

## Health Stones 16

UK Health and Learning Disability Network

For information, queries and to contribute to FPLD health stones contact

Janet Cobb [jcobb@learningdisabilities.org.uk](mailto:jcobb@learningdisabilities.org.uk) or [janet@jan-net.co.uk](mailto:janet@jan-net.co.uk)

Please copy me into any replies.

Thanks

Janet

### 1. PEG feeds

Can anyone tell me how long somebody with a PEG feed should remain upright after their feed has finished?

How soon can the person lie down flat on their backs?

Does it depend on the individual or are there guidelines we should be following?

*Tess Ellis*

[tess.est@btinternet.com](mailto:tess.est@btinternet.com)

07803 875374

EST Partnership Ltd Developing Individuals, Services & Communities

<http://www.est-pcp.com/>

*attached link to enteral tube feeding information from archives*

[http://www.rcn.org.uk/newsevents/campaigns/nutritionnow/tools\\_and\\_resources/learning\\_disabilities](http://www.rcn.org.uk/newsevents/campaigns/nutritionnow/tools_and_resources/learning_disabilities)

*Janet*

### 2. Triangle of Care

Our mental health NHS trust is committed to rolling out Triangle of Care - a partnership between service user, carer and professional which includes a new universal self-assessment tool.

As LD Services are part of the organisation we are included in this. Has anyone used Triangle of Care in the LD setting?

I would be interested in finding out how you found its implementation in practice?

*Sue Bridges*

[Sue.bridges@nsft.nhs.uk](mailto:Sue.bridges@nsft.nhs.uk)

### 3. Podiatrist in Private Practice with experience of LDs

Does anyone know of a podiatrist in Greater London in private practice with experience of working with people with learning disabilities? Although we are the DSA, we have received an enquiry from the parent of a 17 year old with learning disabilities (not Down's syndrome) who has difficulties with his feet and ankles.

*Stuart Mills*

Information Officer Down's Syndrome Association

[stuart.mills@downs-syndrome.org.uk](mailto:stuart.mills@downs-syndrome.org.uk)

### 4. Breathing exercises, pain management

Can anyone point me to a visual aid showing deep breathing and relaxation exercises?

Also does anyone know of a visual or aural resource on pain management?

*Alix Otten*

[alixotten@phonecoop.coop](mailto:alixotten@phonecoop.coop)



## 5. Charles Bonnet Syndrome

Anonymous query please reply to [janet@jan-net.co.uk](mailto:janet@jan-net.co.uk)

A woman who is 85 has experienced hallucinations for two years. She lives alone in her own home and is generally in good health. She is aware that this condition is named as Charles Bonnet Syndrome.

The hallucinations in her home are very real to her and whilst she can rationalise how the hallucinations are constructed, when she is outside her home, as soon as she returns to her home environment the hallucinations return. This is becoming increasingly problematic because she is reluctant to go to the bathroom because "people" are in there. She is forced to watch football on TV because "the male visitors" insist on watching the match. She does not like to leave her home because the "children" are too young to leave alone.

What "therapist" are available? She will not take medical suppressants, she does not consider herself to have a "mental health" problem. This is reinforced to others because when she is outside her home she is back to her typical confident self! Any suggestions would be very welcome.

*Anonymous response received*

*Hi, I also work with a lady who is in her early 70's with Charles Bonnet syndrome. She used to be able to recognise that the visions were not real, however, more recently she has also become distressed at home to the extent that she is unable to remain there. She has been given quetiapin but this does not seem to help, other than to reduce anxiety as she feels she has been given something to help - more of a placebo effect really.*

*One of the theories is that the brain constantly creates images but the visual system normally interrupts these and so they are not noticed. Without the visual stimuli the brain has free reign to produce the visions that are "seen". This would suggest that other stimuli can replace the visual aspect and engage the brain thereby preventing the visions - I certainly notice that if I can engage the lady in conversation she is less likely to respond to her visions as she calls them. It may be that your lady is OK when out and about because she is stimulated in many other sensory ways but in the house sensory input is limited.*

*Does your lady live alone? Even with 24/7 support it is not possible for one person to engage a client constantly and we have found that being in a small ward environment with the gentle but constant activity around her is best, we are struggling to find a service that can replicate this in the community at present though.*

## 6. Men who have a learning disability and are also s\*x offenders

Anonymous query please reply to [janet@jan-net.co.uk](mailto:janet@jan-net.co.uk) I am currently doing some work in a group which is a therapeutic group for men who have a learning disability and are also s\*x offenders.

My role as a learning disability nurse is one of an observer, and after a somewhat personal sceptical view, I am so pleased to see the progress the men are making and their recall and participation in this work. The programme used in our area is based on The Ministry of Justice publication, Becoming New Me, Treatment Manual 2009. It is of course adapted from this publication to fit the needs of the men in the group, and in my opinion works very well. I am therefore interested in knowing what else is going on in the country that addresses the needs of this group of men, and would appreciate any evidence of such.

*Response received*

*Our film [Getting Together](#) is designed for people with learning disabilities and it's about making friends and starting relationships. While it is not about s\*x offenders as such, the content can be helpful in the setting you describe, as part of a therapeutic process, through encouraging empathy and enabling men with learning disabilities to understand the other person's point of view.*

*The DVD comes with an easy-read booklet and contains six stories - including one about a date that goes wrong, one about a young woman's experience with a predatory man, one about a young gay man looking for a partner, and one about a couple building a successful relationship step by step - this last story can be watched as a clip on our website: [http://www.leedsanimation.org.uk/films/get\\_together.html](http://www.leedsanimation.org.uk/films/get_together.html)*

*The DVD packs are available from us at the address below. (Bulk discounts on 2 or more copies of any title. Email us for special offers.)*

*Best wishes, Terry*

*Terry Wragg*

*Leeds Animation Workshop*

*45 Bayswater Row*

*Leeds*

*LS8 5LF*

*[info@leedsanimation.org.uk](mailto:info@leedsanimation.org.uk)*

*[www.leedsanimation.org.uk](http://www.leedsanimation.org.uk)*

## **7. CALL FOR ABSTRACTS: Special issue of British Journal of Learning Disabilities**

Special Issue - Ageing and People with Learning Disabilities

Older people with learning disabilities have been largely invisible within research and policy, falling between the cracks of more generic initiatives relating to both older people and services for people with learning disabilities. Within policy circles there has been a received wisdom that people with learning disabilities do not live to older age, or that it is unusual for them to do so, and they have therefore not been a priority. However, more recent policy developments, such as the closure of long stay institutions, and more general improvements in health care for people with learning disabilities, have led to a growth in the number of older people with learning disabilities who are known to services and we know that the actual number of older people with learning disabilities will be higher than this (Emerson and Hatton, 2011). Understanding of the needs and experiences of older people with learning disabilities is currently limited and this collection will highlight and build on recent work in the area.

We are seeking papers on any aspect of ageing and people with learning disabilities which will enable us to build a better understanding of the needs and experiences of this group. This might include, but is not limited to, research papers, service evaluations, theoretical papers or personal narratives and reflection. Interested authors should submit an abstract of no more than 400 words, along with author details to Nicki ward at [n.j.ward@bham.ac.uk](mailto:n.j.ward@bham.ac.uk) by 1st August 2014.

Timeline:

Deadline for Submission of Abstracts: 1st August 2014

Notification of Acceptance: 1st September 2014

Full papers due: 5th January 2015

Revised final draft due: April 2015

Expected publication date: December 2015

If you wish to discuss your ideas informally then please contact Nicki Ward:  
*Dr Nicki Ward*  
*IASS, School of Social Policy*  
*University of Birmingham*  
*Edgbaston,*  
*Birmingham*  
*B15 2TT*  
*E: [n.j.ward@bham.ac.uk](mailto:n.j.ward@bham.ac.uk)*  
*T: 0121 414 5713*

**8. Looking for professionals with a knowledge of, and interest in, health conditions that are more common in Down's Syndrome**

In the past, the majority of calls to our Helpline about health issues have been in relation to children. Over the last couple of years we have seen an increase in the number of calls to our Helpline about health issues in adults with Down's syndrome. To help us ensure that we are responding appropriately to adult health enquiries, we have established a small but growing informal network of professionals with a knowledge of, and interest in, health conditions that are more common in Down's Syndrome. We circulate a regular bulletin to network members with updates about out health related work. We may, from time to time, approach members for their input and advice about adult health matters.

If you would like to be part of this informal network, would you please email [stuart.mills@downs-syndrome.org.uk](mailto:stuart.mills@downs-syndrome.org.uk) with your contact details and professional role.

*Stuart Mills*  
*Information Officer Down's Syndrome Association*

**9. RCN Safe staffing levels publications**

<http://bureau-query.funnelback.co.uk/search/search.cgi?query=safe+staffing&collection=rcn-meta&section=pubs&form=publications>

*Ann Norman*  
*RCN Adviser - Criminal Justice Nursing/ Learning Disability Nursing*  
[ann.norman@rcn.org.uk](mailto:ann.norman@rcn.org.uk)

**10. PAMIS The Bereavement and Loss Learning Resource Pack**

Further details and an order form are attached, with additional information on the PAMIS website <http://www.pamis.org.uk/>  
[http://www.pamis.org.uk/\\_page.php?id=70](http://www.pamis.org.uk/_page.php?id=70)

**11. Updated 'frequently asked questions' section on personal health budgets**

If you have a question about personal health budgets, start with the nhs England's newly updated FAQ section which explains some of the fundamentals about what a personal health budgets is, who can request one and what has been learned so far about how they can work well for people.

<http://www.personalhealthbudgets.england.nhs.uk/News/item/?cid=8806>

**12. Think Local Act Personal weekly update**

<http://www.thinklocalactpersonal.org.uk/nl/view.cfm?nid=782>

- 13. Parliamentary Inquiry into childcare for disabled children**  
<http://www.edcm.org.uk/childcareinquiry>
- 14. National group to drive improved healthcare support for people with learning disabilities**  
<http://www.england.nhs.uk/2014/07/14/learning-disability-support/>
- 15. NSPCC The Underwear Rule guide recommended by parents**  
[http://www.nspcc.org.uk/news-and-views/our-news/child-protection-news/underwear-rule-recommended-parents/underwear-rule-recommended-parents\\_wda97966.htm](http://www.nspcc.org.uk/news-and-views/our-news/child-protection-news/underwear-rule-recommended-parents/underwear-rule-recommended-parents_wda97966.htm)
- 16. Disabled children and abuse**  
By David Miller (February 2002)  
[http://www.nspcc.org.uk/inform/research/briefings/disabledchildrenandabuse\\_wda48224.html](http://www.nspcc.org.uk/inform/research/briefings/disabledchildrenandabuse_wda48224.html)
- 17. The Public Health England Obesity**  
Briefing papers: Obesity and disability - children and young people  
[http://www.noo.org.uk/NOO\\_pub/briefing\\_papers?](http://www.noo.org.uk/NOO_pub/briefing_papers?)
- 18. Integrated Personal Commissioning (IPC) programme**  
High-need individuals to be offered ability to control their own blended NHS and community care, in partnership with voluntary sector.  
The NHS will offer local councils across England a radical new option in which individuals could control their combined health and social care support, Simon Stevens CEO of NHS England will announce today.  
Speaking at the annual conference of the Local Government Association in Bournemouth, Stevens will set out plans for a new Integrated Personal Commissioning (IPC) programme, which will for the first time blend comprehensive health and social care funding for individuals, and allow them to direct how it is used...  
Source and full article at <http://bit.ly/1k8vkV5>
- 19. Fundamental standards: improving quality and transparency in care**  
The government has announced legislation which introduces fundamental standards for health and social care providers. Subject to parliamentary approval, they will become law in April 2015.  
The new measures are being introduced as part of the government's response to the Francis Inquiry's recommendations (<http://bit.ly/1q1jWCy>) and are intended to help improve the quality of care and transparency of providers by insuring that those responsible for poor care can be held to account.
- How the fundamental standards will work in practice:
- the fundamental standards will define the basic standards of safety and quality that should always be met, and introduce criminal penalties for failing to meet some of them.
  - the standards will be used as part of the Care Quality Commission's (CQC's) regulation and inspection of care providers. The CQC will be able to hold providers to account if they are not being met, including through the courts where appropriate. Registration with the CQC will also be dependent on compliance.
  - the duty of candour will require NHS bodies to be open and transparent with service users about their care and treatment, including when it goes wrong.
  - the fit and proper persons requirement means that all directors of NHS bodies must

pass a test proving they are fit and proper persons. The CQC will be able to insist on the removal of directors that fail.

These measures were recommended by the Francis Inquiry report and thousands of people responded to a series of consultations about their introduction. Most of those who responded to the consultations were in favour of the measures and the responses were used to improve the development of the regulations.

The government's response (<http://bit.ly/1IWsi60>) to these consultations explains the changes it has made as a result of the feedback received in full.

As part of the fundamental standards, a new duty of candour and fit and proper persons requirement for directors will be introduced for NHS providers from October 2014, and will be extended to all providers by April 2015, subject to parliamentary approval.

The fundamental standards are:

- care and treatment must be appropriate and reflect service users' needs and preferences
- service users must be treated with dignity and respect
- care and treatment must only be provided with consent
- care and treatment must be provided in a safe way
- service users must be protected from abuse
- service users' nutritional and hydration needs must be met
- all premises and equipment used must be clean, secure, suitable and used properly
- complaints must be appropriately investigated and appropriate action taken in response
- sufficient numbers of suitably qualified, competent, skilled and experienced staff must be deployed
- persons employed must be of good character, have the necessary qualifications, skills and experience, and be able to perform the work for which they are employed
- registered persons must be open and transparent with service users about their care and treatment (the duty of candour)

**20. Autism is the most costly medical condition in the UK**

<http://www.lse.ac.uk/newsAndMedia/news/archives/2014/06/Autism.aspx>

**21. BBC: Father of son with autism calls for local treatment**

The father of a boy with severe autism who is being treated at a unit 260 miles away from his family has called for local care to be provided.

<http://www.bbc.co.uk/news/health-27633817>

**22. Winterbourne View: One autistic boy's tragic tale**

<http://www.telegraph.co.uk/health/healthnews/10865366/Winterbourne-View-One-autistic-boys-tragic-tale.html#>

**23. Danshell vacancies**

<http://jobs.danshellgroup.com/vacancies/#results>

**24. YORK Danshell Training & Development Manager Holgate Park.**

Circa £40,000 per annum (pro rata)

Vacancy Reference Number: T&DMYork0614

Full or Part Time considered

[http://jobs.danshellgroup.com/vacancies/1700/training\\_development\\_manager/holgate\\_park\\_york/](http://jobs.danshellgroup.com/vacancies/1700/training_development_manager/holgate_park_york/)





We are seeking to appoint an organised and resourceful manager to provide leadership to our team of regional trainers and the implementation the organisational training and development strategy. Candidates need strong managerial background, ability to work to tight deadlines and manage and produce relevant data and reports. Experience working within the care sector is desirable but not essential. The Training Manager posts re-ports to Debra Moore, Director of Nursing, Quality and Governance and works closely with colleagues in operational and clinical roles. Danshell is committed to the delivery of high quality, person centred care and we expect the successful candidate to be able to demonstrate their ability to en-sure our training programme supports and strengthens our mission and values. For an informal discussion contact Debra Moore, Director of Nursing, Quality and Governance at [debra.moore@danshell.co.uk](mailto:debra.moore@danshell.co.uk) To apply please send your CV to [emma.falkingham@danshell.co.uk](mailto:emma.falkingham@danshell.co.uk) or complete the on-line application form at [www.danshell.co.uk](http://www.danshell.co.uk) Please read the job description and person specification in full. Closing Date: Friday 25th July 2014

**25. LONDON Young People's Schools and Forensic Therapist (£31,067-FTE at 28 hours/week)**

The post will work in Respond's Young People's Project. It will involve providing individual and group therapy to young clients with learning disabilities primarily in London based schools. In addition you be part of our forensic services offering risk assessments and therapy to young people exhibiting sexually harmful behaviour. Non-clinical responsibilities could include: delivering external training and an outreach programme to young people and/or parents/carers.

<http://www.respond.org.uk/who-we-are/work-for-us/>

Closing Date for applications: Friday 1st August 12pm 2014

Interviews will be Tuesday 12th August 2014

For more information and an application form please call on 020 7383 0700

email [admin@respond.org.uk](mailto:admin@respond.org.uk) or visit our website [www.respond.org.uk](http://www.respond.org.uk)

**26. National charity, Epilepsy Action, has launched a new online course for people with epilepsy.**

*Epilepsy and your wellbeing* is a free course designed to help people manage their epilepsy and take steps to improve their wellbeing.

It's packed with simple tips, tools and information to help people with epilepsy feel good and function well.

The course includes:

- Seizure diaries
- Goal setting for wellbeing
- Seizure triggers
- Epilepsy medicines
- Stress and epilepsy
- Memory

*Epilepsy and your wellbeing* is broken down into bite-size sections and includes useful quizzes to determine stress and wellbeing levels. The course is a practical way for people with epilepsy to start improving their health and wellbeing. It is also a useful resource for health care professionals, who can encourage their patients to take the course to help them better manage their epilepsy.

Anyone can access *Epilepsy and your wellbeing* by visiting [epilepsy.org.uk/wellbeing](http://epilepsy.org.uk/wellbeing)

**27. LGBT Learning Disability Project**

<http://www.lgbthealth.org.uk/node/822>

**28. Stonewall Easy Read Versions**

[https://www.stonewall.org.uk/what\\_we\\_do/2583.asp#Easy\\_read](https://www.stonewall.org.uk/what_we_do/2583.asp#Easy_read)

**29. Working with lesbian, gay, bisexual and transgender people - people with learning disabilities: Richard's story**

<http://www.scie.org.uk/socialcare/videoplayer.asp?guid=C3F92700-3F9A-4B50-AB5E-13A70C952D73>

**30. LONDON RSM event Getting hospital care right for people with intellectual disabilities - 17 September 2014**

The direct web link is <https://www.rsm.ac.uk/events/events-listing/2013-2014/sections/intellectual-disability-forum/ide03-getting-hospital-care-right-for-people-with-intellectual-disabilities.aspx>

**31. LONDON Women and girls on the autism spectrum - 9 October 2014**

This conference, organised by The National Autistic Society, aims to further the discussion around diagnosis and support for girls and women with autism. Delegates can choose the seminars from three streams: health, social care and education. Dr Wenn Lawson (formerly Wendy Lawson) will be giving the keynote address at the conference on the unique challenges that women on the spectrum face and their unique strengths.

<http://www.autism.org.uk/news-and-events/nas-conferences/upcoming-conferences/women-and-girls-on-the-autism-spectrum.aspx>

**32. NEWCASTLE Shape of a caring review - engagement event**

I am supporting Lord Willis with the Shape of Caring review which has been commissioned by Lisa Bayliss-Pratt, Director of Nursing at Health Education England.

The review aims to build on recommendations from previous reviews and through identification of good practice, develop a blue print for nurse and healthcare assistant education and training for the next 10-15 years.

Lord Willis is undertaking a number of engagement events across the country and is keen to engage with LD, Mental health and prison nurses in Newcastle on the 31 July.

Date: 31 July

Time: TBC either am/pm

Venue: TBC somewhere in Newcastle

*Suzie Loader*

*Nurse Advisor: Shape of Caring*

*Health Education England*

E. [Suzie.loader@nhs.net](mailto:Suzie.loader@nhs.net)

W. [www.hee.nhs.uk](http://www.hee.nhs.uk)

**33. WALKERN LODGE Vacancy Alert**

<http://www.cambiangroup.com/OurServices/Service/Home.aspx?Id=93>

MAKE A REFERRAL

To arrange an assessment or discuss suitability of a potential referral, please contact Ben Davidson on 07958 752838 or at [ben.davidson@cambiangroup.com](mailto:ben.davidson@cambiangroup.com)