NHS
Frimley Health
NHS Foundation Trust

Palliatiivravist Inglismaal

Tiina Tamm
Anestesioloog ja intensiivravi arst
Frimely Health
Wexham Park Hospital, UK
tiina.tamm@nhs.net

Frimley Health NHS Foundation Trust (Wexham Park, Frimley Park)

- Teeninduspiirkond 800 000 - Berkshire, Hampshire, Surrey and South Buckinghamshire
- Elanikkond paljurahvuseline, vähemalt 30 erinevat keelt
- 1370 voodikohta

2018:

- > 220 000 erakorralist haiget
- 17465 haiglaepisoodi
- 1518 995 ambulatoorset vastuvõttu
- 9,101 sünnitust
- 2570 surma

Suurbritannia elulõpu statistika

- Igal aastal sureb 1% elanikkonnast
- 54% sureb haiglas , umbes pooled neist võiksid surra kodus
- 15% erakordsetelt hospitaliseeritutest on terminaalselt haiged patsiendid
- Surm haiglas:

36% kolme päeva jooksul pärast hospitaliseerimist

56% esimese nädala jooksul

- Haiglaravi elu lõpus on 2x kallim kui hooldusravi ja 4x kallim kui kodune hooldus
- Üks haiglaravi episood £3200, keskmiselt 3x haiglas viimase eluaasta jooksul

The Nuffield Trust 2015

The Economist | Intelligence Unit

An Economist Intelligence Unit study, commissioned by the Lien Foundation

THE 2015 QUALITY OF DEATH INDEX
RANKING PALLIATIVE CARE ACROSS THE WORLD

- Analüüsiti 80 maa palliatiivravi kvaliteeti
- Suurbritannia kõrgeimal positioonil
- Rikkamad maad edestavad vaesemaid
- Hiina kõige haavatavamal positioonil (kõrge nõudlus/madal kättesaadavus)

As governments across the world work to improve life for their citizens, they must also consider how to help them die well. The Economist Intelligence Unit has assessed the availability, affordability and quality of palliative care available to adults across 80 countries. Countries were scored out of 100 on 20 indicators in five categories:

Palliative and healthcare environment (20% weighting)
Covers the general palliative andhealthcare framework

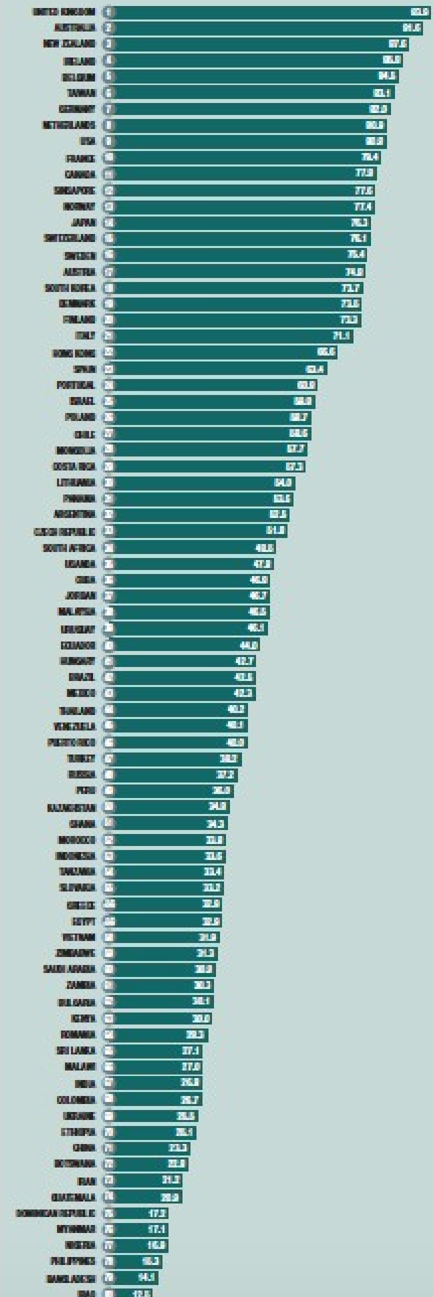
Human resources (20% weighting)
Measures the availability and training of medical care professionals and support staff

Affordability of care (20% weighting)
Assesses the availability of public funding for palliative care and the financial burden to patients

Quality of care (30% weighting)
Evaluates the presence of monitoring guidelines, the availability of opioids and the extent to which healthcare professionals and patients are partners in care

Community engagement (10% weighting)
Measures the availability of volunteers and public awareness of palliative care

OVERALL RESULTS



Suurbritannia edu saladus

- Põhjalikud üleriigilised juhendid
- Palliatiivravi kuulub kindlalt esmatähtsate tervishoiuteenuste hulka
- Väljakujunenud ja tunnustatud hospiitside võrgustik
- Avalikkuse teadlikkus, kaasatus ja sügav huvi osaleda palliatiivraviga seotud probleemide lahendamisel. Pikk heategevuse traditsioon

Palliatiivravi Inglismaal

- 1967 Dame Cicely Saunders founded St Christopher's House
- 1991 The National Council for Hospice and Specialist Palliative Care Services
- Late 1990s – Liverpool Care Plan (LCP)
- 2004 The National Council for Palliative Care
- 2008 National strategy for end-of-life care
- 2009 Dying Matters Coalition
- 2011 NICE quality standard for end-of-life care
- 2013 Neuberger review *More care, less pathway.*
- 2014 LCP phased out and replaced by more individualised care plan
- 2015 '*Dying without dignity*' Investigations by the Parliamentary and Health Service Ombudsman into complaints about end of life care
- 2015 Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020
- 2016 DoH Commitment for EoLC

Palliatiivravi Inglismaal

- Kes?
  - Palliatiivravi õed ja arstid, perearst, pereõed, hospiitsi personal, vaimulikud, heategevusorganisatsioonide töötajad, nõustajad, füsioterapeudid
- Kus?
  - kodus, hooldekodus, hospiitsis, haiglas – võimalikult palju arvestatakse inimese soovi
- Millal?
  - Siis kui vaja
  - 24/7 nõuandetelefon
  - “kiirreageerijad”

Hospiitsid

What is hospice care?

There are more than
220
hospices in the UK

90%
of hospice care is delivered through day services or at home

Hospice teams work with **local hospitals** and **care homes**

www.hospiceuk.org

National Palliative and End of Life Care Partnership

Association for Palliative Medicine; Association of Ambulance Chief Executives;
Association of Directors of Adult Social Services;
Association of Palliative Care Social Workers; Care Quality Commission;
College of Health Care Chaplains; General Medical Council;
Health Education England; Hospice UK;
Macmillan Cancer Support; Marie Curie;
Motor Neurone Disease Association; National Bereavement Alliance;
National Care Forum; National Council for Palliative Care;
National Palliative Care Nurse Consultants Group; National Voices;
NHS England; NHS Improving Quality;
Patients Association; Public Health England;
Royal College of General Practitioners;
Royal College of Nursing; Royal College of Physicians;
Social Care Institute for Excellence;
Sue Ryder and
Together for Short Live

Riiklikud ja erialaseltside juhendid

NICE National Institute for Health and Care Excellence

NICE guideline

Care of dying adults in the last days of life

NICE guideline
Published: 16 December 2015
nice.org.uk/guidance/ng31

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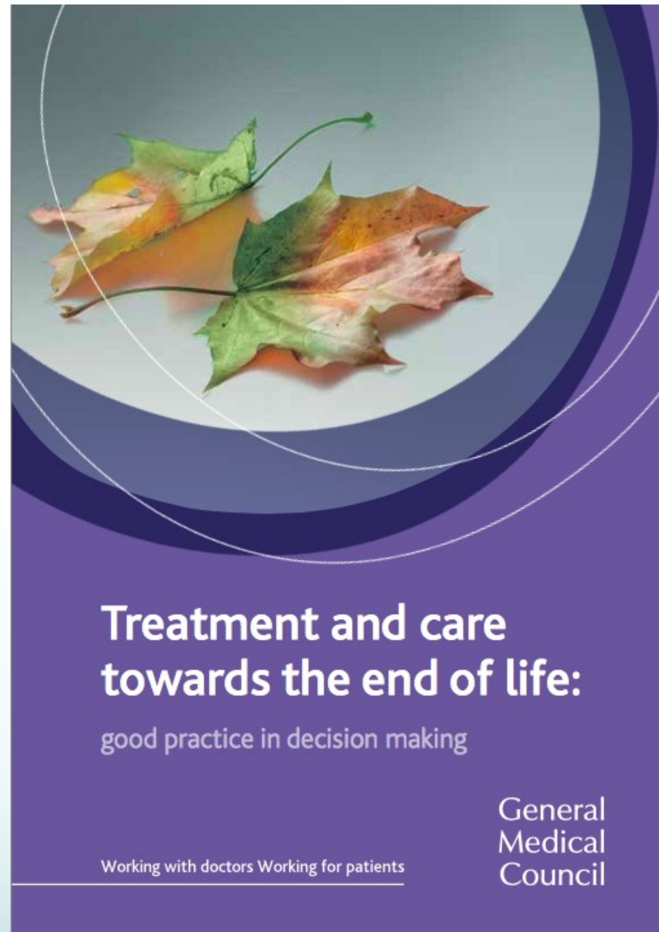


The Intensive Care Society

Guidelines for limitations of treatment for adults requiring intensive care

intensive care society
care when it matters

October 2014

3rd edition

Decisions relating to cardiopulmonary resuscitation

Guidance from the British Medical Association, the Resuscitation Council (UK) and the Royal Colle

(previously known as the "Joint Statement")

End of Life Care Strategy

Second Annual Report

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

Dame Cicely Saunders

Founder of the Modern Hospice Movement

August 2010

The care of all dying patients must improve to the level of the best

Advance Care Planning:

A Guide for Health and Social Care Staff

www.endoflifecareforadults.nhs.uk

Mental Capacity Act 2005

CHAPTER 9

CONTENTS

PART 1

PERSONS WHO LACK CAPACITY

The principles

1 The principles

Preliminary

2 People who lack capacity
3 Inability to make decisions
4 Best interests
5 Acts in connection with care or treatment
6 Section 5 acts: limitations
7 Payment for necessary goods and services
8 Expenditure

Lasting powers of attorney

9 Lasting powers of attorney
10 Appointment of donees
11 Lasting powers of attorney: restrictions
12 Scope of lasting powers of attorney: gifts
13 Revocation of lasting powers of attorney etc.
14 Protection of donee and others if no power created or power revoked

General powers of the court and appointment of deputies

15 Power to make declarations
16 Powers to make decisions and appoint deputies: general
17 Section 16 powers: personal welfare
18 Section 16 powers: property and affairs

NICE juhendid ja kvaliteedistandardid

- End of life care for infants, children and young people (QS160)
- End of life care for adults (QS13)
- Care of dying adults in the last days of life (NG31, QS144)

List of statements

Statement 1. People approaching the end of life are identified in a timely way.

Statement 2. People approaching the end of life and their families and carers are communicated with, and offered information, in an accessible and sensitive way in response to their needs and preferences.

Statement 3. People approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment.

Statement 4. People approaching the end of life have their physical and specific psychological needs safely, effectively and appropriately met at any time of day or night, including access to medicines and equipment.

Statement 5. People approaching the end of life are offered timely personalised support for their social, practical and emotional needs, which is appropriate to their preferences, and maximises independence and social participation for as long as possible.

Statement 6. People approaching the end of life are offered spiritual and religious support appropriate to their needs and preferences.

Statement 7. Families and carers of people approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences.

Statement 8. People approaching the end of life receive consistent care that is coordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the person's current medical condition, care plan and preferences.

Statement 9. People approaching the end of life who experience a crisis at any time of day or night receive prompt, safe and effective urgent care appropriate to their needs and preferences.

Statement 10. People approaching the end of life who may benefit from specialist palliative care, are offered this care in a timely way appropriate to their needs and preferences, at any time of day or night.

Statement 11. This statement has been removed and replaced by NICE's quality standard on care of dying adults in the last days of life. For more details see update information.

Statement 12. The body of a person who has died is cared for in a culturally sensitive and dignified manner.

Statement 13. Families and carers of people who have died receive timely verification and certification of the death.

Statement 14. People closely affected by a death are communicated with in a sensitive way and are offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences.

Statement 15. Health and social care workers have the knowledge, skills and attitudes necessary to be competent to provide high-quality care and support for people approaching the end of life and their families and carers.

Statement 16. Generalist and specialist services providing care for people approaching the end of life and their families and carers have a multidisciplinary workforce sufficient in number and skill mix to provide high-quality care and support.

In addition, quality standards that should also be considered when commissioning and providing an end of life care service are listed in related NICE quality standards.

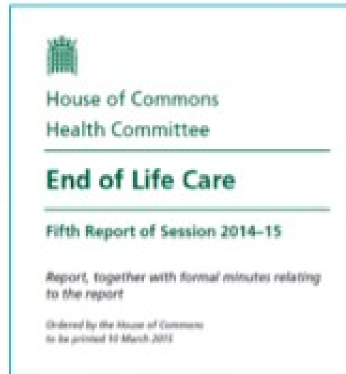
COMMITMENT STATEMENTS
ONE CHANCE TO GET IT RIGHT

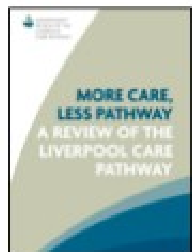
Actions for End of Life Care: 2014-16

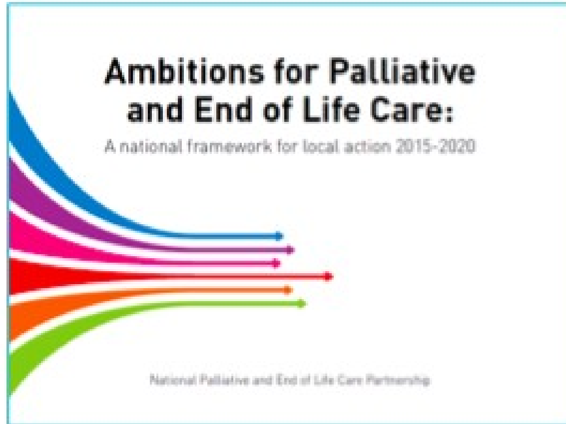
Every Moment Counts

What's important to me.
A Review of Choice in End of Life Care

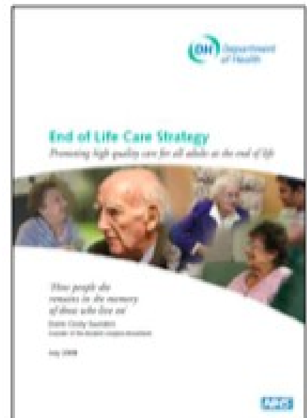
NHS
England


House of Commons
Health Committee
End of Life Care
Fifth Report of Session 2014–15
Report, together with formal minutes relating to the report

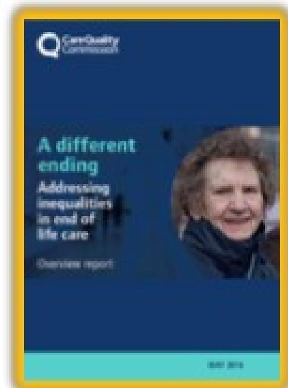

MORE CARE, LESS PATHWAY
A REVIEW OF THE LIVERPOOL CARE PATHWAY


Ambitions for Palliative and End of Life Care:
A national framework for local action 2015-2020
National Palliative and End of Life Care Partnership

Dying without dignity
Investigations by the Parliamentary and Health Service Ombudsman into complaints about end of life care


Department of Health
End of Life Care Strategy

Department of Health
The Government's mandate to NHS England for 2016-17


CareQuality Commission
A different ending
Addressing inequalities in end of life care
Overview report

Department of Health
Our Commitment to you for end of life care
The Government Response to the Review of Choice in End of Life Care

Department of Health

Our Commitment to you for end of life care

The Government Response to the Review of Choice in End of Life Care

July 2016

Igal elupiiril oleval haigel peab olema võimalus

- ausale vestlusele oma soovidest ja vajadustest
- teha informeeritud valikuid
- koostada endale individuaalne raviplaan
- kaasata oma lähedasi raviotsuste tegemistesse
- individuaalne kontaktisik, kes toetab ja suunab

Valitsuse seatud prioriteedid tervishoiutöötajatele olukordadeks kui patsiendi surm on lähedal

1. Saa aru, millal surm on lähedal
2. Suhtle patsiendi ja lähedastega
3. Surija ja tema lähedaste kaasamine oluliste otsuste tegemisse
4. Surijale ja temale oluliste inimeste vajaduste hindamine, tunnustamine ja täitmine.
5. Personaalse raviplaani koostamine, dokumenteerimine ja täideviimine

End of Life Care Audit – Dying in Hospital

National report for England 2016

National End of Life Care Audit 2016

	CLINICAL AUDIT Cases in clinical audit Clinical audit indicator	National result n=9302 % of cases
1	Is there documented evidence within the last episode of care that it was recognised that the patient would probably die in the coming hours or days? **%YES**	83%
2	Is there documented evidence within the last episode of care that health professional recognition that the patient would probably die in the coming hours or days (imminent death) had been discussed with a nominated person(s) important to the patient? **%YES**	79%
3	Is there documented evidence that the patient was given an opportunity to have concerns listened to? **%YES or NO BUT**	84%
4	Is there documented evidence that the needs of the person(s) important to the patient were asked about? **%YES or NO BUT**	56%
5	Is there documented evidence in the last 24 hours of life of a holistic assessment of the patient's needs regarding an individual plan of care? **% YES**	66%

National End of Life Care Audit 2016

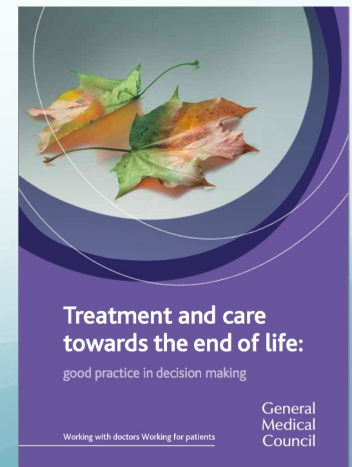
	ORGANISATIONAL AUDIT Sites in organisational audit Organisational audit indicator	n=142 % of sites
6	Is there a lay member on the trust board with a responsibility/role for end of life care?	49%
7	Did your trust seek bereaved relatives' or friends' views during the last 2 financial years (ie from 1 April 2013 to 31 March 2015)?	80%
8A	Between 1 April 2014 and 31 March 2015, did formal in-house training include/cover specifically communication skills training for care in the last hours or days of life for **medical staff**?	63%
8B	Between 1 April 2014 and 31 March 2015, did formal in-house training include/cover specifically communication skills training for care in the last hours or days of life for **nursing (registered) staff**?	71%
8C	Between 1 April 2014 and 31 March 2015, did formal in-house training include/cover specifically communication skills training for care in the last hours or days of life for **nursing (non-registered) staff**?	62%
8D	Between 1 April 2014 and 31 March 2015, did formal in-house training include/cover specifically communication skills training for care in the last hours or days of life for **allied health professional staff**?	49%
9	Was there face-to-face access to specialist palliative care for at least 9am to 5pm, Monday to Sunday?	37%
10	Does your trust have one or more end of life care facilitators as of 1 May 2015?	59%

National End of Life Care Audit 2016

- 97% haiglatel oma palliatiivravi teenistus
- 37% haiglates võimalus näost –näkku palliatiivravi konsultatsiooniks iga päev 9-17
- 96% haiglatel kohustuslik palliatiivravi kooolitusprogramm

General Medical Council on EoLC

- Põhilised käitumisjuhendid elu lõpuga seotud meditsiiniliste otsuste kohta
- Võtab arvesse seadusakte, kuid ei asenda juriidilist nõuannet
- Juhend hõlmab erinevaid suremisega seotud aspekte:
  - advance decisions - elutestament
  - teadaolevad soovid ja keeldumised
  - kunstlik toitmine
  - elustamisotsused



Seadusandlus

- Aruselge patient võib ravist keelduda isegi kui see võib teda kahjustada või põhjustada tema surma (kaasaarvatud rasedad)
  - See otsus kehtib ka siis kui patsient ei ole enam aruselge (kui on kindel, et patsient ei ole muutnud oma seisukohta)
- Kui arstide arvates ei ole ravi sobiv, ei pea seda haigele pakkuma
- Püsivas vegetatiivses seisundis oleva patsiendi kunstliku toitmise lõpetamiseks ei ole enam kohtu otsust vaja

Mida ütleb seadus?

- Ravi lõpetamine - “hoidumine” mitte “tegu”
- Arst ei ole kohustatud jätkama aktiivravi kui see on kasutu või põhjustab asjatud kannatusi
- Kogenud ja kompetentsel arstil on õigus teha lõplik otsus
- Kui perekond arsti otsusega ei nõustu, on vajalik kohtu otsus

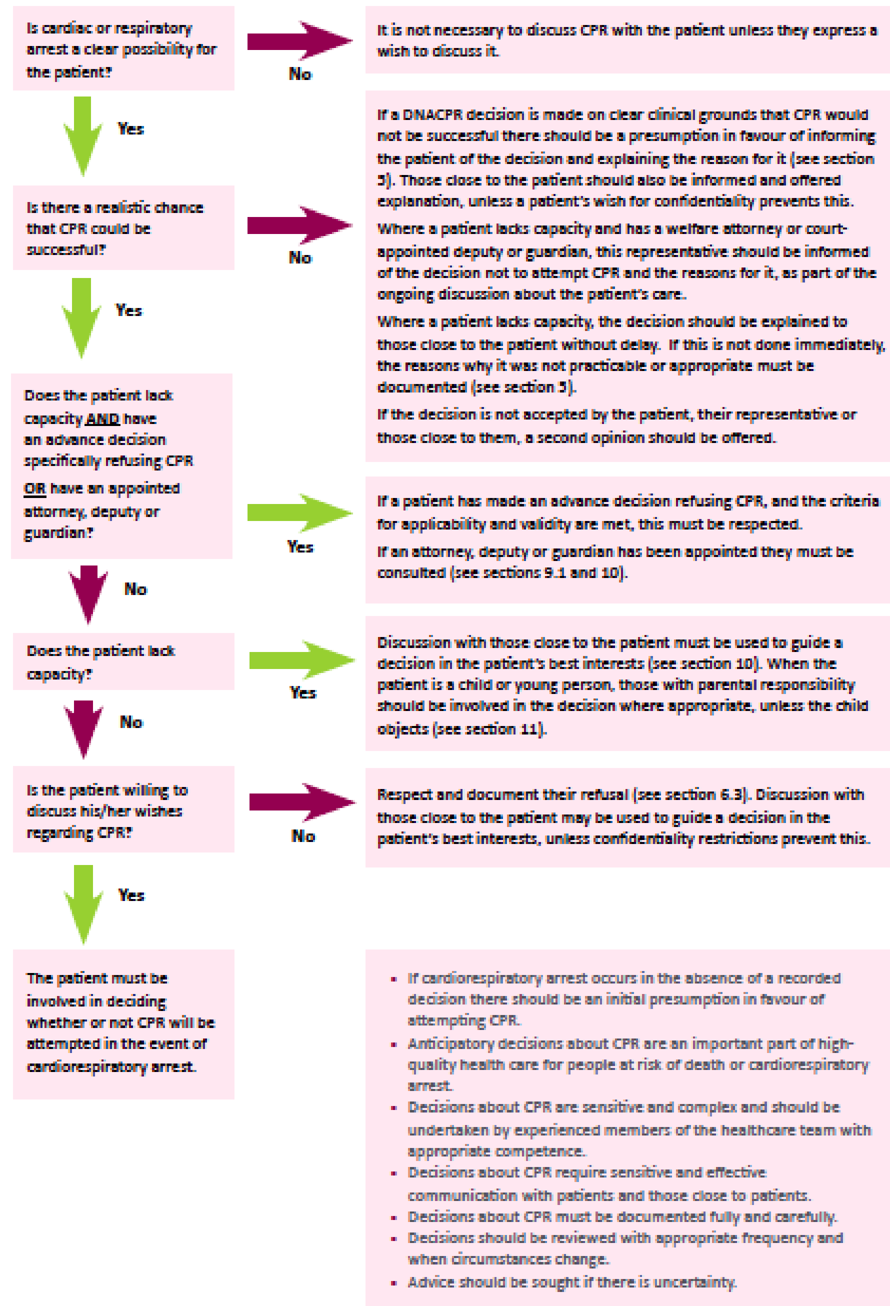
Decisions relating to cardiopulmonary resuscitation

Guidance from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing

(previously known as the 'Joint Statement')

3rd edition (1st revision) 2016

Decision-making framework



DNACPR (**D**o **N**ot **A**ttempt **C**ardio-**P**ulmonary **R**esuscitation) - elustamiskeeld

LILAC FORM STAYS WITH PERSON WHEREVER THEY ARE BEING CARED FOR.
WHITE FORMS FOR AUDIT AND NOTES.

UNIFIED DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION (DNACPR)

In the event of cardiac or respiratory arrest no attempts at CPR will be made. All other appropriate treatment and care will be provided.

Version 1 – April 2013

Name:
Address:
Post code:
Date of birth: / /
NHS or hospital number:

Date of DNACPR Decision / /
NHS North of England North West
Institution Name
Form completed electronically? Yes ☐ No ☐
Before completing this form, please see explanation notes

1. Reason for DNACPR decision: (select A, B or C)

☐ A) CPR is unlikely to be successful due to

This decision has been discussed with the person Yes ☐ No ☐ If No state reason
The relevant other has been informed of the decision Yes ☐ No ☐ If No state reason
Name of relevant other:

☐ B) CPR may be successful, but of life followed by a length and quality which would not be of overall benefit of the person.
- Person involved in discussions? Yes ☐ No ☐ If No state reason
- Person lacks mental capacity and has a legally appointed Welfare Attorney:
- Person lacks mental capacity and does not have a legally appointed Welfare Attorney. Decision is made on the balance of overall benefit to the person in discussion with:

☐ C) There is a valid advance decision to refuse CPR in the following circumstances: All circumstances Yes ☐ No ☐
Specific Circumstances (please state):

Attach a copy of the Advance Decision to Refuse Treatment (ADRT) to the back of the DNACPR form.

2. Healthcare professional making this DNACPR decision:
Name: Position: GMC/NMC:
Signature: Date: / / Time:
If decision has been made by a delegated professional, the decision needs to be verified at the earliest opportunity:
Name: Position: GMC/NMC:
Signature: Date: / / Time:

3. Review: (Select ONE box only) ☐ This is an indefinite decision / ☐ Needs reviewing
Review date if appropriate: / / Outcome of review: DNACPR to continue? Yes ☐ No ☐
Name: Position: GMC/NMC:
Signature: Date: / / Time:

uDNACPR

4. Who has been informed of this DNACPR decision?
Please Tick
☐ GP ☐ Ambulance Warning Flag ☐ Out of Hours
☐ Care Provider (Please state)
☐ Other (Please state)

5. Other important information:
For example, ambulance crew instructions on transfer, Ceilings of treatment, Preferred place of care/death.

Cut off slip and place in "message in a bottle"

Name:
Address:
Post code:
Date of birth: / /
NHS or hospital number:

The DNACPR form is located:

Important: this form MUST be printed on lilac paper

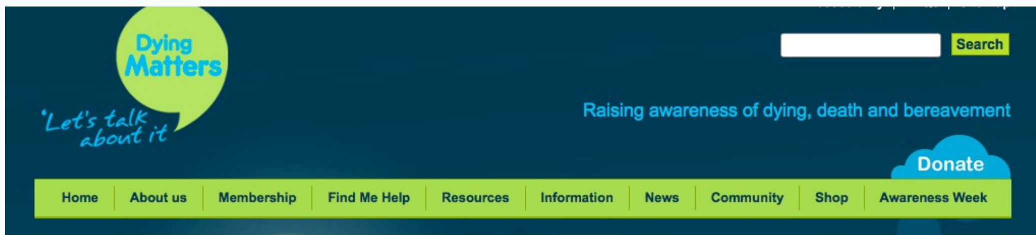
- Ei tähenda ravi lõpetamist
- Aitab vältida asjatuid elustamiskatseid
- Aitab planeerida elu lõpuga seonduvat
- Eeldab patsiendi ja tema sugulaste soovidega kursis olemist
- “kiri pudelis”

Message in a bottle

Let the emergency services know your medical history.

/messageinabottle #messageinabottle

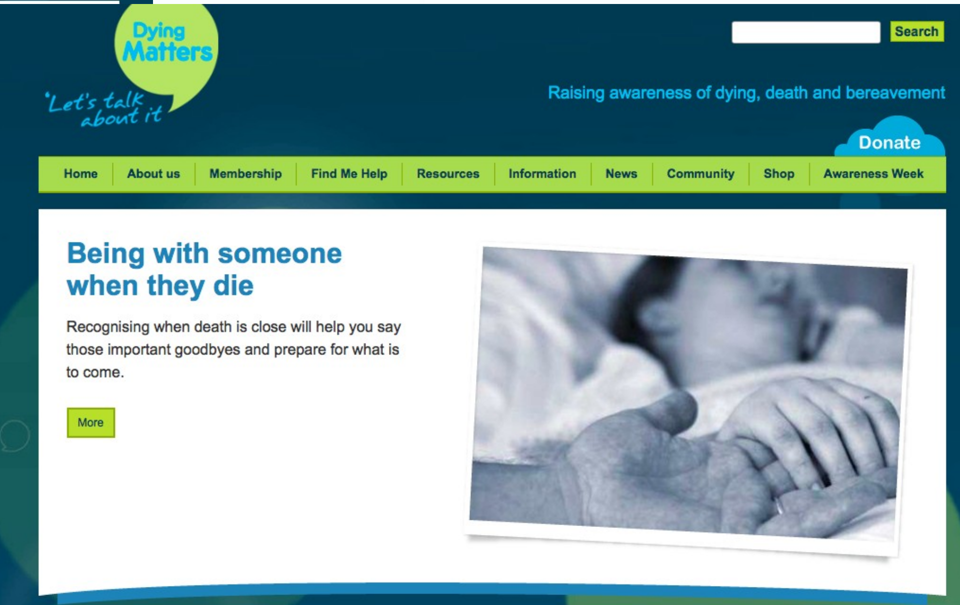
Elanikkonna teadlikkuse tõstmine

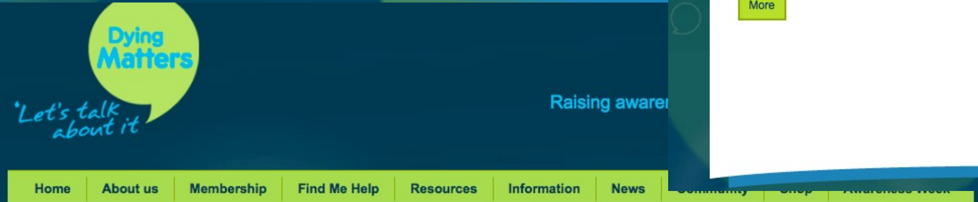


The Dying Matters Podcast

Everything you wanted to know about dying, death and bereavement from experts in the field

Listen here





Dying Matters Awareness Week 2019

Are We Ready? Make sure you are and download our social media assets for Awareness Week

Find them here

End of life care

Death and dying are inevitable. The quality and accessibility of this care will affect all of us. The needs of people of all ages who are living with dying, death and bereavement, their families, carers and communities, must be addressed, taking into account their priorities, preferences and wishes. Personalised care at end of life will result in a better experience, tailored around what really matters to the person, and more sustainable NHS services.

If you would like more information on the End of Life Care Programme, please email england.endoflifecare@nhs.net and follow our personalised care Twitter account @Pers_Care.

About end of life care

Context and challenges around palliative and end of life care and why progress is needed.

NHS England's end of life care partners

Who NHS England is working with to improve palliative and end of life care.

What NHS England is doing to improve end of life care

NHS England's End of Life Care Programme aims and objectives.

Personalised end of life care

How NHS England is enhancing personalised care at end of life to support a better experience.

Addressing inequalities

Why ensuring equality in end of life care is important and resources to help commissioners, service providers and health and social care staff achieve this.

Resources for commissioners

Tips for commissioners, service providers and health and social care staff, providing end of life care to people from specific population groups.

Additional resources

Ambitions for palliative and end of life care

End of life care commitment

Palliatiivravi intensiivravi osakonnas

- 60% intensiivravi surmadest pärast ravi lõpetamist
- Enamik sureb intensiivravi osakonnas
- Kui eeldatakse, et peale ravi lõpetamist patsient ei sure 24 tunni jooksul, viiakse patsient tavaosakonda eraldi palatisse
- Mõnikord soovib patsient surra k

Intensive Care Society

- Ravi lõpetatakse ainult juhul, kui see ei ole enam patsiendi huvides või kui kannatused, mida ravi põhjustab, ületavad oodatava kasu
- Patsiendi soove tuleb püüda uurida ja arvesse võtta.
- Intensiivravi alustades tuleb teha raviplaan, mis hõlmab ka võimalikke ravipiiranguid. Vajadusel hinnatakse raviplaan ümber
- Vastutava arsti kohus on ära tunda surev patsient ja aru saada, millal palliatiivne ravi on eelistatud agressiivsele aktiivravile
- Kui aktiivravi lõpetatakse, tuleb jätkata ravi ja toetust eesmärgiga tagada kannatuste leevendamine ja väärikus. Ravi eesmärgiks on kannatuste leevendamine, mitte surma kiirendamine
- Ravi, mis säilitab surija organite funktsioone pikendades suremise protsessi, tuleb lõpetada
- Surijale tuleb tagada privaatsus ja tema lähedastele vaba juurdepääs

Heatherwood and Wexham Park Hospitals NHS
NHS Foundation Trust

Help and teach medical/surgical multidisciplinary teams to:

- Manage symptoms
- Break significant news
- Manage complex ethical, legal, clinical and spiritual dilemmas at end of life
- Support patients and families emotionally, psychologically and spiritually
- Arrange complex hospital discharges at end of life

Help patients, families and carers to:

- Understand the diagnosis
- Communicate
- Make decisions about treatment options and symptom management
- Explore issues surrounding planning for the future
- Find out about financial and support services available
- Cope with bereavement

Contact details

For telephone advice: 01753 860441 ext 6137
To fax a referral: 01753 636139

Palliatiivravi intensiivravi osakonnas

- Ravi eesmärkide seadimine intensiivravi alustades
- Patsientide ja nende perekondade kaasamine raviotsuste tegemisse.
- Varane palliatiivse ravi/nõustaja/vaimuliku kaasamine
- Kultuuriliste ja religioossete eripärade arvestamine
- Dokumenteerimine
- Kvaliteedi hindamine (kohalikud ja üleriigilised auditid)

Mida teha, et Eesti palliatiivravi jõuaks maailmatasemele

- Riigi kohustus tagada oma kodanikele inimväärikas elu ja surm
- Erialaseltside toetus
- Palliatiivravi koolitus arstiteaduskonnas
- Täiendõpe; Raskete kõneluste koolitused
- Oma tegevuse auditeerimine ja analüüs
- Arstide-õdede koostöö patsientide ja nende lähedastega
- Suurendada arstkonna ja kogu elanikkonna teadlikkust

Haigused on paratamatud. Abita jäämine elu raskel hetkel ei ole paratamatu. Hoolivas riigis nii ei tehta…

[Vabariigi Presidendi kõne Eesti Vabariigi aastapäeva vastuvõtul 24. 02.2019 Estonia teatri- ja kontserdimajas]