

Principles & Practice

in

End of Life Care

Registered Practitioners

2019

hello
😊

my name is.....Linda Rendle

Linda Rendle – linda.rendle@pilgrimshospices.org

www.pilgrimshospices.org

Thinking about the words we use

(SCIE & NCPC 2014)

- Understand the impact of the terms used.
- Try to explain in plain English, rather than unfamiliar terms.
- Whatever terms used, always check understanding.
- Consider your communication skills (speak in a kind & caring way to all).

-  Film from SCIE & NCPC - worth a look!

- https://www.youtube.com/watch?v=nokDDalo_gM
- <https://www.scie.org.uk/socialcaretv/video-player.asp?v=palliative-care-or-end-of-life-care>

What else helps good end of life care?

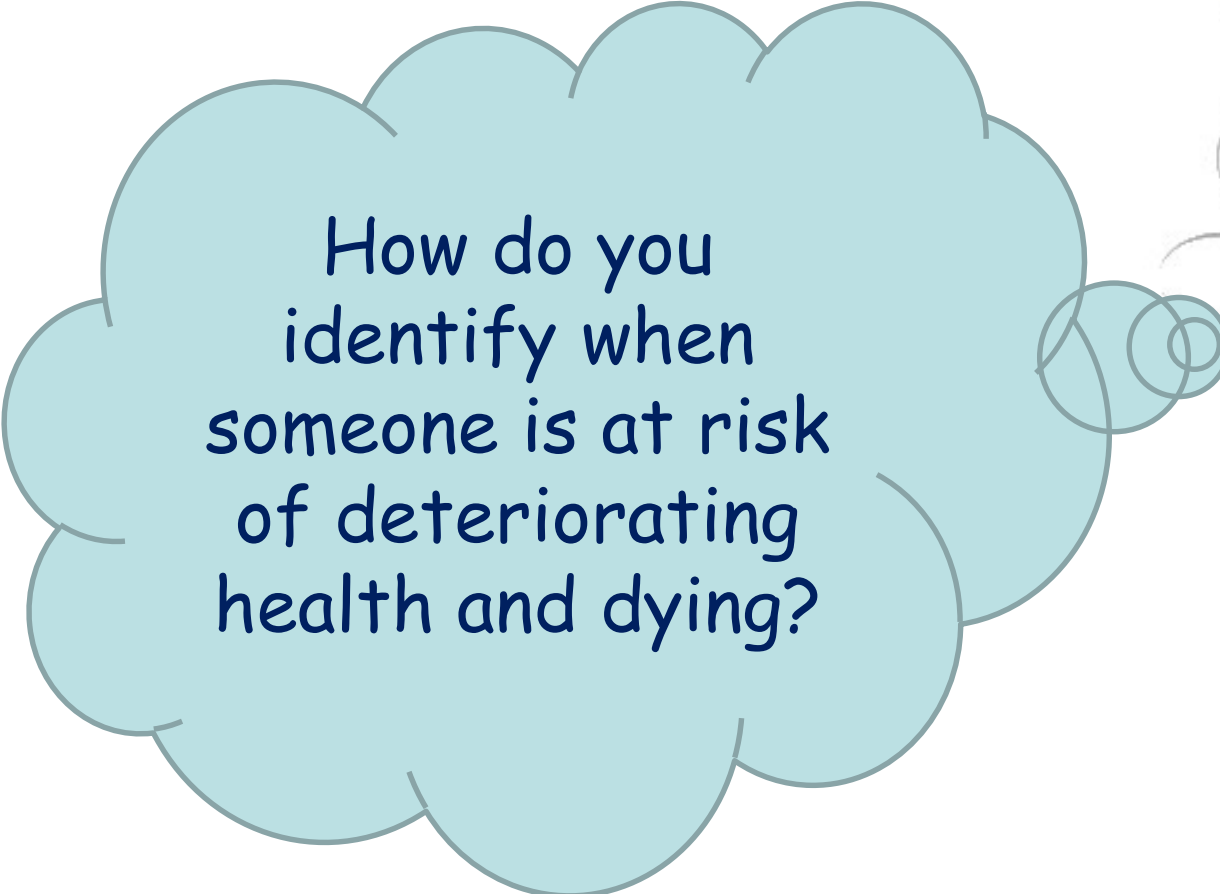
Palliative care / end of life care



Definitions – Check out appendix A – of
Ambitions for Palliative & End of Life Care

<http://endoflifecareambitions.org.uk/>

www.pilgrimshospices.org


A large, light blue thought bubble with a dark blue outline, containing the text. It has several smaller circles leading to a larger white thought bubble on the right.

How do you
identify when
someone is at risk
of deteriorating
health and dying?



SPICT™

Supportive & Palliative Care Indicators Tool 2017



Supportive and Palliative Care Indicators Tool (SPICT™)

The SPICT™ is used to help identify people whose health is deteriorating. Assess them for unmet supportive and palliative care needs. Plan care. Look for any general indicators of poor or deteriorating health.

- Unplanned hospital admission(s).
- Performance status is poor or deteriorating, with limited reversibility. (eg. The person stays in bed or in a chair for more than half the day.)
- Depends on others for care due to increasing physical and/or mental health problems.
- The person's carer needs more help and support.
- The person has had significant weight loss over the last few months, or remains underweight.
- Persistent symptoms despite optimal treatment of underlying condition(s).
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

Look for clinical indicators of one or multiple life-limiting conditions.

Cancer	Heart/vascular disease	Kidney disease
Functional ability deteriorating due to progressive cancer.	Heart failure or extensive, untreatable coronary artery disease; with breathlessness or chest pain at rest or on minimal effort.	Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.
Too frail for cancer treatment or treatment is for symptom control.	Severe, inoperable peripheral vascular disease.	Kidney failure complicating other life limiting conditions or treatments.
Dementia/ frailty	Respiratory disease	Stopping or not starting dialysis.
Unable to dress, walk or eat without help.	Severe, chronic lung disease; with breathlessness at rest or on minimal effort between exacerbations.	Liver disease
Eating and drinking less; difficulty with swallowing.	Persistent hypoxia needing long term oxygen therapy.	Cirrhosis with one or more complications in the past year: <ul style="list-style-type: none"> diuretic resistant ascites hepatic encephalopathy hepatorenal syndrome bacterial peritonitis recurrent variceal bleeds
Urinary and faecal incontinence.	Has needed ventilation for respiratory failure or ventilation is contraindicated.	Liver transplant is not possible.
Not able to communicate by speaking; little social interaction.	Other conditions	
Frequent falls; fractured femur.	Deteriorating and at risk of dying with other conditions or complications that are not reversible; any treatment available will have a poor outcome.	
Recurrent febrile episodes or infections; aspiration pneumonia.	Review current care and care planning.	
Neurological disease	<ul style="list-style-type: none"> Review current treatment and medication to ensure the person receives optimal care; minimise polypharmacy. Consider referral for specialist assessment if symptoms or problems are complex and difficult to manage. Agree a current and future care plan with the person and their family. Support family carers. Plan ahead early if loss of decision-making capacity is likely. Record, communicate and coordinate the care plan. 	


Please register on the SPICT website (www.spict.org.uk) for information and updates.



App available

Helping families, friends, care staff and individuals recognise palliative care needs.

SPICT-4ALL



SPICT-4ALL is a free care staff, individuals and their families friends. It can be difficult to know when to ask for more help and support or how to talk about this.

You may be the person who knows what is needed and what could help.

SPICT-4ALL uses non-medical words but is similar to the SPICT for health professionals. You can use it to help you talk about more help from a doctor, a nurse or another professional.

SPICT-4ALL aims to make it easier for everyone to recognise and talk about signs that a person's overall health may be declining so that those people and their carers get better coordinated care and support whether they are at home, living in a care home or in hospital.

SPICT-4ALL is available to download from the SPICT website <http://www.spict.org.uk>

Please feel free to take a copy from below

Supportive and Palliative Care Indicators Tool (SPICT™)

The SPICT™ helps us to look for people who are ill with one or more health problems. It can be used to help you to plan care and to talk to the person about their needs. It can be used to help you to plan care and to talk to the person about their needs. It can be used to help you to plan care and to talk to the person about their needs.

Look for signs of poor or worsening health which can mean things are changing:

- Unplanned admission to hospital in a nursing home or the person makes a great recovery. (It can be a sign that the person is getting worse and needs more help.)
- It can be difficult to know when to ask for more help and support or how to talk about this. SPICT-4ALL can help you to talk about more help from a doctor, a nurse or another professional.
- It can be difficult to know when to ask for more help and support or how to talk about this. SPICT-4ALL can help you to talk about more help from a doctor, a nurse or another professional.

Linking SPICT-4ALL to the person's needs:

- Look for signs of poor or worsening health which can mean things are changing:
- Unplanned admission to hospital in a nursing home or the person makes a great recovery. (It can be a sign that the person is getting worse and needs more help.)
- It can be difficult to know when to ask for more help and support or how to talk about this. SPICT-4ALL can help you to talk about more help from a doctor, a nurse or another professional.


Linking to the person if they are able and want that and their family:

- Unplanned admission to hospital in a nursing home or the person makes a great recovery. (It can be a sign that the person is getting worse and needs more help.)
- It can be difficult to know when to ask for more help and support or how to talk about this. SPICT-4ALL can help you to talk about more help from a doctor, a nurse or another professional.

Linking to health professionals:

- Unplanned admission to hospital in a nursing home or the person makes a great recovery. (It can be a sign that the person is getting worse and needs more help.)
- It can be difficult to know when to ask for more help and support or how to talk about this. SPICT-4ALL can help you to talk about more help from a doctor, a nurse or another professional.

A number of local care homes are undertaking the Gold Standards Framework training programme & are using the Gold Standards Framework Proactive Identification Guidance (2016)



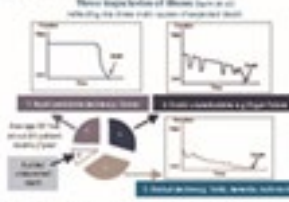
The Gold Standards Framework Proactive Identification Guidance (PIG)

The National GSF Centre's guidance for clinicians to support earlier identification of patients nearing the end of life leading to improved proactive person-centred care

GSF PIG 18th Edition Dec 2016 K Thomas, John Armstrong Wilson and GSF Team, National Gold Standards Framework Centre in End of Life Care
<http://www.goldstandardsframework.org.uk> for more details see GSF PIG

Proactive Identification Guidance – proactively identifying patients earlier

This updated 18th edition of the GSF PIG, renamed as Proactive Identification Guidance and formerly known as Prognostic Indicator Guidance, aims to enable the earlier identification of people nearing the end of their life who may need additional supportive care. This includes people who are nearing the end of their life following the three main fractions of stress for expected death – rapid predictable decline e.g. cancer, cardiac disease e.g. organ failure and gradual decline e.g. frailty and dementia. Additional contributing factors when considering prediction of likely needs include current mental health, co-morbidities and social care provision.



Why is it important to identify patients early?

Earlier identification of people who may be in their final stage of life leads to more proactive person-centred care. About 1% of the population die each year, with about 20% hospital patients and 80% of care home residents in their last year of life. Most deaths can be anticipated though a minority are unexpected (estimated about 10%). Earlier recognition of decline leads to earlier anticipation of likely needs, better planning, fewer stress hospital admissions and care tailored to people's wishes. This in turn results in better outcomes with more people living and dying in the place and manner of their choice. Once identified, people are included on a register and where desirable the local electronic register triggering specific active supportive care, as used in all GSF programmes within GSF areas boundary care sites.

The 3 key steps of GSF

- Identify** – patients who may be in their final stage of life and identify their needs (support, care, etc.)
- Assess** – current and future, physical and personal needs
- Plan** – living will and dying will

PIG and GSF – Early proactive identification of patients is the crucial first step of GSF, used by many thousands of doctors and nurses in the community and hospitals. For more information on GSF, visit its website or practice to help identify patients early, assess needs and wishes through advance care planning discussions and plan care tailored to patient choices, see the GSF website.

National Policy support for earlier identification, General Medical Council – 2010

www.gmc-uk.org/ethics/terminally_ill_patients_statement_1_identification

The GMC definition of End of Life Care: 'People are approaching the end of life when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:


- Advanced, progressive, incurable conditions.
- General frailty and co-existing conditions that mean they are expected to die within 12 months.
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition.
- Life threatening acute conditions caused by sudden catastrophic events.'

NICE Guidance in End of life care 2013 Quality statement 1

<https://www.nice.org.uk/guidance/qs13/chapter/Quality-statement-1-identification>

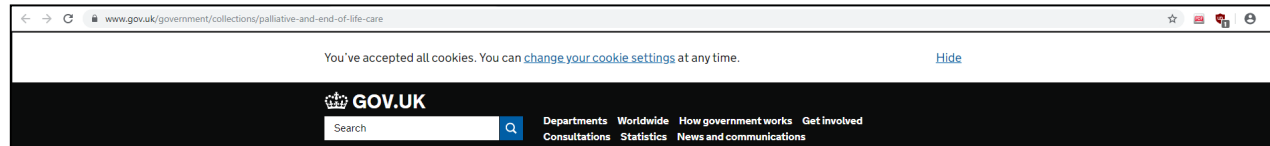
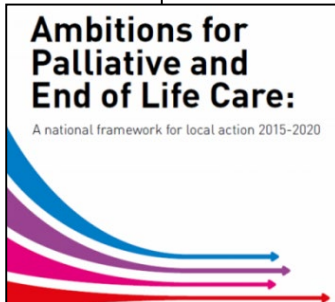
- **Identification** – People approaching the end of life are identified in a timely way
- **Systems** – Evidence of local systems in place to document identification of people approaching the end of life.

Proactive Identification Guidance – GSF PIG Flow-chart



The GSF Proactive Identification Guidance (PIG) 2016 will be the Gold Standards Framework Centre in End of Life Care the main reference in the development of the GSF PIG, its use in practice, evidence base, applications and where referencing it, please refer to www.goldstandardsframework.org.uk/PIG For more details contact info@goldstandardsframework.org.uk 01763 291180

Current developments in End of Life Care



Palliative and end of life care

Information and resources for health and social care professionals to improve the quality of services and reduce inequalities in care.

Published 6 September 2019
From: [Public Health England](#)

Contents

— Palliative and end of life care



NICE National Institute for Health and Care Excellence

NICE Pathways NICE guidance Standards and indicators Evidence search BNF BNFC CKS

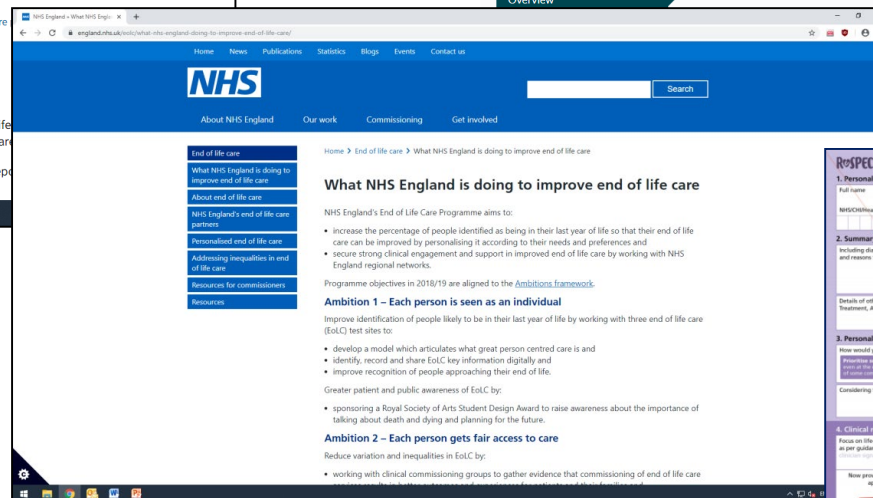
Home > NICE Guidance > Health and social care delivery > End of life care

End of life care for adults

Quality standard (QS13) Published date: November 2011 Last updated: March 2017 [Uptake of this guidance](#)

Quality standard Tools and resources History

Overview



What NHS England is doing to improve end of life care

NHS England's End of Life Care Programme aims to:

- increase the percentage of people identified as being in their last year of life so that their end of life care can be improved by personalising it according to their needs and preferences and
- secure strong clinical engagement and support in improved end of life care by working with NHS England regional networks.

Programme objectives in 2018/19 are aligned to the [Ambitions framework](#).

Ambition 1 – Each person is seen as an individual

Improve identification of people likely to be in their last year of life by working with three end of life care (EoLC) test sites to:

- develop a model which articulates what great person centred care is and
- identify, record and share EoLC key information digitally and
- improve recognition of people approaching their end of life.

Greater patient and public awareness of EoLC by:

- sponsoring a Royal Society of Arts Student Design Award to raise awareness about the importance of talking about death and dying and planning for the future.

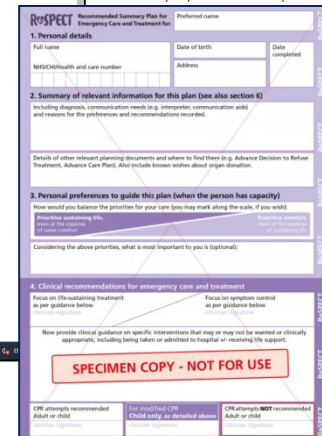
Ambition 2 – Each person gets fair access to care

Reduce variation and inequalities in EoLC by:

- working with clinical commissioning groups to gather evidence that commissioning of end of life care

life care for people with life-limiting conditions

for adults (aged 18 and over) who are
This includes people who are likely to die



Have you heard of Dying Matters?



www.dyingmatters.org

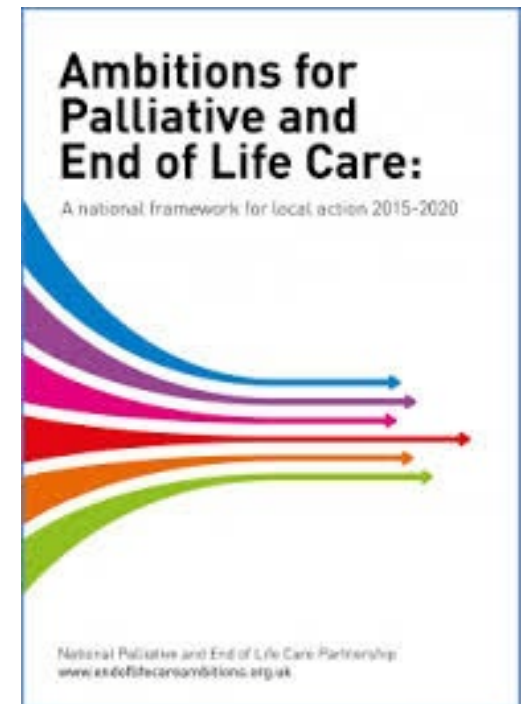
www.pilgrimshospices.org

Ambitions for Palliative & End of Life Care

‘End of life care is care that affects us all...’ (NPEoLCP 2015)

1. Each person is seen as an individual
2. Each person gets fair access to care
3. Maximising comfort & wellbeing
4. Care is coordinated
5. All staff are prepared to care
6. Each community is prepared to help

<http://endoflifecareambitions.org.uk/>



Care in the last days or hours of life

(will be covering this on day 6)

- Priorities of Care for the Dying Person
Duties & Responsibilities of Health & Care Staff

Visit NHS Improving Quality
website

Link to handy reference guide:

<http://webarchive.nationalarchives.gov.uk/20160805125329/http://www.nhs.uk/media/2483136/pfcdp-leaflet2.pdf> (in NHS Improving Quality archives)

Priorities of Care for the Dying Person



NICE Guidance

National Institute for Health & Care Excellence

End of life care for adults (QS13)

<https://www.nice.org.uk/guidance/qs13>

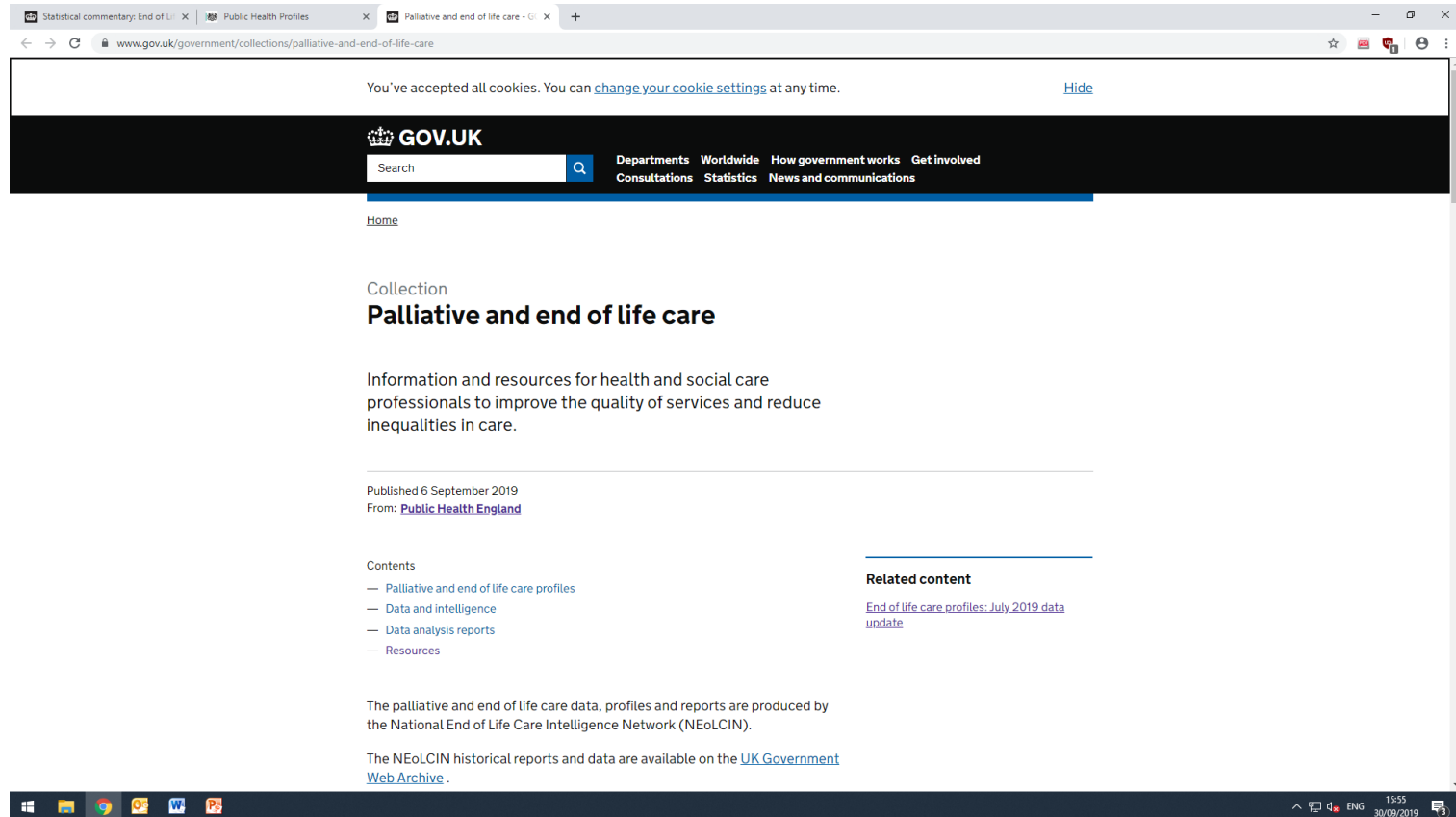
(NICE 2011 Last updated: March 2017)

Care of dying adults in the last days of life *(NICE 2015)*

<https://www.nice.org.uk/guidance/ng31>



Interesting end of life facts & figures



The screenshot shows a web browser window with the URL www.gov.uk/government/collections/palliative-and-end-of-life-care. The page features a black header with the GOV.UK logo, a search bar, and navigation links. Below the header, the page title is 'Collection: Palliative and end of life care'. The main content area describes the collection as 'Information and resources for health and social care professionals to improve the quality of services and reduce inequalities in care.' It also mentions the publication date (6 September 2019) and the source (Public Health England). A 'Contents' section lists links to 'Palliative and end of life care profiles', 'Data and intelligence', 'Data analysis reports', and 'Resources'. A 'Related content' section links to 'End of life care profiles: July 2019 data update'. At the bottom, it states that the data is produced by the National End of Life Care Intelligence Network (NEoLCIN) and is available on the UK Government Web Archive.

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Collection

Palliative and end of life care

Information and resources for health and social care professionals to improve the quality of services and reduce inequalities in care.

Published 6 September 2019
From: [Public Health England](#)

Contents

- [Palliative and end of life care profiles](#)
- [Data and intelligence](#)
- [Data analysis reports](#)
- [Resources](#)

Related content

[End of life care profiles: July 2019 data update](#)

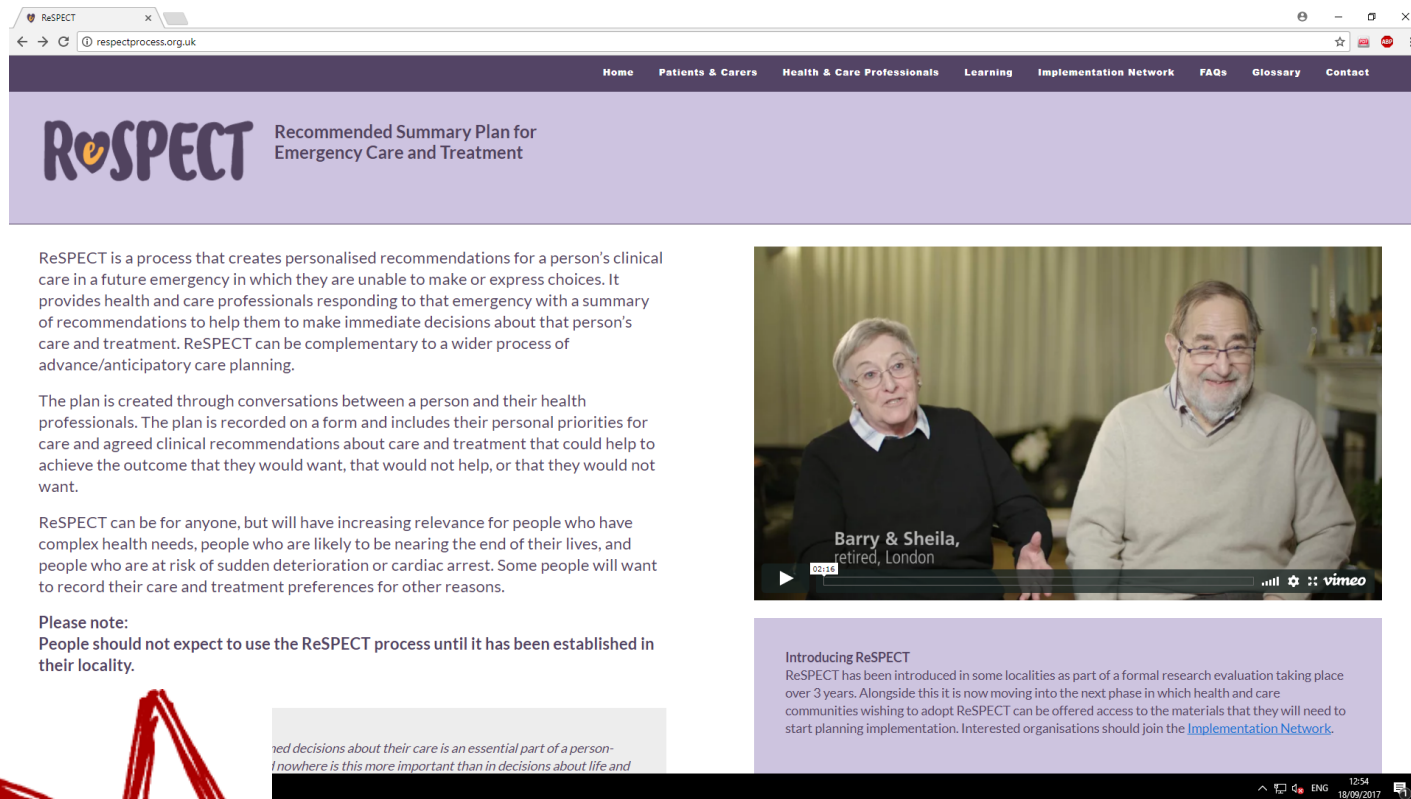
The palliative and end of life care data, profiles and reports are produced by the National End of Life Care Intelligence Network (NEoLCIN).

The NEoLCIN historical reports and data are available on the [UK Government Web Archive](#).

<https://www.gov.uk/government/collections/palliative-and-end-of-life-care>

Have you heard about ReSPECT?

(will mention more later!)



The screenshot shows the ReSPECT website interface. At the top is a navigation bar with links: Home, Patients & Carers, Health & Care Professionals, Learning, Implementation Network, FAQs, Glossary, and Contact. Below this is a purple header with the ReSPECT logo and the text "Recommended Summary Plan for Emergency Care and Treatment". The main content area on the left contains three paragraphs of text explaining the ReSPECT process. To the right is a video player showing a couple, Barry and Sheila, with the caption "Barry & Sheila, retired, London". Below the video is a purple box titled "Introducing ReSPECT" with text about the research evaluation and implementation. At the bottom of the page, there is a quote: "ed decisions about their care is an essential part of a person - /nowhere is this more important than in decisions about life and".

ReSPECT is a process that creates personalised recommendations for a person's clinical care in a future emergency in which they are unable to make or express choices. It provides health and care professionals responding to that emergency with a summary of recommendations to help them to make immediate decisions about that person's care and treatment. ReSPECT can be complementary to a wider process of advance/anticipatory care planning.

The plan is created through conversations between a person and their health professionals. The plan is recorded on a form and includes their personal priorities for care and agreed clinical recommendations about care and treatment that could help to achieve the outcome that they would want, that would not help, or that they would not want.

ReSPECT can be for anyone, but will have increasing relevance for people who have complex health needs, people who are likely to be nearing the end of their lives, and people who are at risk of sudden deterioration or cardiac arrest. Some people will want to record their care and treatment preferences for other reasons.

Please note:
People should not expect to use the ReSPECT process until it has been established in their locality.

*ed decisions about their care is an essential part of a person -
/nowhere is this more important than in decisions about life and*

Introducing ReSPECT
ReSPECT has been introduced in some localities as part of a formal research evaluation taking place over 3 years. Alongside this it is now moving into the next phase in which health and care communities wishing to adopt ReSPECT can be offered access to the materials that they will need to start planning implementation. Interested organisations should join the [Implementation Network](#).



<http://respectprocess.org.uk/>

www.pilgrimshospices.org

Action planning – day 1 - 2019

Principles & Practice in End of Life Care Registered Practitioners

Skills that can improve practice in end of life care

What can we do differently?

*If you change
Nothing,
nothing will
change.*

Life of an Educator. J. Tarte 2013

Always remember!

hello
my name is...

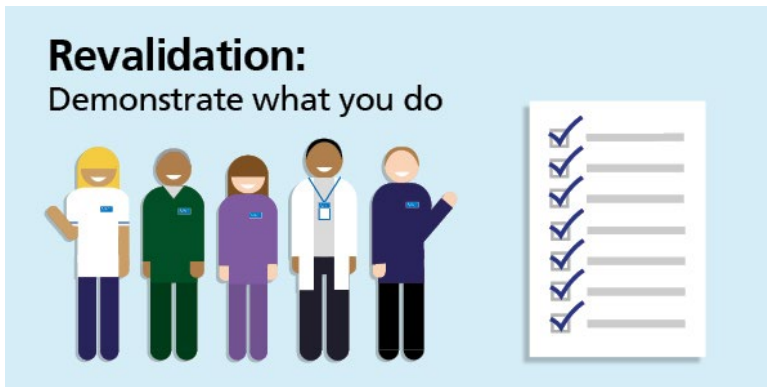
hello my name is
<https://www.england.nhs.uk/tag/hellomynameis/>
<http://hellomynameis.org.uk/>



www.pilgrimshospices.org

Practice Development Workbook

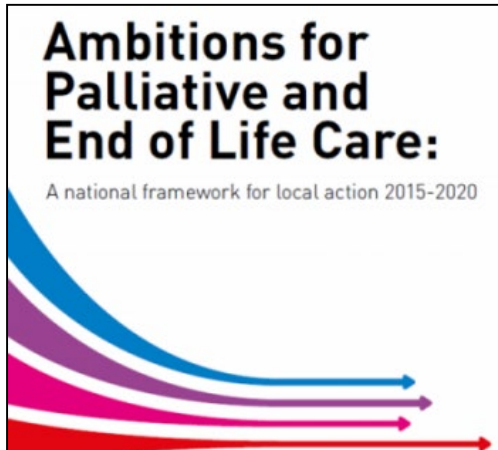
- Work through PDR following each session.
- Complete action plans
- All useful evidence to support continuing professional development portfolios!



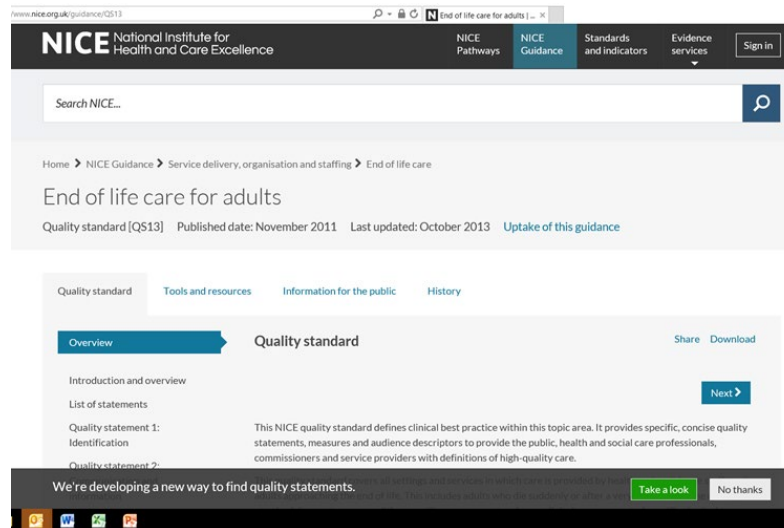
What can **we** do differently?

- Check you have read, understood & are implementing up to date guidance

<http://endoflifecareambitions.org.uk/>



<https://www.nice.org.uk/guidance/QS13>



<https://www.nice.org.uk/guidance/ng31?unlid=3733136482016228163854>

Priorities of Care for the Dying Person



Check out SPICT™ resources

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- Persistent symptoms despite optimal treatment of underlying condition(s).
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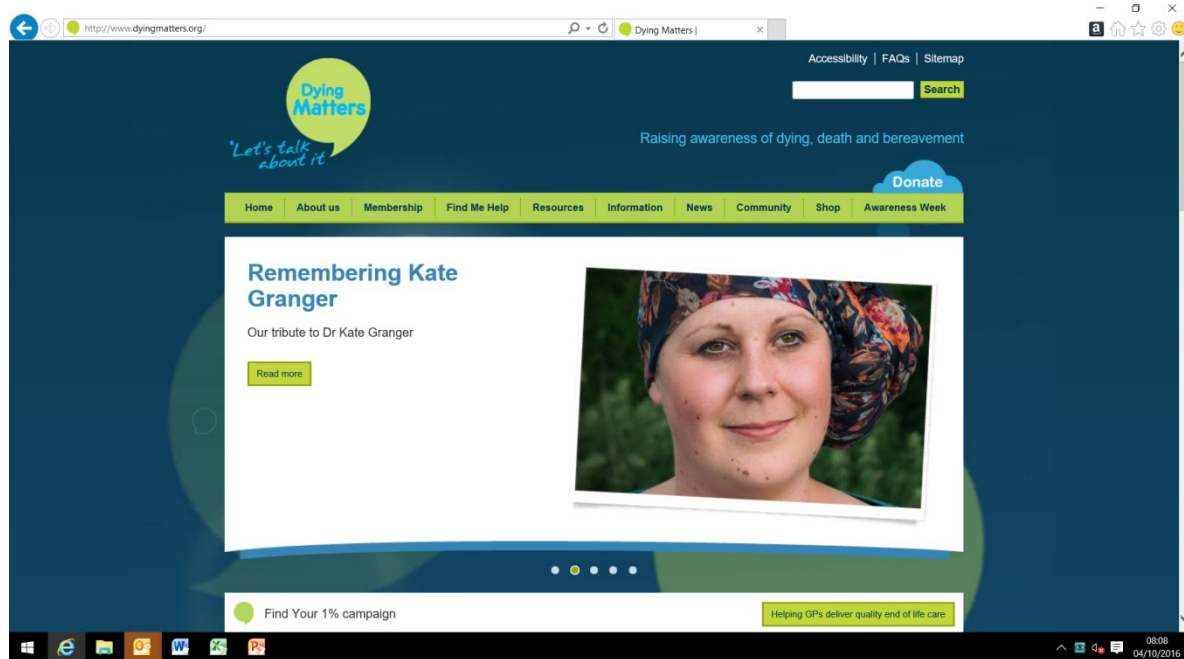
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Too frail for cancer treatment or treatment is for symptom control.	Severe, inoperable peripheral vascular disease.	Kidney failure complicating other life limiting conditions or treatments.
Dementia/ frailty	Respiratory disease	Liver disease
Unable to dress, walk or eat without help.	Severe, chronic lung disease; with breathlessness at rest or on minimal effort between exacerbations.	Cirrhosis with one or more complications in the past year:
Eating and drinking less; difficulty with swallowing.	Persistent hypoxia needing long term oxygen therapy.	• diuretic resistant ascites
Urinary and faecal incontinence.	Has needed ventilation for respiratory failure or ventilation is contraindicated.	• hepatic encephalopathy
Not able to communicate by speaking; little social interaction.		• hepatorenal syndrome
Frequent falls; fractured femur.		• bacterial peritonitis
Recurrent febrile episodes or infections; aspiration pneumonia.		• recurrent variceal bleeds
Neurological disease	Other conditions	Liver transplant is not possible.
Progressive deterioration in physical and/or cognitive function despite optimal therapy.	Deteriorating and at risk of dying with other conditions or complications that are not reversible; any treatment available will have a poor outcome.	
Speech problems with increasing difficulty communicating and/or progressive difficulty with swallowing.	Review current care and care planning.	
Recurrent aspiration pneumonia; breathless or respiratory failure.	• Review current treatment and medication to ensure the person receives optimal care; minimise polypharmacy.	
Persistent paralysis after stroke with significant loss of function and ongoing disability.	• Consider referral for specialist assessment if symptoms or problems are complex and difficult to manage.	
	• Agree a current and future care plan with the person and their family. Support family carers.	
	• Plan ahead early if loss of decision-making capacity is likely.	
	• Record, communicate and coordinate the care plan.	

Please register on the SPICT website (www.spict.org.uk) for information and updates.

SPICT™, April 2017

<https://www.spict.org.uk/>

Check out Dying Matters website

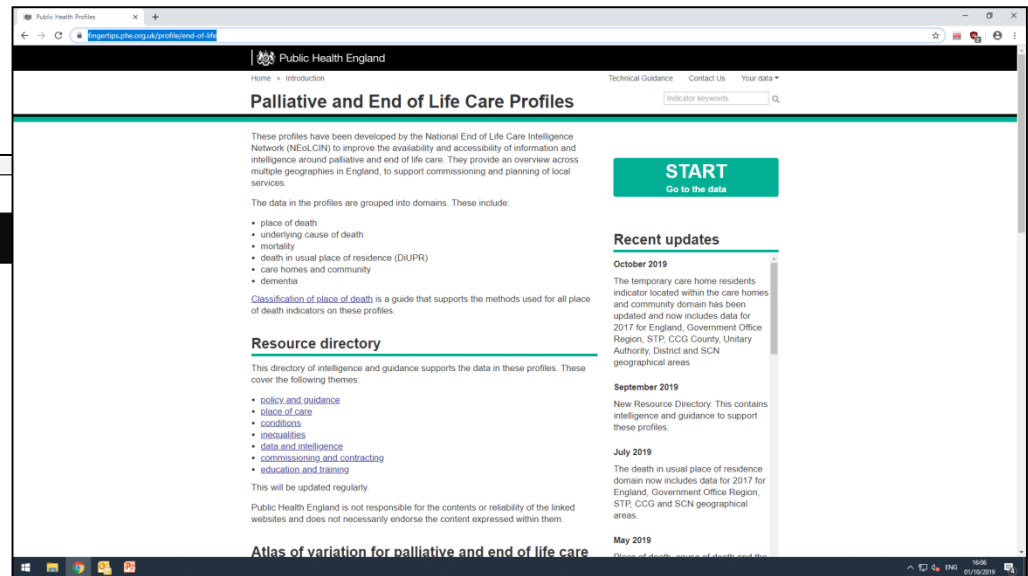


<http://www.dyingmatters.org/>

www.pilgrimshospices.org

Check out some statistics

<https://fingertips.phe.org.uk/profile/end-of-life>



<https://www.gov.uk/government/statistics/end-of-life-care-profiles-may-2019-data-update>

www.pilgrimshospices.org

Do not forget to visit /register to the following e-learning resource!

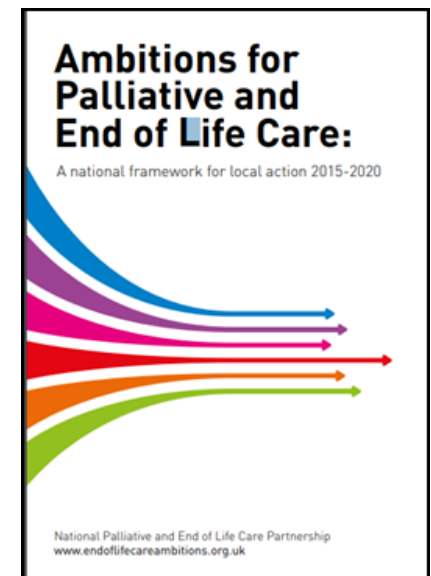


- e-ELCA (End of Life Care for All e-learning website)
 - <http://www.e-lfh.org.uk/programmes/end-of-life-care/>
- A number of sessions are available for all healthcare workers to access.
- Check out the sessions that support Priorities for Care of the Dying Person
- Add certificates & reflections to your portfolio!

Week 6 presentation

- 5 minute presentation
 - Very informal
 - Can be fun!
 - Any format accepted
 - Can either deliver individually or as a pair.
 - Relate one of the -
Ambitions for Palliative & End of Life Care
to your own role & area of work

Remember this will be very useful evidence
for portfolios!



Develop an action plan

‘It’s often the small things
that make a difference to
patients & families..’

(Hansford 2015)

