The Hope for Home Study

Dr Adrian Treloar
Dr Dimitrios Adamis
Dr Monica Crugel

Background

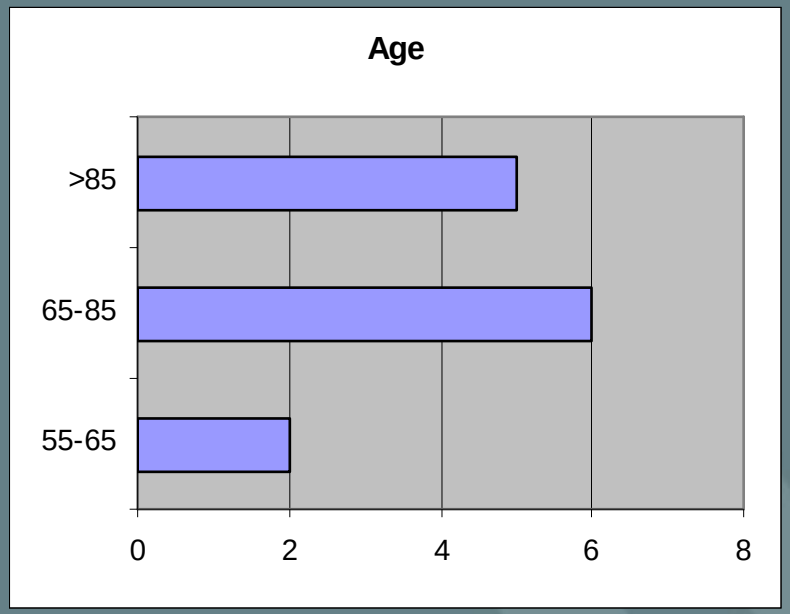
- Home care of dementia until death a rare event, poorly understood and not encouraged by statutory services
- A few carers do this, on their own and with little support and some obstruction
- Development of local expertise in Hope for Home care appeared to show feasibility and benefit.

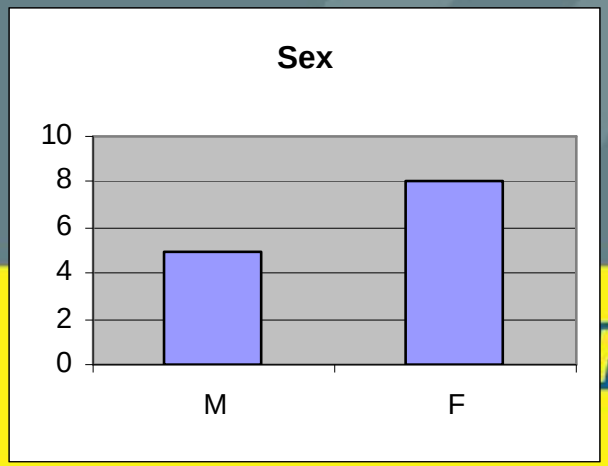
Study

- Qualitative study of 13 patients interviewed >3 moths after death of patient, exploring issues associated with care.
- Qualitative study allows non statistical methods of study and the use of themes arising form interviews to generate results.
- Semi structured interview recorded and transcribed for analysis

Demographic details

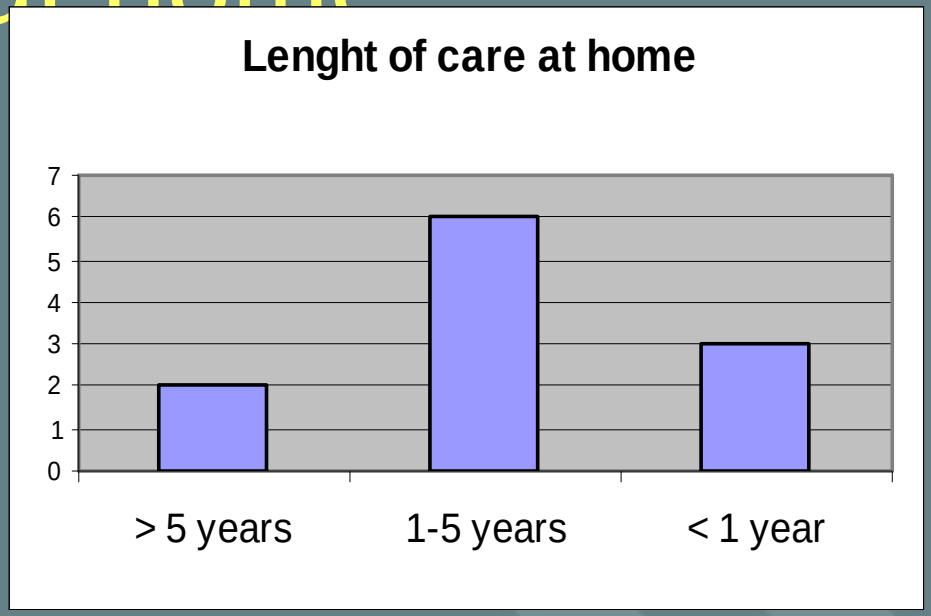
- **N=13**
- **Age of patients**
  - Between 55 and 95
  - Mean 81.15
  - Median 84
- **Sex**
  - M=5
  - F=8





Care at home

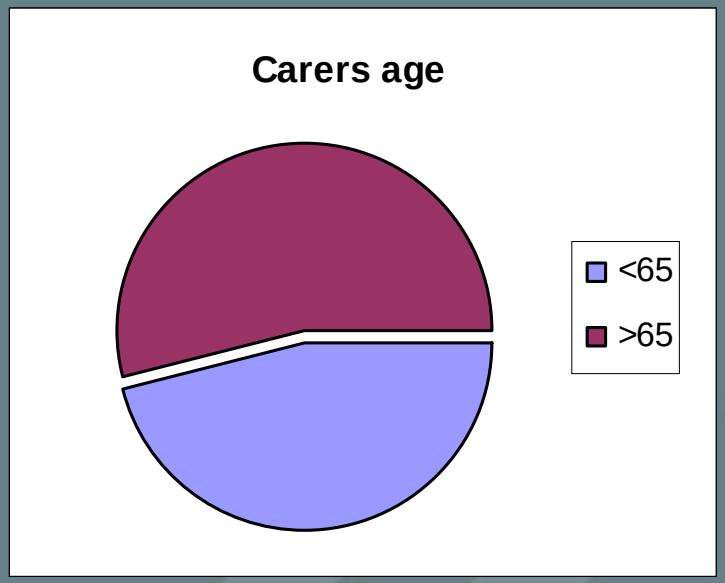
- **Date of death**
  - Between 2003-2006



- **How long was … cared for at home?**
  - > 5 years 2
  - 1-5 years 6
  - < 1 year 3

Main carers

- **Carers age**
  - Between 36y and 91y
  - Average and median - 68y
  - <65=6; >65=7

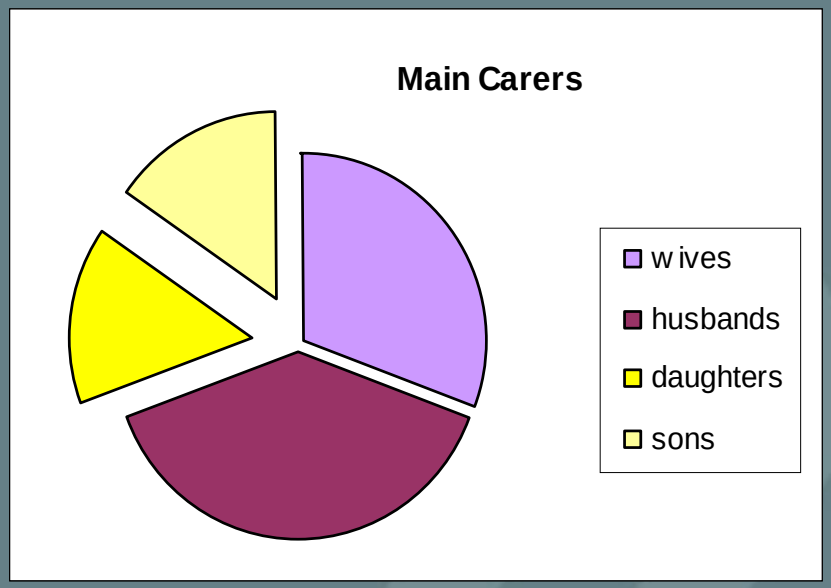


- **Carers sex**
  - F=6
  - M=7

Main carers

Relationship

- Wives 4
- Husbands 5
- Daughters 2
- Sons 2



Diagnosis

- **Primary diagnosis**
  - All had dementia
- **Secondary diagnosis**
  - 9/13:
    - Parkinson's
    - Heart conditions
    - Cancer
    - Renal failure
    - CVA
    - Blindness
    - COPD

Size of property

- 25m^2 to 200m^2
- 2-12 people living in property.
- Large Detached Victorian houses to 1bed flats and small cottage.

Results

- **Did you need any post bereavement counselling or support?**
  - YES – 2 NO – 11
- **How well would you say you coped with the bereavement in the end?**
  - Most coped well , interviews sooner after death (3-6 months) show less good adjustment.

How was bereavement

I coped because I was doing something for her. I had a goal, which was something beneficial to her- I could manage. As long as I was able to do that what she would have loved. I don't have time to mourn.

On the whole quite well. Its hard to explain how you get through the day. Nights are the worst. Alone waiting for the dawn.

Quite well, stayed with sister for 2/52 then stayed home 2/52 with dog then round at sisters, so ongoing support.

How would you describe the personality and key characteristics of P?

- All had positive description of personality

What was the religion of P (if any)?

- C/E 7
- R/C 5
- Orthodox 1

- **Did P have an advance directive?**
  - YES – 1 NO – 12
- **Were there any previously stated wishes of P relevant to this episode?**
  - None 10
  - Care home 1
  - Own home 2

Place of death

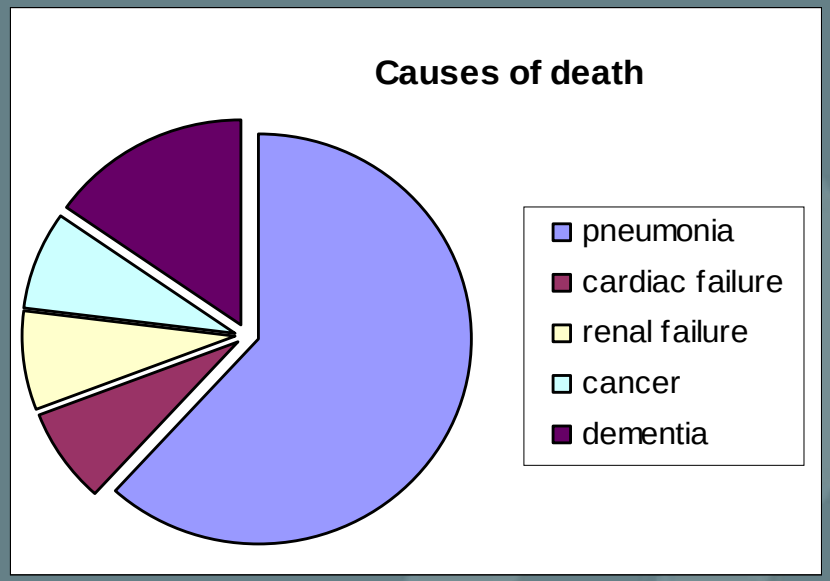
- At home 8
- Hospital 5

Time in the hospital before death:

- 3 weeks rapid deterioration, police called due psychosis
- 5 days distressed at night following stroke, GP sent in
- 12 days deterioration with pneumonia, not able to support at home
- 2 weeks bed sores and septicaemia
- 7 days intended to stay at home but v distressed in night and no services to support there

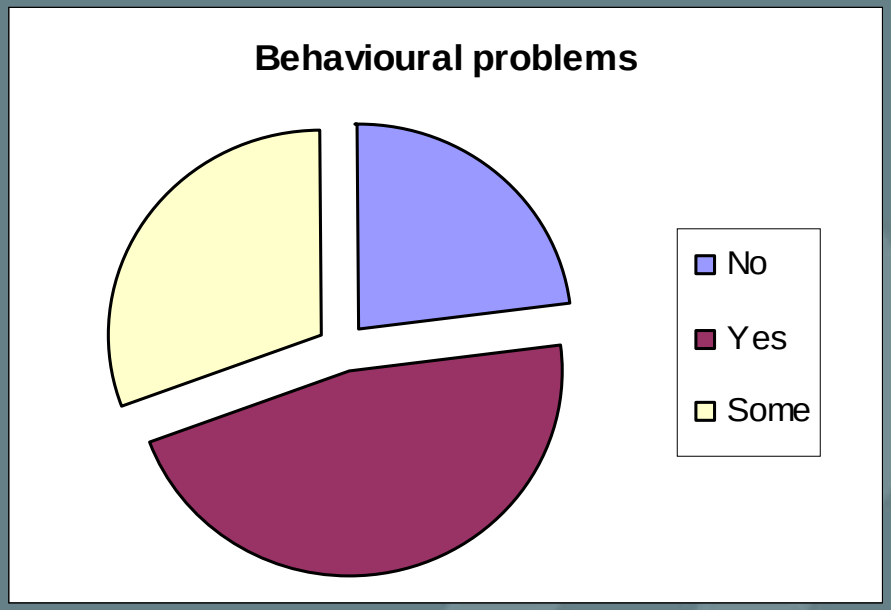
What in the end was said to be the cause of death?

- pneumonia 8
- cardiac failure 1
- renal failure 1
- cancer 1
- dementia 2

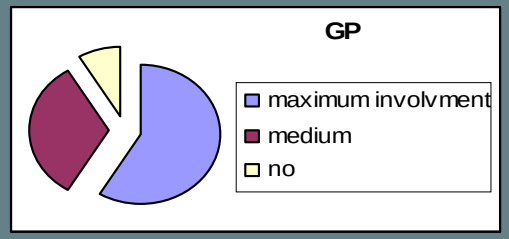


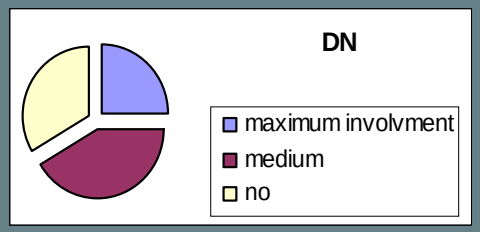
Were there any behaviour problems?

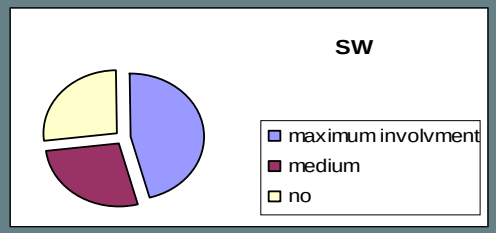
- No 3
- Yes 6
- Some 4

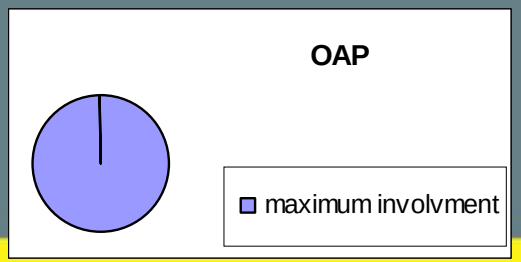


Expertise









Palliative care team (Macmillan/ Ellenor etc.)	2 cases
Carers Centre	4 cases
Crossroads (or similar)	2 cases
Expertise from other voluntary orgs	1 case
Volcare (or similar) Link (or similar)	2 cases
Advice and support from friends etc	2 cases

- GP was very good when could get to surgery but when it came to visits was a problem. Rarely made house calls except in the last few weeks. Probably pressure in the surgery. It would have been useful even as a routine thing for 5 minutes, that would have made a difference to mum. Just that short visit would have been helpful.
- GP never came out.
- Psych;- he looked forward to the psychiatrist coming. . you would call in sit there holding his hand. When he could talk he did like a good talk. Just popping in was brilliant, his face would light up.
- Psych was the only one who kept in contact and visited when he didn't have to.

Obstructions and blockages

- Did any of the above put blocks in your way?
  - YES 3
  - NO 8

- Did you need the expertise help earlier than you got it?
  - YES 7
  - NO 5

- Until she was actually got attendance allowance no-one wanted to give any help at all. Until she was actually registered as having attendance allowance there was actually a blank wall.

- With social services, as K was less than 65 she did not it into a box. So she was not helped. Told not eligible for direct payments.

- Social services had excuses all the time “We don’t think you need this, we don’t think you need that”. I used to phone them and request about certain things and they did not used to turn-up. I used to call them. When you managed to get in touch with the person you needed they were out for a visit or they were never there. They never got back to you.

How did carers get hold of what they needed.

- Often there was someone who obtained what was needed, perhaps a doctor who knew what to get, an OT, someone who worked a as home help and then obtained things despite the non availability.

Equipment

- **Indispensable:**
  - Continence pads and sheets (13/13)
  - Commode (11/13)
  - Hospital Bed with Mattress and mattress elevator(10/13)
- **Very useful:**
  - Chair and cushion (8/13)
  - Wheelchair (8/13)
  - Electric hoist (8/13)
  - Hospital bed (7/13)
  - Zimmerframe (7/13)
  - Chair (7/13)
- **Other useful equipment:**
  - Shower bath aids
  - Toilet raiser
  - Shower wet room
  - Shower stool

Equipment

- The right stuff is essential

We only got the pads as we knew who to contact ordinary people don't know and just have to wait. Some don't even know they can have them. The home care team would heave left Nobby as he would have said "go away". It needs special skills to engage and clients don't mean to say "go away".

Appliances

- Bed
- With raise of bed and
- Raising backrest

Chair and cushions

- Proper pressure cushions, allowing longer comfort.

Wheelchair

Bath seat

- Goes up and down

Commode

- Available on request in Greenwich, no reason needed
- Other varieties available

Zimmer

- Even if not used by patient!

Hoist, (with moving and handling training!)

And a second hoist for transfer from chair to commode, with cleaning etc

Essential equipment

- Carpet cleaner
- Complete with operators!

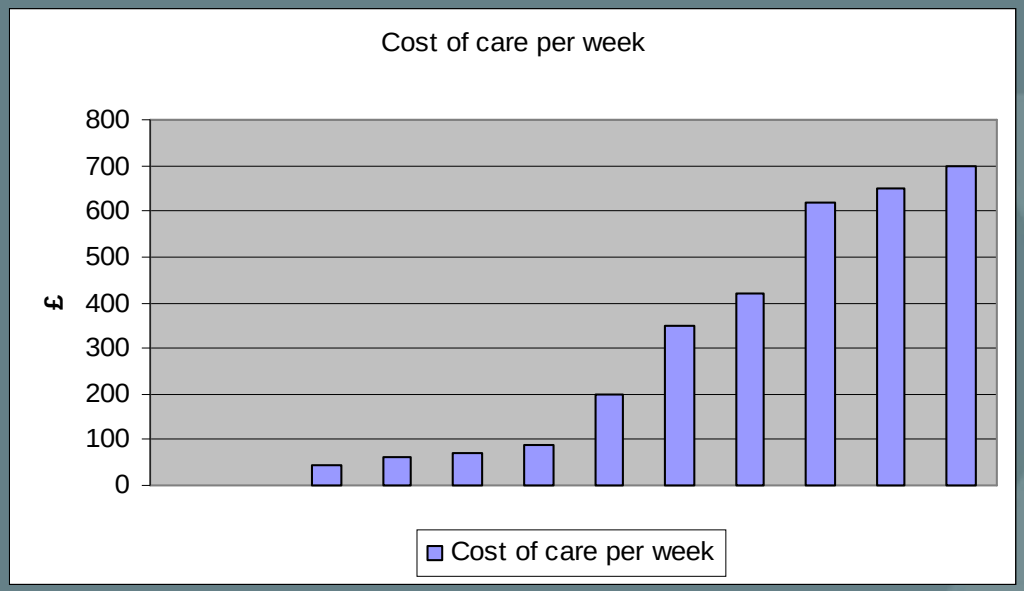
Funding

- Sources of funding
  - Social services: 8/12
  - Primary care trust: 1/12
- Issues of funding
- At least 7 bought at some of their own equipment

Social services had excuses all the time “We don’t think you need this, we don’t think you need that”. I used to phone them and request about certain things and they did not used to turn-up. I used to call them. When you managed to get in touch with the person you needed they were out for a visit or they were never there. They never got back to you. I found no excuse for them not to pick up the phone and call back even out of respect or decency, too call back and say “I’m sorry, what’s the problem”. I used to call 3-4 times in one week.

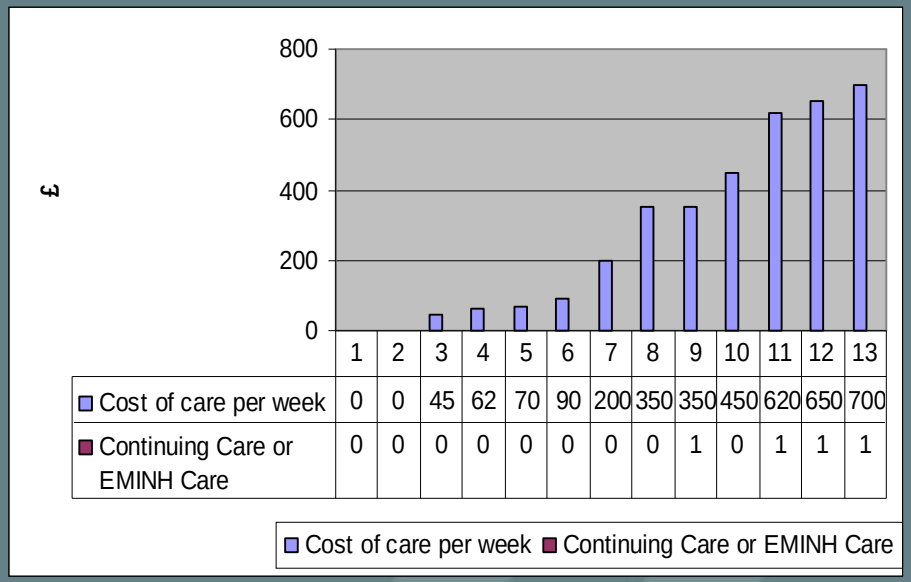
Cost per week

- £0 – 700



Eligibility for care and cost of package

- Those eligible for continuing care cost more.
- Costs of all care were lower than that for which patients were eligible. EMI NH care costs £670 per week.



	1	2	3	4	5	6	7	8	9	10	11	12	13
Cost of care per week	0	0	45	62	70	90	200	350	350	450	620	650	700
Continuing Care or EMINH Care	0	0	0	0	0	0	0	0	1	0	1	1	1

Freedom to spend money as one wishes issues of control

- Care package trust was not helpful. When they came they found that [pat] could not pen her bowels on demand. I felt at their mercy and vulnerable. They were difficult.

Carers

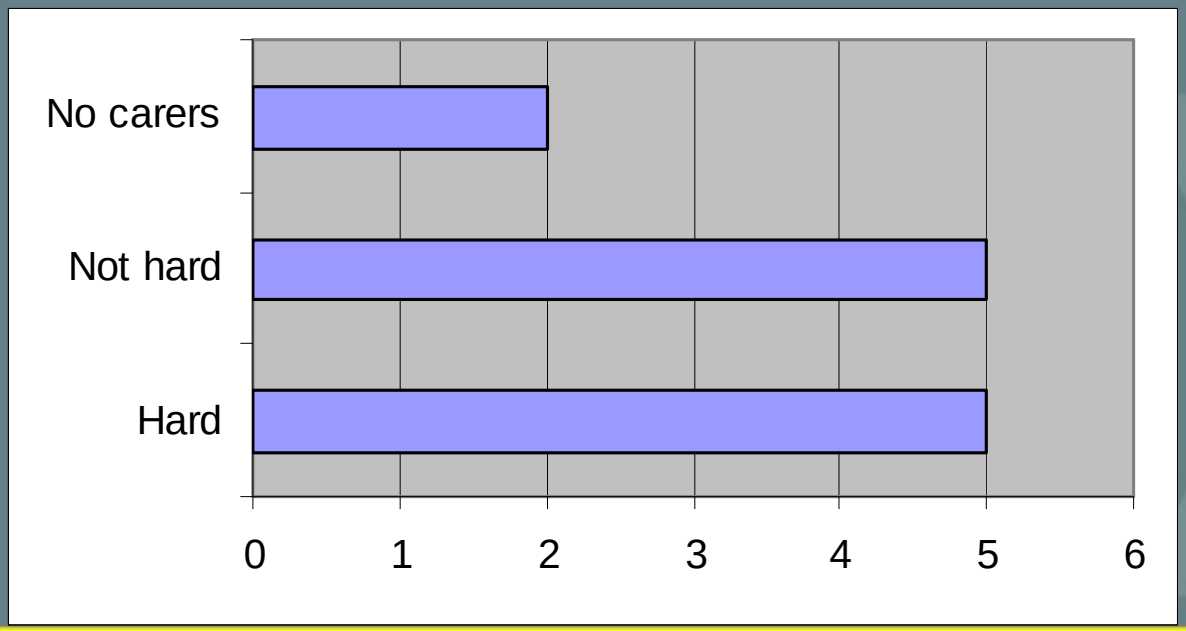
- Tried social service carers for 6 weeks. In that time 21 different people came. It just was not helpful to have to show so many people how to do it.
- Carers came in twice a day for half an hour twice a day. Morning one was very good evening one was less regular. Evening one was irregular, never knew when they would turn up.
- Excellent, lovely, the girls were fantastic. Always cared of mom as well as dad. After they have done dad they would say “would you like a cup of tea or is there anything you need Elsie, are you coping?” Very helpful.
- Mom would not have coped without them. They were worried about her feet because she was sitting next to dad continuously and her feet were getting so swollen.
- 90% of the carers were quite good.

Good regular carers

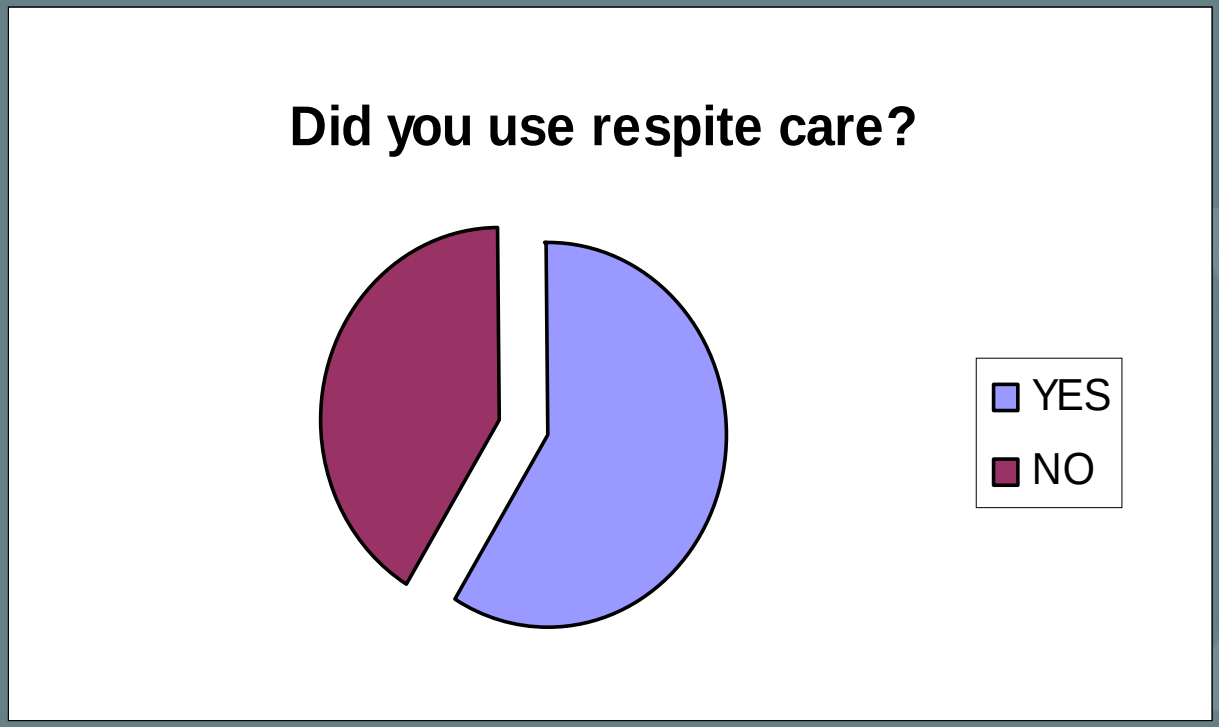
- With control of these by carers and not statutory services
- Can be Amazingly reliable
- Fantastic skills
- Really caring and motivated
- (except for one or two)

How hard was it to get the carers?

Carers recruited by personal contact, advert in News Shopper, and via statutory agencies.

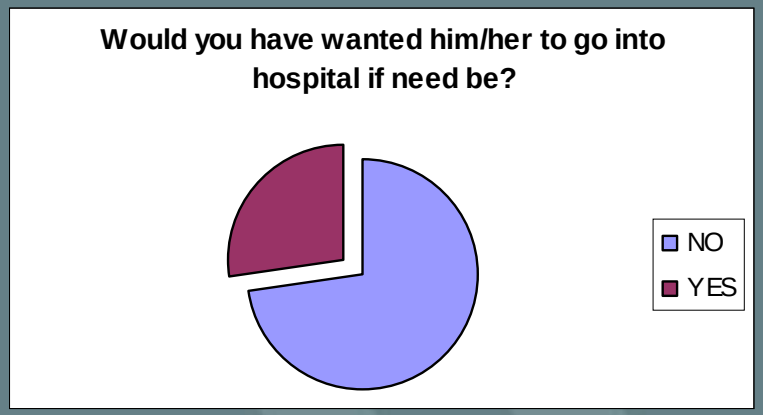


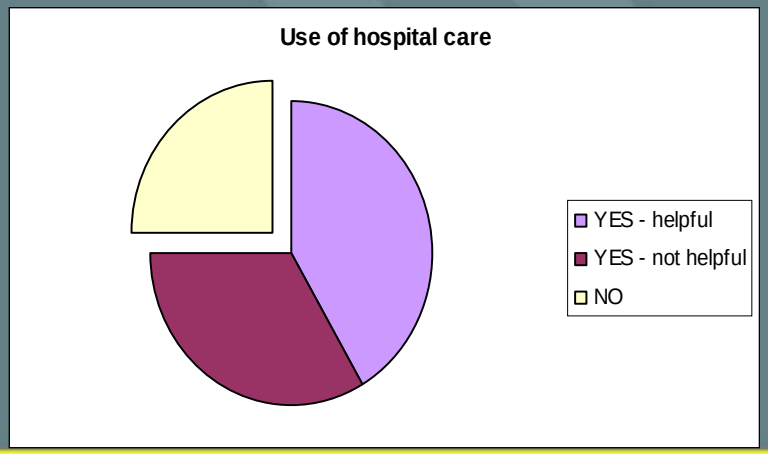
Did you use respite care?



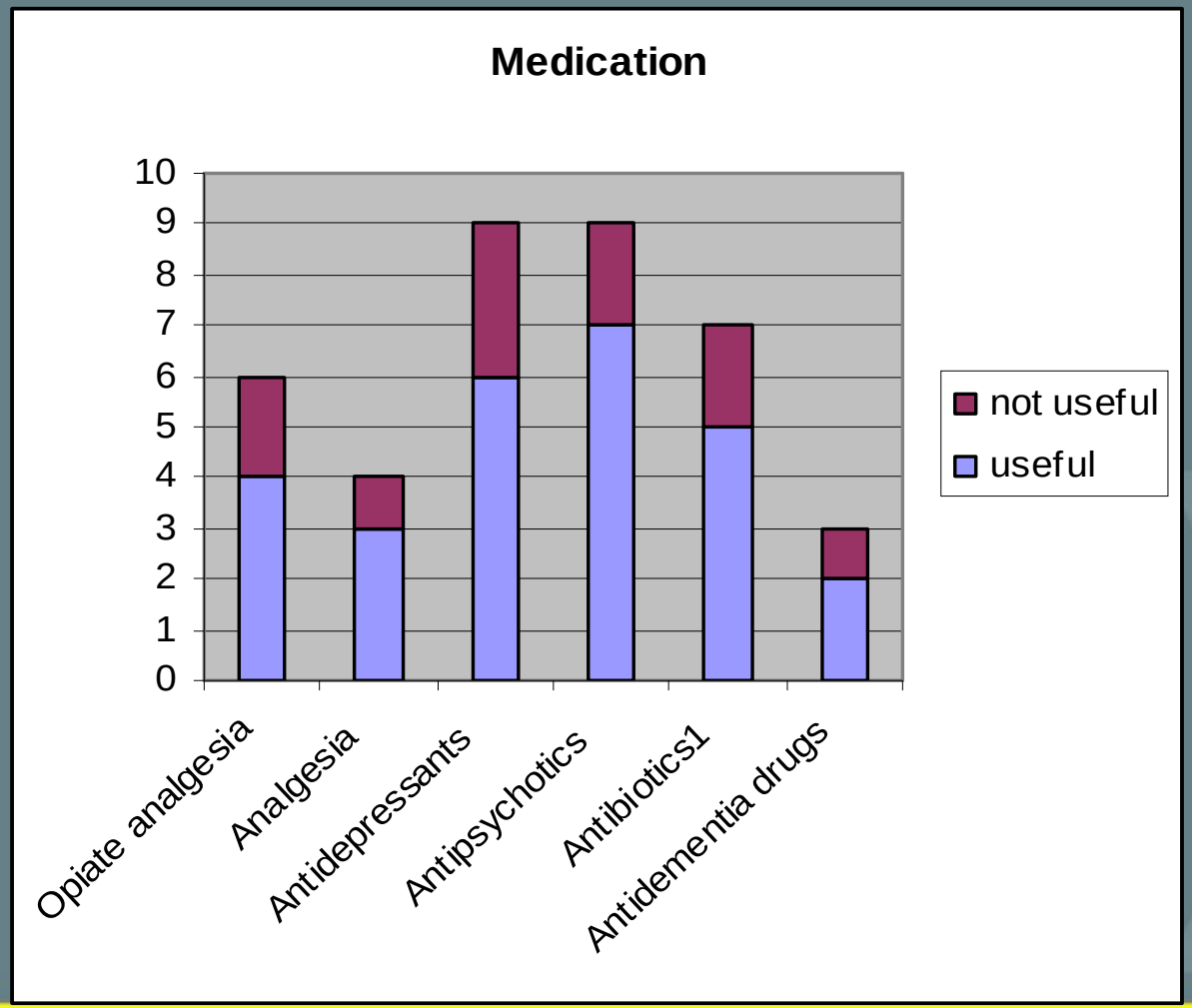
End of life care

- Wanted to go to hospital?
- Why might have gone
  - Anything that I could not have managed myself. Especially treatment. Perhaps a fractured hip, little else.
  - Only in emergency situation.
  - He went in because of distress at the last minute



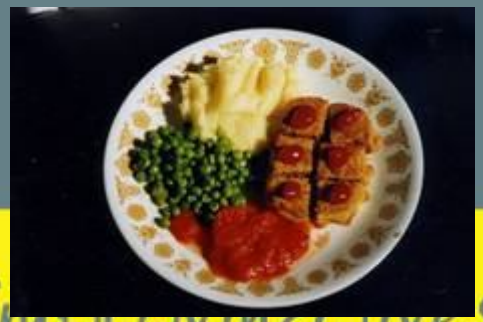


Medication


Medication
10
9
8
7
6
5
4
3
2
1
0
Opiate analgesia
Analgesia
Antidepressants
Antipsychotics
Antibiotics1
Antidementia drugs
not useful
useful

Food

- Giving her food that you know would keep an even bowel. All chopped up looking nice.
- Baby food, chocolate, KFC, anything he wanted
- Nice food so that he would enjoy eating it.
- I would talk to him a lot it provided company. He ate everything there was nothing in particular.
- Ham and bacon scrambled eggs, corn beef sandwiches Fish fingers She refused now and then gave cornflakes A cooked meal in the evening. It was hard to get her to eat near the end.



Food

- She always had a good dinner, later on she used to eat and then choke. There were no special tricks
- Soft and nourishing, peanut butter sandwiches, needed soft and lumpy things could eat anything, best to let her feed herself as well.
- Good nutritious food like Irish stews.
- She ate like a sparrow, we tried to make it little and as attractive as possible, not force or make an issue of it. Soups useful as well. Fruit juice, guava juice a standby and kept her going for quite some time.
- Allowing her not to eat was very important.

Special Foods

- Guava Juice
- Thick Soup
- Rice pudding for tea
- Prunes
- Complan and milky drinks
- Irish stews
- Peanut butter sandwiches
- Ham and bacon scrambled eggs, corn beef sandwiches, fish fingers
- NICE FOOD
- Baby food, chocolate, KFC
- Chinese meal

Special Techniques

- People dying of dementia lose weight and do not eat enough.
- But should not fight too hard to ensure adequate diet;- this causes distress
- Can keep people going for a long time
- D was very crafty she would sing dance and persist

improving lives

Overall experience (11 positive, 2 less so)

•Would do it all again. Looking after Grace was not hard work.

•I would think when we look back very beneficial for us, but also very taxing, challenging, we were not able to have a normal life from the point of view of relaxed retirement life until she died. Social life we came to be extremely restricted. And yet for you it was better;- now that it has passed I look back and think thank goodness we did look after her. When I see old peoples homes I do not like what I see.
The first time she went to Baugh House she quite enjoyed it, she had her sight but then the home went downhill reached the point where it had no staff who were overworked

•Very positive

•Theresa had done it before and I am a born carer. (so I am told) from the old school, if you can, ;- do your best

•Quite tiring, start early, working at same time, then bath and make drinks , hard work didn' t mind it, thought that would go on for ever. Good and hard work friend at work did it for one weekend and felt would not manage.

•Learnt an awful lot, a priceless experience, got depressed at times but needed more

•I loved it, really enjoyed doing it. “not a cure” very tiring but I coped;- not sure how I did that.

•It was lovely something that I always wanted to do. But she was so independent. She let me. Ron says that I did it well.

•I was only too pleased to. We just went ahead and organised it.

•It was heartbreaking. Very hard, harder than I imagined

•It was heartbreaking. First of all it took me many years to digests of the news of Alzheimer's.
•I suppose in a way it was a challenge. If I had to do it again I would do it again. We were soul mates. Good,… yeah

Would you do it again

- Would you do it again 100%
- Glad you did it 100%
- Right to risk own health doing it 10/13

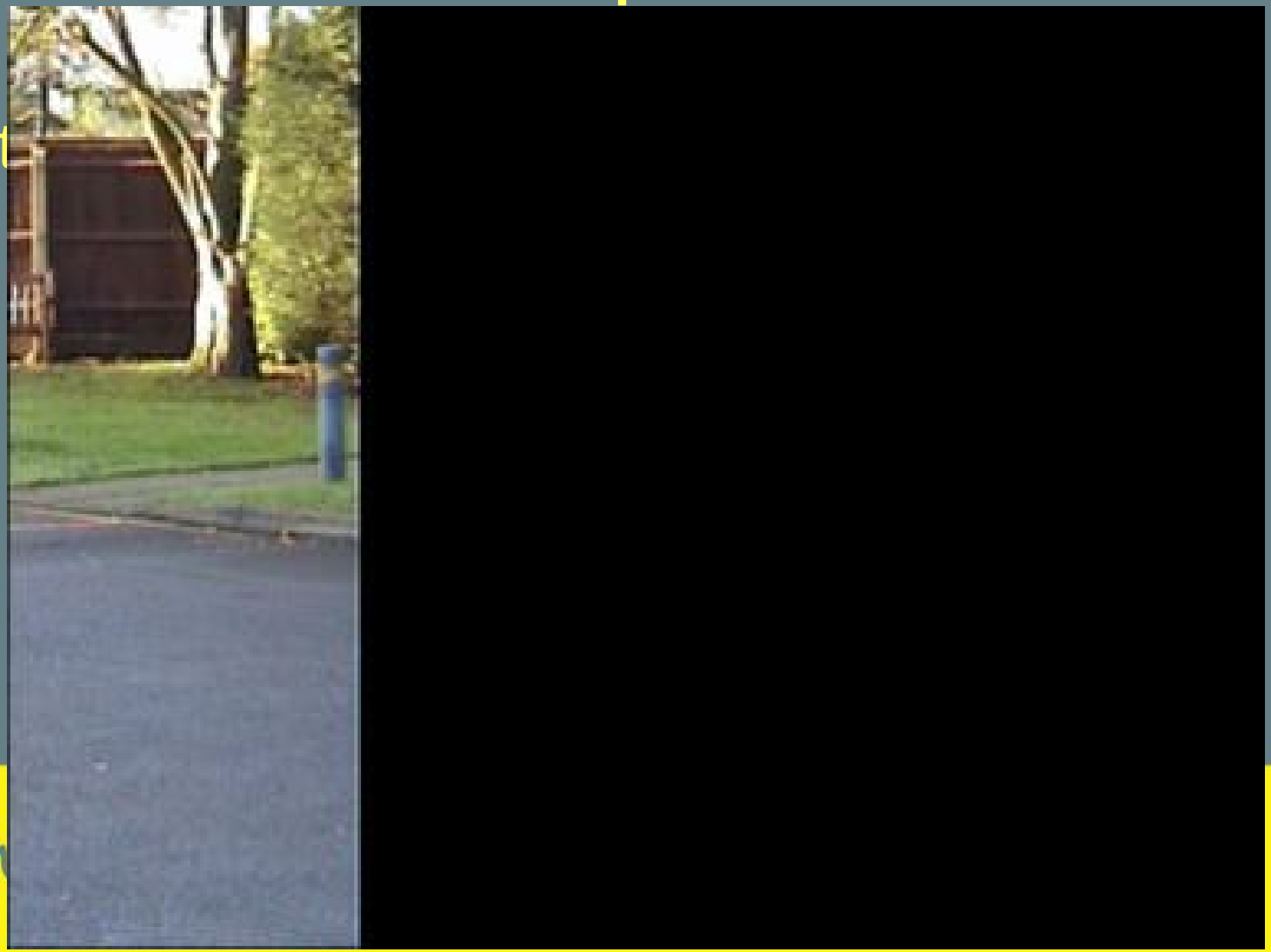
(2 who said not sure are parents of young children)

Extra comments

- GP never came out. He should have phoned once a week just to see if he was needed. Would have come daily ? What this means Need someone willing to be a sitters o the other can have some time away. A team would be nice team needs to understand the difference between no and no. and to ignore foul language.

Next steps

- What to do?



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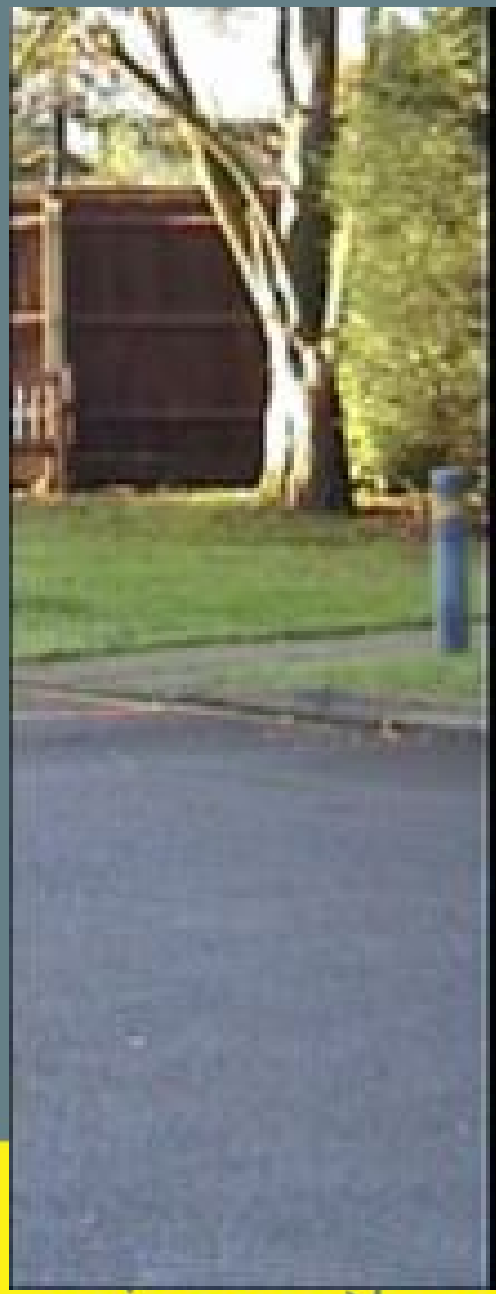

Answers

- First do no harm
- Interestingly it was not Hippocrates but seems to have been coined in the 17th - 18th centuries

First do no harm

- There are some issues with this in palliative care, chemotherapy, treatments with side effects
- In dementia we cannot avoid potentially harmful treatments which will help that person
- While we must never intend to harm, we must intend to treat and reduce suffering when we can, but we must also accept that almost everything we do may be harmful.

Hippocratic oath

- I will prescribe regimens for the good of my patients according to my ability and my judgment and never do harm to anyone.

- Our first aim is to do the good of our patients
- But there are then some absolute exclusions including giving a lethal drug.
- Hippocrates was more absolute, simply saying he will never harm

Why is that important?

- Because those with dementia and incapacity seem often to be neglected because they resist treatments
- Are not taken to hospital when needed for fear of assault (avoid doing harm at all costs)
- With the result of neglect occurring

Double effect

- Accept risk of harm for a clear benefit
- Classic example = opiates in pain, although in appropriate doses these may not be associated with shortening life
- Better examples =
  - Chemotherapy
  - Antipsychotics in dementia;- known to be harmful but may be the only way to alleviate severe distress

Burdensomeness

- A crucial concept
- Helps us to be sure we act reasonably

Good clinical care

- Proper understanding of the symptoms of distress
  - Anger/ Frustration
  - Aggression/Agitation
  - Fear/ Anxiety
  - Tearfulness/ misery
  - Pain when still
  - Discomfort on moving
  - Restlessness
  - Insomnia
  - Calling out/ vocalisation

Are these symptoms different from pain in the physical sense?

Causes of severe distress

- Depression
- Psychosis
- Pain
- Poor understanding,
- Fear and anxiety
- Insomnia
- Hunger and diet
- Boredom, isolation and spiritual care
- Poor Environments
- Environmental interventions

Approach to palliative care in dementia

- Cherish and value life
- Accept natural death
- Distress reduction is key
- Be willing to limit care to that which is not burdensome etc
- Talk to and discuss with relatives etc
- Remember that palliative care of dementia can provide excellent results

How do we know when palliative care is indicated in Dementia

- Arguably from diagnosis
- But patients and carers want more treatment/ cure / health preservation early on
- Definitively in the terminal phases
- But probably at some point during the illness where distress reduction and limitation of ineffective and burdensome treatments are important.

The Gold Standards method

- The gold standard method
  - Would you be surprised if this patient died in the next year
- Is simple, but hard to predict and probably will not work all that well

A criterion based approach

- Works well in testing
- Leads to helpful conversations with carers and patients
- Allows discussion of palliation at an appropriate time.

Criteria

1. A diagnosis of moderate/ severe dementia
2. And
   a. Severe distress
   b. Severe physical frailty
   c. Another indicator for palliative care