As part of our work, following the BBC Radio 4 programme on supported living, Learning Disability England asked organisational members what they are doing to ensure they learn from deaths and incidents. The following blog is from L'Arche.

L'Arche is an international organisation that runs independent local communities. People with learning disabilities and non-disabled people live together within these communities. L'Arche support people in their own homes, run supported living as well as activities.

Kevin Coogan is a Registered Manager and community Leader at L'Arche Manchester. He has written a blog about what they do differently now since Joe died in hospital. Joe's inquest was live tweeted & you can see examples of the media coverage here and here.

L'Arche: Learning from when someone dies that leads to change

Our learning was focused on our experience once we entered the health system.

Joe, one of our members, had a fall. The fall was while doing everyday things, so while it was potentially preventable, preventing it would have been very restrictive. Joe went in to hospital and after 3 weeks he died.

So, our learning is really around our interaction with the hospital.

The big learning point for us is about how we communicate as a staff team supporting someone. Now as a matter of course, when someone we support goes into hospital we immediately start a WhatsApp group for the people principally involved with supporting them in the hospital.

On this we share which doctor came to see the person and when, what they said and how the person was about it. We also share our impressions of how the person is feeling or reacting to treatment. If, as in the case of Joe, the person can't express if they are hungry or in pain, the cumulative subjective opinion is helpful to the friend/support worker standing in front of the specialist doctor who asks, 'And how are we today?'

The other advantage is that you can get advice quickly. 'The doctor says we should either try x or y. What do we think?' Or 'The doctors have recommended a complicated Latin term. Does anyone know what that actually means?' etc.

All the messages stay in one place and can be accessed by anyone in the group so even at 3am in the morning you can look back and see what the advice was from 2 days ago.

Basically, it almost replaces the 'memory' of the person with learning disabilities as they are passed through the hands of various practitioners hearing complicated

terms. It is contemporaneous and immediate. So, it allows immediate input into decision making. 'Please tell the doctor they will need a plan to stop her pulling the tube out of her arm. That's what happened last time.'

The potential problems are that it breaches confidentiality – this is addressed by the fact that it is a closed group that is, apparently, extremely secure (end to end encrypted, they say) so, if you only invite the appropriate people into the group it is perfectly appropriate to share information within it.

The other potential problem is that you can minimise or ignore the input of the person themselves, which is not very person-centred! But that problem is always there regardless of how you share the information. So, you always need to guard against that anyway.

As is so often the case with systems intended to improve things for people with learning disabilities, it is actually very useful for people without a disability too! How many times have I walked out of an appointment and wondered 'did the doctor say **always** take this with food or **never** take this with food? I've forgotten already.' And we all want advice from our trusted friends when a doctor gives us difficult decisions to make. It's a good test that what we are doing is, indeed, in the person's best interests. I always ask, 'would I like someone to do this for me?'

Finally, it is also a support to carers themselves. A hospital ward can be a dark and lonely place at 3am when you are tired and maybe upset. It feels good to be connected to others who know what you are doing and also love the person you are supporting. It's good to recognise that.

Share your story?

Would you like to share with us what your organisation has learnt or what structures you have out in place to learn incidents and from deaths of people with learning disabilities who use your service? Do you have examples of what you have changed as a result?

We would welcome you to share anything, from a paragraph to a blog like Kevin. If you are interested please contact Rachael on, Rachael.hall@LDEngland.org.uk