



Learning Disability
Carers Information Newsletter
(May 2007)

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2007 –traditional

May Day Photos to brighten us up in the rain!

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.

In this issue there is an update on the Rural Carers Project, information from Carers UK and other items of interest - some of which you might want to become involved in such as the **BILD Quality Network Review**. The following article has been contributed by Ellen Sanford, Occupational Therapy Lead.

"BILD quality network comes to Devon

The British Institute of Learning Disability (BILD) has been engaged to introduce their Quality Network programme to assist the Learning Disability Partnership in developing a sustainable, ongoing programme to review the quality of people's lives. 10-12 adults with a learning disability will be asked to participate in each audit. They will receive a series of visits at home by an audit team member who will be finding out about the quality of their lives.

- Are people involved in making choices and decision making?
- What kind of activities do people participate in at home and in their local community?
- Do people feel safe and stay healthy?

These are a few of the areas. Following the review visits, an action plan is made that tackles areas highlighted through the audit. People from the wider community, who can help make the action plan happen, will be invited to hear about the plan at an early stage.

The County Choice and Control JIP (Joint Investment Planning) group is leading on this piece of work. They will be recruiting people who want to be visited, and the review team, who will receive training and undertake visits to adults with learning disabilities at home.

We are hoping to undertake our first audit in the early autumn after the team have had training led by BILD. It looks likely that we will audit lifestyles of people who have had Person Centred Plans as compared to some people who have not.

Are you interested in joining the review team or just finding out more?

Contact - J. Ellen Sanford on 01392-208373 at the Exeter Community Team, ellen.sanford@devonptnrs.nhs.uk

To find out more about BILD and the Quality Network go to www.bild.org.uk and select Quality Network”

Learning Disability County Carers Forum

The last Forum meeting took place on 20 March in Exeter, where Carolyn Elliott, Head of the Learning Disability Service, presented an Action Plan – ‘Working with Carers’, the progress of which will be updated at all future meetings.

It was decided a small group of people would meet before the next Forum to discuss future facilitation of the group, together with a countywide structure to feed into the County Forum.

A full copy of the Minutes can be seen on the Carers pages on our website

www.learningdisabilitydevon.org.uk

If you would like a copy of the Minutes and/or would like to attend the next forum meeting to be held on Tuesday 26 June in Exeter, please contact [Hilary Allen](mailto:Hilary.Allen@devon.gov.uk) on 01392 208639 or e-mail hilary.b.allen@devon.gov.uk

(The next meeting will include Speakers on the Mental Capacity Act and the evaluation of the Mid-Devon Short Breaks pilot scheme)

(Amendment to March KIN’s Forum – Carolyn Elliott’s (Assistant Director, Learning Disability) name was omitted from the attendees of the meeting held between Northern Devon Family Carers Group and David Johnstone, Director, Adult and Community Services.)

Health Matters

Dil Thomas (Action for Health), has spoken to me about work he is undertaking with Cancer Research UK. They have asked him how specialist health services support people in cancer prevention and what tools and information are used for people with a learning disability suffering from cancer.

In future they would like to produce information (nationally) which would help people with a learning disability in cancer prevention, and those who may suffer from cancer in the future. They also wish to help Carers and are asking for your views on the following:-

- What gaps in cancer services for learning disabled people have you noticed as carers?
- If your cared-for has used the service, was the information given to them and to you understandable and informative?
- How can we improve this information?

We would like to hear from Carers of any improvements that could be made, and the information will be given to Cancer Research UK. **It will be treated as confidential and no individual information will be passed on.**

Please contact [Dil Thomas](mailto:Dil.Thomas@devon.gov.uk) on 01392 208641, e-mail dil.thomas@devon.gov.uk, or myself, [June Wilkins](mailto:June.Wilkins@devon.gov.uk) on 01392 208769, e-mail june.wilkins@devon.gov.uk. We can

arrange for someone to visit you in your home if you would prefer.

We do appreciate that this will be a very sensitive issue for some families and is an upsetting subject, but your help now could help others in the future.

Many thanks for your assistance.

Healthy Eating Course

A subject many carers of adults with Learning Disabilities are concerned about is how much weight their cared for gain when they go into supported living. So with this in mind I have been in contact with SPARC at Dartington, South Devon, who are happy to arrange a FREE course designed especially for Carers and their cared for.

The Healthy Eating Course will be a one day course held on **Saturday 23rd June** from 10.00am to 3.00pm at SPARC in Dartington. If you live in Devon and are interested in coming along to this fun day please contact **Jackie Milan 07879 881298** or e-mail jackiemilan.sdcc@tiscali.co.uk to book as numbers are limited and will be on a first come first served basis. Directions to SPARC can also be obtained from Jackie.

(Jackie is the Learning Disability Carers Worker for South Locality)

Carers UK

Keep Counting Carers Campaign – “For the first time ever, a question on carers was included in the 2001 Census. This gave us unprecedented

knowledge about carers and has helped local authorities and health bodies plan services. It is at risk of not being included in the 2011 Census and we need your help to save it” For more information and how you can help save the question, contact Kate Groucutt, Policy & Public Affairs Officer at Carers UK. E-mail:

kate.groucutt@carersuk.org

Tel. 020 7566 7616

Review of National Carers Strategy 2007 - Carers UK is holding 3 consultation events with carers to look at how carers can be involved in reviewing the Strategy.

- ❖ Wednesday 6 June, London (with James Purnell MP, Minister for Pensions)
- ❖ Friday 29 June Manchester
- ❖ Friday 27 July Birmingham

Carers can sign up through the website:

<http://www.carersuk.org/Getinvolved/Events/CarerConsultationEvents>

Updates on progress about consultation with carers can also be found on www.carersuk.org

Funding for emergency breaks for Carers – “On 21 February, Government announced that there would be £25 million additional spending for emergency breaks for carers in England.” (*Devon’s share of this is £334,000*)

“The Dept. of Health will be issuing guidance and good practice to Local Authorities....around June/July time about how to spend the monies.”

(Local Authorities will receive the full year’s monies in October – so watch

this space for details of emergency schemes!)

New Rights for Working Carers – the Work and Families Act 2006 came into force on 6 April 2007, which gives employees the right to request flexible working “if you are an employee with 26 weeks continuous employment at the date you make an application, and you are

- A parent with a child(ren) under 6 or a disabled child(ren) under 18 or
- A carer – to qualify as a carer under the legislation, you must be, or expect to be, caring for a spouse, partner (who you live with), civil partner or relative, or live at the same address as the adult in need of care. ‘Relative’ includes adult child, adopted adult child, siblings.....”

(This covers families with a learning disabled adult living with them)

Carers UK have various informative booklets available for carers, one of which is ‘An employees guide to work and caring’. To order booklets, call the Publications Hotline on 0845 241 0963, or e-mail publications@carersuk.org

Direct Payments –

Advance notice of Roadshows being held by the Direct Payments Team for Carers and Service Users to find out what Direct Payments are and what help and advice is available to enable someone to use them.

❖ Thursday 6 September – Isca Bowling & Bridge Centre, Exeter Arena, Summer Lane, Exeter
9am – 12.30pm

❖ Thursday 13th September - St Cuthberts Centre, Buckfast Abbey, Buckfastleigh
9am -12.30pm

A further roadshow is planned for Tiverton to cover North and Mid-Devon areas. If you would like an additional roadshow for North Devon, please let [Kathryn Bird](mailto:Kathryn.Bird@exeter.gov.uk) know on [01392 208768](tel:01392208768)

BBC Radio Devon article In March KIN

Carolyn Elliott, Assistant Director, Learning Disabilities, will write a response to the above for July’s KIN. In the meantime, we have received the following from Learning Disability staff in East Devon.

“19th April 2007
Response to BBC Radio Devon report in the March KIN Newsletter

We as staff who support people with higher support needs, were saddened to hear that Sarah suffered depression due to lack of stimulating fulfilling opportunities.

I know that through our highly committed & trained staff team in the High Support Fulfilling Lives service in the Axminster/ Honiton area, we work very closely with individuals; the very needy have 1-1 support and we work alongside other professionals such as Occupational Therapists, Physiotherapists, Speech and Language Therapists, and others that ourselves,

Carers or Service Users feel may give us some training and/or support to be able to deliver a meaningful and constructive Fulfilling Lives service to all of our service users whatever their needs.

We also work closely with parents and carers, sharing information regarding likes/dislikes etc, this is then put into the service user's plan of care to ensure that all staff know how to communicate and work with individuals, promoting their choice and meeting their needs.

We work with people coming through education and transition, well before they come into the service; we assign a Keyworker who liaises with the school to receive as much information as possible about someone; they do visits, and we have that person in to receive trial stays so we build a relationship with them and their Carers before they begin a full service.

All this is done as part of integrating our service users into the community in a meaningful way, using the facilities in the town and not segregating people into artificial groups; service users do not sit around all day as some people may think, but get out and about as much as possible, using the Library, swimming pools, local pubs to play skittles, country walks, and many more. We believe that we provide excellent opportunities for the people we work with which is reflected in feedback from Service Users and Carers in our area.

We welcome people who would like to visit us to see what we offer service users in our high support service.

Lorna Hughes. Fulfilling Lives Team Leader, higher support.
Based at: Phillips Centre

Axminster, 01297 33793

Rural Carers

Devon Rural Carers Project Update

The research for the Devon Rural Carers Project has now been completed. Projects have been formulated using the research and are to be taken forward in the next 6-8 months.

The research focused on the needs of rural carers and how we can improve support to carers who live in rural areas of Devon. The research involved nearly 5,000 questionnaires being sent out to carers – 465 of which were returned (a 9.5% return rate). Consultations with carer support organisations provided 102 returned responses and 6 carer focus groups were also held.

Prizes were given to carers who responded: an M & S prize hamper was awarded to Mrs McKay from East Devon and 14 £20 'W H Smith' gift vouchers were provided to young carers.

The findings of the research are many and varied; highlights of which are shown below:

- Caring responsibilities usually fall on the immediate family and as such the majority of carers live with the cared for.
- Carers are often prepared to travel to their local village or town to access support services. Support services outside of these areas are not so readily accessible for rural carers.
- Lack of time and not wanting to leave the person being cared for are major issues in preventing carers from accessing support services.
- The post office, village shop and local pub are used by many carers. These local services are therefore

prime targets for identifying carers. They also provide scope for additional support services in rural communities.

- Demand for online support groups, telephone support groups and more local support groups.
- Over a third of carers gave up work to undertake care. However, only 18% would return to work. Further training and assurance of more flexible working patterns could help carers return to work.

The findings of the research have been used to formulate projects, which have now been agreed by the Steering Group. Projects include marketing and raising awareness of carer support networks, telephone, online and informal support groups, getting carers back into work through training and promotion of rural community transport.

If you would like a copy of the Executive Summary or detailed Papers on the research or a summary of proposed projects then please contact Jo Pickering on 01626 203050 or ruralcarers@teigncvs.org.uk

(Thanks, Jo for sending us this update on the Generic Rural Carers Project – talking of Rural Carers, we know of an isolated rural carer who is keen to start a Support Website for carers. If you are interested in getting involved with this project, contact me, [June Wilkins](#), contact details on last page, and I will pass your details on.)

What do you know about Carers Assessments?...

Since the Carers (equal opportunities) Act came into force in 2005, Local Authorities have a duty to inform Carers that they are

entitled to a carer's assessment in their own right. Carers who have taken up this offer have often found the experience quite daunting, so to try and improve the process the generic Carers in Devon Involvement Framework agreed to work with carers and staff to make assessment more user friendly. Countywide workshops were held, which have influenced the introduction of a revised Carers Assessment Form and new supporting factsheets, as suggested by Carers.

Carers can obtain an assessment in a number of ways. The carer can have their needs assessed at the same time as the cared for person using the Single Assessment Process, known as SAP. If the carer would like an individual assessment, they can request this at a time and place convenient to them. Whichever method is chosen, carers are entitled to confidentiality and the process should identify agreed outcomes and/or action plans and provide an opportunity to share outcomes with other professionals at the discretion of the carer.

Many carers having completed assessments have been able to initiate action themselves with guidance or support from a third party. Some carers who have identified needs that might be met direct by Adult & Community Services may have to consider the Fair Access to Care eligibility criteria, others may be able to consult local direct access services run by generic Carers Links in their area, or other specialist voluntary client specific organisations. **For many carers, the actual task of sitting down and asking oneself difficult, and sometimes challenging, questions about how this caring role is affecting them, is in itself the single most important part of the exercise.**

If you would like to find out more about carers assessments and you do not currently have a key worker or care manager, **contact My Devon for further information on 0845 155 1007**

You can find Devon County Council factsheets by logging on to

<http://www.devon.gov.uk/index/socialcare/factsheets.htm>

(My thanks to Denise Macdonald, North Devon Carers Link Project, for much of the above article)

Carers Week takes place this year from 11 – 15 June.

The Exeter Cathedral Service will be held on Monday 11 June from 12 – 1pm, followed by refreshments in the Chapter House. The service this year is being led by parent carers and will include readings by the winners of the poetry competition.

Sonia Barton, writes:

“ We are holding our CARER, YOUNG CARER, GP PRACTICE, PHARMACY, CARERS WORKER AND, IF APPROPRIATE, LIFETIME ACHIEVEMENT AWARD. They can be nominated for by Families, Carers, Statutory or Voluntary Sector workers. GP Practice and pharmacy need to have shown a good understanding of carer issues.

Nominations to be sent to me by 20 May.”

Sonia can be contacted by email on s.barton@westbankfriends.org or at Westbank League of Friends, Farmhouse Rise Exminster Exeter EX6 8AT.

For details of Carers Week events in your local area, contact your local Carers Link direct (see last page)

Information from Localities.....

Teignbridge

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

Kingsteignton - at the Kingsteignton CRC.

Wednesday **30 May**, 18 July
10.30am – 12 noon

Newton Abbot - at the Scout Headquarters (next to ASDA)
Tuesday 3 July. 10.30 – 12 noon

Dawlish - at the Methodist Church Hall.
Tuesday 24 July. 10.30am – 12 noon

Ashburton - at St Andrew's Church Hall.
Monday 25 June. 10.30am – 12 noon

All Carers are welcome to join **Jackie** for a free lunch after the meetings.

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

Members of Teign Area Gateway Club went to Flambards at the end of April and had a wonderful time. Days out like this give Carers a Break, knowing the person cared for is well looked after.

Does your son or daughter enjoy meeting and making new friends? Then maybe joining their nearest Gateway Club would give them a chance to socialise and give you some respite.

Teign Area Gateway Club meet every other Saturday from 6.30pm - 9pm in Teignmouth and also every other Tuesday in Kingsteignton from 7pm - 9pm. For more information please call Sue on 01626 774457.



(That's Jackie, second from left – looks like a good time was had by all!)

South Hams & West Devon

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

Tavistock: Tuesday 5 June in Tavistock Library. 2pm – 3.30pm

Kingsbridge: Wednesday 27 June at the Ropewalk Centre. 10.30 – 12 noon

Totnes: Thursday 19 July in the Mansion House. 10.30 – 12 noon

Gateway Clubs in South Hams

Tavistock Gateway meet every Thursday from 7pm - 9pm at the Alexander Centre. For more information please call Pam on 01822 613306.

Marlborough Gateway (near Kingsbridge) meet on Tuesdays from 4.30pm - 7pm. For more information please call Ann on 01803 865614.

The Totnes Tuesday Club meet on Tuesdays from 7pm - 9pm in the

Methodist Church Hall, Fore Street. For more information please call Yvonne or Kim on 01803 845343.

The next generic South Hams Carers Forum will be held at Follaton House, Totnes on Tuesday 5 June from 10.30am – 12 noon, followed by a buffet lunch. Further details can be obtained from South Devon Carers Consortium on 01803 294275

Exeter

Good News – a Learning Disability Carers Support Worker has now been appointed for Exeter and she has sent us the following information:-

Carers Worker (Learning Disability)

My name is Tracey Adams and I have just been appointed as the new Carers Worker for Adults with a Learning Disability covering Exeter. I would like to take this opportunity to invite all of you living in Exeter to a meeting so that you can meet me and I can meet you. (Details below) This will also be an opportunity to air your views about the direction you would like this group to take as well as raising any issues that are important to you. This will be an informal get together with tea and cakes. In the meantime please contact me with any concerns that you may have. (Even if the person you care for no longer lives with you, you

are still carers and I will be pleased to meet you) I can be contacted at Exeter CVS, Wat Tyler House, King William Street, Exeter, EX4 6PD

Tel 01392 202055 or email me at tracey.adams@exetercvcs.org.uk.

My hours of work are between 10.00a.m. and 2.00p.m. on Tuesdays, Wednesdays and Thursdays but if you leave a message on my answer machine I will get back to you

Exeter Carers Learning Disability Group to be held at Exeter CVS Office, Wat Tyler House, King William Street, Exeter EX4 6PD on Friday 22nd June 2007 2.00-3.30pm

Exeter Carers Focus run training days for all Carers on topics such as 'Making your Voice Heard', 'Improve your Confidence', 'Develop your meeting skills', 'Mental Capacity Act Information Sessions'. If you are interested in joining one of these days, contact Lynsey Self, details below.

Dates for Exeter Carers Forum and Focus Days 2007:

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@exetercvcs.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.exetercvcs.org.uk/projects/exeter-carers.html#news>

Magic Carpet, the theatre group, still have funds available to work with Carers in **Exeter** and **East Devon** on 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.

East Devon

**Learning Disability Carers Support Group
Honiton and surrounding area
Otter Nurseries
Monday 2nd July 2007
10.30am-12.30pm**

The Staff at Otter Nurseries are going to give us a talk on Sensory plants & herbs.

There will also be a chance to win a planted container in the **free raffle**.

If you are caring for an Adult who has Learning Disabilities, (they don't have to be living with you), come along and meet other Carers for this interesting talk and a chat in the café afterwards.

For more details contact Brigid, details below.

**Learning Disability Carers Support Group
Exmouth and surrounding area
Open Door Centre, Exmouth
Tuesday 10th July 2007
10.30am – 12.00pm**

Ena McCarthy from The Department from Work & Pensions will be giving us a talk and advice on benefits for older people. If you are caring for an Adult who has Learning Disabilities, (they don't have to be living with you), come along and meet other Carers for this interesting talk and a chat over a cup of tea / coffee. For more details contact Brigid, details below.

(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

Don't forget, the East Devon Carers Support Scheme newsletter can be found at www.edvsa.org.uk

You can find it under:
Projects East Devon Carers Support Scheme

North Devon

Don't forget the 'Living Options' housing options day for people with a Learning Disability and their carers in North Devon.

- ❖ Bideford 7 June
10 – 12 noon and
4 – 6pm

Venue details from Louise Richards on 01363 776961

Boost your confidence at a free workshop for Carers!

If you sometimes struggle to speak up for yourself – whether it is to a health or social care staff member or

someone much closer to home, help is at hand.

There is an opportunity for you to brush up your skills and build your confidence at a 3-hour workshop being held at two local venues, so you can choose the one that is closer to you.

BOOK NOW For a Speak Up with Confidence Workshop

18th June at the Appledore Baptist Church

and

25th June at the Castle Centre, Barnstaple

both from 10.00am until 1.00pm followed by a sandwich lunch

They will be run by Lyndy Pooley from Exeter Council for Voluntary Service, and she promises that the workshops will be fun as well as practical. You will be able to learn how to be heard, get your own way and make a difference for yourself and other carers

Places are limited so book a place quickly.

To book a place contact:
Janet Sapiano, Exeter CVS, Wat Tyler House,
King William Street,
Exeter EX4 6PD - 01302 202055
janet.sapiano@exetercv.org.uk

Mid-Devon

Don't forget the Carer Surgeries being held in Tiverton by the Fulfilling Lives team on the 1st Tuesday of the month on a bi-monthly basis. Contact **Sue West** on **07855 381173** for the date of the next surgery.

And finally.....

We would really like Carers to have some input into the following countywide groups – you can attend one of the meetings, telephone, e-mail or write with your views. 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 **10 July** in Exeter.

Did you know.....

There is a way of avoiding junk mail and unwanted telephone sales calls – just contact one of the numbers below and ask to be put on their lists -

Mail Preference Service: 0845 7034599

Fax Preference Service: 0845 0700702

**Telephone Preference Service:
08450700707**

E-mail Preference Service:

www.emailpreferenceservice.com

Carers Links contact details For Carers Week information

East Devon Carers Support Scheme

Tel. 01404 44411

e-mail: carers@edvsa.org.uk

Exeter Carers Focus. Tel: 01392 202055
e-mail: lynsey.self@exetercvcs.org.uk

UNITE, Tiverton. Tel: 01884 257511
e-mail: info@unitemd.org.uk

N Devon Carers Link. Tel: 01271 372811
e-mail: ndevoncarerslink@hotmail.com

S. Hams & W Devon. Tel: 01803 862622
e-mail: carerslink.sdcc@tiscali.co.uk

Teignbridge. Tel: 01392 824752
e-mail: r.whitehurst@westbankfriends.org

Websites of interest

www.caringchoices.org.uk.

(A collaboration of a number of Older People's charities and organisations have formed the 'Caring Choices' coalition to seek views and opinions on a number of issues related to the provision of future care. Regional debates will be held to focus on key questions.)

<http://www.devon.gov.uk/mentalcapacityact>
(lots of information on the Act)

www.mencap.org.uk - for their latest newsletter

<https://www.drc.org.uk/helplive/>

(DRC is the Disability Rights Commission online messaging service for enquirers who find using the telephone difficult or impossible because of their disability. If you have a learning disability and find using the telephone difficult, we hope that HelpLive will also make it easier for you to have a conversation with a DRC Helpline adviser.)

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

*Please send any comments, feedback, articles by **the end of June** 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!****