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NaCCRA
NATIONAL CONTINUING CARE RESIDENTS ASSOCIATION

LifeLine

Representing CCRC (Life Plan) Residents Nationwide from 1999–2020

Opportunities Lost – Maybe

Jim Haynes ~ Falcons Landing

During the recent LeadingAge Annual Meeting, NaCCRA released and posted in our booth a paper, *CCRCs from 2010 to 2019 - A Missed Opportunity*. Our Board wanted to understand why, since 2010, there has been a trend toward for-profit, no-entry-fee, rental facilities to grow at an accelerating rate and gain market share. This growth rate contrasts to the 2% per year growth for not-for-profit, entry-fee CCRCs, where most of our members are residents. This paper is available for viewing and can be downloaded in PDF form from our Document Library. You can also get a bound copy of this 36-page booklet at the NaCCRA Store on our Home page for $25.

One section discusses "What Went Wrong"? Another explains "Entry Fee - What Is It?" There are several sections on financial soundness.

I hope this paper will be a catalyst for the senior living industry to take a fresh look at this vast and growing segment of our population.

On the following page, you will find an article by Gerard Hyland, the leader of the team of authors of this paper.

An opportunity that was not lost was our plan to partner with our Virginia friends at VaCCRA. As of October 1st, National members in Virginia can become members of VaCCRA when they renew with NaCCRA, and VaCCRA members can renew their National membership with one simple step. This partnership will strengthen both organizations. As of this writing NaCCRA membership has increased over 25%. I believe VaCCRA's membership could show similar gain as their members renew.

We hope that other state organizations will pursue similar partnerships with NaCCRA. ■

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How Did the Idea for the Paper, CCRCs from 2010 to 2019 - A Missed Opportunity, Happen?

~ R. Gerard Hyland, NaCCRA Board

During the 2010 National Continuing Care Residents Association (NaCCRA) meeting held concurrently with the American Association of Housing and Services for Aging (ASSHA) Annual Meeting and Expo in Los Angeles, ASSHA celebrated, with great fanfare, the coming of an unprecedented explosion in the aging population—spurred by the pending retirement of 78 million Baby Boomers. They will present serious challenges to both consumers and providers of long-term services and supports. The aging of the U.S. population will also give consumers and providers an unprecedented opportunity to create a consumer-responsive service and support system that meets the individual preferences of older citizens while facilitating healthy aging for all. To lead the way, AAHSA changed its name to "LeadingAge."

Fast forward to 2019. NaCCRA held another meeting concurrently with the LeadingAge Annual Meeting and Expo in San Diego. During the NaCCRA dinner meeting, keynote speaker Lisa McCracken, Director of Senior Living Research for Ziegler, described key senior living trends. During the LeadingAge educational sessions at least two sessions were based on one of the trends described by Lisa McCracken. Since 2010, there has been a trend of for-profit, no-entry-fee, rental facilities growing at an accelerating rate and gaining market share relative to the constant 2% per year growth for not-for-profit, entry-fee CCRCs.

The trends since 2010 described at the 2019 NaCCRA and LeadingAge meetings contrast sharply with the fanfare and celebration at the 2010 AASHA meeting over the growth LeadingAge foresaw with the coming of 78 million Baby Boomers.

These observations were reported to the NaCCRA Board Members along with observations as to why this might have happened, based on years of investigations by members of the NaCCRA Financial Soundness Committee.

NaCCRA's mission is to collaborate nationwide with residents and prospective residents of CCRCs and allied organizations for the purpose of promoting, protecting, and improving the CCRC lifestyle.

With concern, NaCCRA Board Members took note of the not-for-profit, entry-fee CCRC industry loss of market share. Board Members reflected on what we, as CCRC residents, see as the reasons for the loss of market share with the hope that the not-for-profit, entry-fee CCRCs will take note and change their ways. The paper *CCRCs from 2010 to 2019 —A Missed Opportunity* was conceived. ■

New Book – Facing Death: Finding Dignity, Hope and Healing at the End

Jim deMaine[1] ~ Skyline at First Hill

For 38 years I cared for very sick, terminally ill patients. Their stories—their deaths and suffering—have become part of me. I have collected and treasured the many kind notes that patients and families have sent me, at times crediting me with powers I do not deserve. As I ministered to patients, their loved ones and caregivers, I was part doctor, part teacher, and part spiritual advisor. In a care conference in the ICU, I would often tell a story to help a family understand the crisis their loved one was enduring. I tend to think in stories and found that, through them, families could more easily grasp whatever lesson I was trying to impart. They, like most of us, had not talked much about death and were unprepared for it. But when death lands on our doorstep, do we lock the door or welcome it in? Dying is different for each of us as we enter the unknowable on our own unique path.

My book, *Facing Death: Finding Dignity, Hope and Healing at the End*, is both a memoir-in-vignettes and a handbook full of practical advice derived from caring for patients in busy hospitals and ICUs. Using stories from my own life and practice, I walk readers through ethical questions around "heroic" interventions. Do we fully understand what we're asking when we tell doctors to "do everything" to prolong life, even in cases when a patient has no chance of regaining consciousness? If we write advance directives outlining the kinds of care we would, or would not want, how can we ensure that they will be followed? The book delves into territory many physicians avoid, such as the role of spirituality, conflicts between doctors and families, cultural traditions that can aid or impede the goal of a peaceful transition, and ways to leave a moral legacy for our descendants.

Until the COVID-19 pandemic, heart disease and cancer were the leading causes of death in developed countries. But in early 2020, the world was suddenly turned upside down. No one, of any age, was immune to a new strain of coronavirus. It engendered a worldwide panic unknown since the influenza epidemic of 1918, and quickly became a leading cause of death in America. The COVID-19 pandemic has forced many to confront death and its painful losses more suddenly than they had anticipated, particularly among Black and Latinx communities. However, most of us won't die from the ravages of COVID-19. We are much more likely to die of a chronic illness in our old age.

Aging itself is loss. We experience it as a prelude to death. Our muscles weaken along with our bones, vision, and hearing. We become forgetful. We lose balance, and we worry. We see friends pass away, attend memorials, and begin to wonder about our own. Medical appointments fill our schedules. Aging is supposed to bring wisdom. But in the age of social media—where attention spans are shorter and the pace of life exponentially faster—it feels more difficult than ever to cope with death creeping closer to our front door.

My medical career began in an era when little could be done for two of our greatest killers, heart disease and cancer. There were no ventilators. I often saw patients die without the benefit of hospice care. ICUs and CCUs had not yet evolved. But with amazing rapidity, medical science has brought us life-saving advances such as hemodialysis and organ transplants. This progress is both marvelous and problematic, as technology continually outpaces our ability to thoughtfully and ethically bring it to the bedside. When should life-prolonging advances be used? How do we decide to whom to allocate these tools when resources are scarce or prohibitively expensive?

My stories are about hopes and fears common to us all. They are about the ethical dilemmas I've encountered and moments that have humbled me. They address advance care planning, medical aid-in-dying, conflicts, medical mistakes, modern hospice, and palliative care. In the last section, I share my thoughts about resilience and leaving a legacy to our loved ones. ■

[1] Jim deMaine, MD, is a retired pulmonary/critical care physician and Clinical Professor Emeritus of Medicine at the University of Washington School of Medicine in Seattle. His blog is www.endoflifeblog.com.

Washington State Residents Take the Lead (Again)

Jack Cumming[1] *~ Carlsbad By The Sea*

In less than 5 years, the Washington Continuing Care Residents Association (WACCRA) has gone from its founding to become one of the most influential advocates for residents in the nation. In just its first year of existence, WACCRA successfully advocated for the first Washington State CCRC law, RCW18.390, effective July 1, 2017. This law requires that CCRCs register with the state Department of Health and Human Services, provide financial disclosures to prospective residents, and allows protections under the Consumer Protection Act. That alone was an extraordinary accomplishment.

Now WACCRA has taken another trailblazing forward step. WACCRA has just negotiated with LeadingAge Washington a breakthrough agreement to provide more information to residents and to establish a procedure for residents to consider and make recommendations on pending management decisions. Their process begins in 2021. So far, all of the Leading Age provider members have signed on. There is one CCRC in the State that is not a member of LeadingAge and has not yet signed on.

Relations between WACCRA and the providers' trade association, LeadingAge Washington, have not always been this amicable. During the 2019 Washington State legislative session, LeadingAge Washington wrote a lengthy email denouncing WACCRA as representing only a small group of malcontents. In short, LeadingAge Washington claimed to represent all Washington State CCRC residents, whereas WACCRA, it reported, included only 10% of the state's CCRC residents and most of them, it further asserted, lived in the full-care-inclusive communities offering resident-protective Type A contracts.

WACCRA, though, took the high road; ignored the slights; and responded to the Washington Legislature's suggestion for LeadingAge and WACCRA to enter mediation to find common ground, while holding its own in its efforts to strengthen resident rights and resident financial security. That effort has now borne fruit in this landmark agreement. Moreover, other states are now looking at the WACCRA approach to try to gain stronger resident protections. FLiCRA, the Florida Lifecare Residents Association, as an initial step, has shared the Washington State development with LeadingAge Florida. Residents at Florida's Oak Hammock have not waited for FLiCRA, though, and they have already opened discussions with their management about a similar covenant to protect their residents. The North Carolina Continuing Care Residents Association (NorCCRA) has also taken note of the Washington State breakthrough and is beginning a process of considering it. The Washington Commitment to CCRC Practices is available on request from WACCRA's President: donna.kristaponis@gmail.com.

In another development, residents at University Village Thousand Oaks in California brought a lawsuit challenging the binding arbitration provision that is often included in the contracts of adhesion that prospective residents must accept unaltered if they want the benefits of community living. The lawsuit built on a California law protecting tenants, and it was contested all the way to the California Supreme Court.

Thus, it is now settled law in California that the arbitration provisions in continuing care contracts cannot be enforced concerning the rental attributes of continuing care contracts. The provider law firm, Hanson Bridgett, is now advising providers to change their contracts so they can continue to mandate arbitration for care and services disputes. Obviously, arbitration does not favor residents, or providers would not be so eager to impose it. This new decision is a victory for California residents. ■

[1] Jack Cumming is the Research Director for NaCCRA.

What Will the "New Normal" Be for CCRCs?

Barbara Thomas ~ Kendal at Oberlin and Glen Blume ~ Foxdale Village

It is imperative that CCRCs address what their community's future "normal" might be, in light of what has been learned during the COVID-19 pandemic. One approach to that has been the establishment of "New Normal" committees. In addition to short-term decisions about reopening, such committees also address longer-term changes that may be needed in the future. The experiences of the New Normal Committees (NNCs) at two communities—Kendal at Oberlin (KatO) in Oberlin, Ohio and Foxdale Village (FV) in State College, Pennsylvania—offer some insights regarding such planning for the future.

The idea for a NNC arose at KatO and was adopted at FV as a result of idea-sharing between the CEOs of the two institutions. They are part of a small, informal group of CEOs whose organizations are affiliated with Friends Services for the Aging. That CEO group has been communicating regularly since the beginning of the pandemic to share ideas and best practices.

It is typical for NNCs to serve at least two functions: advising the administration and communicating internally and externally. At KatO, the committee was charged with advising the facility's board and administration regarding effective restoration of vital and engaged living and communicating recommendations and policies. To some extent, New Normal committees' recommendations are constrained by federal regulations (e.g., CMS, CDC), state mandates, and, in the case of multisite facilities, corporate-wide requirements. In addition, some variation in committee's goals and membership might be dictated by local or countywide risk estimates based on COVID-19 data and site-based needs and resources. It is important for Residents Associations to offer input as a partner in NNC decision making but also to understand that final decisions rest with the facility's administration and governing board.

Because NNCs act in an advisory capacity, it is important for them to include the voices of residents, staff, the governing board, and the administrative team. KatO's NNC consists of 12 members, a mix of staff and residents drawing on leadership skills, professional training such as medicine and epidemiology, and gender and other aspects of diversity. The 13 members of FV's NNC include the four Residents Association officers, three members of the Executive Team (CEO, health services, and environmental services), four staff members (dining, wellness, information technology, and residency planning/marketing), and two members of the Board of Trustees.

Residents' lives have been altered in a variety of ways by COVID-19, leading to a variety of concerns. These have included concerns such as limitations on access to facilities, restrictions on travel outside the community, limited dining options, and scaled-back wellness programs. Each community's NNC will have a unique set of concerns to be addressed; however, the following are some issues that might arise.

Which current restrictions can be relaxed or eliminated? Under what conditions might pandemic-related restrictions need to be reinstated? How does the emerging science enter into the decisions?

How should on-site medical appointments best be conducted during and after the pandemic (e.g., in person or via telehealth)?

Which current protocols might need to remain in place for a limited time, or perhaps permanently?

What guidance governs decisions about family members visiting residents in skilled nursing and personal care (e.g., outside and with a barrier in place for physical distancing)?

What safeguards will continue to be needed for residents in skilled nursing and personal care, and how do seasons of the year impact feasible solutions resulting in adaptations to insides of buildings or the outside of campuses?

Which, if any, resident activities (e.g., instrumental performances, resale shop, garage sale, community garden) can proceed as in the past, and when can they resume? Prior to availability of a vaccine, what decision is made about choral groups?

- What room capacities and furniture arrangements need to be established, and what time limits per room are necessary with protocols for cleaning between uses? How will Residents Association meetings be

continues

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held? Where and how will resident committees meet?

- What, if any, health screening of residents will be necessary prior to their participation in activities? How frequently should staff health screening and virus testing occur (when not mandated by local, state, or federal requirements)?
- When and to what extent will visitors (family members, guests, program presenters) be permitted on campus? What is the COVID science that is driving these decisions?
- Can individuals or families create a "two-household bubble" that, after isolating and/or testing negative, can gather together regularly?
- What guidelines should be in place for leaving campus? What travel restrictions are recommended? After travel to certain locations and under what conditions do residents (and staff) need to self-isolate for 10–14 days upon return?
- Under what conditions can land-exercise and water-exercise classes resume?
- What changes, if any, need to be made to community-provided resident travel (e.g., medical appointments, grocery trips, day trips)?
- How, if at all, might congregate dining differ in the future from what it has been in the past?
- How frequently should updates regarding the community's results of COVID testing be communicated to residents, and in what form should that information be distributed?

Senior-living communities need to plan for the post-COVID-19 future in ways in which they have not needed to plan in the past. Forward-looking NNCs, with substantial representation from residents, can serve a much-needed role in the gradual reopening of communities as well as in recommending longer-term changes to communities' ways of operating. ■

The Fog That Follows Change: The Normality Following a Major Life Shift

Harvey Austin[1] ~ StoneRidge

Each of us has had the experience of walking through the front door of our brand-new home with that strange name, Independent Living Facility. Excited, nervous, and a bit scared, we are greeted by a welcoming staff and we look forward to getting settled and comfortable.

We have thought a lot about this move into our new life, our new adventure, and our new lifestyle. Perhaps we feel the relief of giving up responsibility, too-long-held. Perhaps we see a new opening for life, a new freedom of choice. Our move may even represent an opportunity for that secretly-longed-for community, so often absent in our successful and busy lives.

For some, we have boarded a Cruise Ship; others have called it a Summer Camp for Seniors. For all of us, it is a major life shift—a good one.

DOGS' TAILS

However, just as a dog's tail always follows a huggable dog's head, we would be wise to expect a tail to this sweet dog as well.

Psychologists tell us that major changes in lifestyle, surroundings, or physical location can be traumatic. Such powerful changes assault "the usual, the familiar, and the comfortable."

On the one hand it is pleasant, desirable, and safe to have come here at our advancing ages. On the other hand, there are often some changes that we prefer not to have.

THE FOG

As a result of conversations with many residents, I am introducing a phrase, The Fog That Follows Change. For short, The Fog.

I believe The Fog to be a common "painful temporary normal." Brad Breeding, author of "What's the Deal with Retirement Communities," recently reading this article, wrote in his blog, "I believe that Dr. Austin has hit the nail on the head with his analysis of "The Fog." (MySite.net July 1, 2019)

[1] Harvey W. Austin, MD, is a retired surgeon.

When The Fog isn't recognized for what it is, you might feel isolated, even if you arrived with your spouse. You might have these thoughts: "I feel out of my element," or "I feel lonely," "confused," or "depressed." Perhaps, even "These are the wrong people—they're old. I'm not."

Sleep may be disturbed, tossing and turning. You might feel tired, a bit confused, not thinking as fast, yet the mind keeps working on, even overtime. Your body may hurt, old hurtings may worsen, or new hurtings may occur. We might wonder, "maybe something serious is wrong with me." You might hear yourself thinking, "I feel out of control." Perhaps you find yourself compulsively eating, jokingly referred to as the newbie weight gain.

The Fog is real. But it is critical that you realize that it is not personal , no matter that it feels that way. The issue is not YOU. The Fog simply "comes with the territory." Though it is usually temporary and self-resolving, you can understand it, watch it, and even ease it.

LOSSES

Above all, let's be realistic about our losses. There are losses as we move here—real losses: loss of home, loss of independent living, and loss of possessions, often sold. These losses are piled onto our earlier but inseparable losses: retirement, a shift of identity from independency to a certain … well … dependency. Not to mention other events that occur, such as our kids moving on, perhaps with its empty nest syndrome, or perhaps the deaths of older members of our family.

MAJOR CHANGE IS EMOTIONAL

It is important to remember that all major changes carry our emotions with it. They always have, and always will. This is true for everyone, not just for some.

FEARS

It is normal to have fears—fear of "losing it," of becoming weak. Fear of losing our identity as a "healthy competent and respected person." Fear of getting sick. Fear of dying. And fear of death, itself. All these get added to our long-standing fear of not fitting in, and the fear of not being seen or understood. Together, these can be overwhelming.

ANXIETY

It is normal to have anxiety, that vague fear of "I know not what." But it is situational, not pathologic.

THE FOG IS AMORPHOUS

It is akin to that ground fog when driving near the ocean—we dip in and out of it. Sometimes we're above it and can see it, and sometimes we're "just in it."

The Fog is full of self-talk: It's full of "I shoulds" and "I wonder what's wrong." "I wonder why I am forgetting things —am I alright?" "Am I getting early Alzheimer's?" And it may be full of the self-talk of "Snap out of it." Sometimes, it's a series of "I just don't wanna's."

And still, we function—reasonably well—perhaps telling ourselves, "Well, I guess I'm just not up to par." Yes, for sure, but that platitude disguises the depth of what is going on.

HOW CAN WE HANDLE THE FOG

Perhaps these can help you handle The Fog:

1. Time. (The Fog passes on its own, slowly.)
2. Noticing it, labeling it, and not taking it personally.
3. Listening is the real key—simply listening. We humans need to be listened to.

But we did not grow up inside a "listening culture." Ours is a "talking culture," an advice-giving culture. That thought is a barrier to telling others what is really going on when we are asked, "How are you?" We lie. "Just fine, thanks. How are you?"

Back at the office, that conversation was called water-cooler talk. Now we call it dinner-table talk, as in, "Hey, how about those Patriots!" and "The string beans are cold again!"

Find someone with kind and open ears. Ask them to "Just listen and let me vent. Please do not interrupt or ask questions. Just LISTEN."

4. A few other things that might be helpful:

a. Say "Yes" to all invitations and opportunities.

b. Tell the truth when asked, "How are you?" (Perhaps you need to hear a hint that the question was real and not just a bit of social grease.)

c. Be kind and patient with yourself. Treat yourself to small things.

d. Add this to your self-talk: "There's nothing wrong. This, too, shall pass."

e. Or perhaps add this, "I do not mind whatever happens!" And chuckle as you discover how just much you do mind some of what shows up.

f. Get out into the woods or visit the shore and be present with your surroundings. Interaction with nature has been found to be very beneficial to one's psychological well-being.

Remember that the "Fog that Follows" is not personal: It is cultural. It does not mean "there is something wrong with you." To the contrary, it points to "something right with you." ■

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[1]If you live in a state that is affiliated with NaCCRA and is using their expanded and optimized system, you are now included in our National database and your state dues are included. This arrangement makes both the State and National organization better able to serve you.