FAMILY PRESENCE POLICY DECISION-MAKING TOOLKIT FOR NURSE LEADERS

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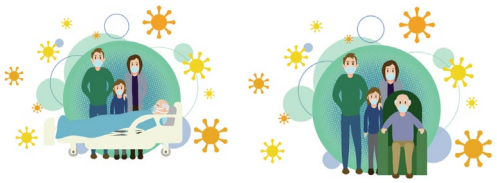

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INTRODUCTION

"As nurses, we know that family presence is critical to generating and continuing the healing process. We must recognize it as fundamental to our obligation in the healing continuum and the healing environment to be advocates for that. My hope, as a nurse, is that this now moves to something definitive, so that it becomes a part of our deliberation whenever we establish standards of nursing practice."

– Tim Porter-O'Grady, DM, EdD, ScD (h), APRN, FAAN, FACCWS, Clinical Professor, Nell Hodgson Woodruff School of Nursing at Emory University

The COVID-19 outbreak has exposed the fragility of partnerships with patients, residents and families* during times of crisis in our healthcare system. This has been particularly evident as it pertains to engaging family caregivers – or Care Partners – as essential members of their loved one's care team. Since the onset of the crisis, healthcare systems have attempted to manage the spread of transmission by enacting restrictive policies that limit family members' physical presence in care settings. These policies have compromised Care Partners' abilities to participate actively in supporting and caring for their loved ones and have contributed to growing moral distress among nurses and other staff.[1]

These restrictions have largely focused on mitigating infection control risks associated with family members' physical presence in facilities. They have largely overlooked, however, the risks to patient/ resident safety and well-being when individuals are separated from those who know them best at times of heightened vulnerability. Notably, many of these policy changes have been implemented with little input from those who would ultimately be most affected by them – patients, residents, family members and nurses whose professional obligations call on them to advocate for the best interests of those in their care.

The risks associated with restrictive family presence policies are well documented, and include risks to patient safety, cognitive functioning, psychosocial well-being, preparedness for discharge, and moral distress among caregivers.[2-9] These unintended consequences underscore that in many instances, limiting connection to family to only virtual visits is often *not* in the best interest of patients/residents and can further social and health inequities.

The potential for adverse outcomes when Care Partners are distant observers versus engaged members of the care team is considerable, including preventable harm, physical and cognitive decline, poor transitions of care and communication gaps. Given this, in many cases the risks of restricting family presence may very well outweigh the risk of virus transmission. The long-term consequences of these policies on patient/resident, family and staff outcomes are unknown but are likely to be significant.

At the onset of the outbreak, there was limited knowledge and little guidance to support healthcare systems in making fact-based adjustments to their family presence guidelines. **We believe the unfortunate unintended ramifications of those early decisions can be prevented in the future with an evidence-informed, transparent, data-driven and person-centered decision-making framework that nurse**

* *Family* as defined by the patient/resident. Family members may include relatives and non-relatives.

leaders and other decision-makers can use to support safe family presence in any health care setting, including (but not limited to) hospitals, long-term care communities, inpatient rehabilitation facilities, assisted living and behavioral health settings.

I am an integral part of the care team working with you and the team for a common goal – the health, safety and comfort of my son. I'm the consistent part through shift changes, noting treatments and medications and watching for irregularities. I have key information and insights to share. I rephrase or translate the medical information into a form that is best understood by my son. I am the extra set of eyes. In all these ways, I support my son's safety and yours as you accomplish your vital work with greater effectiveness, efficiency and safety." – Lisa Keitel, Care Partner

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About the Toolkit

This Family Presence Policy Decision-Making Toolkit was developed by a coalition of nurse leaders, patients/family/elder advocates and other clinical and non-clinical partners. Its foremost intent is to appropriately support family presence in healthcare settings through an evidence-informed, transparent, data driven and person-centered process of decision-making. The framework is meant to drive organizational dialogue to better understand the benefits and risks of family presence. This dialogue then positions decision-makers to establish and modify policies in consideration of a broad range of factors, including local conditions, current evidence and equitable impact. The toolkit was created to be used:

- By nurse leaders and other decision makers – with the understanding that the evaluation of the factors will include input from key stakeholders, including nurses at the point of care and patients/residents and families.
- To guide a process for assigning levels of Care Partner access across the organization as conditions change. Teams are encouraged to use the tool proactively to establish family presence policies that respond to current conditions independent of individual cases. This minimizes the influence of more subjective judgments in case-by-case family presence determinations. When decisions about family presence vary from one case to another, it may heighten disparities and add to staff burden.
- During any time of crisis that may strain the healthcare system, not just during this current crisis.

"We have an obligation to prioritize relational care as reflected in our code of ethics by respecting the uniqueness and dignity of every person and treating everyone fairly." – Cynda Hylton Rushton PhD, RN, FAAN, Anne and George L. Bunting Professor of Clinical Ethics, Berman Institute of Bioethics/School of Nursing, Johns Hopkins University

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Underlying Assumptions

1. As members of the leadership team, nurse executives are organizational decision-makers with the authority and responsibility to act in the best interest of patients/residents, families and their organization. It is incumbent on nurse leaders to use their influence and authority to advocate for the importance of family presence to the healing process.

2. Care Partners are essential members of the care team who partner with (and do not replace) paid caregivers. They are integral to patient/resident care. 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 physical, emotional and/or psychological harm. A balanced approach for safely integrating Care Partners rests on the expectation that Care Partners will conform to evidence-based safety precautions and infection control guidelines.

3. Virtual visitation platforms alone are not sufficient replacements for the in-person presence of Care Partners and may increase inequities in care for those less able to use and/or access technology.

4. The safe establishment of family presence must take into consideration not only the safety and well-being of patients/residents and family, but also the safety and well-being of nurses and other staff. This requires sufficient resources to support the transition to broader access to Care Partners in ways that are not disproportionately shouldered by nurses at the point of care.

References

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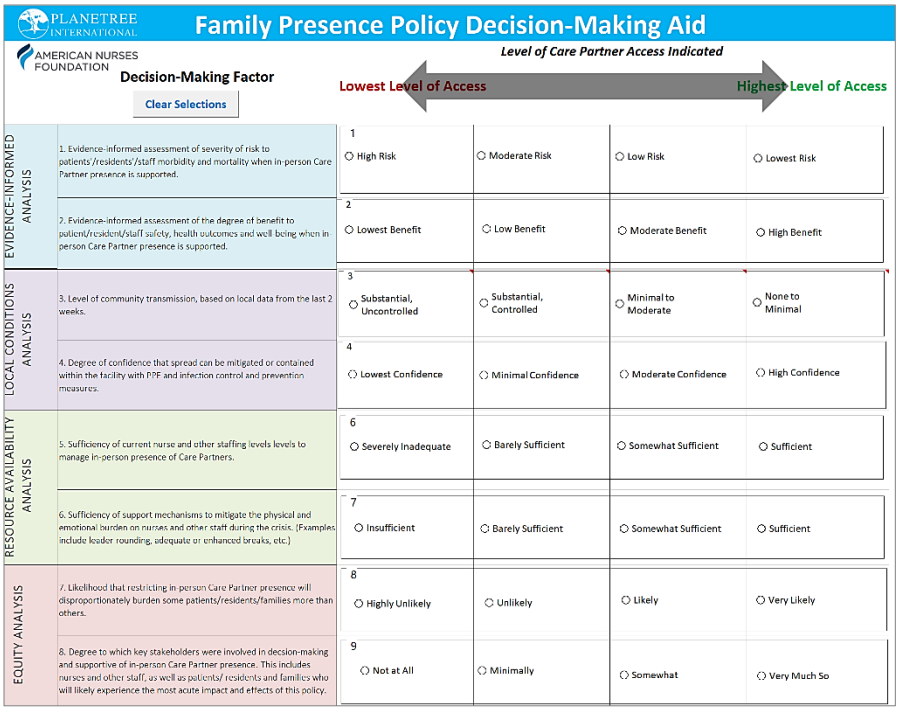
FAMILY PRESENCE POLICY DECISION-MAKING FRAMEWORK

The Family Presence Decision-Making Toolkit presents a framework that guides decision-makers in a wide-ranging dialogue with a broad stakeholder group. Together, stakeholders consider the impact of changes to family presence policies based on the four areas seen here. Decision-makers then draw on this dialogue to determine appropriate family presence guidelines for current realities.

The evidence base	Local conditions
Resource availability	Equity

To facilitate an evidence-informed, transparent, data-driven and person-centered decision-making process, teams begin with the discussion guide. This set of questions (see page 8) is provided to generate evidence and broaden the risk/benefit analysis of Care Partner presence under current conditions. Teams are encouraged to use the discussion guide to explore the issues and collect the data necessary to complete the decision-making aid *(pictured here),* which incorporates an abbreviated set of questions. (See recommended workflow.)



The decision-making aid features 8 questions. They are distributed across the four impact areas. This safeguards against decision-making unilaterally focused on just one impact area.

Direct link to download the decision-making aid:

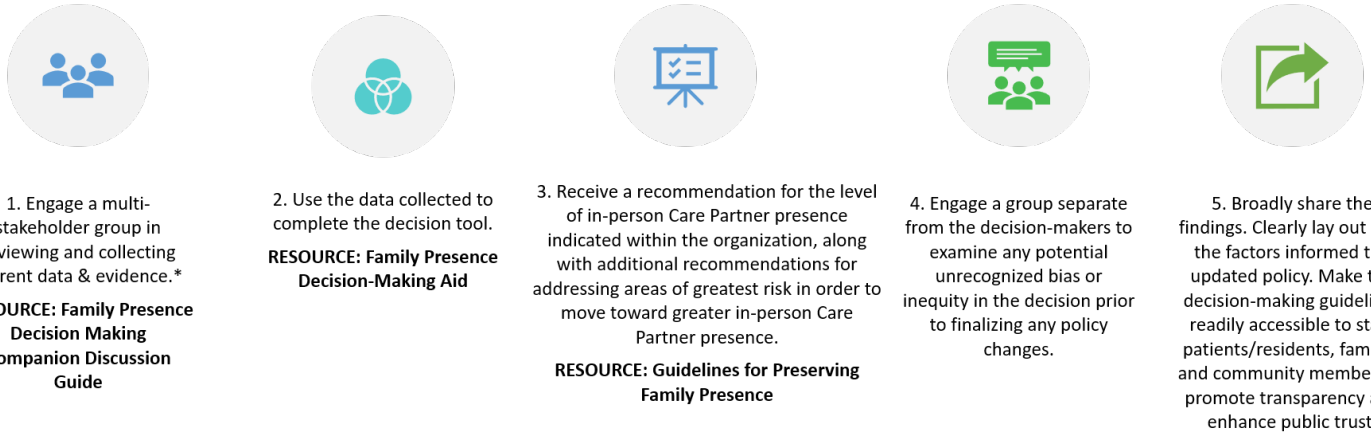
https://resources.planetree.org/wp-content/uploads/2021/04/PlanetreeFamilyPresenceDecisionAid-2021.xlsm

Decision-Making Aid Instructions for Use

Once you download the tool, for each question select the most fitting response for your organization. Each response is associated with a risk/benefit score indicating the degree to which the safety, quality and well-being benefits of the in-person presence of Care Partners outweigh potential risks. Higher numbers equate to conditions that support higher levels of access for Care Partners. Based on responses, a total score will be calculated. The score will generate a recommendation for the level of in-person Care Partner presence indicated based on all the factors addressed in the tool.

Note: the link provided here will take you to an Excel file to download. (If prompted, enable the macro.) The file is designed to generate a recommendation based on your responses. This functionality, however, requires that you complete the tool digitally rather than printing it out and completing a hard copy version.

Recommended Workflow



*What Applies as Evidence for Making Evidence-Informed Decisions?

Evidence informed decisions around family presence take into consideration:

- Local conditions
- The "lived experience" and expressed needs of patients/residents, family and staff
- Expertise from local, federal, and other authorities, and
- The best available evidence from research.

Family Presence Decision-Making Discussion Guide:

Questions to Guide Evidence-Informed, Data Driven and Person-Centered Decision-Making

These questions are provided to guide organizational dialogue and data collection with a broad stakeholder group when family presence policies are under review. As a first step in the decision-making process, teams are encouraged to use this discussion guide to explore these issues and collect the data that will be necessary to complete the decision tool, which incorporates an abbreviated set of questions.

1. Evidence-Informed Analysis.

- *What evidence supports restrictions to Care Partner presence to benefit patients/residents and/or staff?*
- *How strong is that benefit likely to be under current conditions?*
- *Is there any evidence that restricting Care Partner presence (either generally or for a specific population) could result in preventable harm to patients/residents and/or staff?*
- *How severe is the risk of harm likely to be under current conditions if Care Partner presence is restricted - either generally or for a specific population? (Consider, for instance, morbidity and mortality, harms of respect and dignity, compromised communication or decision-making, isolation, safety, patient/resident distress, lack of decisional capacity, end of life experiences, comprehension of treatment or diagnostic results, etc.)*
- *Are the proposed changes consistent with organizational practices and policies already in place to limit risk of transmission for other highly transmissible viruses spread in the same way (for example, via respiratory droplets or aerosols)?*

2. Local Conditions Analysis.

- *What is the current state of community spread (e.g., % of positive tests within past 14 days or increase in number of cases above accepted levels)?*
- *Has the local health department determined there has been a sudden increase in the number of infections in the local community or geographic area?*
- *What is the current rate of vaccination in the community?*
- *Can risk of spread within the facility be effectively managed with PPE and infection prevention and control measures?*
- *Does the proposed policy align with state and local mandates? If not, is there an opportunity to influence those mandates to align with evidence-based guidelines?*

3. Resource Analysis.

- *What is the availability of personal protective equipment (PPE)?*
- *What is the availability and accessibility of rapid testing?*
- *Are there sufficient material resources to support evidence-based safety and infection control measures?*
- *What is the availability of nursing staff to help manage and coordinate family presence?*
- *What is the availability of non-nursing staff, including chaplains, patient/resident advocacy personnel, patient/resident experience staff and security, to help manage family presence and address non-compliant visitors?*
- *What resources will be needed to adequately communicate the policy change to the patients/residents/families and the community?*

4. Equity Analysis.

- *Does restricting in-person Care Partner presence disproportionately benefit or burden some patients/residents/families more than others? (Consider, for instance, access to technology, language and cultural factors, cognitive barriers, age-related issues, mental health-related issues, complexity of health needs, etc.)*
- *Does restricting in-person Care Partner presence disproportionately benefit or burden some staff roles/departments/locations more than others?*
- *If yes, how can we lessen the discrepancies between the benefits and burdens created by these policy changes?*
- *What support mechanisms are available to lessen the physical and emotional burden on nurses during the crisis? (e.g., leader rounding, adequate breaks, etc.)*
- *Have we involved stakeholders who may most benefit and/or be most burdened by these policy changes in this consideration process?*

Sources of COVID-19 Guidance on Family Presence

- **CDC Updated Healthcare Infection Prevention and Control Recommendations in Response to COVID-19 Vaccination** (April 27, 2021): https://www.cdc.gov/coronavirus/2019-ncov/hcp/infection-control-after-vaccination.html
- **CDC Interim Infection Prevention and Control Recommendations to Prevent SARS-CoV-2 Spread in Nursing Homes** (March 29, 2021): https://www.cdc.gov/coronavirus/2019-ncov/hcp/long-term-care.html
- **Updated CMS Nursing Home Guidance with Revised Visitation Recommendations** (March 10, 2021): https://www.cms.gov/newsroom/fact-sheets/cms-updates-nursing-home-guidance-revised-visitation-recommendations
- **World Health Organization -- Infection prevention and control guidance for long-term care facilities in the context of COVID-19** (January 7, 2021): https://www.who.int/publications/i/item/WHO-2019-nCoV-IPC_long_term_care-2021.1
- **World Health Organization – Infection Prevention and Control During Health Care When Coronavirus Disease is Suspected or Confirmed** (June 29, 2020): https://www.who.int/publications/i/item/WHO-2019-nCoV-IPC-2020.4
- **CMS Hospital Visitation – Phase II Visitation for Patients who are Covid-19 Negative** (June 26, 2020): https://www.cms.gov/files/document/covid-hospital-visitation-phase-ii-visitation-covid-negative-patients.pdf
- **State & Territorial Health Department Websites:** https://www.cdc.gov/publichealthgateway/healthdirectories/healthdepartments.html

Summary of the Evidence Base Related to Family Presence During the COVID-19 Pandemic

Reference	*Findings*
Altarum. (October 2020). *Experiences of Nursing Home Residents During the Pandemic What we learned from residents about life under Covid-19 restrictions and what we can do about it*. https://altarum.org/sites/default/files/uploaded-publication-files/Nursing-Home-Resident-Survey_Altarum-Special-Report_FINAL.pdf	"The broader evidence in the literature, as well as our survey findings detailed in this report, suggest that social isolation has produced a devastating emotional impact on many residents—and that this has also translated into accelerated physical and mental health decline."
Hado, E., & Friss Feinberg, L. (2020). Amid the COVID-19 Pandemic, Meaningful Communication between Family Caregivers and Residents of Long-Term Care Facilities is Imperative. *Journal of aging & social policy*, *32*(4-5), 410–415. https://doi.org/10.1080/08959420.2020.1765684	Older adults residing in long-term care facilities are especially vulnerable for severe illness or death from COVID-19. To contain the transmission of the virus in long-term care facilities, federal health officials have issued strict visitation guidelines, restricting most visits between residents and all visitors, including family members. Yet, many older adults rely on family care for social support and to maintain their health, well-being, and safety in long-term care facilities, and therefore need to stay connected to their families. The federal government, state and local leaders, and long-term care facilities should take further actions to enable the relationship between residents of long-term care facilities and families during the COVID-19 pandemic.
Jones-Bonofiglio, K., Nortjé, N., Webster, L., & Garros, D. (2021). A Practical Approach to Hospital Visitation During a Pandemic: Responding With Compassion to Unjustified Restrictions. *American journal of critical care: an official publication, American Association of Critical-Care Nurses*, e1–e10. Advance online publication. https://doi.org/10.4037/ajcc2021611	No circumstance, even a global public health emergency, should ever cause health care providers to deny their ethical obligations and human commitment to compassion. The lack of responsive protocols for family visitation, particularly at the end of life, is an important gap in the current recommendations for pandemic triage and contingency planning. A stepwise approach to hospital visitation using a tiered, standardized process for responding to emerging clinical circumstances and individual patients' needs should be considered, following the principle of proportionality. A contingency plan, based on epidemiological data, is the best strategy to refocus health care ethics in practice now and for the future.
Oseroff, B. (June 18, 2020). Hospital Delirium and the Long Tail of COVID-19. *Harvard Medical Student Review.* https://www.hmsreview.org/covid/hospital-delirium	Hospitals and post-acute care facilities should consider how to develop new strategies to mitigate the delirium-related impact of COVID-19 in a way that is safe for health care workers, volunteers, families, and patients…. Allowing limited family and caregivers to visit would be an important step to reduce patient isolation and manage delirium. However, required personal protective equipment may limit the quality of in-person interactions and will likely contribute to further sensory impairment and disorientation for patients…[V]irtual visiting should only be a temporary substitute.

Reference	*Findings*
Reinhard, S., Drenkard, K., Choula, R., & Curtis, A. (July 2020). Alone and Confused: The Effects of Visitor Restrictions on Older Patients and Families. *AARP Blogs*. https://blog.aarp.org/thinking-policy/alone-and-confused-the-effects-of-visitor-restrictions-on-older-patients-and-families.	"Being in the hospital can bring out behavioral and psychiatric symptoms of dementia like fear and anxiety for older patients with cognitive impairment and lead to agitation on a normal day...During the pandemic, these issues are exacerbated especially when a family caregiver is absent."
Research, Analysis, and Evaluation Branch (Ministry of Health). (September 2020). *Impacts on Quadruple- Aim Metrics of Hospital Visitor Restriction During COVID-19*. https://esnetwork.ca/wp-content/uploads/2020/10/Evidence-Synthesis-BN-Quadruple-Aim-Metrics-of-Hospital-Visitor-Restrictions-16-OCT-2020.pdf.	No scientific evidence was identified about rates of transmission attributable to visitors. There is limited scientific evidence on the benefits or harms of visitors for COVID-19 patients in hospitals, but jurisdictional experiences reflect permissible visitor policies with accompanying public health measures and alternative communication modalities.
Research, Analysis, and Evaluation Branch (Ministry of Health). (September 2020). *Impacts on Quadruple- Aim Metrics of Long-term Care Facility Visitors Restrictions.* https://esnetwork.ca/wp-content/uploads/2020/10/BN_Quadruple-Aim-Metrics-of-LTC-Visitor-Restrictions_26-OCT-2020_v.1.pdf.	Overall, the scientific evidence linking visitors' and caregivers' presence in LTCFs to COVID-19 infection rates in LTCFs is limited.
Verbeek, H., Gerritsen, D. L., Backhaus, R., de Boer, B. S., Koopmans, R., & Hamers, J. (2020). Allowing Visitors Back in the Nursing Home During the COVID-19 Crisis: A Dutch National Study Into First Experiences and Impact on Well-Being. *Journal of the American Medical Directors Association*, *21*(7), 900–904. https://doi.org/10.1016/j.jamda.2020.06.020	These results indicate the value of family visitation in nursing homes and positive impact of visits. Based on these results, the Dutch government has decided to allow all nursing homes in the Netherlands to cautiously open their homes using the guidelines.
Valley, T. S., Schutz, A., Nagle, M. T., Miles, L. J., Lipman, K., Ketcham, S. W., Kent, M., Hibbard, C. E., Harlan, E. A., & Hauschildt, K. (2020). Changes to Visitation Policies and Communication Practices in Michigan ICUs during the COVID-19 Pandemic. *American journal of respiratory and critical care medicine*, *202*(6), 883–885. https://doi.org/10.1164/rccm.202005-1706LE	Restricted visitation may inadvertently exacerbate preexisting disparities.
Voo, T. C., Senguttuvan, M., & Tam, C. C. (2020). Family Presence for Patients and Separated Relatives During COVID-19: Physical, Virtual, and Surrogate. *Journal of bioethical inquiry*, 1–6. Advance online publication. https://doi.org/10.1007/s11673-020-10009-8	This paper will examine ethical issues with three modes of "family presence" or "being there or with" a separated family member during the current COVID-19 pandemic: physical, virtual, and surrogate. Physical visits, stays, or care by family members in isolation facilities are usually prohibited, discouraged, or limited to exceptional circumstances. Virtual presence for isolated patients is often recommended and used to enable communication. When visits are disallowed, frontline workers sometimes act as surrogate family for patients, such as performing bedside vigils for dying patients. Drawing on lessons from past outbreaks such as the 2002-2003 SARS epidemic and the recent Ebola epidemic in West Africa, we consider the ethical management of these modes of family presence and argue for the promotion of physical presence under some conditions.

Evidence in Support of Family Caregiver Presence

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RESOURCES

- Person-Centered Guidelines for Preserving Family Presence in Challenging Times
- Sample Care Partner Program Brochure (Hospital)
- Sample Care Partner Agreement & Safe Visiting Practices (Long-Term Care)
- Sample Care Partner Education on Safe Visiting Protocols

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