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Planning for a 'Good Death'

Dr Kirsty Boyd

Consultant in Palliative Medicine

Honorary Clinical Senior Lecturer

THE UNIVERSITY OF EDINBURGH

Primary Palliative Care
Research Group

www.rcpe.ac.uk

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Principles of a good death

- ✓ To know when death is coming, and to understand what can be expected
- ✓ To be able to retain control of what happens
- ✓ To be afforded dignity and privacy

- ✓ To have control over pain relief and other symptom control
- ✓ To have choice and control over where death occurs (at home or elsewhere)
- ✓ To have access to information and expertise of whatever kind is necessary
- ✓ To have access to any spiritual or emotional support required

- ✓ To have access to hospice type care in any location, not only in hospital
- ✓ To have control over who is present and who shares the end
- ✓ To be able to issue advance directives which ensure wishes are respected
- ✓ To have time to say goodbye
- ✓ To be able to leave when it is time to go, and not to have life prolonged pointlessly

Richard Smith – January 2000

www.rcpe.ac.uk

BMJ Helping doctors make better decisions

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A 'Good Death'?

"I'm not afraid of death; I just don't want to be there when it happens."
Woody Allen

The art of living well and dying well are one.
Epicurus

"For life and death are one, even as the river and the sea are one."
Kahil Gibran

"Love is how you stay alive, even after you are gone."
Mitch Albom

Do not go gentle into that good night,
Old age should burn and rave at close of day;
Rage, rage against the dying of the light.
Dylan Thomas

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" A person's death is the final chapter of their autobiography. The views people have held in life, the manner in which they have lived their life, their attitudes towards their physical body and the significance of their mental life will determine the type of death they consider appropriate."

Farsides 1996

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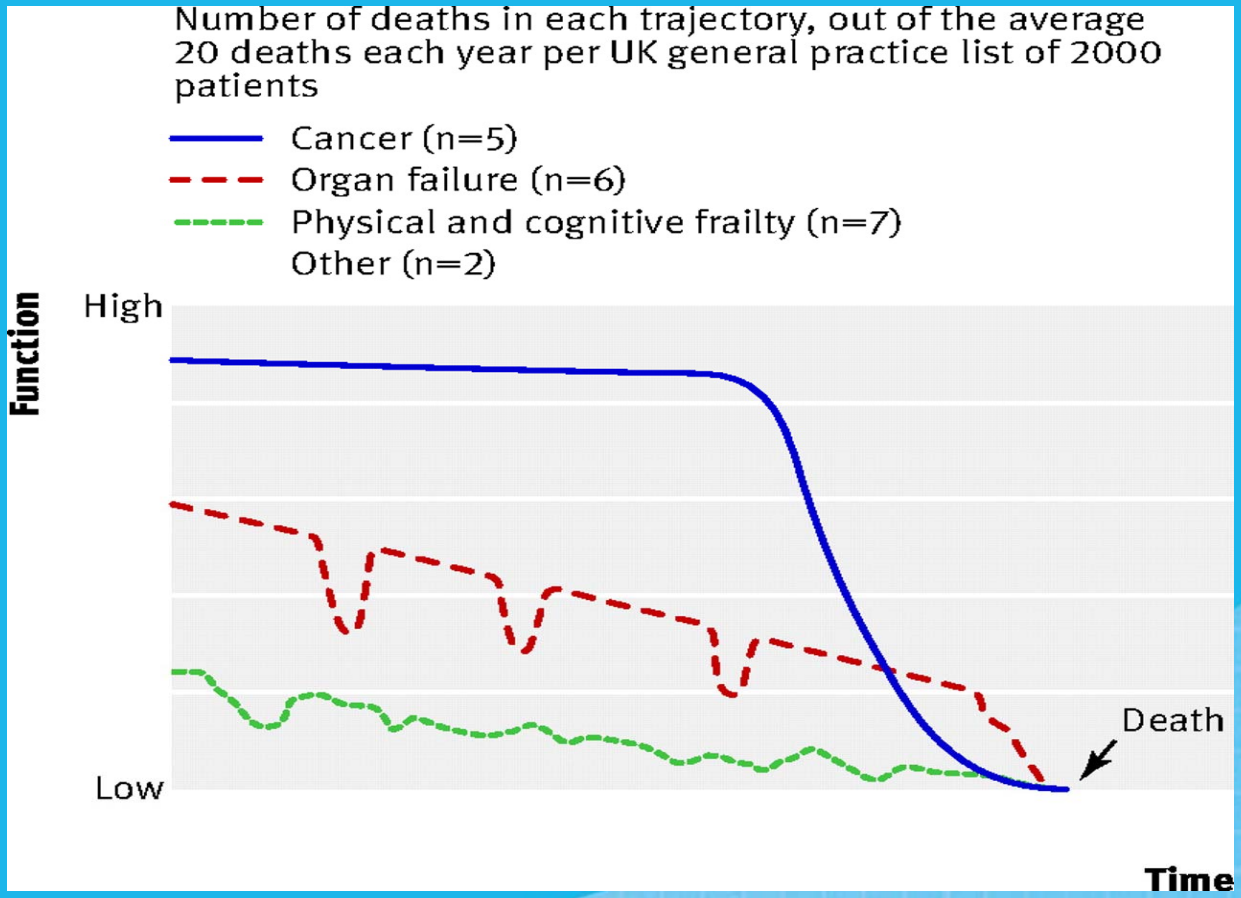
A 'Good Death'?



Murray, S. A et al. BMJ 2008;336:958-959

www.rcpe.ac.uk

BMJ

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Cancer narratives

Beginning
I was scared when they told me when they said there was a tumour. It knocked me for six. I thought, O my God, I am going to die…Mr C, brain tumour

Middle
I honestly sometimes think there's nothing wrong with me…. Mr E, Lung Cancer

End
The main thing is, how long am I going to live? Ms I, Lung Cancer

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Living with advanced conditions

Beginning

How it started is anybody's guess…Mr N, chronic lung disease

Middle

It's one day on top and the next day back under again…Mr O, heart failure
"I couldn't lie down. Very, very frightening.." Mrs J, heart failure

'It's like I feel I am in prison here with him, and each day is just like the last…'
Carer, Mr R heart failure

End

I know it won't get better, but I hope it won't get any worse… Ms S, heart failure

As long as the damn thing just keeps working the way it is working I'll be quite happy…Mr T, Liver Failure

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Living with Frailty

Beginning

It was all due to an accident [story of a fall] but I've never really been the same you see… Mr V

Middle

*It's just a gradual deterioration, you can't expect anything else…*Mr X

You get annoyed at yourself for not being able to do it…. Ms Y

" Well it's just part of getting old…" Mrs P

End

I said "I'm going home" I said "you're no putting me into any [nursing] home" Mrs X

I find, em preparing people for something that could happen tomorrow but actually might not happen for a year or two, you know, so it's quite difficult. GP of Mr W

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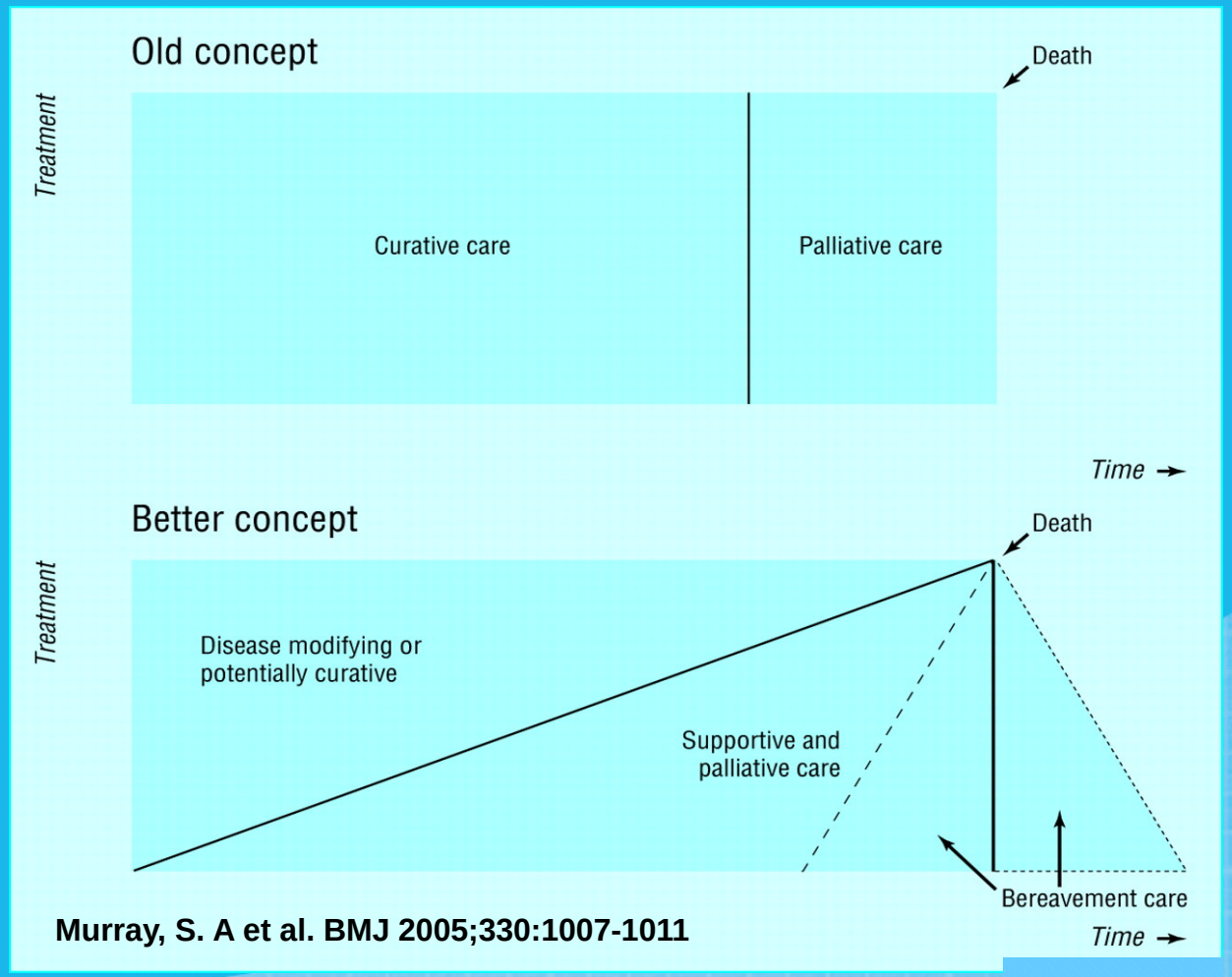
A 'Good Death'?



Murray, S. A et al. BMJ 2005;330:1007-1011

www.rcpe.ac.uk

bmj.com

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A 'Good Death'?

Original Article

PALLIATIVE MEDICINE

Palliative Medicine
1–6

DOI: 10.1177/0269216314526443
pmj.sagepub.com
SAGE

Imminence of death among hospital inpatients: Prevalent cohort study

David Clark[1], Matthew Armstrong[2], Ananda Allan[3], Fiona Graham[4], Andrew Carnon[3] and Christopher Isles[5]

- 10,743 inpatients in 25 Scottish hospitals on 31 March 2010
- 21.2% had died by 6 months, 25.5% by 9 months, and 28.8% by 12 months
- 50% of health care expenditure occurs in the last 6 months of life

Should we give the " compression of morbidity" a research status equivalent to that now given to the prolongation of life?

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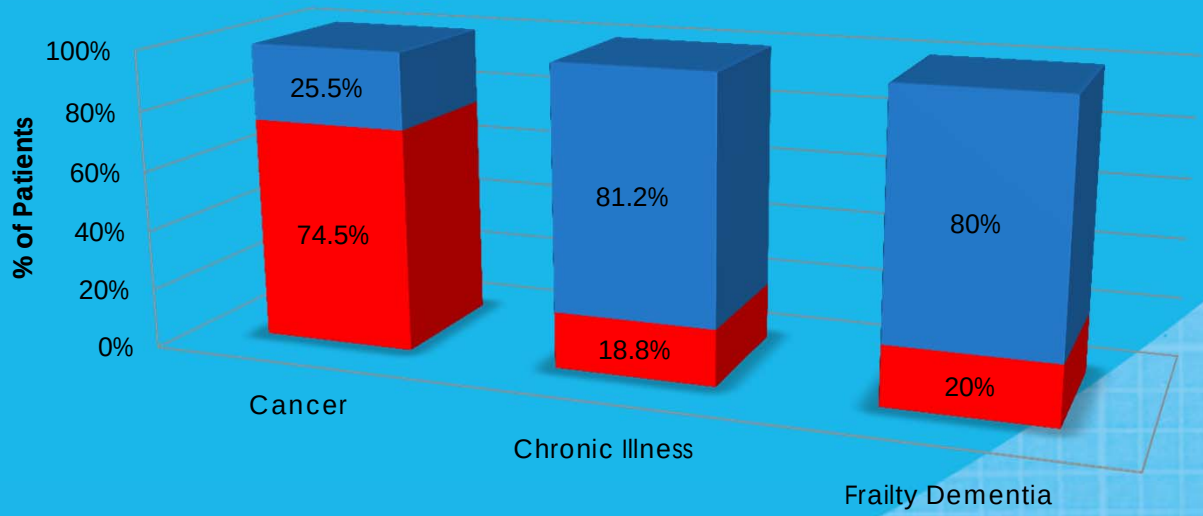
Patients on the GP Palliative Care Register



	Cancer	Chronic Illness	Frailty Dementia
None	51	138	128
PCR	149	32	32

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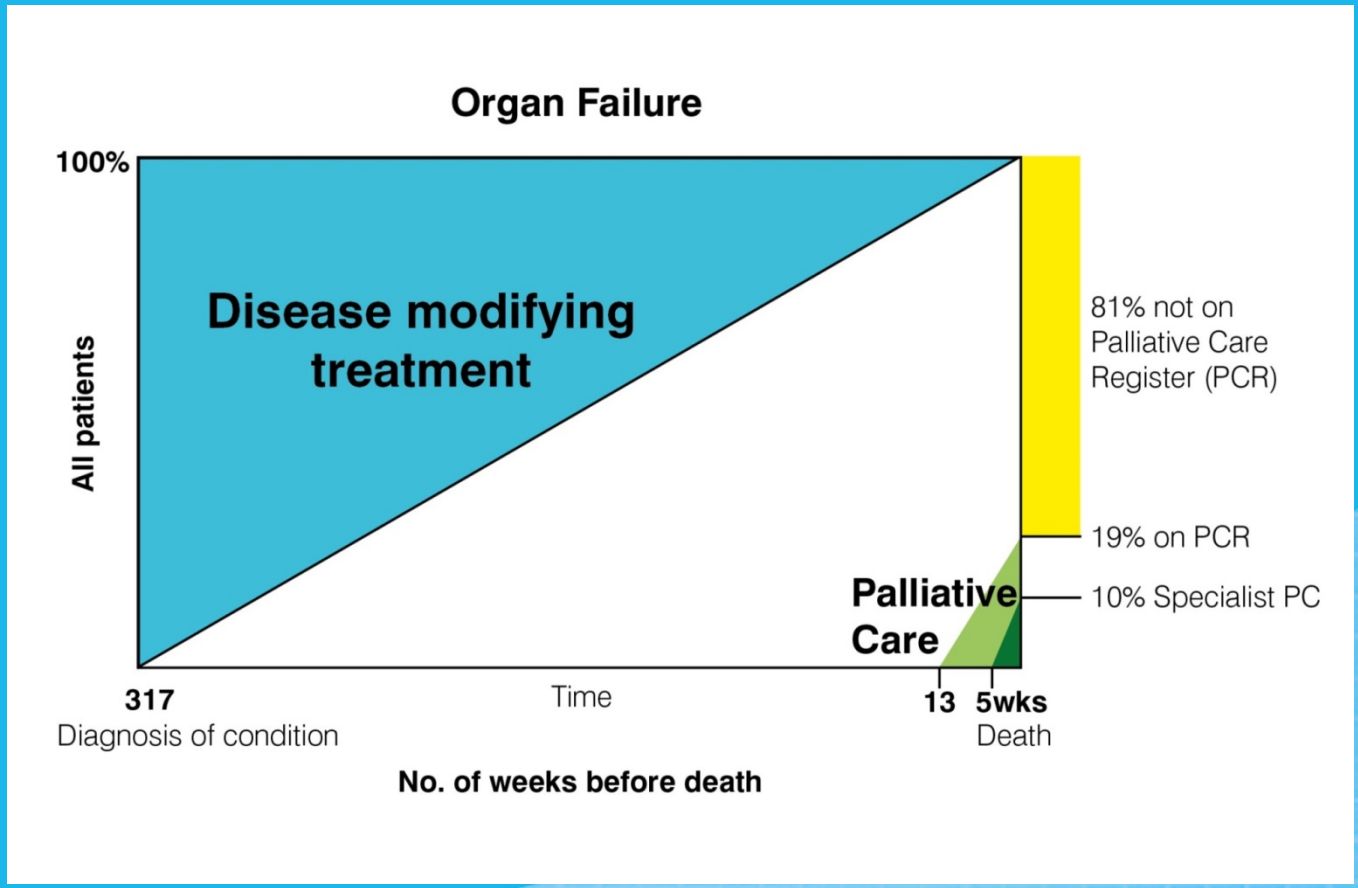
Patients on the GP Palliative Care Register



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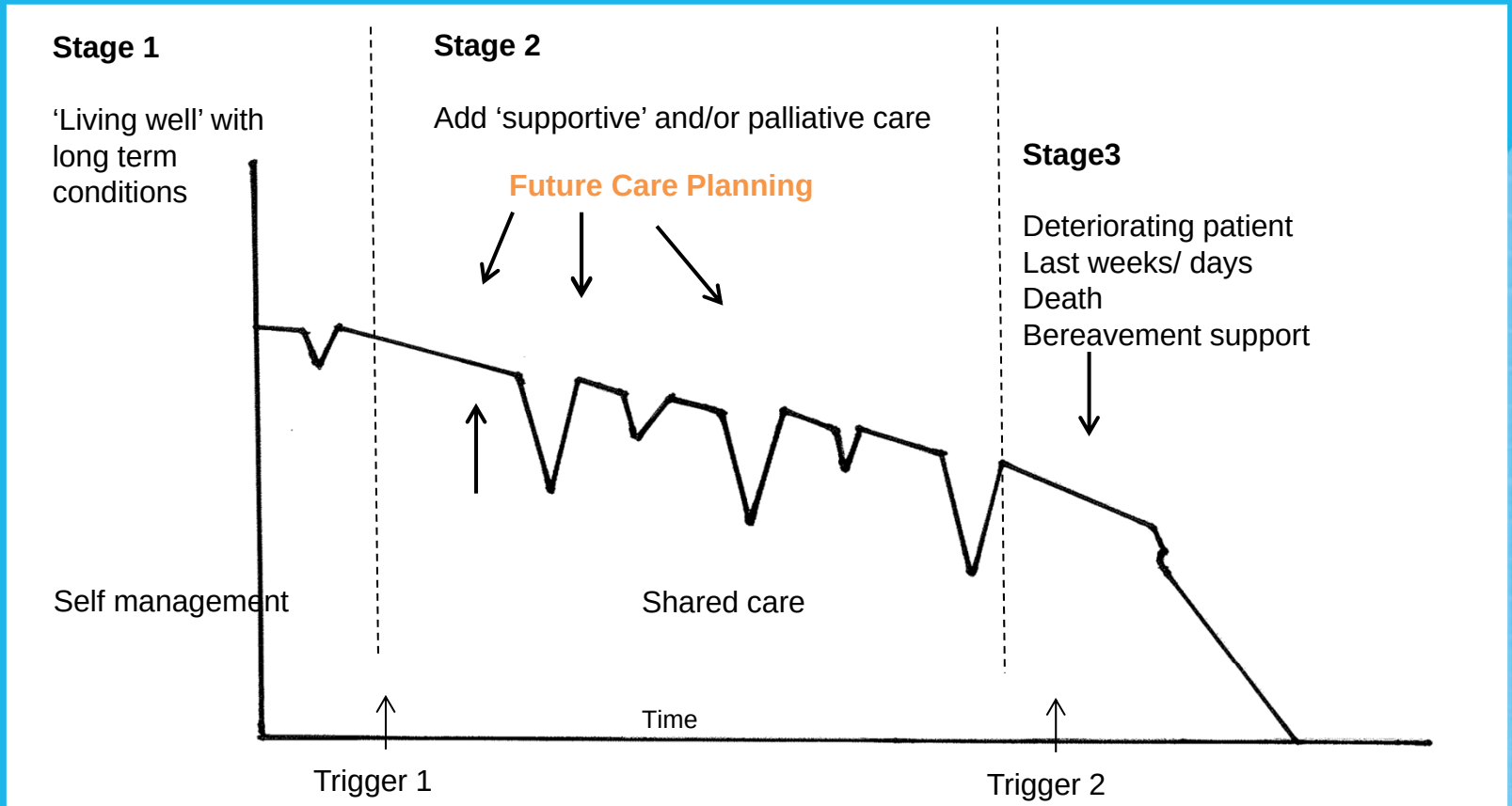
Living with multiple advanced illnesses



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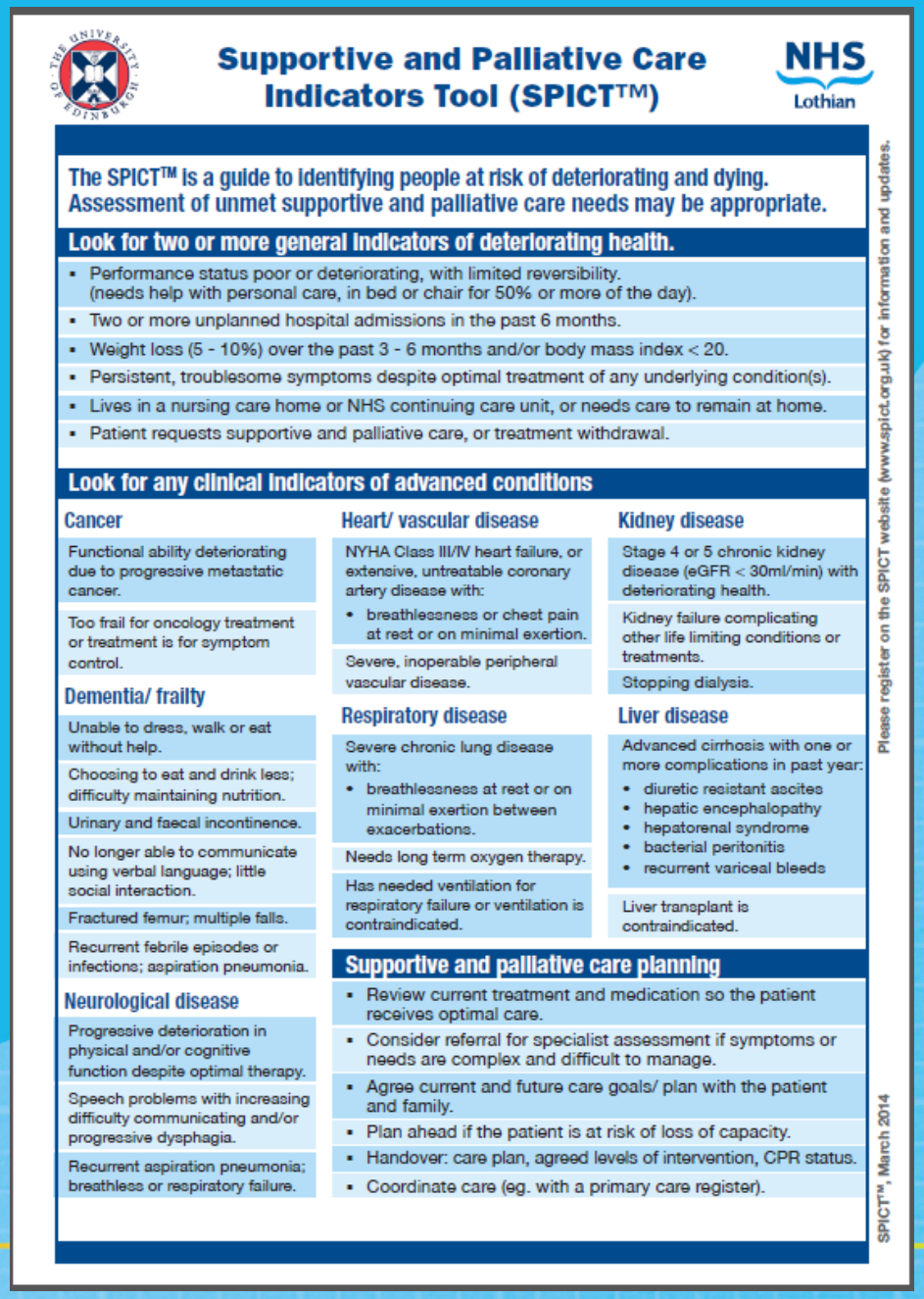
- Less able to manage own care; more dependent on others
- Persistent symptoms despite optimal treatment
- Life-prolonging therapies not likely to help or not wanted
- Lots of hospital admissions

www.spict.org.uk



Supportive and Palliative Care Indicators Tool (SPICT™)

NHS Lothian

The SPICT™ is a guide to identifying people at risk of deteriorating and dying. Assessment of unmet supportive and palliative care needs may be appropriate.

Look for two or more general indicators of deteriorating health.

- Performance status poor or deteriorating, with limited reversibility. (needs help with personal care, in bed or chair for 50% or more of the day).
- Two or more unplanned hospital admissions in the past 6 months.
- Weight loss (5 - 10%) over the past 3 - 6 months and/or body mass index < 20.
- Persistent, troublesome symptoms despite optimal treatment of any underlying condition(s).
- Lives in a nursing care home or NHS continuing care unit, or needs care to remain at home.
- Patient requests supportive and palliative care, or treatment withdrawal.

Look for any clinical indicators of advanced conditions

Cancer

Functional ability deteriorating due to progressive metastatic cancer.

Too frail for oncology treatment or treatment is for symptom control.

Dementia/ frailty

Unable to dress, walk or eat without help.

Choosing to eat and drink less; difficulty maintaining nutrition.

Urinary and faecal incontinence.

No longer able to communicate using verbal language; little social interaction.

Fractured femur; multiple falls.

Recurrent febrile episodes or infections; aspiration pneumonia.

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.

Heart/ vascular disease

NYHA Class III/IV heart failure, or extensive, untreatable coronary artery disease with:

- breathlessness or chest pain at rest or on minimal exertion.

Severe, inoperable peripheral vascular disease.

Respiratory disease

Severe chronic lung disease with:

- breathlessness at rest or on minimal exertion between exacerbations.

Needs long term oxygen therapy.

Has needed ventilation for respiratory failure or ventilation is contraindicated.

Kidney disease

Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.

Kidney failure complicating other life limiting conditions or treatments.

Stopping dialysis.

Liver disease

Advanced cirrhosis with one or more complications in past year:

- diuretic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

Liver transplant is contraindicated.

Supportive and palliative care planning

- Review current treatment and medication so the patient receives optimal care.
- Consider referral for specialist assessment if symptoms or needs are complex and difficult to manage.
- Agree current and future care goals/ plan with the patient and family.
- Plan ahead if the patient is at risk of loss of capacity.
- Handover: care plan, agreed levels of intervention, CPR status.
- Coordinate care (eg. with a primary care register).

Please register on the SPICT website (www.spict.org.uk) for information and updates.

SPICT™, March 2014

SPICT™

NHS Lothian

You are not logged in. (Log in)

Home | About SPICT™ | The SPICT™ | SPICT™ Projects | Other Resources | Contact Us | Log In

Supportive & Palliative Care Indicators Tool (SPICT™)

The SPICT™ is a guide to identifying people at risk of deteriorating and dying.

Assessment of unmet supportive and palliative care needs may be appropriate.

SPICT™

- Includes evidence-based clinical indicators of advanced conditions and multimorbidity
- Can be used by a range of professionals in all care settings; community, care homes and hospitals
- Provides clear information, in accessible language, that can be discussed with patients and families and communicated between professionals and teams
- Uses a simple, one-page format
- Prompts assessment and review of the current and future needs of patients and their families
- Promotes early supportive and palliative care in parallel with optimal management of the patient's underlying condition(s)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NHS Lothian

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- Choosing to eat and drink less; difficulty maintaining nutrition.
- Urinary and faecal incontinence.
- No longer able to communicate using verbal language; little social interaction.
- Fractured femur; multiple falls.
- Recurrent febrile episodes or infections; aspiration pneumonia.

Neurological disease
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- Handover: care plan, agreed levels of intervention, CPR status.
- Coordinate care (eg, with a primary care register).

Please register on the SPICT website (www.spict.org.uk) for information and updates.

SPICT - March 2014

The SPICT™ is sometimes used in combination with the "Surprise Question":
Would you be surprised if this patient died within 12 months?

To access SPICT™ and join with a growing community of SPICT users, please register.

About SPICT

Who developed it? How can you use it?
click to find out more >>>

The SPICT

Register to download the SPICT and join the SPICT forum - it's free.
Click to register >>>

SPICT Projects

Help develop the SPICT - become a Partner.
Click to find out more >>>

Other Resources

Links to other relevant sites.
Click to explore >>>

Contact Us

Still have questions?
Click to contact us >>>

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"Living well" with advanced illness

- Agreed goals
- Treatment reviews

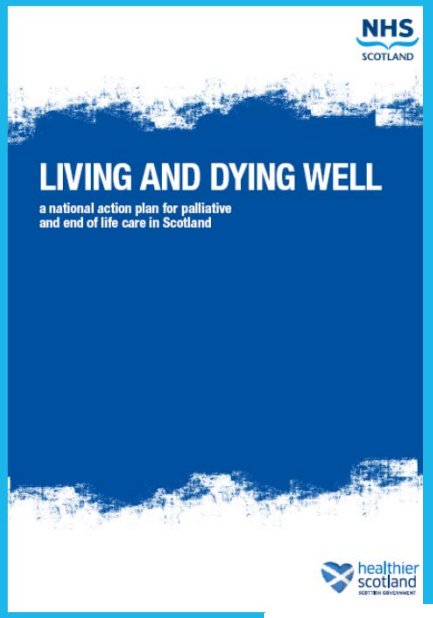
  stop if it no longer helping..

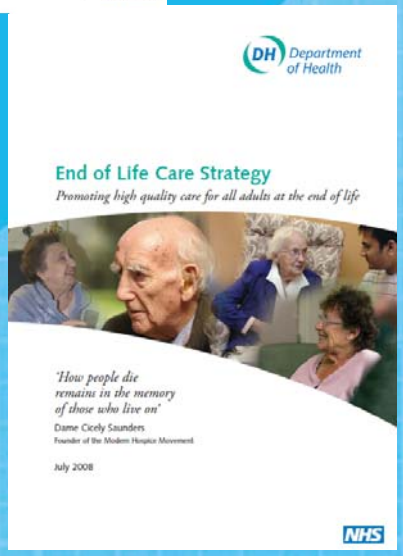
- Advance care planning

  make choices while you can..

- Anticipatory care planning

  what to do when s/he gets worse....





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- What do we need to know about you to look after you well?

I've discussed it with family and I've just said, 'no', and they're in agreement with me. What's the point of being resuscitated and end up a vegetable, what's the point? Its difficult for them but they accept my decision (Patient)

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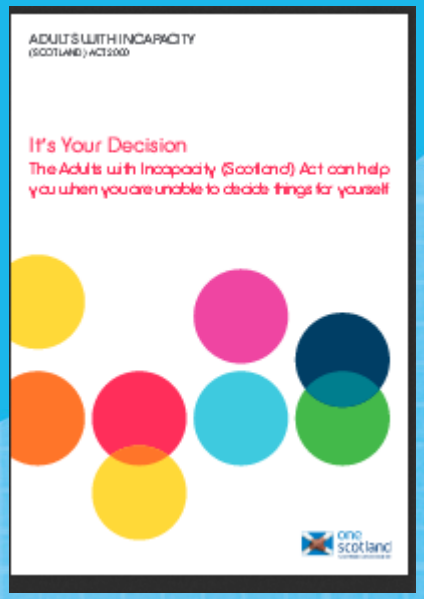
Adults with Incapacity Act

- Power of Attorney (Finance)
- Welfare Power of Attorney



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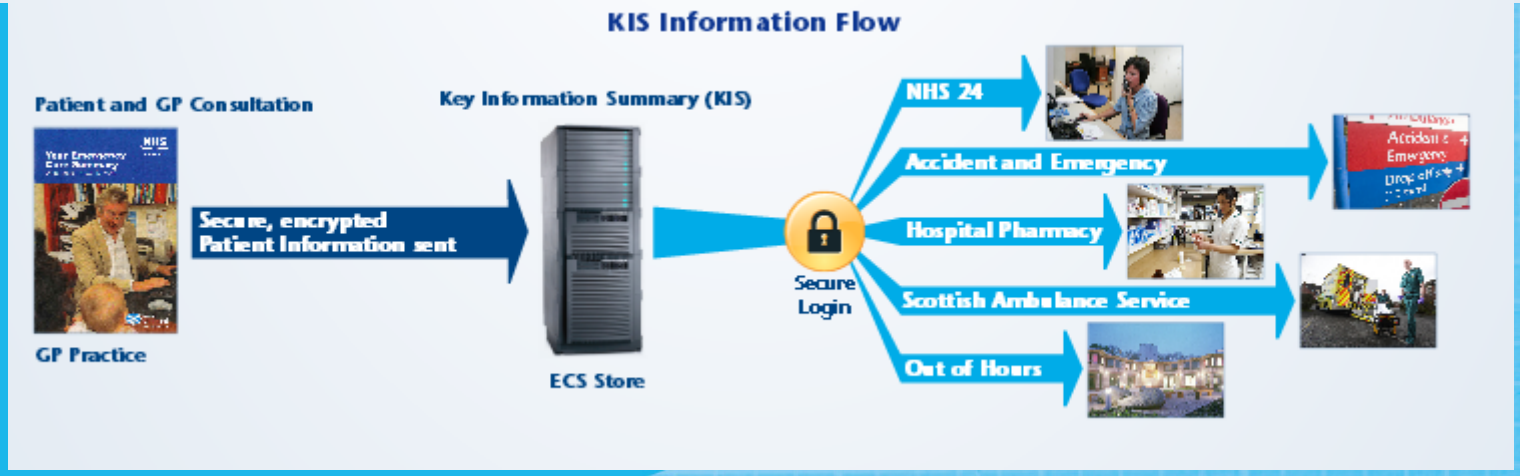
Key Information Summary (KIS)

NHS National Services Scotland

Improving patient experience through better communication of important information



www.ecs.scot.nhs.uk/kis

www.rcpe.ac.uk

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- **Information**
- **Pain & symptom control**
- **Emotional, spiritual and family support**
- **Practical care**
- **Future care planning**
- **Person-centred end-of-life care**

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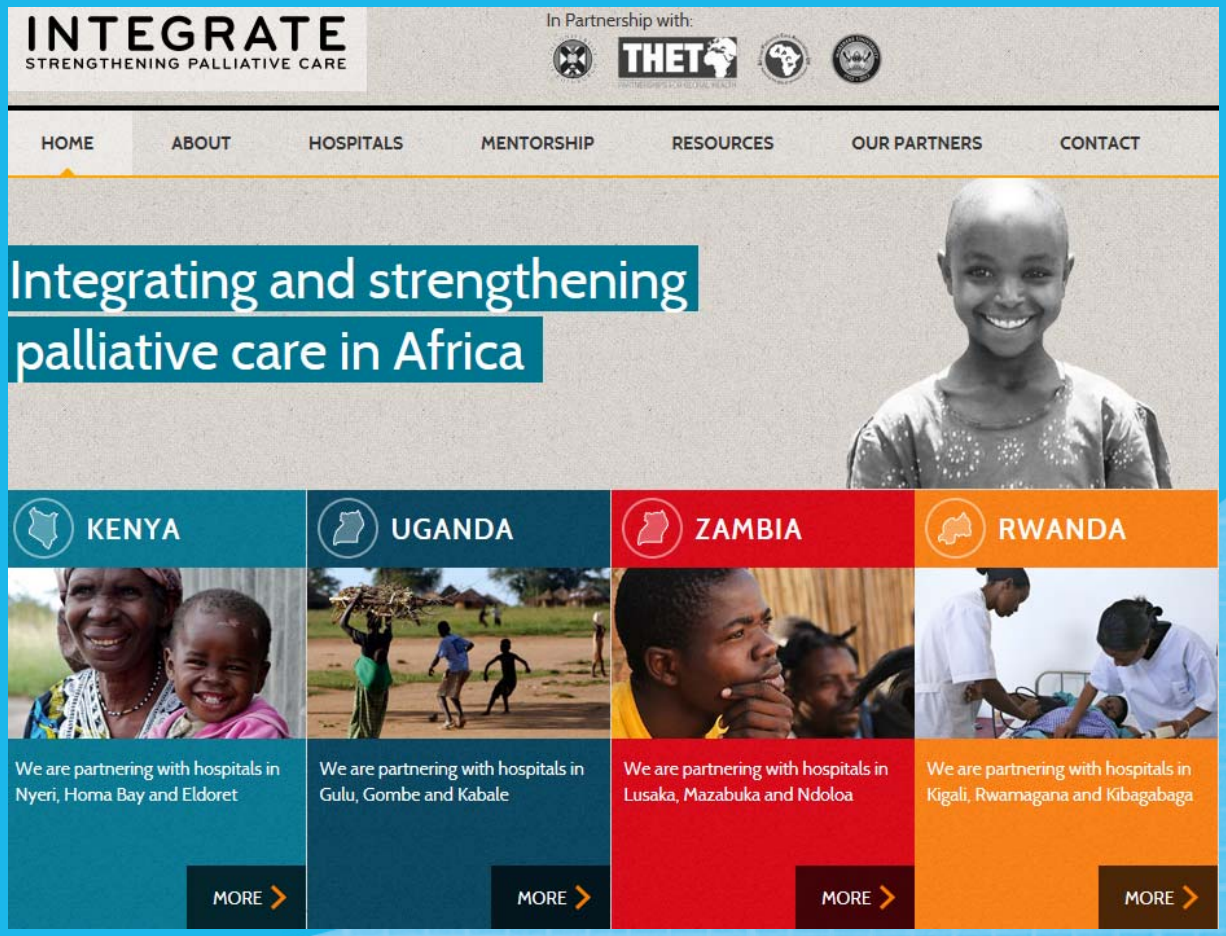

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good life good death good grief

home | about us | why be more open about death? | get involved | support | news | resources | contact us

YOU ARE HERE: HOME

welcome

Death is normal. We can all help each other with death, dying and bereavement.

Good Life, Good Death, Good Grief is working to make Scotland a place where there is more openness about death, dying and bereavement so that:

- People are aware of ways to live with death, dying and bereavement
- People feel better equipped to support each other through the difficult times that can come with death, dying and bereavement

our aims

Good Life, Good Death, Good Grief brings together individuals and organisations that share this vision. We are interested to hear from any person or organisation who wants to work with us to make Scotland a place where people can be open about death, dying and bereavement.

It is never too early to think about **planning ahead** for illness and death – making plans when you're healthy means there is less to think about if you get sick.

latest news

Volunteers sought to participate in filming

Do you have happy memories of someone who is now dead?

More news ...

Search this site ...

Text size: A A A

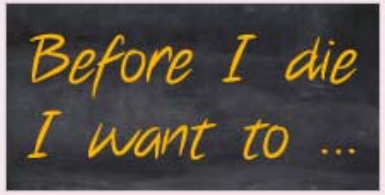
facebook | twitter

Good Life, Good Death, Good Grief

Like

756 people like Good Life, Good Death, Good Grief.

Facebook social plugin



Scottish Partnership for Palliative Care

My Funeral Wishes partners

Dying Matters has joined forces with the National Association of Funeral Directors and Perfect Choice Funeral Plans to bring you My Funeral Wishes.

Find out more

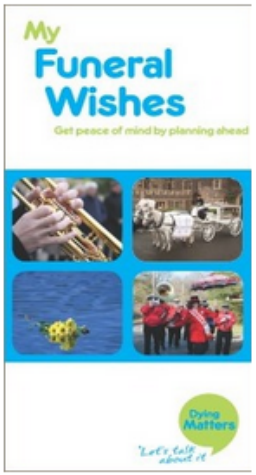
In the words of others...

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

Dame Cicely Saunders (founder of the modern hospice movement)

Celebrate your life, your way, with My Funeral Wishes

Have you ever thought about what you want for your funeral? You probably already know whether you want to be buried or cremated, but what about the details? Where do you want your funeral to be held? Do you want readings and, if so, which ones and read by whom? Perhaps there's even a particular route you would like your hearse to take.



By taking the initiative and setting out what you want now, you can get on with living your life, knowing that when the time comes your loved ones will know what you wanted and be spared from having to make difficult decisions.

To help you do this, Dying Matters and the National Association of Funeral Directors have produced My Funeral Wishes. It's a simple form which lets you create a personal funeral plan that reflects you as an individual.

↓ Download My Funeral Wishes

E-newsletter sign up

Getting the latest Dying Matters news delivered straight to your inbox.

Sign up today!

What's on

There are hundreds of events relating to death, dying and bereavement happening countrywide. View them here.

What's on in your area

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What on earth is a death cafe?

At Death Cafes people drink tea, eat cake and discuss death. Our aim is to increase awareness of death to help people make the most of their (finite) lives.

http://deathcafe.com

The Guardian, Saturday 22 March 2014

www.rcpe.ac.uk

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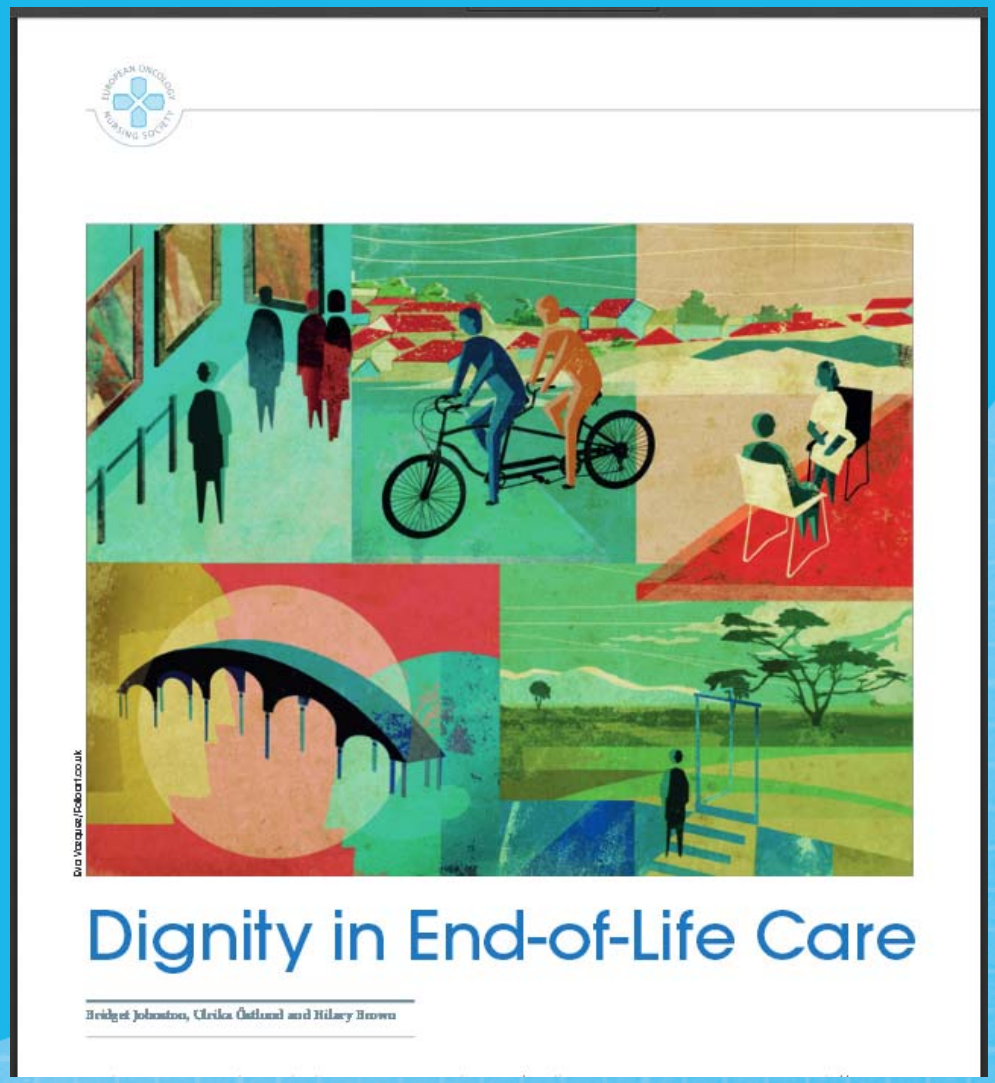
Chochinov – 2007

- Attitude - positive
- Behaviour - respect
- Compassion - care
- Dialogue – *knowing 'me'*

- Illness related concerns
- Personal resources
- Social interactions



http://www.cancernurse.eu/documents/newsletter/2010autumn/EONSNewsletter2010AutumnPage10.pdf

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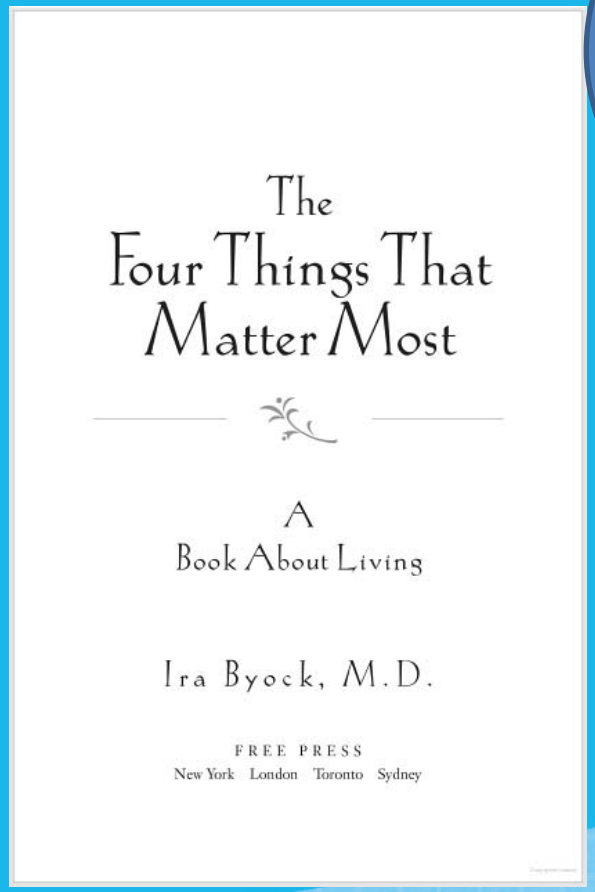
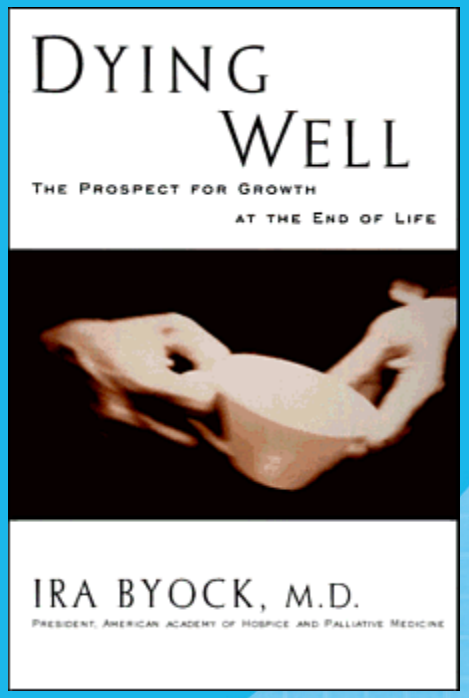


I'm sorry

Thank you

I love you

Goodbye



- **Complete worldly affairs**
- **Complete community relationships**
- **Find meaning in one's life**
- **Experience self worth**
- **Feel valued and accepted by others**
- **Complete close relationships**

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A 'Good Death'?

- **All of my life I put my labour first.**
  I made my mark, but left no time between
  The things achieved, so, at my heedless worst,
  With no life, there was nothing I could mean.
  But now I have slowed down. I breathe the air
  As if there were not much more of it there

- **And write these poems, which are funeral songs**
  That have been taught to me by vanished time:
  Not only to enumerate my wrongs
  But to pay homage to the late sublime
  That comes with seeing how the years have brought
  A fitting end, if not the one I sought.

Clive James New Yorker, May 28, 2013

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

Cecily Saunders

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