
Authority, Influence and Power engaging with the emerging End of Life Care Strategy

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End of Life Care Strategy

- The professional challenge – levers for change
- Context
- Scope and goals
- Challenges
 - Patient and carer perspective
 - Societal perspective
 - Service perspective
- Possible ways forward
- Next steps

Professional Challenge

- The genesis of patient and family centred care recognising the value, dignity and individuality of people during the last months of life has largely come from cancer care.
- The recognised discipline of palliative care was grafted within the cancer discipline and largely by nurses.
- Major cancer charities have made enormous contribution to the way people are cared for – Macmillan and Marie Curie ‘Nurses’
- Prominent nurse leaders in clinical, management, strategic, research and education

Professional challenge

- Cancer nurses have always pushed at the boundaries and are an articulate and powerful voice – spring board for clinical innovation and strategic influence
- The first clinical nurse specialist – breast and palliative care
- The professional debate on site specialism vs. palliative care
- Nurse led clinics
- Multiprofessional teams
- Equal place in teams at clinical, trust board, network and SHA- recognisable and accountable

Professional challenge

- NHS Cancer Plan (Calman-Hine)
- NHS Trust – Lead Nurse (managerial/advisory)
- Cancer Networks – Nurse Director
- Nurse Consultants
- Similar journeys and roles in other countries

Levers for success

- What have been the levers for success?
- Driving up standards – IOGs, Manual, Peer Review
- Climate for innovation – service configuration, patient pathways, patient partnership groups, information, communication, psychological, spiritual and emotional support
- Driving change across geographical areas – challenging and reviewing the location and function of services, ambassadors between NHS and VCS (social care)
- A voice and influence at each table.
- But now.....

Levers for change

- What structures do we now have?
- What are (will be) the levers of influence and change
- Structures and colleagues may have changed but you and your patients have not
- End of Life Care Strategy is an opportunity and familiar ground

Look back at achievements and forward with commitment and hope.

Mechanisms for implementation

- **Messages**

- Whole system integrated approach
- Challenging the local silo bound approach
- Partnerships – Networks – coordination
- Community Matrons
- White paper
- Role of information – tracking patient data

- **Structures**

- SHA level
- PCT (locality level)
- Provider level FT
- Third sector
- Payment by results
- Practice Based Commissioning

All against a background of financial constraint

End of Life Care Strategy - Context

- Government commitment to increase choice so more people die at home if that is their wish (2005)
- White Paper – ‘Our health, our care, our say’ (2006)
 - End of Life Care Networks
 - Rapid Response team
 - Hospice at home services
 - Extension of the current end of life programme
- End of Life Care Strategy announcement June 2006
- Investing in Community Hospitals (2006)
- The Healthcare Reform Agenda – strengthening commissioning (2006)
- Dignity and care for older people (2006)

Building on...

- NHS Cancer Plan (2000)
- District nurse programme (2001)
- £50m for specialist palliative care (2003)
- NSFs – CHD, Older People, LTCs, Renal, Diabetes, Children and young people, Musculoskeletal
- NICE Supportive and Palliative Guidance (2004)
- Building on existing End of Life Care programme(2003)
- Health Select Committee (2004)
- GMS contract QOF (2005)

Touchstone for future direction of travel – the personal perspective

Choice at the end of life - what does it mean what do I want?

- Personal preferences – flexibility – responsiveness
- Dignity and respect
- Time to plan or go in a ‘flash’
- To be with those who are close in comfortable and safe surroundings
- Home?
- Care home?
- Hospital side room?
- Dying with or without every effort made to prolong life.

What does a patient-led service *feel* like?

- Getting good treatment in a comfortable, caring and safe environment, delivered in a calm and reassuring way.
- Having information to make choices, to feel confident and to feel in control.
- Being talked to and listened to as an equal.
- Being treated with honesty, respect and dignity.

“Now I feel tall. What a patient-led NHS feels like”.

(December 2005)

What the public tell us

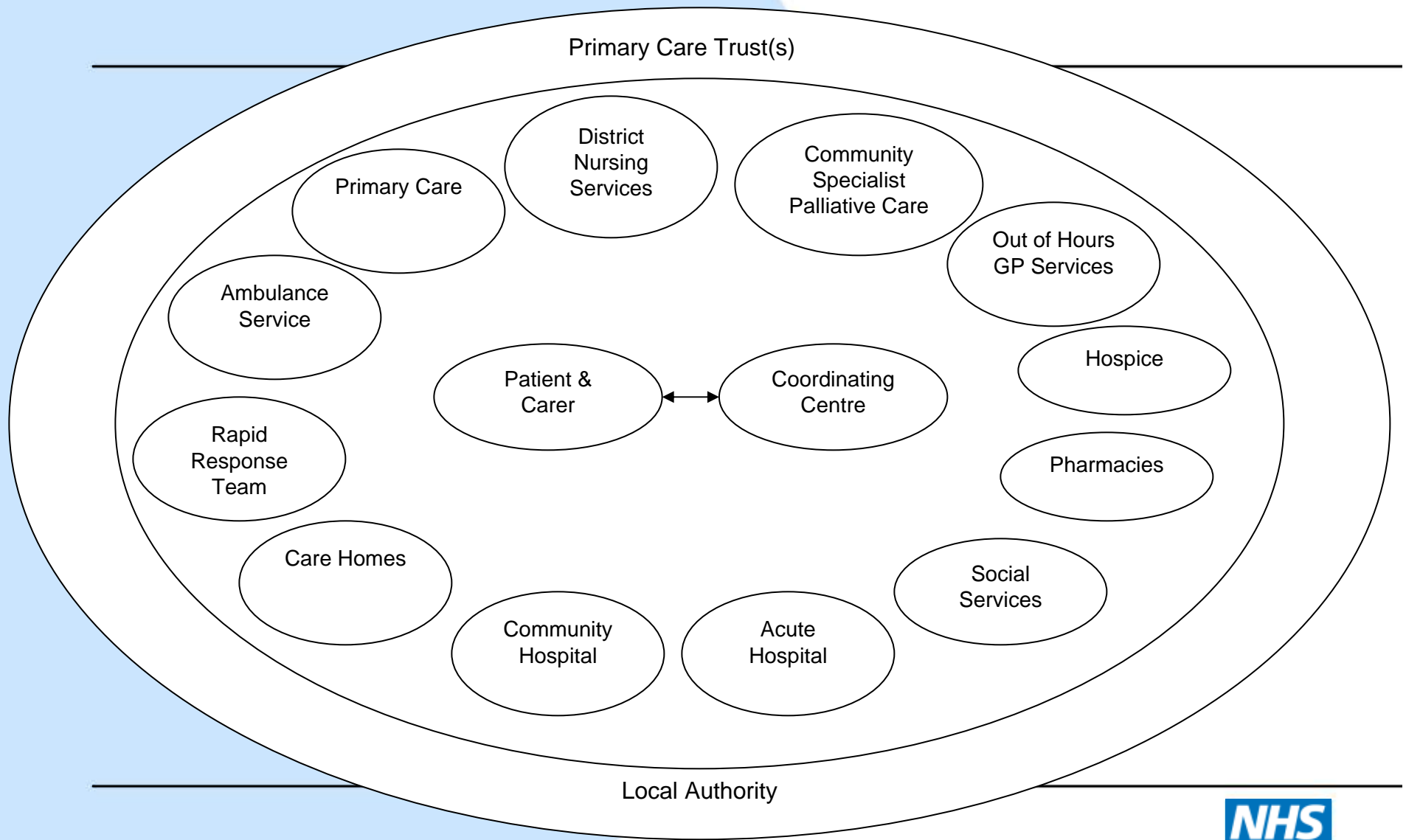
- Need to know how to find support
- Someone to help them navigate through system
- Feared admission – impersonal, felt anonymous
- Repeated asked the same questions by different staff
- Carers told of guilt when could no longer cope
- Needed to have their health and social care needs assessed regularly
- Doctor often reluctant to be open and honest about the ‘time that was left’

5 October 2006

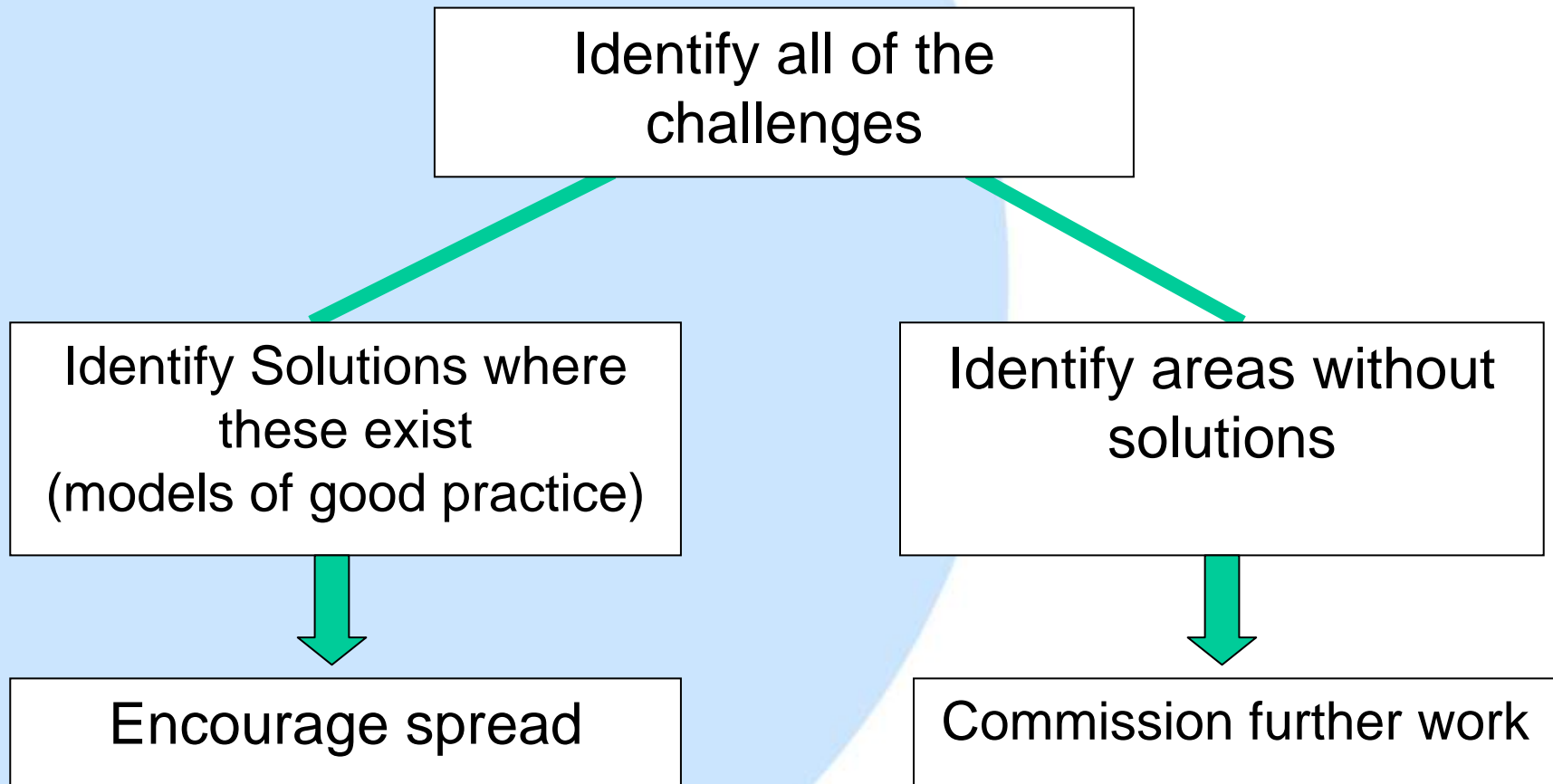
- June 2006: Development of strategy announced
- July 2006: Request for ideas and models of good practice
- 5 October: Synthesis, joint discussion
 - Identify areas of agreement / disagreement
 - Identify gaps where further work is needed

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- White Paper – ‘Our health, our care, our say’ (2006)
 - End of Life Care Networks
 - Rapid Response team
 - Hospice at home services
 - Extension of the current end of life programme

End of Life Care: Model for Coordination



The End of Life Care Strategy Broad Approach



The End of Life Care Strategy

Scope

- All diseases / conditions
- All locations (e.g. home, hospitals, care homes, hospices)
- Not children (parallel initiative)
- Not assisted suicide or voluntary euthanasia

Goals of End of Life Care

What should patients approaching the end of life be able to expect?

- Their care will be planned with them
- Services will be available without delay
- Services will be well coordinated
- They will be treated with humanity, dignity and respect at all times
- Their suffering will be minimised
- Their carers will be supported

Are these the right goals?

Challenges – patient and carer perspective

- Many receive good care – but many cancer patients
- Unmet need – which could be alleviated by expert assessment and intervention
- Patients' preferences are not elicited by health and social care
- Many do not die in place of choice
- Delay in accessing services or receiving support
- Avoidable admissions to hospital
- Carers not supported and needs not met during illness and after death
- Carers not able to stay with patient in hospital

Societal perspective

- Lack of familiarity with death and dying
- Death is not a topical subject with the public or media
- Death-denying society – personal control
- Illness or the effects of ageing are not accepted as part of living
- Planning for death is an uncomfortable concept
- Only minority discuss death with loved one

Challenges: Service Perspective

- Multiple challenges have been identified (around 50)
- These have been grouped under 20 headings, though there is inevitably some overlap (e.g. training)
- What have we missed?

Challenges: Service Perspective

1. Profile
2. Service Planning
3. Care Planning
4. Care Coordination
5. Community Services
6. Care Homes
7. Primary Care
8. Community Hospitals
9. Acute Hospitals
10. Social Services
11. Hospices & SPCs
12. Last few days
13. Management after death
14. Informal carers
15. Specific groups
16. Training
17. Information
18. Measurement
19. Standards
20. Commissioning

Possible Ways Forward

1. Raising the profile

- This strategy
- Engaging PCTs / LAs / Providers / Clinicians
- Engaging the public

2. Service Planning

- Networks / partnerships

3. Individual Care Planning

- Entry onto the care pathway = Difficult
- The 'surprise' question?
- Clinical indicators?
- Advance care planning

Possible Ways Forward

4. Individual Care Coordination

- Registers
- Coordination Centres
- Dedicated helplines

5. Community services

- Rapid response teams
- Ongoing support
- Drugs
- Equipment

Possible Ways Forward

6. Care homes
 - GSF / LCP
 - Partnerships with hospices

7. Primary Care
 - GSF
 - OoH Services

8. Community Hospitals
 - An opportunity

Possible Ways Forward

9. Acute Hospitals
 - Specialist palliative care services
 - LCP
 - Discharge services
10. Social Services
 - Engagement
 - Integration

Possible Ways Forward

11. Hospices and SPCs
 - Apex of service delivery
 - How can they best be used?

12. Last few days of life
 - LCP

Possible Ways Forward

13. Management after death
 - Models of good practice?

14. Informal Carers
 - Training?
 - Support?

15. Specific groups
 - Models of good practice?

Possible Ways Forward

16. Training

- GSF / LCP / PPC
- Communication skills?

17. Information and navigation

- Leaflets
- Dissemination

Possible Ways Forward

18. Measurement of quality
 - Establish a subgroup?

19. Standards
 - Defer until later?

20. Commissioning
 - Commission guide?
 - Action plans?
 - Joint commissioning?

The End of Life Care Strategy

We need to consider both

- 'What' needs to be done?

and

- 'How' can we drive change in health and social care?

i.e. What are the 'levers for change' Choice, PBRs, stronger commissioning etc

The next steps

Ongoing workstreams

- Entry points to the end of life care pathway
- Measurement
- Funding
- Training
- Social Services
- Report back to Ministers

