

# PMLD LINK

sharing ideas and information

Health and Wellbeing

Winter 2018



Vol 30 No 3. Issue 91

ISSN 2042-5619

# Winter 2018 contents



**06** Recognising anxiety in my child



**13** Timmy's story



**27** Co-authoring Sensory Stories

Page		
1	Guest Editorial: Health and Wellbeing	Jeanne Carlin, Sue Thurman and Rob Ashdown
2	The PMLD Standards and Health and Wellbeing	Guest Editors
3	Health Commissioning in Hull	Jill Burton and Melanie Bradbury
6	Recognising anxiety in my child with profound and multiple learning difficulties and how we deal with it	Emma Murphy
9	NEWS and SBAR – making these tools work for people with profound and multiple learning disabilities	Sally Wilson
13	Timmy's story	Alison Pettit
16	Working in partnership to create a more effective service in Hull	Michaela Marr and Suzanne Nicholls
18	LeDeR Report 2017 Deaths of people with profound and multiple learning disabilities	Michael Fullerton
22	Sensory Engagement for Mental Well Being	Joanna Grace
24	Dysphagia in people with profound and multiple learning disabilities	Hannah Crawford
27	Co-authoring Sensory Stories	Lynsey Robinson
32	A new task force on people with complex support needs	Angelika Hild and Guillaume Jacquinot
33	NEXT ISSUE: Communication	Wendy Newby and Becky Loney

## GUEST EDITORIAL

# Health and Wellbeing

**W**inter is upon us and with it comes our Winter edition of PMLD Link. This issue focuses on health and its impact on people who have profound and multiple learning disabilities / impairments. For many families, caring for someone with PMLD means that health issues dominate their lives as they enter a world of new jargon, medical procedures, and an array of professionals. Having a good health experience can make an enormous difference to the lives of people with PMLD.

The second annual LeDeR report and the subsequent government response have shocked many of us. It is clear that unless we do something to improve the health response for people with learning disabilities they will die 20 years earlier than their non-learning disabled peers. Monitoring premature death is not sufficient – action on change is needed. The article by Michael Fullerton looks at these documents and discusses how the recommendations relate to the PMLD population. We have included an article by Hannah Crawford on Dysphagia – one of the causes of premature deaths on the PMLD population. The contribution from Inclusion Europe shows that work is being done across Europe to raise the profile of those in the learning disability community with the most complex needs.

The PMLD community has responded to many of the health issues for this population by developing a set of standards to be used in services across the country.

We would like to thank the two parent carers, Alison Pettitt and Emma Murphy who shared their stories about their sons. Both are very moving accounts and highlight the importance of both physical and mental health issues. The importance of listening to parents and responding in creative and flexible ways come over so strongly.

We have included three articles to broaden our understanding of how health services work. One is an article by Mel Bradbury and Jill Burton explaining how health services are commissioned to meet the needs of the local population and focuses in particular on the PMLD population and listening to the voice of carers. The second is an article written by Michaela Marr, a liaison nurse working in hospitals, and Suzanne Nichols, a liaison nurse working across primary care focuses on how they have worked in partnership to ensure a more effective and comprehensive coverage of the learning disability population. Sally Wilson has written an article explaining what NEWS and SBAR are, and their importance in responding to health concerns within the broader context of an individual.

Both Jo Grace and Lynsey Robinson have written articles on sensory stories and working in a creative and exciting way with individuals who often process their world through their senses rather than relying solely on cognitive methods. Their articles remind us that ‘health’ encompasses mental and emotional well being as well as physical health.

We are also mindful that PMLD Link is now 30 years old and many articles on Health and Wellbeing have been written over those years. We have identified those articles which have appeared in the past 10 years which Rob Ashdown has collated in his article. All of them can be found on our website: most issues of PMLD Link are downloadable for free on the PMLD Link website by anybody but the issues of the past three years are available only to members (i.e. paying subscribers). If you cannot access an article and need to know more, please contact us. The articles have been grouped according to their main topic but it is worth noting that a few articles arguably could have been placed in two or more groupings. For each article the authors’ names and article title are given with the PMLD Link journal issue number and the starting page shown in brackets.

Guest Editors

Jeanne Carlin, Sue Thurman and Rob Ashdown

### Contact Us

#### Subscriptions

Rob Ashdown  
15 Cliff Gardens,  
Scunthorpe,  
North Lincolnshire, DN15 7PH  
info@pmlmlink.org.uk

rob.ashdown@ntlworld.com  
Tel: 01724 852818

#### Production

Paul Bramble  
The University of Northampton  
Email: info@pmlmlink.org.uk

**Website:** www.pmlmlink.org.uk  
**Twitter:** @PMLDlink

**ISSN 2042-5619**

# The PMLD Standards and Health and Wellbeing

## Guest Editors

The PMLD Standards were published last year (Doukas et al, 2017) to ring in endorsements. The document outlines key objectives and principles that ideally should be evident across all education, health, and social care services.

The hope is that these standards should be adopted by commissioners and providers of services. Moreover, if they ensure families and other key stakeholders have awareness of these standards, then there should be clarity, from the outset, of what level and type of standards may be expected for the persons with PMLD whom they represent and for whom they act as advocate.

There are two main components to the standards. The first set of standards aims to give guidance and support to organisations on how to provide high quality care to people with PMLD. Their emphasis is on what people at all levels and ranks of an organisation's structure should contribute to delivering such support. A second set of standards, focuses on the individual and their specific needs and organisations are expected to self-assess against these standards to identify actions to improve the quality of the support they provide for them.

As regards Health and WellBeing in particular, organisations need to comply with the following standards in order to provide quality of care and life to the person with PMLD.

### Standard 6 for Organisations: Health and Wellbeing

Organisations should be able to show that they:

- Ensure effective support to promote the health and wellbeing of each person, including any specialist health care needs that increase the vulnerability of the person.
- The service has signed up to and demonstrates commitment to the Health Charter for Social Care Providers (Public Health England/VODG, 2017).

### Standard 2 for Individuals: Health and Wellbeing

Organisations should be able to show through self-assessment that their services will achieve the following outcomes:

- Each person's health and wellbeing are actively promoted and supported, to enjoy a full and long life. This will include a clear focus on postural care management and a recognition of the holistic

vulnerability of people with PMLD.

- Each person has a thorough Annual Health Check with their GP and a Health Action Plan informed by health professionals involved with the person and made meaningful to the person by those who know them well.

For both sets of standards possible evidence of their achievement is described. This list will greatly aid the process of evaluation and self-assessment.

### Contact Details

The Guest Editors

sue@thurmancc.co.uk  
jeanne@jcarlin.karoo.co.uk  
rob.ashdown@ntlworld.com

### References

Doukas, T., Fergusson, A., Fullerton, M. and Grace, J. (2017) *Supporting People with Profound and Multiple Learning Disabilities: Core and Essential Service Standards*. (downloadable pdf document available at: <http://www.pmlmlink.org.uk/resources/#pmlid-standards>)

Public Health England/VODG (Voluntary Organisations Disability Group) (2017) **Health Charter for Social Care Providers** (downloadable pdf document available at: <https://www.gov.uk/government/publications/improving-healthcare-access-for-people-with-learning-disabilities>)

# Health Commissioning in Hull

Jill Burton and Melanie Bradbury

In this article, Jill Burton and Melanie Bradbury describe NHS commissioning of services in England and how they involve carers in the way that they commission health services in Hull.

**C**ommissioning is the process by which health and care services are planned, purchased and monitored.

Commissioning comprises a range of activities, including:

- assessing needs
- planning services
- procuring services
- monitoring quality

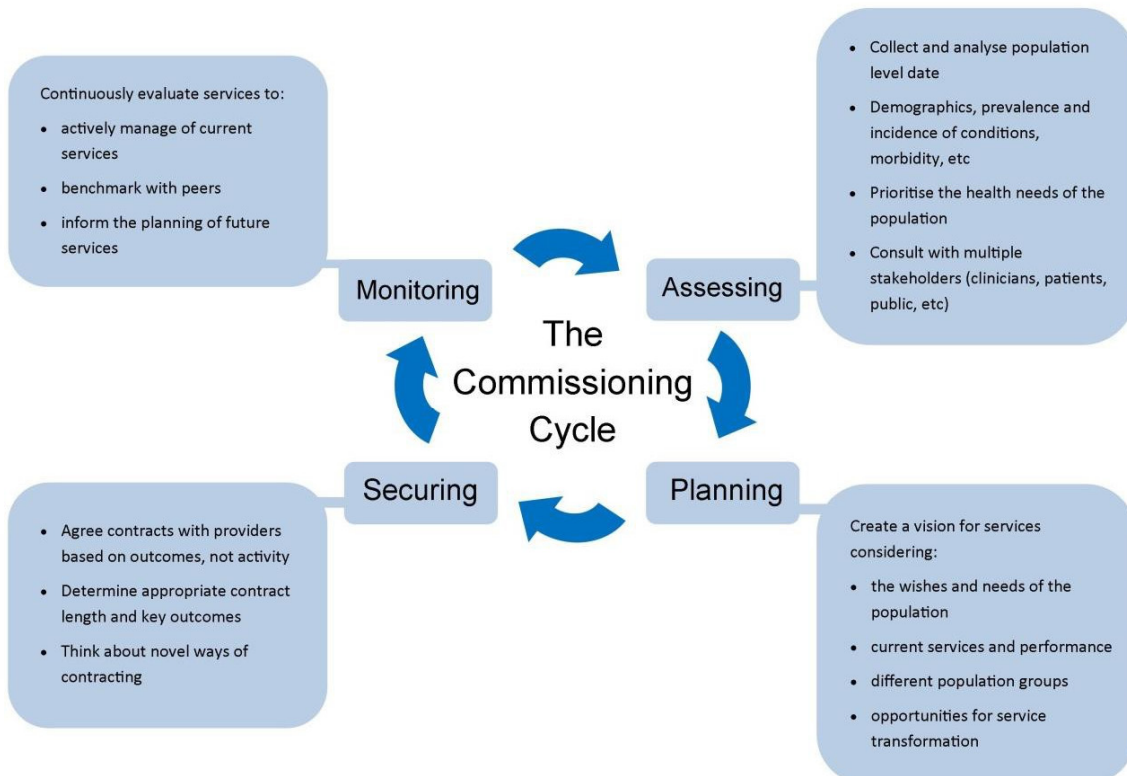
The concept of commissioning was introduced into the NHS in the early 1990s, when reforms separated the purchasing of services from their delivery, creating an 'internal market'. It was argued that making providers compete for resources would encourage greater efficiency, responsiveness, and innovation.

In its simplest terms – you need to purchase a new car. While this seems straightforward there are a lot of things to take into consideration.

- 1 What do you need the car for?
- 2 What size of car is practical for your needs?
- 3 What type of journey will you take in the car?
- 4 How many people will regularly travel in the car?
- 5 How much is your budget?

So – you wouldn't go into a garage and buy a two-door sports car when you are a farmer and the vehicle will frequently be used off road – you need a four wheel drive.

You also need to test drive the car – will it provide the performance and fuel economy you need? The NHS frequently commissions in this way – we call it 'piloting' services – we try out a new idea and see how it works. We evaluate and monitor the impact of the 'car' we are testing – will it deliver what we need. This way the local area Clinical Commissioning Group (CCG) can make an informed choice before spending public funding on a service which, put simply, is just not fit for purpose and doesn't respond to what you need = Commissioning!



### Who commissions health services in England?

Approximately two-thirds of the NHS commissioning budget (£73.6 billion in 2017/18) (NHS England, 2017) is allocated to local CCGs. CCGs are groups of local GP practices whose governing bodies include GPs, others clinicians such as nurses and secondary care consultants, patient representatives, general managers and – in some cases – practice managers and local authority (council) representatives (NHS Commissioning Group, 2012).

CCGs have a statutory responsibility for commissioning most NHS services including urgent and emergency care, acute care, mental health and community services. Increasingly they are also involved in commissioning primary care and some specialised services.

NHS England is responsible for directly commissioning some more specialised services, including renal dialysis, neonatal services and treatments for rare cancers, and primary care, including GPs, pharmacists and dentists – although increasingly this responsibility is being shared with CCGs. NHS England also commissions health care for people in prisons and secure units and some services for the armed forces. NHS England's total spending on direct commissioning in 2016/17 was £25.4 billion (NHS England, 2018).

### Creating a healthier Hull

NHS Hull CCG brings together 39 local GP practices and a dedicated team of commissioners with a vision to create a healthier Hull now and in the future. The CCG has a responsibility to commission the healthcare services for the 300,000 people who live in our city (with the exception of services commissioned by NHS England as detailed above).

NHS Hull CCG works closely with Hull City Council to support more integrated health and social care. An example of this in Hull is the Better Care Fund (NHS England, no date), a national programme which sees CCGs and local authorities working together by pooling their budgets.

The approach taken to commissioning services for people with profound and multiple learning disabilities is essentially no different to the commissioning of other services. In Hull we would consult with clinicians, patients and the public around the launch of new services or change to current services to ensure that they continue to meet people's needs. The PMLD focus group for Hull is led by two family carers and works with Hull CCG, Hull City Council and the local mental health trust to enhance the health care we commission for this group of people. In addition, over the last year, families and health professionals have worked very closely with Hull CCG to launch a new care pathway and clinical guidelines for children and young people with Down's Syndrome.

Whilst all CCGs are expected to commission healthcare service to meet the needs of their local population in addition there are specific services NHS E will direct commissioners to ensure are in place. For example, in mental health care the Five Year Forward View for Mental Health was published in 2016 has a number of Priority Actions for the NHS by 2020-21 which include a taking a much more integrated approach to mental and physical healthcare. CCGs frequently have to make decisions and balance the requirements set out by NHS England with the needs of the local population all within a clearly defined budget – CCGs are not allowed to use more money than they have allocated to them each year!

### The valuable contribution of carers

It is true to say that healthcare commissioning is complex – and the description in this article by no means covers the day to day role of healthcare commissioners - in this time of austerity it is often difficult to balance the varying competing demands and, like other public services, many CCGs across England experience financial pressure. The NHS is 70 years old in 2018 and this is definitely a time for celebration – however the NHS simply cannot do its job without the goodwill and support of the public and carers. It is estimated that there are five and a half million carers in England. Those carers are not just adults but also children who provide care for their own parents and siblings. In the years to come many of us will be expected to take on caring responsibility at some point in our lives and yet we don't always appreciate the contribution family carers make or the impact they have on their loved ones' health and wellbeing. Carers can offer a unique perspective on health services and they have a wealth of experience and knowledge about the person they care for.

So when we ask what is commissioning – it is all that is described in this article and more..... Commissioners like the team at NHS Hull CCG couldn't do their jobs without the input of patients, clinicians, families, carers to provide expert advice and a unique insight into population health need. That is co-production. It is how we should all be working – doing with and not for, or to, people – not just sometimes, but all the time.

### Contact Details

Jill Burton Commissioning Manager and Melanie Bradbury Strategic Lead

Mental Health and Vulnerable People Commissioning. Hull CCG

[www.hullccg.nhs.uk](http://www.hullccg.nhs.uk)  
@NHSHullCCG

### References

NHS Commissioning Group (2012) *Clinical commissioning group governing body members: Role outlines, attributes and skills* (Available online at: <https://www.england.nhs.uk/wp-content/uploads/2016/09/ccg-members-roles.pdf>)

NHS England (2017) *NHS England Funding and Resource 2017-19: supporting 'Next Steps for the NHS Five Year Forward View'* (available online at: <https://www.england.nhs.uk/wp-content/uploads/2017/03/nhse-funding-resource-supporting-fyv.pdf>)

NHS England (2018) *Financial performance reports*. (available online at: <https://www.england.nhs.uk/publication/financial-performance-reports>)  
NHS England (No date) *Better Care Funding* (available online at: <https://www.england.nhs.uk/ourwork/part-rel/transformation-fund/bcf-plan>)

## New Subscription Rates from 1<sup>st</sup> April 2019

Due to the ever-increasing costs of producing, printing and mailing the journal, the Trustees of PMLD Link have decided that we must increase the cost of subscriptions by a few pounds from 1<sup>st</sup> April 2019 just to cover the actual costs of producing, printing and mailing the journal. We have no staffing costs since all the editorial team are volunteers who provide their services for no fee.

We have decided that there should be a survey of existing subscribers to get your views about the new subscription rates and other arrangements.

We have determined that we should retain a difference in rate between organisations and individuals because organisations such as schools and services and universities have the ability to share access to the member's pages of the PMLD LINK website with students, staff and others.

Each type of subscription needs to be increased by a minimum of 3 to 4 pounds for PMLD Link's income to be sufficient to meet the current costs. We will make the change from 1st April 2019.

We will continue to provide subscribers with both an online copy (downloadable from website) and a hard copy of each issue. However, we would like to ask how many of you would be interested in receiving an e-copy only (either sent directly) or downloadable from website. Also, what would be regarded as a reasonable cost per annum for this type of subscription.

We are putting together a consultation document that we will e-mail to all listed subscribers soon. We hope to include final notification of change in the Spring 2019 issue.

As regards overseas subscribers, we will write to you seeking your views too. The cost of overseas subscriptions will have to reflect the different international zones' postal rates.

If you have any comments on this proposal please contact Rob Ashdown, PMLD Link Treasurer (email: [rob.ashdown@ntlworld.com](mailto:rob.ashdown@ntlworld.com)).



## Recognising anxiety in my child with profound and multiple learning difficulties and how we deal with it

Emma Murphy

Emma is mother to an eight year old boy called Hugh. She explains how she learned to recognise symptoms of anxiety in Hugh and common triggers. She describes the carefully planned strategies she has evolved to reduce his anxiety when he is away from home and when introducing him to new places and experiences.

**A**t eight years old, my son Hugh is a happy and sociable little boy. His smiles are from the heart and they simply light up a room. He uses a wheelchair as he is unable to sit or stand independently and he communicates through his facial expressions and body language. He has a severe cortical visual impairment and although registered blind, his vision is improving all the time. He has progressed from not being able to differentiate between light and dark at birth, to tracking and following and being able to recognise familiar toys and objects and reaching out for them. We get occasional, fleeting eye contact now too and he seems to be trying to focus more on faces.

When the extent of Hugh's profound learning disabilities became apparent, anxiety wasn't one of the things I worried about. I was more concerned with fire-fighting the vast array of complex medical conditions that came with his rare diagnosis of FOXG1 syndrome and keeping him out of hospital as much as possible. His mental health needs didn't even appear on my radar.

Hugh had always been fairly content to go to new places. He accessed respite at our local hospice and settled in for nights away without any concerns. We'd happily take him everywhere we went and he would sleep in his chair when tired or contentedly sit and smile. A friend commented how her son with complex needs struggled in different environments and that she could visibly see



him relax the moment he arrived home. I realised that Hugh didn't appear to have an awareness of 'home'. He didn't appear to recognise that home was different from anywhere else, or if he did, he didn't prefer it.

Over time, however, his awareness increased. After we extended our house and changed the entrance as a result, the two bumps backwards up the front step and straight into his bedroom were replaced by a smooth ramp into a large hallway. That first day home from school Hugh was inconsolable. It didn't feel like home to him. Every day, for a week, I had to wheel him straight to his bedroom and lie him on his bed to reassure him he was actually home.

This new level of awareness was fantastic and I delighted in the fact that he was aware of the difference. Yet this awareness came with something I wasn't expecting – anxiety.

Holidays started to become stressful experiences. He would cry and scream until he made himself sick. The first two or three days of any holiday were spent wondering if it was worth going away at all. Hugh appeared to hate it; we struggled to keep him happy. It was our desire to ensure our older son had a break away that kept us persevering. Even visits to my mum's house or our friend's house's became stressful as Hugh would become overwhelmed and upset.

For a long time, I put Hugh's crying down to pain from reflux. Invariably he would scream until he started to retch and vomit. I reasoned the pain from the reflux was causing the upset and I'd remove him from the situation to either clean him up or take him home. I'm still not sure whether the vomiting is a symptom of the anxiety (I know when I feel anxious I feel sick) or whether it's actually a clever communication tool to ensure he is removed from the situation that is upsetting him; one I'd been unwittingly rewarding and reinforcing for some time.

By far the biggest cause of anxiety for Hugh is being away from home, in an unfamiliar place, with unfamiliar people- something he started doing at the age of two when he began having respite at the hospice. Initially he was happy to stay, but as his awareness of the world around him increased this began to pose a problem. The first time he had a huge seizure there and ended up in hospital, I wasn't overly concerned. His seizures aren't well controlled, it was bound to happen sooner or later. It happened the next time he stayed too. Again, I dismissed it. The third time I put it down to an unfortunate coincidence. We asked staff about his behaviour in the day, but he'd been absolutely fine. By the fifth time, alarm bells were ringing. There must be something about being at the hospice that was causing



his seizures. After staying in the room with him, to observe what happened, we discovered he was becoming increasingly anxious the longer he was there. I could quite visibly see the anxiety building and as it did so I could see a big seizure coming, to the extent that I had his rescue medication ready. Thankfully, I managed to calm him down and we left. He hasn't stayed since. Hugh communicated with us, very clearly, in perhaps the only way he could, that he didn't want to stay there. If I'm honest, I feel incredibly guilty that I took so long to listen and understand.

If Hugh had a choice, I think he'd choose to stay at home, in his bedroom preferably, most of the time. But that's not good for him, or us. Over time, we've learnt different strategies that help manage Hugh's anxiety. Recognising it as anxiety in the first instance and knowing what his triggers are have been key in enabling us to deal with it effectively.

Since we know that new places cause anxiety, we try to be better prepared. When we go on holiday, for example, we bring a lot from home that is familiar to Hugh – his PPod (beanbag), his disco lights and his favourite music. We follow the same night time routines, with the same songs and allow him to sleep in his PPod. This helps to reassure Hugh and he adjusts much more quickly to being away from home.



Another thing that helps is ear defenders. In some circumstances, noise doesn't bother Hugh, but in new situations and environments we find that ear defenders help to keep him calm by, I assume, reducing the noise.

Hugh has reasonable head control but will often drop his head to chest. Many appointments with wheelchair services failed to find a suitable solution to keep his head up. I realised that this is actually his own choice – in new environments or times he feels overwhelmed Hugh will drop his head on purpose. It's a clever strategy he's taught himself, I think to reduce the visual stimulation. When he does this, we no longer force him to lift his head up (by tilting his chair) no matter how uncomfortable it looks. Sunglasses also appear to help in some situations.

When Hugh is crying and visibly upset then getting him out of his chair, talking and cuddling him would seem like an obvious solution, however this simply serves to make Hugh even more stressed. I think the additional sensory information just heightens his anxiety. Instead, holding and squeezing his hands is much more reassuring for him. Hugh finds being outside less stressful than being inside so if he does become overwhelmed then taking him outside can also help him to calm down.

Hugh thrives on familiarity, consistency and routine but with careful planning and support we can enable him to

appreciate and enjoy new places and experiences too. Being aware of and recognising his mental health needs allows us interpret his responses, to really listen to and understand what he is telling us and ensures that he lives a happy, fun-filled, life.

## Contact Details

Emma Murphy  
emma.murphy@live.co.uk  
www.littlemamamurphy.co.uk

## Connect with us on social media



@PMLDlink on twitter

Facebook pages:  
PMLD Link

Raising the bar - COP for the PMLD care standards

Join in with the #pmldchat conversation focused on making a positive difference to the lives of people with PMLD.

See you online

# NEWS and SBAR – making these tools work for people with profound and multiple learning disabilities

Sally Wilson

Family carers often report it is difficult to get healthcare professionals to understand their concerns about the health of their offspring. In this article Sally Wilson explains how having a shared understanding of tools used in the health service may improve communication between carers and health care professionals. This could potentially improve the health outcomes for people with profound and multiple learning disabilities.

“A nation’s greatness is measured by how it treats its weakest members” Mahatma Ghandi once said, and this quote has stayed with me throughout my career. Of particular interest to me is the learning-disabled community and how we are meeting their health needs. As a learning disability nurse who has worked in acute care for the last ten years I know only too well that if we can get it right for people with learning disabilities we can get it right for everyone.

Since December 2017 the updated version of the National Early Warning Scores (NEWS) has been formally accepted by NHS England (NHSE) and NHS Improvement (NHSI) as the early warning tool for identifying acutely ill patients in hospitals in England (Royal College of Physicians, 2017). NEWS was developed by the Royal College of Physicians to improve detection of and response to patients whose health was deteriorating. The NEWS is a simple scoring system which looks at clinically measured physiological responses and allocates them a score. These measurements are routinely recorded in clinical practice and can also be measured both in clinical and homecare settings, with minimal equipment.

There are six measurements which form the NEWS score;

1. Respiration rate (how many times a person breathes per minute)
2. Oxygen saturation levels (measured as a percentage of the oxygen saturated haemoglobin in the blood)
3. Systolic blood pressure (the systolic is the top number of a blood pressure reading representing the highest pressure when your heart beats and pushes blood around the body)
4. Pulse rate (the rhythmic throb of arteries as the blood is pushed through them)
5. Level of consciousness or new confusion – this may be subjective. It is now acknowledged that a sudden onset confusion can be indicative of physical deterioration. The Glasgow Coma Scale score for ‘orientation’ may measure confusion using

‘AVPU’ (which refers to being Alert, responding to Verbal stimulus, responding to Pain or being Unresponsive.) (GCS, no date)

6. Temperature (measured in either degrees Centigrade or Fahrenheit)

If each recorded measurement is within the identified normal parameters, the score will be low, and this will result in overall low NEWS. The score increases as the measurements vary from the normal parameters. This means the higher the score, the sicker the patient is (West of England Academic Health Science Network, 2016).

Saving lives or reducing premature mortality is a key priority for everyone working with people with learning disabilities, and wider than that, the Learning Disabilities Mortality Review (LeDeR) is now being discussed in acute services across England as services are being held to account for their actions and inactions when managing acute care for people with learning disabilities.

The NEWS scoring tool is now being used in over 70% of acute hospital trusts in England, and through this standardisation there is a real chance to improve the clinical response to physical deterioration as well as potentially saving lives. NEWS has a value in any environment where observations are taken and recorded. It is used as a communication device to provide a simple summary of a patient’s condition which in turn can prompt healthcare staff to initiate an intervention, escalate care or make specialist referral.

When healthcare staff escalate concerns about deteriorating patients using NEWS there is an agreed standard clinical response. A high score requires a senior review or emergency input from a registrar, consultant or critical care outreach team. A lower score may be managed by a senior nurse or junior doctor.

**National Early Warning Score (NEWS)\***

PHYSIOLOGICAL PARAMETERS	3	2	1	0	1	2	3
Respiration Rate	≤8		9 - 11	12 - 20		21 - 24	≥25
Oxygen Saturations	≤91	92 - 93	94 - 95	≥96			
Any Supplemental Oxygen		Yes		No			
Temperature	≤35.0		35.1 - 36.0	36.1 - 38.0	38.1 - 39.0	≥39.1	
Systolic BP	≤90	91 - 100	101 - 110	111 - 219			≥220
Heart Rate	≤40		41 - 50	51 - 90	91 - 110	111 - 130	≥131
Level of Consciousness				A			V, P, or U

**What is SBAR?**

In clinical environments, NEWS is often used alongside the Situation, Background, Assessment, Recommendation (SBAR) tool to transfer the clinical information between professionals and/or clinical care areas. SBAR stands for:

- **Situation** – Patient/client/person details, identify the reason for this communication and describe your main concern
- **Background** – How long have you been concerned? What other significant clinical history is there for this person? Include medications, investigations, treatments, allergies.
- **Assessment** – What is your assessment of the current situation with the person? Include clinical impressions, NEWS, vital signs and concerns
- **Recommendation** – Be specific, explain what you need for the person. Make recommendations and clarify who is doing what and when it will be done.

**Clinical Challenges and Reasonable Adjustments**

People with learning disabilities have a higher prevalence of physical health problems than the rest of society, and frequently experience health inequalities and disparities in accessing healthcare services (NHS Health Scotland, 2017). This has been well documented in several key reports such as Treat Me Right (Mencap, 2004) and Death by Indifference (Mencap, 2007). A progress report, Death by Indifference: 74 deaths and counting, (Mencap, 2012) highlighted inadequacies in basic care provision, communication and assessment of pain as some of the ongoing factors contributing to

avoidable deaths for people with learning disabilities. The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD 2013) provide more evidence of these issues.

People with learning disabilities account for approximately 2% of emergency department (ED) attendances, and often encounter inequalities when accessing healthcare facilities (Ali et al, 2013). There are many reasons why these health inequalities continue to exist, but for this article I'd like to consider issues relating to communication and the way in which health professionals respond to carers. The provision of reasonable adjustments is a legislative requirement under the Equality Act 2010, but the practical application of reasonable adjustments is yet to be embedded in many mainstream healthcare settings.

People with learning disabilities may struggle to articulate their symptoms. People with profound and multiple learning disabilities rely heavily on their carers to explain their symptoms to health professionals. I once worked with a lady who used the word 'itchy' to describe pain. Without her mother's interpretation of that health professionals could have taken a very different diagnostic pathway. I have also had many referrals for what health professionals have identified as an acute need, when careful assessment and questions reveal that the condition has been a long term one that has been managed by the person's GP.

Health professionals have reported various difficulties with their communication with carers. There is a common misconception amongst medical staff that all adults with learning disabilities live in nurse led

accommodation. When carers inform the medical staff they are not medically trained there can be an immediate barrier. This can be further exacerbated by carers' use of language when describing symptoms and health care professionals not acknowledging the role carers play in daily management of the health of the person they care for. I remember running health assessments for people with learning disabilities where paid carers often described the person as 'being a bit off colour' or 'not their usual self.' As a practitioner I want facts and details like 'for the last two days he's had a temperature of 38 degrees and paracetamol hasn't reduced it'.

Health professionals seem to struggle to modify their communication style and continue to use complex medical terms which go misunderstood. In my experience health professionals are often quite anxious about assessing learning disabled patients, as they do not routinely see this patient group. So, people with learning disabilities may not understand the healthcare professionals, the healthcare professionals may not understand what they told by or about people with learning disabilities and this can lead to catastrophic results.

Carers have reported that they do not feel listened to by medical staff, and while they may lack medical training, they are experts by experience and as such have a right to be listened to. Carers know the patients better than medical staff ever will and are often much more in tune with the small changes in behaviour which indicate physical distress or deterioration. But are they able to articulate this in a way to which the medical staff can respond?

**Some solutions**

Speaking the same language is crucial to getting the right diagnosis and pathway for all vulnerable patients, especially people with profound and multiple learning disabilities. I suggest that carers are trained and enabled to use NEWS. Testing and scoring NEWS requires only a small amount of equipment, much of which could be purchased from a chemist and the recording forms can be downloaded from the internet. Checking oxygen saturation levels or systolic blood pressure can be taught very quickly in a classroom or clinical environment, and once a baseline is established for the person, carers will easily see if there is a clinical change. I would recommend that NEWS is scored and recorded weekly when there are no physical or clinical concerns about the person. This would establish a robust baseline and in addition would provide some de-sensitisation so should the person become unwell, a blood pressure monitor or thermometer would not be a threatening piece of equipment.

I feel the SBAR process would also be useful. As a nurse, it is a tool I use almost instinctively when I need to escalate a patient or a complex situation for more support. It provides a structure which could be really supportive for carers when they are managing someone who is deteriorating. A sudden change in physical health can be a very stressful time and having a structured way of telling people about the deterioration can be very useful so important details don't get missed (e.g. We Communities, 2018). The use of NEWS and SBAR by carers when communicating about deteriorating health could be invaluable. There is a need to train and support both family carers and paid carers, to work with these tools with confidence. The resulting understanding and shared language between carers and healthcare professionals may just reduce some of the avoidable premature deaths for people with learning disabilities.

**Conclusion**

I believe that if carers spoke a shared language using NEWS and SBAR to communicate to healthcare providers, healthcare staff will understand their concerns more quickly and be able to assess and initiate treatment appropriately. It is important to recognise though, that NEWS alone is simple tool and does not provide a comprehensive description of a person. Using NEWS to communicate clinical deterioration may be effective in securing timely assessment and treatment, but people with learning disabilities will still need to have a hospital passport and a full care plan to share with healthcare staff so that all their needs can be met.



Training in the support and clinical management of people with learning disabilities should also be mandatory for all healthcare staff who have contact with patients. This includes the importance of carer handover of early warning signs of deterioration.

## Contact details

Sally Wilson has worked as a learning disability nurse for over twenty years and is currently working in an acute hospital as Matron for Vulnerable Patients and Safeguarding Lead.

Sally is a founder member of Team @WeLDNurses, which runs a fortnightly twitter chat for LD professionals (see <http://www.wecomunities.org/tweet-chats/chat-archive.>)

e-mail: [sally.wilson27@nhs.net](mailto:sally.wilson27@nhs.net)

## SUBSCRIPTIONS

Subscription rates for 12 months are currently: UK Individual £20.00; UK Organisation £30.00; Non UK Individual £27.00; Non-UK Organisation £40.00.

Subscriptions are for 12 months from the point of subscribing. You will receive 3 issues of the PMLD LINK journal. During this period you will have access to the members' page of the PMLD LINK website ([www.pmlmlink.org.uk](http://www.pmlmlink.org.uk)) which allows you to access downloadable versions of back issues from the last three years. Subscribers only can access these. Other older issues are in the public domain of the website.

In order to access the members' page on the PMLD LINK website, you need a Username which is your e-mail address and a Password. You will be sent a link to your personal website account and you can create/reset the password.

We have a limited number of copies of back issues remaining which are available at £5 per copy so may be able to provide you with copies of issues that you may have missed.

If you have any queries about subscriptions or accessing the website, please do not hesitate to contact Rob Ashdown, PMLD Link Treasurer (email: [rob.ashdown@ntlworld.com](mailto:rob.ashdown@ntlworld.com)).

## References

Ali, A., Scior, K., Ratti, V., Strydom, A., King, M., and Hassiotis, A. (2013) Discrimination and other barriers to accessing health care: perspectives of patients with mild and moderate intellectual disability and their carers. *PLoS ONE* 8(8): e70855. (available online at: <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0070855>)

CiPOLD (2013) *Confidential Inquiry into premature deaths of people with learning disabilities: Final report* (available online at: <http://www.bris.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf>)

GCS (no date) *The Glasgow Structured Approach to Assessment of the Glasgow Coma Scale* (available online at: <https://www.glasgowcomascale.org>)

NHS Health Scotland, (2017) *People with Learning Disabilities in Scotland: 2017 Health Needs Assessment Update Report* (available online at: <http://www.healthscotland.scot/media/1690/people-with-learning-disabilities-in-scotland.pdf>)

Mencap (2004) *Treat Me Right* (available online at: [https://www.mencap.org.uk/sites/default/files/2016-08/treat\\_me\\_right.pdf](https://www.mencap.org.uk/sites/default/files/2016-08/treat_me_right.pdf))

Mencap (2007) *Death by Indifference* (available online at: <https://www.mencap.org.uk/sites/default/files/2016-06/DBIreport.pdf>)

Mencap (2012) *Death by indifference: 74 deaths and counting - A progress report 5 years on* (available online at: <https://www.mencap.org.uk/sites/default/files/2016-08/Death%20by%20Indifference%20-%2074%20deaths%20and%20counting.pdf>)

Royal College of Physicians (2017) *National Early Warning Score (NEWS) 2* (available online at: <https://www.rcplondon.ac.uk/projects/outputs/national-early-warning-score-news-2>)

We Communities (2018) *Sepsis and people with learning disabilities* <http://www.wecomunities.org/tweet-chats/chat-details/4167>

West of England Academic Health Science Network (2016) *Implementing the National Early Warning Score (NEWS)* (available online at: [https://www.weahsn.net/wp-content/uploads/NEWS\\_toolkit\\_njd\\_19Apr2016.pdf](https://www.weahsn.net/wp-content/uploads/NEWS_toolkit_njd_19Apr2016.pdf))



## Timmy's story

Alison Pettit

Alison shares a personal and powerful story of her son Timmy and the battles his family faced with health services during his life. This heartrending account underlines the need for all professionals to listen carefully and sensitively to what parents are saying about their child and maintaining good records that enable them to understand needs and document changes for better or worse in health and wellbeing of individuals.

**W**hen I had a beautiful two-and-a-half-year-old placed with me for adoption I couldn't believe my luck. I had wanted this for so long. Timmy allowed me to become a mum. His profound disabilities were no barrier to love. Ensuring his health and happiness became my world from day one. I watched him grow and develop, in both positive and challenging ways. He learned to sit, crawl and pull up to stand. He became the child who never stayed still, which was both wonderful and a nightmare at the same time. As he got older, keeping him safe when out of his wheelchair became an exhilarating challenge, especially when away from home. In the early years he learnt to communicate with a small range of symbol cards, which remained with him until the very end of his life. He also began his lifelong battle with intractable epilepsy after having his first (recorded) seizure 3 months after placement with me.

The arrival of a sister, and subsequently a second mum during his childhood simply enhanced his and my happiness, and whilst the road was often exhausting and challenging, we were a happy family with a boy who loved to be read to, was passionate about Rosie and Jim and the Teletubbies, and spent very many hours on the swing, having long walks in his wheelchair and drives in the car. His happiness was ours, and as parents, our lives revolved around the children.

We were no stranger to hospital stays with either child, and the bumps in the road of surgeries, emergencies and medication changes. We had learned to avoid time on the children's ward at all costs with Timmy because he needed a special 'Safespace' style bed to keep him safe and the hospital refused to provide one. Nights spent on the hospital floor could be amusing if a little dangerous

when he was small (he once appeared in the next cubicle in the middle of the night on his hands and knees) but became unbearably hard to manage as he got older. However, due to time spent on the Ketogenic Diet, his seizures had been minimal for several years and Timmy's health had been settled.

## **Problem number one: Being believed – “He’s got PMLD, what do you expect?”**

Nothing could have prepared us for how life changed when Timmy's epilepsy, accompanied by severe agitation, re-emerged towards the end of his fifteenth year. We sought medical help – it was obvious that something was very wrong with our boy. His quality of life diminished virtually overnight. We were met with scepticism after some basic tests revealed nothing. During months of taking him backwards and forwards to hospital begging for help. In desperation we lugged a portable Safespace bed onto the ward and got him admitted for observation. The paediatric neurologist advised us to send him away if we couldn't cope with his screaming, and recommended the anti-psychotic drug, risperidone.

## **Problem number two: Stuck in limbo – healthcare in transition**

That was the end of our relationship with local paediatric services. So where to turn? We were unable to be referred to either of the large children's hospitals because by now Timmy was heading towards seventeen years old. At an adult gastro outpatient appointment the doctor told us he usually only saw “normal” people. We did not believe adult clinics would provide the specialist support needed to investigate Timmy's problems thoroughly. Good fortune via a Ketogenic Diet contact allowed us to access a paediatric neurologist at a children's hospital seventy miles away. Here Timmy was welcomed and treated with no discrimination despite his age, disabilities and being out of area. The strain of the journeys on the family was far outweighed by the joy of hope. A paediatric nurse from our local area said to us “How many hospitals are you going to drag him to before you accept there is nothing wrong with him?”

After fifteen months of admissions and appointments this wonderful hospital discovered what was wrong with Timmy. The boy whose sudden change in behaviour had been previously disregarded as ‘behavioural’, ‘puberty’, ‘the parents, and ‘what do you expect - he's profoundly disabled’, was diagnosed with a very rare and incredibly painful gut disorder known as superior mesenteric artery syndrome (SMAS). His duodenum was severely distended, the extent of its swelling reflected the period of time where we had clearly seen significant changes in him. His daily screams had been of agony, with the increased seizures secondary to this. Our boy underwent

major surgery that week, and slowly began to recover. His smile was back, the pain was very obviously gone. By then he had turned 18 and made what seemed to be a positive transition into adult respite, whilst enjoying family life once more.

Our hearts broke slowly and painfully when his symptoms began to return, and within a few short months Timmy had become too ill to attend school at all. He was now classed as an adult and was fully funded by Continuing Health Care (CHC.)

## **Problem number three - CHC did not find out what Timmy wanted**

We now had our beautiful boy at home full time, often too poorly to sit up in his chair. The clash between his pre-existing disability (never staying still, constantly moving, semi-mobile with no sense of danger) and his new feeding regime (using a pump feed through a jejunostomy (jej) tube to assist with his deteriorating digestive system) meant that he needed constant untangling, amongst other things. He had no understanding that he needed to stay within the range of his feeding tube, and not spin round to avoid it becoming wrapped round his neck. We were exhausted and unable to cope. We had to dismantle his beloved “soft play” style bedroom and hire a large wooden cot to restrict how far he could crawl away from his feed pump. We squinted at a small video baby monitor screen constantly to make sure he wasn't getting strangled or disconnected, flooding the bed with sticky feed. Our carers were not trained to give meds and so we were not allowed to leave him with them. Allocated hours were inadequate, and our CHC lead professional did not wish to put support into the home. She decided, without reference to Timmy's wishes, or ours, that his needs would be better met in full time nursing care. Why would it be in his best interests to move him out of his family home at the poorest point of his life? No answer was given. This caused the greatest strain on the family imaginable. After some months of agonising, unable to fight this any longer, he moved into the nursing home on the same site as his adult respite. Our hearts broke in two.

## **Problem number four – No one believed he was ill as they didn't know him before he became unwell**

We had been told by the children's hospital, at the time when he left for the last time, that Timmy had one to two years to live. It was all too obvious that he was unable to benefit from their final attempt to combat his illness with jej feeding. He was a pale shadow of the boy who previously never stopped bouncing, who lived every minute of life to the full. Our beloved son was exhausted, in terrible pain, thin, and joyless. Heartbroken



and worried we spent long hours making a photographic scrapbook detailing all his current needs outlining how to recognise his pain levels, how to judge what he could cope with in terms of activities, what he liked, and what he used to be like too. We wanted the staff at the nursing home to understand just how ill he was, and that what they saw now was not the boy he had always been.

Our information largely fell on deaf ears. His illness had by now gone on for nearly four years. None of the professionals now involved had known him prior to his illness, and it was repeatedly assumed that what they saw now was the sum total of Timmy. With the exception of his wonderful keyworker, we repeatedly met the same problem. What were signs of pain, exhaustion or agitation were just seen as part of his disability. He was stimulated when he couldn't cope with it, taken out his most comfortable place, his bed, and put into his wheelchair despite being able to use symbols to express his wish to stay in bed, and denied access to pain medications because staff believed that they knew more about the meaning of his non-verbal cues than we did. His pain and other symptoms went unrecognised again and again, until we found that when his keyworker was not on duty we had to be there to ensure he was kept as comfortable as possible.

Many of the staff (who came and went from employment at the home with unbelievable frequency) did not believe he was dying. This was the cruellest situation for us all. We were robbed of an End of Life plan for Timmy, and despite obvious deterioration and increased symptoms, these were left uncontrolled. The lead professional during his final months was a GP who had only just met him. There was nothing in writing from the children's hospital to say that he was dying. We were accused of over exaggerating his symptoms and wanting unnecessary pain relief for him. Treatment plans changed as professionals came and went. His illness was rare and not understood. We had gained a significant amount of knowledge about it but our understanding of SMAS went unheard. Dieticians who had never met Timmy wanted to increase his feed, which we knew would have a disastrous effect on what was left of his wellbeing.

Timmy was finally referred to an adult palliative doctor, despite still being under the children's hospice that he attended on and off since he was five years old. The children's hospice offered him a stay for symptom control but a week later withdrew their offer, saying he would have to attend the adult hospice. He could not attend the adult hospice as they didn't have a Safespace. The children's hospice had several. He went without symptom control.

We felt that the only way to stop them was to go to the Court of Protection. Instead of being at Timmy's side, we found ourselves at the high court, with solicitor and

barrister, trying to prevent further harm being done to our dying son. An 'expert witness' gastroenterologist was brought in, who had met Timmy for fifteen minutes the week before. He appeared to have minimal knowledge of SMAS and told the court that we had been misled, Timmy simply needed to be fed. The final and cruellest blow of all was that it appeared that all our efforts over four and a half years to help Timmy meant nothing. The expert instructed the dietician to ignore any symptoms. The court inevitably ordered an aggressive refeeding programme.

Timmy suffered terribly in the last seven weeks of his life. We saw him deteriorate whilst many of the professionals involved in his care watched on, believing that he was now on the mend. We were robbed of our chance to just be with our dying child. We forced ourselves to video his increasing pain, anticipating a return to court might be necessary. We buckled to pressure to get him up in his chair, having also been reported for "keeping him in bed", and our hearts bled as his distress could last so long after just ten minutes in his chair. Even in the last week of his life, by now tolerating an oxygen mask after several collapses, the palliative doctor told us his quality of life was worth maintaining, and it was only three days before the end that doctors agreed that he was indeed dying. At last we could hold his hand and tell him that the big swing in heaven would fly so wonderfully high, and he could laugh again soon. Timmy's transition held no continuity of care. His wishes were ignored as were ours. His family and close friends upheld his health and wellbeing despite the professionals in his life before and during the long four and a half years of his illness, until he died, aged twenty in 2017. Better practice must come.

### Contact details

Alison Pettitt  
e-mail: [alison.pettitt@ymail.com](mailto:alison.pettitt@ymail.com)

# Working in partnership to create a more effective service in Hull

Michaela Marr and Suzanne Nicholls

There are many areas in the country where there are staff who work as Acute Liaison Nurses in hospital setting and nurses who work with primary care teams with a specific focus on Learning Disabilities. However, in Hull the two people in these roles, Michaela Marr and Suzanne Nicholls, have formed a partnership in order to work more creatively and effectively. They work for different trusts yet that has not deterred them from working together to create this partnership. Both Michaela and Suzanne are required to work in an innovative manner in order to reduce the health inequalities that people with a learning disability experience, to prevent premature deaths and ensure that reasonable adjustments are in place to improve patient journeys and health outcomes.

**D**eveloping and delivering learning disability awareness training is a significant part of the liaison nurse role. By working together Michaela and Suzanne can share resources, cover a wider group of staff and develop a more effective and consistent message across both primary care and hospital settings. They both support primary and acute hospital staff to feel more confident in looking after their patients, and helping the voice of the patient/family/carers be heard – an essential role for people with PMLD who so often do not get heard because they do not use language to communicate their needs.

One of Suzanne's main responsibilities is to support GP practices with annual health checks for patients aged 14 years and over who are known to have a learning disability. Yearly health checks allow the practice to build up a relationship with patients and carers and gather baseline screenings, earlier identification of health issues, and providing opportunities for health promotion advice/support. For people with PMLD it is essential in identifying health issues at an early stage. Screening discussions should form part of the annual health check process, and include what reasonable adjustments are available/required and what is in the patient's best interest.

Michaela's main focus is improving patient and family/carer experience through the acute hospital journey – this covers both out-patient appointments and stays in hospital. In collaboration with the patient and/or family carers, she highlights reasonable adjustments required, and works with acute staff to support implementation of these. For people with PMLD reasonable adjustments may cover their methods of communication, how the person indicates pain as well as issues around postural care and diet whilst in hospital.

Suzanne and Michaela see the patient journey as a continuum throughout primary, community and acute care settings, and to improve the patient experience and health outcomes, services need to work together. Through collaborative working and supporting each other in their respective roles they are able to provide support, education and advice to patients, families/carers, and other health and social care professionals to promote greater understanding of the needs of people with learning disabilities, the barriers they face in accessing health care, the reasonable adjustments required to overcome these barriers. This has been integral in ensuring that a much wider and consistent approach is used across primary and acute care, resulting in identification of unmet health needs and better health outcomes.

Key projects they have worked on include:-

- The development and promotion of a Health Check Booklet which is a co-produced easy read document to support people with a learning disability when accessing their annual health check. It complements the Patient Passport in identifying baseline health/physiological measurements, reasonable adjustments and support needs, to assist primary and acute staff in understanding the person's needs better and promoting more timely diagnosis and treatment options.
- Improved access/uptake of breast screening through production of accessible video and training.
- Creating and implementing flagging systems across primary and acute services – to identify individuals with a known learning disability and highlight their communication needs, and promoting the use of Enhanced Summary Care Records.
- Promoting and implementing quiet/accessible waiting areas within outpatient and GP reception areas.

- In collaboration with Community Learning Disability Nurses and a Lead Pharmacist, developed a bowel management programme which will include training in bowel massage, review of medications/ medication optimisation, awareness raising, timely identification of bowel issues, and more effective monitoring/treatment.
- Working together to maximise Learning Disability awareness training across both primary and acute services, addressing in particular communication differences and diagnostic overshadowing, highlighting everyone's joint responsibility to work in partnership.

Many of these initiatives are in line with the recommendations of the second annual LeDeR report and the government's response to that report.

On Friday 9th February 2018, they worked in partnership with organisations across Hull and East Riding to host an event aimed at people who have a learning disability and/or autism, carers, friends, family and staff. The event titled 'Differently Abled' showcased over 85 services from birth to end of life, providing information, raising awareness and encouraging networking.

People had the opportunity to speak directly with professionals from a number of different service areas, including dentistry, epilepsy, speech and language therapy, physiotherapy, sexual health, benefits and welfare advice, SEND (Special Educational Needs and disability) services, transition, and other LD and Autism services, primary and acute services.

Staff attending the event were encouraged to network with all services, resulting in partnerships forming across organisations, training needs identified and better signposting for patients and carers.

On the day over 1,000 people attended, almost half being differently abled. Feedback from the day included 'lots of people and services dealing with similar topics were in the same place at the same time, making it better and easier to see the bigger picture.'

People with PMLD/or their family carers are often excluded from events as organisers fail to make the necessary adjustments. Suzanne and Michaela worked with carers, parents, families, and people with PMLD to ensure the event was accessible to all, and it was encouraging to see how many family/carers felt able to support individuals with PMLD to attend.

Following on from the success of Differently Abled there is great demand to make this an annual event. Plans are well-developed for the next event in February 2019 and arrangements are in place to maximise the attendance of people with PMLD and their families/ carers through

installation of a changing places facility, and rooms for sensory stimulation, quiet areas, and areas/equipment to support individual dietary needs.

### Contact Details

Michaela Marr  
Learning Disabilities Acute Liaison Nurse  
Humber Teaching NHS Foundation Trust

Suzanne Nicholls, Learning Disabilities Primary Care  
Liaison Nurse, City Health Care Partnership CIC

If anyone would like further information about Differently Abled please contact the Wellbeing Service on (01482) 335642 or email [chcp.wellbeingLD@nhs.net](mailto:chcp.wellbeingLD@nhs.net)

## IN THE NEXT ISSUE

Winter Vol. 32 No. 1 Issue 90

### Communication

Do you have any stories to share?

If so, contact the Guest Editors:

Wendy Newby [wennewby@aol.com](mailto:wennewby@aol.com)  
and  
Becky Loney [becky.loney@gmail.com](mailto:becky.loney@gmail.com)

**Copy date**  
**25th February 2019**

More information on page 33

# LeDeR Report 2017

## Deaths of people with profound and multiple learning disabilities

Michael Fullerton

The Learning Disabilities Mortality Review (LeDeR) programme was established to support local areas in England to review the deaths of people with learning disabilities (aged four years and older) and identify learning from those deaths to make continuous improvement to the support and services on offer to people with learning disabilities. More widely, the LeDeR Programme collate and share anonymised information about the deaths of people with learning disabilities so that common themes, learning points and recommendations can be identified and taken forward into policy and practice improvements.

**H**ealth inequalities for people with learning disabilities are well documented and led to this programme, commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England and delivered by the University of Bristol. Work on the programme started in June 2015, for an initial three year period which has now been extended to May 2019.

The LeDeR Programme published an Annual Report 2017, in May 2018. It is that report, its key findings, recommendations and government response I would like to focus on – as it relates to people with profound and multiple learning disabilities (PMLD).

The 2017 Annual Report focuses on deaths notified to LeDeR from July 2016 to 30th November 2017. During this period 1,311 deaths had been notified to the LeDeR Programme – however only 103 reviews had been fully completed. The challenges in delivering greater numbers of completed reviews included the fact that this is a new system with large numbers of deaths being notified, the low proportion of people trained in LeDeR methodology who went on to complete reviews as well as reviewers having time from their other duties to complete a review. Some of the participating NHS and social care organisations were clear that because of other pressures, that time invested in LeDeR couldn't be prioritised.

Of the 1,311 deaths notified to the programme, the severity of the person's learning disability was reported for only 828 people. 25% of notifications were made through Community Learning Disability Teams, perhaps often by individuals who did not know the person well and therefore uncertain as to the degree of learning disability. As the actual degree of learning disability for the other 483 people would only be established during

the course of a review there is potentially a higher number of people with PMLD – however, the report indicates that 11% of those people were people with PMLD.

### Key Findings

**Place of death** – The numbers of people with a learning disability who die in hospital is much greater than for the general population i.e. 64% compared to 47%. The number of people with PMLD dying in hospital was even higher - 71%. There is no explanation of exactly why that is the case.

**Age of death** – The median age of the deaths of people reported was 58 years. The median age of death decreased with increasing severity of a person's learning disability – so the median age of death for people with mild learning disabilities was 63 years, and for those with a PMLD it was 41 years. In the general population (England and Wales 2010), the median age of death was 81.8 years for males and 85.3 for females. While there is no breakdown of the gender differences in median age of people with PMLD, those people tend to die at about half the age of the general population.

**Cause of death** – These figures need to be read with caution as less than half of the notified deaths stated a cause of death at the time of notification. So therefore, for the others, the exact cause of death would only be confirmed during the review process – and only a small proportion of reviews were complete during this period. It is also the case that some of the causes of death provided when the death was notified could change in light of a post-mortem. However, with the information available the most frequent causes of death, as specified in Part 1 of the Medical certificates of cause of death (MCCD) are:

Most frequent causes of death	No	%
Pneumonia – unspecified	140	24
Aspiration pneumonia	96	17
Sepsis	66	11
Dementia	34	6
Epilepsy	28	5
Down Syndrome	25	4
Cardiac arrest	24	4
Respiratory infection	22	4
Total (where cause of death is reported at notification)	576	n/a

Within this data there is no significant difference between genders, and no detail as to figures specifically for people with PMLD. However, we do know that people with PMLD experience significant difficulties with their respiratory health, in addition to other significant health issues.

Reviewers overall assessment of care received by the person – Overall 44% of reviewers assessed that the care provided was ‘excellent’ (i.e. better than the good quality care that any ‘patient’ should expect to receive). Reviewers also indicated that in 13 (13%) people’s health had been adversely affected by one or more of the following: delays in treatment; gaps in service provision; organisational dysfunction; or neglect or abuse. An example of a failure to provide good support was a person who was discharged home with a catheter and the care staff had not been provided with training on catheter care. The person was readmitted with possible urinary sepsis and subsequently died.

**LeDeR Recommendations**

The LeDeR report made nine key recommendations, a summary of which is on page 20. The government, through the Department of Health & Social Care responded to the recommendations in September of this year (The Government response to the Learning Disabilities Mortality Review (LeDeR) Programme Second Annual Report). I am not able within this article able to outline all of the responses, so would urge you to read through these, via the [www.gov.uk](http://www.gov.uk) website (see references below). For each of the recommendations, the government has indicated actions and timescales for those actions.

It is important that we see progress in relation to all of these recommendations, for the benefit of people with PMLD.

Strengthening collaboration, communication and information sharing is a recommendation that is made

time and time again. It is one that is critical given the complexity of lives of people with PMLD – however it often feels like a holy grail. We need to look at the Government’s response and ask if what they are recommending is different to recommendations that have been made in the past. The government makes reference to Health Action Plans, the Annual Health Checks, the Named Social Worker Model and the NHS Digital projects – all important to improve the lives of people with PMLD. However will they make a difference to the way that organisations collaborate, communicate and share information? We also need to ensure that the quality of Health Action Plans and Health Checks is recognised. For people with PMLD, their annual health check would be more effective if it was carried out by a GP who knows the individual, understands the complexity of their health and acts proactively as the individual often cannot communicate verbally of their pain, discomfort, etc.

Recommendations which may move collaboration forward within health are seen in the greater use of digital technology. For people with PMLD this could lead to easier access to their health history across the system. It would be hoped that if the ‘flagging’ system was further developed reasonable adjustments for people with PMLD should be more effective when they go to hospital appointments or are admitted as in-patients. Bearing in mind the higher death rate of people with learning disabilities in hospital greater recognition of support needs and the associated reasonable adjustments is essential, but once again this will come with a cost.

Recommendation Four (in both the report and response) is one that is vital for people who have PMLD. The recommendation states that people with two or more health conditions should have a local, named health care facilitator. This could make considerable difference to the health and wellbeing of people with PMLD and their life expectancy. However, without the additional funding to boost the numbers of learning disability nurses employed

	Recommendation	Responsible Agency
1.	Strengthen collaboration and information sharing, and effective communication, between different care providers/agencies	Commissioners
2.	Push forward the electronic integration of health and social care records to ensure agencies communicate effectively, and share relevant information in a timely way	NHS England
3.	Health Action Plans, developed as part of the learning disabilities Annual Health Check should be shared with relevant health and social care agencies involved in supporting the person (with consent/following Best Interest Decision Making)	NHS England/ Commissioners/ Providers
4.	Everyone with a learning disability with two or more long term conditions (related to physical or mental health) should have a local, named health care coordinator	Commissioners
5.	Providers should clearly identify people requiring reasonable adjustments, record the adjustments that are required and regularly audit their provision	Providers
6.	Mandatory learning disability awareness training should be provided to all staff, delivered in conjunction with people with learning disabilities and their families	Commissioners/ Providers
7.	There should be a national focus on pneumonia and sepsis in people with learning disabilities, to raise awareness about their prevention, identification and early treatment	NHS England
8.	Local services strengthen their governance in relation to adherence to the Mental Capacity Act, and provide training and audit of compliance 'on the ground' so that professionals fully appreciate the requirements of the Act in relation to their own role	Commissioners/ Providers
9.	A strategic approach is required nationally for the training of those conducting mortality reviews or investigations, with a core module about the principles of undertaking reviews or investigations, and additional tailored modules for the different mortality review or investigation methodologies	NHS England

one does need to question how this will happen on the ground. Having someone who sees the person with PMLD as a whole person, across all the specialist health areas that may impact on their lives could make a crucial difference to the health and the length of life of people with PMLD. This is even more essential for adults who do not have family or a person to follow up on health appointments and treatments.

Crucially (in relation to Recommendation Six – Mandatory Training) the Department of Health & Social Care, in conjunction with partners, will complete a consultation on proposals for mandatory learning disability awareness training by March 2019. Obviously being aware of the needs of someone with a mild learning disability is quite different to awareness of someone with PMLD. It is therefore critical that advocates of people with PMLD become involved in this consultation.

Pneumonia and sepsis are significant health risks for people with profound and multiple learning disabilities. There are recommendations and actions to seek to improve preventative actions, identification and early treatment – all of which is important, so the actions are welcome steps to assist in improving the life chances for people.

In terms of monitoring the actions the Department of Health & Social Care and NHS England will establish a LeDeR oversight group, which will include people with lived experience and family representatives. I am not clear how or when this group will be set up but it would be of benefit to ensure there is representation related to people with PMLD.

As it stands the contract for the LeDeR programme has been extended to May 2019. It would be comforting to know that this focus would continue indefinitely to constantly improve the life chances for people with significant health issues. It would equally be useful, with annual reports to refine the quality of information so that we can understand more acutely what is making a difference in increasing the median age of death for people with PMLD.

#### Contact details

Michael Fullerton  
Director of Quality and Clinical Care with CMG, a social care provider.  
e-mail: [michaelfullerton@cmg.co.uk](mailto:michaelfullerton@cmg.co.uk)

#### References

Department of Health & Social Care (2018) *The Government Response to the Learning Disabilities Mortality Review (LeDeR) Programme Second Annual Report* (available online at: <https://www.gov.uk/government/publications/government-response-to-the-learning-disabilities-mortality-review-leder-programme-2nd-annual-report>)

The Learning Disabilities Mortality Review (LeDeR) Programme (May 2018) *Annual Report 2016-17* (available online at: <http://www.bristol.ac.uk/sps/leder/news/2018/leder-annual-report-2016-2017.html>)



# Sensory Engagement for Mental Well Being

Joanna Grace

People with PMLD and their carers are at high risk of experiencing mental ill-health. In this article, Joanna reflects upon the support their mental health needs of people with PMLD, rather than physical health needs, and various simple sensory strategies that can be used to support mental wellbeing. She urges carers to look after your own mental wellbeing too.

**T**oday, as I write this article, it is World Mental Health Awareness Day and social media is awash with uplifting posts. Things are changing, and changing for the better but, as too often is the case, people with PMLD are being left behind with many not even being eligible for mental health support. Not because they do not need the help - indeed research indicates that your risk of experiencing mental ill health increases the more disabled you are, putting people with PMLD among those in greatest need – but because help is not allocated according to vulnerability but according to who is able to access the services.

## Awareness

**I**n our work to raise awareness of the new Core and Essential Service Standards for Supporting People with PMLD we need to ensure we are raising awareness of the needs that are not being met. Awareness is key. We need service providers to be aware of the mental health needs of the people we support. We need the care teams around those people to be aware of their mental health. And we need to be aware of their mental health. Often when physical health care needs are so high people adopt a mindset where everything is interpreted through the physical. A medical model approach to supporting people tends towards a presumed underlying physical condition for any distress witnessed and so professionals supporting people with PMLD will often look for physical causes before considering mental or emotional ones. For family carers often the journey of caring for someone with PMLD pre-disposes them to considering physical health first and foremost. It is easy to see why.

Recently I have been offering my support to a family whose complexly disabled 18 month old child is about to come home from hospital. That child's parents have had to learn how to be medical professionals in order to bring their child home. The shock of their child's birth, and the trauma of all the medical interventions undergone between then and now are overwhelming. As they bring that child home they will be focusing on physical health. And I expect to see, as the years go by, they – as I have seen with many other families – gradually get the hang of the rollercoaster they are on. I know families of children who are 8, 9, 10 years old. They are just beginning to get

more adventurous, for example, they know how to pack medical supplies to enable them to go on a weekend away. These small but bold adventures, that to the family of a typically developing child would be normal, are only just being realized nearly a decade after birth.

Physical health fills our minds because it is so very important and without it we die. But mental health is mightily important too, because without it we do not feel our lives to be worth living. Simply recognizing mental health can be a big turning point. Emma Murphy, has written an insightful article in this issue of PMLD Link about her experiences with recognizing and managing anxieties in her son Hugh.

## Sensory strategies to support mental well being

**O**n my Sensory Engagement for Mental Wellbeing day my delegates and I explore simple sensory strategies that can be used to support mental wellbeing. None of the strategies are magic wands to fix mental health problems, they are all little things that can be done daily to support good mental health. They are the sensory mental health equivalent of physical health strategies like eating an apple instead of a packet of crisps or taking the stairs instead of the lift. Not impressive in themselves but repeated overtime far more likely to be effective than a big one off event like an aerobics class!

## Greetings – in settings.

**I** once heard a wise woman say that there is nothing that informs a person more about what they mean to you than how you respond when they enter the room. If when they enter the room you slump in an “Oh goodness they're here”, they sense that, they know that, and it doesn't matter how well you slap on a smile and say “Good to see you” they know that to you they are bad news. That first moment of greeting a person tells them what they are worth to you.

Sadly in many settings when a person with PMLD arrives in the morning they are not greeted at all. This is not out of malice, or a lack of care. Often it is because of how



much people care! You see when that person with PMLD arrives it is likely that they arrive pushed by another person, a person who carries a lot of important information about how they slept last night, and whether they had any seizures, and what medication is in their bag and so on. The person in the room who is about to take on the responsibility of caring for that individual has only a few seconds to get as much of that information as they can out of the person behind the wheelchair. It is common for me to see people arriving in a room to no greeting at all as this important conversation goes on above their heads. Imagine how you would feel if you entered a room and experienced this response.

That first moment is an opportunity to really meet a person with PMLD, to go over to them, to use their name, to touch them if appropriate, and to show them with all the joy on your face, in your voice, in your touch, in your nearness, just how delighted you are that they are there today. And when you do that, not only do you inform them of just how precious they are to you, you send a message to those around you about who has top priority.

If you work in a setting remember that a person with PMLD does not enter your room once in a day. It is likely that you have multiple opportunities to inform them of their worth through the warmth of your greeting: when they return from the toilet, when they return from a trip to the sensory room, when you return from your break. All of these tiny opportunities add up over the course of a day and are worth taking advantage of.

### **Greetings – out and about.**

**A** person's name is one of the easiest sounds for their brains to process. Saying a person's name creates a connection. And connection between ourselves and others is good for our mental wellbeing. Creating connections within a wider community by enabling the use of a person's name is a lovely way to extend that opportunity to have wellbeing reinforced and also to start up conversations and to feel more connected ourselves.

A simple way to support this type of greeting and connection is to find a way to display a person's name on their wheelchair or clothing. Of course if you support someone who is ambulant then strangers knowing their name could pose a danger, this strategy is for people who are unable to move independently. I actually did it with my own son when he was small, I stitched a small sign that said "Hello I am \_\_\_\_\_" with his name on and velcroed it to the front of his buggy. What this meant was that when I was waiting in a queue at the post office or standing in line at the chemist and the person ahead of me in the queue turned around to look at my son they

would bend down and instead of saying "Hello there how are you?" they would use his name. He heard his name from me, from his Daddy, from his family and from his community. Hearing your name in this way helps you to feel more a part of things, more included. And often the invitation of the "Hello" gives people who might have wanted to say Hi but were unsure whether they should or not the confidence to come forwards. By reaching out like this we can all make new friends and that is good for everyone's wellbeing.

### **And finally**

Whoever you are if you support people with PMLD, you likely put their needs above your own. I have lost count of the number of times I have heard loving people call themselves selfish for wanting some 'me time.' Looking after your own mental wellbeing, in whatever way you do that, is not 'me time' it is as important for the person you care about as it is for you. They need you to be well, both physically and mentally, it is not selfish to look after yourself. Take the time you need to be well yourself, both physically and mentally – and if I can't persuade you to do it for yourself, do it for them, they need you to.

### **Contact Details**

Jo Grace  
Founder of the Sensory Projects

For more information about Sensory Engagement for Mental Well Being please visit:  
[www.thesensoryprojects.co.uk/sensory-engagement-for-mental-well-being](http://www.thesensoryprojects.co.uk/sensory-engagement-for-mental-well-being)

# Dysphagia in people with profound and multiple learning disabilities

Hannah Crawford

This paper describes some key findings from research done in partnership with families of people with profound and multiple learning disabilities (PMLD) and eating and drinking difficulties (dysphagia). Families and health professionals often have different points of view regarding eating and drinking, giving rise to conflict. Policy documents and guidance recommend person centred care and caring for carers, but clinical experience suggests that very little is known about the lived experience of food and mealtimes from the perspectives of people with PMLD and equally important, their family and carers. The author worked with three mothers and their adult children with PMLD (see note on names at end) and undertook in depth, semi- structured conversations.

## Mother and child relationships

All three mothers in the study described a deep communication between their adult child and themselves. The individual with PMLD communicated their wishes about eating and drinking to their mothers through non-verbal means. This communication was intimate and idiosyncratic. Their child communicated their wishes and intentions to their mothers, who in turn represented this to others.

*“and we go past fish and chip shop, if he smells the fish and chips he’ll sign”*

*“I give her a little bit of wine on her tongue and ... then sometimes she’ll look as if to say well I’ll have a little bit more of that”*

All three mothers talked about how important food was in terms of their relationships with their children. For two of the mothers it was a time of reciprocity and mutual joy.

*“I loved to feed her. I loved to see her eat her food... my time was the feeding”*

For one mother it was a difficult time, and negatively impacted on her relationship with her daughter.

*“I can remember thinking, saying, for God’s sake Grace will you just eat! You know because you get so frustrated and you don’t want to get angry but it just builds up and you’ve two hours of trying to get especially when its medication as well and you know that she’s got to have that medication.”*

All three mothers were the main carers for their adult children. While there is limited literature relating to the role of the mother with adult children with disabilities, this finding resonates with the literature that describes that in the western world mothers are still more likely to be the primary caregivers of children. This figure is even higher when the children have disabilities (Traustadottir, 1991; Read, 2000; Landsmann, 2005; Green, 2007).

As part of being the main carer, the mothers talked about other roles that they play. They often felt they had to act as ‘professionals’ when supporting their adult children, attending meetings and liaising with health professionals. They reported that they often would dress differently and prepare for meetings, making sure they had all the information they needed to be respected by the others at the meeting.

*“I didn’t just go as Jack’s Mam cos I didn’t feel I could”*

## Relationships as support

The mothers described a range of relationships that supported both themselves and their child. Margaret and Samantha described their partners as being supportive but leaving them to make important decisions, especially those associated with food, mealtimes and support for their children’s dysphagia. Their partners performed a physically and psychologically supportive role to the mothers, with regards to food and mealtimes.

*“he’s only been like on the periphery with like most men, work, so – you yes I support you whichever way you decide to go cos you’re the one that knows everything that’s gone on”*

*"You need somebody to bounce things off don't you and sometimes you need somebody to sit you down and say no you know it's not working because sometimes you can get very tunnelled you tunnel vision as to what you think's best"*

While all the mothers talked about social events during the interviews, they were often focussed around family, rather than wider social networks. Margaret and Charlotte both reported that friends seemed to fade away after their child was born, and Margaret in particular felt let down by her friends at the time. The falling away of friends and the social isolation is also described by Read (2000) in her study of the mothers of young disabled adults.

Charlotte's support from friends came from church as she and Jack are involved in a vibrant and dynamic church. In addition, her new husband was also a source of friendship and support to Charlotte. Samantha was involved in a more traditional local catholic church, which encompasses many members of Samantha's family, and the local community. This provided Samantha with some outside interests and friends within the church.

### Professionals

In addition, most of the individuals with PMLD accessed a range of different support and intervention from different hospitals, health professionals and social care providers. In most cases the mothers felt to manage these packages of care, they had to act as care co-ordinators. It was clear from the study that the mothers all had extensive knowledge of their children's physical health and they all had complex medical knowledge that allowed them to support their children.

All three mothers talked at length about their experiences of relationships with professionals. They described particularly definitive events and were clearly able to extrapolate what they felt were positive and negative traits in professionals from these. These positive and negative traits are directly echoed in the literature by Read (2000), Hewetson and Singh (2009), Rouse et al (2002), Sleight (2005) and Craig et al (2003).

In terms of negative traits, the mothers were particularly dismissive of professionals who did not appear to value their child as an individual, but also who did not recognise the importance of the family unit. They experienced frustration when professionals did not listen to the expert knowledge they have about their children. They were also frustrated if professionals were not knowledgeable themselves. While they reported the need to be in control, once their child became ill and needed treatment they describe how important it was that the professionals were knowledgeable with answers

and treatment recommendations. The mothers reported anger and frustration when professionals don't value the life of their child and see treatment as futile.

In contrast the mothers valued professionals who understand the needs of their child, but who also display their ability to be family centred. They discussed the need for information and recommendations to be appropriately timed and paced. They valued professionals who are confident and knowledgeable in the management of their child. The mothers have a wealth of information about their own children, but they expect professionals to be expert in their given field, and to support them in their decision making. The positive interactions that resonate were where professionals are judged to have gone out of their way to help or have made an extra effort. The mothers all described professionals with whom they had had contact who were 'lovely'. These professionals were spoken about with trust, respect and affection, and the mothers followed their advice.

*"I did have a fantastic relationship with his consultant....and his thing was he provided family centred care, if I wasn't right how could he [Jack] possibly be right"*

The mothers talked about the challenge of being in control or out of control of the care of their child. This is a theme that also appears in the work of Hewetson and Singh (2009) in relation to children with disabilities and dysphagia. All the mothers without exception reported the need to be in control of what happens to their child, from the care they receive in the family home, through to the activities they take part in, and what happens to them when they are in hospital. The mothers all described themselves as 'control freaks'. In situations where they lose control, or are out of control, it is clear to see from the language they use, how difficult and uncomfortable this is for them.

### Quality of life

The concept of quality of life was individual for each of the mothers and their children. Samantha and Charlotte both felt that the maintenance of some level of oral intake was crucial to their child's quality of life. They reported that a range of tastes was extremely important and contributed positively towards quality of life. In addition to enjoying the taste of food, and eating food, it was often an important factor in activities that contribute towards the child's quality of life. Examples of valued activities included Charlotte and Jack's curry night, and Samantha describing the foods Cinders liked to eat while on holiday.

*"But it just used to be lovely, and it was like we spent time together on our own doing something nice cos he loved chicken tikka masala and for all he couldn't manage the rice I got round that I just didn't used to give him the rice...I used to blitz up a bit of the chicken and the curry and give him that but that was something me and him could do together that actually involved food."*

Margaret on the other hand reported the opposite and felt that Grace's health was paramount. Margaret believed that eating and drinking makes Grace unwell and further compromised her extremely vulnerable respiratory status. She felt that if Grace is not healthy she will not be happy and hence have a poorer quality of life. Margaret also described how Grace's valued activities (such as being with her young nephews, her dogs and watching DVDs) are not affected by her inability to eat. None of this is dependent on her being able to eat, so the inability to eat did not detract from her quality of life.

### Some conclusions

Many of the interviews were emotionally laden. Emotions were diverse and extensive and included guilt, devastation, trauma, sadness, distress, joy, love, sacrifice, depression, worry, anxiety, relief, anger, fear, loss, grief, frustration, and happiness, and often made food and mealtimes challenging. Whilst the emotional experience of caring for a child with disabilities is reported in other research, my research identified that the lived experience of PMLD and dysphagia for family carers (particularly mothers) is especially emotionally charged. As a result of this study, I was able to make recommendations for health professionals and policy makers. Of paramount importance is the need to:

- Investigate to what extent individuals with PMLD have autonomy and choice about their food and drink.
- Take time to understand how and what the individual with PMLD communicates with their primary caregiver about food and drink.
- Make all possible attempts to honour these choices within a mutually negotiated set of conditions.
- Determine the role food plays in the relationships between the primary caregiver and the individual with PMLD and offer support accordingly.

It is my experience that practitioners working within dysphagia often feel bound by their perceived medical duty of care to work. This research shows that the lived experience of food and mealtimes for people with PMLD and dysphagia, and their family carers, steps well outside of medical frameworks. The information I gathered while undertaking this study demonstrated the importance of being open, honest, reflective, compassionate, flexible and family centred.

Note - All names were chosen by the mothers: Charlotte mother to Jack, Margaret mother to Grace, and Samantha mother to Cinders.

### Contact Details

Hannah Crawford  
Consultant Speech & Language Therapist and  
Patient Safety Expert Advisor  
People with Learning Disabilities – NHS  
Improvement  
e-mail: hannahcrawford@nhs.net

### References

- Craig, G.M., Scambler, G. and Spitz, L. (2003) Why parents of children with neurodevelopmental disabilities requiring gastrostomy feeding need more support, *Developmental Medicine & Child Neurology*, 45, pp 183-188
- Green, S.E. (2007) "We're tired, not sad": Benefits and burdens of mothering a child with a disability, *Social Science & Medicine*, 64, pp150-163
- Hewetson, R. and Singh, S. (2009) The lived experience of mothers of children with chronic feeding and/or swallowing difficulties, *Dysphagia*, 24: 322-332
- Landsmann, G. (2005) Mothers and models of disability, *Journal of Medical Humanities*, Vol 26, No 2/3 Fall 2005, pp 121-139
- Read, J (2000) *Disability, the Family and Society: Listening to Mothers*, Buckingham, UK, Open University Press
- Rouse, L., Herrington, P., Assey, J., Baker, R. and Golden, S. (2002) Feeding problems, gastrostomy and families: a qualitative pilot study. *British Journal of Learning Disabilities*, 30, 122-128
- Sleigh, G (2005) Mothers' voice: a qualitative study on feeding children with cerebral palsy. *Child: Care, Health and Development*, 31, 4, 373-383
- Traustadottir, R (1991) Mothers Who Care: Gender, Disability and Family Life, *Journal of Family Issues*, Jun 1, 1991, 12, 2, 211-228



## Co-authoring Sensory Stories

Lynsey Robinson

To celebrate National Multi-Sensory Storytelling Day 2018, Sensory Projects and the Sensory Trust headed out together for another adventure, to co-author a sensory story with young people with PMLD. Following the success of previous collaborations they were thrilled when they were invited to run a workshop day at the National Star College in Cheltenham, as part of Sensory Trust's Sensory Nature Adventures and Play Project.

National Star College is a further education college for 17 to 24-year-olds, working to enable people with disabilities to realise their potential through personalised learning, transition and destination services. Their amazing theatre was our base for the day. Our plan was to co-author a sensory story with three groups of student authors. Many of the students had already been taking part in a week of activities around sensory stories. They had listened to them, felt them, smelt them, and touched them. Now it was their turn to help author one of their very own. These students are therefore referred to as 'authors' throughout this article.

As in previous workshops Joanna and I had set up the room ready for the authors. We'd selected a range of sensory experiences relating to nature, incorporating the main seven senses. The experiences were there to be enjoyed at a pace set by the author. They could work around them and return to them, spending as much or as little time with each one as they wished. Some

experiences were very individual, some were done as small groups, some flowed from one to another and then back again. Volunteers from the staff of National Star acted as observers for the sessions. As the authors explored, the observers moved through the space noting the actions of the authors and the responses to the stimuli; sometimes from afar, sometimes through direct interaction. Joanna and I were also observing and interacting. Every author had something to say to help us build up the picture of the story.

We ran three sessions throughout which 39 authors visited the space. Each session had a unique atmosphere and there was a feeling in the room which developed and changed during the sessions. Responses noted included movements, unexpected words, questions, noises, looks and gestures, and genuine expressions of emotions that all contributed to the story.



After the sessions Joanna and I retreated along with the other observers and shared our findings. Working collaboratively to bring the story together was a new experience for us as previously it has just been Joanna and I. Having the other observers with us we were able to incorporate more viewpoints and experiences as we pulled together the story. This was important whilst working with such a large group – when there are fewer authors you can spend more time observing each one, but in larger groups the more eyes you have on the experiences the better. The more experiences that are collected, the richer the story can become.

The story began to form from the emotions, journeys and experiences we had collected. The mood in the room helped to build the tone of the story. We had some clear moments that we knew had to feature, some relating to the sensory experiences we had put out and others that had evolved on the day. This reminded us of the need to always be open and allow that creative expression to come from wherever it needs to in the moment. As we mapped the moments we had recorded, those moments began to assemble into a story all by themselves. And it was not the story we had expected back at the beginning of the day.

Some of the highlighted experiences demonstrated a connection that went beyond words, an interpersonal moment in time. Within the workshops there is something very special about connecting with someone you have not previously met, looking deep into their eyes and communicating an emotion, a sentiment or an experience. One such moment on the day ended up inspiring the last line of the story and the title – ‘You, Me

and the Stars’. One of the sensory experiences was a shelter with black fabric attached to it and star fairy lights covering the underneath. Many of the authors connected with this space and took their time moving through, sitting or lying underneath the stars and gazing up at them, sometimes reaching out but sometimes just taking it all in. It was one such moment when an author gently took my arm and encouraged me to join them in the space, we sat and then reclined to look up at the stars. We turned to each other with our faces close, looking into each other’s eyes. The author then pointed straight at me, then to herself and then up to the stars above our heads – indicating ‘just you, me and the stars’. We both looked up at the stars, lost in the moment, and looked back at each other knowing that we had shared something personal and beautiful.

The story writing, led by Joanna, happened organically although quickly. As we discussed our findings we found the story became a romance: A tale of two people meeting, flirting, dancing and being under the stars. It was great to be able to pull together the story by combining words supplied by several of the authors with the atmosphere and general experiences that had come to light in the sessions. After some frantic writing and editing we had a story that was rich with experience, with contributions from each of the groups. We were nearly ready to share it back with the authors and their friends to see how it would be received. After restructuring the fabric and the star light, tidying the theatre and finishing a brief discussion about choreography we could open the doors and let in the audience.

For the final telling of the story we had around 75 people in the room. Typically, stories are shared in small groups or one-to-one. This number of people was going to be a challenge! However, the telling of the story felt very special. We took our time with every line of the story and worked our way through the audience to ensure everyone was clear about each sensory experience. The other observers helped which enabled us to cover more ground as we went through the audience. The story was rich and powerful. It had movement, taste, dancing, touch, starlight, a moon, and to finish a huge explosion of stars! There were some wonderful moments of recognition by the authors who responded to their contributions. The story exceeded our expectations and the responses to it were heart-warming. The feeling in the room after the sharing was one of excitement and wonder. It felt genuinely special.

Some people might find it unbelievable that young people with PMLD could co-author a story and think it is a process that is done 'on behalf of' young people with PMLD. However, the method we have come up with is a genuine collaboration. It may not be the typical way of story writing (thinking of characters, plot, build in a journey, an element of jeopardy and so on) but it remains a valuable approach. You still end up with something that shares emotion; something that takes you through a narrative experience, giving you the opportunity to connect and engage with a real story.

It is worth saying that this is not an easy process; it is one that requires a lot of effort. The experiences offered need to be carefully constructed and the observation needs effort and focus. Those putting together the story need to be reserved in their interpretation of the events, to make sure they are genuinely representing the authors and not adding their own feelings into the mix. Running the sensory story workshops is an absolute pleasure. Every time we learn more about the process and what is achievable. We are incredibly proud of the authors. Our hope is that this can be replicated in other settings by as many authors as possible. We have proved that all of us can be creative – all we need is the right opportunity.

*"It was fantastic to see the students so engaged, there was recognition when the story was shared back with everyone, we are so proud of creating our own story, hopefully the first of many!"*

(Quote from teacher at National Star College)

#### Contact details

Lynsey Robinson  
www.sensorytrust.org.uk,  
@sensorytrust on Twitter  
@sensory\_trust on Instagram

## Get Involved!

All contributions to our journal PMLD Link are welcomed. Share your ideas about future topics for the journal or make suggestions of authors we might approach. If you want to write for us yourself, it's easier to get your experiences and thoughts into print than you might think. We also welcome shorter items about new resources, books, websites, events, courses or news in general.

PMLD Link readers include family members, carers and professionals working across child and adult services for people with PMLD. To see typical contributions, look at some recent back issues. You can download a free copy of PMLD Link from [www.pmlmlink.org.uk](http://www.pmlmlink.org.uk) or sign up as a 'Guest' to view back issues of our journal.

Our Editors are keen to support new writers. We will provide support at every stage - from the germ of an idea through to the finished piece in print. Articles are usually between 1-4 pages of A4 (about 350-1500 words). They can be very practical in nature or have a more research /academic approach. We are very flexible in our requirements! To see our Guidelines for Writers visit the 'Get Involved' pages on our website [www.pmlmlink.org.uk](http://www.pmlmlink.org.uk).

**For more information contact Rob Ashdown ([rob.ashdown@ntlworld.com](mailto:rob.ashdown@ntlworld.com)).**

# You, me and the stars

A Sensory Story written by the students of National Star College

## Introduction

This is a romantic story of two people catching each other's eye during the harvest, stealing away to dance together, before ending their day lying gazing up at the stars at the beginning of a love that will last forever.

### You will need -

- A recording of birdsong
- Packets of seeds
- Cut grass (optional)
- Honey
- Red cellophane or thin material you can see through
- Bamboo fronds with leaves
- Recording of the song 'Barfeootin' by Robert Parker
- Recording of 'Star of the Lid - The daughters of quiet minds'
- Fairy lights, star lights, or a projection of stars
- Cut out stars to shower over people

Get your props ready in sequential order before you begin the story. Have them all within reach and any audio queued up ready to play.

Have fun with the story and take your time to make sure everyone participating gets to fully engage with each line of the text and sensory experience.

This story was developed during a workshop with The Sensory Projects and Sensory Trust





## **You, me and the stars**

A Sensory Story written by the students of National Star College

**It's early, time to stretch my limbs and head out to the fields to sow the seeds.**

Hear Birdsong. Stretch limbs.

**Work is dirty, and hard: Pass more seeds and turn the soil:  
pass more seeds and turn the soil**

Pass the seeds around in a rhythmic way, as you pass the seeds chant in a tired way the refrain of "pass more seeds and turn the soil"

**At last a chance to relax tired limbs on the grass.**

Rub your limbs to relax them and enjoy the feel of the grass against your skin and its fragrance all around you.

**The sweetness of my tea revives my senses...**

Taste (or smell) the honey.

**...and everything is red.**

Look through red cellophane to see the world rose tinted.

\_\_\_\_\_ **(no words for this part)**

Use the bamboo fronds to reach to another person, shimmy them, and rustle them, peak out from behind them.

**"Where shoes?"**

Dance to the song 'barefootin'. At the end of the dancing, breathe in heavy satisfied sighs, akin to the type of deep ssshhh one would use to calm a baby.

**"When the moon comes out do you sleep or do you dance?"**

**"Can you touch the stars?"**

**"Can you see the moon, is it spinning around?"**

Listen to "Stars of the Lid – The Daughters of Quiet Minds"

See the stars twinkling around you (star fairy lights)

Intersperse the sentences for this section of the story periodically over the music allowing a generous pause between each one for reflection.

**"It's just you, me and the stars"**

Point to you, then me, then up to the stars. Shoot star cannons – or shower with golden stars.



# A new task force on people with complex support needs

Angelika Hild and Guillaume Jacquinot

Inclusion Europe is the European association of people with intellectual disabilities and their families. It has 74 members in 38 countries representing an estimated 7 million people with intellectual disabilities, as well as their family members. People with intellectual disabilities and family members are directly represented in governing bodies and activities of Inclusion Europe. Inclusion Europe has created a task force on people with complex support needs and has identified issues to be addressed in the coming years.

The movement for people with intellectual disabilities needs to become more inclusive for people with complex support needs because "they have too often been left behind": This is why Inclusion Europe has created a task force on people with complex support needs. Different developments led to the creation of the new working group:

At a discussion on independent living for people with complex support needs during the Europe in Action conference in 2016, family members deplored the general lack of support they receive. Many voiced the fear that the situation of their relative with complex support needs would greatly deteriorate once they would not be able to care for them anymore.

During a meeting with other European organisations of people with disabilities and service provider associations from Germany, the Netherlands and Spain in 2017, several points were raised that could improve the situation:

- Making sure that service providers are trained to support people with complex support needs. This includes learning how to communicate in non-verbal ways (for example alternative and augmentative types of communication).
- Drawing up a continuous monitoring framework where people with complex support needs and their families are included to ensure that the new services are truly respectful of the individual.
- Retraining professionals who previously worked in institutions on how to provide a different, more person-centered type of support.

As for the field of education, a study on pupils with complex supports needs also identified a number of areas of improvement, such as:

- More investment in inclusive education
- Better promotion of inclusive education to raise awareness of its benefits amongst the general

public

- Support for family members
- Support for teachers to introduce flexible curricula

Based on this, the new Inclusion Europe taskforce met for the first time in September 2018 to discuss how the inclusion movement could become more inclusive for people with complex support needs. The six participants from Austria, Denmark, Luxembourg, Slovenia, Spain and the United Kingdom shared examples of good practices support inclusion, for instance through sports, which does not require any verbal communication skills, or through better involvement of self-advocates with complex support needs. An example that was met with particular interest was a Swedish organisation which is "led and governed" by people with complex support needs.

The task force has set itself the goal to work on a number of issues in the coming years:

- Defining complex support needs in a way that is not purely medical but still makes it possible to establish the number of people with complex support needs
- Sharing knowledge, talk about key concepts around the empowerment of people with complex support needs
- Identifying good and bad practices regarding the inclusion of people with complex support needs, and drawing up recommendations based on these practices
- Discussing about the core messages, values that Inclusion Europe and its members should promote and stand for.
- Putting together a number of demands addressed towards European countries, which distinguish themselves from each other in various ways such as existing support of and available resources for people with complex support needs and their families

Concrete next steps will be the preparation of a workshop on people with complex support needs at the next Europe in Action conference, regular contributions in journals focusing on people with complex support needs, communication on successful stories of inclusion, and the involvement of people with complex support needs at the 2019 Hear our Voices conference. Recently, Inclusion Europe published a study on inclusive education for children with complex support needs. Inclusion Europe recognised the specific situation of people with complex support needs already in 2007 when it contributed to a study on "The Specific Risks of Discrimination Against Persons in Situation of Major Dependence or with Complex Needs" which listed a number of policy recommendations including the introduction of personal budgets/direct payments, an increase in flexible services and more cooperation between agencies such as education, housing, social care, employment and health.

#### Contact Details

Angelika Hild,  
Communications Officer and Guillaume Jacquinot,  
Policy Officer  
Inclusion Europe [www.inclusion-europe.eu](http://www.inclusion-europe.eu)

If you are interested in any of the initiatives mentioned in this article, please email Guillaume who coordinates the task force on people with complex needs [g.jacquinot@inclusion-europe.org](mailto:g.jacquinot@inclusion-europe.org)

## In the Next Issue Communication

Communication is a fundamental human right for all people. It is a responsive and reciprocal two-way exchange that can be verbal or non-verbal, intentional or non-intentional. It provides us with the opportunity to share meaning, express our feelings, preferences, and decisions and develop relationships.

The *Core and Essential Service Standards in Supporting people with profound and multiple learning disabilities* recognise the significance of communication at both organisational and individual levels. The standards specify, "These individuals all have great difficulty communicating, often requiring those who know them well to interpret their responses and intent".

Communication for these people is a complex and multi-faceted system. The standards highlight this emphasising the need for collaboration, the development of warm trusting relationships, and a total communication environment, the use of appropriate equipment including high and low technological tools, therapeutic interventions and staff training to name but a few.

The Spring issue will explore this and share good practice. It will endeavour to ensure meeting the communication standards for people with PMLD remains a focus. It will recognize that communication is everything and that all behaviour is communication.

We would welcome any further contributions and articles that reflect positive practice and innovative ways to support communication.

Please send your contributions for this next issue by the 25th February to the lead editors

Wendy Newby  
[wennewby@aol.com](mailto:wennewby@aol.com)  
and  
Becky Loney  
[becky.loney@gmail.com](mailto:becky.loney@gmail.com)

# A Decade of Articles in PMLD LINK on Health and Well-Being

Rob Ashdown

## Respecting Individuals' Rights and Best Interest Decisions

In 2008 the Parliamentary and Health Service Ombudsman produced an overarching report and detailed investigation reports which identified a catalogue of serious failures which led to the unnecessary deaths of six people and subjected them to appalling pain and suffering. The Ombudsman confirmed that they were discriminated against and that their human rights were violated. Mencap said at the time that it wanted every person working in the NHS, from the nurses onwards to the chief executives of strategic health authorities, to treat this issue as a priority. Yet a decade later Mencap still believes that 1,200 people with a learning disability die avoidably every year and has a campaign, 'Treat me well', which calls on NHS staff to make reasonable adjustments for people with a learning disability which can help to save lives (<https://www.mencap.org.uk/get-involved/campaign-mencap/current-campaigns/treat-me-well>). The Mencap response to the original report was reproduced in PMLD LINK and is well worth rereading.

**Mencap's response to the Health Ombudsman's investigations into the deaths of six people with a learning disability (62, p.25)**

## Best Interest Decisions

Professionals treating some people with severe learning disabilities who are seriously ill may have to make plans not to prolong life through cardiopulmonary resuscitation. This article addressed concerns that such decisions and planning are made in ways which are not always fully compliant with legislation and clinical guidance. The authors show how, for people who do not have the capacity, shared decisions can be made in partnership with health professionals and family and carers.

**Claud Regnard, Dorothy Matthews and Lynn Gibson 'Do Not Resuscitate Decisions in People with Learning Disabilities: Whose Best Interest?' (76, p.22)**

## Recognising and dealing with pain and distress

There is overwhelming evidence that people with PMLD are at high risk of experiencing pain and developing respiratory problems. These articles treat with specific management plans and signs of distress that may be provided by community and specialist healthcare professionals.

**Lauren Allan 'Assessing pain in children with profound and multiple learning disabilities: a student nurse perspective' (73, p.28)**

**Claude Regnard, Dorothy Matthews and Lynn Gibson 'Can Anyone Hear Me?' (77, p.13)**

**David Standley 'Respiratory Care in People with PMLD and Complex Physical Disability' (85, p.23)**

## Protecting health and body shape through postural care

People with learning disabilities who find it hard to move are most at risk of developing body shape distortions if they too often sit and lie in limited positions. Postural care is about using the right equipment and positioning techniques to help protect and restore body shape.

**Anna Goldsmith 'Protecting body shape through postural care investment in the family' (59, p.15)**

**Mike, Julie, Ruth and Rebecca Ormian 'Postural Care – a Vital Therapy A family's story' (70, p.12)**

**Jenny Whinnett and Anna Waugh 'Craig's experience and the Postural Care Campaign' (70, p.15)**

**Sarah Clayton 'Postural Care: We've a mountain to climb and we've only just got our boots on!' (76, p.18)**

**Tess Ellis 'Person Centred Postural Care' (83, p.17)**

**Janet Robertson, Chris Hatton, Susie Baines and Eric Emerson 'Postural care: What the research does (and doesn't) tell us' (85, p.8)**

**Michelle Morrison, Lynn Frew, Clare Boslem, Kate Jordan and Diane Sloan 'Working together to improve 24 hour postural care within NHS Lanarkshire' (85, p.10)**

You can get more details about postural care from the websites for Mencap (<https://www.mencap.org.uk/advice-and-support/pmld/pmld-postural-care>) or PAMIS (<http://pamis.org.uk/services/postural-care>) or Public Health England (<https://www.gov.uk/government/publications/postural-care-services-making-reasonable-adjustments/postural-care-and-people-with-learning-disabilities>).

## Mental Health

Mental health issues often go unrecognised in people with learning disabilities. These articles consider matters surrounding the identification of mental health problems and ways of proactively promoting emotional wellbeing.

**Maureen Phillip 'Improving the emotional and mental well-being of people with profound and multiple learning disabilities: How far have we come?' (76, p.3)**

**Barry Carpenter 'Mental Health & Emotional Wellbeing in Students with Profound, Multiple and Complex Learning Disabilities' (76, p.6)**

**Andrew Colley 'The Wellbeing of Young People with Profound and Multiple Learning Difficulties in a School Setting' (77, p.9)**

**Clive Smith 'Managing anxiety and developing relaxation skills - a sensory perspective' (85, p.49)**

## Clinical Care Procedures and Technologies

Children and adults with PMLD often have complex medical conditions and special planning and procedures are required to meet their needs. The articles here looked at best practice in clinical procedures and the need for sensitive support for families and carers.

**Michael Brown and Jenny Miller 'Invasive procedures and people with PIMD: PAMIS investigates invasive procedures in Scotland' (64, p.6)**

**Mary Codling 'Mary Codling discusses epilepsy and its management in people with profound and complex disabilities' (64, p.8)**

**Rob Ashdown 'Children with complex health needs in schools and early years settings' (64, p.13)**

**Sian Burton, Anne Laverty and Margery Macleod 'Home enteral tube feeding – a consensus statement' (64, p.26)**

**Jill Davies 'New resources to help children with complex health needs live "An Ordinary Life"' (72, p.12)**

**Jeanne Carlin 'Medical technology – children and adults with profound and multiple learning disabilities and complex needs' (73, p.25)**

**James Hogg, Brenda Garrard and Loretto Lambe 'Delivering Invasive Health Care Procedures to People with Profound Intellectual and Multiple disability: From Research to Policy' (76, p.8)**

## Wheelchair usage

Wheelchairs are very important for people who are physically dependent upon them to get around. Getting the right chair is helpfully explored in these articles.

- Helen Daly 'Getting to the good-life: the wheelchair' (71, p.3)**  
**Liz Platt 'Powered Mobility for Young People with PMLD' (79, p.24)**  
**Helen Daly 'Getting a suitable wheelchair: A step by step guide' (85, p.15)**

## Personal Health Care

These articles provided practical guidance and awareness raising in relation to visual impairments, nutrition and avoiding constipation.

- John Shields 'PAMIS: Healthy Lifestyles Project' (64, p.11)**  
**Selina Masters 'The British Society for Disability and Oral Health' (BSDH) (64, p.17)**  
**Sian Burton and Sue Cox 'Fluid – the forgotten nutrient' (64, p.21)**  
**Sian Burton and Sue Cox 'Menu planning – basic ingredients for success' (64, p.23)**  
**Louisa Whait 'Making reasonable adjustments for people with learning disabilities in the management of constipation' (85, p.29)**

## Planning Integrated Services

Some articles that have given pointers to good practice in inter-agency communication and planning to ensure a holistic approach to meeting the needs of individuals and their families and carers. The first two articles were in an issue with an international theme and talk about developing services in Ireland.

- Roy McConkey and Rosario Baxter 'The development of an Integrated Care Pathway for service to children with complex physical healthcare needs' (65, p.2)**  
**Niamh Rowe 'Traumatic brain injury in Ireland: an inclusive rehabilitative approach within the community' (65, p.7)**  
**Sue Turner 'Improving Health and Lives – the Public Health Observatory for People with Learning Disabilities' (69, p.29)**  
**Helen Campbell, Sarah Ballard and Helen Booth 'Delivering Effective Therapeutic Assessment and Interventions for People with PMLD Using an Integrated Multidisciplinary Approach' (76, p.28)**  
**Debbi Cook 'Southern Derbyshire Service for People with Profound and Multiple Learning Disability' (85, p.34)**

## Learning Disability Nurses and other Nurse Specialists

Some articles have explored the experiences and roles of learning disability nurses and other specialist nurses, making recommendations for planning of professional development opportunities.

- Neil Summers, Kim Scarborough, Jackie Clarke and Eric Broussine 'Community participation in learning disability nurse education' (60, p.2)**  
**Mark Whiting "SALLY!" (76, p.32)**  
**Sadie Clarke and Rebecca Crossley 'Acute Liaison Nurse Role' (85, p.36)**  
**Elaine Thomas and Gwen Moulster 'Using the Health Equalities Framework (HEF) to improve health and well-being: A case study' (85, p.42)**

## **Recognising and Meeting the Needs of Individuals with Complex Health Needs**

People with PMLD require particular consideration of their healthcare in a different way to the general population and this does not have to be stigmatising, but is most necessary for maintaining a good quality of living and in some cases sustaining life. Complex needs have to be met by complex means. If not, the outcomes may be disastrous for the individual.

**Steve Carnaby 'Good health care for people with profound and multiple learning disabilities' (64, p.2)**  
**Michael Ormian and John Gurney 'Good Health! What carers say about hospital care for their learning disabled family members' (69, p.25)**

**Jeanne Carlin 'Medical technology – a parent's perspective' (73, p.23)**

**Janet Cobb 'Healthcare - How Should We Influence the Current Changes?' (76, p.11)**

**Paul Pargeter 'Standing up to Health Inequalities : A provider's response' (85, p.2)**

**Dominic Slowie and Crispin Hebron 'Raising our sights, combating nihilism to improve outcomes for people with profound and multiple learning disabilities (PMLD)' (85, p.5)**

**Marion Mc Ardle 'Separation and Health' (88, p.15)**

**Hannah Young 'Separation and Health: In Response to Marion's Article' (88, p.17)**

## **Primary Health Care and Continuing Health Care Services**

There have been important developments in NHS care services for the general population and these articles look at the steps necessary for ensuring that people with learning disabilities have equality of access to this provision, inevitably, with special arrangements to ensure this.

**Fiona Richards 'The Importance of Good Primary Healthcare for People with Learning Disabilities' (76, p.13)**

**Alison Giraud Sanders 'NHS Continuing Healthcare – What's It All About?' (76, p.15)**

**Rhea Sinha 'Getting it Right at GP Surgeries Matters' (76, p.25)**

**Lisa Donaldson 'Everyone deserves an equal right to sight' (85, p.31)**

## **Personal Health Budgets**

Families of people with PMLD may need support on how to use a personal health budget and advice and guidance regarding the employment of staff. These articles set out what personal health budgets are, how they work and what may be done to support individuals and their families.

**Jill Davies 'Personal Health Budgets' (79, p.17)**

**Glenys Newman 'Personal Health Budgets' (85, p.46)**

## **Physiotherapy and Hydrotherapy**

Surprisingly few articles have appeared in PMLD LINK about physiotherapy and hydrotherapy of late. The editors would welcome contributions about these topics. But see:

**Bev Brown and Di Foxwell 'The therapeutic and educational value of hydrotherapy as an intervention with young adults with PMLD' (60, p.8)**

**Jenny McLaughlin 'Aquatic therapy' (70, p.17)**

**The Physiotherapy Team 'Physiotherapy opportunities for people with profound and multiple learning disabilities in Newham, and the Olympics legacy' (70, p.36)**

## IN THE NEWS

### Exhibition Celebrating 50 years of Supporting People

Innovate Trust is a provider of inclusive services for disabled people in Wales (<https://www.innovate-trust.org.uk>). It has its origins in a student volunteer project called Cardiff Universities Social Services (CUSS), founded in 1968, one of whose leading lights was the late Jim Mansell who was then a student at the university. (Jim went on to be a leading campaigner and researcher and author of many papers, books and reports including the 2010 Raising our Sights report on services for adults with learning disabilities.) Over the past year the Trust has been running a heritage project, supported by national lottery funding, which has been documenting the history of supported living for people with learning disabilities and the story of how CUSS founded a home in the local community for five young adults with severe learning disabilities (residents of Ely Mental Handicap Hospital) supported by live-in volunteers, mostly students. Jim Mansell and other CUSS members and various campaign groups were effective in cajoling and persuading people and organisations to allow this development to happen in 1974. At the time it was one of just a few such projects in the UK and its success was a stimulus for later developments in support for individuals with learning disabilities to live in their community.

The heritage project team organised a launch of an exhibition about the history on 27th June at the Senedd, the Welsh assembly building in Cardiff, sponsored by Mark Drakeford AM. Over 100 people attended the event, including some of the original CUSS volunteers and residents of that first home. The exhibition was at the Senedd for two weeks and will feature in Cardiff Story Museum (<https://cardiffmuseum.com>) from 8th December until 3rd March. To find out more get in touch with the heritage project team – Kieran Vass ([Kieran.Vass@innovate-trust.org.uk](mailto:Kieran.Vass@innovate-trust.org.uk)) or Georgia Oliver ([Georgia.Oliver@innovate-trust.org.uk](mailto:Georgia.Oliver@innovate-trust.org.uk)).

### Awareness Week

Hosted by the Mental Health Foundation, Mental Health Awareness Week 2019 will take place from Monday 13 to Sunday 19 May 2019. The theme is due to be announced before the end of 2018. <https://www.mentalhealth.org.uk/campaigns/mental-health-awareness-week>

### BBC Radio 4 podcast - “Transforming Care - Is it Working?”

On October 2nd 2018, BBC Radio 4’s File on 4 ran a 40 minute piece reviewing on progress in reducing the number of people with learning disabilities and autism in unsuitable hospital placements such as Assessment and Treatment Units. After the Winterbourne View scandal the government pledged to reduce the reliance on unsuitable long-term hospital placements and to increase supported community living settings. However, the programme shows that many live in unsafe and unsuitable accommodation, with little hope of moving on, due to failures at national government and local authority levels to ensure that there is the necessary expansion of capability to provide care for people in their own homes or communities. The programme insists that the system is overstretched and at breaking point and as a result some people continue to suffer serious injuries, harm or abuse.

<https://www.bbc.co.uk/sounds/play/m0000mkd>

### NICE Guideline Published

The Mental Capacity Act 2005 applies to everyone over the age of 16 and this NICE guideline focuses on decision making for people who may lack capacity now or in the future. Published in October, this guideline sets out recommendations about: supporting decision-making; advance care planning; assessment of mental capacity; and best interests decision-making. It is intended to help those working directly with young people and adults aged over 16 to support them to make their own decisions where they have the capacity to do so and to keep people who lack capacity at the centre of the decision-making process. Note that the guideline does NOT cover Deprivation of Liberty Safeguards processes. It is available at: <https://www.nice.org.uk/guidance/ng108>

The Council for Disabled Children and partners have developed an interactive training webinar aimed at practitioners who want to learn more about mental capacity and supported decision making which can be accessed for free at: <https://councilfordisabledchildren.org.uk/transition-information-network/news/its-my-life-decisions-capacity-and-ehc-plans-webinar>

The Council has also made available a Decision Making Toolkit at: <https://councilfordisabledchildren.org.uk/help-resources/resources/decision-making-toolkit-0>



## Mental Health NHS long-term plan 2019 – 2029

It has been clearly indicated that services for people with a learning disability and people with autism will be a priority in the forthcoming 10 year NHS plan from 2019 to 2029. As reported by Learning Disability England, events run by NHS England have given people the opportunity to talk about what the priorities should be to improve the lives of people with a learning disability (<http://www.learningdisabilityengland.org.uk/news/update-on-the-nhs-long-term-plan-from-nhs-england>).

To keep up to date on what is happening with the NHS long term plan you can sign up to the NHS England Learning Disability and Autism Forum (<https://www.england.nhs.uk/learning-disabilities/about/get-involved>) for email updates about work at NHS England of interest to people with a learning disability, autism or both and families, carers and supporting organisations. Email [engage@nhs.net](mailto:engage@nhs.net) to sign up.

Perceived priorities for people with learning disabilities and their families, carers and others were indicated by NHS England as:

- Stop preventable deaths
- Awareness training “a must”, ideally led by people and families
- Greater involvement in service planning and decisions
- Services making reasonable adjustments for people’s different needs, person-centred
- Change of culture and attitudes
- Keep on with Transforming Care programme and other important work happening now
- People’s needs considered in all priority areas and mainstream services
- Better health and support in the community and in hospital
- Equality of rights and inclusion
- Joined up working across teams and services
- Advocacy, self-advocacy

## Request to Government for Urgent Action on Sleep-In Crisis

On 1st October, various organisations supporting the delivery of care published an open letter to Caroline

Dinenage, MP and Minister of State for Care, requesting urgent clarity from the government about payments to staff for sleep in support. This is an open letter because of the frustration of successive efforts to engage the government in this long-standing issue. The authors note that adult social care faces a £3.5 billion funding gap by 2025 just to maintain existing levels of care and the pressing need to know what staff are entitled to, and precisely how the government and commissioners will fund this. Thanks are due to Learning Disability England for making this available and for a full discussion go to: <http://www.learningdisabilityengland.org.uk/news/demand-for-urgent-government-action-on-sleep-in-crisis/>

## Single Complaints Statement - Adult Social Care Guide

Councils and care providers are being encouraged by the Local Government and Social Care Ombudsman and Healthwatch England to adopt a new statement which sets out best practice in receiving and dealing with comments, complaints and feedback about their services. It is aimed at supporting a more consistent understanding of handling of complaints

The statement offers a simple bulleted guide for each stage of the complaints process. Launched alongside the complaints statement is a another document created for service users to help them understand and use the complaints process. An accessible 'EasyRead' version is also available.

[https://www.lgo.org.uk/adult-social-care/adult-social-care-resources?utm\\_source=Sign-Up.to&utm\\_medium=email&utm\\_campaign=32163-269055-July%2023rd%20Newsletter-Preview](https://www.lgo.org.uk/adult-social-care/adult-social-care-resources?utm_source=Sign-Up.to&utm_medium=email&utm_campaign=32163-269055-July%2023rd%20Newsletter-Preview)

## The Isle of Brimsker

Frozen Light Theatre have been touring this Autumn with this new multi-sensory story. A lighthouse keeper lives alone on a desolate outcrop surrounded by stormy seas. Change is on the horizon but not in the form she expects. One day a runaway lands on the shore and together they face the inevitable.

Tour dates for the Spring and Summer have now been posted on the website. They will be visiting various places in England, Wales and Scotland. For information go to: <http://frozenlighttheatre.com/isle-brimsker>

# RESOURCES

## Girls and Autism: Educational, Family and Personal Perspectives

Title: Girls and Autism: Educational, Family and Personal Perspectives

Editors: Barry Carpenter, Francesca Happé, Jo Egerton

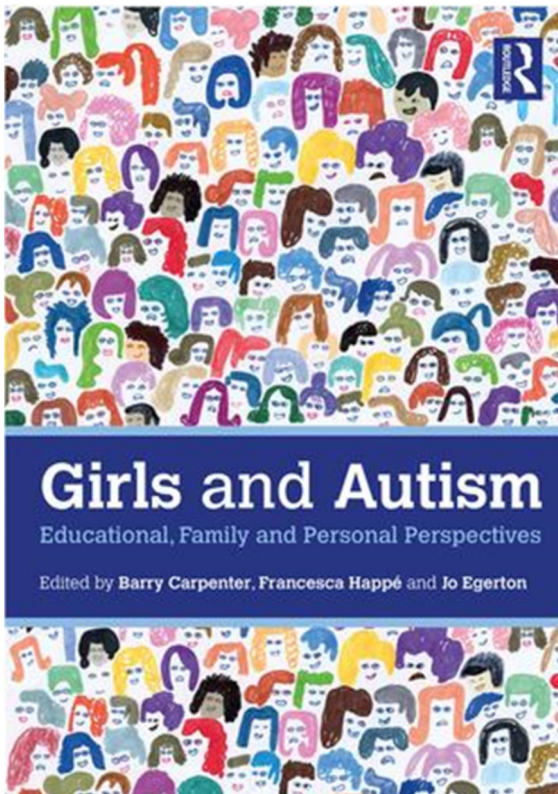
Publisher: Routledge

Pub: 1st edition, forthcoming, February 2019

Pages: 208 pages

Paperback: 9780815377269

Cost: £29.99 (Available for pre-order at £6 saving)



## Very Special Maths: Developing Thinking and Maths

Title: Very Special Maths: Developing Thinking and Maths Skills for Pupils with Severe or Complex Learning Difficulties

Author: Les Staves

Publisher: Routledge

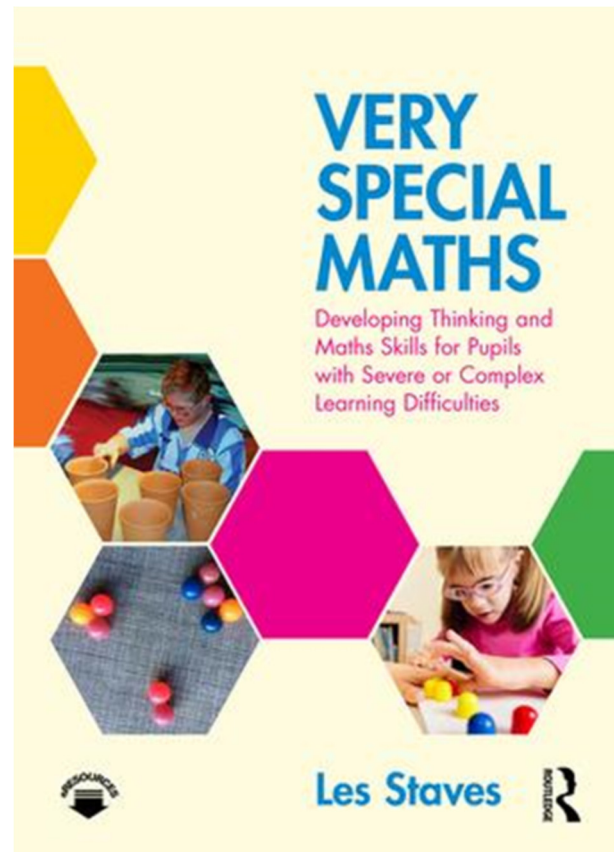
Pub: 1st Edition, August 2018

Pages: 220

Paperback: 9781138195530

Cost: £22.99

Also available to buy or rent as e-book.



## Council for Disabled Children Health Resources Overview

The council published a printable overview of all of its health related resources with weblinks. This covers more recent work, with a particular focus on the Council's health related resources and guidance. This overview contains guidance, recent reports, links to e-training and good practice. Links are given to websites of other organisations where you can find further advice and support. This is a useful document for any professional working with disabled children. It can be downloaded at: <https://councilfordisabledchildren.org.uk/sites/default/files/uploads/CDC%20Health%20Resources.pdf>

## Sensory Stories

Title: Sensory Stories

By: Joanna Grace

Ernest and I (Product code: AWMT14630)

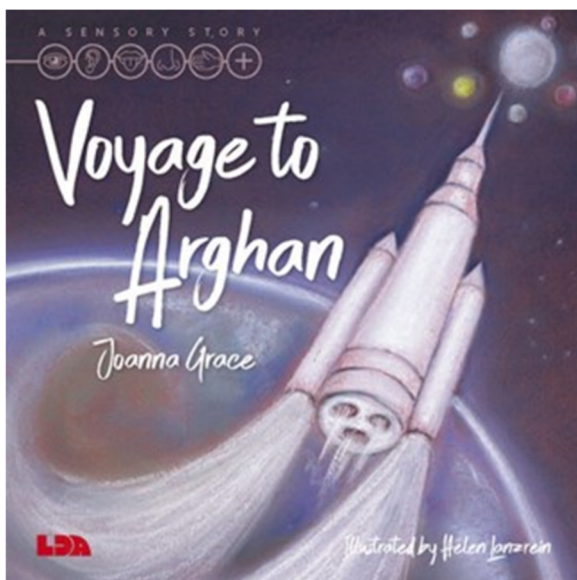
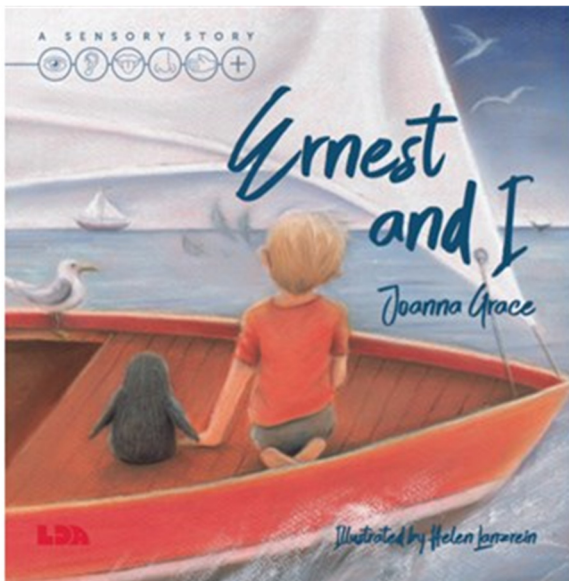
Voyage To Arghan (Product code: AWMT14631)

Publisher: LDA

Paper Backs:

Cost: £12.99

<https://www.ldalearning.com>



## Public Health England/ VODG: Charter and guidance on improving healthcare access for people with learning disabilities

**V**ODG (Voluntary Organisations Disability Group) is a national charity that represents organisations who provide services to disabled people in ways that promote independence, choice and control. For more information go to: <https://www.vodg.org.uk>

VODG, Public Health England and other stakeholders have developed a health charter to support providers to improve the wellbeing of people with learning disabilities with the aim of reducing inequalities in health and social care. All learning disability organisations are being encouraged to take up the health charter and help close the health inequality gap experienced by people with learning disabilities. The associated practice guide sets out key outcomes and contains much useful advice and links to resources to help organisations implement the charter.

Public Health England also offers online and downloadable guidance leaflets on such topics as reasonable adjustments, annual health checks, the Mental Capacity Act, pain assessment, admissions to hospitals, etc. Go to: <https://www.gov.uk/government/publications/improving-healthcare-access-for-people-with-learning-disabilities>.

## Hospital Passports

**H**ospital passports have been developed by a number of trusts, local authorities and third sector organisations across both children's and adult services. They vary in length and content but typically aim to present personal information about the individual, outline their communication methods, their likes and dislikes, and their health and support needs. The Council for Disabled children has made available details about some different passports at: <https://councilfordisabledchildren.org.uk/help-resources/resources/hospital-passports>

A range of templates are also available through CALL Scotland website to assist in developing communication passports: [www.communicationpassports.org.uk](http://www.communicationpassports.org.uk)

## Infections and Sepsis

Sepsis was briefly mainstream news a few months ago. It is a rare but serious reaction to an infection. Sepsis is when our immune system response becomes overactive and starts to cause damage to the body itself. The LeDeR Programme has produced an information leaflet for carers about infections and recognising symptoms of sepsis.

[http://www.bristol.ac.uk/media-library/sites/sps/leder/Infection%20\(sepsis\)%20poster.pdf](http://www.bristol.ac.uk/media-library/sites/sps/leder/Infection%20(sepsis)%20poster.pdf)

## Information for families following a bereavement

NHS England have put together information for families who have a loved one that has died while being looked after by the NHS. These documents explain what happens after someone dies, including how to comment on the care your loved one received and what happens if a death will be looked into by a coroner.

[https://www.england.nhs.uk/publication/learning-from-deaths-information-for-families/?utm\\_source=Sign-Up.to&utm\\_medium=email&utm\\_campaign=32163-269055-July%2023rd%20Newsletter-Preview](https://www.england.nhs.uk/publication/learning-from-deaths-information-for-families/?utm_source=Sign-Up.to&utm_medium=email&utm_campaign=32163-269055-July%2023rd%20Newsletter-Preview)

## My Health Guide

This is an app which enables adults with learning disabilities to use the technology that they like to use (e.g. ipads, iphones, etc) to understand information about their health needs and support workers' concerns about their health. Because the app allows presentation of information in a format that suits them (text, images, video and audio) it offers the possibility that they may become genuinely involved in their health care and articulating their needs and concerns, helped by parents, carers and relatives if need be. A video showing My Health Guide in action demonstrates its positive impact and potential (<https://www.youtube.com/watch?v=7FieF46Frtg>). For more details about the My Health Guide app go to: <https://www.myhealthguideapp.com>.

## Webinar: JSNAs and people with learning disabilities or autism

People with learning disabilities suffer inequities in health which start early in life and die sooner than the general population. They should be specifically included in JSNAs to identify current and future health and wellbeing needs in a way that will inform future service planning. This webinar will:

- explore to what extent the needs of people with learning disabilities or autism are currently included in Joint Strategic Needs Assessments (JSNAs)
- look at what data and evidence is available about the needs of people with learning disabilities or autism that can be used to inform JSNAs
- signpost to some examples of where the needs of people with learning disabilities or autism have been covered well in JSNAs
- open a discussion with attendees about how local plans are put together and ideas for other sources of data and evidence

This webinar is for colleagues who are involved in any way in putting together JSNAs in their area, those who are keen to see more about the health and wellbeing of people with learning disabilities or autism included in their local JSNA and public health colleagues who link in with colleagues involved in preparing JSNAs.

To request an invitation email [LDT@phe.gov.uk](mailto:LDT@phe.gov.uk)

## Learning Disabilities Mortality Review (LeDeR) Programme

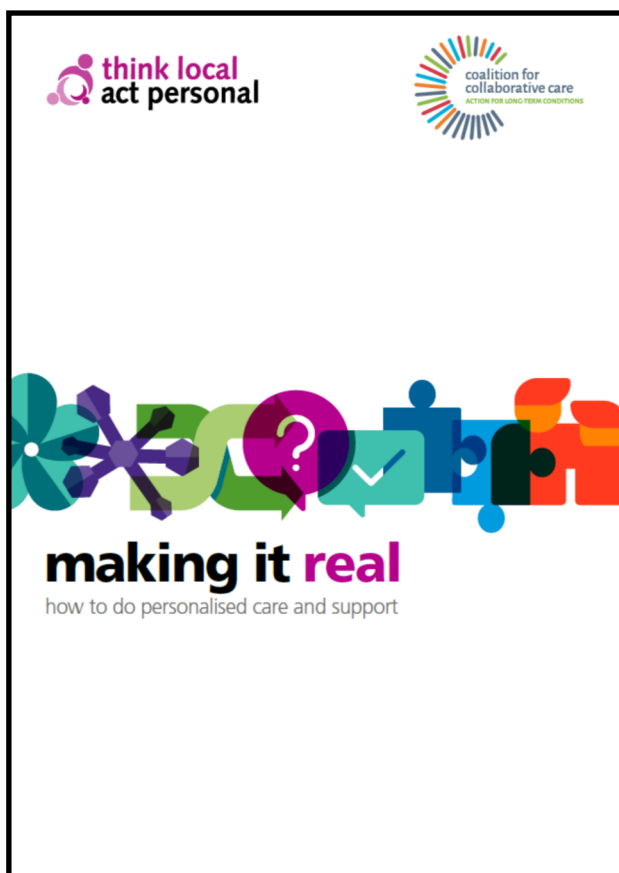
The Learning Disabilities Mortality Review (LeDeR) Programme is delivered by the University of Bristol. It was commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England and has a contract until the end of May 2019. As stated on its website, a key part of the LeDeR Programme is 'to support local areas to review the deaths of people with learning disabilities'. As well as promoting the implementation of a new review process, it offers support to local areas to take forward the lessons learned in reviews in order to make improvements to service provision. The LeDeR Programme also shares useful links and resources on its website: <http://www.bristol.ac.uk/sps/leder/>

## Making it Real

**M**aking it Real is a framework and a set of statements that describe what good, personalised care and support look like from the point of view of people with disabilities. The fundamental purpose of Making it Real is to support change and improvement. The statements are intended 'to inspire and motivate organisations to keep getting better at what they do'. They apply to a broad range of organisations and there no labelled groups of people with disabilities 'as these principles should apply to everyone'.

Making it Real is not a step-by-step toolkit or a performance management framework. Organisations will need to decide for themselves how to make best use of it but it is expected that any work must involve people with disabilities as equal partners in designing their support and achieving outcomes agreed through a personalised care and support plan. Also, people (and their families) have knowledge and experience that should be used to support improved planning and decision-making at the strategic level.

[https://www.thinklocalactpersonal.org.uk/\\_assets/MakingItReal/TLAP-Making-it-Real-report.pdf](https://www.thinklocalactpersonal.org.uk/_assets/MakingItReal/TLAP-Making-it-Real-report.pdf)



## People's experience in adult social care services: improving the experience of care and support for people using adult social care services

**N**ICE printed this guideline in February. It covers the care and support of adults receiving social care in their own homes, residential care and community settings. It aims to help people understand what care they can expect and to improve their experience by supporting them to make decisions about their care. It includes recommendations on: providing information; assessing care and support needs and care planning; providing care and support; staff skills and experience; and involving people who use services in service design and improvement. It is aimed at: practitioners working in adult social care services in all settings; service managers and providers of adult social care services;; and commissioners of adult social care services. It is downloadable from: <https://www.nice.org.uk/guidance/ng86>. An easy read guide for people using services is also available called What To Expect During Assessment And Care Planning: <https://www.nice.org.uk/about/nice-communities/social-care/quick-guides>

## PAMIS: Bereavement and Loss Learning Resource Pack

**P**AMIS provides this pack for supporters of bereaved people with PMLD and their parents and carers. It is for parents, paid carers and professionals, and emerged from the shared experiences of people with PMLD and those caring for them. The pack has two units.

Unit I: Supporting bereaved people with PMLD. It covers understanding how bereavement affects us, supporting people with profound learning disabilities, and supporting spirituality Unit II: Supporting bereaved parents and carers who have cared for someone with PMLD. It covers caring for someone with complex healthcare needs, and experience of bereavement for families who cared for someone with complex healthcare needs.

The pack includes a DVD with two 20 minute video clips

of parents sharing their own experiences and those of their sons and daughters. The pack may be supplemented by a two-day training course for supporters which facilitated by the PAMIS Bereavement and Loss Project Team. Information is available from [j.bolton@dundee.ac.uk](mailto:j.bolton@dundee.ac.uk).

## Royal College of Nursing Guides

The Royal College of Nursing have produced three guides for mainstream health services to deliver healthcare to people with learning disabilities. In each of these guides the College provides suggestions on how professionals can make a big difference by making small 'reasonable adjustments'. While designed primarily to support the nursing workforce, other health care and social care staff may also find these publications useful.

They are:

- Meeting the health needs of people with learning disabilities (2013) (<https://www.rcn.org.uk/professional-development/publications/pub-003024>)
- Provision of mental health care for adults who have a learning disability (2014) (<https://www.rcn.org.uk/professional-development/publications/pub-004445>)
- Dignity in health care for people with learning disabilities (2017) (<https://www.rcn.org.uk/professional-development/publications/pub-006605>)

The publications may be downloaded as pdfs.

## Raising Our Sights Guides

As reported in previous issues of PMLD LINK, Mencap and the PMLD Network produced a series of how-to guides' and associated films to help local commissioners and providers of services to meet the needs of people with PMLD. They are also aimed at families. Two of the guides are of specific relevance to the theme of health. 'How-to guide 2' is on clinical procedures. 'How-to guide 4' is about understanding and meeting the health needs of people with PMLD. The guides and films can be accessed at: <https://www.mencap.org.uk/advice-and-support/pmlD/raising-our-sights-guides>. The guides only are available on the resources page of the PMLD LINK website.

## Routledge

Routledge is a leading academic publisher (<https://www.routledge.com>). It is well worth visiting its website to see what books are available as regards inclusion and special educational needs and teaching/ supporting learners with severe, profound and multiple learning difficulties. It publishes useful books by the likes of Peter Imray, Penny Lacey, Dave Hewett and others. Of late it has started to reissue some books from its back catalogue that may be of interest, although they are mostly being sold either as Routledge Library Editions (expensive hardbacks only at £80 to £100 or more) or as electronic versions to buy (about £40) or, rather more affordably for students, to rent (from £20 for six months to £24 for 12 months).

Books of particular interest include:

Educating Children with Profound and Multiple Learning Difficulties, 1st Edition (1994) Edited by Jean Ware  
Problem Behaviour and People with Severe Learning Disabilities: The S.T.A.R Approach, 1st Edition (1994) By Ewa Zarkowska, John Clements

The Education of Children with Severe Learning Difficulties: Bridging the Gap between Theory and Practice, 1st Edition (1986) Edited by Judith Coupe, Jill Porter

But some books are possibly of historical interest only:

The Curriculum Challenge: Access to the National Curriculum for Pupils with Learning Difficulties, 1st Edition (1991) Edited by Rob Ashdown, Barry Carpenter, Keith Bovair

What needs to be borne in mind is that these are just reprints. It may still be possible to obtain used copies of the originals all of these books through internet sources at much cheaper prices.

## The Pete Wells Sensory Stories Podcast

**J**oin Pete Wells for his podcasts. In each one, he shares a sensory story with you. He chats about its origins and discusses tips for telling the story as well as giving ideas for props and how best to use it with learners.

The podcast podcasts all have news from the world of special education and also include interviews with guests from the world of special education who share their insights, knowledge and expertise; to date guests have been Flo Longhorn, Les Staves, Peter Imray and Keith Park.

You'll find all the files you need at [www.sensorystoriespodcast.com](http://www.sensorystoriespodcast.com).

## The UK Health and Learning Disabilities Network

**T**he UK Health and Learning Disabilities Network has been available on the internet since the early 2000s. The network offers a means of connecting people with an interest in the health of people with learning disabilities in the UK and has proved to be a key place to share information. The network aims to assist health practitioners in both mainstream and specialist services but everyone who has an interest in the health of people with learning disabilities is welcome to join.

You can use the network to: find/request information on health and people with learning disabilities; share your own knowledge and experience; highlight and discuss concerns; provide and gain mutual support; find out learning disability related news, events and information; and connect with other like-minded people.

The website also hosts the PMLD Network which serves as an online meeting place for people committed to improving the lives of people with PMLD.

The UK Health and Learning Disabilities Network is run by Foundation for People with Learning Disabilities, in partnership with Together 4 Change

<https://www.learningdisabilitieshealthnetwork.org.uk/>

## What to expect during assessment and care planning: A quick guide for people using adult social care services



Adult care and support should help you live your life the way you want to. You should be treated as an individual, and your care and support should be based on what you can already do, what you want to achieve and the help you need. Social care staff should always involve you and respect your right to make your own decisions. They should give you any support you need to express your views and wishes.

# REPORT BACK

## Raising the Bar II

**W**here to begin? There was so much going on throughout the day, insightful and inspirational speakers, exciting and educational workshops and a chance to talk to some of the most fantastic people. The Venue, The Great Hall at the University of Birmingham, was magnificent, a fitting setting for the conference.

I arrived at 9 O'clock and walked into a vibrant atmosphere with people talking and sharing ideas already! I bumped into a familiar face as soon as I arrived and we both shared how hugely excited we were to be there and ready to soak in as much as we could. After exploring the stalls and getting a number of free pens (Thank You!) we were all taken to the lecture hall. Throughout the day I was lucky enough to listen to some of the most inspirational, motivational and moving speakers I have ever heard. Listening to Sandra Archibald, Rachel Wright, Elly Chapple and Rebecca Pender's powerful words gave me a valuable and incredibly moving insight into being a parent of a child with PMLD.

The workshops I was lucky enough to attend were fascinating. Annie Fergusson's session on Aromatherapy was very interesting and has changed my practice in my classroom. Joanna Grace's session of Mental Health and Wellbeing was a microcosm of the conference as a whole for me. It was challenging and brought home how low the bar currently is. It was also full of inspiration and hope that we can change things.

Overall Raising the Bar II was a brilliant day and will be life changing for so many people. It showed that when we work together we can and will change the world and Raise the Bar.

The conference was brought to a close by the fabulous Flo Longhorn whose quote and message has stuck with me. "When you wish upon a star you will raise the bar".

Contact details:

Iain Mackie

PMLD Teacher at Fairfield School, West Yorkshire  
e-mail: [iainmackie@fairfieldschool.uk](mailto:iainmackie@fairfieldschool.uk)  
twitter: @iainMackie2

# SHORT COURSES & CONFERENCES

January	
Title:	Learn Network – External Validation (Moderation) meeting for 'Next Steps' within learners' personalised assessment systems (non-subject specific).
Date:	Thursday, 31st January 1-3pm
Location:	Ash Field Academy, Leicester, LE5 4PY, 0116 273 7151
Provider:	Ash Field Academy
Contact:	Ellen Croft – Assistant Headteacher – SLE SEND – <a href="mailto:ecroft@ashfield.leicester.sch.uk">ecroft@ashfield.leicester.sch.uk</a>
Title:	Story Massage
Date:	29th January
Location:	Birmingham
Provider:	Story Massage
Contact:	<a href="mailto:info@storymassage.co.uk">info@storymassage.co.uk</a> <a href="http://www.storymassage.co.uk">www.storymassage.co.uk</a>
March	
Title:	Exploring the Impact of the Senses on Behaviour
Date:	18th March
Location:	Birmingham
Provider:	The Sensory Projects.
Contact:	<a href="mailto:sensorystory@gmail.com">sensorystory@gmail.com</a>
Title:	Story Massage
Date:	19th March
Location:	Hinckley, Leics
Provider:	Story Massage
Contact:	<a href="mailto:info@storymassage.co.uk">info@storymassage.co.uk</a> <a href="http://www.storymassage.co.uk">www.storymassage.co.uk</a>
Title:	Postural Care for Adults with Complex Body Shape
Date:	25th March
Location:	Tamworth
Provider:	Simple Stuff Works
Contact:	<a href="mailto:trainingadmin@simplestuffworks.co.uk">trainingadmin@simplestuffworks.co.uk</a>
Title:	Postural Care for 0-3 Year olds
Date:	27th March
Location:	Tamworth
Provider:	Simple Stuff Works
Contact:	<a href="mailto:trainingadmin@simplestuffworks.co.uk">trainingadmin@simplestuffworks.co.uk</a>



<p>Title: Postural Care for Adults with Complex Body Shape Date: 29th March Location: Tamworth Provider: Simple Stuff Works Contact: trainingadmin@simplestuffworks.co.uk</p>	<p>Title: Special seating – A Master class Beginner/Intermediate Date: 4th April Location: Tamworth Provider: Simple Stuff Works Contact: trainingadmin@simplestuffworks.co.uk</p>
<b>April</b>	
<p>Title: Develop Your Sensory Lexiconary Date: 4th April Location: Truro Provider: The Sensory Projects. Contact: sensorystory@gmail.com</p>	<p>Title: Special seating – A Master class Intermediate/Advanced Date: 5th April Location: Tamworth Provider: Simple Stuff Works Contact: trainingadmin@simplestuffworks.co.uk</p>
<p>Title: Therapeutic Benefits of Laughter, Katie Rose White from The Best Medicine Speaker: 11th April Date: Tamworth Location: Simple Stuff Works Provider: trainingadmin@simplestuffworks.co.uk Contact:</p>	<p>Title: Postural Care for Scoliosis Date: 6th April Location: Tamworth Provider: Simple Stuff Works Contact: trainingadmin@simplestuffworks.co.uk</p>
<p>Title: Ambitious and Inclusive Sensory Story Telling Speaker: Jo Grace from The Sensory Projects Date: 14th April Location: Tamworth Provider: Simple Stuff Works Contact: trainingadmin@simplestuffworks.co.uk</p>	<p>Title: Measurement of Body Symmetry Dates: 9th and 10th April Location: Tamworth Provider: Simple Stuff Works Contact: trainingadmin@simplestuffworks.co.uk</p>
<p>Title: Sensory Engagement for Mental Well Being Speakers: Jo Grace from The Sensory Projects Date: 15th April Location: Tamworth Provider: Simple Stuff Works Contact: trainingadmin@simplestuffworks.co.uk</p>	<p>Title: Person Centred Reviews and Meetings Dates: 8th and 26th April Location: Tamworth Provider: Simple Stuff Works Contact: trainingadmin@simplestuffworks.co.uk</p>
<p>Title: Develop Your Sensory Lexiconary Date: 26th April Location: Bath Provider: The Sensory Projects. Contact: sensorystory@gmail.com</p>	<p>Title: Communicating with relatives and carers Date: 30th April Location: Tamworth Provider: Simple Stuff Works Contact: trainingadmin@simplestuffworks.co.uk</p>
<p>Title: Communicating with Relatives and Carers Date: 26th April Location: Tamworth Provider: Simple Stuff Works Contact: trainingadmin@simplestuffworks.co.uk</p>	<p>Title: Special seating – Foundation in Sleep Assessment and Management Date: 12th April Location: Tamworth Provider: Simple Stuff Works Contact: trainingadmin@simplestuffworks.co.uk</p>
<b>June</b>	
<p>Title: Postural Care for Children and Young People Date: 2nd April Location: Tamworth Provider: Simple Stuff Works Contact: trainingadmin@simplestuffworks.co.uk</p>	<p>Title: Europe in Action. Dates: 5-7 June 2019 Location: Vilnius, Lithuania Provider: Inclusion Europe Contact: www.inclusion-europe.eu</p>

**Subscription prices are:**

<b>UK:</b>	Personal	£20.00	Organisation:£30.00
<b>Non UK:</b>	Personal	£27.00	Organisation:£40.00

**Name of Subscriber:** .....

**Address:** .....

**Telephone No.** ..... **e-mail:** .....

**Place of work** (if applicable).....

**Contact name within organisation** (if applicable) .....

This is a new subscription / renewal subscription

I/we enclose a cheque for £ ..... (made out to PMLD Link)

I/we have set up a standing order for £ ..... with our bank starting on .....

How did you hear of PMLD LINK?..... Date: .....

**Please send this form with payment to: Rob Ashdown, 15 Cliff Gardens, Scunthorpe, North Lincolnshire, DN15 7PH**

*If you require a receipt please enclose a stamped addressed envelope marked Receipt.*

<b>Gift Aid Declaration</b>	
<b>Name of Charity:</b>	<b>PMLD LINK</b>
<b>Details of donor:</b>	
Title .....	Forename(s).....Surname.....
Home Address:.....	
.....	
.....Post Code:.....	
<b>I want all subscriptions and donations that I make from the date of this declaration to be treated as Gift Aid until further notice</b>	
You must pay an amount of Income Tax and/or Capital Gains Tax at least equal to the tax that the charity reclaims on your donations in the appropriate tax year (i.e 25p for each £1 you give on or after 6 April)	
<b>Date</b> .....	...../...../.....

### STANDING ORDER MANDATE (Send to *your* bank)

Please pay: HSBC Bank plc, Ross-on-Wye branch  
 For the Credit of: PMLD-Link  
 Account No: 81156284  
 Sort Code: 40-39-06

The sum of: £.....

Commencing: .....

Account to be debited: .....

Account No. ....

Signature(s): .....

Date: .....

## About Us

The editorial team is drawn from a variety of settings and currently includes:

- Rob Ashdown** Former teacher of pupils with severe and profound and multiple learning difficulties and special school Headteacher.
- Jeanne Carlin** Retired Disability Consultant and a parent of a young woman with PMLD.
- Helen Daly** Mum to a young Adult with PMLD, previous career in Further Education for 20 years - including Curriculum Team Manager for Inclusive Learning and Developing an Improving Choice Programme for people with Complex Needs. Currently involved in carers groups in the Eastern Region, Learning Disability Partnership Board and associated projects.
- Ann Fergusson** Annie is a senior lecturer in the SEN & Inclusion team at the University of Northampton, teaching on undergraduate and postgraduate courses relating to severe, profound and multiple learning disabilities. Her research interests relate to person-centred working, meaningful participation and the voice of the individual in promoting positive mental health and wellbeing. She works one day a week in a special school with a role for training and looking at impact. Annie has a brother with a learning disability. She is a family member of the Learning Disabilities Mortality Review Programme Advisory Group.
- Michael Fullerton** Michael the Director of Quality and Clinical Care with CMG, a social care provider supporting adults with profound and multiple learning disabilities. Michael is a registered learning disability nurse and leads a health team focused on the quality of life of people with PMLD.
- Martin Goodwin** Martin is a teacher of pupils with PMLD and a Regional Tutor/Visiting Lecturer for the Severe and Profound Multiple Learning Disabilities course at the University of Birmingham. Martin has specialised in approaches to improve interaction, communication and participation of people with severe and profound learning disabilities. Martin has experience of working in play and leisure, education, residential and advocacy.
- Joanna Grace** Joanna Grace is a sensory engagement and inclusion specialist. She is the founder of The Sensory Projects which are run on the principle that with the right knowledge and a little creativity inexpensive items can become effective sensory tools for inclusion. Joanna tweets for us on @PMLDlink follow for ideas and information.
- Rachel Parry Hughes** Lecturer in Social Work, Goldsmiths, University of London, researcher in the field of profound and multiple learning disabilities
- Becky Loney** Becky has a background in running creative services for adults with PMLD within the voluntary and statutory sector and she established the Lambeth Mencap Carousel project. Becky is passionate about intensive interaction and sensory storytelling, and spreads the word by training staff teams in high quality activities and creative approaches.
- Wendy Newby** Deputy Headteacher at The Shrubberies School, Stonehouse, Gloucestershire. This is a school for students with Severe and Profound Learning Difficulties
- Sue Thurman** Former NHS Speech and Language Therapist for adults with learning disabilities with a particular interest in PMLD. Now writes and trains about communication and is a Registered Intermediary assisting vulnerable witnesses to communicate at police stations and courts.
- Bella Travis** Policy Lead, Mencap

**Disclaimer:** Views expressed by contributors to **PMLD Link** are their own and do not necessarily reflect the policies and opinions of the editorial team

# PMLD LINK

sharing ideas and information

PMLD Link is a journal for everyone supporting people with profound and multiple learning disabilities.

Visit [www.pmlmlink.org.uk](http://www.pmlmlink.org.uk)

**Vol 30 No 3. Issue 91**

ISSN 2042-5619