

PMLD LINK

sharing ideas and information

Loss - looking ahead

Winter 2019



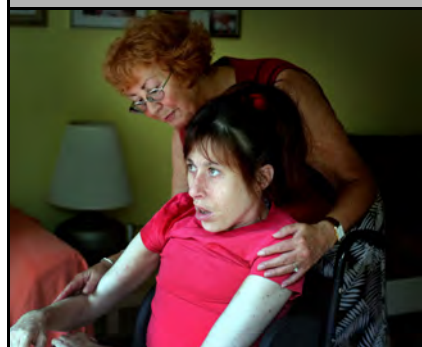
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Cover picture of Sam and Sarah:

From a photographic collection entitled *Our Human Condition* by Professor Paul Wenham-Clarke about sibling relationships and disability.

GUEST EDITORIAL

Loss - looking ahead

In this issue we want to shine a positive light on Loss, a subject that is often avoided. The generosity of individuals to openly share their lived experiences in this edition allows us to consciously contemplate the inevitability of endings and death. It enables us to consider how best we can respond and support each other through the inescapable process of grief and remembrance.

Everyone experiences the natural and inevitable loss that accompanies change from life events, some of these more significant than others. As we finalise this edition in the run up to Christmas we recognise this, and other annual events, bring a mix of sadness and joy. They are a time to celebrate with those we love yet equally create markers in time for lament, remembrance for those who are no longer with us, for whatever reason.

This issue is filled with heartfelt contributions offering valuable reflections from families and professionals from every perspective. The articles actively demonstrate the courage and efforts of people to put as much thought into every phase of someone's entire life, with equal planning for a good death as that assumed in planning for a good life. Articles encourage us to be less protective, to be brave and include people with profound and multiple learning disabilities more in the processes of end of life or of experiencing loss and grief, in ways that can be meaningful and supportive. We offer insights, practical ideas and resources that can enable us to support others in tangible ways, to remember people who were important to us and those who we no longer have in our lives.

Loss is as much about acknowledging individuals for who they were and what they meant to us when they were part of our lives. In this edition we also celebrate the lives of some individuals with profound and multiple learning disabilities whose contributions to others has been acknowledged in this year's Leaders List.

Finally we dedicate this special edition to all those who have loved and lost and, to those living without them. In particular, we mark the life of Liam Daly, who had such a positive influence on the work of PMLD LINK. He lived and loved life in equal measure.

With good wishes from everyone at PMLD LINK for a happy and healthy 2020

Annie Fergusson and Jeanne Carlin, Guest Editors

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Loss, Love, Life

Helen Daly

From the moment of his birth our son Liam was always likely to die before us. Grey and unresponsive, he found breath. With primal calm his Dad baptised him. Sometimes life and loss have no plan. Just love.

He breathed his loved life for 27 years. From 8.25am 16th February 1989, 9.50am 2nd February 2017. Amongst all the joy, our family life would be punctuated by, that call, the slightest change, the indication that all was not well and a trip to hospital was on the cards. Our minds and bodies always prepared for the worst, hoping for the best.

In every life plan there was an unseen plan for loss. Let's forget, for a moment, the dead hand of social, health and educational care plans. Forget, pretending to be normal. Pretending our gorgeous man would be like every other man if only he had a plan to demonstrate he could 'take part' in making his ***** bed. Why? One suspects an attempt to cut the domestic staff and give the job to a support worker or personal assistant.

The best plans, with loss so close, were about living life. Holidays, festivals, family, music, love. In the last few weeks of Liam's life, in the midst of his increasing medical paraphernalia, Liam had his final filmed panto role. The crocodile from Peter Pan. Life was moving fast

towards death. Making crocodiles, reading favourite enormous crocodile stories, watching versions of Peter Pan and getting in a few precious moments of film. Liam had his last Christmas.

What we learnt about planning for Loss.

- 1) The medical paraphernalia may be an essential part of making life good to the end.
- 2) Palliative care can be shrouded in myths. It has costs. Some financial some emotional.
- 3) Palliative care plans can be for a long time. You are trying to manage decline. Liam's was over a year. A dear friend's child for 2 years.
- 4) Palliative care doesn't always mean withdrawing medication, or not giving anti biotics. It depends on what is best.
- 5) Involve all the care team. You don't need special nurses to do many of the medical tasks. You need good training, for familiar staff, who have invested their time and life in your child. Many have become part of the family.

- 6) We benefitted from a very good team at the Arthur Rank Hospice, Cambridge, who provided emotional and practical training to the whole team. Many of Liam's team, from Orchard Manor, Meldreth, were young. Came of age with Liam. Their new skill, courage and love was just phenomenal.
- 7) Things can go wrong, even close to the end. We planned a hospice. It nearly didn't happen. A bed has to be available. Others may plan for a home death. It may not happen for all sorts of reasons. The main thing is your loved one is comfortable. Keep some familiar special items at hand – Nice smells, a familiar blanket, whatever you want to help your loved one feel comfortable, wherever their death happens.
- 8) We had a drugs plan that involved a pump, included heavy opiates and anti-sickness drugs. You do need a nurse for this. The pump took away any distress from Liam. He was peaceful.
- 9) We made Liam's funeral as accessible as possible. It was in a church. Churches and funerals can be very sensory occasions. It was lovely to hear the noises and calls of Liam's PMLD friends in the church. For those who couldn't make it we held a special day memorial at Liam's care home too.

Loss continues. Life goes on. Crocodiles still snap.

Contact details

Helen Daly has been a long-standing member of the PMLD LINK Editorial Group and trustee.

A Poem for Liam

Kevin Daly

Lightsome Liam of Silver and Gold hair
Winsome face borrowed from Angels
His coming awaited, his arrival our care
A risk threatened entry to a world full of dangers

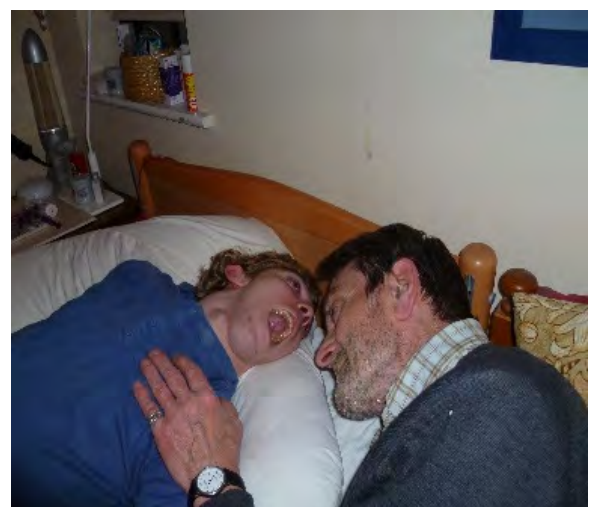
Against expectation Liam breathed in his first
With everyone around him urging him to fight
He challenged life to do its worst
And then worked to live, his laughter bright

Angels we know are not able to sin
Liam we saw could not produce Bad
That didn't interfere with his mischievous grin
He learnt from his Grandad to be one of the lads

Your eyes followed Mum all around the room
Your Mother, your Guardian, your vigilant Teacher
You the fruit of her nourishing womb
Your parents proud of you – their very best Feature

Liam's mission here on earth?
Though clever, he wasn't an eloquent Speechmaker
He bore witness to the unfairness of Birth
And settled for being a willing Heartbreaker

Shine on, smile on, Liam Goodbye
We'll catch up with you later, there with you on high.



Thinking Ahead: an approach to talking about, and planning for, the future

Christine Towers

One of the biggest worries for parents who have a son or daughter with learning disabilities is what is going to happen in the future, particularly when they are no longer alive or unable to provide advocacy or support for their relative. In response to this, *Thinking Ahead: a planning guide for families* was written setting out information, ideas and tools to help families think about how to plan for their relative to have a life with opportunities whilst also being safe and well. Thinking about the future can pose specific difficulties for parents and other family carers of people who have profound and multiple learning disabilities: there are usually more limited support options available locally; support is provided across a wide range of health and care organisations which needs to be co-ordinated and parents are aware of how much they have to speak up for their relative and worry who will step in and do this in the future.

There are nine sections in the guide (see the diagram on the next page) and two of these, *Making plans for the future in a person-centred way* and *Building friendship and support networks* (including ideas about developing circles of support) can provide a useful starting point to help with these difficulties. In the guide there is a story from a family who were finding it difficult to think about the future, even though they felt the need, until they came along to a Thinking Ahead workshop and used the person-centred planning section.

“We made a very difficult decision that we needed to start planning for our daughter, who has very complex support needs, to move away from home as we were not getting any younger. The care manager gave us the names of a few places to look at- the first one we went to was just not what we had in mind for our daughter and it put us off doing anything more. Now that we have found out about person-centred planning, we can see that this is where we need to start - looking at what is important to, and for, our daughter, and planning her support around this. We can now see a way forward.”

There is a companion guide, called *I'm Thinking Ahead*, which was written to involve people with learning disabilities in planning their future. The ideas and templates can also be used by family, friends and supporters to gather information and ideas for future plans for people who wouldn't have the cognitive ability to meaningfully understand the future or express their wishes. A group of people who know about the needs and preferences of someone with profound and multiple learning disabilities can meet together to gather information, think through options and make plans that they, and others, can action.

A useful section in *Thinking Ahead*, for families where

someone with profound and multiple learning disabilities still lives at home, is the section on making a plan for emergencies. Making such a plan can help think through the options should a parent or other important carer become unwell or otherwise unable to provide their usual support. It can often be harder for local authorities to find appropriate support at short notice for someone with profound and multiple learning disabilities and also the essential detailed information about a person's needs, when others step in, is usually vital for their safety. Therefore, it becomes more important to have thought about the options, discussed this with people who would support its implementation and to have it written down and known about. *Thinking Ahead* provides a structured process to follow as well as a template to complete an emergency plan. There are two free versions of both the guides: firstly, one that can be read on-line, downloaded and printed and alternatively, there are interactive PDFs of each section which have text boxes that can be filled in on a computer, saved, shared with others and updated when necessary. This latter format is particularly useful for an emergency plan and person-centred planning where sharing information and regular updates are likely to be needed.

Thinking Ahead was originally written with families in mind who were considering significant changes, such as a move from the family home, but in practice it has been used just as much by families of young people who are thinking about the future, post school or college. Mike Nelson, a father of a young man with autism, has written about how they used the guide to look at decision-making, writing a will, setting up a discretionary trust and making an emergency plan. Before he came across *Thinking Ahead*, he said they had avoided doing anything about these things as it meant conversations about getting older and bereavement. You can read Mike's

story here <http://www.togethermatters.org.uk/planning-the-future/> . Essex County Council provide an interesting example of taking an all-age approach to embedding the Thinking Ahead guides in their practice. We have provided training on using the Thinking Ahead approach to all the social work and family support teams covering children with disabilities, transition and adults as well as in some schools and colleges. Workshops for family carers have also been run through a variety of family support organisations across the county.

If anyone has any stories about how they have used the Thinking Ahead guides to help plan for the future with someone with profound and multiple learning disabilities it would be great to hear from you. Together Matters is always keen to learn from people who have used our resources and also share this with others. We are particularly interested in developing our understanding about how the guides could be of greater use to families of people with profound and multiple learning disabilities and whether there may be a need for additional, complementary information. We would be interested in hearing from you if you think there is any scope for carrying out any fact finding or research about this.

Contact details

Christine Towers, Together Matters
Email christine@togethermatters.org.uk about the article above or to receive information via Together Matters' occasional newsletters.

Content of the guides

<p>Thinking Ahead: a planning guide for families</p> <p>Making decisions Making plans for the future in a person-centred way Building friendships and support networks Talking about difficult subjects Making financial plans Housing and support Making a plan for emergencies Keeping an eye on things Making a plan for the future</p>
<p>I'm Thinking Ahead</p> <p>How to plan How to make choices How to get the right housing and support.</p>

The guides can be downloaded free from <http://www.togethermatters.org.uk/resources-and-information/> . Please email for information about purchasing hard copies.

Thinking Ahead Planning Guide



It's all in the preparation

Jeanne Carlin

'There is nothing more we can do to get her bowel working. She is at high risk of her bowel perforating and if that happens she will not survive'

These were the stark words said to me by a bowel consultant about my daughter, Erica, in May 2016. Erica has survived and is still with us, however this opinion led her to be put onto 'end of life care'. I wanted to write about what this meant to me and how we prepared for the possible death of our daughter.

At the time we were working with and had the support of a specialist doctor in learning disabilities (Dr. Lia) and a community nurse for Learning Disabilities (Theresa). Our thinking needed to change as we moved from a stage of 'fixing' or 'treating problems' to aiming for 'pain-free days' that gave Erica a good quality of life rather than quantity, in other words extending her life. That has remained our goal for the past three and a half years.

Immediately after being told that Erica was at high risk of her bowel perforating, we met together with Dr Lia and Theresa to write an Advanced Care Directive. This ensured that if Erica's bowel did perforate, she would die at home rather than in hospital – attached to numerous machines. This led to a referral to the MacMillan team who provided 'in case' medication and a syringe driver. It felt like we had been hit by a whirlwind, but we understood the necessity for this. The advanced care directive has now been replaced by a ReSPECT document – this is a process that creates personalised recommendations for Erica's care in a future emergency in which she would be unable to make or express choices. The 'in case' meds are still in place and have to be checked and updated regularly by the district nursing team.

The next thing that happened is that my husband and I had a conversation about what type of funeral we would want for Erica. Although we both have 'spiritual beliefs' we do not follow a traditional religion. We planned a humanist funeral, asked a friend if he would lead the service. The reason for this is that we did not want to use a humanist 'minister' who perhaps did not understand profound and multiple disabilities and therefore the value of Erica's life and we did not want statements like – 'she is in a better place' or 'her life has been so limited that death is a relief' to be said. We contacted a funeral director and planned and paid for Erica's funeral. We had wonderful support from Dr Lia and Theresa and also some friends who had been through the death of their baby many years ago. They all

reinforced the value of thinking through the issues, preparing ourselves and of putting plans in place in advance. Erica has survived so the plans are on the 'back boiler' but it is reassuring to know that they are there as and when they are needed.

We have not limited Erica's life in any way – she still enjoys a variety of activities – all based on our belief that we need to aim for quality rather than quantity. We also made a decision for Erica to go and live in residential care. This was made as her health care became more complex and we started to feel that we were no longer the best people to respond to her health needs. Her home is five minutes away from us and we are still very much part of her life. She has benefitted because her life is built around her health – in terms of her sleep patterns and activities. This has led to a reduction in the amount of morphine she needs to control her pain and that of course, has a positive knock-on effect on her bowels.

There are some issues which I struggle with – one of those is about feeding. We had discussions with Dr Lia and Theresa around the fact that as people approach the end of their life they often stop eating – which allows their systems to close down. Erica is fed via a gastrostomy tube and therefore she would continue being fed to the end with no choice. Although Dr Lia felt we would know when to stop feeding Erica I do struggle with this and am not sure that we will know.

Moving to 'end of life' care or 'palliative care' has been a journey for us. It meant that we needed to change the way we think about Erica's care and treatment and keep repeating – 'it is about quality and not quantity' or 'we are aiming for pain-free days'. It is these two mantras that determine all the decisions we make about Erica. Although her health is now stable, we know that it is stable because of the vast amount of medication she takes each day. Erica's life did not end in 2016 but we have benefitted by going through the preparation and thinking that we required if it had happened. I feel at ease with 'what will happen will happen' because of the journey we went through and the preparations we made.

Contact details

Jeanne Carlin, parent and member of PMLD LINK Editorial Group

The importance of autonomy at the end of life

Melissa Bloomer, Hille Voss and Joanne Watson

It is fair to say that few people would ever really be prepared for the death of a loved one who they may care for. Rather, the grief associated with a death is often described as intense and overwhelming. For parents, the death of a child is considered to be one of the most devastating events endured. Advances in technology and health care mean that people with profound and multiple learning disabilities (PMLD), in line with the general population, are living longer lives than ever before and therefore are at greater risk of dying from aged-related illnesses. This creates a clear need to consider the end-of-life care needs of people with PMLD.

There are widely-held perceptions that people with disabilities do not have the capacity to contribute to decision-making (Watson, Voss, & Bloomer, 2019). Even so, providing a person with PMLD an opportunity to attempt to express their wishes and preferences and have these responded to should be a priority. Article 12 of the Convention on the Rights of Persons with Disabilities (United Nations, 2008), was the first international human rights treaty to specifically recognise that people with disabilities have a right to autonomy. In accordance with this treaty, mechanisms should be developed to support autonomy for all citizens, across the lifespan, including at the end of life. This may include acknowledging, interpreting and responding to the preferences about the type of care the person wishes to receive, including the location of care and preferred place of death. The opportunity to express autonomy at the end of life has been found to contribute to a person's psychological, spiritual, physical and social needs (Detering, Hancock, Reade, & Silvester, 2010). Advance care planning (ACP) is recognised worldwide, and is designed to honour a person's preferences for care, particularly at the end of life (Advance Care Planning Australia, 2018). But it is not clear whether or how ACP should be used for people with intellectual disabilities (Voss et al., 2017).

Family members and primary carers can play a very important role in providing opportunities to have preferences responded to at the end-of-life. Supported decision-making mechanisms, which rely on the expertise of those most intimately involved in the care of a person with PMLD, such as family and carers, may help to achieve autonomy for the person at the centre of care. One example is the work of Dr Jo Watson from Deakin University in Australia. In her research, the will and preferences of people with multiple disabilities were identified, interpreted and explored through examining carers' intimate knowledge of and interactions with the

person (Watson, 2016). In this way, the autonomy and opportunity to contribute to care planning was seen as a relational construct, realised through collaboration.

Efforts to facilitate autonomy and to understand the end-of-life preferences of person with PMLD, is also important for family carers. This is because, in the event of hospitalisation, and deterioration in the person's condition, the increasing focus on patient and family-centred care means that family carers are frequently called upon to participate in decision-making on behalf of their relatives (Digby & Bloomer, 2014). Families value effective communication, shared decision-making, and respectful, compassionate care for their family member in hospital (Virdun, Lockett, Davidson, & Phillips, 2015). Achieving this is more likely when the family carer has some understanding of the person's expressed or inferred wishes and preferences. Honouring a person's preferences at the end of life is arguably one of the most profound gifts one person can do for another (Watson et al., 2019), and perhaps, for the bereaved family carer, knowing the person with PMLD's wishes were honoured, may give some sense of comfort.

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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, please do not hesitate to contact Rob Ashdown (PMLD LINK Treasurer) via info@pmlmlink.org.uk

Life and Death

Anne Laney

Within our work we are privileged to support the people we see through all of life's ups and downs. This includes spending precious time with people at the end of their lives. How can Intensive Interaction maximise the preciousness of these times and be useful in coming to terms with feelings of grief?

The nature of what we do as Interaction Practitioners, means that we recognise and value the moments of human contact above all else. How best can we support someone who may be expressing fear, sadness, regret, anger, and when they may not understand what is happening to them? What is our role when someone is moving towards the end of their life?

Dealing with terminal illness is pertinent to us here at Us in A Bus as we come to terms with the fact that Emma, someone we've known for many years, is dying. In asking ourselves these questions, we have concluded that they are ultimately often answered with further questions!

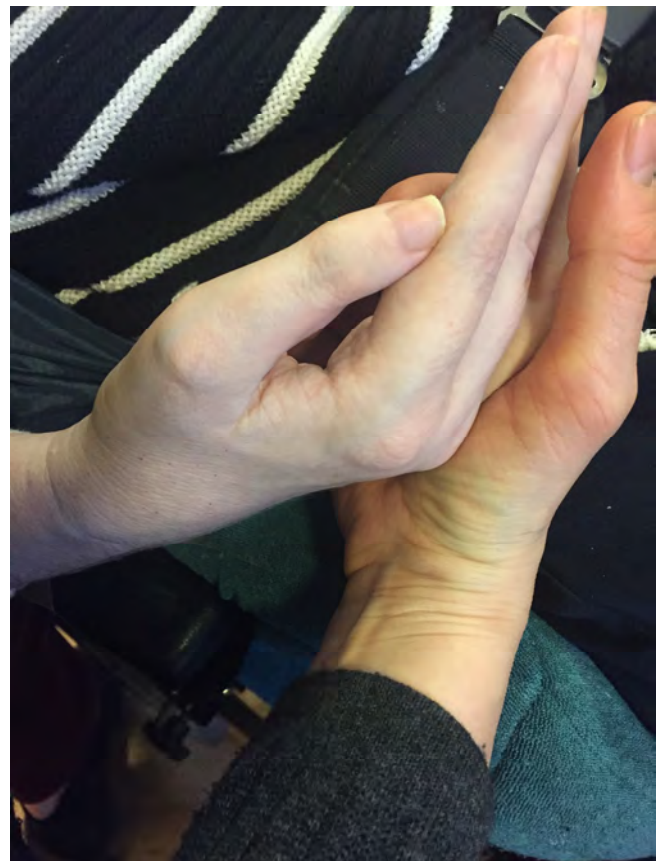
As Emma moves through her illness, the changes in her physicality and personality are becoming more pronounced and the distress she shows almost constantly is, to us, extreme and upsetting. As Emma has always had a considered and restrained approach to physical contact, the fact that she now seeks out our hands to hold (anyone's hands to hold we suspect) indicates to us that she is anxious at the very least, may well be fearful and possibly terrified. Our opinion is further reinforced when we hear her distraught sounding voice and observe her pained and frightened expression. She is clearly experiencing pain (we know she is receiving the strongest medication to reduce this so probably considerable pain) and is, we suspect, recognising that this is 'different' from other experiences from her past. She reacts to this knowledge by becoming fretful and afraid and by seeking comfort.

The root of our dilemma is this: do we have any responsibility, to anyone, to help this person understand the notion/concept of her death?

In the relationships we foster with the people we work with, we aim for equality during our time together. We value what people offer us, celebrate their personalities and share parts of ourselves too. We keep our communication honest and our focus on the person we are with. We sometimes draw support from those we're working with as we tune in so carefully to the connection we have. This is an uncommon dynamic within 'pmld land' as people with complex and profound disabilities rarely have the opportunity to provide emotional support

for others. Suddenly being in receipt of knowledge about the person we are with (i.e. they have a terminal illness.....and all the details that may go with this) and not knowing if they have the same knowledge feels very strange, unfair (to them) and in truth a little emotionally burdensome. As humans we want to help, to 'make things better' and to be honest. What do we do?

Our starting point is that we do not and cannot know what level of understanding our wonderful lady has. We have our thoughts about it, as everyone does, our hunches based on our observations over the years. But, she doesn't speak and uses no formalised communication so we do not have a definitive answer. She is, without doubt recognising pain and fear and difference but whether this is the result of an intellectual understanding of the situation, an emotional response or a combination is impossible to tell.



Is there ANY benefit to her in having an explicit conversation about dying? In doing so would we be meeting our needs rather than hers? Would we be adding to her distress with our openness rather than alleviating it? What purpose would we be achieving by openly confronting death?

Because of all these unknowns we have concluded the approach we will take is one of 'responding in the face of death as we respond in the face of life'. For us this means supporting Emma in her times of pain and fear and empathising with her, not trying to alleviate her worries by trying to cheer her up or 'jolly' her along. This is how we always work. Intensive Interaction works when we are mindful of someone's emotional state and join them in their feelings landscape.

If someone is having a particularly uncomfortable day which we cannot alleviate in a physical way, maybe saying "Aw, I can see you're not comfy today" and mirroring their facial expressions is a respectful way of showing we are listening and that we care. We will make extra time for her, believing the others she lives with would want this for her. We will explore the recent changes in her desire for physical contact by holding her hands and 'dancing' with them. We will tell her she's beautiful. We will stroke her hair.

We will reminisce with her about the past: good times we've had and people she has known. Celebrating our history together seems especially important at this time. This may lead onto the fact that some of these people have died and we have decided to focus on the fact that this means they are no longer in pain. We think Emma is a person of Faith and are still debating what her understanding about the 'transition from life to death' might be. There may be a moment when 'words' about this seem appropriate but for now we will use Emma's language, as always, to express our love of her and desire to comfort her in the best way we can."

*This article first appeared on www.usinabus.org.uk in January 2018 and is reproduced here with kind permissions from Us in a Bus

Contact details

Anne Laney
Practice Manager, Us in a Bus

Us in a Bus work with a wide range of people who are often isolated and can find communicating with the world (and the people in it) a huge challenge. The people we support have profound learning disabilities and complex needs, often with sensory and physical difficulties that makes life more difficult. We primarily use Intensive Interaction to connect with them and explore communication and sociability in the way they want to.

For more information about Us in a Bus please contact us at www.usinabus.org.uk

Look around you. He is part of a loving family

Anonymous

Some people reading this story will be able to work out where this story takes place and possibly even who we are. If you do, then please do not tell. It happened and it is our story. We only tell it because it deserves telling. Situations like this help make us who we are. We are lucky to have each other. We hope it may help others in similar situations.

Having been teachers it has always amazed us what goes through the minds of children yet we never truly know and they constantly amaze us. We feel we are a normal family, two parents with four children, three sons and a daughter. The only thing that sets us apart is that our eldest son has PMLD. So to the other three a normal childhood was one spent visiting hospital to see their brother, missing the start of holidays or having to come back early. A whole life arranged around their eldest brother. Up until they were teenagers, they thought every family had a brother like him. They missed some subtle changes in our lives such as when we stopped climbing mountains on holiday because their brother was too heavy to carry or when we stopped sailing for safety reasons.

They have all left home now having had fulfilling school lives with a good balance of sport, music and activities that have taken them around the world. They have all got successful careers. They are decent, thoughtful, well balanced people who make us proud. We are also now grandparents. Their elder brother spends his time between us and respite care and receives as good care as we can arrange from some excellent professionals and carers who arrange for him a varied social life.

Last year our three younger children told us something which took the wind out of our sails and made us wonder what kinds of thoughts they had had through all those years and what kind of strain having a brother with PMLD really put on them.

What they told us took place more than 20 years ago when their brother was 14 and they were 12, 9 and 6. Once again we were on the children's ward at the hospital on the 13th floor. It was a Sunday in late September. He was desperately ill with pneumonia, not the first or last time we had been in this situation. This time was so desperate because of a complete white out of one lung, that his paediatrician spent all afternoon with us, and the ward sister flitted in and out. The children spent their time in and out of his room and the playroom. The paediatrician had arranged for a couple of doctors from intensive care to come up with a view to him going to spend some time there.



At this point we were all in the room, the other three over in the corner chatting and looking out of the window. The views up there were wonderful. That's what we thought they were doing anyway. Our minds were concentrated on the two intensive care doctors who were trying to persuade us that intensive care might not be the way forward for our eldest. We should consider what quality of life he would have after intensive care. It was a very bleak few minutes.

The paediatrician we could see was getting quite irate and merely said "Look around you. He is part of a loving family". After the doctors had gone one of our eldest's siblings came across and asked if he was going to die. "No, he isn't" was the reply - but we had fingers crossed behind our backs. Our eldest ended up in intensive care and lives for us to tell the tale for him.

What we didn't know though was that over in the corner our three younger children were not discussing the views from the windows. They were arranging between themselves a pact. If their eldest brother did die, they were going to try and find a way of jumping out of the window so they could join him.

The parents want this story told anonymously.

Since writing this article Matthew died peacefully with his family around him on the 19th November 2019.

The 2020 National Learning Disabilities Awards celebrate excellence in the support for people with learning disabilities and aim to pay tribute to individuals or organisations who excel.

The Supporting People with Profound and Multiple Learning Disabilities Award

Many people with profound and multiple learning disabilities (PMLD) face disproportionate challenges in life. With person-centred, collaborative and creative support, people with PMLD can lead a full, healthy and active life and be active citizens in their community. This award celebrates innovative and inspiring practice that achieves positive outcomes for people with PMLD. The judges are looking for evidence from social care, health and education of teams or individuals who are having a profound impact on the lives of people with PMLD.

Who should apply? The awards represent all areas of care and support for people with learning disabilities and autism, whether it be young or older people, supporting people in their own homes, the residential care sector or the voluntary sectors. From frontline staff such as care workers and care managers to people who have made an impact in other ways such as training and innovation.

Closing date for nominations is 30th April 2020

<https://www.nationalldawards.co.uk/>

A GOOD DEATH

The role of the Learning Disability Nurse in supporting a family through the loss of a son

Theresa Lambert

I have been a community learning disability nurse for the past 35 years. In this time I have supported many families through the loss of a loved one. To be able to offer support to a family at such an emotional and often painful time is a privilege. Most importantly, to be able to prepare and support a person with a learning disability to have a “good death” will remain one of the things that I am most proud of in my role.

I had been working with Jay, who had profound and multiple learning disabilities (PMLD) for 18 years. He lived at home with his mum, who provided the highest level of care to her son, with the help of his dad who, although divorced from mum, would return to the family home each day to support their son to get ready to attend his day service.

My role initially had been to monitor and respond to Jay’s changing health needs. He had problems with chronic constipation and intractable epilepsy. When Jay had been very young, he had been hospitalised on several occasions due to both conditions, which left mum with constant anxiety of a relapse at any point. Initially mum’s high levels of anxiety were impacting on Jay’s quality of life as she would prefer to keep him at home, in her sight and use a lot of medication to stimulate regular bowel movements in the hope of avoiding any obstruction or constipation.

I worked to gain mum’s trust and to ensure that Jay’s health needs did not prevent him from living a life full of the things that I knew he enjoyed.

Jay loved to attend his day service. He was a very sociable young man and enjoyed spending time with his friends. He was cheeky and fun-filled, and knew exactly how to command the attention of his carers. Jay experienced the world through his senses. He loved nothing more than to rifle through a box full of crinkly paper and different materials, throwing them all over as he did so. He would hold them close to his ears to listen to their individual sounds and then pass them to care staff to do the same as if he was letting them in on some big secret. Jay would smile throughout this interaction and expect carers to enjoy the activity as much as he did. Jay was very brave; he would bounce back from illness or seizures, keen to get back into his routines with his friends. If held back from his routines, due to people’s concerns about his health, he would quickly become sad and appear passive and disengaged.

By 2017, Jay’s health had deteriorated considerably. He had been diagnosed with severe Pancreatitis. He was now receiving all his nutrition via a gastrostomy and spent most of his time in bed at home. Having remained as Jay’s community nurse for many years, I had been able to gain the trust of his family and lead and guide them in all decisions that we had to make in his best interest.

As Jay moved into the palliative phase of his life, more professionals became involved. The palliative team were on board, but happy to be guided by myself and family. Mum needed a lot of support to understand what was happening to Jay and the interventions necessary to keep him comfortable. At a best interest meeting at the GP surgery, mum felt confident and able to say that she wanted her son to remain at home for the final part of his life. When I first started working with mum, if Jay was ill, she only felt safe when he was in hospital. Hence this was a result of a long standing relationship built on trust and support, which had enabled her to feel able to keep her son in his preferred place of care and continue to provide for all of his needs as she had done all of her life.

Jay’s health needs were being met by myself, the palliative team and a very supportive GP; however I was always concerned about Jay’s lack of access to stimulation, knowing what a sensory being he was. I was always looking at how I could support his emotional wellbeing as well as his physical needs. I spent many years supporting mum to understand why Jay would rock so much, rather than sit down and why he would pinch her newspaper and flap it around his ears to listen to the ‘secret crinkle’. She did not always seem to be able to process this information as her main anxiety was around his health needs. Imagine my surprise when in October, I visited the home to find it fully decorated for Christmas. Jay looked as if he was laid in the middle of a grotto. Mum had hung decorations from the ceiling and had Christmas lights all over the bed. I asked “why?” and she replied that she had been listening to me for years talking about Jay’s sensory needs and had noticed that

Christmas always seemed to make Jay smile! When I looked at Jay, who had been sleeping a lot due to the Morphine in his syringe driver, he had the biggest smile on his face. At this moment, I remembered why I had become a learning disability nurse. Jay passed away later that day. I was with him, holding his hand and crinkling some Christmas paper, one last time. Mum wanted me to be there. She wanted to scurry around, making tea and talking to family, whilst I sat with Jay in his 'grotto'. After months of Jay having a crinkled brow, due to discomfort, mum's lasting memory of Jay was of his smile as he looked up at his Christmas decorations in October.

I had the honour of providing last offices for Jay and remained with him until he was taken from his home.

I was aware that I could not make Jay well; however I was pleased that I was able to ensure that he had a good death. Jay passed peacefully and his very special mum still talks about her beloved son in his 'grotto' smiling. She has been left with this legacy and this has helped her to know that at the end of Jay's life, she had been able to provide the same level of care that she had done all of his life.

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Raising the bar - COP for the PMLD care standards

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

See you online



Victoria Willson: a teacher and pioneer

Jean Willson

At six months old, Victoria was diagnosed with Tuberous Sclerosis. This affected her brain, skin, and later her kidneys. She had profound physical and learning disabilities, scoliosis, uncontrolled epilepsy, and behaviour which could challenge. She communicated with her eyes, was a full time wheelchair user and was totally dependent on others for all her needs. Throughout her life she had major health problems, often in hospital with critical conditions. However, she lived an amazingly full and active life, in spite of her disabilities. Victoria was a pioneer, innovator, teacher, activist and actress and a wonderful role model. She had a wicked sense of humour and loved music, food, men, fun and adventures; going to operas, concerts and pubs; and hosting parties in her house.

Victoria's illness

In 2006 her renal team diagnosed many tiny tumours in her kidneys; and transplant and dialysis were not an option. So began the long process of kidney failure. In 2011 the ELiPSe Palliative Care team entered her life. Her palliative nurse had never worked with people with learning disabilities. The care provider, Centre 404, provided a highly skilled and well-staffed team very able to support someone living in the community. Her parents, sister and two friends were able to demonstrate and articulate just how they wanted Victoria to remain living in her own home.

Everyone had to learn to work together and using a Person Centred approach; good listening skills, reflecting back and being honest it began to work. Initially the Palliative team were surprised by our experience and expectations! We were relieved when we found they could open doors and had the professional ability to apply and get other medics to follow our protocol. For example Victoria would never now go hospital, but could be treated either at home or in an ambulance. Both provider and palliative team followed the family's wishes. Together we wrote her End of Life Advanced Care Plan. We all agreed that no radical treatment would be given, and she remained happily in her own home, until she died peacefully on 22 Sept 2014, aged 43.

Who was involved?

Victoria lived safely and happily as a tenant in a house near Kings Cross for 23 years with another disabled woman. They had a 24 hour package of support. Centre 404 was the service provider, and the ELIPSe Palliative team were involved from 2011.

Victoria's parents, sister, and five of her Circle of Friends were a constant source of support and guidance. For the last two years of her life her mum visited the house most days.

There were many professionals who were totally committed to Victoria continuing to live in her own home. They were her GP, community nurses, physiotherapist; occupational therapist; social services; masseuse, hairdresser and a psychologist who supported her team during the last year.

Care planning

Victoria had the most detailed Health Action Plan, Health Passport, Care Plan and finally Advanced Care Plan. These documents were jointly written by her teams and parents and proved invaluable working guidelines.

As her physical condition deteriorated with her kidneys failing, great care had to be taken with hygiene, eating and drinking, showering, changing and moving her. She developed chronic anaemia, itchy skin and bouts of nausea and diarrhoea. She needed great encouragement to eat and drink and take her medication. Between us we worked together on solutions, i.e. giving crackers before eating, using Aloe Vera for her skin. Her exceptional team became even more patient, inventive and highly skilled. As she grew weaker and more tired, pacing her and her moods was imperative. Now the world came to her, and to keep up everyone's spirits we had themed tea parties and visitors to the house. Together we sought new things for her to experience when she was awake. Her bedroom became an emporium full of smells, sounds, things to look at, and tactile objects to feel. It was made more colourful with fairy lights and flowing silk drapes. Music, her passion, was used to pacify or stimulate and we all became experts in reading her body language.

The end of life

Everyone knew Victoria was dying, but no one knew when. Victoria, always the enigmatic woman, would decide when she had had enough.

For two long years, her and Lisa's home was always full of marvellous music, fun, love and laughter, with visitors raising their spirits. Visitors told us they were apprehensive about visiting a dying woman, especially one with such profound disabilities. However, all of them left inspired and humbled by the love and care that

surrounded our daughter, and Victoria certainly showed enjoyment at seeing guests!

Gradually Victoria's strength diminished and she came more and more tired and crises were coming more frequently. In the week leading up to her death, many people popped in to say goodbye. Someone was always holding her hand. We all sat in her bedroom, gossiping, drinking tea, telling her what was happening in our world. Very moving moments.

Victoria's mother describes the last day. On Saturday 21 Sept the Palliative team told us to stop food and drinks, and we, her family knew this would be her last day, and we told her staff and Lisa (her flatmate) to say goodbye. This was so poignant and heart-breaking as each spoke personally and movingly to her. At 11 pm I told my husband and daughter to go home and get some rest. I would stay with Victoria and her night worker. At 3 am with both Emma and I holding her hands, in her own beloved bedroom, surrounded by things she loved, soft twinkling lights, and 'Namaste' her Buddhist Monk's music quietly playing, Victoria died very gracefully and peacefully. Her face immediately lost its pain and grey colour, and once again our much loved daughter became beautiful and at peace. My husband and her sister arrived, we all cried, and said our goodbyes. When the death is good all the pain is forgotten. We three women then washed and dressed Victoria in her specially chosen clothes. This was our last and final gift to her.

It was a colourful pink funeral, with a pink coffin and was a celebration of her life. A staff member, her three friends, a doctor and all her family all spoke. Her favourite music was played. It was held in our local church, which has strong links with our learning disabled community. Over 400 people attended, and everyone wore something pink, orange or red. Vic's colours.

Victoria's legacy

Victoria left an extraordinary legacy as a courageous and inspirational young woman, who made us realise what's possible for people with profound and multiple learning disabilities. She was able to make everyone who met her give her unconditional love; she brought out the very best in people, she made family and professionals work in a team. The amount of love, energy and drive that Victoria inspired around her was undeniable. She taught us patience, tolerance, and some understanding of what it was like to have such a profound disability, and how she made sense of the world, and in doing so we have worked hard to improve the lives of other people with learning disabilities. It feels to me that Victoria was a pioneer; some of us who were involved in her care had very little previous experience of taking care of such a vulnerable but simultaneously powerful person in the final stage of her

life so she was a great teacher who has helped prepare us to care for others in similar circumstances” Palliative Care Clinical Nurse Specialist.

Victoria was able to breach the biggest barrier in the disability world and that was to change attitudes. In 2011 Victoria was nominated by Mencap as one of their top twenty inspirational public figures who had made a difference and she became a Mencap Ambassador. She was “the face” of many campaigns of change for people with learning disabilities such as Valuing People, Death by Indifference and Changing Places.

Looking back

“I will always cherish the memory of supporting Victoria in the end stages of her life in both a professional and personal sense. Like her health deterioration, the journey for everyone else wasn't smooth or 'by the book'. I remember some emotional and frustrating lows but also some unexpectedly jolly highs. One of the challenges was watching Victoria become less able to go out and do as she pleased but it was also fun creating ways that we could make the day enjoyable if it's going to be a day in bed or a day without food!” Team Leader

I hope that the workers, who were with her all the time, realise how grateful wider health care professionals were to see the quality of the care that Victoria was in receipt of from them and how impressive their adaptability was as Victoria condition deteriorated. I will always remember a happy, tinfoil and pink feathers laden home where the workers wanted to be there and where the love and protection of the family was always present.” *Palliative Care Clinical Nurse Specialist.*

“Her family look back now with peace and pride in being part of the team that enabled Victoria to live happily and die majestically.” *Jean Willson (mother)*

“I've learned that supporting someone in their death is just, if not more, rewarding and important than supporting them in their life. I've also learned the meaning of a 'good death' which was a term I hadn't really heard or understood before. I've learned that when it's my time to go I hope to do so just like Victoria, in the comfort of my own bed with loved ones and fairy lights and music.” *Team Leader*

“I've learned that there are communications that can extend beyond verbal and nonverbal cues – like transmission of a feeling; for months with Victoria I had to rely a lot on people who knew her well for insights and then one day, I got it – she let me see something. It wasn't that she couldn't communicate with me, or that I wasn't able; she took her time to decide whether I was Ok or not. It's very precious when you get that

look.” *Palliative Care Clinical Nurse Specialist*

Together, her family, her circle of friends, Centre 404 the service provider and the palliative care team gave an outstanding end of life support to Victoria. We now want to continue this work for other people with learning disabilities and their families

Contact details

Victoria and Jean's story is from the Palliative Care for People with Learning Disabilities Network website and has been reproduced here with their kind permission. To read this and other stories in full on the PCPLD website see: www.pcpld.org/real-life-stories/

A bond beyond

Sarah Walker

*A lifelong contract to love and care broken too soon
A 'sacrifice' as instinctive as breathing
A sibling bond beyond
My child, my everything, my core
The future shattered into a stranger
I have lost and am lost
My identity so implicitly conjoined with yours
Tormented by the trauma of those final minutes
Watching a life your life stolen away
To witness the sorrow of a team so used to this and yet touched by you
Taunted with regret
Wrapped in memories, reaching for you
You're almost in my arms, an imprint, a tattoo of touch
I carry you always
A bond beyond*



The image accompanying Sarah's poem and the article Loss are from a photographic collection entitled Our Human Condition by Professor Paul Wenham-Clarke about sibling relationships and disability. The photo here is included with his kind permission.

More on this 'siblings' project: <https://www.wenhamclarke.com/our-human-condition>. Visit the exhibition: 8th – 19th Jan 2020, The Gallery@OXO, Oxo Tower, Wharf Bargehouse St, South Bank, London SE1 9PH.

Loss

Sarah Walker

Loss. As we move through December, I am reminded of the poem featured during the funeral in the film 'Four Weddings and a Funeral'. The poem is Funeral Blues by W.H. Auden.

"Stop all the clocks, cut off the telephone,
Prevent the dog from barking with a juicy bone,
Silence the pianos and with muffled drum
Bring out the coffin, let the mourners come."

My little brother Sam passed away suddenly this March. This December marks two firsts, on 12th December it is his birthday and then of course we have Christmas. It feels disorientating that everyone is going around seemingly oblivious to our pain and loss. I am usually the biggest fan of all things Christmas but this year the whole spectacle feels like a personal affront. Jolly Christmas songs, beautiful lights, cards and gifts, they all clash against this fog of grief. I'm stunned when people tell me to have a Merry Christmas; I feel as though surely my heartbreak is written across my face for all to see. Sometimes it feels like the Victorians had it right. If I was wearing mourning clothes then perhaps it would remind those around me. A woman in full mourning wore a veil to cover her face when she left the house, that sounds tempting some days!

Sam is not our only loss. Our bereavement has also brought with it the loss of friends, some of whom we have counted as close for over 3 decades. Where have they gone? When I reflect on my own behaviour after friends of mine have suffered a close bereavement, I realise that I was not there anywhere enough for them. I have apologised to some because this experience has taught me just how isolating grief is. People are worried about saying the 'wrong thing' so they say nothing at all. Yes, some people say ridiculous things but in the main I'd rather that than trying to guess if they even know or if they just don't feel the need to mention it.

A common quote I've seen across social media is "If you know someone who has lost a child and you're afraid to mention them because you think you might make them sad by reminding them that they died, they didn't forget they died. You're not reminding them. What you're reminding them of is that you remember that they lived, and that's a great, great gift." Elizabeth Edwards.

I know this is about the loss of a child, but I think one thing that is often overlooked with my grief is that a sibling carer such as myself may experience the same kind of loss as that of a parent losing a child. Everyone's



grief is different and valid but for me the loss is dizzying and all consuming. I have lost someone that I saw as a part of every single day of my future. Caring for Sam was my first consideration for any plans I made and thoughts of the future I had. That future is now lost, and all the time spent worrying about how I was going to manage caring for both my brothers Dan and Sam (once our parents could no longer share it with me) seems a complete waste of time.

Lots of people say "I think of you every day" but unless they actually pick up the phone or pop round, then that sentiment feels empty. Today we received a Christmas card from a family friend. We have not seen or heard from them since Sam's funeral and inside was a generic message that will have been written to their entire Christmas card list. What is the point?

I usually enjoy making well over 100 cards each year. Not this year. I won't sign a card without adding Sam's name and the entire thing seems pointless for those who have been unable to stand with us in our grief. I hope Christmas can bring happy memories again at some point. Sam truly loved the tree and all the songs but for this year Christmas is a painful milestone to get through.

W.H. Auden's Funeral Blues poem continues with "He was my North, my South, my East and West, My working week and my Sunday rest, My noon, my midnight, my talk, my song; I thought that love would last forever. I was wrong."

The first 3 lines feel so accurate, but I don't agree with the 4th - love last s forever, that's why this hurts so much.



Contact details

Sarah Walker

Sarah has two blogs:
<https://saydubaitotherain.home.blog/> about her brothers Sam and Dan

<https://bemoresam.home.blog/> is a newer blog about grief and living with loss
Her Facebook page: #sibliffe is for adult siblings.

For information on ATRX syndrome:
<https://www.atrxsyndroom.nl/en/home-2/>

'Funeral Blues', originally written in 1936, is included in a recent collection - W H Auden (1994) Tell me the truth about Love: Ten poems

"If you know someone who has lost a child and you're afraid to mention them because you think you might make them sad by reminding them that they died, they didn't forget they died. You're not reminding them. What you're reminding them of is that you remember that they lived, and that's a great, great gift."

-Elizabeth Edwards

When dad dies...

Helping people with profound learning disabilities cope with bereavement

Irene Tuffrey-Wijnes

The death of someone close to us is one of the hardest things we ever have to cope with. We can never be really prepared, nor can we make the process of grieving quick or easy. It takes years to adjust to a world that doesn't have the person we love in it. That world can never be the same again.

How much more difficult is this for someone with profound learning disabilities? Their world may be utterly shattered by the death of a parent, for example. It's something most parents of people with disabilities will have thought and worried about for a long, long time. *"What will happen to him when I am no longer there?"* The question is not only a practical one (*"Who will look after him, and will they do it properly, with love and care?"*) but also an emotional one (*"How will he cope with missing me?"*).

In this article, I will share some of the things I've learned over the past 35 years of living and working with people with learning disabilities, many of whom had to cope with significant bereavements; and of doing research into death, dying, bereavement and learning disabilities. I am going to tell you the real-life story of Carlina Pacelli (not her real name), who moved into a community-based home for six people with learning disabilities where I was the manager at the time. Carlina, a woman in her 30s, had profound learning disabilities and was a wheelchair user. Until the move, she lived with her parents, who were getting increasingly frail and were struggling to support Carlina. This was a huge transition for the parents as well as Carlina. Her family was close and loving; her parents, brothers and aunts visited often, and she went to see her parents at their home every other week.

Helping Carlina to cope with her parents' deaths

Five years after the move, Carlina's father became gravely ill. We could not explain this to Carlina, as she did not understand words at all, and did not use them. The only way to 'tell' her was through experience, and through showing her. We took her to visit her father several times in hospital. When he died, the family felt unable to support Carlina, as they were coping with their own strong feelings of grief. How could we help her? I have always found it quite helpful to think about the

'tasks of bereavement' (a concept suggested by Worden (2009) in bereavement counselling). These tasks are in no specific order and each one may be revisited or repeated, depending on the needs of the person:

1. Accept the reality of the loss
2. Process the pain of grief
3. Adjust to a world without the person who has died
4. Find an enduring connection with the person who has died

How could Carlina be best helped to understand the bad news of her father's death? It's difficult to 'accept the reality of the loss' if you don't know or understand what has happened. It was the first time someone in Carlina's close family circle had died. Verbal explanations made no sense to her. Staff tried to talk about Dad with a sad facial expression, but Carlina, who was highly sociable and loved people talking to her, was mostly excited and pleased when they did so.

We took Carlina to the chapel of rest so she could see her father's body in the coffin. She was initially highly excited about this unusual outing, but when the initial excitement of the outing had subsided, she became very quiet, staring at him. She was helped to stand up from her wheelchair so she could touch her father's body. She didn't seem to understand and made it clear that she wanted to leave.

Funerals are important rituals where people with and without learning disabilities can share their grief. Even if someone is unable to understand what has happened, they are likely to pick up on atmosphere and emotion. There is nothing wrong, in my view, with sharing tears and distress – rather, the opposite is true! When I go to a funeral and feel sad, it helps me to see that other people are also sad. Carlina had never been to a funeral before. Unfortunately (I thought), but perhaps understandably, the family not want Carlina to attend her father's funeral, as they thought that she would not grasp what was

happening. They worried that her excited noises at seeing so many familiar faces gathered in one place would upset the family. I tried to explain that we could support Carlina at the funeral so the family didn't have to, but the family were adamant. In the end, we felt that we could not go against the family's wishes at such an emotive time. With the family's agreement Carlina attended the wake, held in the Catholic church the night before the funeral, with only immediate family present. She was very excitable at the start of the wake but became subdued after ten minutes. The atmosphere in the church was quiet and sad.

Over the next few months, we helped her to visit her mother at least once a week. At first, Carlina seemed surprised that her father's armchair was empty and she seemed to be searching for him, trying to wheel her chair through the house. Staff also invited Carlina's mother to visit regularly; these visits were different from before, as her mother would never have visited without her father. As the weeks went by, Carlina became more withdrawn and often seemed lost in her own world. We think it took her about a year to work out that her life had changed.

When Carlina's mother died three years later, exactly the same pattern was followed. Carlina saw her mother's body at the same chapel of rest; she attended the wake (but not the funeral); she visited her old family home, now empty, one last time before it was sold; and her brothers, rather than her mother, now made the Sunday afternoon visits to the residential home. Carlina was again withdrawn and subdued in mood for about a year. Grief has its own time table. We felt that this time, she was less excitable at the chapel of rest and at the wake, and seemed to grasp the sadness of the situation better.

I told this story in my book *How to break bad news to people with intellectual disabilities* (Tuffrey-Wijnes, 2013). Carlina's parents died more than 20 years ago. Since then, Carlina has been to a lot of funerals, as many of her fellow residents and friends have died. Earlier this year, we were devastated by the death of Carlina's housemate Carol, who moved in at the same time as her. They had lived together for 30 years. I was sitting at Carol's open coffin, which had been brought into the church the night before the funeral. Friends were coming and going, including people with learning disabilities. Some stayed for just a few seconds, others sat for a long time. Carlina came in and this time, she seemed to understand immediately what this was about. She looked, she was quiet, she seemed sad. She stayed for longer than I had expected, then wheeled herself out. I think that after all these decades of repeating the same patterns when somebody dies, she now understands death in a way that she couldn't when her father died. Explanations do not have to involve words.

The four tasks of mourning

1. Accepting the reality of the loss

Carlina's story illustrates how she was helped to understand the reality of her parents' deaths, and later, of the deaths of her friends. There were other ways in which we tried to help Carlina understand that Carol had died. We kept Carol's empty bedroom open, with flowers and photos, for several weeks. Carlina would often wheel herself past that room, hesitate, have a look. I think it's a good idea to try and find ways to let someone with profound learning disabilities see for themselves what has changed. Of course, you also need to take the person's lead; if they indicate that they want to leave, then they should leave. Helping someone understand the reality of a death can take years, but it is important.

2. Processing the pain of grief

I have found that many people try to protect or distract someone with learning disabilities from painful emotions. Perhaps this is because we worry that the feelings are overwhelming and will never stop. In my experience, however, most people (including people with learning disabilities) will find a balance between expressing distress and 'getting on' with life. Both of these are important. You cannot be in deep distress all of the time, but similarly, you cannot be cheerful all of the time either. People are truly supported by knowing that their sadness is normal, and that it is allowed. You can help by acknowledging their feelings and by sharing your own emotions about the loss (it's OK to cry!). Finding ways to remember the person who has died, with all the sadness that may evoke, is also helpful. You could use photos, storytelling, or anything that reminds them of the person – favourite objects, items of clothing, music they liked... anything!

3. Adjust to a world without the person who has died

This is hard. And the bigger the changes, the harder it is to adjust. Most parents will have thought about this (Carlina's parents did). If the death of a parent happens at the same time as a move into another home, there are so many changes and losses to cope with at the same time. Sometimes this is unavoidable, but it really is worth planning for change. If the change is unplanned, then try and see if people's routines or familiar surroundings can be maintained at all. Would it be possible, for example, for the person to stay in the parental home, at least for a while, perhaps with carers moving in? It's also worth planning for difficult times, such as birthdays and Christmas.

4. Find an enduring connection with the person who has died

People with profound learning disabilities need help in accessing memories. I've heard some inspirational stories and innovative ideas of helping people with this. Turning

a dead father's favourite jumper (which still smells of him) into a cushion; the son often cuddles it, and seems comforted by it. Or how about a group of proactive parents who are audio-recording their voices so that this can be used to 'talk' about them after they have died? I think that's brilliant. In fact I wish my own mother, who died five years ago, had done the same... I would love to hear her sing the songs of my childhood. Initially, it would have made me sob. But now it would make me smile. Our connections with the people we loved do indeed endure.

And when it comes to grief, really, we all need the same things.

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Irene's website offers some unique and flexible guidelines for use by practitioners, families and carers to ease the process of breaking bad news to people with intellectual disabilities

Irene leads a programme of research aimed at improving health care and end of life care for people with intellectual disabilities. She is a trustee of the Palliative Care for People with Learning Disabilities Network (which she chaired from 2008 to 2014) and chairs the EAPC Irene Reference Group on Intellectual Disabilities.

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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 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.

For more information contact The Editors (info@pmlmlink.org.uk).

Reproduced from Winter 2013 Wellbeing issue 76, pp34-36

Remembering Larry

Julia Barnes

During the half term holiday of October 2011, 15 year old Larry (a pseudonym) died unexpectedly. He was a real character with a fabulous smile, a contagious laugh and an amazing determination. Larry didn't speak but his vocalisations, gestures and facial expressions left you in no doubt at all as to what he was thinking! He was the king of 'if looks could kill' if you offered him something he didn't like but would also reach out to give you a full blown hug if he felt like it.

Hearing of his death was a shock – it wasn't believable, he had been so full of life and joy. It was hard for the staff to understand but how to explain it to his peers? As a special needs school we have to confront death more frequently than a mainstream school would expect to. As a staff we are necessarily resilient and can be philosophical over the vulnerability of many of the young people we work with. Even after ten years of working in a special school it is still something I find very difficult. During the school week I spend significantly more time with my pupils than I do with members of my own family. This time is not solely spent 'educating' but also caring; ensuring that our pupils with more complex needs are comfortable, pain free, not hungry or thirsty and are feeling happy, valued and respected. In these circumstances strong bonds are formed between staff and pupils. But it is still very, very difficult; a colleague discussed how we have to juggle our 'personal' response with our 'professional' response. All the time we are grieving we are mindful of how to respect pupils' responses, and sometimes accept a lack of them. I can feel myself welling up as I write this over two years on.

Our school caters for 138 pupils with a wide range of special educational needs, including moderate, severe and complex learning difficulties, profound and multiple learning difficulties, autistic spectrum disorders, sensory impairment, and physical disabilities. Students are in mixed ability pastoral groups of the same chronological age and attend some lessons in their pastoral groups and others in ability based groups.

The pupils in Larry's pastoral group had been supported to help them understand the deaths of other pupils and were familiar with some of the language we use. One pupil pointed out that; "Larry will now be able to walk and talk, as heaven is a wonderful place". But it was the students with PMLD whom I felt more concerned about. A classmate, Carl (a pseudonym) who had shared the same lessons for most of their past 3 years appeared to

be looking for him. Carl seemed quieter than usual, resting his head on the table rather than joining in with some of his favourite activities.

I searched for guidance on how to support young people with PMLD deal with the bereavement of a friend but there was very little information out there. It was a matter of doing what came naturally. In his book 'My Right to Play', Robert Orr described using the empty wheelchair of a recently departed peer to help to explain their absence to an individual with complex needs. In our Sensory Lesson Larry had often used his standing frame. We brought it into the room and encouraged the five remaining pupils to look and touch it to recognise that Larry was no longer there. We also found his favourite toy, a keyboard with a demo that Larry used to play and replay, which we all must have heard hundreds of times! I'm unsure how meaningful exploring the empty standing frame was but again two pupils looked around when hearing the familiar tune on the keyboard as if they were looking for Larry. Perhaps we helped to confirm a feeling of puzzlement rather than loss? One of Larry's classmates with severe learning difficulties used Larry's standing frame as an item for reverence. On more than one occasion he visited it and sat on the floor next to it; when asked what was the matter, he replied; "He's gone".

During the same lesson we read 'I'll Always Love You' (Wilhelm 2003), a children's book about a young boy whose dog dies and goes to heaven and misses his owner just as his owner is missing him. We have used this book successfully to support other pupils accept and deal with the death of a friend but somehow it didn't appear to reach this group of pupils with more complex needs. It went 'over their heads' and I could see pupils 'glazing over' appearing lost in the volume of text, while we adults didn't have a dry eye between us.

Crying and feeling sad was something we did not avoid,

we cried in front of students, explaining that we were feeling sad because we were missing Larry. Although the students with PMLD did not cry with us they did gently try to comfort us in their own way, leaning onto us and resting their heads against us. I am quite convinced that they understood that something sad had occurred.

During the following week I racked my brain over what we could do that would meaningfully support pupils to understand the loss of Larry. I didn't want us to simply have a single session of 'missing' Larry and that be it. As described by Penny Lacey (2009), introducing new activities, not even concepts, to our group of pupils with complex needs takes many, many repetitions before they can recognise what is happening and join in. I felt we would have to remember and show we were missing Larry many times before pupils would understand he really had gone. Not on holiday, not off poorly, but that he had died and 'gone' and would not be coming back.

In a supermarket I saw some tete-a-tete mini daffodil bulbs and bought a pot for each pupil in the group. I printed photos of Larry looking at his happiest, smiling and laughing. During the next lesson pupils were supported to look at and select photos of Larry and we glued them to the outside of the pots. Whilst we were looking at his photos and talking about him we played The Three Tenors, one of his favourite albums. Although it was a sad time it felt a more meaningful activity than sharing the story had done the week before.

The pots sat on the windowsill of the classroom and during each week's lesson we would play The Three Tenors, lift the pots down, look at the photos of Larry and water the bulbs. The bulbs sprouted, grew leaves, buds and then flowers. Over the weeks I looked forward to tending the bulbs and talking about Larry. Although poignant, it became a less sad time. Some of the pupils in the group who use spoken language would look towards the pots and talk about "Larry's daffodils".

As spring became summer the flowers died and we planted the bulbs on the hillside directly outside the classroom window. The change to the routine from lifting 'Larry's Daffodils' off the windowsill to water them to taking them outside, removing them from the pots and planting them in the grass seemed to be a little unsettling or perhaps unexpected for some of the pupils. We then removed Larry's photos and recycled the plant pots and the curriculum carried on. We did not make a point of talking about Larry from then on but we did mention him each time something such as a wobbling jelly reminded us of him!

When Larry's family were ready the School Chaplain held a whole school memorial assembly to celebrate Larry's life which his Mum, Dad and younger brother attended.

Photographs of Larry were shown and his family were presented with his Record Achievement. It was an emotional occasion for his family and for many of the staff and pupils but provided a definitive occasion in which to say goodbye to him.

A year passed from Larry's death and spring returned again. The daffodils poked their heads up above the grass and bloomed. I found that many members of the school community had been aware of our 'remembering Larry' project and people came into the classroom to look out of the window at the bulbs and chat about Larry, his life and to share fond memories. We remembered how his death had been a shock and hard to accept but a year later it seemed easier to be philosophical about losing him.

The pupils who had tended the daffodils in pots found looking out onto the hillside difficult due to the height of the windows and individual's visual preferences so we went out to look and touch them whilst remembering Larry. Students appeared to recognise the activity and repeated the familiar language about Larry 'gone' which we had used when tending the daffodils the previous year.

While I am not suggesting that the events I have described were the right way, they did help me and the other staff deal with the death of Larry. Neither am I suggesting that the activities helped the pupils understand that Larry had died but it did provide us with a regular opportunity to discuss him and his absence. At first, pupils saw and felt our grief and we were able to acknowledge their sadness or 'quiet feelings'. Over the weeks that followed we were able to talk about Larry with happier voices, without tears and I believe pupils felt this shift in our grief. It was also reassuring to know that our 'remembering Larry' project was acknowledged and supported by members of the wider school community and provided them with opportunities to talk about Larry and celebrate his life.



Reflections in 2019

Since the 'Remembering Larry' project I have discovered Erica Brown's book; 'Loss Change and Grief - An Educational Perspective' which explores the subject of bereavement in the mainstream and special school. I would recommend it to special needs teachers who feel they need extra information to support themselves or pupils dealing with death, not solely to cope at the time but to plan so that you are able to offer the most appropriate opportunities for pupils, staff members and families.

Since writing the 'Remembering Larry' article in 2013, we have experienced a further thirteen deaths of students from our school community. I imagine that isn't as many as some other settings but it requires resilience from everyone to continue dealing with the shock and grief within the school community.

There have been a few resources that have helped support us respond to these sensitive situations:

1. The Bereavement and Loss Learning Resource Pack from PAMIS clearly explains the process of bereavement as it might be experienced by someone with PMLD. There are valuable suggestions on how to write a personalised Multi-Sensory Story about bereavement and the concept of a Memory Box of important memorabilia.
2. Our local Children's Hospice which supports several of our students, delivered a workshop to teachers on bereavement. Experiencing training alongside colleagues was supportive and allowed for discussion. It became apparent that we all reacted differently - in experiencing grief, in our understanding of what was expected of us and, our support for students to deal with their grief was inconsistent. As a result, a Bereavement Policy was developed. Sharing this with the staff team has enabled a more consistent response. The workshop discussed different practical strategies to demonstrate the concept of death - the one which I have used successfully involved a bunch of flowers to show how things die. Having experienced another bereavement of a student I purchased a bouquet of white carnations which were placed in a (sturdy) vase. Students were involved in keeping the vase water topped up but inevitably the flowers withered and died. They stayed in place and their transformation from living to dying was discussed on

a daily basis. To emphasise the irreversibility of death students were asked to suggest ways to 'revive' the flowers. We tried warm water in the vase, adding sugar to the water and even planting them in the ground to confirm that it was impossible. The comparison to the death of their peer was made; discussing that there wasn't anything that could be done to bring them back.

3. Erica Brown's book, 'Loss Change and Grief - An Educational Perspective' comprehensively explores the subject of bereavement in mainstream and special schools. I would recommend it to special needs teachers who feel they need extra information to support themselves or pupils with a variety of abilities dealing with death, not solely to cope at the time but to plan so you can offer the most appropriate opportunities for pupils, staff members and families.
4. Joanna Grace has produced a beautifully sensitive Sensory Story called 'When You Were Gone'. This can be told in a generic manner or be personalised to the death of an individual. The materials provide a clear rationale of what to do and explanations of why. Fortunately, I haven't needed to use to use the story since I purchased it but it is on my bookshelf ready.

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Time to Say Goodbye

Julia Hancock

Many years ago I worked in a large hospital for people with learning disabilities. It could be a big, confusing place and little attempt was made to explain to its residents what was happening and sometimes people just disappeared with no explanation. Many residents showed signs of depression and bereavement for some years after losing a close friend, having been denied the opportunity to attend their funeral or to grieve in any way.

Over the years I have worked with families, carers and therapists to improve this situation and to talk about things which may be difficult – such as death, people moving away or an elderly parent being unable to visit. When someone died, particularly if it was a member of the household, there was a sadness, an uncomfortable atmosphere in the home, so it is important to give people the news as soon as possible. We cannot be sure how much an individual understands, or whether they can relate to photographs, so I would always use several props, backed up with simple words and phrases, “Mary has died”; “We won’t see her again”; “We feel sad”.

For example, when telling someone that their friend, with whom they lived, had died we would use the individual’s empty wheelchair, a hat that they always wore, or use a sound that we associated with the person who had died. If it seemed appropriate we would sing a goodbye song. We would pass round a photograph, all the time acknowledging peoples’ reactions and acting accordingly. It was rare for someone to react immediately by crying or openly seeming upset. If they did, it may have been in response to the sad atmosphere or uncertainty.

Wherever possible people should attend the funeral of a family member or friend, funerals are to say farewell. We should not just avoid a situation in case the individual becomes upset as it is an important part of the grieving process, but we can attempt to help their understanding and be sensitive to a person’s mood. Again we would use photographs, objects and music familiar to the person.

I have been with people who have responded to the death of a close person in very different ways. One lady took me to the bedroom of the person who had died every day for 15 days so we could check that she was not there. On the 16th day she decided not to come with me – she didn’t need to look any more. It was fortunate that the home staff didn’t clear the deceased’s room until after that point. Another person didn’t appear to react at all to the news that his mother, who visited him every week, had died. He showed no response to the sadness

of other family members, at the funeral or to his mother’s absence. Several weeks later he went off his food, became withdrawn and agitated with no other obvious cause. We talked about his mother, made up a memory box and supported him throughout. Everyone reacts differently, so we have to watch out for any change in behaviour, mood or physically.

Care homes these days are much more aware of the emotional well-being of their people and have a policy on how to support them through bereavement, responding to their needs sensitively and respectfully. It’s always important to acknowledge a loss, to speak about a carer who is leaving or a friend who may be moving away from the area and to recognise that an individual may experience similar emotions to when someone has died.

The staff at Us in a Bus feel a close connection to the people they support and they take time at every Staff Meeting to remember any who have unfortunately passed away. This is done fondly with love, remembering the good times and the person’s many accomplishments. Us in a Bus has also developed a set of guidelines to help their staff support someone following a bereavement and there are many other resources available to help.

*This article first appeared on www.usinabus.org.uk in June 2017 and is reproduced here with kind permissions from Us in a Bus

Contact details

Julia Hancock, Chair of Trustees, Us in a Bus

Us in a Bus work with a wide range of people who are often isolated and can find communicating with the world (and the people in it) a huge challenge. The people we support have profound learning disabilities and complex needs, often with sensory and physical difficulties that makes life more difficult. We primarily use Intensive Interaction to connect with them and explore communication and sociability in the way they want to.

For more information about Us in a Bus please contact us at www.usinabus.org.uk



Rationale for writing 'After You Were Gone'

Joanna Grace

After You Were Gone is a sensory story. I wrote it in response to being asked so many times for help from people supporting individuals with Profound and Multiple Learning Disabilities who had experienced a bereavement.

In days gone by we may have considered people with a profound learning disability to be unaffected by death. The idea that they did not understand it so it did not impact on them was common. It is not an idea that stands up to much scrutiny. Clearly not understanding death does not prevent you from experiencing a bereavement. Indeed there are arguments to say that people with profound and multiple learning disabilities experience more bereavements than those with the cognitive ability. They experience bereavement when someone they are close to leaves their life, perhaps because they move between classes or care settings. Someone they loved and trusted used to be there and now is not: they are gone. The person experiencing this absence is bereaved.

The question I was asked by people supporting people with Profound and Multiple Learning Disabilities who had experienced a bereavement was simple: "What do I do? How can I help?" What struck me was who was asking these questions. They were not naïve people, not people new to supporting people with complex disabilities, they were parents of teenagers with profound and multiple learning disabilities, teachers with decades of experience supporting people with complex disabilities. Not the usual people who ask for help. Something about death undermined the confidence of these people in their

abilities to communicate with and support the people with profound and multiple learning disabilities in their lives.

I am not an expert in bereavement by any measure. I have a lay person's understanding of the cycles of grief, the denial, the anger, the acceptance and so on. And I have experienced, so far, relatively few bereavements in my life. Like most of the population I have some basic skills for coping with death and supporting those who experience bereavements. I know remembering the person can be joyful and sorrowful at the same time. I know that individuals want to speak of the people who are gone, to say their name, to hear the stories of them and the things they did. I know people need us to accept them and their emotions as they are, when they are. I would never tell a bereaved person to "cheer up." And I know that time does not heal, the grief stays the same. People sometimes confess to me that they feel guilty for "not having got over it yet" as if you could in any way "get over" the death of a child or of a loved one. People grow with their grief, they develop more coping strategies to deal with it, but it does not go away, and many people would tell you they do not want it to. Their grief and their memories are what they have left of their loved one.

There is no difference in my head between my own emotional response to death and bereavement and the emotional response of people with profound and multiple learning disabilities. I expect them to feel as I would. Perhaps this indicates I have an accepting nature of difference, or perhaps it indicates I am autistic and prone to thinking that other people think like me. Whichever it is it seems to have been useful in this case. As when those people came asking “what do we do?” the answer to me did not seem complicated. You do what you would do for any other person.

If my friend were to experience a death of a loved one I would make myself available to them, I would encourage them to talk about how they were feeling, but I would not force them. I would ‘be’ with them. I would aim to demonstrate that I was accepting of them in their sadness. I did not need them to be happy for my sake. And I would bring up the dead person in conversation, I would speak their name. Perhaps because of the work I do I have had more second hand experience of death than the average person. I have heard plenty of families talk about the phenomena of people not mentioning their loved one to them as they do not want to open the wound or remind them that they are gone – as if they could ever forget, as if they don’t carry that person with them all the time. Speaking their name does not remind them of their loss, it reminds them that you are with them in that loss.

I would do these things regardless of disability, ability, and neurodivergency. I would do these things, or I would try (and most likely fail in a variety of ways as I am nothing if not human) for all my friends.

The people who asked me what to do would not have been stumped in other situations, in the face of a complicated hospital visit they would have found sensory ways to bring up the topic of hospital with the person they were supporting. In their responses to big emotions that person has, fear for example, or anger, they would have held the space and shown their acceptance of that person and their recognition of their emotion. They would be with them in their emotion, and would not insist on children’s TV levels of jollity at all times.

I wrote *After You Were Gone* to give those people the confidence to do the things they already know how to do. And to open up a space, a sensory conversation space, for people with Profound and Multiple Learning Disabilities who have experienced a bereavement to be in. The story talks about the things we did after you were gone, how we listened to your music, and shared the games you used to play. It is an invitation to sharing memory. It isn’t anything particularly impressive and you can do it yourself without the story. Just do not let death frighten away your confidence in your communicative

abilities. Words are a very poor currency indeed when tackling the highs and lows of life, so forget about them. Often the best thing we can do is simply be with a person.

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After You Were Gone can be purchased from:
<http://www.thesensoryprojects.co.uk/sensory-stories>

Reproduced from Summer 2012 Family & Friends Issue 72, p14

For my Daughter

Jo Roach

And you Suzie, what should I leave you?

Not the pewter statue of the boy

his right hand missing,

let him stay on the mantelpiece

for the second hand dealers.

Not photos of my mother who died

before you were born into that grieving time.

Not money, to be banked for you

by someone else.

Not my poems, you'll never read them.

But the very fiercest of watchdogs

who wouldn't sleep for a hundred years.

Constantine D & O'Donoghue [2007] Oxford Poets: An Anthology 2007 Carcanet Press

To read more of my work <http://www.poetrypf.co.uk/joroachpage.html>

Remembering - as all our lives matter

Sam Clark

“... A young tree grows better when it's planted in an area with older trees. The reason ... is that the roots of the young tree can follow the pathways created by former trees and implant themselves more deeply. ... Stronger trees share resources with weaker ones so that the whole forest becomes healthier... If you don't pass on your life experience by leaving a legacy, the wisdom you've gained through decades of difficult learning will disappear (Bozak, n.d.).”

At the Open University Social History of Learning Disability conference in 2018 there was a conversation about remembering the lives of people with learning disabilities and how often their experiences and contributions are lost if not recorded in some way. Jan Sunman and Jan Walmsley have taken inspiration from the conference and are working with some families and Learning Disability England to create obituary or remembrance pages, as a way of celebrating and documenting the achievements and the lives of people whose lives have ended, but who should not be forgotten.

The Guardian's 'Other Lives' obituary pages have also started to include obituaries of people with learning disabilities. The first one I remember reading was Carol Bell's, which filled me with a mixture of sadness and excitement: sadness at her passing and excitement that her life was being noted and celebrated in such a way. And when I read of Malcolm Barron's passing – a man I knew through his work as a self-advocate in the North East – I cried. I reflect that I reacted as I would to the death of any fondly remembered colleague.

This has, for me, underlined the importance of publicly

acknowledging the contribution of people with learning disabilities during their lives and also when they die. Their lives and impact will last as long as we remember their stories.

One of the values of inclusion is that 'We are all born in.' By ensuring all our movement's (LDE's?) members are celebrated through our rituals of death and remembrance, we affirm the value of their lives and the legacy they leave behind.

Death and dying are hard for many of us to face, but I think if we can actively remember people's lives, we can begin to challenge some of the assumptions about the status of people with learning disabilities. All people.

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Values of Inclusion

Everyone is born in

We are born among people, and only sent away later

All means all

Everyone capable of breathing is entitled to be included. No one is too difficult, too old, too poor or too disabled to qualify

Everyone needs to be present

If we have never been present, no one will know when we're missing

Everyone needs to belong

We need to know there's a place for us, not just a space for us

Everyone is ready

None of us has to pass a test or meet a set of criteria before we can be included

Everyone can learn

As human beings we all grow and change and make mistakes: and we are all capable of learning

Everyone needs support

Sometimes some of us need more support than others

Everyone can communicate

Not using words doesn't mean we don't have anything to say

Everyone can contribute

We need to recognise, encourage and value each person's contributions - including our own

Taken from the Scottish Human Services

Capture the moment - Making memories

Lowri Jones, Leigh Wharton and Natalie Williams

As an old English adage states, 'a picture is worth a thousand words'. Since our time working with learners with PMLD and complex medical needs we have come to realise more than ever how powerful, pertinent and true this statement is.

There is an irony about trying to make memories in that we will not really know the value of a moment until it becomes a memory. That is why it's important to try to capture the little moments. When asked why we take so many photographs and videos and document so much of our learners' lives, our reply is that someday memories are all that we may have left.

Making Memories

Wiking (2019) states that "memories are the cornerstone of our identity, They are our superpower which allows us to travel in time and sets us free of the limitations of the present moment."

As educators of learners with PMLD we have an immense responsibility, not only to our pupils' education but also to their lives. We must fulfil and engage our learners with the best experiences possible and available to us, ensuring we are teaching them "What matters". We believe we learn best by doing and experiencing things. The best things about memories is making them.

We are so lucky to be working in an environment that celebrates the lives of all learners within our care. Every aspect of the day is special to our pupils. From the first greeting when they arrive through the school doors, to the fun and engaging activities throughout the day. Good home-school links are essential to the development of progress in the classroom and importantly, to relationships between staff and families in the present and, when looking to the future. Parents often find it very difficult when their child start school and more so when a child also has complex medical needs. We, as a team, feel very fortunate to be able to work with each individual family and learner to enrich their lives when they are in our care.

Every opportunity in school is taken to push the boundaries. With our learners, this is key to their development and also to create those special memories that will become so important in the future. We feel passionate about immersing our learners in all the activities that their mainstream peers are fortunate to experience (and sometimes take for granted). Pupils regularly go out on the school bus, take part in after-school activities and experience residential holidays.

Fundamentally positive risk taking for people with PMLD is important, because there are very real risks involved when you do not take positive risks. By not taking risks we may deny opportunities for development, for growth and for happiness. Without positive risk taking we restrict people's lives with less learning and less adventure. Embedding positive risk taking can be the difference between existing and living, between surviving and thriving (Veale, 2018). Every learner deserves the opportunity to achieve their potential and develop their skills to live life to the max.

Benefits of capturing the moment

There are many benefits from capturing the moment. These might include a photograph or video that can take us back in time; helping us to relive the little moments and becoming an emotional tie. It allows the person viewing those records to focus on the good. "A moment captured is worth so much more than a moment forgotten. No matter how imperfect" (Cooper, 2017).

So, what can we do we with all the photographs and videos?

Some practical ideas. Every photograph and video is uploaded to a cloud drive. One such cloud drive is Google Drive which can be found at <https://www.google.com/drive/>. Google Drive offers 15GB of free space, but you can purchase more space if needed. Other cloud-based drives include, for example, Dropbox (https://www.dropbox.com/en_GB), OneDrive (<https://onedrive.live.com/about/en-gb/>) and iCloud (<https://www.apple.com/uk/icloud/>). For the purposes of this article we will describe how to upload and archive to Google Drive.

1. You will need to create a Google Drive account. Once this account is created you will be able to access Google drive on your mobile device via an app or via <https://drive.google.com/>. You can then upload images and videos to Google Drive.
2. Open the Google Drive app.
3. Click on the plus symbol (Figure 1).
4. Click Upload (Figure 2).

5. Click Photos and Videos (Figure 3).
6. Select your images by clicking on the images and videos. These will then upload to your Google Drive account (Figure 4).
7. Once uploaded to Google Drive you can then create specific folders. When we create folders, we label them with the activity and date. If you have a group of individuals with PMLD you might add in their name or initials for easy retrieval purposes (Figure 5).

See next page for the figures.

This is a good tool to keep track of all your photographs and videos in one place and it can act help track progress of individual achievement. Should the time come when we have to say goodbye to one of our learners, we can easily retrieve images and videos. This approach makes it easy to share insights with new staff or a different setting – or for family to make a memory book or video.

Remembering

When compiling a book of memories, you can involve the person's peers to pick the images that they have a memory attached to, including them in this important process. You can use different approaches to do this. This could include having images and videos on a large screen with peers using eyegaze or a switch to select their favourite images. Alternatively, you could try using a e-tran frame with thumbnail images printed out - or simply review the photos one at a time.

Software such as Pic Collage enables you to create collages with several pictures and texts. Microsoft Publisher, Powerpoint or the BookCreator app allow you to create books, whilst video editing software such as iMovie or Movie-maker can create a bespoke video incorporating mixed media such as photographs, videos and music.

It's really important to involve everyone around the person in the process – whoever might be significant, from the office staff, dinner supervisors, nurses, educators, peers and their families. You can ask them to write down or share their favourite memory or even ask them to contribute photographs or a video.

Bensi (2019) perfectly sums up our feelings about making memories and capturing the moment. 'Parents, carers, colleagues and readers who have lost children: we want you to know something. We don't forget your children. We mourn with you. We question every decision. We relive every moment. We think of you on holidays and special occasions. We fight against the easier path, which is to feel numb so we don't have to feel the gut-wrenching pain of losing people. Ultimately, we want to feel with you. Your children walk beside us every day making us better at our jobs, helping us to connect more deeply. We carry your children as we carry on'.

Contact details

Lowri, Natalie and Leigh are Team Seren Fach, in the PMLD base, Ysgol Tŷ Coch, Pontypridd. @lowrijones110 @nataliejanewill @Leighwharton Ysgol Tŷ Coch is a 3-19 maintained special school in Rhondda Cynon Taf. The school was shortlisted for TES Special School of the Year 2019. www.ysgoltycoch.co.uk

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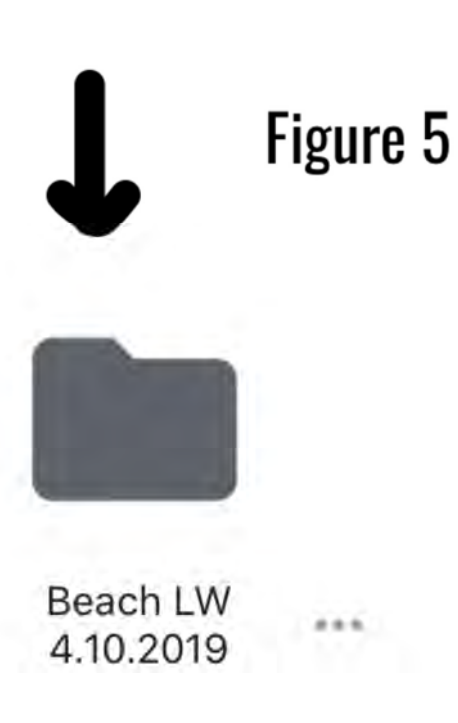
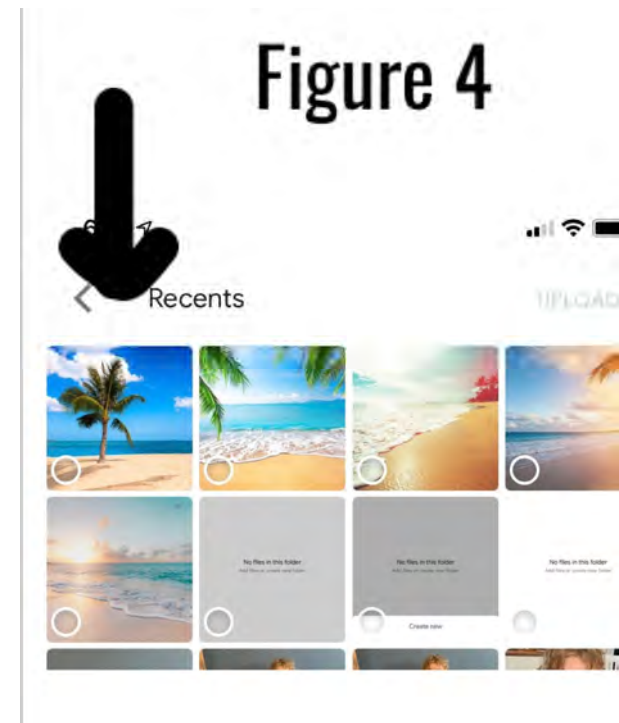
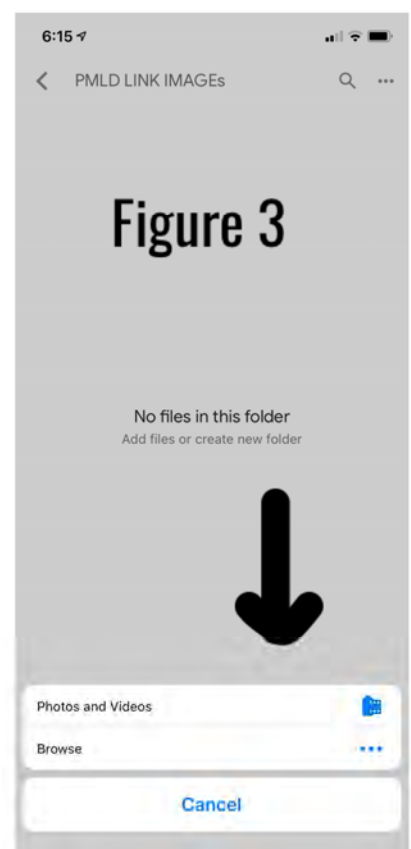
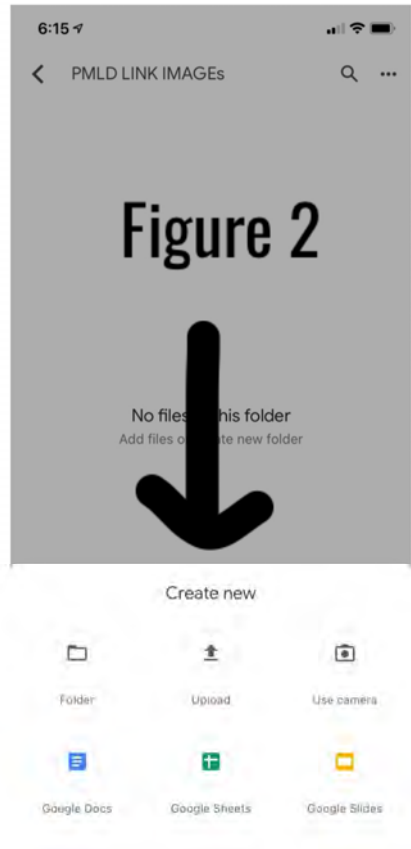
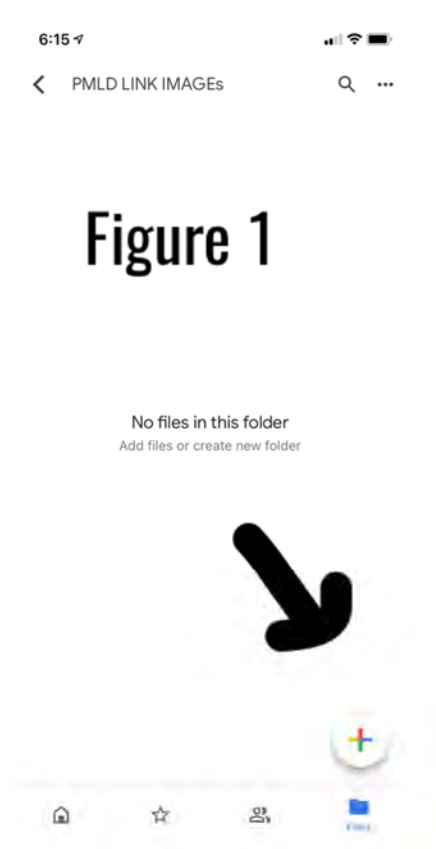
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Useful Apps

<https://piccollage.com/>
<https://bookcreator.com/>

Useful Software

<https://www.microsoft.com/en-us/p/movie-maker-10-tell-your-story/9mvfq4lmz6c9>
<https://www.apple.com/uk/imovie/>





Celebrating Lives ~ Living life to the full

The Leaders List 2019

PMLD LINK shines a spotlight on four award winners, sharing extracts from their inspiring stories that led to them being included on this year's Learning Disability and Autism Leaders List.

Steve Scown, CEO of Dimensions, told us, "The winners of the Dimensions' Learning Disability and Autism Leaders list in 2019 includes successful athletes and dancers, political campaigners and passionate self advocates, published authors and experts by experience. They are also individuals with mild, moderate, profound and multiple learning disabilities. Individuals whose autism manifests in many different ways and individuals with a wide variety of health needs. They are also individuals who have had to work harder than others to get where they are because, although we have come a long way, our society still isn't shaped with disability in mind."

"In this second year of awards we are thrilled that our judges chose to award several people with profound and multiple learning disabilities. And I'm especially delighted to see them featured on these pages as well as www.dimensions-uk.org/leaderslist2019. Enjoy their stories, and please share them widely - to inspire others."

This year's winners were announced at a glamorous Awards Ceremony in Birmingham at the end of November. Congratulations to everyone.

Campaigners Samir El-Ziftawy and Francesca Dunn

Winners in the category: The 2019 Michael Ludlam Award for Advocacy, policy and the media
Samir and Francesca in action (see image above)

Samir and Francesca are involved in a campaign they feel passionate about called "Changing Places", which calls for community spaces (like shopping centres, cinemas, restaurants, parks etc.) to have Changing Places toilets to make going out and staying out possible for people who have severe disabilities.

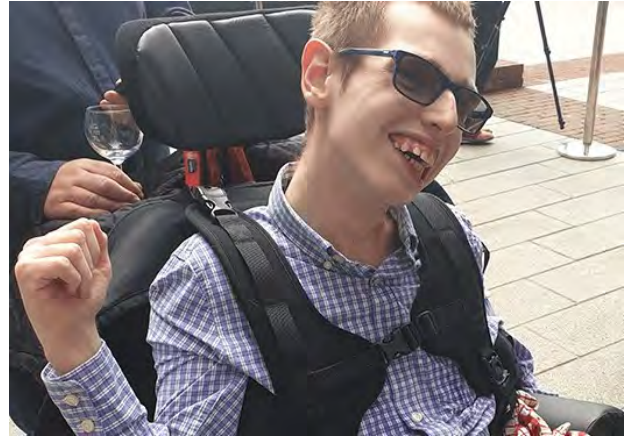
Through their involvement with self-advocacy group "Campaign 4 Change" Samir and Francesca were supported to speak to several large shopping centres in Brighton about Changing Places toilets. Both have also been involved in the group's presentations – Samir uses a specially designed switch to change slides. Samir and Francesca work together as a team... 'they come as a duo and support each other'.



Young Leader Rosa Mae Hancock

Winner in the category: The 2019 Oliver McGowan Award for Sports, arts and entertainment

Rosa acted as a consultant to co-produce and test out a sensory social story about what it might feel like to visit the circus. As a result of her work, anyone with additional needs planning to attend a Circus Starr performance can request these sensory resources - to help them prepare for their visit and know what to expect. Hopefully Rosa's valuable feedback and the insights reflected in these resources will enable people to have a much more enjoyable circus experience.



Determined self advocate James Walker

Winner in the category: Local communities

A chance trial of eye-gaze technology when aged 16, showed James had a great aptitude to with cause and effect games using this software – and even to speak through it to say 'Hello Mum' for the first time in his life. This fortuitous opportunity to try out this technology has enabled James to finally have a real voice. Now aged 21 and in his third year at college he is developing his skills of literacy and numeracy. Through his participation in a local Youth Parliament James now has his say on city-wide decisions and an influence on his local community.

To find out more and read the full stories of all award

In the Next Issue Spring 2020

Our Spring journal is a general issue without any theme. It is going to be a wonderful pick and mix of ideas and insights into the lived experience of having profound and multiple learning disabilities. As a reader you can expect a little bit of everything, a treasure trove of perspectives and inspiration, but we want you to consider your potential as a writer too!

Do you have a topic in your mind that relates to the lives of people with profound and multiple learning disabilities? It could be something you are worried about, it could be a piece of action research you have carried out, it could be something you discovered recently that works for you and your family that you think might help others.

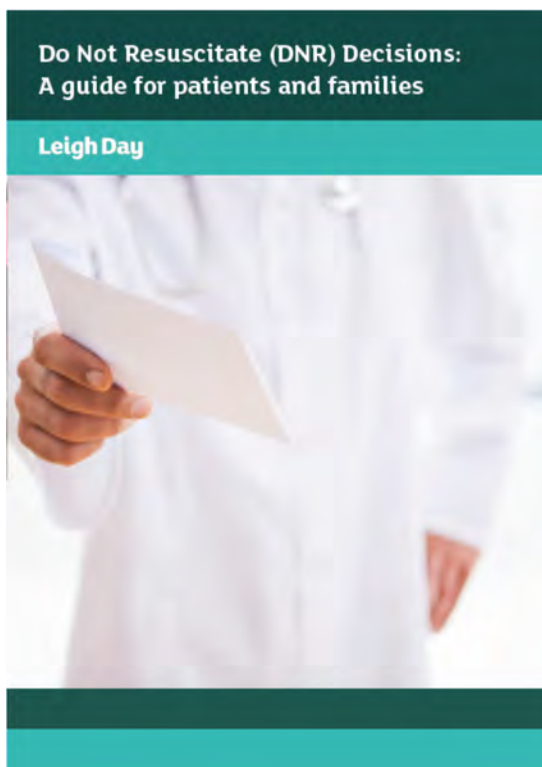
Our friendly team of editors are very happy to help you shape your contributions. We welcome submissions from those who have already published articles and those who have never been published before. Your insights are valuable and by sharing your knowledge, understanding and ideas you can have a positive impact on other people's lives as well as your own. We want to hear from you!

We are always keen to share relevant news, events, new resources or publications- so please let us know about these too.

All contributions
by 28 February please
to
info@pmlmlink.org.uk
or
sensorystory@gmail.com

Spring issue Editors: Joanna Grace, Bella Travis,
Maureen Phillip and Rob Ashdown

Do Not Resuscitate (DNR) Decisions: A guide for patients and families



Here is the link to a guide for patients and families about Do Not Resuscitate (DNR) decisions, written by Merry Varney from Leigh Day Solicitors:
www.leighday.co.uk/LeighDay/media/LeighDay/documents/Guides/DNR-leaflet_final.pdf

Introduction to the guide:

'DNRs, DNARs, and DNACPRs are all abbreviations referring to an advance decision made by medical staff not to attempt cardiopulmonary resuscitation (CPR) on a patient who has stopped breathing, or whose heart has stopped. In more medical terms, when a person is suffering respiratory and/or cardiac arrest. DNR is used throughout this guide, as it is the most commonly used abbreviation by patients and families.

Thinking about medical treatment at the end of your life is highly emotional for many people. It can be hard to listen to a doctor saying that they are unlikely to be able to restart your heart or breathing.

It is also hard for a professional who has spent their life trying to heal patients to deliver this news.

It is important that you know how these decisions are made so you can have informed discussions with your healthcare professionals, and hopefully reach an agreed decision. These discussions should take place between the patient and his/her healthcare professionals, with relatives and carers involved if the patient wishes or the patient lacks the capacity to have the discussion.'

Planning and supporting end of life situations and experience of loss: Information and resources

Life Story Books for people with learning disabilities- a practical guide

Helen Hewitt

Identity is what makes us unique. People with a learning disability are often denied the opportunity to consider who they are and how life events affect their identity. This is pertinent where individuals are faced with many transitions in their lives which can lead to lack of continuity and even loss of identity if their past experiences are not acknowledged. A life story book is an account of a person's life, including stories and memories of past events and relationships – all kinds of experiences that make us who we are.



Published by BILD. <https://www.amazon.co.uk/Story-Books-People-Learning-Disabilities/dp/1904082769>

Bereavement and Loss Learning Resource Pack and Training Learning Resource Pack

PAMIS Bereavement and Loss Learning Resource Pack is for those supporting bereaved people with profound and multiple learning disabilities and their parents and carers.

It is for parents, paid carers and professionals, and emerged from the shared experiences of people with profound and multiple learning disabilities and those caring for them.

The Bereavement and Loss Resource Pack is relevant to anyone involved in the lives of people with complex disabilities, including parents, paid carers, teachers, speech and language therapists and psychologists. The resource explores the following issues:

Unit I: Supporting bereaved people with profound and multiple learning disabilities

- understanding how bereavement affects us
- supporting people with profound learning disabilities
- supporting spirituality

Unit II: Supporting bereaved parents and carers who have cared for someone with profound and multiple learning disabilities

- caring for someone with complex healthcare needs
- experience of bereavement for families who cared for someone with complex healthcare needs



The Pack also includes a DVD with two 20-minute video clips of parents sharing their own experiences and those of their sons and daughters.

Free for families in Scotland or £24.99 to order from <http://pamis.org.uk/resources/bereavement-and-loss/>

Thinking Ahead; a planning guide for families



This guide, including easy-read and editable versions free to download from <http://www.togethermatters.org.uk/resources-and-information/>

Also available in hard copy through this website. See the article by Christine Towers on using this guide on pages 4-5 of this journal issue.

Written by Christine Towers



HfT - What happens when I'm no longer around?

HfT have produced a film for family carers who have a relative with a learning disability, autism, or both. It addresses the key areas of planning for a relative's future when you're no longer around. The film includes people describing the use of the 'Thinking Ahead' resource from Christine Towers at Together Matters. Their page also has links to further information and advice. Their Family Carer Support Service is available if you have further questions. Freephone 0808 801 0448 – answered Monday to Thursday 9am to 4pm. If you call outside of those hours, or if they are busy with someone else when you call, please do leave a voicemail – they'll call you back within seven working days.

<https://www.hft.org.uk/our-services/family-carer-support-service/fcss-updates/what-happens-when-im-no-longer-around/>

Delivering high quality end of life care for people who have a learning disability. NHS England and PCPLD

An accessible but detailed guide on all aspects of end of life care. Offers some very practical 'top tips' and signposting.

<https://www.england.nhs.uk/wp-content/uploads/2017/08/delivering-end-of-life-care-for-people-with-learning-disability.pdf>

NHS My Pain Profile – two versions to share information

A user-friendly, seven-page template to help share important information about how an individual may uniquely present pain and distress. This profile valuably shares information and advice on a person's 'usual well self' and by comparison how they may communicate or demonstrate when unwell, uncomfortable or in pain. Sections also include practical ideas on how to respond to pain and distress eg aromatherapy, gentle massage, pressure relief and positioning.



<https://www.dyingmatters.org/sites/default/files/user/images/pain%20assessment%20tool%20Notts%20final%20doc.pdf>

Handy two-page version of this pain profile template <https://www.stfrancis.org.uk/docs/default-source/education/education-resources/deserving-dignity-july-2019/2-my-pain-profile.pdf?sfvrsn=2>

PCPLD Network - Palliative Care for People with Learning Disabilities

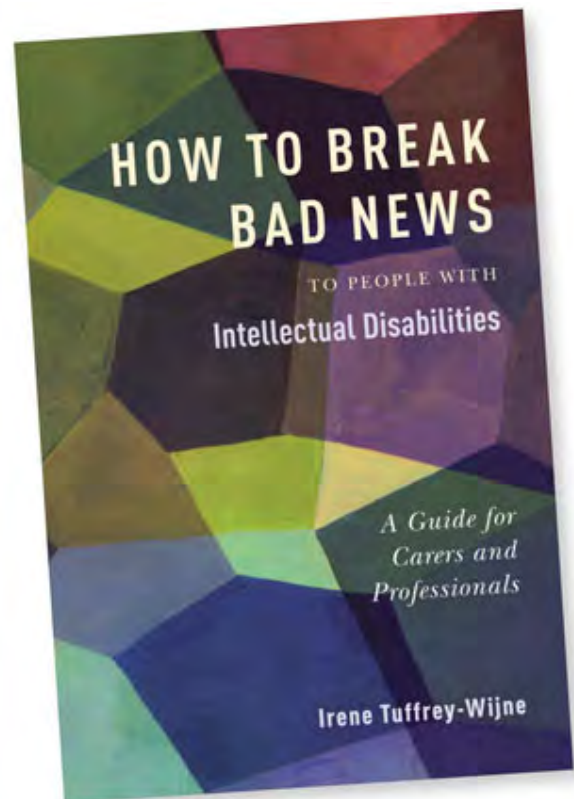
This website offers very valuable information and signposting to resources on many issues relating to end of life and palliative care. Topics addressed include pain and distress, planning for end of life, advance care and funerals, supporting people through diagnosis and loss, grief and mourning. <https://www.pcpld.org/links-and-resources/> Valuable insights are shared through some very positive stories about supporting people at the end of their life. In particular PMLD LINK readers will appreciate reading Jean Willson's story about her daughter Victoria, who lived and enjoyed her life to the full. <https://www.pcpld.org/real-life-stories/> Jeanne has written a number of articles on this journey for PMLD LINK – these can be accessed as a Guest Subscriber on our website <http://www.pmlmlink.org.uk/the-journal/back-issues/>

Breaking Bad News website – Irene Tuffrey-Wijne
This site offers information and advice about supporting individuals with learning disabilities who are experiencing loss and grief. It shares unique and flexible guidelines that can be used by practitioners, families and carers to ease the process of any type of situation involving breaking bad news to people with intellectual disabilities. These guidelines are adaptable to individual communication ability and level of understanding and include background information, explanations of the guidelines, practical tips and exercises. Ideal learning resource for social care, medical, nursing and other healthcare students, as well as postgraduate professionals. <http://www.breakingbadnews.org/>

How to Break Bad News to People with Intellectual Disabilities. A Guide for Carers and Professionals

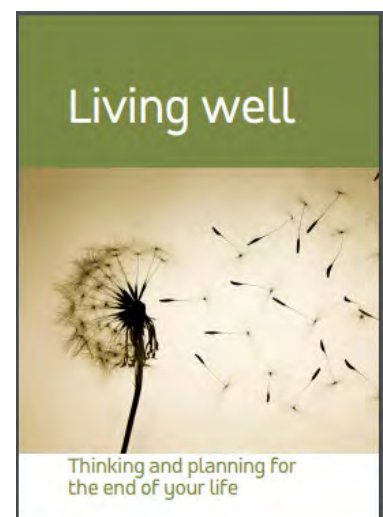
Irene Tuffrey-Wijne

This book offers unique and adaptable guidelines that can be used by practitioners to ease the process of breaking bad news to people with intellectual disabilities. It provides effective tips and support that will help social workers, counsellors and caring professionals relay all types of bad news as sensitively and successfully as possible. <https://www.jkp.com/uk/how-to-break-bad-news-to-people-with-intellectual-disabilities-2.html>



Living Well – HSA and Lancashire County Council publication

Living Well is a person-centred approach to supporting people to live well with a long-term condition. It also provides a structure to help people think about and plan for the end of life
<http://helensandersonassociates.co.uk/papers/living-well-planning-end-life/>



We all Grieve – Winston's Wish



We All Grieve from Winston's Wish, looks at how children with SEND are affected by a bereavement, how those around them can support them and help to develop the child's understanding of death and loss. Winston's Wish report 'There is a short section specifically on supporting a bereaved child with profound and multiple learning difficulties (PMLD) as well as more general information that could be relevant' This book is designed for parents, carers, educational professionals and other adults supporting children and young adults with SEND who have experienced the death of someone close to them. It offers information, practical suggestions and ideas for activities as well as where to find other support. <https://www.winstonswish.org/>

Sense publications to help families think and plan for the future

When I'm Gone, their 2018 report explains the issues in detail, tells families' personal stories and sets out their recommendations for change about family concerns. In response to these issues, they produced a toolkit called Decisions to make, steps to take. This is aimed at disabled people and their families, to guide them through the process of making choices about the future



<https://www.sense.org.uk/support-us/campaigns/when-im-gone/>

Gift Aid

Are you a tax payer?

Is your subscription to PMLD LINK for yourself and do you pay tax? If this is so and if you sign a gift aid form, then PMLD LINK can get an extra 25p for every £1 you pay to us for your subscription, in a tax refund from the government. This will help PMLD LINK significantly.

If you pay online via the website, you will be given the opportunity to fill out a gift aid form. If you have forgotten to do so or if you are paying by cheque or by setting up a bank mandate, please fill out the subscription form available on the last page of this journal or downloadable from the subscribe page of the PMLD LINK website (www.pmlmlink.org.uk). Send it to the PMLD LINK Treasurer at the address shown on the form.

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Many thanks for your support.

REPORT BACK

Raising the Bar III – PMLD LINK conference: October 2019, Birmingham



Friday 25th October 2019 was my first time at Raising the Bar, and I found the prospect of attending alongside a large number of professionals such as Learning Disability Nurses, Teachers, Parents and other Practitioners quite daunting. Nonetheless, it soon became the highlight of my year!

Raising the Bar gave me the opportunity to network with a range of inspiring people, who I felt an instant connection with, given that we shared a passion and ambition to improve the lives of children and adults with PMLD. This is what makes Raising the Bar so unique. It is a day filled with families, advocates and professionals who all share a genuine passion, the right type of knowledge and a keenness to learn and share. Everyone who attended Raising the Bar has an absolute commitment to people with Profound and Multiple Disabilities to lead an ordinary life.

The day was jam packed with a busy programme of events, from exhibition stands, presentations and a great range of seminars. I, along with everyone else there, was spoilt for choice. From the beginning to end, Raising the Bar had much to offer. Each presentation and keynote speaker showed insight into the lives of those who live with PMLD, each will stay with me forever. This day brought on a lot of emotions, thoughts and inspiration for us all, as well as highlighting the urgent need to raise standards of care for all people with PMLD.

Carrie-Ann Sutton, Creative Arts Practitioner



The day was absolutely packed with information, ideas and real insights into the need to raise the standards of provision for people with profound and multiple learning disabilities. Meeting so many amazing and passionate people was a real learning curve. I was especially moved by the stories of parents who shared their stories with a wonderful mixture of hard-hitting reality, joy and humour.

When PMLD LINK suggested that we have a stand at the conference, I was keen to attend as many families, organisations and schools find the programme helpful for children and adults with PMLD. I certainly didn't expect to attend a day where there was such a strong commitment for genuine movement for change.

It was a thought-provoking day with much food for thought and reflection. And plenty of laughter too! Thank you.

Mary Atkinson, Co-Founder, The Story Massage Programme



I was delighted to attend the Raising the Bar 2 conference on 25th October 2019, arguably the PMLD event of the year. The excitement could be felt in the air as over 200 attendees arrived at this sold out event which proved to deliver an inspiring and informative day to a wide ranging audience of professionals, family members, and people with PMLD.

As well as providing a packed programme of speakers, workshops and stalls to browse, the conference enabled attendees to take time out from their busy day to day lives to reflect, share ideas and gain new knowledge. It was a great opportunity to meet up with colleagues and friends, and to network during coffee and lunch with like minded people sharing a passion for supporting people with PMLD. At the end of the day who would not have left feeling enthused, recharged, fired up and ready to take the challenge of Raising the Bar of care, support and service provision to the next level?

Julie Calveley, PHD, RNLD, BSc(Hons) -
Independent Intellectual Disability Consultant and
Associate of the Intensive Interaction Institute

Sensory Symposium

In June Frozen Light co-hosted- Sensory Performance Symposium: 'Making, touring and programming theatre for and with young people and adults with complex needs', at Capital Theatre in Edinburgh, alongside partners Upfront Performance Network, Independent Arts Project and Capital Theatres.

Ellie Griffiths, the incoming Artistic Director of Oily Cart, has just toured her production Sound Symphony (designed for and with audiences with profound autism), around Scotland, and the symposium provided an opportunity at the end of the tour to share the experience of creating the show.

It was exciting to hear from artists passionate about making theatre accessible, and meet new people eager to make theatre for audiences with PMLD. Greta Mcmillan, a teenage Edinburgh artist who communicates and paints with 'eye gaze' technology, gave a keynote presentation, supported by her parents, about her artwork. Academic Ben Fletcher Watson gave a fascinating overview of the history of accessible theatre with complex needs. Eva Von Hofsten spoke about how the Scen:se project aimed to make the arts and theatre sector accessible to children with profound disabilities in Sweden. The project did this through the multi-sensory Sinnerligt exhibition and two sensory theatre performances as well as training in schools for teachers. In her presentation we saw how much is possible when people have a passion to create change, and make the arts more accessible.

Suzie and Kerry from Tenterhooks spoke about how their new multi-sensory clowning show MESS will tour SEN schools around Scotland this year. Natalya Martin from Feel Theatre spoke about how their UV show Sensory Circus is still touring SEN schools after two years, and they are currently developing new small scale sensory theatre that can tour in people's own homes. We also heard from Daniel from Concrete Youth who are a new company making theatre for audiences with PMLD, information on their new show is currently top secret-but watch this space!

Lucy, from Frozen Light, focused on Frozen Light's experience of touring to theatre venues across the UK, and reaching adult audiences with PMLD. Frozen Light have just completed a 13 month tour of The Isle of Brimsker performing 222 shows across 55 venues, and their presentation looked at what venues can do to reach audiences with PMLD.

During the day we also heard from Nwando Ebizie, who's sensory work made about neurodiversity 'Distorted Constellations' has attracted interest and enjoyment from adults and young people with complex needs and PMLD, which she is interested in developing in future work. As an art installation it offers a new genre in the sensory field. Also experimenting with new genres are Interplay who are exploring the use of VR technology within their work.

We took a moment, led by Dr Gill Brigg, to remember Matt Marks, a musician who passed away recently, who had created and performed in both of Gill's theatre pieces for audiences with PMLD, White Peacock and WAVE. He was also a regular performer for Bamboozle Theatre and extremely passionate about accessible theatre. It was a touching tribute followed by some clips of his music.

A panel discussion with venue programmers and festivals demonstrated the industries desire to want to programme more work for audiences with PMLD, and how programmers want to create more opportunities for artists making accessible theatre. The day ended with breakout discussions in the areas of research, artist development, play and working in the community. It was exciting to have so many people at the conference wanting to reach audiences with complex needs, and we really hope that now, post conference, there are more people eager to make theatre for audiences with PMLD.

Amber Onat Gregory
Co-Artistic Director
Frozen Light
www.frozenlighttheatre.com

Belonging and Not Belonging Social History of Learning Disability conference July 2019

Melanie Nind

The Social History of Learning Disability Research Group, based at The Open University are committed to researching and disseminating learning disability history in ways which are inclusive of people with learning disabilities, their carers, relatives and advocates. We are well-known for our inclusive conferences and the one held in July 2019 conference was no exception. The theme of the two-day event was Belonging and Not Belonging. Jan Walmsley, Dorothy Atkinson, Craig Hart and Ian Davies gave the opening keynote telling the history of the group as a space for belonging. The keynote on the second day was given by Sheila Hollins, tracing the shift from concern with 'an ordinary life' to the present day BELONG manifesto and #LDBelong campaign.

Other papers focused on the Hidden Lives Remembered project (Solihull), belonging in the business world (Barod), on TV (Beth Richards), in the community (Building Bridges), and in learning disability history (Simon Jarrett, David O'Driscoll, Nigel Ingham, Teresa Hillier). Most powerful perhaps were the individual and family voices from Ian Davies and Lyn and Sue Dumbleton and the joyful self-advocacy of People First Merseyside. I'm pleased to say that the one of the sessions was given over to the belonging of people with PMLD. Here research (myself and Iva Strnadova) and family perspectives (Virginia Bovell) brought a mix of celebration and challenge. We also celebrated the life of Johanna de Haas who died earlier this year, but who left a lasting impression as the person with PMLD who had co-presented with her mother Catherine de Haas at previous conferences, and who showed by her strong presence that people with PMLD belong too.

SUBSCRIPTIONS

Subscription Rates

UK Individual £25.00
UK Organisation £35.00

EU/Overseas Individual £32.00
EU/Overseas Organisation £45.00

The journal remains the only UK journal focussed on the needs of children and adults with PMLD. Thank you for your support for it.

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) 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, please do not hesitate to contact Rob Ashdown (PMLD LINK Treasurer) via info@pmlmlink.org.uk

IN THE NEWS

New research from Lancaster University about the everyday lives of people with PMLD seeks participants for steering group

Valuing people now? Exploring everyday experiences of belonging in the lives of adults with profound and multiple learning disabilities.

Alex Kaley

Research on the impact of certain aspects of personalisation has revealed some very positive outcomes on the lives of people with learning disabilities (Hatton & Waters, 2013). Indeed, personal budgets (alongside an emphasis on community-led forms of support) have enabled some people with learning disabilities to access various services and community-based activities. This reflects a core aim of the personalisation agenda, which was about providing people with learning disabilities with opportunities to be more independent, have greater control over their lives and be more included in their communities. However, it was acknowledged in the Government White Paper Valuing People Now (2009) that not everyone with a learning disability is experiencing these positive outcomes equally (see also NDTi report, 2015). Indeed, many people with PMLD continue to lead very segregated and institutionalised lives, with limited opportunities to participate and be included in their communities.

The concept of belonging is increasingly being used as a framework for understanding the in/excluded positions of disabled people (e.g. Hall, 2013; Power & Bartlett, 2017). This concept has been used to capture people's emotional and embodied attachments to place, of feeling secure or 'at home' in familiar surroundings (Antonsich, 2010). Importantly, belonging is about more than mere location. People can be physically present in public or community spaces without ever feeling like they truly

belong there. Theories of belonging are, therefore, highly critical of social inclusion policies that seek to 'place' people in community spaces, without proper recognition of the fact that people also need to be 'actively involved in their communities and the activities they do' (core and essential service standard 4, p.33) and 'to participate and be actively engaged in activities personally enjoyed and with people they like to spend time with' (core and essential service standard 5, p.34). Belonging in the lives of people with PMLD continues to be an under-researched area. Melanie Nind and Iva Strnadvoa's forthcoming edited volume 'Belonging for People with Profound Intellectual and Multiple Disabilities: Pushing the boundaries of inclusion' is, therefore, a much-needed examination of how people with PMLD find belonging in education, research and in their communities. This leads me on to the focus of my research – which is understanding more about how people with PMLD experience a sense of belonging in their local communities. I am currently inviting people to take part in my research project steering group to help shape this research. If you live in the North West of England and want to share your experiences of supporting an adult with PMLD, then I would love to hear from you! (see project information below)

Research project information

Exploring everyday experiences of belonging in the lives of adults with profound and multiple learning disabilities

We need your help!

Would you like to take part in this research?

- Do you support an adult with a profound and multiple learning disability?
- Would you like to be part of a research project steering group for a study that aims to understand how people with profound and multiple learning disabilities find belonging in their local communities?

If so, we would love you hear from you!

What would be involved?

- Attending two meetings (each meeting lasting 2 hrs) to discuss your experiences of supporting a person with a profound and multiple learning disability.
- During these meetings we would like you to help us identify key areas of priority to ensure that research is aligned with your concerns and aspirations.
- The advice gained during these meetings shall help to inform the design and conduct of the research.

When and where will the meetings take place?

- The meetings shall be organised in February and March 2020 at a convenient location for participants.
- We can reimburse your travel expenses. You will also receive a £10 gift voucher as a thank you for your participation.

If you would like to participate in the study and for more details please contact the researcher by email or phone:

Dr Alexandra Kaley
Department of Health Research
Lancaster University
LA1 4YW
a.kaley@Lancaster.ac.uk
O: 01524 594636
M: 07795650949

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Government announce plans for mandatory learning disability training for health and social care staff

As a consequence of the 2018 report recommendations from the Learning Disabilities Mortality Review (LeDeR), and much campaigning (eg Mencap's #Treat me well and Parliamentary petition led by Paula McGowan, whose son, Oliver, died in hospital in 2016), the Government has agreed that all relevant NHS staff should be trained about learning disability and autism.

The results of their public consultation earlier in 2019 have informed what the Government plan to do next, and how they roll out learning disability training to NHS staff in England. On 5 November they announced that:

- all health and social care staff will receive training on autism and learning disability
- trials will begin in NHS and social care settings from next year, supported by £1.4million of Government funding
- a training package will be named after Oliver McGowan, who died in 2016
- every NHS and social care worker will receive mandatory training relevant to their role
- they will run a series of trials early next year to test the new training package, ahead of a wider roll-out.

These actions aim to helping to close the health inequality gap by improving the quality of care people with a learning disability and/or autism receive. Their plans were announced as new statistics revealed people with a learning disability are more likely to die before the age of 75 than any other member of the public. The Government's announcement is an important step in bringing about a fairer healthcare system for people with a learning disability.

To read more: <https://www.gov.uk/government/consultations/learning-disability-and-autism-training-for-health-and-care-staff>

Building Better Together - research project aims to make GP surgeries more accessible and comfortable places to visit

A national research project wants to find out how NHS primary care buildings (e.g. GP surgeries) could be better for disabled people and people with autism. The project is called #My GP and Me: Building Better Together and is being undertaken by care provider Dimensions.

Dimensions are conducting this national research on request from an organisation called Assura. They build NHS primary care buildings (including GP surgeries) and would like to know how they can make them more accessible and comfortable places for people with disabilities and/or autism.

The first stage of the project is a national survey, asking for the views from people with disabilities (this includes learning disabilities and/or physical disabilities), people with autism, family members, carers and/or support staff and staff at primary care buildings.

Following that, once the survey closes in mid-December, Dimensions will be carrying out small focus groups and interviews to hear people's stories and good ideas in more detail.

If you are interested in taking part in this research project, please email: mygpandmebuildings@dimensions-uk.org

Find out more www.dimensions-uk.org/pr.../help-make-gp-buildings-accessible/

Adult sibling survey

This study seeks to understand more about the experiences of adults who have a brother or sister with a learning or developmental disability. Researchers want to explore sibling relationships alongside the adult siblings' caregiving role or their expectations for caring in the future. The study is also interested to explore the needs and wellbeing of adult siblings. They suggest 'this is important, because it will help us consider ways to support the wellbeing of siblings of people with intellectual/developmental disabilities and to support whatever role they decide to take in the lives of their brothers and sisters'.

To take part in this research you can complete an online survey about these topics. Participation is open to adults (aged 18 years and over) living in the UK who have a brother or sister with a learning/developmental disability.

Nikita Hayden, a PhD researcher is conducting this study, under the supervision of Professor Richard Hastings (Professor and Cerebra Chair of Family Research, University of Warwick) and the UK charity Sibs. Sibs have contributed to the design of this study, which is funded by the Economic and Social Research Council.

To get involved contact: Nikita Hayden, PhD student, Centre for Educational Development, Appraisal and Research, University of Warwick. N.Hayden@Warwick.ac.uk or Tel : 02476 150571

Find out more from: https://warwick.co1.qualtrics.com/jfe/form/SV_9sCVIC1HdmP3Qgd

Annual Health Checks – Skills for Care Survey

Everyone with a learning disability is entitled to a free annual health check from their doctor from the age of 16 years (14 years in some places). More Annual Health Checks are carried out in some areas than others and Skills for Care want to find out why, so this can be improved. They want the views of:

- People with a learning disability (and/or autism),
- Family members, carers or friends
- Doctors and those that work in doctor's surgeries that do and don't offer Annual Health Checks
- Health and social care providers that support people with a learning disability

<https://skillsforcare.researchfeedback.net/wh/s/AnnualHealthCheck>

Inclusion Europe welcomes new vice- president



Bryndís Snæbjörnsdóttir is the new vice-president of Inclusion Europe. A mother of two daughters with disabilities, Bryndís has lived experience of services, fighting for her daughters' right to education, a social life and independent living. Bryndís has been actively involved in the Icelandic disability movement for many years. In recent years lobbying for the rights of people with disabilities and meeting with ministers, parliamentarians and other politicians, officials of government institutions and municipalities.

Founded in 1988, Inclusion Europe influence EU policy through its projects and campaigns. Now representing 39 European countries the organisation raises the profile of

people with intellectual disabilities and their families, lobbying for their equal rights and full inclusion in all aspects of life. <https://www.inclusion-europe.eu/>

WEBINARS

Recordings from LDE to watch on replay. *A simple sign-in is needed for GDPR to access recordings

No-one is too disabled to have an eye test

See-Ability: Lisa Donaldson (Head of Eye Health), Scott Watkin (Head of Engagement) and Aylee Richmond (Senior Eye Care Advisor)

This webinar busts myths around eye care for people with learning disabilities

<http://events.genndi.com/r/3/0/>

[replay/169105139238468974/5dc568fd3f/0/140011860](https://www.youtube.com/watch?v=ukniWOHYHw0&feature=youtu.be)

Social work with adults with learning disability – putting good relationships with people who use services at the centre of practice

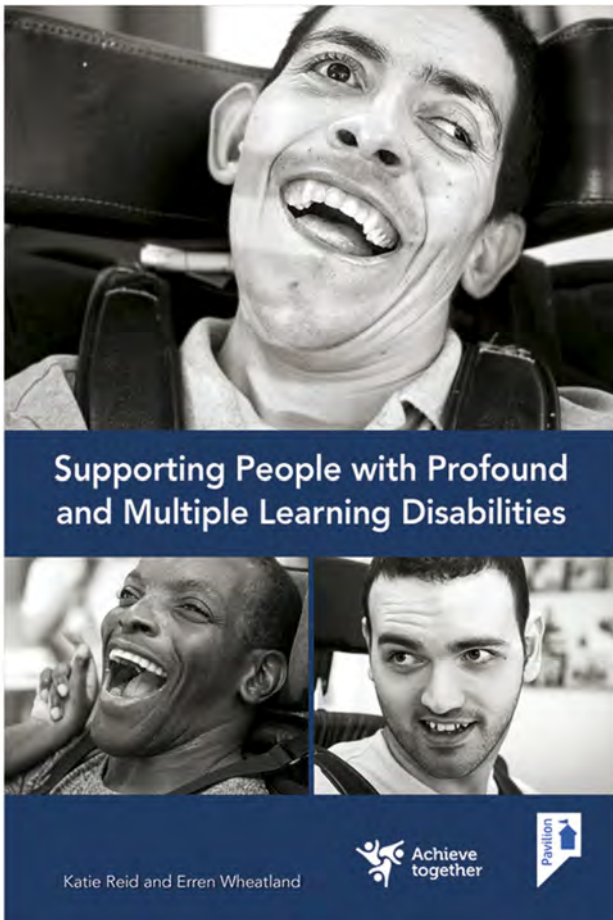
Dr Godfred Boahen Policy Lead British Association of Social Workers (BASW)

In this webinar, Godfred explains why how this organisation was asked by the government to find out the skills, knowledge, and values that are needed for good social work with adults with learning disabilities. Together with adults with learning disabilities, carers, social workers and their managers, BASW co-produced the Capabilities Statement for Social Work with Adults with Learning Disability <https://www.youtube.com/watch?v=ukniWOHYHw0&feature=youtu.be>

RESOURCES

Supporting People with Profound and Multiple Learning Disabilities

A training pack and self-study guide by Erren Wheatland and Katie Reid

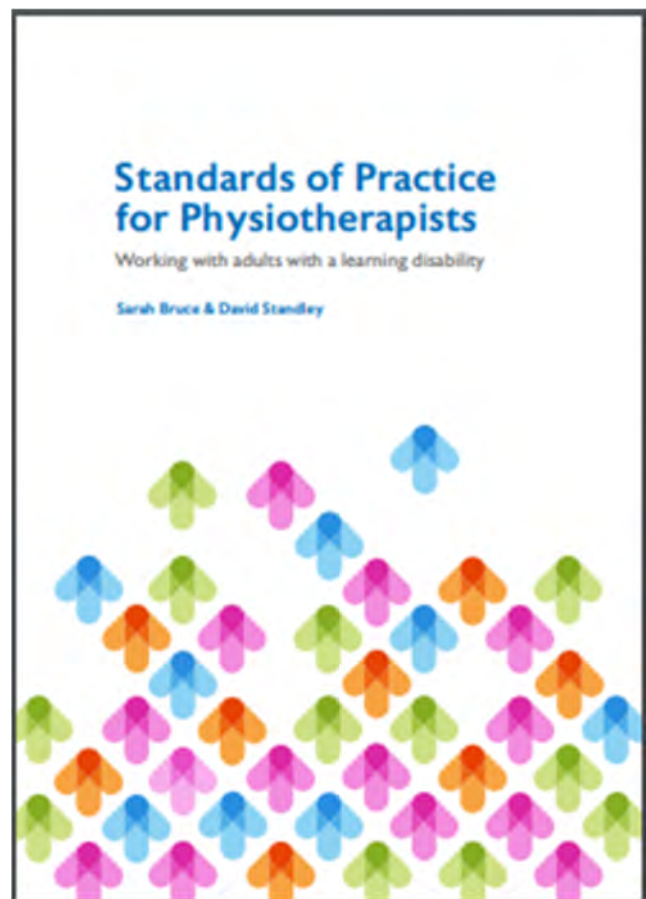


Supporting People with Profound and Multiple Learning Disabilities is a valuable new training pack and a self-study guide which will help support staff and others to understand and respond to the complex and holistic needs of people with profound and multiple learning disabilities. Written by expert trainers and practitioners in the field, they will help to develop knowledge in how to support, communicate, engage and develop appropriate strategies to provide effective, meaningful support. The training pack provides full guidance for running up to two days' training, including online, printable resources and video clips. The self-study guide includes key knowledge, case studies, reflective

exercises, learning points and links to video clips to enable staff to study at their own pace as part of their continuing professional development or to support any qualifying training in the field.

A copy of the self-study guide is included in the training pack, however this guide can also be purchased as a separate publication. Published by Pavillion <https://www.pavpub.com/>

New 'Standards of Practice for Physiotherapists working with Adults with a Learning Disability'



The standards of practice were developed in response to evidence and feedback that highlighted wide variations in the provision of the specialist learning disability physiotherapy across the UK which has impacted on the management of the physiotherapy needs of people with a learning disability.

The standards aim to improve and standardise the delivery, development and commissioning of specialist physiotherapy to adults with a learning disability. The standards include 1. Main document. 2. Executive summary for professionals. 3. Executive summary of the for carers and 4. Toolkits and supporting documents.

These can be accessed from the Association of Chartered Physiotherapist for People with Learning Disabilities (ACPPLD) section of the Chartered Society of Physiotherapy (CSP) website <https://acppld.csp.org.uk/standards-of-practice> 2

Handbook on Co-production

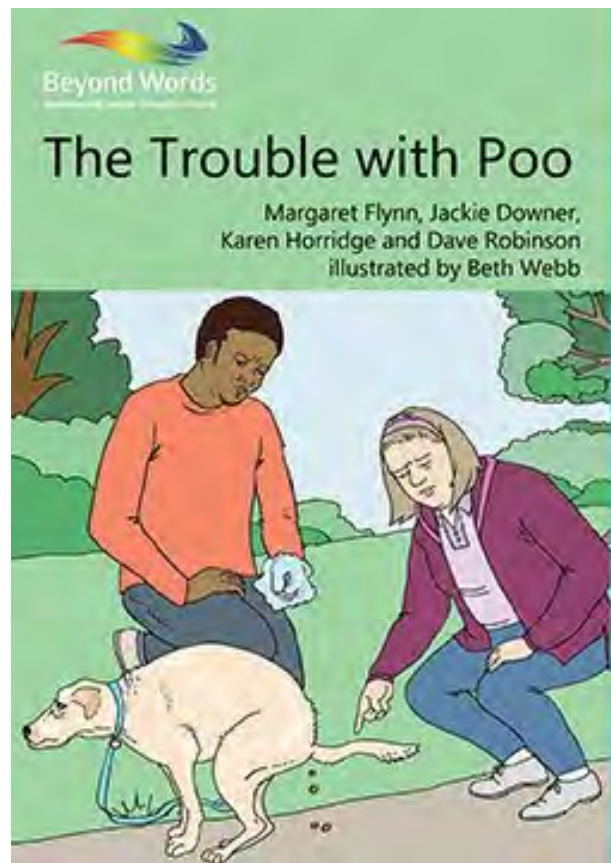


The Handbook is designed to help anyone do co-production, whether new to it, or with years of experience.

Co-production is not a new or difficult concept but understanding 'how to do it' can be a challenge. In simple terms, co-production is problem-solving together - working together to change or improve something. However it is a different way of working for many people and organisations, and this can be why it's a bit of a challenge to know where to start. For this reason Oxfordshire County Council has created the 'Working Together Handbook' – a user-friendly collection of best practice guidance to getting it right.

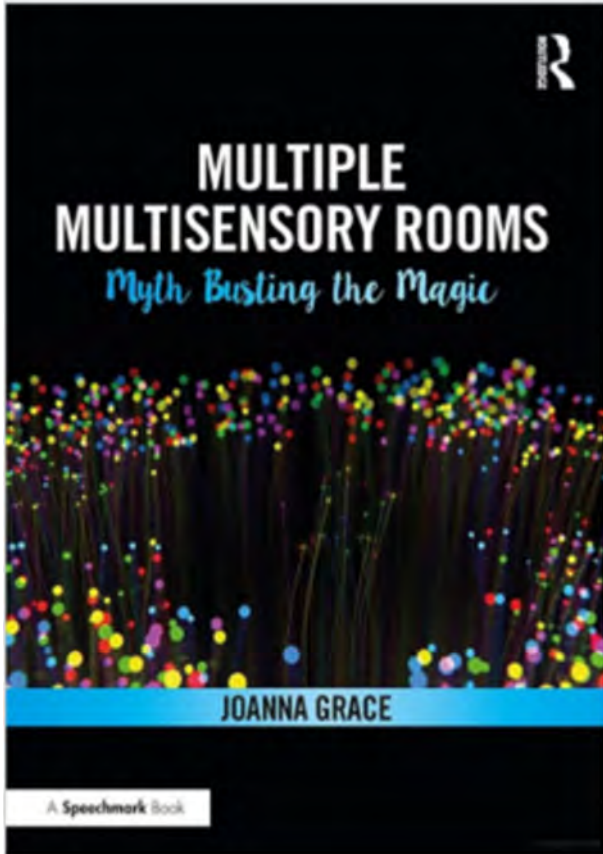
You can download a free copy of the full Handbook, just the guidance sheets or the best practice grab sheets, on the county council website at: www.oxfordshire.gov.uk/coproductio

Beyond Words launches new a book about constipation



Launched at the end of November this new book aims to overcome some of the challenges of talking about constipation. Many people with learning disability experience problems with constipation and although a common health condition, too many of them rely on medication to control it. This book helps recognise constipation and explores the influence of lifestyle to improve it. <https://booksbeyondwords.co.uk/>

Multiple Multi-Sensory Rooms: Myth Busting the Magic



The publishers Routledge describe this book: Multisensory rooms are widely used across the country in schools, care settings, hospitals and homes. Even settings such as football stadiums and airports are installing multisensory environments. Nevertheless, a significant lack of effective research has led to a sense of unease around sensory rooms. This crucial book explores the use of multisensory rooms in order to ease that anxiety; taking the mystery out of multisensory rooms, and supporting the reader to reflect and make the most out of their space.

To accompany this book Jo has created a collection of images to inspire readers to create their own multisensory environments. These photos are in a free to access album on her Facebook page, entitled 'Alternative Sensory Spaces' https://www.facebook.com/pg/TheSensoryProjects/photos/?tab=album&album_id=741268032940594

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.pmldlink.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.pmldlink.org.uk.

For more information contact The Editors (info@pmldlink.org.uk).

BOOK REVIEW

Responsive Communication: Combining attention to sensory issues with using body language (intensive interaction) to interact with autistic children and adults

Phoebe Caldwell, Elspeth Bradley, Janet Gurney, Jennifer Heath, Hope Lightowler, Kate Richardson and Jemma Swales (2019). London: Routledge £24.95

There are an immeasurable number of fascinating insights in Phoebe Caldwell's latest book 'Responsive Communication' but most welcome to me is the authenticity with which Phoebe writes, and the depth of expertise she and the other six contributing authors offer. There's no show, no flashing lights or pound-shop plastic from the all-singing, all-dancing sensory bandwagon. This book is above all about the person, and looks at the intrinsic link between their communication and sensory needs. It couldn't be more person-centred or more thoughtfully explained.

I first came across Phoebe Caldwell's work in the 1990's when I was lucky enough to work in a stimulating – and better funded – social care environment. My first job supporting people with profound and multiple learning disabilities, and I was trained to within an inch of my life in sensory integration and intensive interaction. So, I grew up with the work of Hewett and Nind, and then Phoebe Caldwell, and have practiced, studied and talked about intensive interaction for the past 25 years. I am drawn to Phoebe's writing because of the simplicity of her approach – it always come back to the person. I've read Phoebe's own first chapter at least three times in the past few months, each time absorbing a little more. This weighty first chapter explores responsive communication, and how it combines intensive interaction - the use of body language to support communication - with attention to sensory issues: the aim being to reduce distress and to support connections and emotional engagement. Phoebe explains in relatively simple terms some of the neuroscience behind the 'immobilisation' or sensory overload that many autistic people experience when being threatened by levels of incoming stimuli. Phoebe stresses the need to listen and learn from people with autism, and how

responsive communication can 'bring about remarkable change to the lives of people who are struggling to make sense of their environment'.

The six contributing authors all offer a different perspective in subsequent chapters: Hope Lightowler's harrowing first-hand account of her experiences as teenager, takes us through her agonising wait for an autism diagnosis, and the pain she endured as an inpatient, where her sensory needs went unrecognised and unmet. The lived experience Hope describes is brutal and gruelling, and should be an essential read for any commissioner or professional involved in Transforming Care or provision of Assessment and Treatment Units. Janet Gurney, a regular contributor to PMLD Link, illustrates the work of Us in a Bus, a unique charity which practices and shares the use of intensive interaction with an understanding of sensory processing issues. Janet guides us through three people's responsive communication sessions, with captivating and often touching descriptions of how these have evolved, led by the person, supported by the practitioners.

Jemma Swales (autism practitioner) explains her personal journey supporting people with autism in Cumbria, people who have been able to describe the trauma associated with their experience of the world. Jennifer Heath (occupational therapist) describes her work in a school and children's home setting, with a detailed analysis of sensory processing and integration work with a young woman called Sophie. Kate Richardson (speech and language therapist) recounts her work on a co-produced project with families that aims to take an 'autism from the inside-out' stance and Elspeth Bradley (psychotherapist and psychiatrist), considers the benefits of responsive communication from a psychiatry perspective, recognising that it could bring 'much needed emotional attunement and understanding' and is a tool that could be invaluable in the psychiatric assessment process.

Responsive Communication might feel initially daunting with a very tiny font and tightly packed pages, but I'd highly recommend perseverance. It is undoubtedly a solid book, one to pick up and soak in over time, taking in small chunks on a bus or train, or with a spare hour over a cup of tea. I've read it all, some chapters 2 or 3 times, but I need to go back and mull over the depth and breadth of the experience offered, brought together by Phoebe's wisdom, and authenticated by the lived experience of Hope.

The book combines personal stories with science and clinical practice and gives so much food for thought to a subject that to my mind, can only make sense: because it starts and ends with the person, valuing them exactly as they are.

Becky Loney—PMLD Link

SHORT COURSES & CONFERENCES

January 2020		February 2020	
Title:	2020 Learning Disability Nursing Now – The NHS and Beyond	Title:	Circus Starr – circus with a purpose
Date:	6 Jan	Date:	1st Feb 2020
Location:	Royal College of Nursing, London	Location:	Burnley
Contact:	Stephanie.robinson@achievetogether.co.uk	Provider:	Tickets - 01260 288690 https://www.circus-starr.org.uk
Title:	Our Human Condition : disability + siblings photography exhibition	Title:	Circus Starr – circus with a purpose
Date:	8th – 19th Jan	Date:	2nd Feb
Location:	The Gallery@OXO, Oxo Tower, South Bank, London	Location:	Wakefield
Contact:	https://www.wenhamclarke.com/our-human-condition	Provider:	Tickets - 01260 288690 https://www.circus-starr.org.uk
Title:	Supporting Adult Social Care Innovation – project launch	Title:	Eye Gaze Exhibition
Date:	13 Jan	Dates:	3rd-14th
Location:	London	Location:	Ysgol Ty Coch, Garth Olwg Life Long Learning Centre
Contact:	https://sascilaunch.eventbrite.co.uk	Provider:	Leigh on
Title:	Sensory Processing and Communication Taster Sessions	Contact:	Leighwharton@ysgoltycoch.co.uk or 01443 203471
Date:	15th January 2020	Title:	Rebound Therapy
Location:	Manchester	Dates:	6-7th February
Provider:	Seashell Trust,	Location:	Bromsgrove, West Midlands
Contact:	0161 696 9396 http://www.seashelltrust.org.uk/	Contact:	01342 870543
Title:	Next Steps with Intensive Interaction	Title:	Improving Oral health in care homes
Date:	22nd	Date:	11 February
Location:	Surrey	Location:	Webinar
Provider:	Us in a Bus	Provider:	Social Care Institute for Excellence
Contact:	01737 823310 or info@usinabus.org.uk	Contact:	kim.rutter@scie.org.uk https://www.scie.org.uk/training
Title:	9th Annual PAMIS Burns Supper	Title:	Rebound Therapy
Date:	25th	Dates:	11th and 12th Feb
Location:	Dundee	Location:	Camden, London NW1 3EX,
Provider:	PAMIS	Provider:	organiser: Ashleigh Johnson
Contact:	https://9thannualburnssupper.eventbrite.co.uk	Contact:	a.johnson@netley.camden.sch.uk
Title:	The Story Massage Programme	Title:	Postural care for children and young people
Date:	29th	Date:	12th
Location:	Birmingham	Location:	Tamworth
Provider:	Story Massage	Provider:	https://thegoldsmithcentre.com/
Contact:	www.storymassage.co.uk info@storymassage.co.uk	Contact:	
Title:		Title:	Postural care for adults with complex body shape
Date:		Date:	13th
Location:		Location:	Tamworth
Provider:		Provider:	https://thegoldsmithcentre.com/
Contact:		Contact:	
Title:		Title:	Including Everyone – What next? Annual Conference
Date:		Dates:	13th
Location:		Location:	Manchester
Provider:		Provider:	Learning Disability England
Contact:		Contact:	https://www.learningdisabilityengland.org.uk/
Title:		Title:	PAMIS Bereavement and Loss (2 day course)
Date:		Date:	20th+27
Location:		Location:	Oaklands School in Edinburgh.
Provider:		Provider:	https://pamisbereavementandlossedinburgh.eventbrite.co.uk
Contact:		Contact:	

Title: Date: Location: Provider: Contact:	The Story Massage Programme 25th North London Story Massage (www.storymassage.co.uk) info@storymassage.co.uk	Title: Date: Location: Contact:	Sensory engagement for mental wellbeing with Joanna Grace 12th Tamworth https://thegoldsmithcentre.com/
Title: Date: Location: Provider: Contact:	The North West Regional Self Advocates Forum 27th of February- 1st of March Blackpool https://www.learningdisabilityengland.org.uk/news/national-self-advocacy-convention-2020-open-for-booking/#more-6991	Title: Date: Location: Contact:	Multi-Sensory Room Day with Joanna Grace 13th Tamworth https://thegoldsmithcentre.com/
Title: Date: Location: Provider: Contact:	Makaton Signing for Babies 27th Huddersfield Kerry Cawley on kerrycawley@outlook.com or 07913008753	Title: Date: Location: Contact:	Introduction to Intensive Interaction 13 March Selly Oak, Birmingham Intensive Interaction Institute https://www.intensiveinteraction.org/
Title: Date: Location: Provider: Contact:	Makaton Level 1 and 2 Workshops 29th Huddersfield Kerry Cawley on kerrycawley@outlook.com or 07913008753	Title: Date: Location: Contact:	Oily Cart's Jamboree (Multisensory Theatre) 13-14 March Warwick Arts Centre, Coventry 024 7652 4524 https://oilycart.org.uk/shows/jamboree
March 2020		Title: Date: Location: Contact:	Postural care for children and young people 17th Tamworth https://thegoldsmithcentre.com/
Title: Date: Location: Contact:	Five Day Course for Intervenors (Multisensory Impaired) 2, 3, 4, 9 & 10 March 2020 Professional Development Centre, Norwich Jenny Fletcher/Sense/NatSIP Bookings: Claire Hogston sensorysupport@norfolk.gov.uk or 01603 704040	Title: Date: Location: Provider:	Postural care for adults with complex body shape 18th Tamworth https://thegoldsmithcentre.com/
Title: Date: Location: Contact:	SEN LAW - CONFERENCE 3rd Central London Venue www.senlawconference.co.uk	Title: Dates: Location: Contact:	Naidex, NEC 17th-18th Birmingham https://www.naidex.co.uk/
Title: Date: Location: Contact:	The Goldsmith Indices of Body symmetry 4th-5th Tamworth https://thegoldsmithcentre.com/	Title: Dates: Location: Contact:	Rebound Therapy (2 days) 18 and 19 March WESC Foundation, Exeter, Devon, , 01342 870543
Title: Date: Location: Contact:	Introduction to Intensive Interaction 5th Gateshead, nr Newcastle Intensive Interaction Institute https://www.intensiveinteraction.org/	Title: Date: Location: Provider: Contact:	An Introduction to Intensive Interaction 19th Surrey Us in a Bus 01737 823310 or info@usinabus.org.uk
		Title: Date: Location: Contact:	EQUALS Spring Conference 2020 20th University of Manchester EQUALS 0191 272 1222 or admin@equalsoffice.co.uk
		Title: Dates: Location: Contact:	Oily Cart's Jamboree (Multisensory Theatre) 20-21 March Stratford Circus Arts Theatre, London 020 8279 1080 https://oilycart.org.uk/shows/jamboree

Title:	Sherborne Developmental Movement Basic Level 2 course	Title:	Intensive Interaction for people with PMLD		
Date:	21st	Date:	24 April		
Location:	Tottenham, London	Location:	Selly Oak, Birmingham		
Contact:	https://www.sherbornemovementuk.org/courses/	Provider:	Intensive Interaction Institute		
Title:	Engagement in a personalised curriculum	Contact:	https://www.intensiveinteraction.org/		
Date:	30 March	Title:	Makaton Level 3 workshop		
Location:	Newcastle	Date:	25th		
Contact:	Hirstwood Training https://www.hirstwood.com/	Location:	Huddersfield		
Title:	Engagement in a personalised curriculum	Provider:	Kerry Cawley on		
Date:	31 March	Contact:	kerrycawley@outlook.com or 07913008753		
Location:	Manchester	Title:	Exploring the Impact of the Senses on Behaviour		
Contact:	Hirstwood Training https://www.hirstwood.com/	Date:	29th		
Title:	Virtual Disability Conference	Location:	Brighton		
Date:	31st	Provider:	https://www.eventbrite.co.uk/e/exploring-the-impact-of-the-senses-on-behaviour-tickets-68463581415		
Location:	online (Australian East Coast Time)	Contact:			
Provider:	Scope/ Univ. of Melbourne	Title:	Sensory Processing and Communication Taster Session		
Contact:	https://virtualdisability.conferenceworks.com.au/	Date:	29th April 2020		
April 2020				Location:	Manchester
Title:	Engagement in a personalised curriculum	Provider:	Seashell Trust,		
Date:	3 April	Contact:	0161 696 9396 or http://www.seashelltrust.org.uk/		
Location:	London	Title:	Sensory Engagement for Mental Wellbeing; Supporting mental health for people with PMLD CLDD		
Provider:	Hirstwood Training https://www.hirstwood.com/	Date:	30th		
Contact:	www.hirstwood.com/	Location:	Brighton		
Title:	Oily Cart's Jamboree (Multisensory Theatre)	Provider:	https://www.eventbrite.co.uk/e/sensory-engagement-for-mental-well-being-supporting-mental-health-for-people-with-pml-d-cldd-tickets-68462149131		
Date:	7-8 April	Contact:			
Location:	Derby Theatre, Derby	Title:	Special seating masterclass		
Provider:	01332 593393	Date:	30th		
Contact:	https://oilycart.org.uk/shows/jamboree	Location:	Tamworth		
Title:	Sensory engagement for mental wellbeing with Joanna Grace	Contact:	https://thegoldsmithcentre.com/		
Date:	16th	May 2020			
Location:	Tamworth	Title:	Makaton Level 3 workshop		
Provider:	Tamworth	Date:	2nd		
Contact:	https://thegoldsmithcentre.com/	Location:	Huddersfield		
Title:	Multi-Sensory Room Day with Joanna Grace	Provider:	Kerry Cawley on		
Date:	17th	Contact:	kerrycawley@outlook.com or 07913008753		
Location:	Tamworth	Title:	The Goldsmith Indices of Body symmetry		
Contact:	https://thegoldsmithcentre.com/	Dates:	5th-6th		
Title:	Postural care for children and young people	Location:	Tamworth		
Date:	22nd	Provider:	https://thegoldsmithcentre.com/		
Location:	Tamworth	Title:	The Story Massage Programme		
Contact:	https://thegoldsmithcentre.com/	Date:	5th		
Title:	Postural care for adults with complex body shape	Location:	Liskeard, Cornwall		
Date:	23rd	Provider:	Story Massage		
Location:	Tamworth	Contact:	www.storymassage.co.uk		
Contact:	https://thegoldsmithcentre.com/		info@storymassage.co.uk		

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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, and now works as a professional advocate and involvement worker for an advocacy charity. She uses creative and arts-based approaches including music, sensory storytelling, and intensive interaction. Becky is also passionate about raising awareness and expectations, to build high quality support that is truly person-centred.
- 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

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sharing ideas and information

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