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**Oxleas Advanced  
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Supporting carers and  
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Co-ordinated care for people with complex chronic conditions

## **Oxleas Advanced Dementia Service**

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## About this research

Age-related chronic and complex medical conditions account for the largest and growing share of health care budgets in all industrialised nations. However, people living with multiple health and social care needs often experience a highly fragmented service leading to sub-optimal care experiences, outcomes and costs. To address this, strategies of care co-ordination have been developed to promote more cost-effective care through integrated services.

For older people in need of both health and social care support, the divisions in the organisation, funding and delivery of care in the United Kingdom (UK) can result in poor user experiences and outcomes. There have been many innovative projects to promote better care co-ordination for older people, but these have often not met their objectives and the failure rate has been high because of poorly designed interventions, difficulties in targeting those most likely to benefit from care co-ordination and the unmet patient needs that improved follow-up can uncover. There is a lack of knowledge about how best to apply care co-ordination tools in practice.

This case study is part of a research project undertaken by The King's Fund and funded by Aetna and the Aetna Foundation in the USA to compare five successful UK-based models of care co-ordination (see Appendix 1 for methods used to collect the study data). The aim of each case study has been to understand the strategies used to deliver care co-ordination effectively; examine barriers and facilitators to successful care co-ordination; isolate key markers for success for the practical application of the tools and techniques of care co-ordination; and to identify lessons in how care co-ordination can best be supported in terms of planning, organisation and leadership.

Further details about this project can be found at: [www.kingsfund.org.uk/coordinatedcare](http://www.kingsfund.org.uk/coordinatedcare)

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# 1 Introduction

## *The health and social care system in England*

The National Health Service (NHS) is responsible for providing health care to the public in the UK. It is publicly funded, mainly through taxation, and services are provided free of charge to all patients in the UK, excluding certain exceptions permitted by Parliament. Since its establishment in 1948, the overarching principle of the NHS has been to ensure that health care is available to all on the basis of need not ability to pay and these responsibilities are formally enshrined in the NHS Constitution (NHS Choices 2013).

Responsibility for health care is devolved to the governments of each of the four constituent countries (England, Scotland, Wales and Northern Ireland). In England, community, mental health and general hospital services are provided by a number of bodies, from statutory NHS organisations to charities, social enterprises and private organisations who provide NHS funded services.

Primary care providers act as the first point of contact for physical and mental health care services. General practitioners (GPs) are local primary care physicians based in GP practices alongside nurses and support staff. They operate as independent businesses paid through a national contract administered by NHS England. Dentists, opticians and pharmacists also provide primary care services.

General practice accounts for around 90 per cent of all patient contacts in the NHS and the majority of people are registered with a GP practice (The King's Fund 2011). When specialist treatment is required, patients are referred to hospital or other specialist providers. In this way, general practice acts as the gatekeeper to specialist care. Urgent and emergency care services are available directly through out-of-hours services and hospitals.

Planning and purchasing of NHS services is referred to as commissioning. In England, general hospital services, urgent and emergency care, mental health and community services are commissioned at population level by 211 clinical commissioning groups (CCGs) who hold the majority of the NHS budget (£65 billion in 2012/13). Each CCG is formed from the GP practices in that locality who come together to assess the needs of their population and commission services from NHS or other provider organisations.

### **NHS England**

NHS England is a statutory body which commissions primary care health services (including GPs), public health and prescribed specialist services such as trauma care on a national basis.

In contrast, responsibility for funding (and some provision) of social care services, for example for assisted living at home and long-term care, is held by local government (through local authorities). Users pay for services directly or gain access through means-testing based on levels of need and ability to pay. Residential and domiciliary care are predominantly privately provided, and there is substantial self-payment. Voluntary sector providers deliver a range of health and social care services. While there are national rules for residential



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care costs, home care is subject only to guidelines and there is considerably more variation in the organisation and delivery of domiciliary services at the local level. Direct payments are increasingly being made available to eligible recipients of local authority-funded social care, allowing individuals to control and directly purchase services to meet their own needs.

Alongside the introduction of CCGs in April 2013, responsibility for public health has shifted to the local authorities. Health and wellbeing boards have been established to support dialogue and the development of joint strategies between the health and social care system. This is underpinned by a statutory duty to work in partnership. Significant emphasis has been placed on health and wellbeing boards to encourage jointly funded and delivered services that promote person-centred care co-ordination as a means to improve the experience of patients and service users and ensure they receive high-quality care.

### *Dementia care in England*

In England, 670,000 people have a diagnosis of dementia, and they are supported by an estimated 21 million family members and close friends. Over the next 30 years, the number of people with dementia is expected to double. Nationally, dementia costs the UK economy about £17 billion per year and will exceed £50 billion in 30 years (Department of Health 2009). Two-thirds of people with dementia live in their own homes with about one-third of these living alone.

Services for people with dementia in the NHS are largely provided by mental health trusts and delivered in community settings. GPs refer patients with symptoms of dementia to memory assessment services (including memory clinics) in mental health trusts for a formal diagnosis and to identify interventions which maximise quality of life and independent living. Following diagnosis, patients are discharged from memory clinics and management of their condition reverts back to the GP. Local authorities are responsible for assessing care needs regularly and putting an appropriate care package in place.

Growing numbers of people with dementia are being admitted to hospital. It is estimated that up to 25 per cent of hospital beds at any one time are occupied by people with dementia (The King's Fund 2012). Patients' experience of dementia patients on hospital wards can be poor, with concerns that staffing levels are not sufficient to provide the care, monitoring, and support needed (Department of Health 2013a). About one in three people with dementia admitted to hospital from home are discharged into a care home (Alzheimer's Society 2012a) increasing the cost pressures on health and social care budgets.

In 2010, 63 per cent of people with dementia died in a care home, 30 per cent in hospital and only 6 per cent at home. In some cases this is appropriate, but it is thought that many of the deaths in hospital result from insufficient support to enable individuals to die at home (Alzheimer's Society 2012b). Compared with cancer care, palliative care services for dementia patients and their carers are not currently tailored to the unpredictable timescale and trajectory of the disease (Treloar *et al* 2009).

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## **Terminology**

The term **carer** is used throughout this report to indicate the family member acting as the primary carer for the person with advanced dementia. Paid care staff are usually employed by social services or other agencies as part of a care package to provide additional support.

**Palliative care**, as used in this research, is defined by the National Council for Palliative Care as:

*the active holistic care of patients with advanced progressive illness with management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and the families.*

(Treloar et al 2009)

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## 2 Oxleas Advanced Dementia Service

### **Summary**

#### ***Background***

The Oxleas Advanced Dementia Service was formed in November 2012. It brought together two services – Greenwich Advanced Dementia Service (GADS) and Bexley Advanced Dementia Care At Home project. GADS started in 2005 to provide care co-ordination, palliative care and support to patients with advanced dementia living at home and their carers. The model was implemented in Bexley in 2011 and they now operate jointly as Oxleas Advanced Dementia Service. The current service consists of a consultant in old-age psychiatry, several specialist nurses and a dementia social worker. The Oxleas service has interim funding until September 2013 and after this date will continue with a smaller caseload until additional support is secured.

#### ***Aims and objectives***

This model seeks to help patients with advanced dementia to live at home for as long as possible in the last year of life with support from family and/or carers. The core team works with GPs, secondary care and social services to support carers in providing ongoing and palliative care. Staff respond to crises at home to prevent unnecessary hospital admissions where possible and reducing the likelihood that patients are placed in residential care.

#### ***Target population***

The Oxleas service caters for people with a diagnosis of moderate to severe advanced dementia, complicated by complex mental and physical co-morbidities requiring social care input, who are being supported to live at home (by family or paid carers). These patients tend to be in the last year of their lives with an average age of 75. The service has capacity to support up to 25 patients, as staff co-ordinate care in addition to their substantive roles.

#### ***Approach to care co-ordination***

In Greenwich care co-ordination is led by a consultant old-age psychiatrist based in the local mental health trust, working alongside specialist nurses called community matrons. In Bexley, the same psychiatrist works with a community psychiatric nurse (CPN), an advanced practice nurse (APN) and a social worker specialising in dementia. Staff in the service liaise with community mental health services and general practitioners (GPs) to provide care in patients' own homes, focusing on supporting the carer and/or family to provide palliative care for the patient.

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## **Results**

An internal audit of the service has shown that 70 per cent of patients die at home, compared to figures for England and Wales of 6 per cent for dementia patients in 2010 (Alzheimer's Society 2012b). Analysis of the first year of the Bexley project observed improvements for the majority of patients on the quality of life in late stage dementia (QUALID) scale and reduced stress levels for carers using the Relative Stress Scale.

## **Case study**

### ***Mrs G's story***

Mrs G, a female patient in her 70s, developed vascular dementia. She became very agitated and was admitted to hospital. Within two weeks, she had lost weight, was distressed and ended up stranded on a dementia assessment ward. Staff on the ward found it difficult to see what could be done to alleviate her distress or to care for her. Following medication with anti-psychotics, anti-depressants and benzodiazepines she settled enough to go into a dementia specialist nursing home. Once there, she lost more weight and her distress continued.

Her husband asked the doctors for permission to take her home. They were reluctant and thought that it was unlikely to work, with a high possibility of death as a result. They thought she was unlikely to survive until her 50th wedding anniversary.

After discussing the possibilities with him they agreed that whatever happened, Mrs G should not suffer, although it seemed that going home would require a lot of support. Although the nurses and consultant psychiatrist were very worried about the plan to go home Mr G insisted, and after discussion it was agreed to try supporting him to care for her at home.

Mrs G did well and the team were able to stop all psychiatric medication as the agitation and distress settled. She gained weight and was happy being cared for by her husband, along with a small group of carers who supported him. She improved to such an extent that she was able to go on trips to shopping centres and the golf club. Mrs G survived for a further seven years dying in bed after their 57th wedding anniversary.

Staff in the advanced dementia service attributed Mrs G's long survival to good care and the slow progress of her vascular dementia. As a result of this case the team strives to help other families who want to take their loved ones from nursing homes and care for them at home.

*Edited case study reproduced and redacted with permission from Hope for Home.*

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## *Oxleas Advanced Dementia Service*

Oxleas Advanced Dementia Service consists of the Greenwich Advanced Dementia Service (GADS) and Bexley Advanced Dementia Care At Home project in London. The catchment area is covered by two neighbouring local authorities, Greenwich and Bexley. The service is hosted by Oxleas NHS Foundation Trust, which provides community and mental health services across 125 sites in three boroughs (Oxleas NHS Foundation Trust 2012). Oxleas Foundation Trust receives funding from clinical commissioning groups (CCGs) and the local authorities of Bexley, Greenwich and nearby Bromley to provide health and social care services.

### *The patient group*

This approach is targeted at complex patients with advanced dementia towards the end of their lives. The majority of the caseload is aged over 65, with an average age of 75 years. Eligible patients are classified as suffering from severe or very severe cognitive decline (stage 6 or 7 of the Global Deterioration Scale for dementia) with accompanying physical ailments such as recurrent infections or fevers, incontinence, pressure ulcers, ongoing pain or general physical frailty. Many patients become bed bound, requiring help with daily activities such as eating and dressing. In addition to physical symptoms, people with advanced dementia may display severe, persistent psychological or emotional distress including agitation, aggression, anxiety and restlessness. These aspects require specialist input from a number of professionals across physical and mental health services as well as social care.

In addition, a patient should have a primary carer (normally a family member) as care co-ordination takes place at home.

### *Programme history*

In 2005, a community old-age psychiatrist from the Older People Community Mental Health Team in Oxleas NHS Trust started the Greenwich Advanced Dementia Service in response to a need to improve continuity and care planning for older patients with advanced dementia. This was based on two issues: a lack of co-ordination between GPs and specialists in secondary care and an inability to secure GP home visits for patients, leaving them without a care plan or guidance on what to do in a crisis.

*[It] was really coming from an understanding that actually people wanted to look after their loved ones at home... trying to avoid burdensome and intrusive care at the end of life... All the family wanted was for them to be... pain free, comfortable and in their home environment.*

GADS team member

The new service brought together like-minded clinicians in the mental health trust and community matrons based in Greenwich to manage palliative care for people with dementia requiring specialist multidisciplinary input. Community matrons are qualified nurses who 'provide advanced nursing and clinical care, as well as effective case management' (Department of Health 2006).

Staff sought to enable patients (with the support of a carer) to stay in their home in the last 12 months of their life through the provision of a single care

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co-ordinator (usually a specialist nurse) to provide advice and work with other care professionals to prevent and manage crises.

From the start, the team conducted home visits as part of their existing workload, co-ordinating care with other care providers to ensure that patients' specialist palliative needs at home were met.

In 2011, a clinician who had worked with the Greenwich team as a specialist registrar was awarded a clinical fellow position (referred to as a 'Darzi' leadership fellowship after the author of the NHS review which concluded that leadership had been neglected (Darzi 2008)) to set up a 12-month project in the neighbouring borough of Bexley. This money funded the fellow for two clinical sessions a week (one day a week) and an advanced primary nurse (APN) was allocated to the service from existing resources. A dementia social worker (funded by Bexley Council) and a district nurse later joined the team.

When the fellowship ended, interim funding was granted until September 2013 from Oxleas NHS Foundation Trust to pay for a community psychiatric nurse (CPN) to act as the main care co-ordinator, and the service restarted in November 2012 (see Table 1). At the same time, the Greenwich and Bexley teams began operating jointly as Oxleas Advanced Dementia Service under a single management structure.

The current team is led by a consultant old-age psychiatrist (formerly the clinical fellow leading the Bexley team). The rest of the team consists of a community matron (based in Greenwich), two specialist nurses (based in Bexley) and a dementia social worker. The service has capacity to support a maximum of 25 patients, as the staff have full-time roles and work in the service in addition to those responsibilities.

Although funding is due to end in September 2013, the service plans to continue after this date with a smaller team and caseload. The Oxleas team hope to secure funding from local commissioning bodies before then to avoid this eventuality.

### **TABLE 1: Timeline of key service developments**

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2005 – Greenwich Advanced Dementia Service starts with the case of Mrs G. The team consists of a consultant old-age psychiatrist (service lead), a specialist registrar and two community matrons.
2009 – Greenwich service wins a recognition award for providing an excellent service at Oxleas Annual Member's Meeting and Awards Ceremony.
June 2011 – A former specialist registrar is awarded a clinical 'Darzi' fellowship to set up a version of the service in Bexley.
August 2011 – The Bexley Advanced Dementia Care Service At Home starts with a clinical fellow working one day a week (service lead) and an advanced primary nurse (APN).
February 2012 – A dementia social worker joins the Bexley team.
August 2012 – The Bexley project comes to an end.
September 2012 – Discretionary funding is secured to fund a community psychiatric nurse (CPN) three days a week (replacing the clinical fellow) in Bexley.
November 2012 – The Greenwich and Bexley services merge to form Oxleas Advanced Dementia Service under the leadership of the former clinical fellow (now a consultant old-age psychiatrist).

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### *Funding*

The Greenwich team did not receive any direct funding; it was run as a part of the services provided by the Older People Community Mental Health Team in Oxleas Foundation Trust, using existing staff time.

The Bexley project was initially funded through a 12-month clinical fellowship in 2011 worth £60,000 which paid for the clinical fellow's specialist input into the service. The APN time was allocated as part of an existing role and the dementia social worker's time was funded by Bexley Council. Once the fellowship ended, the service continued with discretionary funding of £52,000 from Oxleas Foundation Trust for a community psychiatric nurse (CPN) working three days a week until September 2013. Funding beyond this date is unclear, although the service will continue to operate.

### *Organisational structure*

Although the service is integrated, the approach to co-ordinating social care differs between the boroughs. In Greenwich, patients known to the social services department in the local authority have a care manager in that service with responsibility for organising care packages, respite care and equipment. If the patient is not known to social services, a care co-ordinator from the advanced dementia service can carry out these tasks directly. In Bexley, a social worker with a special interest in dementia organises all the care packages.

### *Primary care and other external care providers*

Liaising with services in primary care and in the community is integral to the Oxleas model. Staff have developed strong links with other professional groups including district nurses, social workers, occupational therapists, physiotherapists and relevant specialist services such as the speech and language team. However, engagement with local GPs is variable and generating referrals has been problematic. This may be due to a lack of understanding or awareness of the service. The service has attempted to actively engage GPs, presenting to GPs at the launch of the new memory service in 2011 and visiting GPs; however, levels of engagement have not improved.

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### 3 The process of care co-ordination

#### *Step 1: Referrals/case finding*

Figure 1 illustrates the care process for a typical patient in the Oxleas Advanced Dementia Service. Referral criteria for the service are based on the presence of a diagnosis of moderately severe or severe dementia as classified on the Global Deterioration Scale stage 6 or stage 7 plus at least one of the following criteria:

- the patient needs a more palliative approach to their care and the clinician would not be surprised if the patient were to die in the next 6–12 months

OR there are

- recurrent infections, significant weight loss and poor nutrition level, recurrent fevers, pains, falls, severe pressure ulcers that are not easily amenable to treatment, severe physical frailty

OR the patient has

- severe, persistent distress (mental or physical) that is not easily amenable to treatment OR another condition (eg, co-morbid cancer) whose co-existence with dementia means that more intrusive treatments would be less appropriate.

(Source: Oxleas NHS Foundation Trust Advanced Dementia – Care at Home Referral Form)

Staff in the Oxleas service use a mixture of case finding and referrals to locate appropriate patients. Community matrons identify relevant patients from their caseload; the consultant psychiatrist and APN see patients through their work with the community mental health team and can bring these cases to the dementia service.

Referrals are made by email, telephone or face-to-face contact and are accepted from APNs, CPNs, psychiatrists, GPs, district nurses, continuing care nurses, hospices and mental health wards.

#### *Steps 2–6: Care planning and care co-ordination*

There is no standardised care package for patients with advanced dementia and other complex needs; care is tailored to each person based on their primary need and the range of services available locally. As the disease progresses, their needs are re-assessed and the care package is adjusted accordingly, for example, increasing the number of visits from a paid carer to help with washing or cooking.

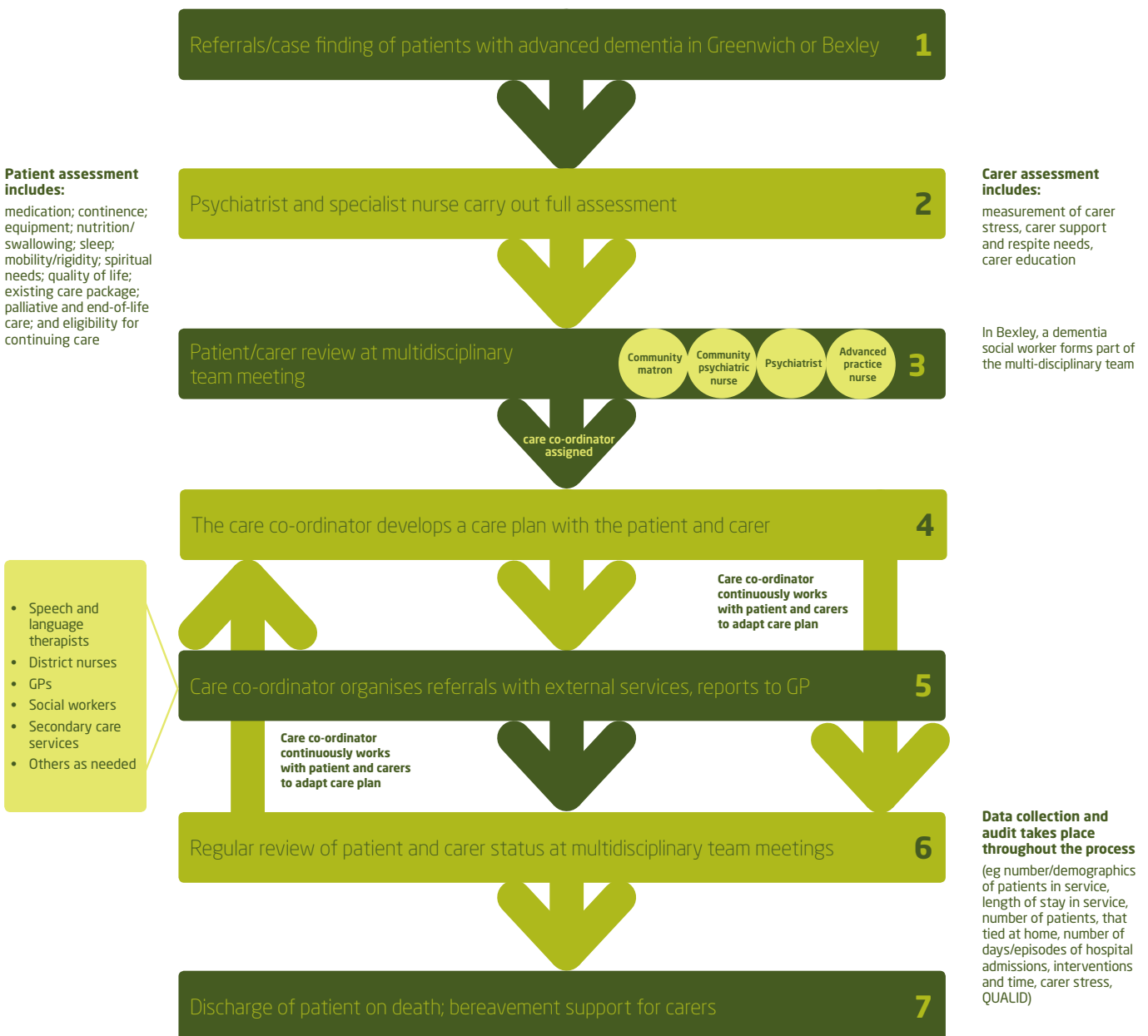
Steps 2–6 can be divided into two elements: the care assessment function and the care co-ordination function.

**Step 2:** On identification of an appropriate patient the psychiatrist and a specialist nurse jointly visit the patient's home to conduct an initial care assessment led by the psychiatrist.

The care assessment identifies the mental, physical and social needs of the person. It covers a wide range of topics including a full medical and psychiatric history, personal and social background, current medications, existing care



**FIGURE 1: Oxleas Advanced Dementia Service Model And Care Process**



package, equipment needs and end-of-life/spiritual wishes. A quality of life assessment ascertains their mental state and ability to carry out daily activities such as washing and dressing. This is followed by a needs assessment drawing out medical, psychiatric, sleep, nutrition and hydration, swallowing, mobility, continence and pain requirements. The carer undergoes an assessment to determine their financial situation, health status, mental state and quality of life, with levels of stress measured.

**Step 3:** The patient is discussed at a weekly multidisciplinary team meeting, and a named care co-ordinator is nominated based on the patient’s prevailing needs – physical, mental or social care.

**Step 4:** Following the meeting, a personalised care plan is produced with detailed action points. This is sent to the patient’s GP and copied to the patient/carer.

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**Step 5:** The care co-ordinator oversees delivery of the care plan, conducting ongoing assessments and setting up a schedule of home visits with the family, liaising with relevant services and attending case conferences. Any changes to medication or the status of the patient prompts a follow-up letter to inform the GP.

**Step 6:** Once the patient's and carer's immediate needs have been met, the care co-ordinator visits the patient regularly as arranged with the carer. If a crisis occurs, they will try to visit on the same day. Although the service is available Monday to Friday, 9am to 5pm, staff are flexible and can usually be contacted by phone outside those hours. If the care co-ordinator is not available, carers are advised to contact the district nurses or failing that to seek help from the emergency services. In the event of a hospital admission, the care co-ordinator liaises with hospital staff to input into discharge assessment and planning.

**Step 7:** Patients on the service are rarely discharged, remaining on the caseload until they die or are admitted to residential care. In their last days and hours of life the district nursing service provide direct care. Following the patient's death, the care co-ordinator can provide bereavement support to the family.

### *Carer support*

A key facet of the Oxleas service is its focus on supporting carers to cope with caring for their relative and providing palliative care in the last year of their life. Caring for a person with dementia differs from other conditions and carers are twice as likely to experience anticipatory grief (ie, before the patient dies). However, those at risk can be identified and interventions put in place to support them before and after death (Chan *et al* 2012).

*The main aim is acting as a focal point for that carer in what can be an incredibly complex pathway... Liaising with other services and getting the support and equipment that someone needs to look after someone with quite advanced dementia at home.*

Care co-ordinator

On the first visit the psychiatrist and nurse conduct a full carer assessment and provide additional support on subsequent visits. When the patient's clinical situation begins to deteriorate, the care co-ordinator or psychiatrist talk to the patient and family about dying and what to expect (see The Marie Curie Palliative Care Institute Liverpool 2010). These discussions are often lacking in interactions with other care professionals, who may be unwilling to initiate an end-of-life conversation (Alzheimer's Society 2012b). The care co-ordinator can refer carers to support groups or charities, and after death can provide bereavement support for relatives if requested.

### *Functional integration*

Communication between staff in the Oxleas service and with other care professionals is not facilitated by the electronic patient records systems used within the trust.

Oxleas Foundation Trust has taken on a variety of community services that continue to use different health records. Although both the community health

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team and mental health staff use RiO, a web-based electronic care record, they cannot access each other's systems without special permission and patients have two separate records.

*We've got so many different systems that don't talk. Much of this [service] depends on clinicians' respect for each other, relationships and the ability to be flexible.*

Senior manager

They have developed mechanisms to ensure that both records are up to date, meeting face-to-face or telephoning to contact other services, followed by a completed form or faxed letter when needed. These personal interactions build rapport and trust between professionals, and appear to be particularly useful in developing relationships with other care providers.

When a new patient is referred and assessed, the care co-ordinator contacts their GP practice for demographic information and other details including medical allergies and next of kin, and they are made aware of changes by letter. In addition, care co-ordinators attend meetings with local GPs to share information. The service relies on 'low tech' solutions to overcome barriers to sharing data electronically. These methods are more time-consuming; however, they help to maintain strong links with professionals outside the service.

### *Team culture*

There is a clear, shared aim among staff in the service to help people in the latter stages of advanced dementia to live well and die at home, with a focus on bringing together physical and mental health. Staff are strongly rooted in their local communities and feel supported by managers to work in an integrated way.

*We [physical and mental health] existed in a slightly parallel universe and there was a yearning for each other's input.*

Clinician

Another interesting aspect is the importance placed on the role of the carer as an essential element of the team. Without the presence of an engaged, willing carer, none of the patients in the service would be able to stay at home.

*The main aim is acting as a focal point for that carer, in what can be an incredibly complex pathway and process.*

Care co-ordinator

This aspect has wider implications for other care co-ordination programmes; an over-reliance on family support or informal networks can become problematic, placing them under undue stress. The service leads have conducted research to understand the impact of the service on carers (Treloar *et al* 2009) and hold focus groups with former carers.

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## 4 Impact

Across the two sites, the Oxleas service has been running for more than eight years, and the service leads have attempted to collect evidence of its impact on costs, clinical outcomes and patient experience. The following data was calculated by the Oxleas Advanced Dementia Service.

### *Costs*

As the Oxleas service is run on a small scale without any analytical support they have not conducted a full cost-effectiveness analysis. Instead they have estimated the value of hospital admissions avoided as a result of providing palliative care at home. These estimates were derived from a commissioning tool produced by the Department of Health to help determine the savings associated with a primary care-based dementia service (Department of Health 2011). The tool uses localised cost estimates for secondary care staff and related expenses to calculate potential savings achieved through the reduction of accident and emergency (A&E) admissions.

Emergency hospital admissions of older people with dementia are associated with an increased risk of short-term mortality of 18 per cent compared with 8 per cent for older people without dementia (Sampson *et al* 2012). Using the tool the average cost per emergency bed day is £523. On average each patient in the service stays for 21 bed days per admission, resulting in a potential saving of £10,983 per person for each emergency hospital admission avoided (Department of Health 2011).

In social care, payment for residential care home places is shared between local authorities and CCGs unless the person is self-funded or qualifies for continuing health care, in which case the NHS pays the full cost. Elderly mentally infirm (EMI) homes are residential homes deemed suitable for people with dementia. These placements costs upwards of £500 per week, compared with home care at £150 per week (Matrix Evidence 2011). The NHS contribution towards the costs of nursing in a care home varies between £110 and £151 per week with the remaining amount for accommodation, food and personal care paid by social services or the individual (Department of Health 2013b; Alzheimer's Society 2010).

An audit of patients cared for by the Greenwich Advanced Dementia Service in 2009 reviewed 23 patients who received palliative care at home. In total, these patients were cared for at home for 6,205 days or approximately 886 weeks. Savings to local health and social care commissioners from these patients can be estimated at between £200 and £350 per week, saving upwards of £177,200 to £310,100 for these patients. These savings are notional as the numbers of people using the service are too small to enable commissioners to release money from closing beds, for example.

### *Outcomes*

In Bexley, 12 patients were evaluated at the end of the first year. Seven out of twelve patients died during the year; the remaining five remained in the service after the project finished, but no new referrals were accepted. Of the seven patients who died, five died at home and two in hospital. Only three patients required hospital admission during the year.

Patients' quality of life in Bexley was assessed using the QUALID scale (quality of life in late-stage dementia). This enables professionals to assess quality of life by asking a family member or a professional carer a series of 11 rating questions. Possible scores range from 11 to 55, with 11 representing the highest quality of life (Weiner *et al* 2000). Scores in Bexley were collected on admission to the service and at three-month intervals for a year or until the patient died. Three of the patients died before the three-month mark; quality of life scores improved or remained stable for seven of the remaining nine patients and deteriorated for two.

**TABLE 2: QUALID scales for nine patients from the Bexley Advanced Dementia Care Service at Home pilot**

<i>Quality of life in late-stage dementia</i>		
<i>Patient</i>	<i>First score</i>	<i>Last score</i>
1	24	29
2	23	15
3	19	19
4	13	12
5	28	28
6	19	15
7	30	21
8	15	20
9	34	29

Stress levels of carers in Bexley were assessed using the Relative Stress Scale (RSS), a tool used to identify carer burden in dementia. This instrument uses a 15-item questionnaire covering feelings of personal distress, changes to their life as a result of caregiving and negative thoughts toward the recipient of care. Scores below 23 are considered normal; carers scoring between 23 and 30 should be observed for signs of depression or psychiatric stress disorders, while a score above 30 represents a high stress level indicating a need for further psychiatric assessment (Ulstein *et al* 2007).

**TABLE 3: Relative Stress Scale for nine family carers of patients from the Bexley Advanced Dementia Care Service at Home project**

<i>Relative Stress Scale</i>		
<i>Carer</i>	<i>First score</i>	<i>Last score</i>
1	36	28
2	39	15
3	8	8
4	10	10
5	28	28
6	6	5
7	32	25
8	28	23
9	30	30

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Each carer was assessed during the initial patient assessment and this was repeated every three months for a year or until the death of the care recipient. The scores improved or remained stable for all the carers measured (Table 3).

There was no attempt to measure differences in outcome between the Greenwich and Bexley teams, and the combined Oxleas service integrates elements from Bexley, including measures of quality of life and carer stress.

### *Patient and carer experiences*

The Bexley service ran two focus groups with carers and relatives using the 'fishbowl method' to let participants explore the difference that the service made to them and the patients. From this work it was clear that carers and relatives valued the co-ordinator's role as the person responsible for organising care, and as problem-solvers.

*...[the service] was very good but without your influence, when you try to call services you find yourself up against a wall.*

Son

*[Before the service] we had all these people involved in mum's care and she was going to the day centre and seeing all these professionals but the responsibility was no-one's.*

Daughter

Supporting carers was another strong theme emerging from the focus groups; having a named person to contact in times of crisis, and the security that they would not be discharged.

*You really need someone like this because even if at the moment you are coping the time will come when you will find it very very hard.*

Husband

*What a [relief] to have someone to check on her and make sure all the other services are connected with each other as well. And not discharge her, as [other services] sometimes think: I haven't heard from them for a while they must be doing really well.*

Daughter

*With this service, in the last year, everything is now on the board... [Dad] knows who to expect, when they are coming and who everybody is. For me this is a very positive thing and I know it is for mum [the patient], she feels more secure.*

Daughter

Several staff members noted the deterioration they had witnessed when people with dementia were admitted to hospital for weeks or even months – compared to their renewed vigour back at home.

*...there [is] a sense of wellbeing... which you generally tend to find where people are cared for in their home environment, they seem more invigorated and lively.*

Care co-ordinator, Greenwich

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## **Mrs K's story**

### ***A service perspective***

Mrs K was referred in November 2011 to the Bexley Advanced Dementia Care at Home project by the advanced primary nurse working within the project. She was already known to Oxleas mental health services but had been discharged in June 2011. Mrs K was diagnosed with moderately severe dementia in 2007 and had been in the care of the older adults community mental health team for several years. They had prescribed anti-depressants and anti-psychotic medication for the management of anxiety and agitation.

Staff from the Bexley team saw Mrs K at home for an initial assessment accompanied by her social worker and her husband who was the main carer. This was supplemented with information from the couple's daughters; one was living locally and had been helping with practical aspects of her care, with the other helping to co-ordinate services mainly by phone and email.

In 2011, Mrs K was in the advanced stages of dementia – stage 7 on the Global Deterioration Scale. She needed help with all activities of daily living. She also had severe communication problems and was unable to express her needs but was occasionally able to tell her husband 'I love you' and smile.

It was clear from the first assessment that Mr K was a dedicated and loving carer who needed support in dealing with emotional and practical issues around his wife's care. He was taking her out every day and spending all his time with her. He believed the care package recommended by the social worker was not necessary as he was able to look after her. However, the social worker and his daughters were concerned about him being under too much pressure without a care package, as he had his own health problems. They discussed placing Mrs K in a residential home but Mr K strongly opposed this.

After the first assessment, the service developed a care plan including referrals for continence assessment, moving and handling, and management of her pressure areas as well as psycho-education on dementia for Mr K. Update letters were sent to the GP and social services and copied to the family.

Over the Christmas period, when the Bexley team was not available, Mrs K was admitted with a urinary tract infection to an acute hospital outside the borough for three weeks. During the admission we liaised with the hospital, which was planning to discharge Mrs K to a care home, and advised them that discharge at home was safe as support was available from our team.

Between January and September 2012 Mrs K remained relatively stable. Initially we visited weekly and when a routine started to establish, every two to three weeks. Mr K became more and more competent in looking after his wife and his stress levels decreased.

In October 2012 a further deterioration was observed; she started to lose more weight and slept more. The community palliative care team became involved towards the end of October. She died at home peacefully and surrounded by her family on 4 November 2012.

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Despite Mrs K's needs gradually increasing between January and November 2012 she had no other hospital admission or A&E visit.

The main interventions from the Bexley team were:

- ensuring Mr K was maintaining adequate hydration and nutrition for his wife and was giving her the medication as prescribed – a special drug chart was designed for Mr K to record administration of his wife's medication with a whiteboard on the wall to remind him about liquid intake and contact numbers
- prescribing liquid thickeners to maintain safe swallowing
- adjusting her constipation medication – together with appropriate hydration and appropriate pads changed four times a day this measure drastically reduced the incidence of urinary tract infections
- ensuring all necessary equipment was in place: hospital bed, pressure mattress, sliding sheet, recliner chair with pressure cushion, hoist and incontinence pads
- supporting Mr K to change care agency (the care significantly improved with the new agency)
- responding quickly if there were indications of infection ensuring prompt treatment and that Mr K understood how to administer it
- visiting regularly to provide support to Mr K and help him manage his diabetes and attend doctor's appointments
- having discussions with the family about end-of-life care, filling in the Do not attempt resuscitation (DNAR) order and supporting Mr K through the grieving process.

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## 5 Challenges and facilitators

### *Challenges*

The service has faced a number of challenges to securing a foothold in the local health and care economy. It began during a period of local **NHS reforms** which continue to the present day. Since 2005, Oxleas NHS Foundation Trust has gone through several organisational changes, becoming a foundation trust and incorporating learning disability and community health services for three local authorities. The Oxleas service has taken advantage of this upheaval to secure limited discretionary funding, but this may also explain why it has been unable to turn this into long-term funding and support, particularly as it caters for a very small number of complex patients.

Providing an **integrated service across two local authorities** initially proved difficult as the health and the social care geographies do not correspond with the boundaries covered by Oxleas NHS Foundation Trust. Cross-borough working has now been implemented between the mental health and community teams and the Oxleas service is managed by a single person based in the Older People's Mental Health Directorate to facilitate integrated working.

It is well known that **organisation of health and social care services** does not support the delivery of care addressing the physical and mental health needs of patients (Naylor *et al* 2012). This has a disproportionate effect on patients with dementia and their families. The Oxleas service model employs the use of a joint assessment addressing mental and physical health to provide holistic care, consulting GPs and other staff with specialist knowledge of physical or mental health when needed.

### **Organisational challenges**

**Size** continues to be a major challenge to the viability of this model. The Oxleas service has cared for a total of 120 patients since 2007, and has a current caseload of up to 25 patients with 14 patients on a waiting list. These are very small numbers, and despite the estimates of impact, commissioners may not take an interest unless the model is scaled up. The service has used information from the Projecting Older People Population Information website to estimate future levels of demand (see Appendix 2) and hopes to use this information to strengthen the case for long-term funding.

**Engagement from and with external providers** has proved highly dependent on the local context and history. Links with specialist services such as speech and language therapy and existing relationships with other district nurses and community matrons work well. Wider GP engagement remains a challenge and is limited to contact on an *ad hoc* basis for individual patients. The lack of GP engagement could be linked to concerns that they do not want to refer patients to a service without the capacity to accept referrals, and the staffing to provide round the clock support to carers.

Despite working for the same organisation **electronic patient information** is not easily shared between team members in the service. Community teams (district nurses, physiotherapists, occupational therapists) use a different version of the electronic patient record system, RiO, from the mental health team. Various mechanisms have been developed to overcome this barrier

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including copying case notes between systems, and information is shared at regular team meetings. Outside the service, communication with other care professionals such as GPs is conducted face to face, by phone or letter.

Occasionally patients and their families have been **unwilling to accept outside help** such as care packages and it has taken time for team members in the Oxleas service to build trust with families struggling to navigate through the system. They have overcome this obstacle by visiting regularly to build trust and providing referrals to educational programmes and wider carer networks.

### *Facilitators*

The absorption of community services in Greenwich and Bexley into Oxleas NHS Foundation Trust has instilled a sense of **common purpose and joint working** in staff. While they use two different IT systems, staff feel part of one organisation and the resulting co-location of community and mental health teams has fostered cross-team dialogue and discussion outside of formal meetings.

*...community services and mental health services are part of the same trust [now], although it's not a real integration, they have different management, they have different computer systems... [but] it's okay to share information.*

Clinician

The **inspiration and vision** for the Oxleas service originated from one key individual, a consultant old-age psychiatrist who was involved in the case of Mr and Mrs G (see patient story above). The service developed slowly over time; initially the psychiatrist acted as the care co-ordinator supporting other families to look after their relatives at home. Testing the model in another area has also driven the service forward, formalising referral and assessment processes and introducing measures of patient quality of life (QUALID) and carer stress (Relative Stress Scale).

The **team culture** has created a strong yet flexible framework around its staff, supporting them to deliver high-quality, personalised care to patients at home and co-operate with professionals across traditional silos. Staff in the Oxleas service are motivated and possess detailed knowledge of services and professionals in the local health economy.

*It's the people involved, actually it's vocation. If you look at the individuals rather than anything else in the system, it's those individuals that have an absolute passion, vocation for caring, particularly for older people, and it's very clinically led.*

Clinician

The service design places patients alongside their families and **carers at the heart of the care co-ordination relationship** with their needs considered alongside that of the patient. This dual focus engenders trust, with carers able to share their fears or worries with staff.

*...it's really crucial [to] understand the carer as much as the client, and the carers' needs as much as the client's needs.*

Manager

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## 6 Key lessons

While this case study draws out the details behind the care co-ordination approach of Oxleas Advanced Dementia Service, it is also part of larger piece of research seeking to identify wider lessons and markers for success. As with many models of care co-ordination certain aspects of this service are specific to the setting and circumstances at the time of its formation.

The existence and continuing success of the Oxleas service is due to a small number of dedicated individuals who have sought to deliver an integrated service for patients and families who often experience a disjointed health and social care system. It has run for eight years, a long time compared with other models of care co-ordination. Despite this, attempts to develop an economic case for funding within the service have proved unsuccessful. The lack of dedicated management support has impeded their ability to produce a long-term business plan and robustly evaluate the benefits of this model. Clear, systematic and on-going evaluation of clinical outcomes, patient experience and the costs associated with care co-ordination projects should be viewed as an essential element of any programme. While the service has succeeded in becoming more embedded as a way of working within the trust as a result of the quality of care it provides, it remains a small service with a limited caseload despite growing demand.

Elements of the care processes used by the Oxleas service are relevant to other models of care co-ordination.

- *Building resilience among carers*

Carers underpin the Oxleas model with team members providing specific care and advice to help them to cope while under enormous stress.

- *Case finding and relationship building*

Staff identify suitable patients through their other roles in the mental health or community teams. A supportive culture surrounds all staff working within the service, and members of the team have built strong links between physical and mental health services.

- *Multiple referrals into a single entry point*

Referrals are accepted from a wide range of health care professionals and a standardised referral form is used to capture information which flows into a single system for assessing and allocating cases to care co-ordinators.

- *A holistic care assessment and a personalised care plan*

A single comprehensive assessment of the patient and carer addresses physical, mental health and social care needs. Following the assessment a personalised care plan is produced to put in place the services required and an emergency plan is put in place to deal with times of crisis.

- *Dedicated care co-ordination*

The care co-ordinator takes on the role of primary contact with the patient and family. This role is filled by a specialist nurse with physical or mental health skills, eg, a CPN, APN or community matron. They do not receive any formal training, but are all experienced case managers.

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- *Rapid access to advice and support from a multidisciplinary team*

The patient and carer are given a phone number for the care co-ordinator; if a crisis occurs (in working hours) or they need advice over the phone the co-ordinator will respond or delegate to another member of the team.

- *Split care assessment and co-ordination functions*

Care assessment is led by the consultant psychiatrist working alongside a specialist nurse. Once a care plan is agreed, care co-ordination is led by a specialist nurse.

The wider lessons identified in this case study are echoed in research undertaken with key carers by the service leads (Treloar *et al* 2009). The study found that access to the right equipment, support for relevant medication, food, and social care needs were essential elements of caring for advanced dementia patients at home. Carers were often blocked from accessing support due to a poor understanding of the needs of advanced dementia care. As a result they valued regular visits from a care co-ordinator who understood these pressures and could give advice if needed.

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## Appendix 1 Methodology

The research team used a mixed-methods approach which involved:

- 14 semi-structured interviews with staff from the Greenwich and Bexley teams, managers, local commissioners and a GP
- observational analysis of a multidisciplinary team meeting
- content analysis of key documents, presentations and impact data provided by the Oxleas Advanced Dementia Service.

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## Appendix 2 People aged 65 and over predicted to have dementia in Bexley, projected to 2020

	<i>2012</i>	<i>2014</i>	<i>2016</i>	<i>2018</i>	<i>2020</i>
Bexley: Total population aged 65 and over predicted to have dementia	2,776	2,893	2,957	3,068	3,182
Percentage increase		4.2	6.5	10.5	14.6

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	<i>2012</i>	<i>2014</i>	<i>2016</i>	<i>2018</i>	<i>2020</i>
Greenwich: Total population aged 65 and over predicted to have dementia	1,916	1,945	2,008	2,090	2,153
Percentage increase		1.5	4.8	9.0	12.4

Tables produced on 16 July 2013 from [www.poppi.org.uk](http://www.poppi.org.uk) version 8.0.

Estimated data obtained from the Projecting Older People Population Information website ([www.poppi.org.uk](http://www.poppi.org.uk)).