

Capital Health
Network

AN ABC OF RESIDENTIAL AGED CARE

a common sense guide



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Network

ACT's primary health care organisation

About the Author

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Introduction

RESIDENTIAL AGED CARE

Residential care can be a bit of a mine field for the uninitiated, which most of us would avoid completely if we had the choice. Unfortunately for some of us there is no choice and we have to place a loved one in care. This is intended to be a brief, common sense guide to some of the issues you may encounter when you take the step of placing a family member in a residential aged care facility (RACF). It has developed from many years of providing general practice care to probably thousands of aged care residents. It is not exhaustive and has no intention of being a scientific guide. It is more an attempt to alert relatives to issues which, if not anticipated and considered, can lead to conflict or distress of various kinds.

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A

IS FOR ASSESSMENT

The first step to placement is the Aged Care Assessment Team (ACAT) assessment, during which a member of the ACAT will interview the patient and if possible their relatives and will make a recommendation for care – high or low level, residential or respite.

Honesty by all parties is critical. A lot of people access their respite allotment to prolong the time a patient can stay at home. There is an annual allowance of respite care. Caring is demanding and very often the carer burns out. Sometimes this can be delayed by putting the patient into a facility for a couple of weeks at regular intervals to give the carer periods of respite. This can't happen until an ACAT assessment has been completed.

Once the assessment is made, and the decision for placement taken, your assessment of facilities begins. If you have accessed your respite option you will have some idea of what the facilities offer and the whole thing becomes a little less scary for you and your Mum (lets say Mum rather than the more stilted term of loved one – who might be a parent, a spouse, a grandparent and sometimes, even more tragically, a child).

There are different levels of care available. Low care always costs a significant bond and, these days, many high care beds are also bonded. Indeed it appears that there are moves to make all beds bonded. The more modern facilities provide the equivalent of 5 star hotel accommodation but it costs money. A mistake many people make, including many who should know better, is to compare the levels of accommodation in facilities with no bonded beds, to that available in facilities that are largely or entirely bonded. As with everything else in life you get what you pay for in terms of room size, private toilet facilities and furniture. Some of the best care is provided in nursing homes with no bonded beds and your assessment should include not just the physical environment but the human elements.

What is the staffing ratio? Are there Registered Nurses on site at all times? How many Registered Nurses are available? Registered Nurses have more training and therefore are paid more than Enrolled Nurses. Budgetary constraints in some facilities mean that ENs are now required to perform many duties that were originally considered the province of RNs only.

Ask what Diversional Therapy is available (non medical activities) – sometimes it is brilliant, sometimes almost non-existent, with everything in between. Don't make the mistake of thinking that "extra services" means extra care it merely refers to fabric - that is - slightly higher quality carpet and furnishings. Some non bonded homes provide higher trained staff ratios than the bonded ones.

Remember also that your Mum has probably shared a room for most of her life and may enjoy the company of a room mate. I know my Mum would have. She always requested a ward bed when she was in hospital and would keep her room mates entertained for hours with stories of her and probably, I regret to say, my and my siblings' exploits. I on the other hand prefer privacy. We also notice that, frequently when Dementia is involved, it deteriorates more rapidly if the patient is isolated in a single room than if a room is shared. Make the decision on the basis of what your Mum wants and/or needs not on what you would want if you were to go into care at this point of your life.

B

IS FOR BLADDER

It is a little early perhaps to be talking about bodily functions since you have only just come to terms with the assessment, but B comes after A so there it is.

Many older people are incontinent, particularly of urine. This can be hormonal in post menopausal women and, as any mother can tell you, pushing babies out can play havoc with the plumbing. This can be permanent and just gets worse in old age. There are of course many other medical reasons for incontinence. Most residents in a nursing home will wear pads or use other incontinence aids. Some will have catheters - either indwelling (IDC - via the urethra and therefore in a male via the penis) or suprapubic - SPC - (which means through the abdominal wall directly into the bladder). When it is my turn if I have to have a catheter I want the SPC option thank you - it is much more comfortable and much easier for nurses to cope with.

Urinary Tract Infections are a huge part of aged care. Again the post-menopausal woman is particularly at risk because of basic anatomy, but men do get them as well. They can be difficult to detect, being silent in some people. We need different cues to tell us there is a problem. We have to add to that the fact that all bugs in urine do not cause infection, which can mean that a positive result will not be treated with antibiotics. Drug resistance can become a huge problem, very quickly, if every episode is treated vigorously and some doctors choose to only treat symptomatic infections or those caused by specific bugs such as proteus. Hydration is also an important factor - but more of that later.

B

IS ALSO FOR BOWELS - MORE BODILY FUNCTIONS

Constipation is probably the symptom I am most often called on to treat. Most nursing home residents have reduced mobility - they sit or lie most of the day. They usually do not drink enough and will often reject the fibre part of the diet. Nursing homes try very hard to provide a balanced diet with plenty of fibre but the old adage applies "you can lead a horse to water but you cannot make him drink". Mobility, fluids and fibre are all required for normal bowel function and if things slow up because of a lack of any or all of these, constipation will be the result. To some patients, the nurse's interest in their bowel function is abnormal and intrusive but after one has seen a couple of good going bowel obstructions due entirely to constipation, one learns to treat the subject with respect.

Narcotic (Morphine like) drugs cause constipation. Anticipation and early treatment can avoid a lot of misery. Incontinence is also an issue with bowels. It is less common than urinary incontinence but it is still often seen in the aged care setting. Please don't complain about poop smells - they can't be helped - we all have to go and it is always hard on the nose. Just be grateful that there are sufficient, committed, hard working people available to deal with it.



IS FOR COMMUNICATION, COMMUNICATION AND MORE COMMUNICATION (AND COMMON SENSE)

Many of the difficulties experienced by users of the aged care system would not occur or would be very much less difficult if there was appropriate communication between all parties. I was recently asked to see a very distressed patient whose carer (with no medical training) told her to get a lesion looked at because it looked like cancer to that carer. A week and much distress later the GP reviewed it. It wasn't cancer. Another very irate call came from a daughter who quite reasonably was upset because her mother had a really bad ulcer that hadn't been attended. She was reassured when informed that her mother did indeed have an ulcer but it had been reviewed by the GP every week and had been treated with antibiotics and was well on the way to healing. These were two minor episodes but both caused unnecessary distress because appropriate communication had not taken place. If you have specific issues to discuss, case conferences can be arranged.

Most facilities will have designated clinical care supervisors who should be familiar in general terms with all patients. There may be one for the whole facility, or one for each ward or cottage – ask about this on admission. These people are usually Registered Nurses and are the ones to speak to initially if any clinical concerns arise. Carers, assistants in nursing and the like, are well meaning but do not have the skills and training at a level comparable to Registered Nurses, so always try to go to the designated person.

I cannot speak for all doctors with patients in aged care but I have fixed visiting times at all facilities and I am happy to discuss issues briefly with relatives while on rounds and regularly do so. I also see relatives at the surgery for more detailed discussions. Again communication solves a lot of perceived problems.

If a problem seems insurmountable there is always the Complaints Commission (details are available at the facilities) but bear in mind that all complaints are treated seriously and the investigation of a complaint takes a lot of time and anguish for staff, with mountains of paperwork involved. This process takes people away from their regular duties and frequently results in nothing more than lingering ill will. Try to resolve issues within the facility and only resort to an official complaint if that has failed.

[That brings us to C for common sense.](#)

I have seen an official complaint made because Mum sat on the toilet for half an hour after buzzing to be taken off. Remember staffing ratios do not allow for one on one care, that many people require assistance, that everyone tends to want to go to the loo at the same time and many people are what is termed “two person lifts”. Residents will frequently have to wait their turn for service. Remember also that while, in your opinion, your Mum is the most important resident, there are also another hundred or so Mums and Dads who are equally important to their relatives, and the staff have to be impartial and attempt to give equal care to all of them. This means that if you tie up staff for hours discussing minor issues other patients are going to miss out and one day it will be your Mum missing out. No one objects to addressing genuine issues but in my experience many hours are wasted on problems that arise solely from lack of common sense, consideration and communication. So remember C is for communication and common sense.

D

IS FOR DOCTORS

Before a patient can be admitted to a facility, they have to have a GP to accept responsibility for on-going care. There begins one of the biggest problems in aged care. There is a significant shortage of GPs Australia wide and this is more marked in Canberra. There is an even bigger shortage of GPs prepared to take on residents of facilities. There are numerous reasons for this and I don't pretend to know them all or speak for other doctors. However I am aware of some ploys used to navigate the difficulties. The GP approached may offer to take on, or continue care if the patient is brought to the surgery. This becomes a major issue if the patient becomes bed-bound or chair-bound. I have assumed care for many patients because their own doctor can't come to the facility and the patient cannot be brought to the doctor - so think carefully. If your usual GP can't provide care, the facility may be able to give you a list of doctors who do attend and, for your Mum's sake, you should try very hard to get one of these to take on the care because, even if she has been going to Dr X for twenty years and she loves him, it won't do her much good if he can't attend the facility in an emergency.

Some doctors have a big patient load in specific facilities, so at least you know they are committed to aged care. They will also probably have a regular time for attending and will usually not object to talking to you on their rounds. No matter how many patients a doctor has they are not going to have time to see every patient every week. Some patients and relatives expect this but it is not a reasonable expectation given that there are (hopefully) trained staff available to cater to Mum's needs 24 hours a day. Every problem does not require the doctor's input, and some problems can be dealt with, initially anyway, by phone. Demanding that the doctor be called on Sunday night for a cold is not likely to end well.

E

IS FOR EXPECTATIONS

Don't expect miracles and you won't then be disappointed if they don't happen. Expect that Mum will be clean, dry, housed and fed by people who will genuinely come to care for her as opposed to taking care of her. There are people who have worked in aged care for twenty years and more. They really like and sometimes even love their patients. Treasure them – they get a raw deal with regard to pay, workload and general esteem in the community, but they keep turning up day after day to wash, feed, medicate and stimulate your Mum. They can't be valued too highly.

All that being said, don't expect one-on-one care for Mum. You may have given her that at home, but facilities are not equipt or staffed to be able to provide the same level of care.

Expect a nutritious diet but don't expect Michelin star level cuisine – not going to happen. The facilities I attend try very hard to accommodate the dietary likes and dislikes of their patients but budgetary and practical considerations make individual diets as impossible as one-on-one care. So called "extra service" wings usually provide a bit more choice in diet but they have a lot more money to work with. A facility with no bonded beds obviously has less money and therefore less flexibility in such matters.

Expect a program of activities to keep Mum interested and alert. Very often, in Dementia, the long term memory is preserved for some time, and it is fascinating, and not a little humbling, to watch people who can't remember if they have had lunch singing lustily along to Vera Lynn or Frank Sinatra - sometimes even the Beatles. They can be pretty darned good at quizzes as well, so long as the questions are geared to happenings in their younger years. Touch is important. One facility I go to has a program of staff giving manicures regularly to all their female patients who want one. It is lovely to watch them pick out nail colours. Most facilities have hair dressing available. People still like to look as good as they can even if their memory and/or health are failing them.

F

IS FOR FALLS (AND FRACTURES)

An incontrovertible fact of life is that old people get unsteady on their pins. There are many and varied reasons for this. Osteoarthritis - which most people will have to some degree on admission to nursing homes - causes pain and disability. Joints can give way. Diseases like Parkinson's specifically affect balance. Diseases of the ear such as Meniere's, can affect balance. Benign positional vertigo can affect balance. Cerebro-vascular disease with and without Strokes can affect balance. Some people will have more than one of the above. Mix in a bit of Dementia and the result is disaster - people will forget to use the walker. They think they don't need the walker to get to the bathroom – it is only a few steps. Often a few steps are all it takes.

We do what we can to reduce the risk. We try to leave the general environment free of clutter – less clutter means less to fall over. We try to ensure sturdy footwear without trailing bits. We provide walking aids - sticks, frames, wheelie walkers. We try to correct biochemical imbalance such as Vitamin D deficiency. And yet people still fall over.

Add to the falls risk the other incontrovertible fact that old people have thin brittle bones. Osteoporosis affects women more than men but does happen in both sexes. The result of the equation is obvious - fractures - particularly hips or to be more precise fractured neck of femur or NOF. These are distressingly common in older people particularly those in residential care. They often result in death and more frequently in increased disability. Patients even contrive to fall when someone is with them and within reach. They fall out of bed. We put up bed rails and they climb over them and fall an even greater distance. Some facilities now lower the bed almost to ground level and put another mattress on the floor next to it. All our efforts reduce the frequency but nothing prevents all falls and fractures.

I guess the moral of this one is, don't automatically cry negligence if Mum goes for a buster. The best facility in the world, with the best staff, will still see some fractures. These are as distressing to staff as they are to you and Mum. What you can do is be involved in supply of appropriate clothes and footwear, and help to instil in Mum the need for care with movement and, where necessary, the need to call for help before moving. Independence is great but not if it leads to awful pain and hospitalisation.

F

IS ALSO FOR FOOD

This has already been mentioned but is worth revisiting. A sound nutritious diet is vital for everyone. Most facilities have a Dietitian, who advises on appropriate diets both in general and for specific patients. The obvious one is the Diabetic Diet. Many people in our community have Diabetes. There is little point in restricting the facility supplied food if relatives are bringing in Mars bars and/or supplying funds to mobile residents so they can go to the Coke machine themselves. Humans are not universally reliable. I have seen plenty of sensible Diabetics out in the community who eat what they like and hope the tablets will do the job. Again add a bit of dementia to the mix and proper diets can end up out the window.

Most facilities are receptive to you bringing in certain food items e.g. specific ethnic foods. Patients should be offered food they can enjoy- but that should, hopefully, be healthy food that they can enjoy.

A last word on food – towards the end of life patients often lose interest in food and drink. Force feeding them does nothing to enhance quality of life and can seriously impact on the duration of that life. Along with disinterest we often see diminishing ability to swallow. Forcing food down can often just result in food being aspirated into the lungs with resultant, often fatal, pneumonia. More of that later.



IS FOR GAMES AND TOYS

Like it or not Dementia can reduce sufferers to a child-like state and children like toys. Most of my aged care residents have from one to a whole collection of stuffed toys. Don't be surprised if a teddy bear comforts just as it comforted you as a child. Another relatively recent discovery is that a baby-sized, shaped and weighted doll can go a long way to allaying anxiety and restlessness in Dementia patients, particularly women. The doll seems to remind them of their mothering days even if they are past the ability to articulate that. Don't be one of those outraged relatives who shout "you are not giving my mother a doll to play with, how undignified!". Dignity is not the first thing you think of when a patient paces endlessly, wailing and hitting any obstacle be it human or otherwise.

If a baby doll can alleviate some of that angst, where's the harm?

Diversional Therapists will often use games to involve patients and keep them interested in life. Games can also be used to encourage mobility and exercise. Balls may be used to improve coordination. Music can be very important. Debilitating illness and even Dementia are not absolute bars to learning new skills and improving general condition.



CAN ALSO BE FOR GUILT

There are often issues with patients and relatives concerning past events. There can be lingering resentment, on one or both sides, for perceived actions or inactions in the past. There can also be guilt due to the decision to put Mum in care. Try to realize that you put her in care because she needs more help than you could give. Try not to let guilt, from whatever cause, swamp common sense in your dealings. I have seen many patients try to punish relatives and vice versa resulting in a less than positive outcome for both. Try to let it go.

H

IS FOR HOSPITAL

A good rule to remember is that hospitals are for the acutely ill. Nursing homes are more for the chronically ill. Sometimes both do duty in the other sphere, but neither is equipped to do so particularly well. Pressure area care is a good example of this. When we lie for long periods, in one position, the skin becomes red and sometimes painful. In older people the skin is much more fragile and can actually break down, producing ulcers, in a very short period of time. Nursing homes are very good at healing and or preventing, pressure areas. Hospitals in my experience are quite good at causing them. This results from different points of reference. Many hospital patients are young and fit, with skin in excellent condition – it takes a while to break down and patients are usually discharged before it gets a chance. Almost all nursing home patients are old, with compromised circulation, and skin breaks down easily and quickly. Hospital staff are not always alert to this possibility and skin has often broken down before it is noticed. The focus of care is different.

Hospitals can administer intravenous drugs, nursing homes can't, so invariably some patients will have to be transferred for treatment that the home can't provide.

As you will notice, changing routines in patients with Dementia causes problems. Just moving someone to a facility can cause worsened cognitive functioning with deepened confusion and disorientation. It takes patients several weeks to adjust. For this reason I rarely do cognitive function tests on admission. The results tend to be far better if we wait a few weeks. Transfer to hospital will cause similar confusion and disorientation. Add to that the burden of acute illness and things go downhill rapidly. It can be really frightening to a Dementia patient to have their routines disrupted, with a whole set of strange people prodding and poking and ordering distressing, invasive tests. This seems to me to be pretty unkind unless the outcome is going to significantly improve the quality of life. Consequently I counsel relatives to think seriously before demanding that Mum be sent to hospital. There are some situations (like fractured NOF) where there is no choice but I have had many relatives demand transfer for a dying patient. The end result can be seriously uncomfortable last days (sometimes never even getting out of Emergency Department with the same ultimate outcome. This does not seem to be a kindness to the patient. Obviously hospitals and nursing homes vary in quality.

H

IS ALSO FOR HUMOUR

Dementia doesn't always prevent people enjoying a joke. Even terminal Cancer doesn't always prevent it. Being able to laugh at the funnier happenings can also be a stress reliever for relatives and staff alike. It is a pretty stressful field to be involved in – humour definitely lightens the load.

IS FOR INJURIES

As has already been mentioned – old skin is fragile skin. Old skin tears alarmingly easily. Just grabbing someone to prevent a fall can result in significant damage. The hard bit is that what takes a second to happen can take months to heal. We have already seen how easily old people fall – fractures are not the only injury sustained. Lacerations can be huge. They usually need a trip to Emergency Department for suturing but minor ones can be “Steri-Stripped” or glued together with great results. Fortunately the cosmetic result is not so important in wrinkly old skin - lesions heal as just another wrinkle. Old people can even hurt themselves in bed just by twisting against bed rails, hence the padding some facilities use.

Musculoskeletal injuries other than fractures will also occur and can take longer to settle than with a younger patient. Sometimes healing is never complete with resulting chronic pain syndromes.

IS ALSO FOR INFECTIONS

The most obvious infection is the follow-up to a fall with skin tear. The tear can become infected very easily and will often develop into a chronic ulcer (sometimes with recurrent infection). Again, nursing homes are very good at dealing with all these events because they are very common and it is impossible to prevent all of them. A large infirm community living in close quarters will always see more than its fair share of pathogenic (disease causing) Bacteria. Bacterial resistance is a huge problem and can lead again to a hospital visit if the bug involved is resistant to all the oral anti-biotics. One point to remember is that a wound can grow a pathogenic bacterium without the wound actually being infected. Lots of bugs just sit on the skin without causing trouble even the dreaded MRSA (Methicillin Resistant Staph Aureus). Clinical judgement will be involved in deciding whether anti-biotics are necessary.

Urinary tract infections are extremely common, as mentioned under bladder. They are pretty sneaky in that frequently there will be no urinary symptoms. We notice that the confused patient is suddenly more confused than usual and the first thought is “do they have an infection?”. When I get a call to tell me someone is “off the planet” my first response is “are they febrile (temperature), are they coughing and have you checked the urine?” Infections are particularly frequent when there is a catheter involved. Any foreign body will predispose to infection.

Chest infections also happen more often than we would like. This can be secondary to viral infections, exacerbations of Chronic Airways Disease from smoking or industrial exposure to irritants and most commonly will result from dehydration. Aspiration pneumonia has also been mentioned. As swallowing integrity fails, food and drink find their way into the lungs and cause pneumonia. Pneumonia in general is not painful and there is good reason for it being called “the old man’s friend”. It can allow a reasonably comfortable exit from an untenable situation.

J

IS FOR JUSTICE

By Justice I mean the legalities of the situation for a family involved in residential aged care. There are two major issues – Enduring Power of Attorney (EPA) and Advanced Care Directive (ACD).

You cannot legally make decisions about your Mum's care without the appropriate legal documentation such as ACD or EPA. I am no expert on legal matters but I know getting a patient to agree to Power of Attorney is easier than having to go to the Guardianship Tribunal when Mum is no longer able to make decisions for herself either because of Dementia or some other condition. Bullying obviously has no place but it is advisable to discuss these issues early so that if a dementing process starts EPA can be sought while Mum is still able to give consent. It is not always an issue and I still, always, consult interested family members when deciding clinical issues but it is reassuring to family if they know they have the legal right to make decisions.

It is also wise to discuss with aging relatives their attitude to end of life care. Issues around life support and what measures they would like followed in the event of certain illnesses should be discussed. For example a Cerebro-vascular accident (Stroke) can result in an inability to swallow. The natural result of this is death unless some artificial means of sustenance is instituted such as Peg feed (tube straight into stomach). Many patients reject this option completely but unless you have discussed it you will not know Mum's view when the situation arises. There are formal ACD forms available on the Internet at www.seniors.gov.au as an example.

Problems can arise if Mum has a living will but no one knows where it is or if family are not aware of its contents. I remember a patient who wrote to her only family member telling her that in the event of a stroke she did not want artificial feeding. She had a stroke, lost the power of speech and the relative was not available at the hospital. A Peg tube was inserted. The patient then cried all day every day for a month or two before finally resolving the issue herself by wrenching the tube out in the middle of the night (no easy task) and she finally had her way. The whole situation was incredibly distressing for her, her relative and nursing home staff. The clue is - discuss ahead of time and hope you never need to act. If you do need to act you will do so confident that you are following Mum's wishes.

J

IS ALSO FOR JUICE

There are studies that indicate that regular ingestion of cranberry either as juice or more conveniently as capsules can reduce the number of Urinary Tract Infections experienced by older patients. Anecdotally I am sure I see less infections than before I instituted regular cranberry.

K

IS FOR KNOWLEDGE

There is an old saying – “knowledge is power”. Your Mum will be a lot better off if you arm yourself with knowledge about her condition, particularly if dementia is involved. Alzheimer’s Australia runs lots of programs to help you – the family – to cope with this specific process whatever its cause. Burying your head in the sand and denying the diagnosis may help you in the short term but ignoring it doesn’t make it go away and denial won’t help Mum. There is still some stigma associated with a diagnosis of Alzheimer’s disease. I had one patient who, when told of her diagnosis of vascular dementia said “thank God it’s not Alzheimer’s”. Dementia is dementia whatever its cause and as already mentioned everyone is different and our job - that is the doctor’s and family’s job is to deal with it in the best way possible to maximise Mum’s quality of life while she has it. Denying the diagnosis and constantly correcting Mum when she makes an error or insisting she has capabilities that are long gone ultimately does her no good. It all just adds to her confusion and distress. In my experience most people with dementia – at least in the early stages – know something is wrong without understanding the process. They get very frustrated and upset trying to figure it out while all the time the memory is getting worse. Jollyng them along and telling them to try harder just increases the frustration as does irritation when they are slow or muddled. Going along to a few sessions at Alzheimer’s Australia will give you a much better understanding of the process and give you tools to handle whatever the disease throws at you and your Mum.

Dementia of course is not the only disease to afflict residents of nursing homes. Diabetes, heart disease, Parkinson’s, stroke, arthritis, and spinal injuries are just some of the possibilities. There are foundations for most of the conditions and information is fairly easy to access. The Internet can also be useful but running the information obtained past a professional is a good idea as a lot of stuff on the net is personal opinion not verified fact.

So, as previously stated, knowledge is power. Knowledge will help you navigate the sometimes treacherous waters of residential aged care for the benefit of both you and your Mum.

L

IS FOR LOVE (AND ACCEPTANCE)

No matter what the ravages of disease, Mum still needs your love and acceptance of her disabilities, no more so than if Dementia is part of the picture. She may not be the same person you have known and loved all your life but she still needs your love. The hardest cruellest thing about Dementia particularly is that people can certainly change and often become considerably less loveable. If this happens try to remember the Mum you love not the Mum that disease has created.

M

IS FOR MOBILITY

Apart from Dementia, mobility loss from any cause is the feature which determines the need for residential aged care. If you can't get to and transfer onto the loo you're going to need help. Some relatives keep their debilitated people at home and help with transfers but if you work or have other responsibilities outside the home this is not an easy undertaking. Even if you try to do it at home the burn out rate is high. The carer's back is also an issue and, unfortunate as it is, residential care does become a necessity for a lot of these people.

As previously discussed the resident will not get the one-on-one interaction they may have had at home but there will be trained backs and multiple lifting devices available in the nursing home.

As people get older their mobility is compromised in many ways - for example by arthritis, various neurological conditions and sometimes dementia itself (if the areas of the brain that are compromised involve balance and mobility centres). Some people with dementia can't stop walking, others lose the ability to start.

As also previously discussed, all these balance, mobility and thin old bone issues lead to falls, which lead to fractures which lead in some cases to further loss of mobility. After a hip fracture a proportion of patients never walk again. No one likes to see a patient lose mobility but yelling at them to get up and walk is not helpful (although the relatives I have heard doing this genuinely think they are assisting). Nursing homes have Physiotherapists who are trained to assess patients, post fracture, and if the Physio says it is not safe for Mum to try to mobilise please believe her. She gets no benefit from saying it, although I have met many relatives who have thought the facility staff and Physio are conspiring to keep Mum bed- or chair-bound.

All those issues aside maintaining mobility where possible will keep Mum alive and well and enjoying the best quality of life. "Use it or lose it" is an often used quote and, to a degree, it is true. But please go along with staff if they tell you that mobilising is no longer safe.

N

IS FOR THE PATIENT'S NEEDS

We all have a need to be fed, clothed, housed, clean, and to have access to toileting as required. There are other needs that can become sidelined in the residential care setting. There is a need to feel like we have some sort of control over what is happening to us. As abilities wane sometimes the need to exhibit control over what is left can loom quite large. Often in the early stages of Dementia particularly, patients will try to assert their independence when it is obvious to all around them that they are no longer capable of exercising that control. There is a time with Dementia when the patient can vehemently reject the diagnosis. This stage is difficult for family and carers alike and has to be negotiated with sensitivity. It is sometimes possible to have the patient think they are in control while decisions are made without them. This is one major reason for getting Enduring Power of Attorney as early as possible.

I do not believe that telling the truth to a patient is always the best way to proceed. Distraction and redirection will often succeed where the truth can lead to significant distress. Sometimes lying is the only way. For example I have had several Dementia patients whose spouses have died. I believe (and this is obviously only an opinion) that they should be told once only. If they are unable to retain the information they have to relive the fresh grief every time they are told, which serves no real purpose. When they ask when the spouse is coming I feel that it is acceptable to say "later". This will frequently allay anxiety and, since very often with dementia the concept of time is lost, this will satisfy them and they can go on to enjoy what quality of life they have.

Residential care patients should be included in discussions about their care where possible. However it is not always productive (e.g. with dementia) to have the patient present when the condition is being discussed. It can be very awkward with patients who retain some abilities to discuss those abilities and the prognosis (projected outcome) in front of them. I have attended case conferences where relatives have insisted that patients be present and both the relatives and the patient refuse to accept the diagnosis. This makes life very difficult for the carers, as one would expect. Try to remember that no-one works in an aged care facility to make life worse for relatives or patients. Staff members are interested in making life as bearable as possible for all concerned.

Even dying patients need to feel that they have some control over the process. If a patient doesn't feel like getting up for a shower, does it really matter if a wash in bed is substituted? If a patient just wants to drink juice, does it really matter when they are dying? If a patient wants to stay in bed rather than get up and sit in a fallout chair, does it really matter? I have seen plenty of relatives try to force their choices on dying patients either to repay previous insults or in the mistaken belief that such forcing will prolong their life. I would imagine that when I am dying I will want to be left alone to make my own decisions regarding sustenance and activity. If I can't have a say then, when can I??

A controversial item under patient needs is the right to die. Do we have right to force investigations and/or treatment on a patient with very limited quality of life who has often expressed a wish to die? Are these processes for the benefit of the patient or the relative? There are no universal answers, each case is different.



IS FOR OUTINGS

This is actually a part of needs. Patients also have a need to feel regarded and valued. Even if they have not much feeling of usefulness they still need to feel valued. One way to show this is to take them out of the facility – to lunch, to Floriade or whatever can be managed. It is important to a patient's self esteem to be able to still enjoy the world.

That being said, remember that most patients will get to the point where they can't or don't want to leave the facility. This is a normal part of the process of illness and ageing and pressuring people who lack the inclination is not always in their best interests.

P

IS FOR PAIN

Most old people – even healthy old people - have pain. There are multiple causes for this such as angina (heart pain), pain from constipation, cancer pain or pain from injuries - whether they involve fractures or not. In my experience by far the most common pain is arthritic pain – just plain old wear and tear on joints. My personal philosophy is that everyone deserves not to have chronic pain and I will do all in my power to keep people pain-free and comfortable. I have already quoted the “use it or lose it” school of thought. That works quite well if you are able to “use it”, but along with the loss of mobility from whatever cause goes the inability to exercise. This leads to stiffness and pain in muscles and joints. The pain and stiffness may not always be severe but is frequent enough to seriously reduce quality of life. Every doctor and facility will have their own way of dealing with pain. I am a great fan of pain patches. This is because along with general deterioration and immobility we often see swallowing difficulties. Quite often the agitation from pain will result in aggression and non compliance, so the people who need meds the most will often be spitting them out. Patches can circumvent these difficulties. We put them in an inaccessible place (Dementia patients will often take them off if they can reach because they do not understand why they are on in the first place) and they give a continuous level of pain killer and are very effective in controlling pain. There are sometimes side effects - any narcotic-like drug will cause constipation for example – but these can usually be dealt with. Sometimes sedation is a problem but I feel it is better to be free of nagging pain than to worry about having more sleep than usual.

Sometimes, in people with Dementia, aggression or agitation are the only sign that there is pain. Asking the patient if they have pain may well not give a usable answer. In this circumstance we use non verbal cues to determine the level of pain, e.g., groaning when attended, grimacing etc. I will often ask for a formal pain assessment to be done to determine the level and frequency of pain. Prn (as needed) pain relief can be successful but as previously stated every patient is different and every patient’s pain needs are different. Some doctors can be resistant to the use of narcotics. I am not. Relatives and sometimes staff (even doctors) worry about the addictive potential of narcotics. If a patient is dying and suffering I feel that alleviation of that suffering is more important than the slight theoretical risk of dying while addicted.

As the end approaches, swallowing can become a huge problem preventing the use of oral medications. Often terminal pain can escalate severely even past the ability of a patch to cope. You will see end of life care coming into play and this will often involve the insertion of a “butterfly” needle which can remain in place for the regular administration of Morphine subcutaneously. Sometimes a syringe driver will be used. Again a lot of this is the personal preference of the treating doctor in consultation with facility staff.

The over riding principle, in my view, should be - comfort first.



IS FOR QUALITY AND/VIS QUANTITY

Some people believe that quantity of life is the most important factor, others believe that quality of life is more important. In aged care, possibly more than any other field we see situations where it becomes quantity versus quality.

I have had several patients who developed symptoms and signs that indicated the possibility of serious illnesses like Bowel Cancer. Investigation of these signs and symptoms can be intrusive, maybe painful and definitely frightening for the most normal of us. If this is compounded by the presence of a significant dementing illness, the fear and suffering can be magnified. The investigations and treatment in this situation will often also worsen the Dementia. This can result in a parent who is treated for and maybe cured of cancer but the brain is even more damaged than it was. Is the end result positive or negative for the patient? Many patients without cognitive deficit will opt not to be investigated or treated which is well within their rights. If you hold EPA for Mum you may be called on to decide for her, in this situation, whether or not to proceed. It helps if such issues have been discussed prior to cognitive loss and/or admission to a facility.

We do all we can to provide the best quality of life possible but sometimes the best possible is still untenable and the decision not to inflict more suffering is, to my mind, the kindest option in many cases. I will reiterate that every patient is an individual with their own special circumstances, all of which should be taken into consideration when decisions have to be made.



IS FOR RESPECT AND RELIGION

We all want to be respected for our humanity. Even if behaviours deteriorate it is incumbent on workers and family to respect the person who was, as much as the person who is. As long as we all remember to do that, life will be as good for Mum as it can be.

Respect for staff is one part of the equation that can be a bit lacking. Facility staff are, in most cases, highly qualified individuals who do not take on the job in aged care without having some regard for the people in their care. Sometimes the media - often fed by disgruntled relatives - can paint staff in an unkind light. Remember to take media reports with a pinch of salt as we usually do in all other matters. Often the reporter's view of an issue lacks any real knowledge of life in residential aged care. If you have concerns, please take them to facility management before unleashing a media blitz.

R is also for Religion

Most facilities provide access to the major religious groups to conduct services. Mum's beliefs and lifetime practices also need to be respected.

S

IS FOR STROKE

Stroke is another word for cerebro-vascular accident (CVA, either a bleed or more commonly a clot in the vessels of the brain). These are very common. A lifetime of high blood pressure and probably high cholesterol leads to damage which leads to stroke. The amount of damage sustained depends on the area of the brain affected, the size of the compromised vessel, the general health of the patient and multiple other factors. Some patients recover well, others do not. One thing we can be sure of is that one of the leading risk factors for stroke is a previous stroke. This means that having a stroke increases the odds that you will have another one. Some people beat the odds and go on reasonably healthily for many years after an event but unfortunately many do not. The damaged vessels remain damaged. We can put in place medication regimes as well as dietary and lifestyle changes to minimise the future risk, but a risk still exists.

Some strokes will affect the ability to swallow and you may be called on to decide whether or not an artificial feeding tube should be inserted. This is another occasion when early discussion of such issues can alleviate a lot of trauma at the time. If Mum clearly stated that she did not want a feeding tube in the event of a stroke, the decision becomes a lot easier. I have had patients who have wrenched the tubes out (no easy feat) because no one knew they didn't want it and they were unable to participate in the discussion and decision. (Strokes will often also rob the patient of the power of speech).

S

IS ALSO FOR STAFFING

It would be fair to say that workers in aged care are underpaid and overworked. There are never enough hands to do the work required. The paperwork demands are huge and most facilities have to employ registered nurses just to do paperwork to ensure the correct levels of funding. Accreditation adds another huge burden and all of this takes time away from residents' needs. If you think this is unfair, to both the resident and the worker, start lobbying your MP because things will not change until a lot of "important" people complain.

My observation is that aged care workers are amongst the hardest working, the lowest paid and are accorded the least esteem of any health workers.

S

IS ALSO FOR SEX

You might think that Mum is a bit past it but unfortunately, for some patients and their families (particularly if there is a spouse at home), Dementia sometimes heightens sexual desire and sexual activity with other patients can be the result. This is a difficult one and there are varying opinions as to what should be done about it, if anything. I have found over the years that distraction and redirection can be highly effective but, if they fail the best thing is sometimes to close the door and leave them to it. This outrages some relatives, but short of prying people apart physically, there may be little else you can do. Remember, one-on-one care is not available and the couple of carers per cottage cannot be everywhere at once.

T

IS FOR THERAPY

This can be Occupational Therapy, Physiotherapy, Massage Therapy or Aromatherapy. You will find that most facilities employ any or all of these modalities, and they all have something to offer. Just remember that there is probably one part time Physiotherapist who will not have time to spend an hour with every patient every day. Some relatives, surprisingly, expect this. If the Physiotherapy offered does not seem enough, you are at liberty, usually, to bring a private therapist into the facility but you will be responsible for the fees.

Massage therapy can be very helpful to those old aching muscles and joints, and the one-on-one time is pretty good too. Most facilities have Diversional Therapists rather than Occupational Therapists and they comprise the team that is responsible for keeping Mum alert, interested and happy. Some do remarkable work. It is the Diversional Therapists who run the games, films, happy hours, armchair aerobics etc otherwise often known as activities.

T

IS ALSO FOR TRUST

Any therapeutic relationship needs trust to allow the best possible outcome. Doctors and nurses don't get a kick out of limiting a patient's mobility or other activities. If we say taking Mum out is not a good idea then that assessment is based on years of experience with many patients similar to your Mum. But in general we have no vested interest in making life miserable. We want to see your Mum enjoying the best quality of life possible for the longest time possible. Trust us!

U

IS FOR THE UNKNOWN

No-one can say precisely how and when your Mum will sever her connection with the facility in which she lives. The how and when of death can cause a lot of distress to relatives. Very often the patient has accepted that death is approaching and I have been asked, and even begged, to end it for some patients because it is all just too much. I see my job in nursing homes as trying to keep patients as comfortable as possible while their bodies wrestle with and finally succumb to their various ills. Try to think about what Mum is going through rather than what you are going through. I have had plenty of relatives pleading with me to save Mum's life even after Mum has clearly stated that she has had enough and the sooner it happens the better. Even more difficult to deal with is the relative who insists that her comatose mother be transferred to hospital for intravenous therapy. The result is usually a far less comfortable death - amongst strangers - than she would have had if just kept comfortable in the facility. If we do "save" her life try to think what we are saving it for - more of the same and probably even worse. Remember that Pneumonia is "the old man's friend".

On the other hand I have seen patients who showed significant deterioration, including difficulty swallowing, who have rallied after all their meds have been stopped, and gone on for considerable periods afterwards. Why? Who knows? It is however not a course we recommend very often. What keeps one person on the earth and sees another off quickly is one of those imponderables of life.

V

IS FOR VISITING

This is a very important part of life for aged care residents. "When is my daughter coming?" is often heard around the corridors. Just because she is in a facility doesn't mean that Mum no longer needs to see and hear about family. In addition, nursing staff always appreciate a bit of help with meals. There are usually many patients who need to be fed and in most facilities I attend there are relatives who come in regularly to assist. I have already mentioned guilt. This can affect both parties and on occasion I have seen both relatives and patients exploit this to manipulate frequency of visiting. Guard against letting guilt be the determinant.

You also need to guard against over stretching yourself. A patient with severe dementia, for example will lose a lot of sense of time. They will not notice if you are not there but may become very distressed when you do visit and this can generate more guilt and over frequent visiting (or the opposite). If staff reassure you that Mum settles very quickly, accept that and continue to visit. Please do visit - it will often be the high point of a resident's day and goes a long way to improving quality of life.

V

IS ALSO FOR VOLUNTEERS

Most facilities have a roster of volunteers to come and help with meals, with entertainment or just to spend some one on one time with a specific resident.

They have often had a loved one of their own in the facility and feel the need to give back a little. They are to be treasured - they are worth their weight in gold.

W

IS FOR WATER

We all know that water is life giving. Most aged care residents do not get enough of it. A lack of water leads to dehydration which leads to constipation, Urinary Tract Infections (UTI) and Pneumonia. Putting a jug of water in front of a patient does not ensure that they drink it. Some patients are unwilling some unable to help themselves. Some will resist vigorously. The term "push fluids" recurs again and again. Just pushing fluids will often alleviate symptoms of infection.

As swallowing deteriorates thin fluids can cause major problems, being inhaled rather than swallowed. Thickening the fluids can help. Unfortunately many old people cannot understand the need for thickened fluids and never come to accept the concept of a cup of tea that has a consistency of thick paste. Your job is to encourage and offer fluids frequently. Fluids do literally mean the difference between life and death.

All that being said, fortunately, dehydration is not a painful way to exit. It is the way most people go. Forcing fluid onto a reluctant terminal patient will not really prolong things much and will just cause distress in the terminal phase. Be guided by staff as to when to accept that the end is near and further attempts to hydrate are unwarranted.

X

IS FOR EXITS

Even though it can be difficult and confronting, the fact is that very few patients go home from nursing homes. The next destination for the vast majority is the Funeral Home.

Families should be asked on admission whether the patient will be for burial or cremation and whether or not a Funeral Director has been chosen. Sometimes facility staff can be diffident about tackling the subject. More frequently relatives are unable or unwilling to think about it. I have attended countless deaths where the relatives have had no idea whether Mum wanted to be buried or cremated and no thought has been given to which undertaker will be used. When someone dies in a facility, things of necessity move quickly and waiting a day or so while family members consider these issues is not feasible. This adds significantly to the stress for some. If these issues can be discussed and sorted in a stress free setting while Mum is still reasonably healthy, things go a lot more smoothly when she does die.

Dying can be unexpected even in sick, debilitated patients. It can be quick. We would all like the instant heart attack or stroke in our sleep. Death unfortunately can be long drawn out and agonising for those watching. There can be ambivalence, with both relief that Mum is finally no longer suffering but also grief that she has gone. There is sometimes guilt about the relief. Any and all reactions are normal. The timing of death can be intriguing. Some patients will wait for someone to come back from a trip. Some will wait for a relative to go on a trip. Some will wait till their loved one is in the room some till the loved one has gone out for a break. Some claim it is all coincidence but you see a lot of strange things in aged care and I believe some patients definitely time their exit. Sometimes patients need permission to go. Quiet reassurance that you will be OK if it is time for Mum can allow her to finally let go.

The mode of exiting the building varies with the home. If there are share rooms the facility will usually have a holding room to which the patient will be transferred prior to pick up. Some facilities are very discreet in the way things are handled and the patient will be taken out a back door. One facility I attend takes them out the front door, the way they came in, with a guard of honour made up of any available staff, family and sometimes other residents. This seems to me to be a great way of honouring that patient.

All facilities will give you as much time as you need to sit with Mum and say goodbye. They will usually be very amenable to you returning in the next day or so, to pack up Mum's belongings. Facility staff will also happily make themselves available if you have any issues you want to go over later.

Many people think it goes without saying but a word or two of appreciation to the staff who may have cared for your Mum for up to several years will be greatly appreciated. Just today I was in a facility when a bouquet arrived for the staff of one ward who had nursed one patient for a year or so up to her death a couple of weeks ago. The looks of delight on the nurses' faces were wonderful. Yes they get paid (even if poorly) but a word of thanks can make their day.

Y

IS FOR YOU

Most of the discussion so far has centred around Mum and her needs. Do not forget your own needs. Your life is still going on. I have seen many family members literally wearing themselves out trying to be all things to all people. Your Mum knows on some level that you have other responsibilities. Even if Dementia makes her demanding do not feel guilty about fulfilling those other obligations. I have seen elderly spouses almost destroy their own health by visiting too long and too often. I have often advised stressed relatives to limit visiting to maybe three days per week. This is purely to maintain their own physical and mental health. Visits, as mentioned previously, can also be disruptive particularly when a resident is settling into a facility. Be guided by facility staff - they see Mum before, during and after visits. They will be able to advise you as to what is best in a given situation.

Z

IS FOR ZEST FOR LIFE

This is a very brief one to end. While zest for life is there nurture it, but be prepared to sit back and accept if, towards the end, it diminishes. It can be a torment to a resident to be forced into the shower and into a chair when all they want is to lie in bed. Having relatives plead with them to get up or they will die does little to allay any anxiety they may have. Sometimes it is appropriate to just let go.

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