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### Tailored resource: The named care coordinator role from the perspective of older people

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## 'Just one person': the named care coordinator role from the perspective of older people

As part of work undertaken by 3 focus groups to explore the named care coordinator role from the perspective of older people, participants looked at several examples of the roles in practice. The group considered the information provided, identified 3 models that they felt would work well for older people with social care needs and multiple long-term conditions, and explained why they regarded each one to be a good example. The practice examples were gathered using information from the Kings Fund research on coordinated care, telephone interview data and supporting documents from the Programme Leads.

#### Practice examples

#### **Oxleas Advanced Dementia Service**

This consultant-led, community based home care service is for people with advanced dementia. Focus group participants felt that this is a particularly good example of a named care coordinator role. They were positive about how the service selects the care coordinator for each person and its strong emphasis on carer support and resilience. They welcomed the clear service model, peer support for the care coordinator, and the emphasis on working together.

#### Sutton Vanguard programme Nursing Home Pilot Scheme

This scheme provides coordinated care to improve older residents' experience of care homes. The group felt that it was valuable to include an example of a named care coordinator role that worked specifically with older people within a care home setting. Participants thought that there were benefits to having a Senior Registered Nurse in the role – they are able to provide the personal care and empathy that the residents require but also the leadership to support the nursing home, liaising between primary care, the residents and their families.

#### Midhurst Macmillan Palliative Care Service

This is a consultant-led, community based palliative care service for terminally ill people living in their own homes. Although the service mainly works with younger people, participants felt strongly that the model would work well for older people with multiple long-term conditions. They felt it was a good example of how crucial the named care coordinator role is when multiple services are involved, and welcomed the benefits of the role for family members and individuals living alone. The group considered that close working with GPs, use of volunteers and support for carers were also important aspects.

The 3 examples of named care coordinator roles selected by the focus group participants are all undertaken by nurses. However, participants emphasised that the functions of a named care coordinator role could be carried out by others, including social workers and occupational therapists. It is more about what the person does and how they do it, rather than their particular job title.

#### Oxleas Advanced Dementia Service

Oxleas Advanced Dementia Service provides care coordination and specialist palliative care and support to people with advanced dementia living at home and their family and/or carers.

#### Establishing the role

A community old age psychiatrist from the Older Adults Community Mental Health Team in Oxleas NHS Trust started the Greenwich Advanced Dementia Service in 2005 in order to improve continuity and care planning for older people with advanced dementia (it became part of the Oxleas Advanced Dementia Service in 2012). Two problems had been identified: a lack of coordination 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. The care coordinator role was established to work with people with advanced dementia and their carers to prevent hospital or care home admission, navigating through the complex health and social care system as a person's needs change.

#### Roles and responsibilities

The care coordinator's job is to assess, review, plan and respond quickly to the changing needs of the person with advanced dementia. They also support family carers, assessing and addressing their needs, and sharing information and advice with them about dementia. Much of the job involves liaising with health and social care services, a task which would otherwise be done by the carer, adding to their stress.

The care coordinator oversees delivery of the care plan, conducting ongoing assessments and setting up regular home visits, liaising with services and attending case conferences. Any changes to medication or the status of the patient prompts a follow-up letter to inform the GP. If a crisis occurs, they will try to visit on the same day. Staff are flexible and can usually be contacted by phone outside normal working hours. In the event of a hospital admission, the care coordinator liaises with hospital staff. The care coordinator also offers bereavement support to the family after the death of the person with dementia.

The service model can be summarised as follows:

- Referrals/case finding of people with advanced dementia in Greenwich or Bexley.
- A psychiatrist and specialist nurse then carry out a full assessment.

- Patient/carer reviews are held as part of multidisciplinary team meetings.
- The care coordinator develops a care plan with the person with dementia and their carer.
- The care coordinator organises referrals with external services and also reports to the person's GP.
- Regular ongoing reviews of the person's and carer's needs are held at multidisciplinary meetings.
- Bereavement support is offered to carers when the person with dementia dies, and then the person is discharged from the service.

#### Requirements of the role

Most importantly, the care coordinator needs experience and knowledge in dementia care. They also need good communication skills and an ability to advocate for the person with dementia and their carer. The team currently employs a range of professionals in the role of care coordinators, including nurses, occupational therapists and consultant psychologists.

#### Allocating a care coordinator

The individual's needs are reviewed by the psychiatrist and a specialist nurse. A named care coordinator is then nominated based on the patient's prevailing needs – physical, mental or social.

#### Care network

Care coordinators liaise with a large number of health and social care services: community GPs, secondary care, day centres, continuing care, care agencies, carer services, acute care, occupational therapists, social workers, respite providers, out of hours services, physiotherapists, district nurses and palliative care. They also work closely with family carers, including extended family members.

#### Health and social care context

The catchment area is covered by 2 neighbouring local authorities, Greenwich and Bexley, and the service is funded by the Better Care Fund. In Greenwich, care coordination 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 mental health nurse and an advanced practice nurse. Referrals come from a range of health and social care services.

#### Making a difference

An audit of the service has shown that 70% of patients die at home, compared to figures for England and Wales of 6% for people with dementia in 2010 (<u>Alzheimer's Society 2012b</u>).

The following outcomes have also been achieved:

- care home admissions have been avoided and hospital admissions reduced
- better access to diagnosis, care, treatment, support and information
- improved home care and better use of new technology
- excellent carer satisfaction reports
- cost-effective service through avoiding admissions and straightening care pathways.

#### Financial benefits

A basic cost analysis was carried out in the first year of the service. The results showed a potential saving of  $\pm 10,983$  per person for each emergency hospital admission avoided.

An audit of patients cared for by the Greenwich Advanced Dementia Service in 2009 reviewed 23 patients who received palliative care at home. The findings estimated savings to local health and social care commissioners of £177,200 to £310,100 for these patients.

#### Learning points

#### Building resilience among carers

Carers are seen as a key part of the Oxleas model. Staff provide tailored care and advice to carers to alleviate stress and to improve their quality of life and ability to care for the person with dementia.

#### Case finding and relationship building

Staff identify patients who could benefit through their other roles in mental health or community teams. Members of the team have built strong yet flexible links across physical and mental health services.

#### Multiple referrals into a single entry point

Referrals are accepted from a wide range of healthcare professionals and a standardised referral form is used to capture information that flows into a single system for assessing and allocating cases to care coordinators.

#### A holistic care assessment and a personalised care plan

A single assessment of the patient and carer addresses physical, mental health and social care needs. Following the assessment, a care plan is produced to put in place the services required and an emergency plan for times of crisis. Care plans are reviewed and updated to reflect the changing needs of the person with dementia and their carer.

#### Dedicated care coordination

The care coordinator takes on the role of primary contact with the person with dementia and their family, liaising with other care providers to coordinate services and providing emotional support for the person and their family.

#### Rapid access to advice and support from a multidisciplinary team

The person with dementia and their carer are given a telephone number for the care coordinator. If a crisis occurs or they need advice over the telephone, the coordinator will respond or delegate to another member of the team.

#### Key contacts

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#### Sutton Vanguard programme: Care Home Pilot Scheme

In October 2015, Sutton Homes of Care launched a Nursing Home Pilot Scheme under the NHS England Vanguard programme. The scheme is delivering a number of initiatives including coordinated care to improve care for older care home residents. The pilot involves 6 nursing homes in the London Borough of Sutton. Each home has nominated 2 members of their nursing staff to be care coordinators for their residents.

#### Establishing the role

A wide range of local stakeholders, including care home representatives, were involved in a <u>Vanguard</u> workshop to look at developing a new model of enhanced health in care homes. As part of this they outlined what a care coordinator role would involve. Care coordinator roles already existed in both residential and nursing homes, with both healthcare assistants and registered nurses taking on this role. Some of their job descriptions were used as templates to build on and a final draft was then reviewed by the Vanguard's work stream group for final approval.

#### Roles and responsibilities

The care coordinator role is carried out by senior registered nurses based in the nursing home. Their job is to provide leadership to improve the standards of care and quality of life for all residents. They are the key liaison point between primary care and the resident and their families, coordinating referrals to other services. The holistic health and social care needs of the resident are considered and a care plan is developed to meet the resident's needs. A key part of the job is to lead weekly health and wellbeing rounds carried out with the linked GP for the home.

#### Requirements of the role

Care coordinators need to have an interest in maximising the health, wellbeing and independence of residents and the ability to advocate effectively. They also need enhanced care skills relevant to the type of home, for example end of life care, dementia care and so on. As part of the pilot, care coordinators have received training from Sutton Care Home Vanguard to increase their clinical and leadership skills on topics such as care planning, safeguarding and team working.

#### Allocating a care coordinator

The care coordinator role is always carried out by a senior nurse, and each home only has 1 or 2 senior nurses so the choice of care coordinator is limited by this.

#### Care network

Care coordinators work closely with a wide range of health and social care professionals and organisations, for example GPs, care home pharmacists, continuing healthcare team, chiropody, dentistry, physiotherapists, challenging behaviour team, befriending services from Age UK, ambulance services and community providers (such as speech and language therapists, dietician, end of life care nurses, tissue viability and occasionally other specialist nurses).

#### Health and social care context

The care coordinator is a permanent member of staff at the care home. The additional support and funding for the role has come from being part of the <u>Vanguard programme</u>.

#### Making a difference

Early findings from the pilot suggest that GPs and nurses have more structured time available to discuss care needs with residents and their families. This helps with decision making and involving the resident in discussions on their needs, both now and in the future. Care coordinators are saying that they have greater confidence in their communication and leadership skills, are more assertive, and have more knowledge now of the support available. GPs report a more professional relationship with the care coordinator, resulting in better person-centred care and a more collaborative approach to decision making.

Overall, the Vanguard programme has seen a reduction in non-elective hospital admissions and ambulance conveyances across all their nursing, residential, learning disability and mental health homes. However, these outcomes cannot be attributed to the care coordinator role alone – the Vanguard programme has many other initiatives to support good practice in care homes.

#### Financial benefits

It is anticipated that the impact of the care coordinator role will be reduced unnecessary hospital admissions, reduced ambulance conveyances and reduced spending on medications through comprehensive medication reviews carried out by the community pharmacist working alongside the GPs and care coordinators.

#### Learning points

An interim evaluation of the pilot is underway. A number of learning points have come to light already:

- the need for a comprehensive, standardised tool to systematically capture the complexity of residents' needs
- the need to regularly attend the health and wellbeing rounds in the first few months after launch to support implementation of the processes
- more encouragement of GPs and care coordinators to submit their monitoring data
- more opportunities for GPs, and for GPs and care coordinators, to come together to reflect on their practice.

#### Key contacts

Caroline Pollington Darzi Fellow and Lead Nurse, Sutton Homes of Care Vanguard

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#### Midhurst Macmillan Palliative Care Service

The Midhurst Macmillan Service is a community based, consultant-led, specialist palliative care service in a rural community in the south of England. The service seeks to provide direct care and support to patients in the last 12 months of life to prevent unnecessary hospital admissions and enable them to live at home and die in the place of their choice. They work mainly with younger people, but also with older people with multiple long-term conditions, including dementia.

#### Establishing the role

The Midhurst Macmillan Service was set up in 2006 in response to the closure of a local hospital with a Macmillan Cancer Support Palliative Care Unit. The closure prompted a consultation among local stakeholders to find an alternative, and their choice was to set up a community-based service. It has access to palliative care consultants based in the community who are able to provide specialist interventions at the patient's home.

#### Roles and responsibilities

There are 3 types of staff in the Midhurst team: medical, clinical and non-clinical. The medical professionals focus on care management, liaising with GPs, district and community nurses, specialists and other relevant medical staff to arrange or change treatment for patients. Care coordination is carried out as part of the district nurse role. They act as the single point of contact for the patient and families. They ensure that information about patients is shared at regular multidisciplinary meetings and logged on the internal IT system. The care coordinator updates relevant team members about a patient's status and liaises with GPs and community health teams. As part of their role, they deliver end of life care training to care agencies, including on care coordination.

#### Requirements of the role

Good communication skills are critical in this role, for identifying a person's needs and wishes and keeping everyone informed. Understanding family dynamics and knowing how community based services work is also important. In some cases the care coordination role needs to be passed on to a different professional for the patient's best interest, in which case the care coordinator needs to be flexible and willing to share responsibility. Good training skills are also required in order to pass on their knowledge to other care agencies.

#### Allocating a care coordinator

The care coordinators are split across 19 GP practices: care coordinators are linked with GP practices and allocated according to the patient's GP.

#### Care network

The care coordinator works alongside a multidisciplinary team consisting of palliative care consultants, specialist nurses, healthcare support workers, allied health professionals and a large group of volunteers. They also liaise with family members, GPs, continuing care teams and a range of other health and social care services.

#### Health and social care context

The Midhurst Macmillan Service is hosted in a community NHS trust. The service and its staff are located at a community hospital, and the funding comes jointly from the NHS and Macmillan Cancer Support.

#### Making a difference

Data from the service for 2011/12 shows that it achieved its target of enabling people to die in their place of choice: 185 of the 348 patients treated in that year died at home, and for 183 (99%) this was the place of their choice. Interviews with staff, commissioners and external care providers have revealed the positive impact of the service. Good clinical outcomes of the service overall can be seen in less frequent A&E attendances and reduced hospital stays.

#### Financial benefits

Unfortunately, they can only provide results of an overall economic review of the service, so not specific to the care coordinator role. The review demonstrated significant savings, mainly through earlier access to community based specialist palliative care before an inpatient stay occurs. If a service such as Midhurst was replicated elsewhere, the total cost of care in the last year of life could be reduced by 20%.

#### Impact on family members

The service lead believes the role of the care coordinator has a huge impact on family members – having 1 person who can build up a rapport with them and who knows what is going on is seen by

family members as extremely beneficial. An evaluation of the service in 2012 showed that: 'patients, carers and staff themselves report that a key aspect of the Midhurst Service is the flexibility of roles of the team members'.

#### Impact on people living alone

The service leads report that those living on their own without family support find the care coordinator role invaluable. Having someone to coordinate their care with professionals is even more important for those without family to hand. In these instances, the care coordinator will have volunteers to work with individuals to ensure they are not lonely and to help with their shopping, general needs and so on.

#### Learning points

#### Awareness-raising and relationship building

The service has been successful in engaging with most GPs in its catchment area to raise awareness of the service and has also built relationships with a wide range of other stakeholders, including consultants, volunteers and local people.

#### Holistic care assessment and personalised care plan

A single assessment process examines the health and social care needs of the patient and their family. It also takes into account their choices about care and treatment options.

#### Multiple referrals to a single entry point

The service accepts referrals from any health professional. All referrals come into the service and are assigned to a nurse specialist from a single entry point.

#### Dedicated care coordination

The care coordinator acts as the principal point of contact with the patient and their family, coordinating care from within a multidisciplinary team and liaising with the network of care providers.

#### Rapid access to care from a multidisciplinary team

Both professionals and volunteers can be deployed rapidly by the service to provide care or support to meet the needs of a person living at home. The service operates 12 hours a day with access to an on-call clinician out of hours.

#### Key contacts

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