HELPING PEOPLE TO LIVE WELL WITH THEIR DEMENTIA

A Family Carer's View

Barbara Pointon MBE

Former carer

Ambassador for Alzheimer's Society & Dementia UK.

Member of the Standing Commission on Carers and two Ministerial Advisory Groups on dementia

barbara@pointon.name

Malcolm in 1992, aged 51, just after he was diagnosed

Spotting tell-tale signs

- Forgetfulness which seriously impinges on daily life
- Making mistakes in an ingrained skill.
- Repetitive questions or comments – no memory is laid down
- Uncharacteristic behaviour and loss of social inhibition; problems handling cash, making out cheques
- Problems with tasks requiring sequencing – e.g. washing up
- Confusing left and right; disorientation
- 84% of people with Alzheimer's have visuo-spatial problems – they can see, but the brain does not accurately process it; results in misunderstanding their environment or other people's actions and not knowing where they are in space – at root of many curious behaviours.
- Losing ability to tell the time from a clock-face (use digital 12hr)

Why early diagnosis is important

- ‘Alzheimers Disease and other Dementias ‘(Graham & Warner)
- GPs don’t have the tools to diagnose the <u>type</u> of dementia (over 100 types, of which Alzheimer’s is the commonest)
- If at all suspicious, GPs should refer on to a memory clinic
- 71% of GPs not confident about dealing with dementia and patients can hold their own and be very convincing for 10 mins!
- Family members/significant others who have concerns about a patient are to be given more ready access to the GP to discuss them.
- Early diagnosis is a gateway to support, information & benefits (e.g. reduction in Council Tax).
- When you understand the reasons behind odd behaviour, you can protect the relationship and also plan ahead


TRIP MD

Support in the mild to moderate stage

- Two thirds of people with dementia are cared for at home: e.g. in Cambs– 4,000 out of 6,000 patients, numbers rising.
- Encouragement and support to do all the things they want to do before it's too late. Make it a Can Do ethos.
- Help people to live well with their dementia – direct families to locality Alzheimer's Society for advice and group support.
- Alzheimer's Society National Helpline 0845 3000 336 and website: info@alzheimers.org.uk – advice sheets.
- Admiral Nurses: Dementia UK direct@dementiauk.org Helpline 0845 257 9406. Uniting Carers groups.
- Include people in conversations, parties, events – stigma is rife.
- If a person is not allowed to drive, prevent isolation by offers of lifts (i.e. a shop outing, rather than doing shopping for them).

Key Message

- Caring for someone with dementia is not the same as caring for the frail elderly whose understanding is still intact.

- Dementia support and hands-on care requires special skills, understanding and the right attitude.

- That applies to both professional careworkers and family carers.

Tips for helping with personal care

- It’s not what we do, it’s the way that we do it that counts
- Allow people to do things in their own way and own time. Don’t take over. Doing <u>with</u>, not <u>for</u> is more acceptable at this stage.
- Give people choice: e.g. between which of 2 garments to wear.
- Preserve dignity and privacy.

- Memories laid down before the illness struck are erased in the reverse order; in another time and place in their head. Explains unusual resistance to showers and daily changes of clothing.
- Many elderly people prefer strip washes (warmer) – don’t impose our own preferences on them

Tips for helping with personal care

- Don’t try to make things “normal”, or scold, correct, contradict or ridicule. Go With The Flow – however bizarre it seems
- Try not to be bossy. Don’t overstep the fine line between caring and controlling – it can cause anger or aggression.
- If resistance is met, walk away and try again later.
- People with dementia can’t concentrate on 2 things at once – distract attention away from the job with talking or music.

- Demand continuity and consistency of paid staff
- Domiciliary care staff who wear a white top or jacket may give the impression that they’re “coming to take me away to the loony bin” and can cause resistance to care.

Talking to people with dementia

- It will take time to reply to your question – don’t jump into the awkward silence with more explanations. Just wait.
- Resist supplying words.
- Deliberately simplify the language you use.
- Answering ‘yes’ (or ‘no’) to everything – a sign that questions are not properly understood.
- ‘Difficult Conversations’ – National Council for Palliative Care
- Gobbledegook – look for clues in tone of voice, facial expression and body language
- The family carer now has a right to be present and involved in diagnosis, assessments for care-plans and hospital discharge.
- Caring from a distance: if the person lives alone, ask GPs, nurses and social workers to inform you of appointments etc.

Preserving continence

- Forgetting where the loo is; if the door’s shut, it doesn’t exist!
- Leave door open; or use picture of a loo near the door handle.
- Keep clothing simple to pull down (jogging bottoms – no zips)
- Visuo-spatial perception: misjudging where the loo bowl is – the floor and the bowl should be in sharply contrasting colours

- Everyone has a basic human right to be helped to use the lavatory, but preserve their dignity – escort, give help with clothing, then retreat!
- Find out the childhood words they used for bodily functions, because they may revert to them.

Dealing with perplexing behaviours

- Hiding and hoarding – feeling that they are losing so much of themselves that anything important is put in a ‘safe’, probably inappropriate place, then forgotten. Accusations of stealing.
- Time-travelling backwards
- Believing that reflections in mirrors (and people on TV) are real
- Behaviours stem from feelings; search for the message. Anti-psychotic medication should be used only as a last resort and in the short term
- Mistaking generations, not recognising family. Visitors fall away.
- G. Stokes: *And Still the Music Plays (Hawker publications)*
- Pointon*: 8 Caregiving Maxims*
- If people cannot enter our world, we must enter theirs – enjoy!
- Celebrate what still can be done, not mourn the losses.


TDK TV240
BUSH
Scot
JVC 180 HR

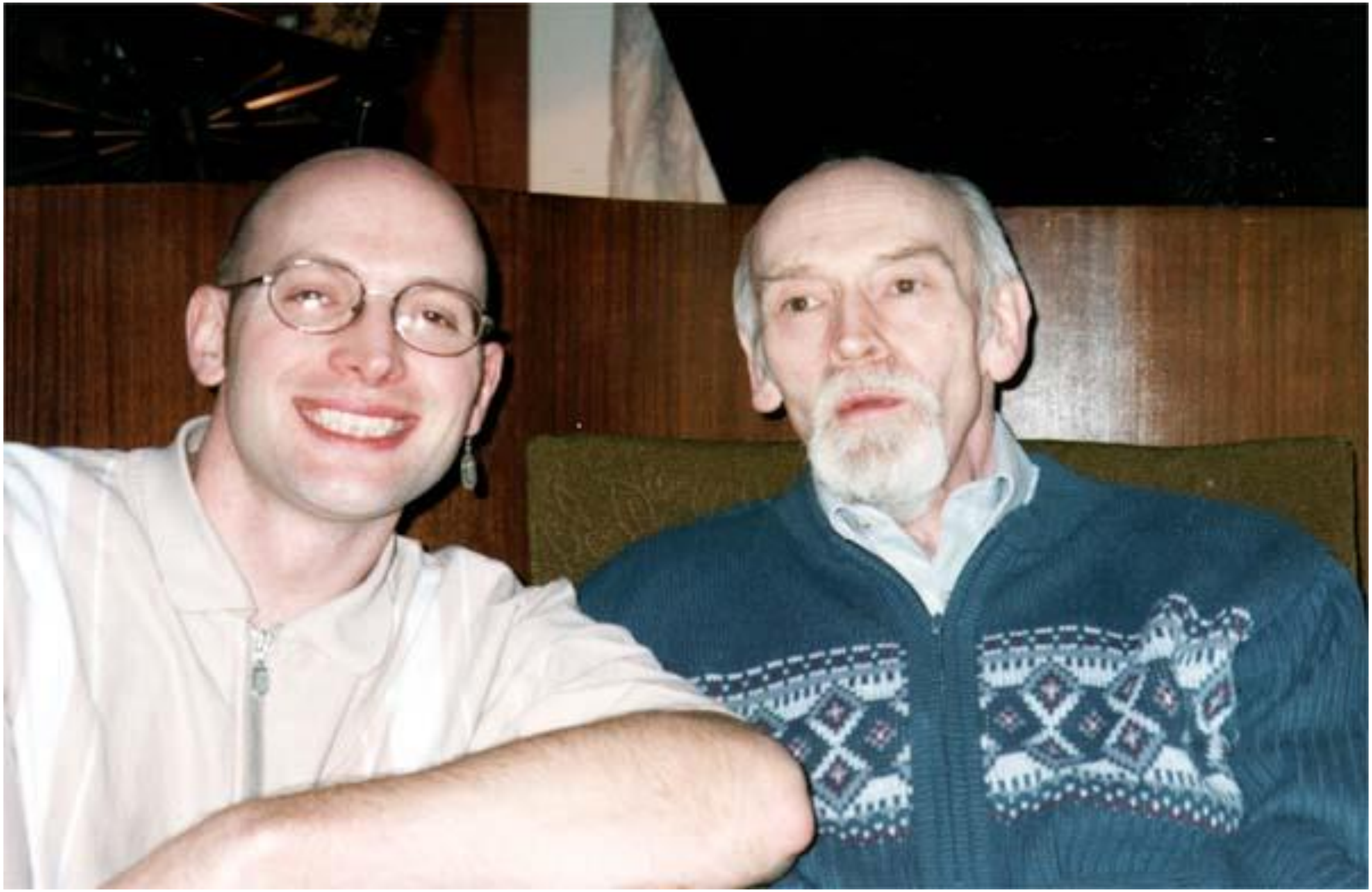
Finding appropriate activities to share

- Depends on pattern of damage in the brain; former hobbies, even primary and pre-school skills may not be retained.
- Malcolm: straightforward tasks of gardening, painting, walks, picnics, music, visiting open gardens, pint in the pub, old photos, shopping (quiet places), picture books, memorabilia.
- Loss of inhibition might open up new activities – e.g. dancing
- ‘Playing’ at their former job.
- David Sheard: *Being* (Dementia care Matters) -
- Going walkabout: I would have liked an electronic device to show me which way he’d gone
- How friends and neighbours can help
- Malcolm became ‘clingy’; how the community helped me to carry on with my own local interests

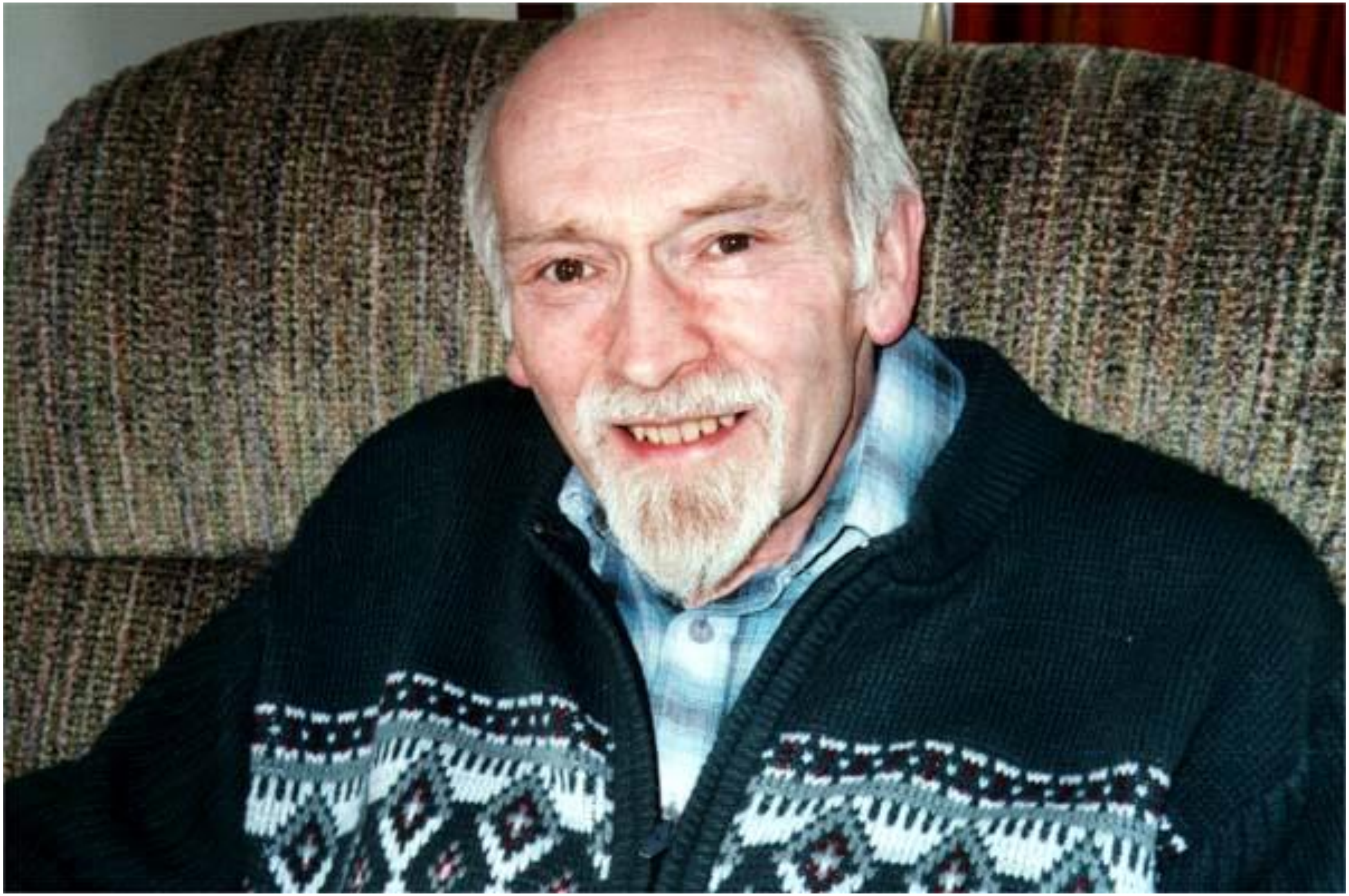
Helping with food and drink

- Think of how children learn to feed themselves, then run it in reverse. Use gradually more simplified cutlery.
- Then give food that can be picked up with fingers before reaching the stage of having to feed the person.
- Problems with eating out – stigma
- Local carers organisations can arrange lunches in sympathetic pubs - patients and carers can relax – nobody minds being messy.
- Had to give up going to theatre and concerts – glares and SShs
- Live-in carers – 14 different ones in 8 months
- Procession of new faces was disastrous – continuity essential
- *Dementia Care Matters* - all carehomes should take note.

December 1999



April 2000



The dining room, turned into Malcolm's room, with electrically-operated recliner chair, hospital bed, hoist and manual wheelchair

The severe stage: 2000-2007

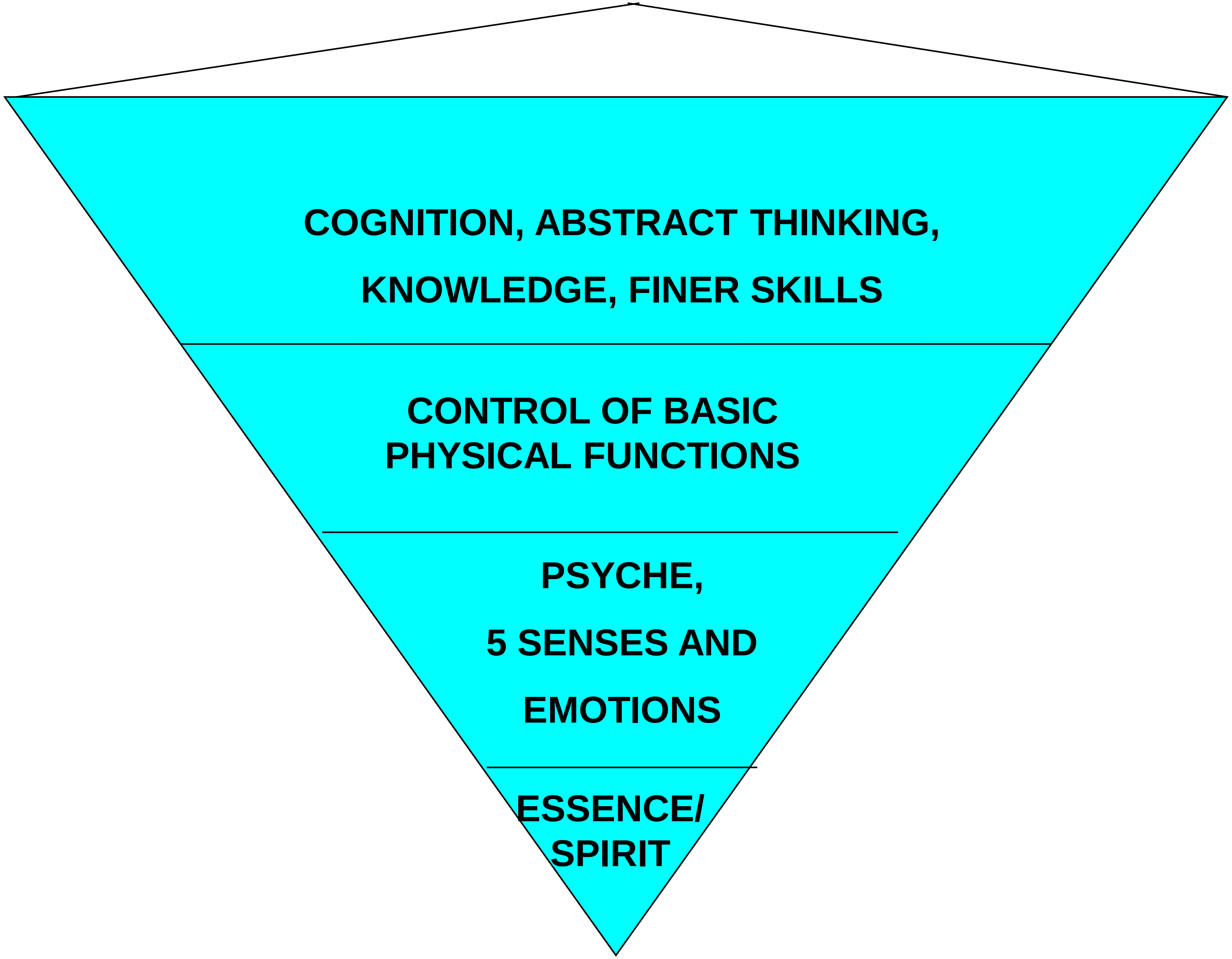
- Tissue viability: no pressure sores. Several transfers a day; pressure relief introduced early; incontinence pads of the right size and absorbency; Forever Living Product’s aloe vera gelly.

- People with Alzheimer’s don’t know where they are in space and resist being rolled on the bed for pad changes – vital piece of equipment: a standing hoist
- Recliner rather than upright armchair – keeling over to one side compresses internal organs

Continuity of staff, plus time and patience are essential.

The severe stage: 2000-2007

- TIME:Up to 45 mins to feed pureed food & thickened cold drink (cold drinks more easily sensed than tepid)
- Very trusting to open mouth; refusing food from new carer - continuity of staff essential.
- PEG (tube) feeding not recommended in dementia
- Weight loss is inevitable in severe stage – the brain is losing control of the extraction of nutrients from food or drink.
- Not usual kind of constipation; paraplegic-like routine.
- All medication reduced in line with severity of dementia; paediatric dosages; adult doses produce severe side-effects
- Family carers need access to expert dementia nursing advice.



COGNITION, ABSTRACT THINKING,

KNOWLEDGE, FINER SKILLS

CONTROL OF BASIC
PHYSICAL FUNCTIONS

PSYCHE,

5 SENSES AND

EMOTIONS

ESSENCE/
SPIRIT

Sensory/emotional/psychological/ spiritual needs

- The person is not “a vegetable”. TIME to stimulate 5 senses:
- Sight: smiley faces, changes of viewpoint, red/yellow spectrum
- Taste: oral feeding; sweeter, stronger flavours;
- Smell: of cooking, aromatherapy; favourite perfume.
- Hearing: favourite music, humming, basic human need to be talked to.
- Touch – the most important. Stroking hands & face; hugs; calming night fears.
- Love is at the centre of all major faiths, but religious or not, we all would want to feel safe and cherished

Barbara and Malcolm, January 2006

Sensory/emotional/psychological/ spiritual needs

- At this late stage (mute, immobile, helpless) - visitors often drop away or don’t know what to do if they do come. The stony face. Just because people can no longer show their emotions audibly or visibly doesn’t mean that needs don’t exist.
- Precious gift of time from neighbours and friends – for both Malcolm and me,

- In the last 7 years, Malcolm became too afraid to go outside his familiar surroundings, so respite for me was through having someone to replace me at home for one day a week – the same person each time. It worked like magic.
- *This is Me* – admission to hospital/carehome. 01753 535751

The dying phase

- Primitive instinct for survival took over
- Knowing when the patient is ready to let go
- Send to hospital for intravenous treatment or remain at home?
- Diary entry, therefore no aggressive interventions or unfamiliar surroundings; allowing nature to take its course at home.
- When someone is dying, they feel neither hunger nor thirst , provided the mouth and lips are kept moist.
- Malcolm died peacefully, physically cradled by our family, including the young grandchildren (who were not at all fazed by the experience).

Over the years, what helped me most?

Belonging to the Alzheimer’s Society for advice and emotional support (but cuts to grants are now affecting voluntary sector services)

Meeting other carers to compare notes, pick up tips and become friends

Access to an Admiral nurse – in our case, by phone.

Regular breaks (new Government money available via GP)

Regular health checks for carers are now being piloted

Our village community – supporting us right to the end, practically, emotionally and spiritually.