A national review of choice in end of life care

A consultation response from Together for Short Lives

About us

Together for Short Lives is the leading UK charity for all babies, children and young people with life-threatening and life-limiting conditions and all those who support, love and care for them. We support families, professionals and services, including children's hospices. Our work helps to ensure that children can get the best possible care, wherever and whenever they need it.

About young adults who need end of life care

We recognise that older people with dementia, cancer and organ system failure represent a significant proportion of the adult population who need end of life care. However, we ask that this review also considers younger adults individuals with rare, life-threatening or life-limiting conditions. We also ask that adults with life-threatening or life-limiting conditions (or combination of conditions) which may not have been diagnosed are considered.

The needs of young adults at the end of their lives can be different from older adults - and also from children. It is challenging to anticipate when young adults are entering their end of life phase, particularly when they are living with a life-threatening or life-limiting condition and/or are cognitively impaired. Young people have a range of conditions with unpredictable trajectories, which may mean they have repeated 'end of life' episodes, any of which could be the final one. Adult palliative care services have relatively little experience of caring for such individuals.

Many young adults who reach the end of their lives will have lived with life-limiting conditions as children and young people - and in some instances from birth. They are likely to have undergone a transition from children's to adult's palliative care services. This group of young adults in growing in number due to improved medical treatments, information and support. There are 56,000 young adults aged 18 to 40 in England who are currently living with life-limiting conditions. This number is growing. Between 2000 and 2010, the prevalence of life-limiting conditions in young adults in England rose from 26.0 to 34.6 per 10,000 population[1].

Adulthood is often the time when young people with life-limiting conditions (for example, Duchenne Muscular Dystrophy) experience a deterioration in their condition. This means that they are more likely to need end of life care once they have started to use adult services.

This review should recognise the need for age-appropriate end of life care to be provided to this unique group, in age-appropriate settings. This means services enabling young adults to do the things which matter to them for as long as possible - for example going out with other young people and maintaining their social networks. Care should be person-centred and appropriate to the young adult's stage of development.

Clear communication between children's and adults services at the time of a young person's transition to adulthood is crucial in making sure that this process is smooth and well-planned. Young adults should also be supported to have conversations about end of life care choices. This must include discussing what is realistic and documenting choices based on informed decision-making.

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[1] Fraser LFK et al 2013, Prevalence of life-limiting and life-threatening conditions in young adults in England 2000-2010

In 2013, Together for Short Lives published the findings of our three year 'STEPP project'[2] - a three year research study funded by the Big Lottery Fund Research Programme. This examined the transition from children's to adult's health care for young people with life-limiting or life threatening conditions. Through the study, young adults and parents described the difficulties they experience in planning for end of life.

Those closest to death were amongst those least willing, or least comfortable, to openly acknowledge the life-shortening nature of their condition. Young people stated:

> "I still haven't made any really proper plans 'cos I still don't know what I really want, and when to decide that. 'Cos I still don't know... I'm too young to think about that."
>
> "There may be things that I'd rather not know if they happen 'cos it may be scary... we'd rather not know certain things."

Very few of the young adults we interviewed had made an end of life plan. However, those that had were relieved to have done so. Parents observed that it enabled ongoing conversations within the family:

> "It wasn't nice but... it, it's something that has to be done. And I am glad because it gives you that feeling of... you're prepared. You're never prepared when something like that happens, but at least the wheels will be in kind of in motion and there won't be any untoward hiccups or things that makes it just more, harder. It's, it's just so comforting knowing that something like that is in place, which I would say any family should do."

In every instance examined by the study, professionals had been involved in instigating conversations about end of life. There was a sense that some families were waiting for professionals to raise the issue, and trusted their judgement on when it should be raised. Some parents said they needed advice and support from the clinic team to raise issues with their son or daughter.

Question 1: What kinds of choices should people be able to make at the end of their life? Please list them in priority order and describe what would need to be in place for them to be achieved.

Priority 1: Young adults should, where possible, be able to choose where they die and where they receive end of life care

In 2011, ACT and Children's Hospices UK (the two charities which went on to merge to form Together for Short Lives) held 37 'Square Table' events across England. The events sought to deepen understanding between those who provide children's palliative care, those who experience it and those that play a wider part in supporting children, young people and families.

One of the themes which emerged from the events[3] was a widespread acceptance that as many children and young people as possible should be supported to die at home if that is their or their

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[2] Beresford B. 2013. Making a differencefor young adult patients: practice prompts - key messages from research. Available to download from: http://www.togetherforshortlives.org.uk/assets/0000/4954/TfSL_Making_a_difference_for_young_adult_patients_A5_Cards_x_12__FINAL_.pdf (Accessed on 30 September 2014).

[3] Square Table: Local Learning and Evaluation Report. 2011. ACT and Children's Hospices UK. Available to download from: http://www.togetherforshortlives.org.uk/assets/0000/6606/Local_Square_Table_Learning_and_Evalulation_Report.pdf (Accessed 29 September 2014).

family’s choice. Parents were very keen to impress on professionals that the option for their child to die at home should only be discussed where services are available to support this. Many bereaved parents described positive experiences of being supported to enable their child to die at home. However, there were some parents for whom this had been a negative and traumatic experience in which they have been inadequately supported. Many professionals expressed particular concern about the impact of public sector cuts and dwindling funding on their ability to provide this choice.

In providing young adults with a choice over where they receive care, young people should also be able to choose who they would like to have with them at the end of their lives.

Most young adults will use adult palliative care services at the end of their lives. However, in some instances it may not be appropriate for young adults to make the transition from children’s to adult’s services - for example because death is expected shortly. As such, some young adults may still be using children’s services when they reach the end of their lives.

Priority 2: Choice over treatment, nutrition or hydration

Young adults should be involved in decisions about the treatment they receive at the end of their lives - if they have capacity to do so. A person’s capacity must be assessed specifically in terms of their capacity to make a particular decision at the time it needs to be made.

Offering choice in treatment is particularly important for young adults given the relatively unpredictable effects that end of life treatments can have on this age group. Some young adults with life-limiting conditions will have been treated with palliative medication over long periods of time. The pharmokinetics and pharmodynamics of these medications will make decisions about initiating treatment for terminal restlessness more challenging in young adults. It is therefore vital that young adults are, as far as possible, able to make informed decisions about their treatment choices in advance of this being required.

It is also important for young adults to be able to choose if, when, or in what circumstances they would wish for nutrition and/or hydration to be withdrawn if they reach their end of life phase. This should be assessed by those competent to assess young adult’s ability to make decisions.

Priority 3: Choice over whether to be resuscitated

Young adults with life-limiting conditions may choose not to be resuscitated if they experience an emergency or a rapid, unexpected deterioration in their condition. Where a young adult does not wish to be resuscitated, and they have capacity to make this decision, this should be reflected in their advance care plan (ACP). Those working with the young adult should make themselves aware of these wishes and ensure that other professionals, including ambulance teams, are informed quickly in emergency situations. Failure to follow resuscitation wishes can lead to poorer outcomes for young adults and their families (particularly for the latter as they try to come to terms with the death).

Doctors now have a legal duty to consult with and inform patients if they want to place a do not resuscitate (DNR) order on medical notes. This follows a ruling by the Court of Appeal in England in June 2014.

Priority 4: Choice over whether to donate organs and tissue

Young adults with life-limiting conditions may decide that they would like to donate organs and/or tissue following their death. These decisions may contrast with those previously made on their behalf by their parent carers. Professionals should support young adults and families in making these decisions. They should also inform young people of their right to make these decisions as part of work to prepare them for the transition to adulthood.

Priority 5: Choice over whether to involve parent carers in choices about end of life care

Where young adults do not have capacity, professionals must involve their families in these decisions. This should be based on good communication and should include those who are involved in the care and support of the young person - including those who are important to the young person such as family members and partners. Where the young adult does not have family or friends to make this decision, an Independent Mental Capacity Advocate may be required.

Where young adults are capable of making important decisions about their end of their life care, it is important that professionals take account of their preferences over whether parent carers are involved in the process. Some young adults will want their parents or guardians to be involved. Young adults will have often undergone the transition from children's services, where decisions may have been taken on their behalf, or where involving parent carers in decision-making has been commonplace.

Professionals in adult services should also be prepared for young adults and parent carers having contrasting views about end of life care choices. While the young adult's views should take precedence in these situations, professionals should take care to be sensitive in managing the views of parent carers. Parents may have become used to making key decisions on behalf of their children and could find it difficult to accept their children having different views from their own.

What would need to be in place for this to be achieved?

Professionals and providers

Together for Short Lives' 'Guide to End of Life Care'[4] states that supporting young adults and their families in their preferred place of care and preferred place of death means that care can take place across many settings. A young adult can be moved from one setting to another during this period of time. Effective and skilled joint working is essential to support families and advance planning should be integral to care. Communicating effectively and explaining to young adults and their families what will happen and what may happen will avoid sudden changes to care, which can be distressing for families. Families should be able to choose the place of death and - where possible - professionals should work together to make sure that this wish is fulfilled.

Depending on where a young adult dies there will be local and organisational policies and procedures that professionals need to be aware of in order to meet the regulatory requirements at time of death.

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[4] Together for Short Lives. 2012. A guide to end of life care: Care of children and young people before death, at the time of death and after death. Available to download from: http://www.togetherforshortlives.org.uk/assets/0000/1855/TfSL_A_Guide_to_End_of_Life_Care_5_FINAL_VERSION.pdf

Because life-limiting conditions in young adults are often unpredictable, it is important that professionals have parallel plans in place which reflect the needs and wishes of young adults. This should include planning for scenarios in which young adults die, stabilise or recover to their prior state of health.

Health, education and social care professionals and providers should work together to make sure that young adults with life-limiting conditions have an ACP in place. This should set out what young adults' (and their families') end of life care preferences are. All professionals involved in caring and supporting young adults with life-limiting conditions should be aware of the content of the plan - and be able to put this into action, particularly in circumstances where a young adult's condition deteriorates rapidly or unexpectedly.

Where a young adult has an ACP in place, this should link to their education, health and care (EHC) plan if they have one. Children and young people aged 0 to 25 who have a special educational need and are in full-time education can now apply for an EHC plan. Where a young adult with a life-limiting condition is at school, an ACP should form part of their individual healthcare plan (ICP). ICPs are required under the duty to support pupils at school with medical conditions[5]. Further and higher education institutions should also take ACPs into account as they provide support to young adults with life-limiting conditions.

Professionals and providers should work with commissioners to make sure that age-appropriate end of life care is available for young adults - whether in hospital, at home or in hospice settings. Children's and adult's professionals should also ensure that they work together to plan a young person's transition to adulthood, mindful of the fact that a young adult may enter their end of life phase while they are undergoing transition. The review should take note of the recommendations of the Care Quality Commission's (CQC) recent thematic review of transitions for children with complex health conditions[6].

CQC recommends that:

1. Health commissioners must listen to and learn from young people and their families.

2. Existing good practice guidance must be followed to ensure young people are properly supported through transition. Every young person with complex physical health needs, from age 14 should have:

    - a key accountable individual responsible for supporting their move to adult health services

    - a documented transition plan that includes their health needs

    - a communication or 'health passport' to ensure relevant professionals have access to essential information about the young person

    - health services provided in an appropriate environment that takes account of their needs without gaps in the services provided by children's and adult services

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[5] Department for Education. 2014. Supporting pupils at school with medical conditions: statutory guidance for governing bodies of maintained schools and proprietors of academies in England - April 2014. Available to download from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/306952/Statutory_guidance_on_supporting_pupils_at_school_with_medical_conditions.pdf (Accessed 29 September 2014).

[6] Care Quality Commission (CQC). From the pond to the sea: children's transition to adult health services. Available to download from: http://www.cqc.org.uk/sites/default/files/CQC_Transition%20Report.pdf

  - training and advice to prepare them and their parents for the transition to adult care, including consent and advocacy
  - respite and short break facilities available to meet their needs and those of their families.

3. GPs should be more involved, at an earlier stage, in planning for transition.

4. Adolescence/young adulthood should be recognised across the health service as an important developmental phase - with NHS England and Health Education England leading this work. This needs:
    - additional recognised training for health professionals; care should only be provided by professionals who have received training in the needs of young adults
    - age-appropriate services should be planned and delivered by professionals from all necessary health and care services, who will have to work together
    - a named lead to coordinate all care services
    - services to be integrated and care co-ordinated around the individual.

Together for Short Lives calls for these recommendations to be implemented.

Community nursing

To make sure that end of life choices are available to young adults, community care is vital. Very often, young adults fall between the gap between children's community nursing (CCN) and district nursing (DN) - for example, where CCNs are commissioned to provide care to young people up to the age of 16 and DNs are commissioned to provide care to adults from the age of 18. A lack of confidence among DNs in their ability to care for young adults can also be a significant barrier.

To address these issues, CCGs should ensure that community nursing is commissioned for young people aged 16 to 18.

The government

The government should develop and an indicator for the NHS Outcomes Framework which measures the number of adults with end of life plans who die in the place of their choice. The NHS Mandate should also emphasise that it is important for commissioners and providers to:

- ensure that, where possible, adults can choose where they receive end of life care - and where they die
- bring about age-appropriate services for young adults, including end of life services.

The government, NHS England and Monitor are developing a new funding system for palliative care in England. In doing so, they should ensure that providers of end of life care to children, young people and adults across the statutory and voluntary sectors can be funded in a way which is fair, sustainable and which reflects the activity they undertake.

Together for Short Lives believes that the next government can take action by developing across-departmental strategy which sets out the actions needed to improve transitions for young people with complex health needs. We are keen to see more integrated assessments, plans and services - and a single point of contact - for children and young people. This would be across the range of services which they need, and between children's and adult's services.

Health and wellbeing boards

In assessing the needs of the populations they serve, health and wellbeing boards should take into account the number of local young adults with life-limiting conditions who could need end of life care. They should be included in joint strategic needs assessments (JSNAs) and health and wellbeing strategies.

Clinical commissioning groups (CCGs)

CCGs should monitor the extent to which end of life care providers are offering choice to young adults. Choice should be included in contracts and agreement with providers.

The Special Educational Needs and Disability (SEND) Code of Practice[7] recommends that palliative care should be included within local offers. These describe the services which are available to disabled children and young people aged 0 to 25. CCGs should work with local authorities to make sure that this is the case.

Clinical guidance

The National Institute of Health and Clinical Excellence (NICE) clinical guideline on care of the dying adult is currently being developed and is expected to be published in October 2015. The guideline should emphasise the need for commissioners and professionals to offer choice in end of life care - and set out how this can be achieved.

Regulating care

The Care Quality Commission (CQC) should assess the extent to which choice is offered to people at the end of their lives by providers of health and social care. The extent to which choice is offered should influence the ratings which providers receive from CQC.

Education and training

Health Education England (HEE) should work with the royal colleges to ensure that providing choice at end of life is included within education, training and ongoing support for health professionals. Similarly, the College of Social Work and the Social Care Institute for Excellence (SCIE) should make sure that this forms part of the curriculum for social workers.

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[7] Department for Education. 2014. Special educational needs and disability code of practice: 0 to 25 years. Available to download from: https://www.gov.uk/government/publications/send-code-of-practice-0-to-25 (Accessed 29 September 2014).

In general

A variety of organisations, including government, the NHS, local authorities, education providers and the voluntary and community sector should work to make young adults and their families aware of the choices they can make. They should also encourage them to exercise choice in their end of life care and highlight the information and support which is available to help them do so.

Together for Short Lives recommends the following in order to facilitate discussions about end of life care with young adults and families[2]:

- Work with a family's pattern of information-sharing and decision-making.
- Use trusted and familiar practitioners; if they are involved with the patient, work with staff from hospice and/or palliative care teams.
- Where possible, share difficult information gradually.
- Avoid decision-making in crisis situations.
- Have conversations in familiar environments, chosen by the family.
- Make a record of decisions and the family's understanding of issues which still need to be discussed or planned for.
- Make a record of the young adult's wishes regarding their parents' involvement in future decision-making.

Together for Short Lives is currently developing a resource entitled 'Difficult Conversations, a guide to talking to young adults about death'. We expect this to be available early 2015.

Question 2: Do you have examples of where people have been able to make choices about the care and support they receive at the end their life?

Question 3: How would we know if a 'national choice offer' improved people's experience of care at the end of life? For example, how we might be able to measure and evaluate the impact on the quality of care and support received. Please share your answers below.

As recommended in our response to question one, we believe that the government has an important role to play by including an indicator in the NHS Outcomes Framework which measures the extent to which people with end of life plans die in the place of their choice. The CQC should also regulate the extent to which choice is offered.

Services which offer end of life care should evaluate their own practice and, where possible, should survey young adults and their families to assess the quality of their care. Commissioners should also assess how much choice is offered in holding providers to account for fulfilling their contracts and agreements.

If you are replying on a behalf of an organisation

Please tell us a bit about the people you support and care for (whether directly through hands on care or indirectly through other activities such as raising public awareness). We're particularly interested in hearing about diversity.

Together for Short Lives is the leading UK charity for all babies, children and young people with life-threatening and life-limiting conditions and all those who support, love and care for them. We support families, professionals and services, including children's hospices. Our work helps to ensure that children can get the best possible care, wherever and whenever they need it.

From the moment of diagnosis, for whatever life holds, we help to ensure that families make the most of their precious time together.

There are an estimated 49,000 children and young people in the UK living with a life-threatening or life-limiting condition that may require palliative care services. We are there for every single one of these children, and their families, so they know where to go for help and are aware of the support available to them.

With the right kind of information, it can become easier to access care and support, as well as practical and emotional help for the whole family when it's needed most. We help families get this information so they know what to expect at different stages throughout their journey. We provide this through our helpline; our advocacy service; our website, and our suite of publications and resources for families and professionals. We raise awareness of life-limiting conditions in children and young people and the services which provide them with palliative care.

We also work closely with the organisations and professionals that provide an important lifeline to children and families. We raise funds for children's hospices and a range of other voluntary organisations to enable them to sustain the vital work they do. We offer resources and training to help them maintain consistent, high quality care from the moment a child is diagnosed, until their eventual death, and to continue supporting families for as long as they need it.

Ensuring that children and families from all backgrounds have access to the support we provide is integral to our approach. For example, our resources for professionals emphasise the varying perspectives which people of different ethnic, faith and cultural backgrounds have on death, dying and palliative care. We encourage professionals to take these into account when providing palliative care to children and young people.

Our work also involves campaigning to make sure that children with life-threatening and life-limiting conditions and families across the UK can access palliative care when and where they need it - including end of life care; we campaign for fair and sustainably-funded services; better co-ordinated health, social care and education; and smoother and better planned transitions from children's to adult's services. By working across the UK, we give a powerful voice to children, families and the organisations that support them, ensuring their views are heard by the government and that they influence policy.

For more information

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