

End of Life Care

“How people die remains in the memory of those who live on”



**Dame Cicely
Saunders**

Founder of the Modern
Hospice Movement

Amanda Rolland - Workstream Lead
Dr Robin Graham Brown – Clinical Lead



Case for change

There is considerable evidence to suggest that the vast majority of people and their carers would choose to spend their last days where they feel the most comfortable; usually at home or within a community setting rather than within an acute hospital setting.

This work stream has supported the roll out of evidence based practice pathways for end of life care across the East Midlands which provide patients and their carers with a choice of settings to be systematically introduced across the East Midlands.

Outcomes of the workstream were to

- Improve public awareness and willingness to talk and plan for their own end of life and death
- Reduce the number of people who die in an acute hospital setting.
- Provide safe and high quality care at the end of life
- Increase the choice and improve the experience of dying for both the person and their family/carers.



Variation & Opportunity



To reduce variation by

- influencing staff behaviour and increase the number of staff broaching the subject of end of life care with patients, families and the public
- increase in the number of patients (and their carers) making choices and decisions about their care and their preferred place of death that is recorded on the GP registers
- improved family experience and memories after death reducing the number of complaints
- for the wishes of the patient and family to be up-held across the patient pathway including DNACPR decisions
- patients receive appropriate, timely and safe analgesia and medications
- suitably skilled and educated workforce to deliver care in line with individual patient needs

Opportunity for a

- reduction in emergency ambulance call outs
- reduction of emergency admission
- reduction in length of stay and timely discharge of those at the end of life in accordance with patient choice
- increased access to services to respond to the changing needs of patients, carers including rapid response services, hospice at home and hospices 24/7
- increased openness about death and dying and people will find it easier to talk about it
- increased assurance of the safety of patients receiving treatment and/or symptom control using medical devices
- increased numbers of NHS staff who will be better trained in recognising and responding to signs that patients are entering the terminal phase of illness



Regional focus: Within the regional work we have a number of priorities and leads are facilitating work at SHA level on each of these:

Leading the way nationally through some of our work

- Workforce modelling lead by Chris Sutcliffe as a national supported pilot
- Pilot the AMBER care bundle (NGH, UHL and NUH) in three of our Trusts alongside The Modernisation Initiative/Guys and St Thomas Charitable Trust
- Development of a staff awareness campaign tackling the fear and stigma associated with talking about dying and death





Products achieved



The NHS East Midlands QIPP End of Life Care work stream has:

Product	Status
Agree a set of standard Do Not Attempt Resuscitation (DNAR) principles, decision tree and standardised form to be used by all health and social care agencies across the East Midlands	In progress; finalisation of product for implementation March 2011
Increase public knowledge and discussion about death and bereavement in partnership with the national dying matters campaign	In progress; roll out and road show planned May 2011
East Midlands organisations are involved in the National pilot for “Mechanisms to identify those approaching end of life Advancing Disease” and further test the use of the “surprise question” and the Amber Care Bundle. The aim of these projects is to enable improvement in the registration of people at the end of life care and thus aid discussion about EoLC choices and decisions	Linked with the National programme Evidence of improvement due March 2011
Utilise the metrics provided through the East Midlands Clinical Observatory to enable and spread recognised, evidence-based good practice support the delivery, commissioning, monitoring and assurance that patients and their families across the East Midlands receive high quality of care and a positive end of life experience	Complete updated with new data in accordance with the Quality Observatory policy
Provide assurance relating to the safety of patients receiving interventions through medical devices.	In Progress; report complete and discussions for ongoing monitoring of Implementation tasking place



Case study / good examples



East Midlands Health and Social Care Awards 2010 - Living the NHS Constitution – Regional Winner

The Nottinghamshire End-of-Life Care Pathway provides consistent quality of care and access to services for patients in the last 12 months of life and their carers.

Set up in 2008 across NHS Nottingham City, NHS Nottinghamshire County, Bassetlaw PCT and their respective Local Authorities, the pathway was successful in changing the way clinical care was delivered. However, findings from a 2009 Nottingham University study^[1] concluded that, despite patients and carers having an in-depth understanding of end-of-life care; their understanding of existing possibilities for more personalised care was more limited:

“But people don’t have choice do they? Not as far as I know...have never heard of planning end-of-life care that you mention”

In response, a group overseen by a carer representative, created a publication for patients and the public that aimed to:

Empower patients and carers to initiate open discussions about death and dying by breaking down existing taboos and making it easier to make informed choices and plans for their end-of-life care

Promote access to local voluntary, health and social care services

Address all stakeholders’ needs while being sensitive to the issues and challenges faced by end-of-life patients and their carers.

We engaged in ongoing consultation with public and patient stakeholders on the appropriateness of the style and content of the document.

Professionals from many different specialties came together to see end-of-life care is everybody’s business. Previously, it was considered to be the remit of palliative care professionals. Patients and carers now also know what to expect or what to do at a given point on the pathway.

Contact: Aimee Baugh, Commissioning Officer on 0115 8839278 [or aimee.baugh@nottinghamcity.nhs.uk](mailto:aimee.baugh@nottinghamcity.nhs.uk)



Case study's available on
www.excellence.eastmidlands.nhs.uk/welcome/improving-care/end-of-life-care/

(Click link in slide show view)



towards
excellence



Securing the benefits



Securing the benefits

	Provider	Commissioner
<p>Agree a set of standard Do Not Attempt Resuscitation (DNAR)</p> <ul style="list-style-type: none"> Principles, Decision tree Standardised form t 	<ul style="list-style-type: none"> Unified approach Increased decision s with the patient about choice Improved communication along the patient pathway Preventing inappropriate resuscitation Reduction in crash team call out Reduced complaints 	<ul style="list-style-type: none"> Improved patient experience and communication across provider transfers and boundaries
<p>Increase public knowledge and discussion about death and bereavement in partnership with the national dying matters campaign</p>	<ul style="list-style-type: none"> Encourage staff to talk to people about death and dying and their wishes Ensure death and dying is seen as a core role of health and social care staff Reduce the taboo around death culturally Promotes discussions about end of live care choices 	<ul style="list-style-type: none"> Improve information, changing population trends and impacts on the commissioning of services in accordance with patients wishes and needs Reduce public anxiety
<p>Supporting the development of a “Mechanisms to identify those approaching end of life Advancing Disease” and further test the use of the “surprise question” and the Amber Care Bundle.</p>	<ul style="list-style-type: none"> Acts as an early warning to enable early decision making Improves patient choice Enable appropriate discharge transfer planning Prevent inappropriate escalation Improved communication and documentation Engages the right level of staff and the MDT in decision making 	<ul style="list-style-type: none"> Facilitate early discharge Inform the commissioning process to ensure community care is available accordance with patients wishes and needs



Securing the benefits



Securing the benefits



	Provider	Commissioner
<ul style="list-style-type: none">• Provide assurance relating to the safety of patients receiving interventions through medical devices.	<ul style="list-style-type: none">• Reduced risk of medication errors	<ul style="list-style-type: none">• Enables the commissioning of appropriate equipment and monitoring or risks and medication errors across the county
<ul style="list-style-type: none">• Workforce Modelling and costing for provision of EoLC outside of the hospital setting has been undertaken across five different disease trajectories	<ul style="list-style-type: none">• Review of competence level required rather than the discipline• Ability to ensure a skill mix more effectively as well as adopt new ways of working	<ul style="list-style-type: none">• The tool will also enable commissioners to scope different whole system scenarios so that they can make informed decisions



Key contacts



Regional Workstream	Name	Contact
Exec Sponsor:	Felicity Cox	felicity.cox@bassetlaw-pct.nhs.uk
Clinical Lead:	Dr Robin Graham Brown	robin.grahambrown@uhl-tr.nhs.uk
Workstream Lead:	Amanda Rolland	amanda.rolland@nhs.net
Workforce Lead	Chris Sutcliffe	chris.sutcliffe@nhs.net
Education Lead	Maggie Hunter	maggie.hunter@nhs.net
Skills for health	Christine Collymore	Christine.Collymore@skillsforcare.org.uk
	Grace Wood	Grace.wood@skillsforcare.org.uk
Communication Lead	Jo Baggott	jo.baggott@nhs.net
Public Health Link	Di Roffe	di.roffe@nhs.net

Children's Lead Sue Dryden
sdryden1@nhs.net

Leicestershire	Name	Contact
Loros	Dr Luke Feathers	lukefeathers@loros.co.uk
Cancer Network East Midlands	Mrs Jo Kavanagh	-

Lincolnshire	Name	Contact
NHS Lincolnshire	Sarah Furley	sarah.furley@lpct.nhs.uk
St Barnabus Hospice	Dr Andy Kutarski	andy.kutarski@stbarnabashospice.co.uk

Northamptonshire	Name	Contact
NHS Northants		-
NGH	Dr Christine Elwell	jill.lee@ngh.nhs.uk

Nottinghamshire	Name	Contact
NHS Notts City	Kathryn Brown	Kathryn.Brown@nottinghamcity.nhs.uk
NHS Notts County	Helen Scott	Helen.Scott@nottspct.nhs.uk
NUH	Dr Vincent Crosby	marianne.dunlop@nuh.nhs.uk
John Eastwood Hospice	Dr Greg Finn	greg.finn@nottscommunityhealth.nhs.uk

Derbyshire	Name	Contact
NHS Derbyshire County	Lynn Woods	Lynn.Woods@derbyshirecountypct.nhs.uk
NHS Derby City	Steph Austin	Stephanie.Austin@derbycitypct.nhs.uk
Derby Hospitals NHS FT Swanwick	Dr Maelie	Linda.Hudson@derbyhospitals.nhs.uk





Challenges



- To ensure that the financial release achieved solely from End of Life Care are identified
- Ensure that there is a continued focus on the improved quality of care for patients at the end of life, in light of the limited financial data available
- Ensure continued commitment to achieving a unified DNACPR principles and a single patient owned form.
- Continuation and deliver of identified Towards Excellence objectives in the current climate of uncertainty on the NHS and ensure the continued engagement of social care and children's services
- Next steps
 - meeting with county groups on delivery
 - Production and publication of products

- Is there something you need between now and the end of March 2011?
- How can we sustain momentum post March 2011?
- What other information do you need?
- What will convince you to implement these objectives?