

Sowing Seeds: what the carers of people with dementia have shared about aiming to achieve happiness



The life cycle of a plant begins with seeds. Tide has learned that in the vast diversity of carers' lives and experiences, some ideas offered in the right time and place generate energy, growth and adaptation.

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Introduction

Tide's Research Carers are used to contributing to research. One carer suggested an "inside-out" approach. Instead of carers participating in the research of others, they could identify practical ways in which carers of people with dementia can benefit from doing their own research and sharing what they learn. He proposed that tide explore what makes people with dementia happy. Drawing on his experience of caring for his wife, he explained:

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Being a carer for someone with dementia becomes very much more enjoyable if the person they are caring for is happy... a carer has to adapt their way of thinking and act to minimise the chances of their own 'burn-out' and to maximise the effectiveness of the care they give.

Happiness?

In discussions and correspondence, carers added their experiences of times, events and activities that resulted in happiness, laughter, joy, well-being and contentment – using a variety of descriptors. The contributions of families, friends, faith communities, organisations and neighbourhood opportunities are centre stage. Some carers find it hard to think about happiness; the distressing course of their relatives' dementia and abandoned retirement plans, for example, made the idea of happiness too remote or unrealistic. Respect for carers' deep immersion in their circumstances is a key consideration. Certainly, the time, effort and occasionally resources necessary for carers to pursue happiness may not always be practical or attainable. The intention is not to raise unrealistic expectations but to share experiences.

Where to start?

Draw on what is known about a person's life before their dementia was suspected or diagnosed:

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Listening to her telling the key stories of her life... after several years she was beginning to forget the details and looked to me to fill in the gaps, provide a scaffold until she could pick up the story again... things she was proud of having achieved and some key childhood memories...we made a book together. I found the photos that went with the stories and wrote her words verbatim... anyone who visited could use it to share her stories.



Help others to engage by telling them a person's story:

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One of the most useful things we did was to develop a "This Is Me" document for the care home staff and a book of photographs throughout his life in chronological order for him...[These] shone a light on his whole life history and personality for those people who had only met him when he was living with dementia...The things that made him happy were things that had always made him happy and reinforced his sense of self.

Think about what gives a person a familiar sense of purpose:

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Mum's passion was words...She kept her reading ability once almost everything else had gone...she used to write, teach English and lost herself in books all her life. She needed a book on her lap until the day before she died. She went back to marking as a teacher, every word on the page.

Dad was able to use his great reading skills and dialects to read poems to other people which he enjoyed and gave him a sense of worth...as his dementia progressed, we had to be careful to help him select pieces that he was still able to read...to avoid him becoming frustrated with himself.

Consider how loving relationships may be sustained:

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He was a great hugger. He loved hugging and being hugged. He loved being with me and treating me. When he moved into a care home, I bought a settee for his room so we could sit together, hold hands and hug.

When dad moved into a care home it was important that he continued to have contact with his great grandchildren. They were between 2-8 years, and dad was able to story tell and keep them entranced. As dad's dementia progressed it was important to brief the children before visiting, to know what to expect, and what prompts they could use to talk...He was brilliant with young children, at drawing them out, being interested in what they were doing and talking to them.

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He became known by his grand children as "Granddad forgetful." When it was suggested that this was potentially disrespectful, a grand-child replied, "He does forget things, but he never forgets that he loves us."



Explore ways of enabling familiar activities to carry on:

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My husband was and continued to be artistic in his way. I still have his pictures on the wall.

When my husband did the Park Run he was fast. I expressed misgivings to the Park Run team about his carrying on with running because he continued to run beyond the finishing line. They told me, "Come next time and we'll sort it." For as long as he was able to run, he had a volunteer who met him at the finish line. He went on to marshal the Junior Park Run...latterly we completed this with the wheelchair. He had a horn which the fast runners got by way of congratulation, slow runners got by way of encouragement and often parents received as well. The horn became famous. He loved it and every photo you can see the smile on his face.



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My wife used to play golf regularly but with dementia she found it very difficult to be part of any group...we found a group that had been set up to allow those with dementia to play together but with volunteer carers to go around with them. It works brilliantly. The group have five hours playing and a stop for lunch.

My wife was a talented artist...we go to a very inclusive art class every two weeks and with a good amount of preparation, she can enjoy painting again. She loved embroidery and quilting...we have not found a way to re-start these...We use the quilts she made on beds for visitors and on our bed. These can all be talking points. She is happy and proud to show visitors her past achievements.

There is companionship in cooking, sharing meals and drinks:

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We found a companion who comes once a week for four hours. She helps my wife with cooking and baking. It's good for her to have company and do things she couldn't do on her own. Lots of laughs occur at these sessions.



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My husband enjoyed social drinking, a good red wine and trying new ones. We continued to enjoy wine together at a local hotel even when using a spouted mug became necessary. The bar staff used his mug to serve his wine...Even after he required feeding he still enjoyed eating out at a restaurant. He enjoyed good food, new tastes, new combinations and ingredients.

Dad enjoyed “going out for coffee.” It was a great social activity, often sharing a table with other people at busy times. This could be both tricky if dad couldn’t remember or duplicated conversations, but also very rewarding as, usually, strangers were very generous with their time and conversation. It reinforced the love of going out to eat and drink and kept the long held, mid-morning ritual of having coffee. [Later it was] important that the care home enabled family members to use their dining room to make coffee so that it could be taken at a time that was important to dad rather than waiting for the coffee round...it also made dad feel more in control.

Prioritise being outside and bringing the outside in:

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He loved his garden, loved what he had created. He enjoyed sitting in the garden listening to the birds, the waterfall, the sun on his face...he loved visiting woods, wooded areas and forests. He enjoyed nature.

She enjoyed wildlife and nature programmes on tv.

As dad’s mobility declined, he would enjoy going for a drive...We would often stop to admire the view and to phone his sister...the view and scenery would give him something to have a conversation about. Dad loved flowers in the garden and in the house. When he was in the care home my sister would bring in fresh flowers, bringing a little bit of nature indoors and providing a talking point for staff and visitors. Even when dad couldn’t get outside, he loved looking out of the window and commenting on cloud formations and what pictures he could see in them.

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My mother liked going to the park where she enjoyed meeting young families. She enjoyed seeing the babies and children. She especially loved watching them play. She enjoyed watching children returning home from school.

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My husband loved God's creation – being out and about enjoying walks by the coast, beaches, Parys Mountain, Plas Newydd. He enjoyed counting the ships at low tide – 18 was the highest total! He did daily rainfall readings and enjoyed taking photos, especially of cloudy skies.



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My husband lived and breathed the 1996 World Cup. I bought a DVD of the match. He was ecstatic as he watched it, cheering, jumping in his seat and shouting, every time he watched it, "We're going to win the World Cup!"



Don't forget that looking forward to events is pleasurable.

Whilst not every plan comes to fruition, anticipating activities can be an enjoyable and positive experience. Planning is a way of looking forward with hope.

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We did "armchair" trips with our mother. We made pictures from flowers and leaves... picking flowers from her garden and putting them in vases where she could always see them and then us admiring the colours and arrangements. Talking and planning about where we could go, looking at pictures that made her happy, but us accepting that actually going would not happen. We "visited" lots of places that way.

We favoured staying at Premier Inns because they are identical and therefore familiar. There were holiday activities that we did not quite finish and would save for the next trip. Now it gives me permission to do them without him.

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My husband loved to listen to me sing and play my ukelele. He enjoyed the music and banner waving when he attended church services.

One thing that has always made my dad happy and instantly changes his mood is music. He is a big fan of The Beatles and The Rolling Stones and from the day he started with memory loss to now, any one of their songs will get him trying to sing along and often dance. This weekend I took him to my cousin's wedding and the moment that some intoxicated 30 odd year olds got up dancing, my dad was straight up there with them joining in! Fortunately, he still has music and dancing, and I make a point of dancing with him as much as I can.

Loud music in the morning after breakfast and gentle ballads during the evening. Clearly the music from artists we had seen live stirred smiles.

We would rotate a series of CDs that we could play with him once he couldn't operate the machine. As his dementia progressed, he increasingly wanted to listen to old songs in Northumbrian dialect from where he grew up – we all had great fun singing along in Geordie accents, and him correcting us if we didn't say it properly.

We both like a sing-along in the house.

In the early years we both sang in a local community choir where I could support her to find the music. In the latter years, a dementia choir.

In conclusion, some suggestions

- People's stories are important
- The things that make people happy are very individual
- It's more about feeling less discontented, less troubled but safe
- For a person with dementia, a busy day is usually a happy day
- There are people and organisations who want people with dementia to remain connected to the activities that mattered to them
- Contact with young relatives is hugely significant
- Dementia is an ever-changing situation. Be willing to take some risks
- Find ways of connecting people to where they are from and remember happy times even in the darkest of times
- Avoid TV serials – it's a challenge keeping up with the storyline. Quizzes are good
- You may be surprised when unfamiliar activities are sampled. My husband believed he wasn't artistic but he got immense joy from going to art classes
- If you are going to meet people, use photographs as a reminder of who they are and the stories about them
- Self-catering holidays in unfamiliar places are hard work!
- Help the person you are caring for to believe that they have some control. For example, I say, "Mum, you asked me to get your drink." Previously, she would have said that she had had her drink
- Always judge the mood. If a suggested action gets a negative reaction, try other ways of doing things
- Preparation matters. Professionals can extend their effectiveness by learning from family carers
- Being with family, friends, fellow worshippers, members of groups and associations may enable people to contribute their gifts

Cherish the moments when you can connect through kindness, love and affection.

Contributors

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