Local Government Association

NHS CONFEDERATION

age UK
Improving later life

Delivering Dignity

Securing dignity in care for older people in hospitals and care homes. A report for consultation.

Contents

Foreword 2

Getting it right for every older person, every time 3

How to respond to the consultation 3

Key recommendations 5

Changing society's attitudes to older people 7

Who we care for 9

What standards of care do people have a right to expect? 10

Mind the gap: moving between home, hospital and care home 20

Providers of residential and nursing home care 21

Commissioning dignified care 29

Patient, resident and public representation 31

Universities, professional bodies and staff development 33

Regulation 34

Making it all happen 35

Case studies 36

Commission members 39

Foreword from the Commission Chairs

Like many others, we've been deeply saddened by reports 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.

Older people and their loved ones deserve so much better.

This is why we set up the Commission on Dignity in Care for Older People, made up of experts from across the system. The interim report we are publishing today for consultation draws on the body of evidence that we have gathered over the past eight months. We would like to thank everyone who has contributed to our work so far.

We know there are some hospitals and care homes providing great care, and we need to learn from them to get dignified care right for every person every time.

Hospitals and care homes should be beacons to the rest of the community, demonstrating how we are all the richer when older people are respected, valued and celebrated.

Delivering dignity will mean changing the way we design, pay for and monitor services that provide dignified care as the numbers of older people in 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 everyone in care thinks about dignity to ensure care is person-centred and not task-focused.

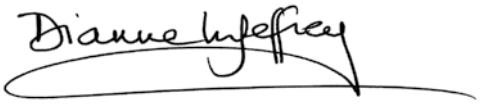
This will require empowered leadership on the ward and in the care home, as well as in the board room. It will mean changing the way we recruit and develop staff working with older people so they have the right values as well as skills.

And we have to do more to listen and respond to patients, residents and their families so we learn from their feedback and continually improve care.

The last thing we want is to produce a report that generates more noise than practical action. It is absolutely clear that we all need to work together to improve dignity in care and earn back public confidence.

We urge all those with an interest in health and social care to respond to these proposals and help make the changes that all of us want to see.

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

Getting it right for every older person, every time

There has now been more than a decade of reports and investigations exposing severe shortcomings in the care of older people, yet the problems persist. The NHS Confederation, Age UK and the Local Government Association established the Commission on Dignity in Care for Older People in July 2011 to identify the underlying causes of these persistent failings, and determine what must change to deliver dignity in the care system, focussing on hospitals and care homes.

This draft report, based on expert evidence, recommends fundamental changes to the culture, leadership, management, staff development, clinical practice and service delivery of care homes and NHS hospitals to secure the dignified care that is the right of all older people, with the belief that if we get it right for older people we get it right for everyone. The three organisations which have established the Commission want to play a major role in supporting hospitals and care homes to improve dignity in care, led by the staff who are working there day to day.

This draft report sets out 'what good looks like', based on evidence from hospitals and care homes that are already providing excellent dignity in care for older people. The report seeks to help hospitals and care homes identify how they need to change to deliver dignity for every person every time. It also sets out the changes that need to take place in the wider health and social care system to support hospitals and care homes in prioritising dignity in care.

How to respond to this consultation

The Commission is issuing this draft report for public consultation. In drafting it the Commission has taken evidence from a wide range of people across health and social care including a literature review of existing publications, written submissions from around 40 organisations, three days of public hearings with evidence from 25 organisations or individuals, feedback from medical, nursing and academic expert reference groups, site visits to hospitals and homes, and meetings with stakeholders and experts.

The Commission will consult publicly on the draft report and recommendations from Wednesday 29 February until Tuesday 27 March, with a view to publishing the final report before the summer. The Commission will then promote implementation of the recommendations through an action plan that asks health and social care leaders to prioritise improving dignity in care for older people.

The Commission is also collating existing tools and guidance that support improved care for older people and identifying good practice examples across health and social care. These will be published alongside the final report to help hospitals and care homes build on current good practice.

You can respond to the consultation by visiting www.nhsconfed.org/dignity and considering the following questions:

- Is the Commission making the right recommendations? If not, how should the recommendations change?
- Are you aware of a particular tool, set of guidance or example of care that the Commission should highlight to help spread existing good practice?
- What would you like to see included in the action plan?

NHS trusts, hospital boards, local authorities, care homes and other interested stakeholders are invited to consider the draft report and respond to the consultation.

Why this Commission was set up – making change happen

This Commission 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. It was the latest in many years of reports identifying what is wrong with the level of dignity in the care of older people and saying what service they should receive. These 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* in 2009, *Patients not Numbers, People not Statistics* by the Patients Association and *Counting the Cost: caring for people with dementia on hospital wards* from the Alzheimer's Society in the same year, and Age UK's *Still 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. We have a good understanding of what the problems are but need to understand why they are persisting and what drives improvement. The aims of the Commission are therefore 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, and drive improvements across health and social care which secure dignity in care for older people in hospitals and care homes. The recommendations in this report are directed at the system in England but we believe that the key messages will 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 document is the beginning of that work. It is based on the knowledge of the commissioners themselves and the many witnesses who gave written and oral evidence. The commissioners bring 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, councils, volunteers, 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. Neither 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 good care for older people; this report and the follow-up programme of activities are therefore intended to build on existing good practice so we get it right for every person, every time.

Key recommendations

Key recommendations for hospitals

1. All hospital staff must take personal responsibility for putting the person receiving care first. Staff should be required to challenge practices they believe are not in the best interests of the people in their care.

2. Hospitals should recruit staff to work with older people who have the compassionate values needed to provide dignified care as well as the clinical and technical skills. Hospitals should evaluate compassion as well as technical skills in their appraisals of staff performance.

3. Hospital boards need to embrace a devolved style of leadership that values and encourages staff and respects their judgment when they are the people working closest with older people and their families. Hospitals must enable staff to 'do the right thing' for patients.

4. The leadership role of the ward sister or charge nurse is crucial. They should know they have authority over care standards, dignity and wellbeing on their ward, expect to be held accountable for it, and take the action they deem necessary in the interests of patients. They should play a leading role in coordinating services to provide the most dignified and seamless care for each person.

5. Hospitals need to provide older people with a comprehensive geriatric assessment when they are admitted, so that a coordinated care plan can be developed. They need to be reassessed regularly throughout their stay in hospital and before they are discharged, and action taken as a result. When undertaking assessments staff must take time to understand and record the needs and preferences of older people and their relationships with family, friends and carers, in addition to recording physical and mental health.

6. Hospitals should see older people's families, friends and carers as partners in care rather than as a nuisance or interference. Hospitals should encourage family, friends and carers to come in and augment care if the older person wishes it, while retaining responsibility for ensuring care is delivered.

7. Boards should regard maintaining each patients' independence as a key measure of their hospital's performance in delivering care for older people. They need to work with patients, relatives and carers to compare a patient's level of independence when they are discharged from hospital with how independent they were before they were admitted.

8. Hospital boards must understand how people experience care in their hospital, and view dignity as a key measure of performance. All boards and management teams must have robust processes in place to collate feedback and complaints from older people, their families and staff so they can identify emerging trends and respond to them. This should include effective whistle-blowing procedures for staff who are concerned about care standards. Hospital boards must respond quickly to any suggestion of deterioration in dignity performance.

9. Feedback from patients and their families should be discussed and responded to on the ward every day. Hospitals should give staff the time to reflect on the care they provide and how they could improve; this is an essential part of giving good care.

10. Hospitals should introduce facilitated, practice-based development programmes – 'learning through doing' – to ensure staff caring for older people are given the confidence, support and skills to do the right thing for their patients.

Key recommendations for care homes

1. The Government should establish a Care Quality Forum (in parallel with the Nursing Quality Forum) to look at all aspects of care home staffing, including issues of status and pay, qualifications, recruitment, retention, development, monitoring and regulation. In the longer term the profession should consider working towards establishing a College of Care to lead on these issues.
2. 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 nationally agreed standards and benchmarks.
3. Care homes need to work with residents to create an environment that make their lives happy, varied, stimulating, fulfilling and dignified. This means involving older people as full and active participants in shaping their daily lives, rather than seeing them as passive recipients of care.
4. Building links with the wider community is an important part of creating a caring environment and developing a culture of openness. Volunteers can greatly enhance the quality of life in care homes.
5. Care homes should invest in greater use of technology to improve the quality of care and support residents in enjoying active and independent lives.
6. All care home staff must take personal responsibility for putting the person receiving care first, and staff should be urged to challenge practices they believe are not in the best interests of residents.
7. Care home providers should invest in support and regular training for their managers. Local authorities have an important role to play in facilitating this as commissioners of care.
8. Boards and managers have a duty to ensure buildings are fit for use for older people, particularly those with dementia.
9. Ensuring access to medical care is an important responsibility of care homes. Residents in a private care home have just the same rights to NHS care as everyone else.
10. Providing end-of-life care tailored to the wishes and needs of each individual is central to dignified care in all care homes. Residents should be allowed to die in their own care home if that is their wish.

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 'population 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 by others, means 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 which 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 Equality Act 2010 is recognition of this. The Act extends the grounds for 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 future needs of an ageing and diverse population, and eliminating discrimination against older people. We need to be alive to trends which appear to exacerbate age segregation, and seek initiatives which can bring different generations together around issues of shared interest and importance.

For any public body to identify what it needs to do to promote age equality, it first needs to understand in its own context what barriers older people face, whether as staff or service users. Ensuring services collect data that can be analysed by age is an essential starting point. Moving beyond this, public bodies need to make sure they engage 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 old people. Such work could eventually make a substantial difference to societal attitudes. Families have an important role to play in helping children 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 to 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 celebrated 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. Among the 8.6 million people over 65 in England, over 400,000 are living in more than 18,000 care homes.

There are 750,000 people currently living with dementia in the UK and this number is projected to rise to 1,000,000 by 2021. The Alzheimer's Society estimates over half a million people will have undiagnosed dementia in that year. About a third of all people with dementia live in care homes. 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 there were 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. The average length of stay is also much longer for older people (the average length of hospital 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. The number of admissions for people aged 75 and over is rising faster than for any other age group.

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 home are discharged to a care home, and many more will be receiving long or short term social care at home or need practical support to get back on their feet. That is just one reason why it is vital that health and social care provide older people with a seamless service. We look forward to the Government's white paper on social care, due to be published in 2012.

Older people often prefer to receive care in their own home, and doing so helps them to maintain their independence, yet many older patients are being 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 around 25 per cent of hospital patients, many of them older people, could be cared for at home or in the community.

Recommendation

1. Securing major reductions in hospital admissions by delivering care at home or in the community when it is appropriate should be a major priority for the health service; it is both cost efficient and care effective and places the patient and their needs at the centre of what we do.

Primary care trusts and clinical commissioning groups should work with local hospitals and primary 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 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 dignity should be as much a feature of the services offered there. Domiciliary and community services should adopt the same principles on dignity as hospitals and care homes, to provide older people with consistently good 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. 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.

For both hospitals and care homes, the Care Quality Commission says providers who 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, to understand the care, treatment and support provided and 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.

Those hospitals, care homes and their staff who provide 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 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 understand their health 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 hospital to a care home, it is essential that knowledge and understanding about them moves with them.

Some of the recommendations made by the Commission are relevant to both hospitals and care homes, while others are more specific to reflect the differences between the two.

Caring for each individual

The way staff interact with an older person has a profound effect on that person's life. If staff assess their clinical and other essential care requirements effectively, find the right way to talk with them, respond to their needs, wants and fears and treat them with respect, the staff will help 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, particularly from carers, revealed how poor or neglectful care even for just a few days can have a devastating impact. Older people describe how their skills, self-help and self-confidence 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 rather than helping them to eat just to save time can feel humiliating and create dependence. Deterioration such as incontinence or immobility can set in extraordinarily quickly.

Recommendation

2. Boards should regard maintaining each patient's independence as a key measure of their hospital's performance in delivering care for older people. They need to work with patients, relatives and carers to compare a patient's level of independence when they are discharged from hospital with how independent they were before they were admitted.

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 with the emotional pain of coming to terms with loss of health. Someone entering a care home for the first time may fear they have lost their independence. They may be frightened, confused, frustrated and angry. Care that is sensitive to life changes and understands the big impact 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, 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 an older person is in contact with a hospital or care home it is vital they are seen as an individual and 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 in the relationship aspects of care. The resulting guidance stressed how patients 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 cognitive impairment, sensory or learning disabilities. Staff should have cultural awareness training 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 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 and comments should never be ignored, even if it is only to take a moment to reassure someone 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 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 well-being. 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 older people are a burden or a nuisance; referring to them by illness reduces them to a clinical condition rather than recognising them as a person; and using patronising language such as 'how are we today dear?' belittles them.

Recommendation

3. 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. Hospitals and care homes should recognise that age is a 'protected characteristic' under the Equality Act 2010, and it should form part of their policies and practice around equality.

Providers of NHS hospital care

Patients and their families

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

- the right to be treated with dignity and respect, in accordance with your human rights
- the right not to 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 you 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.

If needs are not known they cannot be met so to begin to uphold these rights, detailed assessment is key for everyone receiving care. Assessment is a continual process. It needs to include issues such as underlying conditions, need for pain relief, mental health, ability to hear, understand and communicate, and important everyday needs such as foot care. The fact that poor care persists indicates that assessment systems such as ward rounds are not always picking up problems and addressing them.

Recommendation

4. Hospitals need to provide older people with a comprehensive geriatric assessment when they are admitted, so a coordinated care plan can be developed. They need to be reassessed regularly throughout their stay in hospital and before they are discharged, and action taken as a result. When undertaking assessments staff must take time to understand and record the needs and preferences of older people and their relationships with family, friends and carers, in addition to recording physical and mental health.

Regular reassessment will help ensure medication is started and stopped at the right times, pain and nutrition are managed and 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. For example the British Geriatrics Society has published a range of good practice guides. Evaluation of the effectiveness of comprehensive geriatric assessment for older people admitted as an emergency (Ellis et al 2011) concluded that the assessment increases patients' likelihood of surviving and returning to their own homes.

Nutritional screening is often overlooked altogether or not maintained, a fundamental and intolerable failing. The National Institute for Health and Clinical Excellence (NICE) recommends nutrition screening for older people in hospitals.

Recommendation

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

Mealtimes are an important part of the day and can be a good opportunity for patients to socialise with each other and with family, friends and hospital staff. This should be facilitated wherever possible.

Recommendation

6. Families, friends and carers should be seen as partners in care, where the older person wishes it, not as a nuisance or interference. They are the people who were there before and will be there after formal care services have gone, and are a vital emotional link.

They can be invaluable in knowing what the person's normal condition and behaviour are like, enabling them to spot changes clinicians have missed or help minimise and manage confusion.

If the older person wishes it, family, friends and carers should be encouraged to come into hospitals and augment care. Company and help at mealtimes, for instance, should be welcomed. Hospitals should review visiting hours and how they work with older people's families and their wider network. However, hospitals must not rely on families to provide essential care.

Working with families is not always easy; the stress of illness can tax even the most loving relationships and family members can sometimes show their anxiety. Staff need to appreciate the pressures on relatives; they may be grieving for a loved one because of changes brought on by dementia or sudden physical decline, and feeling a range of powerful emotions including anger and guilt. All this requires skilled, sensitive and empathetic handling.

Understanding the older person as an individual, rather than just their medical condition, is key to providing care tailored to the needs of each individual. The Commission has identified a number of practical tools hospitals can use to help staff 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

7. The Government should consider the best way of providing a 'This is Me' record for older people as part of its forthcoming 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, can be adapted for use by older people and their families to develop a 'This is Me' record that can be shared with all the professionals in a hospital, care home, the GP clinic and other support services involved in an individual's care.

Recommendation

8. Older people and their families should be urged to give feedback to help hospitals continually learn and improve. Hospitals must put in place simple mechanisms to ensure direct feedback and any complaints are gathered from older people and their support network, alongside confidential feedback, for example through anonymous surveys.

For example, in the Belfast Trust in Northern Ireland, Professor Tanya McCance has initiated a system with the Nursing Leadership Group to use complaints as one method of evaluating how person-centred the care is in different wards and departments.

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

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, reluctant to criticise staff, or have low expectations when they are feeling unwell. Hospitals should use staff, advocates or volunteers who have the time, skills and training to secure feedback.

Hospitals 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.

Ensuring 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 feel valued and empowered to make decisions will be the ones who support dignified care. Staff who are denied the right training and development, do not feel valued by their organisation, are not encouraged by their managers, and who do not feel they have the freedom to make the right decisions for patients are far more likely to deliver poor 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 make compassion and kindness an integral part of their everyday vocabulary and practice.

Recommendation

9. All hospital staff must take personal responsibility for putting the person receiving care first. Professionally registered staff are required to challenge poor care, and they should be urged to do so as soon as they see any shortcomings. This helps colleagues understand how their interaction with a patient can be improved. Other staff, such as healthcare assistants, should be encouraged to take the same approach.

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

10. Hospitals should introduce facilitated, practice-based development programmes to ensure staff caring for older people are given the confidence, support and skills to do the right thing for patients.

There is little evidence that traditional NHS 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 which is 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 the patient is cared for. 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 need to invest in facilitators who can lead active learning to give staff the confidence to challenge poor care and do the right thing.

Staff can also benefit from carrying out 'peer reviews' of services within or between hospitals to learn from what is working well and constructively challenge what needs to change.

Recommendation

11. Hospitals should recruit staff to work with older people who have the compassionate values needed to provide dignified care as well as the clinical and technical skill.

For example, some hospitals include meetings with patient and service user panels in their recruitment process to assess candidates' values and how they interact with patients, while others use psychometric testing.

Hospitals should consider compassion as well as technical skills in their appraisals of staff performance. Some hospitals include compliments, complaints and feedback from patients and their families in appraisals so that staff learn what they should keep doing and what they need to change.

If a health 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.

Medical revalidation, expected to be introduced for doctors in 2012, offers an excellent opportunity to capture evidence about whether doctors are providing dignified care. Ward round practice and initial patient assessment would be valuable information for the revalidation process.

Recommendation

12. With around a quarter of people in hospital having dementia, national clinical director for Dementia Professor Alistair Burns has argued that 10 per cent of staff should be dementia experts, 50 per cent dementia trained and 100 per cent dementia aware. We recommend all hospitals use this benchmark.

While existing 'dignity champions' perform an important role, everybody involved in the care of older people must feel personally responsible for championing dignified care.

Effective and supportive leadership

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.

Board members, senior managers and senior clinical staff need to be united around a common culture and values. The medical director, nursing director and other senior clinical staff not only need to feel they have more freedom to make major decisions about patient care but also take much more responsibility for securing dignity. This includes working with managers to ensure the hospital enables staff to do the right thing for older patients. For some hospitals this will all be a big cultural shift. The tone of the conversation between the board and senior clinicians is set by the chief executive. It is crucial the relationship is one of collaboration, not conflict.

Securing dignity is not just about nurses, doctors and other staff doing a better job, it is also about chief executives and hospital boards running their organisations in a way that enables staff to do the right thing for the people in their care. If senior managers impose a command and control culture that demoralises staff and robs them of the authority to make decisions, poor care will follow. A major study of health service leadership by the King's Fund health think tank (2011) called for leadership development to extend 'from the board to the ward' to give individuals 'the ability and the confidence to challenge poor practice'.

Recommendation

13. Hospitals need to embrace a devolved style of leadership that values and encourages staff and respects their judgment. This type of leadership is the foundation on which excellent care is built.

Leadership on the board

Recommendation

14. Boards must understand how people experience care throughout their organisation, and see it as a key measure of performance. All boards and management teams must have robust processes in place to collate feedback and complaints from older people, their families and staff so they can identify emerging risks and respond to them. This should include effective whistle-blowing procedures for staff who are concerned about care standards. Boards must respond quickly to any evidence of deterioration in the delivery of dignified care.

In this context individuals' stories can bring individual experiences of care alive in a way data never can; some boards begin each meeting with a patient story so they can consider how the organisation needs to change to become more person centred. We consider this to be good practice for both hospitals and commissioners, as long as the lessons learned from such stories lead to the board implementing improvements throughout the hospital, and reviewing progress at future board meetings.

Every non-executive director and senior manager needs to invest sufficient time in seeing what is happening to get a personal impression of how care is being delivered. This should include talking with patients, their families and carers.

Staff seeing non-executive directors and managers around the hospital and hearing their questions about dignity will understand that the organisation sees dignified care as a priority.

Boards and managers have a duty to ensure buildings, beds and equipment are suitable for use with older people, particularly those with dementia. Refurbishments and the design of new buildings should be suited to the needs of older people and those with dementia or disability. The University of Stirling Dementia Services Development Centre published guidance on building design in 2007 drawn from case studies and international good practice, while 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.

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, particularly older people. This drive must continue, but, as single rooms become more common in hospitals, staff must ensure they do not lead to older people feeling shut away and isolated.

Leadership on the ward

Recommendation

15. The leadership role of the ward sister or charge nurse is crucial. They should know they have authority over care standards, dignity and wellbeing on their ward, expect to be held accountable for it, and take the action they deem necessary in the interests of patients.

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, sisters and charge nurses should build on what is already being done correctly. They must ensure every member of staff coming onto their ward understands the standards of care expected of them, and they should be managed in a way that ensures those standards are met.

Wards are the hub of multidisciplinary teams which include care assistants, doctors, nurses, cleaners, kitchen staff, porters, allied health professionals, clerical staff and managers. The sister or charge nurse should play a leading role in coordinating services to provide the most dignified and seamless care for each patient.

Recommendation

16. Feedback from patients and their families should be discussed and responded to on the ward every day. Immediate feedback to staff is important – discussion on the ward 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. Just as individuals' stories offer powerful insights for boards, they are vital for learning on the ward.

Recommendation

17. Hospitals should 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 a responsibility of the sister or charge nurse to make sure this happens. UK hospitals are increasingly using an approach developed by the Schwartz Center for Compassionate Healthcare in Massachusetts to give care staff scheduled time to openly and honestly discuss 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.

Sisters, charge nurses and other senior and experienced staff 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 patients with dementia. Supporting colleagues in this way should be a formal part of their role.

Although hospitals 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. Hospitals should ensure appropriate managers and suitably qualified staff are available on all shifts, and that night staff have adequate support in emergencies.

Many families, friends and neighbours will visit outside normal working hours, for example in the evening or at weekends, and it is important they are able to raise issues with senior staff. Hospitals may wish to consider how they can best manage their working patterns to engage with families, and how they can make sure issues raised outside core working hours that cannot be resolved immediately are logged and followed up promptly by senior staff.

The boundaries of responsibility between different groups of professionals are a fact of NHS 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 examining, leaving that to the nurse. The result is that responsibility for people's care is divided up between, for example, the ward sister or charge nurse, a physiotherapist and doctors overseeing different conditions.

One doctor graphically described to the Commission how this works in practice: 'Twenty years ago, when the music stopped I was always holding the parcel. Now when the music stops several hands could be on the parcel or it could be on the floor.' Shared responsibility must not lead to shared abdication of responsibility.

Recommendation

18. All clinical staff must understand they have a professional duty to challenge and correct poor care no matter who is technically in charge.

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 consistent record keeping when abuse arises. Hospital 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 nurses are also not always aware of their responsibilities in this regard.

Recommendation

19. It should be mandatory for hospitals to ensure staff are appropriately trained in the Protection of Vulnerable Adults process.

Mind the gap: 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 can 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 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.

Too often older people discharged from hospital have to endure the stress and anxiety of a new social care assessment and a change of caseworker which 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 be working with social care partners to make sure the support the person will need when they are discharged is in place. The objective of discharge is not simply to get the person out of hospital, but to ensure seamless clinical, physical and emotional support and the best possible return to their home or care home.

Recommendation

20. 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 needs to be discussed with the person themselves, family, carers and others such as the GP, care home manager and social workers, to ensure 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 family given their contact details.

It is common for older patients who have previously lived in their own home to be discharged directly 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 a temporary arrangement. Where appropriate, support should be put in place to help the person return to their own home.

At present discharge summaries are not routinely shared with a patient's GP. These documents contain valuable information which can help 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. 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 put in place when the patient was discharged are still appropriate. The outcome of the assessment needs to be discussed with the person themselves, their family and carers, as well as their health and social care support.

Providers of residential and nursing home care

Hospital care is largely a publicly delivered service which is centrally funded, universal and free at the point of delivery, with extensive national guidance and a large proportion of highly trained and regulated staff. In contrast, residential and nursing home care is predominantly delivered by independent organisations, varying substantially in size from large national companies to small individual homes. State funding of the NHS is nearly 14 times that allocated to social care, and 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. Many older people fund their own care.

Care home providers are often involved with more than one party when supporting a resident. A local authority commissioner may have contracted for the care home place, or families and carers may have made arrangements on an older person's behalf. But irrespective of who has commissioned the care, the care home must focus on supporting the resident with the best care possible.

Recommendation

21. Care homes should apply the same values and respect for human rights irrespective of narrow legal differences around the rights of residents depending on who is funding their care.

Where there are commissioners involved, they must ensure their values and priorities support the resident in getting the care they want.

The quality of the staff and the relationship each resident has with them is key to dignified care. Care home staff undertake demanding work but they are often poorly paid, poorly regulated, have too little access to training and support, and lack professional status.

Recommendation

22. The Commission recommends that the status and role of those working in the care sector needs to be elevated to assist the better integration of health and social care. The Government should establish a Care Quality Forum (in parallel with the Nursing Quality Forum) to look at all aspects of care home staffing, including issues of status and pay, qualifications, recruitment, retention, development, monitoring and regulation. In the longer term the profession should consider working towards establishing a College of Care to lead on these issues.

There needs to be a more consistent approach to defining care quality to help older people, relatives and carers make decisions about care, as well as help care homes improve. Nationally agreed standards and quality indicators would help drive up quality and guide those choosing a care home in understanding what is important. The Government and professionals within the care sector have shown a strong interest in this approach.

Recommendation

23. 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 nationally agreed standards and benchmarks.

The Care Quality Commission should take these into account when undertaking inspections and producing reports.

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.

Building a caring community

Care homes are exactly that – they are the place that 400,000 people call home, and the health and social care providers must reflect this in their work with older people. 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.

Recommendation

24. Care homes need to work with residents to create an environment that make their lives happy, varied, stimulating, fulfilling and dignified. Being a caring community must be the overarching principle that guides home life. The My Home Life movement (see case study) aims to support care home managers in achieving this.

Care homes must be more than just aimless places where the only goal is to keep residents clean, dressed and well-fed. This means turning on its head a task-orientated approach to care giving. 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.

Recommendation

25. It is important that care recognises what the person would like to do for themselves. Homes should ensure that every resident has a care plan that refers to residents' personal wishes, preferences and priorities and to the support they need in order to retain and develop their sense of dignity and personal identity.

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 and friends. 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 and 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 home should seek to achieve to ensure everyone feels valued (Nolan et al 2006). These are:

- **A sense of security** – to feel safe and secure. That is to feel free from threat or harm, but not to the extent that no risks are allowed, and also, for example, to feel free to be able 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 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 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 develop a caring community, such as by having a choice of communal areas where people can socialise with other residents, staff and visitors and enjoy their hobbies and interests, and facilities such as gardens.

Recommendation

26. Boards and managers have a duty to ensure buildings are fit for use for older people, particularly those with dementia.

Refurbishments to existing buildings and the design of new ones should be suited to the needs of older people and those with dementia or disability. The University of Stirling Dementia Services Development Centre published guidance on building design in 2007 drawn from case studies and international good practice, while 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

27. Families, friends and carers should be seen as partners in care, where the older person wishes it, not as a nuisance or interference. They should be encouraged to be an active part of the care home's community.

A move into a care home can put strain on 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 they are an important part of the day and a good opportunity for residents to socialise with each other and with family, friends and staff.

Recommendation

28. Building links with the wider community is an important part of creating a caring environment and developing a culture of openness. Volunteers can greatly enhance the quality of life in care homes.

For example, getting older does not mean the desire to learn new skills or pursue hobbies and interests is lost, and 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 coordinator is not enough.

More should be done to ensure care homes are part of the wider community by fostering links with local organisations, for example with schools, community groups and the voluntary sector. This could include opening up care homes to wider community activities by offering facilities for local groups to meet. Welcoming volunteers and seeking to build links with the wider community is also an essential component of developing an open culture that embraces transparency and scrutiny and does not hide behind closed doors.

The use of technology is currently limited in many care homes. While technology cannot be used as a substitute for appropriate numbers of properly trained and managed staff, it has huge potential to improve quality of life, maintain independence and improve safety. The use of pressure and infra-red sensors, for example, can alert staff to someone getting out of bed who may require assistance. Using systems, for example swipe cards or CCTV, in parts of the home open to the public can enhance the safety of both residents and staff. Providing access to technologies to assist those lacking mobility or with sensory loss could enable them to enjoy a more independent life. Helping residents keep in touch with family and friends through Skype and similar systems could help maintain important relationships and reduce isolation. Electronic tablets and other computers could help residents pursue interests and access facilities such as e-libraries. Technology should be available to residents in their rooms if they wish.

Recommendation

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

Ensuring every member of staff is responsible for dignity

Working in care homes has its own particular pressures. Staff can feel isolated, and it may be difficult for them to see excellent care in action and to get the right development. These can be tough issues to solve, particularly for small care homes.

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.

As care home staff are often not qualified or regulated, having good recruitment procedures in place is essential. Staff must have the right attitudes towards being in a caring role. Relatives and residents 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. The selection and recruitment of staff should include an opportunity for candidates to demonstrate how they interact with residents.

Having recruited staff, there needs to be a strong focus on training on the job, along with providing a rewarding working environment which recognises good performance and is set within a sound career structure.

Recommendation

30. Regular appraisal is an essential part of staff development and quality improvement. Care homes should include 360 degree reviews of staff that incorporate feedback from residents, relatives, carers and independent advocates as well as peers and managers.

Just as in hospitals, staff need to be clear it is their responsibility to challenge neglectful behaviour as soon as it occurs, and make compassion and kindness an integral part of their everyday vocabulary and practice. Staff need to focus on each individual, not on systems and tasks in themselves. 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

31. All care home staff must take personal responsibility for putting the person receiving care first, and staff should be urged to challenge practices they believe are not in the best interests of residents.

Working with families is not always easy. Moving to a care home is often a stressful time for residents and their families. 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 the pressures on relatives and respond to them with skilled, sensitive and empathetic support. Training and development for care home staff and managers needs to incorporate working with families.

There are many examples of good practice in end-of-life care for care homes. 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 staff should have an understanding of end-of-life care.

Recommendation

32. Ensuring access to medical care is an important responsibility of care homes. Residents in a private care home have just the same rights to NHS care as everyone else. Managers need to ensure there is effective cooperation with NHS community services, and all care home staff, including assistants, should be given basic training such as first aid and identifying the warning signs for pressure sores.

Recommendation

33. Providing end-of-life care tailored to the wishes and needs of each individual is central to dignified care in all care homes, whether they are residential or nursing facilities. Residents should be allowed to die in their own care home if that is their wish; hospital admissions should be avoided where possible if that is not the wish of the individual, and should not be made simply because it is easier for the home. NHS services should give the support to enable people to die in their care home, an important example of integrating health and social care.

Effective and supportive leadership

To create a caring community, the values of dignity must be consistently communicated throughout the organisation – by owners, the executive, managers, team leaders and nursing and caring staff themselves. But caring and compassionate values will only lead to changes in behaviour if staff feel committed to them and believe they can act on them.

Leadership at the top

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. This variety in size and type of organisation means it is difficult to set out a consistent approach to quality management. But it is vital that all care home providers invest time and resources in looking at what will work best in their organisation to ensure they understand the quality of care provided and drive continuous improvement.

Recommendation

34. The boards of large care home organisations must understand how residents experience care and see it as a key measure of performance. All boards and management teams must have robust processes in place to monitor key quality indicators and collate feedback from older people, their families and staff so they can identify emerging issues and respond to them. This should include effective whistleblowing procedures for staff who are concerned about care standards.

In this context individual stories can bring residents' experiences of care alive in a way data never can; some boards across the health and care sector begin meetings with a service user story to better connect with real life experience of the care being provided and focus attention on continuous quality improvement.

Recommendation

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

Everyone who becomes aware that non-executive directors and senior managers are asking questions about residents' care will realise that the organisation values dignity.

Leadership in the care home

Care home managers should be recognised as experts in their field. They have demanding jobs, leading and motivating teams of relatively low paid staff doing difficult work. They can feel isolated, and with little back up they 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 share ideas.

Recommendation

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

Building a caring community means giving managers and staff time and tools to focus on improving quality. The 'six senses' framework emphasises the importance of developing an 'enriched environment' for staff as well as residents by ensuring they too have a clear sense of purpose and achievement.

Care home managers and other senior and experienced staff are an important source of emotional support for less experienced team members, particularly in helping them with demanding areas such as end of life care and caring for patients with dementia. Supporting colleagues in this way should be a formal part of their role.

Although care homes are 24-hour businesses, managers and senior staff often work 'office hours', while the staff on duty outside regular hours often do not have the skills, experience or support to make and manage urgent decisions. Care homes should ensure managers and suitably qualified staff are available on all shifts, and night staff have adequate support in emergencies.

Many families and friends will visit outside normal working hours, for example in the evening or at weekends, and it is important they are able to raise issues with senior staff. Care homes should consider how they can best manage their working patterns to engage with families and friends and how they can make sure issues raised outside working hours, that cannot be resolved immediately, are logged and followed up promptly by senior staff.

Making care homes more accountable to residents

Choosing a care home will have a huge impact on a person's subsequent quality of life, yet often little information is provided beyond glossy brochures picturing the facilities.

Recommendation

37. All care homes should provide a residents' charter laying out their care standards and residents' rights.

Involving residents in decision-making should go beyond just consultation and 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.

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 also include provisions for an effective residents and relatives group, where staff, managers, residents and relatives regularly discuss management of the home.

Recommendation

38. Older people and their families should be urged to give feedback to help homes continually learn and improve. Care homes must put in place simple mechanisms to ensure direct feedback and complaints are gathered from older people and their support network, alongside confidential feedback gathered by independent advocates and via anonymous surveys. Care homes must then be able to demonstrate how they have acted on that feedback.

Feedback and complaints should be regularly discussed with staff, managers, resident groups and by owners or boards.

It is important to recognise there may be reluctance on the part of residents to complain or provide negative feedback. Residents cannot easily move care homes and may be fearful of being seen as trouble makers. As a result, some people may not fully articulate their concerns if they are not sought out. Care homes should use trained independent advocates who have the time and skills to support older people and their families to draw out feedback.

Commissioning dignified care

Commissioners of 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 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. Primary Care Trusts, Clinical Commissioning Groups and the NHS Commissioning Board must be held to account alongside the providers they buy care from for ensuring care is dignified and person-centred.

Recommendation

39. When the NHS Commissioning Board is deciding whether to authorise a local clinical commissioning group, it needs to judge the effectiveness of the group's plans to secure dignified care for older people through its contracts with providers of NHS funded services.

Primary care trusts and clinical commissioning groups commission on behalf of the patient population they serve, and have a duty to ensure there is evidence that dignity in care is being provided. Commissioners give considerable attention to financial performance; the same energy should be invested in securing dignity.

They need to set out in their contracts for NHS care the dignity standards they expect, and ensure the service providers regularly report on progress in meeting them. Commissioners should assure themselves the hospital's leadership – including the board – are acting upon the feedback. Primary care trusts and clinical commissioning groups should satisfy themselves that there are robust measures in place to capture feedback on dignity in hospitals from older patients, their families and carers.

Recommendation

40. The NHS Commissioning Board must satisfy itself that commissioning organisations properly specify the dignity standards they expect to be delivered. The NHS Commissioning Board should review and comment on the extent to which commissioning organisations performance-manage providers to deliver required dignity standards.

Primary care trusts and clinical commissioning groups must consider the performance of hospitals in the delivery of dignity standards at their own board meetings and take action where standards fall below those set out in a contract.

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 needs to be reinforced by making payments to hospitals dependent on meeting high dignity standards.

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

Recommendation

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

NHS organisations should be required to include their performance on this standard as part of the 'quality accounts' they now produce. The national quality standard describes high quality care for adults using NHS services and sets out fourteen quality statements including:

- Patients are treated with dignity, kindness, compassion, courtesy, respect, understanding and honesty.
- Patients have opportunities to discuss their health beliefs, concerns and preferences to inform their individualised care.
- Patients experience care that is tailored to their needs and personal preferences taking into account their circumstances, their ability to access services and their coexisting conditions.
- Patients have their physical and psychological needs regularly assessed and addressed, including nutrition, hydration, pain relief, personal hygiene and anxiety.
- Patients' preferences for sharing information with their partner, family members and carers are established, respected and reviewed throughout their care.

NICE's quality standard is supported by a clinical guideline on patient experience in adult services which sets out evidence based advice for healthcare professionals to help them deliver high quality and dignified care.

A national conversation about the meaning of dignity in care is needed, coordinated by a national body such as NICE. Every care provider should have a strategy that defines dignity and incorporates a dignity improvement plan.

Commissioners of care home placements

Recommendation

42. Organisations commissioning care home services should incorporate dignity into all their standards and requirements. Standards must reflect the need for care homes to involve residents in decision-making so relationships between residents and staff are based on interdependence rather than dependence.

When local authorities place clients in care homes they should make sure each older person has a care plan that includes providing dignity in care, maintaining personal identity and giving effective support when their circumstances change. Identical requirements should be placed on care homes to ensure residents funding their own care receive the same protection.

Local authorities should monitor individual care plans, and contracts should place clear obligations on providers to follow these plans.

Patient, resident and public representation

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 care home by engaging with the staff or taking people's complaints and insights straight to the senior management and board. They can ensure patients and residents know dignity is a right not an aspiration, and 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 to criticise their treatment when first asked. The barriers to people being able to highlight or complain about poor care are immense and the stress of having to do so can undermine their well-being. Advocates can give them a voice, taking the time to put people at their ease to gently persuade them to explain how they feel. People are often more willing to express themselves to an independent person 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 those views are heard and acted upon.

There are four factors which help advocates 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; and 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 to feed back what they have learned constructively.

Recommendation

43. 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.

The role of HealthWatch

The Government's proposed health reforms include plans for a new organisation, HealthWatch England, to be the 'consumer champion' of users of health and adult social care. From Late 2012 the national body will advise the Secretary of State for Health and NHS Commissioning Board among others, 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

44. 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 local government

The health and wellbeing boards being established under the proposed health reforms will have a powerful role in promoting dignity. Bringing together clinicians, local authority professionals, local HealthWatch and – crucially – locally accountable councillors, they will be uniquely placed to encourage and champion dignity right across the care system.

The role of charities

There is much the NHS and social care can learn from charities, who 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 who have much to offer. Charities can help hospital and care home management teams keep a strong focus on dignity, and work with advocates and volunteers to give older people a voice and enrich their lives. Charities also run care homes, many of which demonstrate innovation and good practice from which others can learn.

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 education providers' courses fulfil this requirement.

Selection processes for health professionals must ensure they understand and embrace the idea that they will spend much of their time looking after older people.

Recommendation

45. Universities and professional bodies responsible for preparing the health and care workforce of tomorrow must satisfy themselves that 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 first day. They also need to understand ageing and dying. Universities and professional bodies must ensure all aspects of their education and training programmes, including those delivering post-qualification, reinforce the provision of dignified care, built on the needs of older people, and should include an understanding of ageing, dementia and dying. Service users should be involved in reviewing teaching programmes and student assessment procedures.

Universities and professional bodies should ensure student placements in hospitals provide a strong grounding in the care of older people, to reflect the fact that older people make up the majority of patients and care homes residents.

Dignified care is underpinned by good communication. Staff need to have an appropriate grasp of the English language to do their job and be able to listen, speak clearly and give people time to understand and question what they are saying.

No-one would suggest paediatric nurses are too qualified to care, yet there is a misconception that nurses are too 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.

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, determining a care plan and managing the condition. Similarly, fall 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.

Regulation

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. We look forward to considering the outcome of the inquiry's work when it is published later this year.

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 have already 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. As one witness to this Commission put it, 'If you had one more pound to spend on care you would spend it on nurse leadership, not on regulation.'

Recommendation

46. 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.

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

Recommendation

47. 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. The Department of Health should consider setting minimum training and qualification standards for healthcare assistants in the NHS. If this recommendation is accepted, the Department of Health will need to resolve how healthcare assistants are registered and regulated.

Primary care trusts, clinical commissioning groups and local authorities should notify the Care Quality Commission when they become aware or have concerns that a hospital or care home provider is failing to deliver dignified care.

Recommendation

48. When regulating care homes, the Care Quality Commission should assess the extent to which residents are given a say in the day-to-day running. The Care Quality Commission also needs to ensure that meeting standards on dignity and nutrition are core components of the compliance regime for care homes.

Making it all happen

This report is just the beginning of a concerted effort to change attitudes and deliver dignified care. When the Commission on dignity in care publishes its final report, by the end of June 2012, the three organisations that have established this Commission – the NHS Confederation, Age UK and the Local Government Association – will have agreed a long term action plan which will focus on working with our partners across health and social care to deliver the recommendations we have made.

The action plan will include:

- a 'hearts and minds' campaign to seek support from leaders across health and social care to prioritise improving dignity in care for older people
- helping hospitals and care homes to learn from good practice
- helping staff across hospitals and care homes recognise good dignity in care and take individual responsibility for it
- working with key national bodies to ensure they prioritise dignity
- helping older people and their families understand the dignity they have a right to expect.

We will be writing to every hospital trust board and all the major care home providers highlighting our draft recommendations and inviting them to respond. We will also be 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.

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.

Case studies

Understanding what matters to patients - Northumbria NHS Healthcare 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 their service goals based on that understanding, setting a work plan to make it happen, measuring the right things well and relentlessly to track delivery and acting quickly on the data.

They understand that what matters to patients are aspects such as consistency and coordination 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. Scores for aspects of care such as dignity and service coordination rose significantly in 15 months.

There has been a strong focus on supporting patients with dementia. One, Christine Bryden, explained why dignified care makes a profound difference to their quality of life.

Christine said: '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.'

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 celebrate successes, and they are supported to make small changes that make a difference to patient dignity.

The dignity programme 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.

It also includes a 'Delirious about Dementia' project. One of the most obvious changes is the way mealtime 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 focusing on familiar routines and activities they enjoy, to ensure they receive dignified essential care.

My Home Life

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

An important part of My Home Life is the year-long 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.

It recognises that good practice depends upon 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 found the programme helped them 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.'

The benefits of advocacy in Barnet

Advocacy in Barnet provides a free, independent and impartial service for people of all ages. Its slogan is 'You talk, we listen, life changes.' Advance is a project to provide advocacy support for older people in the London borough of Barnet in more than 30 care homes, day centres and housing services with 'a voice for older people through advocacy'.

It aims to dramatically improve the way in which people in the community are able to address issues about their care, significantly improving standards and helping people to have a richer quality of life.

They recruit volunteers over 50 years old and train them in advocacy skills. They then visit people at care homes, day centres and lunch clubs, chatting and getting involved in activities. They support people in advocacy issues such as obtaining services from the NHS, council and local community, raising concerns over care, and helping negotiate care home placements.

Sometimes the advocates speak on behalf of the older person, but often they help the person speak up for themselves, by doing the research to help them put their case.

One beneficiary was Nadim. He lived in a residential home, was sight impaired and frustrated about not being able to read books. He was feeling lonely and wanted to meet other people to keep his mind active. His advocate found out about a cassette library and the Housebound Reader Service. Nadim is now going to a book group in his local library and attending a discussion group in the community centre.

Commission members

Commission chairs

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

Commissioners

Gillian Buck, service user representative

Yvonne Franks, associate chief nurse, Programme Director for Older People, NHS London (alternate for Trish Morris-Thompson)

Martin Green, chief executive, English Community Care Association

Dr Elizabeth Kendrick, GPwSI Older People, County Durham & Darlington NHS Foundation Trust, and chair, End of Life Clinical Innovation Team, NHS North East

Lise Llewellyn, former chief executive, Berkshire Primary Care Trust

Professor Hugo Mascie-Taylor, medical director, NHS Confederation

Professor Trish Morris-Thompson, chief nurse, NHS London

Jenny Owen CBE, deputy chief executive and executive director, Adults Health and Community Wellbeing, Essex County Council

Councillor David Sprason, lead member for adults and communities, Leicestershire County Council (alternate for David Rogers)

Professor Heather Tierney-Moore OBE, chief executive, Lancashire Care NHS Foundation Trust

Catherine Wescott, service user representative

With special thanks to **Professor Brendan McCormack**, Director of Institute of Nursing Research, University of Ulster and all the members of the academic, nursing and medical reference groups advising the Commission.

Report author

Richard Vize, journalist and communications consultant

Notes

The Commission on Dignity in Care is an independent body set up by the NHS Confederation, the Local Government Association and Age UK.

Age UK is a charitable company limited by guarantee and registered in England (registered charity number 1128267 and registered company number 6825798). The registered address is Tavis House 1–6 Tavistock Square London WC1H 9NA. Age Concern England (registered charity number 261794) and Help the Aged (registered charity number 272786), and their trading and other associated companies merged on 1 April 2009. Together they have formed the Age UK Group, dedicated to improving the lives of people in later life. The three national Age Concerns in Scotland, Northern Ireland and Wales have also merged with Help the Aged in these nations to form three registered charities: Age Scotland, Age NI and Age Cymru. ID200357 03/12