End of Life Care

London Borough of Redbridge

JOHN POWELL

Director of Adult Social Services and Housing

3rd National

End of Life Care Congress

Joining up Services across Health and Social Care

18th October 2011

End of Life Care

London Borough of Redbridge

Content

Key messages from July 2010

Challenges for Implementation of Framework

Progress in London

Challenges for Social Care and Partnerships

A personal experience

18th October 2011

The Social Care Framework

- KEY MESSAGES

- Social care has a vital role to play in supporting people to live and die well, in the place of their choosing.

- The social care workforce – from domiciliary care workers to social workers and their managers - may need training and support to recognise the skills they have to facilitate this and to develop further skills.

The Social Care Framework

- KEY MESSAGES Con't
- Social care services are undergoing a transformation in the ways in which they are conceived and delivered; social care at the end of life belongs to this agenda for change.
- Social work education and training are undergoing significant change, and training and skills development for the whole social care workforce is a government priority; education, training and support for the social care workforce in end of life care must be embedded in these wider changes.

The Social Care Framework

- KEY MESSAGES Con't
- The personalisation and re-ablement agendas offer significant opportunities for improving the care that individuals and their families receive at the end of life. However, commissioning processes should also take account of the needs of people unable to take full advantage of these approaches.
- Palliative care social work is an educative and consultative resource for end of life care in mainstream services, as well as making a valuable contribution in specialist settings; strengthening this service offers considerable potential for increasing social care capacity in end of life care.

The Social Care Framework

- KEY MESSAGES Con't
- Greater integration is needed across all care and support services, particularly social and health care, to improve the experience of dying for the individual and those around them. This includes tapping potential in the wider community (and other public services) to enhance quality of life at this stage.
- There needs to be a robust evidence base to support the development of good social care practice in end of life care.

The EoLC Implementation Challenges

London Borough of Redbridge

- Key points
- *Strategic commissioning*
- *Care planning*
- *Co-ordinated care*
- *Rapid access to 24/7 care*
- *Delivery of high quality care in all locations*
- *Use of an integrated care pathway*
- *Partnership with and support of carers*
- *Education and training of the Workforce*

London Progress

- **Hounslow**
- 5 year (2011-2016) EoLC Joint Commissioning Strategy for Adults
- The strategy includes 9 pledges:
  - Dignity
  - High Quality End of Life Care for All
  - Equitable Access
  - Caring for Carers
  - Supporting and Developing the workforce
  - Partnerships
  - Listening and Learning
  - Strategic planning and Commissioning
  - Ensuring continuous improvement

London Progress

- **Redbridge**
- Dementia End of Life Care Project (supporting families at home) DELCAP
- Close working with partners, Crossroads, Alzheimer society, LBR, NHS Redbridge and Redbridge Respite Care Association.
- Task and finish cross partner working in place following Scrutiny report recommendation: http://www.redbridge.gov.uk/cms/the_council/public_meetings/scrutiny_in_redbridge/scrutiny_reviews/review_completed_in_2011.aspx
- Excellent fast track agreements with NHS jointly commissioning services for end of life

London Progress

- **Coordinate My Care Pilots**
  - Sutton
  - Merton
  - Croydon
- Adult Social Care profile agreed to be incorporated into Web database
- Dr Julia Riley to give progress update on implementation and inclusion of Adult Social Care into the programme

Challenges for Social Care And Partners

London Borough of Redbridge

- Specific local resources allocated by organisations when National Strategy introduced now not available.
- Still need more work with Care Home providers who continue to send residents to hospital near end of life.
- Key issue for GP support to homes and training for Senior Care staff/decision makers.
- Potential of reduced capacity at the front line, less face to face contact between partners, service users and key staff.
- That there is a reduction in strategic leadership as senior staff become stretched and have broader responsibilities.
- Communication networks being open e.g. access to N3

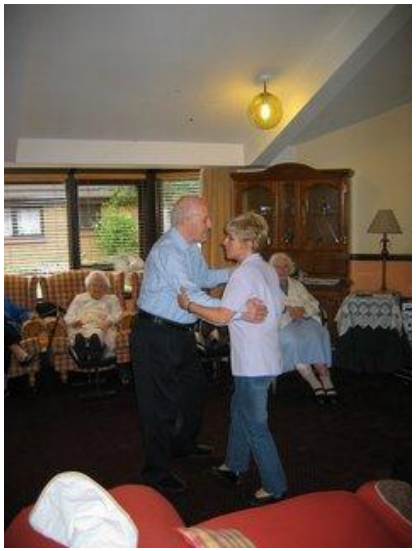
My life, my way, with your support

London Borough of Redbridge

- George's story

My life, my way, with your support

London Borough of Redbridge



a better place to **live**

My life, my way, with your support

London Borough of Redbridge

What made the difference for George?

- Confidence in staff/family to advocate
- Desire to maintain independence - including taking risks to enable this to happen
- Prepared to challenge stereotype of residential/nursing care/hospital as only solution
- Confidence in managing situations that may not be the norm – wanting to die at home
- Creative solutions – assistive technology
- But most of all TRUST

My life, my way, with your support

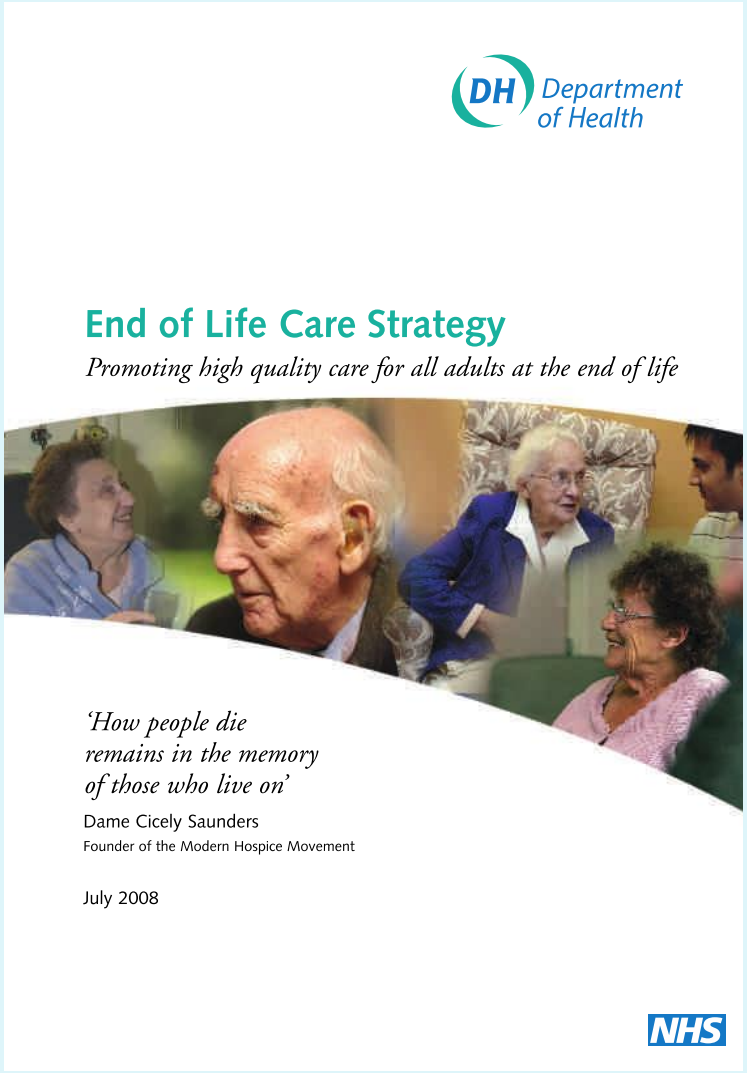
London Borough of Redbridge

What made the difference for Me?

- Knowing dad trusted me to do the best for him
- Knowing the professionals where he lived supported the plan
- Knowing that fighting to get dad home from hospital was the right thing to do
- Knowing that dads wishes had been carried through and that he died at home with the people around him that meant the most to him

A clinical service that coordinates care giving patients choice and improved quality of life

Coordinate My Care



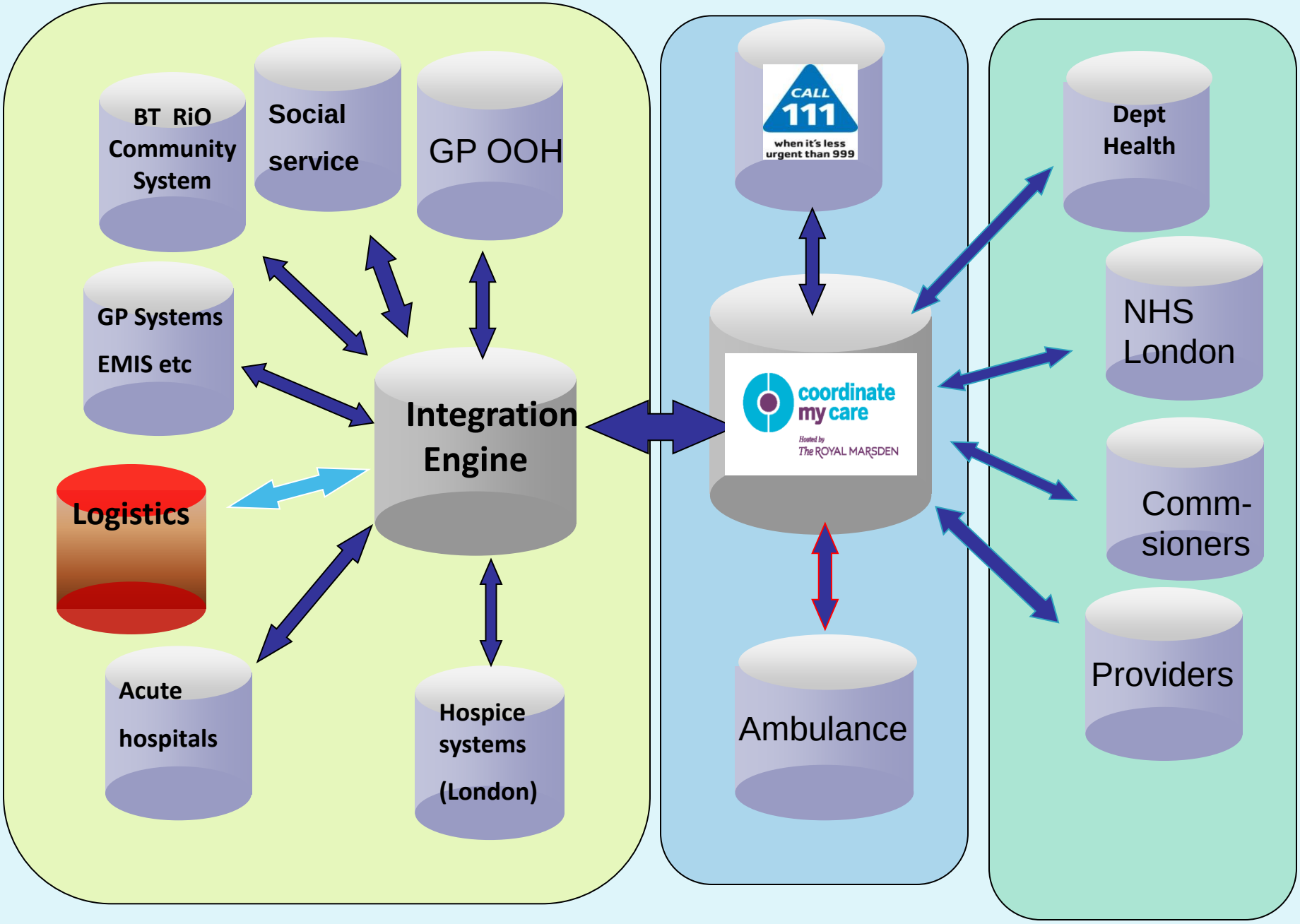
'Nothing about me without me'

"Establishing a locality-wide register for those approaching the end of life"

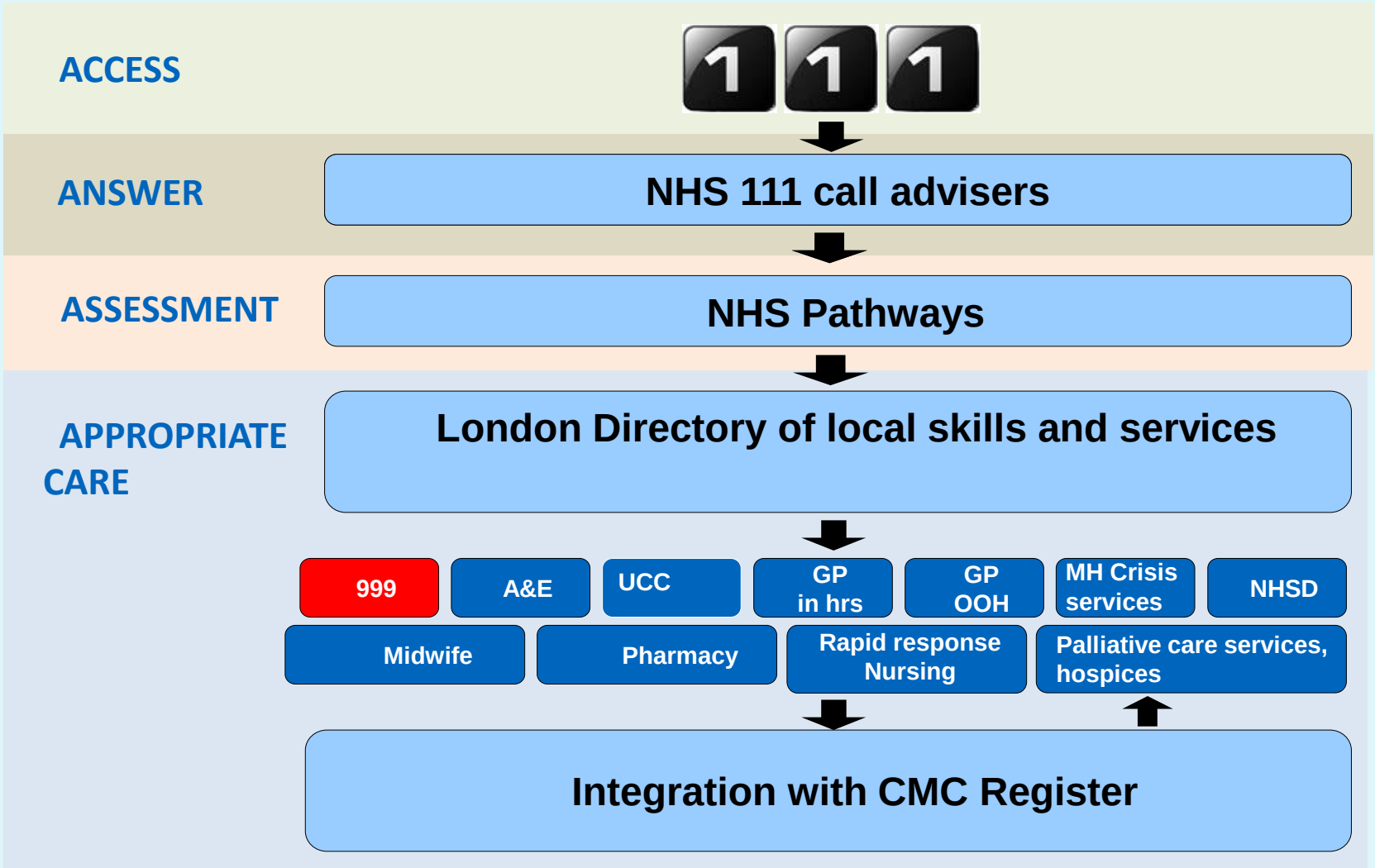
Pan London – Coordinate My Care

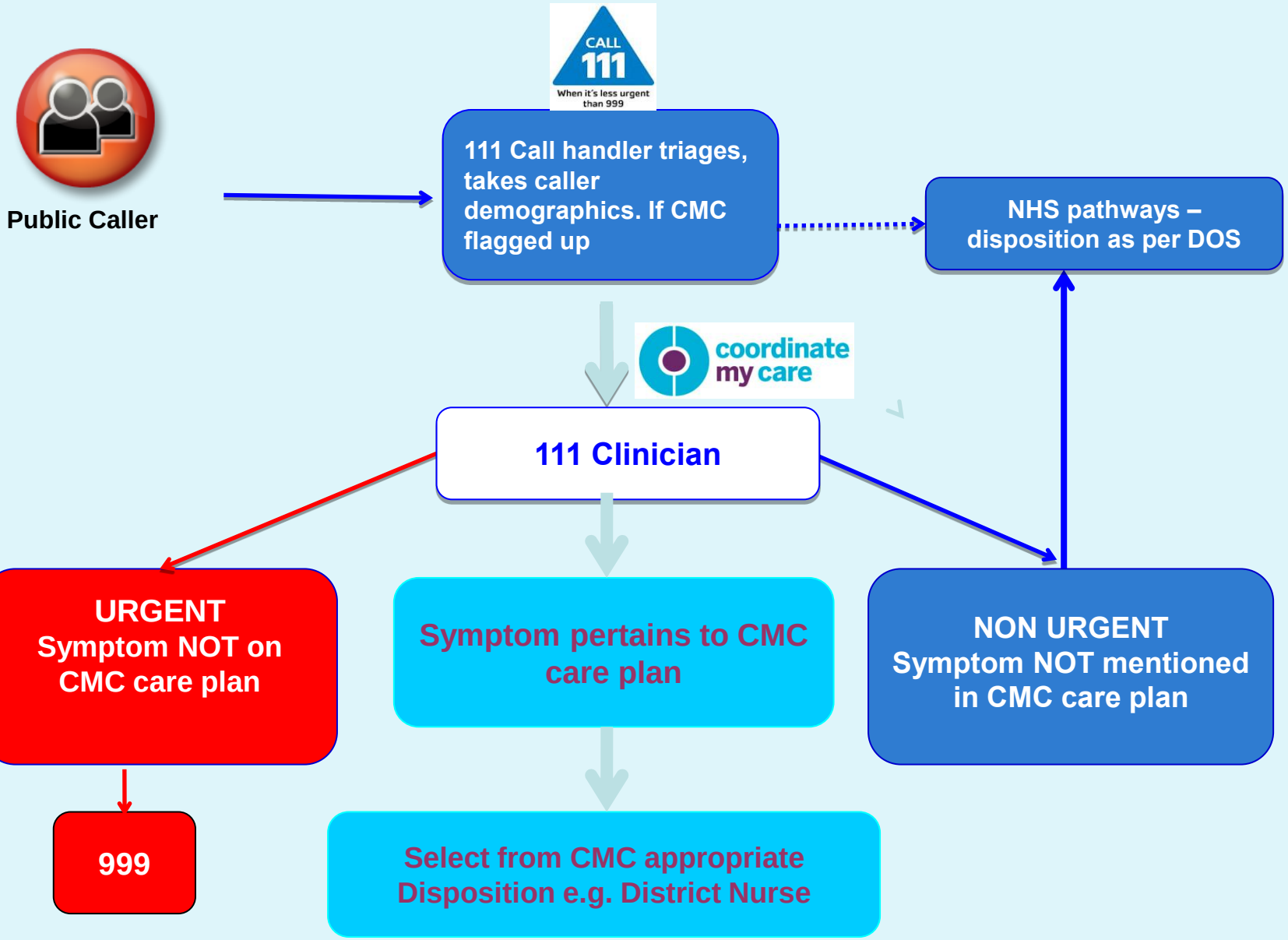
Coordinate My Care: Approach

Merton&Sutton


BT RiO Community System
Social service
GP OOH
GP Systems EMIS etc
Logistics
Integration Engine
Acute hospitals
Hospice systems (London)
CALL 111
when it's less urgent than 999
coordinate my care
Hosted by The ROYAL MARSDEN
Ambulance
Dept Health
NHS London
Comm-sioners
Providers

London NHS 111 Service Operating Model




Public Caller
CALL 111
When it's less urgent than 999
111 Call handler triages, takes caller demographics. If CMC flagged up
NHS pathways – disposition as per DOS
coordinate my care
111 Clinician
URGENT Symptom NOT on CMC care plan
Symptom pertains to CMC care plan
NON URGENT Symptom NOT mentioned in CMC care plan
999
Select from CMC appropriate Disposition e.g. District Nurse

George's story

June 2003

- wife/ main carer died
- moves in with son – dementia 'uncovered'
- Chooses to move home – fails to cope

October 2003

- Moves to sheltered housing, attends memory clinic

2004

- Starts to wonder at all times day and night
- Referral to social services – move to extra care sheltered housing service

February 2005

All care staff made aware that **George wishes** to end his life at home – no documentation

Son has enduring power of attorney, arranges finances and aware that George does not want to go to hospital

September 2008

Puts himself to bed, refuses to eat or drink

GP called – locum comes, care staff explain Georges wishes

Ambulance called, George admitted

Son arrives at hospital, expresses fathers wishes – no documentation - George admitted for 13 days

- Discharged with full continuing care (DS1500) Emergency Duty Team
- Died at home

Son's comment:

"George did not want a slow death, he did not want to be a burden to the State, did not want to tie up resources (bed, equipment, nurses) but he did want to die at home with the carers he knew. He got his final wish but at a cost to himself, his carers, his family and the State. All because there was no written, End of Life Care plan."

Places of identification

Health and Social Care

- Hospitals
- Hospices
- Care homes
- Nursing homes
- Residential home
- Home

Prior to George deteriorating:

George able to consent

George able to make decisions about his medical care

George able to make decision about his social care

George able to make decision about financial issues

George able to express a PPC and PPD

Question 1

Look for two or more **general** indicators

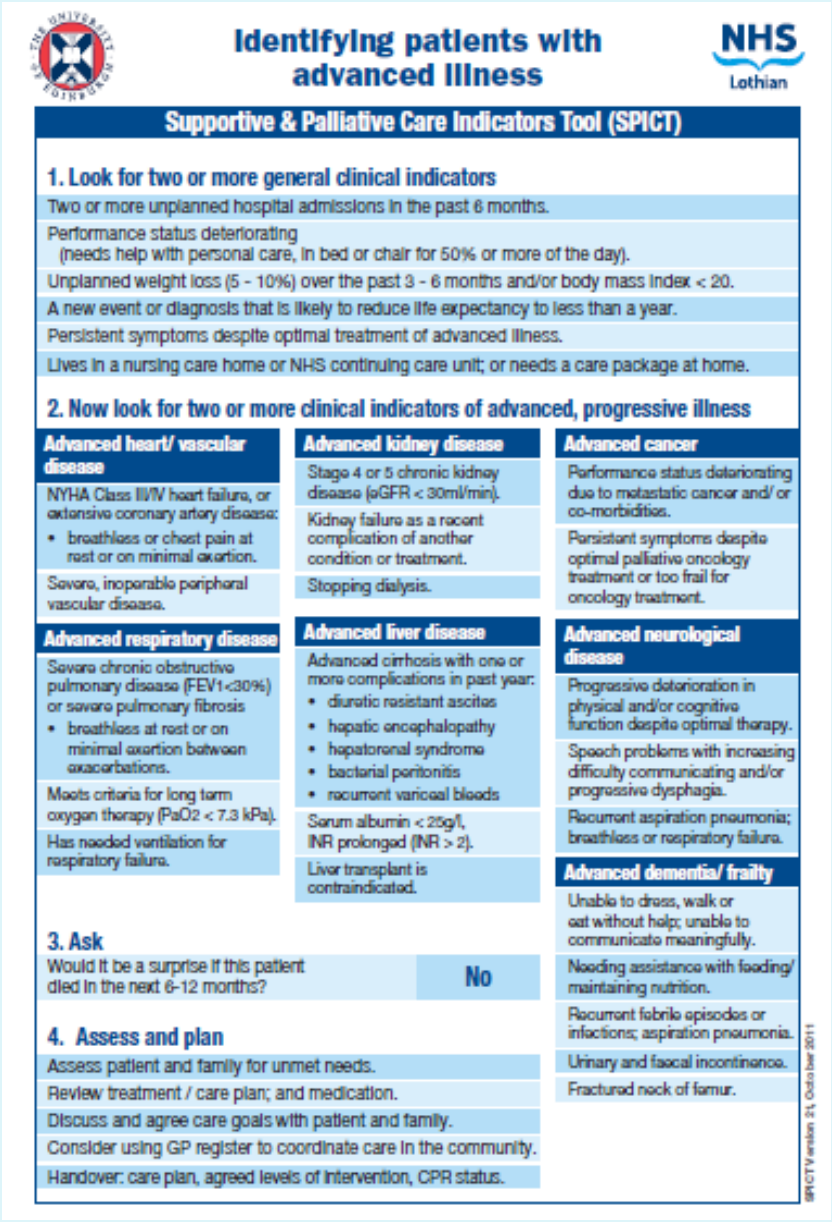
Question 2

Look for 2 or more **clinical** indicators of advanced or progressive disease

Question 3

Would it be a surprise if the patients died in **6 – 12 months**?

Assess and plan



Identifying patients with advanced illness

NHS Lothian

Supportive & Palliative Care Indicators Tool (SPICT)

1. Look for two or more general clinical indicators

- Two or more unplanned hospital admissions in the past 6 months.
- Performance status deteriorating (needs help with personal care, in bed or chair for 50% or more of the day).
- Unplanned weight loss (5 - 10%) over the past 3 - 6 months and/or body mass index < 20.
- A new event or diagnosis that is likely to reduce life expectancy to less than a year.
- Persistent symptoms despite optimal treatment of advanced illness.
- Lives in a nursing care home or NHS continuing care unit; or needs a care package at home.

2. Now look for two or more clinical indicators of advanced, progressive illness

Advanced heart/ vascular disease

- NYHA Class III/IV heart failure, or extensive coronary artery disease:
  - breathless or chest pain at rest or on minimal exertion.
- Severe, inoperable peripheral vascular disease.

Advanced respiratory disease

- Severe chronic obstructive pulmonary disease (FEV1<30%) or severe pulmonary fibrosis
  - breathless at rest or on minimal exertion between exacerbations.
- Meets criteria for long term oxygen therapy (PaO_2 < 7.3 kPa).
- Has needed ventilation for respiratory failure.

Advanced kidney disease

- Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min).
- Kidney failure as a recent complication of another condition or treatment.
- Stopping dialysis.

Advanced liver disease

- Advanced cirrhosis with one or more complications in past year:
  - diuretic resistant ascites
  - hepatic encephalopathy
  - hepatorenal syndrome
  - bacterial peritonitis
  - recurrent variceal bleeds
- Serum albumin < 25g/l, INR prolonged (INR > 2).
- Liver transplant is contraindicated.

Advanced cancer

- Performance status deteriorating due to metastatic cancer and/ or co-morbidities.
- Persistent symptoms despite optimal palliative oncology treatment or too frail for oncology treatment.

Advanced neurological disease

- Progressive deterioration in physical and/or cognitive function despite optimal therapy.
- Speech problems with increasing difficulty communicating and/or progressive dysphagia.
- Recurrent aspiration pneumonia; breathless or respiratory failure.

Advanced dementia/ frailty

- Unable to dress, walk or eat without help; unable to communicate meaningfully.
- Needing assistance with feeding/ maintaining nutrition.
- Recurrent febrile episodes or infections; aspiration pneumonia.
- Urinary and faecal incontinence.
- Fractured neck of femur.

3. Ask

Would it be a surprise if this patient died in the next 6-12 months? **No**

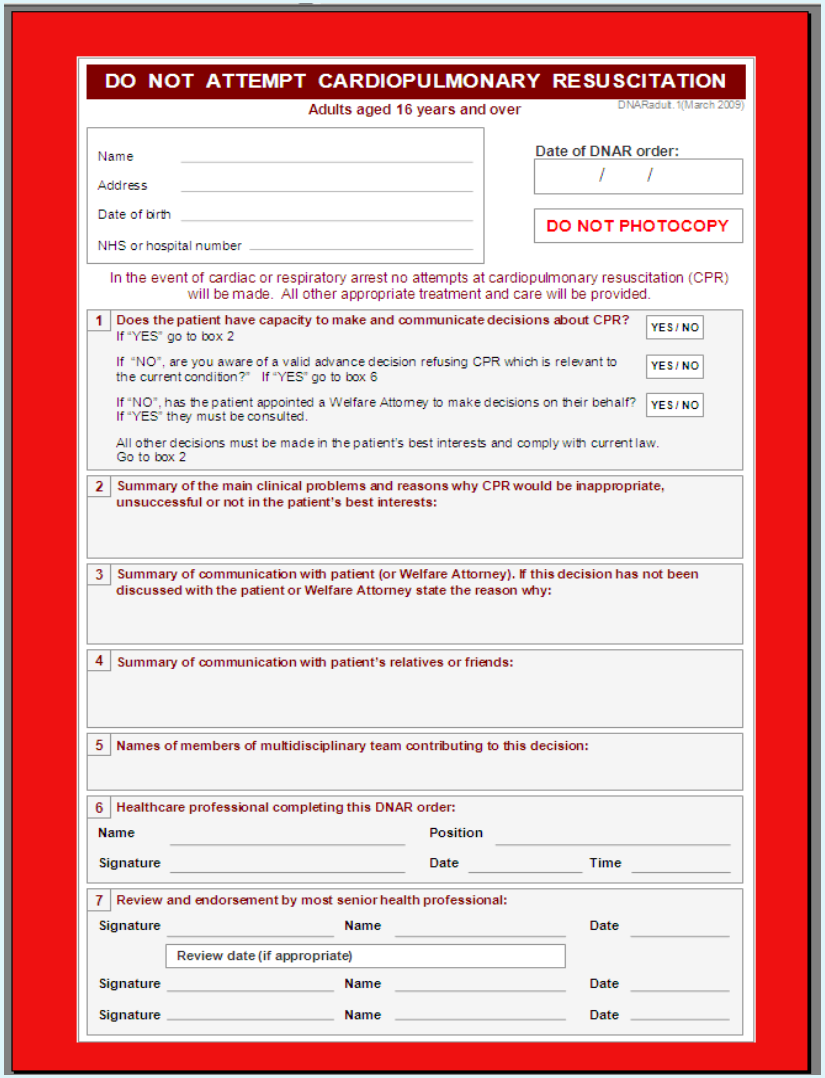
4. Assess and plan

- Assess patient and family for unmet needs.
- Review treatment / care plan; and medication.
- Discuss and agree care goals with patient and family.
- Consider using GP register to coordinate care in the community.
- Handover: care plan, agreed levels of intervention, CPR status.

SPICT Version 21, October 2011

Advance care plan

Personal preferences and choices for end of life care



DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION

Adults aged 16 years and over

DNARadult 1(March 2009)

Name

Address

Date of birth

NHS or hospital number

Date of DNAR order: / /

DO NOT PHOTOCOPY

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

1 Does the patient have capacity to make and communicate decisions about CPR? If "YES" go to box 2 — YES / NO

If "NO", are you aware of a valid advance decision refusing CPR which is relevant to the current condition? If "YES" go to box 6 — YES / NO

If "NO", has the patient appointed a Welfare Attorney to make decisions on their behalf? If "YES" they must be consulted. — YES / NO

All other decisions must be made in the patient's best interests and comply with current law. Go to box 2

2 Summary of the main clinical problems and reasons why CPR would be inappropriate, unsuccessful or not in the patient's best interests:

3 Summary of communication with patient (or Welfare Attorney). If this decision has not been discussed with the patient or Welfare Attorney state the reason why:

4 Summary of communication with patient's relatives or friends:

5 Names of members of multidisciplinary team contributing to this decision:

6 Healthcare professional completing this DNAR order:

Name Position

Signature Date Time

7 Review and endorsement by most senior health professional:

Signature Name Date

Review date (if appropriate)

Signature Name Date

Signature Name Date

Wishes executed…

- 111
- GP
- 999
- hospital

George

- Stayed at home
- Avoided 13 days in hospital
- Avoided CT scans and numerous investigations
- Avoided long protracted dying phase
- Avoided

ACHIEVED HIS WISHES…. “nothing about me without me”

Cost savings

- Ambulance journeys
- Hospital bed nights
- Investigations
- 24/7 care package
- Equipment

coordinate my care

A clinical service that coordinates care giving patients choice and improved quality of life

Thank you

To George and

His family