

# Making the most of life

Young people: life-limiting conditions  
but life-enhancing choices



IF YOU  
TAKE CONTROL  
AWAY, I LOSE  
EVERYTHING...

A Marie Curie Cancer Care programme designed and managed  
by PublicServiceWorks, funded by the Department of Health

# Where does this come from?


## Words

On behalf of Marie Curie Cancer Care, PublicServiceWorks spent several months speaking with young people, their families and professionals who work with them. What they said formed the core of a long report ([www.mariecurie.org.uk/youngpeople](http://www.mariecurie.org.uk/youngpeople)). Marsaili Cameron wrote this summary of the report.

## Link to video

[http://youtu.be/7aF3WcsBG\\_o](http://youtu.be/7aF3WcsBG_o)

In this short film, professionals like physiotherapists and social workers talk about what they have learned through their work with young people and their families and how they aim to put that learning into practice. Cass Productions  
[www.cassproductions.co.uk](http://www.cassproductions.co.uk)



*The words in the speech bubbles in Kate's illustrations come directly from the people who were interviewed.*

## Illustrations

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## Design

Sign  
[www.signgraphicdesign.co.uk](http://www.signgraphicdesign.co.uk)

# What's it all about?

Everyone knows that it's tough to grow up. And everyone knows that it's even tougher to grow up with a life-limiting condition. But not everyone knows that it's really, really hard to move from children's to adult services.

## **It doesn't have to be this way!**

If professionals listen carefully to what young people and their families say, there are lots of things that can be done to make life easier. This booklet describes some of what's going on to make a real difference.



# The story so far

As they get older, many young people and their families are not happy with the support they receive. Marie Curie wanted to find answers to the questions:

- **What is going wrong, and why?**
- **What changes would young people and their families like to see happen, and why?**

So, in early 2011, Marie Curie asked us, a team called PublicServiceWorks, to invite young people, aged 13-25, and their families to speak about their experiences and their hopes. We also spoke to different professionals who plan, pay for and run services that young people use.

We have put together this booklet to tell you about what people said – and to let you know about what’s going to happen as a result.



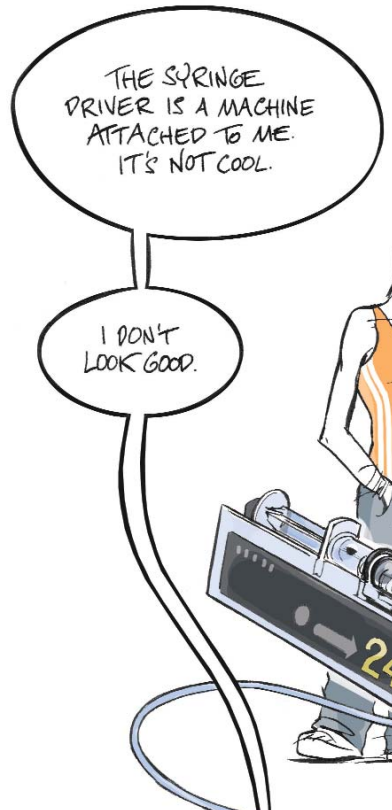
# It's good to talk...

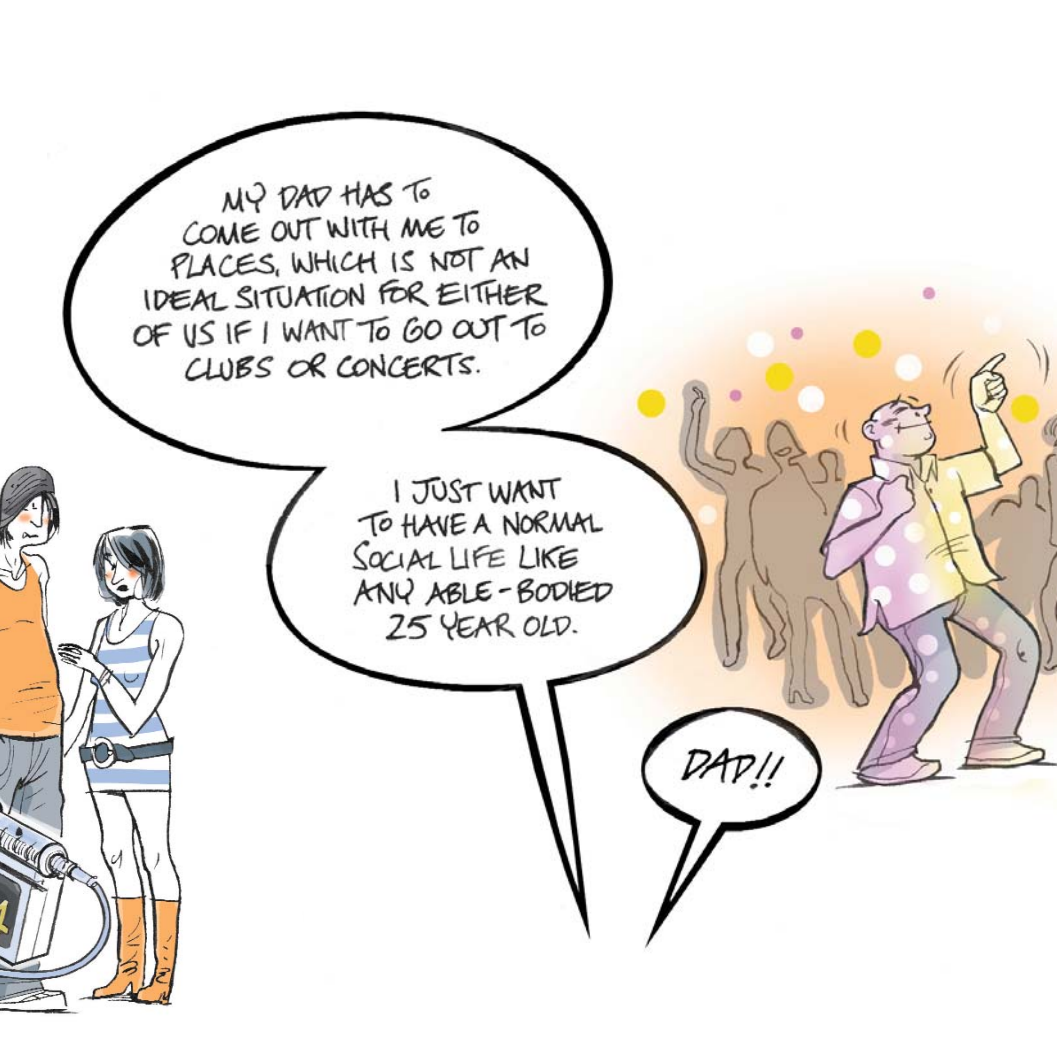
## **We talked with you and your families**

We asked you and your families about things that are hard for you as you get older. We also asked about what would make things better for you.

# You told us...

- It's very hard to move from children's services to adult services – suddenly, you can't get care that you need, and you don't feel in control any longer.
- What you want is a normal life, as far as that's possible – opportunities for education and work, and an active social life.
- You worry about your parents' health – caring for someone is hard work.
- You'd like the chance to help others as well as being helped yourself.





MY DAD HAS TO  
COME OUT WITH ME TO  
PLACES, WHICH IS NOT AN  
IDEAL SITUATION FOR EITHER  
OF US IF I WANT TO GO OUT TO  
CLUBS OR CONCERTS.

I JUST WANT  
TO HAVE A NORMAL  
SOCIAL LIFE LIKE  
ANY ABLE-BODIED  
25 YEAR OLD.

DAD!!

# Your families told us...

- It's really hard to move from children's to adult services – especially when you feel that you no longer matter, and your parents have far fewer short breaks.
- Your parents sometimes find it difficult to give you the space you need as you get older – it's hard not to worry!
- Your parents would like the chance to meet up with other parents facing the same challenges.







I DO THE  
MAJORITY OF THE  
CARE ON MY OWN.  
I'M A SINGLE PARENT.  
I DO EMPLOY MY  
PARENTS AND SISTER  
AT TIMES...

KEYWORKER?  
DON'T MAKE  
ME LAUGH...

# Who else did we speak to?

We spoke to doctors, nurses, social workers – people who design and run the services that are important for **you**.

We also spoke to people from organisations that pay for the services **you** use.

# They told us...

- They need to spend more time looking at the world from your point of view – and to do this, they need to make sure that they are able to listen to what you say.
- They need to do more talking and working together. Because they've been trained in different ways, they don't always understand the other person's point of view.
- They need to find ways of mending the gaps between services so that you and your families get the support you need when you need it.
- In some places, professionals, young people and their families are already working together in new ways to make the most of life.

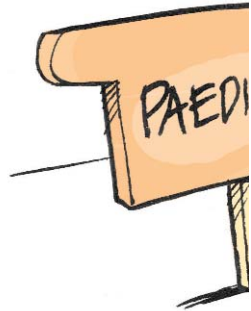
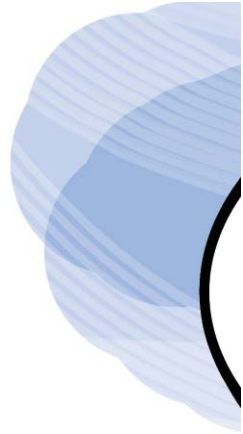
If you'd like to know more about what professionals think, see [http://youtu.be/7aF3WcsBG\\_o](http://youtu.be/7aF3WcsBG_o). This shows people at different events across the country talking to us.

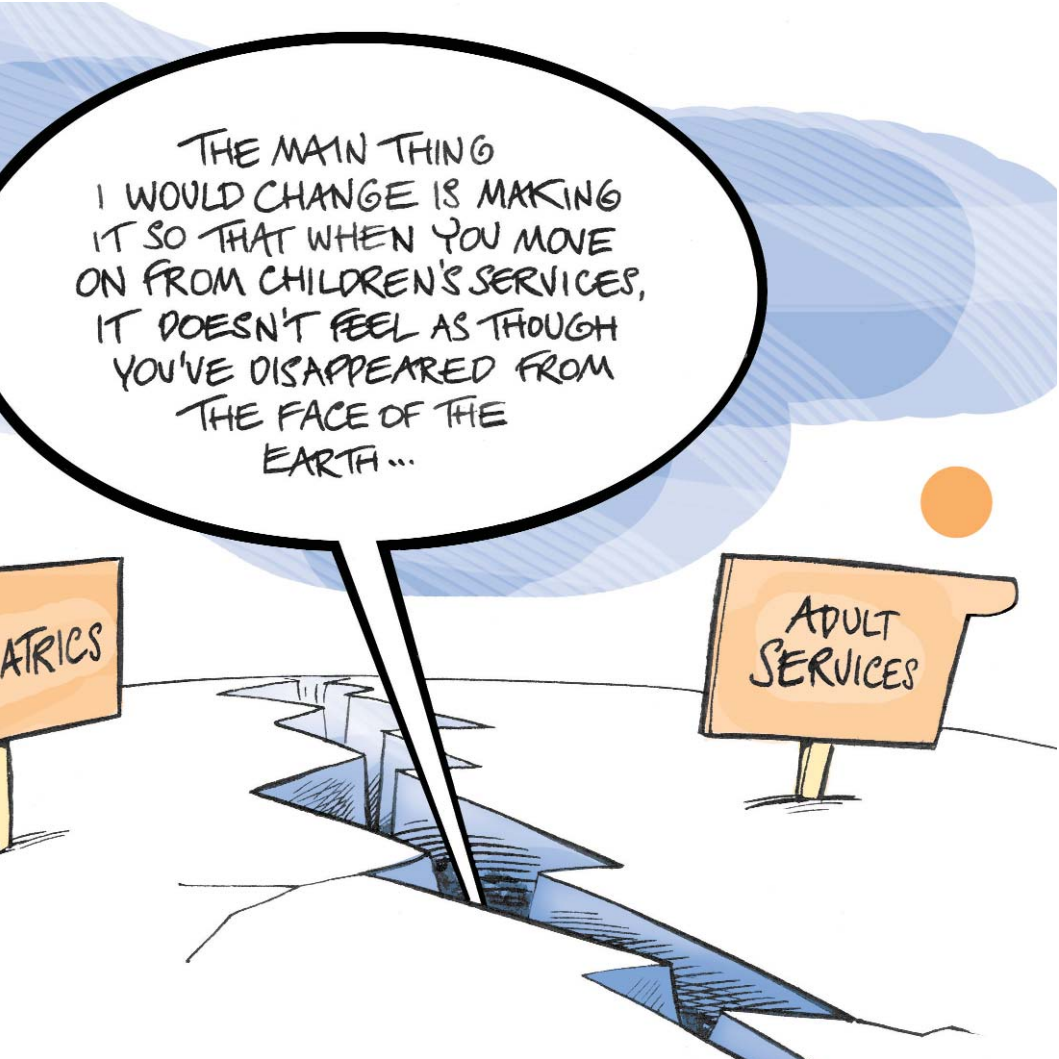
# What else did they say?

Most of them agreed with what you and your families said. They understand that, as things are at the moment, there are big gaps between children's and adult services – and this means that it can be scary and difficult to move between the services.

They also understand that professional people, like doctors and nurses and social workers, can sometimes forget that, just like other people, you need to be at the centre of your life! A social worker said,

**“We may miss some of the very simple but important things young people want to do”.**





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'VE DISAPPEARED FROM  
THE FACE OF THE  
EARTH...

ATRICS

ADULT  
SERVICES

# It's even better when what **you** say makes things happen

## What did we learn about what needs to change?

We found that four main things stood out as really important.

**1** You and your families need to be at the centre of your care and lives – systems and arrangements have to fit round you rather than the other way around.

**2** Professionals from different backgrounds would like more opportunities to learn and work together.

3 You want to live as normal and full a life as possible – so the support you get has to reflect the fact that social needs are as important as medical ones.

4 There are some really exciting creative developments in parts of the UK – these need to be spread more widely.




I WANT  
TO SEE THEM  
PLAY AND MEET  
THEM. I'VE ONLY  
SEEN ONE GAME  
LIVE ...

# So, what will happen next?



During 2011 and early 2012, we will work with different people and organisations to build on our findings in a practical way. In particular, we will:

- explore with you different ways of working with professionals
  - offer you the chance to apply for a small grant to support activities enabling normal life
  - get people, and organisations, to think about how to spend money in a way that you'll really benefit from it
  - open up opportunities for you to get involved in making films and doing drama and sports
  - explore with you and others ways in which you could make the most of the internet and social media
  - develop local networks to try out new ways of meeting your needs
- 





... TO TAKE MORE  
RESPONSIBILITY  
FOR CHORES  
AROUND THE  
HOUSE ...

... TO TOUCH  
A KILLER  
WHALE ...

SUPPORT... BUT  
I'D LIKE IT IN  
A SECRET WAY  
NOT IN MY FACE...

... IT'S HARD TO MET  
UP WITH FRIENDS-  
THERE'S NO SUPPORT  
TO HELP ME OUT...

... TO GET  
MARRIED...

HOW CAN YOU  
HELP TO MAKE  
THINGS BETTER?



If you feel enthusiastic about the ideas outlined in this booklet and would like to work with us, please get in touch.

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**Marie Curie Cancer Care**

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