

# Palliative Care in the COVID-19 Pandemic

## Briefing Note

# How People with Pre-Existing Palliative Care Needs are Affected by the COVID-19 Pandemic

### Issue

The urgent need to scale up social and clinical support for adults and children with pre-existing palliative care needs during the COVID-19 pandemic.

### Background

Palliative care (PC) is a holistic approach to care that encompasses the medical, physical, emotional, psychological, spiritual, social and practical needs of patients and their caregivers. Adults and children needing PC, especially in lower- and middle-income countries, often face difficulties in accessing the required services. Their particular vulnerability during the COVID-19 pandemic is exacerbated by their inability to access all needed services, treatments, medications, and support for managing life-threatening illness and serious health-related suffering (SHRS).

### Key Facts

- Patients with PC needs include those with life-threatening, life-limiting, chronic or acute infectious disease illnesses, which may include cancer, HIV/AIDS, neurodegenerative disorders (including forms of dementia), progressive neuromuscular diseases, metabolic disorders, terminal organ failures, cardiac or respiratory conditions, liver conditions, COVID-19 and others. Approximately 21 million children globally have palliative care needs.<sup>1</sup>
- Patients with PC needs are often invisible to mainstream society and are 'left behind' by healthcare advocates and policymakers. Many patients fear that mainstream society sees their lives as not 'worth saving'.
- Understanding of the value of palliative care remains limited and patients often access services very late in the disease course;
- People with PC needs fear being left alone, isolated from family members and carers, including at the end of life; parents are worried that they will be prevented from accompanying children who may have to be hospitalised and isolated;
- Access to communications technologies and devices is not universal, and patients with PC needs often have limited inability to use devices to stay in touch with loved ones and the outside world;
- Shortages of personal protective equipment (PPE) limit patients' ability to protect themselves, their families and external care professionals (who may be employed directly by the patient). This may force the removal or reduction of outside support, putting pressure on family members or friends to provide care to their loved one and isolate with them.

[1] Estimating the Global Need for Palliative Care for Children: A Cross-sectional Analysis, Connor, S R., Downing, J., Marston, J., 2017.



## Current Status

- Patients are having trouble accessing and paying for medications and supplies; non-oral or highly specialist medicines are increasingly scarce; quarantines are preventing patients from collecting medications and related supplies from hospitals, pharmacies or providers.
- COVID-19 is exacerbating long-standing issues relating to availability of opioid medications in many health systems; including as-needed, hospital-based or home-care interventions such as palliative radiation, ascites tap, intravenous or subcutaneous infusions, wound care or specialist palliative procedures.
- Patients and families are facing challenges with practical issues such as suitable housing or accommodation, access to affordable food and other products including basic hygiene items, travel for medically necessary outings, and household income whilst family members (including parents of children with PC needs) unable to work as a result of lockdowns.
- Isolation, including lack of human or familial contact is aggravating social, emotional and psychological needs due to anxiety and distress related to fear of contracting COVID-19 in their already-frail state; individuals with a learning disability or autism on top of PC needs, have additional difficulties understanding and coping with the situation.
- Confusion and fear around what treatments hospitals will provide people with pre-existing PC needs if they are infected with COVID19, prevails;
- There is a vacuum of reliable information: guidances have been provided, withdrawn and changed in some contexts and not provided in others;
- Limited resources are forcing difficult frontline clinical decisions that may mean many with pre-existing PC needs are denied intensive or life-prolonging interventions if they were to become infected with COVID-19 or suffer another life-threatening illness during the pandemic. Some health systems are enforcing DNACPR (Do Not Attempt Cardiopulmonary Resuscitation) orders as a standard protocol without considering individual cases.

## Recommendations to UN member states and civil society organisations

- Provide patients with the information necessary to keep themselves safe and to continue to maintain optimal management of their symptoms and conditions, as self-care is vital at this time.
- Continue to support patients even when physical presence is not possible, by telephone or video consultations and check-ins, and to ensure visits are available when medically necessary (with appropriate PPE).
- Ensure access to medications and support patients to access them, including by providing financial assistance and subsidies;
- Ensure patients receive alternative interventions or medicines to alleviate symptoms and to manage or control their condition as necessary when standard interventions are unavailable;
- Only raise DNACPR with patients in situations where it is clinically beneficial; ensure conversations involve an open discussion and shared decision making. Decisions cannot be imposed.
- Keep this patient group at the forefront of our minds, as they are the hidden victims of this pandemic. Their health needs and symptoms remain throughout the pandemic as they existed before it, and indeed may well be exacerbated by it.
- Ensure people with existing palliative care needs, and in particular children, are accompanied according to their wishes, including during necessary hospital visits and at the end of life.

### References

- 'Make Every Child Count', (2020) Fraser, L. Gibson-Smith, D. Jarvis, S. Norman, P. Parslow, R.
- <https://www.togetherforshortlives.org.uk/wp-content/uploads/2020/04/200415-Prevalence-report-Final.pdf>
- Estimating the Global Need for Palliative Care for Children: A Cross-sectional Analysis Stephen R. Connor, PhD, Julia Downing, PhD, Joan Marston, RN, MA <https://doi.org/10.1016/j.jpainsymman.2016.08.020>
- Alleviating the access abyss in palliative care and pain relief - an imperative of universal health coverage: The Lancet Commission report.

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