



Don't let me down

Ensuring a good transition for young people with palliative care needs

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1. Foreword

Medical advances are enabling more young people with life-limiting or life-threatening conditions to live longer. But this places a new responsibility on those who commission and provide the services which these young people and their families require.

The point at which young people move from children's to adult services – commonly referred to as “transition” – represents a particular challenge. It needs to be planned for years in advance, yet planning is often poor. The reduced support then offered by adult agencies comes as a shock to many young people and their families.

Much of the excellent activity around transition to date has addressed services for children rather than adults and dealt with disabled young people as a whole rather than young people with complex needs who require palliative care. This report seeks to fill a gap by focusing on the part played by adult agencies in making transition work for these young people needing palliative care.

It forms part of a larger project to improve young people's experience of transition, which is being undertaken by Marie Curie Cancer Care and Together for Short Lives with the National Council for Palliative Care and Help the Hospices.¹

The project team has gathered the views of young people and families directly, asking them what would make a difference to their quality of life in the move to adulthood. It has also spoken to commissioners and providers. The findings below reflect what we were told.

This report aims to help stimulate improvements in the transition support provided by adult agencies. We look forward to the day when all young people who need palliative care, and their families, can access adult services that are well planned, co-ordinated and supportive.



Sir Thomas Hughes-Hallett
*Chief Executive,
Marie Curie Cancer Care*



Barbara Gelb
*Chief Executive,
Together for Short Lives
and on behalf of the
Transition Partnership*

Notes

NB: We have made it easier to type in the URLs for documents by shortening them using bit.ly.

¹ *Young People and Transition: Improving services for young people*, Marie Curie Cancer Care, ongoing (bit.ly/MC_MarieCurie)

2. Executive Summary

The challenge of providing support for an ageing population is often taken to refer just to older people. But these days, thanks to medical advances, it applies increasingly to younger people, not least those who once would have died in childhood.

Adult services are increasingly being required to provide services for young people who previously would not have been expected to live into adulthood. This means that there is a growing focus on ensuring that young people with palliative care needs have a positive experience of moving from children's to adult services – often called 'the transition'.

Marie Curie Cancer Care and Together for Short Lives, working with Help the Hospices and the National Council for Palliative Care, have come together to undertake research into the transition experiences of young people with palliative care needs. This research draws heavily on the experiences and views of young people with palliative care needs, their families and their carers. This report gives voice to these experiences and seeks to set out how we can improve the services available to young people and their families and improve the co-ordination, integration and communication of those services.

Growing numbers

There are more than 40,000 children and young people aged 0-19 in England who have long-term health conditions which, for most, will eventually end their lives and for which they may require palliative care. This represents a 30 per cent increase over ten years. The highest rate of increase is among those aged 16-19, who now account for 4,000, or one in ten, of 0-19-year-olds with palliative care needs.

The majority of young people who may require palliative care have a range of severe disabilities and complex health needs. Cancer represents just under 14 per cent of diagnoses. Medical advances mean that more young people with a range of different conditions are living into adulthood than ever before.

Palliative care

Those who are unlikely to be cured by treatment are offered palliative care. Palliative care for young people is not simply end-of-life care but focuses on enhancing the quality of life. In their young to mid-teens, young people receive palliative care and other support from children's services. In their later teens they start to receive services from adult agencies, who assume responsibility at different points after the young person's 16th birthday. This transition process can often be a complex one.

Transition

Successful transition needs to address both the transfer of responsibility for young people from children's to *existing* adult social care, health and education services and the development of *new* adult services tailored to young people's additional needs.

Achieving this is challenging, particularly at a time of reduced budgets and growing demand. But the costs of bad transition for young people can include greater illness, adverse social and educational outcomes, and even earlier death.

The challenges ahead

Many young people and their families find transition daunting. On leaving the comprehensive care offered by children's services, they will often have to deal with and establish important relationships with a range of agencies and professionals. The result can be gaps in services or fewer or less appropriate services.

All this happens at a time when young people's needs may be greatest, as many chronic progressive conditions now reach a crisis during late adolescence and young adulthood.

Given their situation, these young people and their families cannot afford to wait and adult agencies need to ensure that their responses are timely and appropriate.

What young people and their families want

Successful transition services are based on listening to what young people and their families want. Young people have told us they find the adult services they need inadequate. They want services which enable them to lead ordinary lives, including a social life. They want a feeling of freedom and not being overwhelmed or bossed around by adults at the same time as being offered appropriate support. The young people's frustrations regarding transition are shared by their parents.

The policy framework

The government is undertaking a range of reforms that have the potential to improve young people's transition experiences. These include:

- Significant changes to social care legislation;
- The forthcoming Care and Support White Paper;
- The potential extension of personal budgets to healthcare;
- Proposals for changes to the Special Educational Needs and Disabilities system; and
- The Health and Social Care Act's emphasis on joint commissioning of services for disabled people.

However, it is clear that success of these changes will depend on how they are implemented. It will be essential that government departments and a range of local service providers work together to ensure that these reforms collectively deliver improvements for young people with palliative care needs.

What is working now?

There is no need for agencies to wait for the reforms to take hold before improving transition services. Much useful experience and good practice in local authorities already exists and can be built on. Providers also have to redesign their services to make them appropriate for young people, and a number are already doing so.

Recommendations

1. The Prime Minister should lead an initiative across government to co-ordinate cross-departmental working on issues affecting young people who need palliative care, and their families and carers.
2. The government should accept the Law Commission's recommendation that local authorities should have the power to assess the needs of, and provide services to, 16- and 17-year olds.
3. Once a young person with palliative care needs has reached the age of 14, a range of children and adult services should come together to agree a five-year rolling plan, encompassing all relevant local services. This plan should taper services to make transition less of a "cliff edge" for families.
4. The Care and Support White Paper should explicitly set out how adult social care services will support Education, Health and Care Plans to deliver a less adversarial and less bureaucratic experience of transition.
5. Levers are essential to ensure that health services observe the new requirement for joint commissioning. In delivering its proposed mandate for disabled children and young people, the NHS Commissioning Board should drive good commissioning by issuing early guidance on commissioning palliative care for children and young people. The health outcomes strategy should measure transition outcomes for young people with palliative care needs.
6. Health and wellbeing boards should consult young people with palliative care needs and reflect their priorities in local health and wellbeing strategies.
7. Those special educational needs and disability (SEND) pathfinders which are addressing transition support should recruit young people with palliative care needs and their families.
8. The SEND Young People's Advisory Group should include young people with palliative care needs who have experience of transition, while the SEND pathfinders' National Advisory Group should include the Association of Directors of Adult Social Services.
9. The government should issue guidance that the new "local offers" for disabled children should state what will be provided by adult services.
10. Young people with palliative care needs can find it particularly difficult to access leisure and recreational activities. They should get priority for leisure services in joint health and wellbeing strategies and from the third sector.
11. In order to plan services for the future, all agencies – including adult agencies – should share data with each other on the numbers and needs of children and young people who require or are likely to require palliative care.
12. All information about young people with palliative care needs should travel with them across organisational boundaries. This could be in the form of a care plan that covers clinical, social and educational needs and which supports the process of transition.
13. Adult services, including hospices, should do an audit of their suitability for working with young people and put in place an action plan to improve their accessibility to young people and their families.
14. The government should review the age at which a young person starts receiving adult services and ensure that this is streamlined and standardised to ensure consistency throughout the transition process.
15. We recommend that young people who need palliative care but do not have a special educational needs (SEN) statement should be offered a transition plan, even though there is no statutory requirement to do so.

3. Introduction

This report addresses the challenges faced by adult services in supporting growing numbers of young people with palliative care needs into adulthood. It focuses on improving the process of transferring these young people from children's to adult services, known as transition.

The challenges should be seen in the context of wider demographic change and the increase in the older population, leading to unprecedented demands on the health and social care system. A recent survey by the Association of Directors of Adult Social Services (ADASS) has underlined the funding and service delivery pressures being experienced by adult services.²

Although the population we are talking about is still relatively small, it has intense and expensive services needs, including social care, health, education, housing, leisure and employment. It is a challenge for adult agencies to devote the necessary time and resource to planning appropriate services for such low numbers and high costs. As a result, one parent told us, *"You are off the radar after 19."*

While it is never going to be possible for them to match the levels of care and support provided by children's services, adult agencies need to find new ways of using their limited resources to make transition work better, not least by planning further ahead and working in an integrated way with children's services from young people's early teenage years.

At a time of major changes to social care, health, education and wider public services, it is important that government policy ensures a stronger focus on the needs of young people with palliative care needs. Properly implemented government policies have the potential to improve the lives of young people with palliative care needs and their families over time. Yet there is much that agencies can be doing now and we signpost some useful guidance and examples of good practice throughout this report.

The report makes a number of recommendations for change at local and national level. In formulating these, we have been mindful that, at a time of shrinking resources, designing appropriate services is going to require creativity and imagination. Our key recommendations are that:

1. The Prime Minister should lead a cross-government initiative to improve support for young people who need palliative care, and their families.
2. The government should accept the Law Commission's recommendation that local authorities should have the power to assess the needs and provide services to 16- and 17-year olds.
3. Once a young person with palliative care needs reaches the age of 14, a wide range of children and adult services should jointly agree a five-year rolling plan which tapers services towards transition.

We have not sought here to address or resolve every issue around transition and adult services. We trust that others may feel inspired to do more work in this area.

This report will help place young people with palliative care needs and their families more squarely on the radar of adult services. These young people face challenging lives and may not live long into adulthood. They and their families cannot afford to wait.

A note on terminology

Finding the appropriate terminology to describe the young people we are talking about is complicated and there is no right answer. Young people are usually said to have a "life-limiting condition" where there is no reasonable hope of cure or a "life-threatening condition" where the possibility of cure exists. While such descriptions can be useful, they are essentially medical, whereas young people's needs extend beyond healthcare to social care, leisure, education and employment.

We have used the term "young people with palliative care needs" throughout this report. While this also has medical connotations, it focuses on needs rather than conditions and it comes closer to recognising needs which are social as well as medical.

² ADASS Budget Survey 2012, Association of Directors of Adult Social Services (ADASS), 12th June 2012 (bit.ly/MC_ADASS)

4. The context

Growing numbers of young people with palliative care needs

The demographic challenge facing health and social services is commonly taken to refer just to older people living longer, often with at least one long-term condition. But these days, advances in medical technology and practice mean that many more young people who would have previously died in childhood will now live into their early adult years and beyond. As the Dilnot Commission recognised, “*Many younger people with a care and support need are... living longer, often now outliving their parents*”³

There are more than 40,000 children and young people aged 0-19 in England who have long-term health conditions which many eventually end their lives and for which they may require palliative care. This represents a 30 per cent increase between 2000/01 and 2009/10. Of these children and young people, 4,000, or one in 10, are aged between 16 and 19, an increase of 44.8% over the past decade.⁴

Data on specific conditions tell the same story. To take just three examples:

- For those with Duchenne muscular dystrophy, the likelihood of living to the age of 25 rose from 12 per cent in the 1980s to 53 per cent by 2002 and new therapies are leading to further increases in lifespan.⁵
- 50 years ago, 25 per cent of those with congenital heart disease survived into adulthood, whereas today 90 per cent do and numbers are predicted to increase by 2,500 adults a year.⁶
- Around half of people with cystic fibrosis will live past the age of 41, and a baby born today with cystic fibrosis is expected to live even longer.⁷

The majority of young people who require palliative care have a range of severe disabilities and complex health needs. Cancer represents just under 14 per cent of diagnoses.⁸ There were 2,776 young people aged 15-24 receiving HIV specialist care in the UK in 2010.⁹

Some young people will have physical conditions, such as Duchenne muscular dystrophy or cystic fibrosis, but full mental capacity. Others will have rare conditions and profound and multiple learning disabilities.

All young people with palliative care needs and their families face particular physical and emotional challenges as they move towards adulthood. The risk or certainty of death in young adulthood adds a degree of complexity and urgency to the support they require. They need access to a package of services which includes both universal and specialist services, and the nature of their illness trajectory means that their social, emotional and physical needs fluctuate.

Palliative care for young people

Those who are unlikely to be cured by treatment are offered palliative care, which is best defined as an active and total approach to care, embracing physical, emotional, social and spiritual elements.

³ *The Report of the Commission on Funding of Care and Support*, July 2011 (bit.ly/MC_Dilnot)

⁴ *Life-Limiting Conditions in Children in the UK*, Fraser L et al, University of Leeds Division of Epidemiology, report for Together for Short Lives, October 2011 (bit.ly/MC_Leeds). As this is based on data of diagnoses, it includes a small minority of children and young people, such as cancer survivors, who may never use palliative care. There is no doubt, however, that the number of children who require palliative care is growing and that the rate of increase is greatest among 16-19-year-olds.

⁵ *Survival in Duchenne muscular dystrophy: improvements in life expectancy since 1967 and the impact of home nocturnal ventilation*, Eagle M et al, University of Newcastle, pub. in *Neuromuscular Disorders*, December 2002 (bit.ly/MC_Duchenne)

⁶ *Discussing end of life in adult congenital heart disease*, paper presented by Dr Sarah Bowater, Queen Elizabeth Hospital, at Beating the Barriers conference, 22 March 2012.

⁷ Cystic Fibrosis Trust (cftrust.org.uk)

⁸ *Life-Limiting Conditions in Children in the UK*, op. cit.

⁹ *People with HIV in the UK*, National AIDS Trust (bit.ly/MC_HIV1)

Palliative care for young people focuses on enhancing the quality of life for the young person and support for the family and includes the management of distressing symptoms, the relief of pain and the provision of short breaks/respite, as well as care through death and bereavement.¹⁰

In their early to mid-teens, young people receive health, education, social care, palliative care and other support from children's services. In their later teens they start to receive this from adult agencies, who assume responsibility at different points after the young person's 16th birthday. This depends on the service and the area and complicates matters. One commissioner told us, *"In mental health young people become an adult at 17, in clinical services they become an adult at 16 or 18, and in social care they become an adult at 19"*¹¹ There is a clear need to standardise the age at which a young person starts receiving adult services in order to ensure consistency throughout the transition process.

The challenge of transition

“ Many children and young people...require increasingly complex levels of support and it therefore becomes much more important that transitions to adult care are carefully considered by commissioners in planning end of life care services.”¹²

The term *"transition"* is often taken to mean the process of moving from children's to adult service providers as if the adult services that young people need are in place. Quite rightly, an ideal is held up of *"seamless and co-ordinated healthcare to prevent medical deterioration or psychological distress, alongside help in managing social, education and employment opportunities and challenges as well as independent living skills and self care where appropriate."*¹³

The reality for many young people, however, is that transition leads to a significant reduction in the support they receive and the range of services they can access. Many parents describe it as like *"standing on the edge of a cliff, about to fall into a black hole"*.¹⁴

We recognise that adult services are never going to be able to provide the same comprehensive, bespoke packages of care and support (social care, health, education, housing, employment and so on) for all young people because of the profound cost implications.¹⁵ This does not mean, however, that more cannot be done to make transition work for young people and their families. As one commissioner we spoke to said, *"We need to think of the best way we can use the limited resources we have."*¹⁶

There is increasing evidence that well organised transition protocols and programmes have measurable benefits for young people and their parents.¹⁷ Equally, poorly planned transition is not just extremely distressing for young people and their families, who already have a lot to deal with. It can also lead young people not to adhere to their treatment, resulting in greater illness, adverse social and educational outcomes, additional health service costs and even earlier death.¹⁸

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¹⁰ ACT 2008 (bit.ly/MC_definition)

¹¹ Head of children's joint commissioning across local authority and NHS, interviewed as part of Marie Curie's *Young People and Transition* programme

¹² *End of Life Care Strategy: Promoting high quality care for all adults at the end of life*, NHS, July 2008 (bit.ly/MC_EOL)

¹³ *Transition Care Pathway for young people with life-threatening and life-limiting conditions*, ACT 2007 (bit.ly/MC_ACT)

¹⁴ *Personal Independence Payment: assessment thresholds and consultation*, Every Disabled Child Matters, 2012 (bit.ly/MC_EDCM)

¹⁵ For example, adult social care directors are reportedly planning a cumulative reduction in their budgets of £1.89 billion in 2011/13. Association of Directors of Adult Social Services (ADASS) Budget Survey 2012, 14 June 2012 (bit.ly/MC_ADASS)

¹⁶ *Young People and Transition*, op. cit.

¹⁷ *Transition: Getting it Right for Young People – Improving the transition of young people with long-term conditions from children's to adult health services*, Department of Health and Department for Education and Skills, 2006 (bit.ly/MC_Getright)

¹⁸ *Getting it Right for Young People*, op. cit.

5. Young people, families & transition

One of the keys to providing transition services that properly meet young people's needs is to listen to what young people and their families want. Drawing on what we were told during our research, we identified five primary areas of concern around the transition from children's to adult services.¹⁹

(i) Small numbers may lead to young people being overlooked

Despite the growth in numbers, there are still relatively few children and young people with palliative care needs, and adult services still tend to focus on those over the age of 60. As a result, the change to adult services can be daunting for young people and their families. Many have to start to interact with a range of new organisations, teams and professionals with different priorities, targets and funding streams. Instead of one family-focused paediatrician, young people must get used to seeing multiple specialists who focus on the individual rather than the whole family.

"The main thing I would change is making it so that when you move on from children's services it doesn't feel as though you have disappeared off the face of the earth"
– Young person in their 20s

(ii) Planning is often poor

There is a statutory requirement for every young person from Year 9 (aged 14-15) who has a statement of Special Educational Needs (SEN) to have a transition plan, and a range of agencies, including adult ones, are meant to attend transition planning meetings.²⁰ However, some adult services do not participate fully and many young people still leave school without a plan. For young people with palliative care needs who do not have a SEN statement, there is currently no statutory requirement for a plan to be put in place.

"When we become an adult... if the adult services were already in place, we could smoothly be transferred onto them, removing all the uncertainty."
– Young person in their 20s

Young people and their families tell us they are not sufficiently involved in transition planning meetings, so the complexity of their needs is not understood and issues are not addressed that matter to them, such as having a social life or understanding benefits and housing. They say the process is fragmented and there is often no consistent key worker to coordinate services. As one parent remarked: *"Key worker? Don't make me laugh."*

For some young people, there is a sense that those involved in transition decision-making do not really understand their positions, experiences and challenges:

"A lot of people are involved when you go through the transition from children to adult services. They must have been through the transition [from child to adult] themselves but

¹⁹ *Young people with life-limiting conditions: transition to adulthood*, Phase 1 report for Marie Curie Cancer Care, Public Service Works, March 2011 (bit.ly/MC_PhaseOne)

²⁰ *Special Educational Needs Code of Practice*, Department for Education and Skills, 2001 (bit.ly/MC_SENcode). This supports the Special Educational Needs and Disability Act 2001.



they didn't have the same experience or difficulties as someone in a wheelchair. They will tell you what they think you would like. – Young person over 18

For many the experience of transition leaves young people and their families feeling frustrated and disillusioned:

"Nothing has gone right with the transition – it is rubbish and all wrong."

(iii) Reduction in services as an adult

A disrupted transition can result in gaps in services or inappropriate services.

"I stopped children's services at 16 and there wasn't anything until 18. I was in a children's home. I came out and there was nothing out there after. I didn't feel safe or wanted." – Young person in their 20s

This picture is replicated across a number of different services:

"The place where I got [physio] closed down. Nowhere provides ongoing physio. If you want it, have to go private. Most of my friends don't get it." – Young person in their 20s

Young people with palliative care needs, and their parents, have told us about having to use children's wards or being placed on wards or in residential care homes for older people, because of the lack of appropriate alternatives.

Young people also report having short breaks withdrawn or reduced just when they most want a social life. There is a sense that many services and sources of support just melt away:

"You need respite; you need a PA to help go out to decrease the isolation. I had a PA to take notes and help with things [at university]. It ended when I left."

– Young person in their 20s

This picture of reduced access to services is borne out by wider research. Half the councils responding to a 2007 survey by the Commission for Social Care Inspection reported that young people's care packages changed at, or after, transition to adulthood and that this generally represented a significant reduction in services.²¹ A more recent study stated:

*"Underlying the challenges to positive transitions are shortfalls in the provision of adolescent and adult services. Research has found a substantial reduction in medical care and therapies for young people with physical disabilities, widespread unmet need for equipment services, paucity of post-school provision and shortages of accessible housing and supported employment."*²²

(iv) The challenge of increasing needs can become a crisis

Extra poignancy is added by the fact that many chronic progressive conditions now reach crisis during late adolescence and young adulthood rather than earlier in life.²³ At the point at which young people enter adult services, therefore, their needs are greatest but support is less.

Agencies may also wish to consider whether they are potentially leaving themselves open to legal challenge. More cases are coming forward and in considering applications for judicial review, the Supreme Court is making robust decisions to protect disabled people's rights even where councils' defence is a lack of money.²⁴

(v) Support is not sensitive to young people's wishes, wants and desires

Like all young people, many of those with palliative care needs are beginning to strike out on their own and to establish their independence. They will be hoping to go into further or higher education, get a job, move into their own home and develop a social life.

"I've got a 'bucket list' – 240 things to do before I kick the bucket. Some are ordinary, eg pass my GCSEs and watch a sunset, and some are more dream stuff – get married and go to a ball. Well, last year I did go to London to a ball." – Young person aged 16

For some young people, the support they most want is in relation to gaining employment:

"I'd like a job. I've been out of college for six years, been on 20 courses but no job."
– Young person in their 20s

For others it is to enable them to live independently:

"I'd like to live in a flat with a flatmate, pay for my own carer, be independent and look after myself and have a job." – Young person under 16

²¹ *Growing Up Matters: Better transition planning for young people with complex needs*, Commission for Social Care Inspection, January 2007 (bit.ly/MC_CCSI)

²² *Models of Multi-agency Services for Transition to Adult Services for Disabled Young People and Those with Complex Health Needs: Impact and Costs*, Sloper P et al, Social Policy Research Unit, University of York, September 2012 (bit.ly/MC_York)

²³ *Children and adult's palliative care: A comparison*, ACT 2009 (bit.ly/MC_comparison)

²⁴ *R (KM) v Cambridgeshire County Council* [2010] EWHC 3065 (Admin) reviewed the lawfulness of community care provision being based in part on a Resource Allocation. A Supreme Court ruling of 1 June 2012 made clear that resources were not to be taken into account when establishing the needs of disabled people. See bit.ly/MC_law.

For others it is support to enable them to socialise with friends:

"I like to go out to concerts and so on. It's hard to meet up with friends. There is no support to help me go out so there is a lot of isolation." – Young adult in their 20s

They want a feeling of freedom and of not being overwhelmed or bossed around by adults:

"I need support but would like it in a secret way, not in my face." – Young person under 18

Like all young people they seek independence, away from adults:

"I would like a bit of adult-free time because I have one following me around 24/7."
– Young person under 18

Some young people also want to use their experiences to make things easier for other people in similar situations:

“ I can pass on my experiences, having gone through the transition period a few years ago now and having since been left to the mercy of adult services! A lot of my experiences haven't been particularly positive, but hopefully by letting others know exactly what is lacking they can be prepared for it and try to push for the services that we should rightfully be receiving. ”

Young person in their 20s

6. The policy framework

The government is planning major changes to social care legislation and to the rules governing special educational needs and disability. Taken together with the reforms to the health services, these have the potential to improve the experience of transition for young people with palliative care needs, and their families. As ever, the test will be how they are implemented on the ground.

Adult social services and transition

In July 2012, the government is expected to publish its Care and Support White Paper, along with responses to the Law Commission's report on adult social care²⁵ and the Dilnot Commission's report on the funding of care and support.

We anticipate that the White Paper will accept the Law Commission's key recommendations, including the core recommendation that adult social care be organised around the overarching purpose of promoting or contributing to the wellbeing of the individual. This could considerably benefit young people during the transition planning process as local authorities would be required to:

- Assume the service user is the best judge of their own wellbeing
- Follow the individual's views, wishes and feelings wherever practical
- Make decisions based upon the circumstances of the person and not unjustified assumptions based on appearances
- Give individuals the opportunity to be involved in assessments and in planning, developing and reviewing their care and support

For young people with palliative care needs, the Law Commission's Recommendation 58 could be of particular benefit. When a young person is moving from children's to adult services, local authorities would have an enhanced duty to co-operate and make specific provision. Councils would have a general power to assess and provide services to 16- and 17-year-olds under the adult social care statute, and would have to explain in writing if they refused an assessment request by a young person aged 16 or 17 or their parents or carers, irrespective of the young person's capacity. They would have to assess certain young people under the adult social care statute and to specify groups to whom this duty was owed.

The government intends for local authorities to provide everyone who is eligible, including carers, with a personal budget, preferably as a direct payment, by 2014.²⁶ Many young people tell us that they feel positive about personal budgets, as do their parents, although there is also wariness. While parents like the idea of more choice and control, they are concerned about having to arrange and oversee their child's care and about becoming an employer. If personal budgets and direct payments are to succeed, it will be essential that young people and their families get the support they need to use them effectively. There also needs to be awareness of young people with cognitive impairment, where further research is necessary about the impact of personal budgets on their care.

²⁵ *Adult Social Care, Law Commission, May 2012* (bit.ly/MC_LawComm)

²⁶ *A Vision for Adult Social Care, Department of Health 2010, para 4.9* (bit.ly/MC_SocialCare), and *Recognised, Valued and Supported: Next Steps for the Carers Strategy, HM Government 2010, p 24* (bit.ly/MC_Carers)

Among other measures that would assist with transition, local authorities and the NHS would have a duty to work together and could consider combining health and social care personal budgets. They would also have to work with housing bodies and children's



social services. Those caring for young adults with palliative care needs would have new legal rights to services.

There would also be a single, streamlined assessment and eligibility framework, a stronger voice for users and improved information provision. If a family moved local authority area, their assessment would move with them so they did not have to start all over again.

Children's services and transition

The government plans to change the system for special educational needs and disability (SEND).²⁷ It published a Next Steps paper in May 2012, and a new Children and Families Bill is promised for early in 2013. The stated intention is to introduce the reforms by April 2014, which may put them ahead of the anticipated social care reforms.

Many measures appear complementary to those anticipated in the Care and Support White Paper, focusing as they do on integration and multi-agency working. To bridge the transition divide, more details will be required of how the partnership between children's and adult services will operate.

The government argues that transition will become easier following the introduction of a single assessment process and an Education, Health and Care Plan from birth to age 25, and by giving families the right to (optional) personal budgets. Local authorities will have to publish a local offer of the education, health and social care services (including eligibility and redress) that will be provided from 0 to 25.

Although post-16 further education options for disabled young people will be increased, some "flexible arrangements" will be allowed for those with "the most severe and complex needs". It is not clear what impact this may have on the continuing education of young people with complex conditions who require palliative care.

Pilots in two or three local authorities will give those up to age 25 the right to appeal and make disability discrimination claims, with a view to extending this across England.

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²⁷ *Support and aspiration: A new approach to special educational needs and disability – Progress and Next Steps*, Department for Education, May 2012 (bit.ly/MC_NextSteps)

A Young People's Advisory Group will "help shape the next stages of the reforms". It is not clear how far these initiatives will involve adult services.

A total of 20 local pathfinders made up of local authorities and health partners are currently testing the reforms: eight of these are specifically looking at ensuring a better transition to adult services.²⁸ While this is a positive development, it is surprising that the pathfinders National Advisory Group includes a representative from the Association of Directors of Children's Services but not the similar body for adult social services, whose involvement might be thought essential.²⁹

Health reforms and transition

The third part of the jigsaw is the changes introduced by Health and Social Care Act 2012. These include a new requirement for health services to commission services for disabled children jointly with local authorities.³⁰ This should improve transition planning and it will be important that relevant bodies monitor implementation across a devolved NHS.

Helpfully, the SEND Next Steps paper suggests that the Secretary of State's annual mandate to the NHS Commissioning Board may/could require health commissioners to concentrate on disabled children and young people. It will also be essential to ensure that the health and wellbeing boards which are to be established in all upper-tier local authorities focus on young people with palliative care needs, particularly when developing their Joint Strategic Needs Assessments and joint health and wellbeing strategies to influence commissioning.

²⁸ These are Wiltshire, Lewisham, Hertfordshire, Oldham, Rochdale, Manchester, Calderdale and North Yorkshire. The full list of pathfinders is at bit.ly/MC_Pathfinders.

²⁹ For those interested in learning from pathfinders as they develop, a "food for thought" web page is carrying links to newsletters, case studies and documentation: see sendpathfinder.co.uk/foodforthought

³⁰ "We intend to legislate through the proposed Children and Families Bill to build on the framework introduced in the Health and Social Care Act and ensure that services for disabled children and young people and those with special educational needs are planned and commissioned jointly between local authorities and clinical commissioning groups." (*Next Steps*, op. cit.)

³¹ *Personal health budgets and NHS Continuing Healthcare*, NHS discussion paper, January 2012 (http://bit.ly/MC_PHBs)

³² *Creating a Fair and Transparent Funding System; the Final Report of the Palliative Care Funding Review*, July 2011

The government hopes that offering personal health budgets, including a direct payment, by 2014 to all those who get NHS continuing healthcare will make the transition from children's to adult services "smoother."³¹ Improvements could also be stimulated by a new Children's and Young People's Health Outcomes Strategy, which will set out how to measure transition outcomes in health and social care for those aged up to 19 who have long term conditions, disabilities and palliative and end-of-life needs.

Finally, the independent Palliative Care Funding Review recognises that some young people might need children's services beyond the traditional transition to adulthood. In the context of developing a tariff for palliative care funding, the review recommends that the "age cut offs between adult and children's classification systems should be used in a flexible way, to best suit the needs of the patient". A young person would not immediately transfer to an adult tariff when turning 18 if their needs were still better covered by the children's tariffs, while a young adult under 18 could be placed on the adult tariff if this was deemed more suitable.³²

7. What is working now

There is no need for agencies to wait for the reforms to take hold before improving transition services. Much useful experience and good practice already exists. For example, the Marie Curie Cancer Care Programme, which is funded by the Department of Health, has supported projects across the county to develop models of care and support in order to improve the well-being of young people and their parents/families. The voices of young people and the parents themselves have been the central focus of these models.

There are also other positive examples of established good practice across the country, as follows:

- In **Bromley**, a transitional healthcare plan is now completed before a young person leaves school. The transition to adult services is smoother and there is a more effective use of limited resources.³³
- In **Cornwall**, a multi-agency protocol and transition plan is involving all agencies as young people move to adult services.³⁴
- In **Northumberland's** integrated health care service, children's and adult community health are managed under one system.³⁵
- In **Northamptonshire**, service users, parents and carers say they lack information and choice during transition. The aim is to create a new, multi-agency transition service for young people aged 14–25.³⁶
- As a SEND pathfinder focusing on transition, **Wiltshire** is working towards an integrated service linked to a personal budgets pilot across education, children's and adults' social care and health for 0–25 year olds.³⁷
- **Essex** is piloting a "whole place community budget"³⁸ with all-age commissioning of learning disability services, including integrated services from 14 upwards.³⁹
- In **Suffolk**, person-centred planning means young people are supported to make a DVD telling their story prior to the Year 9 transition review.⁴⁰
- In other areas, young people are being supported to prepare person-centred statements to guide services.⁴¹

Hospice services

Improving transition is not a matter just for statutory services. Other providers – not least hospice services for both children and adults – also have to redesign their services to make them more appropriate and accessible.

Over the years, children's hospice services have made some good progress. A UK-wide 2011/12 survey reports that a third (33 per cent) now have a separate wing or building for young people and most (86 per cent) have staff trained to work with young people. Over half (58 per cent) also provide services for adults, with 84 per cent of these making internal arrangements for the young person's transfer between their child and adult services.⁴²

³³ *Case Study: London Borough of Bromley, Transition Support Programme*, 2011 (bit.ly/MC_Bromley)

³⁴ *Transition to services for adults*, Cornwall Council, May 2012 (bit.ly/MC_Cornwall)

³⁵ *Transition for young people with life-limiting conditions: the UK picture*, McNamara K, Together for Short Lives, December 2011 (bit.ly/MC_ACTcases)

³⁶ *Transitions project proposal: This Time it's Personal*, Northamptonshire County Council (bit.ly/MC_Northants)

³⁷ Bromley & Bexley and Wiltshire case studies from report of SEND pathfinder single assessment process and Education, Health and Care Plan event, 2 March 2012 (bit.ly/MC_Pathevent)

³⁸ This new model looks to organise public spending by place rather than agency and brings all agencies together to redesign services around local people's needs. The partners agree common outcomes and pool resources and join up activities to get there. Improving quality and making efficient use of public money are important dimensions.

³⁹ Draft scoping document, Health and Wellbeing domain, Essex Country Council (bit.ly/MC_Essex)

⁴⁰ *Person Centred Approaches in Transition Planning*, National Transition Support Team, 2011 (bit.ly/MC_NTST)

⁴¹ See examples for three young people at bit.ly/MC_Ben, bit.ly/MC_Laura and bit.ly/MC_Praful.

⁴² *Children's Hospice Service Provision 2011/12*, Durham University Mapping Unit with Together for Short Lives, to be published in July 2012. Of 35 children's hospice organisations in the UK, 33 participated in the data collection and reported on 43 services (six organisations provide more than one service and completed a questionnaire for each). Not all children's hospice organisations participated and the results should be read with this in mind.

Some positive examples are below.⁴³

- The **J's Hospice** in Essex and **Douglas House** in Oxfordshire exist specifically to support those aged 18–40 and 16–35 respectively.
- **Jacksplace** is a purpose-built unit for young adults attached to Naomi House Children's Hospice in Hampshire.
- **EllenorLions Hospice** in Kent runs a hospice-at-home transition service, ChYps, to help young people move into adult care.
- **St Oswald's Hospice** in Newcastle has a transition worker and runs a unit for young people who have used the hospice to help them clarify their future options.
- **Richard House** children's hospice in east London has a specific worker to develop bespoke arrangements for young people, which has been funded by the Marie Curie Cancer Care programme. It works closely with **St Joseph's** adult hospice in east London, which offers a full range of services to young people and hosts monthly social groups for young adults who use Richard House.
- **Havens Hospices** in Essex comprises **Fair Havens** for adults and **Little Havens** children's hospice. They have developed a transition strategy and are working closer together to meet young people's needs when moving to adult services.
- **Children's Hospice South West**, the Marie Curie Delivering Choice programme and Marie Curie Nursing Service are working with North Somerset Primary Care Trust, NHS Somerset, NHS Bristol and Somerset County Council to address commissioners' perspectives and develop transition planning tools.
- **The Children's Hospice Association Scotland (CHAS)** and the **Marie Curie Nursing Service** are working together in Scotland to make planned overnight visits by Marie Curie Nurses more available to young people and their families. This includes providing the right training and competencies to ensure that staff can care for young people and their families.

Children's hospice services and young people

Of the 7,632 children and young people who use children's hospice services in the UK, over a fifth (22 per cent) are aged 16–25, with a further 1 per cent aged 26–30. The upper age limit for children's hospices ranges from 18 to 35 years, with an average age limit of 22. Some hospices support no young people while others support as many as 76, with an average of 12 young people in transition at any one time from children's hospice services.⁴⁴

The services provided include end-of-life care, family support services, sibling support, dedicated hospice care, short breaks, telephone advice and contact, symptom management, emergency care, education and training (for carers and staff), day care, practical support, complementary therapies, spiritual support, community nursing and care, neonatal support, contact and key worker visits, physiotherapy, music therapy, play therapy, psychological therapies, consultant-led specialist palliative care, hydrotherapy and antenatal support.

⁴³ See *Transition for young people with life-limiting conditions*, op. cit., for more examples.

⁴⁴ *Children's Hospice Service Provision 2011/12*, op. cit.

8. Our top to-dos

The recommendations below are directed at ensuring that adult services engage fully with children's services in putting young people with palliative care needs on their radar. Young people and their families need to be at the centre of the planning of their own care and support. The support required is wide-ranging and expensive but we owe it to these young people, their families and ourselves to make their lives less challenging and more ordinary.

1. The Prime Minister should lead an initiative across government to co-ordinate cross-departmental working on issues affecting young people who need palliative care, and their families and carers.
2. The government should accept the Law Commission's recommendation that local authorities should have the power to assess the needs of, and provide services to, 16- and 17-year olds.
3. Once a young person with palliative care needs has reached the age of 14, a range of children and adult services should come together to agree a five-year rolling plan, encompassing all relevant local services. This plan should taper services to make transition less of a "cliff edge" for families.
4. The Care and Support White Paper should explicitly set out how adult social care services will support Education, Health and Care Plans to deliver a less adversarial and less bureaucratic experience of transition.
5. Levers are essential to ensure that health services observe the new requirement for joint commissioning. In delivering its proposed mandate for disabled children and young people, the NHS Commissioning Board should drive good commissioning by issuing early guidance on commissioning palliative care for children and young people. The health outcomes strategy should measure transition outcomes for young people with palliative care needs.
6. Health and wellbeing boards should consult young people with palliative care needs and reflect their priorities in local health and wellbeing strategies.
7. Those special educational needs and disability (SEND) pathfinders which are addressing transition support should recruit young people with palliative care needs and their families.
8. The SEND Young People's Advisory Group should include young people with palliative care needs who have experience of transition, while the SEND pathfinders' National Advisory Group should include the Association of Directors of Adult Social Services.
9. The government should issue guidance that the new "local offers" for disabled children should state what will be provided by adult services.
10. Young people with palliative care needs can find it particularly difficult to access leisure and recreational activities. They should get priority for leisure services in joint health and wellbeing strategies and from the third sector.

11. In order to plan services for the future, all agencies – including adult agencies – should share data with each other on the numbers and needs of children and young people who require or are likely to require palliative care.
12. All information about young people with palliative care needs should travel with them across organisational boundaries. This could be in the form of a care plan that covers clinical, social and educational needs and which supports the process of transition.
13. Adult services, including hospices, should do an audit of their suitability for working with young people and put in place an action plan to improve their accessibility to young people and their families.
14. The government should review the age at which a young person starts receiving adult services and ensure that this is streamlined and standardised to ensure consistency throughout the transition process.
15. We recommend that young people who need palliative care but do not have a special educational needs (SEN) statement should be offered a transition plan, even though there is no statutory requirement to do so.

9. Further information

Guidance for good transition

- *Transition Care Pathway for young people with life-threatening and life-limiting conditions* (ACT 2007)⁴⁵
- *A Transition Guide for All Services: key information for professionals about the transition process for disabled young people* (CDC, DCSF and DH 2007)⁴⁶
- *Transition: Moving on Well – A good practice guide for health professionals and their partners on transition planning for young people with complex health needs or a disability* (DH and DCSF 2008)⁴⁷
- *Using person-centred thinking with children and young people with palliative care needs* (graphic based on the transition care pathway)⁴⁸

Case studies of successful transition

- Pathfinder case studies are being posted at sendpathfinder.co.uk/foodforthought
- The Transition Information Network (TIN) issues a monthly e-bulletin and its website signposts to case studies, information and organisations that support transition (transitioninfonetnetwork.org.uk).

Research into what works

- *Transition to Adult Services for Disabled Young People and Those with Complex Health Needs* (SPRU 2010)⁴⁹
- *Information and Learning from the Aiming High for Disabled Children Transition Support Programme* (NTST and CDC 2011)⁵⁰
- The STEPP project is looking at transition services across conditions and aims eventually to provide resources for services who want to improve transition support to young people with palliative care needs.⁵¹

The law

- *Transition to Adulthood* – This chapter of a longer handbook deals with the law relating to disabled young people as adult agencies become responsible for their care.⁵²
- *Cemented to the Floor by Law: Respecting Legal Duties in a Time of Cuts* is aimed at commissioners, managers and professionals working in local authorities, health services and other public bodies. It includes some of the most important legal duties to consider when making funding decisions and outlines the distinction between duties and powers.⁵³

⁴⁵ bit.ly/MC_ACT

⁴⁶ bit.ly/MC_transitionguide

⁴⁷ bit.ly/MC_movingon

⁴⁸ bit.ly/MC_HSA

⁴⁹ *Models of Multi-agency Services*, op. cit.

⁵⁰ See *Information and learning from the Aiming High for Disabled Children Transition Support Programme*, National Transition Support Team and Council for Disabled Children, October 2011 (bit.ly/MC_TSP). The Transition Support Programme ran from 2007 to 2011 and has been superseded by Preparing for Adulthood, a two year programme funded by the Department for Education to help deliver the SEND reforms.

⁵¹ See bit.ly/MC_STEPP

⁵² *Disabled Children: a Legal Handbook*, Broach S, Clements L and Read J, Legal Action Group, 2010 (bit.ly/MC_transitionlaw)

⁵³ Broach S, Council for Disabled Children, November 2010 (bit.ly/MC_legalduties)

For more information contact:

Sharon Manwaring
Marie Curie Cancer Care
89 Albert Embankment
London SE1 7TP

Phone: 020 7091 4182

Email: sharon.manwaring@mariecurie.org.uk

Twitter: @MarieCuriePA

The Transition Partnership

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