

Black Birds - Alzheimer's Conference 2018.

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My Mum, Shirley, was diagnosed with dementia, most likely mixed type vascular and Alzheimer's 13 years ago. One of the more terrifying insights I've gained into dementia during that time was listening to her tell me about the hordes of black birds that she would hallucinate quite early on in her journey. They would swoop out of nowhere. I would be standing at the kitchen bench, talking about the day's activities and she'd fling her arms up to defend herself. But she knew, she was lucid enough to know they weren't supposed to be there, but her brain was in the beginning stages of letting her down.

My presentation is based on my own experiences of Alzheimer's. One in which, my Dad has been full time support carer for my Mum and still takes on this day-to-day role with absolute gusto. I have watched on while they've both learnt to adapt to the sometimes slow but often rapid changes that Alzheimer's brings. And at times, I have wondered how the healthcare system has got it all so very wrong. My personal viewpoint is that caregivers should be supported regardless of what pathway they choose for them and their loved one...whether that be going into residential care or choosing to remain in their own home setting.

Some of you will know the figures already, that we're looking at an aging population in New Zealand that will see the number of people aged 65 and over double by 2051. A study by Badkar and Manning projected that the number of paid caregivers needed to meet these higher health needs, needs to treble to counteract this. Despite this, dementia care in New Zealand is still dominated by residential and out of home facilities. Why is this when there is plenty of research that indicates people prefer to stay within their own home setting?

As recently as last year, CarersNZ had an article on their website titled "Dementia Caregivers Feeling overwhelmed", the article findings were based on comprehensive InterRai assessments but it highlighted the extraordinary toll support caregivers, specifically those caring for people with Alzheimer's, face in their day to day routines.

Whether it be the physical challenges or behavioural changes that caregivers are expected to anticipate and cope with, we all need to see the fundamental differences between caring for someone with Alzheimers and the role of other caregivers in New Zealand. All valuable, don't get me wrong, but all within their own context.

Throughout the numerous articles, I read while undertaking my own literature review on this topic, there was plenty of the usual doom and gloom about increased likelihood of back problems, exhaustion, fatigue, isolation and stress, usually referred to as 'caregiver's burden', I'm sure you've all heard of it... But it's not ALL bad!

There was also a scattering of mentions about things like self-love, self-respect, becoming more self-sufficient, gaining more worth, having a sense of pride in the caregiving role, strengthening connection to care recipient and an overarching sense of satisfaction.

I can attest to this personally, especially in the self-sufficiency stakes, as I've watched my Dad go from making 'younger' me meals, without Mum's supervision, that consisted of leftover peas or spaghetti on toast...served cold...to now creating meals for Mum and himself that not only look appealing, but hit on all the nutritional targets...who knew he had it in him? Absolute self-sufficiency at its finest.

So, while I'm not disputing that caregiver's burden exists, I would love to counteract that with Caregiver's Satisfaction...where we realise that to have continuation of care at home, we need to provide caregivers with the toolkit they need to balance their own health and wellness with that of the person they're supporting. Collectively, as healthcare professionals, family and friends and other support people, let's focus on helping a caregiver gain the most satisfaction from their role as possible.

So, HOW DO WE DO THIS?

## Findings from Literature review

From my own literature review on how health professionals can better support caregivers choosing to remain in their own home...multiple barriers were identified to gaining adequate supports. As listed on the slide.

While some comprehensive support programs have been trialed in New Zealand addressing these, based on my own findings we're still a few steps behind overseas countries in how we support caregivers at home.

The three barriers that I found most interesting and would like to discuss briefly are the following...

Gaining access to equipment. Hoists, grab rails, wheelchairs, incontinence products and ramps. This currently seems to occur in an "ambulance at bottom of cliff" context, where you apply for said equipment after you've actually started needing it. And then, caregivers utilize the well known 'trial and error' method of learning how to use the equipment with varying rates of success.

Believe me, from my own nursing experiences in manual handling, I can hand on heart tell you that getting a compliant able-bodied person, who's able to follow commands into a hoist during training sessions is an absolute breeze, compared to a resistant and possibly combative person who isn't able to follow instructions.

I vividly remember watching one RN I was working with sock a blow to the side of the head for his efforts in using a standing hoist...and he was a professional. So, it always baffles me somewhat the expectations on caregiver's to instinctively know how to handle new equipment.

Another one is gaining access to respite care, facilitated in own home, that works in with holidays, weekends, short term care and emergency care. Again, I speak from personal experience when I say organizing in-home respite care when an emergency health situation arises for a caregiver..is infinitely more challenging than wrangling all 5 of my children away on a family outing that none of them want to attend...and I've got teenagers, so that's saying a lot.

And finally, Support with the grief process. This ties in with the guilt and anxiety that seems to run hand-in-hand with caregiving. Caregiver's grief is often anticipatory and a long process. The outcome for their loved one is somewhat set in stone from the point of diagnosis currently...but the pathway to getting there is fluid. We need to look at how we facilitate coping and dealing with grief in a way that allows caregiver's to openly communicate their concerns without us instantly putting 'rest home' brochures under their nose. Let's look at what we're doing right and what needs improving with existing programmes.

## PROGRAMMES

The World Health Organisation reported in 2012 that providing caregivers intensive and structured supports from numerous services early in the dementia journey resulted in delaying residential care home admissions by up to 40%.

In New Zealand, we're possibly half way there in following that through. We provide supports early in the journey, from numerous types of mediums, as seen on the slide...but what stages of Alzheimer's are we addressing? The focus is somewhat on challenging behaviours, communication, preventing wandering, assisting loved one with remaining safe. All completely necessary in the beginning stages of Alzheimer's. Where the wheels start to fall off...and caregivers begin to feel unable to cope and start seeking out-of-home care options.. is in the later stages. Which, unfortunately at this point in time are inevitable.

**One of my recommendations is that we seek to produce more intuitive Alzheimer's programmes.**

We already know the broad stages of dementia.

We also know that the journey with dementia is very personal and that sometimes the stages may last for longer or shorter periods of time. But ultimately, the stages still happen. Does it not make sense then to pre-empt challenges that could arise for a caregiver and give them the tools necessary to cope prior to occurrence?

We're in a unique position to actively predict needs. I have listened to a variety of caregiver's and their regret at having to place a loved one into care because they just do not feel like they have the tools necessary for keeping them at home. Incontinence is a big one. How different, and easier, my dad's journey would have been had he had products on hand 'just in case' and gained an informed understanding of how incontinence was likely to present itself. Taking away the frustration and stress of the unknown, by being proactive and prepared.

Overseas, the programmes that have shown the greatest success in delaying residential care admission and improving caregiver wellbeing – programmes such as the Savvy Caregiver, REACH2 and studies into comprehensive Family programmes – have the following key themes **Support** – Such as counselling and caregiver support groups. **Team based care** which has to be accessible (possibly portable). Programmes need to be **specific** to Alzheimer's/dementia **AND** must include **Practical training sessions**, including a mix of caregiver and caregiver with care recipient training

So, I'd like to briefly touch on how we fund these programmes?

## FUNDING

Ultimately , it's done by prioritizing what matters most to caregivers. Again, what can we do as healthcare providers and communities as a whole, to increase Caregiver Satisfaction and decrease Caregiver Burden?

The Objectives found in the Caregiver's Action Plan are now more relevant than ever and as we move beyond the timeframe that the Ministry of Social Development set for itself...how we fund actionable change moves to the forefront. Putting in place trainings and offering resources before they become a desperate need.

By strategic subsidies, I'm referring to things like a Caregiver's Health Passport, one that allows fast-tracked delivery of services from GP's, hospitals, counselling services and pharmacies.

Strategic in the way that keeping our caregiver's healthy, both physically and mentally, means those figures I mentioned earlier, of having to treble the number of paid aged care employees... can be alleviated by people choosing to stay in their own homes longer.

And also Strategic, because let's face it, it's in the Ministry of Health's best interest to start making the admission rates into residential care more manageable...and to do that, we need to fund better wraparound services for those wanting to stay at home. A core component of those services needs to be implementing evidence-based training sessions....

## TRAINING

While on clinical placement early in my bachelor of nursing degree, I spent time in a D6 level care unit. I loved it...the residents were amazing and the opportunities to complete in-service trainings were brilliant. Over the course of my few short weeks there, I completed Spark of Life training, manual handling and attended a session on identifying depression in people with dementia.

I would go back to Dad and pass along all these amazing things I had learnt during these professionally run sessions, which only cost me my time. Now, is it just me, or are we missing a huge opportunity to train and arm caregivers with tools, by not running these training sessions for caregivers out in the community? Even with a small cost involved, the broad range of in-service trainings available to DHB staff as seen in the slide, would be worth every penny to caregiver's about to face challenges ranging from pain identification to maintaining dignity. Imagine, being a caregiver who felt well-equipped and prepared for those end stage obstacles such as loss of mobility, incontinence and medication management. Better still, could some of these sessions be run with the caregiver AND the care recipient both present. Being part of the journey and having an active voice in what care may look like throughout the stages of Alzheimer's is incredibly empowering for those that want to have it.

I'd also like to touch briefly on mental health first aid courses, which are now available in New Zealand, prior to April this year they were run predominantly in Australia and overseas. Facilitating enrollment into these courses by people in incidental or prolonged contact with caregivers seems like a no-brainer in early identification of increased risk of depression.

Let's not assume all caregiver's are in a constant state of depression and anxiety, lets instead be proactive in identifying those more at risk by knowing what challenges they might be encountering and when they're most likely to need more support. MHFA gives those who complete the course key questions to ask, provides strategies to help identify signs of depression, and gives practical tips on how to support a caregiver who may be feeling like they're unable to cope..again this becomes a preventative technique to maintain Caregiver's Satisfaction within their role. Incidentally this would also address the stress and isolation often associated with caregivers' burden.

Final slide, I'd like to introduce what my literature review showed to be the four cornerstones of supporting caregivers.

## Four Cornerstones of Supporting caregivers

As healthcare professionals, we need to implement more face-to-face training with caregivers to gain better understanding. Keeping in mind, that how a person living with Alzheimer's presents at respite or when placed in an aged care facility can be significantly different to their behavior and overall personality when they are in their own home with people they know and trust.

**My advice would be....If you want to know what's important to caregivers, just ask them!**

The relationship between a supportive caregiver and the care recipient is often undervalued by other people believing their 'helpful' advice or suggestions will make tough decisions easier. We should not be telling caregivers who they are, what caregiving should look like or what they are doing right/wrong. Family and support network opinions can hugely influence outcomes to care, so education and reduction of stigma is key to allowing impartial, unbiased choice for caregivers.

The government and MOH's role is to support caregivers regardless of whether they choose residential care, home care with respite options or full-time home care, providing full supports whatever the outcome. Much the same as they do in situations like women choosing whether to deliver their child at hospital, at home or at a birthing center or allowing people with significant disabilities a Choice in Community living, how they live, where they live and who they live with. Our health services need to walk alongside caregiver's to ensure the best quality of life for both them and the care recipient, during what is an undeniably an incredibly stressful and isolating journey.

Finally, let's stop focusing social media campaigns solely on reducing the stigma associated with Alzheimer's and seek to also reduce the stigma surrounding caregivers who stray from the expected pathway. Let's give those caregiver's value and importance by recognizing the determination it takes to advocate for another person in your care 24/7 around the clock.

I can only hope that my children look at their grandad in awe of the sacrifices he's made to ensure for the last 13 years, that his focus for his wife has been on keeping her safe and well in their home.

To any caregivers or support people in the audience, please do me a favour. Each night before bed, look at yourself in the mirror and know that you are an exceptional person for what you do for others and just keep on persevering, because it turns out New Zealand can't do this without you. Thank you.