

NURTURING THE PERSON WITH DEMENTIA AND THEIR CARER

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After diagnosis

- No information about the illness, legal and financial issues, or where to turn for help (better these days, but still very patchy)
- No guidance as to how to help Malcolm live well with his dementia
- In dementia, experiences are not converted into memories
- So no use scolding, contradicting or correcting.
- Preserve their self-confidence and protect the relationship

The early years

- Needing help with personal care
- It's not what you do, it's the way that you do it that counts
- Bossiness is not on
- Do with people, not for them
- Giving choice, preserving autonomy, protecting relationships.
- It's the small details that make the difference between well-intentioned but damaging care and truly enlightened care that nurtures

The middle stage

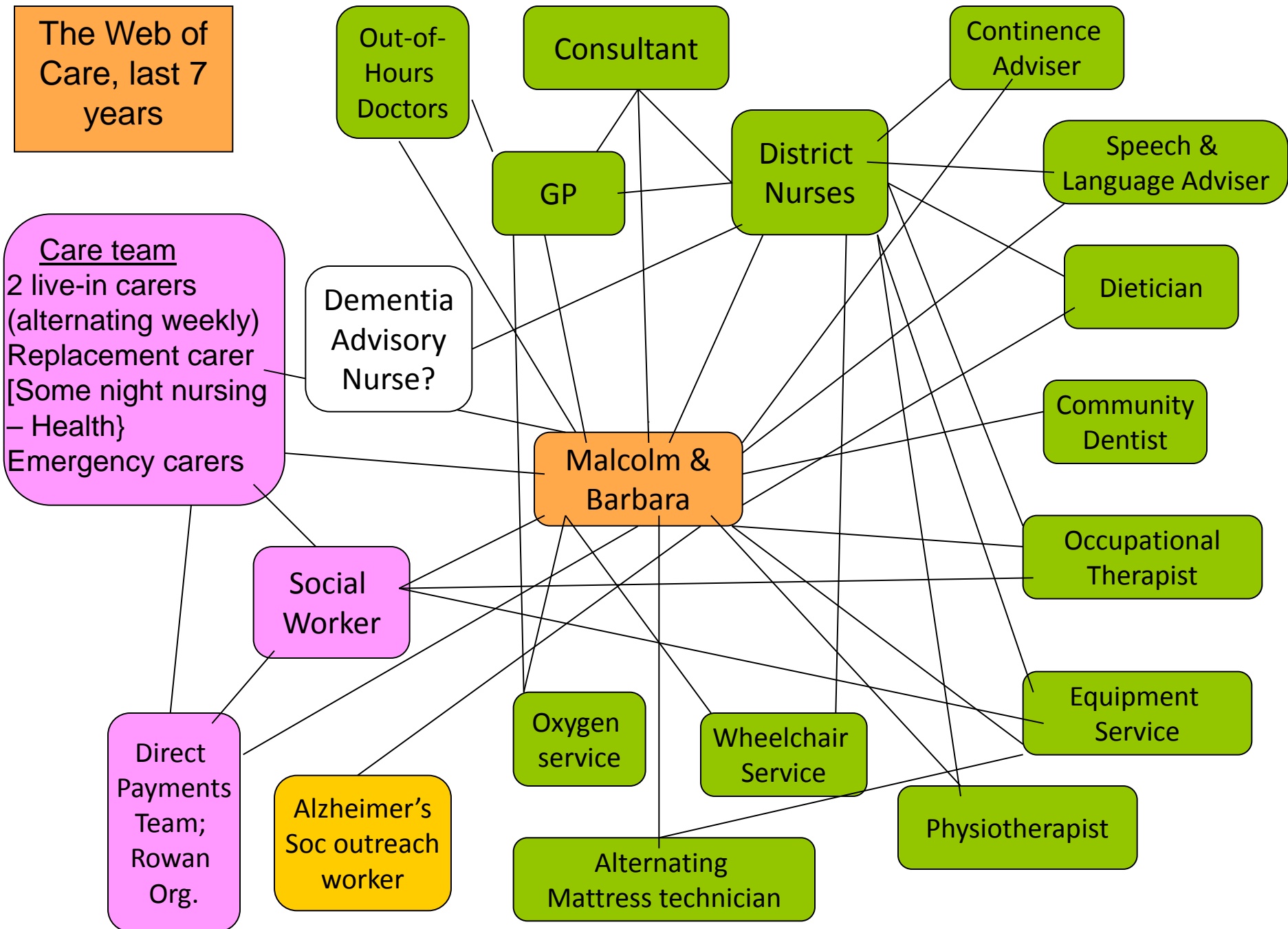
- Perplexing behaviour: the story of the mirror.
- Time-travelling backwards; not recognising himself.
- Visuo-spatial perceptual problems: reflection mistaken for reality
- Who is this strange man in my house?
- Aggression countered with anti-psychotic medication instead of which I should have simply taken the mirrors down
- A dementia nurse would have told me that there's nearly always a reason behind a perplexing behaviour which gives the key to dealing with them

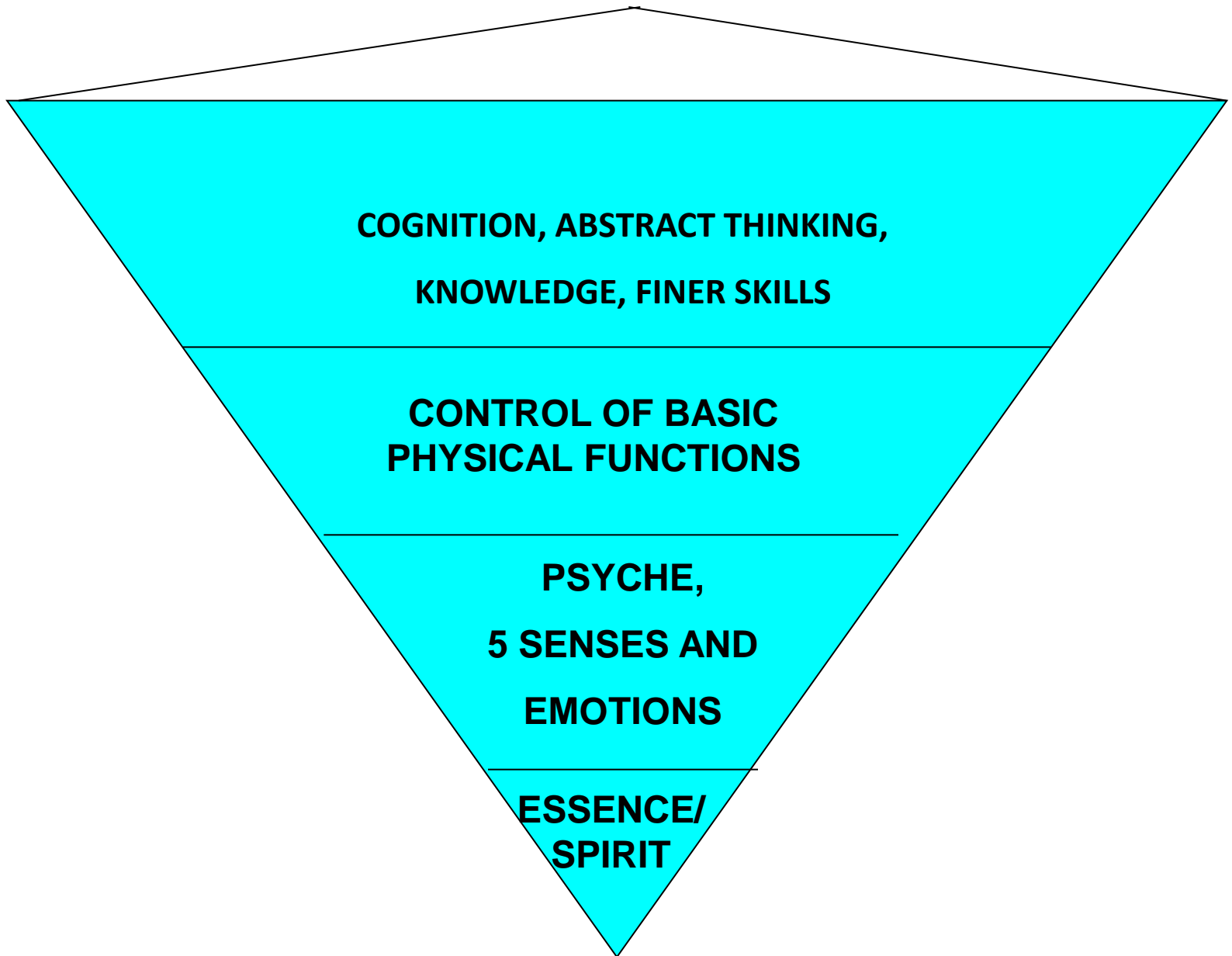
The later stages

- Doubly incontinent, lost mobility, became mute and developed swallowing problems
- Normal nursing procedures may have to be amended because of the overlay of dementia
- District nurses out of their depth – dementia advisory nurse required.
- Problems with rolling the patient on the bed.
- Catheterisation not normally recommended in dementia – answer was a standing hoist
- When swallowing problems developed, GP and nurse said he should be PEG- fed. Not recommended in dementia – equal chance of choking on regurgitation.

The later stages

- All medication should be reduced in line with severity of dementia
- Normal adult doses become like overdoses to the compromised brain, producing unwanted side-effects.
- Weight loss is inevitable and part of the disease process.
- Specialist nurses brought in to advise tended to see only their bit of the jigsaw and sometimes gave conflicting advice





Sensory/emotional/psychological/ spiritual needs

- “He’s no trouble now”? Needs TIME to stimulate 5 senses:
- Sight: smiley faces, changes of viewpoint, red/yellow spectrum
- Taste: feeding by mouth, sweeter and stronger flavours
- Smell: of cooking, aromatherapy, favourite perfume
- Hearing: favourite music, humming, basic human need to be talked to (we talk to babies, don’t we?).
- Touch – the most important. Stroking hands & face, hugs, calming night fears.
- Feeling safe and nurtured

Nurturing the carer

- Being watchful and supportive of the carer -if the carer goes down, the whole ship goes down with them
- Supportive peer groups
- Triggering carers' breaks, finding good replacement care
- Help with form-filling if required
- Contactable by phone in an emergency
- Giving a hug when the carer is down, or a shoulder to cry on
- Bringing hands, head and heart to the job

The wider reach of a dementia nurse

- Supporting and advising on dementia nursing care in carehomes and hospitals
- Residents in carehomes are still NHS patients and part of the community.
- Bedsores are a sign of neglect – not an inevitable part of the illness
- We have practice nurses in surgeries for all kinds of conditions – why not for dementia?
- Burgeoning elderly population tend to have complex needs and would benefit from nurses with crossover mental and physical health skills