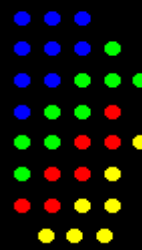


EVIDEM: Evidence-based interventions in dementia

Newsletter 5 Autumn 2009

[**www.evidem.org.uk**](http://www.evidem.org.uk)



Welcome

Welcome to the Autumn 2009 edition of the EVIDEM newsletter. In this edition you will find an update on the End of Life project; Interviews with EVIDEM volunteers; and an update on 'EVIDEM – Outputs'.

A busy summer has seen the second annual EVIDEM Summer School. Feedback on this event can be found on page 2. The team has also contributed to several events including the 3rd International Dementia De-

velopment Service Centre conference, The British Society of Gerontology's Annual Meeting, and the Dementia Care Congress.

The team would also like to take this opportunity to welcome Dr. Ingela Thuné-Boyle. Ingela is a chartered and registered Health Psychologist with a research background in health service provision, coping and illness adjustment in patients with chronic/terminal illness and their carers. She will support the EVIDEM-ED and EVIDEM-E trials.

EVIDEM Volunteers Perspective: Carer & CNWL Staff

In 2007 Carol Walsh's husband, Michael passed away. For a few years up to then Carol and Michael were living with dementia. As a vocal member of her community, Carol is passionate about ensuring people are well informed; and so with these experiences she kindly volunteered to be an EVIDEM advisory group member. We recently caught up with Carol and below are some of the highlights:

How did you come to be involved with EVIDEM?

I'm a member of the Alzheimer's disease Society, and we get a regular magazine, 'Living with Dementia'. It was in here that I read about EVIDEM. Having just lost my husband I was interested in the End of Life study, so I got in touch with Professor Claire. However, I soon realised that it was too soon and so I ended up helping Professor Vari and Laura on their continence study.

What does your role involve?

I help out with the advisory group along with two or three other carers. I'm there to help the research by addressing the grey areas. I

recognise that continence is a stigmatised issue; it's a problem which people won't talk about. I know Vari has had difficulty collecting data as people are reluctant to talk to professionals; they don't want to be identified as a person with these issues. I think Vari and Laura are going the right way about it.

Although I would get up five times a night to ensure my husband didn't have continence issues; I knew of challenges such as the provision of pads and how this can affect people. Also, given my husband's experience of a late diagnosis, I knew early diagnosis is very important.

What do you hope EVIDEM will achieve?

I hope the whole EVIDEM programme will address the issues where we're lacking; if we don't it can lead to stress, health and anxiety problems, which can in turn lead to increased hospital stay and affect the overall health of the home. Also, I hope that it helps to open up people's thoughts not to leave a problem to linger. So long as they have information they have a choice.

Jean Hibbert is Senior Occupational Therapist for the Intermediate Mental Health & Physical Care Service (IMPS) based at St Charles Hospital. Jean discovered her interest in older adult mental health during her rotation at St Mary's Hospital. Below Jean talks about her experience of the EVIDEM Programme:

How did you come to be involved with EVIDEM?

Its funny, but I'd heard of EVIDEM a few times. I received an email that had been sent out, and at the same time my supervisor raised it in one of our sessions; she invited me along to an advisory group meeting and I joined her.

What does your role involve?

We've helped recruit participants for the study and I'm a member of the advisory team (EVIDEM-C), I think it's gone pretty well; we've had a little friendly competition to be the team

with the most recruits.

What has it been like to take part in EVIDEM ?

I never thought I'd be involved in anything like this, I thought you had to be higher up the ladder. I have quite enjoyed the experience and I hope I'll get a chance to do a little more in the future, perhaps through a Masters degree.

What do you hope EVIDEM will achieve?

I hope it helps raise awareness, as challenges with continence is obviously a big issue. It's sad how people have very effective strategies for covering their issues up; and the professionals with all the information sometimes struggle to spot the signs. If it's spotted earlier, then people would gain access to a wealth of information that could help them. I think as professionals we need to be ready to discuss these issues with the people we come into contact with.

If you'd like to get involved: please contact Laura Cole (020) 8725 3867

EVIDEM Summer School—2009

This year the EVIDEM Summer School was delivered as a road show, with EVIDEM teams leading workshop based sessions at Bentley House (Harrow), St Charles' Hospital (Kensington), the Woodlands Centre (Hillingdon), and the Willesden Centre (Brent). Spread over 13 days, forty six people registered to attend one or more of the eight workshops and many more joined us on the day. Most delegates favoured the new road show format that gave them the freedom to dip in and out of sessions close to their work base.

The positive and constructive feedback described presentations as "excellent", "very good" and "very very interesting". The session surrounding behavioural and psychological symptoms of dementia led by Dr James Warner drew notable praise with one participant suggesting

".. these sessions should become mandatory for all staff working with older adults in the trust".

Prof Manthorpe's Mental Capacity Act workshop was described as "really relaxed" and the "style of presentation....was excellent", and we're glad delegates were comfortable with the atmosphere.

Although the events were well attended, we'd like to improve on this next year. The feedback indicated that only a small number (7%) felt that their colleagues wouldn't be interested in the sessions. We'd be extremely interested to hear from anybody who didn't attend Summer School and would have liked to.

If you have any ideas or indeed would like to get involved in the organisation of summer school 2010, please do get in touch (David Lowery (020) 3214 5889).

Delegates were also very keen to get an update on the EVIDEM projects. Some preliminary findings were reported and I'm happy to say that this coming year will be an exciting time for the EVIDEM programme. The teams should be ready to present more detailed findings at **Summer School 2010.**²

An Update on EVIDEM-EoL

What we are doing—

EVIDEM – EOL is focused on: ***Understanding end of life care and support needs of older people with dementia living in care homes.***

Currently in Phase One (of two), we aim to describe the different characteristics of the end of life pathways of people with dementia.

- We will explore the support needs of people with dementia, their carers and primary care staff;
- Investigate how end of life care is assessed and the influence of context models for older people's end of life care experience;
- Explore the implementation of existing support tools and access/use of services.

We are using various methods, including case note reviews, focus groups, and interviews.

Phase one will inform the development of educational support tools with the care homes.

How far we have come—

We have:

- Recruited: 140 older people through 6 care homes
- Conducted: 2 interviews with District Nurses/ 3 care home staff focus groups/ interviewed 5 care home managers
- completed baseline data collection for the older people

What our next steps will be—

- Interview NHS professionals who visit care homes (i.e, GPs, District Nurses and more)
- Conduct further staff focus groups
- Continue case note reviews
- Start the development of the educational tool (Phase Two)
- Explore what might help staff identify when a person with dementia is approaching end of life.

Barriers to recruiting Participants

The Mental Capacity Act (2005) has impacted on the time taken to recruit older people. There are a number of factors which impact on the ability of someone living in a care home to give informed consent. For example, communal environments, ubiquitous to care homes, make it difficult to speak to a resident individually, and often residents who need assistance with mobilisation may not wish to move to a more private area, even if such an area were available. In addition, some Care Home Managers try to protect vulnerable residents, and so will suggest that some

are not able to give informed consent. In this case we are obliged to write to that person's consultee, or person that knows them best, usually a relative, and follow up with a phone call where no response is forthcoming.

Recruitment has been a challenging process not only because of the time and resources involved but also because careful consideration had to be given as to whether this was appropriate for that family. However, with support and help from Care Home Managers we were able to contact many consultees. In total we invested 146 hours to reach our recruitment target.

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Preliminary Findings—

Decisions during unexpected events

Early findings from interviews with Care Home Managers suggest that where an emergency ambulance has been called for a resident, there may be some important issues around whether or not, after being treated, a resident needs to be transferred to hospital. Care Home Managers have also highlighted that decisions regarding resuscitation are very difficult when an unexpected event occurs, especially if the wishes of the older person have not been recently, or fully, documented.

Preliminary Findings— Opinions of the value of the dementia diagnosis

The culture of a care home shapes the decisions surrounding end of life care for any given individual. It is also apparent that, between the care homes, there is a range of views about the value of a diagnosis of dementia. For some it seems an unhelpful label whilst for others it is considered a tool to enable better access to health or social care.

EVIDEM Outputs

International Journal of Geriatric Psychiatry

1. **End of life care for community dwelling older people with dementia: an integrated review online access** Goodman C, Wilcock J, Froggatt K, Sampson E, Drennan V, Blanchard M, Bissett M, & Iliffe S (2009) in press/available online

Journal of Integrated Care

1. **Commissioning Dementia Care: Implementing the National Dementia Strategy** Iliffe S & Wilcock J (2009) Volume 17 issue 4 pages 3-11
2. **Mental Health in Later Life: Better Outcomes through Wise Commissioning.** Manthorpe J (2009) Volume 17 issue 5 in press.

Signpost

1. **Keeping on Track** Manthorpe J, Iliffe S, Rait G, Goodman C & Warner J (2009) in press

If you would like more information or would like to get involved in EVIDEM please contact:

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020 7830 2239 (ex.38370)/j.wilcock@pcps.ucl.ac.uk

or David Lowery (CNWL NHS Foundation Trust)

020-3214-5889/d.lowery@ucl.ac.uk

Alternatively you can visit us at our website:

[**www.evidem.org.uk**](http://www.evidem.org.uk)

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