# 6<sup>th</sup> Annual SOARS Lecture When is a Life Complete? What Next? **Phil Cheatle SOARS** Coordinator

# Introduction - Me

- Former Research Scientist for HP future of digital photography
- Right to Die activities:

Supporter in principle since early '80s.

Experience of mother and aunt.

October '13 – Joined DiD

March '14 - Formed DiD Bristol group

March '14 – Joined SOARS

August '14 – Met Michael – invited to join SOARS EC

October '14 – Became SOARS Associate Coordinator

October '14 – Asked to leave DiD Bristol group!

February '15 – Formed SOARS Bristol Die-alogue group

Oct '14 - Oct '15 - Drafted and revised the "Completed Life" document

September '15 – Became SOARS Coordinator

# When is a Life Complete? What next?

- Review the "Completed Life" concept and feedback
- What next for "Completed Life" concept
- What next for SOARS
- Discussion

# Origins of the "Completed Life" concept

### **Huib Drion**

Former Dutch Supreme Court judge and Professor of civil law (1917-2004)

"It appears to me... that many old people would find great reassurance if they could have a means to end their lives in an acceptable way at the moment that to them... appears suitable." NRC Handelsblad 1991

- People aged 75 or over
- Living alone,
- Option of medically assisted suicide
- Before the final stages of decline and dependence. (Obituary in BMJ 13 May 2004)

# 'The Self Chosen Death of the Elderly' Aug 2011 Wouter Beekman (Of Free Will)

http://www.worldrtd.net/sites/default/files/newsfiles/UVW%20engels%20definitief%201.1\_0.pdf

### **James Leonard Park**

"Completed Life or Premature Death?" http://www.tc.umn.edu/~parkx032/CY-CLPD.html

# Jain tradition of Santhara / Sallekhana

Tradition of voluntary peaceful death dating back to 250BC

'Over 200 Jains embrace death every year' India Express 30<sup>th</sup> Sept 2006

Requires permission of a religious leader Possible reasons include:

- Old age with failing health
- Terminal illness in which death is imminent

'10,000 Jains shave heads to protest high court ban on Santhara' Times of India 23<sup>rd</sup> August 2015

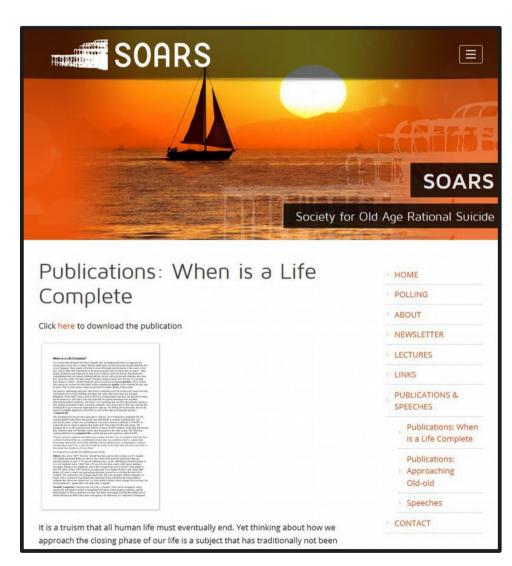
# Background within SOARS

SOARS project over last 12 months

"When is a Life Complete?" document

Valuable feedback from SOARS supporters

Revised version now published on website



http://soars.org.uk/index.php/publications-and-speeches/publications-completed-life

# A Completed Life: The SOARS view

'Elderly, mentally competent individuals may consider that their lives are complete when they have a chronic health problem (or a combination of more than one condition) which is causing them increasingly unbearable, irreversible suffering, with the additional loss of independence, purpose and meaning in their lives, so that they would now prefer to die rather than stay alive, especially as they dread what the future will soon bring.'

# "Completed Life" or "Life Cut Short"

'Elderly, mentally competent individuals may consider that their lives are complete when they have a chronic health problem (or a combination of more than one condition) which is causing them increasingly unbearable, irreversible suffering, with the additional loss of independence, purpose and meaning in their lives, so that they would now prefer to die rather than stay alive, especially as they dread what the future will soon bring.'

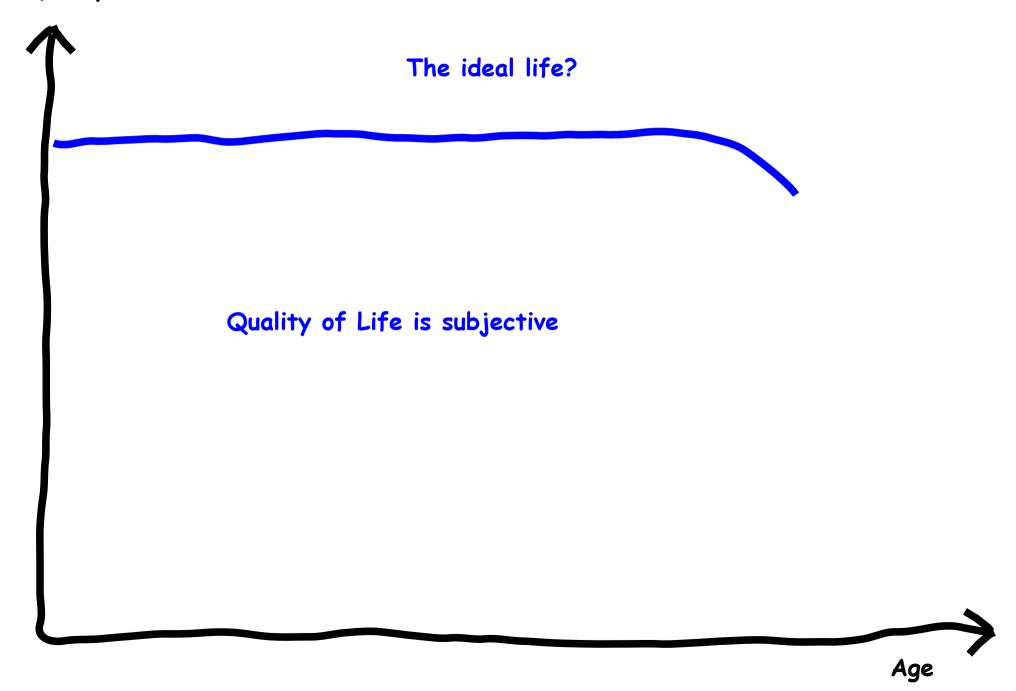
"Completed Life" is sufficient but not necessary for Medically Assisted Rational Suicide (MARS) – younger lives are cut short by illness that destroys quality of life.

"I hope not to feel old at 90!"

# Failing health is the root cause

'Elderly, mentally competent individuals may consider that their lives are complete when they have a chronic health problem (or a combination of more than one condition) which is causing them increasingly unbearable, irreversible suffering, with the additional loss of independence, purpose and meaning in their lives, so that they would now prefer to die rather than stay alive, especially as they dread what the future will soon bring.'

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# Cilla Black

Died August 2015 age 72

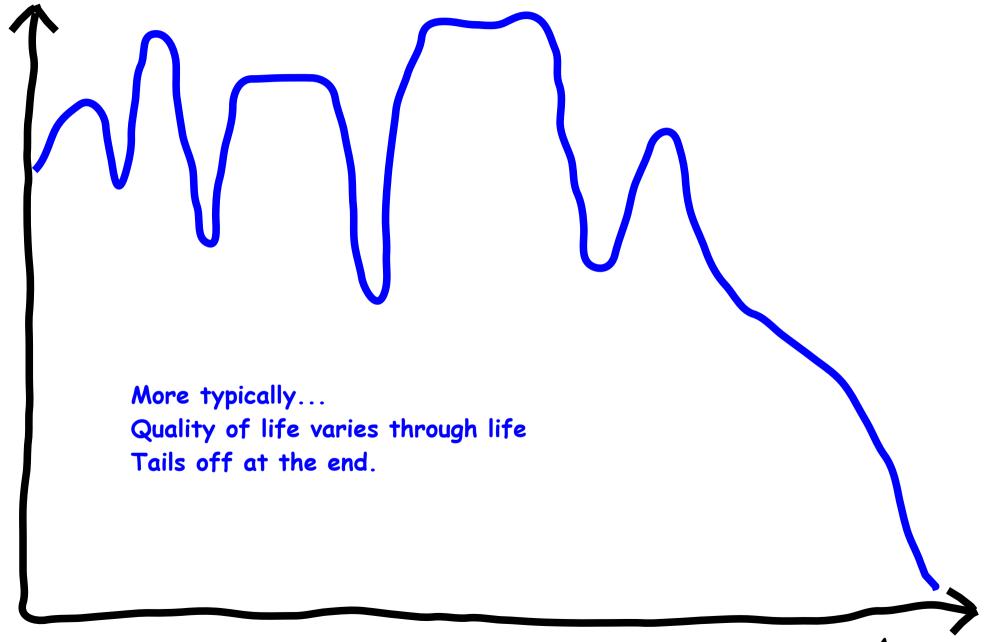
Cause: a stroke after falling and hitting her head after sunbathing in Spain

Daily Telegraph, August 3<sup>rd</sup>:

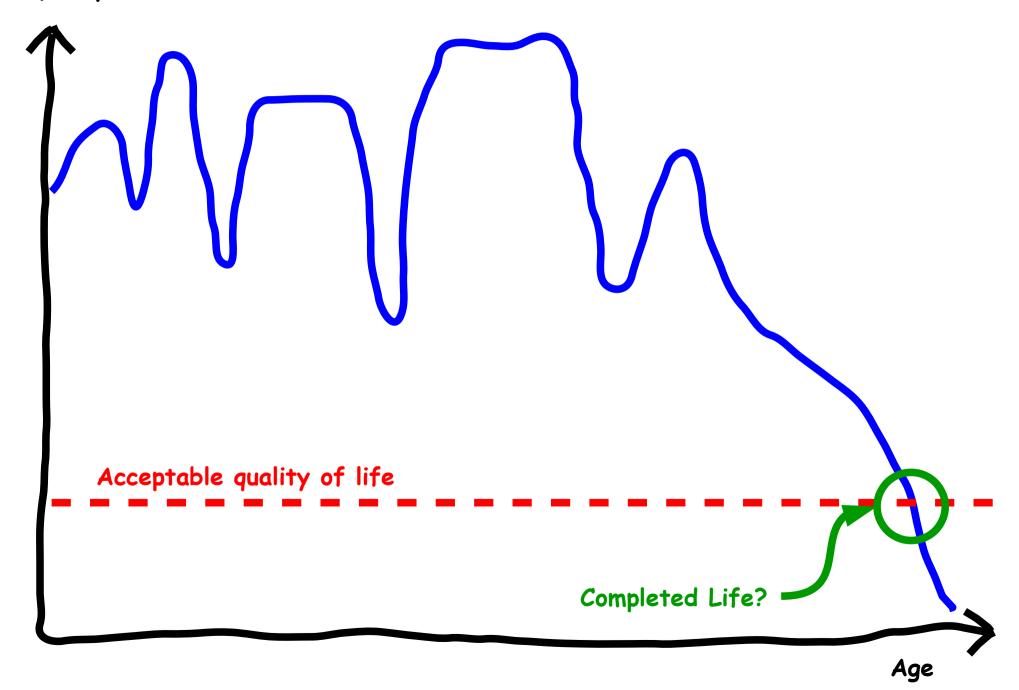
"She made no secret of her desire not to linger into old age"

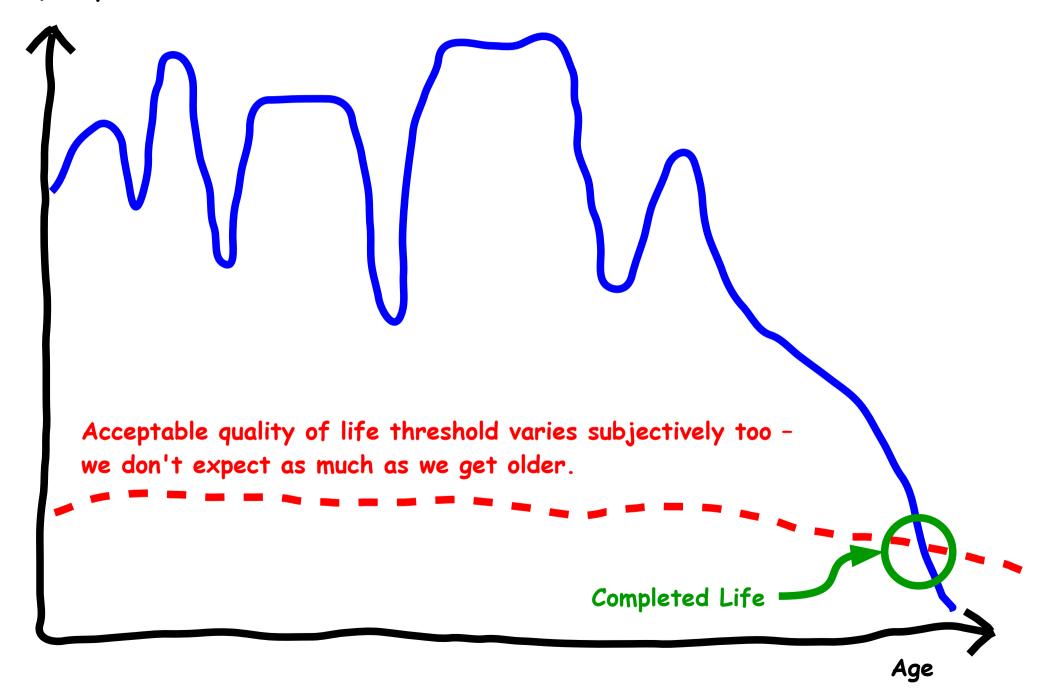
"The star spoke openly of her desire to die before illness could rob her of the ability to enjoy life"

"Seventy-five is a good age to go if things start to drop off. I don't want to linger. I don't want to be a burden on anybody. I know that 75 is only four years away, but I take each day as I find it"







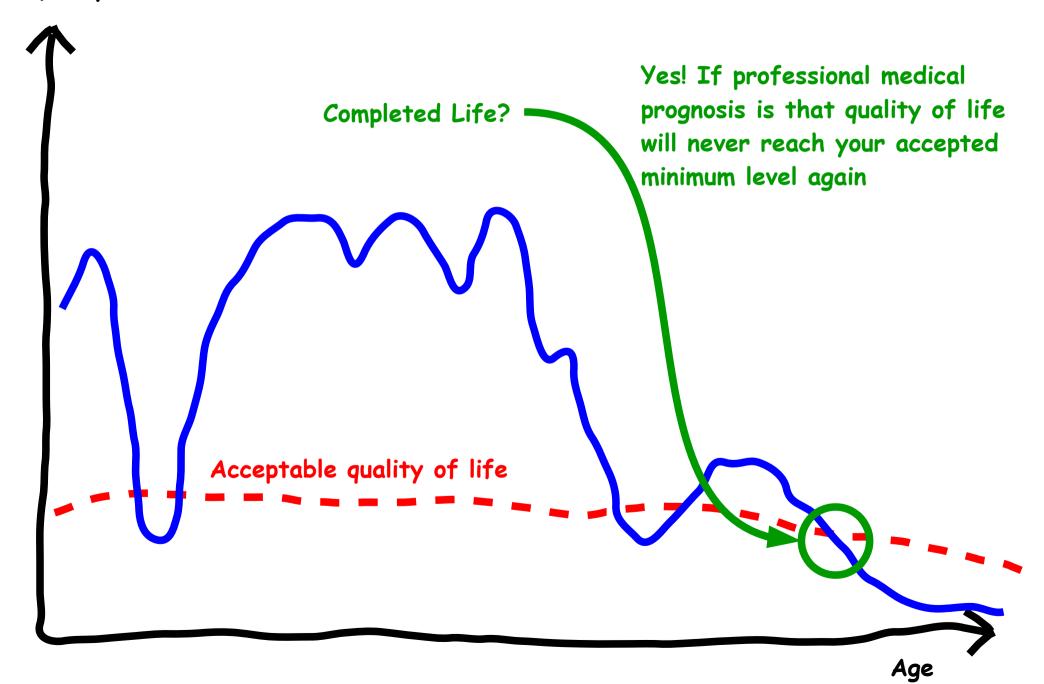


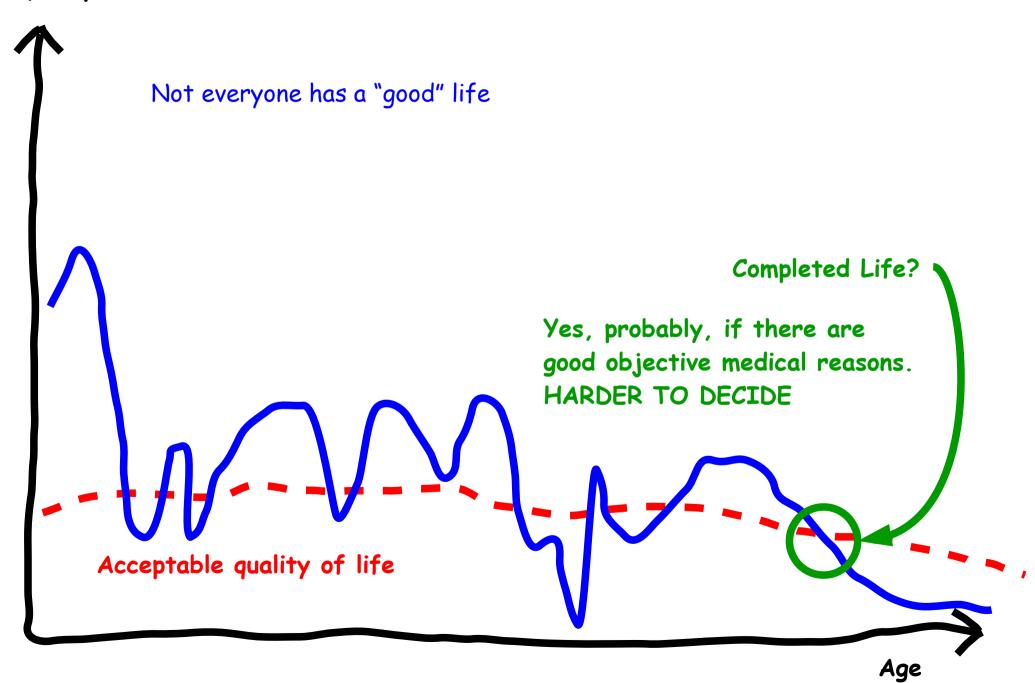
# Quality of Life Acceptable quality of life

# Quality of Life Acceptable quality of life Completed Life?

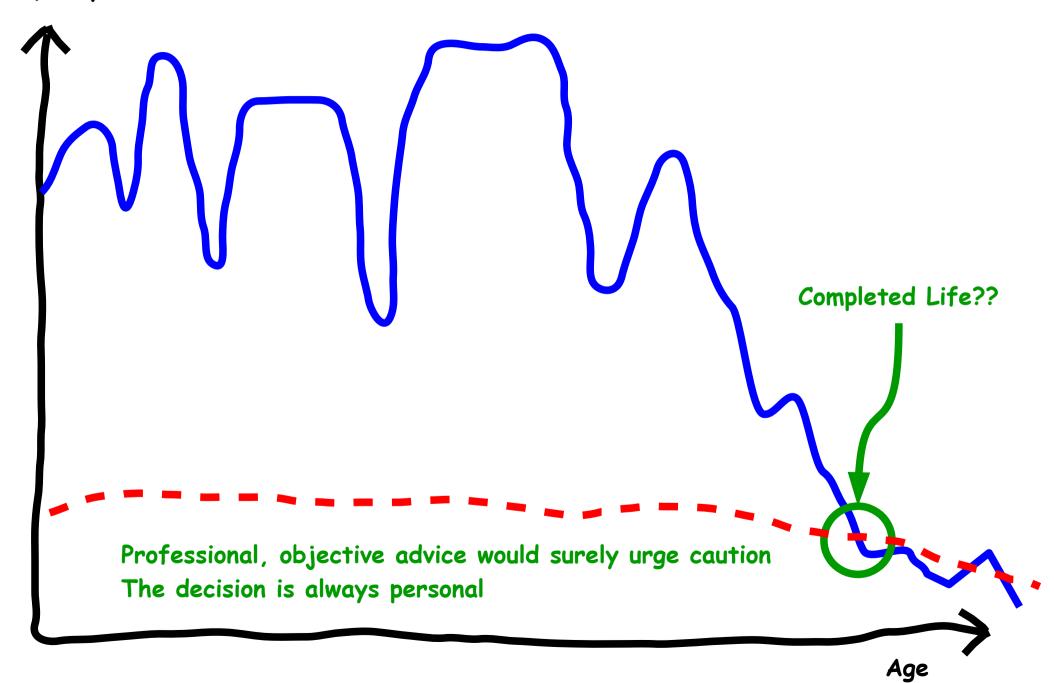
# Quality of Life Acceptable quality of life NO! Seek help: Friends, GP, Completed Life? Counsellors, Samaritans...

# Quality of Life Acceptable quality of life Completed Life? No: Seek professional realistic medical prognosis









# Depression / Mental health problems

'Elderly mentally competent individuals may consider that their lives are complete when they have a chronic health problem (or a combination of more than one condition) which is causing them increasingly unbearable, irreversible suffering, with the additional loss of independence, purpose and meaning in their lives, so that they would now prefer to die rather than stay alive, especially as they dread what the future will soon bring.'

Who is mentally competent? Dementia??

What is a "rational" decision?

# Rationality vs Irrational Autonomy

"Anyone capable of making decisions has an absolute right to accept or refuse medical treatment, regardless of the wisdom or consequences of the decision....

The temptation to base a judgement of a person's capacity upon whether they seem to have made a good or bad decision, and in particular upon whether they have accepted or rejected medical advice, is absolutely to be avoided."

Mr Justice Peter Jackson ruling on case of schizophrenic refusing leg amputation. February 2014

Would the same argument hold for medically assisted suicide?

# Feeling a Burden?

Nobody should be made to feel a burden.

Long term dependency makes people feel a burden... ...not legalisation of medically assisted rational suicide

Some people never want to be a burden.

"I simply do not want to be remembered as someone wholly dependent on others especially for the most personally private aspects of my life, nor can I tolerate the thought of outstaying my welcome, an increasing burden to my family, so that no one can be truly sorry when I die and they are free" Lady Warnock, First Annual SOARS lecture, 17<sup>th</sup> Sept 2010

Cilla didn't want to be a burden.

I don't want to be a burden to my children, to NHS, or to social services. ... but to my partner, if I have one at the time???

# Difference of opinion between partners?

Completed Life choices are very personal

Every relationship is different!

Huib Drion criteria – living alone

### Companionship and Friendship

# **Support**

A partner may want to provide it A partner may feel they deserve it

### Selfishness

Is it selfish to want to be cared for?

Is it selfish to want your partner to continue living when they don't want to? Is it selfish to want to end your life when your partner values your presence?

Help prepare your partner for life without you

# Jeffrey Spector

Died May 2015 age 54

Cause: Medically assisted suicide at Dignitas

Jeffrey had a spinal tumor which would leave him paralysed

"Rather than go late I am jumping the gun. I call it the least worst option. What I am doing is in the best long term interests of my family"

"I am going before my time but I am not scared. The tumour could stabilise but I cannot take that chance."

# Gill Pharoah

Died July 2015 age 75

Cause: Medically assisted suicide at Lifecircle

Gill was reasonably healthy.

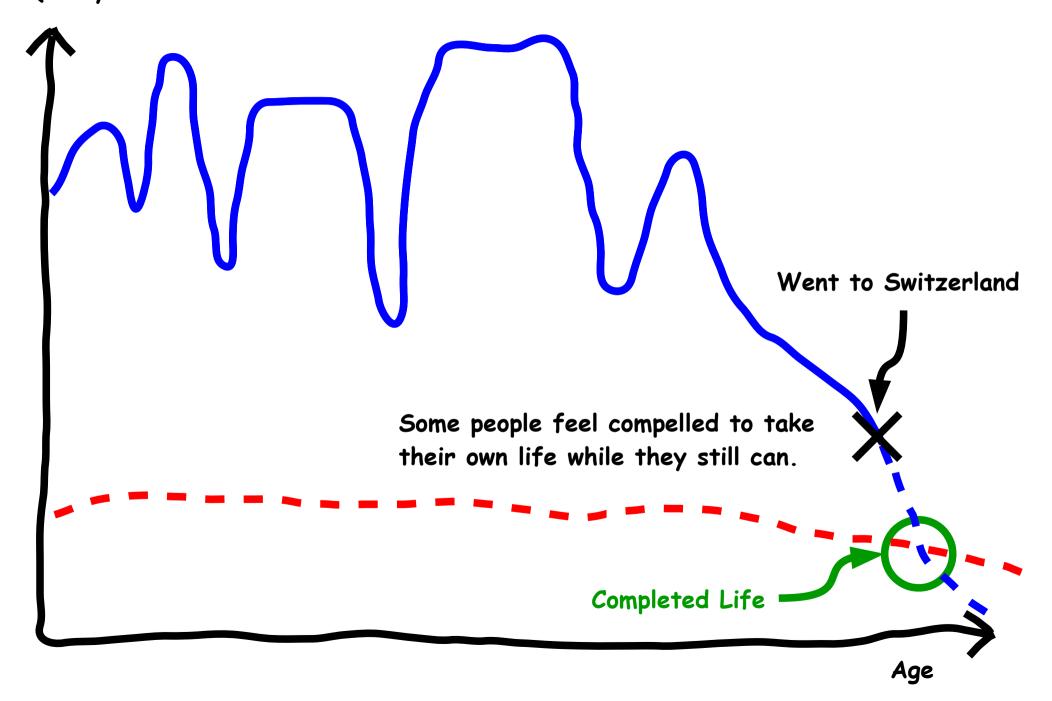
From Gill's article "My Last Word":

"I feel my life is complete and I am ready to die"

"I have to take action early on because no one else will be able to take action for me."

"I want people to remember me as I am now – a bit worn around the edges and not quite at my peak, but still recognizably me!"

http://yesiambovvered.com/my-last-word/



# My Mum



93. Now living in a dementia nursing home.

Confused and frightened.

In pain from a rectal prolapse.

Doubly incontinent.

### Feb 2015

"All I seem to do is to create problems for myself and other people."

"I just don't want to go on."

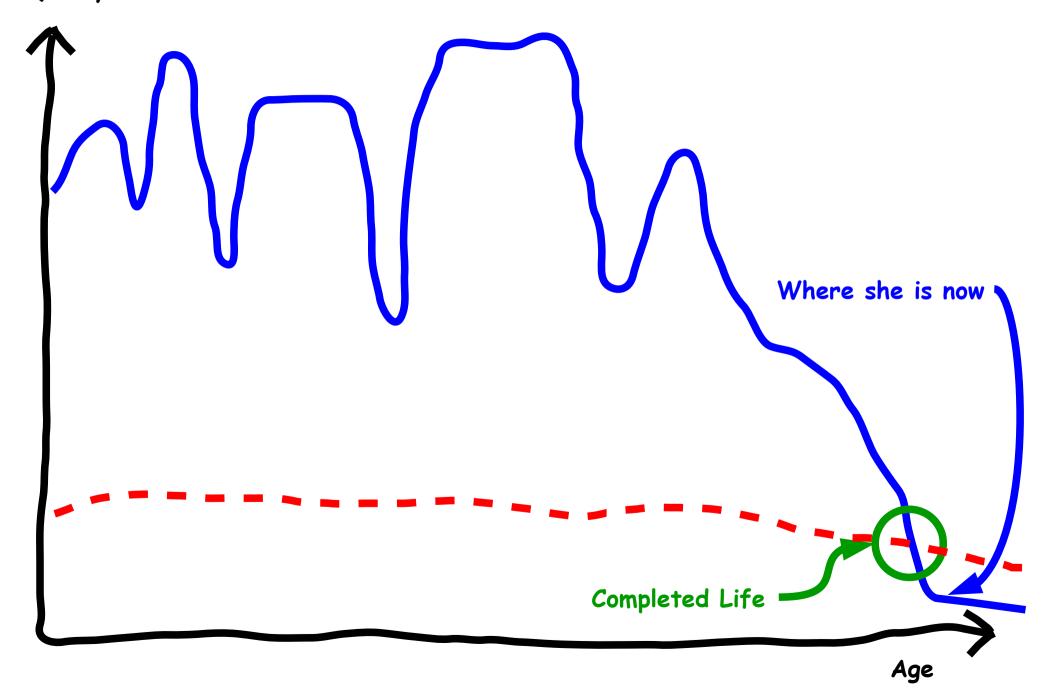
"There are times when I feel very much alone."

# August 2015

"I feel more frightened than ever before"

"I don't have the courage to ask for help"

"Isn't there anyone who can help me?"



# What Next for "Completed Life" concept?

"Completed Life" does NOT necessarily lead to decision to end life

### Make difficult conversations easier

- Help people talk about the issues and their feelings
- Help explain personal decisions for those who opt for MARS

# Public Right to Die Debate and Campaign

Beyond physical pain and 6 month terminal illness

# What Next – for SOARS?

Responding to the reasons for the Marris Bill defeat:

- 6-month terminal illness criteria
   Many high profile cases would not be helped because of this restriction
   The wrong approach for UK?
- Belief of "faith leaders" and some MPs that the current law is satisfactory Evidence gathering? Legal challenges?
- Belief that extending palliative care is a better approach
   Respect dying person's wishes even if they want MARS
   Widen the debate to issues beyond just physical pain.
- Belief by many doctors that medicine should be about extending life.
  A new medical specialty for MARS to be workable in UK?
- Protecting "vulnerable elderly people"
  Extended Advance Decisions.

# A Way to Protect "Vulnerable" People: Extended Advance Decisions (EAD)

A statement of future wishes added to an Advance Decision, e.g.:

"I wish to have the **option** of a medically assisted suicide if my quality of life is ever permanently reduced below the minimum level acceptable to me."

"For me, a minimum quality of life requires me to be:

- Free from intolerable pain
- Able to recognise close family and friends
- Able to hold a meaningful conversation

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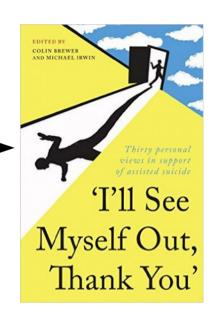
- Signed and witnessed:
  - When there are no health issues which seriously degrade quality of life
  - When the person is mentally competent and acting on their own free will
  - Periodically re-signed over a number of years to demonstrate a settled view
- Legislation might only permit MARS to people who had written a valid EAD
- · Important for judicial oversight

# What SOARS supporters can do

Talk about completed life issues.

With family – about your own wishes With friends - recruit some SOARS supporters! With local groups eg U3A – spread the ideas.

- Promote "I'll See Myself Out Thank You"
- Promote advanced decisions.
- SOARS Die-alogue groups.
  Brighton, Bristol, N London, S London... Your town/city?
- Share news, views, feedback with SOARS EC and offer help! SOARS wants to engage with its supporters. mail@soars.org.uk



# 6<sup>th</sup> Annual SOARS Lecture Questions? Discussion?