

FULL OF LIFE

PARENTS SUPPORT GROUP



ADVOCACY NEWSLETTER

Volume 10
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FULL OF LIFE INFORMATION SERVICE

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Welcome to Full of Life
Full of Life is a self-help group managed by parents of children with disabilities in Kensington and Chelsea.

We were founded in 1994 by parents who were dissatisfied with the lack of information and support available to help them bring up their children. In particular they wanted to establish a single organization that could help with every aspect of their needs. Over the last 16 years we have worked hard to ensure the voices of disabled children and their families are heard.

Our time is given freely to ensure that our expertise as parents of disabled children (parents' decisions being taken about health, play, education and future career progression).

Latest News
A HUGE Thank you from Full of Life Update... Full of Life's Deal at Portobello Special Educational Needs Training for Parents Decision Time... Money... (John Gans for 2010)

FULL OF LIFE MARKET STALL PART II

On the 27TH August Young People with complex needs who have taken part in our summer project had a market stall on Portobello Road. This was our first attempt at a mini social enterprise; all products on sale were made by our young people.

Due to our success and high demand from the public for our wonderful products we are going to hold another one. We will be working on the production while the day and venue are confirmed.



Full of life young's people social enterprise-Portobello Market

The Information Service was launched at the beginning of 2010 and is a specialist service which has been created to provide practical information for children with disabilities or special educational needs and their families who live in Kensington and Chelsea. For practical support, advice and up to date news, visit the information service at www.fulloflifekc.com.

You can also ring the service on 05601 535 446 or email info@fulloflifekc.com Adrian Graham our Information Officer. For instance updates on services and news for your family, follow us on Twitter at www.twitter.com/folkinfo.



If you hear about any services that you think maybe useful to other parents, or you have had some difficulty accessing services, please us 05601 535 446 or email info@fulloflifekc.com

TRIPS OUT AND ABOUT

Following consultation with carers it has been agreed that Full of Life's Carers Grant will be used for trips to theatre productions. The first will be to see Cirque du Soleil brand new touring show, the fascinating TOTEM. This event will take place on the **12 of January** at Royal Albert Hall at 8.00 pm.

If you if you want to be part of this trip, please contact Patricia at the office on 0208 962 9917 or email patricia@fulloflifekc.com before the **20 of December 2010**.

Please note the funding for this trip is to assist parents/carers who care for adults with learning disabilities only.



NEW FULL OF LIFE PRODUCTION: GREASE!

Full of life spectacular new summer production Grease took place this year at the Chelsea Theatre, Kings Road. The show was written and directed by James Rigby, music by Gabriel Krchnavek and performed by the cast of [Full of Life](#).

Our fabulous young people worked hard throughout the summer, learning lines, dances and music, it definitely paid off!



The funds raised on the day will be used in the development of our social enterprise for young people with complex needs.

Everyone was given a standing ovation. A second performance will take place at St. Charles Hospital on the 27th November 3pm.



SPECIAL EDUCATION NEEDS TRAINING

Transition Planning and the Role of Parents

Full of life has been running a series of Special Educational Needs Training sessions run by Asset.

ASSET is a small independent charity which provides information and advice about education to parents/carers of children with special educational needs (SEN).

Our training sessions have proven to be a big success.

On the 18th of December the last session will take place which aims to provide parents with the

transition planning information going through the Role of the connexions service, the role of the tribunal and a question and answers sessions.

For more information about ASSET visit their website www.asset-gb.org.

Please call us on 0208 962 9994 to book your place. Lunch will be provided.

LONDON FAMILY- CARER HEALTH AND WELLBEING EVENT



Valuing People
Support Team

The department of Health and Valuing People are inviting London families to a Carer Health and Well being event which will take place on the 22nd November from 10 am to 3pm at Skipton House, 80 London Road, SE1 6LH.

This is an event for family carers of people with learning disabilities. You will have the opportunity to learn about how to protect your own health and well being and to become part of the London wide network of family carers to begin to change things locally.

There will be a structured program in the morning where you will hear about staying well and what is going on across London.

From lunchtime onwards you will have the opportunity to chat, learn more about what is going on, and have a nice relaxing head and shoulder massage!!

Places are limited. If you want to book your place please contact Sally: email: sally.hall-demir@dh.gsi.gov.uk , phone: 020 7972-4035

CARERS RIGHTS DAY IN KENSINGTON AND CHELSEA

It is Carers Rights Day on 3 December 2010. To celebrate this, Carers Kensington & Chelsea will be running an "Information day and Carers Appreciation Event at the Isaac Newton Centre.

Please feel free to drop in for tea, cakes and



information between **11am and 2pm** on **Friday 3 December 2010**.

There will be information available on the new service for carers – Carers Kensington & Chelsea – as well as information about the other groups, services and organizations that support carers in the borough.

“All carers who look after somebody who lives in the Royal Borough are welcome”



If you need respite care to attend this event please call **Vitalise** on: **020 7376 4640** (with five days notice).

The Isaac Newton Centre is at 108a Lancaster Road, London, W11 1QS. It's just round the

corner from Ladbroke Grove Underground Station.

For more information contact Peter Beard on 020 8962 4861 or email: peter.beard@kc-pct.nhs.uk

There will also be an information day at **New Horizons** from **1 to 4pm** run by **Time for Me**.

There will be staff available from the Pensions Service, Citizens Advice and Carers Kensington & Chelsea. Come and meet them and find out more about what you could be entitled to.

Time for Me at New Horizons, Guinness Trust Estate, Cadogan Street, SW3 2PF. **Tel: 020 7590 8970**

CARERS KENSINGTON AND CHELSEA HUB SERVICE

The Royal Borough of Kensington and Chelsea are announcing their “Carers Hub Service”. This service is for all carers and was developed to ensure that carers not known to social services or health could also access information and support. From the 6th December 2010 all carers who look after someone will be provided with advice and information on:

- How to get support
- The benefits that carers can claim and how to get help with the benefits
- Health support for carers
- Local services that support carers
- How to get support for the person you look after

The advice line number is 0800 032 1089

LEARNING DISABILITY PARTNERSHIP BOARD

CARERS SUBGROUP

The carers sub group meeting lead by Caroline Mclean, aims to deal with specific issues proposed by the carers of adults with learning disabilities and focus on the outcomes.

Summary of Minutes of the meeting 24th September

Caroline Mclean suggested that the team would work with carers jointly to produce a carers pamphlet. She also would like to use this group to find out which meetings are most important to carers.

Concerns were raised about how the NHS staff struggle to communicate with service users. The group also discussed how some professionals seemed to blame carers.

Caroline Mclean explained that it is a training issue with hospital staff around communicating with service users. There is also some e-training for other services. In addition the Learning Disability service is starting to tie in generic services e. g. dementia clinics, rather than duplicating services for people with learning disabilities.

Caroline told the group that NHS acute services have asked if they can become part of the partnership board.

Participants express that The Dental Nurses at St. Charles Hospital are excellent interacting with service users. Their news letter is actually very good too. They also suggest creating a DVD for medics in the borough.

Carers would like to know what the plans for the services in the Borough are. It was explained that

we will know more after the October review is announced.

It was said that there is a group called Rouils which is a group that pools together peoples' Personal Budgets (PB). So they can get better value for money around the services.

It is likely that we will be jointly working with Westminster and Hammersmith.

Issues to take to the partnership board:

- Health (How professionals communicate with service users and carers)

If you want to be part of this group or have any issues that you want to raise please contact Patricia at the office on 0208 962 9917 or email patricia@fulloflifekc.com

FAMILY SUPPORT AND ADVOCATE FOR PARENTS AND CARERS



My name is PATRICIA TORRES. I have replaced Susan Bowyer as the Parents/Carers advocate at Full of Life.

If you have any queries or need support you can contact me on the usual number from Monday to Friday from 10am-4pm. 0208 962 9917 or email me at patricia@fulloflifekc.com

Full of life:
Unit 7, Conlan Street
Buspace Studios
London W10 5AP



Nearest Underground tube stations:
Kensal Green, Ladbroke Grove



Buses: 23, 70, 295, 452, 18, 28, 228, 52, 316

IMPORTANT DATES FOR YOUR DIARY	
22 nd November 10am – 3pm *London Family Health event Carers Health and Wellbeing Event	Skipton House, 80 London Road, SE1 6LH
24 th November 11 am – 2pm Carers Forum	Isaac Newton Centre 108a Lancaster Road, London, W11 1QS
27 th November 3.00 p.m Full of Life- Grease performance	St. Charles Hospital Exmoor Street W10 6DZ;
3 rd of December 11 am and 2.p.m. Carers Day Carers Appreciation Event and Information Day	Isaac Newton Centre 108a Lancaster Road, London, W11 1QS
3 rd of December 1 to 4pm Carers Day Time for Me	Time for Me at New Horizons, Guinness Trust Estate, Cadogan Street, SW3 2PF
6 th of December 10:00 a.m. to 1:00. Learning Disability Partnership Board	Isaac Newton Centre 108a Lancaster Road, W11 1QS
16 th December 11 am – 2pm Carers Forum	Isaac Newton Centre 108a Lancaster Road, London, W11 1QS
12 th January 8.00 pm *Cirque du Soleil "TOTEM" <i>Performance for Parents and Carers of adults with learning disabilities</i>	Royal Albert Hall Kensington Gore, London SW7 2AP
Carers Sub group	To be announced
Full of Life Market stall	To be announced

**You need to confirm your attendance to this event*

This newsletter was stapled together, folded, packed, stamped and posted by young people with complex needs who attend our afterschool and Saturday provision as part of their volunteering/work experience within Full of Life.

Please read it!



These pictures were taken by Toby, Tess and Phillip