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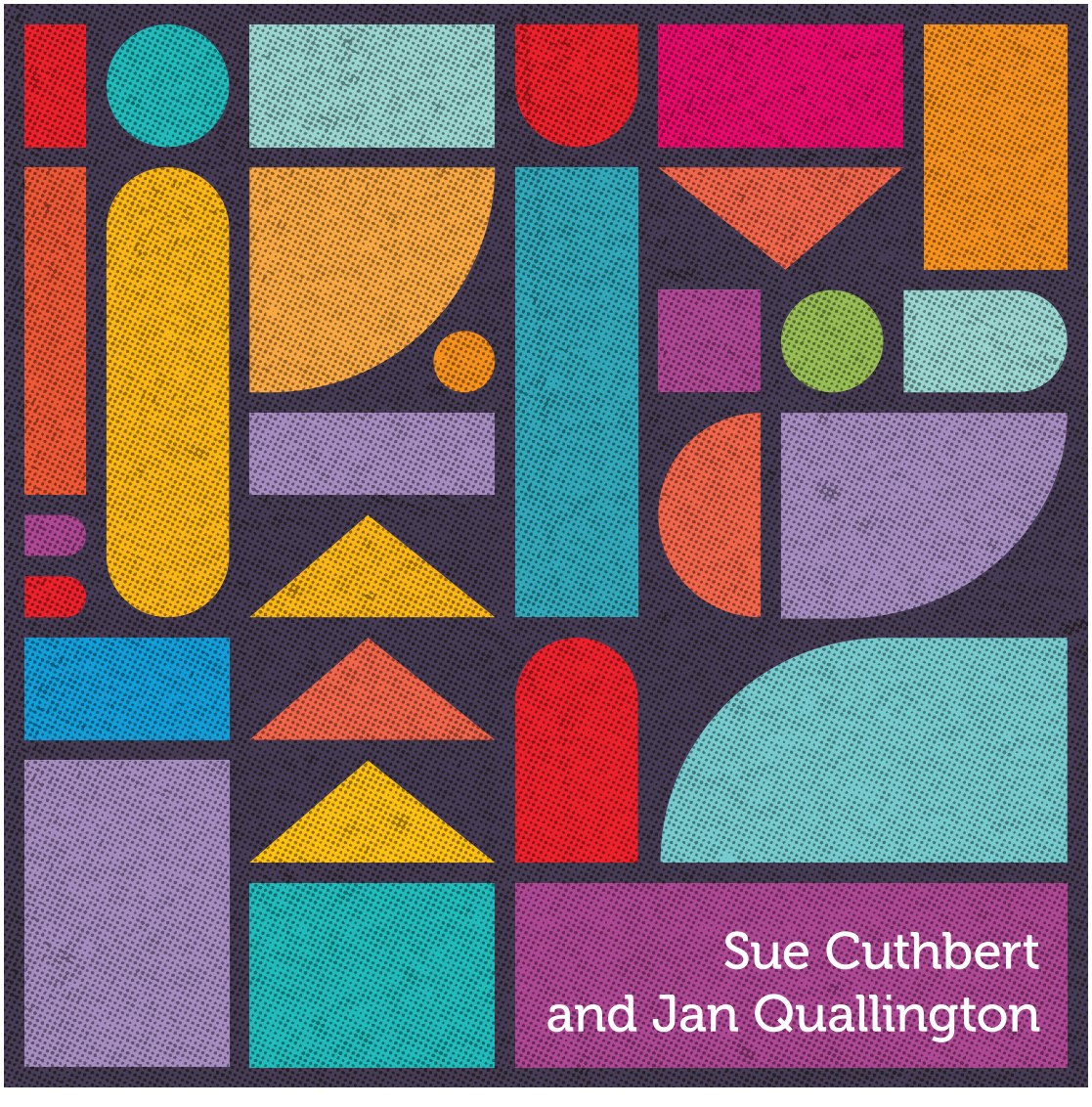

Values and Ethics for Care Practice

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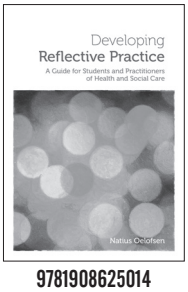

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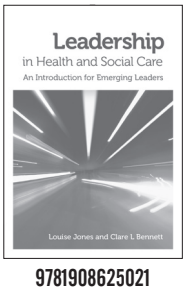

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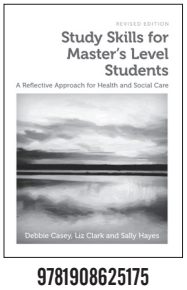

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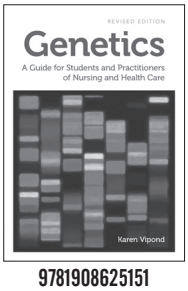

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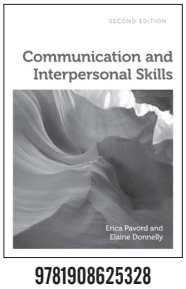

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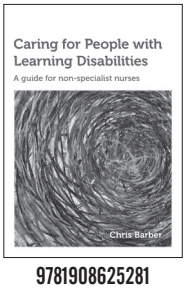

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Sue Cuthbert & Jan Quallington
University of Worcester

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The authors and publisher have made every attempt to ensure the content of this book is up to date and accurate. However, healthcare knowledge and information is changing all the time so the reader is advised to double-check any information in this text on drug usage, treatment procedures, the use of equipment, etc. to confirm that it complies with the latest safety recommendations, standards of practice and legislation, as well as local Trust policies and procedures. Students are advised to check with their tutor and/or mentor before carrying out any of the procedures in this textbook.

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ABOUT THE AUTHORS

Dr Sue Cuthbert is the Head of Collaborative Programmes at the University of Worcester.

Sue qualified as an RGN and practised in care of the older adult and in women's health settings. Since moving into higher education in the 1990s, she has taught values and ethics in both nurse and midwifery education, as well as in applied health courses for undergraduate and postgraduate students. She now oversees the quality and delivery of a range of collaborative course developments with partner organisations, including Foundation Degrees in health and care.

She has an MA in Medical Ethics, where her research focused on reproductive choice, rights to healthcare, resource allocation and access to infertility treatment. She has since completed a Doctorate in Medical Ethics, also at Keele University. Her doctoral research examined the notion of choice in childbirth and competing models of autonomy in midwifery care, advocating for a pluralist view of values important to women's personal choices and decision-making, but where autonomy in midwifery practice is viewed through a social-relational lens.

Sue is also an informal family carer who has supported and cared for both her parents through the progressive effects of Alzheimer's and vascular dementia, and has therefore seen health and social care, both good and less satisfactory, from 'the other side'. This has further reinforced her conviction in the importance of practising values-based care and the centrality of respect, dignity and compassion for good holistic care.

Dr Jan Quallington is Head of the Institute of Health and Society at the University of Worcester.

Jan qualified as an RGN (Adult) and undertook specialist education in cardiothoracic nursing. Her clinical practice was in acute medicine, coronary care and intensive care. Since moving into education in a University setting Jan has studied for an MA in Medical Ethics and Law and has gained a Doctorate in Medical Ethics from Keele University. This focus on ethics has shaped the way that she thinks about practice.

Jan is passionate about educating and developing a workforce that will be effectively prepared to provide values-based, compassionate care. She believes that practitioners of the future must be confident to work collaboratively within a multiprofessional context, reflecting on and challenging with a view to leading, and enhancing practice.

Jan has undertaken a number of roles in higher education and has taught and learned from students across the health and social care spectrum. She currently leads a large multiprofessional team to deliver a wide range of health and social care education in partnership with health and social care providers and service users.

Jan has written on Ethical Reflection and on Leadership in health and social care.

05

RESPECT AND DIGNITY

LEARNING OUTCOMES:

In this chapter you will:

- define respect and dignity and consider what it means to be respectful and to have respect for others
- identify the moral justification for a duty of respect for persons and consider the notion of personhood
- discuss duties and rules arising from the value of respect for persons and their implications for practice
- explore the concepts of dignity and privacy in relation to practice
- reflect on care strategies that promote respect and dignity.

INTRODUCTION

People value their dignity. While they may not identify exactly what this means, they know when it has been compromised or threatened. People are particularly vulnerable to loss of dignity in healthcare as their care needs bring what is normally private into the public realm and require the intervention of relative strangers. Dignity is closely associated with the values of respect (of self and others), respect for persons and respect for a person's autonomy. We will discuss autonomy in detail in *Chapter 6*.

Recognition of your humanity through respect for you as a person is fundamental to maintaining your dignity and to your feelings of self-esteem and self-worth. These notions of respect and dignity have attracted considerable attention in recent years, both in theory and in practice. They are at the forefront of government policy and are reflected in a range of government reports, particularly in responses to inquiries into incidents of poor and inhumane care (DH, 2014; 2012; 2012a and b; DH and Poulter, 2013; Francis, 2013).

Professional and policy expectations of respect and dignity

Respecting people and their dignity are fundamental expectations for you as a practitioner and core values for all health and care services, reflected in national standards and strategies throughout the UK.

Respect and dignity are:

- principal values in the NHS Constitution (DH, 2015a, p.5)
- central to the vision and strategy for nursing, midwifery and care staff (DH and NHS Commissioning Board, 2012c)
- fundamental aspects of care in the *Essence of Care 2010* benchmark (DH, 2010b)
- central to the mental health strategy, *No Health without Mental Health* (DH, 2011a)
- featured in the fundamental standards in 'The Health and Social Care Act 2008 (Regulated Activities) Regulations 2014' (DH, 2014a, b, and c)
- key values in the National Occupational Standards for Health and Social Care (2013) (see *Box 5.1*)
- integral to the *Core Competences for Healthcare Support Workers and Adult Social Care Workers in England* (Skills for Care and Skills for Health, 2013b)
- reinforced in the *Care Certificate Standards* for healthcare support workers (HCSW) and adult social care workers (ASCW) (Health Education England, Skills for Care and Skills for Health, 2015).

BOX 5.1

The National Occupational Standards for Health and Social Care (2013)

These identify the principles and values that underpin the rights that individuals (children, young people and adults) and key people have:

- to be treated as an individual
- to be treated equally and not be discriminated against
- to be respected
- to have privacy
- to be treated in a dignified way
- to be protected from danger and harm
- to be supported and cared for in a way that meets their needs, takes account of their choices and also protects them
- to communicate using their preferred methods of communication and language
- to access information about themselves.

See for example: National Occupational Standard (SCDHSC0234) *Uphold the Rights of Individuals* (Skills for Care and Development, March 2012) available at tools.skillsforhealth.org.uk/external/SCDHSC0234.pdf (accessed 14 December 2016)

Health and social care professions view respect as fundamental to the healthcare relationship, both with patients, service users and their families as well as respecting

each other as members of the care team. Respecting 'dignity, humanity and equality' is one of the key *Principles of Nursing Practice* identified by the Royal College of Nursing (RCN) (Jackson and Irwin, 2011). Similarly, Skills for Care identify seven core principles essential to supporting dignity in adult social care (Skills for Care, 2013).

The concepts of respect, individual autonomy and preservation of dignity are also fundamental to many codes of practice and professional conduct for health and care practitioners such as the *Code of Conduct for Healthcare Support Workers and Adult Social Care Workers in England* (Skills for Care and Skills for Health, 2013a) and the *Standards of Proficiency for Social Workers in England* (Health and Care Professions Council, 2017).

The Code: professional standards of practice and behaviour for nurses and midwives (NMC, 2015) puts 'prioritising the interests of people' first. This expects practitioners to treat people as individuals and uphold their dignity, listen and respond to people's preferences and concerns, make sure that people's physical, social and psychological needs are assessed and responded to, act in the best interests of people at all times and respect people's right to privacy and confidentiality (NMC, 2015, pp.2–6).

The right to be treated with respect and dignity is also enshrined in law, with various pieces of legislation supporting this legal right, most significantly the Human Rights Act (1998) and the Equality Act (2010) but also laws associated with mental capacity, data protection and freedom of information.

Despite all this, incidents of poor care continue, and certain groups of patients and service users have been particularly vulnerable to disrespect and undignified care resulting in significant harms and loss of self-worth and self-esteem. These include older people, people with learning disabilities, and those with dementia or mental health problems. For example, the National Service Framework (NSF) for Older People (DH, 2001a) aimed to address the widespread infringement of dignity of older people. Yet respect and dignity were still found lacking in the care of older people a decade later (Parliamentary and Health Service Ombudsman, 2011).

Similarly, *Valuing People: a new strategy for learning disability for the 21st century* (DH, 2001b) emphasised the importance of placing the individual with learning disabilities at the centre of care. But respect, dignity and person-centred care and support for people with learning disabilities, their families and carers were still found wanting and their importance re-emphasised in *Valuing People Now* (DH, 2009) and *Transforming Care: a national response to Winterbourne View Hospital* (DH, 2012b). However, the values of respect for persons and dignity are not exclusive to particular service user groups. They are relevant to whoever you will meet in your practice, including staff and other carers, and in your everyday life.

Despite many references to the values of respect and dignity in health and social care policy, codes and guidelines, assumptions are made about practitioners sharing a common understanding of these concepts. As dilemmas in care indicate, these values are more complex in their meaning and their application than professional rules for practice alone can convey.

This chapter aims to develop a deeper understanding of the moral values of respect for persons, dignity and privacy and explores their centrality to good health and social care. It encourages reflection on the attitudes and behaviours that impact on an individual's dignity and sense of self-worth and supports development of care strategies that promote respect for persons and dignity-enhancing care.

WHAT DO WE MEAN WHEN WE USE THE TERMS 'RESPECT' AND 'RESPECT FOR PERSONS'?

Thinking about respect as a value

Respect is important to daily life, although this is often equated with simply respecting the authority of others, such as people in power, the law or religion. The word 'respect' has become commonplace in everyday language, both in the general public domain (for example, respecting nature and the environment, respect for human life in debates about abortion, respecting cultural difference and diversity) and in political debate. For example, the UK coalition government of 2010–15 espoused a commitment to building a fairer society and to support social action to change culture and attitudes through the 'Equality Strategy', with the aim of 'building respect for all, tackling discrimination, hate crime and violence' (HM Government, 2010).

Respect for self and others is a fundamental element of living together in a society. However, there are many ways to think about and use the term 'respect' and it may have different meanings to different people and according to the context in which it is used, such as 'respect me for who I am' or 'respect my authority'. Both of these demand acknowledgement, recognition and consideration by others, although the reason for giving (or owing) such respect is different.

ACTIVITY 5.1

Reflection

Have you ever experienced a time when you felt that you were not respected or felt undervalued? This may have been, for example, in a family or personal relationship, in an interaction with someone you know or with a stranger, or in a work environment.

- Describe this significant incident. Where were you? Who was involved? Were there any specific circumstances?
- Then think about and write down:
  - How did this make you feel?
  - Why did you feel this way?
  - What did you do?

You may have identified a number of feelings, such as anger, upset, sadness, disbelief, concern, being belittled. It may have been harder to identify exactly why you felt this way; you may have felt that it just wasn't 'fair' or 'right'. However, it is important as a reflective practitioner that you keep asking yourself why you believe something is right or wrong or should or should not be the way it is. You may have said that it was disrespectful of you as an individual. This idea of respect and respect for persons needs further exploration.

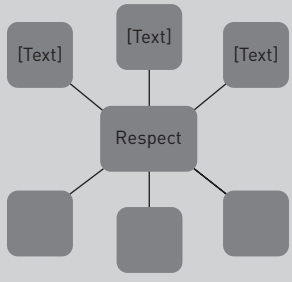
Defining respect

There are various ways to define respect. The term 'respect' can refer simply to a *behaviour* that avoids violating or interfering with a boundary or rule; for example, a driver respecting a speed limit or a smoker refraining from smoking in public places. Respect can also involve an *attitude or feeling*, as when we speak of having respect for another person. Practitioners in health and care are expected to respect boundaries or rules, such as the law associated with consent to treatment, policies, competencies for practice and the rules outlined in codes of conduct. However, what we are most concerned about here are the *values and attitudes* associated with 'respect for persons' and their influence on a practitioner's behaviours and practice.

ACTIVITY 5.2

Defining respect

1. Think about and write down your definition of 'respect'.
2. If you find this difficult, start a concept map showing different words, phrases and ideas that come to mind when you think about 'respect' (you may well identify many more words and ideas than indicated by the six arrows below).



3. Look up 'respect' in a dictionary and add the definition to your 'mind map' (but remember a dictionary definition will only start to identify its meaning).
4. Now talk to some relatives, friends and/or colleagues about their understanding of the term 'respect'.
5. Try rewriting your definition now.

Respect in the health and care context can be simply defined as the recognition of the *unconditional value of patients, service users, clients and carers as persons*. This requires both *a belief* that persons should be valued and that your *actions should reflect such a belief* (Beach *et al.*, 2007). Respect seen in this way necessarily involves respecting autonomy but this alone is not a sufficient understanding of respect for persons in care relationships. Respect can mean not only a symbolic recognition of status or social position but also paying proper attention to the 'object' of respect and acknowledgement of the value and worth of something or someone. Thus, being respectful reflects an individual's:

- beliefs
- evaluative judgements
- commitments
- dispositions of attitude and behaviour towards the person who is being respected.

ACTIVITY 5.3

Reflection

- Think of a situation where you feel that another person has been treated with disrespect. Identify what form/s of respect were disregarded. Was it someone's authority or position that was ignored or undermined? Was it the attitude of a person towards another that seemed disrespectful? Were any rules or boundaries broken? Was it a combination of some or all of these factors?
- Can you identify why the person was treated this way?
- In your view, how should this situation have been handled? What should have happened?

The principle of respect for persons

As children we are generally taught to respect significant others such as parents, elders, teachers and people 'in authority'. As we get older, we may develop a deeper understanding of respectfulness and the value of respect for others, connected with their feelings, rights and differing opinions. We may have great respect for some people based purely on a positive assessment of their merits or social standing and consider them exemplary; we may lose respect for others, depending on our judgement of whether they are truly worthy of our respect. We may also come to believe that all people are worthy of respect, regardless of whether they display any merits, because of their humanity, as unique individuals and simply because they are persons.

Respect for persons as persons should be distinguished from respect for persons in particular roles or based only on the positive assessment of the merits of an individual. Respect for persons is not simply about 'liking' or even 'agreeing with' someone. Although it involves an emotional response, it is not merely about sentiment but requires a corresponding disposition to respond and act respectfully towards the 'object'

of respect, the person. Equally, respect is more than just respectful behaviour, because simply to behave in a way that appears respectful, without valuing that respect, is deceitful. The idea of paying proper attention to the person central to your respect means trying to see the person clearly in their own right and through their own eyes; trying to identify their values, desires, strengths, wants and needs and not seeing them solely through the filter of your own feelings and dispositions (Dillon, 2014).

The *motive* behind your show of respect for another person is as morally important as knowing how to act respectfully. For example, not using racially inappropriate language while caring for an Asian family simply because you do not want to be caught breaching race discrimination laws is not sufficient motive to be considered respectful. In this case, your fear of legal recrimination is more about self-interest than the value of respect for others, even though on one level you are showing respect for the authority of the law. The motive for your action should come from the value you attributed to them as persons with equal rights to respect and because you believe all individuals are unique and valued members of society.

Dillon (2014) identifies what he calls 'care respect', which

> '… involves regarding the object [of respect] as having profound and perhaps unique value and so cherishing it, and perceiving it as fragile or calling for special care and so acting or forbearing to act out of felt benevolent concern for it.'
>
> (Dillon, 2014, p.7, Sect. 1.2)

Thinking of respect as 'care respect' encompasses the belief that persons have a unique value deserving of special concern and care.

Harris (1985, p.193) adds, 'having concern for the welfare of others' as another essential component of respect for persons. Concern for the welfare of others may be mutually compatible with respect for autonomy (often associated with respect for persons), although many moral dilemmas in health and social care practice arise when these two values come into conflict, as you will see when we talk about risk, protection from harms and acting in a person's best interests.

BOX 5.2

Respect for persons

This at the very least requires:

- a belief in the value of persons as individuals and as members of society
- an obligation to respect individuals as human beings
- treating people in the manner in which you would expect to be treated
- showing consideration for another person's feelings and interests
- an attitude demonstrating that you value another person.

Many of the ordinary rules and judgements of common social morality (our ordinary shared moral beliefs) presuppose respect for persons as a foundation of all other moral principles, duties and obligations. In this way, the principle of respect for persons can be considered to be *universal* and should not have any national, cultural, legal, or economic boundaries. This is evident in much of the discussion of values and ethics associated with health and social care, where respect for persons and the worth of all human beings is seen as an essential guiding principle that underpins all others (Banks, 2012; Beauchamp and Childress, 2013; Seedhouse, 2009). For example, if you act according to the principle that it is wrong to harm another then this will, in part, be based in you valuing their humanity and them as a unique individual, with feelings and interests that should not be violated.

THE MORAL DUTY OF RESPECT FOR PERSONS

Much of the contemporary discussion of respect for persons is credited to the work of an eighteenth-century German philosopher, Immanuel Kant, who put respect for persons at the very centre of his deontological moral theory. His original writings are complex and open to misinterpretation but some of the key points from his work are relevant to the value of respect for persons in care practice.

Kant argued that all people are bearers of fundamental rights and that persons have an absolute dignity that is independent of rank or merit and must always be respected. Thus, persons have absolute value, unconditional worth and exist as 'ends in themselves', in contrast to things that are valuable merely as a means to an end or as objects of affection. This value is common to all people and is concerned not with being human beings in a genetic sense, but with our humanity and the associated possession of the special features that make us *distinctively human*. This includes the capacities of 'reason and freedom of will', i.e. the ability for self-directed rational behaviour and to choose and follow our own moral goals. We will come back to some of these ideas in the discussion of respect for autonomy in *Chapter 6*.

Kant stated his principle of respect for persons as a 'categorical imperative'; an absolute requirement that *we should always act in ways that treat humanity as an end in itself, never merely or exclusively as a means to another person's ends*.

Thinking about this statement, you should be able to recognise that there is something intuitively wrong in treating human beings as merely instruments to achieve our own goals. An extreme example of this would be slavery. However, this does not totally rule out using people for our own purposes and we do this on a regular basis. For example, when I employ a plumber to fix my central heating, I am using him as a means to my own ends. What is important, however, is that I am not treating him

merely as a means to my own ends because, in employing him, we both enter freely into a 'contract' (in this instance, involving payment). The plumber is able to make choices as to whether or not he wants to do this work or something else, he can influence when he is available, how much it will cost, etc. The same can be said of any person employed to provide a service, paid or voluntary, including care workers, as they have all chosen to enter into their role and with some purpose of their own. Conversely, a slave is treated as a means to someone else's ends, they are not free to make choices about how they live their life and their sole purpose is to fulfil another person's wishes and commands.

One example of the notion of 'using people as a means to an end' in healthcare occurs when human research subjects are recruited to participate in trials for the testing of a new drug or treatment, as they are obviously being used for the potential benefit of others. Some people may get involved for *altruistic reasons*; their contribution to improving treatments for others and society. Others will do it for *their own benefits*, including financial reward, or they may have both motives. In either case, they have not been used merely as a means to another's ends; they also had a purpose to their involvement and a choice to participate or not. This is morally permissible, provided they made their decision freely and that the necessary conditions for informed choice and consent have been met, such as the provision of sound information. These expectations for consent relate closely to the principle of respect for autonomy to be discussed in *Chapter 6*. There are rigorous guidelines for the ethical approval and conduct of medical research, which up to 2016 included the Research Governance Framework for Health and Social Care (DH, 2005b). The Health Research Authority (HRA) will publish a new UK policy framework for health and social care research following consultation in 2016 (HRA, 2016). However, the application of published rules and guidelines still depends on the moral integrity and values of the people conducting and participating in research and on those that make judgements on the nature and moral imperative of the research itself in approving the research proposal.

Due respect for humanity

What Kant also required was not just a sense of respect for others but that, morally speaking, you should act with *due respect for humanity*. On this basis, you should foster an attitude of due respect rather than simply a 'feeling' of respect. This is particularly pertinent to a value-based approach to caring for others. We owe persons respect simply because *they are persons*, regardless of whether we like them, they are useful to us or even if they have wronged us. Think about the value of respect for persons as you consider *Case study 5.1*.

CASE STUDY 5.1

Alfred in A & E

Gemma is a healthcare assistant. She usually works in a medical ward but she has been sent to cover the evening shift in Accident and Emergency. Alfred, an elderly man, is brought in by ambulance; he is unkempt and smells strongly of alcohol. His clothes are stained with urine. He is well-known to the locals; he is homeless and has been living on the streets for several years. Some passers-by called the ambulance when they saw him fall down a small flight of steps. Following initial assessment, he has no serious injuries but he has grazes on his hands and a small cut on his forehead. He is to be kept in overnight for observation. Staff usually take this opportunity to provide basic hygiene and clean clothes. Gemma is asked to wash Alfred's hands and face and to stay with him until a registered nurse is available to suture the cut. However, he has become extremely vocal, is swearing at any member of staff that goes near him and he is disturbing other patients and relatives. As she enters the cubicle, Alfred hurls verbal abuse at her and, when she offers to wash the blood from his hands and face and to get him some clean clothes, Alfred pushes her away forcefully.

Gemma starts to think that she's drawn the short straw. She doesn't see why she should subject herself to Alfred's vile language and abuse and if that's the way he feels and he doesn't want helping, then why should she bother? It is Alfred's choice after all.

- What are your initial feelings about this case? Should Alfred's desire to be left alone be respected? Provide a justification for your answer.
- Can a person forfeit their right to be respected? If so, give some examples of your reasoning.

This is an example where the desire to provide care and act in what you believe to be a person's best interests can come into conflict with duties arising from respect for them as persons, a conflict made more complex in this case by the individual's behaviour. You may feel that Alfred's behaviour is unacceptable and there are limits to what you should have to endure in providing care, as you too are deserving of respect as an individual. However, in these kinds of situations, it is not the case that the patient no longer deserves respect for their humanity or as a person, even if they have quite different interpretations from yours of what is in their best interests. You may have identified that Gemma had obligations to ensure (as far as possible) Alfred's safety while in hospital, although this does not extend to insisting that he washes and changes his clothing.

Tadd *et al.*'s (2011) research of older people in acute hospital settings identified issues associated with risk management and the 'unintended consequences' for a person's self-respect and dignity. The priority given to safety and risk management is often appropriate and both patients and their relatives have interests in being kept safe and to prevent them coming to harm (we explore this further in *Chapter 8*). However, they

concluded that attempts to minimise uncertainties through clinical governance and the regulation of risk can impact on approaches to care delivery as staff become unduly risk-averse. Such approaches then threaten respect for individuals and their dignity.

Tadd *et al.* (2011, pp.90–91) describe practice where concerns for patient safety, particularly for confused patients or those with dementia, meant that staff focused much of their time in preventing patients from moving out of their chairs. They found other examples where patients' freedom and mobility were restricted, such as the use of bed rails, being told to stay sitting down, or being placed in a wheelchair, thus preventing their ability to stand. Care practices tended to be risk averse and did not balance the risk of falling with the possibilities of harm to the person's sense of worth, their identity and their dignity.

Tadd *et al.*'s (2011) work formed part of the Prevention of Abuse and Neglect in the Institutional Care of Older Adults (PANICOA) research initiative. The studies drew on the priorities of older people, their relatives and carers and the summary report identifies eight core 'domains' of the overall care experience that would benefit from improvement in policy and practice, including 'dignity and respect', 'involvement and control', 'communication and information', 'community and relationships' and 'identity and meaning'. These informed two 'Templates for Good Practice', which include specific actions necessary to ensure a 'respect and protect' care culture (Lupton and Croft-White, 2013, pp.4–5).

You may also have considered in *Case study 5.1* whether Alfred was capable of understanding what was in his best interests at this time and whether he was in full control of his decision-making and behaviour, particularly if he was under the influence of alcohol. This links to the discussion of competence and capacity in personal autonomy in *Chapter 6*, but may also raise questions of how we define 'persons' when we talk about the value of respect for persons and those deserving of respect.

Defining the 'person'

One consideration important to the discussion of respect for persons is whether the terms 'human being' and 'person' are synonymous. There are two common interpretations of the term 'human being'. First, a human being is a member of the species *Homo sapiens*; this has genetic, biological and scientific relevance. However, when we refer to the value of human life we mean much more than a preference for our own species. What is often intended when we talk about the value of the 'human being' is consideration of what makes them a 'person'.

Recognition as a 'person' is significant in society because it lies at the centre of debates about the status, respect, rights and treatments that are obligatory to different types of living beings. Thus, the value of respect for persons inevitably requires some definition

of what is meant by 'persons' although this in itself can be contentious. For example, in philosophy and applied ethics, the definition of 'person' used can often exclude human beings who are incapable of certain kinds of thought, such as embryos, fetuses, newborn infants or adult humans who lack the capacity for higher brain functions. There are many definitions of 'person' put forward in the literature that incorporate a wide range of defining characteristics and the recognition of status as a person is known as 'personhood'.

One significant definition of 'persons' comes again from Kant who makes assumptions about 'persons' being rational beings, capable of self-determination, where rationality relates to being able to give reasons for your actions and self-determination means being able to make decisions and act according to your own choices and desires (Banks, 2012, p.43). Kant also saw persons as having the ability to determine their own moral rules and obligations that guide their actions, and that it is this that makes them intrinsically valuable.

Other common characteristics that feature in definitions of the 'person' include:

- possessing human genetic material
- having potential for human development
- the necessity of birth
- personal identity
- individuality
- presence of self-concept and self-awareness
- a sense of self that persists through time
- someone capable of valuing their own existence
- development of communication and language
- the ability to reason
- reflective capacity.

Further definitions of persons and personhood can be seen in *Box 5.3*.

If you hold the view that persons are identified simply by 'being human', i.e. the possession of human genetic material, then this would suggest that some of the practices that society already endorses are immoral, for example, termination of pregnancy (which does concur with some people's views). However, you can see in the definitions in *Box 5.3*, that persons can be defined as beings capable of having interests that other living things do not, or cannot, have and suggests that it is these capacities that lead us to attribute value to persons.

If you believe the value of people is based purely in their capacity to be rational, self-determining, able to value themselves and to reason, then there could be a significant number of people to whom any duty of respect would not be owed, such as those with complex learning disabilities, severe mental health problems or some forms of dementia. To judge who is owed respect simply on the basis of such capacities does not sit well with our intuitions about valuing and respecting humanity. Also, there

BOX 5.3

Some definitions of persons and personhood

Singer (1993, p.86) refers to Fletcher's (1972) 'indicators of humanhood', seeing these to be synonymous with personhood, i.e:

- self-awareness
- self-control
- a sense of the future
- a sense of the past
- the capacity to relate to others
- concern for others
- communication
- curiosity.

Locke (1690, cited by Gillon, 1986, p.51) defined a 'person' as

'... a thinking intelligent being that has reason and reflection and can consider itself as itself, the same thinking being in different times and place; which is inseparable from thinking and as it seems to me essential to it.'

Warren (1973) includes in her definition of the 'person' possession of:

- consciousness... (particularly) the capacity to feel pain
- reasoning (the developed capacity to solve new and relatively complex problems)
- self-motivated activity
- the capacity to communicate... on indefinitely many possible topics
- the presence of self-concepts, and self-awareness.

According to Lockwood (1985, p.10), a person

'... must have the capacity for reflective consciousness and self-consciousness. It must have, or at any rate have the ability to acquire, a concept of itself, as a being with a past and a future.'

may be many beings who are not rational and self-conscious (thus not fulfilling these criteria of personhood) and yet are capable of experiencing pleasure and suffering and to whom we would still attribute value and respect. Singer (1993, p.101) refers to these as *conscious beings*. Many non-human animals may well fall into this category but it could also include, for example, newborn infants and those in persistent vegetative states.

People may also retain the ability to value one thing over another and exhibit this through emotional and non-verbal responses even after they have lost the rational ability to formulate and communicate a particular decision, as with severe dementia. These abilities

ACTIVITY 5.4

Persons worthy of respect?

- Can you identify any potential problems in your practice if the definitions of persons identified in *Box 5.3* were to be used in judgements of who (or what kinds of people) should be worthy of respect?
- Make a list of examples where there may be conflict with the above definitions of persons.
- Talk to friends or colleagues about what features in your list. Do they agree? If not, what are the reasons for their differences of opinion?
- For example, these definitions are commonly used as just one of the arguments to justify the act of abortion, i.e. if the fetus is not capable of reasoning and self-awareness then it is not a person. It then follows, in this argument, that if the fetus is not a person, it is not deserving of the same level of respect as the 'fully fledged' human being. Therefore, on this account, termination of pregnancy is morally permissible.

to value may still be evident through gestures and emotions, for example, to music or pets (Nuffield Council on Bioethics, 2009). Thus, valuing conscious life and the very fact that someone *is human* is as important as valuing 'personhood' as defined by rationality, and emphasises that respect and dignity relate to every human regardless of their capacities; hence why we have talked here about respect for humanity as well as persons.

It is the commonly held notions of personhood that include rationality and their interpretation, which can cause dilemmas in practice, including in judgements about an individual's competence and capacity to be autonomous in their decisions about their own care. Such dilemmas can give rise to paternalism, where a person's own autonomous choices or preferences are overridden on the grounds that you believe you are acting in their best interests, although paternalism is sometimes too easily dismissed and confused with motives of exploitation and control. We explore paternalism further in *Chapter 6*.

Challenging the classic rationality-based view of personhood

Tom Kitwood's (1997) work on dementia and person-centred care challenged the classic rationality and capacity-based view of personhood. He argued for the recognition of *the person* in every individual, regardless of how advanced their dementia was. He claimed that despite loss of function and capacity, persons with dementia do not lose their essential *non-cognitive attributes of humanity*. Thus, even if the person's mood, behaviour and memory change quite profoundly, the person with severe dementia is still the same *person* as before the onset of dementia. Other factors support their identity as a person, such as their physical presence and their interpersonal identity established through relationships with others. Kitwood (1993) viewed agency, sociability and sentience

(the ability to feel, perceive, or experience) as the central attributes of persons and described personhood as:

> '… a status or standing bestowed upon one human being, by others, in the context of social relationship and social being. It implies recognition, respect and trust.'
>
> (Kitwood, 1997, p.8)

Thus, although carers and relatives may refer to someone with dementia as not being 'the same person' as they once were, this tends not to be meant literally but due to changes in behaviour and mood which can be distressing and generate feelings of loss (Nuffield Council on Bioethics, 2009).

In addition, Kitwood viewed personhood as transcendent, sacred, and unique, affording absolute value to people with dementia and resulting in an obligation, '… to treat each other with deep respect.' (Kitwood, 1997, p.8).

In establishing his philosophy of person-centred care, Kitwood demonstrated how personhood could be eroded by the actions of carers, even if these were not maliciously intended. He termed the adverse effects of these actions on the wellbeing of people with dementia, 'Malignant Social Psychology' (Innes, 2009). These interactions, what he called 'Personal Detractions', could range from mild (when no malice was intended) through to very severe (when a carer was aware of the impact their actions would have on the person with dementia). Kitwood identified seventeen 'personal detractions' which are incompatible with respect for persons and potentially damaging to a person's dignity regardless of whether they have dementia (Kitwood, 1997, pp.46–7):

- Treachery
- Disempowerment
- Infantilisation
- Intimidation
- Labelling
- Stigmatisation
- Outpacing
- Invalidation
- Banishment
- Objectification
- Ignoring
- Imposition
- Withholding
- Accusation
- Disruption
- Mockery
- Disparagement.

You may well recognise some of these approaches from your experiences of care practice or in your everyday life. They need not be stark, malicious approaches but could be quite subtle interactions, for example 'talking over' an individual and asking a relative for information about medications without involving the person concerned. Think back to *Activity 3.1* in Chapter 3. The nurse involved was at least guilty of ignoring what she was told about the woman's discomfort, which led to disempowerment and infantilisation, and some degree of objectification through concentrating on the medical aspects of the woman's treatment rather than her 'holistic care', comfort and wellbeing.

Kitwood (1997) claimed that the personhood of individuals with dementia could be maintained through *person-centred care*. He placed the individual at the very centre of dementia care through creating and sustaining meaningful relationships with, and genuine concern for, the individual. Although Kitwood's account is not without criticism (for example, Nolan *et al.*, 2002), Dewing (2008) reminds us that Kitwood's ultimate purpose was of that of the *moral concern for 'others'*. This accords with respect for humanity and with the accounts of compassion previously explored.

Building on Kitwood's vision of care, Brooker (2003, 2007) identified four major elements (VIPS) that define her concept of person-centred care and Brooker and Latham (2015) use the 'VIPS framework' to promote service improvement through person-centred dementia care. The VIPS elements are (Brooker and Latham, 2015, pp.12–13):

- ***Valuing people*** with dementia and those who care for them; promoting their rights and entitlements regardless of age or cognitive impairment (V)
- Treating people as ***individuals***; appreciating that all people with dementia have a unique history, identity, personality and physical, psychological, social and economic resources, and that these will affect their response to cognitive impairments (I)
- Viewing the world from the ***perspective of the person*** with dementia; recognising that each person's experience has its own psychological validity (P)
- Recognising that all human life, including that of people with dementia, is grounded in relationships and that people with dementia need an enriched ***social environment*** that compensates for their impairment and fosters opportunity for personal growth and relative wellbeing (S).

You should be able to see similarities between these elements of person-centred dementia care and the values of compassion and care identified earlier and the notion of social-relational autonomy in *Chapter 6*.

Although defining persons is not straightforward, the value of 'respect for persons' is a starting point for good morality because it accepts the basic premise that other people matter, and this is an important value in a societal context. Humans do not live as isolated beings and, consequently, mutual respect should be a fundamental principle. Downie and Telfer (1969) characterise respect as 'valuing and cherishing

ACTIVITY 5.5

Using the VIPS elements to guide reflection on your interactions with people with dementia and their families (adapted from Brooker, 2012), ask yourself:

- Does my behaviour and the manner in which I am communicating with this person show that I respect, value and honour them?
- Am I treating this person as a unique individual with a history and a wide range of strengths and needs?
- Am I making a serious attempt to see my actions from the perspective of the person I am trying to help? How might my actions be interpreted by this person?

For further guidance and resources see the 'Care Fit for VIPS' Tool Kit at carefitforvips.co.uk (accessed 14 December 2016)

persons for what they are' – valuing their capacity *to be* rather than to do or think. This encapsulates an important view in the care context as it allows for difference, without a value judgement being placed upon that difference. From this, the fundamental duty to respect others should be independent of a person's personal characteristics and be afforded to all humans equally, regardless of their merit or ability.

Valuing People Now (DH, 2009) is one example where policy aspired to reinforce the value of respect for persons and set out to influence the ethos of services and practitioners working with people with learning disabilities and challenging behaviour. Its vision was based in the premise that:

> '… 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. They and their families and carers are entitled to the same aspirations and life chances as other citizens.'
>
> (DH, 2009, p.3)

This vision reflects an understanding of mutual respect for persons where all people are of equal worth and their lives, regardless of difference, are equally valuable. Despite reports of discrimination, poor access to services, abuse and neglect of individuals with learning disabilities (DH, 2012b; Mencap, 2007; Michael, 2008) and the slow progress made in delivering change following the Winterbourne View Review (Bubb, 2014), examples of good practice take account of the value of respect for persons, their humanity and dignity and provide person-centred care (DH, 2012d). The Royal College of Nursing (RCN, 2013) guidance is based on the users' experiences of healthcare and is relevant to any practitioner who cares for people with learning disabilities, regardless of the practice setting. The examples of 'positive experiences' clearly reflect a 'valuing persons' approach, whilst also suggesting ways to improve and provide dignity-enhancing care.

Respect for persons and dignity give rise to other duties, including respect for privacy. However, the relationship between respect for persons and dignity is often taken for granted. Whilst they are interrelated, it is important to understand the contribution made by the concept of dignity to value-based practice.

THE MORAL VALUE OF DIGNITY

The notion of dignity has become a dominant feature in contemporary accounts of healthcare. Appeals to the concept of dignity abound in the media and in legal, religious, political and ethical debate, with claims of 'rights to dignity', to be treated in 'a dignified way', to 'die with dignity' (Tadd, Bayer and Dieppe, 2002). Yet dignity has been criticised as an elusive and useless concept (Macklin, 2003), because it is difficult to specify what the value of dignity requires in ethical reasoning that is independent of the value of respect for persons and their autonomy (Schroeder, 2010). Häyry (2004) reminds us that although dignity is a multifaceted concept, its use can lead to constructive dialogue between people and cultures. Thus various attempts have been made to specify the concept of dignity as a value in its own right.

Given the number of inquiries and reports over recent years highlighting cases of inhumane and *undignified care*, it has become even more important to have a clear appreciation of what dignified care requires (Commission on Dignity in Care for Older People, 2012; RCN, 2013). The starting point for this is to explore how dignity may be defined and what the value of dignity entails.

Defining dignity

Nordenfelt (2004) proposed four types of dignity in his research investigating the care of older Europeans. He distinguishes types of dignity according to their position on a value scale: one that has *intrinsic worth* (that belongs to us by virtue of our nature of being *Homo sapiens*, oriented toward reason and freedom) and three with *contingent worth* (conditional on other factors; conferred on us by certain attributes, good fortune or personal merit; in some sense 'accidental' to who we are). These are further specified through their relationship with the notions of rights, respect and self-respect. The resulting four types of dignity identified by Nordenfelt (2004) are shown in *Box 5.4*.

What is common to all of these types of dignity is that the person's dignity is worthy of self-respect as well as the respect of others. They may all be evident in healthcare, although 'dignity as merit' and 'dignity as moral stature' are less relevant, as healthcare practitioners should treat people with respect for their dignity regardless of any perception of merit or moral status. These may have initially been called into question in *Case study 5.1* if Alfred was considered to be less deserving of respect or had in some way forfeited his right to be respected due to his behaviour towards another. Yet, the

BOX 5.4

Nordenfelt's four types of dignity

Dignity of* Menschenwürde *(intrinsic) – *Menschenwürde*, German for 'human worth', signifies a universal dignity that pertains to all human beings to the same extent 'just because we are all humans' and cannot be lost as long as the persons exist.

Dignity of merit (contingent) – linked to position in society; there are many kinds of this dignity and it is unevenly distributed among human beings. Dignity of merit exists by degree and can come and go. People have rights on the basis of holding certain roles or office or because they have earned merit through their actions.

Dignity of moral stature (contingent) – comes as a result of the individual's moral deeds; emerging from actions or omissions and from the kind of person he or she is. Similarly it can be reduced or lost through immoral deeds. This links with having a 'dignified character' and dignity as a virtue. The dignity of moral stature is a dignity of degree and is unevenly distributed.

Dignity of personal identity (contingent) – reflects the integrity of the person's body and mind; often, although not always, dependent on the person's self-image. It relates to one's identity as a person, to self-respect and to concepts such as autonomy and inclusion. This dignity can come and go as a result of the actions of others or as a result of changes in the person's body and mind. Thus, this kind of dignity can be violated by physical intrusion, being treated as an object or by emotional or psychological interference, for example, being humiliated or insulted.

From Nordenfelt, 2004, pp.71–9.

ACTIVITY 5.6

Reflecting on types of dignity in healthcare

Look at Nordenfelt's four types of dignity (*Box 5.4*).

Which do you think have most relevance to patients or service users in your care setting?

Can you identify examples where any of the types of dignity have been compromised or enhanced through your practice? Write down some examples.

inalienable, universal human dignity ('*Menschenwürde*') gives rise to due respect for our dignity simply because of our humanity, an absolute inner worth and the basic human right to be treated equally.

The *dignity of identity* is most relevant in the context of illness and disability where our personal identity and self-esteem may fluctuate due to ill-health or treatment, or

may be threatened by medical intervention or care practices that invade our personal space or alter our personal identity (Killmister, 2010). Illness or disabilities may result in changes in identity over time, may restrict abilities to be autonomous or personal identity may be threatened through inadequate support or poor environment.

Jacobson (2007; 2009) views dignity as encompassing two distinct (though related) phenomena: *human dignity* and *social dignity*. *Human dignity* is the value belonging to everyone simply by virtue of being human (like Nordenfelt's universal dignity), whereas *social dignity* is generated through the interactions between individuals, groups, and societies. *Social dignity* is divided into two types: *dignity-of-self* and *dignity-in-relation*. 'Dignity-of-self' consists in the personal qualities of self-respect and self-worth, demonstrated through individual characteristics like self-confidence, integrity and *being dignified*. 'Dignity-in-relation' is concerned with the ways in which respect and worth are evident in individual and collective behaviour. Thus, expectations of dignity may depend on the moral values, beliefs and traditions of particular societies or cultures (Jacobson, 2009, p.1538).

'Dignity-in-relation' has specific relevance in healthcare because as practitioners we should uphold personal and professional values and standards of behaviour and avoid humiliation in our interactions with others as part of the obligations we afford one another as bearers of dignity (Killmister, 2010, p.160). Recognising the distinction between *dignity as a constraint* and *dignity as empowerment* is significant here (Beyleveld and Brownsword, 2001, cited by Nuffield Council on Bioethics, 2009, p.32). Certain actions may be absolutely forbidden because they are counter to human dignity (using the value of dignity as a constraint). However, thinking about dignity may also empower individuals as it supports the value of respect for persons and the obligation to treat people in ways that uphold their value as a human being.

Dignity and rights

In law and politics, the value of dignity is often interconnected with human rights. For example, the Universal Declaration of Human Rights (1948) attributes dignity to all human beings, with no reference to possession of particular conditions or qualities and starts from the assumption that it is an inalienable right that must be respected and protected. The rights arising from the Declaration apply simply because we are human beings, and would include those without capacity for rational thought.

Similarly, the importance of upholding the dignity of individuals is enshrined in UK law through the Human Rights Act (1998) which places dignity and the expectation that everyone should be treated equally, whatever their circumstances, at the heart of human rights.

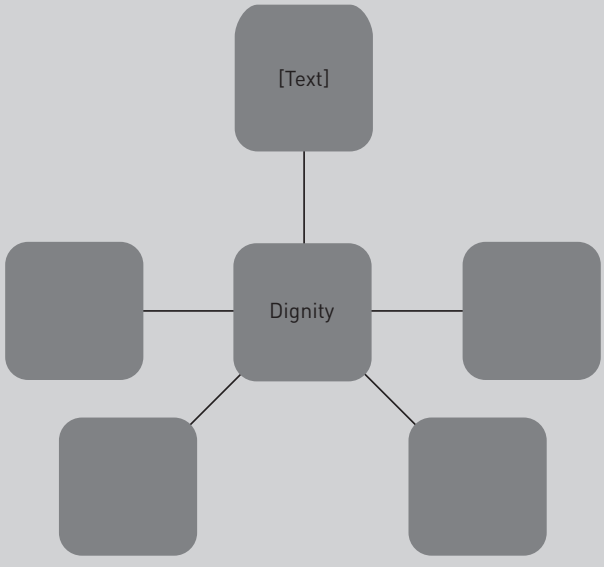
These declarations of rights accord with the common use of the value of dignity in healthcare; the expectation that all people, regardless of difference or diversity, are worthy of respect and that we should practise in ways that uphold their dignity and self-worth. Dignity is not something that can be given to people in care, but neither must it be compromised or diminished through the healthcare system or care relationship (Levenson, 2007).

People's personal views of dignity

Although there are a number of formal interpretations of dignity, what matters most in the care relationship is understanding what dignity means to individuals and the value they place on maintaining and upholding their dignity in their experience of healthcare. Complete *Activity 5.7* to establish your personal viewpoint on the value of dignity.

ACTIVITY 5.7

What does the word 'dignity' mean to you? Create a concept map that identifies the words and concepts that you associate with dignity.



How important is it to you to have your dignity respected? Identify reasons.

It may help to think about an experience where you felt that your dignity was compromised.

Although the value of dignity in itself can be hard to define, what is clear is that people recognise, and can experience significant harms, when they have not been treated with respect and due consideration for their dignity (Healthcare Commission, 2007; PHSO, 2011; Social Care Institute for Excellence (SCIE), 2006). The Health Ombudsman's Report (PHSO, 2011) provides a salutary reminder of the effect of 'casual indifference' to the values of care, respect, dignity and compassion:

> '… Older people are left in soiled or dirty clothes and are not washed or bathed. One woman told us that her aunt was taken on a long journey to a care home by ambulance. She arrived strapped to a stretcher and soaked with urine, dressed in unfamiliar clothing held up by paper clips, accompanied by bags of dirty laundry, much of which was not her own. Underlying such acts of carelessness and neglect is a casual indifference to the dignity and welfare of older patients. That this should happen anywhere must cause concern; that it should take place in a setting intended to deliver care is indefensible. The NHS must close the gap between the promise of care and compassion outlined in its Constitution and the injustice that many older people experience.'
>
> (PHSO, 2011, p.10)

The 'Dignity and Older Europeans Study' set out to establish how older people across Europe view dignity in their lives and how health and social care practitioners observe dignity when planning and providing elderly care services (Tadd, 2004; Tadd, Vanlaere and Gastmans, 2010; Woolhead *et al.*, 2004). The researchers examined the perceptions of older people from a range of different socioeconomic backgrounds, levels of health and disability, living in both institutional and community settings. Dignity was viewed as a multi-faceted concept (Woolhead *et al.*, 2004), involving:

- dignity of identity (self-respect/esteem, integrity, trust);
- human rights (equality, choice); and
- autonomy (independence, control).

Dignity was clearly important in the everyday lives of older people and, when experienced, enhanced their self-worth, self-esteem and wellbeing. However, they tended to identify dignity mostly through describing situations where they felt it was absent or jeopardised rather than enhanced.

Woolhead *et al.* (2004) found evidence of humiliation, poor communication, exclusion and a general insensitivity to their needs. Older people experienced loss of self-esteem from being treated as an 'object' and being patronised and excluded from decision-making. They were concerned about maintaining their autonomy and remaining independent, without being lonely or lacking support. They felt an inability to trust others and an increased vulnerability. Equality was important but they felt government policies did not support their rights. Woolhead *et al.* (2004) concluded that age discrimination for eligibility to services needed addressing and highlighted

the need to balance care and support with promoting independence. Dignity for older people was most likely to be respected through person-centred care which focuses on communication, privacy, personal identity and feelings of vulnerability.

Tadd, Vanlaere and Gastmans (2010) use Nordenfelt's (2004) four types of dignity in their analysis of responses from the 'Older European' study and found that the *'dignity of identity'* raised most concern for the older people studied. Frailty, disability, illness and the ageing process may affect their identity, not only in looks but through impairments to their independence and autonomy. Ageist stereotypes can marginalise older people and make them question their value in society. With retirement and changes in their economic contribution to society, they lose not only their employment but also a sense of their identity, leading to social exclusion and isolation.

Participants wanted to be their own person with freedom and choice for as long as possible. Care supporting daily living activities and preventing burden on relatives must be balanced against fear of losing independence and choice through the interference of health and social care services. They wanted to retain control over decisions about their care and valued being informed. Poor communication, patronising and disrespectful language and manner threatened their dignity of identity while kindness, willingness to listen and politeness were valued attitudes (Tadd, Vanlaere and Gastmans, 2010).

Although these studies focused on older people, the findings start to inform what might be expected of respectful and dignified care practice for any person and in any setting.

RESPECT, DIGNITY AND PRIVACY IN PRACTICE

Defining dignity in practice

Dignity is a complex and multifactorial concept and practitioners, patients and service users may use the term in ill-defined ways. Dignity could be a subjective concept; different people may have particular understandings of when their dignity is respected or not. What is experienced as undignified care by one may be acceptable to another. Respecting dignity could become a futile objective without some consensus on a working definition and clarifying what dignity entails in practice (Tadd, 2005).

Whilst respect for persons is one of the defining attributes of the concept of dignity, it also includes privacy, autonomy and self-worth. Johnstone (2009, p.175) identifies the following elements which should inform a definition of dignity in practice:

- The intrinsic, inalienable moral worth of persons which gives rise to a duty of respect (for persons and for their humanity)
- Maintaining individuals' sense of self-worth, self-respect and self-esteem

- Respect for the autonomy of persons and as beings capable of exercising self-determination
- Supporting individuals in their exercise of autonomy, within the realms of their capabilities.

These core elements are evident in the working definitions of 'dignity' that have been presented by professional and sectoral organisations for nursing and social care (see *Box 5.5*).

BOX 5.5

Defining dignity in care

Social Care Institute for Excellence in the SCIE Guide 15 'Dignity in Care' (first published 2006, updated 2013) uses:

'... A state, quality or manner worthy of esteem or respect; and (by extension) self-respect. Dignity in care, therefore, means the kind of care, in any setting, which supports and promotes, and does not undermine, a person's self-respect regardless of any difference. Or, as one person receiving care put it more briefly, "being treated like I was somebody".' (Policy Research Institute on Ageing and Ethnicity, 2001)

Skills for Care (2013, p.4) define dignity in the introduction to their seven common core principles to support dignity in adult social care, as:

'Dignity focuses on the significance and value of every person as a unique individual. We show our commitment to upholding other people's dignity by the ways in which we treat them; fairly, truthfully and with care and compassion. We respect others' views, choices and decisions and do not make assumptions about what they want, like or how they want to be treated... Dignity embodies the belief that everybody has equal worth and is entitled to be treated respectfully. Each individual, regardless of age, ability to consent, gender or disability, should be valued and treated as if they were able to think, feel and act in a way that would uphold their own self-respect and dignity.'

The Royal College of Nursing (RCN, 2008) defines dignity as:

'... concerned with how people feel, think and behave in relation to the worth or value of themselves and others. To treat someone with dignity is to treat them as being of worth, in a way that is respectful of them as valued individuals.'

Matiti and Baillie (2011) summarise further key themes essential to the understanding of a concept of dignity in healthcare practice:

- Dignity is inherent in human beings
- Dignity is an *internal quality*: related to self-concept, self-identity, individuality
- Dignity is *dynamic*: people adjust their perceptions of dignity as illness progresses or during hospitalisation

- Dignity has *an affective component*: it *relates to feelings* such as self-esteem, self-worth, pride, hope, confidence, self-respect, wellbeing, feeling important and valuable, comfortable
- Dignity relates to *behaviour* (and attitudes): behaving according to one's personal standards, courteousness, conveying respect, treating people as individuals and as competent adults
- Dignity is *relational*: it can be reciprocal and interpersonal
- Dignity as a sense of *personal control*: relates to autonomy, self-determination and independence
- *Presentation of self* in public: physical identity, modesty
- Dignity involves *privacy*: maintaining one's personal boundaries and space, being in control of one's privacy, respect for and protecting privacy.

(Adapted from Matiti and Baillie, 2011, pp.15–16)

Keep these different features of dignity in mind whilst completing the activity in *Case Study 5.2*, which requires you to think carefully about the values of respect for persons, dignity and privacy in your practice.

Older people may use strategies to maintain a sense of self-worth and meaning in their lives, such as focusing on simple pleasures and maintaining their sense of normality, having connections with their families and remembering their previous lives and achievements. However, dignity can be undermined by the attitudes and approaches of health and care workers in their everyday interactions with people in their care (Tadd, Vanlaere and Gastmans, 2010; Tadd *et al.*, 2011).

This was clearly evident for Barbara in *Case study 5.2*, with inappropriate and insensitive care impacting on her dignity of identity (wrong clothes, change in hairstyle) and in respect for her as a person and her universal human dignity (through the use of flippant, discourteous and condescending language, denial of personal space to meet with relatives). Reinforcing the negative aspects of the person's situation, such as their vulnerability, dependency and fragility, can make them feel insignificant and unrecognised as individuals, which, in turn, compromises their self-respect, self-esteem and dignity (Tadd, 2004; Tadd, Vanlaere and Gastmans, 2010; Woolhead *et al.*, 2004).

Jacobson (2009) suggests any human interaction between individuals or groups can be a *'dignity encounter'*, in which dignity is either violated or promoted. She identifies a number of attitudes and behaviours that can violate a patient's dignity in healthcare. These include rudeness, indifference, condescension, dismissal, disregard, dependence, intrusion, objectification, restriction, labelling, contempt, discrimination, revulsion, deprivation, assault, and abjection (being forced to compromise closely held beliefs, e.g. practices considered unclean). When a person's dignity is violated it can result in a number of potential harms to the individual (and to others in connection or relationships

CASE STUDY 5.2

Barbara and residential care

You are visiting your mother, Barbara, who is 82 years old. She is dependent on a wheelchair for mobility and has recently chosen to move into a residential home as she was finding it increasingly difficult to cope on her own (you are her only close relative and live some distance away). When you arrive she is sitting in the main living room. She is wearing clothes you do not recognise and her hair appears to have been blow-dried (for as long as you can remember she has always had a weekly 'shampoo and set'). She is normally chatty, cheerful and pleased to see you but today she is tearful and agitated.

You ask a member of staff if there is a room where you can take your mother to talk (she shares a room with two other women and one is already resting in the room). They say that all the other rooms are occupied and suggest you simply move to the other corner of the sitting room away from the television. They seem to stay nearby as if to hear what you are saying to each other.

Your mother reveals tearfully that when she was taking her daily bath that morning, one of the male care assistants had entered the bathroom to get a commode and trolley that were stored in the corner of the room. The female member of staff assisting your mother had made light of the incident, saying light-heartedly, 'Barbara, fancy your "boyfriend" coming to see you in the bath!'. Your mother is obviously upset but says the young woman meant no malice and urges you not to make a fuss.

- What issues are there to be considered here in relation to respect, dignity and privacy? As well as specific aspects of care practice, think also about other features, such as the care environment.
- What would you do differently in this situation?
- Having thought about the importance of maintaining respect and dignity in this case, make a list of ways in which you can practise to ensure that your care respects individuals and maintains their dignity.

Discuss your list with a colleague and add any new ideas that emerge from your conversation.

- Now find out whether there is a dignity policy in your work environment. If there is, read it and make notes of the key principles to be observed in your workplace.

with them) which can be physical, emotional, psychological, social, relational, spiritual and moral in nature.

Dignity is more likely to be violated if one or more of the following exists in the care relationship (Jacobson, 2009, p.1538):

- When the person (patient) is *vulnerable*, for example because of illness, helplessness, confusion or belonging to an oppressed group

- If the carer or practitioner is in *a position of antipathy*, is arrogant, hostile or impatient
- Where the care relationship is *unbalanced and unequal* – where someone, for example a practitioner, carer or relative, is in a position of greater power, authority, knowledge, or strength
- Where *practice settings* are hierarchical and rigid, where there are distractions, stress and urgency and lack of resources.

Whilst the physical environment and culture of an organisation can affect delivery of care (RCN, 2008), the values, attitudes and behaviours of individual practitioners play the most significant role in the patient's experience of dignified care (see *Box 5.6*).

BOX 5.6

RCN definition of dignity in practice (2008)

'... In care situations, dignity may be promoted or diminished by: the physical environment; organisational culture; by the attitudes and behaviour of the nursing team and others and by the way in which care activities are carried out. When dignity is present people feel in control, valued, confident, comfortable and able to make decisions for themselves. When dignity is absent people feel devalued, lacking control and comfort. They may lack confidence and be unable to make decisions for themselves. They may feel humiliated, embarrassed or ashamed. Dignity applies equally to those who have capacity and to those who lack it. Everyone has equal worth as human beings and must be treated as if they are able to feel, think and behave in relation to their own worth or value. The nursing team should, therefore, treat all people in all settings and of any health status with dignity, and dignified care should continue after death.'

The professionals involved in the 'Dignity and Older Europeans Study' viewed dignified care as that which

> '… promotes autonomy, independence, engenders respect, maintains individual identity, encourages involvement, involves effective communication and is person-centred and holistic.'
>
> (Tadd, Vanlaere and Gastmans, 2010, p.269).

Barriers to delivering dignified care included aspects of governance, protocols and staffing. Nurses recognised that patient-centred care was integral to respecting an individual's dignity, yet these behaviours were rarely seen in practice (Tadd *et al.*, 2011). Similarly, Matiti (2002) found that practitioners identified the importance of privacy for a person's dignity, yet did not see themselves as intruders of the patient's privacy. They appeared to see the care relationship as giving certain permissions to disregard respect for an individual's privacy and the usual boundaries of personal space. Yet the

value of privacy is a fundamental component of dignity and can too easily be violated through inconsiderate care.

The value of privacy

Respect for persons is not only concerned with dignity and self-worth. It is also closely associated with respect for privacy. Although privacy may be an essential aspect for preserving dignity, the two concepts are quite distinct. A simple definition of privacy would be 'freedom from unauthorised intrusion' (DH, 2010b). However, privacy can be viewed in a number of ways.

Beauchamp and Childress (2013, p.312) and Allen (2011 and 2011a) identify several forms of privacy that involve limited access to the person:

- *Informational privacy* – limiting access to or keeping information about the person private
- *Physical privacy* – focuses on personal space, solitude, bodily modesty and bodily integrity; expectations that you will not be needlessly touched or exposed
- *Locational privacy* – focuses on environment, having control and choice of one's surroundings
- *Decisional privacy* – concerned with autonomy and personal choices in healthcare decision-making; for example, reproductive decisions including contraception, abortion, assisted reproductive technology; choosing medically unhealthy lifestyles; the right to refuse care
- *Proprietary privacy* – 'property interests' of the person; privacy of the body; self-ownership and control over personal identifiers such as keeping their image private, genetic data and body tissues
- *Relational or associational privacy* – concerned with the relationships within which people make decisions with significant others, such as families or intimate relationships. This would include intimate sharing of their experience of death, illness and recovery.

Individuals generally value their bodily modesty, intimacy and bodily integrity. Most patients tend to be discreet and reserved when sharing sensitive health information (Allen, 2011a) and would expect the same from practitioners.

Normally restrictions are placed on access to health information and the law imposes obligations to respect informational privacy through the Data Protection Act (1998). However, preserving privacy is too narrowly construed if the focus is on one or other of these forms of privacy, and all forms identified above should be taken into account when devising policy and care strategies. Conditions of access to the person should be agreed in relation to what will constitute the violation of their right to privacy. Practitioners should respect the person's privacy (in all its forms); their bodily modesty, intimacy, bodily integrity, and self-ownership (Allen, 2011a).

Privacy in practice

You may think about privacy from a very practical viewpoint; for example, maintaining privacy by drawing curtains when meeting patients' hygiene needs or knocking on doors before entering cubicles. You could also identify with the underlying moral values related to maintaining privacy, such as establishing a relationship of trust, the importance of respecting the person, treating them as an individual and promoting and supporting their independence. All of these perspectives are important in developing and enhancing your practice, as you need to think not only about what you should do but also the value associated with practising in a certain way.

You will have recognised violation of a number of aspects of a person's privacy in *Case study 5.2* and identified different approaches that would demonstrate respect for Barbara as a person and provide care in a way that maintains her individuality and protects her privacy. It is often in the fundamental aspects of care, such as meeting hygiene needs, that dignity, respect and privacy can be most at risk. This is particularly relevant if care becomes routinised and you underestimate the importance of the aspects of care that are taken for granted. Practitioners must be wary of becoming desensitised to some of the expectations placed on people in their care.

The reality for people requiring care in hospitals, care homes or in their own homes is that they will inevitably expose themselves, both physically and emotionally, to practitioners and carers in ways that would not occur in their normal everyday lives. Sleeping in rooms with other people, sharing bathing and toilet facilities, using commodes with only the 'protection' of a flimsy curtain, discussing personal thoughts, feelings and intimate information with relative strangers in the process of assessment and diagnosis are all examples that can compromise a person's privacy and challenge their ability to maintain their self-respect and dignity.

There will inevitably be times when total privacy cannot be maintained. However, you should seek permission from the patient wherever possible and must be able to justify any compromise of privacy, both on practical grounds and in terms of the person's moral right to privacy. It is essential that you take responsibility for safeguarding the privacy and dignity of patients and service users in your delivery of care.

In their research with cardiothoracic patients, Whitehead and Wheeler (2008) set out to ascertain the patients' experience of how they thought their privacy needs were met, and how the care environment could enhance the patients' privacy during their hospital stay. The key themes that patients identified reflect the different types of privacy identified by Beauchamp and Childress (2013) and Allan (2011). They also start to identify what kinds of approaches would be important to protecting the privacy of people in your care (see *Box 5.7*).

BOX 5.7

Patients' concept and definition of privacy

Important themes for patients included:

- Privacy of information, e.g. one's conversation not being overheard
- Privacy of person and body, e.g. not being viewed during one's private moments
- Exerting personal control, e.g. matters relating to one's care
- Able to be alone at one's choosing
- Gain respect from professionals
- Having one's hospital records and files removed from visitors' attention/space
- Having one's own personal space
- Everyone valuing privacy as essential
- The value of single as opposed to mixed-sex wards/bays
- Freedom and privacy to worship
- Right to perform intimate activities of daily living, e.g. using the toilet, in private and alone, only having staff present if essential.

Adapted from Whitehead, J. and Wheeler, H. (2008) Patients' experience of privacy and dignity. Part 2: an empirical study, *British Journal of Nursing*, **17(7):** 458–464.

One of the common patient experiences where a person's dignity and privacy are at risk of compromise, is in the performance of intimate personal care, such as washing and assistance with using the toilet or continence care (see *Activity 5.8*).

ACTIVITY 5.8

Privacy and dignity in continence care

- Reflect on how you would feel if you were dependent on others for aspects of your own personal care, such as washing, going to the toilet and managing your continence.

For applications of values of respect, dignity and privacy in practice see the reports from the 'Privacy and Dignity in Continence Care Project' (Centre for Health Services Studies, British Geriatrics Society and Royal College of Physicians, 2009) at rcplondon.ac.uk/projects/continence-care-privacy-dignity or kar.kent.ac.uk/24800/1/Phase_1_Privacy_and_Dignity_in_Continence_Care_Report_November_2009.pdf

- Think about your current practice in relation to continence care:
  - Are there things that you could do better?
  - How will you achieve these goals?
  - How will you know when you have been successful in improving your care?

Pols (2013) examined different interpretations of dignity in care practices in psychiatric hospitals and residential homes and carers' views about 'good care', including the washing of patients. She found that, '… geriatric assistants enforced cleanliness far too routinely for the taste of the psychiatric nurses who came to work in the residential homes' (p. 191). The latter preferred approaches that allowed residents to influence the organisation of their washing practices, whereas for the geriatric assistants, '… washing patients was never questioned: it simply needed to be done' (Pols, 2013).

ACTIVITY **5.9**

Read pages 191–7 of Pols' (2013) article and make notes from her analysis of why there were differences in expectations of practice between the two different groups of practitioners and settings and their ways of achieving dignity.

Pols, J. (2013) Washing the patient: dignity and aesthetic values in nursing care. *Nursing Philosophy*, **14(3):** 186–200.

What is evident from Pols' (2013) study is that practitioners working in multidisciplinary teams may have different philosophical standpoints of what constitutes care, dignity and respect and how this should be achieved. This in part can relate to them as individuals, to the organisational or practice setting and to differences in role and professional discipline.

Protecting and promoting respect, dignity and privacy in practice

Ensuring that respect, privacy and dignity are protected and promoted is everyone's responsibility. It is therefore essential that you observe professional standards and policies put in place to ensure this. However, this is only the first step to understanding the value of respect for others and to preventing circumstances in which a patient's privacy and dignity may be infringed. You need the knowledge, skills and values that will enable you to practise with sensitivity. Also, if you are serious about the importance of respect for persons and dignity in your care then it is essential that you are not lulled into a false sense of security provided by simply claiming to follow routines, protocols and guidelines. Observing these is only the first step to being committed to seeing, understanding and knowing the value of respect for others and to prevent behaviour and attitudes that degrade, devalue and humiliate individuals in your care.

As Levenson (2007, p.14) states:

> '… Dignity is not a formula or a recipe that can be rigidly applied from a manual. In particular, the 'toolkit' approach, while useful for improving practice and as a

benchmark for assessing performance, cannot fully address the 'care' component of dignity in care. Indeed, a formulaic approach, taken outside the context of values and principles, can lead to a situation where all the right boxes are ticked, but still standards fall short of what older people (and other age groups too) want.' (p.14).

She identified a number of core principles that underlie dignity in care (*Box 5.8*).

BOX 5.8

Core principles that underlie dignity in care

- Dignity in care is inseparable from the wider context of dignity as a whole
- Dignity is about treating people as individuals
- Dignity is not just about physical care
- Dignity thrives in the context of equal power relationships
- Dignity must be actively promoted (rather than simply attempting to eradicate indignity)
- Dignity is more than the sum of its parts.

From Levenson, 2007, p.13.

In a survey conducted for the Royal College of Nursing (Baillie, Gallagher and Wainwright, 2008), respondents identified care activities that can compromise an individual's dignity, including many physical aspects of care such as personal care, procedures involving intimate areas of the body or that were potentially painful or anxiety-provoking, as well as aspects of mental healthcare and care involving emotions. The main factors identified in either promoting or diminishing dignity in care were grouped according to *the 'three Ps':*

- *'Place'* (physical environment and organisational culture)
- *'Process'* (the nature and conduct of care activities)
- *'People'* (attitudes and behaviours of staff and others).

Reflecting on the factors that impact on the 'three Ps' should help you to identify the specific aspects of practice essential in providing respectful and dignified care in your care setting and any changes that need to be made to improve the patient and service user experience. The RCN Dignity 'pocket guide' provides a useful summary of practical ideas in providing dignified care grouped according to the 'three Ps' (available at rcn.org.uk/professional-development/publications/pub-003292 (accessed 14 December 2016).

Respect for persons and their dignity is most likely to be achieved through inclusive and person-centred approaches to care which focus on personal identity, promoting

ACTIVITY 5.10

Preserving and promoting dignity and privacy in healthcare

1. Reflect on your own practice and identify which people are most vulnerable to loss of dignity and why this is the case.
2. How might you work to protect or minimise loss of dignity when you are caring for these people? What are the key aspects and approaches in your practice

   that are important in providing dignified care? You should have some ideas that you can take from your list created in response to *Case study 5.2*.
3. Think about and list the key aspects and approaches you identify according to the categories of 'Place', 'Process' and 'People'.
4. Discuss your list with a group of practitioners and refine your 'guide' to preserving and promoting dignity and privacy in your care setting.
5. Identify **one aspect of practice** where you could make a simple change today that would maximise positive impact on patient or service user dignity.

Useful sources include:

Baillie, Gallagher and Wainwright (2008) '*Defending Dignity: challenges and opportunities for nursing*' on the RCN website at rcn.org.uk/professional-development/publications/pub-003257 (accessed 14 December 2016)

Commission on Dignity in Care for Older People (collaboration established by the NHS Confederation, the Local Government Association and Age UK) (2012) *Delivering Dignity. Securing dignity in care for older people in hospitals and care homes. Final Report*.

Jackson, A. and Irwin, W. (2011) Dignity, humanity and equality: Principle of Nursing Practice A. *Nursing Standard*, **25(28):** 35–37.

Essence of Care 2010 – benchmarks for the fundamental aspects of care (DH, 2010b) particularly the section 'Privacy and Dignity' and the indicators for best practice identified by patients, carers and professionals.

autonomy and enhancing privacy, using respectful communication and building caring relationships that recognise human rights such as fairness and equality (Tadd *et al.*, 2011). The individual must be seen as central and any feelings of vulnerability recognised and addressed (see *Box 5.9*).

The Dignity in Care campaign, launched in November 2006, aims to place dignity and respect at the heart of UK care services (National Dignity Council, 2015). The campaign has over 70 000 registered 'Dignity Champions' (as at April 2016), who work individually and collectively to ensure people have a good care experience.

BOX 5.9

Patients' views of how their dignity needs might be met

- Absence of embarrassment, e.g. not shown up in front of others
- Having one's privacy and dignity respected
- Being treated humanely, like a human being and not as an object
- Being treated with respect as well as respecting others
- Being treated with sympathy, consideration and compassion
- To be treated as an individual
- Staff introducing themselves and saying who they are before treating you
- Being able to maintain one's privacy, e.g. treated in private, out of public gaze
- A feeling of being in control, e.g. over decisions and private bodily functions
- Staff explaining treatment, any changes and what is going to happen
- Being listened to and being heard
- Desire to have own personal space and independence
- Acknowledgement of the need for peace of mind at a stressful time.

Adapted from Whitehead and Wheeler, 2008, p.461.

ACTIVITY 5.11

Being a Dignity Champion

If the term 'champion' is used to describe someone who is a 'defender', a 'supporter' and a 'campaigner' (as well as a 'remarkable person', someone demonstrating 'excellence') what *qualities* would you expect a 'Dignity Champion' to have?

Find out how to become a Dignity Champion and the qualities required at dignityincare.org.uk/Dignity-Champions/Becoming_a_Dignity_Champion/ (accessed 16 December 2016)

The *'10 Dignity Do's'* (previously the 10 Point Dignity Challenge) (Dignity in Care, 2015) describe the values and actions that should be expected of high quality services in respecting people's dignity. They should:

1. Have a 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 carers as care partners
9. Assist people to maintain confidence and positive self-esteem
10. Act to alleviate people's loneliness and isolation.

Good interpersonal and communication skills, both verbal and non-verbal, are essential to respectful and personalised care. They include interactions that promote dignity through helping people to feel comfortable in the care relationship, in control and valued as individuals (see *Table 5.1*).

Table 5.1 *Interactions that make patients feel comfortable, in control and valued*

Interactions that help people feel comfortable	• Sensitivity • Empathy • Developing relationships • Conversation • Professionalism • Family involvement (if desired by the patient) • Friendliness and reassurance • Humour (if used sensitively and appropriately)
Communication that helps people feel in control	• Giving explanations and information • Providing informed consent • Offering choices and negotiating • Enabling independence
Communication that helps people to feel valued	• Listening • Giving time • Showing concern for patients as individuals • Being kind, considerate and helpful • Showing courtesy: addressing people by their preferred name, introducing self, being polite and respectful, including respect for culture and religious beliefs

Source: Baillie and Black, 2015, p.125, originally adapted by Baillie and Black from Baillie, 2007 and RCN, 2008.

The Health Foundation (2014) identifies examples of practical tools to support dignity in care. These include:

- introducing yourself by name and profession (the *'Hello my name is'* campaign)
- using *one-page patient profiles* as a focused strategy to getting to know what is important to the patient and the personalisation of their care
- gathering *patient stories and shadowing patients* on their care pathway, observing and recording what happens, and seeking their feedback on each step

BOX 5.10

Practice notes – enablers of respectful and dignified care

- Be self-aware and develop courteous, respectful communication and interpersonal skills, including active listening, politeness, allowing time for provision of information, for understanding, and questions.
- Act fairly, compassionately and sensitively.
- Introduce yourself and ask individuals how they would prefer to be addressed, i.e. first name, surname, family name, etc.
- Ask for consent to share information with other carers.
- Where possible, orientate individuals to their environment including information about quiet areas, privacy and confidentiality.
- Ensure the physical environment takes account of specific needs including appropriate signage, careful use of colour, information and date boards, safe walking spaces and communal areas to improve social interaction and engagement.
- Provide gender-specific facilities; for example, wards, toilets and washing facilities.
- Take account of personal preferences, lifestyle choices and cultural factors when assessing their needs and providing support for care.
- Ensure people receive care or treatment in a dignified way that does not embarrass, humiliate or expose them; this includes the way information is exchanged at the bedside or in other communal environments.
- Don't make assumptions about appropriate standards of hygiene or appearance for individuals and provide support to maintain appearance to their level of expectation, e.g. hair, standards of dress, etc. (for example, just because you shower every morning does not mean they should).
- Maintain confidentiality of personal and treatment information.
- Particular care is needed to maintain privacy when using interpreters; individuals may prefer to use a family member or the same interpreter on each occasion.
- Demonstrate respect for personal belongings, for example, access to individuals' own clothing, access to bed lockers.
- Respect privacy of personal space, for example, knocking on doors before entering rooms. Use ways to prevent being disturbed when providing care at the bedside, such as pegs and signs for curtains.
- Provide areas for private conversations, needs assessment, phone calls, etc.
- Enable individuals to personalise and make choices about their living environment, particularly in care homes.
- Be confident to challenge the negative attitudes of others and report through the appropriate channels practice that diminishes dignity.
- Be reflective – exercise critical value-based reflection on your own and others' practice.

Compiled and adapted from SCIE, 2013; DH, 2010b; Jackson and Irwin, 2011 and Tadd *et al.*, 2011a.

- implementing *Schwartz Rounds* – an approach to help providers of health and social care develop their organisational culture and support staff by allowing time for staff reflection and sharing insights.

See more at: health.org.uk/newsletter/seven-practical-tools-support-dignity-and-compassion-care (accessed 16 December 2016)

The practice notes (see *Box 5.10*) provide a summary of ways to enable the protection and promotion of respect, dignity and privacy in your practice.

CONCLUSION

Being worthy of respect and the value placed on dignity are based in our shared humanity and the intrinsic value attributed to every human being. One important implication of respect for persons and human dignity is that every person should be acknowledged as an inherently valuable member of the community and as a unique individual entitled to the same level of respect as any other. Respect for persons and human dignity should have no boundaries and go beyond any social order, such that they cannot be legitimately violated by society. In this way, respect for persons and dignity are the basis for human rights and are fundamental to our feelings of self-esteem and self-worth. What is clear is that practitioners should never take for granted the values of respect for persons and dignity nor the implications of their consideration in practice.

In this chapter you have explored the value of respect for persons as a core value and, if this is properly understood and integrated into care, many of the other values flow from it. Having respect for persons and their humanity facilitates a philosophy of care that promotes dignity for patients and service users, even in situations of great dependence. The importance placed on privacy in maintaining an individual's dignity and the need to develop care strategies that protect and promote privacy have been emphasised.

We have identified that respect for persons is associated with a number of other values such as valuing humanity, dignity and privacy. However, we have consciously separated out respect for persons and autonomy, as it is important that you recognise and remember that although they are interrelated they are also distinct. Respect for persons is a value that implies a broader set of obligations than simply respecting an individual's autonomy, which has self-determination as its main focus. The value associated with respect for autonomy is important in today's health and care practice and gives rise to a number of guiding principles and procedural aspects of care which we explore in *Chapter 6*.

CHAPTER SUMMARY

Four key points to take away from Chapter 5:

- The values of respect, dignity and privacy are fundamental to care practice.
- If respect is properly understood and integrated into care, many of the other values will flow from it.
- Having respect for persons and their humanity promotes the dignity of patients and service users, even in situations of great dependence.
- Dignity and privacy can easily be compromised if care becomes routinised; therefore you must be critically reflective of your own and others' practice and adopt enabling approaches that protect and promote the dignity and privacy of individuals in your care.

FURTHER READING

Brooker, D. and Latham, I. (2015) *Person-Centred Dementia Care: making services better with the VIPS framework,* 2nd ed. London: Jessica Kingsley.

Hughes, J.C. (2014) *How We Think About Dementia: personhood, rights, ethics, the arts and what they mean for care.* London: Jessica Kingsley.

Matiti, M.R. and Baillie, L. (2011) *Dignity in Healthcare: a practical approach for nurses and midwives*. London: Radcliffe.