

Bulletin



www.familycarers.org.uk

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Welcome to this week's Bulletin from the National Family Carer Network. You are receiving this because you are members of our organisation. If you no longer wish to subscribe, please contact info@familycarers.org.uk.

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National Family Carer Network
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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. Promoting family-led support: help us by completing a survey about your relative's support

For many years family carers have designed, developed and managed support for their learning disabled relatives. Their intimate experience of what good support looks like, their energy and passion, and their lifelong commitment to their relatives means that they are often best placed to lead this process.

Family-led support comes in various shapes and sizes; it can be 'hands-on' or 'arms-length'. It includes:

- Leading planning
- Managing a relative's direct payment to pay for personal assistants
- Coordinating 'pooled funding' on behalf of several people with learning disabilities
- Setting up a service
- Working in partnership with an agency.

Changes to the way that support for people with learning disabilities is funded and purchased means that families will have an even more important role to ensuring their relatives get good quality support. However, many families never consider the option of 'doing it themselves' because they do not know what it would involve, what the benefits are, or where they could get help.

Over the next two years the National Family Carer Network will be working to promote family-led support. We want to:

- Understand more about the experiences of families that have developed their own support;
- Find out family carers views family-led support and what help they would like to consider it as an option;
- Develop practical resources that provide families with the information, advice and assistance they need when thinking about arranging support themselves.

You can help by filling in a survey telling us about your current involvement in your relative's support and your views about what might happen in the future.

Click [here](#) to take part in the survey online.

To find out more about the work or request a paper copy of the survey, please contact Paul Swift:

Telephone **07740 946564 / 0117 9294365** or email: paulswift.research@gmail.com.

2. Safeguarding Questionnaire update

Dear members,

Thank you to all our members who completed or helped to distribute our questionnaire about safeguarding training for family carers.

We received 266 responses and we feel that the high level of responses really reflects the concerns of family carers at this present time.

63% of family carers do not know how to find out where to go if they have concerns, what their rights are or where to go for help. Many don't even know what safeguarding is.

Although there have been many changes to the way that hospital and treatment units are being inspected by the CQC, that there are national programmes of work by the Joint Improvement Board etc. many families told us that hearing what had happened at Winterbourne had made them worried. 83% of respondents felt that issues around keeping their relatives safe made them worried about their future.

We are shocked that 17% of family carers say that they are currently dealing with safeguarding issues.

The issues reported to us included family members assaulted in trusted care, worry about being able to find good quality providers, worries about safeguarding out in the local community. Other issues included uncertainty around deprivation of liberties, and what to do when services do not respond.

Family carers wanted to be proactive and know what they could do to ensure that their sons and daughters would be safe when they either reached adulthood, or for older carers, they were no longer able to care for them. They want to know what local services are expected to do in responding to issues and how to teach their sons/daughters how to report problems. Family carers have reported that worrying actually makes them feel ill and that it affects the whole family. One family carer felt that they should be able to enjoy their retirement and not be worrying about the future of their son.

We wanted to raise some money to run free safeguarding workshops for family carers. Unfortunately we were not successful with the first funder that we approached but will continue to approach others. In the meantime, we want to let you know that we can still provide the training in your area if any Local Authority or Carers centres/forums /groups would like to work with us to provide training for families on safeguarding in your area.

We also have free resources on our website: [Making sure your relative is safe – top tips](#) and [Making sure your relative is safe – essential guide](#).

The CQC have told us that they have a leaflet for families on how to complain about a health care or social care service. Click [here](#) to read.

Please do contact us if you have any comments or would like more information about the training by emailing: info@familycarers.org.uk.

3. SCOC response to the 'Refresh' of the NHS Mandate

The Standing Commission on Carers' response to Refreshing the Mandate to NHS England: 2014 – 2015 can be read on our website [here](#).

4. People will have a right to have a personal health budget by October 2014

Norman Lamb, The Minister of State, Department of Health has announced that people receiving NHS Continuing Healthcare will have the right to have a personal health budget from October 2014.

To read the full ministerial statement, please visit the Parliament UK website [here](#). You can also read the latest Personal Health Budget news on the NHS England [website](#).

5. A survey about health services for people with learning disabilities

[BILD](#) wants to find out about current health services for people with learning disabilities. They want to find out what's good, but also where improvements need to be made and how things can be made better. BILD also wants to find out, in particular, about reasonable adjustments and the mental capacity act in healthcare.

The information you provide will help BILD in its work, particularly at their annual conference in October where there will be a health zone to discuss these kinds of issues. It will also help their work helping to develop the organisations and services that offer support to people with learning disabilities.

The survey will take no longer than 10 minutes to complete and BILD would really like to hear your views.

If you would like to take part in the survey, please click [here](#).

6. Couple's tribunal win adds weight to bedroom tax campaign

A tribunal's ruling that a disabled man and his wife do need to sleep in separate bedrooms has added fresh weight to the campaign to defeat the government's so-called "bedroom tax".

The couple's local authority, Herefordshire council, decided last year that their housing benefit had to be cut because they were "under-occupying" their two-bedroom flat. But Judge David Jackson, sitting in the first-tier tribunal, decided this week at a hearing in Hereford that the council's decision should be over-turned because the couple needed to sleep in separate bedrooms, due to the husband's impairment.

To read the full article, please visit the Disability News Service website [here](#).

7. Further bedroom tax developments - advice for families

Over the past few weeks there have been some successful appeals against cuts to housing benefit under the 'bedroom tax' or cuts to housing benefit. These decisions provide some hope for families who have a small box room that is being treated as a 'spare' bedroom.

Derek Sinclair Contact a Family's welfare expert, has some important advice for families of disabled children who are faced with cuts to housing benefits because of the 'bedroom tax'.

"We have started to hear of cases where tenants have successfully appealed housing benefit cuts, by challenging whether a room in their property is a bedroom.

The law on overcrowding says that a room is too small to be treated as a bedroom if it's less than 50 square feet, and is too small for anyone except one child aged under 10, if between 50 and 70 square feet.

Over the past few weeks, some families have successfully argued at appeal that these rules should also apply to the bedroom tax, and that box rooms of this size should not be counted as a spare bedroom.

However the Department of Work and Pensions (DWP) states that these overcrowding rules aren't relevant and are appealing these decisions. In the meantime, you should seek further advice about lodging an appeal if you do not agree with a decision to treat a room in your property as a bedroom."

Further advice is available free from Contact a Family's helpline on 0808 808 3555.

Are you affected by bedroom tax and want to help with Contact a Family's campaigning?

- Got a photo of your "spare room" used for storing disability equipment? Please send them to Head of Policy, Una Summerson, una.summerson@cafamily.org.uk.
- Need a spare room for an overnight carer or are a separated parent paying bedroom tax for a room used when your disabled child comes to stay? Contact a Family need case studies. Email Una Summerson, una.summerson@cafamily.org.uk.

8. Free access to images, symbols, photos and accessible information

The Leeds and York Partnership NHS Foundation Trust have developed a new 'easy on the i website' which provides free access to a fully updated database of accessible images, artwork, symbols and photographs.

To find out more, and to register for the image bank, please visit the website: <http://www.easyonthei.nhs.uk/>.

9. A fresh start for inspecting adult social care service

In her first major announcement as the Chief Inspector of Adult Social Care, Andrea Sutcliffe has outlined her priorities for transforming how the Care Quality Commission (CQC) will monitor, inspect and regulate care homes and other adult social care services, with a greater focus on public involvement and improvement.

Key proposals include awarding ratings to every care home and adult social care service by March 2016 to help people make informed decisions about their care and establishing expert inspection teams involving people who have experience of care services.

The Chief Inspector's plans and priorities are set out in A Fresh Start for the Regulation and Inspection of Adult Social Care, ahead of a full public consultation in spring 2014.

To read the document, please click [here](#). You can also read more on the CQC [website](#).

10. Petition to protect vulnerable patients with a learning disability from dying due to poor and unequal care

Christine Papalabropoulos is petitioning Jeremy Hunt, Secretary of State for Health to protect any more vulnerable patients with a learning disability from dying due to poor and unequal care.

To read more about Christine's campaign and to sign the petition, please visit the Change.Org website [here](#).

London

11. The Gate Escape: an evening of musical entertainment Friday 25th October. Doors open at 6.30pm, show starts 7.30pm The Tabernacle, 35 Powis Square, London, W11 2AY

Moment by Moment Theatre present their latest production 'The Gate Escape': an evening of musical entertainment performed by artists with learning disabilities.

Tickets: £7.50 or £5.00 concessions on the door.

For more event details and further information about Moment by Moment Theatre, please click [here](#).

For venue details and to book online, please visit the Tabernacle website [here](#).

Yorkshire and Humber

12. Health event for family carers

Monday 4th November 10.30am – 3.00pm
Oxford Place Centre, Leeds, LS1 3AX

Does your relative with learning disabilities or autism live in supported living or a residential home? Are you worried about their health? People with learning disabilities have poorer health and are likely to die earlier than the general population:

- they need access to good healthcare
- they need sensitive support to prevent them falling ill or their health getting worse
- they need effective support to manage ill health

Social care providers want to get better at supporting people with their health. [Improving Health and Lives](#) is writing a health charter for social care provider organisations so that they can sign up and improve their practice. The charter will be accompanied by guidance including stories and advice from family carers.

Come to a meeting ... tell us:

- what is working well – so we can encourage good practice
- what isn't working – so we can explain how to avoid it
- what sort of support makes a difference to your relative's health

The event will be hosted by Liz Wilson, Family Consultant Dimensions / NDTi Associate and Carol Robinson, NDTi Associate.

A sandwich lunch will be provided and reasonable travel expenses will be paid. For directions to the venue, please click [here](#).

South East

13. The Grace Eyre Foundation needs your vote!

From 23rd September to 1st November the Lloyds Bank Community Fund is giving you the chance to vote for a local good cause, and [The Grace Eyre Foundation](#) has been nominated for Brighton.

The Foundation supports over 350 people with learning disabilities across Sussex to fulfill their dreams and wishes. They are fundraising for a desperately needed training kitchen so young people and adults can learn the basic skills of cookery, enabling them to make healthy meals safely.

If you would like to vote for The Grace Eyre Foundation, please visit the Lloyds Bank Community Fund website [here](#).

14. Sing-Along Cinema, Aldershot

Saturday 2nd November 2013 2.30pm
West End Centre, 48 Queens Road, Aldershot

An afternoon especially for young people with disabilities, their families and friends: come and sing your heart out to a sing-along film showing of Grease at the West End Centre, a friendly and accessible multi-arts venue.

Cost: £2.50 per person or £10 per family (up to 5 people).

Click [here](#) for more details and [here](#) to visit the West End Centre website.

The box office can be contacted on 01252 330040.

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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.