Planning for a ‘Good Death’

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www.rcpe.ac.uk
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

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“For life and death are one, even as the river and the sea are one.”
Kahlil Gibran

“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

“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
A ‘Good Death’?

Number of deaths in each trajectory, out of the average 20 deaths each year per UK general practice list of 2000 patients:
- Cancer (n=5)
- Organ failure (n=6)
- Physical and cognitive frailty (n=7)
- Other (n=2)

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
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
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
A ‘Good Death’?

Old concept

Treatment

Curative care

Palliative care

Death

Better concept

Treatment

Disease modifying or potentially curative

Supportive and palliative care

Bereavement care

Death

Time

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?
Patients on the GP Palliative Care Register

<table>
<thead>
<tr>
<th>Condition</th>
<th>None</th>
<th>PCR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer</td>
<td>51</td>
<td>149</td>
</tr>
<tr>
<td>Chronic Illness</td>
<td>138</td>
<td>32</td>
</tr>
<tr>
<td>Frailty Dementia</td>
<td>128</td>
<td>32</td>
</tr>
</tbody>
</table>

- 74.5% of patients have Cancer
- 18.8% of patients have Chronic Illness
- 20% of patients have Frailty Dementia

Percentages:
- 81.2% of Cancer patients have Chronic Illness
- 80% of Chronic Illness patients have Frailty Dementia
- 25.5% of patients have Cancer

Source: www.rcpe.ac.uk
Royal College of Physicians of Edinburgh
Educating doctors, improving care.

Patients on the GP Palliative Care Register

Diagram:
- Disease modifying treatment
- Organ Failure
- All patients
- Diagnosis of condition
- Time
- No. of weeks before death
- 317
- 81% not on Palliative Care Register (PCR)
- 19% on PCR
- 10% Specialist PC
- 13 weeks
- 5 weeks
- Death

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Living with multiple advanced illnesses

Stage 1
‘Living well’ with long term conditions

Stage 2
Add ‘supportive’ and/or palliative care

Stage 3
Deteriorating patient
Last weeks/days
Death
Bereavement support

Time
Trigger 1
Trigger 2

Self management
Shared care

Future Care Planning

High

Low
- 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 & 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)

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.
“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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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? It’s difficult for them but they accept my decision (Patient)

What do we need to know about you to look after you well?
Adults with Incapacity Act

- Power of Attorney (Finance)
- Welfare Power of Attorney
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Key Information Summary (KIS)
Improving patient experience through better communication of important information

KIS Information Flow

Patient and GP Consultation → Key Information Summary (KIS)

- Secure, encrypted Patient Information sent
- ECS Store

NHS 24
Accident and Emergency
Hospital Pharmacy
Scottish Ambulance Service
Out of Hours

www.ecs.scot.nhs.uk/kis
www.rcpe.ac.uk
• Information
• Pain & symptom control
• Emotional, spiritual and family support
• Practical care
• Future care planning
• Person-centred end-of-life care
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Integrating and strengthening palliative care in Africa

KENYA

We are partnering with hospitals in Nyeri, Horna Bay and Eldoret

MOORE

UGANDA

We are partnering with hospitals in Gulu, Gombe and Kabale

MOORE

ZAMBIA

We are partnering with hospitals in Lusaka, Mazabuka and Ndola

MOORE

RWANDA

We are partnering with hospitals in Kigali, Rwamagana and Kibagabaga

MOORE

www.rcpe.ac.uk
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 anyone 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.
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
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
Chochinov – 2007

- Attitude - positive
- Behaviour - respect
- Compassion - care
- Dialogue – knowing ‘me’

- Illness related concerns
- Personal resources
- Social interactions
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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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.
How people die remains in the memory of those who live on.

Cecily Saunders
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