

Caring for Dementia Workshop

The Potting Shed in association with the IDI and DCC.



Table 1

Insights:

- Many of those with dementia, and their carers, want to stay at home rather than move into care
- People are more comfortable in surroundings they recognise.
- Many carers reach a “Crisis Point”, which usually involves giving up their day job.
- Those with dementia may not be able to continue to stay at home due to deterioration, fear of falls, danger of going missing.
- Falls are a huge fear.
- Some with dementia never want to leave their room, others will climb out a window to escape.
- Getting out of bed, toileting, washing, dressing, and eating may all need to be looked after.
- Interest in nutrition and hygiene can disappear and can be clear signs of deterioration.
- Repetition of questions can be endless.
- Joint bank account issues when one holder has dementia and can’t OK decisions.
- Accessibility out and about can be further reduced if a wheelchair is required.
- Easing separation between carer and loved one with dementia is important. They need time to breath.
- Carer guilt is a complex and lonely emotion, their “new life” is full time and can come about when they themselves are reaching an elderly age.

Areas to look at:

What would give a carer reassurance? What would set them up to be comfortable at the start of the day? What would let them know that their loved one is OK at points throughout the day but allow them to separate for a few hours.

How can local business get more involved? Can we demonstrate the value and advantages to their business of being more dementia aware/considerate? Can we show this would bring in more customers and promote their profile and an agent for good? How can we encourage business to develop technology related solutions to this?

Could local supermarkets be encourage to reinvest the human element, that has been removed with self-checkouts, into store experience providers who are on hand to help any kind of shopper from those with dementia, special needs, under pressure, elderly, etc.

How can we remove the stigma felt by those with dementia and those caring for them? How can we engage the general public to be more aware, more empathetic, and vigilant with regards to dementia and the increase in cases expected as generations live longer and longer? Can we give the general public an idea of what dementia is like through everyday experiences, give them and better understanding and working towards removing stigma?

Table 2

Insights:

- The early days are the hardest. Frustration levels are hard to manage, you're at the end of your tether.
- As a carer you feel anger and anxiety, you are always concerned with safety.
- The burden on a carer is not shared equally between families, communities, or state bodies.
- Medication, while important, changes alertness and the fear/risk of falls increases. This can be fatal for a loved one of an older age.
- Dementia is like tinnitus, a constant distraction and irritant.
- Music is great for triggering strong emotional memories. Dancing is another great way to trigger memories using that music, get aerobic exercise, and bring some fun in.
- Texting is great also as it gets a message across clearly and quietly, you don't have to whisper anymore.
- Charity shops are great to occupy someone, they can spend their time browsing, it's nostalgic, has purpose, and is affordable to do regularly.
- White plates are a problem when eating or dining out as you can't distinguish the pale foods, rice, mash, and fish, from the plate and so you lose your appetite for them. Blue plates work great as there are no blue foods.

Areas to look at:

Can we create a past time or activity that engages with people's memory in a nostalgic way and also give them a new found purpose. Can we create something active that people can be good at and enjoy.

Can we use library resources as a place to engage with those with dementia, using memory triggers like images and music, discussions around landmark event of previous decades, or record and document their oral history?

Can we engage people with historical sporting recreations of GAA and football finals of the past, transporting them back as well as a celebration of club history for the teams and fans.

What will change in 10 years' time as the tidal wave of connected technology continues? Will the person, who needs to have every step of their early morning routine written on white boards, be guided through their rituals instead by a collection discreet screens, soothing voices, and data gathering sensors? What technology that exists now could allow this to happen and give the carer some piece of mind that there is a safety net in place.

Table 3

Insights:

- Awareness is as important as help in a supermarket “they’re not a basket case.... They’re a person”
- Being able to take a moment to realise a person who may look dishevelled and confused is not “trouble” or “mad” but someone suffering from a disease that deserves
- Shop spaces are cluttered, need more definition.
- It’s all visual over physical. Best before dates, prices, and signs are all a problem.
- Familiarity is key “The hair dressers is great, I can leave for 30mins” Empathy, care, and respect shown.
- Creating familiar environments is important, but you need trust and contact details for anyone you’re leaving a loved one with.
- There is stigma, people tend to whisper rather than shout when looking for help.
- A new layout means forgetting how to type into keypad.
- Music is the last thing that goes.
- Nervousness is a major feeling as a carer, but it’s normal.
- Sometimes a wheelchair is just easier
- Quality of life of carer changed massively with loved ones’ deterioration.

Areas to look at:

Could we see Carer Cards used at supermarkets, it could be used as a bank card but with subtle restrictions, it could notify employees of their presence in the store and that they might need help, it employees could then alter or change in music and lighting etc. to be less stimulating “Little Bit Of Help”

Could we see dedicated shopping evenings in supermarkets for those living with dementia where a more suitable atmosphere is created through music, lighting, and assistance, allowing for some independence and a chance for carers to take a break?

Could there be an aisle dedicated to the essentials that any person, young/old, with/without dementia may be looking for? Tea, bread, milk, biscuits etc, to remove the need to search for everything. These aisles could also be designed to appear more relaxing with lower lighting, larger print, somewhere to sit, appropriate music, and semi manned by a helpful staff member.

Can we incentivise local business with an inclusivity rating, such as a blue flag beach or a green flag school?
Can we award badges to staff and businesses who have taken the steps to adapt their premises and train their staff to accommodate those who would benefit from additional support?

Table 4

Insights:

- This life (a carer) is barely imaginable if you're not doing it.
- We are undervalued.
- Relief and respite are vital.
- Need to get a way for short periods, get a break from the other part of my life.
- Getting away and forgetting what's happening at home is important.
- It's time off.
- If there is a break on the horizon, it makes it easier.
- Things could be repeated 40 times an hour.
- Helpfulness, friendliness, politeness, and kindness are so important for carers.
- We're not superheroes, we're regular people, plunged into the carers role and struggling.
- Everything is a challenge with Dementia
- When shopping there is difficulty using money, recognising symbols, getting to the right location.
- Digital challenges if input and options are not simple and restricted, buttons are confusing and too many options is a no-no.
- Attention span is short and there is a need for routine.
- Community is hugely important, they can help, keep an eye out, understand, accommodate, and afford some rest to carers and those with dementia.

Areas to look at:

Clarity. Can the symbols, signage, and text we use in everyday life be made more accessible for all? Can a standard or system be found to allow those with dementia to recognise and understand words and symbols in everyday life, reduce unnecessary options, and also allow business to keep some form of originality or differentiation from competitors.

Could companies provide extra support if notified while booking events or travel, "tick a box for dementia support" "Special assistance available"

Can businesses earn a symbol/badge to show they are friendly/suitable for those with additional needs.

Can shopping centres and larger businesses create comfortable, staffed, waiting spaces with music, tv, refreshments etc to allow a carer to drop off a loved one and get the shopping done. We want to keep the carer and loved one's world as big as possible for as long as possible.