

What Can I Hope For In My Old Age

(I don't know who I am , where I am, what I am. I'm going queer, you don't leave me, I'm frightened. My mind always goes back to the happy days spent on the moors where we had tea and cakes - just been thinking of my old pals.)

These are some of the jottings my mum has been writing down for the past 5 years and gives me an insight into her thoughts and concerns.

My perspective for this talk is drawn from an 8 years experience of first, being a long distance carer for Mum (Inverness to Doncaster) and over the past 5 years, a personal carer since I brought Mum up to live with me in Nairn. She is 93, a widow for 17 years, physically fit and diagnosed with Alzheimer's which is demonstrated by a bad short term memory, periods of anxiety and depression .

I am single and so responsibility for her care is totally mine . In preparing this talk, I initially thought, this may put me at a disadvantage , but I fear with small families nowadays and they being so geographically scattered and traditional caring neighbourhoods less prevalent, in fact single carers or no carers at all is probably the sad but realistic situation for the future ,for many .

From these experiences, what would I hope for in my old age, if diagnosed with Alzheimers.?

Firstly, sadly, it would be best if I was not living in the Highlands. In the 5 years of living here Mum has had 9 different psychiatric doctors assessing her condition every 6 months , because of shortage of such doctors in the north., so there is none of the continuity of oversight , I would wish for . I naturally would hope that medical advances would assist my condition, but in the meantime expect that medication (which Mum receives) would still be available and not rationed by funding.

I would sincerely hope that my own GP is familiar with the symptoms of alzheimers and would refer me for assessments and give guidance and support to me and my carer including some home visits. Indeed it would be an advance if I could identify those GPs with a sensibility for treating dementia, frankly I don't know how this is done, other than word of mouth. It does seem to require the GP to make any initial referral to memory clinics, CPNs or social work - if that is not done, I will have problems.

Also, the local CPN I have discovered is there only for emergencies, and so she has not seen Mum for 3 over years.

With NHS seemingly only funding acute health care , unless the condition requires specialist doctoring ,I find dementia services, are being deemed as a social problem, but Council funding for social care is now prioritised for critical need . After an initial assessment , the services from Social Work I find are reactive, not proactive and pared to the bone .

Day Care Centres for dementia patients need high staffing levels and so are expensive

and rationed - in Nairn , only 8 places are available 2 days a week, and it is now full. I would like dietary advice and assistance for Mum - but from which service ? Without additional financial resources put into Council social Work and NHS support for dementia care and treatment, especially with the growing ageing population, I do fear for the future, especially if the two services do not better inter-relate - at present dementia care does seem to fall between the two stools .

I have been fortunate in relying on Nairn Crossroads to provide day and overnight care for Mum (allowing me to be here today) ; incidentally, over 50% of their case load is now in support of carers of dementia sufferers.

Ideally I would like to see the return of a home help , who would provide care and support, have the time to sit and chat , do some housework and prepare a main meal- a comforting familiar face with the special understanding and patience of caring for people with dementia . A series of different personal carers flying in and out, and at varying times , as I find happens with Social Work's personal care , would be distressing and even alarming (Mum is aware she shouldn't let strangers in, but since she cannot remember different faces, it is frightening for her to have strangers, as she sees them ,coming in and out of the house) If possible, I would like to exercise some preference for my home carers - after all we all have our own personal likes and dislikes about people .

In addition, I hope come my time ,the availability of Admiral Nurses would have spread to Scotland with their trained support for sufferers and carers , in the role of MacMillan nurses for cancer patients.

In an ideal situation, for my future I envisage living in my home , or sheltered housing, hopefully with good neighbours, home help or a warden , close to a special community nursing home with an active assessment centre and friendly day care centre and a base for Admiralty nurses and special dietary and physiotherapy advice and support for the elderly and those with dementia . Also it would have a respite centre (the latter, incidentally, so essential for carers , I would like to ensure my own carers have some relief .) This multi- purpose home , should be properly funded by a seamless service of Social Work and NHS .

I would like to become familiar with the staff and the services offered by the home ready for the time I need to become a permanent resident. A place that would be homely and comforting, with some familiar ornaments or furniture and where my condition would be understood and my individuality respected and I would not be frightened and confused. (a kind of hospice equivalent) .

Perhaps such places in the future would be so popular that house prices would rise in their vicinity, as happens now in the neighbourhood of good schools.

Of course if I do wander, alarm devices are now around to forewarn carers and residential staff and these will advance in technology. I hope, indeed, that I may be allowed ,and have the freedom, to wander, in safe surroundings, if I am trackable and

traceable , since I may have a purpose for this wandering in my own head. Hopefully, kind neighbours or the home carers will be around to watch over this wandering. Indeed CTV may have a friendly purpose in this respect. (A friend of mine whose mother had dementia, was a police lady who often went out at night on shift work - this explanation for her wanderings should be acknowledged and , where possible accommodated for.).

Having dealt with my hopes and expectations for services I would hope to receive, what can I do for myself in preparation for the future ?- apart , that is, from keeping my 15 Godchildren in line in expectations from my will and hope they would take on some caring responsibility in return ! .

In order to help my carers and family and welfare attorney ,when I unable to express myself, I would get an advance statement prepared , and especially a ‘statement of values‘. Using this faculty I could outline my preferences , what makes life worth living , and what I fear.

I have noted , when Mum is particularly depressed or anxious , how playing cds of Al Jolson or the Black and White Minstrels take her back to happier times and she sings along . I will organise an IPOD of my favourite 60s music (they say the music you heard in your late teens and early 20s stays with you to the end.). Also I would organise and write down my personal life story, a life diary, with photos (the photo album is a favourite for Mum - she can name all the fellow pupils on a school photo. of 80 years ago , while not remembering a visitor of 10 minutes ago) ; possibly having an undemanding pet around for company - in Mum’s case, Joey the Budgie , which has been so good for Mum

Mum expresses her worries and anxieties - making sure the doors are locked (a result of childhood experiences) , not wanting white flowers (a sign of death) .She must have her daily newspaper, but has no interest in magazines. Mum can still play serious dominoes, - indeed, I hope my own cribbage skills remain as fresh and competent. ! ..

However, in the end, there is only so much I can do for myself in preparation for the illness, I hope and expect, that public perception will change regarding the elderly with dementia ; it will become more sympathetic . As we have changed from a ‘ Does he take sugar ‘ attitude towards the physically handicapped , so I hope the dismissive attitudes to the elderly with dementia will change too and we see people as they are and not their handicaps.

So much though will have to be in the hands of people with understanding of my illness, backed by adequate financial resources from the State, especially for Council social work services - and for ancillary charitable support services such as Crossroads and Alzheimer Scotland .All this, I acknowledge, does need a change in the political will, to allocate appropriate funding, but I really do hope the pressure of public demand , especially from this post -war bulge generation, of which I am one, will move the politicians in that funding direction.

I hope to be cared for with security , understood and loved with dignity, and respect for my individuality - and hope to have the pleasures of sitting under apple blossom trees and my own Joey the budgie to be with me and remind me of happy times past, as Mum does. .