

## Tip Sheet: What you can do to make sure your loved one is happy

Kathleen is an 85 year old widow, living alone in the home that she and her husband bought in 1974 when their kids were still in primary school. Now Kathleen's two daughters are in their late 50s, and because of her dementia and arthritis, they share the responsibilities for caring for her at home.

Kathleen and her daughters have known for some time she will eventually have to move, but have put it off until there was simply no choice. It is no longer safe for at-home care providers and her daughters to drop in on her occasionally. Kathleen needs full time care.

That's the factual part of the story. But the real story is entirely about emotions. For Kathleen, the dementia means she feels confused, anxious, scared and occasionally angry as she does not see herself as being so old that she needs permanent care. In her more lucid moments, she fears leaving her home of more than 40 years, her garden, her kitchen, and the home of her memories with her late husband. And she fears being suddenly thrust into a home with a hundred or so strangers, and all of the horror stories she has heard about such homes.

For her daughters, the emotional journey is largely about guilt, sadness and some relief (but then more guilt for feeling relieved). The guilt comes as they feel somehow they could keep her at home longer, despite what medical professionals are saying. Of course they can't, but that doesn't stop the guilty feelings that maybe they are making this decision to shirk more care responsibilities. Sadness relates to the unavoidable truth that this move will be their mother's last and they cannot ignore how little time they have left with her any more.

This heart-wrenching story is very typical. We could replace Kathleen with a widower and replace the daughters with daughter-in-laws or sons, or even a living partner, but the journey is the same for everyone. There is no miracle cure to aging, the conclusion is inevitable and denying it is not helpful for anyone. This is a grieving process, and it is healthy. Getting through this grieving process means Kathleen's daughters can help her enjoy her new life. Taking the time to find the right care home and then taking the time to make her life there as comfortable as possible; that's the best they can do.

So what can be done to make Kathleen's new life as happy as possible? This comes down to three key areas:

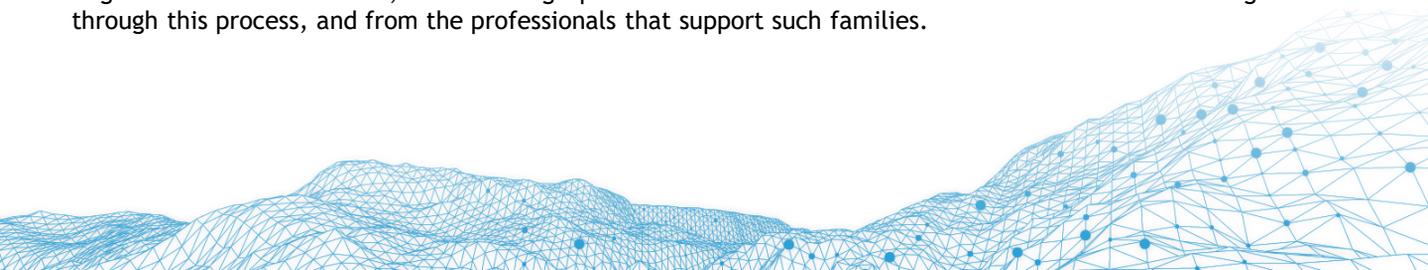
1. Moving day - minimising the stress and confusion
2. Settling in - making sure you provide her with creature comforts that make it seem like home
3. Ongoing care - understand what care she should be getting and how you can help (and how you can't!)

The thought of moving or even talking about moving is usually the biggest hurdle that families like Kathleen's must wrap their heads around. This becomes a larger hurdle than the logical decision itself.

For someone with dementia like Kathleen, at some point the decision to move is impossible to make; they will feel safer saying 'no' than agreeing to change. Dementia robs a person of the sense of safety that comes from understanding your environment and adapting to change. While they will say no, there is often relief when someone makes that decision for them. Typically that someone is that person's children, albeit guided by medical opinion. And that decision and the communicating of that decision with their parent, is often said to be one of the most stressful days of their lives.

For someone that has had a fall or an illness that has put them into hospital, but they don't have dementia, they will at least have the capacity to understand the need to move. Although this won't change the reluctance, fear and anger surrounding the thought of moving.

Regardless of their situation, the following tips are the best we've heard from other families that have gone through this process, and from the professionals that support such families.



### Talking about moving

- Try to make it a shared decision. If it is their choice, it will be easier on them.
- Don't bring it up without notice. They will need time to get used to the idea and emotionally prepare themselves to accept it.
- It will likely take a few conversations to let this sink in and become more their decision and for them to accept it. Don't leave it to the last moment, or you will cause your loved one unnecessary stress, and more guilt and angst for yourself. It isn't always possible, but if you start early enough, you can talk about the home as being "just in case something happens". This also means you can start looking at some homes which helps reduce the fear of moving into an unknown home.
- If possible, a conversation with a medical professional, particularly if it is a long-term family doctor, can reduce the anger and feelings of personal rejection, burden and abandonment. And it gives you the chance to say "So what do you think about what he said?" rather than have to open the conversation.
- If you are one of several children, decide who is best to have the conversation eg. fathers tend to listen to daughters or mothers to their sons; and some people are more sensitive than others. Don't gang up on them - safety in numbers is for your benefit only, not theirs.
- Be clear in your own mind what it is that you are talking about. Is it definitely time for an aged care home, or do you want to discuss more care at-home? Is it definitely an immediate move, or is there some flexibility on time?
- Rather than talk about the home, talk about the challenges for them personally and those around them rather than making it about them only. Allow them to decide that the home is the right choice, if it is. For example, ask them how they feel about their health. For those with dementia, they may not see a problem.
- Be prepared for an angry reaction and think about how you will respond.
- Pre-empt their feeling of being abandoned or old and useless. Our society doesn't value the elderly, but you can choose to remind your loved one of their value to your family.
- Pre-empt your need for support. Make sure you have a friend, partner or someone else that can support you, preferably one that has gone through this already.
- Pre-empt the possibility that they will simply not have the discussion no matter what. Be clear about what you will do next if that is the case. Who else can you bring into the conversation to break the deadlock? What options are there to ensure that your loved one's safety is not put into jeopardy by the lack of a decision to move.
- Remember always, that despite the natural resistance, most people that go into care are relieved once they are there. Eating, cleaning, looking after themselves typically becomes too painful and slow. The fear of the unknown subsides, they get over the loss of independence, and they realise they are still themselves. Particularly if you can make them feel like little has changed other than the roof over their heads, which brings us to the next list: How to make it feel like home.

### Choosing when is the right time

- The next decision is the actual time to choose to move, or at least to put your loved one on a waiting list. In many cases, a fall or ill-health makes this decision for you, and you are moving them from hospital to the home. But in the case of dementia, typically you need to pick the time yourself.
- The right time needs to be signalled by “warnings” and not “alarms”. Caregivers, usually including parts of the family, will know what this means. If you wait for “alarms” such as a fall when they are by themselves or mental capacity falling so low that they endanger their own lives eg. forgetting medication or wandering off, then you may put everyone under unnecessary pressure to move quickly. This will impact your family’s emotional and financial resources more than necessary.
- The right time can also be defined by the caregiver no longer being able to cope. Caregivers often have their own lives, including partners, dependent children, jobs, bills to pay, and so at some point they will reach a tipping point in which they either suffer unduly or they put their loved one at risk by dropping the ball on the care needed. More often than not the need for care is progressive - it increases gradually and so the tipping point can sneak up on caregivers.

### Planning moving day

- Planning for moving day is critical. It will be a very stressful day so don’t leave everything to decide on the day. Much like planning what to take to hospital when you or your wife go into labour, everything will be so much less stressful with a plan.
- Think about what you can and should take into the home. Photo frames, special memorabilia, favourite items of clothing are the obvious things. For some people, a favourite sitting chair, certain books, a TV, DVDs, whatever it is that gives them comfort and reflects their routine at home. You can always bring other things later or remove things, but try to get the favourite items from home into the environment for when they arrive on the first day.
- For those with dementia, the new environment is particularly difficult to adapt to as their ability to learn the new environment is diminished. So any visual cues from home that you can use to at least help in their bedroom and bathroom, will be valuable. Remember that with dementia, people’s long-term memories are stronger than short-term, so if they have been living in the same home for a long time, they are likely to take to visual cues strongly.
- Get an idea of how they are likely to react on the day and think through what you will do to make it easier for them and yourself. Think about someone else that you might want there, whether it is a friend of yours, of theirs or one of your siblings, grandchildren etc.



### Moving day - the toughest day

- The exact day will depend upon availability in your chosen home of course. So once on the waiting list, one day the call will come that there is a room available and you will be told what day and time.
- Then comes the toughest day - moving day. For some, this can be relatively easy, but not for many. Recall dropping your kids at day care or school on that very first morning when you eventually had to turn your back on your screaming, pleading child. We could sugar coat it, but almost every family says this is the toughest day. Read “Mary”, a personal story from a book from Canadian aged care specialist Peter Slin. It isn't easy to read, but useful to get yourself prepared.
- Get help from the home itself. Remember they do this every day, just like the child care or school teachers do. Walk through a plan of how the day will go, who will do what, and what time you will leave. It will never be the right time, but you have to stick to the plan.
- Some homes organise some day visits before the moving day to ease into the move. Ask the question and consider this, but only you know your parent well enough to decide if this is beneficial or risky.
- Be ready for resistance, particularly in the case of dementia. Remind them that it isn't a prison, so if it isn't right, they can come home after a month or two and try again. Some people go back and forward between the aged care home and their old home, if they have a spouse still at home. Some people simply lie and say it is for financial reasons or that the doctors just want to do some tests for a while. Clearly how you go about this is a personal decision, but the key is that you have a plan and have thought about what you are prepared to do and not to do.
- Walk into the home yourself and get a sense of how foreign the environment is. Different lighting, long hallways, new smells, rows of wheelchairs, loud televisions, strangers walking the halls. You have the choice to leave any time, but imagine walking into that environment knowing you had little choice about leaving.
- When you arrive with your loved one, there will be interviews to get more information about medical needs, routines, personal habits etc. Your loved one will be taken to the dining hall or the lounge area to be introduced gently into the home. You should be given a tour and if they don't offer, ask, and take your loved one on the tour, dementia or not.
- See if you can stay for the first meal at least, if not at least a coffee. Stay as long as you can, or leave but come back.
- Even if you have provided written notes on care needs, repeat it to the nurse(s) on duty that day - don't assume they have had the time to read all of your notes. Let them know how your loved one is accustomed to care being given or even simple things like how they like their bed or their tea.



### Settling in - the next three months

- Typically the settling in period is 3-6 months. This might seem like a long time, but with diminished ability to learn and the resultant stress comes a diminished ability to cope with change.
- New customs, new routine, new people - these are the sorts of significant changes we experience when starting school, leaving home, moving to a new town, getting married or having kids, but in all of these cases we have the ability to adapt and we are constantly changing. For those entering care, they lack the ability to change and they haven't had to change environments for 20-30 years in many cases.
- Expect to see significant changes in behaviour. This will be noticeable to you because they can no longer hide their condition using the cues of their familiar home, and because they are stressed, anxious and confused.
- Sadly, there could also be significant changes in behaviour or health because the care simply isn't very good. Overmedication, undermedication, poor diet, social neglect - these will all lead to changed mental or physical health.
- On a more positive note, after this settling in period, you might see health and behaviour return to normal or even become better than before the move due to proper care that they just couldn't get at home.
- Other possible reactions are depression or withdrawal. In the case of depression, it is a response to the stress of the new environment. Don't try to cheer them up or tell them to snap out of it, but talk to them about how they, and you, are feeling. In the case of withdrawal, this is a social reaction to the new people and foreign environment. It isn't depression, but rather a social reaction like withdrawing to the corner of a noisy party, and the solution in this case is to find a way to break them out of this rout, like finding a new friend or activity.
- Sometimes these reactions are a response to some particular person or thing in the new home. Remember that you can always work with the staff to try to find a solution. It helps the staff as much as it helps you and your loved one to get them out of their slump.
- In any of these cases, many homes will have access to a psychologist or other therapists that can help. Similarly the solution could be medication, just like with any other anxious or depressed person. Medication doesn't have to be permanent of course, and could just help through the settling in period.
- Don't rely upon your own views or the views of the staff in isolation, when it comes to how your loved one is settling in. You and the staff will see different responses as you might hear more complaints than they will, or maybe they don't want you to worry and cover up their challenges or even trying to make you feel guilty. Compare notes with the staff.



### Settling in - the next three months

- It goes without saying, but visits are the highlight of their lives in care homes. Organise a schedule with your family members so that you can fill more time with visits than if you all showed up at once. Get everyone ready for the challenges when they leave at the end of a visit to someone with dementia though, as they will often wonder why they aren't going with you.
- The moving day and the settling in period will be worse for anyone that has not had time to prepare themselves. That brings us back to the points about planning, planning and more planning in each of the prior pages.



### Dignity and care - what to expect from the staff and home

- The staff at almost every home are busy - very busy. They can't plan to spend a long time with any one patient as the next call button or crisis is just around the corner.
- But that doesn't excuse poor care. Your loved one deserves to be cared for and they deserve to live with dignity in their final years.
- There is no escaping the difference in quality that should be expected between an expensive home and the lower cost one, but there are minimum standards of care. The Australian Government's information website on what those standards are is useful, albeit long-winded:  
<https://www.agedcarequality.gov.au/consumers/standards/new-standards-resources>
- In short, the standards set an expectation that this is your experience at the home: *The staff are friendly and respectful, and they respond to your particular needs. You are well cared for, by people who know their jobs. You've got people to talk to about things that matter to you. The organisation providing the care is well-run.* This is a standard, not a set of rules, so it is vague, but if you feel this does not describe the home you have chosen, you should approach the home with your concerns.
- Clearly the horror stories on programs like Four Corners fail to meet this standard in every sense, and you would obviously act in the face of this treatment. But it is the hidden failings in care that are harder to address and may only become obvious when the damage has already been done. These don't just relate to medical care failings, but also to nutritional care and a culture that provides dignity to residents, not that treats them like a task that just needs to be "completed".
- To provide a "checklist" of what areas of care are critical to be covered, consider the following list as comprehensive albeit high level. These are all essential for all humans, but for the elderly neglect of any one of these will accelerate illness and shorten their lives:
  - Good nutrition (including water)
  - Exercise as appropriate, but no less
  - Social interaction
  - Mental/cognitive stimulation
- This final tip is not for everyone and you should not feel bad if you cannot or do not want to do it. But there is value in it, so we've included it. Every home is organised differently. The greater the extent to which you can understand the roles and responsibilities of each person that interacts with your loved one on a daily basis, the greater your ability to help them get the best care they can. If you know who does what, if you see some small improvement that could improve their dignity and quality of life, you can easily make it happen. Just note that aged care homes are foreign, complex environments for anyone from outside the health sector, so this is not a small task.

### **“Mary”: a personal account**

The constant and intense nature of Mum's behavior finally made me aware that life was becoming difficult for her. My concerns had already been growing: for her safety, her inability to prepare meals, the danger of kitchen fires, her vulnerability to theft and mugging, her inability to handle medications. I was receiving repeated worried phone calls from her throughout the night.

Mum's obsession with bowel movements finally resulted in her referral to the university Alzheimer clinic. My sister Faye came to the coast to be with us for the tests. After they were finished, the doctor, a kind and compassionate man, assured Mum that she was healthy and had performed the puzzle tests very well. In private he told Faye and me that there was no evidence of stroke or accidental trauma to the brain, so in all likelihood Mum had Alzheimer disease.

We were to do the following immediately: arrange for power of attorney, prevent Mum from driving her car, and put her in a safer living environment. We were not to tell her she had Alzheimer's disease, correct her mistakes, or argue with her. We were to try to prevent confusion as much as possible. Power of Attorney was surprisingly easy to obtain. Faye and I calmly approached Mum on the premise of being able to look after her affairs if she ever needed our help. The first two attempts were met with a definite "No." The next day Mum was more agreeable, so off we went to see a lawyer.

*“I'll always remember the guilt I felt when I signed my name on the power of attorney form.”*

Then came the letter from the Motor Vehicle Division requesting that she appear for a driving test. She failed but was given a learner's license. She drove on her own anyway! We were finally able to get her to stop driving by taking her car in for servicing. We delayed returning it for as long as possible.

This time in our relationship can be described only as ugly. Mum was livid about the car. Her accusations of theft and her threats to commit suicide, to involve police, and to buy another car were relentless. Her threat to buy another car opened up a new worry. We appealed to her bank to curtail her withdrawals. They were sympathetic but would agree only to red flag her account. I would be contacted if a large amount of money was being withdrawn-but they reminded me that it was her money. To take more drastic action, I needed to get a Power of Attorney. Then I would have the legal right to control her finances. So we began our expensive visits to a lawyer to declare my mother mentally incompetent.

The Health Department became involved with us when Mum was diagnosed with Alzheimer's disease. The caseworker assessed Mum in June. She advised us that Mum needed more structure to her days but was basically managing well on her own. We got her a companion and found her an adult day center to go to a couple of days each week.

*“During that summer I took the caregivers course put on by the Alzheimer Society. This was invaluable.”*

I now realized why Mum acted as she did. I was given strategies to ease Mum's agitation and, for the first time, I was given a clear picture of where we were heading with Mum. They said it was imperative that she be placed on a waiting list for nursing home care immediately.

We set out to find a room that would please Mum. We toured several homes, each one being met with great resistance from her. She repeatedly told us, "I have no intention of moving. I am perfectly safe and happy where I am." But I eventually got her name on a list.

This was the first time that Mum had let us see her account books. It was probably the clearest picture I had that her disease was progressing. It also showed me what a struggle Mum was having. I realised it was only a matter of time before I'd have to assume full control of her financial affairs. Finally there came a time when I knew I was no longer going to be able to supervise Mum's daily routines.

*“Every Sunday she came for a visit and dinner. Every time I would have a good ten-minute cry after Mum returned home in the evening.”*

The moment we'd both been both waiting for and dreading arrived. Mum was to go to Bayview Manor Centre. We chose a day when she would be at her day care. My husband and I went to her apartment in the morning to pack and label her necessities. We gathered a few treasures to help her like her new home, such as her comforter, a TV, and a cozy chair. We took these to Bayview and got her room ready.

Mum's companion picked her up at the day care and brought her to Bayview at 1:30pm in the afternoon. The companion said her good-byes and the staff took over. Mum was most anxious. She knew what we were up to and she knew she was powerless to stop us. We took her to her room and pointed out her clothes, her dresser, her chair, and her TV. We told her she would stay there only until I returned from summer holidays.

*“Mum was not to be persuaded. She paced the floor. She ripped her name off the door. She shouted.”*

I will never forget Mum's phone calls and her constant attempts to escape care in the beginning. She'd try every door and gate. Finally she turned to me and said, "This is a terrible thing you did to me."

I still dream about that first day. But then I only have to think about the next day when Faye and I packed up her apartment to realise it was the only thing-and the best thing that we could do for Mum. I had had no idea about the kind of filth Mum had been living in. Envelopes of uncooked rolled oats were stashed all over the place. There were bugs everywhere. Mum had been the most fastidious person I knew. To see that she had been living in such filthy conditions was heart wrenching.

I view the first year that Mum was in Bayview as a time of adjustment for both of us. Her TV became a problem, so we took it home. She had lost the ability to concentrate anyway. She insisted on wearing glasses that were the wrong prescription. They were weak and, as she no longer read, I realised it didn't matter that they were not the proper ones.

Bayview did its best to make families welcome, but it's hard to feel like a family when you have no living room setting in which to socialise. But a living room was our way of socialising, not Mum's. We slowly accepted it.

*“I've had to learn how to visit.”*

I worry about Mum's jealousy and possessiveness with me and the other residents. She becomes angry and vocal if I socialise with them. I am constantly trying to think of things I can do with her. She can no longer visit, so we must be where there are distractions to comment on. I realise that, to be successful, everything must be done in short intervals: half-hour car drives, short-order restaurants, rants, picnic lunches, and outings for an ice cream.

Mum is content just to walk the halls at Bayview-up and down, around and around. I have tried crocheting, playing cards, crossword puzzles, photo albums (all things she used to love), but found these activities bothered her, so I try something else. The important thing is to keep trying.

*“The most difficult part of visiting is saying good-bye. Rarely does Mum say good-bye without putting up a fuss.”*

She wants to come home with me. I find it helps to reassure her that I'll be back in a couple of days. "Give me a kiss, Mum. I must go." Then I turn around and leave. It's difficult; I won't pretend that it isn't. I have no easy solutions.

I am losing my mother. Every month this loss becomes more apparent, and I have to attempt to replace her in my own memories to make the pictures of my family fit.

My greatest comfort is knowing that Mum is safe. She is cared for by knowledgeable and compassionate staff members. Programs are numerous, especially music therapy, art therapy, and look good / feel good programs. I appreciate the coordinated effort of many: the social worker, administrator, program coordinators, nurses, and nurse's aides. I am made to feel that they care about her and that her needs are special.

Through all of this, my sister Faye, although living a great distance away, was an immense help with Mum. We were always in complete agreement as to Mum's diagnosis and care. Faye, too, joined the Alzheimer Society. We phoned each other at least once a week. She flew out to be with me on the tough days. Family support was so important because it helped me share my guilt.

Joining the Alzheimer Society and taking the caregiver course were essential. They matter-of-factly talk about the disease and let you know where you are now and show you where you are headed. They offer strategies to cope with your loved one's needs. They discuss your individual situation and advise you on not only what must be done but also how to go about doing it.

I found that my feelings of isolation diminished when I talked to others. I would advise other people in this situation to find someone who has been a caregiver or is going through similar experiences. Friends who do not share your experiences can only be of limited help. They don't understand the depth of the disease, the constant worry, and the ever-changing and ever-present challenges. You think you've conquered one hurdle, only to come up against another.

*“I had to learn that my feelings of guilt are normal.”*

I was making decisions for her that caused everyone much distress. I often worried, "How do I know this is the right decision?" I kept a diary and recorded unpleasant incidents and also the accompanying emotions. I had a desk calendar on which I recorded every contact that had been made with Mum that day. This record keeping allowed me to transfer my feelings to paper. It also showed me how increasingly dependent and frightened Mum was becoming. It helped ease my guilt because I could see how we had no choice.

Life goes on. I am coping no longer as a caregiver but once again as a daughter.

*“Believe me, this is much easier.”*

