



# PART ONE Aging Expectations & Family Resilience

This first part of a two-part article examines how to consciously change the care journey from one of managing health concerns to a supportive environment encompassing mind, body and spirit.

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When a parent or loved one needs assistance, most families truly want connection, cooperation, and a positive quality of life for everyone involved. However, the realities of a care journey often trigger more frustration and conflict than harmony.

This two-part article examines how families can consciously create a culture of care that supports more of what they want (and less of what they don't) when a loved one needs assistance. It explores aging, not as a solitary pursuit, but as something we learn in family, in community, and culture, and reveals how negative expectations of aging contribute to many unnecessary negative outcomes. It also describes how to avoid creating a care environment that focuses on illness management, which diminishes resilience, and outlines how to create a care environment focused on supporting resilience and well-being in body, mind and spirit.

Aging services professionals currently provide clients access to advance directives, medical power of

attorney, and Five Wishes documents. Aging industry professionals can elevate the industry standard for family support by helping clients and families explore how expectations of aging and family aging scripts create a care environment that significantly impacts the care journey.

### Aging Attitudes and Scripts

No one ages in a bubble. Instead, ideas about aging come largely from parents and grandparents, elders in the community, and cultural perspectives of aging. Families share a culture that influences aging trajectories, and shapes health and aging outcomes (Utz et al., 2016). Intergenerational studies show quality contact with grandparents curbs ageism among children (Flamion et al., 2017), and observe that ageist attitudes appear to block young adults' ability for compassion toward frail older adults (Bergman & Bodger, 2015). Experiences and observations throughout one's lifetime inform beliefs about aging and essentially develop "scripts" for how to respond to aging challenges, make health decisions and create care environments.

### Aging Scripts

Consider your personal aging scripts and where they came from. How long will you live? How do you envision your last years? Where will you live? What will you be doing? What strategies will you use to create a care environment if you or a loved one ever needs assistance? Personal aging scripts impact both your aging journey and your perspective on the aging journey of others (see sidebar).

Aging scripts influence what are considered "normal" aging experiences and directly impact responses to common challenges. For example, consider the following scenario. A ninety-year-old woman falls and breaks a hip. Her family isn't surprised because she had been using the walls and the furniture for support to get around the apartment for some time. If this woman had a broken arm or a skin rash, it would have been promptly diagnosed and treated. Yet far too often, being ninety and demonstrating symptoms of physical frailty such as using walls and furniture for balance results in no response. Doctors don't suggest treatment, families don't intervene, and the individual doesn't ask for help. Why? Usually it's because people simply *expect* someone who's ninety years old to be physically frail.

### Common vs. Normal

Physical frailty is very common and predictable with age, but it's not normal in the sense that we should just accept it as inevitable. Almost 30 years ago, a

## PERSONAL AGING SCRIPT

I personally learned about an ageless attitude from both sets of grandparents who retired in their early 60s (as expected in the 1950s), then got bored and started over with new challenges. One set came out of retirement to buy, remodel and run a small motel. The other set, who had sold their ranch to retire to town, lasted eight months before buying and renovating a fixer-upper working ranch where they raised cattle into their 90s.

landmark research study with 100 nursing home residents showed that even frail residents in their 90s could regain strength and function through strength training (Fiatarone et al., 1990). Decades of research since clearly demonstrates that lifestyle issues, not age, drive frailty (Weening-Dijksterhuis, 2011). Believing frailty is "normal" can lead family members (and aging service professionals) who recognize functional issues to stand back and wait for a crisis rather than seek (or advise) intervention. It can also keep many older adults from actively seeking solutions to functional challenges and trigger a seemingly illogical refusal to embrace solutions if they are presented.

Normalizing physical frailty has a compounding negative impact on individual well-being by accelerating a decline in self-esteem, self-efficacy, and hope: three primary building blocks of resilience. And it drives families to just accept with resignation that a fall and fracture is the beginning of the end, ushering in a "new normal" of managing illness until death. Again, it is very common and predictable for a fall to hasten disability and death, but research shows that a positive mindset about aging directly impacts outcomes. One study found that older adults with positive age stereotypes were 44 percent more likely to recover fully from a severe disability than those with negative age stereotypes (Levy et al., 2012). Frailty as a normal experience of aging can become so deeply imbedded into aging scripts that any hope for a different outcome feels like futile resistance to the inevitable.

### Shared Goals and Disconnects

*Aging in Place in America* (Clarity Report, 2017) reports that older adults and their family members generally want the same outcome: the ability for a loved one to live independently in their own home throughout their lifespan. In fact, 89 percent of older adults report wanting to age in place and 94 percent of baby

boomers feel it's important for their parents to do so. However, more than half of older adults are concerned about their ability to age in place and almost 80 percent of adult children share their concern. In addition, 63 percent of baby boomers surveyed already provide some kind of assistance to a parent or adult loved one. An estimated 58 million adults over age 40 provide regular or full-time care to a parent or loved one with significantly diminished capacity.

Shared goals seem like a good foundation for success, yet without a well-defined plan it's easy to trigger family conflict when a loved one is struggling to live independently. Exploring how expectations of aging impact behaviors and outcomes can help families prevent health setbacks from becoming new set-points, and establish a common language and approach to navigating the care journey.

### Expectations Impact Culture of Care

Many problems occurring after a parent or loved one exhibits symptoms of decline may actually be created or compounded by failure — on the part of the individual, friends, family and healthcare — to simply *expect* wellbeing. It's easy to blame decline on age. An illness or disability poses certain challenges, regardless of age, but expectations and personal beliefs drive behaviors as well as final outcomes.

Consider what happens when a 40-year-old has a stroke. Generally that person's family, friends and healthcare all focus aggressively on returning the individual to their highest function possible — which demonstrates a mindset of "wellness recovery." Yet when a 75-year-old has a stroke, it's more common to focus instead on doing what's necessary to get this person out of crisis and returned home with strategies to *cope* with functional deficits, demonstrating a mindset of "illness management." In short, expectations can create a care environment that either actively promotes independence and wellbeing, or effectively sabotages possibilities for positive outcomes.

### Family Expectations

Expectations also forge family scripts about what constitutes a loving care environment. Are safety and security, health care, and comfort the highest priorities? Do basic human needs beyond the physical, such as the need for autonomy and control, to give as well as receive, and for well-being in body, mind, and spirit, share priority status or only exist as after-thoughts? Is the care environment essentially a "safety bubble" where others take care of everything and the individual needing care isn't expected to contribute?

This is a very common and understandable reaction

## FAMILY DYNAMICS COMPOUNDING CAREGIVING

**Case Study:** Roxa fell and broke her ankle and arm. Unable to walk even with crutches, she required a lot of assistance. The son who was available to help happened to be the one who was, as she put it, "a very difficult teen and young adult". In her words, "*This young man, who I could never get to do (or not do) anything I asked, is now at my beck and call.*" She described a powerful sense of bonding with him over her injury and needs, and also a powerful sense of the control she never had. It took a lot of self reflection for her to realize that she allowed the intensive level of care to go on far longer than physically necessary because of past unmet needs.

to a health crisis. But a care environment without a shared sense of responsibility forges distinct roles: that of care-giver(s) and a care-receiver. The care-receiver often becomes a passive customer of illness management services and learned helplessness is a common undesirable outcome. Family dynamics can further compound this outcome (see sidebar).

### The Family Journey

How challenges are described, and solutions framed, *before* a health crisis forces a change can either enhance family well-being or set up power struggles that degrade family well-being. Interactions may include:

- Pointing out deficiencies in upkeep of the house/ yard
- Suggesting that home, hobbies, or whatever are "too much" to handle
- Pointing out inconsistency in memory
- Noting changes in physical function and criticizing lifestyle (i.e. lack of exercise, poor nutrition, smoking, etc.)
- Pointing out the unsuitability of a current lifestyle or living arrangement
- Potential solutions begin with *you should...., why don't you...., or I don't understand why you never/ always....*

These interactions are fertile ground for resentment from a loved one to perceived interference, family member frustration at the perceived lack of cooperation or appreciation for their efforts, and family conflict over different roles and approaches. One family member may take the role of cheerleader (*you can do anything you put your mind to*), while another may take on the role of pointing out deficits and “documenting” why the individual can’t live independently. Someone may take the “helicoptering” role, “saving” a parent from a perceived lack of understanding by other family members about what a loved one needs or wants.

Having a plan in place before a crisis is the most obvious, but least employed, solution. Raising awareness about how aging expectations and the care environment impact a family’s care journey is a positive step forward, and an important value-added service aging industry professionals can provide.

### Care Environments

Lessons learned from the disability movement illustrate the power of expectations and environment to determine outcomes. Thirty years ago, people born with disabilities were commonly institutionalized. Their physical needs for safety, shelter and personal care were met but other aspects of well-being were left to chance. This lack of positive expectations resulted in a tragic waste of human potential. Changed expectations, opportunities, and environments have empowered young people with severe physical and cognitive challenges to use adaptive strategies to overcome and live fully in spite of these challenges. But the same approach doesn’t usually apply to older adults challenged with disability.

### Overcoming vs. Coping

Age, like disability, is just one factor. It doesn’t define who a person is or what they’re capable of accomplishing. Yet, adults who are physically or cognitively challenged later in life are often given strategies and resources to *cope* with challenges rather than overcome. For example, Kevin M. Connelly was born with no legs yet as a young man traveled the world by himself on his skateboard documenting how people reacted to him, and then wrote his book *Double Take* (Connolly, 2009). Kevin was raised to believe that having no legs was simply an engineering challenge to overcome, not a disability, and was given resources, tools and encouragement to live fully in spite of those challenges. In general, the response to an older adult who loses the ability to walk is very different — centered instead on *coping* with that challenge by making

their world smaller and more manageable. There is a profoundly different mindset between coping vs. overcoming challenges, resulting in profoundly different outcomes. A robust body of research validates the power of negative expectations on outcomes, including the finding by Levy et al. (2012) that positive age stereotypes improved the odds of recovering from a severe disability by 44 percent.

A care environment of well-being and resilience focuses on possibilities rather than disabilities and supports well-being in all dimensions of health, regardless of age or challenges. Families can envision a care environment that supports resilience by asking what resources, tools, and encouragement a young person with the same challenges would receive to live fully in spite of challenges.

### Supporting Well-being vs. Managing Illness

Families often sacrifice a great deal to keep a loved one at home, yet fail to realize that the physical environment is only one aspect of the culture of care. Once basic physical needs are met, the emotional environment, whether it’s focused on managing illness or supporting well-being, has far more impact on quality of life than the physical environment. Being “home” doesn’t automatically support autonomy and control, a sense of meaning and purpose, and feelings of value to self and others. If the care environment focuses heavily on functional deficits and medical management of physical or cognitive conditions, it will garner the same loss of self-esteem, self-efficacy and hope that people fear from being placed in a care facility. Planning for and prioritizing a positive emotional environment of care lays the foundation for creating a culture of well-being.

### The Transition

First, consider how a care environment evolves after a health crisis. Far too often, the medical model of care, which focuses on problems and prioritizes physical and healthcare needs, hitchhikes home from the hospital. Basic human needs, such as purpose and value, are left to chance. Other dimensions of wellness, such as social, emotional, intellectual, spiritual, and vocational issues, are not addressed. The resulting *illness management* focus accelerates the loss of independence, resilience, and well-being, which in turn fosters feelings of powerlessness.

After a health crisis, there must be a deliberate transition from a mindset of managing illness to a mindset of well-being. This requires creating an environment that actively supports a sense of self apart

from medical conditions or functional challenges. It also requires creating common goals and a common language around well-being in all dimension of health, and consciously building a care partnership that supports the needs of all family members. This is a significant shift in mindset for most families. It acknowledges that although the needs of an individual who requires assistance are often more urgent, they are not more *important* than the needs of other family members. In a care partnership, each individual, regardless of challenges, understands they have a role in supporting the well-being of others. This understanding builds the foundation for cooperation and connections that are difficult to create in a transactional care-giving and care-receiving relationship (see sidebar).

## Summary

Aging is a family affair — and so is the care journey. Expectations of aging and family aging scripts influence the care environment, which in turn impacts the care journey. A culture of care focused on illness management actively diminishes resilience. A culture of care focused on creating a care partnership and enhancing well-being in body, mind and spirit actively builds resilience. CSAs are in a position to help clients and their families take a fresh look at this important issue.

Part two of this article, in the next issue of the CSA Journal, will provide practical strategies and resources to help families evaluate expectations of aging and family aging scripts, and outline a step-by-step plan to create a care environment that supports resilience and well-being. •CSA



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## CARE PARTNERSHIPS

**Case Study: After Mom's stroke I tried repeatedly, but unsuccessfully, to convince her to come out and ride the four-wheeler that she used to love. Finally, one day I asked her if she would drive the four-wheeler behind me as I took down an electric fence around an 80-acre pasture to save me miles of walking. The first approach focused on getting her to do something that would be fun or good for her; the second acknowledged her value as someone who could be an asset. She happily embraced the opportunity to help and repeatedly said how good it felt to do something for someone else.**

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