

A response from Together for Short Lives

Introduction

1. We are the UK charity for children's palliative care. We are here to support and empower families caring for seriously ill children, and to build a strong and sustainable children's palliative care sector - so that no family is left behind.
2. Families of children babies, children and young people with life-limiting and life-threatening conditions rely on a range of professionals, including doctors, nurses, healthcare assistants, social workers, counsellors and many others. They provide palliative care across a range of settings, including in hospitals, children's hospices and in the community.
3. Together for Short Lives is keen to make sure that there are enough professionals in the UK who have the skills, knowledge and experience needed to provide palliative care to children. We welcome the opportunity to respond to this consultation. Please note that we have adapted the consultation questions slightly so that they relate specifically to the current and future children's palliative care workforce.
1. **Do you support the six principles proposed to support better workforce planning; and in particular, aligning financial, policy, best practice and service planning in the future?**
4. Together for Short Live broadly welcomes the six principles.
5. We note that the opportunity for staff to earn more may not necessarily improve quality. For example, if NHS pay increases, it could make it more challenging for voluntary sector providers, such as children's hospices, to match this and attract staff. Such providers already find it difficult to match the terms and conditions offered by NHS providers. We ask NHS employers to take account of the wider health and care sector when setting pay and conditions - and recognise that voluntary sector providers play a critical role in offering lifeline care and support.
2. **What measures are needed to secure the staff the children's palliative care sector (including the statutory, voluntary and private sectors) needs for the future; and how can actions already under way be made more effective?**
6. We call on NHS trusts and other providers to consider jointly-funding posts with voluntary sector services such as children's hospices. For example, Acorns Children's Hospice jointly funds senior nursing posts and a level four children's palliative care consultant with Birmingham Women's and Children's NHS Foundation Trust.
7. Undergraduate medical and nursing students should have opportunities to experience placements in children's hospices. In a survey about funding for student placements in voluntary sector providers of children's palliative care in 2015¹, Together for Short Lives found that placements play a vital role in educating the future nursing workforce in the

¹ Together for Short Lives. 2017. The state of the UK children's hospice nursing workforce: a report on the demand and supply of nurses to children's hospices April 2017. Available to download from: http://www.togetherforshortlives.org.uk/assets/0001/9508/Together_for_Short_Lives_-_The_state_of_children_s_palliative_care_nursing_in_2017.pdf

UK. We estimate that voluntary sector providers of children's palliative care offer placements to over 600 pre-registration nursing students every year:

- Nearly two thirds (63%) of the voluntary sector providers of children's palliative care which responded cited the availability of mentors being the biggest challenge to providing these placements.
 - If our sample represents all voluntary sector providers of children's palliative care in the UK, we estimate that 40% receive no funding for the placements they offer.
 - These payments vary widely in their size, their origin and in the way in which they are calculated: of those voluntary sector providers of children's palliative care that are paid for providing placements, two thirds were paid directly from the universities themselves. The remaining third got this funding from Health Education England (HEE) local education and training boards (LETBs).
8. We call for voluntary sector providers of children's palliative care to be recognised and reimbursed for the placements they provide to undergraduate nurses in a consistent and transparent way across the UK. This would help make sure that providers can maximise the number and quality of placements on offer. It would also help to make sure that more generalists have experience in providing children's palliative care. In England, we call for children's hospices to be given access to the education and training tariffs determined annually by the UK Department of Health and Social Care².
9. We also call on universities to make sure that, through placements, undergraduate doctors and nurses have opportunities to provide palliative care to children in a range of settings, including home, hospitals and children's hospices.
10. We are concerned that HEE does not assess the demand for nurses from children's hospices and include it in their planning models. We call on them to do so - and commission sufficient education places to help meet the shortfall in children's hospice nurses.
- 3. How can we ensure the system more effectively trains, educates and invests in the new and current children's palliative care workforce?**
11. We call on HEE to take into the account the number and needs of babies, children and young people with life-limiting and life-threatening conditions in England³. Only by doing so can health workforce planners understand the demand for children's palliative care - and assess the number of health and care professionals that will be needed to meet this demand.
12. We call on education providers to offer a range of opportunities, including online modules and learning events, for undergraduates and training professionals to learn how to provide children's palliative care. We particularly ask that generalists, including GPs and level 2 and 3 paediatricians who may not routinely care for children with life-limiting

² Department of Health. 2016. Education & training tariffs: Tariff guidance for 2016-17. Available to download from: <https://hee.nhs.uk/sites/default/files/documents/Education%20%26%20Training%20Tariff%20Guidance%202016-17.pdf>

³ 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. Available to download from: <http://bit.ly/1yvEeHs>

conditions, but whom may be asked to do so during their careers, are given access to such learning opportunities.

4. What more can be done to ensure all staff, starting from the lowest paid, see a valid and attractive career in the children's palliative care sector, with identifiable paths and multiple points of entry and choice?

13. We ask that HEE focusses specifically on outlining career pathways and providing guidance for delivering outcomes-led education for children's palliative care nurses.

14. We also call on employers across the statutory, voluntary and private sectors to make sure that all health and care professionals have opportunities access education to continue their professional development.

5. How can we better ensure the children's palliative care workforce meets the needs and aspirations of all communities in England?

15. We call on organisations providing children's palliative care across the statutory, voluntary and private sectors to make sure they advertise roles in places which will be seen by a diverse range of potential candidates.

16. We also call on providers to train and educate staff to make sure that processes to recruit to fill vacancies are not discriminatory, either consciously or subconsciously.

6. What does being a modern, model employer mean to you and how can we ensure that children's palliative care providers meet those ambitions?

17. Employers will improve the extent to which they are attractive to potential employees by demonstrating that they provide excellent services across a range of settings.

18. Offering employment terms and conditions which can be transferred from NHS employers to voluntary sector organisations can also help the latter to recruit and retain staff.

19. Employers can be more attractive by showing that they have implemented and adapted to new technology. Within our sector, this includes providing mobile units, simulation suites for training and adopting different models of practice.

20. It is important that children's palliative care providers help their employees to be resilient. Their work is emotionally challenging and involves providing increasingly complex care and support. Providers need to continue to provide opportunities for their employees to develop.

7. Do you have any comments on how we can ensure that professionals providing children's palliative care make the greatest possible difference to delivering excellent care for children with life-limiting conditions and their families?

21. It is vital that professionals, whether they work in hospitals, children's hospices or in the community, have access to the financial resources they need to provide children's palliative care.

22. It is also crucial for employers take care of employees; in children's palliative care, it is particularly important that professionals are supported in respect of the highly emotional nature of the care they provide - and the increasing complexity of the care they provide.

23. We call on education providers to offer modules which can be taught across a range of care and support settings. To make learning as flexible as possible, we ask for education resources to be developed which can be accessed wherever professionals are.

For more information

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Appendix: background information about the children's palliative care workforce

What is the children's palliative care workforce?

We want to make sure that professionals in the UK have the skills, knowledge and experience needed to provide palliative care to babies, children and young people with life-limiting and life-threatening conditions.

What do we know about the children's palliative care workforce in the UK?

The children's hospice nursing workforce

From a survey of children's hospice organisations which we undertook in 2016⁴, we know that:

1. The nurse vacancy rate among children's hospice organisations is equal to that of the NHS in England. The average vacancy rate was this year found to be over 11% which is an increase on 2015's findings of 10%. This represents over 130 whole time equivalent (WTE) posts unfilled.
2. There is an increasing shortage of experienced nurses in children's hospice organisations. In 2016, the number of vacancies was highest at a salary equivalent to Band 6 compared to salaries equivalent to Bands 5 and 7. In 2015, the highest number of average WTE vacancies were in Band 5.
3. There is a lack of skilled nurses available to fill posts. More than half (61%) of children's hospice organisations cited lack of available appropriately skilled nurses being available to fill posts - similar to the 65% which reported this in December 2015.
4. It is getting harder for children's hospice organisations to fill nursing posts. Nearly two thirds (65%) of vacancies are described as hard to fill (vacant for over three months). This is greater than the 57% reported in 2015.
5. These shortages are forcing children's hospice organisations to cut back the palliative care they can offer to children and families: A majority of organisations (58%) now state that vacancies are having a negative impact on care - including a reduced offer to families or reduced short breaks offer. This is greater than the 43% of children's hospice organisations which reported this in 2015. Nearly one fifth (17%) stated that they were being forced to close beds. Three (13%) services reported that vacancies affected their ability to provide 24/7 care, making 2016 the first year that this was specifically mentioned.

The community children's nursing workforce

The [Royal College of Nursing \(RCN\) recommends](#) that for an average-sized district, with a child population of 50,000, a minimum of 20 whole time equivalent (WTE) community children's nurses are required to provide a holistic community children's nursing service⁵.²⁰ The Office of National Statistics estimates that there are 13,770,873 children aged 0-18 in

⁴ Together for Short Lives. 2017. The state of the UK children's hospice nursing workforce: A report on the demand and supply of nurses to children's hospices: http://www.togetherforshortlives.org.uk/assets/0001/9508/Together_for_Short_Lives_-_The_state_of_children_s_palliative_care_nursing_in_2017.pdf

⁵ RCN. 2014. The future for community children's nursing: challenges and opportunities. P.10. Available to download from: <http://bit.ly/1QgLhZb>.

England. If the RCN recommendation were to be met, this would therefore require approximately 5,508 community children's nurses. [There are currently just 535 community children's nurses in England](#)⁶.

The children's palliative care medical workforce

The Royal College of Paediatrics and Child Health estimates that there are currently fourteen children's palliative care consultants in the UK and several paediatric consultants who practice with an interest in palliative care. There are many regions in the UK with no access to children's palliative medicine specialists. Many single-handed consultants have no cover for leave or sickness and 'reprieve' from service requirement can be very challenging.

RCPCH also report that children's palliative care specialists in the sector are very concerned about untrained, self-nominated paediatricians taking on the 'lead' for palliative care services without having key capabilities in place. Lack of access to fully trained specialists for advice and support is resulting in observed propagation of poor practice in some instances.

Education for children's nurses

From a small sample (25%) of children's nursing degree courses which we have obtained data about earlier in 2017⁷, we know that:

1. A third (33%) of children's nursing degree courses are planning to increase the number of places which they offer to undergraduates.
2. Most if not all include some educating nurses about children's palliative care.
3. Most incorporate what we recognise as elements of good practice in children's palliative care education in their curricula.
4. There are some significant gaps in the way in which undergraduate children's nurses are educated about children's palliative care:
 - One in five (20%) of course leaders state that their students are unable to learn from parents and carers about what it is like to have a child with a life-limiting condition as part of their course.
 - Over a quarter (27%) stated that they had not devised children's palliative care competencies for their students.
 - Just over half (53%) stated that they are planning to further develop their children's palliative care education.

The impact of our findings on children with life-limiting conditions

We are concerned that the findings we have identified across our three surveys are having a negative impact on the lifeline care which children's hospice organisations are able to offer to children with life-limiting and life-threatening conditions and their families. This includes

⁶ NHS Digital. 2016. NHS Workforce Statistics - September 2016, Provisional statistics: Staff Group, Area and Level. Available to download from: <http://bit.ly/2j2srhm> .

⁷ Together for Short Lives. 2017. The state of the UK children's hospice nursing workforce: A report on the demand and supply of nurses to children's hospices: http://www.togetherforshortlives.org.uk/assets/0001/9508/Together_for_Short_Lives_-_The_state_of_children_s_palliative_care_nursing_in_2017.pdf

end of life care and short breaks for respite. The shortages in nurses working in children's hospice organisations:

1. Are undermining children's hospices' ability to provide around the clock children's palliative care out of hours and at weekends.
2. Are undermining children's hospices' ability to help children, young people and their families to choose where they receive care, which is an aspiration set out in policy strategies across the UK^{8 9 10}. Many children's hospices offer hospice at home services which mean that families can access children's palliative care where they need it. As well as affecting inpatient care, the current nursing shortages reduce the extent to which children's hospices' can provide this care in the community too.
3. Could be leaving more families of children with life-limiting and life-threatening conditions under pressure and at greater risk of separating. Nurses working for children's hospice organisations help provide short breaks for respite, which can¹¹:
 - reduce the need for children to be placed long-term residential care away from the family home
 - reduce stress among parents, families and carers
 - reduce incidences of siblings with behavioural and emotional difficulties.

What are the UK's governments doing to make sure there are enough professionals with the knowledge, skills and experience needed to care for children with life-limiting conditions?

In October 2017, the Secretary of State for Health announced that the government would increase the number of nurses trained by 25%¹². This would represent a permanent increase of more than 5,000 nurse training places every single year. This would be achieved by increasing university places. It would also be achieved by tripling the number of nursing associates who can become a registered nurse after a four-year degree apprenticeship without having to do a full-time university course.

What would Together for Short Lives like to happen?

We believe that the UK's governments, workforce planners and universities all have an important role to play too in making sure there are enough nurses available to care for

⁸ Department of Health. 2016. Our Commitment to you for end of life care: The Government Response to the Review of Choice'. Available to download at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/535048/choice-response.pdf

⁹ Northern Ireland Department of Health. 2016. 'Providing High Quality Palliative Care for Our Children: A Strategy for Children's Palliative and end-of-life care 2016-26. Available to download at: <https://www.health-ni.gov.uk/publications/strategy-childrens-palliative-and-end-life-care-2016-26>

¹⁰ Welsh Government. 2014. 'Together for Health - Delivering End of Life Care: A Delivery Plan up to 2016 for NHS Wales and its Partners'. Available to download at: <http://gov.wales/topics/health/nhswales/plans/end-of-life-care/?lang=en>

¹¹ NEF Consulting. 2009. The social and economic value of short breaks. Available to download at: https://councilfordisabledchildren.org.uk/sites/default/files/field/attachemnt/the_social_and_economic_value_of_short_breaks_full.pdf

¹² Conservatives. 2017. Hunt: Conference Speech. Available to download at: <http://press.conservatives.com/post/166001211125/hunt-conference-speech>

children with life-limiting conditions. Together for Short Lives is keen to work with them all to increase the number of nurses in the UK who are able to provide children's palliative care.

We would like:

1. The Council of Deans of Health to encourage university undergraduate nurse programmes to adopt the [elements of our recognised good practice in curricula for children's palliative care nursing education, which we set out in part II of our report](#).
2. The Nursing and Midwifery Council (NMC) to review its standards for pre-registration nursing education¹³ to make sure that it reflects competencies in children's palliative care and good practice elements of children's palliative care nursing education.
3. Health workforce planners to assess the demand for nurses from children's hospice organisations and include it in their planning models. If it is found that there are too few children's nurses likely to fill posts across all types of healthcare provider, we call on universities to increase the number places they offer to undergraduates. We would like the UK's governments to recognise the importance of children's hospice nursing by including these vacancies in the wider NHS nurse vacancy figures.
4. An urgent UK-wide summit to discuss the children's palliative care nursing workforce with the UK's governments, the NMC, the Council of Deans of Health and the agencies who are responsible for commissioning nurse education places across the UK.
5. Health workforce planners in Northern Ireland, Scotland and Wales to commission sufficient undergraduate places for people to study to become children's nurses.
6. Children's hospice organisations to satisfy themselves that they have a compelling offer of pay, conditions and shift patterns to attract children's nurses to work for them. They should also communicate the additional, unique benefits which they may offer compared to other providers - for example, free workplace parking, free food and/or free childcare.
7. Children's hospices to be reimbursed for the placements they provide to undergraduate nurses in a consistent and transparent way across the UK. This would help make sure that providers can maximise the number and quality of placements on offer. In England, we call for children's hospices to be given access to the education and training tariffs determined annually by the UK Department of Health¹⁴.
8. The UK Government to make sure that the UK's exit from the European Union does not have an adverse impact on the supply of nurses available to children's hospices. Consistent with the Royal College of Nursing, we call on the UK Government to preserve the rights of European Economic Area nationals currently working in the sector. We also ask ministers to put appropriate education and regulatory frameworks in place to make sure that providers can continue to recruit from other European countries.

¹³ Nursing and Midwifery Council. 2016. Standards for Pre-Registration Nursing Education. Available to download from: <https://www.nmc.org.uk/globalassets/sitedocuments/standards/nmc-standards-for-pre-registration-nursing-education.pdf>

¹⁴ Department of Health. 2016. Education & training tariffs: Tariff guidance for 2016-17. Available to download from: <https://hee.nhs.uk/sites/default/files/documents/Education%20%26%20Training%20Tariff%20Guidance%202016-17.pdf>

9. Health Education England to focus specifically on outlining career pathways and providing guidance for delivering outcomes-led education for children's palliative care nurses.