



# Supporting Parents of Children with Palliative and Complex Health Care Needs in a Time of Crisis: A Health and Social Care System-wide Response



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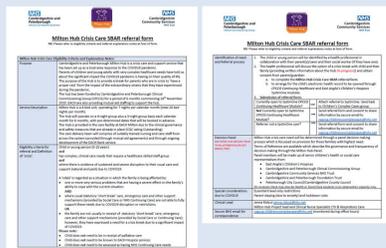
## Introduction

During COVID 19 pandemic children (CYP) with highly complex medical health care needs experienced crisis due to disruption in usual care. This collaboration project provided crisis led short break care (SBC) using system-wide health skilled staff in-reaching into a children's hospice.



## Methods

**Eligibility for service:** children (0-18 years) with complex needs requiring healthcare skilled staff and evidence of sustained / severe disruption to usual care due to COVID 19.



**Crisis defined as:** a situation affecting family ability to cope with current situation and, if usual SBC / support mechanisms not able to meet needs.

### Governance:

- All healthcare organisations conform to NHS Information Governance standards.
- Use of shared system of electronic record keeping (SystemOne).
- Referral Panel documents (and any subsequent documentation e.g. where further information or clarification is required / obtained) scanned to the electronic record
- Care planning processes in advance of stay
- Where any paper care records are used (e.g. Paediatric Early Warning Score chart, Medicines Administration Record, fluid chart) these will be scanned to the electronic record at the end of the stay.

**Evaluation:** Survey used to capture parent/carer reported expected measures on child admission to the Hub and repeated on discharge. Anonymous survey to capture staff feedback.

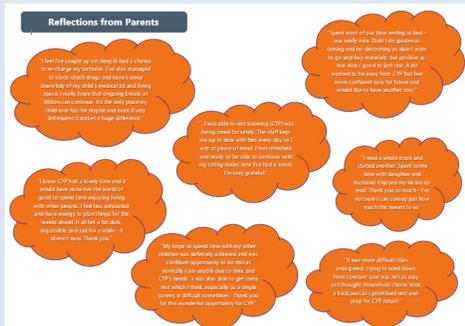
## Findings: Child and Family Experiences

50 CYP were considered for crisis care:  
9 CYP were declined by the Referral Panel  
8 CYP meeting criteria did not stay (deferred / died / unknown reason)

From 1.11.2020 to 31.10.2021:  
279 nights over 35 stays for crisis care were delivered to 33 CYP  
22 CYP received multiple stays.

**Quantitative feedback** on defined experiences noted agreement in admission and discharge responses: 59/65 achieved proper rest  
57/65 achieved good night's sleep  
55/58 achieved quality time with family members.

**Qualitative analysis** of parents hoped for achievements identified 5 themes: increasing trust in professionals; prioritising 'me' time; performing household tasks; break from alarms; socialisation for CYP.



## Findings: Workforce

Staff (n=37) felt useful and valued and felt able to make a difference especially during the pandemic. There was an increased sense of developing team working and support, and individual skill development.



## Learning and System Benefits

Vital support was given at a reliable location at times of extreme stress / anxiety to hard to reach families, with opportunity to develop trust in professionals.

Service provision challenges:

- Maintaining delivery of hospice 'usual business' i.e. end of life care provision
- Impact on choice of place of care for others needing end of life care
- Communicating and managing decisions when families were well known to the system who didn't meet eligibility
- Ensuring external professionals understood referral criteria
- Staff absence (sickness) was sometimes hard to cover
- Satisfactory induction to hospice processes for system wide staff
- Care planning in advance for safe care
- Distance and travel time for some families to get to the Hub
- Providing clarity about extend of service at the Hub e.g. play therapy, art, music and fun!



## Conclusion

There were mutual benefits gained from system team working, sharing information, assessment and care planning to form a holistic view of support for families either independently or as a planned intervention; including the clinical safety and observation at a time when many of the children were having less contact with schools and health care professionals face to face.

Positivity expressed by professionals at being able to offer a service to families in desperation.

*"...A break; my sanity; just to be 'me' for a short time; for my child to have a break..."*

## References

INSERT – QR code for newspaper articles and video link  
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