

Cross Party Group on Dementia

Minutes: June 2019

Inquiry into hospital care evidence session

Tuesday 11 June 2019, 12-1.30pm

Conference rooms 4 & 5, Tŷ Hywel

Video link – National Assembly office, Colwyn Bay

Chair: Lynne Neagle AM



Present: Lynne Neagle AM (Chair), Dr Dai Lloyd AM

Sophie Douglas, Huw Owen, Sue Phelps (Alzheimer's Society Cymru), Linda Willis, Ceri Higgins, Dr Katie Featherstone (Cardiff University), Valerie Billingham (Age Cymru), Nicola Davis-Job, Lisa Turnbull (Royal College of Nursing Wales), Gwyneth Sweatman (Marie Curie), Dr Rosslyn Offord (British Psychological Society), Suzanne Duval (Diverse Cymru), Jayne Goodrick, Chris Roberts, Monica Reardon (Marie Curie), Dr Andy Northcott, Dr Jane Harden, Ray Morrison (Bluebird Care), Irina Erchovaia, Meryl Randell-Jones, Jackie Askey, Dr Sofia Vougioukalou

Lynne Neagle AM welcomed everyone to the meeting and thanked the panel for attending.

Sophie Douglas gave an update on the inquiry into hospital care so far and plan for next steps:

- An online survey is gathering the views of individuals across Wales – we've had over 200 responses from people, a mixture of those affected by dementia and people working in hospitals, have responded and shared their experiences.
- The survey remains open and will be promoted again in the media to encourage more responses from individuals across Wales.
- Four roundtable discussions with people affected by dementia, volunteers and professionals, hosted by Assembly Members have taken place:
 - Pontypool – Lynne Neagle AM
 - Newport – Jayne Bryant AM
 - Wrexham – Mark Isherwood AM
 - Llangefni – Rhun ap Iorwerth AM
- Alzheimer's Society Cymru is holding a number of evidence sessions with professional organisations to hear the experiences of those working across the health sector.

- The evidence gathered throughout this process will be analysed and put into a report making recommendations to Welsh Government.
- We anticipate provisional findings to be discussed in the autumn, with a full report launched in the late autumn or spring.

Lynne Neagle AM outlined the plan for the evidence session and welcomed **Linda Willis** and **Ceri Higgins** who would be asking the questions to the panel.

please note these minutes report the questions and answers given in note form and is not a full transcript – written answers to questions will be provided by the panel to accompany the minutes

Question 1: What needs to change in terms of training for hospital staff?

Dr Katie Featherstone

- It's not just nurses who need training
- People living with dementia are a key population in hospitals
- There is a need for training and leadership
- Nurses are leaders on the ward

Valerie Billingham

- Based on feedback from local partners Age Cymru put together 'Staying on my feet' report, broader than just falls prevention
- Strong strand of feedback on multi-disciplinary training and care home staff – they have untapped knowledge as they know the patients in depth – could share that knowledge more productively between care homes and hospitals
- Training one key person on the ward is not sufficient – ward staff should ideally be trained together

Lisa Turnbull

- In terms of registered nurses the first thing to look at is the degree course – worth considering its content, recommend writing to the CNO
- Second point is how education reaches both registered nurses and HCSWs once they are employed
- access to training is a problem – Health Boards are reluctant to allow staff time to train as they have to fund the backfill on the ward – Health Boards do not employ enough nursing staff to allow training nor do they support it.
- Agree that expertise lies in care homes – referred to Triangle of Care document developed by the RCN in conjunction with Carers Trust. This assessment tool allows care to be assessed by staff, patient and carer together and is available in Welsh.
- Also consider Welsh language – need to work to encourage people to use their Welsh, regardless of proficiency
- Exposure to CPD is essential

Nicola Davis-Job

- People affected by dementia want experienced, educated staff who have *time* to care
- SPACE principles:
 - o Staff who are skilled and have time to care. 2) Partnership working with carers. 3) Assessment and early identification. 4) Care that is individualised. 5) Environments that are dementia friendly

Question 2: Where do you see gaps or room for improvement in the training of hospital staff?

Dr Katie Featherstone

- Dementia Friends is a good start however it is not sufficiently in-depth, gets used as a 'tick-box' exercise
- Because training is compartmentalised, only mental health nurses get comprehensive training – adult nurses need the training
- Student nurses report not feeling prepared

Lisa Turnbull

- The pre-registration curriculum is undergoing a change, so this is a good moment to look at it
- The main problem with access to CPD once in employment is *time* to do it. Health Boards do not support this.
- Members struggle even to have a loo break or have a drink
- Monitoring and prioritising access to CPD
- Best to refer to training and *education* rather than 'training' – This has a broader context. Training refers to teaching someone a task in particular way whilst education is about the understanding and knowledge behind why some methods are more suitable and the ability to judge how and when to deploy methods.

Valerie Billingham

- Strongly support comment on 'education' – it's a case of 'consciousness raising'
- Families are pleading for staff to communicate with them
- Culture dictates that the staff don't inform the family
- Care homes are unclear what happens to patients upon admission
- There needs to be mutual professional respect between care homes and hospitals
- Important that a care home is treated as the residents' *home*

Nicola Davis-Job

- We need to learn the lessons from the *Trusted to Care* report which recommended e-learning be made compulsory

[**Chris Roberts** comment – e-learning is not sufficient, students report that hearing directly from people affected by dementia is the most effective part of their training]

Specific questions to **Age Cymru**

Question 1 - You state in your written evidence that if people with dementia were supported to leave hospital one week earlier than they currently do, significant savings might be achievable across the system as a whole. Where would you like to see those savings invested?

Valerie Billingham

There are four areas:

1. Freeing up staff time
 - a. A basic level of care is still not achieved – there needs to be time to deliver dignity, hydration and nutrition
2. Assessments under the Social Services and Well-being (Wales) Act
 - a. Better diagnosis rates
 - b. Hospitals as a point of access to diagnosis and assessment
3. More support for carers and care staff
 - a. NHS acknowledges that care takes place within the family
4. Resources into prevention

Question 2 - Do you have any examples of the appropriate community services that you refer to?

Valerie Billingham

One example is the Madeline project in the CVUHB area – incorporating 3 GP units, 3 universities, forming a new model

Specific questions to **Royal College of Nursing Wales**

Question 1 - You state in your written evidence that Betsi Cadwaladr UHB appointed to the role of Dementia Nurse Consultant in 2012. Do you have any examples of how this has improved outcomes for patients affected by dementia in the Health Board area?

Nicola Davis-Job

- There has been a drop in consultant nurses in general
- Only 22 across Wales
- Their job descriptions map 5 pillars of practice
- 4x less people doing research in dementia than into cardiac conditions and cancer
- Recommend pushing for more

Question 2 - You state in your written evidence that a significant barrier to frontline staff developing their skills and knowledge is workforce pressures. Do you have any examples of how the Nurse Staffing Levels (Wales) Act 2016 has alleviated workforce pressures?

Lisa Turnbull

- Pressures are intense
- Wales doesn't publish data on vacancies, RCN estimate at least 1500 nursing vacancies in Wales today

- Plus every week the additional hours put in by existing nurses equates to another 1000 hours' worth of work
- Extraordinary amount spent on agency nurses
- This is the biggest barrier to high quality care
- Hence the RCN campaign for safe staffing legislation. RCN looking at evidence now, working towards an interim report in July 2019 with a final report due in December 2019
- Health Boards and Welsh Government have clearly stepped up their workforce planning on nursing in response to this legislation,
- Suggested the Cross Party Inquiry consider whether amending statutory guidance and operational guidance could be useful since these specify how to calculate the level of acuity on the ward and how to respond to it. as well as inquiring whether they take account of people living with dementia specifically – recommend speaking to leader of welsh government safe staffing programme.

Specific questions to **Dr Katie Featherstone**

Question 1 - What aspects of ward culture/practice could be changed to improve outcomes for patients with dementia?

- Timetables and tightly-bound task-based work, highly-paced – no sense that staff can interrupt the timetable, tension of the timetables 'running away'
- The way it's designed and delivered needs to change
- Targets e.g. falls prevention / pressure sores are very crude metrics which lead to a culture of containment and restraint
- Goes back to the need for ward leadership
- Need a move from fast-paced tasks to 'what do our patients need?'

[Comment from **Nicola Davis-Job** – encountered a nurse crying because there were not enough staff to allow patients safely out of bed]

[Comment from **Lisa Turnbull** – it comes back to safety and having enough people]

Question 2 - You state in your written evidence 'there is a significant need for evidence-based interventions and training to support people living with dementia and ward staff.' What would you suggest the Welsh Government can do to support evidence-based interventions and training?

- Small interventions that hospitals see as 'a good thing' are often very reactive, e.g. enhanced 1-1 care, this leads to agency staff coming in and focusing on restraint

Open Questions

Lynne Neagle AM invited questions from meeting attendees.

Jayne Goodrick

- Main thing is about communication

- E-learning doesn't give enough knowledge – we should utilise the expertise of people affected by dementia
- Response to RCN – not just ensuring water is there, need help to actually drink
- E.g. saw a lady tethered to her bed for her own safety, staff continued to re-tether her when she got up, without asking *why* she was getting up – whether she needed a drink or to use the toilet for example
- People with dementia being ignored even though they can communicate

Lisa Turnbull

- Thank you for the point – to clarify, meant nurses are under pressure so revert to a task-based approach e.g. has everyone got a glass of water

Nicola Davis-Job

- Leadership summit this year was on compassionate care and individual care

Dr Katie Featherstone

- Support Jayne's point
- Evidence-based - systematically happening across all our wards
- Continence care is another huge issue – people are not given access to the bathroom
- Mobility – maintaining skills is vital
- Nutrition – staff label patients 'feeders' (i.e. they need to be fed)

Suzanne Duval

- What about patients who speak other languages? E.g. BSL

Lisa Turnbull

- Support that concern – the question should be put to Local Health Boards, they should look at needs in the workforce plan
- Hospitals were not originally designed as a place for the care of people, just for specific procedures

Dr Katie Featherstone

- Intersectionality of identity is important to consider – the ward is a microcosm of culture and research shows individuals do have worse experiences

Ray Morrison

- Care homes – we do have staff carers in people's own homes
- Also have wealth of experience and knowledge – good source to aid a multi-disciplinary approach with e.g. pharmacists, OTs etc
- Some of our carers do access to nursing courses – already have experience of social care
- What about nurses doing some training with social care workers?
- Everyone needs to do Dementia Friends as a basic level of understanding

Jackie Askey

- Husband died in hospital through misdiagnosis of 'end stage dementia' – he had oral thrush
- Essential hospitals listen to carers
- Education of doctors as well as nurses
- Won a competition with a proposal – everyone who goes up to the bedside physically offers the patient a drink

Nicola Davis-Job

- Similar project called 'drink a drop' piloting in Cwm Taf

Jackie Askey

- He had no stimulation on the ward, I provided a radio and came in to find it tuned to a totally inappropriate station for my husband – the staff had tuned it to a station of their choice

Chris Roberts

- Difference between dementia and delirium often misunderstood
- People with dementia now have a stronger voice than ever

Ceri Higgins

- I educated myself to understand more about dementia and help my father
- On the degree course everyone should be trained in dementia

Linda Willis

- Been to 3 different hospitals in 2 months and not seen a single person wearing a Dementia Friends badge – seeing the badge makes a huge difference
- Positive feedback – had procedure yesterday, it was 90 minutes late, however the nurses were brilliant

Lynne Neagle AM thanked the panel and confirmed the CPG will write to each organisation with further questions that we have not covered in the evidence session.

Lisa Turnbull offered the support of the RCN as an ally in the next steps

AOB

Lynne Neagle AM confirmed she will submit written questions to the Minister for Health and Social Services re the DOIIG

Future meetings

Tuesday 8 October 2019 – AGM (will need to elect/re-elect Chair and Secretary)

Tuesday 3 December 2019

Tuesday 3 March 2020

Tuesday 19 May 2020

All 12 noon – 1.30pm in Y Pierhead