

Delivering Dignity

Securing dignity in care for older people in hospitals and care homes



This report has been produced by the independent Commission on Dignity in Care, a collaboration established by the NHS Confederation, the Local Government Association and Age UK.

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Foreword from the Commission chairs

In February 2012 the Commission on Dignity in Care for Older People published its draft report, *Delivering Dignity*, for consultation. Like many others, we had been deeply saddened by investigations highlighting the undignified care of older people in our hospitals and care homes. In too many cases, people have been let down when they were vulnerable and most needed help.

We set up the Commission because older people and their loved ones deserve so much better. Following the extensive media coverage of our draft report, almost 230 organisations and individuals responded with their insights and ideas, demonstrating the tremendous commitment across the health and social care system to providing older people with the dignified care that is their right.

We received comments from national and regional bodies, service providers and commissioners, local authorities and academics. We are particularly grateful that many staff, service users and relatives wrote to us; their personal observations were invaluable.

In addition to written submissions, we attended meetings with older people's groups where we heard directly about their experiences and how they would like to see care changed. Many nurses participated in consultation events, doctors commented through our clinical reference group, and an academic reference group reviewed the evidence.

Several respondents said that the recommendations we made were just as relevant to other vulnerable groups in the care system. We hope that this will be reflected in policies and practice for their care as well.

Many submissions to the consultation called on the Commission to extend its recommendations to care in the community and in a person's own home. We agree that this whole area deserves more focus, and the three organisations that established the Commission will now consider options for taking this forward.

This final report draws on all the submissions to the draft report, in addition to the body of evidence that we gathered over the first eight months of our work. We would like to thank everyone who has contributed.

Delivering dignity will mean changing the way we design, pay for, deliver and monitor care services as the numbers of older people receiving care continues to grow.

Alongside the consistent application of good practice and the rooting out of poor care, we need a major cultural shift in the way the system thinks about dignity, to ensure that care is person-centred and not task-focused.

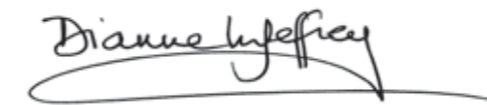
This will require empowered leadership on the ward and in the care home, as well as a lead from boards and senior managers. It will also mean changing the way we recruit and develop staff working with older people.

We have to work with older people to shape services around their needs, and listen to patients and residents and their families, carers and advocates, so we learn from their feedback and continually improve dignity in care.

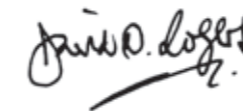
We urge everyone with an interest in care to support the changes that the Commission recommends in this report. Since February 2012, we have taken every opportunity to highlight the work of the Commission and its recommendations, and will continue to play our part over the coming months, working with others across the health and social care system on an implementation programme to help make dignified care a reality for every older person.



Sir Keith Pearson JP DL
Chair, NHS Confederation



Dianne Jeffrey CBE DL
Chairman, Age UK



Cllr David Rogers OBE
Chair, Community Wellbeing Board,
Local Government Association

Making change happen – why this Commission was set up

The Commission on Dignity in Care for Older People was established following the publication in February 2011 of *Care and Compassion?*, the report by the Parliamentary and Health Service Ombudsman, Ann Abraham, which exposed shocking failures in the care of older people.

This was the latest in many years of reports highlighting what is wrong in the care of older people and identifying what service they have a right to expect. These reports include:

- *Defending Dignity: At the heart of everything we do*, a Royal College of Nursing campaign in 2008
- the Nursing & Midwifery Council's *Guidance for the Care of Older People* (2009)
- *Patients Not Numbers, People Not Statistics* by the Patients Association (2009)
- *Counting the Cost: Caring for people with dementia on hospital wards* from the Alzheimer's Society (2009)
- Age UK's Hungry to Be Heard campaigns 2006–10.

The NHS Confederation, the independent body representing organisations providing and commissioning NHS services, joined with the Local Government Association and the charity Age UK to establish the Commission on Dignity in Care for Older People. The aims of the Commission were to:

- understand the aspirations of older people and their families
- identify the physical and personal care that older people have a right to expect
- establish what works in improving care
- drive improvements across health and social care.

Although the 37 recommendations in this report are directed at the system in England, we believe that the key messages will also be of value to practitioners in Scotland, Wales and Northern Ireland, several of whom were generous enough to share their expertise with the Commission.

This final report is based on the knowledge of the commissioners themselves (please see the Appendix on page 38 for a list of Commission members), the many witnesses who gave written and oral evidence, and almost 230 submissions from organisations and individuals in response to our consultation document, published in February 2012.

The commissioners brought expertise from right across the care system, including nursing, social care, medicine and commissioning, as well as insights from representatives of service users. The witnesses to the Commission included academics, managers, regulators, local authorities, volunteers, service user representatives, charities and royal colleges. They all provided evidence and insights in a shared determination to make dignified care a reality for older people.

This report is not a repetition of the well-documented problems. Nor is it a best practice guide for managers and staff, as excellent materials already exist. Instead we have focused on how to tackle the underlying causes of poor care. Some hospitals and care homes are already providing dignified care for older people; this report and the follow-up programme of activities are intended to build on existing good practice, so that we get it right for every person, every time.

How the Commission has responded to the consultation

The responses to our consultation document strongly endorsed almost all our recommendations. A summary document setting out the feedback we received is available on the NHS Confederation website: www.nhsconfed.org/dignity

In light of the comments we have received, this final report stresses the importance of human rights legislation and the 2005 Mental Capacity Act, as well as meeting people's spiritual and religious needs. There is also a section highlighting 'always' events for dignity in care (see page 12) – basic rules for delivering dignified care.

The references to the provision of NHS services to care home residents have been strengthened, while the role of foundation trust governors in championing dignified care has been recognised.

In terms of the structure of the report, many people urged us to provide one integrated set of recommendations for both hospitals and care homes, rather than giving them separate sections. We agree that our recommendations overwhelmingly apply to both, so this final report is substantially structured around who is responsible for implementing different changes – managers, commissioners and so on – rather than splitting it between hospitals and care homes.

We begin by looking at the issue of the personal responsibility that each member of staff has to provide dignified care and to challenge poor practice. We then consider the leadership required from ward sisters, charge nurses and care home managers, and boards and senior management teams, before looking at: the wider context of how services are commissioned; the role of professional bodies, universities and regulators; and patient and resident rights and representation. There are also specific recommendations for the Government.

We have retained a separate section on the particular issues around building a caring community in residential and nursing homes (see page 21).

Several responses to the consultation pressed the Commission to make recommendations on staffing levels, particularly for hospitals. The commissioners felt that it would not be helpful to, for example, propose a particular staffing ratio for older patients; indeed, there can be sharp variations in quality between identically staffed wards in the same hospital, depending on the leadership from the ward sister or charge nurse.

But staffing levels are clearly a pertinent issue. The Commission noted evidence from the Royal College of Nursing (RCN) that older people's wards routinely have lower staffing levels than other wards, which the RCN believes has a significant impact on quality and safety.

There is a need for enough staff to provide personalised care, rather than rushing through each task as quickly as possible, and the additional needs of older people should be taken fully into consideration when making staffing decisions. So we have stressed the responsibility of ward sisters, charge nurses and care home managers to raise concerns if the number or skill mix of staff on duty is inadequate, and the responsibility of managers to respect and consider those concerns. One of the recommendations in this report is that the Government's Nursing and Care Forum should examine many of the issues around staffing and dignity in care.

It was always the intention of the Commission that its investigation would be followed by action. Plans for a programme to support the implementation of the recommendations will include activities to enable hospitals and care homes to learn from good practice and to raise older people's expectations of dignity in care.

Changing society's attitudes to older people

Undignified care of older people does not happen in a vacuum; it is rooted in the discrimination and neglect evident towards older people in British society. Age discrimination is the most common form of discrimination in the UK. Increased life expectancy is a positive development, but our view of older people focuses almost exclusively on biological decline, and we tend to discuss older people as a problem for health and social care services, a 'demographic time-bomb' or a crisis we cannot afford. In contrast, the economic and social contribution offered by older people – for instance in employment, volunteering, or caring for partners, children and other family members – is rarely acknowledged.

The effects are damaging, both to individuals and society. The stereotyping of older people as passive and dependent erodes individuals' sense of self-worth. Research has revealed how people aged over 70 are persistently seen as incapable and pitiable, when compared with other groups. The unthinking disregard for older people's preferences and aspirations in the design and delivery of public and private services, and the lack of consideration towards them, means that those who need support most often do not receive the right help or treatment. The issues raised in this report have a great deal of relevance to other services, such as housing and transport.

The Government needs to take a lead, by setting a positive tone for debate about our ageing society, celebrating the contribution that older people already make and seeking to build on this, rather than casting them as a problem to be solved. Political parties should devise policies that promote the rights of older people and challenge and change attitudes.

Awareness of ageism and its effects has increased in recent years, and the introduction of age discrimination legislation in the 2010 Equality Act recognises this. The Act extends protection against discrimination, harassment or victimisation on grounds of age. It also introduces a duty on public bodies and those carrying out public functions to eliminate discrimination, advance equality of opportunity and foster good relations between different groups. The effect will be that public bodies will have to consider how their policies and services affect older people.

The legislation is a useful start, but by itself will not be sufficient to change attitudes towards ageing. Public services should be designed with the aim of promoting equality between people of different ages, addressing the current and future needs of an ageing and diverse population, and eliminating discrimination against older people. We need to be alive to trends that appear to exacerbate age segregation, and we need to seek initiatives that can bring different generations together around issues of shared interest and importance.

A public body seeking to identify what it needs to do to promote age equality first needs to understand in its own context what barriers older people face, whether as staff or service users. Ensuring that services collect data that can be analysed by age is an essential starting point. Moving beyond this, public bodies need to make sure that they engage effectively with older people, to understand their needs and views.

This positive attitude towards ageing needs to be reflected in the training of public sector staff. As older people are among the highest users of many public services, this could be a powerful lever for improving older people's expectations and sense of self-worth.

Links between older people and young people are invaluable, helping to break down prejudice on both sides and fostering understanding. Schools need to play a more active role in promoting understanding of ageing and respect for older people. Such work could eventually make a substantial difference to societal attitudes. Families have an important role to play in helping children to understand what it means to grow old.

The care system must bar the way to prejudice. Instead of absorbing poor attitudes to ageing and older people from wider society, care staff and their organisations should be beacons for the rest of the community, demonstrating how we are all the richer when older people are respected, valued and celebrated.

Who we care for

The fact that so many of us now live such long lives should be hailed as a success in which care services have played their part. The number of people in the UK aged 65 and over in 2010 was 10.3 million (17 per cent of the population). In the 25 years prior to that, the number of people aged 85 and over more than doubled to 1.4 million. In England, more than 400,000 people aged over 65 are living in over 18,000 care homes.

There are 800,000 people living with dementia in the UK and, according to the Alzheimer's Society, this is projected to rise to 1 million by 2021. If the current extent of diagnosis remains unchanged, up to half of these people will not have had their condition identified. About a third of all people with dementia live in care homes, while around a quarter of older people on acute wards in hospitals are estimated to have dementia, much of it undiagnosed.

Caring for older people is a major part of the work of the NHS on most wards in most hospitals. NHS data shows that there were approximately 3.8 million finished consultant episodes for those aged 60 to 74 in 2010–11, and 4 million for those aged 75 and over. This compares with 9.5 million episodes for all other age groups. Older people tend to stay in hospital much longer; the average length of stay for patients over 75 years of age is more than ten days, compared with just over four days for those aged 15–59. About 60 per cent of people in hospital will be over the age of 65, and this proportion is growing.

We need to change the ways we provide services, to acknowledge this shift in care needs. This means looking at NHS hospital services less from the perspective of diagnosing and treating single acute illnesses and more from that of managing long-term conditions for older people with often complex, multiple medical needs. Hospitals should present themselves to older people as places where they are welcomed and valued, and where their needs are understood and met.

A significant minority of older people who enter hospital from their own homes are discharged to care homes. Many more will be receiving long- or short-term social care at home or will need practical help to get back on their feet. That is just one reason why health and social care must provide older people with a seamless service. The Government's White Paper on social care and the draft Care and Support Bill (due to be published in 2012) must deliver this move to more integrated services.

Older people often prefer to receive care in their own home, and doing so helps them to maintain their independence. Yet many older people are taken into hospital even when their condition does not warrant the disruption and distress this causes for the patient and their family. The Department of Health estimates that around 25 per cent of hospital patients, many of them older people, could be cared for at home or in the community.

Older people need to be provided with care in the right place for their needs and preferences. This includes delivering care at home or in the community, when that is effective and it is what the older person wants. Commissioners should work with local care services to deliver care at home or in the community where that is an appropriate alternative to hospital, and demonstrate to their local HealthWatch (see page 32) and health overview and scrutiny committee that they have done this.

Although the Commission has not considered evidence about care provided in a person's home, we believe that dignity should be as much a feature of the services offered in a hospital or a care home. Domiciliary and community services should adopt the same principles on dignity as hospitals and care homes, to provide older people with consistently dignified care.

What standards of care do older people have a right to expect?

Dignity in care means bridging the gap between the principles and rights set out in the NHS Constitution and the reality of being an older person in care. While the Constitution is primarily intended for the health service, it articulates what the whole care sector should be aiming to achieve. The overarching commitment is to help keep us mentally and physically well, to involve us in decisions about our care, to help us get better when we are ill and, when we cannot fully recover, to stay as well as we can and live as independently as we can until the end of our lives.

The Care Quality Commission 2010 guidance on meeting essential standards of quality and safety says that hospitals and care homes that comply with its regulations will:

- recognise the diversity, values and human rights of people who use services
- uphold service users' privacy, dignity and independence
- provide information that supports service users, or others acting on their behalf, in understanding and making decisions about the care, treatment and support provided, and enable them to make decisions about it
- enable service users to care for themselves where possible
- encourage service users to be involved in how the service is run.

The NHS Constitution, enshrined in the 2009 Health Act, identifies several rights that are particularly important for older people, including:

- the right to be treated with dignity and respect, in accordance with their human rights
- the right to not be unlawfully discriminated against in the provision of NHS services, including on grounds of age

- the right to accept or refuse treatment that is offered, and not to be given any physical examination or treatment unless they have given valid consent. If someone does not have the capacity to do so, consent must be given by a person acting on their behalf, or the treatment must be in their best interests
- the right to be given information about their proposed treatment in advance, including significant risks, alternative treatments and the risks in doing nothing.

Those hospitals, care homes and staff providing excellent care recognise the humanity and individuality of each person they are working with, and respond to them with sensitivity, professionalism and compassion. This means that as well as providing the physical elements of care – access to food and drink, help to maintain good hygiene, clean surroundings – staff also talk and listen to those receiving care and meet the emotional needs of each individual.

For older people it is important that their care is shaped not just by their illness or frailty but also by the wider context of their life and relationships. They should be treated with respect and supported to maintain their dignity – and their identity should not be lost when they enter the care system.

Hospitals, care homes and their staff working with older people when their circumstances are changing – for example following the loss of a partner, being admitted to hospital, moving into a care home or towards the end of their life – need to do everything possible to help the person retain their sense of identity and self-worth. This is when care and compassion matter most. Hospitals and care homes must help older people to understand their health and care needs, work with them and their families to help them manage these needs, and support them physically and emotionally to live as well as possible if they cannot get better.

When older people move, such as from home to a hospital, or from hospital to a care home, it is essential that knowledge and understanding about them moves with them.

Caring for each individual

The way in which staff interact with an older person has a profound effect on that person's life. If staff assess their clinical and care requirements effectively, find the right way to talk with them, respond to their needs, wants and fears, and treat them with respect, then the staff will help to sustain and enhance that person's self-confidence, independence of thought and action, and determination to remain as active as they can – physically and intellectually.

But evidence to the Commission revealed how poor or neglectful care – even for just a few days – can have a devastating effect. Older people describe how their skills, self-confidence and ability to look after themselves can deteriorate as a direct result of the way they are treated, such as being spoken to as if they are a child or having things done to them, rather than with them. For example, feeding someone just to save time (rather than helping them to eat) can feel humiliating and can create dependence, while telling them what to wear or what time to go to bed robs them of choices and dignity. Deterioration, such as incontinence or immobility, resulting from undignified care can set in extraordinarily quickly.

All staff, boards and management teams must recognise their responsibility to maximise older people's independence. Hospitals need to work with patients, relatives and carers to monitor the extent to which they are ensuring that patients are as independent as they can be when they are discharged from hospital, or that there are plans in place for rehabilitation as far as that

is possible. Care homes must ensure that the way in which care is organised and delivered promotes independence and choice.

By its very nature, there is an imbalance of power in the relationship between a person receiving care and the staff delivering it. Those staff who provide dignified care constantly seek to redress this imbalance, by involving the individual in decisions wherever possible, explaining what is happening and why, listening to and addressing concerns, and – above all – treating each person as someone deserving respect, understanding, empathy and kindness. In short, they recognise care as a partnership, instead of treating older people as passive recipients.

An older person arriving in an emergency department after a fall may be coping not just with physical pain but also with the emotional pain of the sudden loss of their ability to live independently. Someone entering a care home for the first time may be frightened, confused, frustrated and angry. Care that is sensitive to life changes, and understands the big impact that these can have on a person's sense of self, can greatly ease distress. It can also help a person to retain their self-confidence, enable them to maximise their self-sufficiency, and encourage them to be ambitious in what they can achieve as they try to recover.

Person-centred care champions compassion and respect, and puts the individual at the heart of all decisions. The focus is on the relationship with the person behind the task, not on the task for its own sake. From the moment when an older person first has contact with a hospital or care home, it is vital that they are seen as an individual and are not defined by their illness – for example, not referring to them as a 'hip patient'. Dr Jackie Bridges' research (City University London, 2009) into patients' and relatives' experiences underlined the value they placed on the relationship aspects of care.

The resulting guidance stressed how people being cared for wanted staff to 'see who I am, connect with me, involve me'.

Chronological age is a poor indicator of health needs. Ageing affects people differently and everybody has had different life experiences. Care should always be appropriate and accessible to people with additional needs, such as sensory or cognitive impairment, learning disabilities or not having English as a first language. Staff should have cultural awareness training that is appropriate to the local population.

Dignity in care must be extended to every older person attending a hospital, even if they are not being admitted overnight. For example, some day surgery units assign a volunteer to support an older person from the moment they arrive until the moment they leave.

Talking with and about older people

Helping staff to talk with older people and listen to them is perhaps where dignity in care begins. Once that rapport develops, the care professional will begin to see the whole person, and the keystone of dignified care is in place. Taking time to engage, even just by asking simple questions – such as 'Do you have everything you need?' or 'Is there anything you would like me to explain?' – and talking through the steps of a task as it is performed allows people to express themselves, allays anxieties and gives them more control over their environment and treatment.

Responding to people is vital. Requests, comments and complaints should never be ignored, even if it is only to take a moment to reassure someone that they have been heard and staff will respond as soon as possible.

Staff development programmes should include helping staff to feel confident about talking and listening to older people and their families, and finding the right words to discuss the most difficult issues, such as disability, dementia, dying and death. Senior staff need to help less-experienced team members to understand these issues, develop their skills and cope emotionally.

Talking with people who have dementia requires specific training. Small changes in the way staff talk, such as being empathetic and warm, make a substantial difference to the person's wellbeing. The Alzheimer's Society provides guidance on talking with people who have dementia, such as identifying yourself by name and providing visual cues.

Individual words matter. Expressions such as 'bed blockers' imply that older people are a burden or a nuisance, while referring to them by illness reduces them to a clinical condition, rather than recognising them as a person. Using patronising language to an older person belittles them. It is not a question of setting inflexible rules; it is the simple courtesy of treating people with respect, which includes asking them how they would like to be addressed.

Recommendation 1 – all staff

Language that denigrates older people has no place in a caring society – particularly in caring organisations – and should be as unacceptable as racist or sexist terms.

‘Always’ events – the foundations of dignified care

The NHS has a category of errors that are so serious, they should never happen. These ‘never events’ include, for example, operating on the wrong leg. We believe that care staff should think about ‘always’ events for dignity in care.

The list in the box below is by no means exhaustive, but it highlights key things that should happen, to ensure that dignified care is delivered. We encourage care organisations to develop their own approach to ‘always’ events for dignity. Checklists are certainly not the answer to dignified care, but they can be useful tools.

‘Always’ events for dignity in care

- **Always** treat those in your care as they wish to be treated – with respect, dignity and courtesy.
- **Always** remember nutrition and hydration needs.
- **Always** encourage formal and informal feedback from older people and their relatives, carers and advocates, to improve practice.
- **Always** challenge poor practice at the time – and learn as a team from the error.
- **Always** report poor practice where appropriate – the people in your care have rights and you have professional responsibilities.

Ensuring that every member of staff is responsible for dignity

Caring for older people is skilled, demanding and often stressful work. Staff who are appropriately trained, and who feel valued and empowered to make decisions, will be the ones who support dignified care. Staff who are denied the right training and development, who do not feel valued by their organisation, who are not encouraged by their managers, and who do not feel that they have the freedom to make the right decisions for patients and residents are far more likely to deliver poor care.

While existing ‘dignity champions’ perform an important role, everybody involved in the care of older people must feel personally responsible for championing dignified care. All members of staff need to be clear that it is their responsibility to challenge neglectful, insensitive and discriminatory behaviour towards older people as soon as it occurs, and need to make compassion and kindness an integral part of their everyday vocabulary and practice.

Challenging undignified care needs to be done in a constructive manner, rather than in a confrontational way, as this is far more likely to engage staff in understanding the right approach and to bring about lasting change. It is individual decisions to do the right thing that ultimately change an organisation’s culture. Every time it happens, it makes it easier for others to follow the example.

Recommendation 2 – all staff

Staff must take personal responsibility for putting the person receiving care first. Professionally registered staff are required to challenge poor care, and they should do so as soon as they see any shortcomings. Other staff, such as healthcare assistants, must take the same approach, and must be given the training and support to help them to do so.

Organisations must recognise that a culture of personal responsibility is grounded in:

- clear expectations of performance
- good training
- mechanisms that enable staff to highlight and correct poor care
- encouragement, praise and support for staff who highlight shortcomings.

There is little evidence that traditional training, often based in lecture rooms, brings about the kinds of changes in attitude and behaviour that are required; in contrast, there have been major advances in learning and development carried out in workplaces. Evidence provided from researchers at the University of Ulster, Sheffield University and Edinburgh Napier University demonstrate the power of running integrated learning and development strategies, which take place in the ward or department where care is being delivered. Professor Jan Dewing at Canterbury Christchurch University and East Kent University Hospitals NHS Foundation Trust has called these ‘active learning’ strategies, which essentially means ‘learning through doing’. Hospitals and care homes need to invest in facilitators, who can lead active learning to give staff the confidence to do the right thing for the people in their care and challenge undignified care when they see it.

Recommendation 3 – managers

Care organisations should introduce facilitated, practice-based development programmes, to ensure that staff caring for older people have the confidence, support and skills to do the right thing for the people in their care.

Staff development can be particularly effective when different groups – such as nurses and doctors – train together. This improves understanding of each other’s roles and helps teams to understand how they can work together more effectively. Staff can also benefit from carrying out ‘peer reviews’ of services within or between hospitals and care homes, to learn from them what is working well and to challenge constructively what needs to change.

Recruiting staff who demonstrate the right values and behaviours is key. Some hospitals and care homes include meetings with patient or resident panels in their recruitment process to assess candidates’ values and how they interact with those in their care, while others use psychometric testing or assessments of a person’s judgement in different situations. In care homes, residents, relatives and advocates should be asked for views on what qualities a good care worker should have, and these should be taken into account when designing job roles.

Recommendation 4 – managers and team leaders

Managers and team leaders must recruit staff to work with older people who demonstrate the compassionate values and behaviours needed for dignified care. This should be considered a core attribute, carrying equal weight with clinical and technical skill.

New staff should have a probationary period, which is sufficiently long to evaluate whether they have the right skills to deliver high-quality, dignified care. Hospitals and care homes should similarly include dignity skills in their appraisals of staff performance. Some organisations include in appraisals any compliments, complaints and feedback from those being cared for and their families, so that staff learn what they should keep doing and what they need to change.

Temporary staff and agency staff must exhibit the same caring behaviour; this should be a requirement of their contracts, and should be reinforced by the way they are managed.

Recommendation 5 – managers and team leaders

Regular appraisal is an essential part of staff development and quality improvement. Appraisals should incorporate feedback from residents and patients, relatives, carers and independent advocates, as well as peers and managers.

With around a quarter of people in hospital and the majority of people in care homes having dementia, it is imperative that all care staff have at least a basic understanding of the condition and demonstrate the skills to maintain the individual’s dignity.

Sisters, charge nurses and care home managers are an important source of emotional support for less-experienced team members, particularly in helping them with demanding areas of work, such as end-of-life care and caring for people with dementia. Supporting colleagues in this way should be a formal part of their role.

Recommendation 6 – boards and senior managers

All health and social care staff involved in the care of people who may have dementia need to have the necessary skills to provide them with dignified care, developed through basic training and continuous professional and vocational development in dementia. All care staff must have basic skills in communicating with a person with dementia, including how to demonstrate warmth and kindness.

Communication training also needs to address the needs of other impairments, such as those to hearing and sight, as well as how to use interpreters.

If a care professional is not fit to practise, their employer and professional body need to take robust action. Employers must similarly act if a healthcare assistant or member of the support staff is failing.

Revalidation, due to be introduced for doctors, offers an excellent opportunity to capture evidence about whether they are providing dignified care. Ward round practice and the quality of initial patient assessments would be valuable information for the revalidation process.

The boundaries of responsibility between different groups of professionals are a fact of life, which has important consequences for dignified care. For example, doctors may avoid intervening on issues such as skin care, which are beyond the immediate medical condition they are treating, leaving that to the nurse. This differs from 20 years ago, when the doctor was ultimately in charge. The result is that responsibility for people’s care is divided up between, for example, the nurse in charge, a physiotherapist and doctors overseeing different conditions. However, shared responsibility must not lead to shared abdication of responsibility. Each professional has a duty to ensure that any shortcomings they observe in a person’s care are addressed.

Working in care homes has its own particular pressures. The work of care home staff is demanding and important, with high levels of responsibility for dignity and safety. But staff can feel isolated, and it may be difficult for them to see excellent care in action and to get the right development. They are poorly regulated, often poorly paid, have too little access to training and support, and lack professional status. Care home workers need a rewarding working environment, which recognises good performance and is set within a sound career structure. This is integral to delivering dignified care.

The Commission recommends that the status and role of those working in the care sector need to be raised, to assist the better integration of health and social care. The prime minister and the secretary of state for health have established a Nursing and Care Quality Forum to improve the quality of nursing across the care system, which provides an opportunity to address this issue.

Recommendation 7 – government

The scope and membership of the Government’s Nursing and Care Quality Forum should be widened to encompass all care staff, including healthcare assistants and those working in care homes. In its pursuit of high-quality care, the forum needs to look at all aspects of care home staffing, including issues of status, pay, qualifications, recruitment, retention, development, monitoring and regulation.

In the longer term, the care sector should consider establishing a College of Care, to promote the status of care workers and to lead on these issues. Care home providers, local authorities and NHS organisations should work together to integrate the development of health and social care staff. Care home and hospital staff have a great deal to learn from each other.

Case study:
Dignity for All –
University Hospitals, Birmingham

University Hospitals Birmingham NHS Foundation Trust runs an award-winning project called Dignity for All. It is a big operation, involving a lead dignity team, 390 dignity champions, dignity clinical educators and many others. It reports to the trust board.

There are dignity champions in every ward and department. They volunteer and are trained for the role, and then train others. Events, newsletters and mentors maintain quality, motivation and momentum.

The campaign is built on listening and learning from patient experience. Champions are encouraged to speak out about their concerns and to celebrate successes, and they are supported to carry out small changes that make a difference to patient dignity.

Dignity for All encompasses everything from falls prevention to mental health, ‘ability not disability’ and end-of-life care. It includes basics, such as the Behind Closed Doors campaign, which pushes the message that whatever a person’s age and physical ability, they should, wherever possible, be able to choose to use the toilet in private.

One of the most obvious changes is the way in which mealtimes are managed. Patients are now encouraged to eat round a table with others, reducing isolation and helping people to stay active. This approach has a great impact on patients who are either distressed or withdrawn.

The key role of ward sisters, charge nurses and care home managers

The leadership role of the ward sister, charge nurse or care home manager is crucial. They should lead by example, helping other members of the team to deliver dignified care and challenging poor practice. In embedding values and behaviours around dignity, ward sisters, charge nurses and care home managers should build on what is already being done well. They must ensure that every member of staff understands the standards of care expected of them, and they should be managed in a way that ensures those standards are met. Other staff, notably consultant doctors in hospitals, should advise and support them.

Sisters, charge nurses and care home managers should have significant responsibility for staffing and budgets. They should be able to determine the shifts for the available staff and control spending on equipment. They should see it as their responsibility to ensure that the right number of staff – with the right skills – are on duty to provide dignified care. If they do not believe this is the case, they have a responsibility to raise the issue with their managers. Managers must be clear that, in turn, it is their duty to address problems.

Although hospitals and care homes are 24-hour services, managers and senior staff often work ‘office hours’, while the staff on duty outside regular hours may not have the skills, experience or support to make and manage urgent decisions. Managers should ensure that appropriately senior and suitably qualified staff are available on all shifts, and that night staff have adequate support in emergencies.

Wards and care homes are the hub of multidisciplinary teams, which include care assistants, cleaners, kitchen staff, porters, allied health professionals, nurses, doctors, clerical staff and managers. Sisters, charge nurses and care home managers should play a leading role in co-ordinating services, to provide the most dignified and seamless care for each person.

Recommendation 8 – ward sisters, charge nurses and care home managers

Ward sisters, charge nurses and care home managers must have responsibility for care standards, care continuity, dignity, wellbeing and safeguarding, must expect to be held accountable for them, and must take the actions they deem necessary in the interests of patients or residents.

Feedback from patients, residents, relatives and independent advocates is important in improving care. Immediate feedback to staff is key – discussion on the day about how care can be improved is far more powerful than discussion in a training room or appraisal weeks later, and can be acted on straight away.

However, hospitals and care homes must also give staff the time and space to reflect on the care they provide and how they could improve; this is an essential part of giving good care. It might be a few minutes at the end of a shift or a formal session where the emotional dimensions of care are discussed. It is the responsibility of the team leader to make sure this happens. UK hospitals, working with the King’s Fund think tank, are increasingly using an approach developed by the Schwartz Center for Compassionate Healthcare in Massachusetts to give care staff scheduled time to discuss openly and honestly social and emotional issues that arise in caring for people. This time has become known as a ‘Schwartz round’, and, in contrast to traditional medical rounds, the focus is on the non-clinical aspects of care and the responses of staff.

The responsibilities of boards and senior management

Recommendation 9 – ward sisters, charge nurses and care home managers

Feedback from patients or residents and their families, carers and advocates should be discussed and responded to every day, such as during the handover between shifts. Staff must also routinely be given time and space to reflect on the care they provide and how this could be improved.

Care home managers should be recognised as experts in their field. They have demanding jobs, leading and motivating teams of low-paid staff doing difficult work. They often have little back-up and are regularly faced with ethical issues, such as those concerning end of life. Supporting dignity in care for older people requires investment in the training and support of care home managers, within a proper training framework. They need a network from which to learn new approaches and to share ideas.

Recommendation 10 – care home providers and local authorities

Care home providers should invest in support and regular training for their managers. As commissioners of care, local authorities have an important role to play in facilitating this.

Case study:

My Home Life

My Home Life (www.myhomelife.org.uk) is a UK-wide initiative promoting quality of life for those who are living in, dying in, visiting or working in care homes for older people through relationship-centred, evidence-based practice. The initiative is led by Age UK, in collaboration with the Joseph Rowntree Foundation and City University London, and has the support of all the national representative bodies for providers of care homes.

My Home Life engages in a number of activities:

- collecting and disseminating evidence of what works
- developing leaders
- creating networks
- supporting change.

An important part of My Home Life is the one-year Leadership Support and Community Development Programme. It is running across 17 local authority areas, and includes supporting care home managers to personalise services and strengthen joint work with the wider health and social care system.

The programme recognises that good practice depends on high-quality relationships between staff, residents and relatives, as well as across organisations and systems. Care home managers are helped to explore their own leadership style, begin a ‘journey’ of culture change within their own homes and share ideas. The programme differs from traditional leadership programmes, which can take staff away from their work. Instead, it aims to bring them closer to their day-to-day priorities.

Managers in Essex have found the programme helped them to reflect on their own practice, increased confidence and improved their relationship skills. One said: ‘I feel uplifted and motivated; it’s not the usual focus on evidence and outcomes, it’s about feeling supported and connected with everyone and growing my own leadership skills.’

Boards and management teams have ultimate responsibility for the provision of dignified care in their organisation. If that is not happening, they are failing in their legal and moral duties to those in their care.

Dignified care requires strong and committed leadership that delivers a coherent approach to dignity at every level and in every part of the organisation. The values of dignity must be consistently communicated throughout – by the board, managers, clinicians, team leaders and all staff. But values will only lead to changes in behaviour if staff feel committed to them and believe they can act on them.

Securing dignity is not just about staff doing a better job, it is also about chief executives, boards and management teams running their organisations in a way that enables staff to do the right thing for the people in their care. If managers impose a command and control culture that demoralises staff and robs them of the authority to make decisions, poor care will follow. The Future of Leadership and Management in the NHS (2011), a major study of health service leadership by the King’s Fund, called for leadership development to extend ‘from the board to the ward’, to give individuals ‘the ability and the confidence to challenge poor practice’. All care organisations should adopt this approach.

In hospitals, the medical director, the nursing director and other senior clinical staff need to feel that they have the freedom to make major decisions about patient care and to take responsibility for securing dignity. This includes working with managers to ensure that staff are able to do the right thing for older patients. This type of leadership – empowering staff at all levels of the organisation – is the foundation on which excellent care is built. For some hospitals this will be a big cultural shift.

Many care homes are small or medium-sized organisations, where those in charge are involved in the day-to-day running of the home. Other homes are provided by large organisations with a board and a substantial senior management team. This variety in size and type of organisation means that it is difficult to set out a single approach to leadership and management. But all care home providers must invest time and resources in looking at what will work best in their organisation in terms of leadership and empowerment to deliver high-quality care.

Recommendation 11 – boards and senior managers

Hospitals and care homes need to embrace a devolved style of leadership that values and encourages staff and respects their judgement. This means enabling staff to do the right thing for the individual patient or resident, not simply to follow process.

Boards and senior management teams must understand how people experience care throughout their organisation, and must see that experience as a key measure of the organisation’s performance.

Recommendation 12 – boards and senior managers

Boards and management teams must have robust processes in place to collate feedback and complaints from older people, their families, carers and advocates, as well as staff, so that they can identify emerging risks and respond to them. This should include effective procedures for staff to raise concerns about care standards with senior managers and boards. Boards and senior managers must respond quickly to any evidence of deterioration in the delivery of dignified care.

Staff who decide that they need to whistle-blow must be supported and protected – but whistle-blowing should never be necessary in an organisation that has the procedures in place to report and address poor care rapidly.

Individuals' stories can bring alive experiences of care in a way that data never can; some boards or senior management teams begin each meeting with an individual's story, so they can consider how the organisation needs to change to become more person-centred. We consider this to be good practice for hospitals, care homes and commissioners, as long as the lessons learned from such stories lead to boards and managers implementing improvements throughout the organisation and monitoring progress.

All hospital trust boards are required to compile an annual report of the complaint information they have received and what the organisation learned from it. As part of their commitment to openness and accountability, trusts should publish this report, with a summary of all feedback from patients, relatives, carers and advocates, and explain how it is being used to improve services.

Every non-executive director and senior manager needs to invest time in getting a personal impression of how care is being delivered. This should include talking with people receiving care, their families, carers and advocates. Staff seeing non-executive directors and managers around the building, and hearing their questions about dignity, will understand that the organisation sees dignified care as a priority.

Recommendation 13 – non-executive directors and senior managers

Non-executive directors and senior managers need to invest sufficient time in seeing what is happening in their organisations to get a personal impression of how care is being delivered. This should include talking with older people, their families, independent advocates, visitors and staff.

Hospital boards and care home managers have a duty to ensure that buildings, beds and equipment are suitable for use with older people, particularly those with dementia. The University of Stirling Dementia Services Development Centre published guidance on building design in 2007, drawn from case studies and international good practice. The King's Fund has been working with NHS trusts on using design to help patients with dementia as part of its Enhancing the Healing Environment project.

Recommendation 14 – hospital and care home managers

Refurbishments and the design of new buildings should be suited to the needs of older people and those with dementia or disability.

Much has been done to improve access to single-sex accommodation, toilets and bathrooms, which helps to support dignified care for people of all ages. This drive must continue, but, as single rooms become more common in hospitals, staff must ensure that they do not lead to older people feeling shut away and isolated.

Building a caring community in care homes

While hospital care is largely a publicly delivered service free at the point of delivery, residential and nursing home care is predominantly delivered by independent organisations, varying substantially in size – from large national companies to small individual homes. Access to publicly funded social care is both means-tested and needs-assessed. Local authorities decide the budget and set local criteria for receiving care. More than 40 per cent of care home residents fund all their own care.

A local authority commissioner may have contracted for a care home place, or families and carers may have made arrangements on behalf of an older person. But irrespective of who has commissioned the care, the care home must focus on supporting the resident with the best care possible.

Care homes are exactly that – they are the place that 400,000 people call home, and care home providers and staff must reflect this in their work. A person may well be in a care home for the rest of their life, and will probably move there at a time of particular stress, such as bereavement or a sudden decline in their health.

Being a caring community must be the overarching principle that guides care home life. Care homes need to work with residents, families, carers and advocates to create an environment that makes their lives happy, varied, stimulating, fulfilling and dignified.

Care homes must be more than places where the only goal is to keep residents clean, dressed and well fed. This means turning a task-orientated approach to care giving on its head. For example, the aim must not be to get the person washed and dressed as quickly as possible in order to move on to the next task, but should be to help the resident choose their clothes and prepare for the day ahead. The My Home Life movement (see the case study on page 18) aims to support care homes in achieving this approach.

Recommendation 15 – care home managers and team leaders

It is important that care plans reflect what the person would like to do for themselves. Care homes should ensure that every resident has a care plan that identifies their own wishes, preferences and priorities, and addresses the support they need to retain and develop their sense of dignity and personal identity.

Needs relating to all dimensions of the person's life should be assessed – not only physical and mental health needs but also social and spiritual aspects.

The care plan should be kept up to date as the resident's circumstances change. This information should be developed in conjunction with the resident and, where appropriate, with family, carers and advocates. This personal knowledge can be invaluable, for example by providing an insight into what the resident's usual behaviour is like, so that staff can identify changes.

Developing an 'enriched' environment for residents, family, friends and staff is central to building a caring community. Nursing experts from Sheffield and Northumbria universities have developed the 'six senses' framework, setting out the key components that a care home should seek to achieve, to ensure that everyone feels valued (Nolan et al., 2006). These 'six senses' are:

- a sense of security – to feel safe and secure (including feeling free from threat or harm – but not to the extent that no risks are allowed – as well as feeling free to complain without fear of reprisals)
- a sense of belonging – to feel 'part of things', both within the home and the wider community, and to be able to maintain existing relationships and to form new ones

- a sense of continuity – so that people’s individuality and life history are recognised and valued, and used to plan and deliver care that is consistent with their wishes and preferences
- a sense of purpose – having valued goals to aim for, the sort of things that make it worth getting out of bed in the morning, and provide a feeling of ‘I have a contribution to make’
- a sense of achievement – being able to achieve your goals and to feel satisfied with your efforts
- a sense of significance – feeling that you ‘matter’, that your life has importance, and that other people recognise you and who you are.

As we age, our sense of significance is threatened as we cope with losses – of work, health, a partner, friends or independence. Creating an environment in which older people feel they ‘matter’ is crucial.

A caring community involves older people as full and active participants, rather than seeing them as passive recipients of care. This means recognising and supporting the roles that everyone plays in developing a sense of community, and creating opportunities for meaningful participation in everyday life within the home.

Providing the right environment can help to develop a caring community, such as by having a choice of communal areas where people can socialise with other residents, staff and visitors, and where they can enjoy their hobbies and interests, and facilities such as gardens.

A move into a care home can strain relationships with families and friends, and residents risk losing touch with people. Creating an environment where visitors are welcome and residents are able to offer hospitality is key to maintaining these links.

Company at mealtimes, for instance, should be welcomed, as meals are an important part of the day and a good opportunity for residents to socialise with each other and with family, friends and staff.

Websites that provide user feedback on care homes enable prospective residents to find out more about individual homes. These websites could bring considerable benefits, if they are widely used by residents and their families.

Volunteers can greatly enhance the quality of life in care homes. For example, getting older does not mean losing the desire to learn new skills or pursue hobbies and interests. There are inspiring examples of volunteers teaching care home residents languages or how to play musical instruments, among countless other pursuits. Activities in care homes need to be varied and tailored to individual residents. Simply having an activity co-ordinator is not enough.

Building links with the wider community is an important part of creating a caring environment and developing a culture of openness. More should be done to ensure that care homes are part of the wider community, by fostering links with local organisations, such as schools, community and faith groups and the voluntary sector. This could include opening up care homes to wider community activities, by offering meeting facilities for local groups.

The use of technology is currently limited in many care homes, yet it has huge potential to improve the quality of life. The use of pressure and infra-red sensors, for example, can alert staff to someone getting out of bed who may require assistance. While technology can not be used as a substitute for appropriate numbers of properly trained and managed staff, access to technologies to assist those lacking mobility or with sensory loss could enable them to enjoy a more independent life.

Helping residents to keep in touch with family and friends through Skype and similar systems could help to maintain important relationships and reduce isolation.

Computers, such as tablets, could help residents to pursue interests and access facilities such as e-libraries. Technology should be provided to residents in their rooms, if they wish. The use of entry systems, such as CCTV and swipe cards, can enhance the security of both residents and staff.

Recommendation 16 – care home and hospital managers

Care homes, as well as hospitals, should invest in greater use of technology, to improve the quality of care and to support residents in enjoying active and independent lives.

Creating a caring community includes ensuring that care home residents have access to medical care. While residents should have the option of continuing with their own GP where that is possible, there are advantages in one GP practice providing GP services for an entire care home. This enables care to be planned, with regular visits and assessments and a strong emphasis on managing long-term conditions, rather than responding to acute illnesses and crises. Local authorities must ensure that there is good provision of primary care when commissioning care home places. Care home staff need training in medicine management, as well as management of key health issues for older people, such as continence and prevention of pressure sores.

Recommendation 17 – care home managers and commissioners

Residents in care home have the same rights to NHS care as everyone else. Managers need to ensure that there is effective co-operation with NHS community services, while commissioners need to ensure that care homes have the right clinical support.

The importance of human rights, equalities and safeguarding

Although delivering dignity in care can not be achieved by regulation and legislation alone, they have an important role to play in establishing what is – and what is not – acceptable.

International and domestic human rights legislation, such as the European Convention on Human Rights and the 1998 Human Rights Act, is important in framing and underpinning the right to dignified care. The Government has clarified that where a care home is providing care arranged by a local authority, the care home is a public body for the purposes of the Human Rights Act. However, people who are self-funded – over 40 per cent of residents – are not offered this protection.

Recommendation 18 – government

The Government must ensure that every person receiving care in a hospital or care home is offered the protection of the human rights legislation regardless of the funding arrangements.

Important rights for those in care include the right not to be treated in an inhuman or degrading way. This includes treatment that causes severe mental or physical suffering or that is grossly humiliating and undignified, whether or not it has been inflicted deliberately. According to the Department of Health 2008 guidance document *Human Rights in Healthcare: A framework for local action*, this encompasses leaving someone in soiled sheets or leaving trays of food when the person needs help to eat. It also includes using excessive force to restrain someone in care. The right to privacy includes treatment on wards or in care homes.

As the Department of Health's guidance says, putting human rights at the heart of the way care services are designed and delivered makes for better services for everyone, with the experiences of patients and staff reflecting the values of fairness, respect, equality, dignity and autonomy. The Department of Health needs to ensure that all staff are helped to put human rights at the heart of care services.

Hospitals and care homes should recognise that age is a 'protected characteristic' under the 2010 Equality Act, and it should form part of their policies and practice around equality. Staff should be helped to understand the implications of this for their work.

There is a lack of reliable data on the abuse of older people in the health and social care system. This needs to change, with organisations having a common understanding of what constitutes abuse and a consistent approach to recording it. Staff are not always aware of the difference between poor care and abuse, so abuse is often not reported through what is known as the 'Protection of Vulnerable Adults' process. Many staff are also unaware of their responsibilities to safeguard people in their care from abuse. It should be mandatory for hospitals and care homes to ensure that staff have received appropriate safeguarding training, and understand the provisions in the Department of Health 2011 guidance *Safeguarding Adults: The role of health services*.

Commissioning dignified care

Under the 2012 Health and Social Care Act, commissioning of hospital services is largely to be the responsibility of local clinical commissioning groups, while the NHS Commissioning Board will be responsible for primary care and many specialist services. Local authorities are responsible for commissioning care home placements, alongside those commissioned by older people themselves and their families and carers.

Commissioning care services involves, among other aspects:

- developing a shared vision of high-quality care with service users and providers
- working with providers to improve quality and integrate more effectively with other services
- listening to feedback from services users and their representatives
- holding providers to account for any shortcomings.

To commission high-quality care, it is important that the shared vision articulates a consistent understanding across the care system of what dignified care means.

Recommendation 19 – commissioners, providers and regulators

The new quality standard for patient experience in NHS adult services from the National Institute for Health and Clinical Excellence (NICE), which includes dignity, should be used by commissioners, providers and regulators across health and social care to provide a consistent approach to defining and measuring performance.

NHS organisations should be required to include their performance on the new quality standard as part of their quality accounts – their annual report about the quality of the services they provide.

Dignity must also be reflected in the forthcoming quality standards in social care, which NICE is now responsible for setting. Every care provider should have a strategy, which defines what the quality standards mean for their organisation, and should implement it through their improvement plans.

Commissioning NHS care

The National Quality Board of the NHS identifies experience, effectiveness and safety as the three pillars of quality, yet a central part of patient experience – dignity in care – is not sufficiently addressed in the work of health commissioners. The extent to which individuals are treated with dignity by care providers is often invisible to them. Commissioners must be held to account alongside their providers for ensuring that care is dignified and person-centred.

The health secretary will lay down the NHS Commissioning Board's objectives from April 2013 in the 'mandate', as stipulated in the Health and Social Care Act 2012.

Recommendation 20 – government

The health secretary's mandate to the NHS Commissioning Board should specify the commissioning of dignified care as a key objective. The board must consider how to specify dignity in its own commissioning, such as for specialist services and primary care.

Improving the quality of healthcare features in the board's guidance to clinical commissioning groups and is integral to both its authorisation process and its annual assessment of performance. As part of these requirements, commissioners should prioritise the assurance of dignity within their plans for quality improvement, putting it alongside other priorities, such as financial performance.

Securing dignity in care means that commissioners must be satisfied that providers have worked effectively with patients and their representatives in developing their plans and assessing their performance.

Recommendation 21 – NHS Commissioning Board

The NHS Commissioning Board must satisfy itself that commissioning organisations properly consider how to specify the dignity standards they expect to be delivered, and have a shared understanding with providers of what that means in practice. The Board should review the extent to which commissioning organisations performance-manage providers to deliver the required standards.

Commissioners have a duty to ensure that there is evidence that dignity in care is being provided, through robust measures put in place by providers to capture feedback from older patients, their families, carers and advocates. Commissioners should assure themselves that a hospital's leadership – including the board – is acting on the feedback. In some cases, commissioners need the levers to decommission where there is failure.

The NHS Operating Framework – the manual which sets out NHS priorities for the year and establishes what hospitals will be paid for their work – has made dignity a high priority for 2012–13. This is a welcome step, but it needs to be reinforced by making payments to hospitals dependent on meeting high dignity standards. The NHS Commissioning Board and Monitor, the foundation trust and financial regulator, should consider how achievement of dignity in care can be reflected in the system for funding hospitals.

The NHS Commissioning Board should constantly reinforce the need to provide dignified care, reflecting the rights set out in the NHS Constitution.

Commissioning care home placements

When local authorities place clients in care homes, they should make sure that each older person has a care plan that includes providing dignity in care, maintaining personal identity and giving effective support when their circumstances change. Requirements should be placed on care homes to ensure that residents funding their own care receive the same protection. Local authorities should require robust data on compliance, with individual care plans to ensure that providers follow them.

Recommendation 22 – local authorities

Commissioners of care home services must incorporate dignity into all their standards and requirements. Standards must reflect the need for care homes to involve residents, families and carers in decision-making, so that relationships between residents and staff are based on interaction rather than dependence.

Assessing needs

If needs are not known, they cannot be met. So to begin to uphold the rights of patients and residents, detailed assessment is key for everyone receiving care. Assessment is a continual process.

Assessment needs to include issues such as:

- underlying physical and mental conditions
- need for pain relief
- wellbeing
- ability to hear, see, understand and communicate
- important everyday needs, such as foot care.

The fact that poor care persists indicates that assessment systems are not always picking up problems and addressing them.

Recommendation 23 – doctors, ward sisters, charge nurses and care home managers

Hospitals and care homes need to assess older people when they are admitted, so a co-ordinated care plan can be developed. They need to be reassessed periodically throughout their stay, and before they are discharged, and action should be taken as a result. When undertaking assessments, staff must take time to understand and record the needs and preferences of older people, including cultural and spiritual needs, and their relationships with family, friends, carers and advocates, in addition to recording physical and mental health.

Regular reassessment will help to ensure that medication is started and stopped at the right times, that pain and nutrition are managed, and that basic errors (such as forgetting to end 'nil by mouth') do not occur.

There is a range of guidance and toolkits that can be used, such as the 2011 *Quality Standards for the Care of Older People with Urgent and Emergency Care Needs*, known as 'the Silver Book'. For frail older people, the *Comprehensive Geriatric Assessment tool*, part of the British Geriatrics Society good practice guidelines (2010), may be appropriate. An evaluation of the effectiveness of the *Comprehensive Geriatric Assessment* for older people admitted as an emergency published in the *British Medical Journal* by Ellis et al. (2011; 343:6553) concluded that its use increased patients' likelihood of surviving and returning to their own homes.

Nutritional screening is often overlooked altogether or not maintained – a fundamental and intolerable failing. NICE recommends nutrition screening for older people in hospitals. Mealtimes are also an important part of the day and can be a good opportunity for people to socialise with each other and with family, friends and staff. This should be facilitated wherever possible.

Recommendation 24 – doctors, ward sisters, charge nurses and care home managers

Nutritional status and needs must be identified on admission, food intake must be constantly monitored, and action must be taken to ensure that each person has enough to eat and drink.

Listening to older people, their families, carers and advocates

Delivering dignified care requires giving older people and their families, carers and advocates a voice. This ranges from personal conversations between an older person and a member of staff to working with families and consulting representative bodies. Each of these points of contact helps to keep the care system focused on the needs of individuals, gives it the insights to drive improvement, and empowers service users to shape the care that is provided.

Families, friends and carers are a vital emotional support, and working with them is one of the pillars of dignified care for older people. Among many other contributions that families, friends and carers make, they can be invaluable in knowing what the person's normal condition and behaviour are like, enabling them to spot changes that clinicians have missed or to help minimise and manage confusion.

But working with families, friends and carers is not always easy. A move to a care home or an admission to hospital is a stressful time for everyone concerned. They may be feeling anxious or guilty about their loved one, coming to terms with changes brought on by dementia or illness, or struggling with the knowledge that their relative is approaching the end of their life. Staff need to appreciate these pressures and respond to them with skilled, sensitive and empathetic support. Training and development for care staff, and policies and practice, need to incorporate working with families, friends and carers as a valued part of the care system.

Many families, friends and carers will need to visit outside normal working hours, such as in the evening or at weekends, and it is important that they are able to raise issues with senior staff. Hospitals and homes should consider how they can best manage their visiting hours and working patterns to engage with families,

and how they can make sure that issues raised outside core working hours that cannot be resolved immediately are logged and followed up promptly by senior staff.

Recommendation 25 – all staff

Families, friends, carers and advocates should be seen as partners in care, where the older person wishes it, not as a nuisance or interference.

If the older person wishes it, family, carers and advocates should be encouraged to come into hospitals and homes to enhance care. Company and help at mealtimes, for instance, should be welcomed. However, hospitals and care homes must not rely on visitors to provide essential care.

Relatives and carers may have an important role to play in representing a person's interests, if they do not have the mental capacity to make decisions without support. Staff need to understand the basic provisions of the 2005 Mental Capacity Act. In particular, they need to recognise that the Act strengthens, not diminishes, the requirement to involve the individual as much as possible in decisions about their care. A person should have as much help as possible to make their own decisions. Where they cannot make a complicated decision, this does not mean that they can not make more straightforward choices.

Understanding the older person as an individual, rather than just their medical condition, is key to providing care that is tailored to the needs of each individual. The Commission has identified a number of practical tools that can help staff to understand the older people they care for, such as a 'This is Me' record, which is owned by the individual, tells something of the person's life story and experiences, explains their preferences, and puts them in the wider context of family, friends and carers.

Recommendation 26 – government

The Department of Health should consider the best way of providing a 'This is Me' type record for older people when implementing *The power of information*, its 2012 information strategy for health and social care.

Local care services may also wish to consider whether existing social networking tools, such as Facebook or LinkedIn, could be adapted for use by older people and their families to develop a 'This is Me' (http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=1290) type record that could be shared with all the professionals in a hospital, a care home, the GP clinic and other support services involved in an individual's care.

Feedback from older people gives care services vital information for developing patient-centred care. Older people, their families, visitors and advocates should be urged to give feedback, to help hospitals and care homes continually learn and improve.

Recommendation 27 – managers and boards

Hospitals and care homes must put in place mechanisms to solicit extensive feedback from older people, their families, carers and advocates – and must act upon it.

Feedback needs to include information gathered after discharge. These mechanisms should be systematic across all services, with regular reporting on progress displayed publicly. Feedback and complaints should be regularly discussed with individual staff, care teams and at board level.

Some people may not fully articulate their concerns if they are not sought out. This may be because they are afraid of causing a fuss, are reluctant to criticise staff or have low expectations.

Hospitals and care homes should use staff, advocates or volunteers who have the time, skills and training to secure feedback. They should also engage with community groups to hear about issues that are raised through other channels, for example by talking to older people attending community centres or older people's forums, including those among minority ethnic groups.

Providing end-of-life care tailored to the wishes and needs of each individual is central to dignified care. All hospitals and care homes need to recognise the right of older people and their families to choose, as far as is practicable, where they die and how their end-of-life care is managed.

Recommendation 28 – hospital and care home managers

Hospitals, community care services and care homes should provide a seamless end-of-life care service to enable individuals and their families to exercise choices in their end-of-life care, including dying at home or in their care home. Hospital admissions should be avoided where possible, if that is not the wish of the individual.

There are many examples of good practice in end-of-life care. These include the *Gold Standards Framework* for end-of-life care and *Six Steps for Success*, developed by Greater Manchester and Cheshire Cancer Network, the Merseyside and Cheshire Cancer Network and the Cumbria and Lancashire End of Life Care Network. All care staff should have an understanding of end-of-life care.

Case study:

Understanding what matters to patients – Northumbria Healthcare NHS Foundation Trust

Northumbria Healthcare NHS Foundation Trust covers the largest area of any health trust in England, providing integrated health and social care through three general hospitals and seven community hospitals.

It aims to deliver exceptional service quality, by understanding what matters to patients, setting its service goals based on that understanding, establishing a work plan to make it happen, and relentlessly tracking delivery and acting quickly on the data.

Staff from the trust understand that the things that matter to patients are aspects such as consistency and co-ordination of care, being treated with respect and dignity, cleanliness and pain control. Everyone in the trust is encouraged to focus on this approach, from the directors to the ward staff.

Measurement is carried out through a wide range of techniques – from major surveys to interviewing 400 patients every month. This includes asking questions such as:

- Did you have enough time to discuss your health or medical problem with the doctor?
- Did the doctor explain the reasons for any treatment or action in a way you could understand?
- Did you have confidence and trust in the doctor examining and treating you?

Results are gathered for each individual consultant. Swathes of detailed data are given to the public. The results are impressive, and scores for aspects of care such as dignity and service co-ordination rose significantly in 15 months.

The trust has a strong focus on supporting patients with dementia. To explain how dignified care can make a difference, the trust quotes author Christine Bryden, who was diagnosed with dementia at a relatively young age and has written about her experience. She has explained why dignified care makes a profound difference to quality of life, saying: ‘As we become more emotional and less cognitive, it’s the way you talk to us, not what you say, that we will remember. We know the feeling but do not know the plot. Your smile, your laugh, your touch are what we will connect with. We’re still here in emotion and spirit – if only you could find us.’

Making care homes more accountable to residents

Involving residents in decision-making should go beyond mere consultation. Care homes must be managed so that residents have a say in how decisions are made. For example, decisions about activities, menus, redecorating the home, or ‘house rules’ should be made in conjunction with residents, families and advocates.

Recommendation 29 – care home managers

All care homes should draft a residents’ charter and promote it to current and future residents, laying out their care standards and residents’ rights. This should be accompanied by an evaluation by residents, their families, carers, advocates, staff and volunteers of how well the home is meeting its commitments.

The residents’ charter should set out how residents and staff will work together to make decisions about day-to-day life in the care home. This should include provisions for an effective residents’ and relatives’ group, where staff, managers, residents, relatives and independent advocates regularly discuss management of the home.

Recommendation 30 – Care Quality Commission

When assessing a care home, the Care Quality Commission should judge the extent to which residents are given a say in its day-to-day running.

The role of patient and resident advocates

Independent advocates for people in hospitals and care homes can be a powerful force for change. They can champion dignified care on the ward or in the home, by engaging with the staff or taking people’s complaints and insights straight to the senior management and board. They can ensure that patients and residents know that dignity is a right not an aspiration, and can strengthen accountability, for example by publishing information on how residents and patients have been cared for and how well the home or hospital has responded to shortcomings.

Most people who are receiving care, and particularly older people, are reticent about criticising their treatment when first asked. The barriers to people being able to highlight poor care are immense, and the stress of having to do so can undermine their wellbeing. Advocates can give them a voice, taking the time to put people at their ease and gently persuading them to explain how they feel. People are often more willing to express themselves to an independent person rather than to a member of staff. Advocates help people feel listened to, respected and supported.

Advocates can have a particularly important role in supporting people with dementia, taking the time to understand their experiences, feelings and concerns, and making sure that those views are heard and acted upon.

There are four factors that help advocates to make a difference:

- they need to be properly trained
- they need to operate autonomously within the hospital or care home
- they need free access to patients and residents, their relatives and friends
- they need to be able to take their concerns straight to senior managers or the board.

Training is required to help advocates talk with patients, care home residents, relatives and staff in an appropriate way, learn how to empathise with both service users and staff, and feed back what they have learned constructively.

Recommendation 31 – managers and commissioners

Hospitals and care homes should work with local advocacy groups to provide access to independent advocates for older people and their families. Commissioners should consider requiring independent advocates in service specifications, who would then give feedback to both the commissioners and the providers.

Case study:

The benefits of advocacy in Barnet

Advance, part of Advocacy in Barnet, provides advocacy support for older people in more than 30 care homes, day centres and housing services in Barnet. It aims to: dramatically improve the way in which people address issues about their care; drive up standards; and help people to have a richer quality of life.

Advance recruits volunteers aged 50+ and trains them in advocacy skills. The volunteers visit people in care homes, day centres and lunch clubs supporting people to:

- obtain services from the NHS, council and local community
- raise concerns about care
- address safeguarding issues
- help to negotiate care home placements.

Sometimes the advocates speak on behalf of the older person, but often they support the person to speak for themselves.

One beneficiary living in a residential home, was sight-impaired and frustrated about not being able to read. His advocate found out about a cassette library and the housebound reader service, and the beneficiary is now going to a book group and attending a discussion group in the community centre.

Advocacy in care settings has a ripple effect, and working with one individual can make a difference to all residents. Advance is currently supporting a nursing home resident to have his personal needs and wishes recognised, in particular a change to a later dinner and bedtime. Advance's involvement has led to staff at the home being more alert and attentive to residents' individual needs.

In another care home, advocates helped one resident to request more engagement activities, resulting in coffee mornings on each floor, and a new rose garden, where residents can plant a rose in memory of former residents and friends who have died.

Spiritual and religious care

Spiritual and religious support is important to many patients and residents. Care planning should take account of religious and spiritual needs, particularly in relation to end-of-life care. Care homes should encourage links with faith communities.

The role of HealthWatch

The 2012 Health and Social Care Act establishes a new organisation, HealthWatch England, to be the 'consumer champion' of users of health and adult social care.

From late 2012, HealthWatch will advise the health secretary and the NHS Commissioning Board, while local HealthWatch bodies will represent the views of service users, carers and the public on local health and wellbeing boards.

From 2013, the local HealthWatch bodies will support people who make a complaint about services.

Recommendation 32 – HealthWatch

HealthWatch England and local HealthWatch organisations should put dignity in care at the centre of their work. In particular, HealthWatch should give a voice to people with dementia.

The role of health and wellbeing boards

The health and wellbeing boards established under the 2012 Health and Social Care Act will have a powerful role in promoting dignity. Bringing together clinical commissioners, health professionals, local authority professionals, local HealthWatch organisations and – crucially – locally accountable councillors, they will be uniquely placed to encourage and champion dignity right across the health and care system.

The role of foundation trust governors

As part of the governance of NHS foundation trusts, governors are the elected and appointed representatives of staff, patients and local stakeholders. They are intended as a link between a foundation trust and the community it serves.

The board of governors has the power to appoint the chair and the other non-executive directors, and also has the authority to remove them. As community representatives, governors should ensure that the foundation trust is delivering dignified care, and should hold the board to account for any failures.

In preparing the foundation trust's forward plan, the board of directors must have regard to the views of the board of governors. The governors should encourage the directors to establish a devolved, empowering leadership style, which enables staff to do the right thing for patients.

The role of charities

There is much that the NHS and social care can learn from many charities, which have an impressively strong commitment to treating older people with dignity, involving them in decisions about their lives and spreading positive messages about the value of older people and their rights as citizens. Age UK, a partner in this Commission, and the Alzheimer's Society are just two among many national and local bodies that have much to offer.

Charities can help hospital and care home management teams to keep a strong focus on dignity, and can work with advocates and volunteers to give older people a voice and to enrich their lives. Many care homes run by charities demonstrate innovation and good practice from which others can learn.

Providing integrated care: moving between home, hospital and care home

The Government is committed to closer integration between health and social care, but there is a long way to go to make it a reality. Too often, older people and their families suffer distress because of the difficulties in these two parts of the care system working together, particularly when moving into or out of hospital.

It is professional boundaries – as well as organisational ones – that stand in the way of integrating health and social care. Staff often make decisions based on the view from their part of the system, rather than from the perspective of the person who has to navigate their way through it. Barriers to accessing healthcare while in a care home are an example of the system losing sight of the individual.

When someone who is receiving health or social care services in their own home is admitted to hospital, these services should maintain contact with the hospital, to ensure continuity of that home support when the person is discharged.

After a spell in hospital, older people often have to endure the stress and anxiety of a new social care assessment and a change of caseworker. This could easily be avoided. Social work teams should not assume that a spell in hospital means a permanent change to care needs.

Being discharged from hospital is a pivotal moment in the care of an older person. Staff should work with social care partners to make sure that the support the person will need is in place when they are discharged. The objective of discharge is not simply to get the person out of hospital, but also to provide seamless support, to ensure a return to their home or care home in the best possible physical, mental and emotional state.

Recommendation 33 – hospital staff

Hospitals should carry out a comprehensive assessment of an older person's health and care needs before they are discharged. The outcome of the assessment must be discussed with the person themselves, their family, carers and others (such as the GP, the care home manager and social workers), to ensure that the right support is in place when they leave hospital. A named staff member should be responsible for each patient's discharge, and the patient and their family should be given their contact details.

It is sometimes the case that older patients who have previously lived in their own home are discharged into a care home, where they remain for the rest of their life. While the move to a care home may be necessary in the short term, it is difficult to make an accurate assessment of someone's ability to live independently while they are recovering from illness. If someone needs to go into a care home after a hospital stay this should, if at all possible, be considered as a temporary arrangement. Where appropriate, support should be put in place to help the person return to their own home.

At present, hospital discharge summaries are often not used effectively as a means of co-ordinating care with a patient's GP. These documents contain valuable information, which can help to determine subsequent care, and should always be sent to the GP. This is in line with the recommendations in the 2012 NHS Future Forum report on information (www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_132086.pdf). The GP should then arrange for a follow-up assessment around six weeks after an older person has been discharged from hospital. This should check whether care arrangements that were put in place when the patient was discharged are still appropriate.

Universities, professional bodies and staff development

Dignity in care should be central to the teaching and training ethos for all health and social care staff, including medical students. Commissioners of education, such as Health Education England and local education and training boards, must ensure that providers of education courses fulfil this requirement. Selection processes for health professionals must ensure that they understand and embrace the idea that they will spend much of their time looking after older people.

Recommendation 34 – providers of education and training

Universities, service providers and professional bodies responsible for preparing the health and care workforce of tomorrow must satisfy themselves that successful applicants have both the academic qualifications and the compassionate values needed to provide dignified care.

Student nurses, medical students and other trainee health professionals need to have dignity instilled into the way they think and act from their very first day. Universities and professional bodies must ensure that all aspects of their education and training programmes reinforce the provision of dignified care, built on the needs of older people, and include an understanding of ageing, dementia and dying. Service users should be involved in reviewing teaching programmes and student assessment procedures.

To reflect the fact that older people make up the majority of patients, universities, service providers and professional bodies should ensure that student placements in hospitals provide a strong grounding in the care of older people. Clinical networks and clinical senates – new professional bodies created under the 2012 Health and Social Care Act – must ensure that dignity is reflected in all their work.

Dignified care is underpinned by good communication. Staff need to have an appropriate grasp of the English language to do their job and to be able to listen, speak clearly and give people time to understand and question what they are saying. Care staff need to have an understanding of how to work with patients and residents who do not have English as a first language.

In public debate about the underlying reasons for poor care, there is often a misconception that nurses are 'over-qualified' to provide for the needs of older people. The myth of the over-qualified nurse is rooted in the wrong-headed notion that caring for older people does not require a high degree of clinical skill; no-one would suggest that paediatric nurses are too qualified to care.

Looking after older people is not simply a matter of common sense and sympathy. On the contrary, an older person is far more likely to be suffering from a range of medical conditions, which require skilled nursing to manage their care and the risks associated with complex needs. Even addressing something as common as incontinence, for example, is not just about visits to the toilet, but also about understanding the reasons, making a care plan and managing the condition. Similarly, falls prevention and working with people who have dementia require training and skill. The myth of the over-qualified nurse is an irrelevant distraction to the debate on securing dignified care for older people.

Regulators

Robert Francis QC is expected to make recommendations regarding the regulation of healthcare in the final report of his inquiry into Mid-Staffordshire NHS Foundation Trust. The three organisations that established the Commission on Dignity in Care for Older People look forward to considering the outcome of that inquiry's work.

The care service will never regulate its way to dignified care. By the time inspectors from the Care Quality Commission have detected problems, poor practice will already have grown deep roots in a hospital or home. Unannounced inspections are a deterrent, but they will not stop poor care. Understanding of shortcomings, a determination to improve, deciding what needs to be done – and doing it all – has to happen locally. But regulation still has an important role, such as in setting the priorities for the care system.

Recommendation 35 – regulators

The regulatory system must place as much emphasis on securing dignity in care as it does on financial and clinical outcomes, when regulating health and social care providers. Professional regulators, such as the General Medical Council, must promote and enforce high standards of dignified care.

Care in hospitals is provided by a mixture of doctors, nurses, allied health professionals and healthcare assistants. With the exception of healthcare assistants, each of these groups is registered and regulated. The question of regulation for healthcare assistants was raised in evidence given to the Commission on Dignity in Care, and a compelling case was made that, to help secure personalised and dignified care, all staff who provide care on hospital wards should be suitably qualified and should have appropriate regulatory oversight.

Healthcare assistants are an integral part of the health and social care team caring for older people. As the NHS strives to improve care standards for older people, employing healthcare assistants who are appropriately trained and qualified will be essential.

Recommendation 36 – government

The Department of Health needs to address the issue of how healthcare assistants should be registered and regulated. It should set minimum training and qualification standards for healthcare assistants in the NHS.

There needs to be a more consistent approach to evaluating care quality in care homes, to help older people, relatives and carers make decisions about care, as well as to help care homes improve. The Government and professionals within the care sector have shown a strong interest in such an approach.

Recommendation 37 – care home providers

The care sector should work with professionals, residents, relatives' organisations, local authorities and government to develop a clear rating scheme for care homes, based on the forthcoming quality standards in social care to be set by NICE.

The Care Quality Commission should take these into account when undertaking inspections and producing reports. Commissioners should notify the Care Quality Commission, when they have concerns that a hospital or care home provider is failing to deliver dignified care.

Making it all happen

This report is just the beginning of a concerted effort to change attitudes and to deliver dignified care.

The three organisations that have established this Commission on Dignity in Care for Older People – the NHS Confederation, Age UK and the Local Government Association – have taken every opportunity to highlight the work of the Commission and are preparing a long-term action plan, which will focus on working with our partners across health and social care to support delivery of the recommendations that we have made. The work will build on all the good practice that currently exists.

The action plan will include the following.

- **Creating a national, regional and organisational sense of urgency to implement dignity in care** – working with the Department of Health, the NHS Commissioning Board, local authorities, professional bodies and individual organisations to build support for prompt and effective action to provide older people with the dignified care that is their right.
- **Encouraging organisations to work together nationally, regionally and locally to build a vision for dignity in care and a commitment to implementing the Commission's recommendations** – bringing together organisations involved in commissioning and providing care with older people, their relatives and representatives.
- **Communicating the vision to users, providers and commissioners of care** – so that everyone knows what standards of care are expected.
- **Empowering people to secure change** – such as by providing patients, relatives and carers with mechanisms to influence how local care is delivered, and putting workforce development programmes in place.

- **Building on existing good practice and creating new examples of good care** – including national showcasing of good practice and showing how it has been achieved.
- **Building momentum to continuously improve care standards for older people** – with staff, boards, commissioners, older people and their representatives monitoring progress and highlighting gaps.
- **Anchoring dignity in care for older people right across the care system** – with service user feedback in all staff appraisals and a continual partnership between older people and staff in designing care provision.

We have begun discussing our recommendations with the secretary of state for health, the NHS Commissioning Board and the Care Quality Commission to agree the best way forward. There will be a launch event in autumn 2012, when we will be inviting people to get involved.

Commissioning and delivering dignified care across health and social care is not something that can be achieved by a series of disconnected projects. Hospitals and care homes need to put in place integrated programmes to improve care, sustained by a long-term investment in energy, time and money to embed cultural and behavioural changes.

If we get care right for older people, we get it right for everyone.

Appendix: Commission members

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Dianne Jeffrey CBE DL

Chairman, Age UK

Councillor David Rogers OBE

Chair, Community Wellbeing Board,
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The Commission especially thanks Professor Brendan McCormack, Director of the Institute of Nursing Research, University of Ulster, and all the members of the academic, nursing and medical reference groups, for their specialist advice.

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This report has been produced by the independent Commission on Dignity in Care, a collaboration established by the NHS Confederation, the Local Government Association and Age UK.

