



NHS Education for Scotland

Transcript of 'Supporting those with profound and Multiple Learning Disabilities and their Carers Around Bereavement (Bereavement Conference 2019)' video

- Patricia Graham and Maureen McClelland

Pat:

My name is Pat Graham, I'm the Chair of a charity called PAMIS, Promoting a more inclusive society. And I'm also a family carer for a daughter with profound and multiple learning disabilities whose now thirty-one.

Maureen:

And I'm Maureen McClelland, I'm a Family Support Director with the Fife Service of PAMIS.

Pat:

One of things that PAMIS is very passionate about is research and that's research always in co-production with family carers. And the, one of the subjects that came up for research was, from family carers, about loss and bereavement, in a family situation where somebody has a profound and multiple learning disability and they identified that this hasn't been looked at, and there was very little research, very little support and so with the support of a family carers, this project which is now a number of years ago was devised whereby there was research carried out into what kind of support family carers needed and what kind of support the person with profound and multiple learning disability needed which was, then became a learning resource, which then became a training course and Maureen and I are two of the people who deliver that training course and so we came today to talk about aspects of that training which includes chronic sorrow and disenfranchised grief.

Maureen:

There was two take away messages from our workshop, which one was that family carers, particularly of somebody with PMLD, experience something that we would call chronic sorrow, and that is often not recognised, but it is often very much there for families and sometimes just giving that a name can be very powerful for families because they understand then more what is going on for them. And the second message was about disenfranchised grief and about people with learning disabilities sometimes having their grief disenfranchised and unacknowledged, unsupported, because they have a learning disability, 'cos people make assumptions that somehow maybe they don't understand about grief or they don't understand the concept of death. So, for us, it is very much about how do you provide support to people with learning disabilities and not disenfranchise their grief.

Pat:

the key thing about chronic sorrow is that it's often described as being a living loss because it's a loss that continues forever. If you have a child with a profound and multiple learning disability, then, that child probably isn't going to get better, and they, they will have a severe learning disability often have chronic health needs and they're very often non-verbal. And so, for the parent of a child in that situation, and when I say child I mean, child right through to adulthood, it's, it's a sorrow that doesn't ever go away. And it is something that recurs all the time, you know, if it's things like, every time your

child doesn't do that first thing that you, anybody would expect their child to do, you know whether it's a first step or a first word, or a first job or a first car, getting married, having children – you're child isn't going to do any of those things and so all of these times you're reminded about that, and I think today I was talking about that and it was interesting because, one of the things that I always say is that every time you talk to a carer about it, and you talk about chronic sorrow, and it's something that's really unknown as a concept, or it's unknown as a name, and, people, when you say that to people they say 'Oh, yes, so that's why it is, that's why I feel like that'.

Maureen:

What we try and do is work through carer workers, work through some of the people that were here today, some medical staff, the nursing staff, parents, carers, because often their grief goes unrecognised, and so it's about raising awareness that actually people with learning disabilities do indeed experience grief and sometimes very profoundly do they experience their grief, and particularly for the group we work with who are non-verbal, it is about how then do we support them? And the only way we can really do that is through the carers, or the parents, or the care workers, to find ways, so sometimes it might be through photographs, sometimes it might be through memory boxes, sometimes it might, might be just about acknowledging that that person has died, sometimes about having conversations about should the person go to the funeral, should they not go to the funeral, if they did go to the funeral, what support do they need in order to do that and so we allow people with learning disabilities to experience the whole process and to have the whole experience of grief and death.

Pat:

One of the reasons that I became involved in PAMIS' loss and bereavement project was because when my Mum died I didn't acknowledge, for my daughter, Lauren, that her Gran had died. Even though she and her Gran had been extremely close for all of Lauren's lifetime, and I didn't do anything about it because I didn't know what to do. I didn't know whether she would understand, she is non-verbal so there is no way that she would be able to explain to me or that I would be able to explain to her, you know, that Gran has gone/your Gran has died, what that would mean for her. So actually, I completely abdicated any responsibility and didn't do anything. And it was only when I became involved in the project that I thought well I'll try and do something. I didn't have much hope or expectation that it would make a difference but actually by doing some of the things that Maureen's just outlined, in terms of memory boxes and so forth, what we actually found was that, Lauren, even though she couldn't express or verbalise her memories, actually did them, and it was a huge pleasure to see how much pleasure she had in talking about her Gran, and so we couldn't say 'Your Gran has died' but actually we could talk about Gran and it was, just a delight to see how she could remember her Gran that was 4 years after the event, and actually 10 years after the event Lauren does still remember her Gran, she can't tell us about it but you can tell from her body language and her facial expressions and her pointing fingers at things. And so, one of the things it makes clear to me is that people with a profound learning disability actually have a much deeper, longer term memory than probably most people would give them credit for.

Maureen:

I think for me it's that conferences like today, we're looking for Scotland to provide bereavement support to everybody, and I think that people with PMLD have as much right to bereavement support, as the rest of the population and yet there are there are no services there really dedicated to providing

support for them. So, it's about not, not forgetting about that group and if it is for everybody in Scotland then please do remember the PMLD group.

The film was produced in March 2020 and can be found at www.sad.scot.nhs.uk or <https://vimeo.com/392434837>

For more information visit www.sad.scot.nhs.uk or contact supportarounddeath@nes.scot.nhs.uk

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