**Keywords:** Dementia/Training/Mental health

This article has been double-blind peer reviewed

A group of trusts and care organisations in London developed an innovative approach to improving care for patients with dementia and support for carers

# Training to promote dementia support

## In this article...

- How the dementia training programme was developed
- Who the programme is for
- Service improvements as a result of the programme

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**Abstract** Kwakwa J et al (2016) Training to promote dementia support. *Nursing Times*; 112: 25, 20-23.

Inadequate care has been identified for those with dementia at all stages, from pre-diagnosis to end-of-life care. Nationally, two levels of initiatives are evolving: basic awareness skilling of frontline care staff and changing services at the strategic level. Senior clinical staff have the potential to fill the gap between the two levels and drive speedier service change. This article describes a multidisciplinary programme developed by Central London Community Healthcare Trust to provide dementia care champions, at the advanced tier 3 level, to drive a range of service improvements across north-west London.

It has been identified that the needs of people with dementia, their families and carers are being inadequately met at all stages. This ranges from delayed diagnosis, fragmented memory service follow-up and insufficient community support through to poor symptom management at the end of life (All-Party Parliamentary Group on Dementia, 2014; Crowther et al, 2013).

The increase in incidence of dementia and earlier diagnosis has a far-reaching effect on services. Currently more than 850,000 patients are estimated to be living with dementia in the UK (Alzheimer's Society, 2014), and the number is expected to double in the next 30 years (Department of Health, 2015). The impact on families and carers encompasses a spectrum of everyday challenges with financial, physical and social restrictions, all of which can adversely affect their own wellbeing; a significant number also have their own health problems (Bradshaw et al, 2012).

Symptom assessment is more challenging for people unable to express their needs and suboptimal control of a range of symptoms has been found to affect the quality of life in the last week of life (Hendriks et al, 2014). In particular, pain management has been described as a "silent tragedy" (Napp Pharmaceuticals, 2014).

Admission into an acute hospital is a potentially risky experience for people with dementia (Sampson et al, 2013). The unfamiliar environment, with many new faces, is likely to cause distress and lead to falls. The quality of support in acute hospitals has also been criticised (Royal College of Psychiatrists, 2013; Sampson et al, 2013).

Unscheduled admission to hospital should be avoided (Russ et al, 2015); not only is this costly to the NHS, but it is most commonly not the preference of those with dementia (Iliffe et al, 2015; DH, 2013). The Care Quality Commission (2013) identified that the number of multiple emergency admissions is estimated to be 10% higher in people with dementia than those without; length of stay has also been estimated as being 27% longer and the number of deaths in hospital is more than a third higher in this group (36%). A study in one North London hospital also found that people with dementia had half the survival time of those without the condition

## 5 key points

1. In the UK, more than 850,000 people are living with dementia and the number is predicted to double in the next 30 years
2. Challenges in meeting the needs of those with dementia can be shared across organisations and disciplines
3. Services can be improved within a short time frame to avoid poor care experiences
4. Dementia tier 3 training is beneficial for patients, families, carers, and health and social care staff
5. The training programme can drive a range of service improvements

The DCC3 programme was needs-led and accessible to staff of any discipline

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TABLE 1. **TIER DEFINITIONS**

| Tier and group | Minimum skill and knowledge level |
|---|---|
| **Tier 1**<br>All staff working in health and social care services | **Basic understanding of:** what dementia is; prevalence and impact; effect of stigma; awareness of the common signs and symptoms<br>**Should:** be able to provide person-centred and advocacy support for people with dementia; have knowledge of how to access local community information and services |
| **Tier 2**<br>Staff who regularly (>20% of the time) care for and support people with dementia and their carers | **Awareness of disease impact on:** behaviours; relationships; activities; reduced ability to communicate physical needs, symptoms and mental distress<br>**Ability to assess and provide support with risks of:** malnutrition; falls; delirium; neglect and abuse<br>**Should:** support environmental adjustments; understand and apply competencies for the care and support of the patients nearing the end of life and those closest to them<br>**May require additional specialist training** |
| **Tier 3**<br>Staff who regularly care for and support people with dementia, and are likely to be in a specialist and/or a decision-making role | **Highest level, includes all tier 1 and 2 skill and knowledge areas, as well as:** specialist training to support leadership role; Expert knowledge, skills and service development |

(Sampson et al, 2013). In 2014, the CQC highlighted the "cracks in the pathway", as people with dementia experienced uncoordinated assessment and care in transfers between hospital and care-home settings.

The government prioritised dementia in planning guidance to 2018/19 (NHS England, 2013). It responded to the CQC's 2014 report by stating that inappropriate admission should be avoided by improving the provision of local community services, education and training (DH, 2015). To meet the needs of the growing number of people with dementia, clinical commissioning groups (CCGs) have to be innovative in reviewing whole systems and services collaboratively with neighbouring CCGs. However, reviewing and planning within a tight fiscal climate inevitably takes time before a positive impact on patient and carer experience can be made.

## Dementia education

In May 2014, the Department of Health published its refreshed mandate to Health Education England. This extended the ambition to have 100,000 NHS staff receive tier 1 dementia training to a further 250,000 by March 2015, with the opportunity being made available to all staff by the end of 2018 (DH, 2014). (Definitions of each tier are outlined in Table 1.) The aim is to promote basic awareness among the front-line workforce, so that staff can advocate and guide those living with dementia with individualised care and support.

At the more advanced level, Dementia UK's Admiral Nurses are overwhelmed by the numbers of patients referred to them (Bunn et al, 2013). Several roles have also been created to upskill the existing workforce, including:

- Dementia specialist nurses;
- Dementia leaders;
- Dementia fellows;
- Hospital Butterfly Scheme champions.

This has resulted in a variety of education initiatives (Mustafa et al, 2013). However, their efficacy at improving the care experience for those with dementia and their carers is not well researched, and the impact on practice improvements has also been questioned (Iliffe et al, 2015; Rampatige et al, 2009). A significant challenge is to find valid quality outcome measures (Elvish et al, 2014).

Skills for Care and Skills for Health produced a set of core principles in 2011 and, in 2013, Dementia UK produced a curriculum with core content guidance appropriate to different staff groups. In London, the Dementia Strategic Clinical Network produced a dementia training guide for staff (LDSCN, 2014), which highlighted the three tiers of dementia training (Table 1).

## The DCC3 programme

The Central London Community Healthcare Trust's dementia strategy outlines the trust's plans and progress towards 100% compliance with all staff being tier 1 trained and specific groups being targeted for tier 2 training. In recognition that the tier 3 level training for the smallest target group was in common with neighbouring trusts, CLCH was funded by Health Education North West London (HENWL) to host joint-tier 3 training for a minimum of 20 applicants from trusts in north-west London.

The collaborative work of the steering group from a range of organisations, together with Buckinghamshire New University, resulted in the new Dementia Care Champion Tier 3 (DCC3) programme starting in June 2015.

The DCC3 programme was a practical, needs-led programme, accessible to staff of any discipline who regularly worked with people living with dementia in north-west London. It aimed to:

- Support the designation of DCC3s in different practice areas in north-west London;
- Better equip and support the champions to identify service deficits in meeting the needs of people living with dementia and their families;
- Put in place remedial actions;
- Further develop service initiatives;
- Support the sharing of practice developments across organisations and disciplines.

### Programme design

The core focus was on improving support for people living with dementia from the start, and to actively maintain this throughout the programme and beyond. The role of the DCC3 is to:

- Review dementia care in their area of work in consultation with those accessing their services, their carers and colleagues;
- Identify areas of potential improvement;
- Act as an advocate for people living with dementia;
- Support the learning and development within their healthcare team.

The application form was designed to contractually clarify and agree, jointly with applicants and their managers, the commitment and support required for the programme and the service development role of a DCC3.

Acceptance onto the programme was contingent on applicants' ability to evaluate practice and implement change in their work-based role. Before they attended their first workshop day, applicants were

TABLE 2. **DDC3 DISCIPLINES AND PRACTICE AREAS**

| | Nurses and their specialties | Allied health professionals | Local government & public health |
|---|---|---|---|
| **Acute wards** | Sisters/managers/senior nurses<br>Clinical education<br>Specialist palliative care | Occupational therapists<br>Physiotherapists<br>Dietitians | |
| **Care homes** | Managers/senior nurses | Dietitians | |
| **Community** | Continuing care assessment<br>Specialist palliative care (hospices)<br>District nursing<br>Care navigators<br>Cognitive impairment and dementia services (mental health) | Occupational therapists<br>Physiotherapists<br>Dietitians | Dietetics |
| **Learning disability services** | Managers | Psychologists | Placement planning and monitoring |

sent mandatory video links and activities to:

- Refresh their dementia awareness;
- Instigate assessment of current practices;
- Assess the "dementia friendliness" of their place of work.

The key tier 3-level dementia training sessions were delivered in three one-day workshops over three months and focused on challenges in practice and implementation of change. The workshops followed tier 3 guidance (LDSCN, 2014). Specialists in their field delivered different topics, focusing on existing service challenges and potential solutions. The experience and insight of carers and individuals as experts living with dementia was also sought in the programme planning, workshop involvement and guidance for service developments. This resulted in a "grounding and guiding" experience for participants and facilitators.

In the month between each workshop, participants were guided to continue evaluating current practice and change planning. A fundamental requirement was to discuss this with peers, managers, their mentor, others on the programme, patients and their families. Optional and separately funded enrolment to a module at New Buckinghamshire University provided the opportunity for the changes in practice to be academically scrutinised and accredited at postgraduate level to match each participant's academic profile.

An NHS Network online DCC3 forum was set up with folders containing the latest evidence and discussion points, and opportunities to learn from other service areas were provided via a placement catalogue. Placement opportunities included:

- Support events with local ethnic and religious groups;
- Memory disorder clinics;
- Namaste Care providers – this programme designed to improve quality of life for people with advanced dementia in care homes and has been shown to reduce their behavioural symptoms (Stacpoole et al, 2014);
- Hospital inpatient acute-care settings.

Participants selected a minimum of two experiential placements to learn about other care initiatives and reflect on their own personal and practice-area service challenges. Using their university placement learning log, they were then able to determine the impact of these on supporting people with dementia.

The 31 multidisciplinary and staff 21 nurses who have undertaken the programme worked in diverse settings including NHS and non-NHS organisations across north-west London (Table 2).

## Evaluation

### Participants' evaluation

All the elements of the programme – the pre-course activity, the placements to understand the holistic experience of patients living with dementia, the teaching sessions and the support including NHS networks information sharing – were well received. Of the placements, participants commented:

*"[It's] useful to support my change-management project to encourage clients with accessing the community."*
*Physiotherapist*

*"A brilliant placement. I learnt a lot on how they are supporting [older] people who are admitted on the wards, how to manage pain and delirium, and find out what support is there for carers and people with dementia."*
*Community psychiatric nurse*

In evaluating the DCC3 NHS Network, one anonymous participant said:

*"[The] network is great, learning new things every day on dementia, meeting new people in different set-ups."*

When feeding back on the overall programme, another participant said its value was in "interacting with other healthcare professionals, sharing ideas and current practice policies". Another had:

*"...recently studied two dementia modules at university, which were not very applicable to practice. The strength of this course is that it is strongly based in practice and allows us to share experiences, information and practice."*

### Individual learning

Due to the diverse experience and roles of course participants, a generic questionnaire was devised to record their baseline knowledge before and after the course. In total, 27 participants completed a pre- and post-course questionnaire; all demonstrated increased knowledge in >50% of the questions. Seven gave in-depth feedback when completing their post-course questionnaire and were able to demonstrate a significantly increased breadth and depth of knowledge.

### Service developments

The dementia friendliness of participants' workplace environments – whether hospital ward, care home, clinic or domiciliary setting – were assessed at the start and, where applicable, staff are working with estates and their practice team to make improvements with, for example, signage and coloured equipment.

A wide range and number of service developments (n=35) were initiated by the 31 DCC3s, including:

- Community nurses supporting the General Practitioner Assessment of Cognition test by identifying those at risk earlier;
- Improving post-diagnostic support with information packs and the introduction of a post-diagnostic clinic;
- A memory-clinic pathway for people with Down's syndrome is being implemented;
- A range of innovative educational sessions and posters/leaflets were designed for staff in care homes and inpatient wards about medicine use, pain management, delirium, dehydration and malnutrition avoidance;
- Assistive technology is being explored to enhance home-based physiotherapy;
- Work is well under way with community matrons to promote independence for longer with assistive technology;
- Life enrichment is being fostered through the introduction of individualised activities and strategies to enjoy "being in the moment";
- Local community information is being compiled to encourage meet-and-greet activity outside the home in surrounding shops and cafes.

Overall, no matter where they worked, participants found opportunities to innovate change to improve the experience of people living with dementia.

## Discussion

The primary focus was on improving the experience of people with dementia who used the services where the participants worked; as such, the training programme was constructed to be embedded into practice and minimise study time away. In an ideal world – in which there are no staff vacancies, there is funding for backfill, and the level of workload and numbers accessing services is static – more workshop days would have added further academic rigour.

The multidisciplinary and cross-organisational discussions provided a rich learning environment for participants and facilitators. Service challenges were explored by sharing tried-and-tested solutions and innovative ideas. The DCC3 NHS Network is a valuable ongoing forum providing access to the latest research findings and guidance to build on the wealth of learning, such as Dementia and Homecare: Driving Quality and Innovation (United Kingdom Homecare Association, 2015), which highlights suggested actions from the prime minister's Challenge on Dementia.

Sustainability of the DCC3 role beyond the programme is important, so continuation of support from mentors and managers is needed to avoid losing the impetus. Plans include:

- Trust-wide recognition of the DCC3s;
- Cross-organisational sharing of progress of practice initiatives;
- Fostering of the "grounding and guiding" input from people living with dementia and their carers.

The need to drive local service changes clearly exists and, although this was a time-limited programme to establish key DCC3s across HENWL, it was noted that, geographically in the HENWL area, there were no applications from some large health organisations or from the offender health sector. There was also under-representation of care-home nursing staff applications.

**QUICK FACT**
**27%**
Estimated extension in average length of stay for people with dementia

## Conclusion

This was a new programme and considerable learning was gained from participants' feedback, as well as the facilitators' and the steering group's reflection to guide future DCC3 programme provision. For truly effective change to take place, a network spanning health and social care of DCC3s – listening to people with dementia and their carers and supported by managers, dementia specialists and CCGs – could deliver even more.

There is much room to improve support and help people with dementia to maintain a good quality of life, for as long as possible, in their familiar environment. This focused programme has shown a new way towards achieving that aim. **NT**

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