

Thinking Ahead in Palliative Care

Annual Conference 2011





COPD: planning for the end in a lifelong condition

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COPD: planning for the end in a lifelong condition

COPD: a lifelong condition

COPD: needs, care, and silence

COPD: the lack of story

HELP-COPD: a new approach

Chronic Obstructive Pulmonary Disease

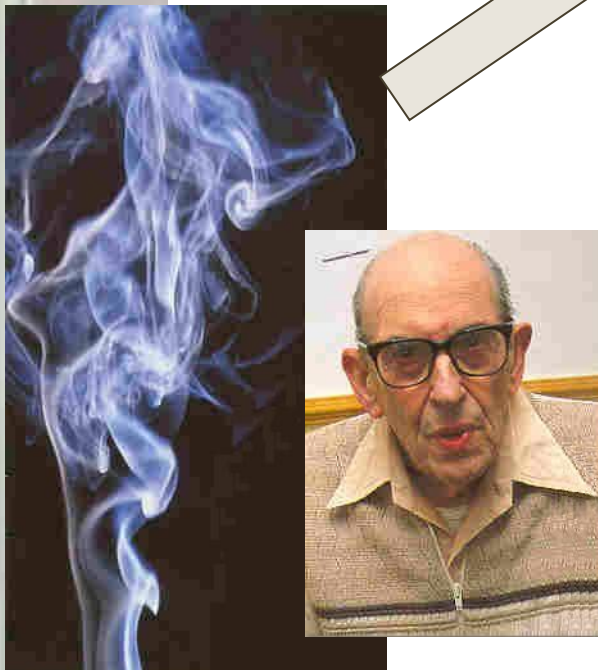
Chronic bronchitis

Chronic productive cough
Recurrent infection (exacerbations)

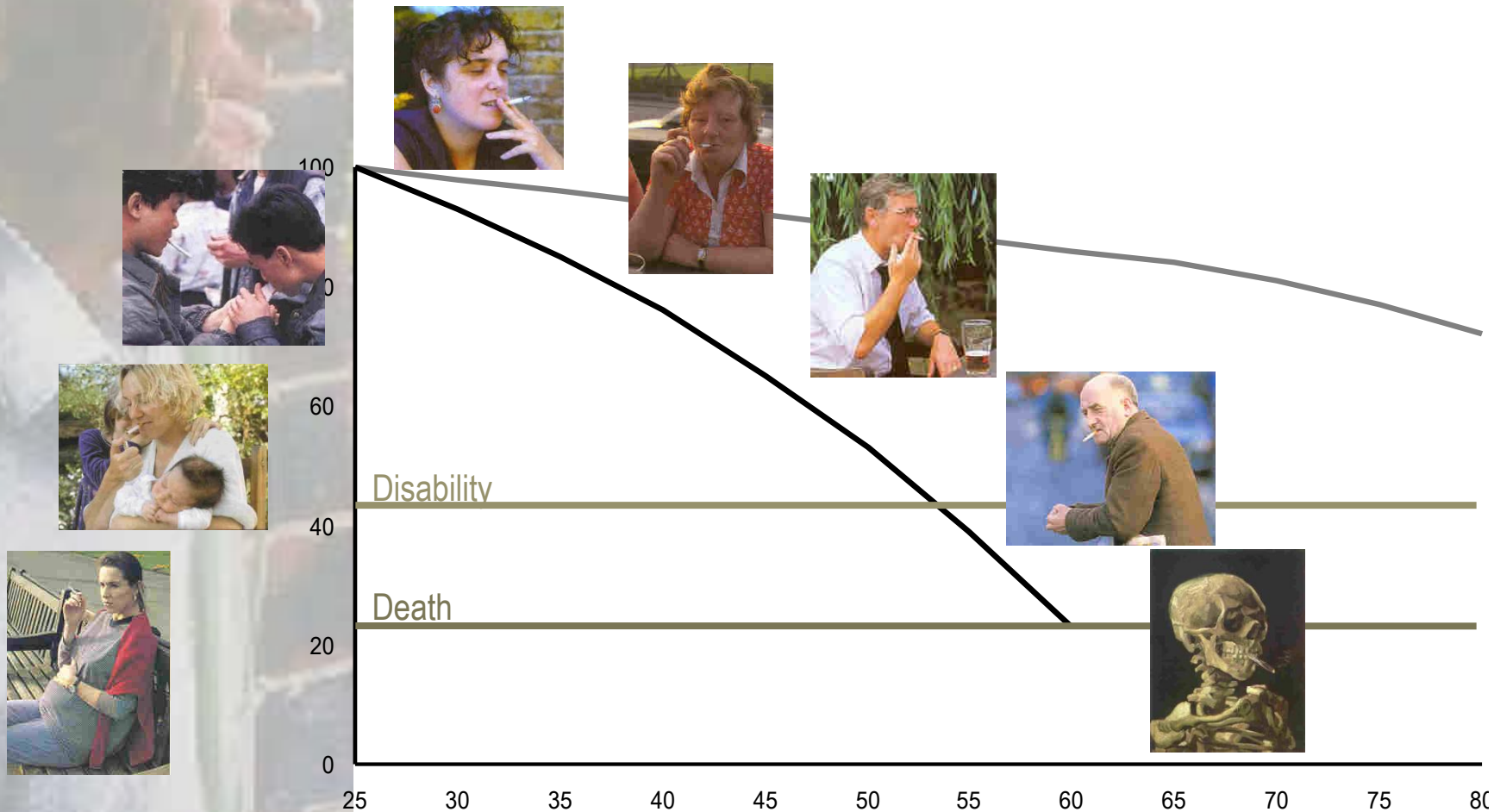
Emphysema

Damage to the structure of the lung
Collapse of the airways
Breathlessness
Sometimes low oxygen levels

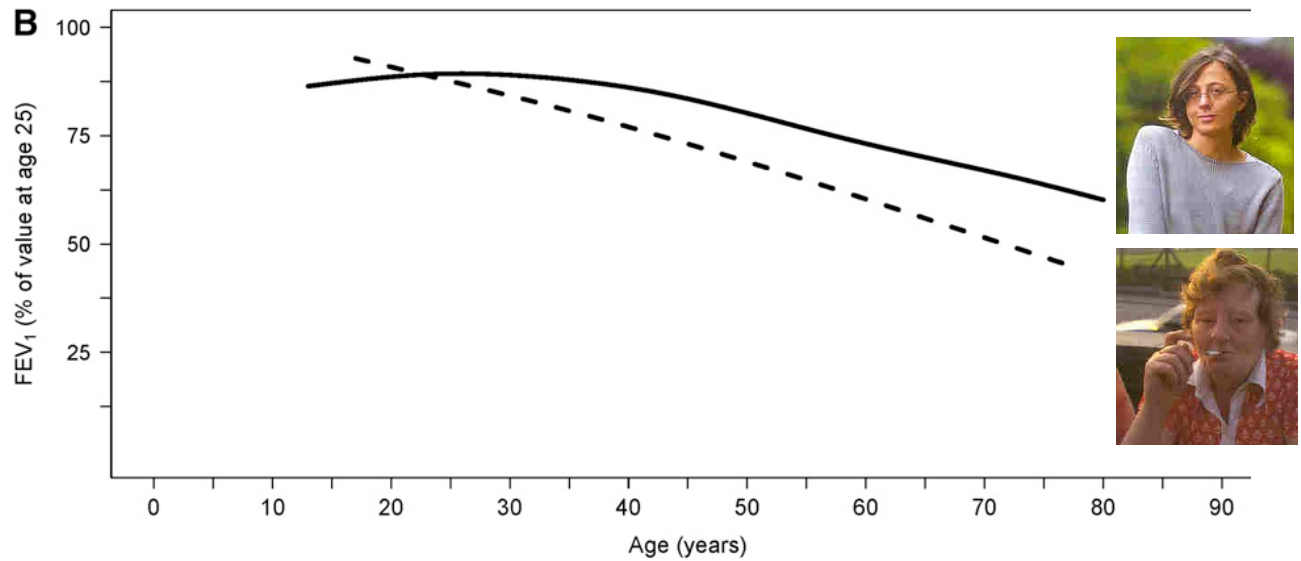
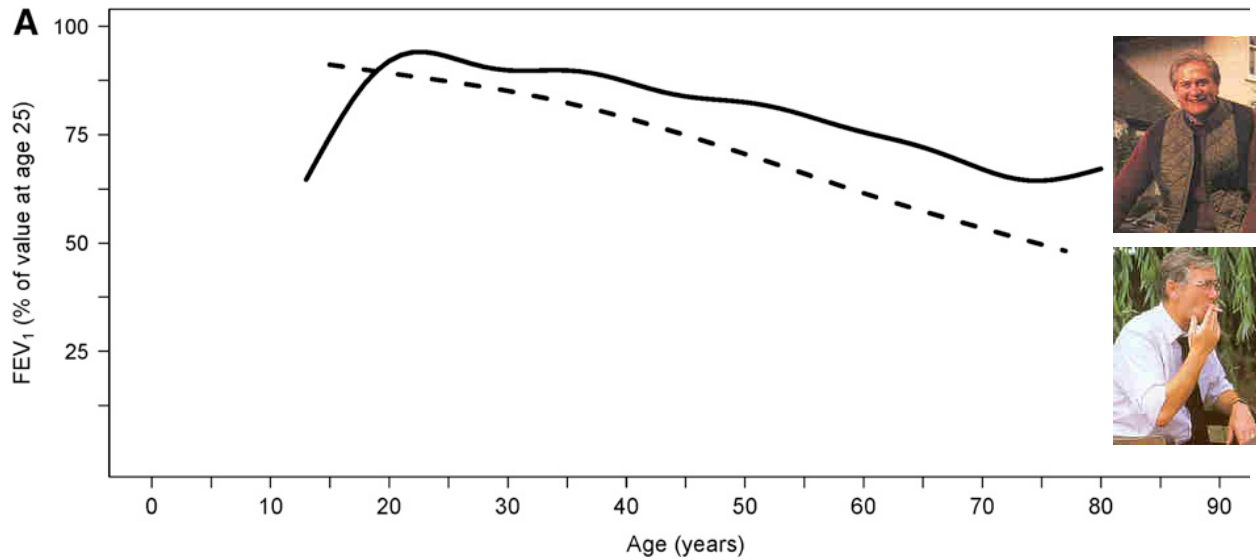
- Genetic factors
 - determine susceptibility to smoking
 - alpha₁ anti trypsin deficiency
- Occupational
- Pollution



The medical story of COPD



The Framingham 'Fletcher-Peto' Lung Curves



Indicators of a poor prognosis?

Hospital admission(s):

Being housebound due to COPD

Having a FEV₁ of 30 or less

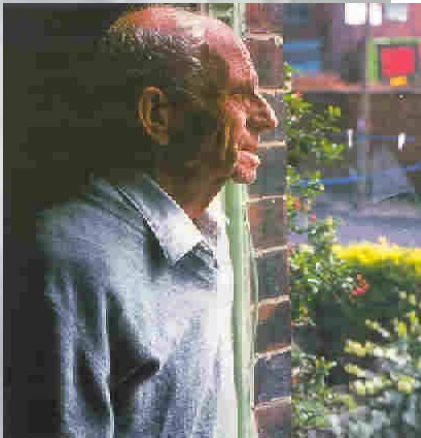
On long-term oxygen therapy

Depression, poor quality of life.

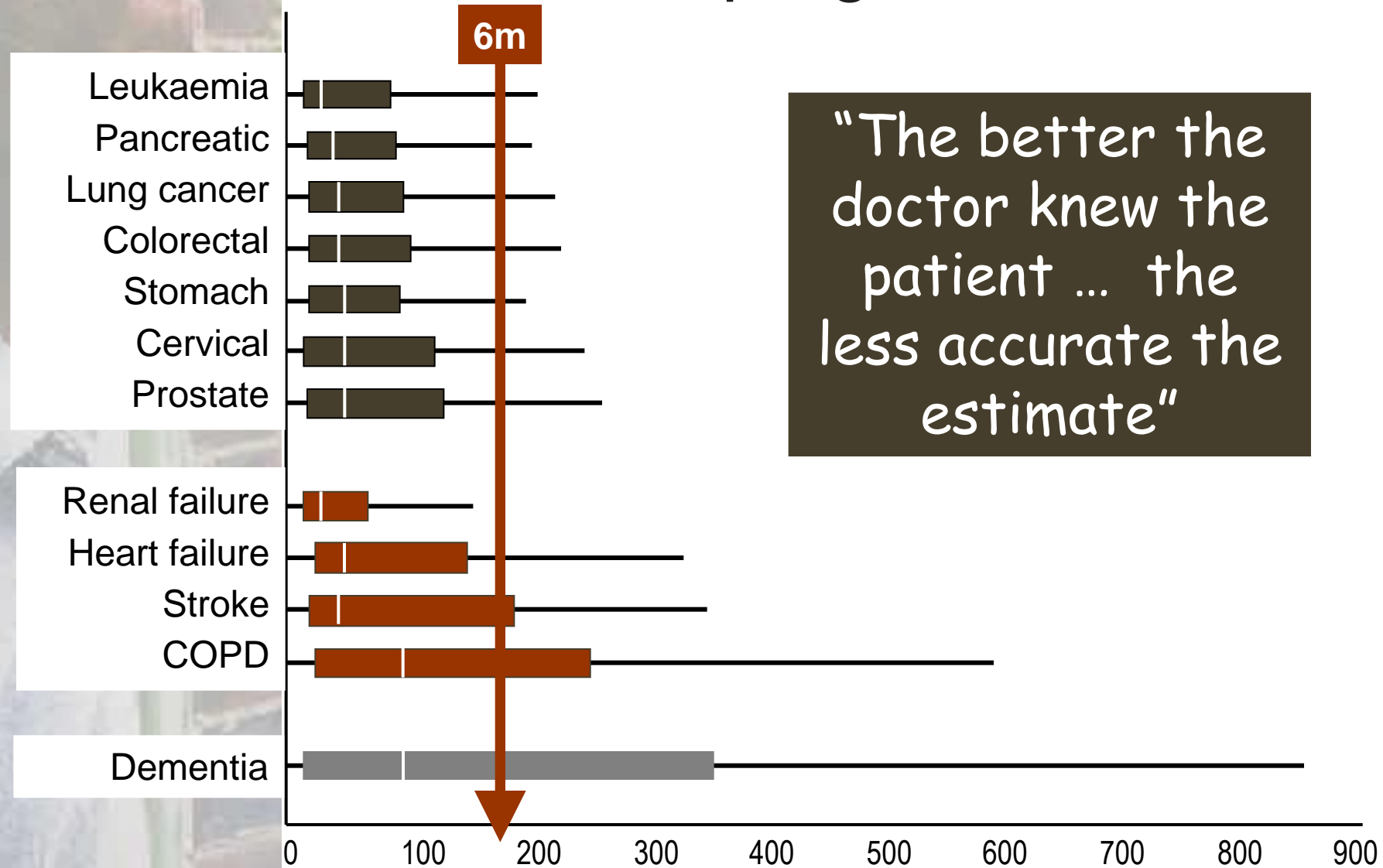
Low BMI

Co-morbidities (especially heart failure)

***Would I be surprised
if my patient were to die in the next year?***



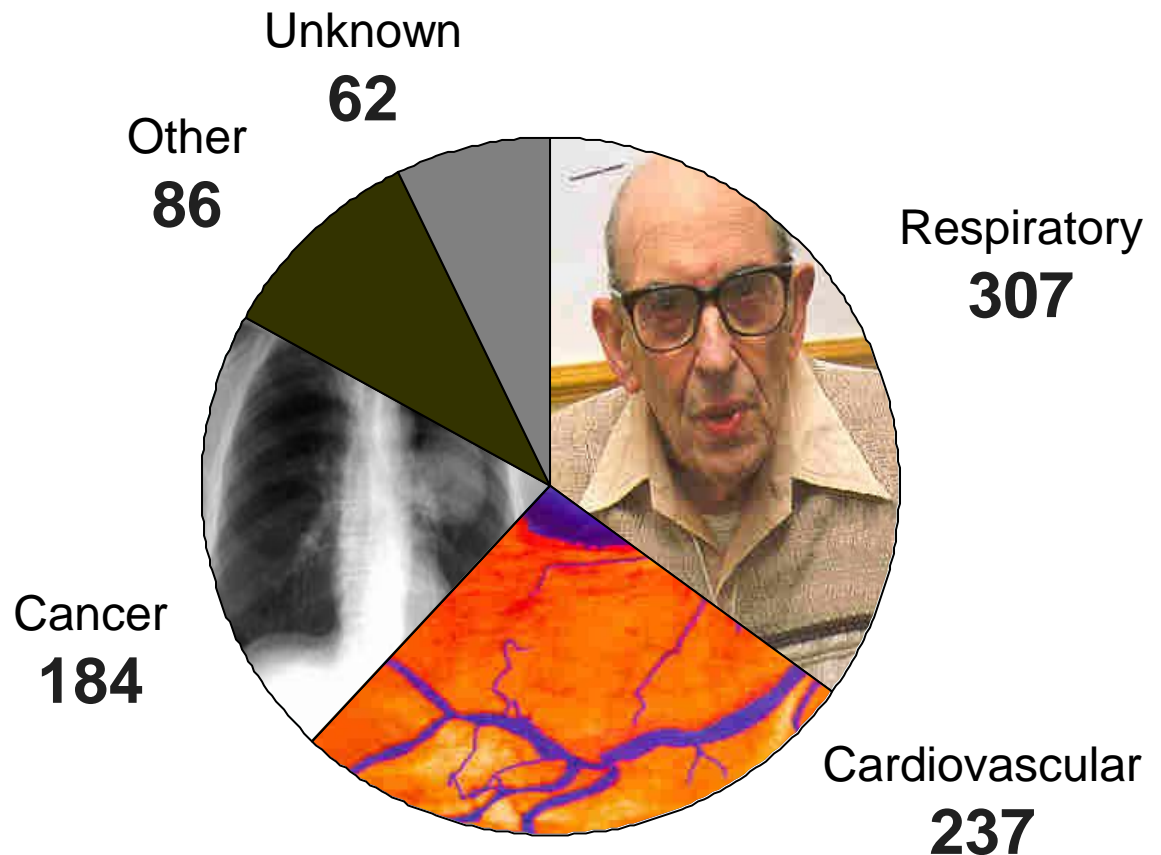
What is the prognosis?



"The better the doctor knew the patient ... the less accurate the estimate"

Causes of death

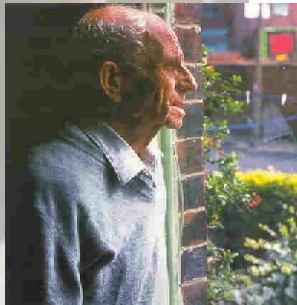
6,111 patients: **875** deaths over 3 years





COPD: needs, care and silence

Needs ...



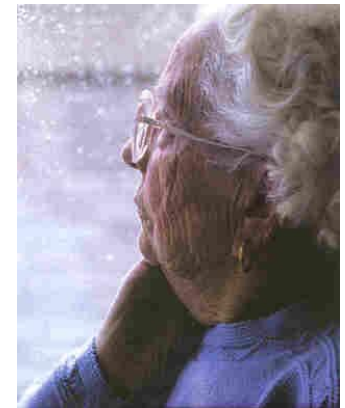
Social isolation



Disabling symptoms



Loss of social functioning



Lack of information



Inappropriate housing



Depression

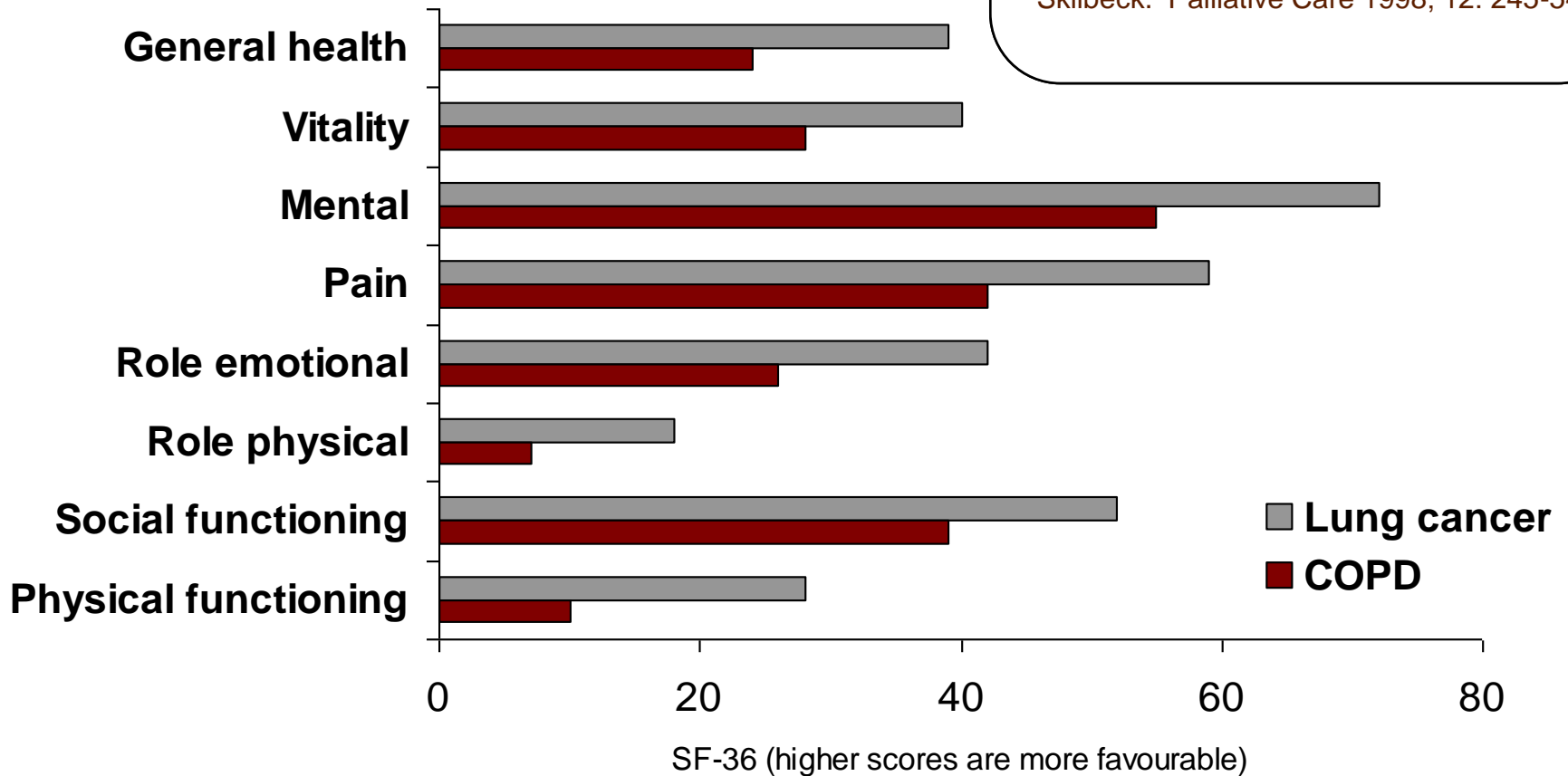


".. it will eventually go down hill like so there is not really any future in it" [F07.1]

Health status ...

"I'm that short of breath,
I get breathless even
going to the toilet"

Skilbeck. Palliative Care 1998; 12: 245-54



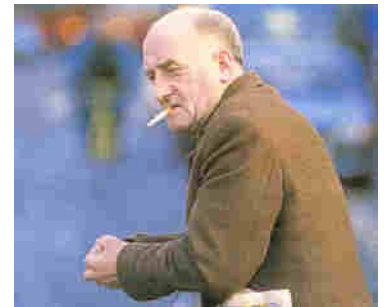
Breathlessness

145 patients from 44 South London practices

Mean age 72 years

Current smokers: 34%

Mean FEV1 : 29% predicted



Interview administered questionnaires



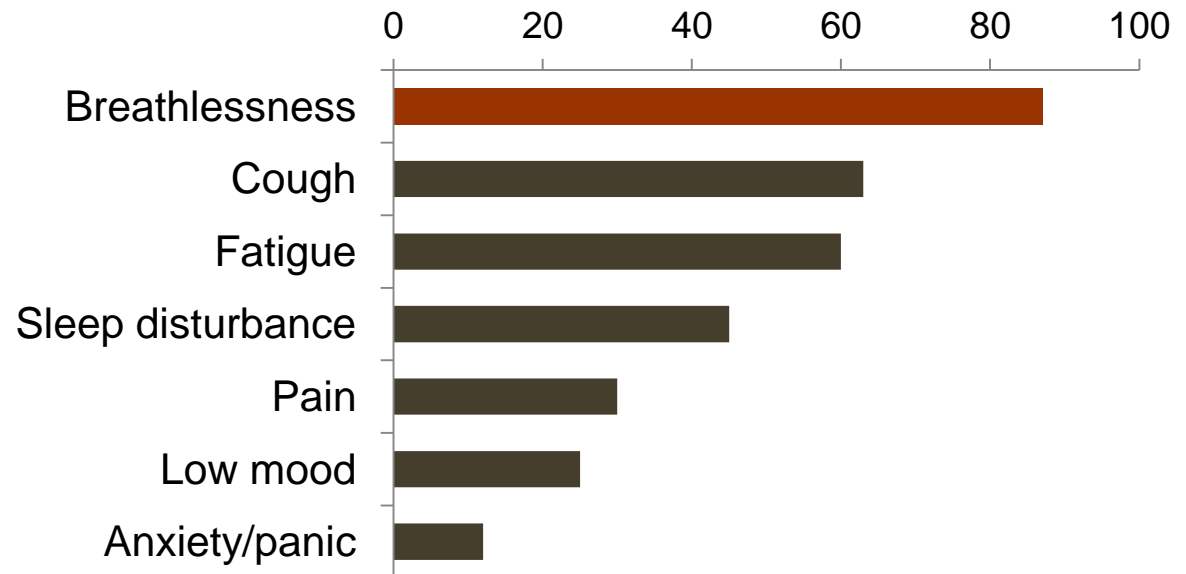
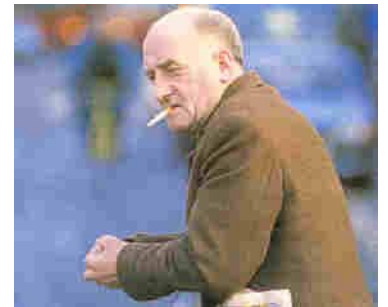
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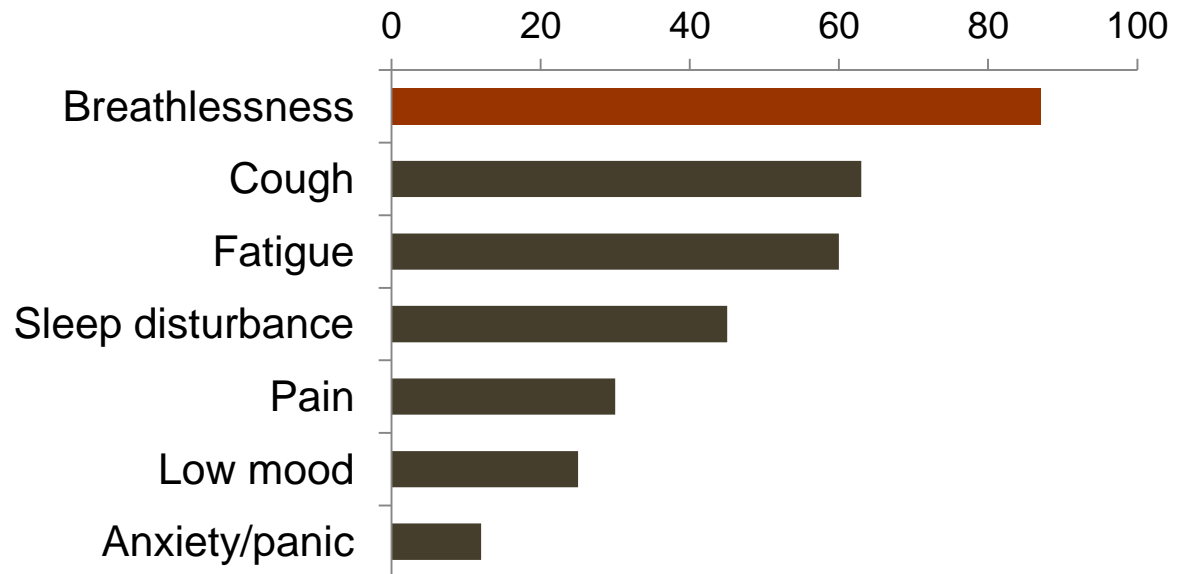
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Breathlessness

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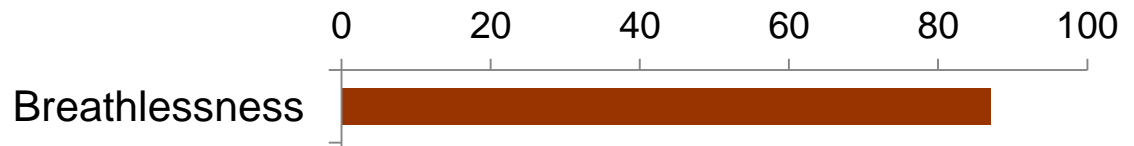
- 8%** MRC:1–3 Breathlessness at worst resulting in slower walking than contemporaries
- 51%** MRC: 4: Stops for breath after walking 100m
- 41%** MRC: 5: Too breathless to leave the house, or breathless dressing and undressing



Breathlessness

145 patients from 44 South London practices

- 8% MRC:1–3 Breathlessness at worst resulting in slower walking than contemporaries
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- 41% MRC: 5: Too breathless to leave the house, or breathless dressing and undressing

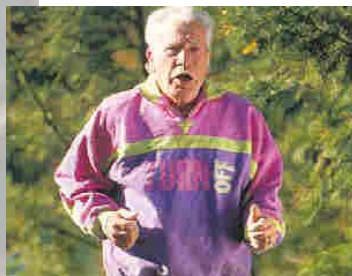
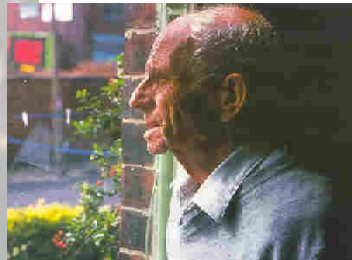


**“Severe breathlessness
in advanced COPD is
a daily reality”**

Breathlessness ladder

Intractable breathlessness affects 46% of people with very/severe COPD

White P, et al. ERS 2011



Intractable breathlessness



Increasing breathlessness

Onset of breathlessness

Referral to a specialist breathlessness service

Oral opiates in low doses
Consider anxiolytics
Oxygen only if hypoxic

Non-pharmacological measures to ease the sensation of breathlessness

Regular long-acting bronchodilators

Short-acting bronchodilators as required

Inadequate services

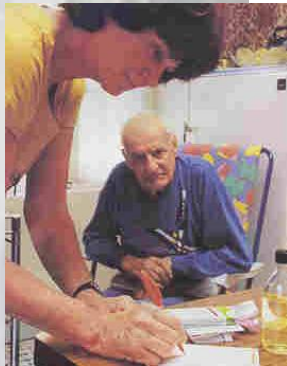


Difficulty accessing care

Hospital avoidance

Limited resources
Reactive care

Time
Workload



"We really only see him when he's not well and we never take the time to go out and chat to him about these things when he is feeling a bit better, you know," [F08: GP]



I - The silence of people with COPD

"Oh I don't ask for anything do I? So, if I asked I think I would get, I am quite sure I would because I do get excellent help from the doctors.

The 'silence' of patients with end-stage COPD

"Patients with end-stage COPD do not actively express a wish for help because they do not consider their limitations to be abnormal and because they do not realise that there are possibilities to improve their situation"

Habraken *et al.* Br J Gen Pract 2008; 58: 844–849



II - Lack of existential needs

Do you want more information about what the future holds?
What will happen if you get another attack or episode?
Have you made plans about care you might or might not like in the future?
Have you discussed plans or thoughts with anyone about future care?

Would you like the opportunity of discussing future care with someone?

Do you feel you have been able to show how you are feeling with family and friends?

With your GP, do you feel able to ask everything you want to?

Is there any treatment that you would not want again?

“...concerns about the meaning or value of life in relation to dying or possible death”



II - Lack of existential needs

35% had considered practical issues



6% had plans that included making a will, DNAR orders, planning funeral arrangements or palliative care



People with advanced COPD in primary care seldom wished to frame their needs within an 'end-of-life care' context

II - Lack of existential needs



102 had had a hospital admission in the previous 2 yrs

101 thought that the admission was the right action

86 would want another admission



None felt admission was futile, none expressed existential concerns about admission, and none wanted to risk treatment at home rather than face admission.



A possible explanation...



‘The Breath of Fresh Air study’

Dr Hilary Pinnock
Dr Marilyn Kendall
Professor Scott Murray
Dr Allison Worth
Professor Aziz Sheikh
Mr Mike Porter
Professor William MacNee
Dr Pam Levack

Dr David Chinn
Sr Anne Aitken
Sr Colette Lamb
Sr Janet Winter

Lay Advisory Group



Serial in-depth interviews

6-9 monthly over 18 months

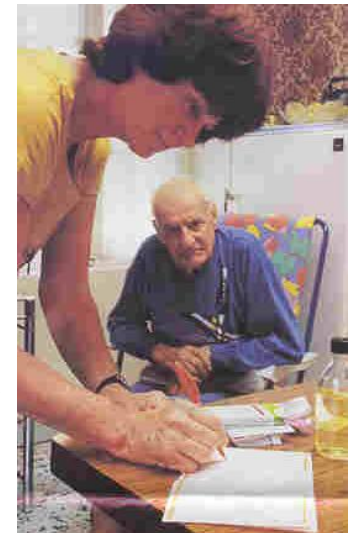
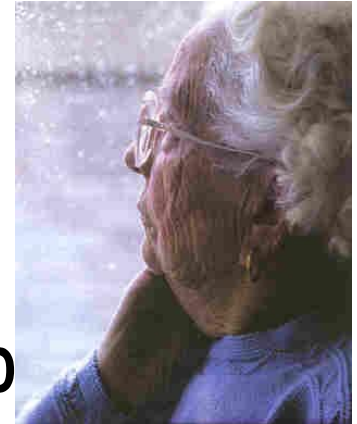
Patients' experience of having COPD

- main concerns
- views on care and treatment,

Carers' needs and concerns

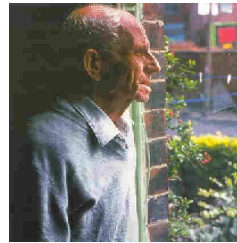
Professionals perception of needs

- services provided
- barriers to the provision of care.



**Bereavement
interviews**

Participants



Male: **14**, Female: **7**

Mean age = **70.9 yrs** (SD 8.0)

Range 50yrs to 83yrs

21

Ex-smokers **16**, Smokers: **5** (Mean 53 pack years)

Spirometry: FEV₁ 0.63 (0.24), % pred **26%**

MRC dyspnoea score **4.6** (0.7)

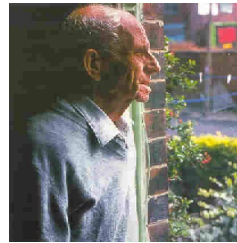
Symptoms for mean **17.8** years

9 used oxygen

13 had had admissions (**6** with respiratory failure)

19 have one or more co-morbidity

Interviews



21

21 patients (10 with carer), 1 daughter, 16 professionals

16

16 patients (9 with carer), 2 daughters, 8 professionals

10

8 patients (2 with carer), 3 professionals

10

7 patients, (1 with carer), 5 professionals

11

Bereavement interviews (2 wife, 3 nurses)

92



The lack of 'story'

Two studies



- 20 people with inoperable lung cancer
- In-depth interviews
- Every four months for one year
- Patient, family and professional carer



- 20 people with severe COPD
- In-depth interviews
- Every six months for 18 months
- Patient, family and professional carers

Lung cancer stories

... it might be best if you kind of started at the beginning really, of how you first found out that you were ill, and ...

“I was just going to say that, it was a shock. Well going back, end of October, I thought I had, there was a lot of flu on the go, I thought I had the flu, I felt terrible, this went on for about 3 weeks, I went to the GP ‘Oh take paracetamol, it’s a virus’, I went back about a week later, I said ‘Look I’m really, really terrible’, ‘Oh, it’s Ok, it’s a virus, just carry on’, so I went back to the Doctor I think it was eh, 30th December, I ended up going to the Doctor, the day before Hogmanay, and eh, she right away said ‘No, this has went on too long’. It was a different, it’s the same practice, but a different Doctor, and then she’s got the needle out, I said ‘I hate needles’, ken, so she said ‘Too bad’, she done all the tests, sent me for an x-ray along to Hospital K., I got a phone call the next day from the Doctor saying ‘Go and collect prescriptions, they had found a shadow on my lung’, but they obviously thought this was some infection I had, so, there was a holiday period, the Hogmanay and that, so I had to go back and see her a week later, once all the tests were done. So I went in and seen her and she looked at me and she said ‘You know, you’re a very sick man. We don’t know what’s wrong with you, it could be TB’”

Mr MM

[3 sides of A4]



The first COPD interview....

Marilyn's field note

*How can I do narrative research
with people with no stories??*

COPD stories-typical transcript structure

So really I've come as I said to listen to you and find out what has been happening. When did you start having trouble with the breathing?

Must have been the beginning of the 80s I'd say, yes

Oh, its been a long time then?

Aye, I was in the hospital, then transferred to Glasgow for 4 months, and they didn't know what it was, they thought it was pneumonia and och they didn't know what it was but actually my wife was sent for twice, you know

Really, it was that bad?

I was in there for 4 months

Mr F



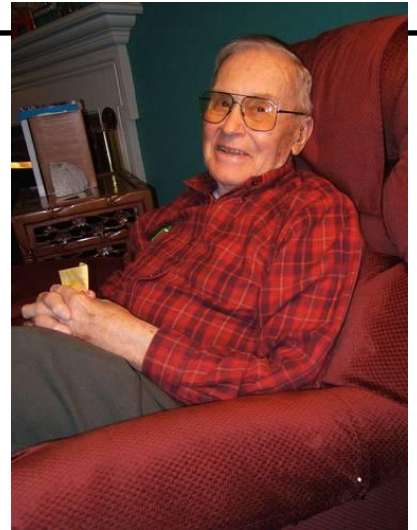
A story with no beginning....

Can you tell me how your illness started, and what has happened since then?

A story with no beginning....

“I’ve had it forever”

T06.1 How it started is anybody's guess; there is no way of knowing. so it has always been my belief that something happened in my younger years that started the damage



A story with no beginning....

“I can't find a beginning,
so I'll pick on a milestone”

T01.1 About 18 months ago. It started off as a chest infection which I couldn't get rid of.

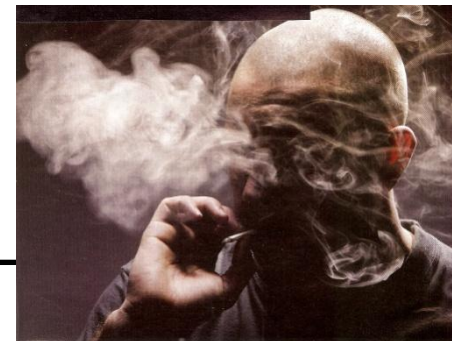


F04.1 I had a major op in the Infirmary in, 1985 was it? No, no, 94, 93. I had an abscess on the bowel. They thought I had cancer. I was worried eh.

A story with no beginning....

“I can't say 'when',
so I'll tell you 'how'”

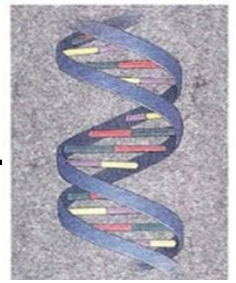
T02.1 Well first of all it was with smoking.
.... I was a smoker and just couldn't
stop. I go right back to 1980.



F07.1 They blame smoking but working in a
mine, I spent years down in the mines
so I swallowed a lot of stoor that
doesn't help any of us



The exception



Wife I suppose the first place to start would be in diagnosis, really wouldn't it, official diagnosis was August 98.

L06.1 Slowly deteriorating from about 92/93, I started noticing getting breathless and getting worse and worse. Now I am a carpet fitter, and I mean a lot of flats and everything, it was up and down stairs and this is getting worse. I was a smoker but it never bothered me before so I thought I have to stop this, so I did cut down on cigarettes, went to the Doctor and got inhalers, take that home try that one, try that one not working, try that one, changed doctor and that is when in 98 he finally found out that it was this Alpha 1 thing. Nothing they could do for it so that was the day before we got married.

Interviewer: Oh my goodness!

Wife Day before the wedding we found out he was basically a dying man



Interviewer: Good heavens how awful

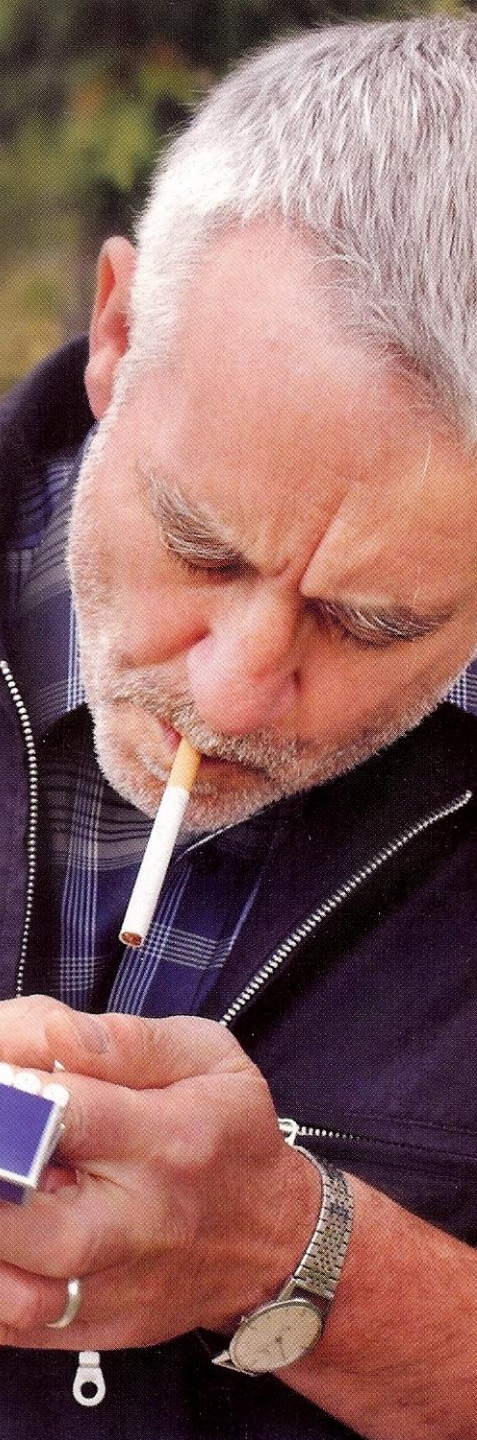
L06.1 So my lungs was away and I was 41

Interviewer: That must have been a shock

Wife Slightly!

L06.1 Because I was always active as a worker like, 18 hours a day sometimes, always busy then suddenly it was stop, because I couldn't do it any more

... a middle that's a muddle ...



... a middle that's a muddle ...

"I'm only ill with exacerbations..."

T03.1 "I'm all right if I sit still. It's all just part of getting older I suppose"



T01.1 "Now I'm fine but I had a bad time over Christmas. I got a chest infection at the beginning of December and it took me till Feb to shake it off. But no, I'm fine again now. Back to normal"



People like Mr X who doesn't really bother us that much, we really only see him when he's not well.

[F08:GP]

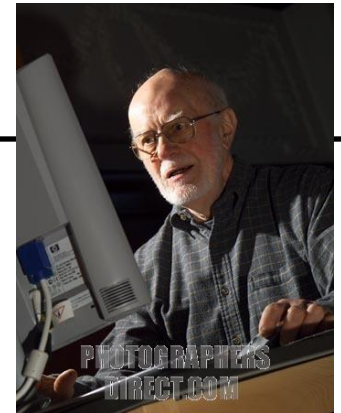


The exception ...

Coming to terms with long-term illness

L06.1 wife "Yes, as I say we have been through the whole spectrum of emotions with it.

The denial part is the hard one because... now we can discuss things quite openly without fear of ornaments getting thrown and things like that but when he was going through his denial phase, it was all my fault"





... an end that is unpredictable ...

... and unlooked for ?

... an end that is unpredictable ...

“ ‘They’ don’t know when I’m going to die”



“And of course because there are people who live with COPD for years, years and years ... it wouldn’t have surprised me if she had maybe died before now but on the other hand it is very difficult to know how long she might carry on” [L03:GP]



“...he has been knocking on death’s door a few times now. I think the last time he came into the Royal we really didn’t think he was going to make it through the night, never mind go home” [L06.1 Hospital doctor]

... an end that is unpredictable ...

“ I don't know when I'm going to die”



So, I'll come and see you again in about 6 months time, see if anything has changed and what is going on

LO5.1 “If I am still alive in 6 months time”

I hope you will be, do you think you might not be?

LO5.1 “I don't know”

... an end that is unpredictable ...
... and unlooked for ?



"Very occasionally I'll bring it [death] up but no...I don't think generally they think they are going to die of that, of COPD" [T01 nurse]



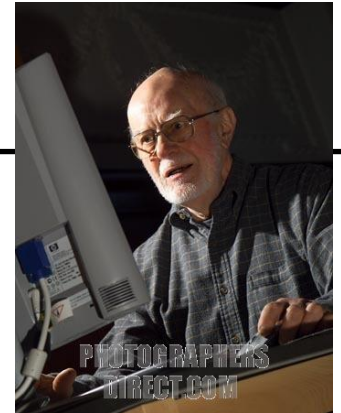
"..we are all going to die aren't we? But it is a case of picking the time and place [to discuss it]" [L06.1 Hospital doctor]

The exception ...

Anticipated and planned for

"It wasn't a difficult decision for me actually because having spoken about it at length before, you know when he had bad episodes about you know, what we wanted to happen etc"

"... as soon as Prof came in January and said 'Well look, we have got some tough decisions in front of us', I said 'Well, actually, no we haven't" [L06.1 wife]





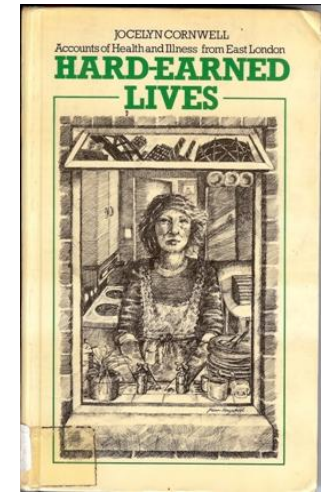
...and a framework...

Not so much an illness, more a 'way of life'



Hard Earned Lives

Classification of health problems



'Normal' illness

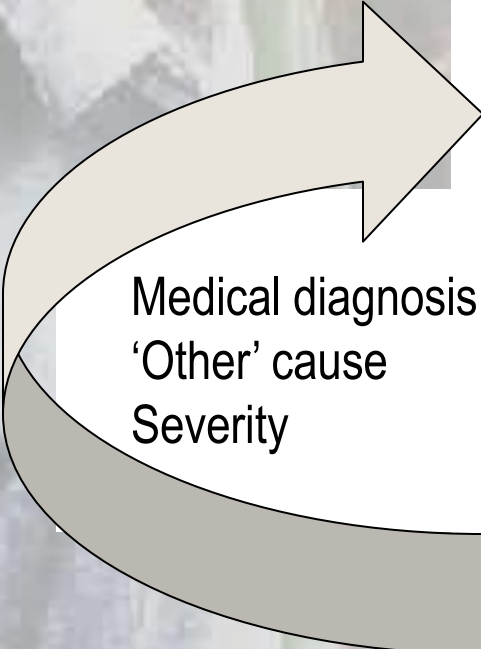
Common infections, childhood ailments

'Real' illness

Disabling and life-threatening chronic diseases
(cancer, cardiovascular disease, diabetes, accidents)

'Health problems which are not illness'

Natural processes or 'related' to person's life
(ageing, menstrual problems/menopause, arthritis, tiredness)



Medical diagnosis
'Other' cause
Severity



Not so much an illness, more a 'way of life'

"See he was a smoker...."

"It's all just part of getting older ..."

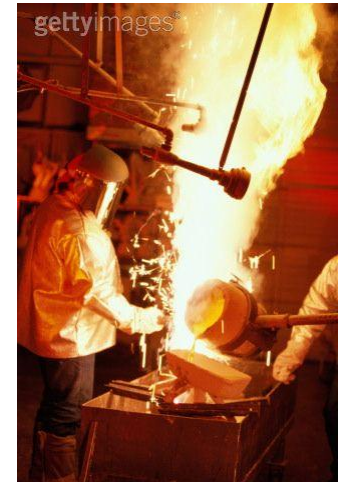
"I've never mentioned it to anybody"

"You just do the best you can with what you've got"

'Health problems which are not illness'

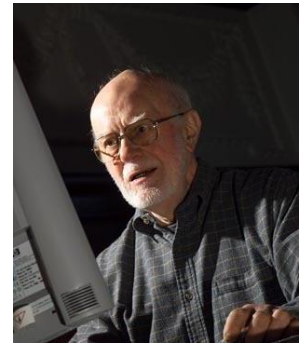
Natural processes or 'related' to person's life

(ageing, menstrual problems/menopause, arthritis, tiredness)



Not so much an illness, more a 'way of life'

"I suppose the first place to start would be in diagnosis, really wouldn't it" [L06:wife]



Alpha1 anti-trypsin deficiency

Medical diagnosis
'Other' cause
Severity

'Health problems which are not illness'

Natural processes or 'related' to person's life
(ageing, menstrual problems/menopause, arthritis, tiredness)

Not so much an illness, more a 'way of life'



"I'm all right if I sit still. It's all just part of getting older I suppose"

[T03.1] 70 yr old female, ex-smoker. 4 admissions (in with respiratory failure)
FEV₁ 47% predicted, MRC: 5, SGRQ: 74

Now I'm fine but I had a bad time over Christmas. But no, I'm fine again now. Back to normal.



[T01.1] 75 yr old male, ex-smoker.
FEV₁ 28% predicted, MRC: 5, SGRQ: 60



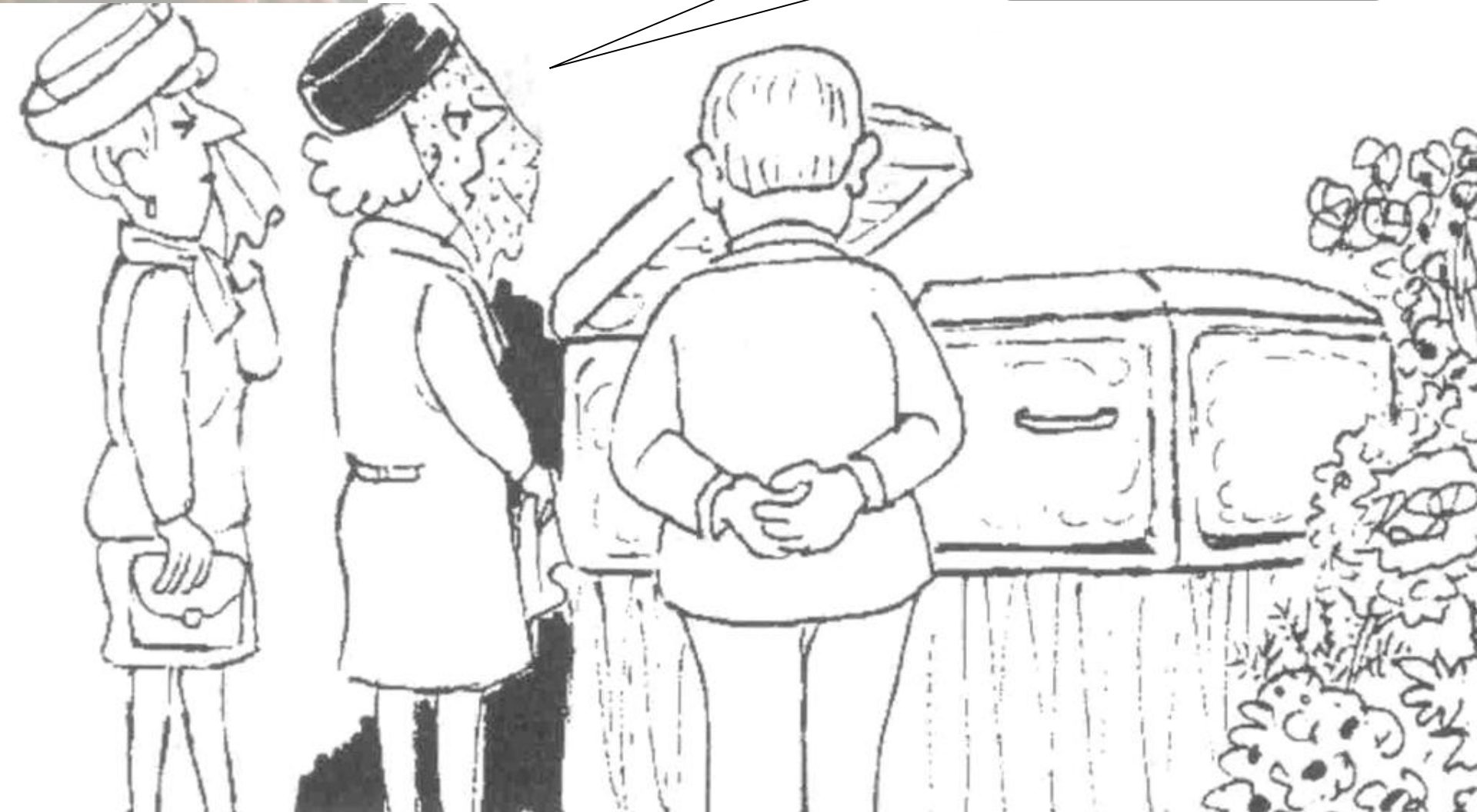
"..we are all going to die aren't we, but it is a case of picking the time and place [to discuss it]" [L06.1
Hospital doctor]



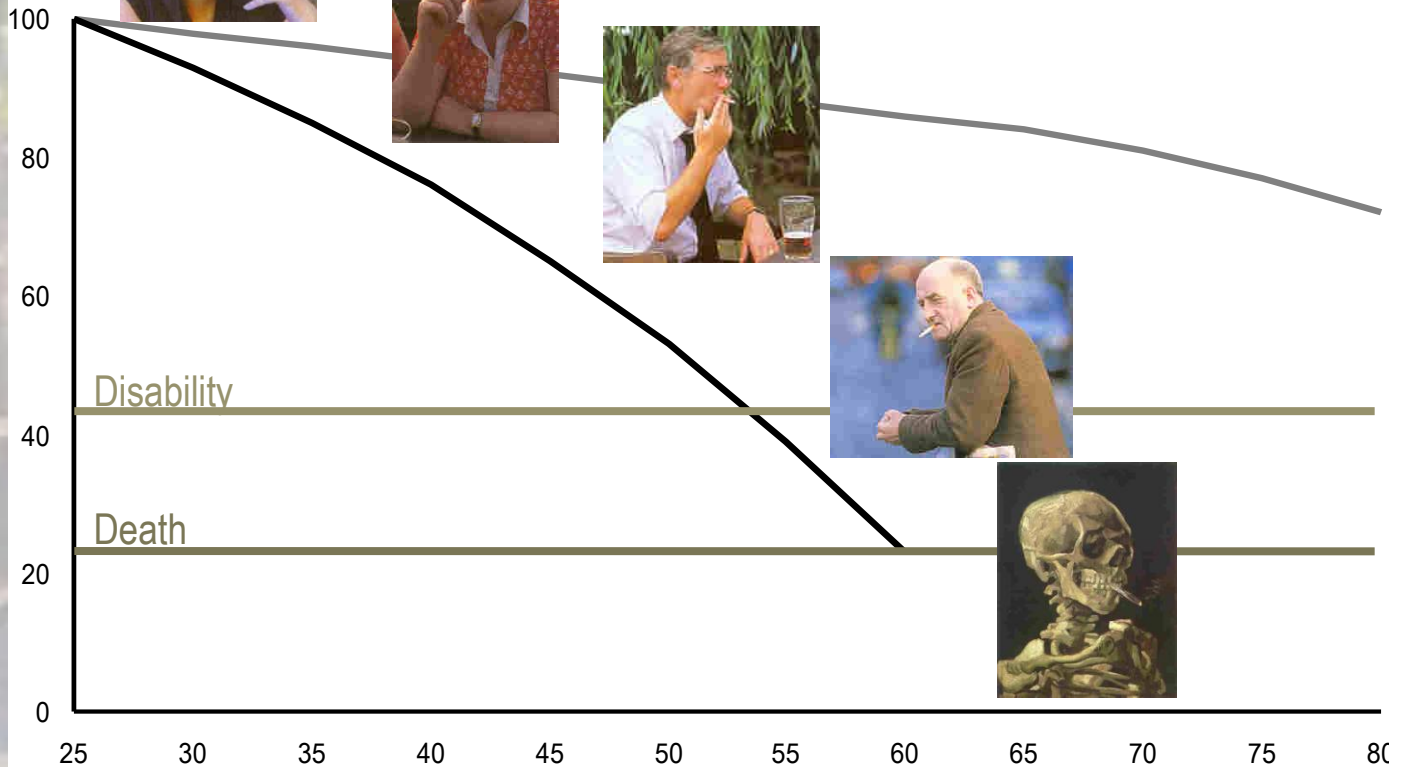
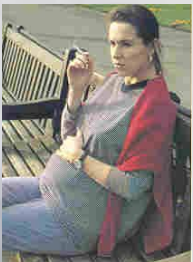
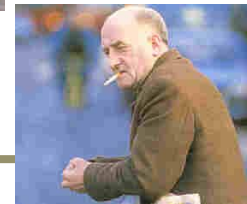
A way of life



It's the first time
I've seen him
without a cigarette
in his mouth



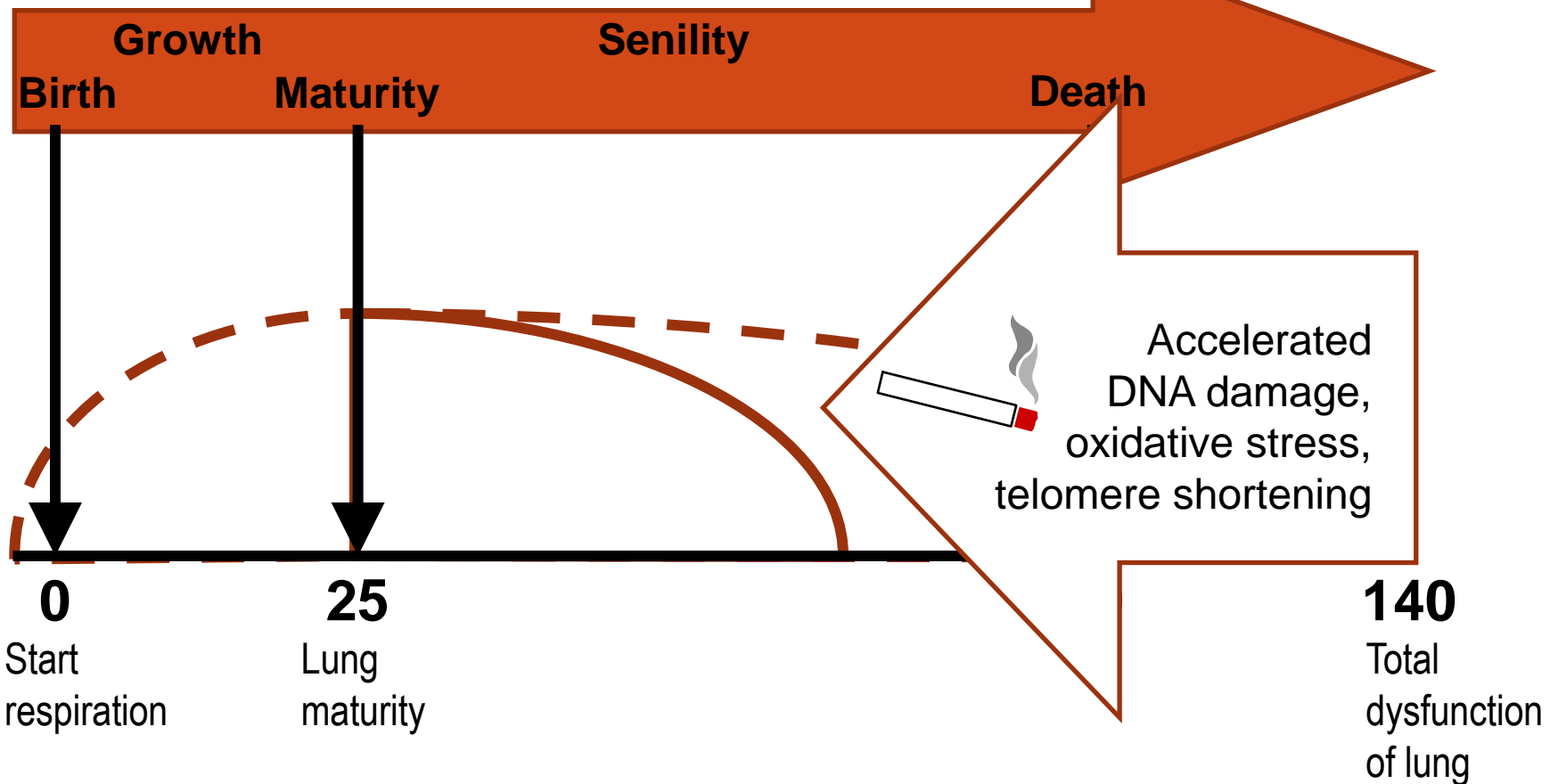
COPD: a way of life



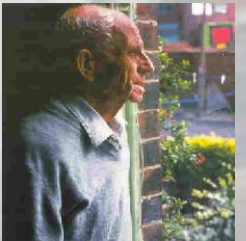
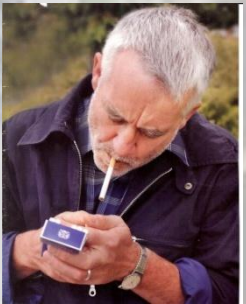
T03.1 "I'm all right if I sit still. It's all just part of getting older I suppose"



Ageing process in whole body



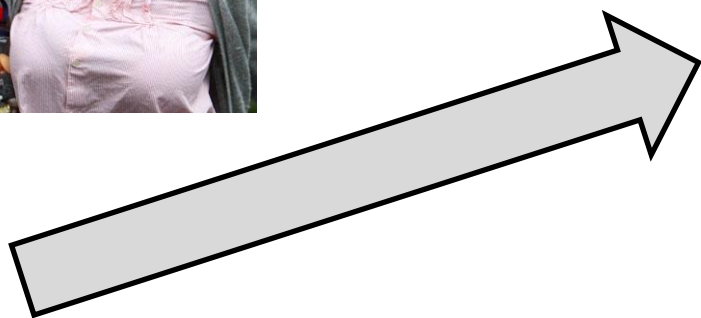
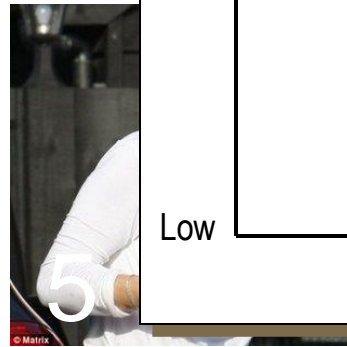
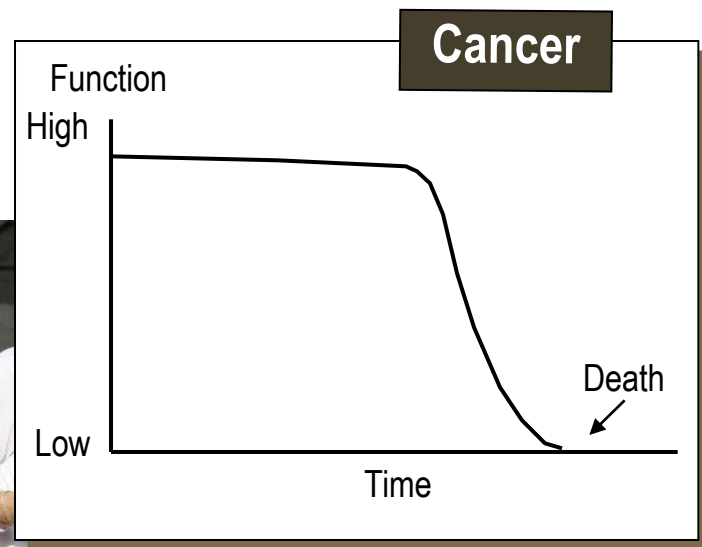
COPD: a way of life



- Can't separate the life story from the illness story
- No biographical disruption, just 'natural' ageing
- Because the COPD story does not start with the possibility of death it is difficult to discuss death at the end of the trajectory
- If COPD is 'just a way of life' how and when is death contemplated?
- We need to acknowledge the importance of the (lack of) story in shaping the end – and the appropriate models of care

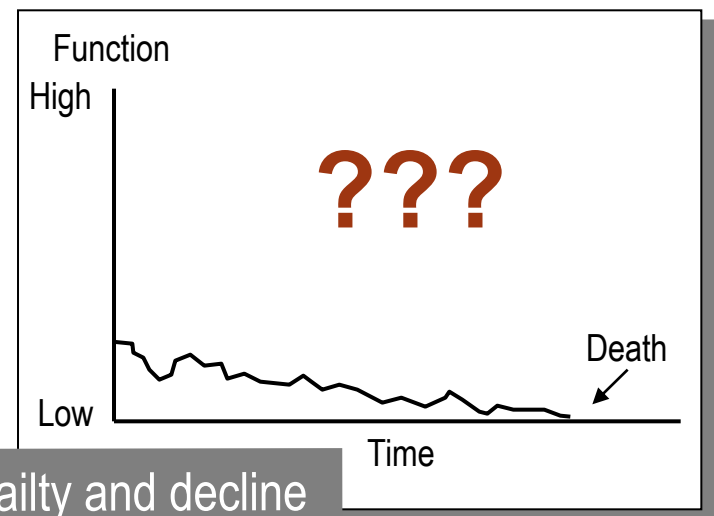
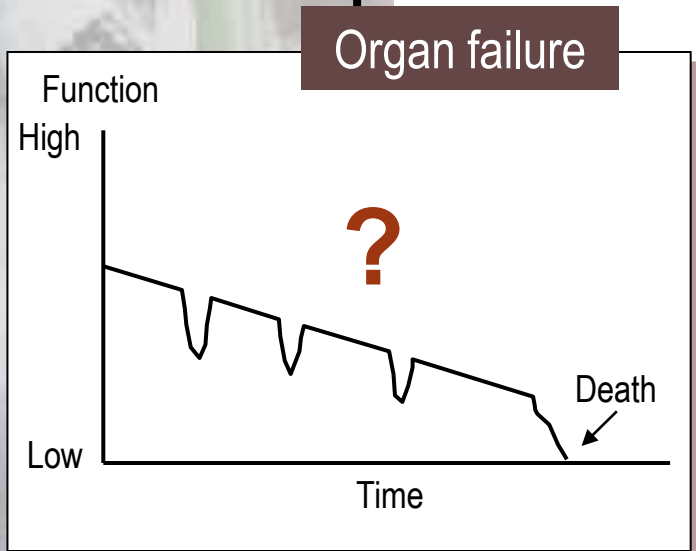
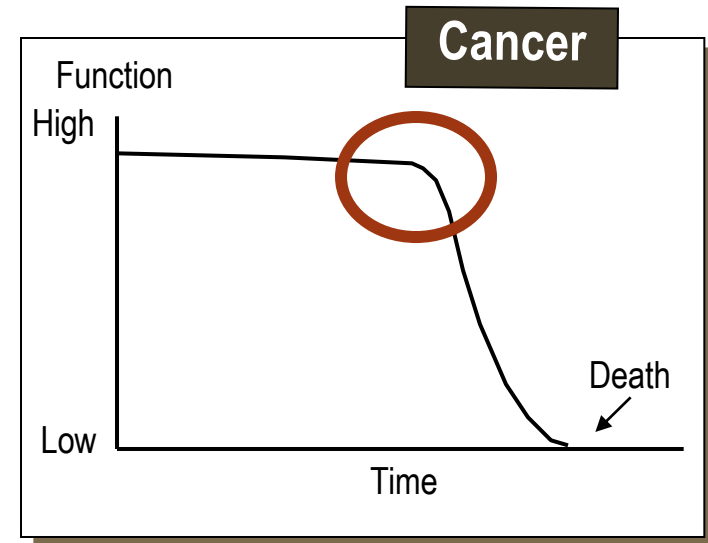
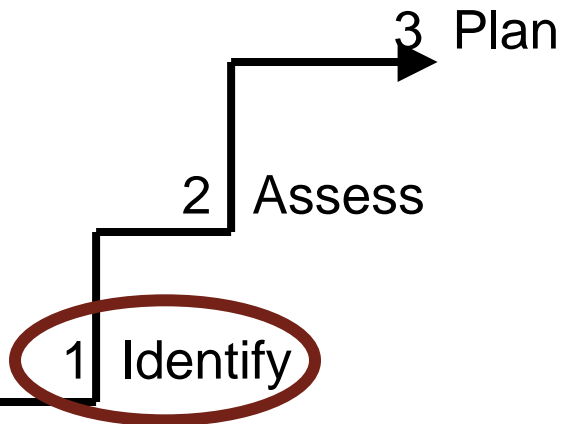


The cancer story

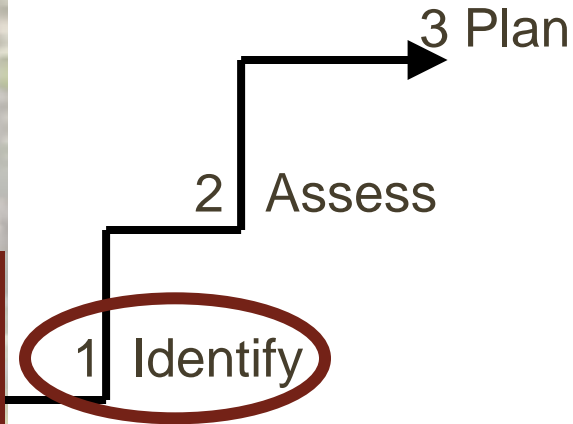


Gold Standards Framework

Palliative care register



Models of care

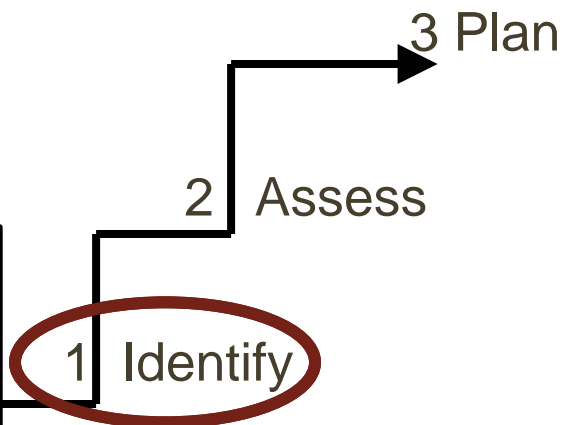


**Palliative
care
register**

Should we stop looking for a transition point to palliative care for people with COPD?

..and instead ensure holistic, pro-active, well co-ordinated, supportive care, throughout the lifetime illness

Triggers not registers



Hospital admission

Physical

Psychological

Social needs

Spiritual

Making a diagnosis

FEV1 < 30%

MRC Dyspnoea score 5

Blue badge

Home adaptation

Retirement on health grounds

HELP-COPD



Physical

What symptoms are a particular bother at the moment?

Psychological

What if anything are you worried or anxious about?

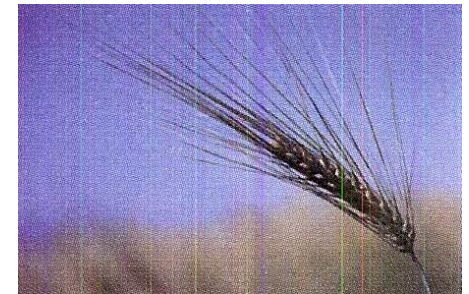
Social needs

How you are managing at home?

Spiritual

How do you see the future?

Is there anything important that we have not talked about?





COPD:

planning for **living with** a lifelong condition

COPD: a lifelong condition with no beginning and an unlooked for, unpredictable end

COPD: needs, care, and silence

HELP-COPD: palliation for symptoms and circumstances + planning for living – but without any pre-requisite for recognising ‘the end’



COPD: planning for **living with** a lifelong condition

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Thinking Ahead in Palliative Care

Annual Conference 2011

