

Bulletin



National
Family Carer
Network

www.familycarers.org.uk

Tel: 07747 460727

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NFCN is an umbrella organisation that aims to promote the voice and rights of family carers supporting a person with a LD. Its membership comprises both organisations and individuals but we cannot be responsible at any time for the views expressed by our members unless explicitly promoted by us.

National

1. NFCN Director in 10km charity run

Oi Mei Li will be taking part in her first [Bupa Great Manchester Run](#) on Sunday 26th May to raise money for the National Family Carer Network.

If you would like to sponsor Oi Mei please click on the following link: <https://mydonate.bt.com/fundraisers/oimei>



2. Funding for free safeguarding workshops for family carers of people with learning disabilities

The NFCN has been trying to get some funding to run some workshops for family carers on safeguarding using the ['Making Sure Your Relative is Safe' resources -Top Tips and Essential Guides](#) and the soon to be launched Resource Guide and DVD from Hft which completes this set of resources. All families who attend will also receive a free resource pack.

We have managed to get to the 3rd stage of the funding process but we need to be able to show hard evidence that there is demand for the workshops and which regions want the training. Hopefully we can run a free workshop for families in your region, but we need your help to show the demand.

If you identify as a family carer, please click here for the electronic version of the questionnaire (it literally takes 2 mins to complete):

<http://www.surveymonkey.com/s/5KSBYQT>

Or print out the [attached](#) questionnaire. There is a freepost address so there is no need to add a stamp when returning it.

Please share with your family carer networks.

The deadline is Friday 31st May.

3. Challenging Behaviour in People with Learning Disabilities

NICE are currently recruiting parent and carer members of the Guideline Development Group for [Challenging Behaviour in People with Learning Disabilities](http://www.nice.org.uk/getinvolved/joinnwc/LayMemberLearningDisabilitiesBehaviourChallengesGDG.jsp).

This group is developing a guideline about the prevention and interventions for children, young people and adults with learning disabilities and behaviour that challenges

Information about the recruitment process and all necessary forms can be found at the following link:

<http://www.nice.org.uk/getinvolved/joinnwc/LayMemberLearningDisabilitiesBehaviourChallengesGDG.jsp>

The closing date for applications is **5pm Tuesday 4th June 2013**.

NICE very much values the input of service users, parents and carers and organisations to the development of their guidance and would welcome an application from you if you have:

- experience of caring for child, young person or adult with learning disabilities whose behaviour can be challenging.
- an understanding of, and a willingness to reflect, the experiences and needs of a wide network of relevant people (perhaps as a member of a support group or organisation)
- time to commit to the work of the group: attending meetings, background reading, commenting on draft documents etc.
- good communication and team working skills

Health and social care professionals will be well represented on the group, so ideally we are looking for someone without a health or social care professional background. Information about joining the Guidelines Development Group for health and social care professionals can be found [here](#). Please note that service users will also be directly involved in developing this guideline.

The draft scope for the Challenging behaviour in people with learning disabilities clinical guideline is now out for consultation. For details please see this webpage

<http://guidance.nice.org.uk/CG/Wave0/654/Scoping/ScopeConsultation>

Registered stakeholder organisations are kept informed of these events, and other developments and may comment on the consultations. You can register at any time using the following link

<http://www.nice.org.uk/ourguidance/niceguidancebytype/clinicalguidelines/shregistration/shregistration.jsp>

4. PIP 20 metre trio win first round of court battle

Three disabled people have won the first round of a legal battle with the government over its decision to tighten eligibility for the new mobility benefit.

The high court has granted the trio permission for a full judicial review of the decision to introduce more stringent criteria for the new personal independence payment (PIP) for people with the highest mobility needs.

All three of the claimants currently claim the higher rate of the mobility component of DLA, but fear they will lose their right to claim the equivalent higher rate of PIP.

The government's own figures show that 428,000 fewer people will be able to claim the PIP enhanced mobility rate by 2018 than would have been able to claim the DLA equivalent.

Under DLA, a person is entitled to the higher rate if they are "unable or virtually unable to walk".

Claimants are usually considered to be "virtually unable to walk" if they cannot walk more than around 50 metres, but the alterations to the regulations – which were suddenly announced in December without any consultation – saw the key PIP mobility criteria reduced from 50 to 20 metres.

You can read the full article on the Disability News website [here](#).

5. Contact a Family: new guide for fathers

[Contact a Family](#) have produced a new guide for fathers who have a disabled child. No matter if you're a new parent or an experienced one - everyone can react in different ways to the news that their child has a disability or medical condition.

It includes tips for dads from other dads, and personal stories from fathers, as well as updated sources of support and useful resources.

Click [here](#) to read the guide.

Parents can call their freephone helpline on 0808 808 3555 and ask for a free copy or if you'd like to order in bulk then please call Natalie Adams on 020 7608 8755.

You can also explore more about family life in Contact a Family's carers, family and friends section and check out the Fathers pages on their website [here](#).

6. RCGP advice on screening carers for depression

Carers should be routinely 'screened' for signs of depression during consultations with their GP as part of a drive to improve the support and services provided to the UK's 'invisible army', say doctors' leaders . The recommendation comes from the [Royal College of General Practitioners](#) who estimate that at least one in 20 patients registered with every GP practice is now a carer. The RCGP is calling for more to be done to ensure that carers do not neglect their own health and that early warning signs of mental health issues, as well as physical conditions, are identified and treated.

Over 7 million people in the UK currently provide unpaid care to an adult or child who could not otherwise live independently - but around 40% of carers experience psychological distress or depression at some time as a result of their caring responsibilities. Many GPs are already broaching issues of depression during their routine consultations with carers, who are now specifically coded on the GP system so that they can be easily identified.

The 'screening' process for depression involves a small number of general, non-invasive, questions about mood and mental wellbeing. It is then left to the patient to decide how the conversation continues. The RCGP has drawn up a nine point checklist as part of new online guidance produced for clinical commissioning groups to ensure that carers' needs are taken into account in the planning and delivery of health services.

The checklist also includes:

- Improving GP access by allocating routine appointments and vaccinations at convenient times for carers
- Identifying carers from ethnic minorities and the lesbian, gay, bisexual and transgender communities
- Appointing a carers 'champion' in all GP surgeries
- Maintaining a carers' register within the GP practice
- Carrying out audits to measure improvements in carer support

RCGP Chair Dr Clare Gerada said: "Carers often neglect their own healthcare needs and in many cases it is only a matter of time before they themselves become ill. They are at risk physically and emotionally with stress related illnesses but it can be hard for them to admit that they are struggling.

"GPs can play a crucial role in identifying potential problems in the early stages and 'screening' for depression is something that many GPs are doing already.

"It does not involve randomly calling in patients and testing them for diseases that they might never get. This is opportunistic, effective testing, targeted at a specific group of people, that can be carried out as part of the routine GP consultation so it is not going to increase workload.

"Commissioners need to invest in supporting carers as a critical asset. They already save the public purse £119 billion a year and this initiative could save even more by ensuring that carers stay well enough to keep on caring."

Carers were identified as a priority by the RCGP in 2006 when the College started working with Carers Trust (formerly the Princess Royal Trust For Carers). Since then it has produced a number of resources to help GPs identify and support carers in their practices, including an action guide and a toolkit to help identify depression.

7. 2011 Census: Publication of further data on unpaid care

The Office for National Statistics has published data today on the age and gender breakdown of people who identified themselves as unpaid carers in the 2011 Census returns. Information on the association of caring with their economic activity (paid employment or full-time education) and their general health, has also been published. Access to these is via following [weblink](#).

8. Mental Health Info Pack

13th -19th May is Mental Health Awareness Week. People with learning disabilities are particularly vulnerable to mental ill-health, in fact research suggests up to 40% of people with learning disabilities are affected by mental health problems. Netbuddy has teamed up with The Judith Trust to launch a [Mental Health Info Pack](#) highlighting some of the issues people with learning disabilities and mental ill-health face, and the resources that are available to support them. Please do share it amongst your own networks, and if you have any resources or tips you'd like to add, Netbuddy would like to hear from you: netbuddy@netbuddy.org.uk

South East

9. Kiss My Disco event

[Kiss My Disco](#) is a collaboration between Stay Up Late and Freshtrack DJ workshops. The idea is very simple. It's a night run by DJs with learning disabilities and open to all. The focus is all on great music, dancing, meeting nice people and having a great time. It will be at the De La Warr Pavilion and is £4 on the door (carers free). For more details see the event on the Stay Up Late site. www.stayupdate.org

Yorkshire and Humber

10. SeeAbility Family Carer Conference

Friday 5th July 10.30am – 3.00pm

Central Leeds ((details of the venue will be sent out upon booking)

SeeAbility are holding a free informative, discussion based conference to highlight the issue of promoting access to eye care for people who have a learning disability. This conference is for parents and family carers of children, young people and adults with learning disabilities. For more information, click [here](#) to read the flyer, or visit the [website](#).

To book your place please email Inclusion North at: info@inclusionnorth.org or call 0113 2626409.

If you would like to know more about this event, please email Laura Christie: l.christie@seeability.org

11. Connect in the North: Free training for directors of DPULOs

[Connect in the North](#) are organising free training which is funded by the Office for Disability Issues from the DPULO (Disabled People's User Led Organisations) Facilitation Fund. They are offering 6 2-hour workshops. These are the six core sessions which they recommend.

1. Introduction to our organisation
2. Responsibilities of directors
3. What support do we need to do our job well?
4. Doing our job well
5. Funding and Finance issues
6. Being Ready for Commissioning

Equality and diversity will be themes throughout the course. Any disabled people's user led organisations (in the North of England) interested should contact Cathy Wintersgill 0113 270 3233 cathy@citn.org.uk

North East

12. Twisting Ducks theatre night

Thursday 30th May 6.00-8.00pm

TD Studio, Westgate Community College, West Road, Newcastle, NE4 9LU

The Twisting Ducks Theatre Company are holding another theatre night, including dance from 'The Shining' at Day Break and performances and films from The Twisting Ducks Theatre Company. Click [here](#) for a poster with more information or visit the website [here](#).

North West

13. Manchester Know Your Rights event

Wednesday 5th June

London Scottish House, 24 Mount Street, Manchester, M2 3NN

Mencap, The National Family Carer Network, and Leonard Cheshire have organised a Know Your Rights event on 5th June to give disabled people, their families and their carers information on their rights to social care services and welfare benefits, and what you can do if your support is cut. Click [here](#) to read the [flyer](#) with more information.

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If you would like to contribute to the newsletter, please submit articles in plain English of no more than 230 words to info@familycarers.org.uk. We reserve the right to edit the articles to fit the newsletter whilst retaining the overall information. Due to the number of articles we receive we cannot guarantee inclusion of contributions.