Living with chronic illness and disability
Principles for nursing practice

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Esther Chang and Amanda Johnson

ELSEVIER
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Preface

We hope you enjoy using the third edition of this text, and that it inspires and encourages you to give the best quality of care for people living with chronic illness and disability. We also hope that this text will improve your knowledge and the development of your skills, and at the same time enhance your confidence when caring for people with chronic illness and disability.

This book is developed for undergraduate nursing students, students in the TAFE sector, newly registered nurses and other health professionals who share our commitment to providing quality of care to people living with chronic illness and disability. This book continues to champion the principles for practice supported by evidence from Australian and international literature to enhance the understanding of some of the issues and challenges of caring for a person living with chronic illness and disability. Across all chapters, the text illustrates a holistic approach highlighting quality of life in all aspects of care for chronic illnesses and disability. Concepts essential for underpinning best practice in self-management of chronic illness and disability are included, such as spirituality, individual education strategies, valuing the person’s expertise, resources, culture, minimising socially stigmatising processes and social isolation. Issues affecting carers and family are also addressed. Attention to these concepts recognises the important shift nurses and other health professionals are making towards working in partnership with individuals, their family and carers. Through education and empowerment, individuals, their family and carers are supported in their adjustment and adaptation to chronic illness and disability to achieve optimal outcomes.

This third edition provides new case studies and reflective questions on chronic illness and disability for discussion. Where relevant, the text is supported by current statistics to illustrate key aspects of the discussion. Acquiring the knowledge and skills for people living with a chronic illness and/or disability is vital in giving competent care. You will find viewpoints that are challenging, but at the same time motivating and thought-provoking. The exercises and learning activities that are presented throughout the text offer a range of helpful suggestions in understanding the context. Chapter 2 of this edition also includes the roles of pharmacist, paramedic and exercise physiologist, and their responsibilities in the interdisciplinary/multi-disciplinary team. In addition, each chapter has recommended readings and online resources for further exploration.

Nurses and other health professionals in clinical practice and academic roles have been involved in producing this text resource. We hope that you will find the text scholarly, accessible, reality-based and practically useful. It is a resource intended for every student, practising nurse, educator and administrator in understanding the issues of caring for people living with chronic illness and disability. By reading
the text, reflecting on the issues and posing possible answers, you should be able to gain a comprehensive view of the issues, challenges and opportunities ahead of them in their practice.

We gratefully acknowledge a number of key people who contributed and assisted us in preparing this third edition for publication. We wish to extend our heartfelt thankfulness and appreciation to the contributors for their shared interest and concern in the issues and challenges of caring for people and their families in nursing. This book would not be possible without them. We would like to extend our special appreciation to members of the Elsevier team: Natalie Hunt, Libby Houston, Karthikeyan Murthy, Margaret Trudgeon and Jon Forsyth for their encouragement and support. Elsevier Australia joins us in thanking all the reviewers who were involved in providing invaluable feedback during the development process (listed on page xiii). Finally, we would also like to thank our families for their endless support and encouragement through the years.

Esther Chang and Amanda Johnson
SECTION 1

Frameworks for chronic illness and disability

1. Chronic illness and disability: an overview
2. Partnerships in collaborative care
3. Models of care
4. Spirituality
5. Psychosocial care
6. Stigmatisation of people living with a chronic illness or disability
7. Sexuality
8. Developmental and intellectual disability
9. Management of chronic pain
10. Rehabilitation for the individual and family
11. Impact of obesity
12. Palliation in chronic illness
CHAPTER 1
Chronic illness and disability: an overview
Amanda Johnson and Esther Chang

Learning objectives
When you have completed this chapter, you will be able to:

- describe the global and local contexts of chronic disease and disability
- describe the key terms used in relation to chronic disease and disability
- understand the role of modifiable risk factors and their prevention in reducing the presence of chronic disease and disability in the community
- develop an understanding of the impact that living with a chronic disease and/or disability poses for the individual and their family, health system and wider community
- appreciate the need for the implementation of holistic care, inclusive of a multidisciplinary approach to promote self-management and optimal functioning.

Key words
chronic disease
chronic illness
disability
nurse
risk factors

Introduction
The greatest health challenge facing the world now and into the 21st century is the rising prevalence of chronic disease, the burden this poses for communities and its impact on healthcare systems. (Chronic disease may also be referred to in the literature as non-communicable diseases (NCDs), chronic illness or long-term conditions.) As we have the technology and treatments to keep us living longer, the world’s populations are growing older, which also gives rise to the presence of chronic disease. This health challenge has the potential to lead to one or more of the following developments: disability; co-morbidity; multimorbidities or premature death. Thus, the presence of chronic disease in our society poses a significant burden – social, economic, wellbeing and productivity – on the individual, family and wider community. Chronic disease is and will continue to place pressure on existing services, which are frequently designed for single disease management and are not necessarily responsive or coordinated to meet the needs of individuals and/or their family. Importantly, the rising prevalence of chronic disease can be reversed if individuals take responsibility for their health, modify risk factors (for example, New Zealand reports that over one-third of all health-loss related to chronic disease is preventable (Ministry of Health (MoH) 2016a), and governments institute healthcare policy focused primarily on prevention rather than intervention.
Chapter 1  Chronic illness and disability: an overview

Globally, nurses hold a pivotal role in coordinating care and acting as educators and advocates. In this context, the role requires nurses to develop caring attitudes, have knowledge of, and the skills in, the principles of nursing practice to provide optimal care to individuals, their family and the wider community. Subsequent chapters in this text use key chronic diseases and/or disabilities to illustrate the nurses’ role and explain how it contributes to an individual self-managing and achieving optimal functioning.

The use of a multidisciplinary approach to care has been reported as making significant improvements in the health outcomes for people with chronic diseases (McDonald, Cumming, Harris et al 2006). More often than not, the care coordination role within the multidisciplinary team is undertaken by the nurse (Parker & Fuller 2016), however, it is not exclusive to the nursing profession and other health professionals are just as able. Chapter 2 explores the role of nurses and other health professionals within a multi-disciplinary approach, as it relates to chronic disease management. Understanding what it means for individuals, families and the wider community to live with chronic disease and disability is as important as having specific practice knowledge, attitudes and skills in providing care.

The intention of this book, therefore, is to give equal emphasis to what it means to live with a chronic disease and/or disability and to gaining specific practice knowledge, attitudes and skills. The chapters are constructed to reflect this emphasis through the case studies presented, highlighting that the person and their family are central to the nurse’s understanding of their needs, as they commence the illness trajectory related to chronic disease and associated disability.

What follows in this chapter is a discussion on the key terms used throughout the text; an overview of the global context of chronic disease and disability followed by information specific to the Australian and New Zealand contexts.

Understanding key terms

To support your engagement in the reading of this text it is important to understand what is meant by chronic disease and the various forms of expression that are used interchangeably in the literature. Irrespective of the term or expression used, it is the challenges arising from these diseases that are the focus of this text. There are also a number of key terms related to chronic disease that need further explanation to facilitate your understanding.

Chronic disease

Chronic disease is often difficult to define and frequently several terms are used interchangeably across the world and within countries. When chronic disease is referred to in a global context and reported on by the World Health Organization (WHO), the term used is ‘non-communicable diseases’ (NCD) (WHO 2014). Non-communicable diseases are considered to be long-term in nature, not acquired by transmission between people, but share many common lifestyle-related risk factors (WHO 2014). In Australia, the term ‘chronic disease’ is more frequently used, and relates to a group of diseases that are long-lasting (Australian Institute of Health and Welfare (AIHW) 2014a). Chronic diseases constitute the main cause of illness, disability and death (90%) in Australia (AIHW 2014b). There are eight most frequently occurring chronic diseases: arthritis; asthma; back problems; cancer; chronic obstructive pulmonary disease (COPD); cardiovascular disease (CVD); diabetes; and mental health conditions (AIHW 2017a). The New Zealand literature is most likely to report on chronic disease using the term ‘long-term conditions’ (MoH 2016b) and are described in the New Zealand context to be ongoing, long-term or recurring conditions that have a significant impact on people’s lives.

Despite the differences in the form of expression, the common features of chronic disease include:

- complex causality, with multiple factors leading to their onset
- a long development period, for which there may be no symptoms
- a prolonged course of illness, perhaps leading to other health complications
- associated functional impairment or disability (AIHW 2012).

Risk factors

Risk factors constitute determinants of health which impact on our health negatively. They may be demographic, behavioural, biomedical, genetic, environmental, social or other factors acting independently or in combination (AIHW 2016). Initially, it was thought that risk factors were exclusively adult behaviours; however, we now understand their importance from the period of gestation until death; for example, the increased numbers of overweight and obese children...
and the increasing incidence of type 2 diabetes found in the younger generation (WHO 2014). In relation to chronic disease, they can affect the onset, maintenance and prognosis of chronic disease. The risk factors associated with chronic disease are:
  - poor nutrition
  - physical inactivity
  - smoking
  - risky alcohol consumption and illicit drug use
  - high blood pressure
  - high blood lipids
  - overweight and obesity
  - impaired fasting glucose (AIHW 2016).

Significantly, the vast majority of these risk factors are modifiable to prevent chronic disease from occurring. The lifestyles engaged in by the populations of developed countries has seen an increasing rise in the prevalence of chronic disease, while those who are vulnerable and poor in our communities tend to have one or more of these risk factors present. As you read over the chapters about specific chronic diseases, you will learn about the identification of risk factors in relation to disease and how these are best prevented and/or managed to prevent development of the chronic disease in the first instance.

**Risk factors in the development of chronic disease**

Controlling body weight, eating nutritious foods, avoiding tobacco use, controlling alcohol consumption and increasing physical activity may lead to the prevention or delay of many chronic diseases (AIHW 2005, p. 1).

Controlling some risk factors and effectively managing others through initiatives such as screening and early intervention programs (AIHW 2006; National Public Health Partnership (NPHP) 2006) can significantly reduce the presence of chronic disease within communities. In Australia, health promotion is acknowledged as the key to preventing chronic disease via prevention and management of risk factors (AIHW 2006, p. 13). The most common modifiable risk factors contributing to chronic disease are unhealthy diet, which leads to raised glucose levels, increased body mass and abnormal blood lipids; physical inactivity, which leads to increased body mass, increased blood pressure and increased blood lipids; and tobacco use, which leads to raised blood pressure (AIHW 2006, p. 13; WHO 2017). These risk factors are said to be modifiable because chronic disease can be prevented by the person changing their behaviour and/or medical intervention (AIHW 2006, p. 13). The two key non-modifiable risk factors contributing to the development of chronic disease are age and heredity (WHO 2005, p. 48). Identification of these factors within population groups allows for the development of prevention and management strategies that may be constructed to meet the cultural and linguistic needs of the group (AIHW 2006, p. 13).

**Chronic illness**

In this text, chronic disease is referred to as chronic illness. This form of expression has been chosen for this book because it emphasises the totality of the illness as experienced by the person. Chronic illness is described as: ‘the irreversible presence, accumulation or latency of disease states or impairments that involve the total human environment for supportive care and self-care, maintenance of function and prevention of further disability’ (Curtin & Lubkin, cited in Lubkin & Larsen 2013, p. 6). The term takes account of the resulting impact on all aspects of the person's life and the requirement by health professionals to address the person's needs holistically (Larsen 2013). The implication, therefore, for nurses and other health professionals is the need to recognise that all dimensions of personhood are affected by the presence of a chronic disease and/or disability.

**Disability**

Globally, The International Classification of Functioning, Disability and Health (2001) (Fifty-Fourth World Health Assembly 2001) defines a person as being disabled when a level of difficulty is experienced in one or more of the following interconnecting areas. The first area is that of impairment. A person with an impairment experiences issues related to body function or alteration to body structure (WHO 2011). The second area is activity limitations. In this area people face challenges in carrying out everyday activities (WHO 2011). The final area identified is participation restrictions. In this area an individual faces problems in any area of their life, not just health-related (WHO 2011). Further, disability arises from several contextual elements: those of health conditions (diseases or disorders), along with environmental and personal factors which can influence an individual's capacity to live in society. This means that interventions need to be much broader than just medical and frequently involve education and welfare support.
Chapter 1  Chronic illness and disability: an overview

In relation to chronic disease, a person may experience disability independent of the disease state, for example, a person who has arthritis but develops cardiovascular disease; or disability may be a consequence of the disease, for example, a person with diabetes who develops blindness; or disability may be present as a side-effect to treatment, for example, a person who recovers from cancer but has reduced hearing due to ototoxicity related to the chemotherapy drugs. It is important to understand that in some contexts the terms ‘disability’, ‘chronic disease’ and ‘impairments’ are used interchangeably within the literature and may mean the same thing.

Co-morbidity
The term co-morbidity describes the presence of two diseases occurring simultaneously in a person (AIHW 2017a). Frequently because of shared risk factors, there is a relationship between the original disease and the second disease that emanates; for example, a person who has diabetes and the person’s diabetic state has lead to the development of atherosclerosis and cardiovascular disease. Of importance to note here is that all of these diseases are preventable through surveillance and prevention. Getting older is also a factor, as with increased life expectancy there is greater opportunity for other conditions to emerge; for example, an older person who has cancer but also has the presence of significant arthritic changes and experiences severe restrictions with mobility as a result.

Multimorbidity
Since our first edition, the term co-morbidity has fast been replaced by the term multimorbidity, where an individual experiences more than three conditions concurrently. For example, in New Zealand one in four adults report two or more long-term conditions (MoH 2016b). People are living longer and as a consequence are acquiring chronic disease earlier and therefore are presenting to health services with multimorbidity; for example, in the United States, 50% of older people have three or more chronic conditions (American Geriatrics Society 2012), necessitating complex interventions.

The global perspective of chronic disease
Now, more than ever, there is a need to globally prevent and control the rise of chronic disease. The world and individual countries, whether low-, middle- or high-income, can no longer sustain now and into the future the human, social, economic and health impacts of chronic disease. In particular, it is the poor and vulnerable populations who are most at risk (WHO 2014). By 2030, it is projected that chronic disease will account for 82% (55 million) of all deaths worldwide; this projection is an increase of 17 million from 38 million in 2012 (WHO 2013). Of the 56 million deaths reported in 2012, 68% (38 million) were attributed to chronic disease; more than 40% (16 million) were premature deaths under 70 years of age, and 48% of them occurred in low- to middle-income countries (WHO 2014). Of concern is the projected increase in these deaths underpinned by four risk factors: tobacco use; unhealthy diet; physical inactivity and harmful use of alcohol (WHO 2013), all of which are directly preventable. The leading deaths specifically attributable to these risk factors are: cardiovascular disease; cancers; chronic respiratory disease and diabetes (WHO 2013). These deaths, and the resultant co-morbidities, multimorbidities and disability evoke much human suffering, impacting at social, economic and public health levels on the individual, their family and the wider community.

To support countries in the leadership of preventing and controlling chronic disease, The World Health Assembly endorsed the WHO Global Action Plan for the Prevention and Control of NCDs 2013–2020 (WHO 2013). The Action Plan offers a means by which to guide countries in establishing multi-sectoral action plans and policies to achieve a reduction in premature deaths by 25% (WHO 2013). The plan articulates nine voluntary global targets for attainment by 2025:

1. a 25% reduction in overall mortality from cardiovascular diseases, cancer, diabetes or chronic respiratory diseases
2. a 10% reduction in the harmful use of alcohol
3. a 10% reduction in prevalence of insufficient physical activity
4. a 30% reduction in intake of salt/sodium
5. a 30% reduction in the prevalence of tobacco use
6. a 25% reduction in the prevalence of high blood pressure
Section 1  Frameworks for chronic illness and disability

Australian profile

Australian governments are informed by the WHO's strategic directions, which lead to a series of National Health Priority Areas (NHPAs) first being identified in 1996. At the current time, there are nine NHPAs (refer to the list below). They are diseases and conditions that successive Australian governments have chosen to focus attention on because they contribute significantly to the burden of illness and injury, and if addressed will result in the improved health of the Australian population.

The nine priorities are:

- cancer control (first set of conditions, 1996)
- cardiovascular health (first set of conditions, 1996)
- injury prevention and control (first set of conditions, 1996)
- mental health (first set of conditions, 1996)
- diabetes mellitus (added 1997)
- asthma (added 1999)
- arthritis and musculoskeletal conditions (added 2002)
- obesity (added 2008)
- dementia (added 2012) (AIHW 2017c).

In 2014–15 more than 11 million people had at least one of the eight selected diseases and seven out of ten (73%) of all deaths were related to chronic disease (AIHW 2016). Many of these diseases also share common risk factors which are preventable or modifiable.

One in four (23%) Australians had two or more of the eight selected diseases (AIHW 2016), the most common co-morbidities being cardiovascular disease (7.4%) or arthritis (5.1%). Of growing concern is the emergence of the population group with multiple morbidities, which places even more pressure on the healthcare system. Two-thirds of the burden created by chronic disease is the result of cancer, cardiovascular disease, mental and substance-use disorders, musculoskeletal disorders and injuries (AIHW 2016). Examples of people with a multiple morbidity are: of the one-third of Australian people (31.8%) who experience a psychotic disorder, they also experience chronic pain; one-fifth (20.8%) have diabetes and just over one-quarter (26.8%) have a heart or circulatory problem (AIHW 2016). By targeting specific areas that impose high social and financial costs on Australian society, collaborative action can achieve significant and cost-effective advances in improving the health status of Australians. Of the modifiable risk

7. a halt in the rise of diabetes and obesity
8. at least 50% of people receiving drug therapy and counselling (glycemic control) to prevent heart attacks and strokes
9. an availability of the affordable basic technologies and essential medicines to treat NCDs (WHO 2013, p. 5).

In 2014, WHO conducted a review on the progress of these targets, documenting varying degrees of success by different countries against the targets. It is evident from the 2014 WHO report that the majority of countries are off-course to meet their global targets and as an imperative need to set national targets and a monitoring framework to track progress towards the 2025 date. The burden of disease for OECD countries (including Australia and New Zealand) is similar; however, the rates for both ischemic heart disease and lung cancer in Australia are significantly lower than in other OECD countries (WHO 2013). This reduction has been directly attributed to the health promotion educational activities.

Australian and New Zealand context

Australia and New Zealand are both fortunate countries as the vast majority of their inhabitants have high life expectancies and consider themselves to be in ‘good’ health (AIHW 2016; MoH 2016a). However, both countries also report chronic disease as a growing problem which is exerting significant pressure on an already strained healthcare system and is a burden on the community (AIHW 2016; MoH 2016b). In Australia, for example, chronic diseases are the leading cause of ill health and death (AIHW 2016). Both countries have recognised that to meet the health challenges they face now and into the future, the health system will need to adapt and be responsive to the changing care needs and the level of complexity presented by chronic disease. Currently in New Zealand, health spending represents 22% of the overall budget in line with other developed countries. However, this current funding level is not sustainable (MoH 2016b); an increased life expectancy and greater percentage of the population with long-term health conditions necessitates a model of care that is different to current practice. The model needs a focus on prevention of long-term conditions or slowing down the development of chronic disease and related co-morbidities/multimorbidities. Further discussion on models of care can be found in chapter 3.
In particular, the National Aboriginal and Torres Strait Islander Health Measures Survey (NATSIHMS), identifies that 31% of chronic disease in Australia could have been prevented by reducing exposure to tobacco use, harmful alcohol use, high body mass, physical inactivity and high blood pressure.

In addition to the NHPAs, the Commonwealth Government, through the Department of Health, has sought to establish a National Strategic Framework for Chronic Conditions in conjunction with the five states and two territories of Australia. The framework is still under development, but will seek to provide a national approach to guide planning, design, delivery of policies, strategies, actions and services to reduce the impact of chronic conditions in Australia (Australian Government Department of Health 2017). It will move away from the more traditional approach of managing diseases specifically to generating principles that can be applied more broadly. Another element to the framework will be how best to provide care through a coordinated approach drawing on a diversity of health and care providers to deliver services. Once completed, it will replace the National Chronic Disease Strategy 2005 (NHPAC 2006). This strategy emerged in response to the growing impact of chronic disease and was aimed at encouraging a coordinated approach.

In 2014–15, more than 50% (11 million) of the Australian population experienced a chronic disease (AIHW 2016). Specifically, those aged 65 and over constituted 87% of the 11 million experiencing a chronic disease, reflecting the ageing population. The AIHW 2016 report also demonstrates that 55% of those with a chronic disease come from the lowest socioeconomic areas in Australia, predominantly in regional and remote areas (54%), compared to the major cities (48%). This is an important statistical fact to consider in understanding how services are planned to promote access and uptake in regional and remote areas. The AIHW report (2016) on the self-reported data showed that the most commonly reported chronic diseases for the period 2014–15 were: cardiovascular and mental health conditions (18% each), followed by back pain (16%). In the age group 45–64 and those 65 years or older, cardiovascular disease (27%) and arthritis (26%) were most commonly identified.

**New Zealand profile**

New Zealanders are living just as long as Australians, with 88% of the population experiencing some form of health loss as a consequence of long-term mental and physical disease (MoH 2016a). In 2013, the Ministry of Health reported over half of the health loss (52%) was attributable to a disability. Furthermore, mental health and dementia are the leading causes of health loss (19%), two areas of practice that are providing the biggest challenges (MoH 2016a). Another emerging area contributing to health loss is the rise of musculoskeletal disorders (13%) due to a higher incidence of obesity (MoH 2016a). As is the case for Indigenous Australians, Māori and Pacific Islanders experience serious inequalities in health outcomes relative to the total population (MoH 2016a). For example, high smoking rates continue to be present in Māori adults, especially for those living in the most deprived areas and Pacific adults experience higher rates of diabetes than any other ethnic group in New Zealand (MoH 2014).

**Indigenous populations**

Worldwide, there are vast disparities in the health of Indigenous people and their subsequent experience of chronic illness and/or disability, as compared to non-Indigenous people (WHO 2008). This disparity is attributable to a life expectancy that is 10–20 years less than for the main population; infant mortality 1.5 to 3 times greater than the national average; and a large proportion of Indigenous people suffering from malnutrition and communicable diseases (WHO 2008). Indigenous people’s health is further exacerbated by damage to their habitat and resource base (WHO 2008). In 2008 WHO, in its report *Primary Health Care: Now More Than Ever*, made explicit that health service providers need to take better account of the lack of services and the disadvantage that remoteness plays in Indigenous people accessing and achieving the same health status as non-Indigenous people.

The health disparity presented worldwide is also true for both the Australian and the New Zealand Indigenous populations. They are more likely to have an increased presence of chronic disease; to be less healthy; to die at a much younger age; and to have a lower quality of life than non-Indigenous people (AIHW 2012; MoH 2012). At the present time, Australian Indigenous people experience 80% mortality as a direct link to chronic disease (AIHW 2017b).

In particular, the National Aboriginal and Torres Strait Islander Health Measures Survey (NATSIHMS), shows that Indigenous people are more than three times likely to have diabetes; have triglyceride levels
that are nearly double the normal levels of good cholesterol, leading to cardiovascular disease, and are twice as likely to have signs of chronic kidney disease (ABS 2014). Of significance, not only do Indigenous Australians experience more chronic disease than non-Indigenous Australians, but they also experience it at a much younger age—35 years onwards as compared to 45–55 years depending on the disease (ABS 2014). This report also revealed that four in ten Indigenous people are obese, a level that is one and a half times more than for the non-Indigenous population (ABS 2014). Obesity is a strong predictor for many chronic diseases, for example: heart disease, diabetes, high blood pressure and some forms of cancer (AATSHIS 2014).

In 2008, Australian Indigenous peoples were more than twice as likely as non-Indigenous people to have a disability (and to have a life expectancy of less than 10 years) (ABS 2013). In New Zealand, the most recently reported figures (2006) show life expectancy for Pacific males as 6.7 years less than total males and for Pacific females it was 6.1 years less than total females (MoH 2012a, p. 25). In New Zealand it is estimated that 18,700 Pacific adults had a disability. For 43% \( (n = 8100) \) the most common cause of their disability was most likely attributed to chronic disease or illness (MoH 2012a, p. 27).

By way of illustrating the disparity, in 2011 Australian Indigenous peoples were 12% more likely than non-Indigenous Australians to experience cardiovascular disease; were 3.4 times more likely to report some form of diabetes, and had a 27% increased risk of having a respiratory disease (Thomson, MacRae, Brankovich et al 2011). In New Zealand, the rate of diagnosed diabetes was significantly higher for Pacific men and women (45–64 years age group) than men and women in the total population by approximately 20% and 12% respectively (MoH 2012a, p. 43). In terms of respiratory disease, the Ministry of Health (2012a) reports Pacific men as being three times more likely to present for hospitalisations and Pacific women five times more likely than the total population.

The factors identified which contribute to Indigenous health are: nutrition; physical activity; body weight; immunisation; breastfeeding; tobacco smoking; alcohol use; and illicit drug use (MoH 2012a; Thomson, MacRae, Brankovich et al 2011). Indigenous peoples have and continue to experience substantial social disadvantage in relation to their health through limited education; reduced employment opportunities; lower than national average income; higher levels of poverty; poorer housing; greater exposure to violence; limited access to services; underdeveloped social networks; connection with land; racism and incarceration; and impaired communication when English is a second language (McMurray & Clendon 2011; MoH 2012a; Thomson, MacRae, Brankovich et al 2011). It is important to recognise that for Indigenous populations both the social determinants of health and the cultural concepts of indigenous health strongly influence the health status of their communities (McMurray & Clendon 2011; MoH 2012a; Thomson, MacRae, Brankovich et al 2011). The presence of these risk factors either singly or in combination lead to a higher proportion of the Indigenous population developing chronic disease and/or disability as compared to the non-Indigenous population.

As a consequence, Indigenous Australians suffer much more ill health than non-Indigenous Australians (AIHW 2012). Indigenous Australians experience higher levels of disability when compared to the general population (36%): 8% experience a severe limitation of a core activity (AIHW 2006, p. 56), which is twice that experienced by non-Indigenous Australians (AIHW 2006, p. 56). In terms of chronic disease, Indigenous Australians experience a higher mortality rate from diabetes (14 times higher than the general population), chronic kidney disease (8 times) and heart disease (5 times) (AIHW 2006, p. ix). The resulting outcome for Indigenous Australians is that they are four times more likely to experience death as compared to non-Indigenous Australians (AIHW 2006).

In New Zealand, 24% of Māori experience disability, followed by 18% of Europeans, and 17% of Pacific peoples (MoH 2005, p. 8). As a consequence, Māori and Pacific peoples have a lessened life expectancy by 8.5 years compared with the European population, largely attributable to the increased incidence of chronic disease in these population groups (McMurray & Clendon 2011; National Health Committee 2007, p. 10).

**Global perspective on disability**

Globally 15% of the world’s population experience some form of disability and it continues to rise (WHO 2011). Reasons for this continued rise relate to: more people getting diseases which can cause disability; people cannot always get access to healthcare; people who are disabled by war, and natural disasters. The
15% equates to 15 out of every 100 people being disabled with 2–4 of those people having severe disability preventing their productive participation in society (WHO 2011). WHO reports several factors that have contributed to this increase: an increasingly ageing population; the rapid spread of chronic disease and better ways of reporting on disability (2011). It is also recognised that there are more vulnerable groups within our communities, for example, the poor; women; older people; those with no employment; those with low levels of education qualification; minority ethnic groups; all of whom are more likely to experience higher rates of disability within their group (WHO 2011). This figure is expected to rise as a result of the world’s ageing populations and the higher presence of disability in older people, as well as the global rise of chronic diseases (WHO 2011, p. xi).

The global impact of disability on communities has only been recently acknowledged by the first world report on disability, The WHO Report on Disabilities (WHO 2011b). This report demonstrates the attitudinal, physical and financial burdens a person experiences every day with a disability. Further, this report shows the need for governments to remove the barriers to participation and to provide sufficient funds to allow people with disability access to health, rehabilitation, support, education and employment (WHO 2011b, p. ix). Finally, the report concludes by illustrating the need for policymakers, researchers, practitioners, advocates and volunteers in disability to work together at local, national and international levels. This is necessary to bring about a reduction of the burden of disabilities to society, to bring about changes to practice and to value more explicitly the contribution that people with disability can make to the productivity of the community.

**Australian profile of disability**

The National Disability Strategy 2010–2020 has as one of its six priority areas: ‘People with disability attain the highest possible health and wellbeing outcomes throughout their lives’ (Australian Government Department of Social Services 2014). It is telling, however, that the health outcomes for people who are disabled are not well featured as part of the national health report (AIHW 2016). In 2015, nearly 1 in 5 Australians (18.3% or 4.3 million) experienced some form of disability (ABS 2015). This figure increased significantly for those aged 65 years or older with 50.7% reporting a disability (ABS 2015). This is important to understand in the context of Australia growing its 65 years or older portion of its total population faster than any other age group. It results in 1 in 7 or 15.1% of the population being in this age group (ABS 2015). Such a result plays a role in the determination of healthcare services into the future. The most common disability people experience is impairment to communication, mobility and/or self-care. In 2015, 5.8% (1.4 million) of the population experienced this form of disability requiring the greatest assistance. More than half those aged 65 years or older were affected (ABS 2015). It is also important to understand that those with a disability were also 3.3 times more likely to have a long-term health condition (AIHW 2016). Two illustrations of why this is the scenario are: 1. in adults with a profound to severe disability they were 70% more likely to be overweight or obese as compared to a person without a disability and 2. those who are profoundly or severely disabled are twice as likely to smoke than those without a disability (AIHW 2016). Services to support Australians who are disabled has fallen under the National Disability Agreement (NDA) with over half the users (55%) in 2013–14 having an intellectual or learning disability (AIHW 2014a). The most commonly reported conditions were: mental and behavioural problems; followed by back problems; deafness; arthritis; cardiovascular diseases; asthma and migraine (AIHW 2016). It is also evident that comorbidity between mental and physical disability exists and is expanding. For example, people with a disability and depression are more likely to develop diabetes (AIHW 2016) as a consequence to changes in lifestyle.

**Aboriginal and Torres Strait Islander people with a disability**

A large disparity exists between Aboriginal and Torres Strait Islander people and non-Indigenous populations of Australia. Aboriginal and Torres Strait Islander people are more than 1.7 times more likely to have a disability than non-Indigenous people (ABS 2012). This disparity exists because of the difference in socioeconomic circumstances and access to healthcare services between these two populations. The report ‘Aboriginal and Torres Strait Islander People with a Disability 2012’ revealed notable differences in the rates of disability in Aboriginal and Torres Strait Islander people and non-Indigenous populations. These differences were: Aboriginal and Torres Strait Islander people experience a higher rate of disability across all age groups and gender than non-Indigenous people;
Aboriginal and Torres Strait Islander children between 0-14 years of age were more than twice as likely to have a disability than non-Indigenous people; and Aboriginal and Torres Strait Islander people aged 35-54 years were more than 2.7 times likely to have a disability than non-Indigenous people. It was also noted that 7.8% of Aboriginal and Torres Strait Islander people had a profound or severe disability impacting on their capacity to communicate, be mobile and or self-care (ABS 2012).

New Zealand profile of disability
In 2013, the total New Zealand population had a disability rate of 24% partially explained by an increase in the age of the population (Statistics New Zealand 2015) reflecting a similar pattern to the Australian and worldwide context. Those aged 65 years or older were more likely to be disabled (59%), with physical limitations being the main form of impairment (Statistics New Zealand 2015).

Māori people with disability
New Zealand’s Indigenous population suffers a similar health disparity to Indigenous Australians. In 2013, the Māori population identified 26% (176,000) of its population as being disabled in a younger age group, an increase of 6% since 2001 (Statistics New Zealand 2015). This equates to one in four Māori who are disabled with an impairment, mostly related to mobility. Impairments for Māori stem primarily (40%) from disease or illness (Statistics New Zealand 2015). Low socioeconomics, ethnicity, poor housing and limited education combine to contribute to the Māori population experiencing a higher percentage of disability than the non-Māori population (Statistics New Zealand 2015).

Impact and challenges of chronic illness and disability
It is difficult to quantify the impact of chronic illness and disability experienced by the individual, family and community, as many of the costs are invisible. For example, in Australia 65% of people who experienced a severe or profound core activity limitation relied on informal carers for such activities as self-care, mobility and communication (AIHW 2006, p. 49). The difficulty arises due to the nature of the chronic illness and/or disability, and the resources available to manage the condition are highly variable, largely determined by each person’s individual situation (Guillett 2004).

Chronic disease is often thought of as a disease of the aged and while it is more prevalent in that age group, we are now seeing evidence of chronic disease in younger generations, which are directly attributable to lifestyle risk factors; for example, children who are overweight and obese (AIHW 2016) (Table 1.1). The implications of this are that individuals who acquire a chronic disease early on in life will need to live and adapt to their illness and sequelae for the rest of their life, placing a significant burden on the community. People living with a chronic illness are more likely than the general population to experience periods of hospitalisation as a consequence of acute flare-ups of their underlying chronic disease. What is emerging is that due to the increasing prevalence of chronic disease, many admissions to hospital now constitute the underlying pathology of chronic disease.

The challenges presented to health professionals by chronic illnesses and disabilities are vast. Consideration must be given to finding new ways of prevention to control the prevalence of chronic disease within our community. Controlling the prevalence of chronic disease is challenging but possible. The following table provides an overview of the modifiable factors that can impact on the health of individuals and the community.

<table>
<thead>
<tr>
<th>Table 1.1 Risk factors and determinants for chronic diseases</th>
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<tbody>
<tr>
<td><strong>MODIFIABLE RISK FACTORS</strong></td>
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<tr>
<td>-------------------------------</td>
</tr>
<tr>
<td>Behavioural</td>
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<tr>
<td>Tobacco smoking</td>
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<tr>
<td>Excess alcohol use</td>
</tr>
<tr>
<td>Physical inactivity</td>
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<tr>
<td>Poor diet</td>
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<tr>
<td>Other</td>
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disease is not the sole responsibility of government or health services, but must emanate from individuals taking ownership of their health behaviours, working in collaboration with government and health services to eradicate the increasing presence of chronic disease in our communities (WHO 2014). Some challenges that have been articulated are the rising costs of care, the number of people needing to access chronic disease care, inequities between the Indigenous and general populations, the changing composition of the population experiencing chronic disease and/or disability, ethical issues, providing culturally competent care, caregiver issues (AIHW 2016; MoH 2016; Remsburg & Carson 2006, pp. 591–599), the mismatch between the needs of people with a chronic condition and what the health system offers (NHC 2007, p. 13).

Other ways in which these challenges can be addressed include: improving the health experiences of various disadvantaged groups in Australia and New Zealand; providing public health programs in a more cohesive and non-fragmented manner; adopting a model of practice that recognises the importance of early life factors and their contribution to creating chronic disease in adulthood; using a multifaceted approach involving others outside the healthcare area to reduce the prevalence of conditions such as obesity and depression to foster social norms of active living; acknowledging the contribution of psychosocial factors, such as resilience and family environment, to chronic disease and the need for multiple strategies to address these factors; and adopting a holistic approach in developing prevention and management strategies (NPHP 2001, p. 2) (Table 1.2).

### Principles of practice

To provide optimal care to a person and their family experiencing a chronic illness and/or disability which ensures all needs are met, a number of key principles of practice must be implemented by nurses in conjunction with other members of the multidisciplinary healthcare team. These principles are to:

- recognise that chronic illness and/or disability affects all dimensions of personhood: physical, psychosocial, emotional, cognitive and spiritual (Guillett 2004; Larsen 2013)
- recognise that cultural responses to illness are important when providing care (Larsen 2013)
- provide holistic care by incorporating a team approach to providing care that is relevant to the needs of the person experiencing the chronic illness and their family (Guillett 2004, p. 19)
- adopt a ‘whole of life’ approach, recognising that risk factors occur across the lifespan and play a significant role in the development of chronic disease (NPHP 2001, p. 4)
- provide care that is person-centred and inclusive of the family, however the person defines this for themselves (Morris & Edwards 2006).

As you read through the following chapters you will see further expansion and application of these principles that will assist you in your understanding of chronic illness and disability, as applied to the Australian and New Zealand context. The authors discuss critical components related to understanding the experience of chronic illness, such as: behaviours that contribute to the development of the condition; the relationship between chronic illness and activities of daily living; the impact of body image and identity on the person and their family or carers; issues concerning quality of life; a range of interventions to support restorative function and quality of life; the role of family and carers; and education of the person and family. Case

### Table 1.2 Comparison between acute and chronic care models

<table>
<thead>
<tr>
<th>ACUTE MODEL</th>
<th>CHRONIC CARE MODEL</th>
</tr>
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<tbody>
<tr>
<td>Disease-centred</td>
<td>Person-centred</td>
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<tr>
<td>Doctor-centred</td>
<td>Team-centred</td>
</tr>
<tr>
<td>Focus on individuals</td>
<td>Population health approach</td>
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<tr>
<td>Secondary care emphasis</td>
<td>Primary care emphasis</td>
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<tr>
<td>Reactive, symptom-driven</td>
<td>Proactive, planned intervention</td>
</tr>
<tr>
<td>Episodic care</td>
<td>Ongoing care</td>
</tr>
<tr>
<td>Cure focus</td>
<td>Prevention/management focus</td>
</tr>
<tr>
<td>Single setting: hospital, specialist centres, general practice</td>
<td>Community setting, collaboration across primary and secondary care</td>
</tr>
<tr>
<td>1:1 contact through visit by patient</td>
<td>1:1 or group contact through visit by patient or health professional, email, phone or Web contact</td>
</tr>
<tr>
<td>Diagnostic information provided</td>
<td>Support for self-management</td>
</tr>
</tbody>
</table>

studies are included to support your understanding and cover issues such as culture; complementary and alternative therapies; rehabilitation/facilitation; financial considerations and their impact on the person’s life; aspects of stigma; self-efficacy and social isolation; sexuality; the impact of psychosocial dimensions of disease, disability and treatments; spirituality; chronic pain; powerlessness; and the nurse’s role in advocacy.

**Conclusion**

This chapter has provided an overview of the gravity of our health needs from a global, Australian and New Zealand perspective. The burden that chronic illness and/or disability currently places, and will continue to place, on our communities is significant. It is important to recognise that with the projected ageing population figures for both countries and the increasing prevalence of modifiable risk factors within our lifestyles and increased survival rates from potentially fatal diseases, chronic disease will emerge as the new epidemic of the 21st century. It is unlikely that our communities will be able to sustain health service provision to meet this growing demand. The resources (informal carers, equipment, qualified personnel and finance) required for the management of chronic illness and/or disability are not found in an endless supply. The challenge for nurses and other health professionals is to provide models of care aimed at preventing, reducing or eliminating modifiable risk factors from their communities’ lifestyle in order to halt the growth of this cancer-like phenomenon and to promote sustainable, healthy communities.

**REFLECTIVE QUESTIONS**

1. What challenges does the increasing prevalence of chronic disease and disability pose for you in terms of nursing practice?
2. What is your understanding of Target 3: insufficient physical activity and your own level of physical activity. Do you meet the WHO guidelines? Note: WHO (2014) recommends 150 minutes’ moderate to intense physical activity per week as a means of reducing the risk of heart disease, stroke, diabetes and breast and colon cancer.
3. How do you see your role as educator and advocator in the support of people to self-manage their disease and/or disability?

**Recommended reading**


**References**


Chapter 1  Chronic illness and disability: an overview


Parker, S., Fuller, J., 2016. Are nurses well placed as care coordinators in primary care and what is needed to develop their role: a rapid review? Health and Social Care in the Community 24 (2), 113–122.


