

Maria Esposito 2014

'I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel.'

Maya Angelou

Participating in the Remembering Yesterday Caring Today apprenticeship scheme was for me like coming home.

My Mother was diagnosed with dementia in 2004. Until then I had no knowledge or understanding of what this disease was and exactly how it would manifest itself. What I quickly realised was that if I wanted to support my Mother I too had to embark upon a journey of discovery. The difference in our journeys was that for my Mother her journey created fear, panic and distress of unknown changes taking place in her brain and causing her to be different to the person she was. My journey was to make her journey as comfortable as possible and make sure that I engaged with her on all levels to continue to stimulate and offer assurance that she still was the same person, my loving Mother.

Through this very personal experience I found I was developing and utilising my own skills of having worked in the creative and broadcast industries for over 20 years, discovering and engaging new ways of connecting with my Mother as well as others in her care home. Of course I made many mistakes along the way but what I didn't know or realise at that time was that I was already developing and practising the basics of reminiscence work. I was without any guidance entering into person–centred care making the person with dementia feel valued and included and above all supported. The essence of person-centred care then became clear to me after reading the VIPS framework of Professor Dawn Brooker's as described in: Brooker, D. (2007) Person Centred Dementia Care: Making services better. London, Jessica Kingsley Publications.

In her book she explains that:

VIPS stands for:

V = *Values people* – *Values and promotes the rights of the person*

I = *Individual's needs* – *Provides individualised care according to needs*

P = Perspective of service user - Understands care from the perspective of the person with dementia

S = Supportive social psychology – Social environment enables the person to remain in relationship

and the guiding principles behind VIPS are:

- Do my actions show that I respect, value and honour this person?
- Am I treating this person as a unique individual?
- Am I making a serious attempt to see my actions from the perspective of the person I am trying to help? How might my actions be interpreted by them?
- Do my actions help this person to feel socially confident and that they are not alone?

I learned through my own discoveries and with RYCT that one of the aims of reminiscence work is to find the 'key' to unlock memories and that this will be different for each individual. Being able to unlock memories may come through, touch, smell, sound, action, a combination of all of these or through a variety of other triggers. For the apprentice as well as the participant the RYCT program offers the chance to explore numerous creative ways of stimulating memories in guided structured sessions over a12 week period.

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Developing and using a variety of creative activities is essential for creating a broad spectrum of experiences that will endeavour to stimulate and engage the person with dementia but also provide ideas and understanding for the carer to be able to continue at least one activity but hopefully more at home. A good RYCT session would aim to include a mixture of these activities and to give examples I have spilt them up in to Action, Visual, Hearing, Tasting and Creating. These all clearly emulate the five senses.

Action includes drama, dance movement and all things that involve making a physical connection however small and to whatever ability. Our bodies quite clearly have a memory of their own and therefore performing what would be familiar actions from the past connected to work, hobbies, fun etc. will often illicit memories very easily. Doing a physical action of a past activity can stimulate the memory into delivering more detail. Performing also offers the person with dementia the chance to communicate and show emotion without words. This is a good way to start a session with everyone sharing an activity and the whole group joining in without the challenge and difficulties of verbal communication. This also often creates and acts as an introductory bonding of shared experience helping the group to come together with ease and fun. This can be crucial especially for those who are not used to being in a group and those who may feel any level of embarrassment. Creating small scenes of a moment in time is another style of sharing the past and when acted out by members of the group it gives the person with dementia the opportunity to see their memory as well as the fun and enjoyment of the other participants. Also creating tableaux to present a single moment in time or recreating a family photograph offers the same.

Visual stimulation offers the chance to enhance and explore memories in a little more detail. It might be that someone has recognition from a picture of an old camper van but leads to discover that theirs was a different colour. Having a good selection of memorabilia both photographic, item and clothing so that the participant can see, feel, touch and smell is incredibly useful as tactile stimuli are extremely good at extracting memories and enhancing the physical body memory of the action of using the item. These stimuli of objects and images are also to interact with the other activities as it further enhances the ability to reach memories.

Hearing sounds and noises also offers the opportunity for great memory stimulation. I have personally found music to be one of the most successful triggers for unlocking memories as music creates an emotional response in all of us whether afflicted with any form of dementia or not. Just as our bodies seem to have a memory of their own, so too do our feelings and emotions and music taps directly into these. How many times have you heard a song on the radio and you are whisked back not just to the year but often the exact day and moment. Using music as a background to a themed activity or as an integral part of the theme for the afternoon is very successful and great fun. Through music we often find that there is also a hidden memory for lyrics, it's again that thing that happens when we go straight to a feeling memory and without thinking start singing the lyrics to a song. On our recent RYCT course the schooldays session evoked such a reaction for one gentleman. We were having a wonderful moment of sharing school songs and this triggered for one of our participants being able to remember and sing his entire school song. Singing is a wonderful activity and I have found through personal experience as well as my recent apprenticeship that songs can arise in every single activity and I really like to encourage this.

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Creating pictures using drawing, colouring in, making collages, arranging pictures is always a great way to sit and share stories on a more one to one level with the participant and their carer, gently teasing out detail from the conversation to create a picture of the subject or theme being explored. We experienced using activities such as drawing a postcard to send home from holiday, from the army, as an evacuee, away at school, drawing the route from your house to your school, drawing an illustrated map of a car journey. I recall that one of the more successful art activities was when one of the RYCT apprentices had brought in many different pictures of the outlines of cars. The participants were able to pick and see which one resembled theirs much more easily than trying to recall the name of the care. This was used in a picture to describe a Bank Holiday car journey. This activity also seemed to illicit the best results in the second half of the session following the first half activities and a very welcome tea break.

Each RYCT session has a tea break and whilst this may seem like a 'break' it is actually a very integral part of the session. It offers the opportunity to stimulate taste and smells. Once again using the theme of the session to reflect through the tea break by having relevant beverages, cakes, biscuits and snack makes continues the process of stimulating memories. In our recent group at Easter our tea break reflected this with a decorated Easter basket with an Easter cake and chocolate eggs.

The aim of a good RYCT session should be to try and make sure there is something that everyone will feel comfortable doing and as the weeks go on you will get to know who responds best to what.

In order to deliver these sessions the facilitators need to have a set of key skills, which include (but are not limited to) listening, reflecting back others voices, being positively receptive, confidence, innate curiosity, humour, flexibility and adaptability, as well as the more caring skills of sensitivity, caring and understanding as well as diplomacy dealing with the more challenging aspects of dementia that can present issues of moving sessions forward.

The skills required by the leader are numerous and are all based on clear interaction with people however there are some basic organisation skills for running and organising a group that are required as well as our own personal presentational skills.

It is important for leading any group that the leader is confident in their preparation, presentation and audibility. Audibility is crucial for RYCT groups not only for the person with dementia but also in some cases for their carer due to the simple fact of age. The other crucial aspect of presentation and communication is the pace at which you speak. Don't expect immediate answers but also don't assume that what you have said has not been heard. You may have to check if it has but it is important to remember that the person with dementia has a slower pace of understanding than those without. Hold back on feeling as though you need to fill a silence both when presenting and when working in smaller groups and individually. I learned from having made this mistake with my own Mother. Early in her diagnosis I would get frustrated until I realised how long it took her to process the information and I could help alleviate her frustration and mine by just taking my time. I stopped being

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frustrated about having to repeat things and soon became understanding of her pace and the ability to keep the focus on her and listen, with the occasional prompt.

Being curious is the perfect attribute for becoming an RYCT group leader. It helps to have an innate sense of curiosity about people's lives and a real interest in hearing their stories of the eras in which they lived, events they have lived through and where they have come from. Listening to stories and having a deep interest means the more effective we are at asking questions, listening and learning from our participants. The focus is on the participant and this makes them feel valued and interesting. An interest in social and cultural history offers a valuable skill to the RYCT leader. I was lucky enough to have both parents come from extremely large families (my Father was one of nine children and my Mother was one of thirteen). I have always been surrounded by many aunts, uncles and grandparents and relished the family get-to-togethers to learn songs from the past and hear more family stories. I was also lucky to have two completely different cultures and this has always inspired me to find out more about immigrant families of the 20th century.

Another skill that I feel is vital to the RYCT practitioner is the ability to share the stories of their own life. Often you may find that you have to take the lead with an activity in order to jump start the group to participate. Enjoying sharing your own life must shine through but you must always stay mindful not to take over the space with one's own stories. The idea of sharing your stories and memories is to prompt others in to sharing theirs.

Using these skills enables the RYCT leader to work effectively to ensure that the participants are able to get the best experience from the project. Participants must feel safe, supported, listened to, understood and valued at all times, whatever stage they are at with their illness and with whatever physical problems they and hindrances they may have. All RYCT activities are adaptable and inclusive for everyone and it is the responsibility of the group leader to ensure that this happens. In our recent group we had a couple and the woman had a very significant speech impediment as well as physical walking difficulties. It was easy to assume at first glance that she was the person with dementia when in actual fact it was her husband. The carers welfare for participation is as important as the person with dementia We made sure that this lady had all the support she needed in order to be understood and be comfortable whilst at the session so that she could participate alongside her husband.

Maintaining awareness for the wellbeing of the participants is extremely important for the group leader as the session may have to alter whilst in progress to accommodate needs. This may be as simple as having the right chair for someone to sit in, making sure they sit near the leader to hear or see better or making sure they always sit together with their carer for assurance. There are a number of very simple things to make all participants feel included and taken care of, the first of which is being met at the door with a warm and friendly greeting and having name badges. Warm friendly introductions can and do make all the difference. However it is important to realise and look out for any activity that may be having an adverse effect. In our recent course we had the session on school days and whilst this did bring to the fore some wonderful memories it soon became clear that for many school, especially in the 1930's, 40's and 50's, was not a particularly happy time. One particular gentleman who was already quiet in his personality became much more withdrawn and sullen and over tea we were able to discover that he had in fact had to leave his rather

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strict school for not achieving the right grades. He was clearly having memory feelings of shame and embarrassment. We swiftly moved the session on to his working life in which we discovered he was a very fine draughtsman and so we focussed on that with lots of positivity, affirmation and praise. We also had a situation in another week of discovering that two people were both evacuees to Wales during the war and yet one had a good experience and the other was particularly sad. During the tea break we made time for these two people to sit together with carers and apprentices to share their stories.

Practicing RYCT work I found that to tapping into someone's sense of humour was a great enhancement for their wellbeing especially, if they have little company and conversation at home. I have found that at whatever stage of dementia a person's sense of humour can be retained and I believe that sharing laughter as the saying goes is the best medicine.

The carer's wellbeing and involvement in the RYCT course is as important as the person with dementia. Carers will often be a family member, husband, wife, daughter, son etc. and they must be treated with the same respect and value as the person with dementia. Just as the life of the person with dementia has and will be changing the same is true for the carer. For them there is often isolation of going through the carer's process and coming together in a group that gives respect to their relationship and family member is very empowering, validating and supportive. The carer, who will often find support in the other carers through sharing their day to day experiences and routines, will soon they realise that they are not alone and that there are others who understand their journey. Each RYCT course will have at least three or four sessions where, for a small portion of the afternoon, the carers are taken aside for a small group chat of their own. This is where they get the opportunity to say if they and their person are benefitting from the work and where they can bond together as carers. It is also important for us as the facilitators to take on board their feedback of what's working and what's not working for them individually or as a group. It is also where we discuss how the work can continue on at home and how to get the best out of taking RYCT into the home for the rest of the family to be introduced to new and creative ways of sharing and being with the person with dementia. As a carer being part of the RYCT course also helps to build confidence in learning new and creative ways of communication and understanding. Even though dementia is now present in their relationship it is important that they know there are still many enjoyable ways to remember, re-live and embrace their past shared experiences.

Through my own personal experiences I feel I have a particular affiliation and empathy for the carer's situation. I feel I have a lot of understanding and validation of what they are going through and hope that I can put that to good use through participating in more RYCT programmes in the future.

My aim for the future is to positively promote this work, continue to hone my own skills of communication, presentation and listening and to see the RYCT programme introduced into new dementia communities. I feel that linking RYCT together with my own work of Life Story films is a perfect symbiosis and hope that the future for those with dementia and their carers is filled with more understanding, wonderful memories, songs and laughter.

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Chips and fish, chips and fish

Eee by gum what a champion dish

Put some salt and vinegar on

As much as every you wish

You can do, do, do without supper

When you've had a bobs worth of chips and fish!

If you're slaving at home or relaxing
Or you're working in a noisy factory
Just set yourself free
When the clock strikes three
'cos everything stops for tea!





