Palliative Care:
How can we make a difference?

Annual Conference 2009

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Make a difference to the majority of people with palliative care needs: people with non-malignant conditions

Jacquelyn Chaplin:
Project Manager: Palliative care for people with non malignant conditions

Aims

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- To discuss how we can make a difference when we meet the palliative care needs of people with non malignant conditions
- Discuss the importance of assessment of need at a
  - strategic level
  - a local level
  - and an individual patient level

Influences

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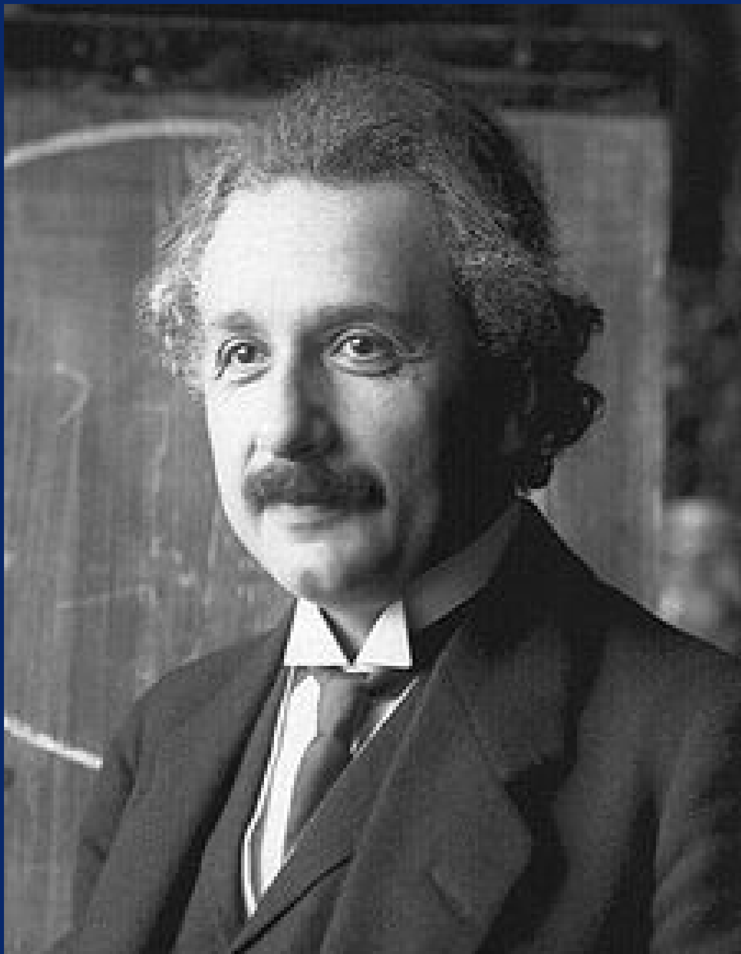

Remember the origins of palliative care – comfort and caring

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- Sensitivity to individual need
- Not just about symptom management
- Value each patient as a unique human being who requires our care and compassion –holistic approach
- Sharing the journey- engaging with people at a human level
- Charismatic leadership
- A spirit of curiosity and discovery

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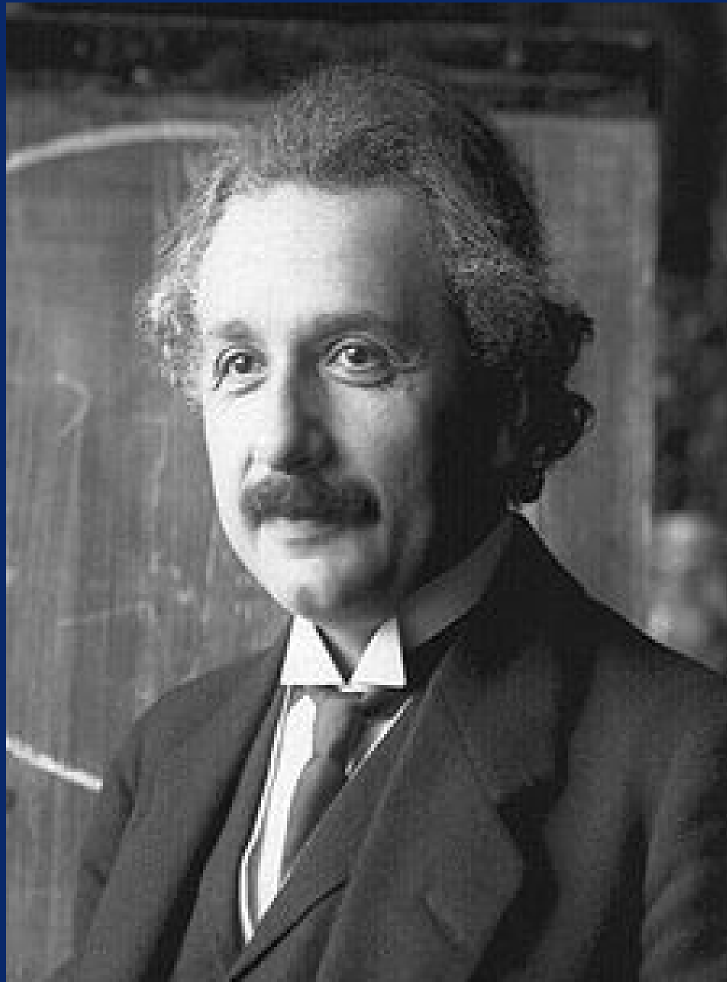
Albert Enstein ….



- Learn from yesterday
- Live for today
- Hope for tomorrow

Non malignant conditions - palliative care needs may be different and different at different times

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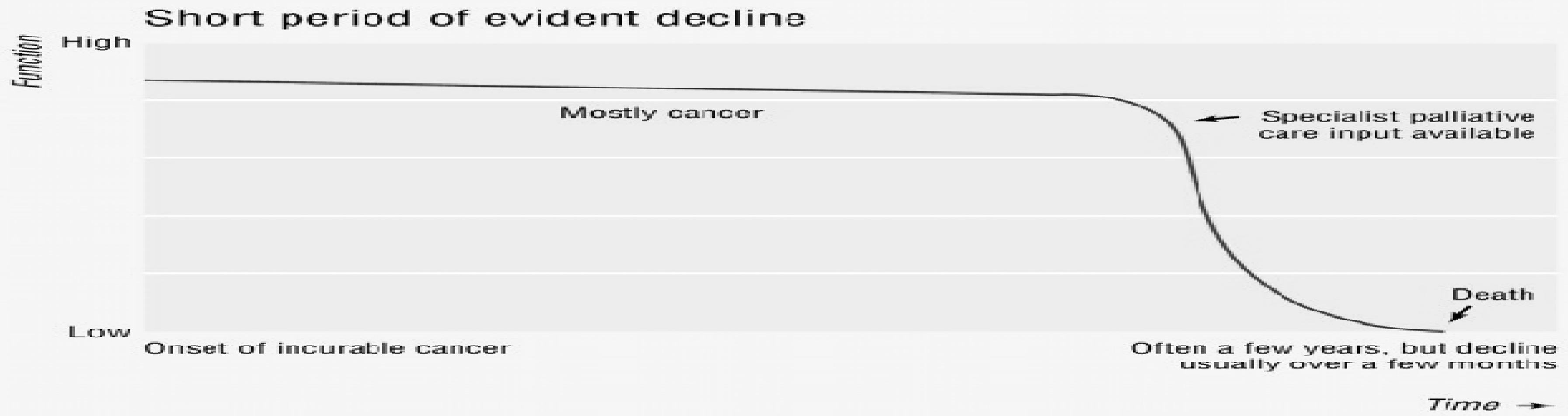
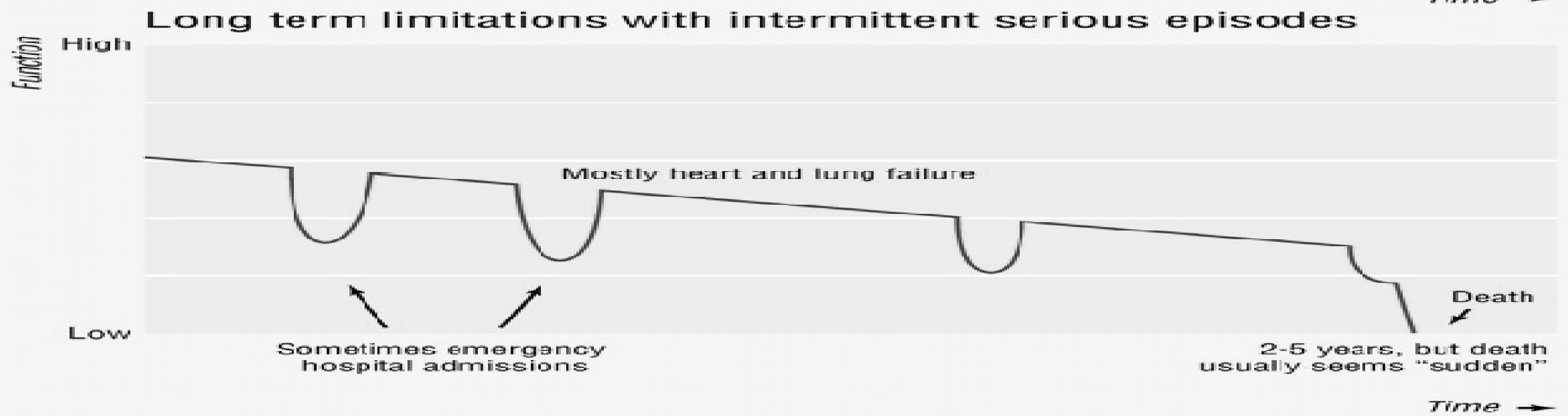
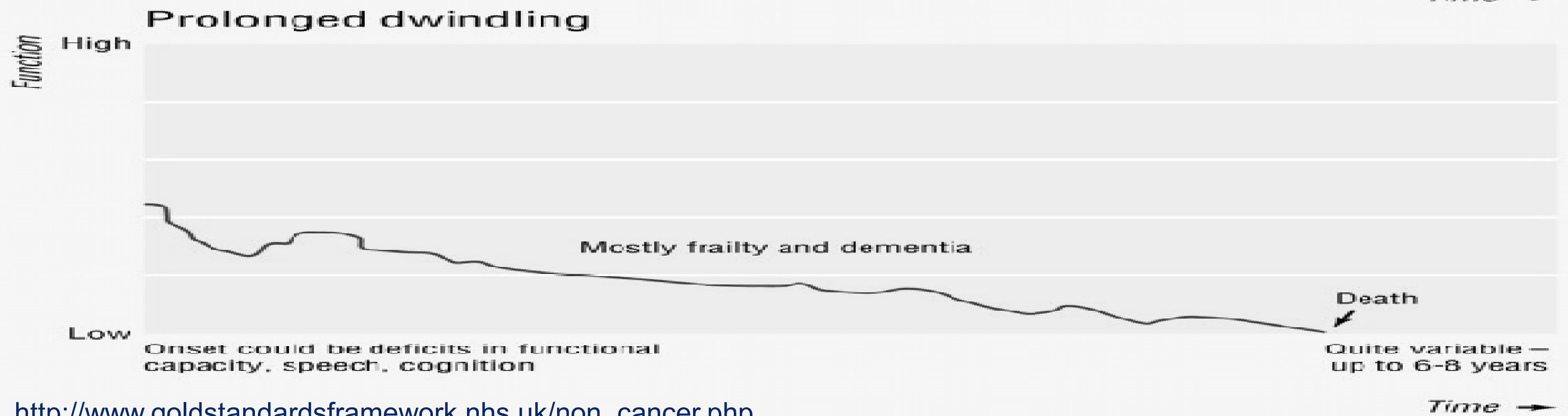
- Chronic Lung Disease
- Cystic Fibrosis
- Dementia
- Heart failure
- HIV/AIDS
- Huntington's Disease
- Motor Neurone Disease
- Multiple Sclerosis
- Muscular Dystrophy
- Parkinson's Disease
- Rheumatoid Arthritis
- Renal Failure
- Frail elderly with multiple co-morbidities
- Liver Disease
- Young Physically Disabled
- Cerebrovascular Disease
- Peripheral Vascular Disease

NB This list is not exhaustive







http://www.goldstandardsframework.nhs.uk/non_cancer.php

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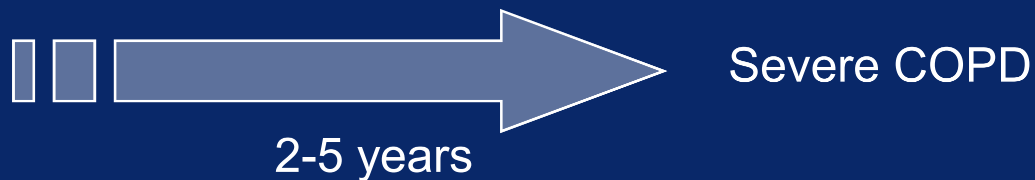
Different timescales



Identifying palliative care needs of people with non malignant conditions – at a population level

Multi-dimensional approach

- Population based – analysis of epidemiological, demographic and socio-economic factors
- Comparative dimension – looking at relative need for cancer and non cancer related palliative care
- Stakeholder dimension – views of patients, carers, professionals and members of general public

Tebbit, P. (2004) *Population – Based Needs Assessment for Palliative Care* London. National Council for Hospice and Specialist Palliative Care Services

Higginson I. et al (2007) Needs assessment in palliative care: An appraisal of definitions and approaches used. *Journal of Pain and Symptom Management.* 33 (5). 500-505

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Annual incidence of deaths and deaths per 100,000 population from cancer, non-cancer deaths and deaths from all causes by Health Boards and Scotland

Health Board	Population	*Annual Incidence Cancer Deaths	Cancer Deaths per 100,000 Population	*Annual Incidence Non Cancer Deaths	Non Cancer Deaths per 100,000 Population	*Annual Incidence All Deaths	*All Deaths per 100,000 Population
Ayrshire & Arran	367590	1,137	309	3,253	885	4390	1194
Borders	109270	347	318	938	858	1285	1176
Dumfries & Galloway	147930	505	341	1,321	893	1826	1234
Fife	354600	1,072	302	2,746	774	3818	1077
Forth Valley	282070	786	279	2,212	784	2999	1063
GG & C	1192256	3774	317	10153	852	13927	1168
Grampian	524020	1,460	279	3,835	732	5295	1010
Highland	302530	948	313	2,530	836	3478	1150
Lanarkshire	628200	1,619	258	4,416	703	6035	961
Lothian	787700	2,085	265	5,411	687	7496	952
Orkney	19500	70	361	167	855	237	1215
Scotland	5100000	15274	299	40334	794	55608	1090
Shetland	21940	49	222	159	725	208	947
Tayside	387950	1,248	322	3,231	833	4479	1155
Western Isles	26260	95	**360**	256	976	351	1337

Data source: GRO (Scotland) – * Figures represent average for 6 years 2003-2008   2008 Figures are provisional.

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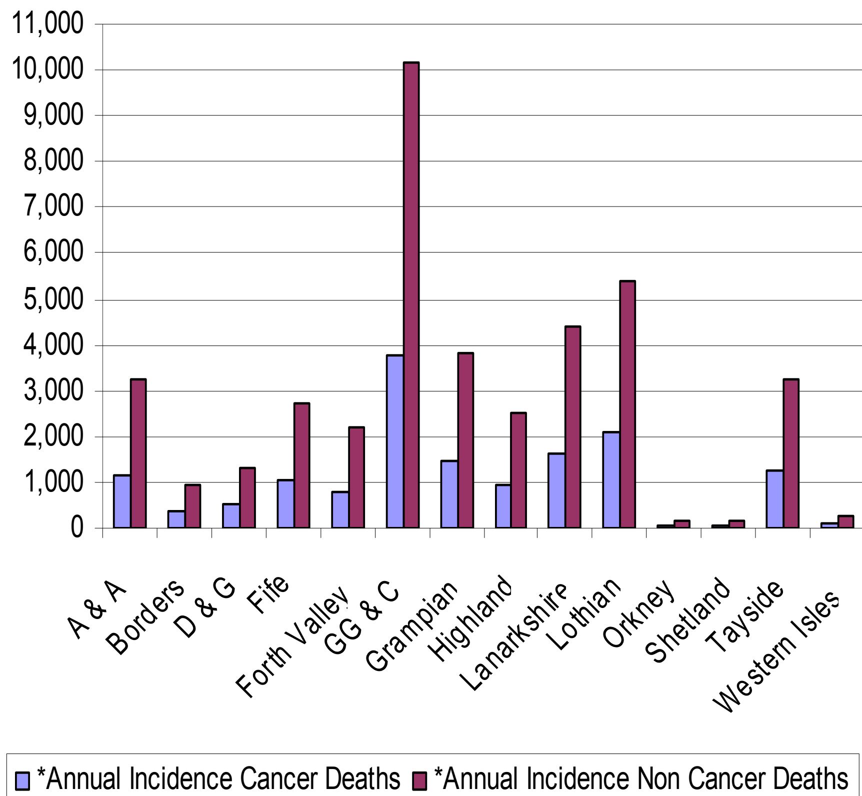
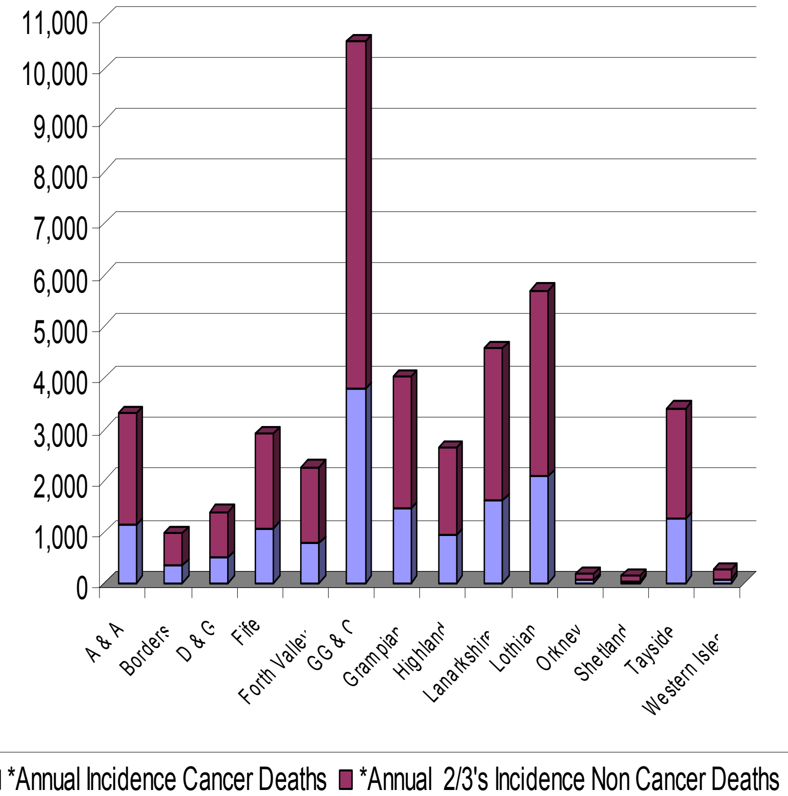
Cancer and non cancer deaths



Estimates of number of people with palliative care needs



Symptom estimates

Cancer – 84% pain, 47% breathing difficulties, 38% depression

Non cancer - 67% pain, 49% breathing difficulties, 36% depression (Cartwright, 1991; Koffman et al , 2008)

Causes of death NHS Greater Glasgow and Clyde

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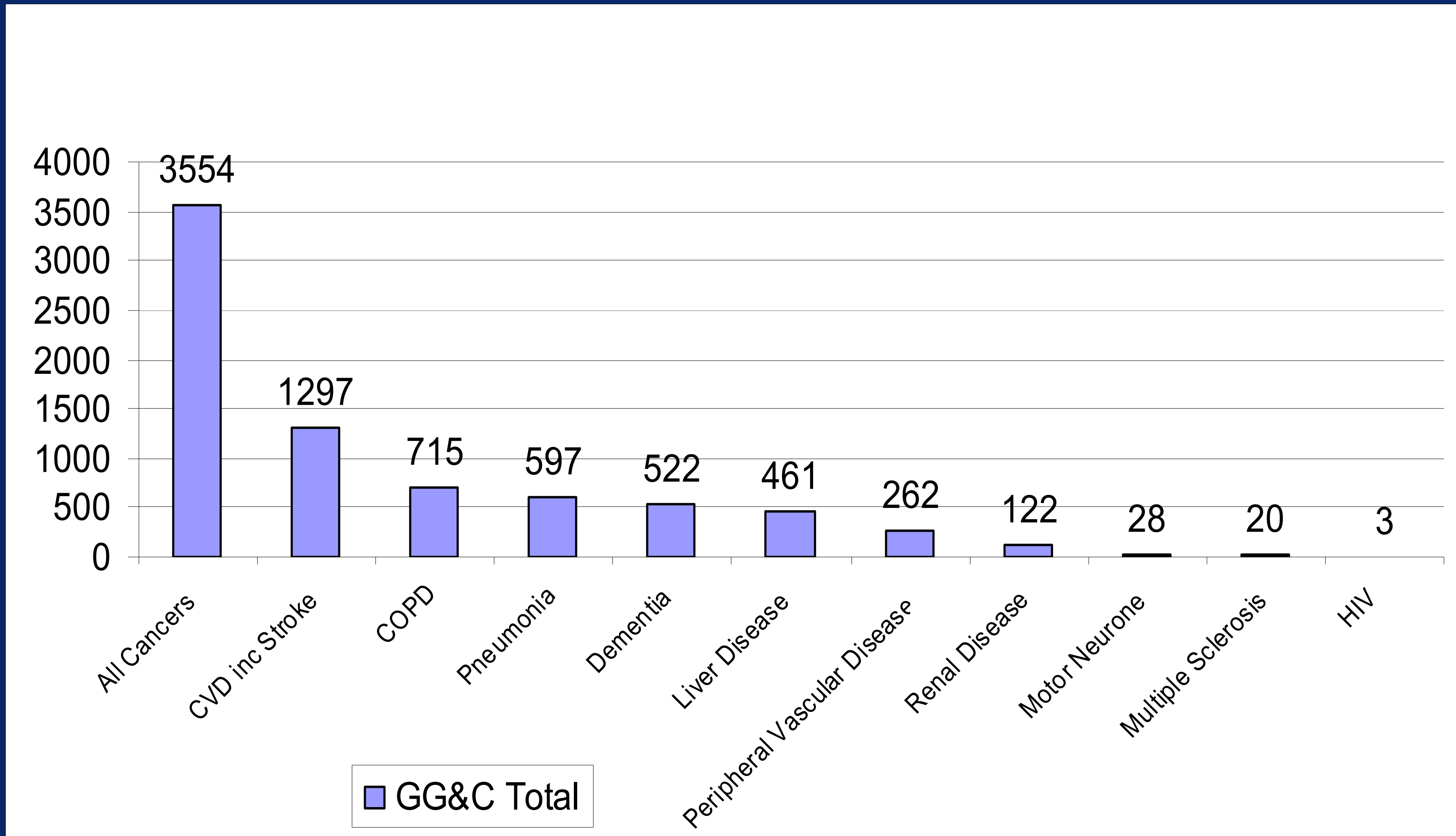

Source : GRO (S) Annual Mortality Data 5 year average 2003-2007

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Place of death – NHS GGC			
Place of death	Preferred place of death*	Actual place of death cancer NHS GGC	Actual place of death – non cancer NHS GGC
Hospital	11%	49%	61%
Care Home	4%	6%	15%
Hospice	24%	21%	1%
Home	56%	23%	23%

*Data Source: Priorities and Preferences for End of Life Care in England, Wales and Scotland, National Council for Hospice and Specialist Palliative Care Services (2003)

Data source: GRO (Scotland) – Figures represent average for 6 years 2003-2008. 2008 Figures are provisional.

Complexities of preferences regarding place of care and place of death and advance care planning

- Most data relate to people with cancer
- Preference re place of care is different from preference re place of death
- Differences between preference of patient and preference of family carer
- Changes in preferences over time
- Dying at home not as important as other factors e.g. freedom from pain, not dying alone, dignity and respect
- What is the optimum way and time(s) when preferences should be elicited, and by whom – recognise that not talking about death is a way of coping for some people
- Variable access to services
- Ethical issues of asking patients their preferences and not having the resources available locally to achieve that preference

(Steinhauser et al, 2000; Grande et al, 2003; Thomas et al, 2004; Gott et al, 2004; Brazil et al, 2005; Clayton et al, 2005; Taylor, 2006; Gomez and Higginson, 2006; Barclay and Arthur, 2008; Costantini, 2008; Grande and Ewing, 2008).

Palliative care needs at a local level

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- Relative needs within a local area need to be considered – variations in life expectancy, deprivation, key health issues
- Identify local priorities and address these via disease specific planning groups/ Managed Care Networks, local strategies, collaborative approach
- Deprivation – areas of intense deprivation may require up to twice the community palliative care resources needed elsewhere
- Recognising that many people will continue to die in hospital and therefore the quality of palliative care in hospital is very important
- Recognising and planning the contribution of hospital palliative care teams - the structure and composition of hospital palliative care teams should take account of - number of beds, in patient episodes of care and number of deaths

(Clark, 1997; Soni et al, 1997; Higginson & Jarman, 1997; Koffman, Harding & Higginson, 2008; Morrison, 2008)

Different conditions – different models

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Model of palliative care for frail elderly people and those with dementia

- **Big question** whether as a society we ensure that our older citizens receive the palliative care services and care that they require?
  - Frail elderly especially those with multiple co-morbidities – 'surprise question' is of questionable value
  - Recognise some elderly people fear what will happen to them at the end of life especially those who live alone – influences need
  - Dying at home Is not always a priority – living at home independently as long as possible may be
  - The key - identify changing palliative care needs - respond appropriately including planning ahead - results in good care – regardless of how close to the end of their life the person is
  - Dementia – needs for advance care planning years in advance of palliative care need
  - Most people with dementia die in care homes – as a priority - support care homes to recognise changing need and respond appropriately
  - Ensure excellent care in last days of life in all care settings – e.g Liverpool Care Pathway for the Dying supported by appropriate education and training

(Gott, 2004; Gomes and Higginson, 2008; Grande et al, 2006 ;Gott, 2008; Barnes et al 2008; Scottish Commission for the Regulation of Care, 2009)

Different conditions – different models

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Model of palliative care for people with chronic lung disease and/or heart failure organ failure

- Identification of changing need – whole system approach - primary care, acute services, disease specific CNS's, specialist palliative care
- Recognition that palliative care needs may be intermittent – need an intermittent model of intervention that can be withdrawn if no longer required
- Ensure system in place to identify changing palliative care needs - key role of Clinical Nurse Specialists
- When admitted to hospital - at every admission reviewed by a consultant who knows them
- Focused specialist palliative care interventions to enhance quality of life e.g. breathlessness and fatigue management, information re financial support, complementary therapies etc
- Excellent care in last days of life

(Gott, 2004; Gott, et al 2007; Grande et al, 2006 ;Gott, 2008; Barnes et al 2008; Glare et al, 2008)

Different conditions – different models

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Model of palliative care for people with long term relapsing debilitating illnesses e.g. muscular dystrophy, cystic fibrosis, multiple sclerosis

- Recognition that palliative care needs may be intermittent
- May need focused specialist palliative care interventions to enhance quality of life – pain management, breathlessness management, day services, focused services e.g. for young adults
- May also need intermittent respite services, carer support, bereavement support etc
- Excellent care in last days of life and ongoing support for families

Hope for the future

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Dual approach

- Focus on specific diseases – across care boundaries – share successes
  - Chronic Lung Disease
  - Heart Failure
  - Cardiovascular disease
  - Liver disease
- Focus on frail elderly/ dementia – complexities of multiple disease processes
  - Home
  - Care homes
  - Hospital
    - acute,
    - medicine for the elderly
    - elderly psychiatry

- Recognising the key role of primary care team
- Collaborative working
  - Co-ordination across care settings
- Building on what works
  - Gold Standards Framework
  - Advance care planning
  - Symptom management
  - Liverpool Care Pathway for the Dying
- Working on issues that are pertinent to high quality palliative care- regardless of diagnosis
  - Out of Hours
  - Respite
  - Carer support
  - Nursing / social care integration
  - Bereavement support
  - Access to complementary therapies

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Hope for the future…

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- In the community – GP and District Nurse are key –
  - Integration of nursing and social care for people with palliative care needs
  - Integration of out of hours services
- In care homes – recognition of changing need, proactive planning
- In hospital setting
  - Supporting care with dignity, respect and compassion
  - Clinical leadership of charge nurse in relation to palliative care
  - Education of all staff - holistic approach
- In hospices
  - Educative consultative role
  - Care giving role
  - Out of hours support

In summary

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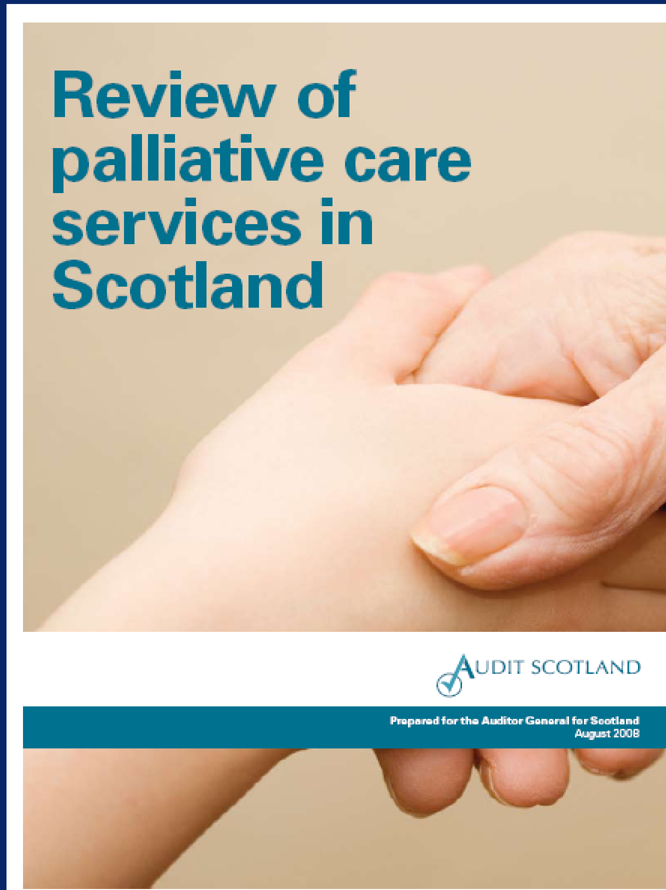
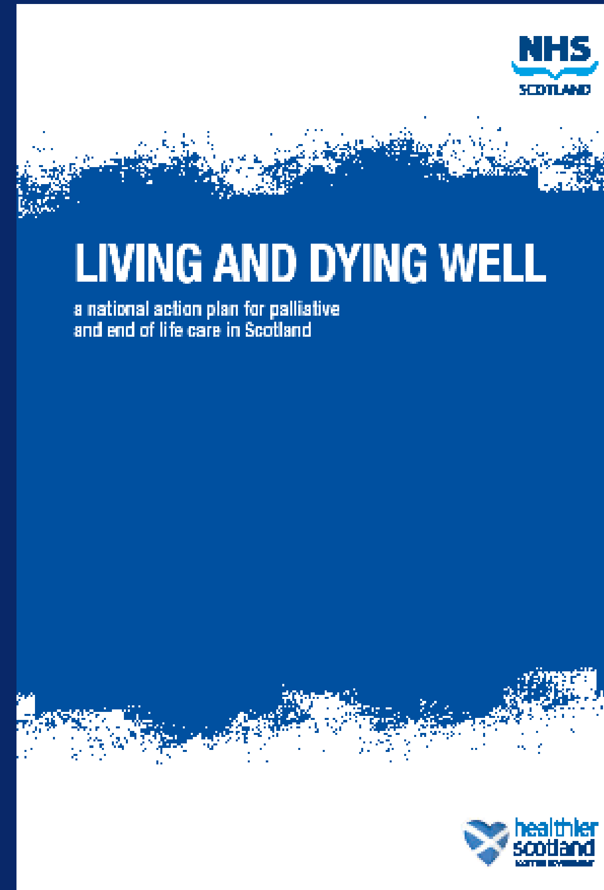
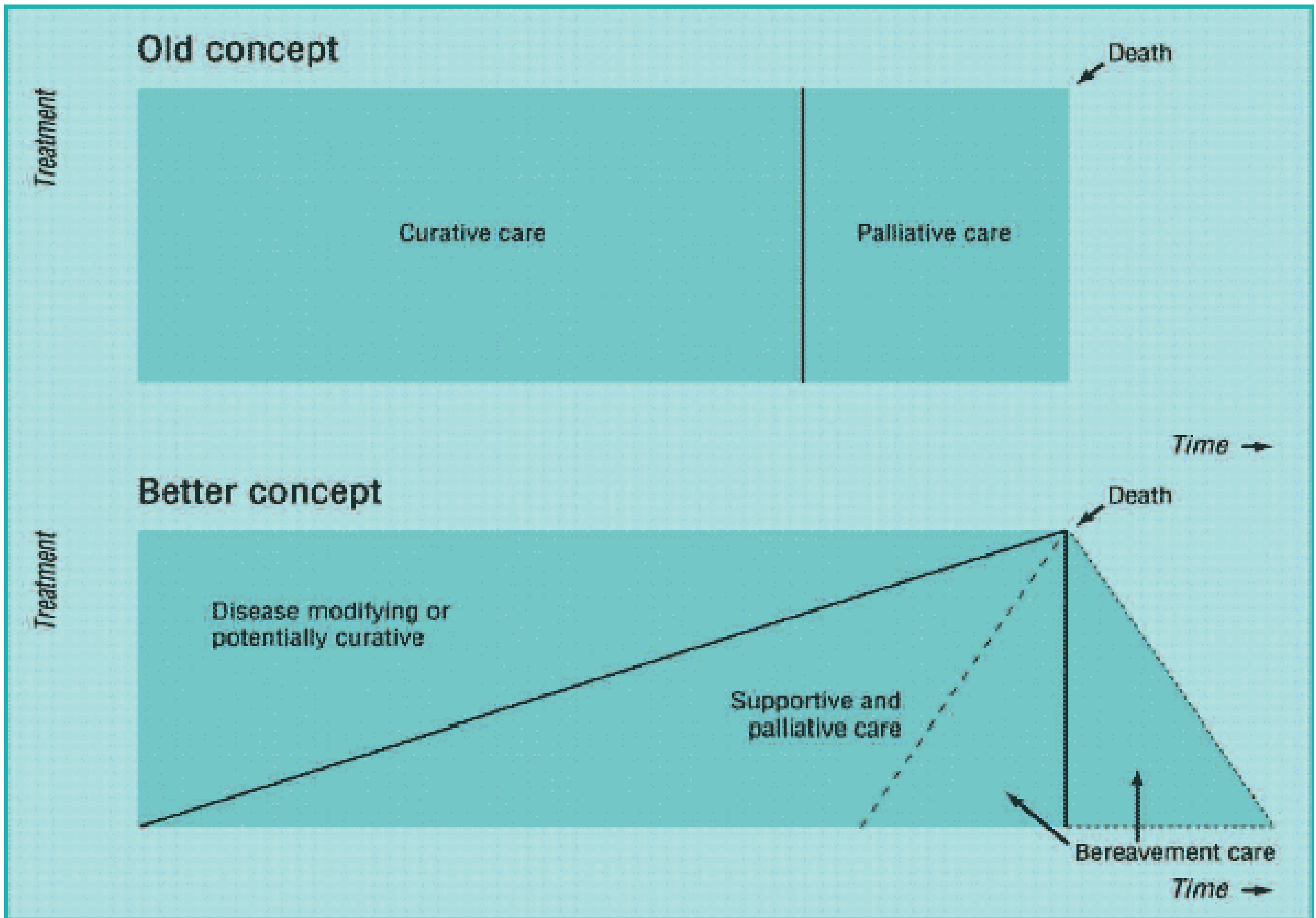
- Strategic level
  - assessment of population need
  - integration with long term conditions and disease specific strategies, guidelines etc - included in ‘Gaun Yersel’, SIGN Heart Failure and NHS QiS Clinical Standards for COPD
  - palliative care not included in
    - SIGN 108 Management of patients with Stroke
    - SIGN 89 Peripheral arterial disease
    - SIGN 86 Management of patients with Dementia
- At a local level
  - ensuring local disease specific strategic plans and implementation plans include palliative care
  - ensuring access to local services meets local need
- At an individual level – accepting uncertainty – palliative care
  - Not about prognosis, time or length of survival
  - Recognising changing need, the speed of that change and responding to that and anticipating what may happen next
  - Person centred holistic compassionate care – we are more than ‘flesh and blood’

Hope for the future







Murray S, Kendall M, Boyd K and Sheikh A. Illness trajectories and palliative care. BMJ 2005 4; 330; 1007-1011 doi:10.1136/bmj.330.7498.1007 (adapted from Lynn and Adamson 2003).

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‘You matter because you are you and you matter until the last moment of your life.

We will do all you can not only to help you die peacefully but also to live until you die.’

Foreword: Oxford Textbook of Palliative Medicine (1996)

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Make a difference to the majority of people with palliative care needs: people with non-malignant conditions

Jacquelyn Chaplin:
Project Manager: Palliative care for people with non malignant conditions