

*At the end of life  
We look back and ponder  
Look at what we thought we had  
And realize it was so little*

*We thought we knew , but now  
We know we knew nothing.  
We felt we were in charge of the pieces of our life,  
But now we see those pieces  
Strewn every which way.....*

[This is the beginning of a poem by Joyce Rupp called 'Is anything left?']

In the early years of living with dementia, my mother struggled to make sense of what was going on around and within her. Sometimes it felt too hard to find words for it.

One day, I happened to have a poetry book in my bag that a friend had given me – I didn't often read poetry, and I don't remember seeing my mother read poetry either. However for years she had loved to read novels – a constant pile of books from the local library, a pleasure to read, a refuge from loneliness, characters who felt like friends; and often she liked to relate the plot of a recently read book.

Dementia didn't take away her linguistic ability to read – but it severely impaired her ability to retain and concentrate, so that books were no longer a pleasure but increasingly a frustration, and then an impossible task.

I had noticed she'd inexplicably stopped going to the library - that was at least a year before I really noticed her failing memory sufficiently to become more protective and actively start to take care of her.

On the day of the poetry book, this was the first time in some years I'd seen her hold a book with real pleasure. She slowly turned from page to page and read out parts of the poems. Joyce Rupp's poems in '*My soul feels lean*' are set out beautifully with short lines and lots of space.

*I lose myself, find myself  
Consistently, unendingly.*

*With each finding I think  
'This is it, the last time,  
now all is well.'*

*Then it happens again.  
Like now, I'm lost,  
yearning, searching  
for the part of me  
that carries peace.  
The settled happy self  
that sings with the stars  
and dreams with the moon.*

*But for now, I'm lost,  
Walking through dim forests,  
snagged by the underbrush,  
moving through tangled days*

*in a fog, doing what must  
be done. Trusting  
I will find my self again.*

My mother read through this poem many times, she smiled to herself....  
She said 'She's so clever, the woman who writes this, she know how you feel, she puts what you feel into the right words...'

And after a long pause, 'it's because I remember how I was , I know this isn't normal. When I get worse, I won't remember so I'll just think all this *is* normal.'

Her grief for what has been lost, and the fear of losing more were both so unbearable – it seems to be this which so often fuels her wish to die – she often says, I don't want to complain about what is going on outside me - but it's what's inside *me*'.

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So far I have been using the word *dementia* as most of us do as a kind of shorthand for both illness & its effect

– but in its medical definition - dementia is not the name of one illness, but an umbrella word to describe a varied set of symptoms which increasingly interfere with daily life, and which are caused by a disease which physically damages the brain.

The set of symptoms include - memory loss, difficulty in thinking, in problem solving & in language, and may include changes in mood and behaviour.

The symptoms vary depending on which parts of the brain are affected.

The most common disease to cause dementia is Alzheimer's disease [ *where brain cells become surrounded by an abnormal protein, cells become damaged and in time connections between brain cells are lost and some cells die.* ]

Vascular dementia is the next frequent cause – may follow a large stroke or many small mini-strokes – damage to brain cells is due to the reduction of oxygen supply.

And there are several other physical illnesses which are less frequent causes of dementia – incl. 'dementia with Lewy bodies', [ *abnormalities within the brain cells* ] Parkinson's disease, Korsakoff's syndrome.

But I am speaking now as a daughter rather than as a health professional - so I will continue to use the 'shorthand' term 'dementia'.

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It has been important for me to hold in mind that my mother's last few years are a fraction of a long and purposeful life, and the person she has been is still there somehow within her.

I will give just a sketch here of the life she has had, of which this is just one part: She grew up in a large extended Iraqi Jewish family in Bombay. In 1946 she and her younger sister , in their early twenties emigrated to London.

She met and married my father in 1948, and spent the 1950s bringing up my sister and me. She worked as a teacher and in shops.

She was widowed at 67 after many years looking after my father, and a couple of years later she chose to move to a small flat in the same road I then lived in – stoically independent, but wanting the security of knowing someone was nearby if needed. – and up till 4 years ago, she indeed retained this independence.

In her last year at home, my visits had increased to daily, and generally several hours each day; but her home nevertheless seemed to become increasingly a fearful and unmanageable place to be.

At one point, - about December 2012, there was a really steep down curve, and she stayed in bed most of the day, and I felt she's just given up.

Then I began to think, perhaps it isn't just memory loss, it really feels like depression is making the memory loss even worse. So I spent a lot more time with her, and tried to find words together for the sad depressed feelings – and for awhile it felt the sense of depression lifted, and with this, her ability to tolerate the memory loss improved and to accept practical help with managing at home.

It's made me realise how much depression is often there with other people I meet with dementia – and how difficult this can be for others to relate to.

Some 6 months later, things again felt unmanageable . then she had a fall, and was in hospital with a broken leg. This was the point of getting formal diagnosis for the first time – of *vascular dementia*.

The diagnosis felt partly a relief to me – an official recognition that she has a difficulty and that I am taking more responsibility.

I also felt a lot of guilt – I had an image of how it is when you have a problem with your computer and you go into a help site and then get a message that says 'are you willing for me to take over your computer screen?' and then you sit at your computer and somebody else is doing all sorts of things on your computer which is quite disconcerting and you can't control it.

That was kind of how I felt – as if I've taken over her life, making the big decisions about residential care but also the smaller decision about which bits of her possessions to bring to her there.

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Around then, I also began to read more and look for articles on the internet to help me with my own feelings and confusion.

One helpful writer was a Swedish medical researcher *Lars Christer Hyden*. He believes there is no clear relation between loss of memory, and loss of identity and suggests practical ways to preserve a sense of identity as long as possible. He writes of promoting Interdependent identities and common ground when someone has dementia. and that identity can be a shared identity (such as two partners, or parent & child) , and that 'memories' can be shared and don't necessarily have to reside in one person's mind.

This made me think more about how we sustain a relationship with someone with dementia – and that it is largely through relationships, and communication ( both verbal and non-verbal), that we help sustain the person's sense of identity.

Also, that emotions – such as happiness, sadness, fear, anger, confusion, joy – are the same emotions in all of us whether or not living with dementia, - and again, those emotions are modulated through relationships and communication.

My mother once said of the people around her in the care home – 'everyone here needs someone to say to how they feel. I have you. Others , you hear them talking to themselves. Some have family, they come maybe every 2 weeks, you see their face light up when they see them, then after that they just look sad again.'

[I think to myself, that even though she sees me most days, it is probably like this for her too]

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Lars Heiden used the word 'narrative scaffolding' to describe a way of helping communication. He developed this in terms of shared story telling about past events – but I found the ideas helpful in all aspects of sustaining communication.

I found I needed to develop my own ability 'just to chatter' about something whether in the present or the past – and that my own words and memories and pauses became the fabric of the 'scaffolding', with gradually my mother connecting to some part of it and making her own input and ownership.

The term 'scaffolding is used by teachers meaning *a framework of support in a learning process to promote a deeper level of learning.*

The elements especially relevant to people with dementia include:

- Intersubjectivity – having time to establish some joint attention with the person.
  - Giving the person enough *time* both to listen & to find their words/or way to respond
  - Breaking up things into small enough chunks,
  - Pausing
  - Showing as well as telling – including pictures and objects
- a sufficient amount of structure, guidance and encouragement for the person to then actively participate to whatever level they can do, and to take ownership of the situation including making decisions.
- also, finding ways of *repair* eg when a person cannot find the words, or can't understand, so that they can re-engage without loss of face or a sense of incompetence. Eg. not to contradict or just take over.

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this helped me to see what often *doesn't* help –

In particular the 'open questions' we often use in social situations 'how are you?' 'what have you been doing today?' – can just draw a blank and direct questions like 'Do you remember when we used to go to the Margate?' may also be hard because the person does not remember.

There used to be an emphasis on 'reality orientation', and this was promoted quite widely especially in care settings but now is seen as less central – it is often just too dissonant with what someone is experiencing.

For example, people in care homes often say 'I have to go home now' and it doesn't usually help if we say 'this is your home, you live here'. 'Going home' often seems to become a metaphor for 'I feel lost, I want to go back to how I was'. Often it is *reassurance*, rather than *reality orientation* which helps.

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On one occasion, my mum summed the idea of scaffolding very well herself – we were sitting together with another resident Marie who took great pride in her Scottish origin, and I said 'well we've got a Scot in our family, Uncle Peter. Mum nodded. You went to visit Peter's mother in Scotland when you first came to England. 'Yes

she was a nice woman' . Can I tell Marie the story of how Peter and Mozelle met? Yes. Then I start to tell the romantic tale of Peter being in the army during the war, posted to India, he and Mozelle met when she was a volunteer at a services canteen in Bombay. And both then waited for each other till the war was over. Mum engages and adds comments as we go along. At the end she smiles broadly at Marie and says 'I tell her my stories, she remembers them, and then I can forget them'

Sometimes a chat about what is going on around us also gives ways of sharing feelings:

We sometimes went to look at the budgerigar which one resident had kept in a corner of a communal area, watching him play, eat, move about....

One time mum said ' It's sad to see a caged bird, it wants to fly'.

And then, some weeks later she said 'Don't feel sad for the bird, it feels safe in the cage, it knows it can't really fly now because it would get lost and wouldn't find food.' Maybe some feeling within her had moved in this time.

Sometimes our talk was very much in the present, and sometimes there was a dream-like mixture of present and past and either imagined or misperceived objects and people.

I learnt generally it doesn't help to contradict – rather to work out when questions mean a need for reassurance rather than information eg 'It's alright we'll sort it out' Sometime the dream-like images seems to give much pleasure, a kind of meditation – she would spend time peacefully looking out of the window at the street and telling me about horses and sailing boats, which I couldn't see.

But at others, the illusions seem more of a nightmare – believing that my father kept walking by and refusing to speak to her and wanted to punish her, I did then say 'you know dad died nearly 30 years ago'. Initially she'd usually say 'how can't I remember he'd died?' I'd say, 'I think about him a lot, and I think you think about him a lot and that can make him feel he's still around and it's hard to remember he died'.

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I became aware that cognitive and emotional memory can be different.

One morning she was very upset when I arrived, in her room, talking only of wanting to die; she'd had a good life but there was nothing now, and nothing else in the future, there was no point.going on..

I know that no words can shift this – just listening, sitting together, but also, that a few pieces of music – gentle old songs – sometimes do help to contain the feelings. An hour later, when she left to go down to lunch, she looked quite calm and happier. I was still in her room, putting away some clothes.

After a few minutes , she returned– having set off to the dining room and forgotten where she was going. She looked surprised and delighted to see me 'What are you doing here? When did you come here?' All cognitive memory of my visit had gone, but some emotional memory of feeling calmer and happier had remained, and she was easily reassured that I'd just popped in to bring some clothes and couldn't stay longer today.

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I often feel very sad for her because she's not having the sort of life she'd wanted – I think she held onto the belief that many of us have that she would get older and then drop dead neatly and quietly - and this hasn't happened.

We both gradually try to accept it is as it is.

I also think I have got to know her more deeply in the last few years. Being with her through his period of dementia, in some ways its been very intimate. It's an intimacy that might not have happened – an appreciation of who she is and a real sense of what she might have been like as a young woman – some of that really shines through.'

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*My Soul Feels Lean – poems of loss and restoration* - Joyce Rupp 2013 Sorin books

*Opening Shutters, Opening Minds* - James McKillop [After the onset of dementia in his early fifties, James McKillop had to give up his job as a lorry driver, and taught himself to become a photographer .

*Narrative Collaboration & Scaffolding in Dementia* - Lars-Christer Hyden, Sweden  
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