

Chapter 1

Nursing knowledge and practice

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KEY ISSUES

SUBJECT KNOWLEDGE

- Definitions, theories and models of nursing
- Role and image of the nurse
- People as recipients of nursing care
- Contexts for delivering nursing care

CARE DELIVERY KNOWLEDGE

- Clinical decision making
- Managing the delivery of nursing care
- Nursing different client groups
 - Child
 - Adult
 - Mental health
 - Learning disabilities

PROFESSIONAL AND ETHICAL KNOWLEDGE

- Exercising autonomy and accountability
- Providing legal and ethical care
- Leadership and management of change

PERSONAL AND REFLECTIVE KNOWLEDGE

- Learning to be a nurse
- Consolidation of learning through case study

INTRODUCTION

Nursing care is provided for people with widely diverse health and sick care needs in multiple contexts worldwide. The knowledge and competence to meet such a wide variety of care needs may be daunting for the student starting a programme of study to become a registered nurse. Nursing programmes are designed to allow knowledge and practice experience to be accumulated and assimilated by the nursing student within the 3 or 4 year course period. However, learning is lifelong, and the journey of learning through a pre-registration nursing programme is only the beginning.

In the United Kingdom (UK), the knowledge and skills necessary to become registered as a nurse are primarily structured so that a student can focus on developing proficiencies to provide care for particular patient/client groups (Nursing and Midwifery Council 2004). Two of the groupings are age related, i.e. you register to deliver nursing care specifically to adults or specifically to children, usually with physical healthcare needs. The other two groupings are health condition related, i.e. nursing care is focused on people (children and adults) with mental health problems or people with learning disabilities. These 'branches' of nursing have their basis in the history of the development of nursing in the UK (Dingwall et al 1988, Nolan 1998). Following a 1-year common generic programme, students begin to accumulate knowledge and experience specific to their chosen branch of nursing.

Curricula for nursing courses worldwide are broad ranging and usually include an eclectic mix of the following areas:

- Knowledge about the individual person, i.e. physical, psychological, social, cultural and spiritual in health and in sickness
- Knowledge about the environment of care to include safety, policy and politics in the delivery of health care
- Knowledge on how to provide evidence-based nursing care to promote health and care for the sick

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to this through the development of electives and exchange opportunities such as Erasmus (<http://www.erasmus.ac.uk>), and also through the development of shared work programmes with schools of nursing in other countries. The advent of video links and web based technology means that it is possible to talk about nursing with nurses from many other countries and even share lessons or conferences together. You can participate in European working through the Students' Union or through the RCN Association of Nursing Students who are members of the European Nursing Students Association (ENSA).

CARE DELIVERY KNOWLEDGE

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p0660 The RCN definition of nursing refers to the 'use of clinical judgement in the provision of care' (Royal College of Nursing 2003: 3). In this section we will first look at the basis for clinical decision making in evidence-based practice before reviewing the organizational approaches in common use to manage the delivery of care. There is a brief overview of the scope for nursing practice in the different branches of nursing.

CLINICAL DECISION MAKING

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p0665 In the delivery of nursing care in institutional settings, nurses are in constant contact with their patients over a 24-hour period. Any changes (physical and/or mental) observed in a patient's condition are first seen by the nurse; therefore clinical decision making is a key application of the nursing role. Nurses very often 'own' and manage the environment of care, ensuring that resources for care are available. A number of services are also 'nurse led' (e.g. tissue viability, diabetic care, 'first contact'), giving the nurse greater autonomy in decision making. However, the majority of decisions in day-to-day practice take place in a complex environment, in collaboration with a diverse healthcare team and in partnership with patients/clients who have complex needs (Gurbutt 2006).

p0670 Knowledge for decision making is obtained from many sources and has been described as both informative (i.e. acquired through the study of written knowledge) and intuitive/experiential (i.e. developed through experience and learning from that experience through reflective practice) (Schon 1991, Benner 2001, Banning 2008). The views and rights of patients/clients and the context of care are also key factors in clinical decision making. In the world of practice, all sources of knowledge are constantly interacting to inform day-to-day decisions in healthcare delivery. Registered nurses need to be able to describe how and why they came to particular decisions in the delivery of nursing care. As a learner in the practice setting you should be able to ask the nurse and other members of the

healthcare team about their decisions and thus learn from practice experience (Standing 2007).

Decision-making exercise

You are allocated to work with a registered nurse (RN) and a healthcare assistant in providing rehabilitation care to a group of 10 elderly people with complex care needs based on a mixture of mental and physical health problems. The RN managed and directed the care during the shift.

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- Describe the RN's approach to organizing priorities in care giving during the shift. u0395
- Under what influence or on what basis did he/she make decisions (try to obtain this information through reflective discussion at the end of the shift). u0400
- Did you experience any changes in decisions over the period of the shift and what do you think influenced these changes. u0405
- Decide how you could record what you had learned so that you could explain your understanding of the RN's decision making to another learner/peer group of learners. u0410

There is an increasing emphasis on clinical decision making being more prescriptive as health care has to become more cost-effective and evidence based. Decisions of all healthcare professionals are now strongly influenced by protocols, clinical guidelines, clinical standards and benchmarks for best practice. Computer decision-support systems are used to make expert knowledge more widely available (Gurbutt 2006). Although clinical research evidence has strongly informed medical practice, the evidence-based healthcare movement is now accepted as a legitimate source for clinical decision making by all health professionals (Muir Gray 2001).

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Sourcing and analysing the evidence

Decisions about groups of patients or populations are made by combining three factors: evidence, values and resources. If decisions are based on values and resources alone, then it is 'opinion based' decision making. The evidence base is produced by research and is the scientific factor in the decision-making process (Muir Gray 2001). Skills needed by any healthcare professional to practise evidence-based clinical decision making include the ability to do the following:

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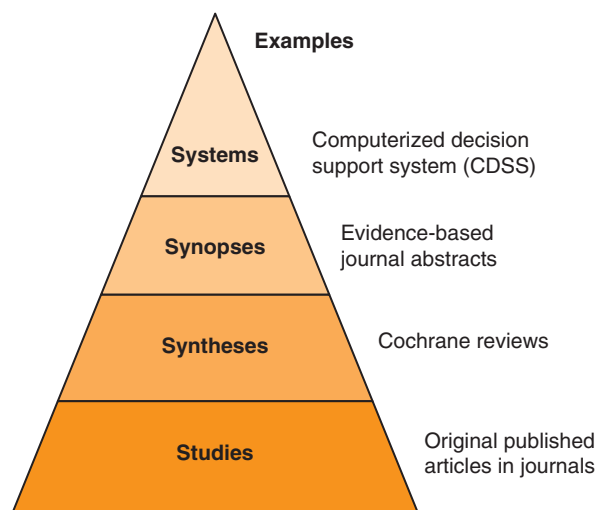
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- define criteria for effectiveness, safety and acceptability u0415
- resource the evidence u0420
- assess the quality of the best evidence available at the time u0425
- judge the reliability and validity of the evidence u0430
- assess whether the results can be applied in the local situation (Muir Gray 2001). u0435

p0735 Criteria for effectiveness and safety are now more often made available to practitioners through national and local guidelines (e.g. National Institute for Health and Clinical Excellence (NICE) guidelines) and are promoted through clinical governance in healthcare delivery (Swage 2003). Resourcing the evidence and making judgements on its quality is facilitated through the availability of centres of excellence in reviewing all the research evidence such as the Cochrane Reviews or the Centre for Evidence Based Nursing at the University of York or the Joanna Briggs Institute for Evidence Based Nursing (see annotated web-sites). The final decision is then based on whether results can be applied in the local practice setting and whether they are acceptable to the patient/client. In summary, core components of evidence-based healthcare include the integration of best research evidence with the clinical expertise of the healthcare professional, the resources available and the patient's values and choices (Pearson et al 2007).

p0740 Strauss et al (2005) refer to a hierarchy of evidence, starting at the base with the original research studies, followed by a systematic review of these studies to decide on evidence for best practice (Fig 1.1). These reviews are then summarized for ease of access and at the most sophisticated level can be incorporated into computer systems that would allow the practitioner to enter the patient profile and obtain a summary of the best evidence to help in the final decisions about care.

p0745 Learning how to make judgements about research-based evidence is obtained through the study of research methodologies which is a core component in all diploma/degree level courses in higher education (see Evolve 1.2).



f0005 **Figure 1.1** A hierarchy of evidence sources for clinical decision making (from Strauss et al 2005; by kind permission of Elsevier).

Evidence-based practice

Gerrish et al (2008) completed a cross-sectional survey of senior and junior RNs in two hospitals in England, using the Developing Evidence-Based Practice questionnaire ($n=598$). Findings revealed that while all respondents demonstrated confidence in accessing and using evidence for practice, they still relied heavily on personal experience and communication with colleagues. Senior nurses were more confident in accessing all sources of evidence and felt able to initiate change. Junior nurses perceived lack of time and resources as major barriers in implementing change, whereas senior nurses felt empowered to overcome these constraints.

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1.2 - NURSING RESEARCH – AN OVERVIEW

- History and scope of nursing research in the UK.
- Overview of research methodologies.
- Application of research findings in practice.

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Managing the delivery of nursing care

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Systems for managing the delivery of nursing care continue to evolve over time. Although changes in these systems can be linked to the emerging role of the nurse as an autonomous practitioner, they are very strongly influenced by policy and politics of healthcare delivery. Table 1.2 describes the features of common nursing care delivery systems, some of which will still be observed in practice settings. As health care becomes increasingly more expensive, care management systems need to be seen to deliver quality and be cost-effective.

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The focus is now on the efficient use of healthcare professionals with care needs being patient centred. The goal is the integration of all services to meet patients' needs, with all professions working collaboratively. The patient's journey through the health and social care system is a key driver for implementing new management systems. Interprofessional working is being promoted through the increasing use of integrated care pathways.

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Integrated care pathways

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An integrated care pathway (ICP) is a multiprofessional plan of care. It comprises detailed guidance for each stage in the care of a patient with a specific condition, stating what should be done, when it should be done and who should do it. It also predicts the type of response to any actions taken and by when the response should have

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10010 Table 1.2 Nursing care delivery systems

Title	Features	Application	Advantages	Disadvantages
Individual case method	Care for all needs of one patient	Private nursing in home Critical care	All patient's needs met quickly Close relationship with patient	Cost – very expensive
Task allocation method	Care divided into tasks with nurses allocated to particular tasks	Providing care in healthcare institutions particularly when shortage of staff	Very efficient way to deliver care. Staff competency matched to complexity of task so may be safer practice	Care of patient fragmented No identified nurse for patient. No accountability for nurse
Team care method	A RN as team leader manages the care of a group of patients. Team members plan and deliver care as a team	Commonly used system in all healthcare contexts including the community	All team members' capabilities are recognized; patient has one accountable nurse (team leader) with access to all others in the team	Requires good team leader and team spirit to succeed. May not be available 24 hours of the day
Primary nursing (primary nurse – PN)	One nurse cares for one group of patients with 24 hour accountability for planning their care. An associate nurse delivers the care when PN off duty	Popular in 1990s as the 'named nurse' in the UK Variable application in institutions but evidence of its application in community settings	Increased satisfaction for patients and nurses More professional system: PN plans and communicates with all disciplines	Intimidating for new graduates with less knowledge and experience Costly as many RNs needed to provide service

occurred. Any deviation from the plan is called a variance, which in turn forms the basis of the evaluation of the interventions. This provides the evidence for day-to-day monitoring and also forms part of the periodic auditing of pathways to ensure their effectiveness and safety.

p0790 Originating in North America in the 1980s, the use of ICPs began to grow in the UK during the 1990s, initially within the area of acute general medicine but more recently in all areas of health care.

p0795 There are many advantages to using ICPs. First, in the UK, they are developed using the latest evidence and reviewed regularly to ensure that they remain up-to-date. Because they are multiprofessional, this helps to ensure that the total package of care delivered by all professionals is based upon sound, contemporary information. Secondly, because all of the documentation is located in one place and available for all involved in the care to see, communication between professionals is clear – all of those involved in the care can see what is done, by whom and when. Thirdly, because time and resources are included in many pathways, it is possible to predict the demands on equipment and staffing. Ultimately this makes it possible to cost patient episodes. Indeed, this was a major impetus for their introduction in North America.

p0800 Interprofessional rivalry can sometimes be a problem in multiprofessional working (Gibbon et al 2002, Rees et al 2004). In many cases this originates from the negative attitudes of the staff involved. As ICPs require multiprofessional working, interprofessional rivalry could in effect

sabotage their introduction. Logan (2003) and Hall (2001) reported that integrated care pathways enhanced multi-professional working; however, they noted that ownership was the key issue in their introduction. A top down approach was doomed to failure. If ICPs were to be introduced successfully, all who were to contribute to care, needed to be involved in developing the pathway.

Evidence-based practice

Allen & Rixson (2008) completed a systematic review of the impact of ICPs on providing an 'integrated service' for patients. The review focused on the care of adult patients who had suffered a stroke and included acute care, rehabilitation and long-term support – in hospital and community settings. ICPs were the intervention of interest and 'service integration' was the outcome. They critically appraised seven papers, representing five studies. Conclusions: ICPs can be effective: in ensuring that patients receive relevant clinical assessments and interventions in a timely manner; in improving the documentation of rehabilitation goals; in clarifying role boundaries and a shared understanding of the work. There is some evidence that ICPs may be effective in bringing about behavioural changes in contexts where deficiencies in service provision have been identified. None of the studies reviewed included an economic evaluation so that it remains unclear whether the benefits of ICPs justify the costs of their implementation.

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The process of nursing

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Regardless of which overall management system is in place, any health or social care professional working on a one-to-one basis with a patient/client will follow a pattern in their decision making on care delivery. This process follows the steps of a problem solving approach and has been termed 'the nursing process' (Carpenito-Moyet, 2005; Springhouse 2007). Similar to the problem solving approach, there are four/five stages to the nursing process; assess, plan, implement and evaluate. These are usually depicted as a cycle of events (Fig 1.2) as the evaluation stage leads back into a reassessment of care needs. A fifth stage can be added after assessment, usually labelled as 'nursing diagnoses' (more common in the USA). Throughout this book, in the Care Delivery Knowledge sections, many authors have chosen to follow the pattern of the nursing process in the layout of the information presented.

Health professionals use a variety of tools to make detailed assessments. When applied to the whole person these tools are designed to follow a particular approach to health care. For doctors their assessment tool kit is organized around physiological body systems; for physiotherapists their tools focus on mobility needs of the client. Nurses may use the particular tool integral to a nursing model, an example of which is an assessment based on the 12 activities of living outlined in the Roper, Logan and Tierney model of nursing (Holland et al 2003). Specific tools are also available for various parts and functions of the person, for example pain level assessment tools, oral care assessment tools, all of which are referred to in more detail throughout the chapters of this book. Integrated patient centred assessment tools, which can be used by all health professionals in a single care plan shared by all, including the patient as a partner in care, are now becoming more common. These are usually designed around a specific condition and treatment plan (see Integrated Care Pathways above).

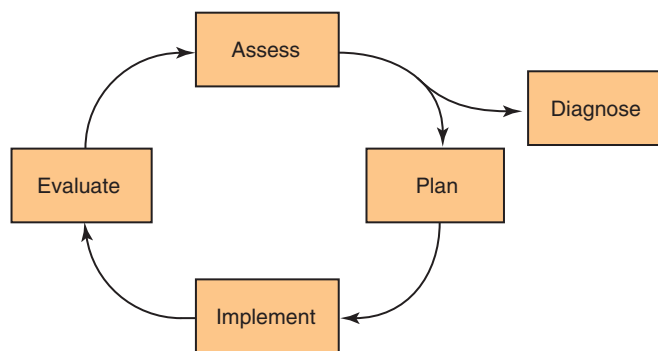


Figure 1.2 The nursing process cycle.

Delivering care to different client groups

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The following section provides an overview of the scope of nursing practice in the four branches of nursing which are registered in the UK.

Nursing children and young people

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Working with children and young people is a specific branch of nursing in the UK today. It is studied after the first-year common foundation programme and focuses upon the care of children, young people and their families. Children's nursing is based upon the philosophy that children are entitled to services which are sensitive to their requirements and designed and delivered around the needs of children and families (Department of Health 2004a). Children's nurses need to empower carers to manage their child's situation positively and proactively. There is a considerable amount of partnership working because the care of the child will be predominantly performed by their families or carers. Nursing care is planned around assessing the needs of children and families and of sensitive working, teaching and assessing carers in sharing the provision of care.

In the UK, there is increasing diversity in the needs of children and their families both from a social perspective and from a health one. Children's nurses work across healthcare settings. In the community they contribute to teams working within children's centres (Sure Start), providing health promotion, support and management of care. They also provide nursing for children who remain in the community rather than attend hospital care settings for treatment. Children's nurses still most commonly work in hospital settings in the UK, where children are acutely ill and cannot be managed at home. These children are frequently technologically dependent or require intensive treatment or surgery. Children's nurses therefore must learn a wide range of assessment and clinical skills. They need to know how to care for children at different ages and stages of development and they need to differentiate their care appropriately to meet individual needs.

In both the community setting and the acute hospital, standards for the care of children are focused around three main documents: the *National Service Framework for Children* (Department of Health 2004b) which determines the expectations of care for children and families; the *Children Act* (Office of Public Sector Information 2004); and the *Every Child Matters* initiative (Department of Education and Science 2003). *Every Child Matters* (2003) and the *Children Act 2004* led to a radical change in child health care in the UK (see Evolve 1.3).



1.3 - STANDARDS OF CARE FOR CHILDREN

- u0455 • The Children Act 2004.
- u0460 • The *National Service Framework for Children* and its influence on your care.
- u0465 • How you can use *Every Child Matters*.
- u0470 • The common Assessment Framework and the vulnerable child.

Decision-making exercise

- p0865 Jody is 3 years old, and does not want to take her medicine today. She says it tastes horrible and she does not like it at all. Sarah is 13 years old and is also refusing to take her medicine. Both have a temperature of 38 degrees Celsius. Both are of a stage of development which is commensurate with their chronological age.
- u0475 • Decide how you would manage these two different situations.
 - u0480 • Would you treat them similarly or differently? What reasons do you have for your decisions?
 - u0485 • If they did refuse their medicines, what would the implications be for each one?

Adult nursing

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Developing knowledge and skills to meet the needs of adults (those over 16 years) is the focus of the second and third year of an adult branch nursing programme. The scope of practice is very broad with healthcare delivery in multiple contexts. The demographics of an aging population and a policy shift to deliver more care in the community (Department of Health 2005) means a greater emphasis on developing nursing roles that are flexible and adaptable to changes in health care locally, nationally and internationally (see Subject Knowledge).

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During your pre-registration programme, you will gain experience and knowledge during the first common foundation year of all branches of nursing. When completing your adult branch, you will gain practice learning experience in acute hospital care and in the community. Although the majority of time on your course may still be spent in learning in the hospital setting, the increasing focus on care in the community is being recognized by those responsible for developing pre-registration programmes with a commitment to more extensive placement experiences in the community. Table 1.3 outlines examples of the scope of current adult nursing roles in the community and Table 1.4 provides a selection of specialities and roles in the acute hospital setting.

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The average time spent in gaining experience in each placement will vary between 6 and 12 weeks, with flexibility within some placements for students to gain observational

t0015 **Table 1.3** Scope of adult nursing roles and placement experience in the community

Role title	Scope of role	Practice learning
Community RN	Delivers care in home within a district nursing team	District nursing team
District nurse (specialist registration)	Directs and manages a team delivering care in home	District nursing team
Practice nurse	Delivers care in GP practice setting	GP practice team
Community matron	Manages a case load of patients with long-term conditions across community and acute care settings	Community matron
First contact nurses	'First stop' health care advisors in NHS call centres or drop in centres	NHS call centres or walk in centres
Occupational health nurses	Health promotion and care for employees in industry and commercial sector	Factories, stores, NHS
Private nurse	Provides care to individuals in own homes for a fee	Private agency work
Prison nurses	Health promotion and care delivery within prisons	Prisons
Care home manager	Manages the care of elderly people in a community nursing home	Care homes
Health promotion nurses	Set up and deliver health promotion programmes in community	Health centres; rehabilitation centres/teams
Intermediate care team nurse	Member of a multiprofessional team for health and social care	Interprofessional learning with intermediate care teams

t0020 **Table 1.4** Scope of adult nursing roles and placement experience in acute hospitals

Role title	Scope of role	Practice learning
Medical nursing	Care for patients with medical conditions especially cardiovascular and respiratory diseases	Areas and teams classified to deliver medical care
Surgical nursing	Care of patients requiring minor or major surgery	Day case surgery units, surgical wards, operating theatres and recovery areas
Elderly care nursing	Care of the older person with acute medical care needs	Areas classified for delivery of elderly and rehabilitative care; stroke units; day hospitals; day centres
Cancer care nursing	Care of people with cancer from diagnosis through to recovery and/or terminal care	Diagnostic centres; cancer care wards; specialist nurses; palliative care and hospice areas
Critical care nursing	Care of critically ill people	Units for: intensive care general/cardiac; high dependency; coronary care; burns; neurosurgical; accident and emergency care
Specialist surgery and medicine	Care of patients with orthopaedic, neurological, renal, gynaecological, genitourinary, eye and ear, nose and throat conditions	Specialist surgical and medical areas to include: outpatients and diagnostic centres; dialysis units; sexual health clinics

experience working alongside specialist nurses in the field and/or with other health professionals. It is important to remember to maintain a holistic approach to healthcare learning, as mental and physical health impact on one another. Insights and knowledge gained of care for children and adults and children with learning disabilities and/or mental health problems during the first year of a nursing programme are also important in adult branch nursing.

s0155 *Mental health nursing*

p0900 People can experience mental health problems at any stage of life and consequently mental health nurses will work with children, adolescents, adults and older people. Although some care is given in hospitals, most people receive care in their own homes and access mental health services at a local mental health centre, or will be visited by a member of the mental health team.

p0905 A good mental health nurse has a number of personal qualities that include an interest in working with people, good listening skills, a compassionate nature and a willingness to help people to develop skills that will help them to recover from their problems and return to their normal way of life. In addition to these skills you need the professional knowledge and skills that enable a nurse to understand a client's psychological, social and spiritual needs, as well as a robust understanding of the physiological aspects of the individual's problems and treatment.

p0910 Mental health nurses work closely with other members of the interprofessional team (which includes social workers, occupational therapists, psychiatrists, psychologists, physiotherapists and healthcare support workers). Assessing

and monitoring mental health problems is not as straightforward as assessing and monitoring physical illnesses, as the signs and symptoms are often not measurable. Mental health nurses therefore need to be confident in their professional ability and able to communicate effectively, both with the person suffering mental distress and with other members of the care team. Many mental health nurses will choose to specialize in an area of mental health following their initial registration, including substance misuse, child and adolescent psychiatry, cognitive behavioural therapy, forensic nursing, assertive outreach and crisis intervention. This enables the nurse to take additional training and develop a specialist career pathway.

Learning disabilities nursing

People with learning disabilities can struggle to cope independently with day-to-day life. It is the role of the learning disability nurse to support these individuals, and their families or carers, to enable the individual to live at home and be included within their local society and activities. Although most learning disabilities become apparent in childhood, they continue throughout adult life and learning disability nurses therefore work with clients and carers from all age groups.

As is the case with mental health nurses, most learning disability nurses work within the community, and this can involve working with people in their homes, in schools, in day centres or in residential care homes. In addition to personal qualities that include patience, understanding, compassion and excellent listening skills, learning disability nurses must acquire a good understanding of social

inclusion and networking, as well as a sound knowledge of physiological conditions that may affect their clients. Learning disability nurses also need to develop skills of assertiveness as often they will be required to support their clients, both within society in general and sometimes within the care team.

p0925 Learning disability nurses work as part of a specialist interprofessional team which includes psychologists, social workers, occupational therapists, physiotherapists, teachers, speech therapists and healthcare support workers. Many people with learning disabilities have complex needs which can include physical and/or sensory impairments, mental health needs and challenging behaviour and these require the nurse to be able to provide a skilled assessment, care planning and intervention.

p0930 Once qualified, many learning disability nurses will go on to manage and lead teams of support staff. However, there are also many specialist career pathways available to learning disability nurses, such as challenging behaviour, sensory disability, education or management, many of which offer the nurse an opportunity of advanced education and training.

PROFESSIONAL AND ETHICAL KNOWLEDGE

s0165 Nursing has a claim to being a profession through fulfilling recognized requirements for professional status (UK Centre for the History of Nursing and Midwifery <http://www.nursing.manchester.ac.uk/ukchnm/publications/bibliographies/nursingprofession/>). These requirements are obtained through what is termed the professionalization process. Professions usually perform a service for the public and have the following characteristics:

- u0490 ● A distinct body of knowledge and skills that can be applied in practice.
- u0495 ● Formal education and training, usually 3 years or more in length with examinations to check knowledge and competence to practise in the profession.
- u0500 ● A regulatory body that has legal power to admit to and remove from a professional register.
- u0505 ● Members have ability and power to work autonomously and take responsibility for own standards of practice.
- u0510 ● Members must adhere to a formal code of conduct/ethics that governs their behaviour.

p0965 Throughout this textbook, authors refer to the professional standards and code of ethical conduct set by the nursing regulatory body in the UK (Nursing and Midwifery Council 2008; see also www.nmc-uk.org/) and also to legal issues as they are applied to the particular knowledge and skills being covered in the chapter. Here we will focus on autonomy and accountability in nursing and provide an overview of the legal and ethical principles that underpin nursing practice.

NURSING AUTONOMY AND ACCOUNTABILITY

Nurses, as professionals, should have the ability and power to work autonomously and take responsibility for their own standards of practice. Accountability for nursing standards is the other side of the coin from nursing autonomy and both can be enhanced or limited by the context in which care is delivered. According to Holland Wade (1999), accountability is the primary consequence of professional nurse autonomy, and empowerment of the nurse links work autonomy with professional autonomy, which leads to job satisfaction, commitment to the profession and the professionalization of nursing.

However, the delivery of health care in the 21st century is very much more focused on being patient centred, risk managed, quality assured and cost-effective. Accountability for the quality of health care delivered to people has become increasingly an organizational responsibility (Tiley & Watson 2005). Under the template of clinical governance, there is an increasing focus on ensuring team care and team accountability. This does not negate individual accountability for decisions made as a professional nurse and being held to account for those decisions.

Evidence-based practice

Rafferty et al (2001), asking the question as to whether teamwork and professional autonomy were compatible, conducted a postal questionnaire survey of 10 022 staff nurses in 32 hospitals in England to explore the relationship between interdisciplinary teamwork and nurse autonomy on patient and nurse outcomes and nurse assessed quality of care. Nursing autonomy was positively correlated with better perceptions of the quality of care delivered and higher levels of job satisfaction. Nurses with higher teamwork scores also exhibited higher levels of autonomy and were more involved in decision making. A strong association was found between teamwork and autonomy; this interaction suggests synergy rather than conflict. The researchers suggest that organizations be encouraged to promote nurse autonomy without the fear that it might undermine teamwork.

LEGAL AND ETHICAL BASIS FOR PROFESSIONAL NURSING PRACTICE

Continuing with the theme of autonomy, it is important to review its meaning in relation to patients' rights. The language of individual 'rights' is a key part of autonomy and has been embodied in law in the UK through the implementation of the Human Rights Act 1998 (arising from the Universal Declaration of Human Rights 1948/European Commission of Human Rights 1954) (McHale & Gallagher 2003).

Chapter 5

Infection prevention and control

Rachel Peto

KEY ISSUES

SUBJECT KNOWLEDGE

- Main groups of microorganisms
- Routes of spread of infection
- Physical and physiological aspects of infection control
- Risk management
- Influences of behaviour, attitude and culture
- Epidemiology of infection
- Health promotion

CARE DELIVERY KNOWLEDGE

- A problem solving approach to infection control
- Standard precautions
- Principles of:
 - Hand hygiene
 - Disposal of healthcare waste, sharps and linen
 - Wearing personal protective equipment
 - Maintaining a clean environment
 - Aseptic technique
 - Personal care

PROFESSIONAL AND ETHICAL KNOWLEDGE

- Professional, ethical and political issues
- Roles of specialist teams in hospital and community

PERSONAL AND REFLECTIVE KNOWLEDGE

- Four case studies related to the four branches of nursing

INTRODUCTION

The prevention of spread of disease caused by infection is fundamental to all nursing care, and is an essential part of all health care in hospital and community settings. With the rise of healthcare associated infections, all healthcare professionals have a key role to ensure that infection control procedures and practices are implemented, both to prevent patients from acquiring an infection and to protect healthcare staff from infection (Wilson 2006).

Infectious diseases have been a threat to health and well-being since human life began, with outbreaks of infection over the centuries often generating great fear in people. Just over 100 years ago the science of microbiology was born when the relationship between disease and microorganisms was discovered by Louis Pasteur. In Britain, major infectious diseases kill only a small number of people compared to the past, but across the world the diseases of HIV/AIDS, tuberculosis and malaria account for millions of deaths each year (World Health Organization 2004).

Today, despite modern healthcare having saved countless lives, infectious diseases remain a massive global threat. Alongside the emergence of new diseases such as AIDS, variant Creutzfeldt–Jakob disease and severe acute respiratory syndrome (SARS), there has been the re-emergence of old diseases such as tuberculosis (Wilson 2006).

In the UK there are two particular infection control challenges in hospital care which cause deaths, impede recovery and make frequent headline news: the increasing number of healthcare associated infections (HCAI) and antibiotic resistant bacteria. Most notably these infections are caused by methicillin(methicillin)-resistant *Staphylococcus aureus* (MRSA), often described as a ‘superbug’, and *Clostridium difficile*. Infection prevention and control in the community is a key service within public health. As with hospitals, MRSA and *C. difficile* are being increasingly noted within the community as patients are discharged from hospital with these infections (Lawrence and May 2003).

Infection prevention and control must be a priority for all healthcare staff and should underpin quality clinical practice across all areas of health care. With the current

challenge to both hospital and community staff of increasing antimicrobial resistance, healthcare staff can no longer rely on treating organisms with antibiotics; instead healthcare staff need to concentrate again on the basics – proven infection control procedures.

p0670 Nurses of all branches have a role to play with their specific patient or client groups. Whether nursing in an institution (hospital or nursing home) or in the community (individual homes, health centres or shared housing), nurses must recognize the sources and modes of spread of infectious microorganisms and understand how to apply evidence-based practice to prevent and control infection.

OVERVIEW

s0030 This chapter aims to provide you with an understanding of what infection prevention and control means for individual people (sick or well) and their carers (health professional or informal family and friends), whether this care is in a home or community setting or in a hospital or institution.

Subject knowledge

s0035 This section introduces the biological aspects of infection, including the four main groups of microorganisms (bacteria, viruses, fungi, protozoa), routes, modes of spread and sources of physiological and physical control.

p0680 The complex psychosocial issues related to the prevention and control of infection are considered, with particular reference to the influence of personal and group behaviour, attitude and culture. Epidemiology and its importance in the identification and control of infection, with particular reference to health promotion, is included.

Care delivery knowledge

s0040 A range of nursing practices is explored using a problem solving approach of assessment, planning, implementation and evaluation. Both standard precautions (Royal College of Nursing 2005) and specific practices to prevent and control infection are considered.

Professional and ethical knowledge

s0045 Professional accountability is highlighted with specific sections on ethical and political issues. The roles of the infection control team in the hospital and the environmental health team in the community are considered.

Personal and reflective knowledge

s0050 Throughout the chapter there are decision-making exercises and suggestions for reflection and portfolio evidence. Case studies related to each branch of nursing are included

here to encourage reflection upon practices you have observed and material you have learned from this chapter.

SUBJECT KNOWLEDGE

s0055

BIOLOGICAL

s0060

CLASSIFICATION OF INFECTIVE AGENTS

s0065

p0705 An infection is caused by the invasion of a person's immunological defences by microorganisms that actively cause harm to body tissues (Wilson 2006). Bacteria, viruses, fungi and protozoa are the four main groups of organisms capable of causing disease (Box 5.1). Protozoa are not commonly encountered in the healthcare environment today (Wilson 2006).

Bacteria are the most common cause of HCAI with viruses considered to be the most common condition in the community, e.g. influenza, common cold. However, not all microorganisms cause infection or disease. Many live quite harmlessly in soil, water, air; and in alcohol and cheesemaking (yeasts). Some bacteria are vital in the production of antibiotics.

Microorganisms capable of causing disease are called pathogens, but the presence of a pathogen does not necessarily mean that an infection will ensue. The surface of the body is densely populated by a wide variety of microorganisms and every day the intestinal system excretes millions of microorganisms. Pathogens that live on their host in a specific body site without causing harm are called commensals and are often described as the normal flora of the body. They only become pathogenic and cause an infection when transferred to an abnormal body site. For example, MRSA is commonly found to be colonized in the nasal mucosa and can live there harmlessly, but organisms from the nose can be easily transferred to other body sites, such as wounds, therefore in some instances it is recommended that patients are decolonized prior to surgery to prevent surgical wounds becoming infected with MRSA (Wilson 2006).

SOURCES OF INFECTION

s0070

Bacteria

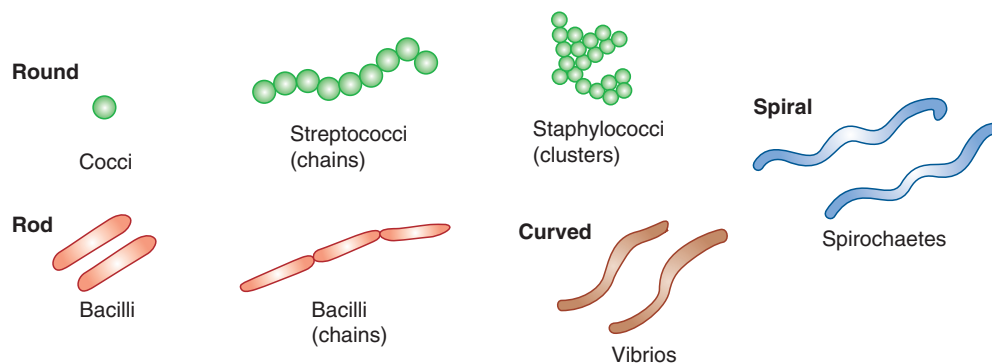
s0075

p0720 Bacteria are unicellular organisms that evolved millions of years ago. They are visible under the high magnification of an ordinary light microscope using an appropriate stain. Surrounding the bacterial cell is a membrane made up of proteins and phospholipids and surrounding the membrane is a hard cell wall, which gives the organism its shape.

Bacteria are most commonly classified by their shape (Fig. 5.1) and their response to a laboratory reaction when

Box 5.1 Common organisms and infections and diseases they cause

Organism	Infections and diseases
Bacteria	
Gram positive	
<i>Staphylococcus aureus</i>	Wound infections, pneumonia, osteomyelitis, food poisoning
<i>Staphylococcus epidermidis</i>	Wound infection, associated with invasive plastic and metal devices, e.g. IV cannulas
Streptococci (group A)	Streptococcal throat, impetigo, rheumatic fever, scarlet fever
Streptococci (group B)	Urinary tract infection, wound infection, meningitis
<i>Streptococcus pneumoniae</i>	Pneumonia, bronchitis, meningitis, otitis media
Enterococci	Urinary tract infection, wound infection
<i>Mycobacterium tuberculosis</i>	Tuberculosis
<i>Clostridium tetani</i>	Tetanus
<i>Clostridium difficile</i>	Diarrhoea, hospital acquired gastrointestinal infections
<i>Listeria</i>	Premature delivery, septicaemia and meningitis in neonates
Gram negative	
<i>Neisseria gonorrhoea</i>	Gonorrhoea, pelvic inflammatory disease, conjunctivitis, infective arthritis
<i>Neisseria meningococcus</i>	Meningococcal septicaemia
<i>Pseudomonas</i>	Wound infections, chest infections
<i>Legionella</i>	Chest infection, legionnaires' disease
<i>Escherichia coli</i>	Wound infections, urinary tract infection, pelvic inflammatory disease
<i>Salmonella</i>	Food poisoning
<i>Acinetobacter</i>	Urinary tract infection, wound infections, respiratory infections
<i>Campylobacter</i>	Diarrhoea, gastroenteritis
<i>Helicobacter pylori</i>	Gastritis, gastric ulcers
<i>Chlamydia</i>	Trachoma, non-specific urethritis in males
Viruses	
Hepatitis A	Infectious hepatitis
Hepatitis B	Serum hepatitis
Hepatitis C	If chronic – liver disease and cirrhosis
Herpes (type 1)	Cold sores, sexually transmitted disease
Herpes (type 2)	Genital lesions
Human immunodeficiency	Acquired immunodeficiency syndrome (AIDS)
Enterovirus	Poliomyelitis
Epstein-Barr	Glandular fever
Virus-like prions	Creutzfeldt-Jakob disease (CJD)
Fungi	
<i>Candida albicans</i>	Vaginal thrush, urinary tract infection
<i>Tinea</i>	Athlete's foot, ringworm
Protozoa	
<i>Trichomonas vaginalis</i>	Sexually transmitted disease in women
<i>Plasmodium falciparum</i>	Malaria
<i>Entamoeba</i>	Amoebic dysentery



f0005 **Figure 5.1** Bacterial classification according to shape.

treated with a dye called Gram's stain. The response is determined by a chemical present in the bacteria's cell wall. Bacteria are termed *gram positive* if they stain blue/purple and *gram negative* if they fail to take up the stain and remain the red colour of the counterstain.

p0730 Wilson (2006) states there are four main groups of bacteria: gram positive cocci and bacilli and gram negative cocci and bacilli, with other important groups including acid-fast bacilli, spirochaetes and atypical bacteria (see Box 5.1).

p0735 MRSA is an example of a gram positive coccus, and as with all bacteria has the potential to cause a whole range of infections including those of the lungs, wounds and urinary tract. More detail regarding specific bacteria, including the increasing problem of antibiotic resistance and methods used to prevent the spread of infection, are included in the Care Delivery section of this chapter.

p0740 Some bacteria have the ability to form spores to allow them to survive for longer when environmental conditions are not suitable for their cells to multiply. An example of this is *Clostridium difficile*, responsible for antibiotic-associated infections of the gastrointestinal tract.

Viruses

s0080

p0745 Viruses are not cells but minute particles consisting of genetic material and protein. Each virus is a piece of nucleic acid that is protected by a protein coat or lipid membrane. Viruses are not usually defined as a living organism, and instead of growing and dividing like cells, they infect cells. For example, the human immunodeficiency virus (HIV) infects human T cells of the immune system; while viruses that cause the common cold attach themselves to the epithelial cell membrane and invade the cell, releasing new virus particles and destroying the host cell. Viruses are extremely small and can only be seen with a high-powered electron microscope. Unlike bacteria, most viruses are very fragile and cannot survive outside a living cell for very long. Viruses are fairly resistant to disinfectants, such as chlorhexidine, which are unable to penetrate the protein coat or lipid membrane.

p0750 There are many viruses (see Box 5.1), of which a number, primarily those transmitted by blood and body fluid, are of particular importance for nurses and other health-care workers. They are referred to in some detail within the Care Delivery section of this chapter.

Prions

s0085

p0755 Prions – virus-like agents – are abnormal proteins that contain no nucleic acid. They are unique among microbes and appear to cause disease by replacing normal proteins on the surface of host cells and then gradually compromising their function. The main prion disease in humans in the

UK is Creutzfeldt–Jakob disease (CJD), although scrapie, a prion disease in sheep, has been known for centuries. CJD is associated with the destruction of brain tissue. In 1996 a new form of CJD was found called variant CJD (vCJD) which generally affects young people under the age of 30. These cause a range of unusual neurological symptoms and it is likely that such cases are linked to exposure to bovine spongiform encephalitis (BSE) (Wilson 2006). Prion proteins are highly resistant to conventional methods of decontamination, including heat and many chemical disinfectants.

Fungi

s0090

Fungi have a more complicated structure than bacteria and contain a nucleus. They are either branch shaped (e.g. mushrooms) or form buds (e.g. yeasts). There are over 700 000 species but few are pathogenic (see Box 5.1).

p0760

Candida, the yeast that is responsible for causing thrush, destroys the normal bacteria of the area it infects, namely the mouth, large bowel and vagina. The most common, *C. albicans*, causes vaginal thrush. *Tinea* is a fungus that produces a superficial infection. It is responsible for athlete's foot, causing a painful and irritant rash in the folds of skin, most commonly between the toes. Deeper fungal infections are more common in hot climates.

p0765

Protozoa

s0095

Protozoa are microscopic single-celled animals (see Box 5.1), and although unusual in the UK, they are very common in other parts of the world. Associated with poor sanitation, UK cases are often acquired from abroad. Two pathogens found in the UK are *Cryptosporidium*, a water borne pathogen which is a common cause of gastroenteritis in children under the age of 5 years, and *Trichomonas vaginalis*, a sexually transmitted infection which causes a foul-smelling, green–yellow vaginal discharge (Wilson 2006). Malaria, caused by the protozoon *Plasmodium falciparum*, remains an endemic disease in many parts of the African, Indian and Asian continents. Although malaria does not occur in the UK, nearly 2000 cases are reported in travellers returning to the UK each year (Health Protection Agency 2005); it can be easily avoided by taking anti-malarial medication and other precautionary measures. Neither *Trichomonas* nor malaria poses any risk of cross-infection in hospitals. A third protozoon, *Toxoplasma gondii*, is a parasite that lives in the intestine of cats, cysts of which are released in their faeces. These parasites can remain alive in soil and it is possible for humans to become infected by either handling cat faeces or contaminated soil. People at particular risk are women in early pregnancy when the infection can cause foetal death or brain damage.

p0770

GROWTH REQUIREMENTS OF LIVING ORGANISMS

s0100

p0775 All living organisms require nutrients: water, oxygen, light, temperature and a suitable pH to grow and thrive (Box 5.2). It is necessary to understand the growth requirements of organisms so that infection control measures can be based on scientific principles, not on rituals. For example, most bacteria that cause HCAI, such as *Pseudomonas*, are not demanding and will readily multiply in any warm moist environment. Others – anaerobic bacteria – require little or no oxygen and are able to flourish deep in the body. Unlike bacteria, viruses depend on living cells for their replication and therefore need an environment that will maintain them.

Box 5.2 Environmental requirements to support the growth of organisms

Water	Most organisms require water Bacteria require a moist external environment to thrive and multiply Spore-forming bacteria can live without water Some organisms die rapidly on drying (e.g. <i>Candida</i> , <i>E. coli</i>)
Oxygen	Aerobic bacteria require oxygen Anaerobic bacteria require no oxygen to survive, e.g. <i>Clostridium</i> Others require it when available, e.g. <i>Streptococcus</i> , <i>Staphylococcus</i>
Food	All organisms require food, e.g. organic matter – <i>Clostridium</i> , undigested food stuffs – <i>E. coli</i> Food can include inorganic matter, e.g. bed linen, work surfaces soiled with body secretions
Temperature	Organisms require a certain range of temperature Some can survive in extremes, e.g. some viruses are resistant to boiling water Cold temperature prevents bacterial growth
Light	Organisms can thrive in dark environments, e.g. in body cavities Ultraviolet light kills some types of bacteria
pH	Acidity determines the viability of organisms Most prefer a slightly alkaline environment with pH 5–8 Some thrive in a high pH, e.g. bacteria in alkaline urine Most organisms cannot tolerate the acid environment of the stomach

TRANSMISSION OF INFECTION

s0105

p0780 A series of interconnecting events has to take place for an individual to acquire an infection. This is called the ‘chain of infection’ (Fig. 5.2). All microorganisms require a reservoir where they live and multiply, which may be in the environment, in a person or in an animal. To cause an infection, microorganisms need to find a way to enter the human body – a portal of entry – and in order to spread to another person they require a way to leave the body – a portal of exit (Box 5.3). Once the microorganisms have left the body in excretions and secretions, they are important sources of infection and may spread by a number of different routes.

p0785 These routes are categorized into airborne, direct contact and indirect contact (Table 5.1). A common example of the indirect route is the faecal–oral route of transmission by which food is indirectly contaminated by unwashed hands, and this remains a common cause of disease. Some diseases spread by a specific route while others might spread by more than one route. For example, if you sneeze the tiny droplets from the nose will become airborne, but if you then put your hand up to your nose as you sneeze the droplets will come into contact with your hand. If you did not then wash your hands you could pass it on by indirect contact to the next object you touch. For this reason it is important that all healthcare workers have an understanding of appropriate infection prevention and control measures (see Care Delivery section).

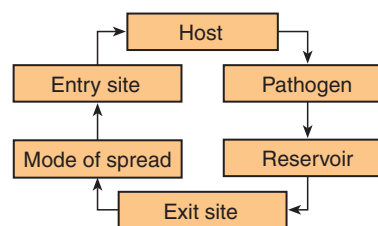


Figure 5.2 Chain of infection.

f0010

Box 5.3 Portals of entry and portals of exit of pathogens

b0015

Respiratory tract	Inhalation and exhalation
Gastrointestinal system	Ingestion and excretion
Skin and mucous membrane	Inoculation
Reproductive system	Sexually transmitted
Urinary tract	Sexually transmitted and excretion
Blood	Congenital and trauma

10005 **Table 5.1** Routes of spread of infection

Route of spread	Source	Example
Airborne	Human	Bedding, skin scales, coughing, sneezing, talking
	Aerosols	Nebulizers, humidifiers, showers, cooling towers
	Dust	Sweeping, dusting, building work
Direct contact	Human	Hands, uniform, sexual contact
	Food	Hands, equipment, uncooked food
	Fluids	Disinfectants, antiseptics, blood, body fluids, water
	Insects	Flies, mosquitoes
	Animals	Cows, pigs
Indirect contact	Inanimate objects	Bedpans, bedclothes, needles, washbowls, surgical instruments

p0790 The sources of microorganisms causing infections or diseases can be classified as either:

- u0590 ● endogenous (or self-infection) which refers to microorganisms that exist harmlessly in one part of a person's body but become pathogenic when transferred to another site
- u0595 ● exogenous (or cross-infection) which refers to microorganisms that do not originate from the patient but are transmitted from another source.

Reflection and portfolio evidence

p0805 Think back to a patient during a placement who had either a MRSA or *Clostridium difficile* infection.

- u0600 ● Using the chain of infection (see Fig. 5.2) – consider the ways that their particular infection might have entered the body, the potential reservoir(s) and exit site(s).
- u0605 ● Reflect upon the specific practices that are required to be undertaken by staff to prevent the spread of infection to staff and other patients.
- u0610 ● Discuss your answers with a member of staff and record your findings in your portfolio.

s0110 The host

p0825 The patient or host is the final link in the chain (see Fig. 5.2) and is the most common reservoir or source of microorganisms in hospital departments, particularly their body secretions, excretions and skin lesions. A person who

acquires microorganisms does not necessarily develop an infection; they may simply act as a source but be a risk to other susceptible patients. These patients are sometimes called 'carriers' as they carry infections around and transfer them to other patients.

The hepatitis B virus and the meningitis bacterium (*Neisseria meningitidis*) are two examples of microorganisms present in carriers. There are between 2% and 10% of those infected who fail to completely eliminate the virus and continue to carry it in their blood (Wilson 2006). Similarly many people are unknowingly carriers of *N. meningitidis* bacteria in their respiratory tract; they show no symptoms but can pass the bacteria on to other susceptible people.

Antimicrobial resistance

Prior to the introduction of antibiotics death from sepsis was common and until recently many infections could be successfully treated despite the increasing problems of resistance to antibiotics. While few microorganisms show resistance to all antibiotics, there are key pathogens which pose significant problems in healthcare settings in the UK. These include MRSA and multidrug-resistant *Mycobacterium tuberculosis* (Wilson 2006). A number of factors are considered to play a key role in the increasing resistance of antimicrobials, including the unnecessary and inappropriate use of antibiotics (Wilson 2006).

Staphylococcus aureus, a gram positive coccus, is an important cause of infection in both hospitals and the community, and remains the commonest cause of wound infection, after either accidental injury or surgery (Department of Health 2005b). Today, owing to this bacterium's remarkable ability to adapt to the presence of antibiotics, approximately 90% of hospital strains and 50% of community strains are resistant to penicillin. Today MRSA occurs worldwide with strains usually resistant to two or more antibiotics (see Evolve 5.1 for more detailed information).



5.1 – METICILLIN(METHICILLIN)-RESISTANT STAPHYLOCOCCUS AUREUS (MRSA)

- Definition and history of MRSA.
- How MRSA affects people.
- Prevention and control of MRSA.
- Screening for MRSA.
- Management of MRSA.

Resistance to drugs originally used to treat tuberculosis has occurred since streptomycin was first used in the 1940s. Treatment regimens were then devised using a

second drug to destroy resistance to the first drug. Today treatment now requires a combination of three or four drugs for at least 6 months. A World Health Organization report has indicated resistance to the four first-line drugs in 35 countries (Lawrence & May 2003). In England, Wales and Northern Ireland, a report covering the years 2002–5 showed 8.7% had a resistance to one or more of the first-line drugs (isoniazid and rifampicin), and 0.9% were multidrug-resistant (Health Protection Agency 2006a). Of particular concern worldwide is HIV related drug-resistant tuberculosis, with infection more likely to become active or a latent infection more likely to reactivate. The poor absorption of drugs and interactions with other drugs makes the treatment of tuberculosis in HIV-positive patients much more complicated.

CONTROLLING THE SPREAD OF INFECTION

s0120

p0880 Both physiological and physical systems of control can be used in the prevention of infection. For such control the chain of infection (see Fig. 5.2) needs to be broken.

p0885 In the past the isolation of patients has been a recognized way to prevention. But since the 1980s and the rise in bloodborne infections a universal approach is for staff to use blood and body fluid precautions regardless of infectious status – i.e. a risk assessment approach. As there is a particular need to prevent the spread of MRSA, ‘source isolation’, with its aim to prevent the transfer of microorganisms from infected patients, has been recognized as a significant measure in the prevention of its spread (Coia et al 2006). Please access Evolve 5.2 for more information on isolation care.



5.2 - ISOLATION CARE

- u0640 • General principles of care.
- u0645 • Management of source isolation.
- u0650 • Management of protective isolation.

Physiological controls

s0125

p0910 The body’s immune system resists the invasion of microorganisms and protects against foreign material. The first line of defence is the non-specific or passive immune response. Body systems play unique roles providing anatomical and physical barriers against the invasion of pathogens (Table 5.2).

p0915 The body’s specific or active immune response involves innate (non-specific) immunity and acquired immunity. Innate immunity is provided by genetic and cellular factors and can be influenced by age, nutritional status and any underlying disease. Active immunity results when the host develops antibodies following immunization. The active

Table 5.2 Non-specific immune response

t0010

Route of spread	Source	Example
Skin	Layers of skin	Mechanical and waterproof barrier
	Sebaceous glands	Secrete sebum – bactericidal properties Fatty acid kills bacteria
Eyes	Tears	Lysozyme – digests and destroys bacteria
	Eyelashes	Blinking reflex protects cornea from injury
Mouth	Mucosa	Mechanical barrier
	Saliva	White blood cells destroy bacteria
Stomach	Gastric secretions	High acidity destroys bacteria
Duodenum	Bile	Alkaline pH inhibits bacterial growth
Small intestine	Lymphatic tissue	Destroys bacteria
	Rapid peristalsis	Prevents bacteria from remaining in intestine
Nostrils	Hairs	Trap inhaled particles and microorganisms
	Turbinal bones	Trap inhaled particles and microorganisms
Pharynx and nasopharynx	Tonsils	Lymphoid tissue traps inspired particles
Respiratory tree (except alveoli)	Cilia	Beat mucus and particles away from lungs
	Mucus	Traps particles during inhalation
	Lung tissue	Isolates focus of infection
Vagina	Secretions	Acid pH inhibits bacterial growth
Urethra	Male length	Prevents migration of bacteria to bladder
Urine	Flushing action	Washes away microorganisms

immune system is made up of two types of white blood cells:

- B lymphocytes, which produce antibodies. u0655
- T lymphocytes, which attack cells invaded by microorganisms. u0660

Lymphocytes have memory cells and if they encounter a particular antigen – a response that may trigger an immune response – they become active and respond by

p0930

producing large numbers of specific lymphocytes and create an antibody to fight the invading microorganisms.

p0935 The body also acquires immunity artificially, through immunizations. Vaccines have been developed since the 19th century, after Edward Jenner demonstrated in 1796 that human beings could be protected from smallpox by inoculation with a similar virus that caused cowpox in cows. Vaccines are given to stimulate the production of antibodies; this induces a specific immune response, but without causing the actual disease.

p0940 The ability for people to resist and fight infection varies widely and can depend upon many factors, such as age, nutritional status and previous exposure to vaccinations and organisms. Young children with an immature immune system and the elderly with a diminished immune response are both at particular risk.

p0945 Physical stress from disease or major surgery are also recognized as important factors when assessing a patient's individual risk of acquiring an infection. Today there are increasing numbers of patients who have or are recovering from illnesses that have caused them to become immunocompromised. They are therefore at much greater risk of acquiring infections. Patients include those with HIV/AIDS, and those who have had an organ transplant, received chemotherapy for cancer, or had multiple episodes of antibiotic treatment when very young.

Physical controls

s0130 Decontamination is the collective term used to describe the three important physical processes of cleaning, disinfection and sterilization. Inadequate decontamination has been cited as being responsible for outbreaks of infection in hospital (Wilson 2006).

p0955 The choice of decontamination method depends on the level of risk the item poses as a source of infection and the toleration of the method of decontamination (Lawrence & May 2003). The emergence of infections such as HIV, CJD and hepatitis C has seen an increased focus on decontamination procedures and policies, with particular attention paid to the potential of medical equipment to transmit such infections. An EU Directive (93/42EEC) prevents the reuse of single-use items by healthcare staff, and national standards for the provision of decontamination processes (NHS Estates 2003) ensures that all reusable medical devices are decontaminated to an acceptable standard.

CONTROL IN RELATION TO RISK

s0135
p0960 The decision as to whether an item requires cleaning, disinfection or sterilization depends upon whether it carries a low, medium or high risk of causing infection to the patient or client. The use of all disinfectants is regulated

by the Control of Substances Hazardous to Health (COSHH) Regulations (Department of Health 2002) which requires employers to carry out a full risk assessment of products to be used and provide staff with appropriate information and training (Royal College of Nursing 2005).

Low risk

Cleaning – the physical removal of microorganisms and organic matter on which they thrive – is considered appropriate for equipment or practices that are considered low risk (Box 5.4). After cleaning, any article should have fewer microorganisms on it, but the dry method might simply redistribute the microorganisms into the air, while the wet method might distribute and increase the microorganisms through the use of contaminated articles such as mop heads and cloths or contaminated water. Approximately 80% of microorganisms are removed during the cleaning procedure, with drying equally important to prevent any remaining bacteria from multiplying (Wilson 2006). While cleaning alone may be an adequate method of decontamination, it is also an essential preparation for items requiring disinfection or sterilization.

Medium risk

Disinfection – the destruction of vegetative microorganisms to a level unlikely to cause infection – reduces the number of viable microorganisms but may not inactivate some bacterial spores (Lawrence & May 2003). It is associated with equipment that may come in close contact with mucous membranes but is not used for invasive procedures (see Box 5.4). Pathogens remaining after disinfection may pose an infection risk to particularly susceptible patients, for example those receiving cytotoxic (chemotherapy) therapy.

The two main methods of disinfection are heat and chemicals (see Box 5.4). Heat is the preferred method for disinfecting articles (e.g. surgical instruments) as it is more penetrative and easier to control than chemicals. Chemical disinfection may be required if heat is unsuitable, for example skin disinfection and heat sensitive items such as fiberoptic endoscopes. The choice is complex and requires a working knowledge of the disinfectants available and the make-up of the article that requires disinfecting (see Box 5.4).

High risk

Sterilization is the complete destruction or removal of all living microorganisms including bacterial spores (Lawrence & May 2003) and involves the use of heat, gas, chemicals or

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b0020 **Box 5.4 Physical systems of infection control****Low risk**

Cleaning	Dry	Mechanical action to loosen and remove large particles but may increase airborne count of bacteria up to tenfold Does not remove stains Sweeping redisperses bacteria in dust and larger particles Dry mops may be specifically treated to attract and retain dust particles Vacuum cleaning should not increase airborne counts of bacteria Expelled air from machine should not blow dust from uncleaned surfaces back into the air Dry dusting increases the air count of dust and bacteria and recontaminates cleaned surfaces
	Wet	Water containing detergents or solvents to dissolve adherent dirt and dust Dispersal of microorganisms into the air is less likely Cleaning fluids may grow bacteria due to contamination Damp dusting is less likely to disperse bacteria into air Need to rinse after cleaning with detergent to prevent build-up of detergent film All surfaces need to be dry before use to prevent contamination from bacterial growth

Medium risk

Disinfection	Heat	80°C for 1 minute or 65°C for 10 minutes kills vegetative organisms Steam heat is most effective, e.g. autoclave Damage relates to time and temperature Disinfection at a lower temperature for a longer time is possible for heat-sensitive equipment
	Chemical	Phenolics, e.g. Stericol, Hycolin, widely used for disinfecting inanimate objects Not active against bacterial spores or some viruses Toxic, unsuitable for living tissue until thoroughly rinsed Chemicals should not be used for food preparation or storage surfaces Hypochlorites (bleach), e.g. Milton, Sanichlor, mainly used for environmental disinfection, active against many microorganisms including viruses May corrode metals and bleach fabrics Chlorhexidine is used clinically, should not be used to disinfect inanimate objects Active against gram positive cocci (<i>S. aureus</i>), less active against bacilli and spores, little virucidal activity Inactivated in the presence of soap Alcohol (70% ethyl or 60% isopropyl) is rapidly active against vegetative bacteria, poor sporicidal Acts rapidly – useful surface disinfectant for physically clean surfaces, e.g. trolley tops, injection sites, hands Evaporates rapidly to leave a dry clean surface Peracetic acid (Nucidex) rapidly kills bacteria, fungi and viruses within 10 minutes. Has a strong smell and needs to be used in an area with exhaust ventilation Goggles and gloves should be worn No adverse health effects known

High risk

Sterilization	Heat	Autoclaves sterilize using moist heat – steam at an increased pressure (134°C) for 3 minutes Suitable for most metal instruments, plastics, glass, fabrics Sterilizing ovens use dry heat, 160°C, for 45 minutes, 190°C for 60 minutes Heat distortion can occur, materials may become brittle or scorched
	Gas	Ethylene oxide is very toxic and requires careful control of temperature, humidity, gas concentration and pressure Used to sterilize manufactured goods
	Chemicals	Used when heat or other methods are not possible or reliable sterilization is difficult Grease, proteins (blood, tissue) or air will prevent fluids coming into contact with all surfaces Prolonged immersion times are required to kill bacterial spores
	Irradiation	Gamma rays are used industrially, e.g. for disposable plastics after packaging Repeated irradiation causes plastics to become brittle Is expensive and uneconomical to use in hospital

irradiation (see Box 5.4). Items requiring sterilization are described as being high risk to patients. Sterilization is recommended for all instruments and equipment used during invasive procedures (for example intravenous (IV) canulas, surgical instruments, urinary catheters). As with disinfection, the choice of method used depends upon the item being sterilized (see Box 5.4).

s0155 OTHER METHODS OF INFECTION PREVENTION AND CONTROL

p0985 Other methods of control include hand hygiene, waste disposal and personal hygiene. These will be discussed in detail in the Care Delivery section. It is now recognized that an unclean clinical environment may contribute towards infection rates (Royal College of Nursing 2005). To assist with this important aspect of infection prevention and control, several pieces of guidance, including a resource to assist in training and setting standards (*The NHS Healthcare Cleaning Manual*, NHS Estates 2004), are available to promote the cleanliness of hospitals. Since the implementation of the Health Act (Department of Health 2006a), all NHS bodies have a duty to provide and maintain a clean healthcare environment.

s0160 Individual susceptibility to infection

p0990 Individual susceptibility varies enormously and can be caused when a person's immunity is impaired. Particular groups of patients are known to be at a greater risk (Table 5.3). The Third Prevalence Survey of HCAI in acute hospitals showed that in 2006 one in seven (7.6%) of patients in UK and Ireland had an infection or were being treated for an infection that they did not have on admission to hospital (Hospital Infection Society 2006). The cost to the National Health Service has previously been

t0015 **Table 5.3** Patients at greatest risk of infections

Group	Examples
Extremes of age	Very young and elderly
Critically ill	Patients in intensive care, multiple injuries
Chronically sick	Patients with heart and respiratory disease
Surgical patients	Abdominal surgery, trauma
Patients with underlying diseases	Patients with diabetes mellitus, malignancy
Immunosuppressed	Patients on steroids or chemotherapy; transplant patients

approximately £1000 million per year (National Patient Safety Agency 2004). While it is acknowledged that not all HCAI are preventable, the 2005 Lowbury lecture stated that globally 10–70% are preventable (Hambraeus 2006).

Decision-making exercise

Identify some of the equipment you have used for moving and handling patients, e.g. sliding sheets, hoist slings. p0995

- How were they cleaned? u0665
- Were they cleaned between patients? u0670
- Do you consider these items to be low, medium or high risk in terms of transmission of infection? u0675
- Discuss your decision with your mentor/educator in terms of current practice observed on your placement area/s. u0680

Although hospital patients are considered to be at an increased risk due to cross-infection between staff and patients, individuals being cared for in their own homes still remain at risk, especially where they have wounds or urinary catheters in situ. p1020

It is important to recognize not only the causal relationship and influence of physical sources and controls of infection and disease, but also the complex psychosocial issues that can be involved. p1025

PSYCHOSOCIAL

BEHAVIOUR

Behaviour is influenced by personal beliefs and attitudes. In the past disease and infections were normally perceived as being outside an individual's own control. For example, in the 19th century, dirty water was associated with infections and diseases such as cholera and typhoid, but it was perceived to be the responsibility of the government to prevent and control such infections (Lawrence & May 2003). Today many psychological, social and emotional factors are acknowledged as being particular influences, with the relationship between individuals and their lifestyle choices recognized as potential causes of infection and disease (Lawrence & May 2003). For example, the practice of sharing blood-contaminated needles and injecting equipment has resulted in the spread of bloodborne viruses (Department of Health 2002); and the practice of unprotected sex despite national campaigns to persuade young people of the benefits of using condoms is still resulting in a rise of newly diagnosed sexually transmitted infections (STI) in genitourinary clinics (Health Protection Agency 2007b). p1030

However, many other groups and individuals also have a particular risk of developing life-threatening diseases p1035

and are often ignorant or unaware of them, for example people living in communal or shared accommodation.

p1040 An important aspect of health behaviour is compliance, the extent to which behaviour coincides with medical or health advice. An example of poor compliance is the failure of healthcare staff to carry out good hand hygiene (Randle et al 2006, Whitby et al 2006), despite knowing how to carry it out (Hambraeus 2006).

Evidence-based practice

p1045 For healthcare staff, it is now recognized globally that non-compliance of a hand hygiene policy is a worldwide problem, with one reason being cited as 'nobody else does'. Studies into reasons for non-compliance were surprisingly similar for two quite different healthcare settings, neonatal nurses in Russia and first-year medical students in London (Hambraeus 2006).

p1050 An area where change in health behaviour has occurred amongst parents has been over the importance of immunizations and attending baby clinics, in particular over the issue of whether the combined mumps, measles and rubella (MMR) vaccination increases the risk of autism. To date (2007) there has been no research published to back up the initial claims (BBC News 2007), but the decrease in uptake of the triple vaccine has already shown an increase in numbers of reported measles cases. The infection prevention and control perspective is that the risk associated with getting the disease itself, for example measles, is far greater. But it is important that parents are listened to when social customs and religious practices conflict with the education that is being put forward by the health visitor.

p1055 People with mental health problems such as depression may not need hospitalization, but may have poor motivation and self-esteem and little desire to care for themselves. This can result in food poisoning leading to gastroenteritis as a result of being unable or incapable of storing, preparing and cooking food adequately, and fungal and bacterial infections of the skin as a result of poor personal hygiene.

p1060 The carer of a person with a learning disability might need to take extra care and pay extra attention to ensure that behaviour and practices do not increase the risk of infection.

Reflection and portfolio evidence

p1065 Reflect upon a placement where you have cared for a person with a learning disability. Observe how any basic infection control practices such as handwashing before meals and after using the toilet were encouraged and carried out.

- In what ways did staff teach and encourage the clients to undertake such practices? u0685
- If such basic infection control practices were not carried out, how might you go about implementing them in a similar practice setting. u0690
- Record your findings and ideas in your portfolio. u0695

CULTURAL BEHAVIOUR

s0175
p1085 Behaviour adopted by particular ethnic, cultural and religious groups can put them at a greater risk of infection and disease. Examples include the eating of raw or undercooked foods by some Far Eastern cultures, the prohibition of contraceptives including condoms by religious groups, and the non-seeking of treatment by men because it is considered unmanly or weak.

Occupation might also increase the risk of infections and diseases, for example those who have worked in a coal mine or with asbestos have a greatly increased risk of developing chest infections and life-disabling and life-threatening lung diseases in later life. p1090

Smoking as a cultural behaviour has over the years received a great deal of attention in the media regarding its effect on the smoker's health as well as on those who are in close contact with the smoker. For example, babies and children who live with parents who smoke have a greater risk of developing recurrent chest infections and asthma (Arshad et al 2005). p1095

Behaviour, attitudes and practices do change, but this can only happen by influencing individuals and groups. This might be by education in the form of knowledge and understanding, by observation of people, peer groups and organizations, and from outside influences. p1100

One example of how culture can cause infection and deaths is that of the outbreak of avian influenza (bird flu) in China, where the practice of living in very close proximity to their hens was considered normal. p1105

Increasing international travel for holidays and business has seen an increase of particular infections, such as hepatitis A, where cultural differences in water and food hygiene in underdeveloped countries are the main cause. During the 1980s, mass media education about safe sexual practices resulted in a dramatic reduction of HIV infections among homosexual men, although numbers among heterosexuals did similarly decline. The outcome of past behaviour is now known to take many years, for example the recent increase in numbers of cases of hepatitis C dates from 1960s behaviour, namely the sharing of needles to take drugs. p1110

Certain customs and rituals, despite being considered infection prevention and control risks, are still widespread among particular cultural groups. Examples include the p1115

practice of religious circumcisions on Jewish baby boys in their own homes and female circumcisions of young and teenage girls from certain African, Arabian and Far Eastern countries. Again the media have highlighted these practices as being dangerous and an infection risk (BBC 2007).

EPIDEMIOLOGY

s0180

p1120 The term 'epidemiology' is derived from the Greek and means 'studies upon people' (Lawrence & May 2003), and is often used to describe the study of disease and ill health in human populations. Incidence and distribution of disease can be assessed to provide data for the control and eradication of disease. Epidemiological studies can be small (micro) or large (macro) in scale. They involve determining an understanding of how infections and diseases spread and who may be at risk or susceptible to the infection. Risk factors might be physical (for example infective organisms) or psychosocial (for example behavioural, such as smoking or eating raw food). The risk to the individual is partly determined by estimating the experience of the whole population.

p1125 To measure the occurrence of a disease within a population two rates are commonly used: a prevalence rate, which measures the number of infections present at a particular time, and an incidence rate which measures the number of new infections that occur in a population. Within a population a disease that is always present at a static level is described as endemic, but if the numbers with the disease significantly increase above the normal endemic level, it is described as being an epidemic. MRSA is now considered to be endemic in many UK hospitals (Coia et al 2006).

p1130 Epidemiologists provide healthcare workers with data to enable planning of the particular health needs and services of a community. Outbreaks of infections are common in both institutional and community care. However, whereas an outbreak of an infection in a hospital ward or nursing home is usually on a micro scale, outbreaks of infections in the community are usually on a macro scale, at times involving hundreds of people. The influenza virus is a common cause of a macro scale infection. In a bid to try and control influenza epidemics, people over the age of 65 years and those considered at particular risk are offered free influenza immunizations.

p1135 An increasing concern to the community is the numbers of refugees and asylum seekers coming to the UK. One effect is that some of the diseases that might be endemic in their country of origin may be uncommon in the UK, which may cause a delay in diagnosis, because health professionals are unaware of some imported conditions (Lawrence & May 2003). However, the rate of infectious diseases among migrants in Britain is low (Health Protection Agency 2006b), although the majority of newly

diagnosed patients of HIV, TB and malaria are born outside the UK.

HEALTH PROMOTION

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Health promotion is an important aspect of infection prevention and control. This can be on a small scale, such as teaching a group of patients or ward staff, or large scale, involving large groups or entire communities.

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Specific groups and individuals have already been noted in this chapter as being at particular risk from infections due to their behaviours, attitudes and beliefs. For these people, health promotion attempts to prevent and control infection either to themselves or to others. The attitudes and behaviours of the health professionals carrying out such health promotion are important. Whether it is meeting a group of drug addicts to discuss the risk of sharing needles or talking to a particular cultural or religious group about child immunizations, health professionals need to be aware of their own personal beliefs, traditions and practices. Often health professionals who are not specifically specialized in infection prevention and control nursing are involved. For example, promoting the importance of immunizing babies to prevent and control potential life-threatening diseases is usually undertaken by health visitors, while community psychiatric nurses usually advise drug addicts about the importance of using sterile needles and not sharing them with others.

p1145

An example of a recent health promotion is the 'clean-yourhands' campaign (National Patient Safety Agency 2004) which involved healthcare staff and was in direct response to increasing national concerns to have cleaner hospitals and lower the rates of infection. It was a bid both to get healthcare staff to disinfect or wash their hands between each patient contact and to empower patients to check that staff had decontaminated their hands before attending to them (Department of Health 2004a, National Patient Safety Agency 2004). Evidence from one of the six acute trusts that piloted the campaign indicates that this health promotion campaign has already had an improvement in hand hygiene compliance (Randle et al 2006).

p1150

The aim of this section has been to enable you to examine and consider some the important biological and psychosocial aspects of infection control. You should by now be more aware of the relevance of the sciences surrounding infection control so that you can apply them to the more practical nursing issues examined in the next section.

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CARE DELIVERY KNOWLEDGE

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The prevention and control of infection is largely founded on nursing practice, and to help the healthcare professional there is a wealth of research based studies on specific

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Chapter 13

End of life care

Jane Seymour

c0013

KEY ISSUES

SUBJECT KNOWLEDGE

- Nursing and end of life care: a historical overview
- The meaning of key terms
- Morbidity and mortality: epidemiological trends
- Dying trajectories
- Death and its definitions
- Grief, bereavement and mourning

CARE DELIVERY KNOWLEDGE

- Concepts of special relevance to the nursing care of those approaching the end of life
- Communication issues in end of life care
- Needs of the person approaching the end of life and their companions
- Nursing care as death approaches
- Providing bereavement support

PROFESSIONAL AND ETHICAL KNOWLEDGE

- The UK policy context
- Ethical issues in end of life care

PERSONAL AND REFLECTIVE KNOWLEDGE

- Gaining self awareness of issues involved in working in end of life care
- Reflection on four case studies

INTRODUCTION

One of the only certainties in life is that we will all die, and the care and support of those reaching the end of their lives and of their companions is therefore a major public health challenge, especially in the light of the changing age structure of the countries in the developed world and the tragedies of the AIDS pandemic in the resource poor nations (Sepúlveda et al 2002). Since the Second World War, one particular philosophy of care at the end of life has gained international recognition: palliative and hospice care (Clark & Seymour 1999). There are many parallels between the emergence of nursing as a profession and the development of palliative and hospice care, with some arguing that the latter is a 'quintessential' example of the contribution that nurses can make to the relief of suffering (see for example Bradshaw 1996).

There are a number of challenges in providing good end of life care. At an individual level these include: identifying those patients who are in need of end of life care; assessing their needs and those of their companions and making plans to meet these; addressing frequently complex clinical, ethical and psychosocial problems; and accessing the health and social care services and informal support which make a difference to the quality of life for people approaching the end of life and their companions. At a societal level, governments and policy makers face huge challenges in making public health plans that can begin to address the scale of needs for end of life care. There are particularly acute challenges faced by policy makers in resource poor nations, where death is often precipitated by poverty, deprivation and lack of access to basic resources. The World Health Organization has promoted palliative care as one means of addressing these latter problems.

OVERVIEW

Subject knowledge

The aim of the first part of the chapter is to enable you to understand some of the historical roots of palliative and hospice care, and to reflect on the links between this model

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Providing bereavement support

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p1135 Bereavement support has three major components, as outlined in the NICE guidelines on improving supportive and palliative care for adults with cancer (NICE 2004). These are:

- u0510 ● Grief is normal after bereavement but many bereaved people lack an understanding of grief and should therefore be offered information and how to access sources of support if needed.
- u0515 ● Some bereaved people may require a more formal opportunity to look at their experience. This need not involve professionals. Volunteer groups, self-help groups, faith groups and others can provide much support at this level.
- u0520 ● A minority of people may require specialist interventions and proper referral in these cases is essential.

p1155 The ways in which nurses and other health professionals interact with people who are bereaved, both before and in the immediate period after a death, can have long-term consequences on the experience of bereavement. It may influence the extent to which the bereaved person can adapt to their loss and thus their physical and mental well-being (Wiseman 1992). Providing sensitive support – which includes accurate and appropriately worded information about what will happen to the body of their dead relative, guidance about access to other services, as well as immediate compassionate help and comfort – to people who have been bereaved is thus a moral good, an issue of rights to correct information and a means of preventing morbidity associated with unresolved grief in the future (Department of Health 2005). In the UK, the importance of such support has been highlighted by events which occurred at the Bristol Royal Infirmary and Royal Liverpool Children's Hospital in relation to lack of informed consent about organ retention following post mortems. The inquiries of 2001 which investigated these issues resulted in a set of guidelines about supporting bereaved people that have wider applicability and which draw on evidence-based best practice (Department of Health 2005). The following key elements have been identified as good practice for health professionals who have to care for bereaved relatives of people who die in hospitals, although many of these are transferable to other care settings (Box 13.6).

p1160 In the days, weeks and months after a death, health professionals may have a role in assessing and providing appropriate support to those who have been bereaved. However, it should not be assumed that everyone will need intervention. Most people cope with bereavement through drawing on their own resources or with the help of their wider social or family networks. However, others may appreciate or need a level of support, which may

range from a follow-up phone call to more intensive and specialist intervention. This may be because of social isolation or because of psychological morbidity due to some characteristic of the person who has been bereaved or the particular circumstances of the death. For example, the death of a child may be very traumatic. However, assumptions about what kinds of person or what kinds of death may lead to a need for intervention are not reliable.

Some of the approaches that might be employed by healthcare organizations that seek to provide support to the bereaved are as follows:

- Individual counselling and support. u0525
- Group meetings for peer support: these may need to be organized according to age, gender or some special characteristic of the death (suicide or child death for example). u0530
- Follow-up contact by way of a telephone call or card. u0535
- Specific interventions for groups with special needs (people with learning disabilities, bereaved children, older people). u0540
- Services of remembrance or other special events to mark loss associated with the institution. u0545

Nurses are most commonly the professionals who are likely to come into contact with those who have been bereaved and have a key role in this important area of care, which should be planned, organized and critically reviewed with the same attention to detail as any other aspect of end of life care. p1195

PROFESSIONAL AND ETHICAL KNOWLEDGE

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THE UK POLICY CONTEXT

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In the UK, policy and practice relating to end of life care reflects the socio-demographic changes described in the first part of this chapter, with attention increasingly focused on the challenges of supporting older people with chronic illnesses to live as well as possible as they approach the end of their lives. The NHS End of Life Care programme (EoLC), which was started in 2004, is one manifestation of this movement in policy. The key objective of the EoLC is to offer all adult patients nearing the end of life, regardless of their diagnosis, the choice and access to high quality end of life care in the place of care that they prefer (End of Life Care 2007). The programme draws upon a body of evidence which suggests that most people, when asked at any one time, will express a preference to be cared for and die at home during a final illness (Higginson 2003). p1200

In enabling this objective, the programme encouraged the implementation of three 'end of life care tools' which were assessed by the National Institute for Health and Clinical Excellence (NICE 2004) as having the potential to

p1205

b0030 **Box 13.6 Good practice in bereavement for hospital staff**

p0165 When it is thought that a patient may die, the person or people closest to the patient should be kept informed and given the opportunity to be with their relative, child, partner or friend when he or she dies, if that is what they and the patient wish.

p0170 Provision of overnight accommodation could be considered where facilities allow.

p0175 When it is certain that a patient will die, issues may arise relating to the donation of organs or tissue for use in transplantation, therapy, education or research. Special training in communication skills will be necessary for staff to manage these situations. Formal, informed consent is needed for the donation of organs or tissue for further information, please see Department of Health 2005.

p0180 Staff should do all they can to maintain the dignity and privacy of the person who has died.

p0185 Ideally, people who are bereaved should be provided with a comfortable private room where, if they wish, they can spend time alone or with the body of the person who has died, immediately after the death. The specific needs of special groups such as children should be considered.

p0190 If the death is to be referred to the coroner it should be clear to all parties involved with the body what is to happen in respect of drips, tubes, lines or other equipment attached to the body.

p0195 In other cases and taking account of religious preferences, accommodating the wishes of the deceased's partner or family should be a priority, for example they may wish to clean the body of the person who has died, brush their hair or change their clothes.

p0200 Sources of support should be offered (for example, chaplaincy services) and it may be helpful to explain the kind of support that faith and other groups of people can offer.

p0205 Relevant professionals in the community (especially the GP) should be informed about the death as soon as possible.

p0210 Nothing should happen to or be done to the body of a person who has died without the knowledge of those closest to that person. Relatives and other close individuals may wish to be involved in laying out the body.

p0215 At an appropriate time after the death, the body should be moved to the hospital mortuary in a safe, respectful manner.

p0220 The possessions of the person who has died should be carefully sorted, cleaned and catalogued before being returned to their relatives.

p0225 The provision of written information (listing and describing sources of support, helplines and web-based information, for example) can help people who are bereaved manage the practical arrangements necessary after a death.

p0230 Written material should be sensitive to cultural values and religious beliefs and to the special needs of those who have lost a child or who have been bereaved through sudden or traumatic death.

p0235 Summarized from: Department of Health 2005 When a person dies. Advice on developing bereavement services in the NHS. London, HMSO.

aid coordination, communication and best practice in end of life care and to support care and death at home if this is what the patient and their family prefer. These are:

- The Gold Standards Framework. u0550
- The Liverpool Care Pathway for the Care of the Dying. u0555
- Preferred Priorities of Care (formerly Preferred Place of Care). u0560

Reflection and portfolio exercise

Go to the NHS End of Life Care website at: <http://www.endoflifecare.nhs.uk/eolc/> and follow the links to examine each of these tools. Compare and contrast the roles they may have in end of life care. Find out what the policy of your clinical area is with regard to implementation.

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In 2007, the intention was announced in the UK to develop, for the first time, an 'End of Life Care Strategy' underpinned by a nationwide baseline review of services for people with end of life care needs to be undertaken by primary care trusts (Department of Health 2007a) and as part of a wider review of NHS services (Department of Health 2007b). This will involve assessing the population need for end of life care services, mapping current provision including its quality; comparing current provision with population need and identifying where service improvements are needed.

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One key area where a great deal of development and policy focus is directed is at end of life care in care homes, where a number of well recognized problems exist and yet which are the place where more than 20% of people aged over the age of 65 die (Office of National Statistics 2000). Older people living in care homes will sometimes die having lived with multiple, often chronic conditions, often over a long period of time. There are also higher levels of mental confusion and impaired sight and hearing (National Council for Palliative Care 2004). Death in a care home therefore occurs typically after the person has had a gradual deterioration in their overall health over a long period which is punctuated by episodes of acute illness. Frequently, after death has occurred, it is possible to identify 'critical' events such as the onset of a chest infection or the reluctance of the person to drink and eat that pinpoint the beginning of a final stage. One of the major difficulties for residents' families, care home staff and visiting GPs in discussing and making appropriate care plans relates to anticipating the meaning and significance of such events as they occur. Highlighting this, one study of death and dying in care homes reports vividly how some extremely frail older people, who are fully expected to die, survive repeated episodes of acute illness and recover to live with a good quality of life for a number of weeks and months

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(Froggatt 2001). End of life care planning is difficult in the context of such uncertainty and delivery of care to a high standard is frequently compromised by a lack of access in the home to adequate resources of knowledge, skills and outside support (National Council for Palliative Care 2004). There are a number of initiatives directed at finding ways to help residents, relatives and staff in care homes to work together with outside agencies to improve the quality of the environment of care homes as places within which to live and die. The *My Home Life* initiative is one example, which builds on a review of the evidence about promotion of quality of life in care homes (Help the Aged 2007).

ETHICAL ISSUES IN END OF LIFE CARE

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p1240 As the means have become available to support life and to defer death for prolonged periods, so the moral and ethical complexities surrounding clinical practice at the end of life have multiplied. It is only possible to give a brief overview of some of these complex issues here. Some selected critical cases, which have either led to changes in the UK law or have led to widespread professional and public debate, are summarized in Box 13.7.

Killing or letting die?

s0225

p1245 As the medical technology exists increasingly not only to relieve the suffering associated with dying, but also to prolong life or to procure early death, the clarification of the distinction between 'killing' and 'letting die' is perhaps one of the most pressing concerns facing society today. In the UK, it is now recognized that where death is inevitable, then *life-prolonging* treatments such as resuscitation, artificial ventilation, dialysis, artificial nutrition and hydration can be withdrawn or withheld, and the goal of medicine redirected to the palliation of symptoms and the provision of '*basic care*' and comfort, which *must* be provided and can never be withheld (British Medical Association 2007). Basic care includes nursing care, pain relief and relief of other symptoms, the offer of oral nutrition and hydration. It is acknowledged that sometimes giving adequate symptom control or withholding or withdrawing life prolonging treatments may hasten a death that is already expected (British Medical Association 2007). It is important to note, however, that this is not euthanasia.

Euthanasia

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p1250 There is a wide spectrum of views about euthanasia and there are many misunderstandings about it. A widely accepted (although subject to fierce debate) definition of euthanasia is the following: 'Euthanasia is killing on

Box 13.7 Critical cases

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Anthony Bland*

s0005

p0240 'Since April 15, 1989, Anthony Bland has been in persistent vegetative state. He lies in Airedale General Hospital in Keighley, fed liquid food by a pump through a tube passing through his nose and down the back of his throat into the stomach. His bladder is emptied through a catheter inserted through his penis, which from time to time has caused infections requiring dressing and antibiotic treatment. His stiffened joints have caused his limbs to be rigidly contracted so that his arms are tightly flexed across his chest and his legs unnaturally contorted. Reflex movements in the throat cause him to vomit and dribble. Of all this, and the presence of members of his family who take turns to visit him, Anthony Bland has no consciousness at all. The parts of his brain which provided him with consciousness have turned to fluid. The darkness and oblivion which descended at Hillsborough will never depart. His body is alive, but he has no life in the sense that even the most pitifully handicapped but conscious human being has a life. But the advances of modern medicine permit him to be kept in this state for years, even perhaps for decades.'

(Extract from *Airedale NHS Trust v. Bland* (C.A.), 19 February 1993, 2 Weekly Law Reports, p. 350, of Hoffman's description of Bland. Cited in Singer 1994: 58.)

p0245

Diane Pretty

s0010

p0250 Diane Pretty was a woman of 43 who had late-stage motor neurone disease and applied during 2002 to the European Court of Human Rights to allow her husband to help her to commit assisted suicide. The application, which was rejected, was surrounded by publicity. Mrs Pretty eventually died in a hospice. It was widely reported that, in the days before her death, she had suffered the very symptoms she had feared, although these had eventually been well controlled. The case was supported by the Voluntary Euthanasia Society and the civil rights group 'Liberty'.

(BBC News, Monday, 13 May 2002: <http://news.bbc.co.uk/1/hi/health/1983941.stm>)

p0255

**Anthony Bland was fatally injured in the Hillsborough football stadium disaster of 1989 causing a persistent vegetative state. His feeding tube was withdrawn after a prolonged legal battle (Airedale Trust v. Bland [1993] 1 All ER 821 (HL)), and he died 10 days afterwards. Public concern about this case pushed forward the establishment of a House of Lords Select Committee on Medical Ethics, which reported in 1994. This committee ruled that Bland's death was a case of 'double-effect' in which death was an unintended, although not unforeseen, consequence of the removal of futile life-prolonging medical therapy (House of Lords 1993-94).*

request and is defined as: a doctor intentionally killing a person by the administration of drugs at that person's voluntary and competent request' (Materstvedt et al. 2003: 98).

p1255 Euthanasia is illegal in the UK.

p1260 When considering euthanasia, we become aware of the conflicts that can exist between an individual's call to be released from suffering and society's efforts to protect and sustain life. Clinically, this tension becomes focused in the health professional's duty to provide beneficial care to those in need, to refrain from harming them, and to respect an individual's choices.

p1265 Periodically, there are attempts to change the law. In the UK during 2004–6, there were a number of attempts to change the law to permit assisted dying under consideration by parliament. In Belgium and the Netherlands, euthanasia at the voluntary request of a competent adult is legal under very tightly defined circumstances. The position taken by these countries is that under certain tightly defined conditions, ending the life of a terminally ill patient in extreme suffering is consistent with the ethic of beneficence in that it is a compassionate and merciful response that brings relief, and is also consistent with the ethic of autonomy, which allows people who competently request euthanasia to have their wish respected. In the UK, a beneficence approach has been dominant (Beauchamp & Childress 1994) in end of life care decision making, which emphasizes the need to act in the best interests of those who cannot speak for themselves (House of Lords 1993–94) and to protect vulnerable people from the potential for harm that legalizing euthanasia may bring.

Advance care planning

s0235

p1270 One of the key elements to support people at the end of their lives is to find out what their preferences and wishes are in relation to where they would like to be cared for and to help them to be involved, if they wish, in decisions about their care and treatment towards the end of life. Advance care planning (ACP), as highlighted in the NICE supportive and palliative care guidance for cancer patients (NICE 2004), is an important process in helping to ascertain this information (Box 13.8).

Do not attempt resuscitation orders (DNARs)

s0240

p1275 Nurses will often be involved in team discussions about cardiopulmonary resuscitation (CPR). One aspect of this may be an assessment of the risks and benefits of discussing this intervention with patients who have palliative care needs, in the light of evidence which shows that the survival rate after cardiorespiratory arrest and CPR is relatively low and carries a risk of adverse effects such as rib

Box 13.8 Advance care planning and associated terms

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Advance care planning (ACP)

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p0260 ACP is a process of discussion between an individual and their care providers irrespective of discipline. If the individual wishes, their family and friends may be included. With the individual's agreement, discussions should be:

- documented u0055
- regularly reviewed u0060
- communicated to key persons involved in their care. u0065

Examples of what an ACP discussion might include are:

p0280

- the individual's concerns u0070
- their important values or personal goals for care u0075
- their understanding about their illness and prognosis, as well as particular preferences for types of care or treatment that may be beneficial in the future and the availability of these. u0080

The difference between ACP and care planning more generally is that the process of ACP will usually take place in the context of an anticipated deterioration in the individual's condition in the future, with attendant loss of capacity to make decisions and/or ability to communicate wishes to others.

p0300

Statement of wishes and preferences

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p0305 This is a summary term embracing a range of written and/or recorded oral expressions, by which people can, if they wish, write down or tell people about their wishes or preferences in relation to future treatment and care, or explain their feelings, beliefs and values that govern how they make decisions. They may cover medical and non-medical matters. They are not legally binding.

Advance decision

s0025

p0310 An advance decision must relate to a specific refusal of medical treatment and can specify circumstances. It will only come into effect when the individual has lost capacity to give or refuse consent. Careful assessment of the validity and applicability of an advance decision is essential before it is used in clinical practice. Valid advance decisions, which are refusals of treatment, are legally binding under the Mental Capacity Act 2005.

Lasting power of attorney

s0030

p0315 A lasting power of attorney (LPA) is a statutory form of power of attorney created by the Mental Capacity Act 2005. Anyone who has the capacity to do so may choose a person (an 'attorney') to take decisions on their behalf if they subsequently lose capacity.

Adapted from: Henry C, Seymour J 2007 Advance care planning: a guide for health and social care professionals. NHS End of Life Care programme, Leicester. Available at:

p0320

<http://www.endoflifecare.nhs.uk/eolc/acp/> (accessed 3 November 2007).

p0325

or sternal fractures, hepatic or splenic rupture, or potentially inappropriate life treatment in an intensive care unit (BMA, Resuscitation Council and RCN 2007).

p1280 Guidelines published in the UK in 2001 and revised during 2007 (BMA, Resuscitation Council and RCN 2007) suggest that where the outcome of resuscitation intervention is uncertain, anticipatory decisions should be sensitively explored with patients in question. Key points highlighted are the following:

- u0565 ● If there is a risk of cardiac or respiratory arrest it is desirable to make decisions about CPR in advance whenever possible.
- u0570 ● There should be a full clinical assessment of the chances of a successful outcome.
- u0575 ● Any CPR decision must be tailored to the individual circumstances of the patient.

- Decisions must not be made on the basis of assumptions based solely on factors such as the patient's age, disability, or on a professional's subjective view of a patient's quality of life. u0580
- Advance care planning discussions must be led by someone with appropriate training and knowledge about the decision under examination. u0585
- There will be some patients for whom attempting CPR is clearly inappropriate; for example a patient in the final stages of a terminal illness where death is imminent and unavoidable and CPR would not be successful, but for whom no formal DNAR decision has been made. In such circumstances, healthcare workers who make a considered decision not to commence CPR should be supported by their senior colleagues and employers. u0590

PERSONAL AND REFLECTIVE KNOWLEDGE

s0245

p1315 Working with people who are approaching the end of life, or caring for the dying and the bereaved, raises significant personal questions about the meaning of life, and may at times raise fundamental anxieties about illness, dying and death. This is especially the case when something in one's personal life intersects with work life or when there are organizational problems which mean that you cannot provide the best care possible. Such work has long been known to induce considerable stress (Vachon 2003). Minimizing stress is crucial: to promote mental health and well-being, to prevent burnout and to ensure that one is in a position to support and help clients and colleagues appropriately and empathically. A key issue is how to contain powerful emotions while engaging in caring. 'Emotional labour' is a useful way of thinking about issues in achieving this balance (Seymour 2004). Similarly, Vachon (2003) draws attention to the importance of being aware of the idea of the 'wounded healer' (Nouwen 1972): a person who, possibly because of events experienced in their childhood or early adulthood, is drawn towards work which enables them to care for others in an unconscious attempt to heal themselves. Such people often have very high expectations of themselves in relation to helping others, but may not have insight into these, and may risk burnout or engage in patterns of behaviour at work or at home which ultimately stop them from being able to give the care that they wish. Of course, experiencing suffering oneself (which is a universal aspect of the human condition) means that one is perhaps better able to empathize with patients; however, it is necessary to 'tread lightly' between empathy and damaging over-identification if one is to survive long-term engagement

in the field of end of life care. Looking after oneself is crucially important and will mean making sure that one gets enough rest, exercise and relaxation to maintain a good home-work life balance, as well as taking time to grieve losses that are experienced through work and finding time to discuss with others (either formally through clinical supervision or informally) events and issues which give rise to stress at work. The sections on clinical supervision and stress management in Chapter 9, 'Stress, relaxation and rest', are useful resources that can help here.

CASE STUDIES RELATED TO END OF LIFE CARE

s0255

The following fictional case studies are provided to help you reflect on issues involved providing care at the end of life. p1355

Case study: adult

s0260

Mr Stewart is an ex shipyard worker aged 67 who has been investigated for the asbestos related disease mesothelioma. The investigations show that Mr Stewart does have mesothelioma, for which the prognosis is very poor. p1360

- What should the healthcare team take into account as they prepare to disclose this news to Mr Stewart? u0595
- What role will the nurse have who attends the meeting between Mr and Mrs Stewart and the consultant? u0600
- What help can Mr Stewart and his family be provided with in the community? u0605
- What issues may need to be taken into account in helping Mr Stewart engage with advance care planning? u0610

Chapter 17

Confusion

Jan Dewing

c0017

KEY ISSUES

SUBJECT KNOWLEDGE

- Physiological factors that may lead to people experiencing confusion
- Psychological factors that may lead to people experiencing confusion
- Environmental factors that may lead to people experiencing confusion

CARE DELIVERY KNOWLEDGE

- Nursing assessment of people who are experiencing confusion
- Risk assessment
- Planning nursing care for people who are experiencing confusion
- Supporting families and carers

PROFESSIONAL AND ETHICAL KNOWLEDGE

- Values and beliefs about confusion and attitudes towards people who experience confusion; discrimination and ageism
- Issues with capacity and consent

PERSONAL AND REFLECTIVE KNOWLEDGE

- Personal reflection on your own values and beliefs
- Application of the knowledge gained from this chapter to all branches of nursing
- Scenarios to develop decision-making skills

INTRODUCTION

There is a difference between the everyday experience and understanding of confusion (for example missing the point or being suddenly caught out and feeling a sense of embarrassment) and confusion in the context of health care. Here, confusion is fundamentally a lack of orientation with respect to time, place and/or self. It is generally marked by poor attention and thinking, which leads to difficulties in comprehension, loss of short-term memory and usually, irritability alternating with drowsiness. Having confusion often means the person does not or cannot act as others would expect them to in any given context or situation. It is vital to appreciate that the lived experience of what it is really like for the person is one where they can feel bewildered, perplexed and unable to self-orientate and it is others around the person who appear to be saying and doing unusual things.

Further, acute confusion or delirium is a clinical sign or more accurately a syndrome (a collection of symptoms) which generally occurs suddenly as an impairment in a person's mental state secondary to a medical condition or as a consequence of some medical treatment. Healthcare practitioners must be knowledgeable about confusion, particularly acute confusion, its possible underlying causes, what it is like to be confused and how to respond to the person and their families or carers in a way that is both compassionate and therapeutic. Confusion can also be seen to be present on a longer term basis, often as part of a neurological condition (for example head trauma or dementia) and again nurses need to have an overall appreciation of the causes and particularly how to respond to the person who is confused in the best way to support their health and overall best interests.

Figures for the rates of delirium vary according to which patient group or setting is being discussed. Delirium occurs in about 15–20 % of all general admissions to hospital (Meagher 2001). There is an increase with age: 0.4% in those over 18 years of age, 1.1% in those over 55, 13.6% in those over 85 years (Burns et al 2004). The incidence is higher in older people and for those with a pre-existing

s0025

p0155

p0160

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stroke or brain injuries, or for any other reason. It provides clear guidelines for carers and professionals about who can take decisions in which situations. At its heart, the Act states that everyone should be treated as able to make their own decisions until it is properly shown that they cannot. It also aims to enable people to make their own decisions for as long as they are capable of doing so, even where those decisions might go against what professionals would feel were best or 'right' in any particular situation. A person's capacity to make a decision will be established at the time that a decision needs to be made (i.e. it is situational). A lack of capacity could be present because of a severe learning disability, dementia, mental health problems, a brain injury, a stroke or unconsciousness due to an anaesthetic or a sudden accident. However, it must no longer be assumed that capacity is lacking simply due to a diagnosis or condition. There is also a new

criminal offence of neglect or ill-treatment of a person who lacks capacity.

The Act also sets out to protect people who lose the capacity to make their own decisions. It will allow the person, while they are still able, to appoint someone (for example a trusted relative or friend) to make decisions on their behalf once they lose the ability to do so. This will mean they can make decisions on the person's health and personal welfare. (Previously, the law only covered decision making for financial matters.) It will ensure that decisions made by others, on the person's behalf, are in their best overall interests and wherever possible will be based on the person's known wishes and preferences. To assist this, the Act provides a checklist of things that decision makers must work through. It also introduces a code of practice for healthcare workers, including nurses, who support people who have lost the capacity to make their own decisions.

PERSONAL AND REFLECTIVE KNOWLEDGE

s0225

APPLYING THE KNOWLEDGE IN THIS CHAPTER TO ALL BRANCHES OF NURSING

You can develop the section of your portfolio on working with people who are experiencing short term or longer term confusion by collecting summarized and synthesized information or evidence gathered from multiple aspects of your work (activities and projects you have been involved in as well as day-to-day practice), clinical supervision, research, websites, journal articles and written reflections. Remember that accounts by patients/users can also count as evidence.

To complete your portfolio you need to provide *synthesized* evidence of insight into personal and professional growth (Stuart 1998). (Descriptive reflection alone is not sufficient.) This is achieved by summarizing from a number of reflections on how your (1) feelings, (2) values and beliefs, (3) knowledge and skills have developed over time, again using structured reflection on your own or alongside mentorship and/or clinical supervision where necessary to assist this process.

Examples that you could include within your portfolio are:

- Evidence of any activity, project and papers/articles that you used when working with a person who was confused or their families/carers showing how you drew on theory to inform your practice and how effective this was.
- Summaries from your reflections of caring with a person with confusion – setting out what you have learned, what you now do differently and what you still need to develop and how this will be achieved.
- Identifying your level/experience/personal ability in caring for a person with confusion and supporting their family/carer.

- Identifying the transferable skills you have developed when caring for people who are confused, that you can use in future practice.

CASE STUDIES ON THE CARE OF PEOPLE EXPERIENCING CONFUSION

Four scenarios now follow, one from each branch of nursing. You should work through the relevant one for you and respond to the questions to help you consolidate the knowledge you have gained from this chapter. Reading through the others might also be of interest to you.

Case study: Mental health

George Ferguson has been referred to the community mental health team. George, a retired local policeman, has lived in the same house since his marriage to Ida 58 years ago. A year ago Ida died and since that time there has been a progressive deterioration in George's behaviour. He has lost a significant amount of weight, and more recently he has been found by neighbours 'wandering' around his village. Neighbours are very supportive. Recently he has taken to sleeping during the day and leaving his house, with the doors open, at night. His neighbours find him very forgetful and generally disorganized. One neighbour contacted the GP after smelling smoke coming from the house and finding a pan of beans burnt out on the gas ring of the cooker.

- What are the possible causes for George's current problems?
- What might George feel his problems or needs are?
- What information should the community psychiatric nurse obtain in the assessment and why?

- u0690 • What support and community services might be available to help George to remain at home for as long as possible?
- u0695 • On what basis would a decision be made that George might require admission to a nursing home?

Case study: Adult

s0245

p1400 Frank Hecker, originally from Austria, is a 58-year-old retired dentist. He is admitted to the accident and emergency department after being found in a collapsed state in the street. He smells strongly of alcohol, is very restless and at times agitated, and appears disoriented of time, date and place. He is also tearful and verbally aggressive towards staff. When you are attending to him he keeps mistaking you for one of his friends and calls you 'Anya'. You notice in your assessment that his chest sounds congested, and you can see and feel his extremities are cyanosed. You also think that you can smell acetone on his breath as well as the smell of alcohol.

- u0700 • What are the possible reasons for Frank's behaviour?
- u0705 • What immediate actions should be taken by nursing and medical staff?
- u0710 • How will you explain to Frank what is happening to him?

Case study: Child

s0250

p1420 Kimberley Kingston, aged 8 years, was cycling when she hit the kerb and fell off her bike, hitting her head on the ground as she landed. She is reported to have lost consciousness briefly and was brought into the accident and emergency department. A skull X-ray shows no sign of a fracture, but she is to be kept in hospital overnight for observation. Kimberley is frightened and does not appear to know where she is or why she is there. She has no recollection of the accident.

- Why has Kimberley's confusion arisen? u0715
- What immediate actions should be taken to help reduce Kimberley's confusion? u0720
- How long would you expect Kimberley's confusion to last? u0725
- How will you explain to the parents and younger sister what is happening and what support might they need? u0730

Case study: Learning disabilities

s0255

p1445 Pravin Dutt, a 34-year-old man, acquired brain damage at birth. Since the death of his mother 9 years ago he has been living in a group bungalow with live-in carers. Using the continued support from his carers Pravin has coped well with day-to-day activities of living. He has also benefited from an active behaviour modification programme.

Recent changes in management and organization at the home with new staff arriving and a new resident have resulted in Pravin becoming much more dependent upon others, in particular with elimination, and he has developed faecal incontinence. His GP felt he might be depressed and prescribed a course of an antidepressant medication. This has been followed by changes in his mental state manifesting as disorientation of time, date and place, restlessness and challenging behaviour.

- Identify the most probable causes for Pravin's change in behaviour. u0735
- What actions should the carers take to relieve Pravin's distress? u0740
- What actions could be taken to minimize Pravin's faecal incontinence? u0745
- What are the likely outcomes of the nursing actions taken and when would you expect them to be achieved by? u0750

SUMMARY

s0260

p1475 This chapter has explored how physiological, psychological and environmental factors can lead to the development of confusion. The main points stressed are as follows:

- o0060 1. An acute confusion/delirium is symptomatic of an underlying pathology and the focus of the initial nursing assessment must be to help identify the cause and establish what symptoms the person who is confused needs nursing interventions for.
- o0065 2. Acute confusion, while a medical emergency, is generally treatable.
- o0070 3. Long-term confusion, specifically associated with dementia, is usually as a result of an untreatable organic pathology and only amenable to symptomatic medical management, although there is much that

nursing can offer to support the person maintain their quality of life for as long as possible.

4. Although older people are the most likely to experience both acute and longer term confusion, there are many stereotyped views on both confusion and older people (especially those living with dementia). Thus, it is important to be aware of these in order to give appropriate and compassionate care. o0075
5. No matter how confused a person appears the fundamentals of privacy, dignity, respect and consent are still central aspects of nursing care. o0080
6. Various strategies from assessment and care planning can help the person and their families/carers while they are experiencing confusion. Central to nursing interventions is providing the best environment possible in which the person is nursed. o0085

- 0090 7. It is important to remember that the use of medication with neuroleptic effects is rarely recommended.

Annotated further reading and websites

Irving K, Foreman M 2006 Delirium, nursing practice and the future. *International Journal of Older People Nursing* 1:121–127

Neville S 2006 Delirium and older people: repositioning nursing care. *International Journal of Older People Nursing* 1:113–120

Bryden C 2005 *Dancing with dementia*. Jessica Kingsley, London
Written by a woman living with dementia, this book offers a detailed and helpful account of one person's journey with dementia, both the desperation and joy of life with a condition that reduces cognitive abilities and ultimately will end her life.

Wilkinson H, Kerr D, Cunningham C, Rae C 2004 *Home for good? Preparing to support people with a learning disability living in residential settings when they develop dementia*. Final Report. Joseph Rowntree Foundation, York

Wilkinson H, Kerr D 2004 *Top tips: fact sheet for caring for people with learning disability and dementia*. Joseph Rowntree Foundation, York
Both the above are available from the Joseph Rowntree Foundation – www.jrf.org.uk

Kerr D 2007 *Understanding learning disability and dementia: developing effective interventions*. Jessica Kingsley, London

This book covers all the essential issues in supporting a person with a learning disability when they develop dementia. It provides essential knowledge for anyone involved in the provision of services, assessment of need and direct care and support for people with a learning disability who also have a dementia.

Buijssen H 2005 *The simplicity of dementia: a guide for families and carers*. Jessica Kingsley, London

This book offers an introduction for relatives, carers and professionals looking after or training to work with people with dementia. The book sets out and draws on two 'laws of dementia'. The author explains the causes of communication problems, mood disturbances and 'deviant' behaviours, with particular emphasis on how these are experienced by the person with dementia. The book contains numerous case examples.

<http://www.alzheimers.org.uk>

This is the Alzheimer's Society website. It is an excellent, comprehensive website that contains resources for practitioners, carers and people living with dementia, not only of Alzheimer disease but also for people who have acquired CJD. The library section also contains an excellent resource of downloadable papers for professional use.

<http://www.alzscot.org/pages/carer.htm>

This is the Alzheimer Scotland website, which also contains useful resources.

http://www.direct.gov.uk/en/CaringForSomeone/DG_071391

A comprehensive website for carers.

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- Department of Health 2001 *National service framework for older people*. HMSO, London
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