



Learning Disability
Carers Information Newsletter
(March 2007)

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March

2007 (Spring is here at last – well almost!)

Welcome to the Devon County Newsletter for Carers of people with learning disabilities, produced by [June Wilkins](#), Learning Disability Lead for Carer Involvement in Devon.

The daffodils, snowdrops and crocus plants are appearing in gardens everywhere ready for 21st March, the first day of Spring. Let's hope the weather will start improving by then so we can enjoy their colours!

In this issue there is information on healthy lifestyles and other items of interest under the 'Health' heading, as well as other topics you may wish to become involved in, such as **Carers Week**. Carers Week this year takes place from 11 – 15 June. The theme is "My Life as a Carer" and the following information has been sent to us by Sonia Barton of Carers UK in Devon.

"We are holding a competition for all adult carers to write a poem/prose based on the theme of Carers Week. There is a prize of £20 for the winner. We are hoping that the winner of the

competition will accept their prize and read their poem/prose at the Cathedral celebration service. All entries should be forwarded to me at Westbank League of Friends, Farmhouse Rise, Exminster, Exeter EX6 8HL or by email to s.barton@westbankfriends.org by Friday 20 April."

Carers UK are also carrying out their Carers Week Annual Survey, which can be completed on-line at www.carersweeksurvey.org.uk, or copies can be ordered from Carers Week, 20-25 Glasshouse Yard, London EC1A 4JT. Completion date for the survey is 30 March 2007.

Learning Disability County Carers Forum.

A successful re-launch of the forum was held on 6 February with approximately 30 Carers attending. Thanks to all of you who took part. The meeting was chaired by a Family Carer and started with carers saying one thing about how they were feeling, which was recorded on a flipchart and added to the Minutes. Carolyn Elliott, Head of the Learning Disability Service, updated Carers with the latest service developments and a positive exchange of views took place between Carolyn and Carers present, which finished with Carolyn requesting that she and forum members work closely together in future to improve both Carers and Service Users' lives. There followed a report from the Northern Devon Family Carers group on the meeting between their representatives

and David Johnstone, Director, Adult and Community Services; a Short Breaks Presentation from Steve Robinson and Glen Walpole, both Short Breaks/Fulfilling Lives Managers (East and Mid Devon respectively), and, finally, discussion on how to continue the forum in a positive way. Some decisions will be made at the next meeting, so please attend if you can! ***If you would like a copy of the Minutes and/or would like to attend the next forum meeting on Tuesday 20 March, please contact me, June Wilkins, on 01392 208769, or e-mail june.wilkins@devon.gov.uk*** The Minutes can also be seen on the Carers pages on our website www.learningdisabilitydevon.org.uk

Health Matters

Each Community Team in Devon organises Healthy Lifestyle sessions for people with learning disabilities, which both men and women can attend. These sessions cover e.g. healthy eating and exercise. These are not run on a continuous basis, therefore there may be a waiting list in your area for the next session.

In addition, separate women's and men's groups are held in East Devon, Teignbridge and South Hams for other aspects of good health. For further details, contact numbers are given below.

East Devon: Ian Hudson, (Health JIP Chair) 01395 282082

Exeter: Pauline Bessell, (Community Nurse), 01392 208373

Teignbridge: Helpdesk, 01626 216262

South Hams: Helpdesk, 01752 891003

North Devon: Helpdesk, 01271 388814

Mid Devon: (Okehampton/Crediton) Community Team, 01363 772804
(Tiverton) Community Team, 01392 381122

(Thanks to Dil Thomas, 'Action for Health' Lead, for this information)

Learning Disability Liaison Nurses

The following article has been sent by an Exeter Carer about her experience using the Liaison Nurse service at the Royal Devon & Exeter hospital.

"Last year my 39 year old daughter was admitted to hospital as a day case on Parkeswell Ward. A few days before I had asked for cot sides to be provided as she is severely mentally and physically disabled and we need to make sure she cannot get out of bed or she is prone to bang her head on the floor. On arrival at the ward we found that there had been a difficulty in locating the cot sides and they had not been provided, although one side was found and by placing the bed next to the wall the problem was solved. Although I had heard that there was a Liaison Nurse I had not thought to involve her, but before leaving the hospital I did tell the Staff Nurse about her. Liz Jennings recently took up this post and she is only too willing to make sure that any arrangements that might be necessary are in place for those adults with a learning disability.

On the next two occasions that my daughter had to attend the hospital I did involve Liz and found her most helpful. I feel very strongly that this post should continue to be funded, Liz has experience of working with people with a learning disability and her support would be especially valuable for anyone coming into hospital alone or with only one parent. I feel there is a strong case for extending the post to include children with learning disabilities. It can be quite daunting for a parent when they first receive a diagnosis or their child goes into hospital for the first time. Having the support of a nurse who understands this and has experience of these children's problems would be very valuable."

*(Thanks for this article. **Liz Jennings** can be contacted on **01392 403737**)*

Torbay Hospital also offer this service. **Tanya Drew** is the Learning Disability Liaison Nurse for South Devon. She can be contacted on **01803 654994**.

Mental Capacity Act

The Mental Capacity Act (2005) is coming into force from 2nd April. Its purpose is to help people in making decisions that they may find difficult to make due to having a learning disability or dementia. **It also specifies that family, friends and others who have an interest in a person's welfare must be involved in decisions made when that person lacks capacity.** Devon County Council has

commissioned a service from 'Living Options', Devon, in partnership with 'Age Concern' to provide Independent Advocates (IMCA's) for people who lack family and friends and who need someone to support them in making a decision. In October, a further part of the Act will come into force concerning new arrangements about the Court of Protection and Enduring Power of Attorney.

More information regarding the Mental Capacity Act (2005), including information for Family and Carers, can be found at the Devon County Council website.

<http://www.devon.gov.uk/mentalcapacityact>

(Thanks to Nory Meneer, Health Development Manager, for this article.)

Dr Rolf Feller, Consultant Psychiatrist, would like to get together with a Devonwide group of Carers, or Carers and People with Learning Disabilities, to look at research and quality control of medication which is used by people with learning disabilities.

If this is something which interests you, please e-mail Dr Feller at rolf.feller@devonptrs.nhs.uk

Direct Payments – information about the Direct Payments Team

The Direct Payments Team.

This team was set up in September 2005 as a short term approach to managing the large numbers of clients in receipt of home care who wished to stay with their provider of choice. ... Clients who prefer to have a face to face meeting are still visited in their own homes. ... The Independent Living Advisors (ILA) have now joined with the Contact team. We have increased the number of ILA hours by 22.5 hours a week. They have organised themselves geographically and reviewed their case loads. This has resulted in increased capacity to identify and support people with more complex needs. They are also working on an improved information pack for people who wish to employ a personal assistant, taking all their referrals via the contact centre and identifying the essential information they need before arranging to visit a client. This will result in a more efficient use of their valuable time. The experienced ILAs act as a resource for clients and staff in understanding how Direct Payments can empower people to buy care to meet their eligible needs.

What can this team do for you?

- We provide telephone support ... on how Direct payments can work.
- We will complete the calculations for individual cases ... on how much the Direct Payment will be and complete the other necessary documentation for the localities.
- We act as a single point of reference for any queries from clients and staff.
- Visit clients in their own homes to discuss and clarify any points raised concerning Direct Payments.
- Attend service user workshops and forums and give presentations on Direct Payments to other groups by invitation.

The Direct Payments Contact Team is based in The Annexe at County Hall, Exeter. They can be contacted on **01392 383107**. e-mail: direct.payments@devon.gov.uk

(Thanks to David Cardy, Team Manager, Direct Payments, for this article)

BBC Radio Devon

Many of you will have heard the recent 'phone in' and news on Radio Devon concerning learning disability services, with speakers from Exeter Mencap and the Director of Adult and Community Services, David Johnstone.

I have been asked by Anne Brand, Secretary of Exeter Mencap, to publish their response to these interviews, which was sent to Justin Leigh of Radio Devon, together with a Parent's response.

"Dear Justin - I wish to thank you for how you have coordinated the discussions of yesterday and tried to give a fair picture and viewpoint of learning disability, highlighting in turn the distress of carers.

Although I am secretary of Exeter and District Mencap I am also a Mother/carer of Lisa who has severe learning disabilities. I was pleased to hear Sarah's mum and Bill Smith speak and others. What wasn't made clear, Sarah's depression developed as a result of the lack of stimulating fulfilling opportunities when she left education. This is the position facing many people with higher support needs now coming through transition and their carers.

I listened carefully to David Johnstone, however it is not money alone that will put this situation right it is the policies initiated under the modernisation and " In Control " model of delivery Devon County are pursuing that need more thought.

These policies are at the root of our concerns. and are being pushed through by this labour government and other bodies and are being used by Devon County Council to cut services not to improve them. Fairer access to care policies have left many without a service.

There is a groundswell of opinion that supported living initiatives and integration into community hubs which consist mainly of local church halls, pubs, cafes and so on is leaving many of our people at risk of financial abuse, emotional insecurity and is undermining their health and well being and above all their motivation. Day centres themselves were not as described by some speakers. The Doyle, Kingsteignton, Nichols and others at one time were centres of excellence and full of energy until the cuts started to bite. People did not sit around all day socialising, a whole range of opportunities were available including work and educational opportunities and not necessarily on site. Enhanced by good creative managers.

While I accept there have been gains for higher functioning people with learning disabilities who now have a voice, the losses have been extensive for those with higher support needs who need continued direction, motivation and support.

I thank both you and Jo for highlighting these important issues for a group of people we in Exeter Mencap sincerely care about. National Mencap are pressing the Government for more money but as I said previously it is not just about money, it is the policies that need revisiting.

My hope rests on a book I have read of recent written by Charles Henley on the Day Care we can't desert. "The Rise and Potential Demise of Day Services for Adults with Learning Disabilities ". I attach a shortened article E mail charles.henleyl@ntlworld.com. Charles

has massive experience of learning disability and the needs associated. I attach also for you to look at a recent article in the Sunday Telegraph which highlights the effects of inclusion in mainstream school a cheaper policy. This profound article can be linked to the present policies for adults in that specialist day services are being closed in favour of Community hubs. It is time we had another CSCI inspection across Devon, also Devon County need to re evaluate these policies and re establish a skills based response for all.

Thank you again Justin

Exeter & District Mencap can be contacted on 01392-494694 or 'E' Mail to me annebrand@tiscali.co.uk "

Parent Response

"Stephen is a young man of 36years; he has a Learning Disability and once worked in the Community Resource Centre 5 days a week and was very settled. He was one of the more able and took great pride in being able to help his less able peers, there was work outdoors cutting grass, and also work at Stover grounds as well as Social activities and sports; in fact they were a community. All this came to an end with the introduction of the Valuing People Paper. Although Stephen is in a flat of his own that he loves, he leads a comparatively lonely life, Luckily Mum is round the corner and on the end of a phone, the calls have now reduced to between 20 and 30 a day!!

Stephen has not the confidence to go out on his own, and will not go on a bus without company, and though he has a friend who calls on him once a week, he is a very lonely young man. I know the Valuing Paper says our people want to be in the community but the 'community' doesn't always make them very welcome.

Stephen has 'work' that he is very proud of; it is for 2 hours a week at a recycling business, voluntary of course, that 2 hours replaces the 5 days a week he used to have at the Centre. Carers do help him with shopping and to make sure he keeps his home clean (just 10 hours a week) the rest of the support is down to Mum. I love my son dearly and willingly support whilst I am able but I am fearful of what will happen to Stephen when I am no longer there."

(Thanks to Anne for these articles.)

Carolyn Elliott, Assistant Director, Learning Disabilities, says " Whilst this is an important story, I would welcome the opportunity, as Head of Learning Disability Services, to put forward Devon County Council's view of the situation."

(This will be published in the May edition of KIN.)

Information from Localities.....

Teignbridge

The following Carer Support meetings are being run by **Jackie Milan** in your area:

Kingsteignton: April 18 at the Kingsteignton CRC.

Speaker: Denise Candy, 'Vocal' talking about advocacy.

Newton Abbot: April 24 at the Scout Headquarters.

Dawlish: May 1 at the Methodist Church Hall.

Speaker: Gill Evans, talking about training and employment.

Ashburton: April 11 at St Andrew's Church Hall

Speaker: Joy Couzens, talking about Housing and Accommodation.

All the meetings take place from 10.30am – 12 noon

For further details contact **Jackie Milan** Learning Disability Carers Worker on **07879 881298**, e-mail

jackiemilan.sdcc@tiscali.co.uk

or write to **Jackie** at South Devon Carers Consortium, 11a Castle Road, Torquay, TQ1 1ZZ

South Hams & West Devon

The following Carer Support meetings are being run by **Jackie Milan** in your area:

Tavistock: April 3 in Tavistock Library. 2pm – 3.30pm

Speaker: Sandy Evans talking about Employment.

Kingsbridge: April 20 at the

Ropewalk Centre. 10.30 – 12 noon

Speaker – Zoe Anderson talking about Intensive Support services.

Totnes: May 3 in the Mansion House. 10.30 – 12 noon

Exeter

Interviews for a Learning Disability Carer Support Worker will take place on Wednesday 4 April at Exeter CVS, King William Street. **If you are able to**

represent a group of learning disability carers in Exeter and would like to be part of the interview panel, please contact me, **June Wilkins**, on **01392 208769** as soon as possible.

Exeter Carers Focus

Dates for Exeter Carers Forum and Focus Days 2007:

Weds 25th April, **Tues 3rd July** and **Weds 10th October**.

Time 11 – 3pm

Please contact Lynsey at Exeter Carers Focus on tel: 01392 202055 or by e-mail:

lynsey.self@exetercvs.org.uk if you would like to attend. Meetings take place at the Isca Bowling & Bridge Centre in Exeter.

Don't forget - you can find Exeter Carers Focus newsletters by clicking on the link below.

<http://www.exetercvs.org.uk/projects/exeter-carers.html#news>

Magic Carpet are a theatre group in Exeter who last year worked with a group of Learning Disability Carers to produce a short animation film entitled 'Making Plans'. A preview of the unfinished film was shown at the Learning Disability Partnership Board in November 2006, where it generated much interest. If you would like to see the finished film, please contact me, **June Wilkins**, (contact details at the end of this newsletter).

Magic Carpet have funds available to work with Carers in **Exeter** and **East Devon** on other creative projects.

If you and a group of carers have a good idea for such a project, **Rob Wynne** of **Magic Carpet** will be pleased to hear from you.

Rob can be contacted on 01392 422938, e-mail

magic.carpet@tesco.net.

Quote from Rob

"These activities will offer flexible, fun, creative support to carers (ie not needing to deal with the issues around caring), we can run short term projects in your community on visual arts, (painting, printing, puppets, mask making, sculpture etc), drama and maybe movement or music. Our workers will also be able to help with pointing people in the direction of other community activities that they may feel able to access with a little confidence or support. We could arrange taster sessions in all or most of these areas. If you have regular carers meeting I would be happy to come along and talk to people about this project and maybe even do a short art session with your group!!"

East Devon

Support Groups

The first Learning Disability Carers Forums took place in Honiton & Exmouth on 22nd January & 5th February. It was good to speak to so many Carers who shared their concerns about the level and quality of services that their loved ones currently receive. Many carers expressed an

interest in meeting on a regular basis so Support Groups are now being arranged and will take place bi-monthly in Honiton & Exmouth. **Brigid** will be sending out details to Carers shortly.

Stress Management training

We are taking names for the next **Stress Management** course. If you would like to attend this course please call **Brigid** on 01404 43128.

Pamper Day - The next East Devon Pamper Day will be held on Thursday 14th June at St.Rita's in Honiton 10am – 3pm. There will be a **Mobility Aids** talk & demonstration in the afternoon so please put this date in your diary now!

Generic EAST DEVON CARERS FORUM.

The next forum will be on Thursday 26th April at Ratcliffe House, Burnside, Exmouth. The meeting will be as follows and everyone is welcome to join us. Please contact us if you have any difficulties with respite or transport.

10.45 am Refreshments on arrival

11am—1 pm Forum Meeting

1 pm Buffet Lunch (no charge)

1.30pm —2.30pm Management Meeting

(carers are invited to attend this meeting as well)

Telephone: 01404 44411 Email: carers@edvsa.org.uk

The East Devon Carers Support Scheme newsletter is now on the edvsa web site: www.edvsa.org.uk

You can find it under:

Projects

East Devon Carers Support Scheme

*(Thanks for all the above information **Brigid**. Contact details: 01404 43128/ 07974675701 or via e-mail brigid@edvsa.org.uk*

The next 'Looking After Me' course being run **Mel Turner**, Expert Patient Co-ordinator, will be in Ottery St Mary from 22 May to 26 June. **Mel can be contacted on either 0845 002 0699, 01392 384449 or 07791 414333, or e-mail Mel on epp@eastdevon-pct.nhs.uk**

'LINK-UP' One to One in Honiton are offering a new "day opportunity" starting in April 2007 as a pilot project.

❖ **Where: Honiton**

❖ **When: Fridays 10 - 4pm**

❖ **Cost: £20 per day**

❖ **Limited Places available**

Further details from Jane Davies or Mary Casey on 01404 41930

Learning Disability Carers will be able to use the 'Take a Break' scheme starting in April in East Devon. Contact your LD Carers Support Worker, **Brigid**, for details.

North Devon

'Living Options' invite you to an open meeting on housing options for people with a Learning Disability in North Devon.

❖ **Barnstaple 22 March**

10 - 12 noon and

4 – 6pm in the Learning

Disability Hub, Barnstaple

Rugby Club, Mill Road.

- ❖ Bideford 7 June
10 – 12 noon and
4 – 6pm (venue to be
arranged)

Further details from **Louise Richards**
on **01363 776961**

*The Northern Devon Directory of
Information and Activities can now be
found on the learning disability website.
www.learningdisabilitydevon.org.uk in
the 'Help and Information where you
live' box.*

Mid-Devon

**'Coffee and Chat' drop in spaces for
Carers are available each month
between 10 am and 12.30.**

**TIVERTON: 1st Wednesday of each
month - Heathcoat Community
Centre Café.**

**CREDITON: Last Wednesday of
each month - Station Tea Rooms.**

**OKEHAMPTON: 2nd last Wednesday
of each month - Puzzle Tree Drop-In
Centre (Table Tennis Club behind
Post Office)**

**Contact Carole Massey at the UNITE
office, 2 Bridge Street, Tiverton,
EX16 5LY, tel. 01884 257511, e-mail
learnsw@unitemd.org.uk**

*(Thanks Carole for the above
information)*

Mid Devon Fulfilling Lives team have
carried out a Carers Feedback Survey
on the new style Short Breaks Service.

The majority of carers were either
"completely happy" or "mostly happy"
with the Short Breaks service.

Some of the comments received are
shown below:-

*"...has developed greatly in the last 9
months and looks forward to her
sessions. Her confidence has
increased."*

*"I'm very happy with the staff and the
care and support they give ..."*

*from a Service User "I am really happy
going out to meet up with friends, and I
loved the 2 breaks away"*

Final comment *"Keep up the good
work!"*

Don't forget the Carer Surgeries being
held in Tiverton on the 1st Tuesday of
the month on a bi-monthly basis.
Contact **Eva Loysen** on **01392 208389**
for the date of the next surgery.

And finally.....

If you would like to have some input
into the following countywide groups,
either by attending their meetings or by
post, telephone or e-mail, please
contact me, **June Wilkins**, for details.

- ❖ Short Breaks countywide
group. Next meeting **23 May**
in Exeter.
- ❖ Learning Disability Partnership
Board – Supporting Carers
sub-group. Next meeting
3 April in Exeter.

Workshops for Carers in Rural Areas

Exeter CVS are running some workshops for carers in rural areas that will be designed around such topics as:

- speaking up on behalf of yourself and other carers
- getting involved in having a say in how services are provided
- listening and negotiating skills
- identifying personal skills and action planning
- problem solving

The workshops will be run over two days (consecutive weeks) from 10.30am until around 3.00pm and will help to build your confidence and give you some time to think about YOU for a change!

The workshops will take place in the following areas:-

Blackdown Hills – venue Highfield Sports & Social Club near Dunkeswell 28 March and 4 April

Mid Devon – Countryman Inn, Sampford Courtenay 1st and 15 May

Torrige – Chilsworthy Village Hall near Holsworthy, 4 and 18 May

We will be able to make a contribution (max £25 per person) towards respite and travel costs, and there will be plenty of discussion, lunch and refreshments and free lucky draw prizes.

For further information or enquiries contact:

Lyndy Pooley, Exeter CVS, Wat Tyler House, King William Street, Exeter EX4 6PD - 01302 202055 – lyndy.pooley@exetercv.org.uk

Websites of interest

www.autism.org.uk/

www.enableholidays.com

(specialise in overseas holidays for disabled people, family and friends. Tel: 0871 222 4939)

www.canbedone.co.uk

(specialise in wheelchair accessible holidays in the UK and abroad. Tel: 020 8907 2400

www.ceacard.co.uk

(Carer's concessionary card for the cinema. Tel: 0845 123 1295

<http://www.choiceforum.org/>

(this is run by the Foundation for People with Learning Disabilities. It's the place to have your say, discuss things with other carers and generally read interesting information. You will need a password to use.)



*The next issue of **KIN** will be published in May 2007*

*Please send any comments, feedback, articles by **the end of April** to **June Wilkins, Lead for Carer Involvement (Learning Disability), The Rowans, Hospital Lane, Exeter, EX1 3RB***
Tel: 01392 208769
e-mail
june.wilkins@devon.gov.uk

Don't forget this is **your** newsletter, so **have your say about anything at all!**