

The crisis facing terminally ill people and their families

For both terminally ill people and the NHS, a crisis is looming:

- Around 50 per cent of people in the UK die in hospital.
- Less than 5 per cent of people say they want to die in hospital.
- Recent research by the Nuffield Trust indicates that there are potential savings from reduced hospital care for people using Marie Curie Nursing Services. Even when costs in other sectors (social care, primary and community care) were considered, the Marie Curie patients' costs were of the order of £500 less. Other community services are likely to have similar cost savings.
- Keeping terminally ill people in hospital beds when they don't want to be there delays life-saving treatment for people who need it.
- The number of people dying is increasing – a 17 per cent rise between now and 2030 – and they are dying at an older age and with increased frailty and illness and higher care costs.
- That's 3 million people over the course of the next Parliament, 1.5 million of whom will die in hospital.
- If we don't act now and shift care for terminally ill people into the community, the NHS is going to face additional unnecessary burden on accident and emergency departments and acute wards.
- This will mean more financial pressure on our already struggling NHS.
- How we care for terminally ill people is one of the greatest public health challenges we face.

WORKING IN PARTNERSHIP



Here is how you and your Party can help us before it is too late to avert this crisis:

1. Make a commitment to introduce 24/7 care, advice and support for terminally ill people and their families, wherever they are: One of the main reasons terminally ill people end up in hospital is because their condition changes in a perfectly normal way – such as a change in breathing – late at night, and their family panic with no one to turn to for advice. They end up calling emergency services and the terminally ill person is taken to hospital, often without any real need to be there. Currently, only 19 per cent of NHS Trusts offer face-to-face access to specialist palliative care for terminally ill people and their families on a 9-5, 7 day a week basis and only 2% of NHS Trusts offer face-to-face access to specialist palliative care on a 24/7 basis. This has to improve because we can't choose what time of day we die.

2. Make social care free and fast for terminally ill people and their families: At the moment, terminally ill people and their families wait weeks and months for social care from their local authorities or exhaust their finances by purchasing their own care. Some will die waiting. Research indicates that having access to social care lowers the chance of going into hospital for terminally ill people. If we can get people access to social care quickly and cheaply, they are more likely to stay out of hospital.

3. Accelerate co-ordination between services: Too often important medical information about a terminally ill person and their family does not go with them when they enter a new care setting (like making the transition from hospital to care home). The new care provider has to start from scratch and this is often where crisis situations develop. This can land the terminally ill person back in hospital even though they don't want to be there. The Government agrees that this shouldn't happen and has made electronically co-ordinated information systems a priority. We want to ensure that this work is accelerated so that nobody experiences an inappropriate hospital admission just because of a lack of information sharing and service coordination.

4. Increase the proportion of the medical research budget dedicated to developing better ways of caring for terminally ill people and their families: 0.1 per cent of the total medical research budget (just 10p in every £100) goes to research concerned with end of life care and terminal illness. Yet all of us die, often with a progressive illness, and all of us would benefit from better end of life and palliative

care. The quality of care that can be offered to terminally ill and dying people and their families is limited by our knowledge. The more we know, the better the care that can be provided to people.

5. Improve data collection to improve care: Recent reports have highlighted deficiencies in care for people who are terminally ill. One of the barriers to improving care is a lack of feedback from patients and their families about their experiences and outcomes of care. Without this information, the NHS cannot properly plan great care for all people who are terminally ill. Real-time, electronic feedback, where it is possible, is a powerful tool and needs to be used extensively in hospitals, hospices, care homes and care at home services – this should be in place and used to drive improvement across the whole of the UK.

We know these are big asks and that the next Government will face the same financial constraints as the current Government. However, we all firmly believe that without change, the NHS will soon face a crisis that will impact on all of us, not just those reaching the end of their lives. Together, we need to act now to ensure that in the future all of us are able to experience the best possible quality of care when we are dying – no matter where we live or what we are dying from – in the place of our choice.

To speak to any of our campaign partners, contact:

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