



# **The Wales Dementia Care Training Initiative**

**Final Report**

**1 December 2010 – 30 September 2012**

**<http://www.dementiatrainingwales.co.uk>**

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### Aims

Overall, the aim of the Initiative was to increase training capacity and expertise in Wales, to lead to sustainable improvements in attitudes, skills and knowledge of those providing support and care to the growing number of people with dementia.

Specifically, the Initiative aimed to produce an incremental shift in dementia training capacity in Wales, producing a cohort of trainers able to deliver transformational training, and embedding within care facilities in Wales staff who will ensure that dementia training remains a priority for years to come.

### Overall Progress

The original project period was extended by six months, to 30<sup>th</sup> September 2012, in view of the delay in appointment of the full-time Training Officer in South Wales (due to the requirements of NHS recruitment procedures) and subsequent slippage. This extension has enabled the planned activities to be completed. Interim reports have been provided to Welsh Government in October 2011, April 2012 and August 2012, and this report provides an overview and evaluation of the main areas of activity.

#### Box 1: The Initiative's achievements

##### I - in terms of deliverables as set out in original proposal

- Web-site with searchable database <http://www.dementiatrainingwales.co.uk/>
- The 'train the trainers' module, specifically for dementia care trainers developed, and accredited by Agored Cymru.  
<https://www.agored.org.uk/default.aspx?id=236&opusid=CCZ001&lang=&natcode=GC83CY009>
- The two-day 'train the trainers' module has been offered 18 times at venues throughout Wales. In total, **134** people registered to undertake this module, and **73** have successfully completed the course.
- These staff form the core of a network of staff with a dementia focus committed to developing dementia care in their work-place.
- Over **2782** professionals and carers have participated in training sessions and courses, offered through, or in collaboration with, the Dementia Care Training Initiative. Of these, **1001** are staff in general hospitals.

## **Box 2: The Initiative's achievements**

### **II - in terms of additional changes extending beyond the Initiative time-scale**

- Introduction of the 'Butterfly' scheme to general hospital wards in two Health Boards, leading to adoption in the majority of Health Board areas in Wales.
- Development of a web-based continuing professional development module for General Practitioners and primary care staff on diagnosis and management of dementia  
<http://www.onexamination.com/self-assessment/all/diagnosing-and-managing-dementia-in-primary-care>
- Development of a rolling programme of dementia training events and a fact sheet with the Wales Mental Health in Primary Care network
- Development and piloting of a newskills-based training programme for family carers that can be implemented by Dementia Advisors

## **Increasing training capacity in Wales – the Train the Trainers module**

The ‘train the trainers’ module, developed by DSDC Training Officer Joan Woods and accredited at level 3 by Agored Cymru in 2011, was offered 18 times during the Initiative at different locations across Wales. These include Aberystwyth, Bangor, Bridgend, Caerleon, Caerphilly, Cardiff, Carmarthen, Chepstow, Merthyr Tydfil, Rhyl, Swansea and Wrexham.

Between the two days of the course, learners conduct a video-taped teaching session in their own work-place, and receive feedback from the course team on this.

A wide range of staff have undertaken this course, including Social Services training officers, staff from the independent sector, health boards (from general hospital and mental health sectors), voluntary sector agencies and social services departments. During the Initiative, 134 people registered for the course. Completion of the course is quite demanding, requiring assessed written assignments as well as the video-taped session, and so, not surprisingly the number who have achieved the award is much lower than the number registering. This also reflects the necessarily high standards set for achievement, resulting in a number of candidates being asked to revise assignments or present additional work. The course helped some candidates to recognise that they were not in fact cut out for dementia training, and so they did not complete the assignments.

As a new course, the verification process with Agored Cymru has taken an extended period, and the first batch of successful candidates received their certificates of achievement in the autumn of 2012. To date, 73 people have successfully completed the programme. Another 16 have completed most of the course requirements and are expected to complete in the next few months.

Further Train the Trainer courses are being offered by the DSDC Training Officer in North Wales, and there continues to be interest in achieving this accreditation. Due to scheduling delays, three Train the Trainer courses specifically for general hospital staff working in Betsi Cadwaladr UHB, who completed two days of dementia training in the spring of 2012, are planned for March / May 2013.

As part of the course involved delivering a training session in the work-place, approximately 356 staff additionally received some dementia training associated with this aspect of the initiative. A number of those who have completed the course successfully are now offering training in a variety of settings. Some extracts from feedback from candidates regarding the training they have gone on to do are given below. They illustrate the breadth of groups being targeted and the range of approaches, from the very informal, working alongside staff, to more formal talks and presentations.

### **Box 3: Further training undertaken by staff completing the Train the Trainers module**

- I have done 6 sessions on 'Dementia Awareness' and 1 session on 'Dementia-compromised behaviours'. The sessions were done with residential care staff at various locations. I will be doing further sessions throughout the year.
- I have carried out two training courses in Dementia Awareness to my team of approximately 13 people.
- I have started an on-going training / staff development series with the memory clinic staff and have been contributing to the development of two dementia training programmes across the trust which will be delivered in the next year. I have also been working on a bit of training for Primary Mental Health staff and we have piloted one of the two dementia training programmes.
- I have delivered some training - we spoke to a group of trained nurses who have all retired and who are now all Parish Nurses working with multi faith organisations visiting people of all ages, including elderly people, and supporting them in their own homes. The talk was a basic "what is dementia" and "what is mild cognitive impairment" and incorporated "what to do" if someone had memory deficits or cognitive impairment.
- I have held a Sonas training session at the Residential Home where I am based. The Train the Trainer course has helped me gain experience towards any future training sessions.
- We have a programme of dementia training. I actually delivered a session in July and I am due to deliver one tomorrow. I have also recently developed a Life Story Work session which we are hoping to include in our training programme over the next few months.
- I have carried out training with my own care staff and also work with ..... to deliver joint training to care workers in care homes and domiciliary care. I have also delivered training to Prison Officers to recognize early dementia in prisoners.
- Since the day that I was observed I have co- facilitated another 1-Day training event for approximately 20 workers from ..... Council and private care providers within the borough. We have recently updated our Dementia training to bring it in line with the QCF Health and Social Care Diploma units and will continue to facilitate more training throughout the year.
- We hold Dementia Awareness Training sessions once a month. They are 90 minutes long and staff from all departments are able to attend. They give an overview of what dementia is, the causes, the statistics, challenge staff's attitude to dementia, use experiential learning and scenarios to learn about person centred care and how to apply it in practice. Each session's discussions have been so different based on the individuals that attend. It is heartening to hear staff be honest about their frustrations and lack of knowledge in caring for a person who has dementia and then to witness the change of attitudes by the end of the sessions. Attendees have learned from each other's contributions and challenges. In addition to this, many have friends, neighbours and family members with dementia so the benefits from the training are reaching the wider community too. 50 staff have attended training so far.
- No formal presentations or training as we have not been allocated time - it can be almost impossible to try and fit it in during a shift if time is not allocated, but I have been giving information to staff during the shifts as we are going about our work so these have been very informal and they have been concentrating on problems associated with patients that have dementia and how to effectively deal with these. I have also told the staff that they can come to me if they are experiencing any difficulties and I will try and guide them in the right direction.

## **Developing training for priority groups**

### ***General Hospital staff***

Successive reports and audits suggest that the care of people with dementia in general hospitals is a major cause for concern, and it was therefore important that the Initiative make a difference in this area.

It is fair to say that despite the Initiative being represented at the Cardiff meeting convened by the Welsh Government in June 2011 on the care of people with dementia in general hospital settings, and the priority given to this area in the Dementia 1000 Lives plus improvement programme, it proved difficult to establish a foothold in general hospitals across Wales. It was helpful that Health Boards were reminded of the availability of training resource through the Initiative by a letter from Dr Sarah Watkins at the beginning of September 2011. The various efforts were worthwhile, as once the offer of training was taken up, and staff were engaged with it, a positive and enthusiastic response was received.

As each Health Board has its own approach in this area and some have existing training initiatives, the input from the Initiative varied from Health Board to Health Board, and so what was achieved with each is described separately.

### ***Abertawe Bro Morgannwg***

ABM has a well-established training team, who provide regular training input to care homes in the area. The Initiative enabled the team to provide three study days and a five-day course targeted at general hospital staff across the Health Board area. The study days were attended by a total of 131 staff from a variety of roles and disciplines, including porters, receptionists, phlebotomists, chaplains, audiologists, physiotherapists, occupational therapists and, of course, nurses.

The intensive five-day dementia care course was attended by a total of 23 staff, the majority of whom were general hospital nurses. Apart from attending one of the study days, very few participating had had any previous dementia training.

Staff attending these courses reported a change in their attitude to the behaviour of people with dementia, of looking for other ways to communicate, of seeing the person rather than the condition and of beginning to see the effect of the environment on the person with dementia.

Eight general hospital staff from ABM registered for the 'train the trainer' module and a further 13 general hospital staff have attended dementia courses provided directly by the Initiative.

### *Aneurin Bevan*

In this Health Board, the emphasis has been on equipping staff with the skills to train others in dementia care in the general hospital context, and ten staff registered for the ‘train the trainer’ module.

### *Betsi Cadwaladr*

In BCUHB, there was a great deal of interest in the Initiative, but it took many months before firm arrangements could be made for specific sessions. It was agreed to offer a two-day course (on consecutive days) for general hospital staff. Four of these courses were held at different locations across the health board area – one was cancelled because of poor sign-up by staff, but was subsequently rescheduled. Forty four staff attended (although potentially 80 places were available across the four courses). As well as nursing staff (qualified and unqualified), physiotherapists and a dietitian took part. The support of senior nurses, including several matrons, was evident.

The response to the training was extremely positive, with there being clear benefits from **not** having mental health colleagues involved. Staff recognised their own responsibility for improving dementia care on their wards and units, and took away many plans to influence their own practice and that of others, especially in relation to communication. A number of participants are now keen to undertake the ‘train the trainer’ module, which will enable the learning to be shared more widely. Additional 2 day courses have been arranged in March / May 2013 for this purpose.

The training courses coincided with work on improving dementia care environments in BCUHB general hospital wards, involving matrons across the health board, with input from DSDC Wales. It has also led to the proposal of a dementia care training framework for all levels of staff in general hospitals across the area, now coordinated by the newly appointed Consultant Nurse in Dementia Care, Sean Page.

### *Cardiff & Vale*

This health board has already had training for general hospital staff underway. Through the Initiative, to date, 170 general hospital staff have attended dementia training.

The Initiative has been able to support the launch of the ‘Butterfly scheme’ in Cardiff & Vale. This is a scheme where staff are helped to identify and respond appropriately to the needs of people with a dementia in a general hospital ward. It has been developed by a carer, Barbara Hodkinson, and uses a butterfly symbol to prompt staff to be especially aware of people who have been identified as having a dementia. The Initiative funded the training sessions on the implementation of the scheme, including input from Barbara Hodkinson, with 230 staff attending these sessions.

### *Cwm Taf*

Ten general hospital staff from Cwm Taf Health Board have attended dementia training, with four general hospital staff undertaking the ‘train the trainer’ module.

The Initiative has also supported training in hand massage techniques for general hospital staff, as this was an area where it was thought that staff could be empowered to take a more proactive and therapeutic role with people with dementia.

### *Hywel Dda*

In Hywel Dda the Initiative was also able to support the training required to underpin the launch of the Butterfly scheme. 180 staff attended these events. In addition, 48 general hospital staff attended further dementia training.

### *Powys*

Staff have been invited to participate in sessions in ABHB, BCUHB and Hywel Dda, including ‘train the trainer’ modules.

### *Velindre*

Eleven staff have attended dementia training through the Initiative, and three staff registered for the ‘train the trainer’ module.

### ***Primary care***

The Initiative established a collaboration with BMJ On Examination, who are based in Wales and provide continuing professional development modules – typically based on clinical vignettes – for a range of medical practitioners. A module ‘Diagnosing and managing dementia in primary care’ has been developed, featuring eleven case vignettes, and is now available on-line:

<http://www.onexamination.com/self-assessment/all/diagnosing-and-managing-dementia-in-primary-care>

The vignettes address some of the most challenging aspects of primary care practice with people with dementia – from differentiating dementia from depression and delirium, to advising regarding driving, to managing behavioural problems in a care home, to issues of capacity. For each case example, the GP selects a multiple-choice response, and receives feedback and further guidance. The module is available to all general practitioners in Wales, free of charge, initially for one year, using a link which has been forwarded to all GPs in Wales by the Wales Mental Health in Primary Care Network, as well as being made available in conference packs. Successful completion of the module results in a CPD certificate for the GP’s portfolio.

With our partners from the Wales Mental Health in Primary Care Network, two half-day events were held in Llandudno (June 2012) and Swansea (September 2012). The programme on both occasions included a presentation on training and timely diagnosis from Professor

Steve Iliffe, who leads the 'EVIDEM-ED: early dementia diagnosis and management in primary care' project based at University College London. Other presentations were on responding to behavioural problems in care homes, and alternatives to the use of anti-psychotic medication, linking with the 1000 Lives plus medications management and dementia domain. The events attracted a total of 145 delegates, fairly evenly split between those from primary care and those working with primary care. There were a good number of GPs present at each of the events. Evaluations were very positive, with knowledge increased, and many delegates reporting they would be taking key learning messages back to their workplaces (see Box 4).

As a result of the success of these two events, the Wales Mental Health in Primary Care network is planning, with the support of the DSDC, to run two further events in February / March 2013, in Cardiff and Wrexham, with a programme including vascular dementia and social care. It is also planning to produce a dementia fact sheet for general practitioners for wide dissemination.

#### **Box 4: Actions to be taken as a result of primary care learning event**

- Spread knowledge to other staff. Inform new care home development
- Organise training for staff locally. Identify key clinicians locally to support therapies.
- Consider own caseload and use of antipsychotic medications – need for review /reduction
- Use life stories.
- Be aware of carer's distress. Look for unseen stressors – pain, constipation etc.
- Encourage review of medication.
- Go on line re BMJ diagnosis module
- More proactive in reviewing medication and reducing antipsychotics. More recognition of carers.
- Make staff aware of effects of anti-psychotics instead of hearing 'can the GP give her something?'
- Share 1000 lives learning more widely through meetings, internet and newsletter
- Use of post diagnosis packs
- Reading. BMJ self-assessment
- Look at our practice dementia prescribing.
- Use pain scales validated in dementia
- Review pain relief and alternative causes for agitation
- BMJ module. Look into how to assess BPSD. Try to use person centred approach in crisis situation as well as long term care.

### ***Younger People with Dementia***

The Initiative organised two study days on Younger People with Dementia, linking in with the newly developed services for younger people with dementia across Wales. Over 250 people attended these events, held in Cardiff and Abergele. Participants included people with dementia and care-givers, as well as health and social care practitioners.

Regular network meetings in both North and South Wales are now running arising from these events and provide an opportunity to address with the newly developed services further training needs.

### ***Family care-givers***

Discussions with the Alzheimer's Society regarding specific training packages for family care-givers suggested that the Society had well-established programmes available across Wales. However, in consultation with professionals and carers, the Initiative identified a need for a structured skills-based training programme for family carers, and has supported the Solace team in Cardiff in producing this. The course, known as the 'Mindful of Memories' course, comprises four skills-based workshops:

1. Understanding dementia
2. Bringing meaningful activity into daily life
3. Managing difficult situations
4. Helping with physical care and promoting independence

This programme has now been piloted, with very positive evaluations from those carers undertaking it, and their feedback has been used to refine the course content. Extracts from carers' feedback regarding their learning from the four workshops is provided in Box 5. The feedback has generally been positive with carers at various stages finding them useful. Those who are experienced carers found it gave them affirmation that what they were doing was right as well as learning new information; while those who were new to the role found that it helped them to understand what was going on in the world of those they care for and that they needed to be mindful of physical as well as mental needs.

The workshop booklets and the trainers' book are now in the process of being finalized for printing and should be ready by February 2013. Once the books are available, the Solace team will organise a half day event in February to train further trainers to lead the course – this will include the Dementia Care Advisers for both the Aneurin Bevan Health Board and the Cardiff & Vale UHB. Courses will then be run in both Health Boards, with a minimum of four workshop courses per year in Cardiff. The DCA's will continue to be supported by Janice Becquer-Moreno and Amanda King.

## **Box 5 – Carers’ Learning points from the ‘Mindful of Memories’ course**

### **Workshop 1 (understanding dementia)**

- The importance of considering the impact of the illness through the eyes of the sufferer
- The importance of documenting the capabilities / likes/ dislikes of the sufferer for healthcare professionals
- How difficult it is to dress yourself when you have a dementia
- That being fed is not a great experience
- The importance of engaging with the person that you are caring for
- Realisation that dementia is a disability and not a disaster

### **Workshop 2 (meaningful activities)**

- The importance of activity when looking after someone with dementia
- Be aware of husband’s strengths. Work on them. Give praise
- Reduce boredom.
- Work on activities together
- Try different activities
- The importance of engaging in day to day activities to stimulate memory
- Memory boxes and how easy it is to put one together
- The simplest things can invoke a memory
- Distraction / rummage boxes
- Life history work

### **Workshop 3 (Managing difficult situations)**

- How not to do certain things i.e. No sudden approaches to the person
- Listen to what they are saying
- Try to keep calm so that your feelings do not transfer to the person
- How people with dementia feel about themselves
- Why they exhibit aggressive behaviour
- How to react in certain situations
- Problem solving
- Understanding behaviours
- Coping strategies
- Understanding ‘needs’ more
- Empathising with frustration and moods
- Coping with pressure, which is advantageous to both patient and carer

### **Workshop 4 (Physical care and promoting independence)**

- How to recognise the differences between delirium & dementia
- Recognise that there can be physical reasons for changes in behaviour
- Different indications of constipation
- Importance of intervention by GP earlier rather than later.
- The amount of help and information available to carers.

## **Sustaining change for people with dementia and their families**

The number of staff and carers who have attended training days and courses offered through the Initiative continues to grow steadily, having reached **2782** by the end of the Initiative in September 2012 (see Appendix 1 for a breakdown of these figures). This includes an estimate of the numbers of people reached through the training sessions undertaken by those who were participating in the ‘train the trainers’ module.

Those who have participated in training include a range of Health Board staff – from consultants to health care assistants; local authority staff working in care homes and in community support; staff from independent sector care homes and independent community care providers; voluntary sector staff, including from museums and galleries as well as organisations such as the Alzheimer’s Society; and family care-givers.

375 have attended courses lasting 2 days or more, including a number of general hospital staff. Many staff in care homes across Wales have participated in the ‘Working with people with dementia and their families’ programme, or other courses involving practical assignments and tutorials between sessions. Practical assignments have included creating a ‘memory box’ with a person with dementia; trying out different approaches to sensory stimulation; and making a life-story book with the person with dementia.

The powerful S4C documentary ‘Un o bob tri’ was screened in February 2012 and looked at life for people with dementia in several care homes in Wales. Two of the homes that provided a positive environment for people with dementia were homes that have participated fully in the initiative, with their staff undertaking the ‘train the trainer’ programme.

Typical comments from participants of training provided through the Initiative include:

*'Really enjoyed the day, learned a great deal about the different types of dementia and different communication strategies'*

*'I feel I have learnt a great deal and will think very carefully when looking after our patients, some of whom have dementia in varying degrees, but the majority are just out of their usual environments-their comfort zones-and adjusting to an environment that they have not experienced before.'*

*'Learnt what person centred care really means and how I can implement it'*

*'Now understand different types of behaviour that I see with patients with dementia and how I can reduce any distress'*

*'Found validation therapy interesting, will definitely use this on the ward'*

*'Feel more confident now when caring for someone with dementia'*

*'Feel I have more understanding and empathy for this client group and would like to learn more'*

*'I am now full of ideas for the workplace'*

*'I learnt that people with dementia can do things that normal people do, and they enjoy doing activities (e.g. dancing, singing)'*

*'It has made me feel more confident with how to approach/care for dementia patients'*

*'I will try to understand more about each person in order to give them individual care'*

*'It really does make a difference to people's lives if you help and understand them'*

*'...indebted for...the absolute difference in improving my workforce and their knowledge of dementia care, but above all the positive changes it has brought to the lives of my service users.'* (Care home manager after completion of certificate programme with staff).

## **Next steps**

In the initial proposal for the Initiative, it was envisaged that (a relatively small amount of) funding would be required beyond the initial period to maintain the impetus that it was hoped to achieve. This on-going funding would be used to:

- Support a network of trainers, including those acting as 'champions' in their own work setting. This would include twice-yearly face to face meetings, web-based forum and newsletters.
- Maintain the database of resources and web-based materials, including further development of 'Signpost' as a vehicle for disseminating good practice. Ensure wide dissemination of new training resources and opportunities.
- Support forums in North and South Wales for younger people with dementia services to share good practice, organise up-dates, seminars and conferences.

In addition, such a resource could be used to facilitate a Wales Dementia Training Forum, based in the Initiative's Advisory Group to share good practice and encourage future developments in this area. The experience gained in the Initiative reinforces the need for this on-going funding.

Bob Woods  
Bangor University  
Co-Director DSDC Wales  
[b.woods@bangor.ac.uk](mailto:b.woods@bangor.ac.uk)

Christina Maciejewski  
Cardiff & Vale UHB  
Co-Director DSDC Wales  
[Christina.Maciejewski@wales.nhs.uk](mailto:Christina.Maciejewski@wales.nhs.uk)

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## Appendix 1

### Training undertaken under the auspices of the Initiative

	Train the trainers			1 day courses and events	2+ day courses	Total
	Registered	Completed	Likely to complete			
Social Services care homes	15	8	2	178	96	289
Social Services community / other	26	16	1	81	15	122
NHS - mental health	29	20	5	157	6	192
NHS – general hospitals	24	13	4	919	58	1001
Independent sector care homes	21	8	3	191	62	274
Independent sector – community	16	7	1	4		20
Voluntary sector & other	3	1	0	77		80
Carers				50		50
Primary care				144	4	148
Younger People with Dementia events				250		250
Participants taught as part of assessment of 'train the trainer' module				356		
<b>Total</b>	<b>134</b>	<b>73</b>	<b>16</b>	<b>2407</b>	<b>241</b>	<b>2782</b>