



We are not visitors: Working together with family caregivers and care partners

A guide for providers, care partners, policy makers, and researchers

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**T H E B E R Y L
I N S T I T U T E**

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About The Beryl Institute

The Beryl Institute is a global community of healthcare professionals and experience champions committed to transforming the human experience in healthcare. As a pioneer and leader of the experience movement and patient experience profession for more than a decade, the Institute offers unparalleled access to unbiased research and proven practices, networking and professional development opportunities and a safe, neutral space to exchange ideas and learn from others.

We define the patient experience as the sum of all interactions, shaped by an organization's culture, that influence patient perceptions across the continuum of care. We believe human experience is grounded in the experiences of patients & families, members of the healthcare workforce and the communities they serve.

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Table of Contents

Chapter 1 Introduction to the Care Partner Guide	8
Chapter 2 The Critical Role of the Care Partner	10
Chapter 3 Caregiving During COVID-19	14
Chapter 4 The Role of the Care Partner in The New Existence	16
Chapter 5 Successful Care Partner-Focused Programs	22
Chapter 6 Care Partners as Advocates	30
Chapter 7 The Role of Healthcare Leaders in Supporting Care Partner Initiatives	40
Conclusion	41

Preface

Throughout the guide, you will see several terms used to refer to the family member, neighbor or friend who supports others struggling with chronic illness, frailty or disability. The terms caregiver, family caregiver, carer, unpaid carer, care taker, informal caregiver and care partner are used geographically, depending on where you are located around the globe, and often used interchangeably.

The word “family” is traditionally used in healthcare to describe anyone the patient identifies as family, has access to medical information and provides care for the patient in some way throughout their healthcare journey. We recognize that not all who care for patients in this way are actual family members, and we have seen a recent trend to replace “family caregiver” with “care partner” in some Western countries. While this is more inclusive language, it can easily be confused with professionals who provide care, often described using the same terminology.

We acknowledge that even as we compiled this guide, we struggled to get the phrasing correct! Since there is no perfect language that is used consistently, we have chosen to primarily use the phrases “family caregiver” and “care partner” throughout this guide, but that is not meant to disregard the support provided by those who are not, technically speaking, family.

About Us

The Family Experience Workgroup, comprised of international members of The Beryl Institute's Global Patient and Family Advisory Board (GPFAB), consists of family caregivers from around the world. We have diverse caregiving experiences which have contributed to our knowledge and expertise on a wide range of healthcare, health policy, advocacy and research topics. We serve as leaders and change-makers on caregiving issues in our respective countries.



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- 34 year care partner
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Understanding the Lived Experience of a Care Partner

Their unborn baby was only 23 weeks old. Photos from the ultrasound showed a beautiful, lively boy growing in his mother's womb. But the doctors kept saying the ultrasound images were inconclusive and more tests were needed. These first-time parents later learned there was a problem with their baby's brain. And while his eventual birth was considered a miracle, the lives of mom and dad would forever be changed. Mom would not be attending soccer games on weekends and dad wouldn't lead the Boy Scouts. These parents would become immersed in a world filled with hospital stays and insurance paperwork, and there were few people available to help them navigate their way through it.

A single mom knew her role as a parent of two. She knew early in life that she wanted to be a teacher, and she educated students in elementary schools for more than 30 years. Early in her career, her father died of a heart attack, but she was forced to retire prematurely after her once fiercely independent mother could no longer drive and needed someone to transport her to numerous doctor appointments, pick up prescriptions and help her with grocery shopping and laundry.

These two stories represent everyday people navigating the role of family caregiver or "care partner." They share a common thread: confronting life-changing responsibilities, often on behalf of close family members, involving tremendous personal sacrifice.

Chapter 1

Introduction to the Care Partner Guide

There are an estimated 53 million family caregivers in the United States alone. Sixty-one percent are women. Sixty-one percent work. Almost a quarter of them are caring for more than one person.¹ In 2017, they contributed an estimated 34 billion hours of unpaid care worth \$470 billion.² In Canada, nearly one in four Canadians aged 15 and older (25% or 7.8 million people) provided care to a family member or a friend with a long-term, physical or mental disability or problem related to aging.³

Family caregivers are critical to positive and successful patient outcomes, and their “caregiver experience” is distinct from the patient experience. The caregiver, as the expert on the patient, is a key partner on the Care Team and plays a critical role in co-designing care for the patient. Caregivers frequently identify gaps in care and services that prevent patients from achieving their goals and function as important voices in decision-making. The caregiver works quietly behind the scenes to assist the patient in navigating the healthcare and social services systems, often administering medication and providing complex care, along with sorting out insurance issues, providing transportation to medical appointments, care coordination and more.⁴

The Family Experience Workgroup has developed a framework that defines the unique components of the caregiver experience. Informed by their own personal experiences, this group has created a vision for the role of family caregiver in **The New Existence** (an initiative of The Beryl Institute). This vision correlates with the *Care Teams* component of The New Existence.

Mission Statement

The mission of the Family Experience Workgroup is to represent the voice of the family caregiver in healthcare. This is achieved by infusing the unique aspects of the family experience into ongoing initiatives of the Institute and GPFAC workgroups. This collaboration will serve as a forum for healthcare professionals to learn how the family experience differs from and influences the patient experience.

Goals of the Care Partner Guide

The goals of the Care Partner Guide are to create consistent global messaging with standard definitions and an understanding of the many roles of the caregiver/care partner. We want to empower caregivers by instilling confidence in millions of family caregivers around the globe and amplify their critical voices as we move into The New Existence. We hope this guide will educate providers across the healthcare continuum, so they have a shared understanding of the caregiver experience, how it differs from the patient experience and the importance of the family caregiver to patient outcomes. Finally, this guide is intended to provide a set of actionable tools for family caregivers to illustrate how they can directly participate in healthcare transformation.

Who is this guide for?

This guide is designed primarily for the caregiver and healthcare provider to use not only as a reference but also as an implementation manual. It is a set of actionable and interactive tools for both. Empowering families on the care team will improve communication, providing a better understanding of the patient's health situation. Providers will benefit from understanding how partnerships with caregivers can improve healthcare delivery, accuracy, safety and outcomes while increasing patient and family satisfaction.

The guide describes the critical role and expertise of the caregiver and how the caregiver, as a trusted partner of the care team, can help co-design care for the patient and use their voice to help transform healthcare. It will illustrate the seven key components of the caregiver experience and their importance in realizing The New Existence in healthcare.

Other stakeholders who can benefit from this guide are:

Healthcare Leaders who want to lead the way by establishing a culture that embraces family caregivers as partners. We have a special checklist for you in Chapter 7.

Boards and Advisory Councils that use patient-centered care and engagement principles to improve business models, quality of care and patient outcomes.

Policy Makers working to create equitable and efficient policies across the care continuum to ensure high-quality, affordable, equitable care.

Researchers who partner with patients and caregivers to identify research questions, develop patient-centered research design and improve the accessibility of research.

Academia and Institutions preparing the new generation of providers with the appropriate tools to ensure true partnerships with the caregiver and patient in a co-design role and understand the benefits to patient outcomes.

Before we go any further, we need to discuss the importance of the care partner and their diverse roles in providing support for those they care for.

Chapter 2

The Critical Role of the Care Partner

"My biggest challenge in interfacing with the healthcare system on behalf of my mom, dad and sister, Karen, was the lack of integration and communication among their practitioners. It was entirely up to me to share any updates, medication changes or treatments with each doctor. Some didn't even seem interested. It was so frustrating and added so much stress to my caregiving journey. I'm happy to advocate for my loved ones, but it would be so much easier to do if the healthcare system would cooperate and collaborate!"

— Amy Goyer, United States

A new paradigm has emerged where patients are considered "partners" of the healthcare system when it comes to their health and healthcare, particularly around shared decision-making. However, the same cannot be said for care partners who must frequently shoulder the burden of implementing care plans in which their role has not been accounted for or make decisions without having been included in critical conversations.

The family caregiver is often the unrecognized member of the patient's care team responsible for managing care but not viewed as an important partner in the process. They struggle to obtain information, coordinate care and services and medically support their loved ones. These behind-the-scenes warriors can be the difference between positive patient outcomes and return trips to the hospital, but they lack the recognition they deserve. Caregivers make ideal partners for the healthcare system because of their dedication and perseverance on behalf of those they care for, in addition to their expertise in a wide variety of issues related to the health conditions they deal with every day.

Caregivers are often responsible for the patient's care at home and in the community. The delivery of care to the patient can be complex, requiring caregivers to coordinate care across multiple healthcare providers as well as supportive services in the community. Caregivers often do not have the tools they need to manage these tasks or navigate complex healthcare systems. To bridge the knowledge gap, caregivers have traditionally relied on "tribal knowledge" or they seek information from sources that are less than reliable, which can put the health of the patient at greater risk. Ultimately, the caregiver's skill level and ability to coordinate with healthcare professionals can remove barriers for the patient and prevent gaps in care.

One of the greatest challenges experienced by caregivers is access to correct and complete information. The day-to-day role of the caregiver can be complex as they

“As a young caregiver, I was “invisible” for years. Every major decision I made... where I lived, my career, my financial well-being... were all impacted by my caregiving responsibilities. Eventually, my own health suffered because of the stress. Nobody knew.”

— **MaryAnne Sterling**, United States

deliver care to the patient and manage the administrative aspects of care, so timely access to information is critical. It is often delayed by antiquated paper-based processes (or technology divides), miscommunication and privacy barriers.

This is also true of care planning. Within healthcare settings, treatment plans have routinely been discussed outside patient rooms without consulting caregivers, thus reducing the probability they will be successful. In addition, caregivers may not be aware of evidence-based practices for achieving the best health outcomes for the patient. They may not know how to manage specific care processes safely or how to meet the patient's needs, from medication and medical supplies to specialized equipment. The care team must recognize these challenges and create processes to help caregivers access, interpret and understand the information they need to provide appropriate care, partner with caregivers on care planning and assure that caregivers understand discharge instructions and next steps in care.

Caregivers develop invaluable experience unique to their role in caring for those with complex conditions that can help inform programs, processes and policies. They assimilate vast amounts of knowledge across the healthcare domain in order to support their loved ones. Caregivers become experts in a variety of topics, including navigation of healthcare and social services, medication administration, diseases and conditions, care management and policies and procedures. This knowledge is critical, though seldom used, to the process of creating, revising and reviewing current practices and future initiatives to ensure they are aligned with the needs of this critical and often hidden workforce. However, providers, researchers and policy makers are not required to include family caregivers in design of new initiatives, studies or regulation. This often results in programs, processes and policies that are not aligned with the needs of family caregivers as they fulfill the role of supporting patients.

Caregivers often sacrifice their health, careers, financial security and social connectivity to care for vulnerable family members, neighbors and friends. These sacrifices often go unnoticed, as the healthcare system assumes the caregiver can manage complex, and often lengthy, caregiving situations with little or no support. The caregiver is then at risk of becoming the patient, potentially leaving the original patient without reliable care.

When clinicians focus narrowly on the medical needs of the patient, the well-being of the caregiver is frequently overlooked. Clinicians who first encounter a family caregiver when the patient is experiencing a health crisis can fail to see the challenges, workload and trauma experienced by these care partners. Caregivers often provide complex care

"Taking care of my late dad who was diabetic for over 25 years helped me understand the need for empathy as a caregiver. In his last stages of life, Dad got worn out with the unending treatments, the long trips just to find a doctor who was able to manage his condition and his deteriorating health. At this point, I knew I had to put myself in his position to try and understand how he felt. Dad breathed his last breath in my hands because, in me, he had found someone who shared his pain."

— **Janepher Wabulyu**, Uganda

with little or no training, function as the healthcare and social services navigator on behalf of those they care for, provide transportation, prepare meals and administer medication, all while managing their own work and family obligations. Patient outcomes rely on the effectiveness, skill and resilience of caregivers who often neglect their own physical and mental health. A broader focus on the well-being of caregivers can both improve patient outcomes, help drive down health care costs and prevent readmissions.

Caregivers play a key role in patient recovery, wellness, and end-of-life care. However, their role is often "informal and unplanned" rather than "formal and deliberate," which can translate into being ill-prepared for the challenges they will face. Caregivers may take a passive role at the patient's bedside in a healthcare facility, simply because nobody has taken the initiative to ask them if they are the patient's care partner and initiate their engagement. This is especially true of adult children who are supporting their aging parents, whose caregiving experiences often lie in stark contrast to the parents of pediatric patients who are engaged by providers in every aspect of their child's care and embraced by the healthcare system as partners.

In reality, most caregivers don't identify with the role of "caregiver," instead thinking of themselves as spouses, daughters, sons, parents, siblings or friends. First-time caregivers may feel overwhelmed by the patient's situation, with no awareness of the challenges that may lie ahead and no idea what to do or where to find support. Complicating the situation, the healthcare system can be intimidating, and caregivers may not feel comfortable speaking up or asking questions, therefore, not getting the support they need.

Equity is a key concern across all aspects of caregiver engagement. The healthcare system has historically delivered inequitable outcomes, especially for vulnerable populations most in need of reliable and consistent care. To ensure equitable support for patients, effective involvement of family caregivers is critical for all patient populations. Equitable engagement of caregivers implies that all caregivers have the same opportunities to be co-creators of a healthcare system that activates, supports, informs, trains and cares for caregivers as partners.

Important Studies of Family Caregivers

Researchers have begun to study the impact of caregiving on care partners, families and society. This complex issue is finally getting the recognition it deserves, as many countries struggle to quantify caregivers and understand the challenges they face. A list of relevant studies can be found below.

United States

From Momentum to Movement: Developing a Unified Strategy to Support Family Caregivers Across the Nation, <https://www.caregiving.org/unified-caregiving-strategy/>

Caregiving in the US 2020, <https://www.caregiving.org/caregiving-in-the-us-2020/>

Caregivers in Crisis: Caregiving in the Time of COVID-19, <https://www.rosalynncarter.org/wp-content/uploads/2020/10/Caregivers-in-Crisis-Report-October-2020-10-22-20.pdf>

Recalibrating for Caregivers: Recognizing the Public Health Challenge, https://www.rosalynncarter.org/wp-content/uploads/2020/10/RCI_Recalibrating-for-Caregivers_2020.pdf

Home Alone Revisited: Family Caregivers Provided Complex Care, <https://www.aarp.org/content/dam/aarp/ppi/2019/04/home-alone-revisited-family-caregivers-providing-complex-care.pdf>

Families Caring for an Aging America, <https://www.nap.edu/catalog/23606/families-caring-for-an-aging-america>

United Kingdom

Carer Facts – why investing in carers matters, <https://www.england.nhs.uk/commissioning/comm-carers/carers-facts/>

Carers UK Policy Library, <https://www.carersuk.org/for-professionals/policy/policy-library>

Carers' lives & caring issues: knowledge & research evidence, <https://www.scie.org.uk/carers/knowledge-review>

The critical role of the care partner has been front-and-center during the COVID-19 pandemic, bringing new urgency to rethinking how care partners are embraced across the care continuum.

Chapter 3

Caregiving During COVID-19

COVID-19 changed the landscape of caregiving, making it more complex and further isolating care partners, often from the very people for whom they provide care. During the COVID-19 pandemic, visitors were banned from healthcare facilities around the globe to address fears of viral spread. This ban included family caregivers. Tragically, these decisions had unintended consequences, even though they were made with the best of intentions.

The hallmark of this slow-moving disaster was the inability of caregivers to be at the bedside of nursing home residents as the virus swept through countries around the globe. Heart-wrenching images of seniors looking sadly at their family members through facility windows were seared into our collective memories. Caregivers had no visibility into the quality of care their family members were receiving, even those whose care we oversaw and monitored on a daily basis pre-COVID. These often-frail family members did not understand what was going on and why we were absent, creating additional stress for both patient and caregiver. If they contracted COVID, we had no idea if we would ever see them again, creating agonizing situations for care partners world-wide, complicated by poor communication and a relentless public health crisis.

However, caregiving challenges were not limited to this type of example or even to elder care. Caregiving in the community was equally fraught across all caregiving situations because we typically care for those who are most vulnerable to the virus – people who live with chronic conditions or disabilities. The pandemic was especially tough for caregivers of those with cognitive challenges like Alzheimer's disease or autism.

"I took my 85-year-old mother, who was in a great deal of pain, into the Emergency Department. I was kept out because of COVID-19 restrictions, regardless of the fact she was not capable of accurately providing necessary information. She was then released to me hours later saying she was just fine, despite my insistence that their assessment was completely inaccurate. I brought her right back the next day, told them to start again (with my assistance). She was finally diagnosed with end stage cancer and died 3 weeks later. The first admission was a complete waste of my mother's time, as well as the provider's. I had all the answers, and a partnership would have gotten to the answers a lot quicker."

— Sydney Graham, Canada

Maintaining daily routines that generally provide some semblance of balance and well-being was difficult, if not impossible. Access to home health services, adult daycare, preventive care visits and other critical services on which we rely practically disappeared in most communities. Many medications used to treat chronic conditions were in short supply.

Caregivers who provide care at home were often essential workers who had to leave their homes to work and acquire food and medication. This created a scenario where caregivers were repeatedly putting themselves at risk for contracting the air-borne virus and bringing it home, which in turn put the people they were caring for at risk.⁵

In the wake of this crisis, many advocates, including The Beryl Institute's Family Experience Workgroup, are pushing to have caregivers designated as "essential care partners" at healthcare facilities, not "visitors" but key members of the care team who play a critical role in patient outcomes. The caregiver is providing their lived experience and expertise, complementing that of the healthcare provider. They should be provided with personal protective equipment (PPE) whenever possible, as would any other care team member to ensure their role continues uninterrupted.

The Workgroup also used the COVID-19 crisis to inform the seven components of the Family Caregiver Experience, to be used as guideposts for care partners, healthcare leaders and practitioners to create an environment that is inclusive of caregivers and honors their unique role in healthcare.

Chapter 4

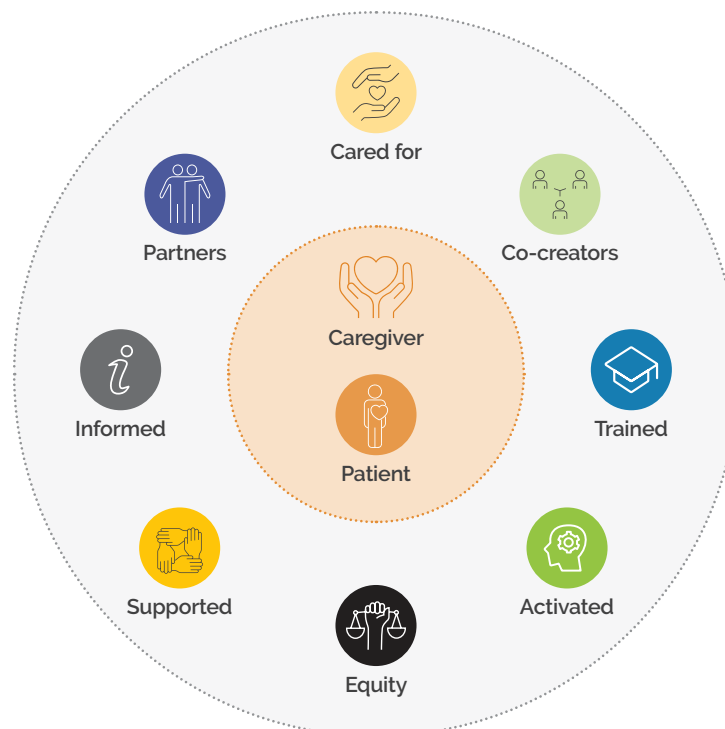
The Role of the Care Partner in The New Existence

“The sum of all interactions, shaped by an organization’s culture, that influence patient perceptions across the continuum of care.”

— The Beryl Institute’s definition of patient experience

Systemic change is happening across the healthcare ecosystem. We are moving from a system-and-provider-centric paradigm to one that focuses on the experiences and outcomes of patients. Family caregivers, as experts on the person they care for, play an integral role in this transformation in addition to their role on the care team in co-designing the planning and delivery of healthcare. To address the unique challenges faced by care partners, the Family Experience Workgroup developed a framework of core components that describe the Family Caregiver Experience envisioned in The New Existence:

Family Caregiver Experience



The Core Components of the Family Caregiver Experience are defined as follows:



Equity (cross-cutting): All components of the Family Caregiver Experience should be viewed through an equity lens with concrete goals to eliminate disparities.



Partners: Caregiver is considered a healthcare system partner and essential member of the patient's care team.



Informed: Caregiver has access to the information they need to plan and make decisions.



Supported: Caregiver has support coordinating healthcare, services and community supports.



Trained: Caregiver is coached on healthcare system navigation and how to provide for the needs of the person they care for.



Co-creators: Caregiver is an equal partner in the transformation of healthcare.



Cared For: Caregiver well-being is an important focus of the healthcare system.



Activated: Caregiver has a defined role and is pro-actively engaged by the healthcare system.

The core components of the framework are closely aligned with the foundational agreements of The New Existence:

- This work is born from our common experience in this moment.
- We are all humans in healthcare and must recognize and act together on what impacts us.
- We insist on equity in healthcare.
- We commit to working better together, through and beyond this moment.
- We will come out of this crisis as better human beings, organizations and systems.

The New Existence focuses on care teams, governance and leadership, models of care and operations, and policy and systemic issues, all of which can benefit from the participation and input of care partners.

The components of the Family Caregiver Experience framework provide a roadmap for healthcare stakeholders to follow as they embrace The New Existence. Each is discussed in detail, with recommendations from the Family Experience Workgroup, below.



Equity: Policies, practices and processes that affect patients and caregivers must be evaluated for equity so that disparities can be identified and eliminated. If engagement of caregivers is not equitable across populations and considerate of cultural, socioeconomic and linguistic differences (among others), outcomes and care are likely to be inequitable as well.

"Being a care partner means that I take an active role in the treatment of my child. When my daughter was first diagnosed, I was the typical scared parent who deferred to all medical professionals and hospital staff, regardless of what we were discussing. As her cancer kept coming back, I became more and more of an advocate for my daughter and would express her or our wishes at times, which I didn't do in the beginning. It could be simple things, such as rearranging the furniture in the room to how she liked it or pointing out that since her cancer had a tumor marker in her blood, some scans are unnecessary and should be avoided (yes, her doctors agreed with us when we pointed this out). Just the fact that a nurse cannot be in the room 24/7 with a child necessitates that we parents be care partners. Cancer treatment is scary, and these children suffer through it. We parents are the comforters and the soothers and the ones who know the moment something is not right and can call/run out for help."

— **Stef Katz**, PFA and Institute Community Member, United States



Partners: Family caregivers should be viewed as critical partners in patient care and embraced as key members of the care team, working alongside healthcare professionals who value their contributions.

A “caregiver” designation should be assigned to persons who accompany a patient, regardless of the patient’s age, diagnosis or their ability to function effectively on their own. The caregiver understands the wishes of the patient, social determinants of health and other roadblocks to effective care and will partner with the care team to ensure appropriate treatment plans that account for these important data points are put into place. In situations where mental capacity is involved, the caregiver’s knowledge and judgement should be considered equally when care decisions are being made.



Informed: The caregiver and care team are proactive and collaborative in exchanging information about caring for the patient, sharing tools, documents and processes to organize and easily access that information, allowing the team to better coordinate care and treatment plans. Data is the currency of healthcare and is often not accessible to family caregivers who struggle

to navigate the healthcare system and make critical decisions without it. Technology is another essential part of this process and should be embraced in ways that are comfortable for the caregiver; however, don't assume that the caregiver has access to technology and is comfortable using it! Ensure that technology-proficient staff (or organizational partners) can help determine the technology literacy of the caregiver and acclimate them to new tech tools.



Supported: Caregivers need support in their efforts to participate in care. This includes information, tools and programs that help the caregiver coordinate healthcare, services and community support on behalf of those they care for, often the most challenging part of their caregiving responsibilities. Ideally, healthcare providers have access to care coordinators and navigators who

can work with the caregiver to understand their caregiving situation and the needs of the patient, thus providing thoughtful, tailored recommendations. Care coordinators and navigators can also play a major role in communicating with the people and organizations they have recommended, ensuring there is no delay in getting care and services to the patient and caregiver. They are skilled at the “language” of healthcare, which helps to bridge the communication gap often experienced by caregivers.



Trained: Today, millions of caregivers provide care that would be considered medical and complex, provided solely by nurses in the past. Eighty percent of adults requiring long-term care currently live at home in the community, and unpaid family caregivers provide 90% of their care. Family caregivers serve as a critical extension of the healthcare system.⁶

Caregiver training should be part of the discharge and planning process for every patient, with at least one caregiver oriented to the patient's discharge and care instructions, ensuring they understand the patient's condition, medications and next steps in care. This is legislatively mandated in most states in the US, thanks to the CARE Act. Hands-on training should be used whenever possible, with consideration given to the time, travel and resources caregivers need to facilitate their learning. Simulation centers can be used to train caregivers of patients needing complex care, which allows caregivers to

practice and build skills in a teaching environment and receive feedback from healthcare professionals. These skills also contribute to lower re-admissions rates.⁷



Co-creators: Family caregivers should be consistently engaged by providers, researchers and policy makers to co-create programs, processes and policies that inform the future of healthcare to ensure these efforts are aligned with the needs of both family caregivers and those they care for, thus improving health outcomes.

Providers:

- Create a Patient and Family Advisory Council that includes family caregivers. Click here to learn more: <https://edhub.ama-assn.org/steps-forward/module/2702594>
- Embrace family caregivers as co-creators of care/treatment plans. Caregivers are generally the ones who must implement the care/treatment plan thus need to assist in creating an approach that accommodates their abilities, work schedule, health and financial limitations.
- Embed family caregivers in academic training, education programs, and Grand Rounds to benefit from their perspective and lived experience. This will ensure buy-in of new care strategies by patients and providers.

Researchers:

- Ensure that family caregivers are included in all aspects of research studies, from formulation of the research question to dissemination of research results. Find out more here: <https://www.pcori.org/engagement/engagement-resources>
- Partner with family caregiver advocates on social media to “get the word out” about studies for which you are recruiting participants.

Policy Makers:

- Ensure that family caregivers are involved in the creation and implementation of health policy.
- Reach out regularly to family caregivers in the communities you serve to keep a finger on the pulse of issues and challenges that can be addressed with policy.



Cared For: The health and well-being of the caregiver should be prioritized and connected to the health and well-being of the patient. The caregiver should be screened to ensure they are physically and emotionally well, able to provide the support the patient needs, and connected to resources that will help them reduce the impact of stress and manage their own health needs. Identifying family caregivers and ensuring their well-being is key to ensuring positive patient outcomes, particularly in situations that require long-duration, high-intensity caregiving.



Activated: Healthcare professionals should proactively engage caregivers, work to understand their roles and limitations and determine the type of support caregivers will need to successfully navigate the healthcare system and provide care, making them key members of the care team in a “formal and deliberate” manner. Engaging caregivers early in the process (not waiting until the patient is discharged) and acclimating them to the needs of the person they will be supporting will help to ensure a smooth transition to the next care setting. More information can be found here: <https://nwh.northwell.edu/your-visit/ken-hamilton-caregivers-center>

The components of the family caregiver experience ensure that caregivers are included and empowered to contribute to the best outcomes for patients. Next, we explore where care partners can get support.

Chapter 5

Successful Care Partner-Focused Programs

A care partner-focused program is one in which the caregiver is the primary focus or joins the patient as a dual focus of the program, where the caregiver's needs and limitations are equally important to those of the patient. The desired outcome of this type of program is a caregiver who is better prepared to support the people they care for and manage their own health and well-being.

Globally, caregiver support programs range from simple and inexpensive to complex and costly. A successful program is often game-changing for caregivers, though it may involve low-tech, practical solutions. Many organizations that offer these programs are non-profit entities that offer on-line informational resources; some offer in-person services for caregivers, and others are government entities or for-profit businesses. This section is devoted to examples of existing programs and the organizations that offer them.

Care Partner-Focused Programs and Descriptions

The following are examples of care partner-focused programs, organizations, and initiatives around the globe. Each has a unique mission, but all are dedicated to better supporting caregivers.

United States

Alzheimer's Los Angeles: *Savvy Caregiver Program*

Description: The Savvy Caregiver and Savvy Caregiver Express are programs specially designed to benefit people caring for a family member or friend living with dementia by providing more understanding and tools to help navigate the journey.

Link: <https://www.alzheimersla.org/alzheimers-los-angeles-services/classes-and-workshops/savvycaregiver/>

American Association of Caregiving Youth

Description: We champion youth who care for chronically ill, injured, elderly, or disabled family members, support their role as caregivers, safeguard, and celebrate their success in school and life.

Link: <https://aacy.org/>

Caregiver Action Network: *Caregiver Help Desk*

Description: Caregiver Action Network (CAN) is the nation's leading family caregiver organization working to improve the quality of life for the more than 90 million Americans who care for loved ones with chronic conditions, disabilities, disease or the frailties of old age. CAN serves a broad spectrum of family caregivers ranging from the parents of children with significant health needs, to the families and friends of wounded soldiers; from a young couple dealing with a diagnosis of MS, to adult children caring for parents with Alzheimer's disease. CAN is a non-profit organization providing education, peer support, and resources to family caregivers across the country free of charge.

Link: <https://caregiveraction.org/>

Courageous Parents Network

Description: Courageous Parents Network is a non-profit organization and educational platform that orients, empowers, and accompanies families and providers caring for children with serious illness. Here—in videos, podcasts, printable guides, Guided Pathways, and blog—you will find wisdom from families and pediatric care providers to help you be the best parent you can be. And get through each moment.

Link: <https://courageousparentsnetwork.org/>

Elizabeth Dole Foundation

Description: The Elizabeth Dole Foundation is the preeminent organization empowering, supporting, and honoring our nation's military caregivers; the spouses, parents, family members and friends who care for America's wounded, ill or injured veterans.

Link: <https://www.elizabethdolefoundation.org/>

Family Caregiver Alliance

Description: The mission of Family Caregiver Alliance (FCA) is to improve the quality of life for family caregivers and the people who receive their care. For over 40 years, FCA has provided services to family caregivers of adults with physical and cognitive impairments, such as Parkinson's, stroke, Alzheimer's and other types of dementia. Our services include assessment, care planning, direct care skills, wellness programs, respite services, and legal/financial consultation vouchers. Ongoing support is available with FCA, also now on a digital service platform. FCA is a longtime advocate for caregivers in the areas of policy, health and social system development, research and public awareness on the state, national and international levels.

Link: <https://www.caregiver.org/>

"The most urgent need for family caregivers is respite! Affordable day programs would be such a relief."

— Sharon Hall, United States

Intermountain Healthcare, Partners in Healing Program

Description: Intermountain's Partners in Healing program provides opportunities for family members to help with basic care for their loved ones, which helps them prepare for taking over care responsibilities when the patient goes home.

Link: <https://intermountainhealthcare.org/news/2018/02/engaging-family-members-in-care-of-hospitalized-loved-ones-enhances-healing/>

Ken Hamilton Caregivers Center

Description: The Ken Hamilton Caregivers Center was set up with the goal of meeting these family caregiver needs. The Center features:

- Caregivers Support Program, offering counseling by our social worker and referrals to community resources
- Trained caregiver coaches who provide support and encouragement to caregivers
- A comfortable place to rest, reflect and refuel
- A space for private conversations
- A library of community resource referrals
- A reclining massage chair in a private area
- A desk area with computers, fax, copier, telephones and internet
- A kitchenette with healthy snacks
- Practical guidance to navigate the hospital system, access community resources and find services after leaving the hospital

Link: <https://nwh.northwell.edu/your-visit/ken-hamilton-caregivers-center>

National Alliance for Caregiving

Description: NAC conducts research, does policy analysis, develops national best-practice programs, and works to increase public awareness of family caregiving issues. We recognize that family caregivers provide important societal and financial contributions toward maintaining the well-being of those in their care. In addition to national research and advocacy, NAC provides technical assistance to a national network of caregiving coalitions representing nearly 30 states and localities in the United States and serves as Founder and Secretariat for the International Alliance of Carer Organizations (IACO).

Link: <https://www.caregiving.org/>

Patient and Family Advisory Councils (PFAC)

Description: Research shows that when patients are engaged in their health care, it can lead to measurable improvements in safety and quality. To promote stronger engagement, Agency for Healthcare Research and Quality developed the Guide to Patient and Family Engagement in Hospital Quality and Safety, a tested, evidence-based resource to help hospitals work as partners with patients and families to improve quality and safety.

Link: <https://www.ahrq.gov/patient-safety/patients-families/engagingfamilies/strategy1/index.html>

RAISE Family Caregiving Advisory Council

Description: The RAISE Family Caregivers Act, which became law on Jan. 22, 2018, directs the Secretary of Health and Human Services to develop a national family caregiving strategy. The strategy will identify actions that communities, providers, government, and others are taking and may take to recognize and support family caregivers. To support the development and execution of the strategy, the RAISE Act also directed the establishment of the Family Caregiving Advisory Council. The council is charged with providing recommendations to the Secretary of Health and Human Services on effective models of both family caregiving and support to family caregivers, as well as improving coordination across federal government programs.

Link: <https://acl.gov/programs/support-caregivers/raise-family-caregiving-advisory-council>

Ronald McDonald House

Description: Our Ronald McDonald House programs, located near top children's hospitals, allow parents who are far from home to stay close to their hospitalized child and benefit from the comforts of home without incurring hotel and food costs. Ronald McDonald Family Room programs offer a quiet respite for all families right in the hospital. And Ronald McDonald Care Mobile programs bring fundamental medical and dental care to underserved communities.

Link: <https://www.rmhc.org/>

Rosalynn Carter Institute for Caregivers

Description: The Rosalynn Carter Institute for Caregivers (RCI) promotes the health, strength and resilience of all caregivers at every stage of their journey.

Link: <https://www.rosalynncarter.org/>

Rush University Medical Center, The Caregiver Initiative

Description: Are you providing care for an adult that is 65 years or more? The Caregiver Initiative can help! We start by getting to know you and what matters to you. We also include what matters to the older adult that is in your care.

What is provided?

- Get personalized support on how to care for the older adult and also care for yourself.
- Build skills to make care easier, like nutrition and feeding, medications, mobility and communication.
- Enhance your confidence by consulting with healthcare professionals.
- Develop personalized care plans that reflect what matters most to you and the older adult.

Link: <https://aging.rush.edu/caregiverinitiative/>

Starbucks (employer): benefits for caregivers

Description: On Oct. 9, 2018, Starbucks launched new caregiver benefits for all of its 180,000 U.S. employees. Each worker is now eligible for 10 subsidized backup care days every year when arrangements with child or adult care providers fall through. The benefits package includes:

- Backup childcare. When caregivers are unavailable, employees can arrange for substitute supervision. The cost for employees is \$1 per hour for in-home care and \$5 per day for a day care center.
- Backup care for adults. Employees also have access to a network of in-home backup adult caregivers for their parents or other adult family members. Employees pay \$1 per hour.
- Senior care planning. At no cost, employees can connect with a senior care advisor for guidance and a customized plan covering long-term caregiver options, housing alternatives, finances and legal concerns.
- A premium membership to [Care.com](#). At this website, employees can access, at no cost, an online marketplace for finding and managing family care—a \$147 value.

Link: <https://stories.starbucks.com/stories/2018/new-starbucks-benefit-offers-backup-child-and-adult-care/>

VA (Veteran's Administration) Caregiver Support Program

Description: Support for caregivers of veterans both at home and in the community.

Link: <https://www.caregiver.va.gov/>

Canada

Canadian Caregiver Network

Description: Our mission is to bring caregivers together to share their experiences. That's why we created Huddol — a community dedicated to your well-being where you can exchange with our network of professionals and others like you.

Link: <https://www.thecaregivernetwork.ca/>

Caregiver Exchange

Description: Elise is part of a team at Saint Elizabeth Foundation that's developed Elizz CareChannel, a website that's home to a series of short, practical videos that teach family caregivers a whole host of hands-on care skills, from how to take care of a catheter to how to wash someone's hair in bed to how to prevent bed sores. Other videos on Elizz CareChannel explain how to look after someone with a particular condition, like diabetes or dementia. Still others explore generic caregiving skills, like taking care of your own health, talking with health professionals, and being a patient care advocate. There are about 100 videos in all. Almost all of them run under four minutes. Many videos are accompanied by a care guide that dives deeper into the topic at hand.

Link: <https://www.caregiverexchange.ca/>

Caregivers Alberta

Description: Caregivers Alberta grew from the ashes of one caregiver's burnout. A group of caregivers banded together to support each other. In 2001 they founded Alberta Caregivers Association, now Caregivers Alberta. Caregivers Alberta is an organization of caregivers, for caregivers. We focus on the caregiver as an individual- helping them maintain their well-being rather than teaching them how to be better caregivers. As Alberta's only dedicated caregiver organization, we improve the lives of Alberta's caregivers by: Providing group and one-on-one supports that help caregivers connect with others, navigate the system and look after themselves while providing care. Increasing communities' capacity to support caregivers by educating professionals, promoting networking and referrals, and sharing programs Advocating for policy changes that will make a difference in caregivers' lives.

Link: <http://www.caregiversalberta.ca/>

Caregivers Nova Scotia

Description: Caregivers Nova Scotia provides free programs, services, information, and advocacy for family and friend caregivers. We are dedicated to providing recognition and practical assistance to friends and family giving care. We

participate in government task forces and working groups to influence public policy for the benefit of caregivers. An important part of supporting caregivers is to listen to what they are saying about their experiences and bring it into the public eye. Caregivers Nova Scotia strives to take the collective voice of caregivers and amplify it. The first step toward better support is being heard.

Link: <https://www.caregiversns.org/>

Carers Canada

Description: Our vision is "a Canada that recognizes, respects, and values the integral role of carers in society". Our mission is to enhance the quality of life for carers through synergistic partnerships and strategic advocacy. Through the leadership of the CHCA, Carers Canada advocates for:

- Enhanced awareness of caregivers' role, value in the health and social care systems
- Recognition of caregivers and understanding of their unique needs
- Improved access to caregiver support services, information, and peer groups
- Less financial burden placed on caregivers
- Supportive workplaces that recognize caregiving obligations

Link: <https://www.carerscanada.ca/>

Family Caregivers of British Columbia

Description: Family Caregivers of BC (FCBC) is a provincial, not-for-profit that proudly and compassionately supports over 1 million people in British Columbia that provide physical and/or emotional care to a family member, friend, or neighbour. FCBC supports caregivers by providing access to information, education and supports that enable caregivers to feel more confident and successful in their important role.

Link: <https://www.familycaregiversbc.ca/>

Ontario Caregiver Coalition

Description: Ontario needs to be a leader in recognizing the value of and supporting family caregivers - the hidden backbone of our healthcare system. The Ontario Caregiver Coalition has called on the Ontario Government to support family caregivers through self-directed respite options and caregiver education programs. But of equal importance is addressing caregiver financial distress and help to navigate the complicated health and community care system. Caregivers are also in need of income support and therefore, we recommend a caregiver allowance and a paid caregiver leave be established. We also recommend that home care client care plans include caregiver needs.

Link: <https://www.ontariocaregivercoalition.ca/>

Ontario Caregiver Organization

Description: If you support someone in need and feel anxious and overwhelmed with your caregiving responsibilities, you're not alone. The Ontario Caregiver Organization (OCO) exists to support Ontario's 3.3 million caregivers; ordinary people who provide physical and emotional support to a family member, partner, friend or neighbour. We support caregivers by being their one point of access to information, so they have what they need to be successful in their role.

Link: <https://ontariocaregiver.ca/>

United Kingdom

Carers Trust

Description: Carers Trust is a major charity for, with and about carers. We work to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems. Our vision is that unpaid carers count and can access the help they need to live their lives.

Link: <https://carers.org>

Carers UK

Description: Carers UK is here to listen, to give you expert information and advice that's tailored to your situation, to champion your rights and support you in finding new ways to manage at home, at work, or wherever you are.

Link: www.carersuk.org

With the arrival of The New Existence, caregivers are instrumental in shaping the future of healthcare, using lived experience to inform the transformation of health policy, healthcare delivery and medical research. Many opportunities exist to engage caregivers in meaningful ways, and many organizations are exemplifying this type of engagement.

Chapter 6

Care Partners as Advocates

“One person caring about another represents life's greatest value,”

— American entrepreneur Jim Rohn

Advocacy is a complex role that caregivers often “fall into” by virtue of circumstances, sometimes without warning. It can take many forms and is commonly mistaken for being solely political in nature. In fact, caregiver voices are critical in advocating for those they care for, advocating for themselves, and advocating for the transformation of our fragmented healthcare system to a person-centric healthcare ecosystem. This section explores how caregiving translates into advocacy and how caregivers can use the skills they have acquired during their caregiving journey to successfully advocate for change.

Caregivers as Advocates for Themselves

The realization that a new existence is required in the healthcare ecosystem could bring policies, practices and processes that benefit caregivers. But before caregivers can be effective, it's vital they know how to advocate for themselves. It can be difficult at times to even know for what they should be advocating. Caregivers often sacrifice their health, careers, financial security and social lives to care for friends or loved ones. By asking why it's important and what they hope will be the result can provide clarity. The answers should lead to valuable resources to help them know how to advocate for themselves throughout the patient's journey.

An informed caregiver can be key to a positive patient outcome and the ability to avoid a return trip to the hospital. Most nurses deal with multiple patients during a shift, so when a caregiver can be at bedside, it becomes a safer environment. Someone familiar with the patient can also tell clinicians when the patient is not acting in a typical way or at their baseline. Communication with members of the patient's care team is vital. They should share concerns, observations and ask questions when something does not make sense. If they do not get the help needed, remember that it's OK to escalate the matter.

Caregivers can feel emboldened as more hospitals and other health facilities focus on patient- and family-centered care. Their experience in caring for loved ones with complex conditions is invaluable. Many learn the intricacies of navigating healthcare and social services, medication administration, care management and policies and procedures. These skills from inside a patient's room can help to transform health policy in the offices of hospital leaders and boardrooms.

"Most important is communication. We want to know everything about our child's health and treatments - not just what the test results are, for instance, but what they mean. We want to be listened to, knowing there is someone else we can turn to if there is some kind of disconnect with any of our child's caregivers, and that action gets taken on anything that's not right or is upsetting a suffering child further. My daughter's bone marrow transplant specialist gave us her cell phone number - that's the kind of thing that speaks volumes, knowing you could always get an answer or share a concern."

— **Stef Katz**, United States

In the 21st century, more hospitals are seeking caregivers for patient and family advisory councils, partnerships and focus groups to help improve the patient experience. Family members and caregivers are sitting alongside staff to rewrite policy, include patients and families in care processes, like physician rounds and nurse shift reports, assist with the creation of training videos for new staff and speak at staff orientation sessions.

Caregivers are also advocating outside the hospital for home and community-based services and other supports which will allow them to better care for their loved ones at home and balance work/life responsibilities.

Caregivers as Advocates for the Person They Care For

Some caregivers are "natural" advocates for the people they care for, comfortable speaking up to intervene on safety issues, incorrect or missing information or unmet care needs. Others are not as comfortable being in this position and find themselves unprepared for situations which require them to advocate. This is often true of caregivers who are new to their caregiving responsibilities and are not yet comfortable interfacing with the healthcare system or their elected officials.

Advocating on behalf of others takes many forms. Here are a few examples of things you can do to advocate for the person you are caring for:

- Ask questions and participate in shared decision-making about treatment choices
- Listen to and champion their goals and wishes
- Teach medical professionals about their rare condition
- Advocate for improved quality of care in a long-term care facility by calling your state's long-term care ombudsman when you encounter care issues
- Represent their voice on a healthcare board or working group focused on improving early detection of cancer or Alzheimer's
- Seek increased federal funding for medical research for their disease or condition

The most important tool that a caregiver has in their advocacy toolbox is persistence. The voice of the caregiver is not embraced consistently across the healthcare ecosystem, so persistence is often critical to your voice being heard. Conversely, caregivers are often reluctant to advocate for their loved ones because they do not feel confident in their own grasp of the healthcare system or the diagnosis and treatment for their loved one's condition.

Here are a few additional tips for overcoming obstacles and advocating successfully for the person you care for:

Ask questions. If you don't understand the answers, say so. It is critical that you have a firm grasp on next steps in the care of your loved one.

Get trained. If you are not comfortable with the medical tasks you are expected to provide post-discharge for the person you care for, let the medical staff know that you require training. In the US, the CARE Act (the law in most states) requires that hospitals provide training for caregivers prior to the patient being discharged.

Know your limitations. Let medical staff know your limitations as a caregiver. For example, if you work during the day and are not able to provide transportation to follow-up appointments, ask the staff if they can connect you with transportation alternatives.

Be creative. As a caregiver (and during your journey through life), you have needed problem-solving skills every step of the way. Use these skills to work with healthcare professionals in brainstorming solutions to challenges that the person you care for faces.

Do your homework. Advocate from a position of knowledge. Be sure to research your loved one's health condition, insurance issues, local support services, or other issues as best you can. This will make discussions with their medical team and social service workers much more productive.

Trust your instincts. Your lived experience as a caregiver has taught you valuable lessons. If something doesn't feel right, speak up!

Be confident in your ability to effect change. Know that your lived experience as a caregiver means that you have skills and expertise from which others can benefit.

Caregivers as System Change-Makers

We live in a society where caregivers often do not self-identify, much less view themselves as having a voice in the transformation of healthcare from its current state to the person-and-family-centered ecosystem of The New Existence. There are, however, invaluable ways that caregivers can contribute their lived experience and knowledge to this vital process. Most caregivers have assimilated a vast array of knowledge to successfully support those they care for. This may include the following:

- Health policy and regulation
- Navigating the healthcare and social services systems
- Disease-specific knowledge
- Medication management

- Delivery of complex care
- Care and services coordination
- Health insurance
- Clinical trials and research

Each of these areas is driven by health policy at the national, state, and local levels, where the voices of caregivers are critically important in the decision-making process. Why? There is no substitute for "lived experience"! Caregivers have a nuanced view of diseases and chronic conditions along with the care experience because they interface with complex health issues 24 hours a day. Caregivers often navigate the healthcare system and complex social services on behalf of those they care for, learning important lessons that are invaluable in re-shaping the healthcare system of The New Existence. If caregivers are not involved in transforming healthcare, key areas in need of improvement may be overlooked.

The New Existence recognizes the importance of the caregiver voice in co-production of healthcare and health research. Co-production means that caregivers are equal contributors and partners of healthcare providers, policy makers and researchers; however, there is an enormous amount of culture change that is required to make this a reality. Caregivers have not typically been viewed in this role, but there are many ways in which they can help transform culture, in addition to health policy, healthcare delivery and medical research. The "new normal" will be one in which caregiver voices are omnipresent, where caregiver advocates are serving on boards, councils, committees and working groups focused on healthcare transformation, as well as a regular presence on Capitol Hill and State Houses across the country, pressing lawmakers on legislative reform.

How can I help transform healthcare?

As a caregiver, your voice is important in helping to transform the entire continuum of healthcare. This includes all aspects of health policy, healthcare delivery and health/medical research. Current advocacy topics range from access to care and telemedicine, insurance coverage, and better support for family caregivers to making clinical trials more accessible and easier to participate in.

Advocacy takes many forms that can easily fit your lifestyle. Choose avenues and activities that fit your interests and time constraints, keeping in mind that a few clicks on your computer or phone can take less than 5 minutes and achieve big results. You can be a powerful advocate without leaving your house!

There are many advocacy organizations leading the way, providing opportunities for caregivers to share their experience and expertise, often sending out "advocacy action alerts" via emailed newsletters. Other organizations welcome caregivers as advisors and invite them to serve on boards, councils, committees, and working groups focused on specific topics in healthcare transformation. Caregivers will find like-minded advocates within these organizations who have advocacy experience they are happy to share. Many are active on social media, sharing research studies, webinar and conference announcements and policy priorities across a wide range of issues.

How do I begin my advocacy journey?

Caregivers have many opportunities to share their knowledge to help shape the institutions, policy and processes that drive healthcare and medical research. There are many ways to begin your advocacy journey:

1. Develop your personal story and practice telling it to others. Link your story to known shortcomings in the healthcare system that need fixing. Examples include staffing shortages in nursing homes or lack of access to clinical trials.
2. Connect with a "disease-specific" advocacy organization that aligns with the disease or condition that matters to you. Examples include Alzheimer's Association, American Heart Association, Autism Speaks, European Cancer Patient Coalition, National Alliance on Mental Illness, National Multiple Sclerosis Society. Sign up for their newsletters. Follow them on social media.
3. Connect with advocacy organizations that focus on topics you care about. Examples include AARP, Carers Canada, Chronic Disease Coalition, Global Health Council, National Alliance for Caregiving, National Organization of Rare Disorders, Partnership to Improve Patient Care (PIPC). Sign up for their newsletters. Follow them on social media.
4. Follow world-renowned medical research institutions. Examples include National Academy of Medicine, National Institute for Health Research (UK), National Institutes of Health, Patient Centered Outcomes Research Institute (PCORI). Sign up for their newsletters. Follow them on social media.
5. Attend healthcare meetings, webinars and conferences hosted by the organizations listed above. Start with the public meetings of the RAISE Family Caregiving Advisory Council to learn more about a national approach in the United States to addressing the needs of family caregivers of all ages and caregiving situations.
6. Apply to serve on the patient and family advisory council of an organization that has one. Examples include The Beryl Institute, Patient Centered Outcomes Research Institute (PCORI) or a Patient/Family Advisory Council (PFAC) at your local hospital.
7. Review key caregiver studies that contain important statistics you should know (see next section for a list of studies to start with).
8. Learn about current healthcare legislation that impacts you and your family (advocacy organizations can help!), then visit your elected officials at the federal, state, and local levels to advocate for their support in getting the legislation passed.

There are many resources available to help caregivers begin their healthcare advocacy journeys, including a wide range of advocacy organizations and research institutions. A list of helpful and informative resources is found below.

Disease and Condition-Specific Advocacy Organizations:

ALS Association, <https://www.als.org/>

ALS Therapy Development Institute, <https://www.als.net/>

Alzheimer's Association, <https://www.alz.org/>

Alzheimer's Foundation of America, <https://alzfdn.org/>

American Cancer Society, <https://www.cancer.org/>

American Chronic Pain Association, <https://www.theacpa.org/>

American Diabetes Association, <https://www.diabetes.org/>

American Heart Association, <https://www.heart.org/>

American Parkinson Disease Association, <https://www.apdaparkinson.org/>

Arthritis Foundation, <https://www.arthritis.org/advocate>

Association for Frontotemporal Degeneration (AFTD), <https://www.theaftd.org/>

Asthma and Allergy Foundation of America, <https://www.aafa.org/>

Beyond Celiac, <https://www.beyondceliac.org/>

Brain Injury Association of America, <https://www.biausa.org/>

Christopher and Dana Reeve Foundation (spinal cord injury), <https://www.christopherreeve.org/>

Chronic Pain Research Alliance, <http://www.cpralliance.org/site/index>

COPD Foundation, <https://www.copdfoundation.org/>

Creaky Joints (arthritis), <https://creakyjoints.org/>

Crohn's & Colitis Foundation, <https://www.crohnscolitisfoundation.org/>

Cystic Fibrosis Foundation, <https://www.cff.org/>

Dementia Action Alliance, <https://daanow.org/>

Dr. Susan Love Foundation for Breast Cancer Research, <https://drsusanloveresearch.org/>

Epilepsy Foundation, <https://www.epilepsy.com/>

European Cancer Patient Coalition, <https://ecpc.org/>

Families for Addiction Recovery (Canada), <https://www.farcanda.org/>

Family Outreach and Response (mental health) (Canada), <https://www.familymentalhealthrecovery.org/>

Global Liver Institute, <https://www.globalliver.org/>

Imerman Angels (cancer support), <https://imermanangels.org/>

International Pain Foundation, <https://internationalpain.org/>

L'Appui (deaf and hard of hearing) (Canada), <https://www.lappui.org/>

Leukemia & Lymphoma Society, <https://www.lls.org/>

Lewy Body Dementia Association, <https://www.lbda.org/>

Livestrong (cancer), <https://www.livestrong.org/>

Lung Cancer Research Foundation, <https://www.lungcancerresearchfoundation.org/>

Lupus Research Alliance, <https://www.lupusresearch.org/>

Lymphoma Research Foundation, <https://lymphoma.org/>

Melanoma Research Alliance, <https://www.curemelanoma.org/>

The Michael J. Fox Foundation for Parkinson's Research, <https://www.michaeljfox.org/>

Myeloma UK, <https://www.myeloma.org.uk/>

National Alliance on Mental Illness, <https://www.nami.org/home>

National Association of the Deaf, <https://www.nad.org/>

National Federation of the Blind, <https://nfb.org/>

National Kidney Foundation, <https://www.kidney.org/>

National Multiple Sclerosis Society, <https://www.nationalmssociety.org/>

National Organization of Rare Disorders, <https://rarediseases.org/>

Pancreatic Cancer Action Network, <https://www.pancan.org/>

Parkinson's UK, <https://www.parkinsons.org.uk/>

Prostate Cancer Foundation, <https://www.pcf.org/>

Scleroderma Research Foundation, <https://srfcure.org/>

Susan G. Komen (breast cancer), <https://www.komen.org/>

U.S. Pain Foundation, <https://uspainfoundation.org/>

Uganda Cancer Program, <https://patientreliefmission.org/> and <http://www.findglobal.com/UG/Kampala/594438644037506/Freedom-Cancer-Patients%27-Hostel>

Uganda Cancer Society, <https://www.ugandacancersociety.org/>

Uganda HIV Program, https://en.wikipedia.org/wiki/Nsambya_Home_Care

UsAgainstAlzheimers, <https://www.usagainstalzheimers.org/>

Vascular Cures, <https://vascularcures.org/>

Pediatric (Children) Advocacy Organizations:

About Special Kids (children with special needs), <https://www.aboutspecialkids.org/>

American Lung Association (asthma), <https://www.lung.org/lung-health-diseases/lung-disease-lookup/asthma/living-with-asthma/managing-asthma/for-parents-of-children-with-asthma>

Autism Speaks, <https://www.autismspeaks.org/>

Brave Hearts for Kids (cancer), <https://braveheartsforkids.org/>

Children with Diabetes, <https://childrenwithdiabetes.com/>

Families for HoPE (holoprosencephaly (HPE) and related brain malformations), <https://familiesforhope.org/>

Feeding Matters, <https://www.feedingmatters.org/>

Feeding Tube Awareness Foundation, <https://www.feedingtubeawareness.org/>

Hydrocephalus Association, <https://www.hydroassoc.org/>

Juvenile Diabetes Research Foundation, <https://www.jdrf.org/t1d-resources/>

Muscular Dystrophy Association, <https://www.mda.org/>

National Down Syndrome Society, <https://www.ndss.org/>

Pediatric Multiple Sclerosis Alliance, <http://pediatricms.org/>

Sickle Cell Information Center, <https://scinfo.org/>

Spina Bifida Association, <https://www.spinabifidaassociation.org/infants-children/>

United Cerebral Palsy, <https://ucp.org/resource-guide/>

Advocacy Organizations Focused on Special Topics:

AARP (seniors/aging), <https://www.aarp.org/>

Alliance for Aging Research, <https://www.agingresearch.org/>

The Beryl Institute (patient experience), <https://www.theberylinstitute.org/>

Chronic Disease Coalition, <https://chronicdiseasecoalition.org/>

Genetic Alliance, <http://www.geneticalliance.org/>

Global Health Council, <https://globalhealth.org/>

National Alzheimer's Project Act (NAPA) Advisory Council, <https://aspe.hhs.gov/napa-advisory-council>

Partnership to Improve Patient Care (PIPC), <http://www.pipcpatients.org/>

Medical and Health Services Research Organizations:

Agency for Healthcare Research and Quality, <https://www.ahrq.gov/>

Centers for Disease Control and Prevention, <https://www.cdc.gov/>

Clinical Trials Transformation Initiative (CTTI), <https://www.ctti-clinicaltrials.org/>

Decentralized Trials and Research Alliance, <https://www.dtra.org/>

FasterCures, <https://milkeninstitute.org/centers/fastercures>

Food and Drug Administration, <https://www.fda.gov/>

Health Resources and Services Administration, <https://www.hrsa.gov/>

National Academy of Medicine, <https://nam.edu/>

National Institute for Health Research (UK), <https://www.nihr.ac.uk/>

National Institutes of Health, <https://www.nih.gov/>

Patient Centered Outcomes Research Institute (PCORI), <https://www.pcori.org/>

Research America, <https://www.researchamerica.org/>

UsAgainstAlzheimer's A-List for Research, <https://www.usagainstalzheimer.org/networks/A-LIST>

In addition to learning from and building on the resources above, healthcare leaders have specific roles they can play in supporting caregivers. We explore these in the next chapter.

Chapter 7

The Role of Healthcare Leaders in Supporting Care Partner Initiatives

Even as they empower caregivers to contribute to better outcomes and more inclusive care, healthcare leaders can use their influence to create an environment that supports a positive caregiver experience. The following checklist contains actionable suggestions that can be implemented within your organization.

Checklist for healthcare leaders:

- Create a culture where family caregivers are perceived as partners and critical members of the care team.
- Create staff accountability in ensuring they understand the importance of the family caregiver experience. Provide education programs, create performance measures and set expectations in hiring practices.
- Ensure that every project has a patient and caregiver as active members of the team, allowing them to contribute their lived experience while creating a safe space to discuss cutting edge ideas for policy and process improvement.
- Reach out to caregivers in the community to serve as special advisers.
- Set goals for implementing new programs and processes to support family caregivers. Create metrics, collect data and measure outcomes.
- Identify educational opportunities for care partners – perhaps co-educational programs alongside staff.
- Include care partners in Grand Rounds.

These actions will ensure that the culture of every organization is ready for meaningful caregiver engagement.

Conclusion

The resources listed in this guide work together with those in The New Existence to support transformation in healthcare. They should be used as a starting point by healthcare leaders to integrate the family caregiver into all aspects of healthcare, research and policy. Family caregivers should embrace the importance of their role in this process and utilize the guide as a tool for educating others and the resources within as a catalyst for their own advocacy journey.

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