to help them die (so-called ‘mercy killing’) or travelling overseas to have an assisted death. Over the last ten years, over 90 British citizens have chosen to have an assisted death at Dignitas in Switzerland.

Also, surveys consistently show that doctors are already assisting their patients to die in the UK.<sup>20</sup> These practices currently take place unregulated, without any safeguards and without any protection for the medical profession and their patients, who are left vulnerable while the practice continues ‘underground.’

Therefore the choice is not between permitting or preventing medically assisted dying. It is between regulating assisted dying

and allowing terminally ill people to discuss their fears openly, or allowing ‘underground’ practices to continue without any safeguards or transparency.

An assisted dying law would allow terminally ill, mentally competent people to choose an assisted death, subject to a range of safeguards, when they feel their suffering has become unbearable. This kind of law would not only give terminally ill, mentally competent people the legal option of an assisted death, it would also improve their quality of life right until their time

of death, giving them the knowledge that the most important decision they can make belongs to them.

Legislation along these lines has already been introduced in a number of countries, and the list is likely to expand.

**Dignity in Dying is calling for a change in the law to allow for terminally ill, mentally competent people to have the right to an assisted death.**

### Debbie Purdy Seeking choice at the end of life

“I was diagnosed with Primary Progressive Multiple Sclerosis in 1995 at the age of 31. I love my life, but I have always been a fiercely independent woman. Should living become unbearable to me, I want to be able to ask for, and receive help to die. British law does not allow this, and makes assisting someone to die a crime punishable by up to 14 years in prison, so my options are to attempt suicide myself, and risk making matters worse, or to travel to Switzerland to have an assisted death.

My husband Omar knows that if he was able to help me with the arrangements for Switzerland, I could delay making this decision, maybe forever, and for this reason he is prepared to risk a prison sentence. But I am not prepared to let him take that risk. I will go overseas to die, alone and unaided, while I still can, if that is the only way I can be in control of my death and protect my husband.

The law in the UK is forcing me to consider dying before I am ready. It should be changed so that I, and others like me, can know that if our suffering does become unbearable we can choose an assisted death.”



Debbie Purdy and Omar Puente



## Helen Rideout Dealing with personal affairs

“When my mother died I was totally unprepared for what would follow. As well as coping with my own sense of grief and loss I felt totally alone as I dealt with all the bureaucracy that comes after the death of a family member. First there was the post mortem, then dealing with solicitors, who were less than sensitive: shortly after my mother’s death I received a lengthy questionnaire wanting to know all about her assets, down to how much money was left in the house. My only other close relative is my father who could not help as he is very ill himself, as well as being blind and nearly deaf.

It was a real struggle to cope with all these unexpected demands, as well as the natural grief I felt on losing my mother.

There should be more support for bereaved relatives – until you have been through it, you have no idea how much paperwork is involved, and the extra strain this places on you in bereavement – as after a short time you are expected to go back to work and get on with ‘normal’ life.”

# After death

## Supporting the bereaved

Following a death, the well-being of family and those close to the individual is paramount. Yet, those who are left to mourn are often left vulnerable, needing help and support in a variety of ways.

Health and social care staff, volunteers and members of the chaplaincy are often the first point of contact for family members in dealing with the death of a loved one. It is therefore essential that health and social care professionals, volunteers and chaplains have the necessary skills to interact meaningfully and sensitively with bereaved family members. A recent survey for Dignity in Dying shows that 77% of people think that bereavement counselling and emotional support are important for bereaved family members and loved ones, while general support from health and social care workers is seen as important by 85%.<sup>21</sup>

**Dignity in Dying wants to see high quality bereavement skills training for health and social care staff.**

## Dealing with personal affairs

Dealing with bureaucracy after a death can be stressful, burdensome and time-consuming. For people who have just lost a partner, close relative or friend, practicalities such as closing bank accounts, selling property and sorting out inheritance will often be seen as daunting tasks.

In many instances, loved ones are under emotional strain and are simply unaware how to go about some of these tasks. It is important that at the time of the death of a loved one, every effort is made to ensure that managing the personal affairs of the deceased do not become a greater problem than they need to be.

**Dignity in Dying is calling for accessible advice services to be made available to bereaved family members.** These services would offer first point of call assistance to other support such as legal and financial advice, as well as referral to counselling services if appropriate.

## Knowing wishes were respected

In our recent survey, 95% of people think that, following the death of a family member, it is important to have confidence that their wishes at death were respected. 87% say that having wishes respected by health professionals is an important factor in considering whether a death is dignified.<sup>22</sup>

The introduction of End-of-Life Care Plans would go some way to making sure that there is a way of assessing whether an individual’s wishes have been carried out throughout their illness and at their time of death.

A robust assessment of whether or not an individual’s wishes (as set out in the End-of-Life Care Plan), were carried out would help to ensure an accurate picture of the standard of end-of-life care. This would also provide a valuable tool for ongoing practical improvements to end-of-life care services in individual health and care facilities and across the board.

**Dignity in Dying wants to see routine monitoring and assessment of End-of-Life Care Plans and their development as an improvement tool for end-of-life services.**

## John and Edna Humble A good death

“My wife Edna and I were long-time Dignity in Dying members, and had discussed and recorded our beliefs on the types of medical treatment we would want as a result. We kept our Advance Decisions on file with our doctor, our daughter and at home.

In 2002 Edna was suddenly diagnosed with advanced lung cancer and given a life expectancy of six months.

Edna was initially treated in hospital but as soon as she was well enough, I brought Edna home to nurse her myself with support from district nurses and hospice-home nurses. Edna really wanted to spend her last months at home and we were very lucky to have the support to allow her to do that. A local organisation, Ian Rennie Hospice at Home, provided a 24-hour service, which gave me and Edna great peace of mind. Knowing that in an emergency, I could contact them whatever the time and a nurse would soon be with us made all the difference, especially as Edna reached the very end stage of her life.

On the doctor’s first visit I showed him a copy of Edna’s Advance Decision and she explained that when she got to the stage where she could no longer communicate she did not want anything that would prolong her life. The doctor accepted this immediately and said that every stage of medication would be discussed with Edna. This was rigorously adhered to and was wholly supported by the nurses who played a major role in Edna’s care and treatment.

Edna died peacefully less than three months after she was diagnosed. I will always be grateful to the doctors and nursing staff whose help, and respect for her wishes, allowed Edna to die in comfort and dignity at home, as she wanted to.”



Edna Humble



# Charter for Dignity at the End of Life

1. Everyone should have the opportunity to create an End-of-Life Care Plan setting out their needs and wishes for the end of life, and should have access to good advice services to inform their choices
2. Health professionals should have a duty to carefully consider people's wishes as set out in their End-of-Life Care Plan, such as their preferred place of care at the end of life
3. Government should promote awareness of Advance Decisions so that everyone knows that they have a legal right to refuse treatment
4. Advance Decisions must be recorded in a central national health register so that health professionals can take them into account in treatment
5. Building on the principles of choice and control at the end of life, Parliament must give terminally ill, mentally competent people the right to have an assisted death
6. More resources should be made available for palliative care - Government must deliver on its manifesto commitment to double funding for palliative care and all political parties should pledge to match this investment
7. Decision makers should end the postcode lottery in accessing palliative care services by providing a consistent and transparent system for commissioning services
8. Carers of terminally ill people should receive more support with a Carers' Benefit introduced for all those providing 35 or more hours of care per week regardless of age; legal protection against employment discrimination for carrying out a caring role; and better access to respite care
9. Health and social care professionals should have access to training on end-of-life issues including offering emotional, psychological and spiritual support to patients; communication skills and high-quality bereavement skills
10. Bereaved people should have easy access to advice services offering first point of call assistance to other support such as legal and financial advice and referral to counselling services, as appropriate

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**This Charter only applies to England and Wales.**

**We aim to launch a separate Charter for Scotland.**

Pictures are not of quoted case studies, unless stated.

