Supporting People with Long Term Conditions

Liberating the talents of nurses who care for people with long term conditions

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DH Department of Health

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Supporting People with Long Term Conditions:

Liberating the talents of nurses who care for people with long term conditions

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Introduction

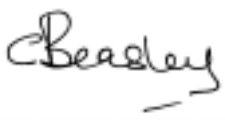
Improving care for people with long term conditions is a priority for patients and the government. I know it is one in which nurses play a central role. This publication supplements *Supporting People with Long Term Conditions. An NHS and Social Care Model to support local innovation and integration* (DH, 2005) by summarising what government policy for long term conditions means specifically for nursing, and how individual professionals can improve care for people with long term conditions.

I know that all nurses are playing their part across the spectrum of long term illness wherever they work. People with long term conditions need care from a team with a range of skills and knowledge. Nurses are one part of that team and some of the roles described here can be delivered by others, in particular allied health professionals.

This publication focuses on patients with the most complex needs and the role of community matrons. Better disease management and supporting self-care are equally important aspects of improving care for people with long term conditions and nurses play a key role here as well. However, practitioners and the NHS have asked me for more information on case management and community matrons. It is also where nurses have the opportunity to take on a new role that builds on and develops their existing skills.

This booklet draws on the experience of those places already delivering services in new ways. I am sure it will be of particular relevance to practitioners working in the community, experienced hospital nurses and the new community matrons who will be in the frontline delivering care. It will be useful to primary care trusts, workforce development directorates and strategic health authorities who will be planning their workforce to meet the needs of people with long term conditions, and also to educationalists and professional bodies who will need to provide professional development opportunities for practitioners as their roles develop to meet changing needs.

I am delighted that our colleagues in the key professional organisations have endorsed the principles contained in this booklet.



Chris Beasley
Chief Nursing Officer
Department of Health
February 2005

'The RCN welcomes this important publication. It is an extremely worthy 'sequel' to the much celebrated Department of Health document: *Liberating the Talents.*

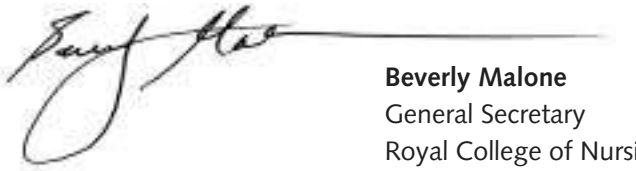
Community nurses are working in a challenging climate as the demands to improve care through the redesign of services and role development are a constant. However nurses know that they cannot avoid the inevitable – an ageing population with an increasing incidence of long term conditions and an explosion in the number of young people suffering from diabetes and other related conditions.

Supporting People with Long Term Conditions: Liberating the talents of nurses who care for people with long term conditions will prove to be a helpful guide for nurses, encouraging them to have the confidence to make essential changes in nursing care and service provision.

Today's nurses are well aware that their core business is that of working closely with patients to help them manage their own conditions and ensuring that however severe illness is high quality of life can be achieved.

The RCN supports all that is called for in this publication and intends to work closely at national and local level with all stakeholders to help turn fine words and ideals into positive action.

The RCN wants nurses to be inspired by this document and we are committed to playing our part in supporting them to make *Supporting People with Long Term Conditions: Liberating the talents of nurses who care for people with long term conditions* happen for patients.'



Beverly Malone
General Secretary
Royal College of Nursing
January 2005

'Community nurses are aware that there is a growing need to introduce innovative ways to care for the increasing numbers of people, mainly elderly, who are coping with chronic illness, many with more than one medical condition and social problems.

There are many new and exciting opportunities opening in primary care for nurses willing not only to embrace change and enhance their role to identify the health needs of both individuals and the communities they serve, to educate and empower patients to not only take responsibility and manage their own illness but also to prevent ill-health.

There are a number of new and exciting opportunities for nurses in the community setting willing to take up the challenge and embrace the new concept of caring as set out in *Supporting People with Long Term Conditions: Liberating the talents of nurses who care for people with long term conditions.* Community nurses are multi-skilled resourceful professionals willing to expand their expertise undertake new concepts of working for the benefit of patients and their profession.

The Community and District Nursing Association welcome the opportunities *Supporting People with Long Term Conditions: Liberating the talents of nurses who care for people with long term conditions* offers to nurses in primary care.'

Anne Duffy
Director
Community and District Nursing Association
January 2005

'Caring for people with long term conditions is a key part of community nurses' work, and the focus of many Queen's Nursing Institute award-winners' projects. The QNI welcomes the new impetus given to this important work by the recent Department of Health document *Supporting People with Long Term Conditions*, and this new publication outlining the central role of nurses and community matrons. We look forward to supporting innovative practice in this area through our awards schemes and professional networks.'

Rosemary Cook
Director
The Queen's Nursing Institute
January 2005

'The concept of *Liberating the Talents* has been embraced by policy makers and practitioners alike as we seek to ensure nurses are best equipped and deployed to meet the complex health care needs of individuals, groups and communities. *Supporting People with Long Term Conditions: Liberating the talents of nurses who care for people with long term conditions* acknowledges the significant contribution made by our district nursing workforce and provides a model for these nurses to build on their success and work with colleagues in new and innovative roles. Through application of an integrated approach to competency development and utilisation, and new models of case management, we will be able to provide the best possible care packages and pathways for us by practitioners working with people having long-term conditions, their carers and their families.'

Mark Jones
Director
Community Practitioners' and Health Visitors' Association
January 2005

1. Why long term conditions matter

Recent changes and developments

Chronic disease was emphasised in *The NHS Plan* (2000).

National Service Frameworks have been developed for some chronic diseases, such as diabetes, and protocols developed to ensure practice is evidence-based and to help integrate care across sectors.

The new general medical services contract that came into effect on 1 April 2004 rewards the practice team for the quality of their management of chronic disease, especially at level one and two of the Chronic Disease Management Strategy. Points, worth set amounts of money, are awarded for the establishment of good processes like registers, call and recall systems, to review and monitor patients with a range of illnesses such as diabetes and heart disease. Most nurses in general practice are contributing to this work. The conditions covered are: heart disease, cancer, diabetes, stroke, hypertension, lung disease, epilepsy, hypothyroidism, mental illness and asthma.

The NHS faces the challenge of responding to the needs and expectations of increasing numbers of people with long term medical conditions. It is estimated that 17.5 million adults in Great Britain may be living with a chronic illness. It is likely that up to three-quarters of people over 75 years are suffering from chronic illness of whom nearly half (45%) have more than one condition.

- More older people are affected than younger people.
- People with more that one condition are high users of all health services including those for emergencies.
- Incidence is highest among the most disadvantaged groups, such as unemployed people.
- As the population ages chronic diseases will continue to rise.
- At the moment patients with multiple needs often receive unplanned and uncoordinated care and are frequently admitted to hospital.
- By making improvements in the management of their care we know we can help these patients stay in their own homes and communities.

With death rates from heart disease falling by 27% between 1996/7 and 2001/03 and from cancer in the under 75s by 12.2% in the last six years, better management of chronic illness is already showing benefits for patients. This has been helped by new treatments, increased investment, changes in services and more staff. People are seen more quickly, disease registers are set up so that the patents are known, and call, recall and review systems make sure that they get the right treatment and are monitored effectively.

Nurses are already caring for patients with chronic illness and make an important contribution to helping them stay as well as possible. They have expanded their skills in areas like diabetes and asthma and are delivering high quality care according to national standards. They are working as generalists advancing their practice or as members of specialist teams.

For patients with highly complex needs, the situation has not been so encouraging. Evidence shows this group of patients, largely confined to their own homes or living in residential or nursing care settings often have reactive, uncoordinated care punctuated by frequent unplanned admission to hospital.

We know that this group of patients are having many contacts with the NHS, yet are still not receiving care that meets all their needs. Data from a UK pilot of the Evercare programme show that only 3% of all people over 65 years accounted for 35% of unplanned admissions. This suggests that those at highest risk are not being identified for special help needed to reduce complications and to maintain function and wellbeing.

Typically, patients receive intermittent, *ad hoc* care in response to a crisis or untoward event, but have little preventative intervention in between. Though many professionals are involved in their care, no-one has responsibility for considering all of their health and social care needs together, or to ensure they are met.

Phase III of the National Primary Care Collaborative focuses on improving care of patients with chronic diseases. Many GP practices have already been involved and have seen improvements in treating patients with coronary heart disease.

In *National Standards, Local Action* (2004) a national target has been set for long term conditions.

"To improve health outcomes for people with long term conditions by offering a personalised care plan for vulnerable people most at risk; and to reduce emergency bed days by 5% by 2008 (from the expected 2003/04 baseline), through improved care in primary care and community settings for people with long term conditions."

Health communities are expected to make progress towards the Public Service Agreement (PSA) target from 2005 onwards, and to have 3,000 community matrons in post by March 2007 to provide case management for the most vulnerable.

The patient's view

I tell people what I need but they don't hear me.

I've learnt a lot from you about my condition and now understand how to treat it.

When I came out of hospital I was frightened, scared to go out, no-one to talk to.

The carer's view

There is a renal nurse in the nearest hospital, 34 miles away, who has the title of 'home sister', she is at the end of the phone and occasionally visits if we have a problem.

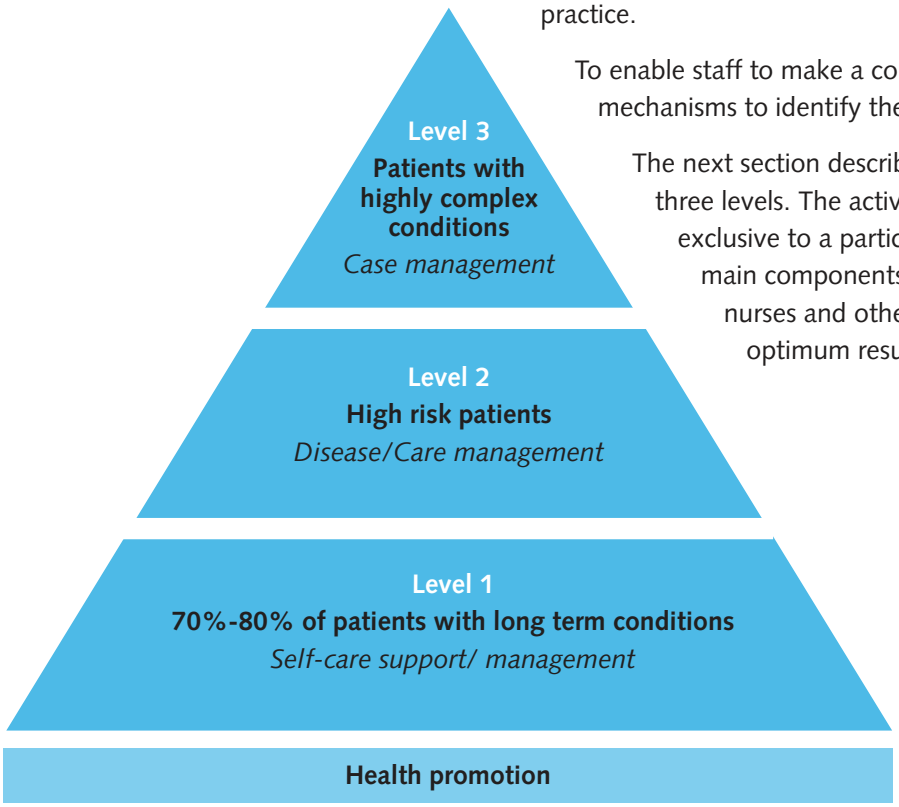
The GP is aware he has a different type of chronic disease to manage in the community, but he calls himself a bone man not a renal man. So where are we in all of this? The patient could give up easily as he gets frustrated

I wonder why the GP cannot communicate with the renal team and vice versa.

2. Improving care for people with long term conditions

The Department of Health's long term conditions strategy *Supporting People with Long Term Conditions. An NHS and Social Care Model to support local innovation and integration* (DH, 2005) provides a framework for improving the care of patients. It groups the population affected into three categories according to their different levels of need.

- **Those requiring more support with self management and self-care** so that they can take an active role in managing their conditions. This group makes up 70-80% of population with long term conditions.
- **Those needing better disease management** from multidisciplinary teams providing high quality, evidence-based care, often through the use of specialist nurses and nurses in general practice. This group is made up of high risk patients who need their condition actively managed to prevent further complications and promote wellbeing.
- **Those patients with complex, often multiple conditions who need case management approaches** in which their needs are identified and met by skilled practitioners working in an integrated care system. It is estimated that there are around 25 patients in this group in a typical general practice.



To enable staff to make a contribution at all levels, PCTs will need mechanisms to identify the population in each category.

The next section describes good practice in relation to these three levels. The activities described are not necessarily exclusive to a particular level, but are illustrative of the main components that are required. We suggest what nurses and others will be doing if they are to achieve optimum results for patients.

Nurses promoting self-care

Level 1: 70%-80% of patients

With the right level of support many people can become active participants in their own care, living with and managing their conditions

Nurses and allied health professionals (AHPs) in all health settings work with people with long term conditions. They support, educate and contribute to patients' ability to care for themselves. They share their skills and knowledge with patients and their carers, acting as a key resource and providing a route to other services and professionals. Health promotion and prevention form part of the care plan and nurses and AHPs work with, and draw on the support of expert patients and local self-help groups. Health professionals take responsibility for making patients aware of the options available to them to choose from.

Most patients with long term disease are actively involved in managing their own condition. Even those with diabetes, are likely to have on average, only three or four hours contact a year with a health professional.

Which professionals? Everyone

If this does not describe what is happening where you are, think about:

- Do your patients and their carers decide what care they want and contribute to their care plan?
- Can your patients access an expert patients programme?
- How can you help patients with long term conditions to learn from each other?
- Do you have preventive programmes such as falls prevention that involve local people?
- What information is available for your patients?
- How do you help your patients manage their own condition?
- How can patients contact the service for advice?
- Have you thought about how new technologies can support self-care e.g. near patient testing, text messaging, digital TV, internet, NHS Direct?
- Do you need to learn new skills in helping your patients to manage their own care?
- Do all of your patients who would benefit have a personal care plan?
- Do you know what is proposed in the *Choosing Health* white paper such as NHS accredited health trainers and personal health guides, which will help to reduce harmful effects of long term disease?

Nurses improving disease management

Level 2: High risk patients

Disease/care management, in which multidisciplinary teams provide high quality evidence based care to patients

Nurses are aware of patients with chronic disease who need specialist clinical interventions to achieve optimum health and reduce risk of complications and deterioration. Generalist and specialist nurses and AHPs work together organising their care seamlessly across the patient pathway. They devise and implement protocols in conjunction with medical staff. Information is shared between health professionals and between them and patients. Nurses operate call, recall and review systems. They contribute to the Quality and Outcomes

Framework. Nurses may lead teams and are accountable for delivering agreed standards of care. Nurses develop care plans with patients and carers and provide secondary and tertiary prevention.

Which professionals? A wide range of generalist and specialist nurses in hospitals and primary care, such as practice nurses, district nurses and specialist nurses in diabetes, heart failure, mental health, chronic obstructive pulmonary disease. Allied health professionals also contribute as specialists in their own right, or as members of multidisciplinary teams.

If this does not describe what is happening where you are, think about:

- Do you know which patients in the practice population fall into this category?
- Do your patients know how to seek help when they need it?
- Do you know what plans are being made by local GP practices to achieve points under the Quality and Outcomes Framework (QOF)?
- Do you know which of your patients should be included within the QOF system?
- Do your patients know how their condition will be managed?
- How do you support people to make healthy choices?
- Do you have the authority to make and receive referrals and order investigations?
- Are you involved with your GP practice in delivering the QOF?
- Are you involved in developing and using protocols to treat long term conditions?
- Do you work collaboratively with colleagues in other sectors to coordinate patient care?
- If you work in a hospital are you able to share expertise with primary care colleagues?
- If you work in primary care, how do you share expertise with hospital colleagues?
- Would your care be enhanced if you could prescribe medicines for patients as an independent or a supplementary prescriber?

Nurses providing case management people with co-morbidities and complex conditions

Level 3: Highly complex patients

Case management to actively manage and integrate care for people with co-morbidities

Data are used to identify patients in this category who are at higher risk of repeated admissions to hospital. Typically, though not exclusively, these patients are older, have some forms of degenerative disease coupled with one or more chronic condition. They take several different medications and may have problems with activities of daily living. Nurses, known as community matrons with case management competencies, take responsibility for a case load of approximately 50 people with highly complex needs at any one time. These community matrons combine high

level assessment, pharmacological management and anticipatory managed care, based on principles of least invasive care in least intensive settings. They help patients negotiate their way around the health and social care system. They refer to other professionals, make clinical decisions and mobilise resources. They enable patients to make personal choices about their care, including the decision to stay in their own home until the end of their life.

Which professionals? Nurses with high level assessment and clinical nursing skills, and knowledge of local communities and other agencies. Experienced nurses come from a variety of backgrounds, from district nursing and the hospital sector.

If this does not describe what is happening where you are, think about:

- Do you know which of the patients in your community or practice are most at risk?
- Do you have agreed criteria for identifying patients in this category?
- How is the care of patients with highly complex needs currently coordinated?
- Do you have all of the equipment and resources needed to care for patients at home?
- Are patients able to choose to have end of life care at home?
- Can your patients and their carers access expert and specialist care within their own home as necessary?
- Do you routinely review and discuss your patients' medicines with them and their carers?
- Do you know what competencies you would need to undertake case management with patients with highly complex needs?
- Do you know what additional learning you would need?
- Do you provide your PCT with information to help them commission effectively for long term conditions?
- Do you have a good working relationship with the patient's GP, consultant, AHP and social worker?
- Do your patients have the social care they need?
- Do voluntary groups and the local community know about the role of community matrons?
- Are you able to prescribe for your patient?
- Do you have a system of receiving feedback about your service from patient and carers?
- Do you have the authority to make referrals to other professionals including doctors?

Phil

– Has heart failure and so is on a complex mix of medicines

– Has atrial fibrillation so is also on warfarin

– Is sometimes depressed

– Has diabetes

– And cares for his wife with dementia

– Is already on simple analgesics, including codeine which has made him constipated

– And has increasing pain in his knee meaning increasingly he cannot cope with his duties as a carer

based on a real patient, with the name changed, source: *Chronic Disease Compendium* (DH, 2004)

3. Community matrons and case management

Who are community matrons?

The NHS Improvement Plan (2004) describes a new clinical role for nurses. Known as community matrons, these experienced, skilled nurses use case management techniques with patients who meet a criteria denoting very high intensity use of health care. With special intensive help, these patients are able to remain at home longer and to have more choice about their health care.

What is case management?

The term case management is used to cover a number of activities like acting as a key worker or as a broker or procurer of packages of care for patients to promote independence. Several models are operating successfully, and many health and social care professionals are involved. The case management work of community matrons is central to the government's policy for the management of people with long term conditions.

In this type of case management, community matrons:

- use data to actively seek out patients who will benefit
- combine high level assessment of physical, mental and social care needs
- review medication and prescribe medicines via independent and supplementary prescribing arrangements
- provide clinical care and health promoting interventions
- co-ordinate inputs from all other agencies, ensuring all needs are met
- teach and educate patients and their carers about warning signs of complications or crisis
- provide information so patients and families can make choices about current and future care needs
- are highly visible to patients and their families and carers, and are seen by them as being in charge of their care
- are seen by colleagues across all agencies as having the key role for patients with very high intensity needs.

The principle of this particular model of case management is that there is one person who acts as both provider and procurer of care and takes responsibility for ensuring all health and social care needs are met, so that the patient's condition stays as stable as possible and wellbeing is increased.

While community matrons will focus on patients with very intensive needs, other patients with long term conditions may continue to receive case management from a range of professionals, like physiotherapists and occupational therapists, whose skills best suit their needs. Children with long term or life-threatening conditions can have case management from children's community nursing teams working in partnership with paediatric departments, and assertive outreach teams will provide similar care for people with long term and enduring mental health needs.

Community matrons are bringing the benefits of case management to a new category of patients hitherto outside its remit, and in so doing, will extend the concept of case management to encompass clinical nursing interventions.

Case management by community matrons will:

- help to prevent unnecessary admissions to hospital
- reduce length of stay of necessary hospital admissions
- improve outcomes for patients
- integrate all elements of care
- improve patients' ability to function and their quality of life
- help patients and their families plan for the future
- increase choice for patients
- enable patients to remain in their homes and communities
- improve end of life care.

Case management – Evercare style

In England nine PCTs have been piloting an American model of case management called Evercare. In this model, PCTs identify their at risk elderly population through scrutiny of hospital admissions and GP practice data. Specially trained nurses, each handling a case load of around 50 patients, combine medical and nursing assessment, and medicines management with proactive, preventative interventions aimed at promoting maximum functioning, independence, wellbeing and quality of life. These nurses call themselves advanced primary nurses.

Some people with long term conditions are able to act as their own case managers – holding their budget for social care and organising packages of care for themselves.

The underlying principles of case management are to:

- provide least invasive care in least intensive settings
- support effective primary care
- focus on patients in the community carrying the highest burdens of disease
- build partnership with secondary care clinicians and social services
- identify patients who are at high risk of unplanned admissions to hospital
- enable each patient to have a personalised care plan based on their needs, preferences and choices
- integrate the patient journey throughout all parts of the health and social care system.

Differences between no overall case management and case management

Nursing in the community has a strong tradition in this country. Case management can add another dimension, structuring activities to achieve clear patient outcomes. We show below the difference it can make to patients.

No overall case management	Case management
Patients are not pro-actively identified as being at specific and immediate risk i.e. only known if referred	Patients with complex needs are identified as being at risk even during periods of relative stability
Patients' problems are treated in isolation from each other, so that their total burden is overlooked	Patients have a comprehensive assessment of their physical and mental health and social care needs and baseline data is recorded. A personal care plan is developed with them that addresses the combined impact of all of their conditions
Patients have to see several health professionals to get all of the care they need	One person has the authority and responsibility for ensuring patients are able to get all of the care they need. They can also provide clinical care, reducing fragmentation
Patients do not receive anticipatory care to prevent acute episodes at an early stage	Patients receive primary, secondary and tertiary prevention to slow down deterioration and protect them against untoward events such as falls
Patients are reluctant to make anyone aware of slight changes in their condition, increasing the likelihood of becoming ill enough to require a hospital admission before action is taken	Patients and their carers are encouraged and know when to report even slight changes as soon as they occur and to call for help so that problems are resolved at an early stage
Patients may become difficult to discharge from hospital as un-anticipated problems emerge	Admission to hospital prompts discharge planning immediately in collaboration with ward and social care staff co-ordinated by the community matron
Patients are required to take a large number of medicines increasing the risk of side effects and adverse events	Medicines are reviewed regularly with the patient, their families and with medical staff to achieve the best result in the least complicated way
Patients and carers remain unaware of how the disease will develop and how it will affect them in the future	Patients and carers learn about their conditions and the likely progression of their illnesses
When a crisis occurs patients may have few options available to them	Patients and their families are able to make plans for the future and to decide between a number of possibilities
Patients are unable to remain at home to die	Patients are helped to prepare for end of life stages and to make decisions about their care
Nurses are encouraged to discharge such patients once their condition appears stable, and they are not seen as having immediate nursing needs	Nurses stay with the patient for life, involving themselves at all stages and in all care settings
Hospital staff and primary and community staff treat patients independently of each other. Patient care may be fragmented, and professionals plan interventions without all of the relevant information	Patient care is managed across the hospital, community and social care settings. Their case manager is as much a part of the ward team as of the PHCT. Patients benefit from integrated and seamless care, with rapid access to expertise when required
No one person involved in providing care for a person with high intensity needs has the authority to obtain and direct inputs from other agencies	Community matrons have the responsibility and authority to procure all elements of a care package. Their referrals will be accepted by other agencies and professionals such as hospital consultants. Holding an indicative or actual budget is a possibility

4. Implementing case management by community matrons

The main steps to implementing a case management model using community matrons are:

1. Identifying the population at risk
2. Defining the case management role
3. Involving users in service redesign
4. Identifying and involving key stakeholders
5. Redesigning the wider workforce to encompass the community matron role
6. Skilling up the workforce
7. Identifying and preparing supervisors and clinical mentors
8. Establishing systems to support case management by community matrons

1. Identifying the population at risk

This means looking at the whole population, not simply at those patients already on nurses' caseloads, or those who present or are referred for care. Criteria must be agreed for identifying those who could benefit from being in the case management system, and patients actively sought.

Examples in practice

Identifying the population at risk

Luton PCT is one of the Evercare pilot trusts. Their challenge was to identify the small percentage of their population who accounted for a large number of hospital admissions. These were the people with the highest needs who could benefit most from care management. Using the hospital admissions data held by the PCT, they identified people over 65 years who had two or more hospital admissions in the previous year and highlighted those whose admissions were unplanned. This provided the first tranch of patients. They also asked GPs and nurses to make nominations. They included people who had recent falls, multiple medications, cognitive impairment and who had chronic disease. Subsequent analysis of data showed the people with two or more unplanned admissions tended to have these characteristics.

GP practices were visited to get their agreement to be in the pilot programme, and letters sent to patients to obtain consent. Very few patients refused.

They feel that the model works because it focuses on all of the needs of the patient. The Advanced Primary Nurse (APN), who acts as a community matron, maintains a life-long relationship with patients and their families, monitoring their progress and staying in contact with them whatever care setting they are in. This includes going into hospitals during periods of admission, talking to ward staff and consultants, and making discharge arrangements.

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The most likely indicators of vulnerability are two or more unplanned hospital admissions in the previous six months, co-morbidities, and poly-pharmacy. Some professionals also want to include patients they instinctively feel to be in a high risk category. Scrutiny of hospital admissions data, singling out those that are unplanned, will show those most at risk within local communities. It will also reveal whether particular groups like children and younger adults need to be included.

2. Defining the case management role

The community matron will:

- take responsibility for around 50 older people with high level needs
- work collaboratively with all professionals, carers and relatives to understand all aspects of patients physical, social and environmental condition
- work in partnership with the patient's GP, sharing information and planning together
- work as members of the primary health care team to ensure a team approach to care
- develop a personal care plan with the patient, carers, relatives and health professionals, based on a full assessment of medical, nursing and social care needs. The plan includes preventative measures and anticipates future requirements
- keep in touch and monitor the condition of the patient regularly. This may be done by home visits or by telephone contact
- initiate action if required such as ordering investigations
- update patient's medical records, and inform other professionals about changes in condition
- work in partnership with other local agencies such as social services, to mobilise resources as they are needed
- show carers and relatives how to identify subtle changes in condition that may precipitate acute exacerbation of underlying condition, or of illness, and to call for help
- generate additional support as needed, for example, from intermediate or palliative care teams, or geriatricians
- maintain responsibility if patient is admitted to any in-patient facility and provide base line health data for the receiving team, to support integrated and consistent care and facilitate timely discharge
- prepare patient and their family for changes in condition, and support choice about end of life care
- evaluate outcomes in collaboration with GP and hospital colleagues.

Choosing Health, **Department of Health 2004**

'Community matrons are ideally placed to promote the health needs of people with long term conditions. In their hands-on case management role they will identify those whose health is at greatest and work with patients and their carers to reduce the effects of disease and prevent accidents, dehydration, infections or other conditions that could result in admission to hospital. Community matrons will also be able to put their patients in contact with NHS-accredited health trainers, who can provide additional practical support to the patient carers on changing their behaviour to prevent further ill health.'

Examples in practice

Coordinating care for patients with complex needs

Castlefields Health Centre has developed an intensive approach to patient care which coordinates their health and social care needs. It has three key elements.
1. All referrals are directed to a social worker and district nurse team who review all referrals and carry out patient assessments within one day. The team can put in place packages of care immediately for the majority of patients.
2. A hospital in-reach programme is in place. If a patient is admitted, the hospital tell the team and the nurse and social worker go to hospital to initiate discharge planning.
3. The practice identifies patients of potentially high need before they are referred for assessment or have an acute admission. They have locally agreed criteria and proactively identify patients for assessment by the team.

The outcomes have included reduced hospital admissions, shorter lengths of stay, closer working between health and social services, and improved patient access to services.

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Examples in practice

Advanced Primary Nurses working within Evercare

Sarah Bray, advanced primary nurse in Luton receives referrals from GPs, district nurses, social services, hospital consultants and the discharge planning team. The criteria for referring a patient to Sarah are that the patient has one of the following:

- two or more hospital admissions in a year
- long term condition has become worse in the last three months
- poly-pharmacy
- has fallen
- cognitive impairment and is medically unstable
- has been recently bereaved and is at risk of medical decline.

At the first visit Sarah takes a full medical history together with more detailed questioning about any specific problems. She carries out a full physical examination, which may be completed over the course a several visits, depending on the patient's physical condition. If the patient has a specific condition the examination is targeted in certain areas. For example for chronic obstructive pulmonary disease (COPD) patients, she will carry out a chest examination, respiratory rate, sputum production, and oxygen salts at each visit. She also carries out a medication review.

Patient visits are planned depending on their level of risk. Low risk patients may be seen every four or six weeks, medium risk patients are seen every two to four weeks and high risk patients are seen each week. Patients move between levels depending on their condition.

Sarah helps patients to learn more about how to manage their own condition so they can be more independent and also know when to call her if they are becoming unwell.

Sarah works with the GP with the aim of managing the patient proactively and for crisis illness to be minimised. She has found that GPs welcome the monitoring the monitoring of patients and this has led to fewer hospital admissions.

If a patient is admitted to hospital, then Sarah will liaise with hospital staff about the patient's medical condition, recent investigations and will follow the patient closely through their stay in hospital. She also

liaises with any support services that the patient may need. A hospital admission tool has been developed and Sarah meets monthly with hospital consultants for the elderly to discuss recent admissions and identify any lessons for future practice.

NB. Sarah's role is closely aligned to that of a community matron

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3. Involving users in service redesign

Patients with long term conditions build up considerable expertise from their own experience as service users. They, their families and carers are aware of what constitutes a good service and know why services can fail to meet their needs. However such people are not an homogenous group and while they share characteristics as a result of their illness, there are also many differences among them as in any other section of the population. Some of these differences may be cultural, gender and ethnic specific while others result simply from individual preferences or views about life. Providing personalised care means being attuned to the differences between one individual and the next.

To ensure redesigned services meet a variety of needs it is vital to engage with a cross-section of the community who will be using them and to obtain as broad a view as possible. This can be

Examples in practice

Case management – the patient's perspective

Before being enrolled on the case management programme, Mrs Lewis experienced 'system failures' when she was admitted to hospital. She had five concurrent chronic conditions and in the course of a year she was admitted to hospital 21 times, with an average length of stay of up to three weeks. She was cared for by different teams and was often assessed by staff who had no knowledge of her conditions and who repeated investigations. For example she had her troponin levels checked 17 times: and all were negative. Each time she was admitted she was cared for by a different specialist team who concentrated on their particular area of expertise: the respiratory team concentrated on the COPD exacerbation while the cardiac team focused on her heart system failures.

Mrs Lewis had a poor understanding of her prognosis and needed extensive support with her coping strategies when her symptoms worsened.

Mrs Lewis was enrolled on the case management programme and since then her admissions have reduced to 11 over a year, with an average stay of just 24 hours. Because she has developed a relationship with the APN, Mrs Lewis now phones the nurses instead of attending A and E, and the Advanced Primary Nurse (APN) can pass her knowledge of Mrs Lewis' 'normal' functional ability and chronic conditions to staff in the acute settings. This has helped to prevent admission and to reduce the length of stay if Mrs Lewis has to be admitted. The holistic approach to investigation and management of Mrs Lewis' episodes of chest pain have resulted in a diagnosis of gastro oesophageal reflux disorder and instigation of appropriate treatment.

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done by liaising with established representative groups as well as using techniques such as rapid appraisal to gather perspectives from those not part of a formal system.

Enabling more people to contribute to the redesign programme will help to establish support for the changes within the constituency most affected, and will ensure the changes achieve greatest benefits.

4. Identifying and involving key stakeholders

Good case management requires 'whole systems thinking'. This is because all of the elements making up a comprehensive care package need to be co-ordinated and integrated. Where one element is missing, or of insufficient quality or quantity, the whole plan of care can collapse.

Involving all key stakeholders, particularly social services departments, at the outset will help to build the commitment needed to ensure success. GPs are a vital link and should play a central role in developing the community matron service, as should those in acute and social care.

PCTs will know who the key players are in their areas, and strategic health authorities and workforce development directorates can bring a consistency across the health community.

Improving the care of very high intensity service users involves considerable organisational change. Introducing community matrons to case manage those with the greatest burden of disease means many people need to work differently and with new partners. This will only happen if all of those affected are involved in a true partnership and competing priorities harmonised around the needs of the patients.

Establishing a steering group made up of all stakeholders can help to get the project established, keep it on course and help to ensure it delivers the desired outcomes.

Examples in practice

The Evercare experience

When Walsall PCT started the Evercare pilot programme they realised they would need the commitment of hospital and local authority colleagues. Establishing good relations between the nurses and the consultants and ward staff has been a vital success factor. The nurses talk to consultants regularly and visit the wards during admissions. Sometimes consultants do joint home visits with the nurse, enabling expertise to come to the patient. They also needed the support of the local authority and have developed good working relations with them. Getting the whole system to work together is crucial. For example, care managers are able to gain rapid access to local authority OT services via their intermediate care team. Usually patients do not need expensive or high tech equipment, but do need to be provided with adaptations such as grab rails as quickly as possible.

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5. Redesigning the wider workforce to encompass the community matron role

There are estimated to be around 250,000 people in England with very high level needs who could benefit from case management, with a typical GP practice having around 25 such patients. Each community matron is likely to have a caseload of approximately 50 people, so PCTs should be able to estimate the numbers of community matrons they will need. This will be an attractive role for nurses. District nurses may already have many of the competencies needed but steps may need to be taken to avoid compromising other community services for patients. The community matron role provides new opportunities for experienced nurses from other settings, such as local hospitals, but learning programmes will need to be flexible to meet the nurse's individual needs.

Trusts have found the following actions to be helpful:

- setting up a learning programme to help newly qualified nurses join primary care
- expanding the role and opportunities for community staff nurses
- encouraging more nurses to work across primary and secondary care
- offering orientation programmes so experienced nurses can move from hospitals into the community as well as into community matron roles
- commissioning extra district nurse training places
- shadowing opportunities so hospital nurses can spend time in primary care
- primary care orientated pre-registration nurse training posts
- joint posts between primary and acute care
- enlarging the role of support workers/assistant practitioners
- strengthening multiprofessional team working.

For more examples, see *Flexible Entry to Primary Care Nursing Project: Improving recruitment and retention in primary care: a guide to attracting and retaining nurses in primary care* (Drennan, Andrews and Sidhie, 2004).

Liberating the Talents (DH, 2002), provides a useful framework for developing nursing in primary care where matching skills to patient need matters more than job titles.

Examples in practice

Delegating to staff nurses

North East London Workforce Development Confederation runs an 18-month rotation programme in community/primary care. It offers a competency-based framework for newly qualified nurses who want to develop skills in primary care, community nursing and care of the elderly settings.

The trusts benefit by an increased number of D grade staff nurses who, at the end of the programme, are potentially competent E grade nurse with a good grounding in primary/community nursing.

Of the nine nurses on the first the programme, eight secured D grade posts in district nursing teams, with four now in E grade posts. The remaining nurse is now working with a local regeneration project.
Feedback from managers, placement teams and programme members has been positive.

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Examples in practice

Delegating to healthcare assistants - making sure they have the right skills

District nurses at Redditch and Bromsgrove PCT are able to delegate more effectively, enabling them to develop more complex skills to meet changing needs. This has been supported by the development of a competency-based intermediate skills programme for healthcare assistants working in district nursing teams, community hospitals and with GP practices. The rolling programme was developed in conjunction with the Worcestershire Support Services Agency and is offered across three PCTs. There are two modules.

Module A is two taught study days

Module B focuses on a range of nursing skills.

Individual training needs are identified at appraisal, personal development plans are created and the skills escalator is introduced as a framework for possible future development. There are a number of key outcomes from the initiative:

- a more confident skilled healthcare assistant workforce enables registered nurses to take on new roles and delegate appropriately
- expanding skills base of the whole workforce reflects the ideas of modernisation
- a robust method of training and development reflects the principles of clinical governance
- partnership working with district nursing teams, community hospitals and GP practices
- the workforce feels valued.

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Examples in practice

Redesigning the service to make better use of staff nurses' skills

Changes at national and local level, including experience as a case management pilot site, prompted Walsall Teaching PCT to review its district nursing service. It recognises the important role they will play in helping to improve the management of long term conditions, but acknowledges that the nurses must first be freed up from some constraints inherent in traditional practice.

The main changes they propose will see multi-skilled district nurse teams organised around clusters of GPs, covering a 7am – 10pm day. Their analysis of patient data showed 50% of patients with chronic disease were admitted to emergency departments over night, so nurses will be recruited to the out of hours teams. Each nurse team will be headed by a district nurse who has additional competencies in physical assessment, care management, supplementary prescribing, intravenous therapy and medicines management. This is in line with the community matron model. Better use will be made of staff at more junior grades who will assess and deliver care to patients with less complex needs, and each team will be supported by an advanced primary nurse who will work collaboratively with GPs to care manage the most vulnerable patients. Building on their success with leg ulcer clinics, more care will be delivered via clinic settings.

In this way, Walsall PCT are taking a 'whole systems' approach to ensure they have a nursing workforce that can meet the broad spectrum of need intrinsic in community nursing. Crucially they are also creating capacity to manage the care of those with highly complex needs in their own homes.

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6. Skilling up the workforce

As well as their core nursing skills and knowledge community matrons will need to be competent in the following:

- advanced level professional practice, including self-directed learning, managing risk, authority to act on behalf of patients, higher level communication and negotiation skills
- care co-ordination and case management (brokerage and provision)
- managing cognitive impairment
- using population and individual information to support decision making
- managing medicines (to include assessment, review and prescribing)
- inter-agency and partnership working
- management of long term conditions (particularly the interplay between multiple diseases)
- working in the home and community settings
- supporting self-managed care
- improving health and promoting wellbeing
- managing care at the end of life.

Community matrons will need both theoretical and practical input to be effective case managers. Their theoretical and practice-based learning should also be underpinned by good mentoring and supervision. While the actual content of learning programmes should reflect individual need, it is likely all will require medical assessment and history taking skills, aspects of chronic disease, mental health, and the ageing process.

Some universities have developed specific programmes, and some PCTs have put together their own programme with local consultants and GPs.

Skills for Health and the Institute for Skills, Learning and Innovation (formerly the Modernisation Agency and the NHSU) are defining community matron competencies to inform training programmes. They are also to develop a self-assessment module to enable potential community matrons to understand their own training needs.

7. Identifying and preparing supervisors and clinical mentors

Nurses advancing their clinical skills to become community matrons will need practical supervision while they are acquiring new competencies. They also need workplace mentors to support their continuing development. GPs are often willing to take on this work, but others such as nurse practitioners, geriatricians and other expert professionals may also be available. The supervisor or mentor should have a clear understanding of the level of practice the student is expected to achieve for each competency and enough opportunity to observe the student at work.

A good relationship between supervisor or mentor and mentee is important and they should be able to discuss freely progress made and identify further training needs. Many senior clinicians enjoy sharing their expertise and developing others, but it is vital that they are aware of the time commitment involved and a plan devised to enable them to meet the obligation to students.

8. Establishing systems to support case management by community matrons

Improving the care of very high intensity users will require more than introducing community matrons. It involves considerable organisational change to make sure that the wider systems support this model of care. Introducing community matrons to case manage those with greatest burden of disease means many people may need to work differently and with new partners.

Community matrons must be able to coordinate care across sectors and will need to be authoritative and knowledgeable about the needs of their patients.

PCTs should consider adapting systems and gaining commitment from many sectors so that community matrons can:

- make referrals and order investigations
- admit and discharge patients
- secure services from others like therapists, social care, and specialist nurses
- access additional support when necessary from intermediate services and out of hours teams
- act to improve the quality of care
- play a full part in clinical decision making
- fulfil the Chief Nursing Officer's ten key roles as appropriate, particularly the ability to prescribe for patients
- have their role understood by all of the key players they need to interact with
- have access to patient information as necessary.

Questions and Answers about community matrons

Is case management only for older people with a long term condition?

No. Many people with complex needs resulting from a long term condition will find their care improves if one person has overall responsibility for ensuring all of their requirements are met. However, patients with very high intensity needs are likely to be older and to be among those who must have the special combination of skills a community matron can bring.

What about other groups of patients like children and people with mental health problems?

Most children with long term or life threatening conditions receive care from specialists like community children's nurses. Such nurses work intensively with children and their families in the home, and with therapists and hospital paediatric departments to offer holistic, integrated care. However, where case management could add value, they may wish to adapt their service to include new elements. Mental health nurses also have a long tradition of using case management via the care programme approach and, more recently through assertive outreach programmes. Trusts may consider utilising case management more widely and may recruit community matrons with skills appropriate for different groups.

What part should service users play in developing community matrons and case management?

Services cannot be planned and delivered effectively without the full involvement of users and carers. Community matrons need to be visible and accessible to local people and responsive to changing expectations.

Do community matrons have to be nurses?

Yes. Furthermore, the title community matron means a nurse to the public, and the patients who will come under their care will have high levels of nursing needs. Different models of case management may be offered by other professionals to meet differing sets of patient needs.

Should community matrons be part of the general practice team?

Yes. Community matrons will need to work alongside GPs and others. GPs are vital to patient care, and community matrons must work with them and other members of the primary health care team to achieve the best outcomes for patients. However, how community matrons are to be deployed is a local decision and depends on the size of the practice populations. An average GP practice will have around 25 patients who are very high intensity service users. Community

matrons can manage around approximately 50 patients at any one time, so it may be appropriate to cluster smaller practices in the same way as community nursing teams, but there need be no single model. Some PCTs may choose to use flexibilities under GMS and PMS to develop alternative approaches.

District nurses used to keep patients on their caseloads to keep a watching eye on them. This practice fell out of favour as they were encouraged to keep their caseloads active. Isn't case management just going back to what we used to do?

No. Case management means a clear set of activities are being performed for each patient. Not least of these is regular physical, psychological and nursing assessments to detect changes and deterioration in condition and preparation of a care plan that is updated to reflect changing circumstances.

Will community matrons work in isolation from district nurse teams?

No. It is vital that community matrons work collaboratively with district nurses and other members of the primary health care team. In some cases they may be members of the district nurse team, in others they may work with more than one team.

Can practice nurses become community matrons?

Many nurses, including those working in general practice, will be able to become competent in the skills and knowledge needed to undertake case management for very high intensity service users.

Will community matrons take on roles other than case management?

If community matrons are to be able to meet the needs of very high intensity service users, it may be difficult for them to make themselves available for other activities. It relies on having one person who can give time to the needs of this group of patients and be free to respond rapidly to prevent a crisis developing. Evaluation of implementation of the modern matron role showed role overload was an impediment to their achieving their key goals.

How will community matrons get specialist help for patients who need it?

Community matrons will need to work closely with hospital colleagues, visiting wards themselves and contributing to the plan of in-patient care. It is also important that patients can access specialist expertise from nurses and others in their own homes. Specialist nurses are crucial to the care of patients and community matrons should develop strong networks with all sources of expertise.

Will community matrons need to practice at master's level?

The level of competence of community matrons needs to be assessed within the Agenda for Change's Skills and Knowledge Framework to determine the appropriate standard of practice. Education programmes can then be developed locally to enable practitioners to meet the appropriate standard. Skills for Health and the Institute for Skills, Learning and Innovation are working to develop a competency framework so there is a consistency of approach across education programmes, whether delivered by HEIs or other organisations.

How will community matrons get the authority they need to act on behalf of patients?

One of the most important things local nurse leaders and managers can do is to ensure community matrons have clear authority to do what is necessary for patients. Along with community matrons they will need to liaise with other agencies to ensure systems and processes are in place for rapid access to the services and resources patients need. Community matrons' referrals must be accepted by hospital consultants and others, and they must be able to request diagnostic tests and instigate treatments and interventions as required.

Will community matrons be budget holders?

This is a local decision. PCTs and partner organisations may wish community matrons to manage the health and social care budget for very high intensity service users. This will enable them to develop flexible packages of care suited for the individual needs of their patients. However, community matrons have a much wider role than simply effective cost management. Holding the budget must support the improvement of patient care.

Do community matrons discharge patients?

The great majority of patients on the community matrons' caseloads will be there for life. This is because the nature and complexity of their condition means they will always be at high risk of complication and deterioration. However good case management means many will go through long periods of stability when actual contact with them can be minimal. The patients and their carers will still need to know that their community matron is managing their case and will be available when necessary. This is a key difference between the work of community matrons and other community nurses who discharge patients when a episode of care is complete.

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Annex 1

Steps to success: Improving care for people with long term conditions

PCTs:

- Implement *Liberating the Talents*
- Commission home health care effectively
- Work closer with hospital lead nurses to enable nurses to work freely across hospital and community care
- Plan, train and deploy the nursing workforce to meet need across the health community
- Value and 'upskill ' the generalist role
- Support district nurses and others to move into community matron roles
- Resource the home as a health care setting
- Ensure community matron posts are established with clear lines of authority and independence to act

Hospital trusts:

- Provide information for identifying patients with high intensity needs
- Plan services with PCT colleagues
- Work closer with hospital lead nurses to enable nurses to work freely across hospital and community care
- Support nurses wishing to take up new opportunities in primary care
- Support community matrons to be part of hospital teams

Nurses:

- Get involved in policy and planning for older people, chronic disease management and palliative care
- Challenge myths that prevent moving forward
- Involve patients in decision making and offer choice
- Look at whole population not only individuals on the caseload
- Lead for change
- Work with PCT to identify priorities and influence commissioning
- Work towards raising profile of primary and community nursing so the public and other professionals understand roles

GPs:

- Involve all nurses working with practice patients with systems and processes for managing patients with long term conditions
- Contribute to establishing criteria for identifying patients who require case management
- Act as mentors and supervisors for community matrons
- Help to ensure community matrons have authority to act on behalf of patients with very high intensity needs by, for example, encouraging other professional to accept their referrals

Education/workforce planning:

- Match learning to health needs
- Promote flexible practice, multidisciplinary/ multi-agency based learning
- Encourage learning with and from patients
- Ensure flexible entry routes and careers
- Stress the ability to move between or combine the functions i.e. public health, first contact care, continuing care
- Emphasise more public health learning

National organisations:

- Challenge the image and the myths
- Support innovation
- Focus on patients and communities
- Provide coherent leadership
- Value the home as a health care setting
- Explore new models of service provision
- Continue to value and raise the profile of the generalist

NPCC focus on diabetes and COPD

The National Primary Care Collaborative works with GP teams to help them improve the management of patients with chronic disease. Their latest initiative focuses on care for patients with long term diabetes and chronic obstructive pulmonary disease (COPD). A large number of GP practices, PCTs, secondary care representatives and patients and carers are working together to improve outcomes for these patients.

Twenty pilot sites have been working to create care pathways between primary and secondary care, adopt best practice guidelines, develop proactive secondary prevention and to have an increased awareness in the use of self-care tools and techniques. Practices are also considering ways of managing highly complex patients.

The results from the first 20 sites have been extremely encouraging and the programme is now available to be role out to all interested PCTs through the National Primary Care Development Team.

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Also under the auspices of the NPDT …

National Primary Care Development Team and Unique Care

NPDT is promoting Unique Care through a number of its programmes. This is an approach to practice-based management of individual patients within the community, taking an intensive, co-ordinated approach to their unique health and social care needs to ensure a responsive service. It uses the principles of case management embedded in NHS primary care, and incorporates hospital in-reach and identification of potentially high need patients before they are referred for assessment or experience an acute admission.

For further information visit the NPDT website: www.npdt.org

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