



# Somerset LeDeR Newsletter

## November 2018 - 1st Edition

### Message from Dr Amelia Randle (Learning Disability GP Lead)



I am excited to be involved with the Somerset LeDeR programme where we are committed to achieving service improvement for people with a learning disability. Research has shown that people with learning disabilities die approximately 20 years sooner than the general population and are three times as likely to die

from a condition that could have been avoided with good quality health care. We are trying to change this by reviewing the deaths of people with a learning disability in Somerset, learning from what has worked well and asking if anything could have been done differently. We will strive to ensure the reviews lead to reflective learning with the assumption of noble intentions in all involved and seek improvements within the system of care to empower everyone to take action. We value the on-going contribution of people with learning disabilities and their families to all aspects of our work and see this as central to the development and delivery of everything we do. I look forward to working with many of you over the coming months and a huge thank you to those who have contributed so far or will do in the future.

### Somerset LeDeR Reviews

From August 2017 LeDeR has been rolled out across the whole of Somerset and as at November 2018 we've had:

**43** notifications received      **32** initial reviews completed  
**11** reviews in progress      **14** cases completed closed  
**0** unallocated cases

#### Main causes of death (where reported):

Pneumonia / Aspiration Pneumonia (12)	Chest / Respiratory Tract Infection (4)
Old Age (4)	Heart Disease / Cardiac Failure (3)

### Call for more Reviewers

If you are interesting in learning more about care for people with a learning disability or are passionate about driving service improvement there is [training](#) available to become a LeDeR local reviewer. For more information please contact us, details overleaf.



### Learning Outcomes

#### Excellent examples of good care

- A care home that collected parents in the snow, as no buses or taxis running so they could see their son as he was nearing the end of his life
- GPs having admission avoidance plans, so someone can be supported in their home at the end of their life and not go into hospital
- Hospital learning disability liaison nurses who help make things easier for the person and work with hospital staff
- Shared Lives carers supporting people with a learning disability and their dedication, becoming like a person's family
- GPs using easy read invites and information for the Annual Health Check
- Carers supporting people in hospital for long periods of time, including visiting on their days off, which made hospital stays so much better for someone
- Use of Hospital Passports have shown that they can make a real difference
- Support from speech and language teams, who often assess if someone can swallow safely, and learning disability nurses around epilepsy management plans

### Areas we can improve on

- Carers not given time to stay with someone who is admitted to hospital, maybe due to being needed at work, leaving someone alone with no one who understands their needs or can reassure them
- Communication between health and social care agencies involved in someone's care; for example sometimes relatives purchase equipment as they aren't aware of or feel there is another option
- Learning disability liaison nurses in hospitals have a valuable role but more resource is needed
- Hospital Passports are not always referred to or followed by hospital staff
- Carers and family who know the person with a learning disability well need to be included in day-to-day decisions especially in relation to quality of life or where the person cannot express themselves easily
- Hospital thought the person's home provided nursing care and was equipped when someone was being discharged, when in fact they had no clinical staff or equipment
- Health providers need to ensure clear recording on how best interest decisions are reached if they assess the person does not have capacity to make a decision, also that forms such as Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) or a Treatment Escalation Plan are correctly completed in hospital



## National Update

Parliament has discussed making learning disability training mandatory so health and care staff have the knowledge and skills they need, watch the debate [here](#).

The government has published a new [Carers Action Plan 2018 - 2020](#) outlining a cross-government programme to support carers over the next two years.

In November the [Learning into Action Bulletin](#) will focus on recognising signs of deterioration, previous issues looked at nationwide areas of work on Sepsis and Aspiration Pneumonia.

[Watch: Reducing health inequalities for patients with learning disabilities](#) a short video to help reduce health inequalities for patients with learning disabilities. It's primarily aimed at GPs and GP surgery staff, but contains useful information about the LeDeR programme for everyone.

For more information on the work being done across England, have a look at the [Monthly Bulletins](#) published by the LeDeR programme.

## Hospital Passport

Reviews have highlighted the importance of having a Hospital Passport when someone is admitted to hospital to give staff important information about the person and their health needs. This is particularly helpful when someone needs support with their communication, or might be anxious about going into hospital. Hospital Passports can be completed in advance (must be kept up to date) so they are ready in case of planned or emergency admissions or outpatients appointments. Somerset Partnership provides a version on their [Learning Disabilities webpage](#).



## In the next Edition

In our next newsletter we will focus on Reasonable Adjustments and duties under the Mental Capacity Act with examples from our reviews so far.

## Notifying of a death

Anyone can notify us of a death online:

[www.bris.ac.uk/sps/leder/notify-a-death](http://www.bris.ac.uk/sps/leder/notify-a-death)

or by phone:

0300 777 4774

## Flu Vaccinations

Everyone with a learning disability, their family carers and paid supporters are entitled to a free flu vaccination. Nationally respiratory problems are a major cause of death of people for learning disabilities, we can see this reflected through LeDeR reviews in Somerset. We need to support everyone who is eligible to get their flu vaccination before winter sets in. More information is available from Public Health England [guidance](#) or speak to your GP or Pharmacist.

## Annual Health Checks

From the reviews carried out we know that Annual Health Checks are usually offered to people with learning disabilities by their GP, however there were two reviews where this had not happened. These are effective in identifying previously unrecognised health needs, including those associated with life-threatening illnesses. If you know someone with a learning disability who doesn't get an Annual Health Check it's really important that they tell their GP and ask to be put on their GP practice Learning Disability register. The practice will then contact them on an annual basis to invite them to make an appointment. Learning disability Annual Health Checks are different from the wider NHS health check scheme for adults. You can watch this online video about [annual health checks for people with a learning disability](#).

## Health Action Plans

An Annual Health Check is really important, however GPs should also help develop a Health Action Plan to give the person information about what they must do to help keep healthy and perhaps improve some aspects of their health. This might include advice on lifestyle choices such as diet, smoking and amount of exercise. This is an area where we need to do more work in Somerset to make sure people can improve their health.

## Local Area Contacts

The Somerset CCG Local Area Contact is:

**Karen Taylor**  
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01935 384101

The [LeDeR Programme](#) contact details are:

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