# Palliative Care in the COVID-19 Pandemic Briefing Note Psychological and Spiritual Impact of COVID-19 on Children wtih Palliative Care Needs

#### Issue

The psychological and spiritual impacts of COVID-19 on children with palliative care needs are significant, with children being isolated, fearful, anxious, and unclear and uncertain about what is happening at home, in their community and around the world.

# Background

The high transmissibility of COVID-19 has prompted a global response. Isolation measures will most severely impact the most vulnerable members of society, including children with palliative care needs, complex medical conditions, or mental illness. Children and families lacking access to electronic media will suffer isolation more profoundly. This Briefing Note offers recommendations regarding the mitigation of the psychological and spiritual impact of COVID-19 on children.

## **Key Facts**

- Physical distancing and other protective procedures are in place around the world.
   Extended quarantine has negative psychological effects, many of which may be long-lasting.
   Associated rules and precautions, including wearing protective uniforms and performing procedures, create undue stress that can be mitigated by compassionate communication.
- The global COVID-19 pandemic is causing widespread fear and stress in adults; children also have fears of dying, their relatives dying, of the actual infection and access to medical care. School closures disrupt routines, a sense of

structure, and peer support, all of which impact on well-being in a significant way.

Some children live in poor, high-density or remote areas, with little access to water or sanitation and may not have a family or a safe place to live. Children with parents may seek more attachment, placing demands on parents stressed by the pandemic. Knowledge gaps in children and families may promote irritability and anger, increasing the risk of verbal and physical abuse within the home. This time of uncertainty and elevated risk may go on for an indeterminate period.

### **Recommendations to UN member states and civil society organizations**

Consider the age of children, young people and those with profound and multiple learning difficulties (PMLD), acknowledge and normalise their anxiety and fears, empower them with age-appropriate information and offer a supportive presence through telephone, WhatsApp, social media etc. Resources such as "My Hero is You: How kids can fight COVID-19', (available in >30 languages) '<u>The Story of the Oyster and the Butterfly: The Corona Virus and Me'</u>, 'Q is for Quarantine: The ABCs of Coronavirus', 'Los Días en que todo se detuvo' and '<u>Hablando con los niños cuando un familiar esta enfermo</u>" or others in your national language may be helpful. A calm parental demeanour is powerful. Encourage use of materials such as the My 2020 COVID-19 Time Capsule to help children document their experience to share with friends and families once social restrictions are lifted. Encourage children to find positive ways to express feelings such as fear and sadness. Engaging in a creative activity, such as playing









or drawing can introduce a sense of inclusion, safety, structure and mastery, all of which are beneficial. Honesty and trust, humility, self-compassion, safety, sensitivity, connection, preparedness, community-building, recognition of death as a part of the lifecycle and legacy are vital at this time. Creative approaches to protective gear may make it more child friendly. Provision of mental health services should continue throughout this pandemic, using social media and other technology such as tele counselling and group discussions.

- Seek information from trusted sources so that practical steps can be taken. Balance is very important; positive
  and hopeful stories may create a positive environment. Maintain familiar routines in daily life as much as possible,
  or create new routines, especially if children must stay at home. Activities that promote learning and a sense of
  belonging are beneficial.
- Encourage a child's expression of spirituality through a search for meaning and purpose, and through connectedness to themselves, to others, to nature and to a Higher Being. Older children and adolescents may look for the meaning and purpose behind all that is happening. Allow spiritual expression through words, poetry, story-telling, art, dance, play and music; promote communication and interaction with others; build the child's self-confidence; spend time enjoying nature or bringing plants and animal into the home; assist them to participate in meaningful religious rituals and prayers; and ensure they feel safe, valued and loved.
- Manage searching questions when a child is dying, either with COVID-19 or from their pre-existing life-limiting condition, with truthfulness and compassion.
- Support the family throughout the illness and bereavement through compassionate use of technology. Leverage technology for pastoral care, grief and bereavement support.
- Train health workers in communication skills commonly used in palliative care and support.

#### References

- WHO. Mental health and psychosocial considerations during the COVID-19 outbreak.
- WHO. Mental health and psychological resilience during the COVID-19 pandemic.
- Marston J, Fogliati GA, Bauer RW. (2020) Spiritual Care In: Downing J (Ed). Children's Palliative Care: An International Case-Based Manual. Springer. UK.
- Weaver MS and Wienner L. (2020) Applying Palliative Care Principles to Communicate with Children about COVID-19. Journal
  of Pain and Symptom Management. Doi: <u>https://doi.org/10.1016/j.jpainsymman.2020.03.020</u>.
- Brooks SK, Webster RK, Smith LE, Woodland L, Wessely S, Green berg N, Rubin GJ. 2020. The psychological impact of quarantine and how to reduce it: rapid review of the evidence. Lancet 395: 912-920.
- Kodde A, Juffermans C en Roelofs E, huisartsen en kaderartsen palliatieve zorg

#### **Authors**

Downing J (ICPCN), Brand T (Umduduzi), Chambers L (Together for Short Lives), Daniels A (ICPCN), de Haan M (Kenniscentrum Kinderpalliatieve zorg), Ferguson J Together for Short Lives), Hunt J (Palliative Care Consultant), Lacerda A (Portuguese Institute of Oncology, Lisbon Centre), Marston J (PALCHASE), Muckaden MA (Tata Memorial Centre), Nakawesi J (Mildmay Uganda), Okhuysen-Cawley R (Texas Children's Hospital), Palat G (MJN Institute of Oncology, Hyderabad), Phillips M (Perth Children's Hospital), Thompson S (Parent).