

Cross Party Group on Older People and Ageing

8 October 2014, Conference Room 24, Tŷ Hywel

Note of Meeting on Public Toilets and the new Public Health Bill

Attendees	Apologies
Mike Hedges AM - CHAIR	Ana Palazón, Director of the Stroke Association
Rosanne Palmer, Age Cymru - SECRETARY	Phil Vining, Age Connect
Jackie Radford AMSS to Aled Roberts AM	Lorraine Morgan, Consultant on Ageing
Frances Laing, Carers' Trust	Phyllis Preece, National Pensioners Convention
Fiona Guthrie, Carers' Trust	
Ryland Doyle AMSS to Mike Hedges AM	Laura Nott, Age Cymru
John Davies, National Old Age Pensioners' Association of Wales	
Iwan Williams, Older People's Commissioner's Office	
Lynda Wallis, Vale 50+ Strategy Forum	
Robin Moulster, BASW Cymru	
Nick Wall AMSS to Mick Antoniw AM	
Nancy Davies, Pensioners Forum Wales	
Maria Cheshire Allen, Centre for Innovative Ageing, Swansea University	
Kieron Rees, Carers' Trust	
Simon Hatch, Carers' Trust	
Mark Isherwood AM	
Iwan Rhys Roberts, Age Cymru - SECRETARY	

Welcome and introductions

Mike Hedges AM welcomed everyone to the meeting and called out the apologies.

Matters arising from previous meeting

- Following on from the recommendations/actions of the 7 May meeting, Mike Hedges confirmed that a letter had been sent to the WLGA regarding access and quality of public toilets, including accessing public toilets in banks and libraries.
- Laura Nott to confirm whether the minutes from this meeting [7 May] had been sent as a letter for the Public Health Bill consultation. (Note – Laura Nott confirmed on 13 October that this has been done.)

‘Supporting and involving carers of people with dementia’ – presentation by Fiona Guthrie and Frances Laing, Carers Trust

Simon Hatch and Kieron Rees introduced this presentation by giving a background to Carers Trust.

Frances Laing began her talk by explaining that her late mother had dementia; that her brother has early onset dementia and her husband has been diagnosed with dementia.

She said that delays in diagnosing dementia mean there's often no help for people living with dementia or their carers in the early stages of dementia.

Frances explained that because of negative experiences she'd had with her brother and his dementia and the lack of support she'd had from care authorities, she was frightened for her and her husband's futures.

They had not been able to find a care centre that was able to provide for Frances' brother's needs due to the lack of provision for early-onset dementia. When her brother was in hospital, Frances said she didn't feel she'd had any support from the hospital.

She also clarified how repeatedly moving her brother around had a detrimental impact on his behaviour and condition.

Despite Frances having power of attorney over her brother's affairs, hospital staff were not listening to her.

He was over-medicated and unable to eat and left with his mouth full of food, which was dangerous.

On one occasion, he had fallen out of bed.

Staff had not checked her brother's medication and his blood pressure had dropped.

Under the supervision of a paid carer, Frances' brother had become so dehydrated that his kidneys could have been damaged and had to be put on a drip.

Also while he was under the supervision of a paid carer, Frances's brother's bedroom had become covered in faeces.

Frances explained that when she had to have her brother hospitalised, she didn't get any advice and reiterated that she was not listened to by the hospital.

She concluded by saying that she felt alone and that we need to have proper facilities of care for people who live with dementia.

Fiona Guthrie added that Frances' story was quite common and that many carers often felt stressed and helpless.

Comments and questions

Mike Hedges AM – far too often, health professionals do things to people rather than with them – “the consultant knows best”. Also local authorities no longer provide social care directly, but commission agencies

Frances Laing – paid carers don’t need to be qualified in dementia.

Mike Hedges AM – paid carers don’t need to be qualified! Care is allocated on price not quality. Investing in hospitals does not solve health problems.

Frances Laing – I was told I could have direct payments, but it did not materialise.

Mike Hedges AM – direct payments would be suitable for Frances, but not for everyone because the system is open to abuse from family members.

Nancy Davies – we need a government sponsored education campaign to teach the general public about dementia.

Robin Moulster – care is about having the right attitude as well as training. In addition, local authorities should, if an individual has an assessment of need and a care plan, take into account the carer’s needs. Carer also has a right to an independent assessment of their needs.

Frances Laing – It was very hard for me to get a carer’s assessment. If you don’t understand the care system it is difficult to get help.

Robin Moulster – communication is key between care organisations and carers. In many cases, care organisations are paid by local authorities to deliver care of the highest standard and that care includes the behaviour of staff. Local authorities have a legal duty to comply with certain standards and should be monitoring agencies to ensure standards are delivered

Frances Laing – it’s difficult to complain about poor care. When you’re faced with it, the last thing you want is to fill in a form. Getting the information you need is also difficult. Closures due to funding cuts are having an impact but service delivery is already badly fragmented.

Simon Hatch – Frances’s experiences are a devastating critique of the way care services have supported her and her family. Her best experiences have come from the charities that have supported her. Legislation is not translating into reality. We need to look after carers. The message that the carer is central is not getting through.

Robin Moulster – social workers should advise carers about the care services that are available. They should feed back carers’ experiences to care commissioners. There are some good services available – such as reablement services, but it is a postcode lottery.

Frances Laing – shouldn't social workers complain?

Robin Moulster – yes, but carers also have a right to complain.

Mike Hedges AM – If the system is working properly, social workers should be picking up the complaint. What about situations where there is a distance carer or no carer? Social workers should manage the care people receive.

Fiona Guthrie – I agree. How many people know what it is like to care for someone with dementia?

Mike Hedges AM – legislation is quite often not a solution. It can come down to individuals and training.

Recommendations / actions

- Mike Hedges to speak to Jane Hutt and Adam Cairn's about Frances Laing's experience

Date of next meeting

11th February 2015