

Young people with life-limiting conditions: transition to adulthood

‘Small numbers, huge needs, cruel and arbitrary division of services’

Executive Summary of Phase 1 report for Marie Curie Cancer Care

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CONTENTS

Acknowledgements	3
Executive Summary	4
What is it for?	4
Where did it come from?	4
What is it about?	4
Who is it for?	4
How was the evidence gathered?	5
What evidence was gathered?	5
What is the key learning?	7
Conclusions & Recommendations	8

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"New ways of thinking and doing in difficult times."



Executive Summary

What is the report for?

The report summarises an intensive three months of evidence gathering and analysis on the situation, needs and aspirations of young people with life-limiting conditions who are growing into adulthood (age range 13-25 years).

The aim is to enable Marie Curie Cancer Care (MCCC) better understand the end-of-life care needs of this group of young people and therefore be positioned to scope effective ways of providing support. The report will also inform MCCC's service development plans, including the possible development of a digital engagement strategy to help meet the identified needs of this group.

Where did it come from?

Children with life-limiting conditions are living longer and thus requiring support into adulthood. There is growing evidence of unmet needs as these young people make the transition from children's palliative care to adult services. Historically, MCCC has cared for comparatively low numbers of young people. Aware that it does not have enough experience in caring for this group of patients to understand their needs, the charity resolved to take active steps to better understand how it can develop services that will be effective.

Accordingly, supported by funding from the Department of Health, MCCC invited bids for the initial, evidence-gathering phase of a two-phase England-wide project to develop and enhance the charity's knowledge of the end of life care needs of young people with life limiting illnesses and their carers. The commission was awarded to PublicServiceWorks Ltd (PSW), who fielded a team of independent consultants with wide-ranging and complementary experience and expertise. Phase 1 of the project took place in the period from January to March 2011 and ends with this report, written by the PSW team. Phase 2, concerned with the design and implementation of strategies and action recommended in Phase 1, follows on immediately.

What is it about?

The questions at the heart of the inquiry are:

- **What are the issues and opportunities for young people with life limiting conditions, and for their families/carers, in managing their own best transition to becoming young adults?**
- **How can we together best tackle these challenges?**

Evidence was gathered from young people themselves, their families/carers and those responsible for their care and welfare at policy, commissioner and provider level.

Recommendations are made for action to build on pioneering excellent practice and to remedy current failings and inadequacies (in many cases, widely recognised by those working in the field) in the level and type of care and support available to these young people and their families/carers.

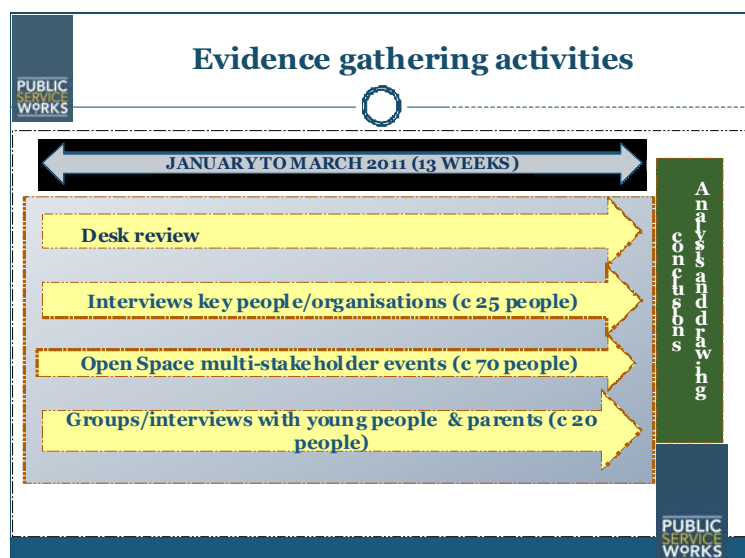
Who is it for?

The report was principally written to inform decision makers at Marie Curie, but its findings will be of interest to a wide range of organisations and people concerned with this field at policy, commissioning and provider level across sectors. The report highlights overarching

issues about processes of transition which are likely to be of help to others struggling with these in other settings.

How was the evidence gathered?

The work was constructed as a set of parallel tracks where multiple sources of evidence could be drawn on so as to create a rich picture that can be acted on in the real world of practice and inform decisions. We focused on gathering evidence in order to understand the people who



create, interact and relate in this field of work. As illustrated left, evidence was sought from young people and their parents, from practitioners, researchers, and from stakeholders in other organisations. We aimed to explore what they do and what they think – i.e. their ideas and practice and the assumptions that underlie both.

The report outlines key learning associated with the work in each of these strands. Crucial to our ability to process much of the evidence gathered was the

learning we gained from working with young people and their parents:

- young people with life-limiting conditions are as **creative and resourceful** as their peers without life-limiting conditions and they have a lot to say
- **language and communication style and skills**, flexible enough to accommodate the huge diversity of young people and their capacities, are critical
- engaging with the young people means **engaging with their parents and carers** who in most cases need to be involved directly
- talking to parents opens up the **whole family setting** to view and this is very important in understanding the issues.

What evidence was gathered?

Young people

Young people overwhelmingly have a **poor experience of transition**, both in terms of services and in terms of having the level of autonomy and control they desire

Young people share a common **aspiration for a 'normal life'** and hold largely reasonable ambitions for what they want to achieve in their lives, such as an active social life, education, work opportunities, and what concerns them as young adults such as friends, relationships, going out and looking good.

Young people are **concerned about their parents** and the strain of their care on parents

Some young people are **keen to engage with others** and to contribute their experiences to help others. Digital platforms are used by most young people as part of their daily life, but

digital platforms development for them should be **gradual** and focus on young people-led options and links to sites used by all young people

Innovative work is being developed within children's palliative care to engage young people in thinking about their move into adulthood, involving group-based social activities, and creative work such as drama, video, radio.

Parents

Parents overwhelmingly have a **poor experience of transition**, both in terms of its impact on the young person and in terms of the impact on themselves of fewer respite and short break services

Parents have **their own transition** to make as their child grows up: to acknowledge and support more autonomy for the young adult and to face the shift from parent to carer of an adult, alongside the painful and growing reality of early death of their child

Parents **appreciate peer support** but this is currently ad hoc and marginal in their lives especially after transition.

Practitioners

Transition is a shock for professionals too.

- They still **live in silos**, locked into separate and differing assumptions, structurally separated systems that are Children's and Adult services and that operate different protocols (for example, in pain relief)
- They **aspire to networks & better partnership**
- They have **few means of sharing insights into each other's work** and culture and find it difficult to identify and adopt good practice
- They **struggle to operate transition planning procedures** across agencies and try to 'work around' the **dysfunctional systems** that confront young people and families
- They recognize the severity of problem – especially in current pressures – and **ALL said that the young people must be put at the centre of the transition process in a person-centred approach.**
- They also noted a **lack of skills** for practice and the communication approaches to do this and would appreciate **more innovative tools** to help with this
- They could offer **no clarity on the necessary cross-system strategic leadership**: neither for clinical responsibility and quality of care, nor for the organizational challenge of the 'key worker' approach, nor for the impetus to create the more flexible networks they felt were crucial to better care and better transition

Institutional stakeholders

The people we spoke to agreed that the fragmented patchwork of services offers no consistent support for these young people, nor the opportunity to have their voices heard and responded to. They also emphasised:

- There is **no clear model** of care underpinning services
- For there to be sustainable improvement in the situation of these young people, **three parallel transitions** have to take place – for the young people themselves, their

family, and the professionals who care for them. Promising innovative work is being undertaken with this end in view, and this needs to be evaluated and learned from.

We found a surprising **lack of capacity to comment** from senior people we would have expected to have a view.

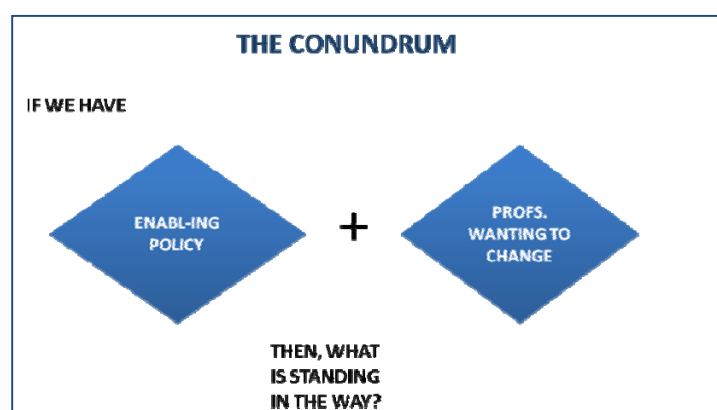
Research and policy

We found that notwithstanding the many instances of good practice taking place at local level and the positive policy context, **much more needs to be done to achieve a step-change** in transforming the outcomes for young people with life limiting conditions at and after transition.

There are **few clear models** for re-working services and transition processes to produce better results of young people's lives and commissioners are hampered by the **lack of detailed information about this group** as well as the inherent complexity of its needs.

Addressing the gaps identified above sets a **challenging action agenda** for governmental and non-governmental bodies and may provide a focus for Marie Curie in Phase 2 of this project.

What is the key learning?



A classic puzzle in public policy, the conundrum shown left, offered us a helpful starting point for understanding why young people and their families/carers continue to suffer from '*a universally awful experience*' in relation to services available to them as they enter young adulthood.

The report describes in some detail the analysis we developed in answer to the conundrum. **Three sets of triple challenges** seem to be involved, as illustrated below.

Core learning: it comes in threes...

- **Triple transition**
 - Young person to adult
 - Parent to carer...
 - Professional learning either to 'let go' or to enable/take on the unknown
- **Triple challenge for families**
 - Many young people die at or just after transition – condition deteriorating
 - Services 'just stop' exactly when they are needed most
 - ...when parents are getting older ...
- **Triple challenge in the current context**
 - Increasing demand as more young people with LLC reach 18+
 - Cuts to services plus additional negative impact on joint working & workforce capacity
 - Major NHS changes through shift to GP commissioning process

These sets of challenges raise a series of critical questions:

Critical questions to move forward.....

- **Transition:** Is it – as currently created - needed at all?
 - **Clinical responsibility:** who best placed to be the young person's clinical specialist to avoid transition trauma?
 - **Age limits:** could the project influence the age limit issues nationally?
 - **Commissioning:** should this be a national function across health and social care? How can health funding be more flexible and personalised?
 - **Local multi-functional networks:** could they have real impact on young people's/family experience?
 - **Key worker concept:** what's the offer? Who should take this role?
 - **Parents:** how can they be seen fully as carers with carer support needs?
 - **Learning:** how best to help children's nursing & adult nursing, social services and voluntary sector learn effectively?
 - **Digital platforms:** could YP-led digital development help reduce isolation, contribute experience, and create links beyond geography?
 - **Marie Curie:** what role in meeting the needs of young people with LLC? Could MC address palliative care needs/be a resource for others?
-

In the light of the challenges and critical questions, what could improve the system so that young people and families have a better experience and the system delivers equity as well as effectiveness? The following elements seem to be essential to any sustainable programme of change:

- a **broadier support system**, taking on the social issues raised by young people
- a continuing **clear clinical lead** role
- **cross-system networks**
- **young person-centred** ethos
- **joint** training and development.

Conclusions & Recommendations

In beginning this section it is worth stating that for this group their **small numbers, huge (and diverse) needs, and experience of cruel and arbitrary divisions of services** makes meeting their needs extraordinarily complex and difficult, as everything in this lengthy report illustrates. Our conclusions are, however, paradoxically brief!

Our conclusion overall is that young people should have the choice to stay with the relationships they have, adapted to age and changing need, and their support needs require creative joint funding under their and their families' control, possibly from a new national 'pot'.

In addition, the consistent messages in the evidence require **flexibility at the frontline** for professionals to negotiate on aspirations and needs with young people and their families:

- To improve directly the experience of young people and parents
- This can only happen through children's and adult services (and their funding) collaborating closely on the question of transition

The messages and issues show **a good fit with *We put patients and families first***, Marie Curie Cancer Care's 2011-2014 Strategy, for example:

- **Better care**: hospices as hubs, understanding need, improving quality links to issues of new local networks
- **Wider reach**: links to carer coordination, extending to young adults, supporting carers
- **Stronger Foundations**: spreading risk through partnership & joint working

The messages from the report also underline that **working with partners is fundamental**

- To work with young people and families in co-producing changes
- To develop networks within health and social care across statutory and voluntary sectors and national, local and regional levels
- To work on digital media in partnership with organisations well placed to take this up in the longer term

Recommendations to take the work forward

That Marie Curie influences the wider context and other key stakeholders through:

1. Feeding the findings into **National Funding Review**, which includes both adults and children, but is not yet explicitly considering teenagers and young adults as a group
2. Highlighting with key stakeholder organisations the very different responses of statutory agencies in **England, Wales, Scotland and Northern Ireland** to the challenge of transition and the practical implications of these, especially in relation to the severe inequalities suffered by these young people and their families
3. Holding a **national launch event** to involve young people directly with policy, commissioning and practitioner stakeholders
4. **Publishing key messages** from the report in a range of media e.g. on website, in popular form; an academic paper
5. Helping shape the **workforce development** agenda in concert with the Transition Partnership especially
6. Disseminating **broader learning** about practice and innovation to other condition areas (e.g. dementia, long term conditions)
7. Using the **database** of people who want to be involved in the future and should be.

That Marie Curie in Phase 2:

1. Continues to develop some elements started in Phase I
2. Fills key gaps that the Phase I activity has revealed
3. Follows new leads as indicated by what we have learned from Phase I, such as promoting local flexible multi-functional networks
4. Develops a limited digital platform offer aimed at young people and at parents