

The Dying Well Community Charter

Principles of care and support

Dying and death remain significant social taboos, despite the inevitable fact that all of us will die one day. Some of us will experience death suddenly; others will die after a period of illness or frailty, which can sometimes be protracted over years.

Whilst many of us hope to die peacefully with dignity, compassionate care, and support for our carers and the people who are important to us, sadly too many people do not have that experience. This continues to be a subject that is frequently perceived as 'too difficult' for individuals, communities and civic society to discuss and so dying is not given priority. Consequently, whilst many people, and carers, understand what is needed to improve the end of life for themselves and the people who are important to them, they struggle to access care and support in coherent and connected ways when they need it.

Dying and death do not happen in isolation from the rest of life. People who are dying may not wish to be isolated and disconnected from their communities. There is more to do to engage communities in the end of life so that those affected by dying and death do not feel abandoned and socially isolated. Care for one another at times of crisis and loss is not simply a task for health and social care services but is everybody's responsibility.

The Dying Well Community Charter provides a visible commitment by individuals, communities and organisations to work together towards the following principles, which should apply for all of us and our communities as we are affected by dying and death.

Recognition and respect

- See dying and death as an important part of our lives.
- Respect each of us and our carers for who we are, how we have lived our lives, the relationships and things that we value, and the legacies we leave behind us.
- Recognise the contribution we may still wish to make to our family, work or community.
- Do everything possible to give us and our carers the level of independence control and participation in decision-making that we wish.
- Treat us always with dignity, respect and compassion.

Communicate

- Communicate with us, our carers, and those who are important to us in kindly words and appropriate manner so that we understand what we are facing and know that you understand.

- Be clear and honest with us, answer our questions as best you can, and tell us what to expect. Where possible and appropriate explain clearly and compassionately the reality that death is coming.
- Talk to us and the people important to us about what we might need in the future, as often as we need you to do this. Respect our pace and recognise that we might not always want to talk about things when you want to.

Involvement

- Listen well to our wishes for the remainder of our lives, including our final days and hours.
- Help and support us and our carers to think ahead to the choices we may face, make decisions about care and support, and give us as many opportunities as we need to do this.
- Remember that we can change our minds about our wishes
- Make sure that our wishes are recorded so that everyone involved in our care and support knows what we want.
- Where we are unable to participate in planning and decision-making, support anybody who has to make decisions on our behalf and ensure they know and understand our wishes and values.

Support

- Make every possible effort to help us to get the end of life support and care we want, including in the place we want to be.
- Encourage and support us to talk about any emotional, cultural, or spiritual needs we may have. Ensure they are respected and met wherever possible.
- Make sure that our carers and people who are important to us are supported before and after we die, including offering information about grief and bereavement and appropriate professional support where possible.
- Recognise and foster sources of care and support within our community.

Help us to **Plan, and Do**

- Give us opportunities to plan our care for the end of life.
- Provide us with someone to coordinate and organise care and support for us and our carers.
- Tell us, those close to us and our carers who to contact for information and support, at any time of day or night, if needed.
- Provide practical support as quickly as possible.
- Do everything possible to alleviate physical, emotional, social and spiritual distress and suffering. Comfort us, our carers and those important to us.