

# MC SULLIVAN

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## Caring for the Caregivers

In the US in 2016-2017, there were more than 49 million unpaid family caregivers. One can speculate as to the causes that might explain this extraordinary fact: increasing numbers of the aging baby boomer population are 'aging in place' in their homes; the increasing number of formerly lethal or fatal illnesses or events that have, through the benefit of medical interventions, become chronic illnesses or conditions that are now more manageable, meaning that the patients with them live longer and their care costs more; and the increasing costs of care generally that are not covered either by public or private methods of healthcare insurance and/or reimbursement mechanisms. Whatever the cause, the figures are staggering, and we must assume that they are increasing.

On the professional caregiving side, we have long seen in the medical and nursing literature articles written and studies done on the subject of "burnout". In fact, in my experience as a clinical ethicist, I have often observed that it is not actually the long working hours and physical fatigue that are the cause of this phenomenon, but rather, it is often what I call a form of "moral distress", that is, the stress and strain felt when trying always to make the correct decisions and "do the right thing", especially when trying to identify and carry through on that option is difficult or not always available/possible.

For the past four years, the Archdiocese of Boston's ***Initiative for Palliative Care and Advance Care Planning*** has presented annual colloquia which have touched on the issues related to caregiving in chronic, complex and life-limiting (both in terms of time *and* function). Indeed, in 2018 and 2019, our themes were specifically *Who Care for the Caregiver?* and *Moral Distress on Both Sides of the Bedrail" Always Wanting to Do "The Right Thing"*. The areas covered included fatal diagnoses, mental illness, and dementias. The response to these programs has resulted in the highest attendance figures in the series. Clearly, these topics are of tremendous importance.

Finally, I serve on the Advisory Board of **Alexandra's House**, a perinatal hospice and refuge for abandoned infants, where parents are referred by high risk obstetricians when the babies are diagnosed, in utero or at birth, with fatal anomalies. Alexandra's House provides support to these parents as they proceed through the pregnancy that includes accompanying them to their doctors' appointments, pastoral care, being present with them if requested at the labor and delivery, organizing and providing without cost to the families the appropriate funeral services and burial arrangements, and continuing bereavement support for the next three years. In addition, if/when the parents become pregnant with other children, support and encouragement is provided if they desire it, as they proceed with that pregnancy.

The strategic ongoing programs in our office provide education about their topics (on palliative care; mental health and illness in the pediatric population; and the opioid crisis and addiction pastoral services) and all address components for the caregivers. It seems to us that is the most appropriate way that our Church can be pastoral and relevant in the face of these issues.