John, The Reimagining Dementia Coalition for Social Justice and Me!

You are my heart's delight, And where you are, I long to be You make my darkness bright, When like a star you shine on me Shine, then, my whole life through Your life divine bids me hope anew That dreams of mine may at last come true And I shall hear you whisper, "I love you".

Land of Smiles (1931)

We were in the final session of a programme for people living with dementia and their families called **Remembering Yesterday and Caring Today – RYCT* (Schweitzer & Bruce, 2008) when John, my partner, went to the piano and sang this song to me, to show what he appreciated about me. As I looked around the room we were all in tears ...

When I say to him how beautifully he plays the piano in a particular track like *Explorations* he exclaims quizzically "Really!! Thats me?" "Yes," I say. Then, laughing with delight he responds, "Wow!!" And continues to tap his feet in time to the rhythm, his whole body resonating with the music. His response brings curiosity and interest to the fore, restores calm when he's anxious, promotes confidence and fluidity of movement, and enables deep emotional connection as we hold hands, maybe meet each other's gaze or are just meditatively "being together in the moment".

This is a snapshot of our lives five years and more after a diagnosis of Alzheimer's. Not the usual narrative of isolation, stigma and decline but one of vibrance and creativity. We were enjoying life together and this is why I have joined *Reimagining Dementia: A Creative Coalition for Justice*. I want to be part of a campaign which conveys a more nuanced message - yes there is loss and sadness but there are new opportunities for connection and love provided there is an ensemble of support and a community to rely on where we can ALL thrive. It goes without saying that of course the political dimension of this campaign is about demanding inclusion and equity, including the funding of a revitalised, integrated social and health care system across the world.

The Reimagining Dementia Coalition is an international group of people living with dementia, carers/care partners, family and community members, dementia activists and allies, health professionals, advocates, artists, academics, policymakers, and others. Earlier

this year, we launched our <u>Let's Reimagine song and video</u> as part of an international campaign with a vision of care and support that promotes inclusion, relationship, creativity, joy and the possibility of growth for everyone impacted by dementia leading to the end of stigma and the predominant tragedy narrative. I hope you will take a look at Let's Reimagine and share with others in your life.

I feel strongly that we need to creatively challenge the biomedical and institutional approaches to dementia policy and practice, and the fear, stigma and hopelessness they lead to. Support is needed for everyone to thrive and grow including those who work in the caregiving sector.

So why not join us? As Mandela said ".... vision with action can change the world!!"

To learn more about, and to join, the Coalition, visit www.reimaginingdementia.com.

References

Land of Smiles (1931). You Are My Hearts Delight, H. Graham (lyrics), F. Lehar (music).

Schweitzer, P., & Bruce, E. (2008). *Remembering Yesterday, Caring Today: Reminiscence in Dementia Care, A Guide to Good Practice.* London: Jessica Kingsley.

* www.rememberingyesterdaycaringtoday.com/index.html

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