Talk delivered to CASCADE conference 2 February 2023

Slide 1 –

Thank you for that introduction. Today's talk is inspired by the narrative therapy work of Australian author David Denborough whose book "R*etelliing the stories of our lives"* introduced me to a strategy known as the journey of life. The starting point for this journey is that I am a retired primary headteacher living in Canterbury with my wife and I was diagnosed with Alzheimer's disease after a series of conclusive scans and tests lasting seven months, 12 years ago aged 55, an event I was honoured to write about in this new edition of the Oxford Textbook of Old Age Psychiatry.

As I look back along my pathway or journey most of my experiences with people who have helped guide me along the dementia pathway have been positive, indeed the best thing about this journey are those I have met along the way, some of whom have enabled me to return to my teacher role in providing insight into my lived experience, whilst others have taught me things which I have taken on board to enable my journey to go more smoothly. Some of these professionals have become friends and fellow travellers accompanying me so are an important part of this narrative. Some are academics, others health and social care professionals in the NHS or third sector, others are undergraduates just beginning their own journey but helping me along part of the way. I know from my wide experience as a headteacher and education advisor that when multi agency support from a range of professionals is forthcoming the journey is much smoother for the person at the centre, be this a child or a person with dementia.

Slide 2–

Covid has placed us all at a crossroads, me with my dementia, you with your desire to improve the care of those affected by dementia. In my case direction of travel is influenced by an at times unreadable map and encroaching dark clouds or fog. I hope I can help you to plot a course which acknowledges that we are better travelling together. I will travel on foot as due to my dementia I no longer feel safe or stable on my much-loved bike to cycle. My early diagnosis set me on this journey earlier than I wished but which may well have benefitted me in developing my coping startegies to enable me to travel as safely as possible. The highs and lows, mountains and valleys, ups and downs, hurdles and fences to clamber over and challenges and rewards I have experienced along the route since my diagnosis are I know going to continue, and we all understand that covid has had a marked, negative impact upon those joining the journey by way of dementia rates so the pathway is going to take on a steeper gradient if we are to reach a safer haven in what we can reasonably call "new normal". I need to make choices about my care pathway so to do know I need help, guidance, signposting and then when at that destination the assurance that I am where I should be and can live as well as possible.

Slide 3

- **To give a sense of the person talking to you today (**including my experience, sense of person, values, beliefs, principles)
- **To share my care plan –** (my route map which is a part of my survival kit)
- **To show how I can still live reasonably well 10 years after diagnosis** (some milestones or favourite places or accomplishements along my route)
- **To explain some of the challenges I face along the pathway** (obstacles and road blocks along the way)
- **To remind you of the specific needs of fellow travellers given that we re all unique and different whilst all having a diagnosis of dementia** (identifying with others who have dementia though everyone is unique and different in the way they tackle the journey of life or how dementia affects them)

All journeys along a pathway need a map and these aims will serve to help guide me today. and my care plan is my route for this and my other journeys with dementia.

Slide 4

I have mentioned some who are travelling with me, but my closest travelling companion is my wife, followed close behind by my three adult children and 3 grandchildren, all of whom are affected to varying degrees by the travails of this journey, but all enjoy the rests we take together, and sometimes stop to admire the views of what I am seeking to achieve in my various dementia and family roles. My wife has provided me a packed meal to take with me as I now no longer feel safe or comfortable cooking food myself. Following them is the support party I am blessed with including a number of good professional and personal friends who recognise and encourage my desire to try and maintain skills learnt from my former life in education and then harness these for the benefit of other travellers seeking to plot their own course. I am energised by the arts and although frustrated that I remember little of what I read, I love reading the words of others and writing my own words some of which I will share with you at journey's end today. I dearly wish that more such activities which I KNOW hold back the wrath of dementia could be socially prescribed. They do work. I and many others have consistently seen the evidence in people's well being not just during the activity but beyond.

I know how lucky I am that the team conducting my diagnosis recognised my need for compassionate truth telling and in sending me off on this journey they delivered an early, accurate diagnosis in a way that I could understand and absorb in order to move forward. I was an energetic, intelligent, high functioning 55 year old being told I was in the lowest 5th to 10 centile in a number of tests and that my scans displayed clear and marked atrophy. I knew that this was making the journey hard, and would make it even harder still in future. How long I asked my consultant psychiatrist would I have before I reached journeys end in the community. She was unsure but best guess was 3 – 6 years. I am still travelling 10 years later because of my map or care plan, the route I am taking and the support I am blessed with.

Slide 5

Support from friends or professionals is not always available as I march on ahead, and I have many difficult days when the only person alongside me is my wife and she sees clearly the real impact dementia has upon me when words evade me, when I cannot judge the safe 2 metre spacing, when what she has told me a number of times has failed to register, when the TV programme we both watched and enjoyed has left my memory so we cannot share a conversation about it, or when the roses which enhance our route are scented to her but lack scent to me and when my balance and increased clumsiness causes me to break or damage treasured items we have amased during our journey together, but dementia will always fail to damage despite its efforts to thwart us the love we share for each other on our journey as husband and wife. A small number of onlookers ignorant of what living with dementia is like for me stand along the wayside questioning my journey. If I was walking with the cancer for which I was originally MRI scanned would they think the same?

Some who are travelling energetically at times along the dementia pathway have the particular needs of someone with Young Onset and we seek and need different support and care from psychiatrists. Often we don't conform to the stereotypical image of a dementia traveller, nor do we share the same physical health and social care issues and yet we are often herded together and treated the same. This lack of understanding is a major obstacle along our pathway. No wonder that some of us youngsters fall by the wayside, and yes conform to the expectations such as I was exposed to at point of diagnosis regarding the length of this journey. All of my care plan or survival kit combines to help me combat the wrath of dementia I face most days, no one element works on its own. I am the person at the centre of this journey and NEVER should dementia been seen as the centre which has the misguided map of a disease focused model which is sometimes referred to as the medical model.

Slide 6

Looking forward with my survival kit in my hand, I do occasionally wonder what the future holds for me around the corner. Where have I come from? Where am I now and where am I going to next? I ask myself these questions frequently along this journey, and I hope that I have given you some food for thought as you have walked a few steps with me today, and to close I would like to share with you some poems from these books I have written during my journey.

Friendship matters p117 haiku from Time and Place

Give Me I will p 348 from Dear Alzheimer's.

Thank you

Keith Oliver