



Cicely Saunders
International

Better care at the end of life

You Matter Because You Are You

**An action plan for
better palliative care**



You matter because you are you. You matter to the last moment of your life, and we will do all we can to help you not only to die peacefully, but also to live until you die

DAME CICELY SAUNDERS,

**founder of the modern hospice movement
and world-renowned researcher into palliative care**

In 2017, we forecast that, due to changing population demographics and disease patterns, at least half a million people in England and Wales would need palliative or end of life care every year by 2040.

But we have already reached that level of demand in 2020 due to the COVID-19 pandemic. We know that many people did not access the palliative care they needed during 2020. It is vital that we learn from this experience now and implement the changes necessary to secure high quality palliative care for everyone who needs it in the future.

Palliative care aims to provide the best possible quality of life at the end of life for patients with life-limiting or life-threatening illnesses. Putting the person before their disease, palliative care addresses what is known as ‘total pain’, which includes not only physical pain, but also other symptoms and conditions, which might be psychological, social or spiritual. It is evidence based, and improves not only patients’ experience of their care, but also the experiences of their families and loved ones at the most difficult of times. In addition, palliative care contributes towards the cost-effective functioning of the health and social care system, enabling greater patient choice where it is available. As the COVID-19 pandemic has demonstrated clearly, such support is needed in all places where people are cared for, whether home, community, hospital, hospice or care home.

The NHS was founded to support us from the cradle to the grave. However, the last part of that journey is under-resourced and under-researched. The Cicely Saunders Institute is calling for focused investment and commitment to making palliative care as integral a part of the NHS as neonatal or any other care, and ensure that it is available wherever people are supported at the end of their life. This action plan details the key steps that are needed to make this a reality and help to build a health and social care system fit for the post-pandemic world.

1

Provide palliative care expertise in places where people are cared for: hospitals, care homes, hospices and at home

CHALLENGE:

Patient surveys indicate that most of us – around 80% – would prefer to die at home or our place of residence, but in some parts of England and Wales, fewer than 50% do because the necessary services are not there to support them. Without expanding the resources and capacity to provide palliative care in all settings – whether home, community, hospital, hospice or care home – we will remain unable to meet the choices of patients and their families.

SOLUTION:

- » Ensure all hospitals are equipped to provide excellent face-to-face palliative care 7 days a week, including symptom management, to patients and their families and carers.
- » Provide 24/7 specialist palliative care advice and support in the community, including in people's own homes and supporting those living in care homes.
- » Provide prompt access to community nursing, pharmacy, physiotherapy and occupational therapy services to support people to stay at home.
- » Support palliative care professionals in all settings to provide symptom management, advice and expertise to patients, carers and care professionals.

2

Make joined up care a reality

CHALLENGE:

One of the restrictions on patient choice at the end of life revolves around coordination and information sharing between health and social care providers. Being unable to share information and coordinate care quickly enough in what is frequently an urgent situation can restrict patients' choices and impact their care.

SOLUTION:

- » Ensure all health and care partners have access to appropriate information and skills to provide the best care.
- » Facilitate greater joint working to identify people who may need palliative care or complex symptom management as early as possible.
- » Provide a named responsible senior clinician and care coordinator for each person who is experiencing severe symptoms or approaching the end of life.
- » Embed processes to support rapid discharge of patients to their preferred place of care at the end of life.

3

Empower patients and carers to have greater choice and control over the things that are important to them

CHALLENGE:

While there may be many reasons why someone is not able to receive care in their place of choice, too many people are not given enough say in where they are cared for or die. The independent Review of Choice in End of Life Care, published in 2015, identified that delivering a national choice offer in end of life care required an additional investment of £130 million.

SOLUTION:

- » Allow patients to request and receive professional palliative care at the time of their choosing rather than having to 'wait' until they are referred or having to negotiate referral.
- » Provide patients and carers with an assigned contact point to liaise with about their care and preferences.
- » Educate patients and carers using practical demonstrations from professionals to encourage and facilitate self-management of symptoms.
- » Provide high quality communication skills training to health and social care professionals, to facilitate wider, richer discussions around patient choice.

4

Invest in community care services

CHALLENGE:

Too many people with life-limiting illnesses – as well as those approaching death – spend long periods of time in hospital, in part due to a lack of social or community care. Meanwhile, hospital admissions are rising to unsustainable levels across the country, something that was made all the more apparent as parts of the NHS risked being overwhelmed during the COVID-19 pandemic.

SOLUTION:

- » Invest in community care, including care homes, to reduce unnecessary hospital admissions for patients with life-limiting illnesses and those in the last months of life.
- » Target palliative care resources towards patients in high-risk groups to increase not only the benefit to those patients, but also the cost-effectiveness of resource allocation.
- » Ensure that home palliative care teams with symptom management expertise are widely available and provided with the necessary resources to provide high quality care.

5

Provide healthcare professionals and carers with high-quality palliative care training

CHALLENGE:

Health and social care professionals – including those who care for dying patients and patients with life-limiting illnesses – receive insufficient training on palliative care. The Royal College of Nursing’s most recent End of Life Care Survey found that only 1 in 10 nurses felt equipped to deliver good end of life care, citing lack of training as a contributing factor. The latest data for medical student training shows that the average number of hours of palliative care training is around 25 hours and varies greatly between medical schools – as little as 7 hours in some cases.

SOLUTION:

- » Provide all health care professionals with updated basic palliative care training, including symptom management and whole person assessment training.
- » Increase training for community health care professionals in symptom management, communication of difficult conversations and anticipatory care planning for older people with uncertain illness trajectories.
- » Develop additional training and education options such as an intercalated BSc in Palliative Care, as well as including palliative care in main health and social care curricula.
- » Develop an education strategy to underpin sustainable improvements in the quality of end of life care including a network of End of Life Care champions and link nurses.

6

Use outcome measures to embed a system of continuous learning and improvement

CHALLENGE:

Outcome measures are becoming more widely used on a national and international scale in order to improve the quality and cost-effectiveness of service delivery. Current barriers to implementation of outcome measures include a lack of time, resources and training.

SOLUTION:

- » Embed monitoring of quality of care in nationally collected data and processes, including by participation in national audit work and outcome measurement, and by taking a proactive approach to seeking feedback from patients, staff, and bereaved carers.
- » Capture person-centred feedback to help health professionals to identify unmet patient and carer/family needs and concerns, and allow them to act to deliver more effective and cost-effective care.
- » Increase investment in resources and training to encourage the use of outcome measures in routine palliative care.

7

Fund world-leading research into palliative care

CHALLENGE:

Palliative care education must be underpinned by scientific leadership and ongoing research. Some symptoms, such as breathlessness, complex pain, fatigue and depression, remain difficult to alleviate and need the same type of intensive and sustained research that discovered better treatments for more common health problems.

SOLUTION:

- » Increase the proportion of the medical research budget dedicated to developing better ways of caring for terminally ill people and their families; currently it stands at just 0.2 per cent, or 20p in every £100.
- » Research new ways to control common distressing symptoms, especially breathlessness, but also complex pain, fatigue and depression.
- » Support multidisciplinary, joined up research which brings together the health and social care disciplines involved in practice.

Improving care and treatment for patients with progressive illness to make high quality palliative care available to everyone who needs it.

We thank the many organisations and individuals who have helped us in creating the Cicely Saunders Institute and supporting our vital research and training programmes. This has included initial grants to enable the charity to begin its work; a vital programme of research into ways to improve the management of breathlessness; care for older people, improving care at home; and the major programme that created the world's first purpose built Institute of Palliative Care, jointly with King's College London.

To continue the legacy of Dame Cicely our charity depends entirely on charitable donations.

You can support us in a range of ways:

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Via our website or by contacting the Administrator as below. Every donation is very important to us and will go towards vital projects looking into improving palliative care.

cicelysaundersinternational.org | admin@cicelysaundersinternational.org