Talk delivered at YOD conference Birmingham 27 September 2016

I am delighted and honoured to have the opportunity of following Alistair Burns this morning and to outline what I see as potential ways forward in meeting the needs of younger people being diagnosed with dementia, or as the late, great Terry Pratchett so accurately labelled it "the embuguerrance"

To express my thoughts on the subject of Young Onset Dementia I apologise that I need these days to read from a script, which when staring talks 5 years ago was font 12, has now moved to font 16 and when it reaches font 20 maybe it will be time to call it a day.

Alistair says about the Dementia Research Institute and I am delighted to say I along with my wife and four other service users - mix of diagnosed and family care givers was on the panel last week for the post of director of the Institute which sends out a powerful message about service user involvement

"For the past six years I have knowingly been increasingly sharing my brain with an unwelcome and unwanted guest; Dr. Alzheimer. You see when you professionals turn off your laptop, or mute your phone and pay attention to something else I do not have this ability. Alzheimer's stays with me 24/7. Sometimes in the background, watching and waiting for an opportunity to make mischief, sometimes leading me up a pathway where I do not seek to go, and on other occasions he is fleeing from the sun, which I strive so dearly to light up my life, brought out by a treatment or intervention or love from a professional, a friend or a family member. I know what young onset is really like because I live with it. My wife knows what young onset is really like because she lives with me. I am reminded of Princess Diana who said there were three in her marriage and Rosemary, myself and the many thousands of other people with Young Onset know who this third insidious member of the triad is, Dr Alzheimer. Others who share my life are so much more welcome and friendly amongst whom are my three adult children and my three grandchildren.

When diagnosed I had the typical impression that dementia was solely the domain of the elderly. My mother developed Alzheimer's in her mid-70s and she was typical of how I imagined people with dementia. Never had I met someone affected by dementia below the age of 65 which is the threshold for someone to be referred to as young or early onset. My diagnosis was very unexpected by both myself, my family and our GP who had sent me for a scan and a neurologist appointment to rule out a brain tumour. Dementia wasn't on anybody's radar until after the scan and the appointment, following which I was referred to the memory clinic in Canterbury for what turned out to be an in-depth 6 month assessment period which culminated with a confirmed diagnosis. During this period I was extremely well supported by the professional team who explained to me the testing and the results of the tests which at best I was performing at average and at my worst at the lower fifth centile. The pacing and the approach were both person-centered. I wanted information and I needed to understand what I was living with, and subsequently this served to allow me to come to terms with moving from a suggested diagnosis to a confirmed one with less of a shock, and then to begin to live as well as possible with dementia. No one, especially someone in their 50s wants to be diagnosed with dementia but because of the impact the disease was having on me by way of my ability to undertake my work, remember conversations and reading, TV programmes, films etc., changes in my behaviour and concentration and difficulties with balance there was some peace of mind in knowing what the cause of these problems was. From this, one is then able to move forward by sorting out a smooth exit from work, financial support, lasting power of attorney and wills and beginning to meet other people who were sharing the same, or similar experiences.

I then felt that information was exerting power over the disease and that I realised I wasn't alone. Indeed, one morning I woke up to open the newspaper and read that my understanding of there being 16,000 people with young onset dementia was incorrect, and that the Alzheimer's Society were suggesting the figure is 42,000. Some would say this is an underestimate as many people either don't or won't come forward or are mis-diagnosed.
Hold up James Warner book
Other people with a diagnosis ask me about helpful books to read. I used James Warner and Nori Graham's extremely helpful little guide during my diagnosis, and as I've got to know them I have on numerous occasions thanked them for "holding my hand" and helping to lead me through the trials and tribulations of my intense diagnosis period. When I first met Reinhard Guss I said to Reinhard, please recommend a book to me which will help me pick up my life after diagnosis and he steered me towards Dancing with Dementia by Christine Bryden.

Hold up Christine Bryden book
Her book has become a source of inspiration and first drew me to the metaphor of the swan - serene on the surface but paddling madly below to keep up. It is also a rarity for me in that I have now read it three times since 2011. I only wish I could better remember now what I read. Another professional friend Penny Hibberd who was running the Dementia Centre at Canterbury Christ Church University and now works as and with the Admiral nurses in London loaned me her copy of Still Alice.

Hold up Still Alice
After reading 20 pages I dashed down to Waterstones to buy my own copy. Speaking of books, I have written about Young Onset dementia in a new book to be titled "Walk the Walk: Talk the Talk", and amongst professional friends who have contributed to this chapter are Tessa Gutteridge, Adrian Bradley and Julia Burton - Jones. My aim is to have the book ready for sale in November ideally by Congress and it will be a bargain at £5 with every penny going to the Alzheimer's Society and Innovations in Dementia who are both sponsoring this venture. To whet your appetite I'm going to read the foreword to the book written by TV and radio presenter Richard Madeley.

People with young-onset dementia require specific treatments, interventions, and support, and alas they are very much a postcode lottery and are few and far between. So many services place younger people in with late-onset service users which is often inappropriate and doesn't engage or meet the needs of the younger person. Usually younger people with dementia don't present with the same co-morbidities, that's a horrible medical phrase, as older people. Often we are physically fitter, have enormous amounts of physical energy - sometimes too much (!) and it's our cognitive functioning which lets us down, frustrates and at times leads to depression. Depression and dementia are a truly toxic partnership and having experienced both after a period of feeling "bullet-proof" it is sometimes difficult to know which is having a greater impact on my ability to feel that I am living well. I have drawn great support from professionals in KMPT, the Alzheimer's Society, Young Dementia UK, DEEP and Age UK, which alongside my own reading have helped.

I have studied in great depth the work of Tom Kitwood, and so much of his writing from the 1990s is still so relevant and important today 20 years later and pertinent to Young Onset. Relatively recently the Alzheimer's Society have had Adrian Bradley in post as "National Lead - Younger People with Dementia" to champion and coordinate the Societies' provision for young people with dementia, and this again is a very positive innovation. Alongside Adrian I serve on the National Network for Young Onset Dementia which has a range of agencies involved and is co-ordinated by Young Dementia UK (YDUK). Together service users and providers will make a difference.

In the case of Kitwood I refer often to his illustration of a flower which has love at its centre surrounded by: attachment, comfort, identity, occupation and inclusion. When these are in place I live well.

Unfortunately there are times when as Kitwood describes: Malignant Social Psychology makes my life much more challenging. Aspects of this negatively impact upon my self esteem and well being and result in fear, self doubt and confusion replacing positivity. The point at which the flower should bloom clearest and the malignant social psychology be dumped in the bin are during and immediately after diagnosis - those
"cliff edge moments". I wonder how many of these you identify with when either delivering or receiving a diagnosis. Although not during my diagnosis I have experienced most of these since, as slips and dips in my mental health have occurred. Without the Kitwood flower and the treatments and interventions we need and crave the diagnosis has little or no benefit and can be cruel and damaging in its impact upon those receiving it.

To conclude, whilst neurologically there are many similarities between young-onset and late-onset dementia, the impact on the individual and their families, and the presentation of the condition are often very different. Consequently the methods of diagnosis and the way this is conveyed, the types of treatments, interventions and support which needs to be fit for purpose, centred on the person and their clear, achievable care plan in order that the person can live as well as possible, with the condition, the diagnosis and what follows for as long as possible. **The future is in all our hands.**

Thank you for listening
Keith Oliver, Canterbury 29 Sept. 2016