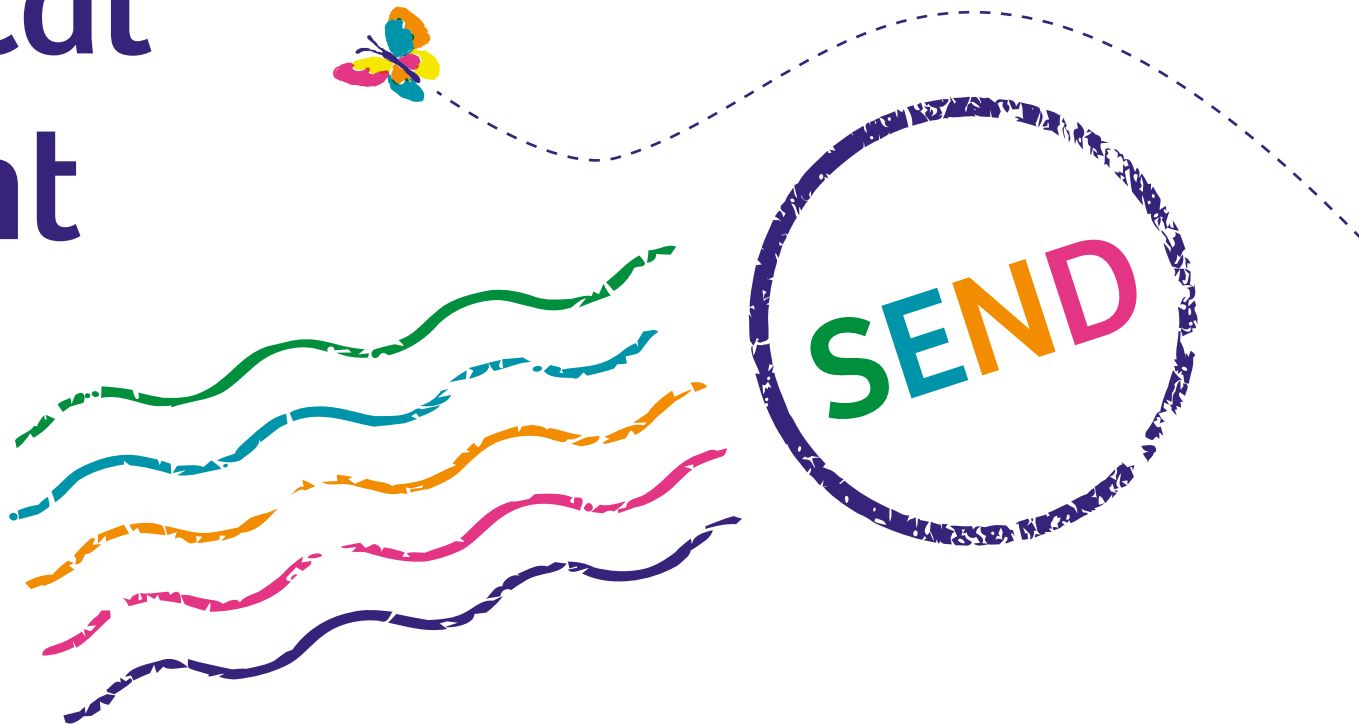


Special Educational Needs and Disability (SEND): Local engagement resource



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Introduction

This interactive resource has been developed by Together for Short Lives for voluntary sector providers of children's palliative care in England. We have produced this to help services identify and engage the people and organisations in their local health, care and education sectors who can be influential in bringing about more integrated assessments and services for children and young people with life-threatening and life-limiting conditions. They include commissioners, providers and other system leaders. Our resource includes:

- stakeholders maps
- advice on how to contact individuals and organisations
- suggested content for introductory emails and letters
- key messages about children's palliative care and life-threatening and life-limiting conditions in children.

Our resource is part of our two-year Department for Education-funded project to better engage children's palliative care in the reform to Special Educational Needs and Disability (SEND) in England. Through the project, we aim to make sure that:

- children and young people with life-limiting and life-threatening conditions are included in pathfinder testing and benefit from greater integration
- children's hospice and palliative care providers play an active role in supporting and pathfinders and in the delivery of the reforms
- schools and health and social care services are better equipped to support children with life-limiting conditions

We hope you find our resource helpful. For more information, please contact

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Stakeholder map

Please click on the image below to enlarge our interactive map which shows how local stakeholders across the health, care and education sectors relate to children who need palliative care and their families.



Stakeholder map – funding, service provision and accountability flows

Please click on the image below to enlarge our interactive map which shows how local providers across the health, care and education sectors are funded and held to account at regional and national levels.



Advice for children's palliative care services on engaging with local SEND stakeholders



Your objectives

In engaging with local SEND stakeholders, your service should consider aiming to achieve these objectives:

- Making sure that children's palliative care and the services that provide it are included in your local offer(s).
- Making sure that single assessments and Education, Health and Care (EHC) Plans can be accessed by all children with life-limiting and life-threatening conditions – and in particular those who use your service.

Make initial contact through a speculative email or letter

The stakeholder maps we provide as part of this resource contains many different individuals and potential points of influence. While contacting them all may at first appear to be a daunting task, it is often the case that forming a relationship with one, well-placed stakeholder will help you to making contact with others more easily. You can use the template messages as emails or letters for this purpose. Alternatively, draft your own based on our SEND key messages set out in this toolkit.

Invite stakeholders to visit your service

If you have not done so already, inviting your key local stakeholders to visit your service (where this is possible) could be an excellent way of showing what you do to support children with SEND. Some stakeholders – particularly locally-elected councillors – will be grateful for support in publicising their visit through local media. Consider inviting families who use your service to be part of the visit so they have an opportunity to speak about the direct impact of uncoordinated services.

Ask families and supporters to contact your local stakeholders too

Weight of numbers can be crucial in any campaign. If a local SEND decision-maker feels that local people are concerned about your service being excluded from your local offer – or that children with life-limiting conditions are not able to access the benefits of the SEND reforms – they are more likely to act. You could consider providing a template letter for families and supporters of your service to use in sending to local stakeholders. The more letters sent, the more effective your campaign will be.

Offer to support or join your local SEND programme board, change board or steering group

If you have capacity do so, offering to provide a representative to play a role on these bodies can help to bring about productive working relationships between your service and influential local stakeholders.

Hold an event at your city, county or town hall

You could consider organising an evening event at your local city, county or town hall(s), to which you could invite the individuals and organisations on the stakeholder map. This would enable people who use and work for your service to network with influential local stakeholders. You could focus the event on a series of short speeches, which could include a young person with a life-limiting condition talking about their experience of good integrated care (or lack of), a senior councillor and a senior representative from your service.



An alternative could be to ask about arranging a photographic exhibition about your service at your local town hall(s) over the course of a week or a few days. You could invite local stakeholders to drop in to the exhibition to speak to you about your service and how it can help the SEND reforms to be implemented locally. Your exhibition could coincide with a meeting of the full council to maximise your chances of speaking to your locally elected representatives.

Raise the profile of the work your service does locally for children with SEND

If your local decision-makers feel that an issue is receiving particular attention in your local media, they will be more likely to act. Through your public relations work locally, you could consider emphasising the role that your service plays in supporting children with SEND and why it should be included in your local offer. You might consider trying to identify case studies of children and families who use your service who:

- have endured adverse outcomes as a result of a lack of joined-up services, such as having to spend unreasonable amounts of time chasing different agencies for funding or securing services; or
- would benefit from single assessments and Education, Health and Care (EHC) Plans.

A local campaign could also provide an opportunity to involve the children and families who use the service – and your supporters – by inviting them to contact their local councillors about including children's palliative care in the local SEND reforms.

If you decide to do PR work as part of a campaign to engage with your local SEND stakeholders, we strongly recommend that you use a positive and constructive tone. Try not to be too critical of local stakeholders – this could

make them defensive and much less likely to engage with you. Emphasise that you are happy to work with your CCGs and local authorities to find a way of better integrating assessments, plans and services for children who need palliative care.

Co-ordinating and planning your organisation's local campaigning

The individuals within services who are responsible for engaging with local stakeholders vary between different organisations. Your service may wish to consider convening an internal campaign group which brings these individuals together. As a suggestion, this should include the individual responsible for statutory fundraising and a member of your communications or PR team. Also include the individual(s) who are responsible for engaging with political stakeholders. Use the group to map your service's local stakeholders.

Consider prioritising who to get in touch with by plotting stakeholders on a matrix depending on the influence they can have and the interest they have in your service. It can often help to assign individual responsibility for different stakeholders – and to keep a record of the contact you have with each one. Once you have determined who your stakeholders are, develop a plan for engaging with them.

Further information

This guidance should be read in conjunction with the **SEND Code of Practice** and the Department for Education's **guidance for implementing the SEND reforms**. Both provide further details of how the new SEND system should operate locally.

Key special educational needs and disability (SEND) messages



For children's palliative care services in England to use in engaging with their local SEND stakeholders

The following text could also form the basis of a briefing which you could share with stakeholders locally.

Why should children with life-threatening and life-limiting conditions have access to single assessments, Education, Health and Care (EHC) Plans?

We know from evidence that a disjointed system of care presents many challenges for families of children with life-limiting conditions. These families routinely deal with over 30 professionals from education, social care, health and other services. Communication between agencies is generally inadequate, leaving families burdened with the stress of navigating their way through an uncoordinated system.

This experience is common among families of disabled children. However, for families whose children's lives are likely to be short, time wasted navigating through the system in this way can be particularly distressing. As one parent said at a recent event:

"It's a minefield and you get frightened going through it. Services don't join up and people don't explain things to you. They don't tell you what all the services actually do. By the time I had made it all fit together my child had passed away – that makes me sad that he could have had so much more out of life".

All the evidence suggests that the best outcomes for children with life-limiting conditions and families are achieved when there is effective partnership working between parents and services and care is co-ordinated around the needs of the family.

It is vital that local authorities enable all children with life-limiting and life-threatening conditions to access single assessments and EHC Plans – including those without SEN. Under the Children and Families Act 2014¹, children and young people who do not require support in school or are not in education or training will not benefit from more integrated services – despite the significant amounts of time and effort that many have to commit to secure the care and support they need. This means that children with conditions such as cancer or cystic fibrosis will not benefit from single assessments and plans.

Why should CPC be included in local offers?

The SEND code of practice² states that, building on the Joint Strategic Needs Assessment, the local offer must include information about healthcare provision for children and young people with SEND. This should include:

- palliative and respite care and other provision for children with complex health needs
- provision for children and young people's continuing care arrangements (including information on how these are aligned with the education health and care planning process locally); and
- support for young people when moving between healthcare services for children to healthcare services for adults.

1. House of Lords and House of Commons 2013. Children and Families Act 2014. Available to download at: <http://bit.ly/1byqpa1> (Accessed on 18 December 2013).

2. Department for Education. *Draft Special Educational Needs (SEN) Code of Practice for 0 to 25 years: statutory guidance for organisations who work with and support children and young people with SEN* October 2013. Available to download at: <http://bit.ly/19S9fop> (Accessed on 18 December 2013).



As set out on the previous page, children with life-threatening and life-limiting conditions – and their families – need palliative care from a range of providers. By including all of these in local offers, local areas have an opportunity to help children and families better navigate the services they need. It would also help those families identify those services which are available to them, but of which they may not have previously been aware.

Why should children's palliative care be commissioned jointly by the NHS and local authorities?

Children who need CPC require holistic support which is currently arranged through health, social care and education. CCGs should consider commissioning CPC in partnership with local authorities to ensure an integrated service for children with life-limiting and life-threatening conditions. CCGs also need to be aware of the joint commissioning duties they must comply with as set out in the Children and Families Act 2014 with regard to all local children and young people with SEND.

CCGs and local authorities should also consider working in partnership with CPC networks and providers in the statutory and voluntary sectors, including children's hospices.

What are the outcomes that palliative care services can help to achieve for children with life-threatening conditions locally?

A comprehensive local CPC service can contribute to improving indicators set out in the Clinical Commissioning Group Outcomes Indicator Set (CCG OIS). These are the outcomes which CCGs must focus on; they are linked to the overarching NHS outcomes framework (NHS OF), which the Government sets for NHS England to achieve improvements against:

Domain one: Preventing people from dying prematurely

C1.1: Combined indicator on potential years of life lost (PYLL) from causes considered amenable to healthcare adults and children and young people (NHS OF 1a i & ii)

Domain two: Enhancing quality of life for people with long term conditions

C2.1 Health-related quality of life for people with long term conditions (NHS OF 2)

C2.2 People feeling supported to manage their condition (NHS OF 2.1)

Domain three: Helping people to recover from episodes of ill health or following injury

C3.4 Emergency admissions for children with lower respiratory tract infections (NHS OF 3.2)

Domain four: Ensuring that people have a positive experience of care

- Improving the experience of care for people at the end of their lives.
- Improving children and young people's experience of healthcare.
- Improving people's experience of integrated care.



A comprehensive local CPC service can also deliver improvements against indicators suggested for inclusion in the NHS Outcomes Framework and the CCG OIS by the Children and Young People's Health Outcomes Forum Long-term Conditions, Disability and Palliative Care Subgroup³:

- Getting a quality multi-disciplinary assessment that reflects all the child's or young person's needs, in addition to those of their family.
- Getting a quality package of care (including a health care plan for emergency situations or an end of life care plan where appropriate) fully integrated across health, education and social care with access to key working support, information to enable the child or young person and family to manage the condition and ensure timely provision of equipment to support maximum participation.
- Ensuring review of the care plan at key points of transition particularly transition to adult life and services.
- Ensuring that the outcome indicators promote a whole family approach because the health and wellbeing of family (carers) directly impacts on children and young people and their resilience.

What are the financial benefits of including children with life-threatening and life-limiting conditions in the local SEND system?

Effective, jointly commissioned and delivered CPC can play a cost-effective role in supporting early discharge for children from acute care settings through step-down care. It can also help to reduce unplanned admissions among children to acute care settings. The Government-commissioned funding review⁴ highlights that hospital admissions in the last year of life for children who need CPC cost an estimated £18.2m. This far outweighs the cost of providing CPC outside of the hospital setting. Research has also shown that short breaks provided by children's hospices – which may include healthcare interventions – help to reduce stress on families and demand on public services⁵. Bereavement services for parents and siblings before and following the death of a child can help to mitigate the need for other service interventions later in their lives.

Joining assessments, plans and services up around children and families can also reduce the strain caused by chasing otherwise disparate parts of the system. This in turn will reduce the risk of families reaching crisis-point.



3. Children and Young People's Health Outcomes Forum – Report of the Long-term Conditions, Disability and Palliative Care Subgroup (2012). Available to download at: <http://bit.ly/Zqlirl>.

4. Hughes-Hallett T, Craft A and Davies C (2011). *Palliative care funding review – creating a fair and transparent funding system*; the final report of the palliative care funding review. Available to download at <http://bit.ly/XQBIE7> (accessed 17 January 2013).

5. NEF Consulting (2009). *The social and economic value of short breaks*. Available to download at: <http://bit.ly/10VnUAG> (Accessed on 1 May 2013).



The NHS Kent and Medway Commissioning Support Unit states that an agreement between NHS West Kent CCG and EllenorLions Hospices to jointly fund 24/7 access to advice and support has led to:

- high parental satisfaction levels
- care provided closer to home
- 130 overnight hospital stays for children with life-threatening and life-limiting conditions prevented over a 12 month period.

Are there any other benefits of jointly commissioning CPC services and making them part of local SEND provision?

Commissioning a comprehensive CPC service will help CCGs to meet their duties under the Public Services (Social Value) Act 2012. Many voluntary sector providers of children's palliative care contribute charitable funds they raise towards patient care on top of the money that they receive from the local statutory sector. They also provide social value to the local community beyond the people they support.

How could I explain what children's palliative care (CPC) is?

Palliative care for children with life-limiting or life-threatening conditions is an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on enhancing quality of life for the child/young person and supporting the family. It includes managing distressing symptoms, providing short breaks and care through death and bereavement⁶.

Life-limiting conditions are those for which there is no reasonable hope of cure and from which children are expected to die. Life-threatening conditions or events are those for which curative treatment may be feasible but can fail.

CPC differs greatly from adult's palliative care. Whereas the majority of adults only need palliative care at the end of their lives, children with life-limiting and life-threatening conditions require palliative care over a much longer period, often from birth. It is common for their conditions to fluctuate and, as such, it is often much more difficult to identify when a child is moving into their end of life phase. Children with life-threatening and life-limiting conditions often have complex disabilities, while the range of health conditions which results in children requiring CPC is more diverse.



6. Together for Short Lives (2013). Definitions. Available to download at: <http://bit.ly/Z34i5s> (Accessed on 15 March 2013).



CPC is an approach to care which can be used exclusively or in conjunction with curative treatments. It can be defined by the following four categories⁷:

1. Life-threatening conditions for which curative treatment may be feasible but can fail – such as cancer or congenital heart disease.
2. Conditions where premature death is inevitable but where there may be prolonged periods where the child is well – such as Duchenne muscular dystrophy.
3. Progressive conditions without curative treatment options, such as Batten disease.
4. Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death – such as severe brain injury.

A comprehensive local CPC service spans health, social care and education. It is a whole-family approach and has the following characteristics:

- It is flexible and focussed on children, their parents and their siblings.
- It is accessible 24 hours a day, seven days a week, 365 days a year – from diagnosis or recognition to bereavement.
- Supports and enables children and families to choose the type, location and the provider of the care they receive and allows them to change their mind.
- It is not age, time or diagnosis specific – 15% of children who need CPC have no definitive underlying diagnosis .
- It is multi-disciplinary and multi-agency.
- It is accessible to people of different faiths, culture, ethnicity and locations.
- It includes pre and post-bereavement support for families.
- It is able to manage symptoms.
- It supports parents in caring for their children according to their needs and wishes.
- It supports and enables smooth transitions for young people with life-limiting and life-threatening conditions who move from children's to adult's services.

Specialised CPC, which includes functions such as managing complex symptoms and prescribing unlicensed medicines, is commissioned directly by NHS England⁸.



7. Together for Short Lives (2013). *A Core Care Pathway for Children with Life-limiting and Life-threatening Conditions*. Available to download at: <http://bit.ly/18Vd3JV> (Accessed on 20 June 2013).

8. NHS England (2013). *E03/S/h – 2013/14 NHS standard contract for paediatric medicine: palliative care particulars, schedule 2 – the services, A – service specifications*. Available to download at: <http://bit.ly/11yitVS> (Accessed on 20 June 2013).



Who needs CPC?

It is estimated that more than 40,000 children (0-19 years) in England in 2009/2010 were living with a life-limiting or life-threatening condition⁹. This represents a very small population in commissioning terms; evidence shows that these small populations make commissioning appropriate services difficult. As well as often being inefficient, it can also prevent effective strategic care planning. Fraser et al⁸ show the prevalence of life-limiting conditions in children and young people for every local authority district in England.

A recent study has found that, among a local population in North Wales of 2,271 children with a life-limiting condition, 501 children per year needed ongoing CPC in contact with hospital services; 24 children required end-of-life care every year¹⁰.

The overall prevalence in England increased from 25 per 10,000 population in 1999/2000 to 32 per 10,000 population in 2009/10. This is due to increasing life expectancy and improving quality of life resulting from advances in treatment and support. Children living with a life-limiting or life-threatening condition may survive to an age where they will need to transition to adult services.

The SEND code of practice states that Health and Wellbeing Boards should consider the needs of vulnerable groups – including those with SEND and those needing palliative care.

Who provides CPC?

Universal, targeted and specialist CPC is delivered by a web of providers; general CPC services may be commissioned from the statutory and voluntary sectors using collaborative commissioning arrangements. A significant proportion of CPC is delivered by the voluntary sector. Voluntary sector providers, including children's hospices, bring social value to communities: when the NHS remunerates these organisations for the CPC they provide, the funding is matched and exceeded by charitable donations which also contribute to running services. Local volunteers also help to provide CPC which are part-funded from statutory sources, further adding value.

Commissioners should ensure sustained and effective delivery of CPC. At all times, locally available and community-led CPC should be at the heart of provision to children. This should be supported by:

- Specialist medical input (e.g. medical consultants with expertise in the child's condition).
- Sustainable community children's nursing teams.
- Children's hospice services.
- Specialist palliative care providers.
- Access to secondary and tertiary care.
- Emotional and psychological support.
- Local authority children's services – social care (including services providing equipment to disabled children), education, housing and leisure.
- Community paediatrics.
- Primary care.

9. Fraser LK, Parslow RC, McKinney PA, Miller M, Aldridge JM, Hain R, Norman P (2012) *Life-limiting and life-threatening conditions in children and young people in the United Kingdom*; final report for Together for Short Lives.

10. Noyes J, Tudor Edwards R, Hastings RP, Hain R, Totsika V, Bennett V, Hobson L, Davies G, Humphreys C, Devins M, Haf Spencer L, Lewis M (2013). *Evidence-based planning and costing palliative care services for children: novel multi-method epidemiological and economic exemplar*. BMC Palliative Care 2013, 12:18.