

Palliative Care in the COVID-19 Pandemic

Briefing Note

The Social Impact of COVID-19 on Children with Palliative Care Needs and their Families

Issue

The urgent need to understand the social impact of COVID-19 on children with palliative care needs and their families, in order to mitigate the impact and make provisions for ongoing support.

Background

Due to the nature of COVID-19 transmission, most countries have enacted measures to reduce transmission, affecting everyone's lives. Isolation measures most severely impact the most vulnerable members of society, including children with palliative care needs, complex medical conditions, or mental illness. Whilst in some parts of the world, children and their families have access to robust telephone and internet networks, along with technologies such as smartphones, tablets and computers, in other regions this is not the case, leaving children even more socially isolated from their friends and family. This Briefing Note offers recommendations regarding the mitigation and management of the social impact of COVID-19 on children with palliative care needs and their families.

Key Facts

- Physical distancing, shielding, isolation and quarantine are in place in many countries around the world. There are reports from quarantine of negative psychological effects, many of which may be long-lasting.
- Children with palliative care needs and their caregivers are often isolated from family members, friends, carers, schools and social support networks, and this isolation is only compounded by the threat of COVID-19 infection and the associated fear and anxiety.
- Families often rely on support from friends, family, schools and health and social care providers to care for their children. Due to the need for shielding and self-isolation, normal support systems are less available, and families can be left struggling at home to care for their children.
- Many parents looking after children with underlying serious health conditions are unable to work, creating serious financial difficulties for families. Arrangements for deliveries of medicines and food must be arranged, potentially for the long term. This is further compounded by difficulties in being able to reach other family members. Social workers need to be innovative in finding potential solutions.
- It is unknown when social restrictions will be lifted, with some anticipating physical distancing to be in place for 6-9 months or longer, potentially resulting in children and their families living with fear and anxiety for an indefinite period.
- Children and young people with palliative care needs, and their families, may not be able to have the end of life care previously planned e.g. the opportunity to make memories or have the funeral and send off, due to the COVID-19 pandemic. Families who have been caring for children and young people with serious underlying health conditions for many years have often had 'near misses' leaving them in fear of their child dying from COVID-19, potentially alone and in isolation.



- The sudden and constant stream of news reports about the pandemic can cause children to feel worried with this amplified through lack of social interactions with friends and family.
- Movement restriction increases the risk of

violence in homes. Home isolation provides power to the abuser with those being abused feeling more trapped and unable to escape. An increased demand for domestic violence services has been prompted by vulnerable families being together 24 hours a day within the home.

Recommendations to UN member states and civil society organisations

- Avoid separating children from their carers, whenever possible.
- Ensure that the child continues to receive care from other trusted individuals throughout the pandemic.
- Provide regular contact with parents and carers, through scheduled telephone, video calls or social media, where available. Identify innovative ideas for encouraging ongoing communication with family, friends, and peers.
- Address concerns in an honest, age-appropriate way. Self-regulation and emotion management strategies modelled by adults to children will help to mitigate risks.
- Encourage parents to find ways to discuss the pandemic with their child and explore their concerns using resources from reputable sources such as the [Harvard Health Literacy project](#), which are available in different languages.
- Limit the amount of time children are exposed to the news to help reduce stress.
- Share the following key messages with children: a) the adults in their lives are doing their best to keep them safe; b) there are things that children can do to feel in control and safe, like asking questions, washing their hands and staying home with their family; and c) emphasize and share that there are positive stories about COVID-19, e.g. people have recovered from the virus or are helping others during this difficult time, spreading kindness.
- Establish new routines as appropriate, to help children feel secure, providing time for them to express themselves through play.
- Ensure that all abuse helplines, for both children and adults, remain in service, and are accessible to those in need, along with shelters and other refuges.

References

- WHO. [Mental health and psychosocial considerations during the COVID-19 outbreak](#).
- University of Birmingham. [Contagion: The Economic and Social Impacts of Covid-19 on our Region](#)
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- [The psychological impact of quarantine and how to reduce it: rapid review of the evidence. Lancet 395: 912-920.](#)

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