



Expert Patients  
Programme  
Community Interest Company

# UPDATE

April 2010

[www.staying-positive.co.uk](http://www.staying-positive.co.uk)

**Staying  
Positive**  
YOUNG PEOPLE'S WORKSHOPS

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## Welcome to the second edition of the Staying Positive Newsletter.



We have had a very busy and positive year developing the programme across a wide range of settings and diverse group of young people. Our contracts with PCTs have increased and we have developed 14 new partnerships, all of which has supported nearly 250 young people to benefit from self management training and support over the last 12 months. We were also pleased to have been a finalist in two categories of the Children and Young People Now Awards 2009 and recently awarded the REACH Standard by Youth Action Network for our commitment to supporting youth volunteering and engagement. This newsletter aims to keep you up to date with developments around the country and share learning amongst the many partners and PCT's we are now working with.



Cathy McMahon, Young People's Programme Manager, EPP CIC

Staying Positive is a self-management programme for young people living with long-term health conditions. The programme is run by young people (aged 15-25 years) who are also living with conditions. It consists of workshops designed to build confidence, skills and social support. Activities cover the key issues faced growing up with a condition including communication with doctors and nurses, medication and treatment adherence, socialising, relationships, feeling down and depressed, transition and independence.



## OCN Accreditation

The Staying Positive Facilitator Training gained Open College Network (OCN) Accreditation in February 2010. Young people will now have their role as facilitators formally acknowledged as 90 hours learning, or 9 Credits at Level 3. We are very pleased to be able to offer a formal qualification to our young facilitators. This award can be given retrospectively so all young people trained to date will qualify for accreditation on completion of one set of workshops and their annual review. We currently have over 100 young people going through this process.

## Quality of Life Measure

A new Quality of Life measurement tool has now been introduced by EPP CIC to help us more effectively capture the impact of participation in the programme for young people. The tool was developed by Dr Kathy Hawley, programme author, in consultation with young people. All young people who take part in workshops from April 2010 onwards will complete a questionnaire pre, post and 3 months following participation. This will provide invaluable data on changes experienced in a variety of domains including medication and treatment, social support and confidence in managing their condition.

## Young people lead consultation with GOSH patients

Nine young people from the Staying Positive Programme facilitated a full day of consultation workshops with Great Ormond Street Hospital patients on 6<sup>th</sup> March 2010. They were supporting GOSH to find out what young people think of their service and how they would like to be involved in decision making within the hospital. This piece of work was part of a wider engagement exercise Great Ormond Street are undertaking in their bid to become a Foundation Trust.

## A positive approach to bullying

We have now introduced a dedicated bullying activity into the Staying Positive programme in response to issues being raised by young people in workshops. The new activity has been added into Workshop 2 and enables a more in-depth discussion on different types of bullying, including cyber bullying, ways of dealing with bullying and getting advice and support.

## Update from Partners

Last summer EPP CIC called for partner organisations to work with us to develop the Staying Positive Programme. Fourteen organisations across the country representing a range of different settings were chosen as partners and given training and support and a small grant to run workshops in their area. Below are just a few examples of the different approaches partners have taken so far:

### ▾ Healthy Schools Programmes

Shaun Cheesman, Healthy Schools Programme Co-ordinator for **North Somerset**, worked with the school nurse in Worle School, Weston Super Mare and the nurse at the local FE college to identify young people who could benefit from attending workshops. Workshops were run in a local hotel, youth centre and church community centre. As a result of positive feedback from young people, a further 2 sets of workshops have now been commissioned and another local secondary school has joined the partnership.

**Bristol Healthy Schools** Programme Co-ordinator Gill Brookman has joined forces with the Youth Service and Bristol Children's Hospital to deliver their programme. The youth service are taking the lead in organising venues, fun activities and provision of responsible adults whilst liaising with a local secondary school and the Hospital to recruit participants.

### ▾ Focus on Diabetes

The **Brighton Diabetes UK** support group wanted to develop their work with children and young people by becoming Staying Positive partners. Three local young people living with diabetes were trained as facilitators in February 2010 and started delivering their workshops in March. Diabetes specific adaptations to some elements of the programme have been made to ensure activities and examples are appropriate for this group.



**Lambeth LINK** (Local Involvement Network) is the statutory body responsible for public involvement in health and social care in Lambeth. They were keen to improve services for young people with diabetes through improved self care and self-management support. They have worked closely with the Diabetes Network for Lambeth, Southwark and Lewisham which includes the specialist diabetes team from Guy's and St Thomas' Hospital, to plan and recruit to workshops. Their experience of working with young people from disadvantaged backgrounds has helped to shape their recruitment strategy which focuses firmly on the fun activity element of the programme, in this case Street Dance lessons, a great venue and providing transport to pick young people up on the day.

For more information about the Partnership offer please email:  
catherine.mcmahon@eppcic.co.uk

## Young people inform recruitment strategy

During September and October 2009, Platypus Research was commissioned by EPP CIC to carry out a series of focus groups with 27 young people from London, Rotherham and Birmingham. All young people involved were living with a long-term condition, had not had any previous involvement with the programme and were aged between 12 and 18 years. The aim

of the research was to explore the potential barriers and incentives to participation in self-management programmes and to inform the refresh of Staying Positive marketing materials. The findings are helping to refine our approach to engaging with young people and a brand refresh and website update will be launched soon.



### New Mental Health programme coming soon...

EPP CIC has been commissioned by the Department of Health to develop and pilot a new self-management programme for young people with mental health conditions. Work to progress this is underway, with a reference group now set up and pilot sites identified. Alongside this, we will also be developing a support programme for parents. More news to follow in our next update...

## Supporting transition in Walsall

Last year Walsall Primary Care Trust commissioned the Expert Patients Programme CIC to run Staying Positive for young people aged 14-18 years who have been identified as a priority for transition support. These young people have a range of physical disabilities and are attending mainstream schools in Walsall.

They are supported by a case manager team of three health professionals. The team has excellent relationships with the young people and their families and as a result successfully recruited 10 participants to attend the first set of workshops. Two

young people supported by the Transition team have also been trained as Staying Positive facilitators and will be supporting delivery of more workshops due to start this month. As a result of participating in the programme young people were able to voice their need for further support and information on preparing for employment and sexual health and relationships. The Transitions Team responded to this by setting up further one day workshops to focus specifically on addressing these issues bringing in specialists, local celebrities and others to support delivery.

## Creative writing captures the imagination in East Lancs.

The poems below are the result of a creative writing workshop run during Staying Positive workshops in Clitheroe, East Lancashire during February and March 2010. The benefits of the workshops are eloquently told in young people's words...

### ↘ The Point (A poem about this course)

#### Outside this place, there are...

Hospital visits  
Blood tests in minutes  
People who talk in seconds

Schools exams  
Big demands

Discrimination  
in this nation

Frustration  
Irritation

#### Inside this place, there is...

A friendly face  
Memories I cannot replace

People I can trust  
(best friends are a must)

Problems I must face  
Darkness I must taste

Time is ticking – must keep my own pace  
Problems and difficulties I must embrace

Positivity I can taste  
I'll put bad memories in a box and tie it  
with a lace

#### My dreams in this place are to...

Leave with new friends  
Meet someone the same as me

To have a good laugh  
To have a calm and relaxed time

To make a difference  
Make sure everyone enjoys themselves

Never forget how much this place has changed  
me

To see things in a new way

#### If I give you this place you would have...

A big embrace  
A very safe place

A positive smile on your face  
Tolerance for every race

An amazing experience  
Something meaningful and hopeful

Confidence  
Positivity!!

Acceptance of your condition  
A better understanding

You would not be alone  
Give love and not hate

#### Without this place there would be...

No saving grace  
No way to take off my negative face

Lost in a maze  
Left out in the cold

Without a friend  
Feel an outsider

I would still be scared  
Have no understanding

Given the cold shoulder and turned away  
No feeling of being bigger and bolder

I wouldn't have met Bex who is ace!  
I wouldn't have met Beckie who is my new best friend

For more information about Staying Positive please contact:

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