



4

Briefing paper

Living with long term conditions

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Key messages:

- Demographic changes have resulted in greater number of older people living longer with more disability and often with two or more long term conditions.
- The training and education of all clinicians should acknowledge future demographics, and include sufficient focus on the key principles of geriatric medicine to ensure all doctors are aware of the specific needs of older patients.
- There is a good case for regarding frailty as a long term condition. Comprehensive geriatric assessment (CGA) – a multidisciplinary, diagnostic process to describe the medical, psychological and functional capabilities of a frail older person – should be used to design a coordinated, integrated plan for long term treatment and follow up.

Introduction and overview

This paper primarily focuses on living with long term conditions in England but includes references to the devolved nations where the situation is similar. A long term condition is any medical condition that cannot currently be cured but can be managed with the use of medication and/or other therapies. This is in contrast to acute conditions which typically have a finite duration such as a respiratory infection or inguinal hernia or a mild episode of depression.¹ Common LTCs (long term conditions) include diabetes, chronic obstructive pulmonary disease, chronic heart failure, osteoporosis and dementia. Currently approximately 70% of the health spend in England is on 30% of the population who have LTCs. It is estimated that over 15 million children, adults and older people in England live with at least one LTC. This figure is set to increase to around 18 million by 2025. People with LTCs are high users of the health services as they account for 55% of all GP appointments, 68% of all hospital and A&E appointments and 77% of all inpatient bed days.² Most LTCs are more prevalent in older age groups – for example the prevalence of diabetes rises steadily with age in men and women peaking at 22% for men and 17% for women in their eighties. Similarly the prevalence of dementia is very low for men and women aged 60-64 at 0.3% but rises to nearly 20% for men and women in their eighties. The majority of people over 75 live with two or more LTCs. There is also a strong link between LTCs and social inequalities – compared to the highest social class, people in the lowest social class have a 60% higher prevalence of LTCs and 30% higher severity of conditions.³ The annual health and social care cost per person per year for a person without a LTC is £1,000, this rises to £3,000 for those with one LTC and £8000 for those with three.⁴

The population is ageing. Between 2005/6 and 2014/15 the number of people aged 65 or over in England increased by almost a fifth and the number aged 85 rose by a third. This increase in the older population is projected to accelerate over the next 20 years. Unfortunately disability free life expectancy is rising more slowly than total life expectancy which means that people are living for more years with disabilities.¹ In the cognitive functional ageing study in three geographically defined centres in England (Cambridgeshire, Newcastle and Nottingham), it was found that between 1991 and 2011 there was a mixed picture in changes in cognitive impairment and disability – there was a reduction in cognitive impairment, an actual improvement in self-perceived health but an increase in less severe disability but not severe disability.⁵ Disability, frailty and multi-morbidity are linked with the presence of LTCs. This is a UK issue. For example, a large scale Scottish study reported that 82% of those aged 85 years or older had two or more LTCs.⁶ In contrast a study in Newcastle showed a higher chronic disease count (a median of five in women and four in men).⁷ People with dementia have on average 4.6 additional chronic illnesses and only 5.3% of people with a diagnosis of dementia have no other long term disorder.⁸ The relationship between mental and physical problems appears to be bidirectional – patients with severe mental health problems such as chronic depression and dementia are at a high risk of

developing long term physical problems and the risk of mental health problems increases in those with physical problems. Patients with multi-morbidity have a high treatment burden in terms of understanding and self-managing their conditions, attending multiple outpatient appointments and managing complex drug regimes.⁹ There is evidence that older people receive poorer levels of care than younger people with the same condition.¹⁰ For example older people are less likely to receive psychological therapies for mental illness. General medical conditions are treated more effectively than geriatric conditions such as incontinence and less than one in four people over 75 self-report receiving any support or advice in falls prevention or managing their own diabetes.¹¹ In addition there are around 6 million people in the UK as a whole, who are unpaid carers for older people and many of these are elderly themselves and have their own health and financial problems.¹² The challenges commonly experienced by older patients with multiple long term conditions are summarised in Table 1.

Table 1: Problems commonly experienced by older patients with multiple long term conditions⁹

- Polypharmacy.
- High treatment burden.
- Mental health problems;
 - anxiety
 - depression
 - dementia;
- Functional difficulties eg falls, incontinence, immobility.
- Reduced quality of life.
- Increased healthcare utilisation with poor coordination of care.

The financial background is bleak as the NHS in England has a projected shortfall of £30billion by 2020 and budget cuts of 12% in social services in the last four years.¹³ We need to examine potential service changes so that an imminent health, social and financial crises in the needs of older people with long term conditions can be avoided or at least ameliorated. Several strategies have been suggested including person-centred care, care pathways and guidelines, case management, integrated care, acute hospital initiatives, and frailty strategies using comprehensive geriatric assessment. These potential solutions are not mutually exclusive and are described next.

Person-centred care

Person-centred care is fundamental to the NHS and has been defined as treating patients as individuals and enabling them to make choices.¹⁴ The aim of person-centred care is to provide a system of care that facilitates an understanding of the person's health and wellbeing and uses co-production of solutions that includes or goes beyond medical interventions. In surveys patients with LTCs say that they want to be supported to engage in their care and contribute to decisions about it. They also want a proactive and seamless service in which the NHS acts as a team and they are treated as a whole person.¹⁵ Unfortunately feedback from patients often falls short of this ideal. Also there are practical problems in older people as person-centred care runs the risk of over emphasising independence and stigmatising dependence and interdependence.¹⁶ Dementia for example may present as failure of self-care and patients with dementia may be heavily dependent on family carers who are also elderly and have social and medical needs. Although person-centred care is the ideal, sometimes relationship centred care is more realistic. Relationship centred care puts the focus on the interaction between patient, family, carers and health and social care staff (a concept also explored in the briefing in this series on *Older peoples' mental health and wellbeing*).¹⁷ These interactions are essential in supporting many older patients with multiple long term conditions in the community.

Care pathways and guidelines

Evidence based guidelines are generally developed for people with single diseases. They can naturally lead on to care pathways to streamline and improve care and make it more efficient. However simple disease guidelines may be inappropriate for people with multiple LTCs. They may result in over-treatment and over-complex regimes of assessment and surveillance.¹⁸ Alternatively guidelines may result in under-treatment as well in patients with multiple co-morbidities, for example a new condition may actually increase the risk of a complication from an old condition and then the argument may be for more treatment, not less. On the other hand when life expectancy is poor from one condition then the potential benefit of treatment of another may be considerably lessened. These clinical decisions require individual clinical judgement in collaboration with the patient weighing up the benefits and risks for treatment for that individual, rather than slavishly following strict single disease guidelines. Similarly care pathways are more difficult in older people with multiple interacting conditions and social and functional constraints. The main aim of care pathways to optimise outcomes and reduce variation is more easily achievable in single disease conditions. NICE (The National Institute for Health and Care Excellence) have recently produced guidelines on care planning in older people with social care needs and multiple long term conditions.¹⁹ The guidelines emphasise identifying and assessing social care needs and working collaboratively and supporting carers. There are new NICE guidelines on managing multiple comorbidities due for publication in September 2016.

Case Management

The concept of case management incorporates case funding, assessment, care planning and care co-ordination. The evidence for the effectiveness of case management is mixed.²⁰ To be successful case management needs to be properly targeted and there needs to be continuity of care with professionals working in multi-disciplinary team. If it works well case management can potentially reduce expensive emergency hospital utilisation by reducing admissions, improve care outcomes and enhance patient experience. Where it has been less successful it has been poorly targeted and although it has been popular with patients and possibly reduced unmet need, it has failed to improve measurable outcomes or reduce hospital admissions. An example of a case management project is the Evercare model of case management. People over the age of 65 years, at risk of unplanned hospital admission were targeted. Evaluations showed that patients valued the improved access to health care, the increased psychosocial support and improved communication with health professionals but hospital admissions were not significantly reduced.²¹

Integrated Care

Improving integration is a common UK theme and being approached differently in the devolved nations. There are many different definitions of integrated care. National Voices, an organisation that represents patients, service users, carers and families defines integrated care from a patient's point of view - 'my care is planned with people who work together to understand me and my carers, put me in control, and deliver services to achieve my best outcomes'.²² Integrated care represents care that is coordinated between all those involved in the delivery of an individual person's care thereby reducing duplication, fragmentation and lack of ownership. The expectation is that integrated care schemes will serve a defined patient group (eg older people), coordinate care delivery, share outcomes, share budgets and share IT systems. The hope is that this will improve efficiency and reduce costs, but there is little evidence of this. Because of the many different definitions of integrated care and the practical difficulties of designing a controlled trial, there are no high quality systematic reviews to guide us. However few would disagree that well coordinated care that is person-centred is better than ad hoc poorly coordinated care. An example of an integrated care system in the UK is the Torbay Care Trust, targeted at older people and is quoted as reducing emergency hospital admissions and admissions to care homes.²³ Unfortunately this improvement in Torbay was not maintained and the Trust has been taken over as part of a reorganisation. Overall evidence from integrated care schemes is mixed in terms of definite outcomes. An evaluation of 16 integrated pilot sites in the UK found no evidence that integrated care reduced the level of emergency hospital attendances.¹¹ There are concerns that the budget cuts in social care will impact against NHS care. Pooling budgets may not be in the interests of the NHS.

Acute Hospital Care Initiatives

Acute emergency admissions to hospital particularly for older people, are increasing year on year. Hospitals frequently have bed crises and emergency departments become overcrowded with older patients with acute illnesses in combination with multiple LTCs waiting to be admitted. The UK has around 2.8 hospital beds per 1,000 population which is considerably lower than most developed countries. Bed occupancies in hospital continually run at over 85%. The Nuffield Trust predicts that at current trends we will need 6.2 million more bed days per year by 2022.²⁴

Hospitals are the only places where 'the lights are always on' when there is a medical crisis. National policy is to try and reduce this dependency on hospitals by increasing community services. It is unlikely this will have much of an effect at least in the short term - this is because new schemes tend to reveal unmet need initially and take at least five years to become established. In the meantime we will increasingly rely on improved hospital measures to assess frail older people at the front door to avoid admission or reduce length of stay (Table 2). We will also need improved measures to avoid delayed discharges with improved collaboration with rehabilitation and social care services. The Future Hospital Commission report recommends that hospitals should increase their emphasis on ambulatory (day care) emergency care, enhanced recovery and early supported discharge.²⁵ There is a potential to develop new systems and ways of working that deliver more specialist medical care outside the hospital setting to enable hospitals to become the hub of clinical expertise for the local population.²⁵ At the moment there is an approximate 50% shortfall of home based reablement and bed based intermediate care outside hospitals to facilitate early discharge.²⁶

Table 2: Improving acute hospital efficiency for older people¹²

- Use of comprehensive geriatric assessment for all frail older people.
- Specialised elderly care units and wards.
- Older people's liaison teams for discharge.
- Old age psychiatric liaison teams for management of mental health illness in old age.
- Frailty assessment units in Emergency Departments.
- Front door assessment by a geriatrician.
- Ambulatory care suitable for older people.
- Surgical and orthopaedic geriatric liaison units and teams.

Frailty and comprehensive geriatric assessment

Frailty is a distinctive health state related to the ageing process in which multiple body systems gradually lose their built in reserves.²⁷ There are two broad models of frailty. The first is the phenotype model which describes a group of patient characteristics (weight loss, reduced muscle strength, reduced gait speed and self-reported exhaustion). The second is the cumulative deficit model which assumes an accumulation of deficits (eg loss of hearing, low mood, cognitive impairment) which occur with ageing and can be combined to measure a 'frailty index'.²⁷ The second model is more in keeping with clinical practice and more easily measurable in primary care. A person with frailty is more vulnerable to illness and typically presents with a geriatric syndrome such as falls, immobility, confusion and incontinence. Frailty, disability and multi-morbidity are distinct but overlapping concepts. Frailty is common (7-16% in people over 65) and predicts disability, falls, admission to hospital and care homes, and death.²⁸ Nearly 400,000 older people in the UK live in care homes and nearly all of these are frail and have high rates of hospital admission.²⁷ A person with frailty is more vulnerable to acute illness which will be more treatable if detected early. An evidence based approach to frailty is CGA (comprehensive geriatric assessment) which is a multidisciplinary, diagnostic process to describe the medical, psychological and functional capabilities of a frail older person in order to design a co-ordinated, integrated plan for long term treatment and follow up.²⁹ CGA has been shown to improve quality of life, reduce mortality and reduce admissions to care homes.²⁹ Identifying frailty can be difficult but one recently established reliable method is to use the eFI (electronic Frailty Index) which uses existing data held in the primary care patient record.³⁰ The eFI is being used to identify

and code for mild, moderate and severe frailty and then combined with interventions, for example health promotion and exercise for mild frailty, case management for moderate and CGA for severe frailty. The eFI is currently in use in over 40 Clinical Commissioning Groups in England. There is a good case for regarding frailty as a LTC,³¹ and this opens up frailty to the application of chronic care models described previously such as person-centred care. Importantly frailty can considerably pre date disability and may be potentially reversible and hence offers greater opportunities for effective interventions eg exercise.

Implications for doctors, nurses and therapists

If we are to attempt to move care of LTCs more into the community away from hospital – then this has huge implications for clinical staff. Moving care into the community does not equate to moving the skill set into primary care. Undergraduate training in geriatric medicine is presently inadequate for modern day needs.³² Few GPs have developed a specialist interest in elderly care. GP trainees should be encouraged to train in geriatrics and complete the Diploma in Geriatric Medicine qualification. The Diploma in Geriatric Medicine is a postgraduate qualification designed to give recognition of competence in the provision of care of older people to general practitioner vocational trainees. The evidence for the required multidisciplinary approach including CGA is greater in the hospital environment and rehabilitation is more time consuming (taking into account travel time) and less cost effective in patients' homes.³³ On the other hand the ideal of the Future Hospital Commission of training more generalists and encouraging more specialists to outreach in the community may not be feasible with the lack of training numbers. Many consultant geriatrician posts at present for example are unfilled with lack of suitably trained applicants. There needs to be a change in the training of all doctors, nurses and therapists which acknowledges future demographics. The development of specialist nurses who can take on specialist assessment of older people is a welcome development. Apart from obstetrics and paediatrics – all specialities will need expertise in managing older frail people and training and education will need to reflect this. Some practical tips for doctors and nurses working in primary care are given in Table 3. It is recognised that to achieve these aims, general practice requires sufficient investment and resources.^{27,34}

Table 3: Practical tips for dealing with the challenges in caring for older patients with multiple long term conditions and/or frailty in primary care. (Resource and investment dependent)

- Identify complex patients (eg use the electronic frailty index) and ensure continuity of care by assigning a named doctor.
- Use clinical judgement rather than single disease guidelines.
- Arrange regular medicine reviews in conjunction with your pharmacist.
- Promote patient-centred care. What matters most to your patient?
- Encourage participation and support self-care.
- Adopt a policy of arranging extended consultation times for your complex patients.
- Give special attention to older people living in care homes as they are likely to be frail and at high risk of admission to hospital.
- Coordinate multidisciplinary team involvement.
- Get to know and use your local geriatrician.

Conclusion

Demographic changes have resulted in a greater number of older people living longer with more disability and often with two or more LTCs. This has resulted in an imminent crisis of care in the NHS with increasing number of hospital emergency admissions and a considerable strain on community health and social care services. This is likely to get worse with the prospect of reduction in health and social care funding. Proposed solutions include more person-centred care with encouragement of self-care, case management and increased integration of health and social care services at all levels. Evidence for these initiatives is mixed. It is possible that combinations of these strategies will help avert a crisis. A new promising approach is to consider frailty itself as a LTC and develop a 'frailty strategy'. This will include better integration of services with speciality outreach from acute hospitals, frailty units in emergency departments to facilitate discharge and reduce length of stay and a comprehensive frailty identification strategy in primary care allied with case management and comprehensive geriatric assessment. This will need to be backed up with increased training and education in the principles of geriatric medicine for all clinicians. There needs to be a change in attitude and culture in the NHS with an acceptance that both primary and secondary care services need to be redesigned to meet the needs of frail older people who are now our major customers.

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