

**PRESENTATION BY THE REV CANON DEAN FOSTEKEW
ONE STEP AT A TIME CONFERENCE
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Pastoral Care for those with Dementia at Home or in a Care Home

A little while ago I came across this anonymous poem:

Some sad news this year.
I have dementia.
I'm being positive
but I hope it's slow.
I'm looking forward to the festivities but
I'd like you to know:
All the anticipation, the dos, and the sparkle
bangs, bells and chaos, hard work and sprouts
... feels like ...
Paddington Station
Whoosh! ...

Friends pass me by
'Don't leave me out!'
Smiles, without seeing,
pretending everything's ok
Wait!
I'm lost

Like to hideaway.
The grandchildren
all the names
it's not the love bit that's the problem
it's remembering what they're called.
I was the one putting up shelves, doing magic tricks
Now, you say; 'Don't worry yourself'
As if you no longer trust me
And there's a little voice in my head that says "bout right'
But I want to, need to, feel of use ...
Sometimes if you help me you can disable me more than the illness
So ...
There's no change but it's all change
And another year ahead.
It may be a bit foggy but there is potential!
Don't pity me, stroke me, make a mess of my hair.
Don't want it to be over - yet!

**Pastoral care at home or in a care home.
How does one do it?**

I am no expert, but I am someone who has tried to engage in this ministry for nigh on 30 years. I can't claim that I have always got it right or even that I get it right most of the time but I can offer you some reflections on how I have gone about ministering to those living with dementia and their loved ones around them.

The poem I began with has for me three important lines:

'Don't leave me out!'

'But I want to, need to, feel of use'

and

'It may be a bit foggy but there is potential!'

How often do we leave people out because they are no longer able to do the things they used to do? When someone is unable to attend worship on a regular basis how often do we ensure they are regularly visited and involved in the extended life of the congregation?

Familiar words

The use of familiar words of liturgy or hymns are important and using them can enable those who remember them to fully engage with worship for that moment, however fleeting.

Familiar words and liturgy are a great asset in the care of those living with dementia, at church we have a weekly Prayer Book communion service which attracts members beyond our usual congregation who love the words they can remember and it has for many become the highlight of their week and the only time they come out of the house. We also have a six weekly 'Afternoon Service' followed by tea and cake. A good afternoon tea served in the company of old friends. It is a short service and an opportunity for good chat over the tea table. It is also less daunting than a larger Sunday service to attend or to get to, part of that being the timing. Early mornings can be difficult for some.

Familiar Clothes!

The other thing I have found that helps in caring for those with dementia is to wear my clerical collar. That's my tradition but for those with dementia it is often a symbol they remember. One of my members does not remember me but remembers the collar and knows that because of it I am her minister. In the dementia club I am associated with there was a lady who liked to see clergy in the full 'polo mint' collar and would tell one so. So I wore it and she would volunteer to read the lessons at our services. If I didn't, she didn't join in.

Feeling needed

Thus far I have mentioned 'getting through the fog to find the potential' and not leaving one out. How can one enable those living with dementia to feel of need; It is I think an important part of their pastoral care and something one can begin to address if one listens to the person.

Recently, I was visiting a member of my congregation who is now unable to get to church and who was distressed that their life was shrinking so quickly as their memory declined. They had been very active in practical ways for many decades in the church. They told me

that they missed feeling useful and that there was nothing left that they could usefully do for anyone, any longer.

As our conversation unfolded and repeated I began to explore with them what praying is all about and I said to them that the most important thing a person of faith can ever do is to pray for others and that they were still able to pray and therefore engage in a very important practical ministry. I now ask them to pray for specific people and we have agreed that if they can't remember the names then God understands their intentions any way. Developing a ministry of prayer with them has brought them comfort and joy and as they have told me they feel useful once again.

Making Time

In all of my chat and examples; what I deeply believe is most important, is to take time and to make time to get to know, really know the person you are visiting.

If you have not known them in their prime chatting to those who have can give you a wealth of knowledge that you can use in conversation and even if no conversation is possible then just taking the time to sit and pray in silence and calm or with familiar words can be of comfort and support to the individual and often their families.

It is also not just me who visits. Members of the congregation who know those now permanently at home or living in care are vital in caring for members of one's congregation. (Elders) They often really know these people and have a shared history that enables them to engage in deep conversations or to stimulate conversation because of their shared memories. Friendships go beyond dementia and it is a bit of life that can remain unchanged in a rapidly changing environment. These visitors will sometimes need support as it can be distressing for them to see old friends slipping away but their support is so rich and encouraging for those living with dementia and their loved ones. For example, the group of friends who still take their friend with dementia golfing each week. He can no longer play but they walk round with him and chat as they always did and then enjoy lunch together. Friendship lasts.

Getting to know

Getting to know who the individual is and what they have done is vitally important as it enables you to 'know' them and to see more than you might initially perceive. I was visiting a close friend in hospital recently; a playwright, actor, theatre director and person with a rich life behind them; when a young doctor came along and started talking to them in a way that pitied them, stroked them and messed their hair (to quote the poem). I could see the tension and anger rising in my friend, so I intervened by talking to my friend about some of the things they had done and still do. The attitude of the doctor changed immediately, and they began to speak directly to my friend in a less patronising way. Sadly, they did not have the time to get to know my friend but even a short chat would have elicited some basic information, that they could have built upon. It acted as a reminder to me not to take for granted that I know anything or everything about those I visit. Helping the individual and their loved ones put together a note of some of the things they have done is useful task as it can give a snapshot of who they are. What do we know of someone from what we see?

Jackie Kay has a poem about her parents, that reminds me regularly not to believe that what I see is who that person is:

***My seventy-seven year old father
put his reading glasses on
to help my mother do the buttons
on the back of her dress.
'What a pair the two of us are!'
my mother said, 'Me, with my sore wrist,
you with your bad eyes and, soft thumbs.'***

***And off they went, my two parents
to march against the war in Iraq,
him with his plastic hips. Her with her arthritis,
to congregate at George Square, where the banners
waved at each other like old friends, flapping,
where they'd met for summary marches over their years,
for peace on earth, for pity's sake, for peace, for peace.***

Would you see two radical socialists in that old couple if you met them without knowing them? Would you see the NASA scientist who designed part of the Apollo rockets communications system as he lay in a hospital bed? Probably not but that's why we need to 'get to really know' those we have pastoral responsibility for and asking others about them is a good start.

I suspect that have told you nothing new today, but I hope that through my examples I have encouraged you to keep on doing what you do in caring for those living with dementia and those who love and care for them too.

As members of the church we have a duty to carry for each other throughout our lives and to be ready to extend the hand of Christian fellowship to anyone who needs it, regardless of who they are and what their particular needs might be.