

## Anderson: The fine art of dining with dementia

By Joel G. Anderson | Posted: Saturday, November 14, 2015 10:30 pm

I'd spent weeks searching for the best butterscotch cream pie recipe I could find. My great-grandmother was joining us for Thanksgiving dinner, and I wanted to make the pie in her honor. It seemed the tastiest, warmest tribute I could imagine, and one I thought she'd relish.



Pie photo for DINING

But Granny, as her devoted legions of offspring called her, wasn't herself. She'd spent much of the past year in a skilled nursing facility due to a fall that had left her with a fractured hip and an increasingly dampened intellect,

which, in turn, had left my grandmother — her daughter and caregiver — at a breaking point.

Granny's dementia was progressing rapidly and, at the time of the hip fracture, her caregiver felt herself increasingly unable to cope with the job's demands, particularly given her own age and health issues.

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**A good deal** of my passion for caregiving comes from spending my many childhood summers in Granny's care. We kids, off from school, were her happy, raucous charges and food was a way she showed her care. Pies, especially butterscotch, featured among the many dishes that she unfailingly provided generations of my family, decade after decade.

So, if she was coming for dinner, I wanted her to have butterscotch cream pie. I wanted her to understand and taste my love and gratitude. It had been a few weeks since I'd seen her, and I looked forward to watching her enjoy the pie I had made from scratch, just for her.

But the woman who was wheeled into the dining room that Thursday in November was neither the Granny I knew, nor the one I had spent time with just weeks before. And, owing to her disease's progression, I had become a complete stranger to her, so much so that she recoiled from my touch, even as she slumped in her wheelchair.

During dinner, I watched her across the table as she sat in silence looking lost, bewildered, and even angry to be thrust into this gathering of people she didn't know or recognize.

And the pie? It sat, uneaten. What I had planned — all my expectations — were replaced by a gnawing sense of loss. Our matriarch, the woman around whom our family orbited, was disappearing right before our eyes in a long, slow, painful goodbye.

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**More than a decade** after witnessing the decline of my great-grandmother and watching my family deal

with her dementia, those poignant memories propel my program of research. I spend my days searching for strategies and tools to manage symptoms — and new and better ways to support those caring for loved ones with dementia.

I pore over studies about the impact providing care for a loved one with dementia can have on families and individuals. While my family's journey with this disease was unique in the sense that it was ours, and ours alone, our experiences with Granny are not uncommon. So the ache I feel each Thanksgiving is, as it is in many families, heightened during holidays when food and eating take center stage.

In my work, family caregivers share with me their own stories of navigating the ever-changing landscape of their loved one's disease, particularly during holidays and celebrations in which food plays a major role. Those who once may have expertly prepared and lovingly staged family dinners now often sit crumpled on their sidelines, as their kin struggle to find new ways of carrying out traditions with the sweet taste of connection and warmth.

Caregivers of those with dementia often struggle to keep their loved one engaged while dealing with the reality of a disease that alters appetite, comes with physical difficulty chewing and swallowing, and is often characterized by apathy and changes in sociability and personality.

Sharing a meal is supposed to bring us together, and in the context of dementia, engagement can be strained to its taut, near-breaking limits. So how, exactly, can family caregivers navigate the holidays without increasing their own stress levels, and that of their loved ones?

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**While there** is no single recipe for success, one basic idea stands out for me as helpful. As with so many arenas in life, approaching your loved one with dementia with purposeful compassion and dignity is critical. While this can be difficult with a disease that robs families incrementally of someone who they hold dear, we human beings need compassion and dignity in our lives, no matter where we come from, and where we are.

When we approach someone with compassion and dignity, we give ourselves permission to make mistakes, to realize that one size does not fit all, and that clear, permanent solutions are as fleeting as a pie's warmth.

Assumptions about what your loved one with dementia can or cannot do, or will or will not want will likely lead to frustration, hurt and disappointment — for you and for them. Caregivers in my research speak of the modifications and changes they realize they must make, through trial and error, to offer their loved ones the best holiday experience.

I baked a pie anticipating Granny's enjoyment — those were my expectations, not hers. Perhaps had we taken time as a family to discuss how to incorporate her into the Thanksgiving holiday as more than merely a dinner guest, the results might have been different. At the least, we would've approached the situation with more compassion, and offered her more dignity.

I don't fault us for doing what we did, all those years ago, with Granny; these days, in the lead-up to Thanksgiving, I mostly wonder.

While it may sound simple, even trite, dignity and compassion are the key components of dementia care. Though these concepts alone cannot solve all of the issues related to caring for a loved one with dementia, I can think of no better place to start. Sometimes the best answers to complicated questions are the most simple — as simple as pie.