

Novel coronavirus (COVID-19) standard operating procedure

Children and young people with palliative and end-of-life care needs who are cared for in a community setting (home and hospice) during the COVID-19 pandemic

This guidance is correct at the time of publishing. However, as it is subject to updates, please use the hyperlinks to confirm the information you are disseminating to the public is accurate.

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Background

This publication has been written in partnership with the Association of Paediatric Palliative Medicine (APPM), which supports health professionals delivering paediatric palliative care, and Together for Short Lives (TfSL), the UK charity for children's palliative care, which has useful information on its website. A clinical reference group was established with professionals working across the community and hospice sector and gave feedback on this document. This publication should be used alongside local operational guidance and policies, and business continuity plans.

This publication is intended to support staff who are providing care or supporting children and young people (CYP) (and their families) who have palliative and/or end-of-life care (ELC) needs in the community (including home and hospice care).

It is essential that **all** providers of palliative care (statutory and voluntary sector) in each sustainability and transformation partnership or integrated care system work collaboratively across health settings to ensure an effective and co-ordinated response to this rapidly changing situation. This needs to be supported by commissioners with additional resources and governance arrangements required to provide the care and services needed.

Care delivery by children's hospice and palliative care community services

Priority for admission to hospice and hospice at home care support:

1. End-of-life care at home and hospice.
2. Supporting rapid discharge of children from hospital to community/hospice to support hospital services.
3. Support NHS intensive care and HDU capacity offering beds for stepdown/LTV to hospices, where possible.
4. Emergency respite and support for both health and social support.
5. Routine respite and support by hospice services.

Service models, where possible and available, consider:

- ways to work more collaboratively with other community services
- flexibility between in-house and outreach hospice service delivery
- telephoning/video-conferencing/virtual clinics with CYP and their families instead of face- to-face visits where a home visit is not essential
- the approach to care in supporting both COVID-19 positive/possible and COVID-19 negative CYP and their families within a hospice setting, including number of family members and access in and around the hospice
- increasing telephone support to identified vulnerable children and their families at home
- if there is any capacity to increase bed numbers and/or community capacity, where appropriate.

Service capacity, where possible, consider:

- redeploying staff from other currently non-essential services
- cancelling all non-essential home visits, meetings, teaching and education
- community hospice staff may need to look at supporting the in-house hospice service and vice versa
- collaborative and innovative working models between children's community nursing teams and hospice services to support ongoing care at home, eg offering a limited syringe driver daily change at home.

Anticipatory planning, where possible, consider:

- reviewing all CYP on the caseload and identifying CYP who are likely to require end-of-life care or may experience increased palliative care needs during this period (can use 'surprise question' or phase of illness assessment)
- specialist palliative care services to provide clinical leadership to support decision-making around care priorities and support provision
- how end-of-life care may be delivered for the individual CYP in the community setting
- reviewing and updating all advance and symptom care plans
- communicating with the CYP and their family about any possible or anticipated changes to previously discussed palliative care support at home

- alternative place of care or support, eg admission to the hospice for symptom control.

Home visits:

- consider if the home visit is essential
- ring ahead to inform the family of the process that will be followed (including the appropriate use of PPE)
- ask that essential family members only be present during the visit
- if a procedure is taking place, ask for a preparation space away from household members
- provide families with advice on limited discussions to ensure visit time is kept to a minimum; further discussion should be followed up in a telephone call after leaving the property.

Preventing delayed transfer from hospital

Where paediatric palliative services are available, they can often support rapid transfer, where appropriate, from hospital to a community setting, to support preferred place of care and death.

During the COVID-19 pandemic, community palliative care services:

- should engage with [COVID-19 hospital discharge service requirements](#) on the NHS England and NHS Improvement website
- may be the single point of contact to support and co-ordinate transfer from hospital to home; mainly for CYP requiring end-of-life care
- may engage and use virtual MDT to support and co-ordinate transfer.

Preventing avoidable admissions to hospital

- All palliative care and hospice services should regularly review all CYP on their caseload.
- Consider regular telephone contact to proactively manage concerns early.
- Ensure anticipatory end-of-life care medication is available or easily accessed for identified CYP.
- Ensure adequate prescriptions of CYP regular medication at home.

- Review advance care plans, symptom, emergency and escalation care plans and consider:
 - the interventions possible and appropriate at home before transfer to hospital
 - revisit discussions about purpose and benefit of hospital admission in the context of the child's current clinical condition
 - discuss an individualised approach to care and decision-making if the CYP were to become, or were suspected to be, COVID-19 positive and hospital admission is considered.

Respite care

Anticipatory planning

- Acknowledge the extraordinary situation, and for highly vulnerable CYP consider limited contact from multiple individuals to minimise the risk of contracting COVID-19 infection.
- Signpost families to sources of support such as Together for Short Lives.
- Professionals should provide telephone or video-conferencing support to families self-isolating, to ensure they are being supported and their needs regularly assessed.
- Consider proactive planning in the case where there is no forthcoming respite provision:
 - simplify the care plan, where possible, and focus on key care priorities for each CYP
 - identify responsible friends/family members who can be trained to be non-expert carers and start doing this now.

If the child's parent or household member has symptoms of COVID-19

- Signpost CYP and or family member to [Testing and tracing for coronavirus \(COVID-19\) - NHS](#).
- Where there are symptoms of COVID-19, ensure all staff have appropriate PPE, including for aerosol generating procedures where necessary, to deliver the care and support required in the home setting. Advice for professionals about the correct PPE can be found on [gov.uk](#). In addition, staff must also follow local policies and guidance.

Determining emergency respite care priorities

- Carry out an individual risk-based assessment on a case-by-case basis for providing emergency respite. The benefits and risks associated with an individual CYP staying at home with no care package or being admitted to a hospice/hospital/respite setting need to be considered alongside the current infection control risks in each clinical setting. With a reduced workforce, child-to-staff ratios may need to be markedly altered in various care settings.
- Priority should be given to those CYP with a high degree of clinical risk, eg requiring assisted ventilation, where the clinical situation is unstable or persistently difficult to manage, or social complexity is affecting the care of the CYP.
- Many of these children will meet the criteria for [children's continuing care \(CCC\)](#) and if so, will be entitled to a package of care that will depend on assessed need. However, not all families will choose to have CCC and some may have opted for a [personal health budget](#).
- Some families will choose not to have additional care and will manage the child or young person's needs themselves. However, these children may have a high degree of clinical risk, the family situation could change at any time and a care package may need to be introduced.

Staff/carer wellbeing

Staff will be experiencing increased emotional/psychological strain while delivering care. Their wellbeing must always be considered:

- each palliative care and hospice service should review and, where appropriate, enhance their support to staff
- consider video calls or teleconference to maintain usual mechanisms of staff support.

Resources

- Information on how you can protect yourself during the coronavirus pandemic can be found on [NHS.uk](#).
- Further information for healthcare workers is available on [gov.uk](#).
- PPE advice can be found on [these pages](#) of the NHS England and Improvement website.

- Access to NHS Supply Chain's delivery schedule is [here](#).
- Paediatric specialty advice is available [here](#).
- APPM clinical guidelines (four nations) are available [here](#)
- Royal College of Paediatrics and Child Health [guidance](#).

