

Caregiving: A Nascent Social Revolution by Zachary White, Donna Thomson

Mention the word “caregiver” and what is the first thought that comes to mind? Older? Exceptional? Isolated and disconnected? Homebound and unemployed? Each of these stereotypes about care and caregivers is becoming increasingly outdated for the approximately 45 million people in the United States and 6.5 million people in the UK who’ve provided informal, unpaid care to a loved one in the last year, because family caregivers have already begun to transform how people care for one another.

By 2060, Americans 65 and older are expected to increase in number from 46 to 98 million, disrupting our current systems of managing care and all those impacted by care in ways that defy comprehension - including patients, providers, caregivers, families, economies and workplaces. Right now, caregivers don’t simply give care, they are also creators of dynamic communities of support and community-based care delivery systems. As agents of change and influence for those at the margins of society including the disabled, the chronically ill and the aged, informal (non-paid) caregivers are at the center of this nascent social revolution. But these innovations - born from love and connection - are largely overlooked.

Here are just some of the ways in which caregivers are the nexus of a growing ecosystem of care that includes government services, medical providers, neighborhoods, families, and non-profit organizations.

Caregivers are modeling how to integrate health care into daily life at home.

The convergence of love and necessity in caregivers’ lives makes them ideally suited to the role of innovator.

“As a caregiver to a son with complex medical needs, I possess a level of knowledge few people do. Our family has learned how to navigate life outside the hospital while using machines you find only in an ICU: a ventilator, pulse oximeter, a feeding pump and oxygen tanks. Whereas medical experts know how these machines sustain your life physically, many lack the experience of troubleshooting a ventilator malfunction while riding public transportation. This is a form of mastery gained exclusively from hands-on experience - an experience few health care professionals have had.” Mother to a son with complex medical needs.

Life is lived and care is enacted in between visits to formal health care providers. The innovation labs of a new, caring society are at home, where there are no “discharge” plans and no role-specific codes of conduct. These “privatized” but vital spaces of care necessitate more ongoing integration of caregivers’ experiences at home with people and services in the community to enhance the likelihood of innovation.

For example, Drew Ann Long is the mother of a child with disabilities and it was her frustrating experience of food shopping that led her to invent “Caroline’s Cart”, an adapted grocery cart for seniors and children with mobility impairments. When architect and innovator Barbara Alink tried to broach the subject of a walker for her aging mother, Alink’s Mom proclaimed, “Over my dead body, I’ll use one of those. They’re for old people!” So Barbara invented “The Alinker”, a neon yellow walking bike for people who eschew the traditional metallic frame. Today, the Alinker is the mobility device of choice for actress Selma Blair who suffers from Multiple Sclerosis.

Caregivers are leveraging new notions of community.

Caregivers’ identities are politicized - always. Caregiving can be viewed as a threat by those who know us best such as family, friends and work colleagues because care experiences challenge so many westernized assumptions about the (un)certainly and (un)predictability of life, our (in)capacity to control situations and outcomes that we didn’t anticipate and don’t want, and the value of (inter)dependence. By necessity, caregivers are creating new and dynamic connections beyond family, friends, and work colleagues for support.

Caregivers are much more likely than non-caregivers to go online for health-related pursuits, such as reading about others’ health experiences, finding others who might have similar health challenges, and posting questions and sharing health information and support. On Facebook, the greatest increase in users from 2011 to 2018 has been amongst those between the ages of 50 and 64; the second greatest increase was among users 65 years and older.

This increase in social media usage reflects a desire and need for the deepening of connections. This “caregiver effect” is a type of innovation because reaching toward others is more about connection and support than followership, subscribers, and likes. It’s about attempting to connect more deeply and authentically with audiences - online and face-to-face - who have similar care-based experiences for the purpose of information sharing, advocacy, and reciprocal personal and community support.

“When my dad started dialysis I had a safe and trusted place to get the information I needed. I could rely on others’ experience and get immediate support, even at 3 a.m.” —Lori J., a member of The Caregiver Space Facebook Group.

Caregivers understand the importance of thinking and acting collectively so they can leverage in-person support of family and friends more effectively. In 2009, Dr. Kathy Marshack created a Meetup group called “Asperger Syndrome: Partners and Family of Adults with ASD” in her native city of Portland, Oregon. Today, Meetups are in almost every US city. They exist to support most major disease or disability-family communities as well as to bring together individuals who share interests or hobbies in ways that may not be possible in face-to-face interactions.

The founder and CEO of Atlas of Caregiving, Rajiv Mehta, is helping caregivers to reimagine the world one care map at a time. Atlas CareMaps require no artistic talent. CareMaps consist of simple figures that represent a person’s web of relationships, showing who cares for whom and how. For many, this leads to improved care, decreased anxiety, and more confidence in managing their care. And when talking with others about their care map, the interconnectedness of community is revealed and made clear in ways not possible when community is divorced from those who are leveraging meaningful ways of creating connection for personal and communal well being.

Caregivers are instrumental in transforming health care systems because of their role as boundary spanners between “private” and “public” systems of care.

Our rapidly evolving health care needs and challenges must be based on emerging understandings of how formal and informal ecosystems of care interact.

Caregivers are drawing on their vast and deep health care experiences to advise on patient safety and health improvement by sitting on hospital advisory boards, patient engagement committees, and in community wellness non-profit entities. Nearly every hospital today hosts a Patient and Family Advisory Committee, or PFAC.

Family caregivers are now sought out as partners in health research. Their experience of navigating health systems from home to hospital and back again makes them invaluable partners in everything from identifying research questions to communicating scientific breakthroughs to patient and family communities.

For example, the Peninsula Childhood Disability Research Unit or PenCRU is a childhood disability research center in Devon, UK. PENCRU is world renowned as a center that seeks out authentic partnerships with family caregivers. The center’s home page features a clickable link titled “Submit Your Research Question” and interested parents are invited to join a “Family Faculty” with members like Ian, the father of a young man with severe autism. Ian joined the family faculty in 2012 and in 2013, submitted his first research question related to testing strategies to treat the dental health needs of young people with developmental disabilities and behavior challenges.

The Caring Collaborative is a new and growing movement of women supporting women when medical needs arise. The model has three core elements: an information exchange using What’s App in which members share information about medical conditions and medical providers; a service corps of women who volunteer to provide hands-on assistance to other members; and small neighborhood groups that meet monthly to talk about health topics and personal concerns.

This more expansive and inclusive approach to well-being can transform caregivers from feeling like they are being acted on - waiting for doctors, appointments, bureaucracies and insurance decisions - to agents of change. In this shift, caregivers are more likely to see themselves and their situations as worthy motivations for engaging others now. Caregivers can positively disrupt ways of thinking that rely too narrowly on the outsourcing of care beyond our “assets” and networks of competency, social expertise, and care. Reciprocity is at the heart of how caring transforms community.

Caregivers don’t have the luxury of choosing only to communicate online or face-to-face; they must create ongoing opportunities to engage others for support, information and reciprocity across platforms depending on their needs. Care for ourselves and one another can’t ever be fully outsourced because it is an individual and collective process shaped by access to knowledge and experts, as much as it is determined by access to the knowledge and care of the everyday experts of our daily lives.

Community and care are inexorably linked. Care can never fully be rendered only by expert providers in formal settings, but by a growing recognition that care is a democratic act that is about what we “give”, what we “receive,” and what we can “create” together.

Donna Thomson and Dr. Zachary White are co-authors of “The Unexpected Journey of

Caring: The Transformation from Loved One to Caregiver.”