



Person-Centered Guidelines for Preserving Family Presence in Challenging Times – May 28, 2020

The following guidelines for preserving family presence were co-developed by an international, multi-stakeholder “pop-up” coalition including patient, resident, family and elder advocates, experts in quality, safety and infection control, clinicians, policymakers, and healthcare executives from a variety of care settings. These recommendations for family presence across the continuum of care reflect the lived experiences of many who have been, in the moment, wrestling with and addressing the critical nature of this issue. The guidelines aim to 1) balance socio-emotional needs with clinical safety needs; 2) balance the needs of individuals with the needs of the community; and 3) support person-centered care principles now and in the future. The focus was to produce an evidence-based, person-centered set of recommendations that will minimize the variation of family presence policies and practice within communities and regions during challenging circumstances. Though the impetus for publishing these guidelines was the COVID-19 outbreak, they have widespread applicability beyond a pandemic.

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The guidelines are anchored by these overarching principles:

- The term “family” refers to any support person *defined by the patient or resident as family*, including friends, neighbors and/or relatives.
- These guidelines specifically pertain to family caregivers who are designated as “Care Partners.” As welcomed members of the care team, Care Partners advocate for a loved one’s needs and support them in managing their health, healthcare, long-term care and overall well-being. Care Partners are distinct from casual “visitors.” Because they know their loved one best, they are uniquely attuned to subtle changes in their behavior or status. This makes the presence of Care Partners an important strategy for reducing the risk of preventable harm.

- Some people may prefer not to have a family member with them. Inherent in these guidelines is the understanding that when family presence is an option, an individual's preference to not have a family member present will also be honored.
- In person-centered care, improvement efforts and process changes are made not *for* patients, residents, and families, but *with* them. Engaging these essential voices in the development of family presence protocols will ensure their critical perspective is part of the decision-making process and the determination of how policy changes are communicated. Enlisting patient family advisors and members of resident and family councils as active participants on teams making decisions that impact safety and family presence policies is essential to meeting community needs in a human-centered way.
- Professional caregivers are under tremendous strain as they strive to deliver safe, quality, compassionate care. While staff cannot replace family, many have assumed the role of de facto support person for otherwise isolated patients and residents. This is not a sustainable model. Family presence protocols must not create undue burden on staff. The implications on staff when restrictions are put in place must be considered in designing person-centered, compassionate family presence guidelines.
- These guidelines are intended to apply across a variety of contexts, including vulnerable populations who have been systematically marginalized, and in resource challenged settings. We recognize that levels of trust and partnership with health and long-term care systems, as well as access to supplies, staffing and technology, vary considerably. These guidelines are intentionally broad so that they may be used in many different contexts.

Background

During this unprecedented pandemic, healthcare teams are working tirelessly under extremely difficult circumstances to provide optimal care for patients and residents and safeguard their communities. Health authorities, health system executives and clinicians have needed to be responsive and proactive amidst rapidly evolving, highly variable conditions. As a result, many care settings have reassessed their customary approach to family presence in an attempt to find the balance between maintaining safety and supporting patients, residents, families and staff.

Due to the circumstances surrounding the COVID-19 pandemic, it may be prudent to introduce temporary measures for managing family presence in a way that supports the need for physical distancing and minimizes the risk of transmission. A pandemic, however, does not negate the importance of patient, resident and family engagement, nor the essential ways in which family presence and participation contribute to a loved one's quality of care and quality of life.¹⁻⁷

¹Bohren MA, Berger BO, Munthe-Kaas H, Tunçalp Ö. Perceptions and experiences of labour companionship: a qualitative evidence synthesis. Cochrane Database of Systematic Reviews 2019, Issue 3. Art. No.: CD012449

When weighing the need to limit family presence, it is important healthcare leaders and local and regional health authorities consider not only the risk that family presence may pose, but also the risk that these *family presence restrictions* may create in the short and long term. This is especially vital when the dialogue shifts from visitation to family presence and participation in cases where a Care Partner is their loved one's primary advocate, their voice, their at-home care provider, and/or their emotional safety net. Examples include individuals who, for a variety of reasons, are unable to provide their own medical history and/or make decisions for themselves, those who react to a medical environment with heightened emotionality and are unable to be calmed without medication or restraint, and once-in-a-lifetime events like childbirth or end-of-life. In cases like these, eliminating a person's ability to have a familiar support person by their side may have devastating long-term emotional, psychological and other health effects.

Unintended consequences that are currently being reported include:

- *Families removing elders from long-term care settings that prohibit family's presence*
- *Women in labor driving long distances to hospitals that allow their birth partner to stay with them during labor and delivery when the local facility has prohibited this, and an increase in demand for home birth options*
- *Parents reluctant to bring their children to the hospital for fear that they will be separated either at the emergency department or upon admission*
- *Individuals with cognitive impairments, when separated from their customary caregivers and routines, becoming traumatized and exhibiting behavioral expressions of distress that impact care staff*
- *Older adults without their usual orienting practices experiencing delirium and its long-term health impacts*
- *Hospitalized patients and residents in long-term care communities dying with no family member at their side to comfort them*
- *Families traumatized by the inability to have a proper burial for their loved one*

² Dokken, DL, Kaufman, J, Johnson, BJ et al., Changing hospital visiting policies: from families as "visitors" to families as partners. J Clinical Outcomes Management 2015; 22(1), 29-36.

³ Fumagalli S, Boncinelli L, Lo Nostro A, Valoti P, Baldereschi G, Di Bari M et al. Reduced cardiocirculatory complications with unrestricted visiting policy in an intensive care unit: results from a pilot, randomized trial. Circulation 2006; 113:946-952.

⁴ Jabre P, Belpomme V, Azoulay E, Jacob L, Bertrand L, Lapostolle F, Tazarourte K, Bouilleau G, Pinaud V, Broche C, Normand D, Baubet T, Ricard-Hibon A, Istrial, Beltramini A, Alheritiere A, Assez N, Nace L, Vivien B, Turi L, Launay S, Desmaizieres M, Borron SW, Vicaut E, Adnet F. Family presence during cardiopulmonary resuscitation. N Engl J Med. 2013 Mar 14;368(11):1008-18.

⁵ Meyers TA, Eichhorn DJ, Guzzetta CE, Clark AP, Klein JD, Taliaferro E, Calvin A. Family presence during invasive procedures and resuscitation. Am J Nurs. 2000 Feb;100(2):32-42

⁶ Parsapour, Kourosch & Kon, Alexander & Dharmar, Madan & McCarthy, Amy & Yang, Hsuan-Hui & Smith, Anthony & Carpenter, Janice & Sadorra, Candace & Farbstein, Aron & Hojman, Nayla & Wold, Gary & Marcin, James. Connecting Hospitalized Patients with Their Families: Case Series and Commentary. International journal of telemedicine and applications. 2011.

⁷ Shulkin D, O'Keefe T, Visconi D, Robinson A, Rooke AS, Neigher W. Eliminating Visiting Hour Restrictions in Hospitals. Journal for Healthcare Quality 2013

- *Families feeling ill-equipped to support loved ones upon discharge to home*
- *Traumatized staff left to care for the physical, psychological, spiritual, and emotional needs of patients and residents without family support, including at the end of life*
- *Staff feeling the burden of longer-term trauma related to unrecognized or immeasurable grief that has little time to be processed or acknowledged.*

We believe these unintended consequences can be avoided with a proactive plan in place for responsibly managing family presence. The guidelines below outline considerations and practical guidance for maximizing the therapeutic benefits of family presence and participation while limiting the risk to patients, residents, Care Partners, staff and the community.

GUIDELINES FOR PRESERVING FAMILY PRESENCE IN CHALLENGING TIMES

1. **Assess the need for restrictions to family presence based on current factual evidence. Continually reassess as conditions evolve.** Assess current risk factors local to the care setting and consult applicable mandates to determine whether there is a need for restrictions to family presence. When making decisions about the number of family members who may be present at one time, age restrictions, duration of visits and ability to move throughout the building, considerations should include:
 - Is there widespread, active community transmission or not?
 - How available is Personal Protective Equipment (PPE) such as masks, gowns and gloves for use by both staff and family members?
 - How adequate are local testing capabilities? Is reliable rapid point-of-care testing available for Care Partners?
 - Is staffing adequate to responsibly manage family's presence?
 - Does the physical layout of the space allow for appropriate physical distancing?
 - Do restrictions to family presence and participation create a safety, clinical or emotional risk to the patient or resident that outweighs that of COVID-19?

This is a rapidly evolving situation. As circumstances change within your community, continually weigh the risks versus benefits of restrictions to Care Partners' presence. On an individual basis, as specific cases arise with special circumstances, use a risk-benefit assessment to determine whether family presence can be responsibly supported. Ensure

that patients, residents and their Care Partners are involved in completing the risk-benefit assessment, as appropriate.

2. **Minimize risk.** We recommend the following guidelines to minimize risk of exposure to the virus.
 - Care Partners are **screened upon entry** for symptoms of the virus and are asked whether they have symptoms or have been in recent contact with anyone diagnosed with COVID-19. Requiring family to log their visits enables the care setting to maintain a record of contacts that facilitates contact tracing if needed. Centralizing this process at limited entry points takes the monitoring burden off staff in different areas of the building.
 - After the screening, at the point of entry, Care Partners are **provided with the appropriate personal protective equipment such as masks and gloves, and instruction on proper use.** Refer to the [WHO's guidelines for rational use of personal protective equipment for COVID-19 and considerations during severe shortages](#), the [CDC's guidelines on strategies to optimize PPE supplies](#), along with guidelines from your local/state/national authorities for further guidance.
 - To limit Care Partners' exposure to multiple sources of infection within the care setting, implement a **designated path to and from areas treating patients with COVID-19.**
 - Depending on the current state of community spread and the feasibility within the physical space, utilize either **physical distancing** protocols within the care setting or institute **sheltering in place for Care Partners.** In cases of physical distancing, Care Partners would be expected to remain in their loved one's room as much as possible and avoid other areas of the building for the duration of their visit. They would be able to visit daily. Care Partners sheltering in place with a patient would remain with their loved one for the duration of the person's acute healthcare episode – for instance, in the case of a parent sheltering in place with a pediatric patient.
 - In care settings without private rooms, **designate dedicated spaces** where loved ones (resident and family member or patient and family member) can be together. Institute appropriate disinfecting protocols between uses of the space by each distinct family unit.
 - Weather permitting, **use outdoor spaces** to support family's presence in a way that allows for appropriate physical distancing.

- 3. Communicate what to expect proactively and with compassion.** Do not wait for family to arrive at your doors to discover they are not permitted to enter. Communicate current family presence policies on public web sites, including restrictions and exceptions. Proactively communicate through emails, letters, telephone and video calls. If systems are currently inadequate for capturing Care Partners' contact information, prioritize processes for making that information readily available in order to facilitate this outreach. In addition, partner with trusted community-based organizations and community health workers to inform the broader community of what to expect.

Use clear and caring language that conveys both what individuals need to know before arriving at the care setting and the “why” behind any restrictions. ([See examples of policies.](#)) Beyond communicating what families *can't* do, be sure to emphasize what they *can* do, i.e. the opportunities for remaining connected with their loved one and their care team (see # 5 below). Enlist the assistance of patient, resident, and family advisors, as well as community health workers, to vet the language and tone of the message about family presence policies. Even if time was of the essence to release revised policies, it is not too late to revisit the language and tone to ensure they are conveying your message in a person-centered way.

Be sure these communications are made available in culturally-informed ways that will meet the needs of the population you serve, including being translated into languages common to your community and possibly expressed in a short video for low literacy populations.

Finally, recognize the inevitability that staff will be the message bearers about the family presence policy. Ensure all staff, including clinical staff, nurse aides, security, greeters, dining services and maintenance staff understand the current standards so that people are not getting mixed messages. Consider offering coaching or talking points to ensure that these messages are conveyed in a compassionate way and are respectful of families and their important roles. Experienced patient and family advisors and resident volunteers could help with messaging and virtual coaching sessions.

- 4. Establish compassionate exceptions.** When exceptions to family presence restrictions will be made, state explicitly what those exceptions are, e.g. pediatric care, childbirth, patients/residents who are non-verbal, have communication challenges, are cognitively impaired or at the end-of-life (with clear guidance on how “at end-of-life” is defined and in consideration of when final good-byes will be most meaningful, including post-death rituals).

Engage a Compassionate Exceptions Committee, inclusive of nursing, social work, the medical staff, and patient/resident/family advisors, that is on call to make timely determinations for exceptions on a case-by-case basis. To support decision-making, it

may be helpful to create a protocol or checklist to ensure fairness and comfort for everyone.

5. **Support meaningful connections to minimize feelings of isolation.** In cases where family is unable to be with their loved one physically, support their sense of connection and emotional and psychological well-being virtually through provision of tablets, video chat or the telephone. Offer accommodations to enhance how individuals with communication challenges use the technology. A virtual family presence suite established within the care setting, equipped with video chat technology disinfected between each use, is another option when being in immediate proximity is not possible and when family is unable to access technology at home.

It is important, however, to guard against over-reliance on technology to support connection in the midst of isolation. We must recognize that, for some, rather than fostering well-being and connection, technology may create anxiety and suffering. Furthermore, access to personal devices and videoconferencing capabilities is a privilege not all have.

Follow the lead of some care settings that have redeployed staff who are not working in their usual functions into a new role as “connectors” between patients/residents and Care Partners who cannot be by their side. Other possibilities include engaging medical students, patient/resident/family advisors and volunteers for this role. These personal “connectors” can be tremendously valuable in low resourced areas where technology is not readily available. If chaplains are available, ask them to visit individuals who have limited interactions with family members, according to the person’s wishes. *See a list of potential roles for connectors [here](#).*

6. **Inform and educate.** In cases where a Care Partner is able to be with their loved one physically, adopt a shared decision-making approach to communicate the risks and benefits of various ways they can remain connected with their loved one. Educate them about steps they can take to minimize risk, including expectations for hand hygiene, use of personal protective equipment and guidelines for physical distancing or sheltering in place (as applicable) within the setting. Use teach-back to ensure they understand the risks and expectations and partner with them in decision-making processes that take into consideration the factors discussed.
7. **Enlist family as partners for quality and safety.** Care Partners, by definition, are members of the care team who share in the responsibility for quality and safety. Understanding this responsibility is a key element of the shared decision-making conversations outlined above. Be explicit about what is expected, including hand hygiene, monitoring their own symptoms, limiting their contacts outside of the care setting, etc. Support staff in managing responsible family presence in line with the established protocols. Talking

points in compassionate language and simulations of challenging scenarios can be helpful to prepare staff for difficult conversations. *Tools to support compassionate communication are included in the appendix [here](#).*

- 8. Enhance discharge education and post-discharge follow-up.** Care Partners are a vital source of continuity that support successful transitions of care. When family presence during a hospitalization is limited, they may have less of an understanding of their loved one's plan of care, who to contact with questions, symptoms to be aware of, and care management needs. Engaging Care Partners remotely in care conferences, rounds and discharge education can help to keep them up to date on their loved one. (See #5 above for recommendations for redeploying staff in a "connector" role. If virtual participation in rounds is not possible, engage these connectors to provide timely check-ins after rounds.)

Discharge information will need to be enhanced with greater detail on what has transpired during the stay since the Care Partner may not have been present to observe and participate. Ensure Care Partners know who to contact with questions and concerns that may arise post-discharge. Pictorial, written and video demonstrations of care tasks that will need to be completed by the Care Partner can help build their confidence and competence remotely.

For patients who have been sedated in the ICU, it is not only the Care Partner who may lack knowledge of what occurred during the hospitalization, but the patient themselves. A tool like the [ICU Digital Diary](#) that documents the patient experience can be useful to help mitigate the risk of post-intensive care syndrome by helping them to fill in the gaps of what happened during that time.

In discharge planning, it will be essential to strengthen connections between the patient and Care Partner and their primary care provider or medical home to enhance support around medication management, ensure follow-up visits (in-person or telehealth) are in place and address non-clinical needs that may affect one's ability to manage their care. Post-hospital check-ins that include discharge follow-up calls, enhanced social work support and home care can further support smooth transitions and improved care coordination.

Planning for the Future of Family Presence in Health and Long-Term Care Settings

The future of health and long-term care delivery has been permanently altered by this widespread pandemic. There will be no "going back to normal." Instead we will need to create a "new normal." However, now is not the time to erode the tremendous progress that has been made to create more person-centered health and long-term care systems. We can build on what

we learn and ensure that person-centered approaches to care continue to evolve and flourish in a safe, compassionate, and evidence-based manner.

In envisioning what family presence and visitation may look like in the future, an important first step will be to revisit pre-COVID 19 policies and assess the gaps between where we've come from and where we are now. How can we integrate the best elements of pre-COVID family presence policies that maximize opportunities for family engagement with new learnings about how to balance risk and safety? Re-integration of a more humanized, personalized approach to family presence will include differentiated standards based on the needs of individuals and distinct populations. The precautions put in place to protect those at greatest risk should be assessed for their impact on those at lesser risk who can safely benefit from their family's physical presence. Furthermore, those at greatest risk of harm due to separation from loved ones will be proactively identified so that safe ways to support family presence can be identified.

What might the future of family presence and visitation look like in acute care settings?

- A limited number of family Care Partners – designated by the patient– may be welcomed as a part of the care team and encouraged to be present with patients at the bedside.
- A screening and health assessment tool may be mandated for all Care Partners.
- Visitation by other family and friends may move to virtual and telephonic platforms.
- Care settings will invest in the necessary equipment, develop expertise in virtual engagement modalities and develop staffing models to keep patients connected to loved ones who cannot be physically present.
- A scheduling system may be developed to monitor and manage the presence of family in a way that supports proper physical distancing, e.g. monitors the number of individuals within the space at one time.

What might the future of family presence and visitation look like in group and long-term care settings (including assisted living)?

- Group and long-term care settings may cluster patients/residents in small cohorts of 5-7, limit interactions outside of the cohort, and use consistent staff assignment within the cohort and whole organization.
- A limited number of family Care Partners may be designated by the individual and be welcomed on-site as a member of that person's support team, as appropriate.
- A screening and health assessment tool may be mandated for all Care Partners.

- Visitation by other family and friends may move to virtual and telephonic platforms, with adequate organizational support for virtual engagement modalities.

What might the future of family presence look like in out-patient care settings?

- A limited number of family Care Partners may be designated by the individual and encouraged to be present during out-patient healthcare interactions either on-site or virtually, as appropriate and desired by the individual.
- Much of routine primary care and on-going monitoring and management of chronic conditions will move to virtual engagement platforms, e.g. telehealth.
- Additionally, there may be an increase in the use of the wearable health devices that can be synchronized with an individual's electronic medical record.
- Clinicians will become skillful at delivering safe and compassionate care virtually with the needed support and training provided to them.

Appendix A: Endorsements



www.planetree.org



www.pioneernetwork.net



www.languageofcaring.org



www.nursingworld.org



www.isqua.org



www.nationalpartnership.org



www.ihl.org



www.paltc.org



www.hphnet.org



www.ahcancal.org



International Institute for Compassionate Care

www.symponesi.org



www.qualityforum.org



American College of Health Care Administrators

www.achca.org



www.vizientinc.com



www.goldfoundation.org



www.morrismosesfoundation.org



www.thegreenhouseproject.org



Center for Patient Experience and Staff Engagement
www.hamad.qa



www.moh.gov.sa



www.childrens.health.qld.gov.au



www.communityhospitalcorp.com



www.edenalt.org



www.hrhcare.org



<https://daanow.org/>



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www.griffinhealth.org

Appendix B: Contributors

AMDA-The Society for Post-Acute & Long-Term Care Medicine

Christopher E. Laxton, CAE
Executive Director

American College of Health Care Administrators

Bill McGinley, FACHCA
President & CEO

American Health Care Association

David Gifford, MD, MPH
Senior VP, Quality & Regulatory Affairs

Holly Harman, RN, MBA, LNHA, FACHCA

Vice President, Quality, Regulatory & Clinical Services

Sara Rudow, MPA

Senior Director of Regulatory Services

American Hospital Association

Akin Demehin
Director of Policy

American Nursing Association

Jennifer Mensik Kennedy, Ph.D., RN, NEA-BC, FAAN
Board of Directors Member

Callen-Lorde Community Health Center

Finn Brigham
Director of Project Management

Centers for Medicare & Medicaid Services

Melonie Tindall
Grants Customer Success Manager

Centers for Medicine & Medical Division of Nursing Homes

Karen Schoeneman
Retired Deputy Director

Children's Health Queensland

Tania Hobson
Executive Director Allied Health

Cleveland Clinic

Adrienne Boissy, MD, MA
Chief Experience Officer

Community Hospital Corporation

April Myers, MBA, FACHE
Senior VP, Post-Acute Operations

Connecticut Center for Patient Safety

Lisa Freeman
Executive Director

Consumer Voice for Quality Long-Term Care

Lori Smetanka
Director

Dementia Action Alliance

Jan Bays
Board Member

Karen Love
Gerontologist

Jackie Pinkowitz

Board Chair

Duke University

Mark McClellan
Founding Director of the Duke-Margolis Center for Health Policy

Gracie Square Hospital

David Wyman
President & CEO

Griffin Hospital

Patrick Charmel
President & CEO

Hamad Medical Corporation

Nasser Said Mohd Al Jaffali
Deputy Chief of Quality, Center for Patient Experience and Staff Engagement

Abdul Majid Tariq Dalvi

Assistant Executive Director Center for Patient Experience and Staff Engagement

Health Care Association of New Jersey

Loretta Kaes
Director, Quality Improvement & Regulatory Affairs

Healthcare Association of New York State

Christina Miller-Foster
Senior Director, Quality & Research Initiatives

HRHCare

Katherine Brieger, RD, CCE
Executive Director

Institute for Healthcare Improvement (IHI)

Maureen Bisognano
President Emeriti

Patricia McGaffigan

Vice President, Patient Safety Programs

Institute Patient- & Family-Centered Care

Deborah Dokken
Coordinator for Patient and Family Partnerships

Institute for Patient- and Family-Centered Care

Beverly Johnson
President & CEO

International Council on Active Aging

Colin Milner
Founder & CEO

International Institute for Compassionate Care

Andreas Anastasiou Ph. D
Board Member

International Network of Health Promoting Hospitals and Health Services

Oliver Gröne, Ph. D
CEO

International Society for Quality in Health Care (ISQua)

Peter Lachman
Chief Executive Officer

It's Never 2 Late

Jack York
Co-Founder, President

Johns Hopkins Hospital

Lisa Allen
Chief Patient Experience Officer

Sue Mead

Parent Advisor

Leading Age

Jodi Eyigor
Director, Nursing Home Quality & Policy

Lown Institute

Shannon Brownlee
Senior VP

Ministry of Health Saudi Arabia

Khalid A Alharbi
Patient Experience Center

Eman Mohammed Alturaiki

Director General, Patient Experience Center

Morris Moses Foundation

Stephen Murathe
Deputy C.E.O.

Alice Naserian Mwongera

Chair C.E.O.

National Academy of Medicine

Ayodola Anise
Director, Value and Culture

National Center for Assisted Living

Lindsay Schwartz, PhD
Director, Workforce & Quality Improvement

National Partnership for Women & Families

Erin Mackay
Senior Leader – Patient & Family Engagement

National Quality Forum (NQF)

Shantanu Agrawal, MD
President & CEO

NYP Westchester Behavioral Health Center

Philip J. Wilner, MD
Senior Vice President & Chief Operating Officer

OptiMedis AG

Keriin Katsaros
Manager of Research & Innovation

PFCCPartners

Libby Hoy
Founder/CEO

Pioneer Network

Penny Cook
President & CEO

Verna Cavey, Ph. D

Volunteer, Clermont Park Resident
Resident Speaker

Joan Devine

Director of Education

Cathy Lieblich

Director of Network Relations

Planetree Brazil

Claudia Garcia de Barros
Director

Planetree International

Susan B. Frampton, Ph. D
President

Lorena Bedoya

Project Coordinator

Sara Guastello

Vice President, Knowledge Management

Karin Jay

Senior VP, Global Services

Jim Kinsey

Vice President, Engagement Strategies & Continuum of Care Services

Bernie Liston, MBA

Manager of Special Projects

Planetree Latin America - Central

Teresa Tono
Director

Planetree Latin America- North

Diego Cevallos
Director

**Planetree Latin America – South
Institute for Clinical Effectiveness
and Health Policy**

Ezequiel Garcia-Elorrio
Director

Natalie Hreczuch
Advisor

**Planetree
Netherlands/Belgium/Germany**

Marita Bossers
Director

Réseau Planetree Francophone

Lucie Dumas
Director

Catherine Wilhelmy
Chief of Communications

Rivas Zorgrop, The Netherlands

Marcel van der Priem
Director

RMB Capital

Mohini McCormick
Senior Vice President
Patient Speaker

Sage

Tim Johnston
Senior Director, National Projects

The Arnold P. Gold Foundation

Richard I. Levin, MD
President & CEO

The Beryl Institute

Tiffany Christensen
Vice President of Experience
Integration

Jason Wolf

President & CEO

The Eden Alternative

Jill Vitale-Aussem
President & CEO

The Green House Project

Susan Ryan
Senior Director

The Joint Commission

Kathryn Spates
Executive Director, Federal
Relations

Barbara Soule

Infection Preventionist

**The Schwartz Center for
Compassionate Care**

Matt Herndon
Chief Executive Officer

Beth A. Lown, MD, FACH
Chief Medical Director

**University of Nebraska Medical
Center College of Nursing**

Carol Wahl
Assistant Professor

Vizient Inc.

Kellie Goodson, MS, CXP
Director

World Health Organization

Olga Fradkina
Administrative Officer

Zeea Han
Technical Officer

Edward Kelley
Coordinator & Head of Strategic
Programs

Pryanka Relan
Physician

Shams Syed
Quality Health Lead

Wynstone Partners

Tom Tischhauser
Principal

Appendix C: Additional Resources

Sample Family Presence Policies:

Guidance for hospitals in areas of low community transmission:

- Griffin Hospital: <https://www.griffinhealth.org/coronavirus-covid19-information>

Guidance for hospitals in areas of high community transmission:

- Beaumont: <https://www.beaumont.org/patients-families/general-information/visiting-information>
- Johns Hopkins: <https://www.hopkinsmedicine.org/coronavirus/visitor-guidelines.html>
- New York State Health Department
https://opwdd.ny.gov/system/files/documents/2020/04/doh_covid19_hospitalvisitation_4.10.20.pdf

Guidance for long-term care settings:

- [Handout for Visitation Policy in Nursing Homes –Netherlands](#)
- [Industry Code for Visiting Residential Aged Care Homes during COVID-19](#) (Australia)
- [COVID-19 and Distance Socializing between People Living in a Residential Facility and Caregivers in the Context of a Visitors Ban](#) (Institut national d'excellence en santé et en services sociaux (INESSS) – Quebec)

Guidance for End-of-Life Care

- [Quebec Guidelines Regarding End-of-Life Visitations](#)

Compassionate Communication Resources:

- [Communication Strategies for Keeping Families Up To Date](#) (AHCA/NCAL)
- [Compassionate Care Amidst the COVID-19 Crisis](#) (AHCA/NCAL)
- [Improving Communication through the PPE Barrier](#) (Card Medic)
- [Framing COVID-19 Resources](#) (Frameworks Institute)
- [Caring Communication and Messages During COVID-19](#) (Planetree International)
- [Medical Planning Guide for COVID-19](#) (Prepare for Your Care)
- [Caring with Compassion: Supporting Patients and Families in a Crisis](#) (Schwartz Center for Compassionate Healthcare)

- [Compassionate Collaborative Care Model and Framework](#) (Schwartz Center for Compassionate Healthcare)
- [Vital Talk COVID Resources](#) (Vital Talk)

Tools to Promote Meaningful Connection When Family Can't Be Physically Present

- [Tell Me More for COVID-19 Care Kit](#) (The Arnold P. Gold Foundation)
- [Resources for Combatting Social Isolation](#) (Pioneer Network)
- [PPE Portrait Project](#)
- [Post-ICU Diary](#)
- [A 5-point strategy for improved connection with relatives of critically ill patients with COVID-19](#)

Functions “Connectors” Can Play

- Check-ins with remote Care Partners
- Support patients/residents and or families in utilizing technology
- Read letters from loved ones
- Scribe letters to loved ones
- Receive digital photos from remote loved ones to share with the patient/resident
- Maintain a daily newsfeed that incorporates updates from both the patient/resident and their medical team to be shared with Care Partners.

Guidance for Memory Care Units

- [Tips on Person-Centered Dementia Care During COVID-19](#) (Person-Centered Universe)
- [CDC Guidelines for Memory Care Units in Long-Term Care Facilities](#)

Tools for Planning Changes to Policies

COVID-19 Impact on Patient- and Family-Centered Care Policies and Practices

- [COVID-19 Hospital PFCC Survey](#) (UCSF and University of Washington Schools of Nursing, and IPFCC)
- [Article: We've Been Here Before: Learning from the Lessons of the Past](#) (Institute for Patient- and Family-Centered Care)

Care for the Caregiver

- [Emotional Support for Healthcare Workers](#) (AHCA/NCAL)
- [Support Resources for NYP Employees](#) (NYP)

Additional COVID-19 Resources to Support Patients, Residents, Families, Staff, Leaders and Communities:

- [COVID-19 Guidance, Resources and Tools](#) (AMDA – The Society for Post-Acute and Long-Term Care Medicine)
- [Article: Even in Independent Living, Community is All-Important](#) (American Society on Aging)
- [COVID-19 Support Resources from American College of Healthcare Administrations](#) (ACHCA)
- [COVID-19 Information for Children, Young People and Families](#) (Children’s Health Queensland Hospital and Health Service)
- [Culturally Competent Healthcare: Lessons from a Safety-Net Hospital in the COVID Era](#) (Health City)
- [PFCC and COVID-19 Resources](#) (Institute for Patient- and Family-Centered Care)
- [COVID-19 and Patient- and Family-Centered Care: Frequently Asked Questions](#) (Institute for Patient- and Family-Centered Care)
- [Psychological Distress Caused by COVID and Measures to Put in Place](#) (Institut national d’excellence en santé et en services sociaux (INESSS) – Quebec)
- [COVID-19 Information and Resources](#) (ISQua - International Society of Quality in Health Care)
- [NQF Healthcare System Readiness](#) (National Quality Forum)
- [PFCC Partners Resources](#) (PFCC Partners)
- [Article: Culture in the Time of Pandemic](#) (Pioneer Network)
- [COVID-19 Resources on Person-Centered Care](#) (Planetree International)
- [COVID-19 Medical Planning Guide](#) (Prepare for Your Care)
- [Cultural Competency and COVID-19](#) (Quality Interactions)
- [Resources for Healthcare Professionals Coping with the COVID-19 Pandemic](#) (Schwartz Center for Compassionate Healthcare)

Additional Resources to Support Development of Family Presence Policies:

- [Better Together: Partnering with Families](#) (Institute for Patient- and Family-Centered Care)
- [Patient-Directed Visitation Primer](#) (Planetree International)