Manual for Promoting Dignity & Compassion in Care

During this module you will be asked some questions to simply provoke thought and test your current knowledge please have a note pad or supervision workbook to hand to make notes. Your performance will only be measured on the answers you select when completing the knowledge test at the end of the module.

Contents

Learning Outcomes

- Understanding what is meant by ‘dignity’ and ‘compassion’
- Knowing the ten points ‘dignity challenge’
- Recognizing threats to dignity
- Knowing how to work in a way that promotes dignity
- Understanding appropriate ways of demonstrating compassion

Complementary Manuals

- Equality, Diversity and Inclusion
- Introducing Person – Centered Approaches
- Safeguarding
- Mental Capacity Act 2005

Introduction

Dignity and compassion should form the basic foundations of care, but they are difficult to define and hard to teach. It is easier to identify a lack of dignity or compassion in the treatment of an individual than it is to put your finger on what it is that makes someone's care dignified and compassionate.

This manual aims to raise your awareness of the ways in which the actions and attitudes of yourself, your employers and society as a whole affect the quality of life and the physical and mental well-being of the people you care for.

In response to recent high-profile news reports about incidents such as the bullying and abuse of people with learning disabilities and the numbers of elderly people becoming malnourished in hospital due to lack of support at mealtimes we want to show you how an absence of dignity and compassion can affect every area of a person's life.

Please take a moment to think about and write down in your note pad some words, phrases or actions that you associate with dignity and compassion:

Chapter One

Dignity definition

"Every life deserves a certain amount of dignity, no matter how poor or damaged the shell that carries it."

— Rick Bragg, All Over But the Shoutin'

In 2006 the government launched a dignity in care initiative to raise awareness of failings in the delivery of health and social care to elderly people. In spite of this proactive approach examples of undignified treatment and lack of respect for vulnerable adults continue to make headlines.

While much of the research into this subject focuses on elderly care it's important to remember that anybody can be affected. Whether we are young or old, rich or poor, black or white, male or female we all require health and social care of some kind and could **suffer from poor treatment in any of the following situations:**

- **At your GP's**

Are consultations private?
Do receptionists maintain confidentiality?
Are the weighing scales in a public area?

- **At the dentist**

Does your dentist put you at ease?
Are you fully informed about what's being done?

- **During childbirth / While having an operation**

Are you in control of who's in the room?
Are you given as much privacy as possible?
Are health staff professional in their conduct?

Of course, there are also factors which increase people's vulnerability to undignified and uncaring treatment and they include:

- Physical disabilities
- Physical frailty
- Old age
- Mental health problems
- Learning disabilities
- Communication difficulties

People of different cultures, ages, religions and backgrounds can have very different values and goals, but dignity is almost universal as a standard for how we would want to be treated. The problem we have is in defining dignity because it can have various meanings.

The dictionary definition of dignity is:

'A state or quality or manner worthy of esteem or respect; and (by extension) self-respect.'

The 2006 dignity in care initiative suggested the following:

'The kind of care, in any setting, which supports and promotes, and does not undermine, a person's self-respect regardless of any difference.'

Compare these definitions to the words you have used on page 4; it's likely that your attempts to sum up dignity have included a range of values and issues that are missing here. The table below shows some of the wider considerations drawn from a range of sources including Department of Health surveys and government guidance documents.

Values associated with dignity	***Support needs***	***Areas of concern / issues***
• Privacy • Autonomy • Respect • Choice • Rights • Individuality • Independence • Control • Partnership • Self-esteem • Self-worth • Personalisation	• Social inclusion • Communication • Equality and diversity • Person-centred care	• Pain control • Nutrition • End of life care • Personal hygiene and appearance • Abuse • Whistleblowing • Staff attitudes

Each of the above will be looked at in this manual so if you can't immediately identify the link between the words and phrases in the table and dignity it will be made clear at some point.

Dignity in care initiative

The following were central to the dignity in care initiative; they are aims for all providers of healthcare to aspire to.

1. Have zero tolerance of all forms of abuse
2. Support people with the same respect you would want for yourself or a member of your family
3. Treat each person as an individual by offering a personalised service
4. Enable people to maintain the maximum possible level of independence, choice and control
5. Listen and support people to express their needs and wants
6. Respect people's right to privacy
7. Ensure people feel able to complain without fear of retribution

8. Engage with family members and care givers as care partners
9. Assist people to maintain confidence and a positive self-esteem
10. Act to alleviate people's loneliness and isolation

Spend some time considering the 10 challenges. What do you think you are already doing to achieve them? What could you do better? Are there any you are unsure about or disagree with?

The Health and Social Care Act 2008 (Regulated Activities) Regulations 2014

Under the act the Care Quality Commission has the power to assess the quality of care delivered by registered providers. The CQC has produced a document 'Guidance for providers on meeting the regulation.' Which gives information on complying with the updated regulations.

The concept of dignity is a fundamental part of the regulations as a whole and is also separately recognised in regulation 10: dignity and respect. See page 3 for an outline of the regulation or download the guidance from www.cqc.co.uk for the complete information

Other acts and guidelines

The amount of information available regarding dignity in care can be overwhelming so I would recommend that you make yourself aware of the most important sources of 'official' advice and guidance regarding best practice and compliance with industry standards.

The adults' services SCIE (Social Care Institute for Excellence) guide 15 Dignity in Care; which is downloadable from www.scie.org.uk , is an in depth analysis of the issues surrounding dignity in care; it includes practical examples and advice on good practice and the law.

Also interesting are 'National Service Framework for Older People', 'Valuing People Now' and 'Putting People First' which were commissioned by the government to outline their strategies for the future of care.

'All people with a learning disability are people first with the right to lead their lives like any others, with the same opportunities and responsibilities, and to be treated with the same *dignity* and respect.' (Valuing People Now)

'This National Service Framework is the first ever comprehensive strategy to ensure fair, high quality, integrated health and social care services for older people. It is a 10 –year program of action linking services to support independence and promote good health, specialized services for key conditions, and culture change so that all older people and their care givers are always treated with respect, *dignity* and fairness.' (National Service Framework for Older People)

'People want, and have a right to expect, services with *dignity* and respect at their heart.' (Putting People First)

Chapter Two

Challenges and threat to dignity

Threats to dignity are social, cultural and environmental issues which reduce the likelihood of individuals receiving care in a way which promotes dignity; they include:

- Prejudice and discrimination
- Low expectations
- Poor use of language
- Lack of resources
- Restricted access to facilities / services

As you work through this course look out for any references to older people or people with disabilities on television or in newspapers and magazines. Consider how they are portrayed; have they been the victims of a crime or have they suffered poor treatment; are they shown in a negative or positive manner and does the tone of the report make you feel sorry for them.

Prejudice and Discrimination

If as a society we have a largely negative view of a particular group of people we can create the impression that some human lives have less 'value' than others.

Examples of the effect of discriminatory attitudes on health care provision:

A 2000 study of the management of elderly blunt trauma victims in Scotland found that significantly more of the elderly died than would be predicted. Once admitted to A&E, older patients were less likely to be admitted to intensive care, less likely to be managed in a resuscitation room, and less likely to be transferred to a regional neurosurgical care centre. (Ageism and Age Discrimination in Secondary Health Care, 2009)

Best interest decisions can be highly biased. The doctors who make them have to be very clear about their attitudes to the quality of life assumptions they make about someone with a learning disability… health professionals often make personal assessments of a patient's quality of life and view this as a caring step to take in their decision-making process. This is despite good -quality evidence demonstrating the very poor correlation between a professional's opinion of a patient's quality of life, and a patient's opinion of their own quality of life and the level of ignorance that exists among professionals about people with a learning disability. (Death by Indifference)

Staff without training tend to stereotype people with learning disabilities; they are less likely to listen, or to believe that a life lived with learning disability, could be a life worth living.

(Healthcare for All, 2008)

However unprejudiced or non-discriminatory you believe you are it is unlikely that all the decisions you make or opinions you hold are entirely unbiased or unaffected by popular stereotypes or common misconceptions. If we are encouraged to see certain groups of people as vulnerable and in need of our pity and protection we also tend to devalue them as people deserving dignified treatment and the same rights and respect as ourselves.

Thanks to changes in the law and people's attitudes studies show examples of direct discrimination, where certain groups are actively excluded from certain services or denied particular treatment options, are now far less common (Ageism and Age Discrimination in Secondary Health Care, 2009). However, incidents of abuse and neglect as a result of prejudice and discrimination still occur.

Some people are openly and actively discriminatory in their treatment of particular groups and individuals; others may believe themselves to be supporting equal opportunities while actually making biased decisions that favour some groups over others. The examples above demonstrate this; it's unlikely that the doctors and nurses responsible for making decisions in A & E realise that they are treating older people differently, or that health professionals involved in treating people with learning disabilities recognise that by underestimating 'quality of life' they devalue their lives and are less likely to use medical interventions in people's best interests.

Minimum expectation

If we fall into the trap of considering groups of people in terms of what they are unable to do then we are likely to have low expectations of what they might be able to achieve**. This can have the following effects:**

- People are given inappropriate activities such as children's games or menial jobs
- People are not supported to achieve their full potential – whether this is in terms of education, independence or relationships
- 'Infantilisation' occurs, staff use baby talk to people they support and treat them as if they were small children
- Health problems and declining physical or mental capabilities are not investigated because they are assumed to be a result of the person's increased age or condition
- Funding isn't available for training, education, physical therapy etc. because other people are seen as somehow more 'deserving' of it
- Elderly or physically disabled people get treated like objects, they are often ignored, and their physical needs are met with minimal interaction – for example, care givers hoist people while talking between themselves; people talk to wheelchair users' companions even if the person in the wheelchair initiated conversation

Language incapacity

Client profile: Mrs Rose – has diabetes, weighs 16 stone, is 80 years old, has depression, uses a wheelchair, has verbally and physically attacked staff and other clients, Christian, from Jamaica.

If you were given the following words to describe Mrs Rose to a new member of staff which might be appropriate, and which would you try to avoid?

Diabetic
disabled
old
obese
'god bothered'
mentally ill
fat
Dependent
challenging
ethnic
unhealthy
foreign
Aggressive
difficult
Awkward

Learning disability is underestimated). Putting a value on lives and making decisions based on who is most 'deserving' leads to resentment and victimization or dehumanization.

Consider the phrase 'bed blocker' usually used to describe an elderly person who is being kept in hospital because no appropriate alternative care can be found; the implication is that the person has no use and no purpose and is draining resources that could be better spent elsewhere.

Access Restrictions to Facilities

The Equality Act 2010 (see Chapter 3) requires service providers and owners of buildings to make 'reasonable adjustments' to support access for all. Most recognize that ramps and other physical changes are necessary for people with mobility difficulties, but it is harder to find providers who recognize the need to cater appropriately for people with so called 'invisible disabilities.

If a person cannot access services and facilities independently they become reliant on others for support; this may mean asking unsympathetic employees for help or hoping that a passer-by will be kind enough to offer assistance. Challenges may include being unable to find your way around due to a lack of appropriate signage; feeling uncomfortable in public waiting areas because of uncontrollable physical or verbal tics or being unable to make yourself understood because staff lack the patience to listen carefully.

Next are some of the concerns raised by over 50 people with learning disabilities invited to discuss their experiences of hospitals in the Manchester area; many felt ignored, scared, bullied and uncared for:

- Medical staff spoke about them, not to them.
- Staff did not listen to them.

- Staff were not explaining medical conditions or treatment in a way they could understand, so they often left the hospital feeling worse, more frightened and confused.
- It was hard to find their way around the hospital.
- They often did not go to the doctor when they knew they should, as there seemed little point.
- They sometimes felt bullied, emotionally and physically, into giving permission for treatment.
- There were problems with the accident and emergency department and theatre, and these were particularly frightening places.

(Now I Feel Tall. What a patient led NHS feels like. DoH 2005)

Chapter Three

Dignity promoting factors

The Social Care Institute for Excellence (SCIE) identifies three factors which protect, support and promote the dignity of people in care:

- Resilience
- Rights
- Person-centred care

In this Chapter we will look at these factors and identify what they mean in practical terms.

Resilience

Few people go through life without experiencing emotionally difficult times or threats to their physical and mental wellbeing; how they deal with these circumstances will depend on how psychologically resilient they are.

Psychological resilience is a kind of mental armour against the problems that life throws at us; our ability to protect ourselves will be strengthened by a sense of self-worth and feelings of both meaning and purpose in life. Resilience can be affected both negatively and positively by care staff who can either promote or damage self-esteem.

Factors that may improve an individual's resilience include:

- Spiritual faith
- Family bonds
- Social contacts
- A sense of usefulness
- Positive experiences
- Independence
- Autonomy (freedom of action / decision making)

Imagine that you are living in residential care; in your note pad write down things which would 'brighten your day' and then write down things that would make life less bearable.

Examples: Being ignored, talking to someone

People's resilience will be threatened if they are treated as less than competent adults; that is if their rights to make choices and take actions for themselves are not supported or if their needs for useful employment or mental stimulation are ignored.

Rights

The rights of the people you support are protected by various pieces of legislation and may be supported by campaigning groups including Age UK who represent the interests of older

people and MIND who champion those with mental health issues. While improvements have been made there is still room for further progress to achieve a fair and equal society for all.

The Human Rights Act 1998

Although there is currently a great deal of negative publicity about the Human Rights Act and its influence on British 'freedom' the Act is not the first or most far reaching attempt to protect the rights of people living in Britain. The first rights charter is generally accepted to be the Magna Carta (signed in England in 1215) and the current Act has its roots in the Universal Declaration of Human Rights which was a charter created in 1948 in reaction to atrocities of the world wars.

Human Rights are based on five principles:

- Fairness
- Respect
- Autonomy
- Dignity
- Equality

Individuals cannot be prosecuted under human rights legislation only public bodies can be held accountable, so local councils and NHS trusts have responsibilities to protect the rights of all people. For good practical examples of how this Act might affect your life or the lives of your clients download 'Ours to Own Understanding Human Rights' from www.equalityhumanrights.com .

The Equality Act 2010

This Act was intended to both simplify and strengthen existing legislation and to go further towards eliminating discrimination in British society. There are now 9 'protected characteristics' which are:

- Age
- Disability
- Gender reassignment
- Race
- Pregnancy or maternity
- Religion / belief
- Marriage or civil partnership
- Sex
- Sexual Orientation

The Act not only makes it illegal to discriminate against individuals it also makes it a legal requirement for employers and the owners of premises to make 'reasonable adjustments' to support equal access for all to education, jobs, services and opportunities.

'Reasonable adjustments' might include widening doors to accommodate wheelchairs; improving rest areas to meet the needs of pregnant women or breast feeding mothers; or providing advocacy services for people with communication difficulties.

General Data Protection Regulation (GDPR)

Freedom of Information Act 2000

These Acts/regulations protect individuals' privacy and give people the right to see any personal information held about them; this should reduce the likelihood of professionals using judgemental or disrespectful language when writing reports.

Mental Capacity Act 2005

The Mental Capacity Act was introduced to protect the rights of potentially vulnerable individuals to take actions and make decisions for themselves. It begins with the principle that everyone must be assumed to have capacity to make decisions until it is proved otherwise and makes it a legal requirement for care and medical professionals to base decision making on the best interests of the people they support. (For further information refer to Approved Care Training Limited manual 'Mental Capacity Act 2005')

Complaints

By being open about your complaints policies and procedures you support people's rights to fair and equal treatment and improve their likelihood of receiving care in a way that promotes dignity and self-esteem. Poor care providers fear complaints and try to avoid dealing with them; good care providers see complaints as a way of improving their service, they are proactive in making people aware of their rights and of ways in which they can give feedback about their experiences.

Complaints are not to be taken personally; people using a service and their families should be fully informed about the way in which they can make a complaint, typically procedure will be as follows:

1. The person / family member writes down their complaint with dates, times and details and addresses it to the registered manager
2. The manager takes up to 28 days to investigate and respond in writing to the person who made the complaint
3. If the manager's response is not satisfactory in-house policies will identify how to proceed

Complaints must be dealt with in a way that maintains the privacy and anonymity of the person complaining; people who make complaints must be secure in the knowledge that they will not be discriminated against or treated unfairly as a result of raising their concerns.

Advocacy

For various reasons some people find it more difficult to communicate their feelings than others. Many people receiving care would benefit from access to advocacy services to support them in understanding choices and contributing to decisions. It's important that you are familiar with advocacy services available in your local area and that you know how to put people in touch with them.

Advocates can help to break down communication barriers between individuals and care staff and can represent people's views in an unbiased independent way.

Person-Centered Values

Make the care of people your first concern, treating them as individuals and respecting their dignity.
(Standards of conduct, performance and ethics for nurses and midwives, NMC 2008)

Person-centred approaches to care are based on several core values which include:

- Independence
- Dignity
- Privacy
- Rights
- Choice
- Respect
- Partnership
- Individuality

By putting individuals at the heart of care planning and shaping services to their needs we are encouraged to make care provision less institutional and more 'human'. Take as an example the common practice of imposing set times for getting up and going to bed; this works for providers as they can make sure that staffing levels are adequate, and they know when everyone will be ready for breakfast but it can have a negative effect on individuals for the following reasons:

- Anything which increases the length of time it takes to get someone up and dressed becomes a problem – people are less likely to be given time and support to do things independently and their privacy and dignity may be compromised if care staff are rushing
- Individuals are denied the right to choose bedtimes / waking times themselves
- The care provider is not working in partnership with the person; rather they are imposing rules to be followed
- Peoples are not treated as individuals but as a group so diverse needs may not be taken into account

Chapter Four

Dignity supporting care practices

In the previous Chapter we looked at some of the values and legal guidelines which can help to promote dignity in care; in this Chapter we will apply those principles to specific areas of care and look at practical examples of how we can improve or maintain good working methods.

Personal Appearance

Another issue concerning relatives of people in care was observing someone they care for being unable to maintain a respectable appearance. People told us how they had noticed an individual's possessions and clothes not being cared for.

For instance, clothes being damaged at the laundry, which the person would then have to wear with a hole in them, or clothes going missing entirely or being given to another person to wear. This is damaging to someone's self-respect and makes it difficult for them to keep their individuality.

('Dignity in Care' Public Survey; DoH 2006)

Many people's self-esteem is affected by the way they appear to others; people who feel dirty or untidy are unlikely to feel comfortable and confident in company. Of course, everybody has different ideas about what is 'correct' but efforts should be made to ensure that however dependent a person becomes they can be supported to maintain their own personal standards.

Care providers have a duty to look after people's belongings; clothes should be properly laundered and pressed and care should be taken to ensure that they are returned to the right person. Whether individuals wish to be dressed in casual comfortable clothes or to be 'smart' is up to them; elasticated waists and Velcro may make life easier but may be unacceptable to some individuals.

Make up, regular hair styling and jewellery may seem like unimportant extras but they can be significant to a person's sense of self; by helping someone to 'beautify' themselves you could be making a great contribution towards improving their self-esteem and personal wellbeing. Imagine yourself lying in a hospital bed waiting for visitors; what difference would it make to you if you were given the chance to freshen up and brush your hair?

People's wellbeing is greatly affected by the amount of control they feel they have over their lives. The more involved they are in everyday decisions and activities the happier, and more resilient, they are likely to be. Simple things like supporting people to choose their own clothes can make a huge difference. Never make assumptions about what a person wants always give them the chance to accept or decline, even if they have had a cup of tea at 10 0'clock every day for a year it's still polite to offer first.

Personal Care	***Poor practice***	***Good practice***
Bathing	Leaving doors unlocked / curtains open Rushing / treating the person like an object Ignoring person while chatting to colleague Using a cold 'institutional' bathroom Bathing everyone in the same way at times / frequency set by the manager without consultation	Ensuring privacy by keeping staff present to a minimum, encouraging person to do as much themselves as possible, keeping intimate areas covered Maintaining conversation with person throughout Providing suitable oils, creams etc Making the experience safe, comfortable and appropriate (i.e. providing choice bath, shower etc.)
Toileting	Imposing rigid toileting programmes without individual assessment Using incontinence pads to reduce the need for regular toileting Leaving people in soiled clothing for long periods of time Punishing individuals who are incontinent e.g. by making fun of them Ignoring requests to use the toilet Exposing person to public view when on toilet / commode	Supporting people to the toilet as regularly as necessary Using signage, walking aids, equipment to allow independent access to toilets Changing people who have been incontinent at the earliest opportunity and with the minimum of fuss Leaving people on their own to go to the toilet and knocking before re-entering the room Providing alternatives to toilet paper when necessary
Feeding	Rushing Standing over the person Feeding cold and unrecognizable mouthfuls of food	Taking time Presenting the person with attractive, appetising food at the correct temperature

	Talking to other people over the persons head Putting person in a bib / using equipment designed for small children	Allowing the person to dictate the pace of feeding Telling the person what you are giving them Sitting down with the person
Hoisting	Hoisting people in full view of others Allowing clothing to 'ride up' exposing underwear Transporting individuals from room to room while slung in a hoist	Involving the person in the process by talking to them / obtaining consent / encouraging participation Closing doors / curtains or (in emergencies) screening individuals from view Using hoists for transfers only, not to move individual around the home

Nutrition

In 2007 the Council of Europe in association with organisations including the NHS, Royal College of Nursing and Department of Health issued a resolution for food and nutritional care in hospitals. The resolution identified 10 key characteristics of nutritional care which could also be applied to other types of care setting:

- All patients are screened on admission to identify patients who are malnourished. (See E-cert Healthcare Training Limited manual 'Malnutrition and Nutritional Care' for further advice on screening)
- All patients have a care plan which identifies their nutritional care needs and how they are to be met
- The hospital includes specific guidance on food services and nutritional care in its Clinical Governance arrangements
- Patients are involved in the planning and monitoring arrangements for food service provision
- The ward implements Protected Mealtimes to provide an environment conducive to patients enjoying and being able to eat their food
- All staff have the appropriate skills and competencies needed to ensure that patient's nutritional needs are met. All staff receive regular training on nutritional care and management

- Hospital facilities are designed to be flexible and patient centred with the aim of providing and delivering an excellent experience of food service and nutritional care 24 hours a day, every day
- The hospital has a policy for food service and nutritional care which is patient centered and performance managed
- Food service and nutritional care is delivered to the patient safely
- The hospital supports a multi-disciplinary approach to nutritional care and values the contribution of all staff groups working in partnership with patients and users

Food plays a very important part in many people's lives; having access to adequate and appropriate food and drink and being supported to eat properly are fundamental to individuals' physical and mental wellbeing. Care staff need only a basic knowledge of nutrition to be able to support clients to have good quality foods in adequate amounts that are safely prepared and fulfil any cultural and religious requirements.

Care staff should make sure that they are familiar with individuals' personal needs and preferences so that they can make sure that they are eating the right foods in a suitable environment and with the right level of support. Every effort should be made to allow people to eat independently, whether this requires the introduction of special equipment or alternatives such as finger foods, but staff must discreetly monitor food intake and recognise when people are struggling to eat by themselves.

Dignity will be compromised if people are expected to use children's utensils or accessories such as bibs, or if their environment is not suitable for eating; e.g. if they are sitting on a commode or if vomit bowls / bed pans etc. are not removed before food is served.

How to promote dignity in food provision?

Do:

- Provide snacks / drinks throughout the day
- Allow people to prepare their own snacks and drinks if possible
- Involve people in laying tables / clearing up etc.
- Talk to people (or their families if necessary) about their preferences / needs
- Support person to make menu choices
- Educate people about healthy eating
- Offer several choices at mealtimes
- Consult people about times of meals and style of presentation (e.g.plated / serving dishes)
- Allow adequate time for people to eat in a relaxed atmosphere

Don't:

- Insist that everyone eat and drink at set times
- Assume that people will or won't eat something based on their cultural or religious background
- Restrict clients' dietary choices for medical reasons (e.g. because an individual has diabetes) – they are still free to make their own choices

- Feed people as a quick alternative to supporting them to feed themselves
- Expect people to eat cold or unappealing food because they need a special diet or help to eat
- Rush people to get the dining area cleared and cleaned within a set time

End of Life Care

Caring for people at the end of their lives requires a great deal of sensitivity and compassion as they and their family and friends may need support to deal with difficult decisions and deteriorating physical and mental health.

Care staff need to be trained to respond to changing needs and to promote good communication between individuals, care staff and other health professionals. Advice and professional support may be necessary and the following are all possible sources of help:

- Doctors - having good relationships with peoples' GPs can mean the difference between them dying in the home or ending up in hospital.
- Specialist nurses – nurses skilled in palliative care, or the treatment of specific illnesses
- Speech and language therapists – to give advice on eating and swallowing difficulties
- Occupational therapists – to give advice on maintaining independence by introducing equipment etc.
- Religious representatives – people to support spiritual / faith needs

For a person to achieve a 'dignified' death it's essential that they are supported as far as possible to die as they want, where they want and to have appropriate treatment after death. This will require co-operation between the person, care givers, doctors and family to discuss treatment options, provide adequate pain relief, and to plan funeral arrangements.

Care of the person's body after death must be in line with their wishes and carried out in a respectful and dignified manner. Sensitivity should be shown to the needs of the family and they should be given space and time to grieve; the behaviour of all staff should reflect the gravity of the occasion.

People who are dying can be empowered by knowledge; this can give them a sense of control; help to prepare them for what is to come and reduce their fear. In your note pad record your thoughts about what people might need to know; what those looking after them would need to know and who might need to be involved

- What information might the person need?
- What information would those involved in their care need?
- Who should be involved in the planning and preparation?

Chapter Five

Identifying loopholes and assisting change

All care workers have a responsibility to promote dignity and to ensure that people are treated appropriately and fairly not only by themselves but also by their colleagues and their employers. If you feel that people are being neglected, abused or let down by care practices you may be worried about speaking out; this is a perfectly natural reaction but there are laws and sources of advice available to protect you and the interests of those you are caring for.

In this Chapter we will look at how you might recognize care practices that undermine dignity and have a negative effect on physical and mental health; and we will show you how you should deal with your concerns so that care provision can improve and people will be protected in future.

Abuse

There is not room here to cover abuse in any detail, your employers should provide you with training to safeguard the people you care for, but we will look at an overview of the issues involved.

Types of Abuse

Generally speaking types of abuse can be put into one of ten categories, these are:

- Physical abuse – e.g. hitting, biting, misuse of medication, poor manual handling practice, force feeding, inappropriate restraint
- Psychological abuse – e.g. threats, prevention of contact with family / friends, humiliation, intimidation, verbal abuse
- Sexual abuse – any sexual contact without consent, use of sexual language, causing someone to view pornography when it's unwanted or inappropriate, incest
- Financial abuse – theft, misuse of funds, restriction of access to personal funds, pressure to amend wills / give money, exploitation, fraud
- Neglect – ignoring physical needs, not providing adequate heat / clothing / food etc. failing to provide access to services
- Self-neglect – a person failing to meet their own needs for health and wellbeing
- Discriminatory abuse – treating someone unfavourably due to their gender / religion etc. abusive language, harassment
- Modern slavery – people working long hours for little or no pay and living in substandard conditions
- Organisational abuse – care providers operating in a way which puts profit above people's needs. Poor management, lack of training, institutional care
- Domestic abuse – any type of abuse occurring between adults who are or have been in a relationship or are related

People with care and abuse

People with care needs are potentially at risk of abuse from anyone who has access to them including care staff, family and friends, volunteers and visitors. People who act in ways that are

abusive or who neglect the needs of others are not necessarily enjoying being cruel or causing suffering; often they are acting under pressure or reacting to stress caused by personal situations. Alternatively abuse and neglect may happen as a result of ignorance as care staff are not always trained to recognize and respond to changing physical and mental conditions.

Consider the following scenario – is Mrs O a victim of abuse? Do you think that her daughter's actions are abusive?

Mrs O lives with her daughter, Patricia; Mrs O has been diagnosed with Alzheimer's Disease and also has mobility problems, she relies on her daughter for all aspects of her personal care.

Patricia is struggling to look after her mother, she doesn't want to ask for help as she is worried that her mother will be put into a home, but she knows little about Alzheimer's disease and cannot communicate with Mrs O or cope with her behaviour.

Patricia has started to put her mother to bed at 6 pm and lock her in her room until 8.30 in the morning; Mrs O becomes distressed by this and her health is rapidly deteriorating.

If you became aware of Mrs O's situation what action could you take?

What do you think could be done to improve life for both women and to support Mrs O with dignity and respect?

If you have reason to believe that someone you care for is being abused or neglected, you have a duty to take action to protect them. The actual steps you take will depend on the situation and may range from reporting suspicions to your manager to making an emergency call to the police. Your employer should be able to provide you with written policies and procedures that will tell you how to report your concerns and how to deal with disclosures.

(A disclosure is when a client tells you that they are being abused; a partial disclosure happens when a client says something that suggests that abuse may be occurring, but they stop short of making an allegation. You should receive training on how to deal with disclosures appropriately.)

Dignity risk recognizing

As this manual is about dignity and compassion in care it makes sense to look at some of the signs you may notice that could indicate that clients are not being cared for in a compassionate way which supports dignity.

The following are all indicators of inadequate care:

- Care givers do not respect confidentiality – personal information is left lying around and people being supported are the subject of gossip
- People are not given private space and time for appropriate intimate relationships
- Care staff enter rooms without knocking
- Mail is opened before people get it; there is nowhere private for them to use the telephone or spend time with family / friends
- Bedrooms are institutional and personal possessions are restricted
- Toilet / bathroom doors are unlockable

- The environment is tatty and uncared for
- Care staff act as if the people they support are another species, they talk about them, make fun of them or use derogatory language
- People are routinely called ‘love’ or ‘darling’ or are talked to like children
- There is a lack of money for meeting the needs of the people being supported
- Routines are imposed to suit the home; residents are not consulted about their preferences
- Staff cannot communicate properly with the people they support
- Complaints are ignored, and no effort is made to protect the identities of people who complain
- Care staff are always too busy to talk
- People are exposed to others while being dressed / toileted or bathed
- People are left in soiled clothing for long periods of time

The above issues may show that there is a poor culture of care in the home or that individual staff members need dignity training. If you recognise that problems exist discuss your concerns with your manager. If, after giving your manager adequate time to deal with the situation you do not feel that the matter has been resolved you may need to consider ‘whistleblowing’.

Whistle Blowing

The Public Interest Disclosure Act 1998 is often referred to as the Whistleblowing Act. It protects your rights to raise concerns about improper actions by your colleagues or your employers.

A good employer will maintain open lines of communication to encourage employees to raise concerns and to be confident that they will be considered and dealt with appropriately. If you raise legitimate concerns in the interests of the people you support, you should not be discriminated against or treated differently by your employer.

Depending on the nature of your concerns and the circumstances you may disclose them to:

- Your manager / employer
- An external regulator e.g. Care Quality Commission
- A wider audience e.g. by contacting a newspaper

If your employer has a whistleblowing policy in place you may lose your legal protection if you do not follow it and raise your concerns internally before potentially damaging their reputation by going to an external source.

Chapter Six

Caring in a Compassionate Way

Person centered care champions compassion and respect and puts the individual at the heart of all decisions.

(Delivering Dignity, Age UK 2012)

Defining and measuring compassion is difficult, teaching someone to be compassionate is almost impossible. Generally speaking people either have the emotional skills to care for others or they don't; some people should be encouraged to recognize that a caring role is not suitable for them and that they may need to look for alternative types of employment.

Caring for someone in a compassionate way requires you to be able to identify with them as individuals and respond sympathetically to their needs without pitying them or feeling that you are in any way superior to them. 'Compassionate' care staff know when to use appropriate physical contact to provide comfort and they recognize when to encourage people to talk and when to leave them alone. If you are sensitive to the feelings of others and people feel comfortable in your company then you are likely to be able to be a good care worker.

This Chapter is a bit different to the others before it; there are test questions at the end of it but there are no questions as to how you should do things; instead there are scenarios for you to consider and record your feelings about. Hopefully these will provide the basis for a discussion with your manager about the role of compassion in care and what your responses suggest about your ability to respond appropriately to people's diverse needs.

Make some notes in your note pad ready to discuss with your manager at your next supervision meeting.

Case 1

Ms R is crying, she misses her family and wants to go home to them. Ms R's family love her but cannot meet her complex care needs. How could you help Ms R to feel closer to her family without changing her living arrangements?

Case 2

Mrs S is in her late 90's and has late-stage dementia; she cannot communicate verbally, has very little sight and poor hearing. Suggest practical ways in which you could provide stimulation to improve Mrs S's mental wellbeing.

Case 3

Mr T moved into your care home from prison. You do not know what he was convicted of but you believe it must have been serious because of the length of time he spent there. He is very 'institutionalised', he seems happy with set routines and is fiercely protective of his personal

possessions. Mr T's doctor has diagnosed an aggressive form of cancer and doesn't think he has long to live. What could you do to support Mr T in his last days or weeks?

Case 4

Miss U is a new arrival at your home; you have heard other care givers talking about her, they were discussing her aggression and physical violence and you are aware of rumours that she seriously injured a care worker at her previous residence. You are asked to get Miss U up and dressed; how will you approach the task?

References

Adults' Services SCIE guide 15 Dignity in Care March 2009

Guidance for providers on meeting the regulations CQC 2015

National Service Framework for Older People 2001 DoH

Valuing People Now: a new 3 year strategy for people with learning difficulties DoH 2009

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

Age UK 2012

Ageism and Age Discrimination in secondary Health Care

Death by Indifference Mencap

Healthcare for All Michael 2008

'***Now I Feel Tall' what a patient led NHS feels like*** DoH 2005

Ours to Own: Understanding Human Rights Equality and Human Rights Commission

Standards of Conduct, performance and ethics for Nurses and Midwives

NMC 2008

Useful Websites

www.cqc.co.uk

www.cpa.org.uk

www.mencap.org.uk