Better end of life care and patient choice in Somerset

The Delivering Choice Programme's project in Somerset is introducing new services to give patients the choice to be cared for at home at the end of their lives.

Introduction

According to recent research, over 60 per cent of people in the UK would choose to die at home, surrounded by their family and friends, if they were terminally ill. In Somerset, only 22 per cent of people are currently able to do so.

The Marie Curie Delivering Choice Programme in Somerset was launched in June 2008 to improve local care and support services so that more people can have the choice of being cared for at home at the end of their lives. The project is a partnership initiative involving the local NHS in Somerset and North Somerset, hospices, acute trusts, social care and a number of voluntary and independent sector organisations.

The programme’s focus on partnership working has been a catalyst for the Somerset project’s success to date. It has enabled all 23 representative organisations involved to take collaborative working to a new and improved level. We are already seeing tangible outcomes, with organisations working across sectors to bring about joined up working to improve care services in Somerset and North Somerset.

Jon Andrewes, Chief Executive
St Margaret’s Hospice

All of the organisations in Somerset and North Somerset involved in the Delivering Choice project have worked extremely hard to design the new service proposals. The new services are now being put in place, and I am confident that end of life care will be more patient-centred, and more integrated than before.

Jan Hull, Deputy Chief Executive
NHS Somerset

How does it work

To understand the needs of local patients and carers, the Somerset project completed a comprehensive review of existing services. Seven workstreams were set up to look at key areas of improvement including information-sharing, coordination, communication, professional development and the provision of high-quality care whenever it is needed.

Over 150 health and social care professionals, as well as patients and carers, attended the workstream meetings to develop proposals for new service models. The working groups explored existing services and how they can be enhanced through the rollout of good practice already taking place and by introducing new services.

Local organisations in Somerset and North Somerset are now rolling out new and improved services to give more terminally ill patients choice in their place of care and death, regardless of their diagnosis. These services will be piloted and evaluated to ensure that they are effective, cost-efficient and are successfully supporting patient choice.

www.mariecurie.org.uk/deliveringchoice
A new care pathway and framework for patients nearing the end of life

As part of the Delivering Choice Programme, an end of life care pathway was developed and endorsed by local partners in Somerset and North Somerset.

The care pathway provides a standardised step-by-step framework for all health and social care professionals working with patients who are nearing the end of their lives.

Karen Burfitt, Programme Manager at Marie Curie Cancer Care said: "At the core of all the services, both new and existing ones, is the Somerset end of life care pathway. The care pathway provides a fresh way of working, focusing on what we can do for patients at every stage of their illness and how we can best support them."

"We want to ensure that patients, families and carers get the care, support and information that they need at the right place and time".

### The end of life care framework

A new framework is also being introduced through the Delivering Choice Programme to enable health and social care professionals across all settings in Somerset and North Somerset to adopt a consistent approach to prioritising patients’ care needs.

The framework uses a traffic light system to categorise a patient’s situation, from stable (green), potential of breakdown (amber) to unstable or the patient is in the dying phase (red). Each category provides a series of prompts to help professionals deliver the care patients and carers need. Examples of prompts include organising "Just in Case" medication, commencing Advance Care Planning and establishing patient’s preferred place of care.

Patients are not only categorised based on their physical condition; the framework also takes into account the patient’s social situation such as carer support and recent discharge from a different care setting.

The categorisation can also change at any time during a patient’s disease progression, and this is particularly relevant for patients nearing the end of their lives with a diagnosis other than cancer.

### The end of life care pathway

| Step 1: The patient is placed on the end of life register. |
| Preferred place of care discussed, recorded and is made available to care professionals in the community. |
| Step 2: A key worker is allocated to the patient. |
| A key worker for the patient is assigned through a multidisciplinary or Gold Standards Framework meeting. |
| Step 3: The patient has an initial assessment. |
| The key worker organises an assessment, prioritises the patient using the end of life care framework and shares information with appropriate professionals. |
| Step 4: A care plan is written. |
| The key worker coordinates the care plan and shares it with the patient and their family for discussion and approval. |
| Step 5: A funding decision is made. |
| The appropriate funding assessment and decision is made. |
| Step 6: Coordination of care. |
| The patient is referred to the central coordination centre which will organise care packages based on the patient’s needs. |
| Step 7: Delivery of high quality care. |
| The patient is assessed and provided with care and support according to the end of life care framework, and if necessary, is referred to the specialist team. |
| Step 8: Last days of life. |
| Ongoing assessment of the patient’s situation according to the end of life care framework, with referral to the specialist team if necessary. |
| Step 9: Care after death. |
| The patient’s death is verified by appropriate healthcare professional. |
New services in Somerset

Somerset's end of life care pathway involves ongoing local initiatives and new services working together. The new services were developed as part of the Delivering Choice Programme. They include:

**Discharge in-reach nurses**

Two discharge in-reach nurses who are based in Musgrove Park Hospital and Yeovil District Hospital will identify terminally ill patients who are nearing the end of their lives and can be cared for in the community.

The nurses will work closely with care professionals in the hospital and community, and with the new coordination centre, to ensure that care packages are in place so that patients can be discharged without unnecessary delays.

This service is provided by St Margaret's Hospice in partnership with Marie Curie Cancer Care.

**Coordination centre for end of life care**

A new coordination centre will be responsible for coordinating nursing and social care for terminally ill patients who are being cared for at home.

In addition, patients and carers can contact the coordination centre directly, seven days a week, for information about the care they are receiving and other relevant services available in their community such as carer support.

Operated by Somerset Community Health, the centre will also maintain the end of life register which provides up to date information on patients’ care preferences.

Sue Balcombe, Chief Nurse at Somerset Community Health said: "We are delighted that the new care coordination centre will relieve the District Nursing teams of an unnecessary administrative burden and release valuable time to provide more care for patients and support for carers."

**Out of hours advice and response line**

Local partners are developing a new helpline that patients and carers can access during the out of hours period for advice and support.

The helpline will triage patients and refer them to the appropriate community teams such as the out of hours GP or District Nursing services. This will help prevent unnecessary hospitalisation in the event of a crisis or change in patient condition.

**Education and training for professionals**

Training programmes provided by St Margaret's Hospice and Dorothy House Hospice are being rolled out to improve the skills and knowledge of domiciliary care workers and ambulance staff in end of life care.

Community staff such as GPs will also be offered training on Advance Care Planning to help them plan future care of terminally ill patients.

**Website for patients and carers**

A website providing useful and wide-ranging information on local care services and support will be available for terminally ill patients, their families and carers.

This website will have information such as the different professionals who are involved in care, community care services that are available in Somerset and North Somerset, and practical advice on caring for someone with a terminal illness.

Most people would choose to die at home, surrounded by their family and friends, if they were terminally ill.
Other ongoing local initiatives are also supporting Somerset’s end of life care pathway.

The end of life register will enable all care professionals in the community to have access to information on patients with palliative and end of life care needs and their care preferences. Those with access to the register will include GPs, out of hours services and emergency care services. This information will help clinicians make decisions about patient care when they are called on for help during a crisis.

The Gold Standards Framework in Primary Care is being used by GP practices in Somerset to help clinicians identify and provide the best care for patients who are in the last year of life. This framework provides clinicians with a set of systematic guidelines in assessing their patients’ care needs and in planning care according to their patients’ preferences.

The Gold Standards Framework in Care Homes aims to improve the quality of care for care home residents who are in the last stages of life and reduce inappropriate admissions to hospital. A number of care homes have completed this comprehensive training programme with the support from a facilitator.

Advance Care Planning ensures that care professionals have ongoing discussions with their patients to find out their future care preferences and wishes towards the end of life.

The Marie Curie Helper service offers trained volunteers who give one-to-one practical and emotional support and advice to patients, families and carers in their own homes. This is a pilot service by Marie Curie Cancer Care.

Delivering Choice in North Somerset

In North Somerset, local partners are also implementing new services developed through the Delivering Choice Programme. These include:

- end of life care facilitators to improve the understanding and use of end of life tools such as the Gold Standards Framework by community care staff
- a single-point of access for the coordination of care packages for patients nearing the end of their lives who are being cared for at home
- the introduction of a team of generic workers to provide health, social and personal care to patients in their homes
- “Just in Case” anticipatory medication boxes for patients who are cared for at home
- a dedicated helpline to provide advice and support to patients and carers

In Somerset and North Somerset, the Delivering Choice Programme has been working closely with a broad range of service providers. They include:

- NHS Somerset
- NHS North Somerset
- Somerset Community Health
- Taunton and Somerset NHS Foundation Trust
- Yeovil District Hospital NHS Foundation Trust
- Weston Area Health NHS Trust
- Avon, Somerset and Wiltshire Cancer Services
- Somerset Palliative Care Partnership
- Somerset County Council
- North Somerset Council
- St Margaret’s Hospice
- Weston Hospicecare
- Great Western Ambulance Service NHS Trust
- Dorothy House Hospice
- Somerset Partnership NHS Foundation Trust
- South Western Ambulance Service NHS Trust
- Registered Care Home Providers Association
- WyvernHealth.Com
- Weston Practice Based Commissioning cluster
- Age Concern Somerset
- North Somerset Crossroads
- Marie Curie Cancer Care

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