Northern Ireland Hospice

Quality, Quantity or Both in End of Life Care

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Quality, Quantity or Both in End of Life Care

Can Natural Death Be Achieved Fairly?

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Can Natural Death Be Achieved Fairly?

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- Background – The Quality / Quantity Spectrum
- Quantity- The Numbers
- Quality – The Markers
- Beyond Numbers and Markers The Essential PLUS

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The Quality Quantity Spectrum
What would you do?

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The Quality Quantity Spectrum
What would you do?

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Better to have something than nothing, or is it?

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Quality or Quantity In End of Life Care, A Spectrum…

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Daily Telegraph September 3, 2009

Dying patients
A group of experts who care for the terminally ill, claim that some patients are being wrongly judged as close to death.

SIR – The Patients Association has done well to expose the poor treatment of elderly patients in some parts of the NHS (report, August 27). We would like to draw attention to the new "gold standard" treatment of those categorised as "dying". Forecasting death is an inexact science.

Just as, in the financial world, so-called algorithmic banking has caused problems by blindly following a computer model, so a similar tick-box approach to the management of death is causing a national crisis in care.

The Government is rolling out a new treatment pattern of palliative care into hospitals, nursing and residential homes. It is based on experience in a Liverpool hospice. If you tick all the right boxes in the Liverpool Care Pathway, the inevitable outcome of the consequent treatment is death.

As a result, a nationwide wave of discontent is building up, as family and friends witness the denial of fluids and food to patients. Syringe drivers are being used to give continuous terminal sedation, without regard to the fact that the diagnosis could be wrong.

It is disturbing that in the year 2007-2008, 16.5 per cent of deaths came about after terminal sedation. Experienced doctors know that sometimes, when all but essential drugs are stopped, "dying" patients get better.

P. H. Millard, Emeritus Professor of Geriatrics University of London
Dr Anthony Cole, Chairman, Medical Ethics Alliance
Dr Peter Hargreaves, Consultant in Palliative Medicine
Dr David Hill, Fellow of the Faculty of Anaesthetists of the Royal College of Surgeons
Dr Elizabeth Negus, Lecturer, Barking University
Dowager Lady Salisbury, Chairman, Choose Life

Numbers

- In Ireland 44,000 deaths (30,000 and 14,000)
- Currently around 60% of all deaths occur in hospital
- Only 20% of deaths occur at home with a further 20% in care homes.
- Nearly two thirds of all deaths occur in people over the age of 75 years.
- Currently 95% of referrals to specialist palliative care services are for people with cancer.

NUMBERS

Source: Government Actuary Department 2004-based Projections for the UK

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NUMBERS

Source: Government Actuary Department 2004-based Projections for the UK

Projected Births and deaths, United Kingdom, 1951-207

The Future, UK P

1100
1000
900
800
700
600
500
400

1951
1971
1991
2011
2031
2051
2071

Year

Deaths

Births

-8%%

+17%

SWINE FLU
NOT A 17% INCREASE!

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Study of End of Life Care

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- National Audit Office
- Report Published 26th November, 2008

Census of:

Primary Care Trusts – 93% response rate (141/152)*

Independent Hospices - 67% response rate (104/155)*

NHS Hospices – 60% (24/40)

Doctors – 1,140*

Nurses -181*

Care Homes 134/1,410 sampled*

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High Level Findings

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- Some people receive high levels of care but many do not – with many aspects not meeting basic needs on dignity and respect.
- Gap between preferred and actual place of death (between 56 and 74 % prefer to die at home) vs 58% in a hospital setting (range 46 – 77% across PCTs) – also varies by age and condition – cancer patients more likely to die at home or in a hospice, over half of deaths from dementia occur in care homes.
- **BUT** Proportion of cancer patients expressing a preference for home care decreases as death approaches (from 90% to 50%) replaced by a preference for hospice care (from 10 to 40%) - 94% of all hospice deaths are patients with cancer.
- Wide variations between care homes in number who die in hospital, (none to all residents).

High Level Findings

- A lack of prompt access to services in the community leads to people being unnecessarily admitted to hospital
- Cancer patients account for 27% of deaths yet are majority of patients receiving specialist palliative care and get active case management.
- Over 70% of PCTs identify the greatest un-met need as people with diagnoses other than cancer.
- Not all carers receive the assessment they are entitled to (only 29% PCTs provide such assessments as standard), and respite care is not available in all PCTs and where it is, it varies widely.
- There is a lack of pre-registration training for nurses and doctors in end of life care (only 29% doctors and 18% nurses), but training in the national tools, LCP GSF
- (

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RESULTS
Cancer

No estimates of full costs of EOLC – estimated PCT spend on specialist palliative care £245 million in 2006-07, but wide variation in spend per PCT per death (£154 to £1,684)

- The cost of care in the last year of life to the nearly 127,000 who died from cancer was approximately £1.8 billion, or £14,236 per patient.
  - hospital = £4128 (£222 per day)
  - hospice = £464 (£132 per day of costs paid by the state)
  - home = £9644 (£28 per day of costs paid by the state)

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Results
Organ Failure

- In 2006 the average organ failure (heart and respiratory diseases) patient had 3 emergency admissions,
- Spent:
  - 40 days in hospital;
  - 0.1 day in hospice; and
  - and the remainder in the community
- The cost of care in the last year of life to the 30,000 who died from organ failure was approximately £553 million, or £18,771 per patient.
  - hospital = £9,665 (£222 per day)
  - hospice = £8 (£132 per day of costs paid by the state)
  - home = £9,068 (£28 per day of costs paid by the state)

Achieving reductions in hospital utilisation

- Reducing admissions requires services to respond quickly to needs 24/7 – (There are a number of service models but few 24/7)

- Reducing average Length Of Stay requires effective and timely discharge arrangements involving multiple agencies with appropriate packages of care.

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- Baseline 2008 data supplied by 43 participating hospitals (24 acute, 19 community).
- Across the two sectors there were just 15% single rooms and bed occupancy was 93%.
- Staff turnover is 15% in acute hospitals and 14% in community hospitals, and the rate of absenteeism is 6% in the acute sector and 5% in the community sector.
- 92% of acute hospitals have a palliative care service but most community hospitals (68%) do not.
- Complaints about end-of-life care seem to represent a relatively small proportion of total complaints in acute hospitals (2.7%)

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- 42% of acute hospitals and 16% of community hospitals do not have written policies, procedures, objectives or targets on end-of-life care.
- Most hospitals do not provide induction training on any aspect of dying, death and bereavement.
- Acute hospitals had 45% of the recommended facilities for mortuaries compared to 40% in community hospitals.
- 58% of acute hospitals and 84% of community hospitals do not meet the standard of having a bereavement service, as outlined in The Draft Quality Standards for End of Life Care in Hospitals.

Quality – The Markers

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'What should move us to action is human dignity the dignity of each of us.
We lose dignity if we tolerate the intolerable.'
Dominique de Menil

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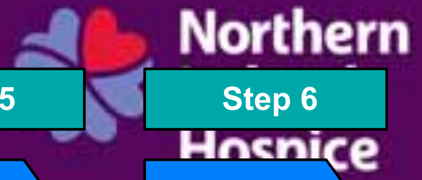
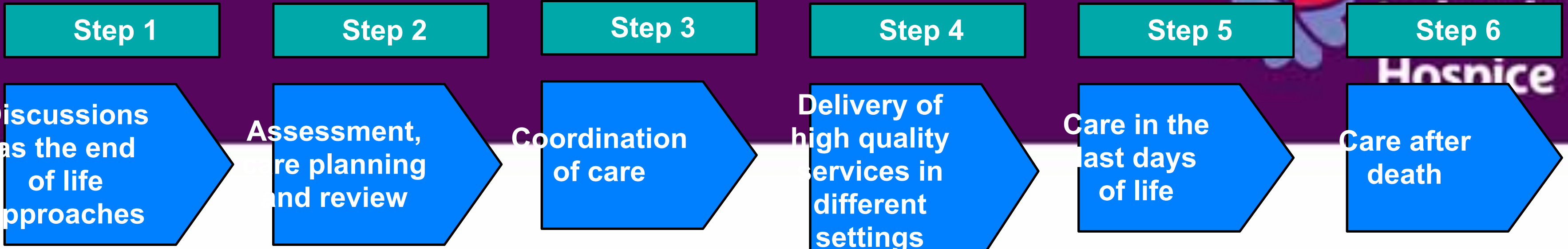
DH Department of Health

The End of Life Care Pathway





Step 1

- Open, honest communication
- Identifying triggers for discussion

Step 2

- Agreed care plan and regular review of needs and preferences
- Assessing needs of carers

Step 3 – Coordination of care

- Strategic coordination
- Coordination of individual patient care
- Rapid response services

Step 4

- High quality care provision in all settings
- Acute hospitals, community, care homes, hospices, community hospitals, prisons, secure hospitals and hostels
- Ambulance services

Step 5

- Identification of the dying phase
- Review of needs and preferences for place of death
- Support for both patient and carer
- Recognition of wishes regarding resuscitation and organ donation

Step 6 – Care after death

- Recognition that end of life care does not stop at the point of death.
- Timely verification and certification of death or referral to coroner
- Care and support of carer and family, including emotional and practical bereavement support

Spiritual care services

Support for carers and families

Information for patients and carers

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End of Life Care Strategy: Quality Markers

These provide PCTs and providers with a simple checklist of areas where they may be able to take action – based on the strategy and appropriate measures

- PCTs 38 QMs
- Primary Care 6 QMs
- Acute Hospitals 14 QMs
- Community Hospitals 11 QMs
- Care Homes 11 QMs
- Hospices/inpatient SPC 9 QMs
- Community SPC 7 QMs
- Ambulance Services 3 QMs
- OOH Medical Services 4 QMs

A Baroness's Story

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- Carers help+++
- Washing helps
- Small amounts of tasty food help
- An electric door opener helps
- Grandchildren help+++
- A disposable vomit bowl supply helps +++

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A Baroness's Story

- Being asked repeatedly where you want to die does not help
- Lack of vomit bowls does not help
- Focus on death targets does not help
- Long tiring visits from intense professionals do not help

Both and….

Death is not primarily a medical event. Death is a personal, relational and spiritual event, yet the majority of professional effort is concerned with the medical aspects of the end of life, often to the neglect of the more pertinent issues facing the dying and their families.

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Both and, not either or…

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- System Centred or Patient Centred
- Health or Sickness
- Palliative or Cure
- Quality or Quantity
- Targets or Individualised
- My way or the wrong way
- My group vs Your group
- Medical vs Non-medical
- Palliative vs Non Palliative

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Client/ patient centred care Require managers with non-dualistic thinking, - Quantity, Quality ***Plus***

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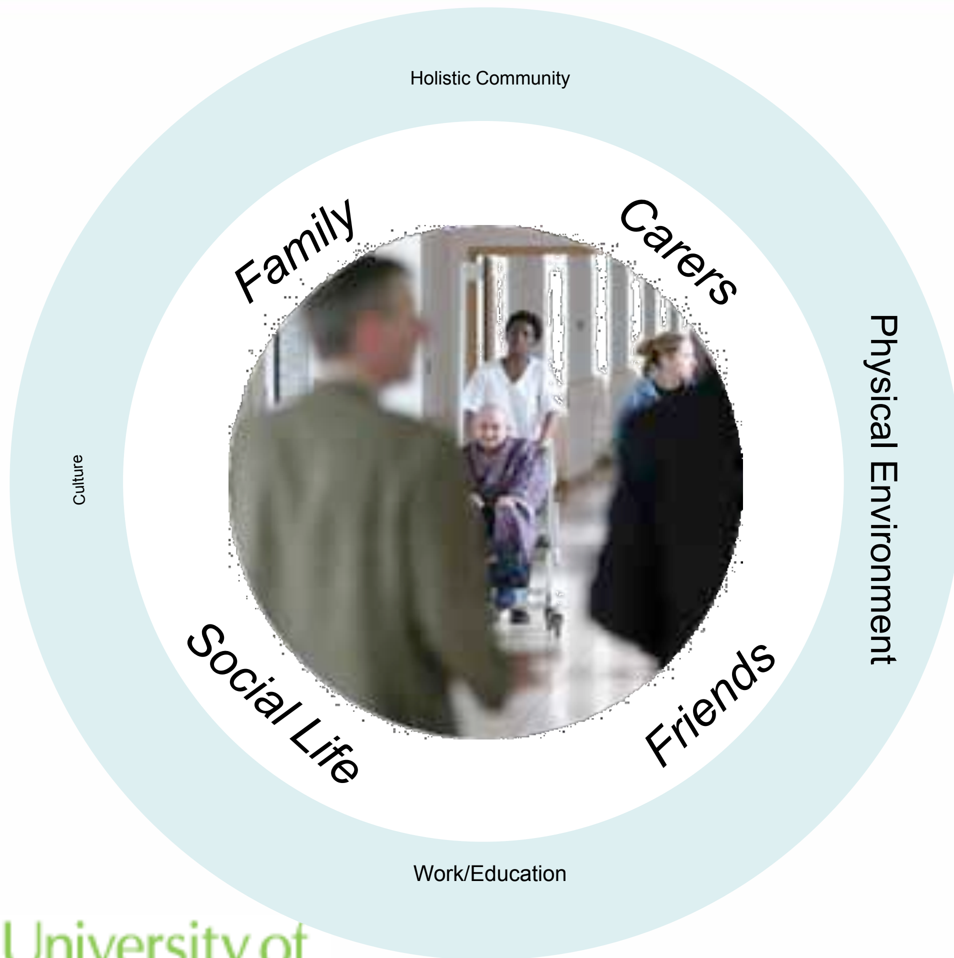

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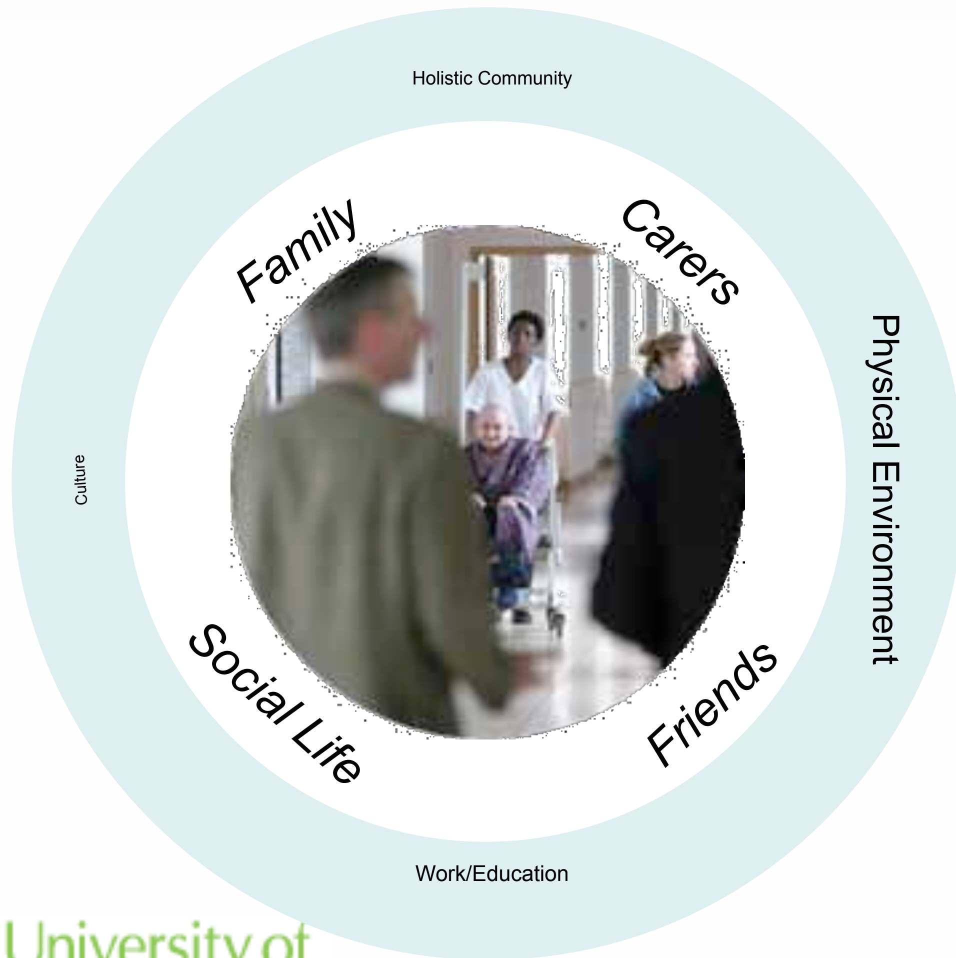

"You matter because you are you, and you matter all the days of your life."

Saunders

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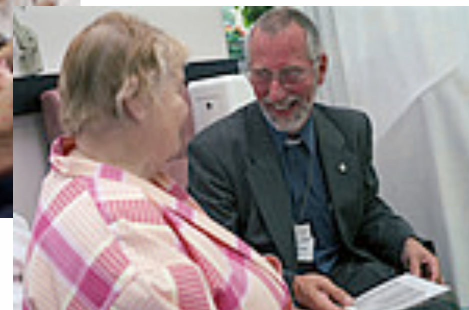

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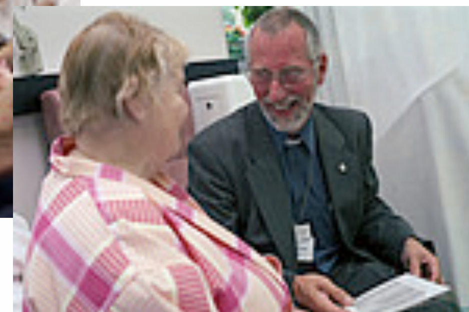

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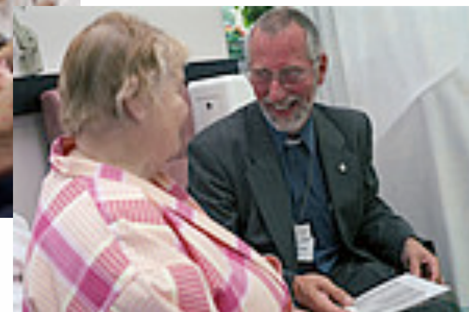

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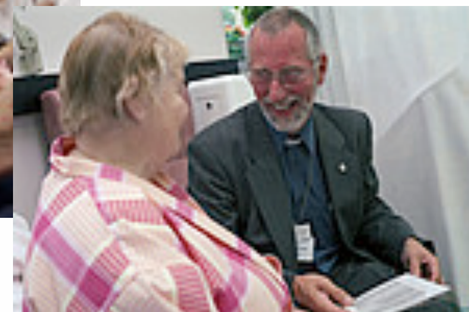

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What Do You DO when systems get in the way of really seeing patients

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Looking is not seeing. Listening is not hearing. It is possible to miss so much that is right in front of us if we lack the categories and skills to notice. The greatest of these skills is, perhaps, to put aside our expectations, and to stay open to the actual.

—**Donald M. Berwick,**
from the Foreword of the book *Organizing for Quality: The Improvement Journeys of Leading Hospitals in Europe and the United States*

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"The finger pointing at the moon is not the moon.".. Thich Nhat Hanh

The PLUS of End of life Care
The Challenge for Managers and Strategists

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- "Not everything that is important can be measured

- Not everything that is measured is important"

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Systems alone cannot create holistic care

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A Natural Death for All?

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Background – The Quality / Quantity Spectrum

Quantity- The Numbers

Quality – The Markers

Beyond Numbers and Markers

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Can Natural Death Be Achieved Fairly?

Quantity…..Plus
Quality…..Plus
Targets…..Plus

"Never alone, always together"

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If we want natural death to be available fairly…?

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If we want natural death to be available fairly…?

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- Do all that you can

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If we want natural death to be available fairly…?

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- Do all that you can
- With what you have

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If we want natural death to be available fairly…?

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- Do all that you can
- With what you have
- In the time you have

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If we want natural death to be available fairly…?

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- Do all that you can
- With what you have
- In the time you have
- In the place that you are

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If we want natural death to be available fairly…?

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- Do all that you can
- With what you have
- In the time you have
- In the place that you are

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- Do all that you can
- With what you have
- In the time you have
- In the place that you are

Nkosi Johnson

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If we want natural death to be available fairly…

"Be the change you want to see"

Mohandas Karamchand Gandhi
1869-1948

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