1. Purpose and aims

The *Care Partners in Hospital Settings: Considerations for COVID-19 Guidance Document* (Care Partners Document) has been developed to provide guidance and recommendations for decision-makers and hospital healthcare workers. The purpose of the document is to support safe and responsible involvement of care partners in hospitals during the COVID-19 pandemic.

Care partner: A caregiver nominated by the patient who agrees to take responsibility to support feeding, mobility, personal hygiene, cognitive stimulation, communication, meaningful connection, relational continuity and/or assistance in decision-making for a person with limitations in their physical, cognitive or psychological functioning. This may be a family member, care support worker or other support person.

The document aims to:

- Acknowledge the important contributions of care partners to the health and well-being of hospital patients
- Acknowledge that the presence of care partners in the healthcare setting should be seen as a benefit to safety, not just as a risk
- Highlight the negative impacts of visitor restriction policies on well-being of patients, care partners and staff and provide guidance on mitigation
- Support the safe and responsible involvement of care partners
- Recognise the complex trade-off between competing risks
- Promote compassionate care for people with increased care needs

This guidance has been developed in consultation with:

- The Statewide Older Persons Health Clinical Network
- Council On The Ageing Queensland (COTA Queensland)
- Health Consumers Queensland
- Carers Queensland
- Palliative Care Queensland
- Queensland with Disability Network
- Queensland Clinical Networks Executive
- Statewide Dementia Clinical Network
- Statewide Infection Clinical Network
- Statewide General Medicine Clinical Network
- Statewide Child and Youth Clinical Network
- Chief Nursing and Midwifery Officer
- Ethnic Communities Council on Queensland
- Dementia Australia
• Queensland Emergency Department Strategic Advisory Panel
• First Nations COVID-19 response team
• COVID-19 Disability Services Clinical Advisory Group
• Health Service Chief Executive Forum
• Executive Directors of Nursing and Midwifery
• Executive Directors of Medical Services Forum
• Private Hospitals

The guidance is based on Australian and international resources regarding care for patients and care partners in hospital during the pandemic, and recognises the rapidly evolving nature of knowledge.

2. Scope

The guidance applies to acute and subacute inpatient and outpatient services of Queensland hospitals. It is designed to inform local hospital policies and has been developed in partnership with patients and care partners. The guidance should support decision-making but is not a mandate and does not replace clinical judgement related to specific circumstances.

3. Background

COVID-19 has been associated with disproportionate mortality and morbidity amongst people with older age, disability, frailty and/or co-morbidities. Hospitals may become sites of transmission between patients and staff and between health care workers. Stringent hospital visitor restrictions introduced to reduce these risks were justifiable early in the pandemic when there was limited information about transmission and limited supplies of personal protective equipment (PPE). However, these restrictions may increase the risk of unintended harm where patients do not have their care needs understood or met, resulting in distress and harm for patients, the staff caring for them, and their family and carers.

Restricting visitors to hospital is distressing for all patients, but particularly for younger children (because of their developmental dependence on family relationships); people with cognitive impairment (dementia, delirium, acquired brain injury or intellectual disability); those with communication difficulties (due to disability, impairment or linguistic diversity); and cultural groups with strong connections to family kinship systems, particularly Aboriginal and Torres Strait Islander people. The hospital environment may be stressful or frightening for these groups, especially when clinicians and care partners wear PPE.

Care partners make a major contribution to the care and well-being of many hospital patients, especially those with increased care needs due to medical complexity and/or disability. Some support roles may be accomplished using telephone or digital technology (e.g. aiding people who are unable to provide their own medical history or make their own care decisions). However, many contributions require physical presence including:

• Direct care provision (e.g. assisting and encouraging basic activities of daily living such as mobilising and eating)
• Assisted involvement in decision-making (e.g. providing trusted clarification of health assessments and advice for people with hearing or speech impairment or cognitive impairment)

• Clinical decision-making in paediatric practice is made in partnership with parents in the best interests of the child, with consideration given to their developing autonomy. Restricted visiting can impact the development of these therapeutic partnerships.

• Emotional support for those who have a heightened emotional response to the medical environment (e.g. people with cognitive impairment, psychiatric illness or past trauma)

• Presence during once in-a-lifetime events (e.g. birth and end of life).

Restricting these care partner roles may have serious implications for the patient, their care partners and healthcare workers. Patients may miss out on cares, leading to serious complications such as delirium, which further increases care needs and compromises outcomes. Patients may experience high levels of anxiety and fear, and those who have difficulty conveying their care needs (e.g. hearing or speech impairments, cognitive impairment, or cultural and linguistic diversity) may demonstrate behaviours that lead to the use of restrictive practices (including sedative medications) in a setting of heightened concern about disease transmission. This can result in distress and patient harm, and can lead to anxiety, guilt and moral distress in care partners.

Care partners who are not permitted to attend the hospital may receive limited information and be ill-prepared at the time of discharge for new tasks or responsibilities. The separation may contribute to their own isolation and anxiety, and not all are able to access technology-based communication portals. Care partners may experience complex grief if the patient deteriorates and dies under care, and separation may contravene important cultural practices without loved ones being able to comfort them at the bedside. Healthcare workers already stressed by uncertainty, rapid practice changes, risks to their own health, and staffing shortages are expected to shoulder significant additional physical and emotional care for their patients. They are also expected to facilitate virtual connection between patients, families and other healthcare workers, often with limited available digital technology and skills.

Compassionate care and human rights must remain strong guiding principles during public health emergencies. The delicate balance between dignified and high-quality person-centred care while upholding appropriate infection control measures may change depending on rates of community transmission, staff resourcing, and individual circumstances.

The principles outlined in this guidance aim to support person-centred local policy for continued involvement of care partners in hospitals. Decision-makers and clinicians must consider on a case by case basis whether restrictions to care partner presence and participation creates a safety risk, clinical risk or emotional risk to the patient that may outweigh that of COVID-19 transmission, along with how the presence of care partners could be safely and responsibly supported.

4. Guiding Principles

The principles that form the foundation for this document are as follows:
1. Care partners are distinct from casual visitors and need to be clearly identified as active and essential members of the care team
2. Care partners are nominated by the patient (or their substitute decision-maker) to meet the patient’s specific needs and must be willing and able to commit to the care partner role. The care partner may change over time or under different circumstances
3. Health services acknowledge the expertise of care partners and their knowledge of the person, their person-centred care needs, behaviours which are normal for them, and signs of distress, pain or deterioration
4. Hospitals should facilitate safe and responsible care partner participation, where possible, which minimises risk to health and well-being of other patients and staff
5. Hospitals have a responsibility for the wellbeing of care partners as well as patients
6. Care partners are obliged to comply with hospital infection control and Personal Protective Equipment (PPE) policies and requirements
7. Staff, patients and care partners must be clearly informed of their rights and responsibilities regarding hospital attendance
8. Decisions regarding care partners should be:
   8.1. Patient-centred and based on individual need and competing risks
   8.2. Applied with compassion and consideration of individual circumstances, including cultural, emotional and spiritual needs as appropriate
   8.3. Adapted based on community transmission conditions and hospital resources (e.g. availability of PPE, staffing and space)

5. Recommendations

Hospitals should work in partnership with consumers and Aboriginal and Torres Strait Islander Hospital Liaison Officers and other appropriate consumer advocacy groups to develop systems to:

1. Identify patients where the involvement of a care partner is an important contributor to care and wellbeing. Examples include children and young people including those with chronic conditions and developmental and mental health disorders, adults with functional or cognitive impairment, major mental health conditions/psychosocial disability, behavioural and psychological symptoms of dementia (BPSD) or intellectual disability, adults with complex home treatment regimens and people at end of life, as well as those receiving palliative care
2. Ensure all children have the right to have a parent, guardian or carer present
3. Support these patients (or their substitute decision-maker if appropriate) to nominate one or more care partners who are readily contactable, have adequate means of transport, and are able to take on the responsibilities of the role
4. Provide clear information about the rights, responsibilities, benefits and risks to potential care partners and respect their autonomy regarding accepting or declining the role.
5. Provide appropriate care partner screening in line with local hospital and public health policy
6. Provide clear identification to be used within the hospital, and maintain records of entry as required by public health policy
7. Provide nominated care partners with clear information and support to meet their infection control responsibilities safely (e.g. provide training in handwashing and provide appropriate PPE, provide clear designated pathways through the hospital to minimise traffic, provide clear guidance about the number of care partners permitted in a given space)
8. Provide appropriate orientation and support for care partners to fulfil their role (e.g. sleeper chair for overnight stays, appropriate access to food and drinks, access to appropriate facilities for self-cares, access to appropriate interpreter and/or culturally sensitive services, information about clinical deterioration processes and Ryan’s rule)
9. Manage individual exemptions on a case-by-case basis
10. Provide transparent systems for dispute resolution
11. Address situations where care partners fail to meet their responsibilities, in particular if they ignore or defy public health infection control or safety requirements
12. Review policies whenever community transmission or hospital conditions change and communicate changes to staff, patients and their care partners in an accessible manner
13. Consider facilitating virtual arrangements where a care partner is unable to be present in person but would still like to contribute in a meaningful way e.g. if care partner has compromised immune system.

6. Related Documents
6.1. Standards, procedures and guidelines


7. Definitions

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<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tr>
<td>Patient</td>
<td>Inpatients and outpatients receiving acute or continuing care in Queensland hospitals.</td>
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<td>Care partner</td>
<td>A caregiver nominated by the patient who agrees to take responsibility to support feeding, mobility, personal hygiene, cognitive stimulation, communication, meaningful connection, relational continuity and/or assistance in decision-making for a person with limitations in their physical, cognitive or mental functioning. In the case of infants, children &amp; young people this is a parent, guardian or nominated carer. This may be a family member, care support worker or other support person.</td>
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<tr>
<td>Disability</td>
<td>A permanent or long-term impairment which affects an area of function such as: cognition/intellectual; physical; neurological; psychosocial; or sensory function. 2) Disability</td>
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<tr>
<td>Term</td>
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<td>Family</td>
<td>Any support person defined by the patient as family, including friends, neighbours, community members and/or relatives.</td>
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<td>Substitute decision-maker</td>
<td>A person authorised to make medical decisions on behalf of the patient, if they lack capacity. They may or may not be a family member or care partner and may designate someone other than themselves as care partners.</td>
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<td>Visitor</td>
<td>Someone who is attending the hospital primarily for social reasons. This is to be distinguished from the presence of a care partner whose primary reason for attending is providing support managing health and well-being needs.</td>
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<td>Acute care</td>
<td>Care in which the intent is to perform surgery, diagnostic or therapeutic procedures in the treatment of illness or injury. Management of childbirth is also considered acute care.</td>
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<td>Subacute care</td>
<td>Subacute care is health care for people who are not severely ill but need: support to regain their ability to carry out activities of daily life after an episode of illness, help to manage new or changing health conditions, assistance to live as independently as possible.</td>
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<tr>
<td>Inpatient</td>
<td>A patient who lives in hospital while under treatment.</td>
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<td>Outpatient</td>
<td>A patient who attends a hospital for treatment without staying there overnight.</td>
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<td>Moral Distress</td>
<td>Distress experienced when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action.</td>
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<td>Personal Protective Equipment (PPE)</td>
<td>Equipment worn to minimise exposure to hazards that have the potential to cause serious workplace injuries and illnesses.</td>
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8. References and resources

1. Frampton S, Agrawal S, Guarcello S. Guidelines for family presence policies during the COVID-19 pandemic. JAMA Health Forum July 6 2020 accessed July 30 2020 at https://jamanetwork.com/channels/health-forum/fullarticle/2768108?utm_source=facebook&utm_campaign=content-shareicons&utm_content=article_engagement&utm_medium=social&utm_term=070920&fbclid=IwAR0ND88H1cQLR59hb04DDaMX3zb9HZ-P0liy3k0MgnrMEFzzYzhuUIKs#XwrcXfh4-iLE.facebook


9. Version Control

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<td>Draft document reviewed by stakeholders. Feedback incorporated.</td>
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<td>Comments and feedback were considered by the author of the document and additional changes were made.</td>
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<td>Document reviewed by the COVID-19 Disability Services Clinical Advisory Group (DCAG). Feedback obtained and incorporated into the text.</td>
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