



# Achieving excellent end of life care locally

How can the public work with Sustainability and Transformation Partnerships to achieve excellent end of life care locally?

## **Acknowledgements**

This information resource was written by Simon Chapman, formerly of the National Council for Palliative Care.

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## **For more information**

For further information please contact Alec Williams, Policy and Advocacy Officer, at [a.williams@hospiceuk.org](mailto:a.williams@hospiceuk.org)

## **About Hospice UK**

Hospice UK is the national charity for hospice care. We believe that everyone, no matter who they are, where they are or why they are ill, should receive the best possible care at the end of their life.

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# What are Sustainability and Transformation Partnerships and what are they trying to achieve?

Sustainability and Transformation Partnerships (STPs) are part of the new way in which local NHS organisations and councils are working together to improve NHS services and outcomes for people in their area. They are not statutory organisations, but local partnerships, with 44 of them covering the whole of England. They are developing plans to improve people's health and wellbeing, care and quality and better use of resources through partnership working and harnessing new technologies. You can find out more about the journey the NHS is on to transform people's care and details of your area's STP plan on [NHS England's website](#).

In March 2017, NHS England published 'Five year forward view: next steps'. This reviewed the progress the NHS has made with transforming care since 2014. It also explained how STP areas are being supported to become [Accountable Care Systems \(ACS\)](#). An ACS is an evolved version of an STP working in an integrated way across the whole health system. NHS organisations (both commissioners and providers) will work closely with local councils and other partners, and take on clear collective responsibility for resources and population health. They will provide joined up, better coordinated care and have more freedom and control over health operations in their area.

## How can STPs help provide excellent end of life care?

STPs and ACS will be bringing in important changes to local health and care services. Caring for people as they approach the end of their lives, and making sure they and the people important to them are supported, is a core part of the work of our health and care services. So it's essential that end of life care is fully considered and included in every local plan.

Over 500,000 people die each year in England. Millions more people will be bereaved as a result. Polls consistently show that many people would like to be cared for and die at home if possible. However, almost half die in hospital. Access to end of life care is inconsistent: it is organised and planned better in some areas than others. The last year of someone's life is generally the time when they have the most contact with the health and care system, and their care costs the most. So it's important that every STP/ACS makes sure that local end of life care is made as effective and efficient as possible, so that people everywhere get the care they need wherever they are.

Getting good end of life care in place locally can prevent people from being admitted to hospital if they don't need or want to be there, and can also enable them to be get home more quickly once they are ready.

In 2016, the government made a new commitment to improve end of life care across the country, and said that every STP should be taking full account of it. This commitment continues into the new parliament. You can read more about this, and the commitments the government has made to everyone who is approaching the end of life, [online](#).

### Government commitments

The government made a six-point commitment to the public to end variation in end of life care across the health system by 2020.

These are to support people approaching the end of their lives to:

- have honest discussions with care professionals about their needs and preferences
- make informed choices about their care
- develop and document a personalised care plan
- discuss their personalised care plans with care professionals
- involve their family, carers and those important to them in all aspects of their care as much as they want
- know who to contact for help and advice at any time.

## How can local people get involved in developing STPs?

All STP areas have published draft plans to improve health and social care. This does not mean that there is nothing more to be done. They need to be developed, and implemented, in partnership with local people and organisations in the community. There are things you can do to get involved. These include:

- [Contact your local Healthwatch](#). There is a Healthwatch in every local authority area. Their job is to make sure the voices of local people and patients are strengthened and heard by the healthcare system. Ask them how you can get involved with them, and what they are doing to ensure local plans fully include end of life care.
- If your local STP has published contact details, you can get in touch with them direct.
- Some areas are holding local events to discuss their plans – [check your local STP website](#) to see if there are any details.

# What questions can you ask STP leads and local leaders about end of life care in your area?

There are lots of things you can ask about what the local STP is doing on end of life care. Here are some of the most important ones.

- What does your STP say about end of life care? Are there detailed plans? Is there a timetable for these? Are local palliative and end of life care providers, for example hospices and care homes, involved in making the plans?
- How is it involving local people in planning and designing new local services? Has it found out what local people who have experience of dying, death and bereavement think about the range and quality of local services? What changes did they want?
- Does it know how many people die each year in the area which the STP covers? What else does it know about them? Where did they die? How old were they? What conditions did they have? How many of them were offered opportunities to discuss their future wishes for their end of life care (this is usually called 'future care planning' or 'advance care planning')?
- How well coordinated are local end of life care services? Do people in the community know who they can contact at any time of day and night? Is there a local system to enable people's records and plans for their future care to be shared with relevant services? How many of the people who died in your area were offered this?
- What provision is there for 24/7 community care? Do people approaching the end of life who are being cared for at home, and their families, get round the clock access to vital services such as specialist palliative care telephone advice, or pain relief and symptom control? How easy is it for people to get drugs and medicines when they need them? Will it be working with local pharmacies to help ensure 24-hour access?
- Has it thought about the needs of the whole community it serves? Not everybody gets good access to palliative and end of life care. What has it done to make sure that people whose needs are often overlooked, for example homeless people, people from ethnic minority backgrounds, or older people living alone, get the end of life care they need?
- Has it thought about how good end of life care can help it deliver other local priorities? Does the STP consider how supporting more people to be cared for and die at home, with well-planned and coordinated care, can help reduce pressures on A&E and hospital beds? Does it consider how joined up health and social care, and collaboration with local charities, such as hospices and care homes, can help improve people's quality and experience of care?

# What should STPs be including in their plans for end of life care?

This will depend on what the current state of access to end of life care looks like, and the most important priorities for local change and improvement that have been identified. However, there are two important national documents that will help STP leads and others local leaders decide their priorities:

- The government's national commitment to improve end of life care (see above). Every area should be making sure it can deliver the government's commitments to everybody approaching the end of life.
- [Ambitions for Palliative and End of Life Care: a national framework for local action](#). This was published in 2016 by 27 national organisations working in palliative and end of life care, and sets out what needs to be done at local level to improve people's quality and experience of care.

We'd love to hear if you find this document useful, and how you are using it. Please get in touch and let us know, or ask any questions, via [policy@hospiceuk.org](mailto:policy@hospiceuk.org)



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Hospice UK, Hospice House, 34 – 44 Britannia Street, London WC1X 9JG