



THE CENTER FOR
CASE MANAGEMENT

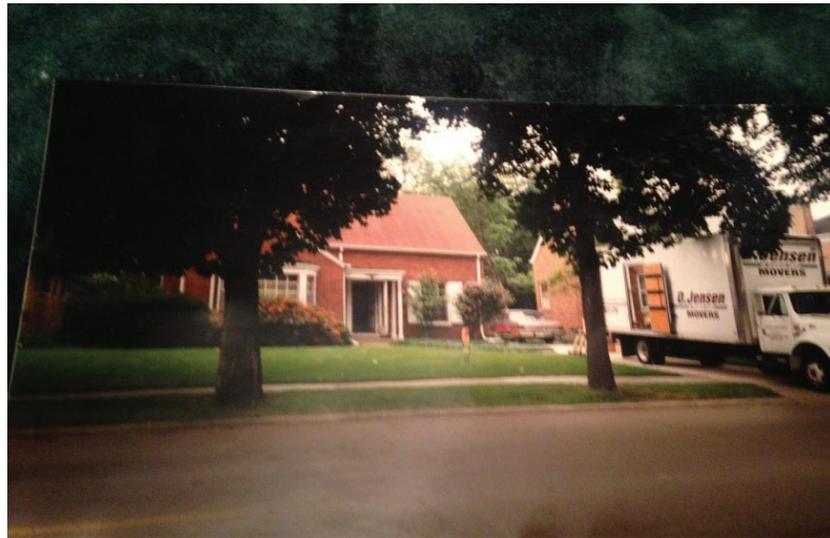
Spring/Summer 2017
Vol. 31 No. 1
ONLINE EDITION

New Definition

• **Karen Zander RN, MS, CMAC, FAAN: Editor**

A Step-by-Step Guide to Moving Mom or Dad into your Home

A Letter from Warna Reynders and Karen Zander



Time has flown by since those carefree days when you were a child. Time has now caught up with you and your parent(s) and this is the guide you never thought you would read. For many reasons, our parents are living longer than they or we ever thought they would and as they age, we may start to feel like their parents. Whether it is a momentary question in your head, or a continuing nauseated feeling every time you call or visit, you know that your parent needs something different to be safe and as healthy as possible — perhaps to move into your home and family.

Warna and I know that it is no comfort to learn that you are not alone: according to a *USA Today*/ABC News/Gallup poll of baby boomers, 8% say their parents have moved in with them. In fact, “some surveys suggest that today’s Baby Boomers — adults born between 1946 and 1965 — will spend more years caring for a parent than for their own children.”¹ We have learned, however, that once the decision is made to move a parent into your home, there is a “rite of passage” for both of you. Although there are cultures that accept this move as part of family life, it has not been standard operating procedure for Baby Boomers. Boomers were raised to be independent and improve their lives over what their parents had. We both experienced living with a parent during the final and usually deteriorating phases of their lives as a challenging journey with an inevitable end. We hope your journey will be filled with pleasurable moments, pride and information.

Step 1: “Something Has to Change”

Usually a crisis is the reason: hospitalization, bad illness, death of a source of significant other, current support system changes/people move away or it can be a slow process of realization by the senior himself: (examples) feeling isolated and lonely, giving up driving, or more often

www.cfm.com

1 A/PACT: Aging Parent and Adult Children Together

by you! Your parent may be confused on the phone, suffer from mental illness/depression, and you may receive reports of negative behaviors from the neighbors or the police or from your church.

Step 2: “Reality Settles In”

The living situation has to change; you have tried everything else; i.e. more frequent visits, having the groceries delivered by the store or by sibs (“the Peapod intervention”), increasing the calls; trading mom or dad for musical chair weekend (the “hot potato” intervention), seeking MD advice, suggesting the “Social intervention” such as Comfort Keepers. But your parent does not want strangers in the house, or is not answering/hearing the doorbell, and worse is not trusting the family. Weather problems may also impinge on the current predicament.

Step 3: “Coming to Terms with Reality”

Give up managing from afar to keep up the illusion of independence of a parent and that you are free is an illusion. This is the last day of your life as you know it — you realize that you now have a “special needs” child. Your parent will see this if he or she is particularly insightful and mature — maybe scared, or seeing the inconsistency of visitor services. He or she may talk about the problem with a trusted person. If your parent does not see it on his/her own, what can you do? Timing is everything: You can try out alternatives (but that is merely temporizing). But ultimately, but both you and your parent must acknowledge the extreme losses of the house, friends, city, history, wishes. You may want your parent’s primary care doctor to talk with your parent.

Step 4: Multidirectional Negotiation — Questions to Ask Yourself

- ✓ Why your house? Size is not important (sometimes smaller is OK)
- ✓ Negotiations with your own spouse, siblings, children
- ✓ Negotiations with your parent if not resolved
- ✓ Legal issues: An unethical approach would be “come for a visit and stay forever”.

Step 5: And the Final Answer is: Move or “What do I do with 50 purses?”

Checklist:

- ✓ Movers
- ✓ Donations: When we moved my mother to my house, she waited for a year before making the decision. We took her back to her independent apartment to say goodbye. She chose what she wanted to give to fellow apartment mates and friends, like her cotton blankets.
- ✓ Sorting
- ✓ Parent involvement in choices
- ✓ Timing of the move is everything, as they say

Step 6: Making it Safe and Comfortable, or “Living in Shorts” because the Heat is On All the Time

Whistles, large-number telephones, notify local fire and police, locks — yes or no; neighborhood watch, throw rugs and thresholds, heat, lighting, rules about stoves and microwaves, stairs, lifeline and other devices are very helpful.

Step 7: Getting the Medical Help your Parent Needs

1. Finding a PCP and specialists
2. Insurance, medications, the donut hole
3. Part-time in-home companions, aides, arranging family help
4. Tolerating the same stories repeated
5. Using a communication log with aides

Step 8: Achieving Quality of Life as Mom and Dad Perceive It

Church, friends, going out for meals, concerts, clothes, grooming, getting hair done every week (very important for women), family events, car rides, weather, legal and financial peace of mind. For a while we would drive my mother to New Hampshire to our lake house, but she became afraid of the elevator, probably thinking she was in a nursing home, and begged us to “not leave her there.”

Step 9: Staying Sane but Responsible

- ✓ Getting the break you need is very important
- ✓ Vacations: my husband and I were so responsible that we would take separate flights to our destinations
- ✓ Weekends
- ✓ Respite care options
- ✓ Getting used to constant change and using your resources: friends, websites, family
- ✓ Find geriatric RN or MSW case managers: A professional geriatric care manager has been educated in various fields of human services — social work, psychology, nursing, gerontology — and trained to assess, plan, coordinate, monitor, and provide services for the elderly and their families. Advocacy for older adults is a primary function of the care manager. Geriatric case manager website: Oct 6, 2008.

Step 10: Planning for the Inevitable: End of Life

Healthcare proxy, end of life 5 wishes are all important. Difficult as the last steps are, the first nine steps are easier than the 10th, which as some point can’t be ignored and certainly can’t be skipped. Once during a seminar at Harvard I, Karen, at the ripe age of 28, asked Dr. Elizabeth Kubler Ross how “normal, non-dying” people could tolerate the concept that we are not immortal. Without hesitating, she answered, “Honey we are dying all the time”. Although this was not the kind of advice I was hoping for, she did make an important point about life and living as well as possible. But you have met your responsibility and your heart is calling to help you parent live as well as possible. What are the signs of the end of life?

Chances are that your parent already has one or more medical conditions by the time they come to live with you. Not every medical condition causes death, but you have inherited a parent that was not raised during the years when we understood as many preventive actions as we do now. We also know now that depression and smoking create a lot of co-morbidities, such as stroke. Senior Health lists the “Top 10 Causes of Death Among Adults Over the Age of 65” as:

1. Heart disease, includes CHF, MI, heart arrhythmias
2. Cancer
3. Cerebrovascular disease: stroke caused by a blood clot or hemorrhage

4. Chronic Obstructive Pulmonary Disease (COPD)
5. Pneumonia is the fifth highest killer of older adults, especially during flu season.
6. Diabetes: Older adults generally have Type 2 Diabetes, which is a disease that requires constant monitoring of blood sugar and food intake. Wound healing of injuries such as from falls or surgical incisions are also a risk.
7. Accidents: Falls are probably the most common accident in older people who are more at risk because of balance problems, eyesight disturbances, and slower reflexes. Arthritis can also cause accidents because of problems holding items and holding onto handrails. Osteoporosis is also a common cause of fractured hips.
8. Septicemia is deadly and often spreads quickly into a total-body infection. The infection can start with something as “simple” as a Urinary Tract Infection, which spreads to the kidneys and beyond. UTI’s can also cause lethargy and confusion in an older adult.
9. Nephritis is a sudden or chronic inflammation of the kidneys. If your parent has abused alcohol in their life, they are prone to nephritis as well as cirrhosis of the liver.
10. Alzheimer’s dementia is probably the most tragic of all lethal diseases in the elderly. It is characterized by progressive memory loss, personality changes, and eventually a complete loss of function and ability to walk, eat, and communicate.

Quality of Life — According to Whom?

We each have the capacity to adapt to our losses. Always be reminded that what healthy people imagine as intolerable and totally lacking in life’s quality might be acceptable to the parent in your home. Just being in your home may meet any wishes and

dreams they had for the end months and years of their lives, as long as they are not in pain. Your parent may deal with losses in their own characteristic methods of humor, anger, or other coping skills. These skills may keep them going until their body gives out. On the other hand, these skills may stop working all together. Consider Hospice Care at the end of life. Home care companies can provide hospice care as a transition for your parent. There are also inpatient hospices. There may be a point in which your parent may become extremely aware of his or her condition, and may even talk about things “being better if I could just die”, or “I don’t want to be a burden”, which might be said once or many times.

There may be times you wish it, but guilt is one of the most terrible feelings and a partner at every step of this journey you are on. These last months, weeks, and days are not different. Whether a parent is either so ill that they are close to death or wishes it, a parent is depressed and not at all ready to die — no one really is. There is no correct response to their comments. Perhaps a reasonable response would be “It may be easier for me and you if you weren’t here, but I don’t want you to die.”

Finally, there may be a point at which you can’t keep your goal of keeping a parent in your house, when it gets too much for one or both of you, NOT BECAUSE YOU DON’T CARE, but because it truly is near the end of life. You have a few options, like home care hospice or an inpatient hospice. Medicare will not pay for a Skilled Nursing Facility (SNF) unless your parent meets national guidelines for 3 overnight stays in a hospital. But remember, any time a parent isn’t in your home, you are back to trips, visits, and the anxiety that comes with having to orient yet another whole staff of people to the unique needs and family relationships with your parent.

Epilogue: Free, guilty, sad, relieved. All feelings are acceptable, and you hung in there. Congratulations!