Complex Conditions in Later Life

**Care Pathway
&
Implementation Guide**

Contents

Executive Summary

Complex Conditions in Later Life are not easy to deal with but they are simple. The major obstacle is the required cultural change to enable health, social care and the independent sector to work together as one team to deliver care in a systematic, integrated, holistic and anticipatory manner.

In England, approximately 6% of the population, or three million individuals, will have a long-term condition that significantly affects their ability to look after themselves. Identifying them is a problem in itself, although there are an increasing number of tools to help.

Assessing functional ability (the ability of someone to look after themselves) is a key issue that clinicians in particular do not do often enough. Within the clinical setting a simple tool needs to be devised that can be routinely used. Once a person is identified as having possible complex conditions a systematic assessment needs to be carried out. A national Self Assessment Process needs to be devised to help in this regard but each locality needs to identify a practitioner who can do this assessment. It makes sense for them to be drawn from health, social services or the independent sector.

Care co-ordination is the cause of some confusion. The care co-ordinator is the individual responsible for ensuring a person with a complex condition has a personalised care plan and that a review takes place. This care co-ordinator needs to be clearly identified from the outset. The key worker, on the other hand, is more important to the patient as they are the ones who are most involved in the delivery of care. They have the most face-to-face contact with the patient and in the case of complex conditions they are likely to be some kind of practitioner. Their role needs to be celebrated and they are certainly needed to be involved in the review.

The success of care delivery depends a great deal on the quality of the infrastructure, district nursing, primary care, out of services, care at home, rehabilitation, care homes etc.

Care homes have particular issues with regards to involvement and co-operation with health and social care. Communication with them tends to be poor to the detriment of the patient. The development of care trusts for older people and complex conditions along the lines of children's care trusts will help enormously as it would encourage the different agencies to work more closely together and even consider pooling budgets. Intermediate care needs the involvement of primary and secondary care, social services, community health services, care homes and the voluntary sector. The main priorities of Intermediate Care are helping people stay in their own homes as well as bed management within care homes. The Preferred Place of Care is a simple programme that particularly applies to care homes and would help involve them in the local care community.

Practice Based Commissioning is a key driver to deliver the cultural change if imaginative and experimental commissioning for long term conditions is high up on the agenda.

Joint training for health and social services and the independent sector will help to build the idea that each is a part of a larger team that can deliver a greater impact collectively.

IT has particular issues. The information on the care plan, the involved practitioners, the contact assessment and the activities of daily living need to be available 24/7 to all interested parties, especially out-of-hours. This involves changes in the current layout of clinical and social care systems and development of the use of codes that capture social as well as clinical data. Whilst we await a single electronic care record, the use of interface software needs to be promoted. For this to happen there needs to be natural leadership most particularly on the issue of 'confidentiality'.

The end result is a better outcome for a person with a complex condition. The systematic, holistic, anticipatory approach will at least improve the patient experience and has the best chance of using scarce resources more efficiently.

Introduction

Improving care for people with long-term medical conditions is increasingly becoming an international issue. With such conditions accounting for 60 per cent of the global disease burden (WHO., 2002), research has shown that a large number of people who are frequently hospitalised have long term conditions (Hutt R., 2004). The establishment of preventative care will assist individuals and health agencies to prevent the deterioration of such patients' health, improving their quality of care whilst reducing the financial burden generated by long-term conditions.

In the England, there are 15 million people with a long-term condition and it is during the last three years of life when most health and social care is consumed. The Department of Health has encouraged a number of initiatives over recent years to support people with long-term conditions beginning with the *National Service Framework for Long Term Conditions*, through to the *Supporting People with Long Term Conditions* policy document in 2005 and policy guidance on nursing role re-design (*Liberating the Talents*, 2005) and culminating with the white paper, *Our Health, our Care, our Say: a new direction for community services,* 2006.

The latter has three main objectives
1. Giving people more control of their own health and social care.
2. Enabling and supporting health, independence and wellbeing
3. Giving rapid and convenient access to high quality cost-effective care

The intention is to bring health and social care closer together to provide multi-disciplinary, multi-agency care with the emphasis on prevention of disease and bringing the care as close to people's homes as possible. The Director of Adult Services at the local authority and the Director of Public Health are given specific duties including the provision of an integrated plan within a Local Strategic Partnership. One expectation, is that all 15 million people with a long-term condition will have a care plan, if they want one, covering health and social needs by 2010.

The Paraeto Principle tells us that 20% of the 15 million people with long-term conditions require 80% of the care. So, we can expect three million people, or about

6% of the total population, to have complex needs requiring help from health, social care and the independent sector.

Within this context, the Do Once and Share complex conditions in later life work stream has developed a person centred care pathway, in which health and social care needs are supported by services orientated around the individual. The complex conditions pathway takes a population wide approach to create a dynamic and culturally competent system suitable for the UK in the twenty-first century (Royal College of Nursing., 1998). The foundation for this pathway is a multi-faceted systematic process of identifying need, holistic assessment and the delivery of a personalised care plan.

Overview of the Care Pathway

For the purposes of this Do Once and Share work stream, a person with complex needs is someone with at least one long-term medical condition together with significant social care needs. Their ability to carry out activities of daily living, or look after themselves, is reduced. The 'end of life' is meant to indicate the last three years of life, during which time people consume the most health and social care. This is true whether the person had a clear terminal illness or not. This document assumes that the last three years of life is more likely to occur after the age of sixty-five, whilst recognising that this is not always the case.

The pathway requires cultural change in health, social care and the independent sector. In order to deliver better care to people with complex conditions, practitioners, in whatever setting, need to anticipate problems, consider issues more holistically, recognise and respect the contributions from other professionals and agencies, whilst addressing the issue of care continuity. Cultural change is the biggest challenge to localities if they want to solve many of the problems inherent in complex conditions and, at the very least, entails health, social care and independent sectors working together in a more formal manner. The rewards gained from an approach such as this, are greater for both patient and professional, however it is important to recognise that a far greater chance of success exists when inter-agency co-operation is effective at both front line and executive board levels.
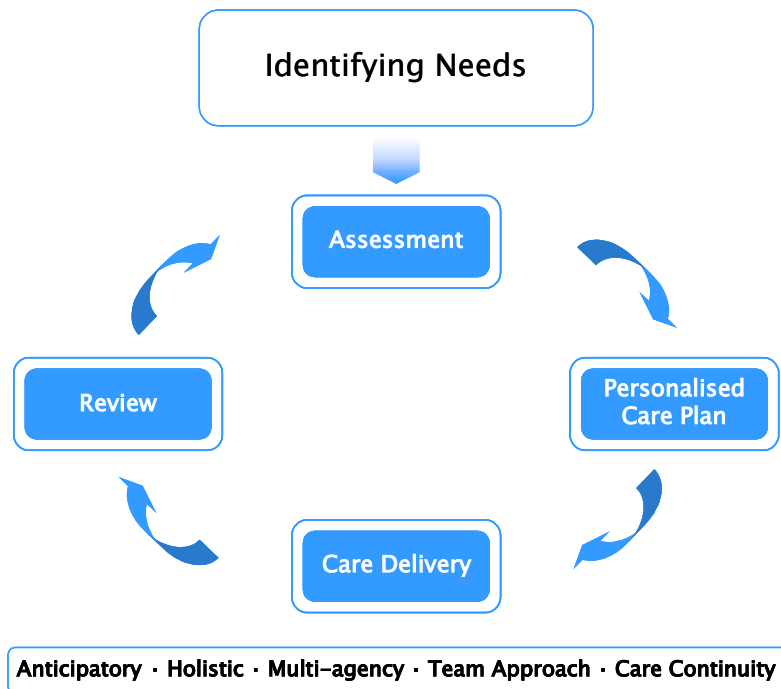
Figure 1 A Population Wide Approach to the Complex Conditions Care Pathway.
Lifestyle support and Screening feed into a cyclical care plan incorporating four distinct phases as shown by the blue boxes. At any point the pathway can be restarted due to default. This system can be applied beyond the remit of older people, providing personalised care to the population as a whole linking with current and future disease specific pathways.

Once an individual is identified as having a problem involving complex needs or is at-risk, they will enter a care plan pathway, which is cyclic in nature, consisting of four distinct phases (Fig 1). Phase one will involve a detailed assessment of the individuals needs and conditions, with a holistic approach addressing health and social needs through a single assessment process. Systematic application of standardised assessment tools would be an essential element of this pathway. The Single Assessment Process (SAP) or Care Assessment Framework (CAF) will help in this regard. A key factor to help determine the presence of complexity and encourage practitioners to consider problems outside of their immediate domain is functional ability. It would be particularly useful if there were a simple tool for screening for poor functional ability that could be applied during a disease management check in primary care, or by practitioners in other settings (See Appendix A). Information sharing between practitioners in different agencies is especially important at the assessment phase.

In phase two a mutually agreed personalised care plan is developed which details the level of input delivered for that individual (Kanitsaki., 1998). This can range, for example, from self-help to disease management to co-ordinated patient care with infinite combinations of support to meet the unique needs of an individual (*NSF for Older People.*, 2001). Disease specific pathways can be applied at this point (See Appendix A), bearing in mind that an individual with a number of different diseases needs a more supportive and coordinated approach to disease management. A care coordinator needs to be clearly identified. The care co-ordinator oversees the plan, perhaps delivering some of it, and ensures review takes place. General Practitioners are ideally suited to this role as they have generalist skills and are sent information from the full range of health and social care settings. However, others such as hospital specialists, nurse practitioners, care home team leaders, district nurses, health visitors and community matrons could fulfil the role.

A key worker is distinct from the care co-ordinator and is probably more important to the person receiving care. This role does not necessarily have to be a health professional; it could be the patient or carer, someone from the voluntary sector or other agency. Under normal circumstances, the key worker will be the practitioner or carer most involved in the person's care. The key worker has the most important role in delivery of care and is most likely to be in a position to know if all is going well or not. This role needs to be emphasised and properly valued. It is essential that the key worker participates both in development of the personalised plan and the subsequent review. It is quite possible that one individual could be both the care co-ordinator and the key worker but, nevertheless, the roles are distinct.

The personalised care plan needs to specify exactly who is responsible for implementing the different aspects of the plan and by when (*NSF for Older People*., 2001). Contingencies for deterioration, especially out-of-hours, can be detailed in the plan, underlying the fact that this process must anticipate future needs as well. Communication between agencies and the members of the public involved is vital at this point (*Our Health, our care, our say: a new direction for community services., 2006; NSF for Older People*., 2001). The care plan needs to be recorded in such a way

that it is accessible by all interested parties across all the different agencies in particular the out-of-hours services.

Care delivery of the agreed plan occurs in phase three with predetermined dates for review (phase four) established. Care delivery will stand or fall according to the quality of the services available in the community. Good infrastructure in terms of primary care, 24 hour district nursing, out-of-hours, home care, palliative care, intermediate care, care homes, voluntary sector, social services, community rehabilitation and other community care is essential and requires sufficient investment.

The care coordinator has the responsibility of ensuring reviews take place and following up with individuals should there be any slippage. Clear lines of communication need to be in place and relationships established with all care professionals and members of the public involved. The team is broader than a practice, health or social services team. At the review, all necessary checks are undertaken, with roles and responsibilities re-clarified. Assessment is repeated and the cycle begins again with individuals having increased or decreased inputs as required.

The philosophy behind the pathway is to be anticipatory, holistic and apply co-ordinated teamwork across agencies to deliver continuity of high quality care to a population.

Culture

Integrated Services

Health and social care need to work together with the independent sector in order to achieve and develop a more efficient care delivery package. The green paper *Every Child Matters* sets out a framework bringing together health and social care with education to improve outcomes for children. In fact, Section 3 'Integrated services and local change' is the perfect blueprint and supports the aims and objectives of the recent government white paper (*Our Health, our care, our say: a new direction for community services*, 2006).

]
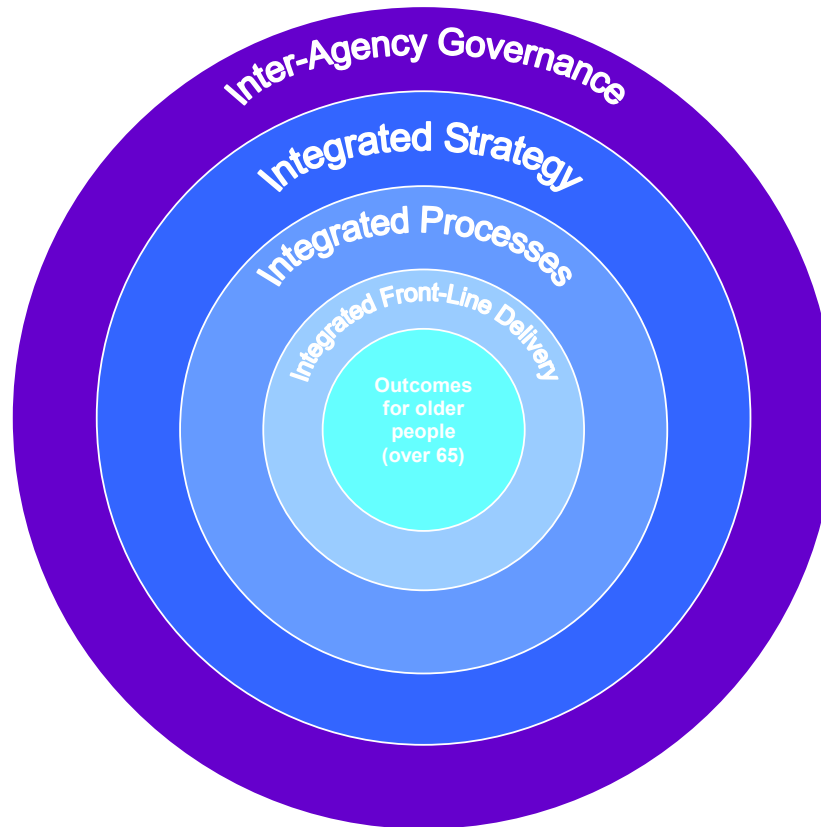
Figure 2 The Conditions Care Pathway in Action *(adapted from Green Paper – Every Child Matters: Change for Children, 2004)*.

It is true that people under the age of 65 present with complex needs, however the vast majority are older people. Social service teams and care homes are largely orientated to deliver care to this age group, making the over 65s an ideal starting point. The white paper exhorts Primary Care Trusts to work with councils, whilst calling for greater involvement with care homes, which are often marginalised within the care community. Care homes have tremendous potential to help with intermediate care and respite. The voluntary sector's potential contribution is also often overlooked. Sometimes, it is the apparently smallest thing, such as Age Concern's befriending service, that makes a huge difference to people's lives.

An 'Older Peoples Trust'

Children's trust arrangements have four essential components, which can be adapted for older people as follows:

- Professionals enabled and encouraged to work together in more integrated front-line services, built around the needs of *older people*;
- Common processes which are designed to create and underpin joint working;
- A planning and commissioning framework which brings together agencies' planning, supported as appropriate by the pooling of resources, and ensures key priorities are identified and addressed; and
- Strong inter-agency governance arrangements, in which shared ownership is coupled with clear accountability.

However, governance arrangements will need to be adapted in order to accommodate the autonomy of older people, and facilitate their right to choose in cases that refuse treatment and care.

The inception of an 'Older People's Trust' could oversee personalised, high quality and integrated universal services, whilst successfully targeting specialist services through a skilled and effective workforce. This approach would be supported through the common assessment framework, local leadership development, needs analysis and information sharing together with strategic planning, joint commissioning and budget pooling. This framework would provide staff with the knowledge and support to work collectively to find flexible solutions to the needs individuals. In the same way that Care Homes need to be built in to the pathway, so do GPs and primary health care teams – both operate as 'independent' small businesses and as such present a similar challenge. GPs and their practice staff are part of the NHS and this should make the pathway development easier to achieve.

The key requirements for such an arrangement to work are:

- Practitioners recognising that they are part of a wider team than just their immediate sphere,
- Practitioners thinking about the person's problems in a wider context,

- Bringing together the different sectors and agencies to work on specific areas in order to work more closely as one care delivery team
- Joint training on issues such as service redesign, care pathways, the use of IT and SAP.

Medicines Management Care Plan

It is thought that a medicines management care plan should form an integral part of personalised care plans (Seal, R., 2006), which currently is often not the case. This would be beneficial as the prevailing consensus amongst community matrons suggests that they have little knowledge or experience of medicines management outside of their own area of clinical practice, (Seal, R., 2006). Achieving this will be very difficult, for example, to commission a care package without access to specialist pharmaceutical expertise. Additionally, a synergistic relationship between hospital and primary care-based pharmacists could improve communication across the interface between primary and secondary care, helping to avoid many of the medicines-related problems experienced by patients.

Role of Health Professionals

Care staff working in the community, (ie. specialist nurses, health visitors, district nurses, practice nurses and social workers), often have informal joint working arrangements to support better delivery of an individual's treatment and care plan. A major drawback to this approach is the lack of formal recognition within the parent organisations employing such staff, in addition to transient organisational changes and financial constraints. As a result, these arrangements frequently break down, and opportunities for cross-organisational development are lost, despite recent guidance designed to develop greater integration of local authority and NHS bodies (DH 2002 - janet). Unfortunately, unforeseen legal and financial obstacles have impeded uptake of these organisational structures, however the government white paper aims to address these issues (Our Health, our care, our say: a new direction for community services., 2006).

Leadership

The model requires leadership at every level, most especially at the top of the organisational structure. In support of this, joint appointments have been highlighted as a key element in the process of bringing PCT and council organisations closer together (Our Health, our care, our say: a new direction for community services., 2006). The practitioners from each of the agencies should develop together and train as a single team in order to drive a unified approach in terms of the pathway, the use and development of tools, communication and the IT.

NHS End of Life Care Programme

The End Of Life programme is an ideal starting point for care homes to become more integrated with health providers. It is meant to apply to individuals who are not expected to live more than a year supported by a variety of tools (the Gold Standard Framework, Liverpool Care Pathway and the Preferred Place of Care tool). Statistics show that during the last three years of life that a person consumes most health and social care. The average length of stay in a residential home from entry to death is 28 months and 16 months for a nursing home.

Preferred Place of Care

Preferred Place of Care (PPC) is a tool to determine and record patient and carers' wishes in relation to their care and ultimate place of death (Meehan H., 2006; Cancer Network., 2006). Since life expectancy on entry to a care home is short, it would be entirely appropriate to apply PPC on entry. The care home staff would need training on the application of the tool along with health and social practitioners in the locality. It enables people to express their desires in a calm, rational manner well before crises develop and, most importantly, records them which can be reviewed and changed. The explicit recording of patients/carers wishes can form the basis of care planning in multi-disciplinary teams and other services, minimising inappropriate admissions and interventions. When health deteriorates every individual concerned, (relatives, care home staff, health and social practitioners etc), are clear as to what needs to be done. It should result in fewer drastic, emergency interventions in frail people at the end of life, which is too often the default action at present.

Intermediate Care

An ideal area for joint commissioning and pooling of budgets is Intermediate Care. Intermediate Care is a particularly thorny issue as the money does not necessarily follow the patient in the current system. Costs could be saved by the NHS on hospital beds, which then have to be paid for by the local authority or the patient themselves in the community. Only by bringing together all parties locally can this problem be solved which must include the hospital staff, the local authority, the care homes, the voluntary sector, the patients and primary and community care. The best examples involve local clinical leadership, especially hospital physicians working with community colleagues, social services and care homes to organise a community based service with criteria allowing step-out from the hospital and step-in from the community and extra support in the community so that people are more able to stay in their own homes.

Practice Based Commissioning

Long-term conditions should be high on the agenda for practice based commissioning as acute admissions account for such a high proportion of the total budget. The commissioners need to be imaginative and experimental in their approach if they are going to make an impact. Those with complex needs are especially important and the concept of a care trust should help clarify their thinking. However, the whole of this Do Once and Share pathway and implementation guide should be useful for them.

POTENTIAL ROLE OF PHARMACISTS

The potential role of pharmacists in the management of complex conditions is often not recognised. There are two dimensions to primary care pharmacy, community and practice-attached pharmacists.

Community pharmacists working in high street shops are traditionally more involved with the supply of medicines and support for self-care through the medicines that they can sell over-the-counter. However, under the new pharmacy contractual framework, their clinical role is being significantly expanded through, for example, medicines use review services and prescription interventions. They are well placed to contribute to the assessment of patient needs as they often have more contact with the patient or carer than other professionals. The majority of pharmacists also provide services to care homes although it is thought that opportunities to improve patient care are often overlooked at these establishments (Seal, R., 2006).

Community pharmacists can certainly contribute significantly to the single assessment process however the frequency of their involvement at this time is unknown. Inconsistency in this area forms one of the major stumbling blocks for making better use of their skills and knowledge, with pharmacists often being overlooked when describing the primary care team.

Practice-attached pharmacists (often funded by the PCT) provide services both to General Practice and patients. They benefit from access to patient clinical care records (an advantage over community pharmacists), with many providing direct services to patients, for example, anticoagulation surgeries, chronic disease management clinics and medication review. However, not every practice has a pharmacist, thus the services provided are patchy. Again, many are involved in service delivery to care homes, whilst an increasing number are involved in targeting people at risk of hospital admission due to medicines-related problems. Clearly, where this is the case, the care co-ordinator should not only be aware of this role but should also be routinely involving them in care planning (see Scenario 2).

GOOD PRACTICE EXAMPLE 1 – *Unique Care*

Ms. Ruth Adams – *Unique Care Development Advisor*
Brent

Brent has an older population of 30,237 of which 12,572 are over 75 (2001 Census). It is the most ethnically diverse multi-cultural borough in Europe and has high levels of social deprivation. With increasing demands on services, it is often necessary to prioritise resources to ensure equity of care. Following a period of service mapping a gap in proactive preventative care to this client group was identified.

To address this, the Care Co-ordination Service (CCS) was piloted as part of the London Older People's Service Development Programme (LOPSDP) that started in October 2001. Initially piloted for 6 months, the service successfully facilitated effective joint working and cohesive patient care across services for older people. As a result, reductions in the number of avoidable admissions to hospital and length of stay were found alongside a significant improvement in older people's perception of the services they received.

The service is now mainstream throughout Brent and consists of 5 Care Co-ordinators (1 per locality) who provide case management to vulnerable older people in the community from a central base. This includes those that are experiencing multiple crises, those failing to attend screening or out patients appointments, those who have undergone a life changing event and those about whom any member of staff or the community has concerns. Posts are open to any profession and the team currently have backgrounds in Social Care and Nursing.

Working across traditional boundaries, the team sits between Brent Teaching PCT, Brent Social Services, North West London Hospitals Trust (NWLH Trust) and the Voluntary Sector and works as part of the Intermediate Care Service. Line management is provided by the PCT and the inter-agency Advisory Group lead on service and professional development. The team begins each new referral with a thorough assessment (NW London Contact & FACE Overview) of individual need. Placing the older person at the centre of their care, client goals are used to drive the case management process.

This involves acting as a single point of reference to co-ordinate input from all services, ensuring that everyone is working towards the same goal. Central to the success of this approach is ensuring the right help is received in the right place, at the right time. Empowering the client to make informed decisions about their care through health education and improving access to a wider range of options available in the local community also helps to promote independence.

GOOD PRACTICE EXAMPLE 2 – *Intermediate Care*

Dr. Mike Cheshire – *Consultant Physician*
Central Manchester

Within one year, the Central Manchester service has developed from a small service with low throughput to a vibrant and effective alternative to hospital with a focus on supporting the patient in their own home. It consists of 12 nursing beds, 30 non nursing residential beds, 30 rehabilitation places in the patients own home and 14 Active Case Managers (ACMs).

Two years ago the PFI development in Central Manchester Hospitals Trust resulted in a plan to close 52 rehabilitation beds, predominantly for the elderly. The intermediate care service was required to re-provide that service out of hospital. We decided to focus on supporting the patient in their own home. We used a point prevalence survey of the use of rehabilitation beds to give some indication of the numbers of home places, nursing and non-nursing beds that would be needed. The pace of change was fast and the timescale for PFI enabling work meant that we were unable to double run the service. We shut the hospital beds and at the same time opened Intermediate care facilities.

The project was jointly run by the Central Mcr & Mcr Childrens Univ Hosp NHS Trust, Social Services and the Central Manchester PCT, who were the leaders of the project. One consultant, Mike Cheshire, switched 3 sessions from hospital to the PCT in order to become the clinical head of intermediate care services and to act as an interface between the hospital and the PCT. Central Manchester PCT and Social Services invested substantial money into a very expanded home care and rehabilitation service and the PCT also invested heavily in Active Case Managers.

The nursing and non nursing beds are owned by two different providers in the independent sector. Rehabilitation staff, nurses, therapists and rehabilitation assistants are employed by the PCT and in-reach into both services. Two GPSIs, a clinical assistant and a consultant physician provide the medical input. The whole service is managed by the PCT with service level agreements with the independent providers.

Access to the service is by an assessment team in the hospital or by senior members of the intermediate care team in the community. There is some step up from the community but the main emphasis is step down from the hospital.

The target for throughput in the first 6 months was 12 patients a week and that has already been achieved. We anticipate that in the mature service excluding ACMs that we will be accepting and returning about 20 patients a week to their own homes. The ACMs are primarily aimed at improving the management of chronic disease in our most vulnerable and frequent users of the hospital and GP services. We anticipate that we will save the equivalent of between 5 and 15 beds in one calendar year and improve the quality of patient care substantially.

The model of care is social not medical, and it has been illuminating to see how the role of the doctor has reduced compared to hospital, without detriment and with some substantial benefits. All patients have a named key worker who agrees a predicted discharge date with the patient at the first assessment. In the residential beds, patients are encouraged to get dressed in the morning and help themselves to breakfast as they would at home. This was difficult to implement but has meant that from the onset most patients understand that rehabilitation is about maximising their independence from the first day. This is an important part of the patient day and in many respects has been instrumental in shaping the patient orientated aspirations of the service.

Our biggest challenge now is to improve the quality and quantity of the service and effectively measure it. Hospital targets are relatively easy to see and to measure, the community service more difficult, and there is no agreed national data set. We are devising a mixture of throughput, quality and capacity measures which will demonstrate effectiveness, efficiency and quality of care.

GOOD PRACTICE EXAMPLE 3 – *Virtual Wards*

Dr Geraint Lewis – *Specialist Registrar*
Croydon Primary Care Trust

Croydon PCT is developing new way of providing targeted community care to those of its patients with the most complex medical and social needs. It is establishing a network of ten *'Virtual Wards'*, the key aims of which are to:

- Act on **evidence-based forecasts** from predictive risk modelling;
- Provide **multidisciplinary case management**;
- Serve as a **communications hub** for all those involved in the care for these patients;
- Offer **intuitive working systems** that appeal to patients and clinicians alike.

Groups of fifteen GPs will be offered the opportunity to commission a *virtual ward*, i.e. one ward per 30,000 or so residents. These mimic the working patterns of a hospital ward - but care for patients in their own homes. Each *virtual ward* has a capacity of 100 *"beds"*. When one of these becomes vacant then a predictive algorithm (such as the King's Fund PARR Algorithm) is used to identify which of the 30,000 residents is at highest risk of unplanned hospital admission. This resident is then offered a *"bed"* on the virtual ward.

Ward Staff

- The day-to-day clinical work of the ward is lead by a community matron. Other staff include a social worker, health visitor, pharmacist, community nurses and other allied health professionals.
- A key member of staff is the ward administrator *("ward clerk")*. With a dedicated telephone number and email address, the ward administrator is able to collect and disseminate information between patients, their carers, GP practice staff, *virtual ward* staff, and hospital staff.
- Medical input is comes from daily telephone contact between the community matron and the duty doctor at each constituent GP practice. The matron is also able to book surgery appointments to see any patient's usual GP.
- The *virtual ward* will develop close working relationships with organisations such as hospices, drug & alcohol service and voluntary sector agencies.

At the time of admission to the virtual ward, the community matron visits the patient at home and conducts an initial assessment. This record, and all further entries by ward staff, is entered into a shared set of electronic notes. A summary from the GP computer system is pasted into these ward notes before the initial assessment, so as to provide background information and avoid unnecessary duplication of work. The GP practice is informed of all significant changes to the patient's management.

Members of the *virtual ward* staff hold an office-based ward round each working day. Patients are discussed at different frequencies depending on their circumstances and stability. Of the 100 patients on each ward, five patients are discussed daily, 35 are discussed weekly, with the remaining 60 patients discussed monthly. The community matron can move patients between these different intensity "beds" according to changes in their clinical conditions.

Every night an automatic email containing a list of each virtual ward's current patients is sent automatically to local hospitals, NHS Direct and GP out-of-hours cooperatives. This information is uploaded onto these organisations' clinical computer systems. Should a virtual ward patient present to their services (e.g. to a local A&E department) then the staff working there will be alerted automatically to the patient's status. They then know that by contacting the virtual ward administrator, they can obtain up-to-date details of the patient's care. They can also arrange early discharge back to the care of the virtual ward team.

When a patient has been assessed by all relevant virtual ward staff, and has been cared for uneventfully for several months in the "monthly review" section of the ward, then the ward staff may feel that the patient is ready to be discharged back to the care of the GP practice. A discharge summary is sent to the practice, and a discharge letter (using lay terminology) is sent to the patient. For the first two years following discharge, the GP practice conducts quarterly - rather than annual -reviews. This not only ensures that the patient is borne in mind, but these quarterly review data are serve as positive feedback to the predictive risk modelling algorithm.

Complex Conditions Pathway – *Identifying Need*

Currently, provision for health and social care is undergoing a transition to a more proactive approach that will ensure optimal service delivery to patients. Systematically identifying need will be at the heart of the new system, thus it is essential that this aspect be delivered across the whole population. Population wide screening should employ both a predictive risk model, (using data available from a variety of sources), and an opportunistic approach. The latter can be undertaken, for example, through systematic clinical screening programmes, contact with services and patient request. Such a screening process can assist diagnosis of long-term conditions impacting on patient health, reduce the load on NHS services caused by unscheduled usage and provide accurate data regarding long-term, complex conditions within a given population or the national population as a whole.

To date, no evidence-based tools currently exist to identify such individuals in the community. However, studies have been undertaken to address this knowledge gap. A number of techniques can be employed to identify individuals including threshold modelling, clinical knowledge application and predictive modelling.

The King's Fund has done a literature review on long term conditions (www.kingsfund.org.uk) and it found:

- The people with the most complex conditions change from year to year
- Clinicians cannot predict who these people be accurately
- Threshold modelling cannot predict them accurately
- Predictive risk modelling can make accurate predictions.

This pathway demands a combination of these approaches as no single technique can identify all targets within a population. Particular consideration applies to housebound people over the age of 65 presenting four or more complex conditions including COPD, heart failure, stroke, mental illness, which are all conditions that are the subject of other DOaS work streams (See Appendix A). Due to the broad range of conditions known to be present in this population, a high degree of interaction with disease specific care pathways will be essential.

Practical examples of tools used to identify high risk patients to date include the following:

- **Patients At Risk of Re-hospitalisation (PARR) case finding tool**

    This has been developed with the King's Fund. It employs hospital data available for patients who have been admitted at least once in the previous 12 months. The tool is applied by data analysts to predict which patients are most likely to experience a readmission using datasets already available to health economies. As an evolving project it continues to be developed and is consequently using Primary Care data to incorporate individuals who have required hospitalisation.

- **Emergency Admission Risk Likelihood Index (EARLI)**

    EARLI has not yet been accepted for publication. It is a simple six item questionnaire, which can be self-completed or used during a consultation. As such it can be posted to all the older people or applied when people attend for their regular checkups for their long-term conditions.

- **Functional Ability Screening**

    Both of these tools have their pros and cons, neither present a perfect solution for the purposes of identifying all people with complex needs at high risk. Functional ability is key to deciding who has complex needs. Regardless of the presence of particular diseases, if someone is unable to care for themselves without help, then they are likely to have complex needs and require a full assessment.

Further research is required increase the number of screening tools available in order to ensure those at risk in the UK have access to the highest standards of health care. Continued development of the examples mentioned above along with the inception of new tools should employ a systematic approach to identifying risk factors, ensuring that future health trends in older people can be accommodated.

Additionally, systematic input should be provided for high-risk patients in terms of lifestyle support, were the benefits of a healthy lifestyle can be highlighted whilst

ensuring important information and guidance are at the patient's disposal. Health promotion in older people can assist individuals on a day-to-day basis, for example, with keeping active and ensuring correct nutritional needs are met. Furthermore, long-term falls prevention advice and support can be provided in a practical user-friendly manner, whilst seasonal issues such as Flu vaccinations can be further highlighted.

Complex Conditions Pathway – *Assessment*

All practitioners currently carry out some sort of assessment and devise a plan with every professional contact with a member of the public. However, their approach tends to be narrowly focused on their area of expertise. A holistic approach to assessment requires practitioners to regard themselves as a contributor to a complete care cycle, thus being aware of all other inputs.

Once a problem occurs or screening identifies an individual for assessment, the process must be holistic addressing health and social needs. This process is designed to stratify the risk relating to a specific individual, in terms of the likelihood of their requiring hospitalisation. The Single Assessment Process (SAP) is beginning to develop a standardised approach to assessment, though delivery of this system requires significant support from all relevant organisations, the number of which will vary depending upon the individual. Disease specific pathways that relate to a persons screening profile should be applied at this point, and information technology must be in place across all parties (NHS, care home, social services) to maintain and develop an accurate and reliable patient assessment and record system.

Joint working between agencies and sectors is essential for this assessment to work properly. At the least, health and social care need to help each other in assessing people identified as having complex needs.

Clinicians are quite good at grading severity in specific diseases. For example, a spirometry test can determine if a person has mild, moderate or severe Chronic Obstructive Pulmonary Disease (COPD). However, having a mild grading for a

number of different diseases often constitutes a significant problem. If clinicians, and practitioners in other settings, routinely considered functional ability, (using a short, simple, standardised scoring tool), it would help to identify at risk people requiring full assessment. Such an approach would encourage an anticipatory, holistic patient centred framework, and stimulate further development of multi-agency interaction. Such a tool could be promoted via the Quality and Outcome Framework (QOF) in the new primary care contract. No such tool currently covers all these requirements perfectly, however a shortened version of the Barthel Index comes closest (Mahoney & Barthel., 1965; Yohannes et al., 1998). Practice nurses would have a crucial role in applying the latter, as they are often the practitioners who carry out the regular checkups called for in the primary care contract. To support this approach the Department of Work and Pensions (DWP) could adopt the same criteria, (for example the full Barthel Index), for the Disability Living Allowance (DLA). Primary care practitioners would then be clearer as to the expectations of the DWP and could use the codes already available for DLA on primary care systems to signify a lower functional ability.

Further research is required to validate such an approach with a short version of functional ability assessment for clinicians to use opportunistically in clinics and surgeries, a more comprehensive version for use during SAP and the most comprehensive for use during DWP assessments.

Complex Conditions Pathway – *Personalised Care Plan*

The development of a personalised care plan has to be flexible and unique to the needs and circumstances of a given individual. When applied across a population a risk stratification process will indicate the level of support required by patients to manage their care plan. A care coordinator should be clearly identified for people with complex conditions to oversee the plan and the importance of the key worker emphasised.

The personalised care plan should be explicit in describing those responsible for specific elements with realistic time frame agreed for care delivery. This will provide

infinite combinations of support from self care right through to complex packages of care from health and social services and other agencies. Contingencies must be made in case of exacerbation of a current condition or the development of a new one. The contingency plan is more likely to involve out of hours services and therefore making the plan available to the other partners, such as NHS Direct, the ambulance services and A&E departments, is essential.
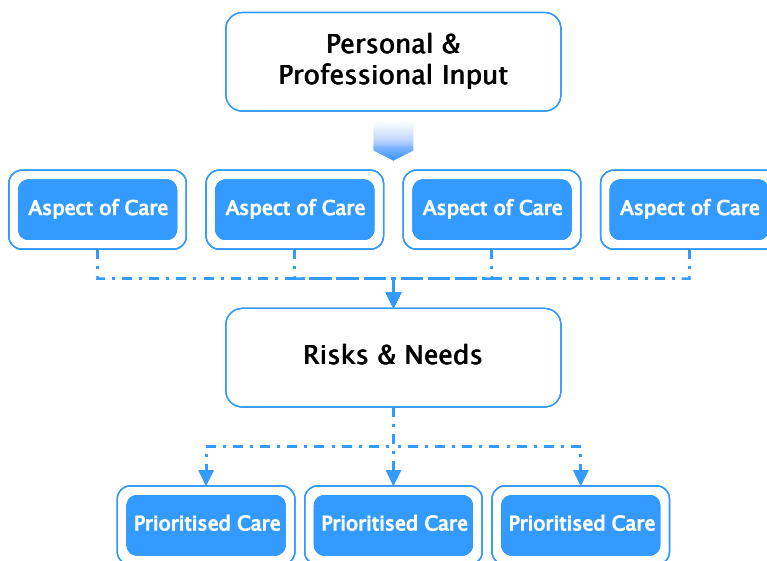
Figure 2 Development of a Personalised Care Plan. – adapted from Good Care Planning for People with Long Term Conditions (2005) *NHS Modernisation Agency*

The fundamental principle of this care plan is the patient setting specific goals with their care coordinator and key worker (Fig 2). Thus, any subsequent document should possess both personal and professional priorities allowing for truly unique health and social care provision around a given individual. Through this, different aspects of clinical, social and emotional care can be elicited, and weighted according to priority. Consequently, a complete picture of patient need is created from the ground up, highlighting the organisations and individuals responsible for providing different elements of care, and prioritising their input. Each practitioner, most notably the care co-ordinator, need to acknowledge that the plan needs to be developed as a team involving professionals from different settings, volunteers and the person and their carers themselves. An agreed date for review will be arranged at this point and the plan recorded in a manner easily accessible by all relevant parties.

Complex Conditions Pathway – *Care Delivery*

It is in this phase of the pathway, that the key worker, the patient and the carer come to the fore. Nevertheless, there needs to be robust structures in place to support all people with long-term conditions not just those with complex needs. Good quality community based services from health, social services and the independent sector are essential and yet are often overlooked. For example, practice nurses have a wealth of experience, knowledge and skill when it comes to supporting people with long-term conditions, yet are often forgotten when Primary Care Trusts set up their strategic groups to drive service changes in long-term conditions. Care homes are too often provided with a woeful lack of information when they accept people into their institutions, both by hospitals and general practice. Sometimes, the information is as basic as a relevant medical history including details on allergies, and is with-held on the grounds of patient confidentiality. Hospital staff, including nurses and doctors are also important players in care delivery.

There is very little research into which elements make the greatest difference. The feeling of the groups, our DOaS team contacted, is that like stroke rehabilitation, we know that it works but we are unable to say which element makes the difference. It is the team as a whole that makes the difference. It is crucial to bear this in mind during this phase and to ensure good communication between everybody involved in a person's care. IT can help significantly at this point.

Demand for streamlined IT employing a single electronic care record, between various agencies capable of adapting to new screening and record keeping tools as and when they become available will be essential. Patient records maintained on a single database incorporating all levels of care (primary, secondary, acute and social care) along with information for other agencies such as social services and care homes will facilitate this. Additionally, the user interface should be identical for all parties, providing a user-friendly coding system for both medical and non-medical conditions. The single electronic patient record is some years away yet; let alone a single electronic care record. In the meantime, there are simple things that could be implemented now.

The technology is already available to provide an interface that allows practitioners in different settings to view each other's records and notes, eg. Graphnet. Practitioners have access at a variety of levels according to their password and they leave a 'footprint' so an audit trail can easily identify anyone attempting to abuse the system. At the very least, all practitioners should have access to the Contact Assessment, the Personalised Care Plan and the contact details of the other practitioners involved. The contact details on a drop-down menu of the care co-ordinator, the key worker, the GP, the social worker, the lead nurse, the carer, the hospital consultant and so on would be extremely useful and could be easily updated at every review. If NHS Direct, ambulance services, district nurse teams, A&E departments and out-of-hours doctors had access to the Care Plan including the Preferred Place of Care, they would be able to make more appropriate decisions when faced with urgent problems.

The layout of current systems could easily be adjusted so that there is an 'at a glance' drop down menu of all the practitioners involved and their contact details. The care plan should have a page or template of its own, along with a contact assessment for SAP.

The main obstacle to using such an interface is often the issue of patient confidentiality, which, under certain circumstances can enhance patient risk. For example, care homes are often vulnerable, with the NHS reluctant to share relevant medical history with the professional staff at the home. The lack of medical information provided to care homes on admission from hospital and the community is alarming, with basic details such as Penicillin allergy absent from patient notes. The benefits of this sort of system are huge and would, undoubtedly have the support of the public and a role based access system (passwords) ensures patient confidentiality.

It is legal to share information for the purposes of 'healthcare', but this term is too loose. Does healthcare include the nurse in a private care home, the social worker who runs a home care service or the volunteer in the role of key worker? In addition, the demands of Clinical Governance and Caldicott tend to encourage clinicians to be risk averse when it comes to sharing information, especially with professionals outside of the NHS. The DoH recommend that it is good practice to gain consent from patients

before sharing information and the logistics of carrying out this huge task is a further disincentive.

National leadership is necessary to overcome this obstacle. If the DoH, the clinical leaders, such as the BMA and the GPC, and the social work leaders were convinced of the benefits and the safety of an interface system, they could encourage practitioners, particularly GPs to participate. The issue of consent needs clearer guidance or instruction from the centre. The single electronic record will require such leadership in any case.

Complex Conditions Pathway – *Care Delivery*
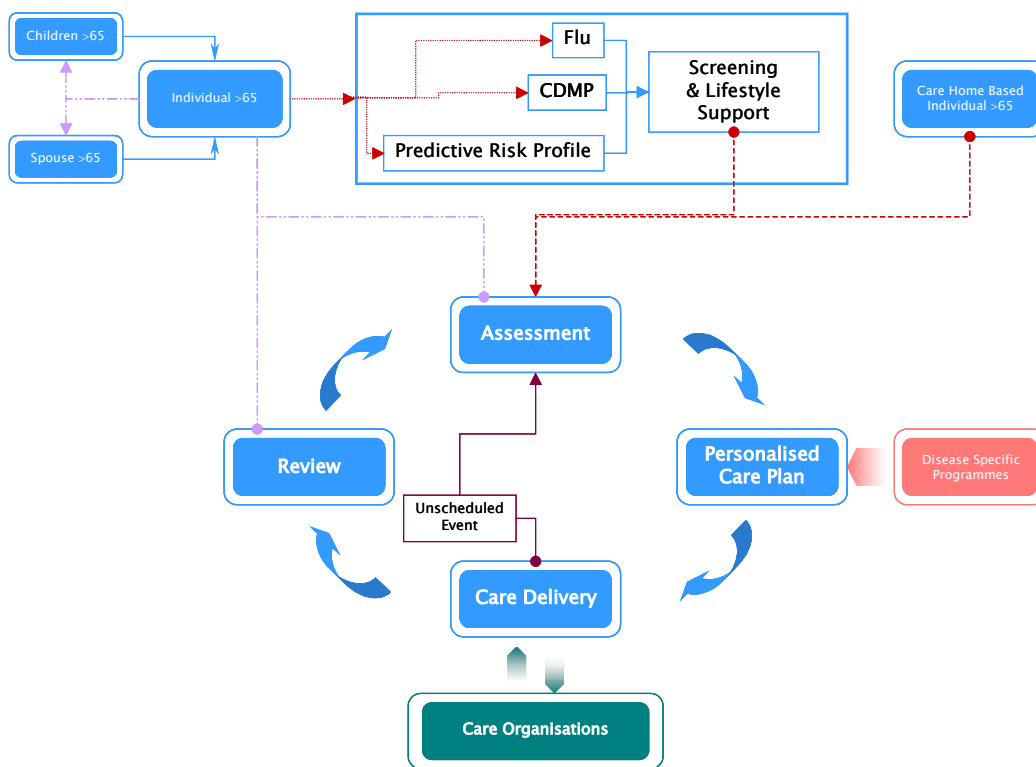
Complex Conditions Pathway – *Review*

At review, the practitioners and all those involved are effectively held to account. Usually one person, the care coordinator, can carry out the review if all the other practitioners' interventions are logged on an electronic record. However, in the case of people with complex needs, it may be necessary for a number of different practitioners to meet with the patient to carry out a review. At the very least, the key worker needs to be involved.

The review period can be initiated through the pre-arranged timetable agreed in the personalised plan, or as a result of a need for reassessment such as new diagnosis, use of unscheduled care, a significant life event (family bereavement, moving home and a carer falling sick etc) or patient request. At this stage the individual can be reassessed and the level of care input altered to suit new circumstances. The review phase forms a key element of the pathways flexibility, providing a monitoring system for coordination and an opportunity for patient feedback. Only specific aspects of the

assessment will be addressed here as a result of issues highlighted by the individual, care professionals and organisations.

Complex Conditions Pathway – *Resources, Training & Development*

The implementation of such a comprehensive screening system will inevitably have a direct impact on primary care resources in terms of time and manpower. No evidence exists that would indicate particular staff are better suited to undertaking the screening process, and all staff involved would need suitable training in the following areas:

- IT literacy for specific screening tools
- Information handling
- Patient confidentiality
- Multi-agency information sharing

Furthermore, it will be essential for screening staff to identify those best placed to undertake the assessment process, based upon the available information for a given individual. A staff support or buddy system would be an important aspect of this role.

The care community needs to work collectively more often especially with respect to training and development. Current research does not indicate that one professional is better suited to assessing an individual over another, thus the assessor should be identified on a case-by-case basis from a pool of suitably trained candidates with a variety of professional backgrounds.

Specific training requirements will vary depending upon professional knowledge. For instance, skill gaps are known to exist around mental health amongst clinical staff who would need enhanced knowledge of social care. Similarly, social workers would require reasonable clinical knowledge. However, expert support of care coordinators should be made available through the buddy system mentioned above.

In terms of specific resource issues, research has shown that care coordinators are most effective when they complement staffing levels rather than redeploying existing roles. Such a philosophy has significant logistical implications for this system, and

will present a challenge to current staffing regime. However, the critical success factors have been shown to focus on effective systems of communication and monitoring, coupled with a positive organisational culture and realistic workloads.

The individuals identified as the care coordinator or the key worker will depend upon the patient rather than specific professional background, and the range of people available to undertake these roles is considerable when voluntary and independent sectors are considered along with patients, carers and relatives.

Gaining the consent of the patient for care delivery is essential as is the involvement of the patient's significant others. Where the patient has capacity issues then the principal worker should seek further advice and support from appropriate professional and legal sources. Training should be provided for principal workers in the legal aspects of consent and capacity where this is an issue. Such training should take into account the implementation of the Mental Capacity Act (2005) and relevant guidance. Such a responsibility would need to be supported by adequate training. Current NHS training platforms could be employed in this regard.

This role also requires a good grounding in the organisational structures employed by relevant parties. Consistent levels of knowledge should be supported and developed through regular training and updates regarding organisational reform. All aspects of this role must be further supported by the buddy system previously mentioned.

Scenarios

Two scenarios have been developed to illustrate how the pathway for complex conditions in later life should be applied. Later life is defined for the purpose of the scenarios as over 65.

Scenario One -   *A person who is in later life, living at home with complex health and social needs. Their main carer also has complex health and social needs in later life.*

This scenario is often apparent in the community; a husband and wife often present this scenario, similarly many older people have children, themselves who are over 65. The pathway could be demonstrated through this scenario as follows.

■   Screening

There is much potential for screening the population to identify the individuals for scenario one:

- Predictive risk profiling
- Chronic disease management programmes in primary care
- Functional Ability Screening
- Public Health Campaigns – Flu Vaccination

At any of these points the complexity of need could be identified along with the need for further assessment of the whole situation.

■   Assessment

Following on from screening, the single assessment process should be instigated. In this scenario both of the people involved, patient and carer should have a holistic assessment as they each have complex health and social care needs.

■   Personalised Care Plans

Individuals will work, with support, on the development of their personalised care plan. For the carer their role of carer and its implications should be taken into account. It is essential that contingency plans for this scenario reflect the importance of the carer's role and responsibilities.

■ Care delivery

This phase can be the most difficult to manage. Due to the intrinsic nature of the patient and carers needs this element has to be carefully managed so that the plan does not detrimentally affect the balance in this relationship.

It is essential that the individuals on the pathway drive the rate and range of the delivery of their own care plan.

■ Evaluation and Review

The plan and its delivery should be evaluated every day, by the individuals, to ensure that it is meeting their identified needs.

Review and reassessment date should be agreed with the flexibility to respond to changes in condition or circumstance.

Scenario Two - *A person who lives in a care home and has complex health and social care needs in later life.*

In many ways this scenario is easier to describe, as many of the screening tools need not be applied in order to identify this person. By virtue of the fact that they have entered a care facility should begin the pathway for them. All other elements of the pathway are implemented as with scenario 1. The main difference is that their home is a registered care facility and their main carer is appointed to them with care home staff taking this formal role.

The pathway should be as thorough and holistic as with scenario 1. In many ways the setting can provide an ideal opportunity for the main principles to be applied. As a key variable – environment – is constant in this scenario and this gives a good foundation for the rest of the process to progress. Care plans that are anticipatory in nature can be applied by trained staff who should be engaged within the local health economy to access the relevant services.

EXAMPLE 1 - *Living at Home*

NAME(s)   -   George and Margaret Brown
AGE   -   76 and 72 respectively
STATUS   -   Married

George and Margaret Brown receive their invitation for the flu vaccination from their GP. Along with their invitation letter is a simple questionnaire for them to complete and bring along with them. The questionnaire is very easy to fill in and consists of six questions.

When they attend the local community centre for the flu clinic they are also invited to have their blood pressure, weight and smoking status checked. George takes advantage of this offer as he hasn't been able to get to see his practice nurse for his regular check due to his concerns about leaving Margaret for any length of time at home alone. He tells the health care assistant this and she suggests that George would probably benefit from a more in-depth discussion about their needs in a more suitable setting – i.e. at home. She tells George and Margaret about the role of one of the nurses at the practice and obtains consent for referral onto this nurse.

———   –   ———

Later that week George receives a phone call from the nurse who arranges a convenient time to call. During her visit the nurse discovers that both George and Margaret have distinct health care needs and also require significant social care support. Using the Single Assessment Process she begins to build a comprehensive assessment of the Browns' needs. This takes several visits from both the nurse and other relevant professionals.
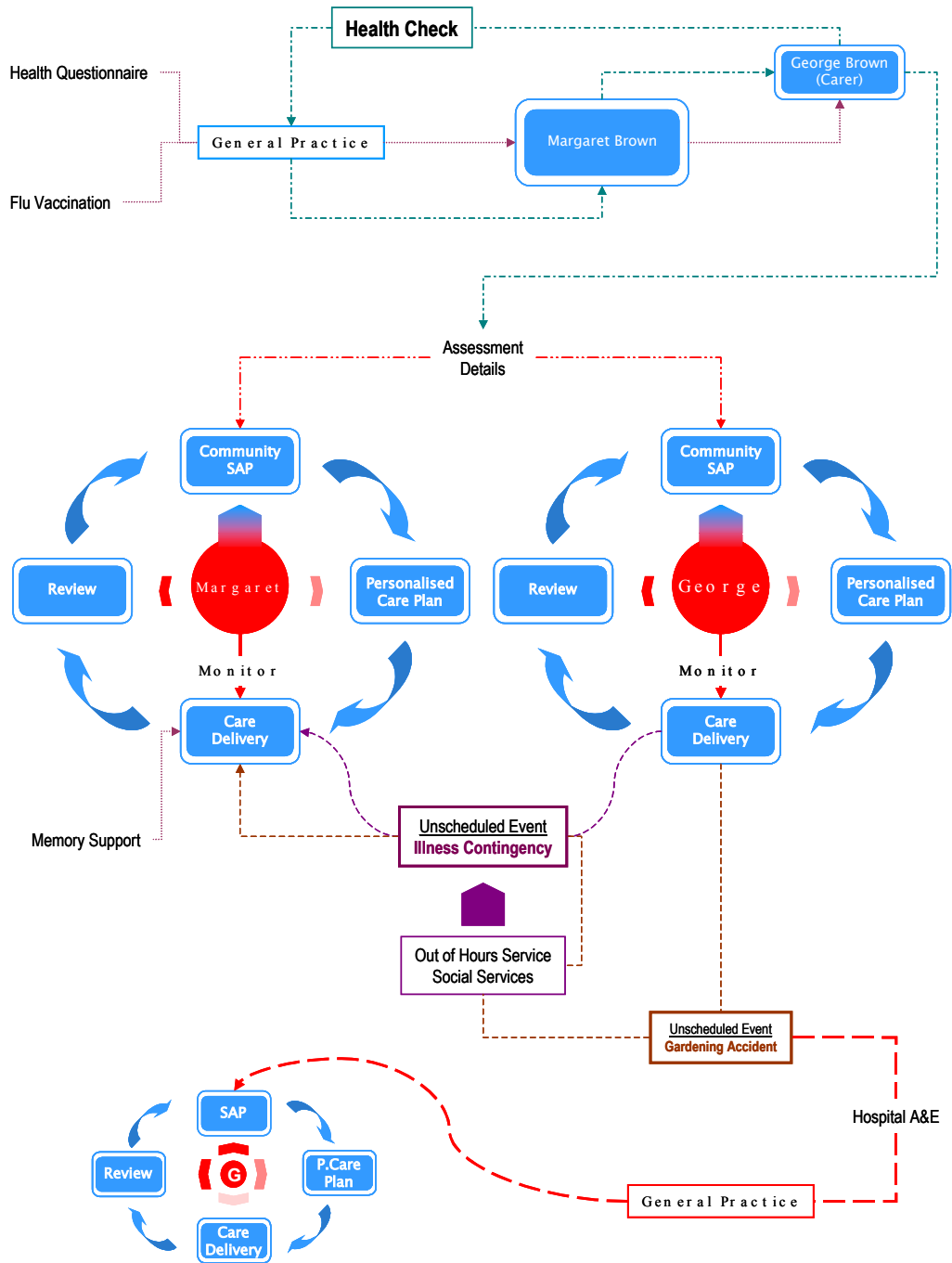
George and Margaret are encouraged to find that they are at the centre of all decision making – Margaret dislikes too many strangers coming into her home and so the assessment process takes place at a pace and setting that she finds comfortable. Before the assessment phase is fully complete several medication issues come to light. These are dealt with immediately to prevent any further problems.

———   –   ———

With the completion of assessment George and Margaret have the opportunity to discuss their own care plans. For George these also include contingency planning in case of him becoming ill – as he is the main care provider for Margaret. Margaret has some problems with her memory and so extra support and a variety of methods are used to ensure that she plays a part in the planning process. The plan is agreed and shared with relevant partners, such as social services and the out of hour's service.

———   –   ———

A date is set for review in three months time. Unfortunately, two months later George injured himself whilst gardening. His visit to the local A&E department triggered a response from his GP surgery in the form of an early review visit and reassessment of need.

George felt that the response was valuable as he had been worrying about how he would cope during his recovery from injury. The visit from the nurse reassured him that he was being supported to continue to be his wife's carer and helped her to remain at home with him.

Health Check

Health Questionnaire

General Practice

Flu Vaccination

Margaret Brown

George Brown (Carer)

Assessment Details

Community SAP

Review

Margaret

Personalised Care Plan

Monitor

Care Delivery

Community SAP

Review

George

Personalised Care Plan

Monitor

Care Delivery

Memory Support

Unscheduled Event
Illness Contingency

Out of Hours Service
Social Services

Unscheduled Event
Gardening Accident

SAP

Review

G

P.Care Plan

Care Delivery

Hospital A&E

General Practice

EXAMPLE 2 - *Nursing Home*

NAME   -   Kris Keiwski
AGE   -   69
GENDER -   Male

Kris Keiwski is a 69 year old gentleman who has recently moved into a nursing home. Kris has been transferred from the local acute hospital following an exacerbation of his respiratory disease. Previously, he had lived alone at home however his increasing breathlessness means he can no longer manage, even with a social care package.

In recent years complications of his diabetes have led to Kris having a below the knee amputation. He is still struggling to adapt to his new physical state and is still under going a programme of rehabilitation supervised by a physiotherapist and occupational therapist.

——— – ———

On his transfer of care Kris is accompanied by a file, which contains relevant assessment details from the hospital for Kris's named nurse to use when completing her element of the SAP.

With as much information as is available and Kris's input too the named nurse begins to formulate a care plan for Kris. This takes into account Kris's interest in gardening and his strong connections to the local church. The named nurse guides Kris through a discussion and formal documentation of his wishes for preferred place of care (PPC) and death (PPD).
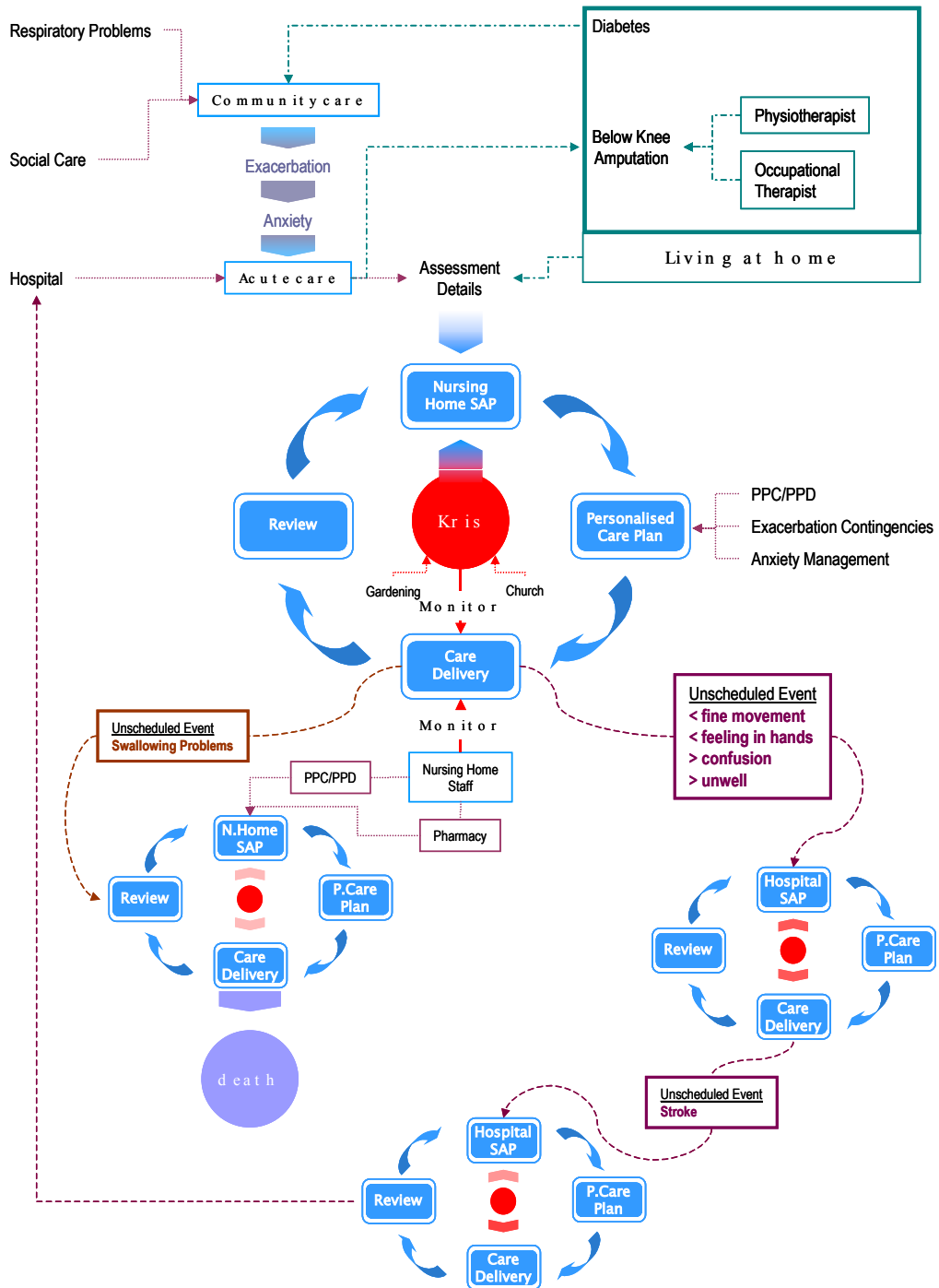
The breathlessness Kris suffers is a considerable problem, and his anxiety about this has caused previous admissions to hospital. The named nurse decides to ask the Practice Nurse to work on a management plan for Kris that will also have contingencies for exacerbations and anxiety management. The plan is implemented systematically and Kris guides its delivery by monitoring his symptoms with the staff.

——— – ———

Following his admission to the care home, Kris has a period of stability and his health appears to be maintained. However, Kris starts to complain that he is losing the feeling in his hands and is struggling to perform fine movement tasks. His named carer also notices that Kris is becoming unwell and confused. Kris is admitted to hospital for an acute urinary tract infection. Whilst an in patient Kris has a stroke which significantly impairs his ability to speak, swallow and perform many tasks he had previously managed independently.

Before discharge occurs, a case conference is held to assist the transfer of care process and to ensure accurate sharing of information with the care home. There are changes made to Kris's care plan. These specifically relate to the effect of his stroke.

——— – ———

On his return to the care home Kris deteriorates and his swallowing problems become worse. The pharmacist reviews Kris's medication and routes of administration. Working alongside the speech and language therapist and dietician, the staff alter Kris's care plan accordingly.

As Kris's condition deteriorates further the team review the Preferred Place of Care documentation and maintain Kris in the care home with dignity and care to his death, as his wishes state.

Respiratory Problems

Diabetes

Community care

Below Knee Amputation

Physiotherapist

Occupational Therapist

Social Care

Exacerbation

Anxiety

Hospital

Acute care

Assessment Details

Living at home

Nursing Home SAP

Review

Kris

Personalised Care Plan

PPC/PPD

Exacerbation Contingencies

Anxiety Management

Gardening

Church

Monitor

Care Delivery

Monitor

Unscheduled Event
< fine movement
< feeling in hands
> confusion
> unwell

Unscheduled Event
Swallowing Problems

PPC/PPD

Nursing Home Staff

Pharmacy

N.Home SAP

Review

P.Care Plan

Care Delivery

Hospital SAP

Review

P.Care Plan

Care Delivery

death

Unscheduled Event
Stroke

Hospital SAP

Review

P.Care Plan

Care Delivery

Summary of Issues

Identifying the 6% of the total population with complex needs

- Screening tools
- Assessing functional ability systematically; a tool needs to be developed that can be used opportunistically by clinicians and more comprehensively by the SAP

Assessment

- Who can carry it out?
- A standardised SAP

Care Co-ordinator and Key Worker

- The distinction between and the importance of these roles needs clarification

Care Delivery

- A robust infrastructure in the community is necessary

Culture

- Services need to be developed around the patient
- Social Services and Health need to come together more closely to serve populations
- The Independent Sector needs to be respected and developed; the Preferred Place of Care programme is a good starting point
- Intermediate Care is such an important issue it needs all relevant parties to come together to develop a local service that allows the money to follow the patient
- Joint Training for health, social care, the independent sector and the voluntary sector
- All practitioners in these organisations need to see themselves as part of one whole team serving the needs of a population

Information Technology

■ Communication between sectors and agencies needs immediate improvement

■ Software Interface programmes can be used now if encouraged by central leadership

■ Current systems need changes so that is more straight forward to see the contact details of the practitioners involved in a person's care

■ The Care Plan and other essentials need to be available to practitioners out-of-hours and other agencies and need to be more easily visible with drop-down menus and separate pages.

■ Coding needs to be improved so that 'social' issues can be recorded on 'clinical' systems and vice versa.

Research

■ Value of core community services needs to be established

■ A tool to assess functional ability or activities of daily living. It needs to have a short version for clinicians to use as a screen, a longer version for formal assessment purposes and it needs to satisfy the requirements of the DWP.

■ National tools for SAP

■ More accurate screening tools to identify those with complex needs.

CONCLUSION

The Complex Conditions in Later Life care pathway is conceptually straightforward, however the complexity lies within its delivery. The implementation of the pathway must be delivered in a systematic, holistic and anticipatory environment whilst realising the multi-agency cultural change. The ultimate objective of this pathway is to ensure a better outcome for the person with complex conditions. At the very least the systematic, holistic and anticipatory approach will improve the patient experience and increase the efficiency of resource management.

It is anticipated that this pathway can be further developed by the integration with the Single Assessment Process DOaS pathway representing leadership from health care, social care and the independent sector.

References

Kanitaski O (1998) Transcultural nursing: challenge to change. *Australian Journal of Advanced Nursing*; 5(3): 4-11.

Liberating the Talents (2005) Policy guidance on nursing role re-design *Department of Health*, Workforce Document.

Mahoney FI and Barthel D (1965) Functional evaluation: Barthel Index. *Maryland State Medical Journal*; 14: 56-61.

Meehan H (2006) personal communication

National Service Framework for Long Term Conditions, The (2005) *Department of Health* - Best practice guidance.

Our health, our care, our say: a new direction for community services (2006) *Department of Health* - White Paper

Royal College of Nursing (1998) The nursing care of older patients from black and minority ethnic communities. London: RCN.

Seal R (2006) personal communication

Supporting People with Long Term Conditions - an NHS and Social Care Model to support local innovation and integration (2005) *Department of Health* Policy Document

Cancer Network (2006) The Preferred Place of Care Plan and why it was developed, from http://www.cancerlancashire.org.uk/ppc.html

Yohannes AM, Roomi J, Waters K and Connolly MJ (1998) A comparison of the Barthel index and Nottingham extended activities of daily living in the assessment of disability in chronic airflow limitation in old age. *Age and Ageing*; 27: 369-374.

Good Care Planning for People with Long Term Conditions : updated version (2005)

NHS Modernisation Agency

Appendix A – *Do Once and Share Disease Specific Groups*

1. COPD/assisted ventilation

2. Diabetes

3. Glaucoma

4. Heart Failure

5. Rheumatoid Arthritis

6. Stroke

Other critical Do Once and Share groups:

1. Falls

2. SAP

Appendix B – *Complex Conditions Team Members*

Contributions from:

Core Action Team

- Dr. David Lyon   -   Clinical Lead
- Suzy Ning   -   Project Manager
- Paula Gandy   -   Core Action Facilitator
- Jayne Molyneux   -   Core Action Team Member
- Dr. Mark Aspinall-O'Dea   -   Core Action Team Member
- Janet Dunn   -   Core Action Team Member
- Damien Nolan   -   Core Action Team Member
- Sue Davison   -   Core Action Team Member
- Hilda Faragher   -   Core Action Team Member
- Denise Thomas   -   Core Action Team Member
- Raye Sutcliffe   -   Core Action Team Member

Extended Action Team

- Linda Spooner (Education and training)
- Linda Holloway (Community Matron)
- Julie Griffiths (Podiatry)
- Diane Platt (Physiotherapy)
- Sue Butler (District Nurse)
- Gill Clare (Medicines Management)
- Dr. Ann Maloney (Consultant)
- Jenny Ellis (District Nurse Liaison)
- Melissa Critchley (Age Concern)
- Sue Lightfoot (Additional Needs Lead)
- Linda Smout (Palliative Care)
- Debbie Eckersley (Dietician)
- Maxine Henderson (Service user and carer co-ordinator)
- Iona Pyle (Speech and Language Therapy)

- Lynne Lomax (Continuing Care/RNCC Lead)

- Marion Hayes (Evenings/Nights District Nurses)

- Heidi Pegnam-Mason (Clinical Development Lead Out of Hours)

- Dr. Schofield (G.P)

- Jo Meek (Rapid Respiratory Response Team)

- Barbara Furnival (Rapid Respiratory Response Team)

- Joan Britton (Community Matron)

- Dr Tseung (GP Palliative Care)

- Brigette Allman (Carer)

- Kay Ellis (Family carer)

- Suzanne Roberts (Independent Sector-Four Seasons Healthcare)

- Betty Carson (Home Manager Mill Brow Nursing Home)

- Sue Williams (Deputy Home Manager Hough Green Nursing Home)

National Contributors

- Good Practice Examples
  - Ruth Adams (Unique Care Development Advisor, Brent)
  - Dr. Mike Cheshire (Consultant Physician)
  - Dr. Geraint Lewis (Specialist Registrar)
  - Helen Meehan (GSF Lead Nurse National Team/Solihull PCT)

National Delegates

  - Penny Banks (Senior Fellow, Kings Fund)
  - Sally Bassett (Nurse Advisor, DH)
  - Lucy Botting (Head of Nursing, Bracknell Forest PCT)
  - Ingrid Darnley (Clinical Effectiveness and Quality Officer, The British Dietetic Service)
  - Cathy Devonport (Assistant National Lead for Large Scale Workforce Change Team NHS Employers)
  - Dr. Helen Gaskell (G. P)
  - Patricia Hamilton (Regional Director of Nursing)
  - Elizabeth Hill (Community Matron)

- Philip Holt (Consultant Audiological Scientist)

- Maggie Ioannoua (Director of Quality, Nursing & AHPs)

- Aileen Jones (Modern Matron)

- Dr. Kevin Kelleher (Geriatrician)

- Philip Lewer (Group Director, Health & Social Care, Calderdale MBC)

- Jo McPartlane (Regional Manager, FSHC)

- Jill Main (Project Lead, Supportive Care Pathway, Birmingham Palliative Care Network)

- Yvonne Ratcliffe (Patient Representative)

- Ken Ratcliffe (Carer Representative)

- Suzanne Roberts (Business Services Director, FSHC)

- Joanne Schofield (Clinical Nurse Manager, 5 Boroughs Partnership)

- Lynda Scott (National Lead for Large Scale Workforce Change Team NHS Employers)

- Richard Seal (Director of Medicines Management)

- Howard Seymour (Director, Innove)

- Dr. Debbie Singh (G.P)

- Mary Anne Smalley (Programme Director, UHC)

- Debra Sprague (Senior Lecturer, Public Health)

- Keith Strahan (Joint Chair, SAP Do Once and Share)

- Diana Susman (Intermediate Care Manager)

- Jan Thomas (Clinical Project Lead)

- Mandy Vernon (Regional Director, FSHC)

- Susan Watson (Practice Nurse, Castlefields H.C)

- Martin Westwood (Charge Nurse)

- Ian Wilkinson (Medical Director, Innove)

- Nancy Williams (Director of Operations, UHC)