DEMENTIA THEN AND NOW
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Thank you for inviting me here today to speak to you. I’m delighted with the progress that the Dementia Action Alliance is making through signing up to the declaration, each drawing up a plan for action, and working in groups to share knowledge and good practice with each other. I’ve called my talk ‘Dementia Then and Now’ and I’d like to take each of the Alliance’s 7 desired outcomes in the Declaration for people with dementia and their carers and contrast what happened to Malcolm and me with what is happening right now and what, as an Alliance we might aim for in the future. I’ll address only one or two of the themes contained in each outcome.

Outcome 1. Choice and control or influence over decisions
Themes: ‘I have received an early diagnosis’. I can make decisions about future care’
Not for Malcolm. For 2 years he was treated for depression; what I now realise are tell-tale signs of dementia weren’t flagged up – like visuo-spatial problems, making mistakes in an ingrained skill (M’s piano playing) or uncharacteristic behaviour such as the usually patient, gentle Malcolm, being exceptionally rude to my mum. I began to scold him for forgetting things or doing things the wrong way. An earlier diagnosis would have enabled me to understand what was going on, therefore make allowances, and protect the relationship. And if only I’d known, we would have had a whale of a time while we still could – I also regret missing the opportunity to discuss his wishes for future care. Happening right now – of course, the new public awareness media campaign, but I still meet people who have only received a vague diagnosis of ‘memory problems’ and GPs who either won’t see the family carer independently to get at the truth, or won’t refer on to a memory clinic ‘because nothing can be done’. So more power to the elbows of Alliance members who are tackling this issue and the fear that surrounds it.

Outcome 2. I know that services are designed around me and my needs. Themes: ‘Staff understand a lot about me and my disability’ – ‘quality of life’
This is a central outcome, because two-thirds of people with dementia are cared for at home. About 5 years after diagnosis we started to use domiciliary care. That stopped when I needed help at M’s bedtime – they wouldn’t send anyone after 7pm. What man in his 50s wants to be in jamas and dressing gown at 7pm? – and it would have put an end to our social life. (These days, normal bedtimes are more respected but we still hear horror stories of people left in bed from 7pm to 10am next day and soaked with urine). We then resorted to Agency live-in-carers, especially when Malcolm became aggressive towards me. But they were not dementia-trained and we were sent 14 different people in 8 months. They had no time to learn how to deal with his complex special needs before they disappeared and I had to start all over again. Malcolm was bewildered and angered by the procession of new faces and I became totally exhausted. Continuity of paid staff, in order to build up a triangle of trust between the person with dementia, careworker and family is a prerequisite of tailored care. Unable to carry on, I put Malcolm in a carehome for 2 years. Guilt was enormous and I still feel it now. It is so good to read in the Dementia Alliance Action plans that education of the workforce is of primary importance and I believe that great strides are being made, especially on the carehome front. And family carers also require education because we form the largest dementia workforce. I know, with hindsight, I made many mistakes which affected M’s quality of life – e.g. Bossiness – ‘C’mon, Malcolm, put your shoes on!’ – treating him like a child. We can’t spin this kind of skilled care out of our humps. But for the future, may I make a plea for the Alliance members to ensure that domiciliary staff not only learn how to offer enlightened dementia care and support but also are given enough time to do the job properly – an end to commissioning ridiculous 15 min calls – and please allow travelling time between jobs – or else the small slot becomes even smaller! Another knotty problem on the horizon with more personal budgets is Personal assistants and self-employed carers for whom there is currently no registration system, even though they are dealing with vulnerable adults.

**Outcome 3. I have support that helps me live my life and (Outcome 6) Sense of belonging to the community**

Themes: *I can have fun with a network of others, including people in a similar position to me. I feel supported in my community.*
Not for M. He went to the only daycare available - designed for very elderly people with an assortment of mental health needs. He was 54 at the time, very fit and mobile and didn’t take kindly to sitting about. What is more, the tests at the hospital showed his sense of number was disappearing and that he had visuo spatial problems. So no wonder when the bingo apparatus came out, he made for the door at great speed; he didn’t want the embarrassment of his loss of numeracy to be made so public, and he tore up his paintings the minute he got home – because he knew they were rubbish. And I had to contend with his self-loathing and anger. That was not quality of life for him or me. It illustrates the need for joined-up thinking and a transparent flow of information between memory clinic and those providing care so that suitable activities can be put in place.

‘Feeling supported by the community’. Malcolm had become a bit messy with his food and we were having lunch in our local pub. A woman at the next table exclaimed loudly, ‘Look at that man – must be drunk or on drugs! Shouldn’t be allowed in here!’ Malcolm heard her, threw his plate on the floor and stormed out. We never ate out again. Stigma and ignorance is still rife among the general public. Later on, pushing Malcolm in his wheelchair, I noticed people would cross the road rather than speak to us.

These days, daycare activities, whoever offers them are much more enlightened and tailored to the individual, though I have to say that provision for younger people with dementia is still thin on the ground. Personal Budgets might enable people with dementia to seek activities within their own community (like 10-pin bowling) – linking to outcome 6 – becoming a valued part of the community – but it will only work if those who run leisure activities are also dementia-aware. In reading the Alliance members’ action plans, there is much emphasis on tailored care and support in every setting – be sure to throw that definition as wide as you can. Personally, I am heartened by being increasingly asked to talk to community groups - like churches, librarians, clubs and associations - on how to better support people with dementia and their carers in their own locality. Community interest is only a spark at the moment – we need to fan it into a national flame.

**Outcome 4. Knowledge and know-how to get what I need.**
What happened to us? This will be quick. Nothing. After diagnosis, I wasn’t told what might lie ahead of us, we were simply dropped into thin air and I had to rootle around, reinventing the wheel. There was no Alzheimer’s Society in our neck of the woods at that point. I had no idea who was responsible for what – dementia cuts across many traditional boundaries. What became obvious to me, not just in the early stages but throughout the long journey -and which is what all carers still say they want – we want one named point of contact. One person who gets to know well the person with dementia, their carer and family and their setting, who has sufficient knowledge to offer sound advice face-to-face about aspects of dementia support and care, tailored to our situation, who has the power to hook in a higher level of expertise if required and generally co-ordinate the web of care, which gets even more complicated as dementia worsens. In the late stages that adviser would need to be an expert in dementia nursing. In Primary Care we have practice nurses for diabetes or asthma – why not dementia? This would achieve integrated care where it matters - at grass roots, patient and carer level, and it came out top in a recent piece of research by Health at Home. This is a role well suited to voluntary sector expertise. The Dementia Adviser role deserves to be strengthened and developed further. Without a key person, people will continue to encounter duplication of effort, or fall through big holes in the net.

Outcome 5. I live in an enabling and supportive environment where I feel valued and understood. And Outcome 7: Research Themes: Behaviour that challenges others; the carer’s role is respected and supported; research is the key to improving care.
So much is changing since Malcolm’s experience of carehome care. Through research and examples of good practice, we now know how important a helpful physical environment is – good lighting, signage, nothing to confuse or worry over: a reassuring domestic scale layout as opposed to hotel-style living, stuff to fiddle with, activities to engage with and above all enlightened and compassionate staff. Running like a red thread through so many of the Alliance’s action plans is education of the workforce both in competencies and in developing the right attitude, wherever care is offered – at home, carehome or hospital. We know now to look first for reasons behind perplexing behaviour, not, as was Malcolm’s fate, to be sedated with anti-psychotics. We are beginning to
understand what makes for better palliative care in dementia wherever it is given and how dementia can affect normal nursing procedures, whereas I had to protect Malcolm from unnecessary overmedication, catheterisation and PEG feeding. And I learned that a person’s psychological, emotional and spiritual needs are as important as their physical ones, right to the end. Throughout all this the carer’s role is to be respected and supported, whatever the setting - being treated as a partner in care and allowed some life of our own outside caring. That was a struggle for me on many occasions. Through the Alzheimer’s Society I met other carers in the same boat, exchanged tips and laughed and cried - those friendships still persist. And latterly I have made new friends through Dementia UK’s Uniting Carers. We never stop learning from research. Only a couple of months ago I learned the most important fact ever. I had always thought that dementias caused loss of memories, full stop. But now I know differently. You and I see, hear, read or experience something – our brains then convert that experience into a memory which is stored. But for people with dementia that action of converting an experience into a memory inside the brain simply doesn’t happen. It isn’t that a person has forgotten something, or can’t retrieve it, it isn’t there in the first place. So it’s no good saying in response to repetitive questions,’ I’ve told you that 3 times already this morning’, or asking if they’ve taken their medication – they won’t know - or talking about what happened yesterday. That fact alone revolutionises care. To reach out to people with dementia, we all have to learn to live in the here and now, or in the distant past where memories still remain. Having to step into their shoes and learn what it feels like to have a dementia from the inside looking out, rather than from the outside trying to look in.
We all still see or hear about practices in carehomes, hospitals or at home which make us squirm. We still find carers worn to a frazzle, isolated and with their own health and well-being undermined. So we look to the Dementia Action Alliance - which has already demonstrated splendid strength, and solidarity with people with dementia and their carers – to continue to work together, creating a chorus of voices, which has more punch than a lonely soloist. We also know in our hearts that the job isn’t over until everyone who comes into contact with people with dementia is singing the same song.