

Nursing Adults with Long Term Conditions

4E

Edited by
Jane Nicol
Lorna Hollowood





Learning Matters
A Sage Publishing Company
1 Oliver's Yard
55 City Road
London EC1Y 1SP

Sage Publications Inc.
2455 Teller Road
Thousand Oaks, California 91320

Sage Publications India Pvt Ltd
B 1/I 1 Mohan Cooperative Industrial Area
Mathura Road
New Delhi 110 044

Sage Publications Asia-Pacific Pte Ltd
3 Church Street
#10-04 Samsung Hub
Singapore 049483

Editor: Martha Cunneen
Development editor: Richenda Milton-Daws
Senior project editor: Chris Marke
Project management: Westchester Publishing
Services UK
Marketing manager: Ruslana Khatagova
Cover design: Sheila Tong
Typeset by: C&M Digitals (P) Ltd, Chennai, India
Printed in the UK

Editorial Arrangement © Jane Nicol and Lorna
Hollowood 2024

Chapter 1 © Jane Nicol, Lorna Hollowood and Jackie
Bentley, 2024; Chapter 2 © Jane Nicol and David
Tyrrell, 2024; Chapter 3 © Lorna Hollowood and Sally
Carvallo, 2024; Chapter 4 © Jane Nicol and Teresa
Shaw, 2024; Chapter 5 © Lorna Hollowood and Karen
Day, 2024; Chapter 6 © Lorna Hollowood and Alison
Gayton, 2024; Chapter 7 © Jane Nicol and Louise
Carter, 2024.

Apart from any fair dealing for the purposes of
research or private study, or criticism or review, as
permitted under the Copyright, Designs and Patents
Act, 1988, this publication may be reproduced, stored
or transmitted in any form, or by any means, only with
the prior permission in writing of the publishers, or in
the case of reprographic reproduction, in accordance
with the terms of licences issued by the Copyright
Licensing Agency. Enquiries concerning reproduction
outside those terms should be sent to the publishers.

Library of Congress Control Number: 2023944520

British Library Cataloguing in Publication Data

A catalogue record for this book is available from the
British Library

ISBN: 978-1-5297-5478-0
ISBN: 978-1-5297-5477-3 (pbk)

At Sage we take sustainability seriously. Most of our products are printed in the UK using responsibly sourced papers and boards. When we print overseas we ensure sustainable papers are used as measured by the Paper Chain Project grading system. We undertake an annual audit to monitor our sustainability.

Contents

<i>About the editors and contributors</i>	vi
<i>Acknowledgements</i>	viii
Introduction	1
1 Long term conditions across the lifespan <i>Jane Nicol, Lorna Hollowood and Jackie Bentley</i>	5
2 The nurse–patient relationship in long term conditions <i>Jane Nicol and David Tyrrell</i>	29
3 Health promotion in long term conditions <i>Lorna Hollowood and Sally Carvalho</i>	52
4 Self-management in long term conditions <i>Jane Nicol and Teresa Shaw</i>	72
5 Quality of life and symptom management in long term conditions <i>Lorna Hollowood and Karen Day</i>	94
6 Managing complex care in long term conditions <i>Lorna Hollowood and Alison Gayton</i>	117
7 Palliative care in long term conditions <i>Jane Nicol and Louise Carter</i>	137
<i>Glossary</i>	162
<i>References</i>	164
<i>Index</i>	181

About the editors and contributors

Jane Nicol is Head of Education and Learning at St Richards Hospice and a Registered General Nurse. During her career she has worked across a range of clinical settings in both primary and secondary care, enabling her to develop a broad knowledge and skill base. She previously taught pre-registration nursing students at the University of Worcester and University of Birmingham. Jane's specialist areas of teaching are the care and management of people living with long term conditions and palliative and end-of-life care.

Lorna Hollowood is a Registered Adult Nurse and Senior Lecturer in the School of Nursing and Midwifery at the University of Worcester. Lorna has a clinical background in District Nursing and palliative care. She teaches on a variety of modules with a focus on public health, health inequalities and long term conditions and contributes to palliative and end-of-life care teaching across the programme. She maintains her clinical activity through assessing and supporting the care home sector in the provision of end-of-life care and is conducting research as part of her PhD, exploring the experiences of the Windrush Generation in UK care homes.

Contributors

Jackie Bentley is a Registered Adult and Children's Nurse and is an experienced Senior Lecturer at the University of Worcester and teaches across a range of modules.

Louise Carter is a Registered Adult Nurse and a Senior Lecturer at the University of Worcester. Louise teaches in year one of the BSc Nursing course, and has an interest in palliative and end-of-life care.

Sally Carvalho is a Registered Adult Nurse and Senior Lecturer at the University of Worcester; she has worked across a range of clinical areas including Accident and Emergency and Major Trauma. She is a previously published author on legal, ethical and professional issues and leadership.

Karen Day is a Registered Adult Nurse and a Lecturer at the University of Birmingham. She has worked in a range of clinical settings with a focus on medicine.

Alison Gayton is a Registered Mental Health Nurse, and a Lecturer at the University of Birmingham, and has worked across a variety of hospital and community settings. Alison teaches across the BNurs Adult, Child and Mental Health programmes and has a specialist interest in older adult mental health care.

Teresa Shaw is a Registered Adult Nurse and is a Senior Lecturer at the University of Worcester. Teresa teaches across year one of the BSc Nursing course and aims to deliver a shared learning experience for learners.

David Tyrrell is a Registered Adult Nurse and a Lecturer at the University of Worcester. David has worked in both clinical practice and clinical research.

Chapter 2

The nurse–patient relationship in long term conditions

Jane Nicol and David Tyrrell

NMC Future Nurse: Standards of Proficiency for Registered Nurses

This chapter will address the following standards:

Platform 2: Promoting health and preventing ill health

At the point of registration, the registered nurse will be able to:

- 2.9 use appropriate communication skills and strength-based approaches to support and enable people to make informed choices about their care to manage health challenges in order to have satisfying and fulfilling lives within the limitations caused by reduced capability, ill health and disability

Platform 4: Providing and evaluating care

At the point of registration, the registered nurse will be able to:

- 4.3 demonstrate the knowledge, communication and relationship management skills required to provide people, families and carers with accurate information that meets their needs before, during and after a range of interventions

NMC Annexe A

Communication and relationship management skills

- 2 Evidence-based, best practice approaches to communication for supporting people of all ages, their families and carers in preventing ill health and managing their care
- 2.1 share information and check understanding about the causes, implications and treatment of a range of common health conditions including: anxiety, depression, memory loss, diabetes, dementia, respiratory disease, cardiac disease, neurological disease, cancer, skin problems, immune deficiencies, psychosis, stroke and arthritis
- 2.2 use clear language and appropriate written materials, making reasonable adjustments where appropriate, in order to optimise people's understanding of what caused their health condition and the implications of their care and treatment

Chapter aims

After reading this chapter, you will be able to:

- identify and describe the components of the nurse–patient relationship;
- explain the importance of engaging in a nurse–patient relationship with people living with LTCs and, if required, their carer and family;
- understand the role that emotional intelligence (EI) and resilience have in the care and management of those living with LTCs;
- recognise the importance of ensuring person-focused communication in the care and management of those living with LTCs.

Introduction

Cure sometimes: treat often: comfort always.

(Hippocrates 460–370 BC)

I will remember that there is art to medicine as well as science, and that warmth, sympathy, and understanding may outweigh the surgeon’s knife or the chemist’s drug.

(Hippocratic oath – modern version)

Engaging in, developing and maintaining caring and compassionate nurse–patient relationships is at the heart of effective nursing care. Doing this allows you to provide person-centred, individualised nursing care. The Nursing and Midwifery Council (NMC) places nurse–patient relationships and communication at the heart of nursing practice, and this is reflected in The Code (2018) and the NMC standards of proficiency (2018).

Those living with one or more LTC can be in contact with healthcare professionals often and over long periods of time. This may involve regular reviews with their practice nurse or receiving treatment as an inpatient due to an exacerbation of their condition. At all stages of a person’s journey, a key element is your ability to provide holistic person-centred care, promoting **concordance** with treatment and management plans, developing **autonomy** and helping people to live satisfying and fulfilling lives within any limitations caused by their LTCs. The development and maintenance of a person-centred relationship is central to this, and may involve not only forming a relationship with the individual, but also their family and carers. For those living with LTCs, and those caring for them, it may not be the ‘what’ of the treatment (such as intravenous antibiotics for an infection) the person remembers but ‘how’ treatment was delivered. For example, were they listened to, was the treatment explained to them, was a friendly face there, did they feel understood? To support you in your delivery of ‘meaningful’ care to those living with LTCs, this chapter will assist you in your development of the knowledge and skills required to successfully establish an

effective nurse–patient relationship with those requiring your care. It also encourages you to look at the three-way relationship between yourself as the nurse, the patient and their carers/significant others. Emotional intelligence is covered, along with some useful communication strategies.

Case study: Bill

Bill and his wife were struggling to manage his long-term conditions (angina and COPD); through working with Bill’s community matron they have become more actively involved in the management of Bill’s cardiac and lung problems. Both Bill and his wife have regained their confidence and are now able to live more independently. Bill told his story to Patient Voices, a programme founded to support the telling of individuals’ stories of health and social care. Figure 2.1 is a word cloud of Bill’s story, allowing you to see the words that appeared most frequently.

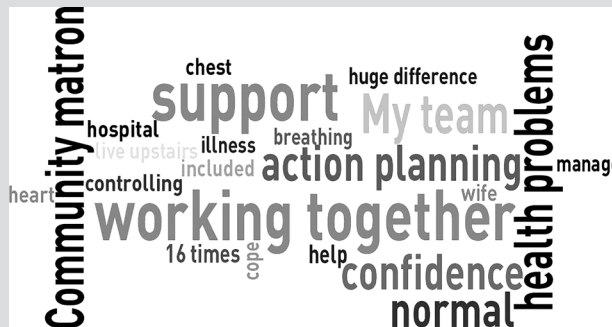


Figure 2.1 Bill’s word cloud

Source: Patient Voices website, reproduced with permission

To listen to Bill’s story, follow the link: www.patientvoices.org.uk/flv/0029pv384.htm

An effective nurse–patient relationship enables us to *work together* as a *team* with individuals and their carers. This will improve confidence in the ability to manage the condition. To support this, care, compassion and communication should be central to everything you do.

Communication strategies in LTCs

To practise effectively, you must communicate clearly (The Code 2018). In your role as a nurse caring for people living with LTCs, you may be involved in their care at different stages in their journey. This may involve helping them to understand their diagnosis, providing them with information during an exacerbation of their condition or caring for them during the end stages of their illness. The questions asked by individuals and the nature of the information given at different stages of a person’s journey change. This

section focuses on specific aspects of communication relating to caring for people living with LTCs. There are many other books available covering more general communication skills and knowledge – for example *Communication and Interpersonal Skills in Nursing* (Grant and Goodman, 2019). When caring for people with LTCs, it is important to recognise what some of the challenges to communication may be (see the box below).

Challenges to communication

Some of those living with LTCs, along with those caring for them, may encounter challenges to communication that impact on their ability to effectively articulate thoughts and feelings. These challenges include sensory impairment, neurological and neurodiverse conditions and understanding of language. As a result, forming an effective therapeutic relationship can be difficult.

Sensory impairment is a reduction in the perception of our environment, including sound and vision. Neurological disorders, such as Parkinson’s disease or cerebrovascular accident, may impede the ability to use verbal and non-verbal communication. People with neurodiverse conditions, such as autism, may experience disorganised thoughts and communicate in particularly challenging ways. Language difficulties may occur when English is not the person’s or carer’s first language. There are some simple strategies to improve communication in these situations.

We can ensure that hearing aids have batteries and glasses are clean. People can access support and equipment through either Action on Hearing Loss or the Royal National Institute of Blind People (RNIB). When English is not the first language, accessing an interpreter service rather than using a family member to interpret is preferable, especially where sensitive information may be discussed. Using other means of communication such as picture cards may offer a quick and simple method to get a point across. The National Autistic Society provides educational material on how to support people who are neurodiverse. It is important to provide information that is clear, to make it available in advance, and allow time for it to be processed (National Autistic Society, accessed online 2023). While these points relate specifically to autism, they are also good practice for communication in general.

As nurses, we sometimes create barriers to communication ourselves: in challenging situations, we may choose to ‘close the patient down’, enabling us to retain some sense of control. Changing the topic or engaging in small talk diverts what could be a difficult conversation on to more familiar, easy ground. But this approach deprives the person of the opportunity to discuss their concerns. Being aware of these barriers, utilising the nurse–patient relationship and developing your emotional intelligence will help to enhance your communication skills.

Due to the ongoing nature of their condition and the focus on promoting self-management, it is important that people living with LTCs are enabled to take an active part in discussions about their treatment and management. To facilitate this, you can encourage them to use the steps outlined below in the acronym PART – for example, before they attend a consultation with a member of their health and/or social care team.

Prepare – identify your main concerns, prioritise them and write them down before the consultation. Try to be open in sharing thoughts and feelings, be prepared to concisely describe your main concern and why this is a concern and bring a list of any medication.

Ask – ask questions about your condition, treatments, plan of care and any follow-up; ensure you get answers you understand.

Repeat – repeat key points in the consultation, to verify your understanding and ensure that the consultation has been understood; this also allows the professional to check your understanding.

Take action – make sure that you understand what is going to happen next, ask for instructions to be written down. If the advice given is not going to be easy to follow, then let the professional know why to see if an alternative can be given.

Case study: Peter

Peter was diagnosed with Alzheimer’s disease about 12 months ago. His main symptoms are difficulty in finding the right words and struggling with remembering directions and the sequencing of events. He has been started on Donepezil (Aricept) and has noticed some improvement in his symptoms, though he is very frustrated and has expressed a wish for ‘assisted suicide’. He is due to attend an outpatient appointment next week. He wants to manage this on his own, but his wife Sarah is keen to go with him.

Activity 2.1 Communication

Read through the case study above. How could you use the acronym PART to support Peter to attend his consultation independently?

A brief outline answer is given at the end of the chapter.

As you can see from Activity 2.1, it is important to listen to the person to understand their perspective and their needs: in understanding their perspective, you will be able to deliver person-centred care. However, in Peter’s case it can be challenging for Sarah to allow Peter to attend his appointment on his own. Supporting Sarah to accept this and providing ways in which Peter can share what has been said with her will demonstrate your ability to develop therapeutic relationships with both of them. Actively listening to the individual is a key aspect of this.

Your listening skills can be improved by paying attention to verbal and non-verbal communication, by asking open-ended questions that encourage the person to give details and prompt you to follow them up. Use paraphrasing by reflecting a summary of what

was said back to the person. Paraphrasing allows you to verify the accuracy of your understanding and demonstrates that you have been listening. Listen first and advise second: if an individual comes to you with a problem, you may be tempted to provide a solution; however, allowing the person to talk may allow them to find their own solution. This committed approach to listening enables you to focus on the person and their needs, demonstrating your commitment to them.

What if your patient or their carer refuses to engage?

Individuals living with serious long term illness are often difficult to engage in ongoing treatment (Dixon et al, 2016). This is true for both mental and physical conditions. Bombard et al (2018) found that some patients felt their involvement was ‘tokenistic’, especially after requests were denied or decisions taken without them. Poor engagement may lead to worse outcomes, relapses and hospitalisations (Dixon et al, 2016). The benefits of engagement are obvious and include increased self-esteem and feeling empowered and independent (Bombard et al, 2018).

Dixon et al (2016) identify factors affecting engagement. They include: a feeling of working together and trust, how care is accessed, and circumstances (for example homelessness). They suggest that in order to increase the likelihood of successful engagement with treatment, the practitioner should consider:

- Autonomy, respect and empowerment
- Technology e.g. apps
- Peer support networks
- Respecting cultural differences

Engagement with treatment is not guaranteed but with careful consideration in your care planning, you can provide an environment that encourages treatment concordance for the benefit of all concerned.

Care and compassion

Care and compassion should be central to the nurse’s role. However, there have been times when this has not been the case. Infamous occurrences where care has been lacking include Mid Staff NHS Trust, Whorlton Hall and the Edenfield Centre. Indeed, the findings of the public enquiry into the events at Mid Staffordshire NHS Trust (2013) between 2005 and 2008 still inform healthcare delivery today. Publications have focused on evidencing the impact of strategies, such as the reports ‘Compassion in Practice’ (2012) and ‘Compassion in Practice: Evidencing the impact’ (2016), and

the article by O’Driscoll (2018) ‘Compassion in Practice: Evaluating the awareness, involvement, and perceived impact’, all of which were borne out of the events at Mid Staffordshire. Initial findings from the 2016 enquiry indicated that the majority of staff across mental health (51.2 per cent), primary care (63.5 per cent) and acute care (59.3 per cent) were aware of the Compassion in Practice strategy and the role of the 6Cs. Based on their 2018 study, O’Driscoll et al. report that, whereas awareness and involvement in compassionate practice was high among senior staff, there was less awareness among more junior staff. The study concluded that ‘*compassion for patients is only sustainable where there is compassion for staff and many participants felt that they were not being treated with compassion*’ (O’Driscoll et al., 2018, p. e1097).

In addition, the use of temporary staff and 12-hour shift patterns can contribute to the ‘pressures’ felt by front-line staff. A study carried out by Ball et al. (2015) concluded that 12-hour shifts have some negative effect on either the quality of care delivered or the health of staff, with fatigue-related outcomes evident. These findings continue to be supported, with a discussion paper by Dall’Ora et al. (2022) finding there is evidence pointing to reduced quality of patient care and an unplanned effect on staff wellbeing. While long shift patterns may contribute to the flexible delivery of services, and offer flexibility to staff, further research into offering mixed shift patterns needs to be undertaken. To address these issues, organisations should have strong leadership and governance that values the contributions that staff make, and the role of regulatory bodies should be more robust.

The Code (2018) requires Nurses and Nurse Associates to ‘treat people with kindness, respect and compassion’. People living with LTCs should be equal partners in their care, confident to say when care is not right. Staff should be engaged with the people they are caring for, putting them first and having the courage to speak up on behalf of patients. However, it is recognised that this will not be easy; compassionate care takes time and in a climate of pressures on the health system, ‘time’ is a precious commodity.

Compassion, a core value at the centre of healthcare practice (The NHS Constitution for England, updated 1 January 2021) is described as how, through the formation of a therapeutic relationship, care is delivered. This relationship is based on empathy, respect and dignity, and is central to how people perceive the care you provide.

Research summary: Compassion

Through analysis of interviews with nurses and hospital patients, Durkin et al. (2021) found touch was important in expressing and receiving compassion for nurses and patients. For patients, the nurse’s touch conveyed ‘comfort and safety’ establishing a connection between them. Nurses use this to express compassion and offer comfort. They

(Continued)

(Continued)

were respectful of the meanings of touch, and understood its use. Touch was considered an essential part of compassionate practice, expressing safety, authenticity and connection. Avoiding or being wary of touch can impact patient care. Durkin et al. (2022) felt that compassion is made up of three themes:

- Amalgamation of various items of knowledge and skills;
- Delivery of meaningful actions which alleviate suffering;
- Meeting individual needs and prevention of further preventable suffering.

A study by Donner et al. (2020) revealed that nurses' understanding of the patient's unspoken needs relies on compassion, a willingness to engage and being prepared to remain uncertain. Balancing the nurses' good intentions and fear of their own limitations requires reflection on actions during encounters with the patient.

Compassion as an empathic gift and nurses who are constantly exposed to patients' suffering can lead to compassion fatigue (Gustafsson et al., 2022). Analysing interviews, Gustafsson et al. (2022) explored compassion fatigue and how it affected nurses. Five themes emerged:

- compassion overload
- exhausting the nurse as a professional and private person
- a crisis with potentially valuable insights
- can be handled by self-care and focus on self
- affected by life itself and multifaceted factors.

Baguley et al. (2022) considered what constituted compassionate care from a patient perspective. They analysed text data looking for word clusters to identify commonalities in the text responses of 767 patients. The patients were considering how they felt compassionately treated by physicians in New Zealand, but the conclusions apply across healthcare disciplines. Seven topics were identified:

- listening and paying attention to the patient;
- deliverables (following up and running tests);
- continuity and holistic care;
- respecting preferences;
- genuine understanding;
- body language and empathy;
- counselling and advocacy.

As these studies demonstrate, the expression of compassion is important and complex. Its delivery involves blending skills and knowledge with meaningful action and the alleviation of suffering to ensure that the care received by the patient is compassionate (Durkin et al., 2022). Overload can lead to compassion fatigue, which can affect the nurse's ability to care (Gustafsson et al., 2022). While these studies explore compassion from different perspectives, the findings can be used to inform your practice.

Activity 2.2 Reflection

Having read the research summary above, consider how you can incorporate compassion into your day-to-day clinical practice. Write down your thoughts so that you can return to them when you have finished working through this chapter and see if you wish to change anything.

As this activity is based on your own observations, there is no outline answer at the end of the chapter.

Activity 2.2 may have highlighted the role that compassion has in your communication and the development of the positive relationships you make with those in your care. This type of nurse–patient relationship differs from ‘social’ relationships.

The nurse–patient relationship

The nurse–patient relationship is a professional, purposeful relationship, the aim of which is to meet the needs of the patient. Through development and maintenance of this relationship, a therapeutic focus is maintained that fosters autonomy and promotes patients’ health and wellbeing. So why is the nurse–patient relationship so important to nursing? The Royal College of Nursing (RCN) defines nursing as:

The use of clinical judgement in the provision of care to enable people to improve, maintain or recover health, to cope with health problems, and to achieve the best possible quality of life, whatever their disease or disability, until death.

(RCN, 2014, p3)

Inherent within this definition is the notion of **enabling**. While the above quote emphasises clinical judgement, if you are to truly enable those in your care and provide person-centred care that meets and addresses their needs, then the development and maintenance of an effective nurse–patient relationship is essential. This relationship is dynamic, displaying positive characteristics of open communication, a feeling of connection and empowerment; negative characteristics include a disconnect between the nurse and the patient which result in disempowerment and vulnerability (Halldorsdottir, 2008). Developing the positive characteristics of this relationship will allow you to ensure that the focus of your nursing interventions is on the whole person and their response to the situation (RCN, 2014). Engaging in, through listening and questioning, and developing, through supporting, a positive nurse–patient relationship allows you to recognise the uniqueness of the person (Grant and Goodman, 2019). Its success depends on your ability to make and maintain a professional relationship with those in your care. The characteristics that define a successful nurse–patient relationship (Chilton et al., 2004) include:

- maintaining appropriate boundaries;
- meeting the needs of the person;
- promoting the autonomy of the person;
- ensuring a positive experience for the person.

We will now look in more detail at each of these.

Maintaining appropriate boundaries

The maintenance of boundaries is crucial: boundaries define and manage expectation, and they ensure all parties are clear about what can reasonably be expected from each other. The Nursing and Midwifery Council (NMC, 2018) states that you will respect professional boundaries at all times; therefore, it is your responsibility to ensure that appropriate professional boundaries are maintained. For nurses involved in the care and management of those with LTCs, the nature of their relationship may vary: specialist nurses may be involved in delivering short-term interventions, while case managers may be involved in longer term care and care planning. These types of interactions will involve different levels of relationship building. Those involved in shorter interventions may focus on the intervention and its success, while those involved in longer term care may be more likely to emphasise the development of a connected relationship, where you view the individual as a person first and foremost (Hallsdordottir, 2008).

The development of a nurse–patient relationship is not without its challenges, and for the majority of nurses boundaries are maintained, allowing for the delivery of more person-focused and person-led care. However, given the ongoing nature of the nurse–patient relationship in the management of LTCs, there may be the potential for boundaries to ‘blur’. The role that social media has in how we communicate with each other has the potential to ‘blur’ these boundaries further. It is important that you, as nurses, do not put yourself in a position where this could happen.

Social networking is a part of our lives and that of our patients. We should consider our activities on these platforms and ensure that we do not overstep the boundaries (Valente, 2017); for example, accepting a request to join a patient or a family member on a social media platform. Teaching learners the concept of professional values can be challenging. Thompson et al. (2023) suggest using reflection and simulation to explore the concept. They also point out that teaching tools must be updated to reflect the ways that culture and social media affect professional boundaries.

Whether in person or on social media, setting professional boundaries is about being personable rather than personal, possessing and using effective communication and interpersonal skills. Table 2.1 outlines some useful questions (Chilton et al., 2004) to ask yourself to promote appropriate boundaries.

Question	Response
Is the focus of this relationship on the person and their needs?	<p>If the answer is no, use the questions below to ensure that the focus remains on the person and their needs.</p> <ul style="list-style-type: none"> • Have you undertaken a person-focused assessment? • Were you listening to the person and using this information to plan their care? • Have you let what you believe is right for the person influence their plan of care?
Is this person beginning to rely on me too much?	<p>If the answer is yes, then it may be helpful to consider the following: ask the individual why they are relying on you, discuss this with them and let them know you may not always be available. Relying on one person can promote overdependence, a potential negative where a large focus of care and management in LTCs relates to self-management.</p>
Am I becoming too emotionally involved in this person’s care?	<p>If the answer is yes, then you need to ask yourself if this is affecting the care you are delivering. (As part of forming nurse–patient relationships you invest part of your ‘self’ in that relationship. Discussing aspects of your personal life may be appropriate if they are used to either help build a relationship or to demonstrate to a person how a situation was managed. However, the focus of that discussion should be the individual and their needs, and not be used as an opportunity for you to discuss your needs.)</p>
Is the person and/or their carer/family viewing me as a member of their family?	<p>If the answer is yes, is this appropriate? (Individuals and/or carers may promote a friendship with you as this ‘normalises’ the relationship and allows them to forget the true nature of their relationship with you. This may be part of their coping mechanism and it may be appropriate for you to discuss this with them in order to find other ways in which they can be supported or accept their current situation. This may be especially true for those who are receiving ongoing care in their own homes.)</p>

Table 2.1 Questions to ask yourself to ensure that appropriate boundaries are maintained

Meeting the needs of the person

In a nurse–patient relationship, the needs of the person are assessed at the outset to identify mutually acceptable goals and who is responsible in the achievement of those goals. The needs of the person are paramount and should be the focus of the relationship. Actively listening to the person, to find out their concerns, worries, etc. reminds us that the nurse–patient relationship is there to benefit the person, not the nurse. Asking a simple question such as ‘What is the most important thing I can do for you today?’ or ‘Can you tell me why I have been asked to come to see you today?’ demonstrates to the person that your focus is on them and their needs, rather than your interpretation of what their needs might be. This is especially true when caring for those living with LTCs, where one of the main cornerstones of management is self-care: in order to promote self-care and management, you must work with them to devise a plan of care clearly reflecting their needs, as this will increase feelings of empowerment and autonomy.

Promoting the autonomy of the person

Autonomy is the freedom to determine one’s own actions and behaviours. A relationship where you encourage active involvement of the individual promotes their autonomy and ensures that they are better able to understand their own situation and take active steps to participate in their care. For those living with LTCs, finding out their level of knowledge and understanding about their condition, and how much they want to be involved in managing their own care, will allow the level of personal autonomy that reflects their wishes. Many people living with LTCs are experts in their care and will possess a great deal of knowledge regarding their care and management. Indeed, it may be you that is asking the person questions about their care and management, rather than them asking you.

It must be recognised, though, that not all individuals will want to be actively involved in their care to the same degree. Some people may take the attitude that managing their condition is the responsibility of the healthcare team: ‘That’s what they get paid for’, whereas others may actively seek to be more involved in their care: ‘I would like to have access to a nebuliser at home and have a clear protocol written that enables me to manage my condition myself should I have an acute asthma attack’. Neither of these approaches is wrong or right, they are just different. By developing a nurse–patient relationship, you will begin to know what is right for that person and how to ensure a positive experience for that individual.

Ensuring a positive experience for the person

Meeting the needs of those living with LTCs in a caring and sensitive manner will promote a positive experience for the person. This person-centred approach will not only increase their ability to participate in self-care and management, it will also assist them in maintaining a more positive outlook in relation to their condition and future.

To promote effective nurse–patient relationships with individuals living with LTCs, it is important to understand the concept of emotional intelligence. Put simply, emotional intelligence is about understanding your own emotions and those of others around you. Recognising and developing your own emotional intelligence will impact on the way you deliver care; recognising and developing the emotional intelligence of those living with an LTC has the potential to influence how they live with their condition.

The nurse–patient relationship and emotional intelligence

Case study: Linda

Linda is 78 years old and has been living with chronic heart failure since the age of 73. Linda started smoking at the age of 19 and has not managed to give up – she smokes ten cigarettes

a day. Since her diagnosis she has made some positive changes in her diet, though she realises that she could do more to help improve her health – for example, take some exercise.

To ensure that Linda’s care is delivered in a non-judgemental manner, you need to have an understanding about how your emotions might impact on the care delivered:

- you may feel that Linda is to blame for her current health issues due to her smoking and lack of exercise;
- you may feel that Linda is being selfish and lazy, and that she should stop smoking and take some exercise to prevent her condition deteriorating further.

Linda’s own emotions may also be impacting on her attitude to her health:

- she may feel that as her health is already damaged, there is no point in stopping smoking;
- she may feel embarrassed and reluctant to ask for help in making a change in her lifestyle.

This scenario shows how easy it can be for our emotions and feelings to impact negatively on our interactions with those in our care. There is also the potential for a person’s emotions to have a negative impact on their condition and the way they manage it.

To understand emotional intelligence as a concept, we need to go back to Howard Gardner’s ‘multiple intelligence’ theory (Gardner, 1983) to see the first recognition of emotional intelligence, described by Gardner as ‘intrapersonal intelligence’. Intrapersonal intelligence is concerned with your capacity to understand yourself, to recognise and appreciate your emotions and to use this information to regulate your life (Gardner, 1999). Acknowledging Gardner’s work, Salovey and Mayer (1990) developed emotional intelligence as a concept. In their theory, intrapersonal intelligence is seen as being part of emotional intelligence. Salovey and Mayer define emotional intelligence as being:

*the ability to monitor one’s own and **others**’ feelings and emotions, to discriminate among them and to use this information to guide one’s thinking and actions.*

(Salovey and Mayer, 1990, p189; emphasis added)

Emotional intelligence abilities	Application to practice
Self-awareness	<p>Being aware of your strengths and weaknesses and looking to manage these.</p> <p>You may feel uncomfortable when being asked about a person’s prognosis, recognising that you do not know what to say. The important thing is to act on this and to put strategies in place to address this; one might be to discuss this with a colleague and ask them how they respond.</p>

(Continued)

Table 2.2 (Continued)

Emotional intelligence abilities	Application to practice
Self-regulation	Being aware of your ‘self’ and your emotions, and being able to regulate these and not become overwhelmed by them.
Motivation	<p>When faced with a person asking about their prognosis, your first response might be to change the subject; recognising this and refocusing on the question the person has asked will increase your confidence in these situations. Working on your communication skills, such as asking reflective questions, will help you manage this.</p> <p>Your ability to use self-awareness and self-regulation of your emotions to inspire yourself and others.</p> <p>Recognising that you find discussing a person’s prognosis with them difficult and having a desire to improve your practice will motivate you to undertake activities that will increase your skills in this area.</p>
Empathy	<p>Your capacity to understand another’s situation, to identify with their emotions and to use this to respond in an appropriate manner.</p> <p>By developing your communication skills and confidence, you will increase your ability to respond appropriately, support people, develop a positive nurse–patient relationship and respond appropriately to individuals/relatives/carers who may be angry.</p>
Social skills	<p>Your capability to influence, maintain and improve interpersonal relationships through the use of effective and supportive communication skills.</p> <p>Through reflecting on your experience of talking to a person about their prognosis and through the development of your communication skills, you have increased your ability to respond positively in these situations.</p>

Table 2.2 Emotional intelligence abilities and their relation to nursing practice

The difference between intrapersonal intelligence and emotional intelligence is the ability to recognise and respond to *others’* emotions. In 1998, the Consortium for Research on Emotional Intelligence in Organisations (Cherniss, 1998) listed the abilities required for emotional intelligence as: self-awareness, self-regulation, motivation, empathy and social skills (see Table 2.2).

As you can see from Table 2.2, emotional intelligence influences many aspects of nursing care. The utilisation and development of emotional intelligence in relation to you and those in your care will have a positive impact on the nurse–patient relationship. In addition, reflecting on your practice using the emotional intelligence abilities will encourage problem solving and will develop your resilience. Resilience is the ability to persist, regroup and grow in a positive way, despite stressful experiences, which is an important factor when working with people who have complex needs. Developing resilience can help protect you against fatigue and burnout, and promote overall personal wellbeing, improve your work relationships and job satisfaction (Delgado et al., 2017).

Resilience and long term conditions

Following the peak of the Covid-19 pandemic, 92 per cent of Trusts felt they were ‘concerned about staff wellbeing, stress and burnout’ (NHS Providers, 2020). Developing resilience is important for nurses because it ensures their wellbeing, the sustainability of the workforce and the quality of care they offer (Barratt, 2018). Not only is it important, both personally and professionally, for you to develop your resilience, it is important that people living with LTCs are supported to develop their own resilience. The role that resilience has in supporting those living with LTCs to adapt positively to their situation has been explored both in relation to specific LTCs, such as Parkinson’s disease (Shamaskin-Garroway et al., 2016), and across a range of LTCs (Robinson et al., 2017). However, as Barratt (2018) notes, it is important that in striving for resilience, it does not become another source of perceived failure. The study by Shamaskin-Garroway et al. (2016) concluded those reporting high levels of resilience demonstrated greater quality of life and better adjustment to their diagnosis. They also found evidence to demonstrate that the degree of non-motor symptoms a person experienced contributed to their ability to adjust to their diagnosis.

Improving resilience can enhance the wellbeing of individuals and may also contribute to a supportive caring culture (Barratt, 2018). Focusing on a specific strategy to increase resilience, Robinson et al. (2017) reported on the impact of a six-week mental health resilience course. The course taught mindfulness techniques and cognitive behavioural therapy to older people living with a range of LTCs. Their findings demonstrated that at the end of the course and three months later participants reported significant improvement in their perceived resilience, evidenced by improved wellbeing, self-management and social interaction. However, it was recognised that due to the short nature of the course, maintaining this over a longer period of time might be

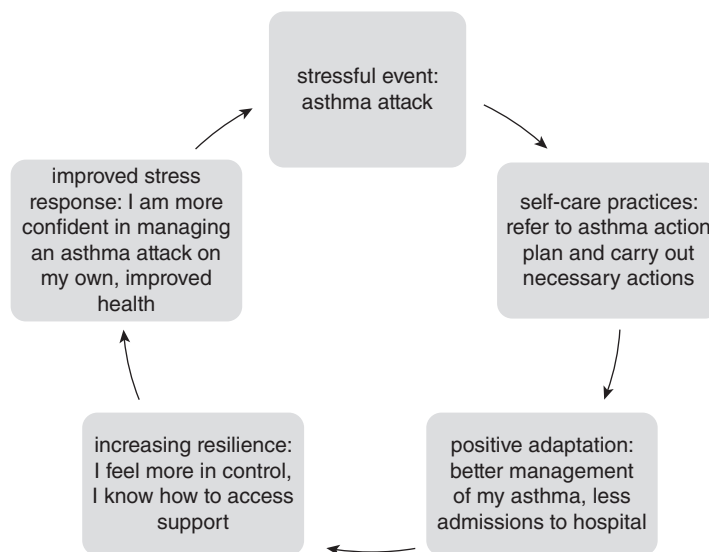


Figure 2.2 An approach to develop resilience based on work by Tebes et al. (2004)

challenging for participants. It is vital to recognise nurses and patients cannot be resilient independently of each other. Finding approaches that can be used on a day-to-day basis is important. Figure 2.2 outlines one such approach and has been applied to a situation which someone living with LTCs may encounter.

Activity 2.3 Critical thinking/reflection

Using the approach to develop resilience outlined in Figure 2.2, reflect on a situation from practice that you found stressful. Use the steps of the approach to structure your reflection and consider what strategies you could have used to improve how you responded in this situation.

As this activity is based on your own observations, there is no outline answer at the end of the chapter.

Completing Activity 2.2 will have provided you with the opportunity to develop your resilience when faced with a challenging situation. This is also important for people living with LTCs, where maintaining a positive attitude and displaying emotional responses can influence how effectively people engage in health-promotion activities and how well they cope with difficult situations – for example, a deterioration in their condition and how they manage the resulting stress (Telford et al., 2006).

The nurse–carer relationship

Census 21 asked if respondents ‘look after, or give any help or support to, anyone because they have long-term physical or mental health conditions or illnesses, or problems related to old age?’ Around 5 million people answered ‘Yes’ to this question (ONS 2021). Carers UK estimates that by 2037, this could be as high as 9 million (Carers UK, 2015). One of the main aims in the care and management of LTCs is to promote self-management and to maintain people in their own homes for as long as possible, with support. This increased emphasis on care in primary care and changes in service provision at local government level has resulted in many aspects of care now being delivered by informal carers. So carers now play a pivotal role in the care and management of those living with LTCs.

This level of care has an impact on many aspects of the carer’s life – financially, socially and health-wise. All carers in the UK have the right to an individual assessment of their needs; this assessment must ensure that their work, lifelong learning and leisure activities are considered. Carer assessments are arranged through the local council, which should explain who will carry out the assessment; this may be done face-to-face, over the phone or via a self-assessment questionnaire. The assessment provides a baseline assessment of how the carer is coping and what they perceive their needs to be in relation to:

1. Aspects and tasks involved in caring, their relationship with the person they are caring for and what practical help they might need.
2. The health and wellbeing of the carer, their free time and any other pressures, such as young children.

This assessment needs to be handled sensitively, with the carer being aware that the information supplied will be used to provide support for them and ultimately the person they are caring for. Therefore, it may be necessary for information to be shared with other members of the health and social care team. For example, if the carer is requesting specific support regarding a nursing intervention, then you, along with a community nurse, may provide the relevant support. Other practical support offered may be advising about benefits that may be available, providing information about local support groups and having access to **respite care** services.

Children who are carers also have the right to an assessment that will focus on the amount and level of care being delivered by the child, and the impact this has on their leisure and school life. It should be recognised that caring as a child can have a significant impact on both the physical and mental health of the child, and can impact on their choices and future life achievements. As part of the child assessment, it may also be relevant to find out from the parent they are caring for the impact their condition is having – e.g. how does your condition affect your children and how can we support you in your role as a parent?

Despite the fact that this has been the case since the early part of the twenty-first century, evidence shows there is still a lack of available support and information, with one in five carers saying they receive no practical support (Carers UK, 2014b). Working carers and non-working carers often have concerns about financial security, which can be due to many factors. The extra cost of heating, transport, hospital parking charges and care services can mean that carers and their families cut back on essentials (Carers UK, 2014a). In a survey of 2,000 carers, only 12 per cent felt that they received enough support from the social care system (Carers Trust, 2020). Financial support is available in the form of the Carer's Allowance and additional benefits; however, this is often a complex area to negotiate. Further research by Carers UK (2022) stated 35 per cent of carers receiving a Carer's Allowance cut back on food and heating, with 8 per cent using food banks (Carers UK, 2022). Research by Carmichael and Hulme in 2008 identified the complexities of financial support for carers, especially in relation to the working/benefits paradox, where carers either felt they had to work as benefits were insufficient, or they did not work, as this would affect the benefits received. This is as relevant now as it was when the research was first published.

A report published in 2017 by COFACE – Families Europe explored the challenges and needs of family caregivers in Europe. This report concluded carers still receive insufficient information to support them in their caring role, specifically in relation to:

- information on rights and available services, e.g. carer assessment, financial support;
- training to improve skills and knowledge as a family carer, e.g. administration of medication, how to notice changes in the person’s physical condition;
- psychological support, or counselling;
- respite care;
- reintegration to work following an extended period of caring.

The timing of providing information is important, and is a continual process, with information needs changing as the person’s LTCs progress. For example, the information required at the time of a diagnosis may focus on prognosis and treatment; as the impact of the LTCs increases this may focus on social support, counselling or respite. To ensure clear communication it is important information is presented clearly, avoiding technical language, and that any information provided should be discussed with the carer to ensure understanding. To be able to provide information to carers that reflects the person’s individual situation, developing a positive relationship with the carer is key.

Coping and support

As a nurse, it is your responsibility to have an awareness of the role that stress and caring have in the provision of care for those living with an LTC. In your role, you can help carers manage stress by increasing your understanding about the situations that can increase carer stress and by providing carers with information about how to manage their stress. Some degree of stress can be productive; indeed, stress can increase our motivation to undertake activities – e.g. for learners, a stress response to a forthcoming examination may be to plan and undertake a programme of revision. However, it should be noted that too much stress can have a negative impact on our ability to cope. Stress can affect a carer both psychologically and physically: psychologically, it can affect their ability to deliver care sensitively and responsively; physically, it can determine their ability to safely provide care, especially that requiring physical interventions, such as bathing. Carer stress is a possibility for any carer; however, those caring for individuals where there is significant physical burden or reduced cognitive ability may be particularly vulnerable. Research (Katbamna et al., 2017) exploring the burden of care on carers looking after people post-stroke found that carer stress was increased due to the uncertain and unpredictable nature of stroke. For carers of a person with dementia, stress can be increased due to a range of reasons; in particular, changes in behaviour, carers needing to repeat information and situations where the person’s behaviour does not conform with social norms (Feast et al., 2016). A systematic review (Yesufu-Udechuku et al., 2018), exploring improving the experience of caring for people with severe mental illness, concluded psychosocial interventions, such as support groups for carers, led to an improved experience of caregiving and quality of life. Being alert to the needs of carers and providing them with information

and support to manage their stress will have a positive impact both on them and the person they are caring for. It can be seen, therefore, that stress can affect a carer both psychologically and physically. Psychologically, it can affect their ability to deliver care sensitively and responsively; physically, it can determine their ability to safely provide care, especially that requiring physical interventions, such as bathing.

Carers undertake many nursing-based activities when caring for people living with an LTC and want to be able to carry these out safely and effectively (Bee et al., 2008). Providing carers with adequate education and information regarding nursing activities relevant to them will enhance the care delivered. Some of the key areas identified by Bee et al. (2008) are as follows:

- Medication and pain management – education regarding awareness and understanding of the medication being taken, including side effects, how and when it should be taken, understanding of assessment and management of pain.
- Personal hygiene – education and advice regarding skin observation and assessment, and use of pressure-relieving aids, management of continence and bathing, and use of technical equipment such as hoists.
- Nutrition – information regarding a healthy diet and specific dietary requirements.
- Management of symptoms – information and advice regarding fatigue, weakness and awareness of a person’s mental health status.
- Emergency situations – education and advice regarding recognising the signs of an emergency – e.g. myocardial infarction and who to contact.

Taking the time to provide practical support and training to carers will increase carer confidence, reduce stress and enhance their coping mechanisms.

Case study: Mary

Mary is 91 years old, takes medication to manage hypertension – she does not know what this is – and had a stroke 15 years ago, leaving her with a left-sided weakness.

She lives alone in a flat above a newsagent’s shop that her daughter runs. It is a family business that Mary and her husband ran when he was alive. She has three daughters, two of whom live very locally and one who lives a few hours away and visits regularly. Mary has a carer three times a day to help with personal care and assist with meals. She spends lots of time in a chair or bed, but is able to transfer with her Zimmer frame and a carer. Mary had a fall recently and was not wearing her pendant alarm, so was on the floor overnight. She sustained a skin tear to her forearm and developed a grade 2 pressure sore to her hip. Her daughters are anxious about her safety when there is no one in the flat, as this is not the first fall she has had. They have decided to put a rota in place so that one of them is there overnight with their mother. After assessment in A&E, she was sent home and referred to the district nurse team for wound care and review.

Activity 2.4 Decision-making

You are spending the day with the district nurse; one of her visits is to Mary (see the case study above). Considering Mary’s needs and the key areas identified by Bee et al. (2008), what information would you provide?

A brief outline answer is given at the end of the chapter.

As you can see from this case study, while Mary has a carer who attends her three times a day, her daughters are also involved in her care. As Mary’s daughters are new carers, it may be worthwhile for them to register as unpaid carers with their GP. Registering will allow them to access a range of support, including providing free annual health checks and flu vaccinations to involving them in Mary’s care planning. As Mary’s daughters are working, registering as unpaid carers would mean that appointments could be made at a time to suit them, minimising disruption.

Allowing flexible working to support working carers has the potential to reduce the financial burden placed on carers. Flexible working has been shown to reduce sick leave and improve productivity, which are benefits for both the employee and employer. Since June 2014, all UK employees, apart from those in Northern Ireland, who have worked for the same employer for at least 26 weeks, have the right to request flexible working. Employers must deal with the request in a ‘reasonable manner’, and assess the advantages and disadvantages of the request. However, employers do have the right to refuse if there is a clear business need that prevents flexible working.

Being a carer is clearly challenging. Research by Pallant and Reid (2013) explored its positive and negative aspects. Their research concluded that carers perceive caring as worthwhile and value their role. Taking the time to positively recognise the role that carers play, and the positive and negative aspects, has the potential to increase the carer’s feelings of self-worth, giving them the confidence to carry on as their role changes.

The carer’s role will change over time because of the nature of LTCs. Most people do not set out to become carers, but rather over a period of time find themselves in that role. It can happen slowly over the course of months or years, due to a gradual deterioration in health – e.g. as a result of heart disease or Parkinson’s disease, or it can happen suddenly due to an acute deterioration in health – e.g. as a result of a cerebrovascular accident or other rapidly developing neurological condition. Often, the assumption is made that carers are happy to undertake this role, as they are there and already involved. However, tension, behaviour, role reversal, and loss of intimacy are often cited as areas of change when a person moves into a caring role, though the change can also encourage a closeness and the development of new ties in the relationship (Carers First, 2023). Developing a positive nurse–carer relationship that promotes resilience and respects professional boundaries will enable you to address their changing needs, allowing them to continue in their role as a carer for as long as they wish to do so.

As discussed above, it is important that a person-focused nurse–patient relationship is in place if you are to provide effective support to a person living with LTCs and their carer. For this to happen, there has to be an open and honest exchange of information, ideas and wishes that informs clear person-centred care and management.

Digital storytelling: a communication strategy for LTCs

Storytelling can be viewed as a ‘children’s activity’, yet it is through the use of stories that we understand, experience, communicate and create ourselves. Our stories, like our lives, are constantly changing; they consist of the process of telling the story as well as the end product – the story itself. This chapter started with Bill, whose digital story, recorded by Patient Voices, allowed him to describe how the input of a community matron had improved his care. Digital storytelling, like Bill’s, is a way of encouraging people to share their stories using digital tools. Their first-person narratives may include words, photographs, music and the person’s own voice, and can be created using a range of digital platforms; they are usually between two and five minutes long. Patient Voices outlines a good digital story as one having the following characteristics.

- Brief: a good digital story is a short digital story.
- Simple: low-technology using a few carefully chosen images, voice-over and/or music and simple titling.
- Personal: reveal something personal about the storyteller.
- About the story: a way of developing associated skills.
- Respectful of others’ feelings and experiences.
- Created in the spirit of collaboration and partnership.

This narrative approach focuses on the person and uses their narrative to understand the importance of the illness from their perspective. This person-centred approach promotes empowerment, placing the person at the heart of the issue, ensuring that the care provided reflects their needs (Matthews, 2014). Using technology in this way, by providing people with different ways in which they can tell their story, allows you to ensure that you are using communication strategies best suited to the person and their needs – for example, someone with low levels of literacy, who has been asked to keep a food diary, may feel more comfortable narrating this, rather than trying to write it down.

Activity 2.5 Reflection

This activity asks us to reflect on a narrative (‘Morning express’) from Patient Voices. You can access it at: <https://www.patientvoices.org.uk/flv/0672pv384.htm>

(Continued)

(Continued)

Using a model of reflection such as the Davis Model of Reflection (Davis, 2011), reflect on one aspect of this narrative (see the further reading section for the full reference).

As the answers will be based on your own observations, there is no outline answer at the end of the chapter.

As you can see from Activity 2.5, while patient or carer narratives can support us to improve our practice, they are not always easy for us to hear. Developing your emotional intelligence and resilience will support you to safeguard your own emotional health. However, the information provided by a narrative gives you useful information that encourages empathy and promotes understanding of the person and their needs. It may supply you with useful clues that can contribute to a holistic assessment of those in your care, allowing you to set a person-centred agenda.

Chapter summary

This chapter has provided you with an overview of the role of the nurse–patient relationship in relation to LTCs; it has also outlined the importance of emotional intelligence as a factor in this, both for you and for those in your care. It has focused on the importance of recognising the role of carers and working with them to support both carers and those living with LTCs. Some specific communication strategies that are useful in the care and management of LTCs have been discussed and related to clinical practice.

Having read this chapter and worked through the activities, you will have developed your knowledge and skills in relation to the nurse–patient relationship and long term conditions. You can improve communication with those in your care and their family/carer in many ways. By increasing your level of emotional intelligence, you can be yourself, be open and honest, recognise and acknowledge your limitations and take personal responsibility. By engaging in a nurse–patient relationship with individuals and/or their carers, you can promote resilience while respecting professional boundaries and working as part of a team, listening and responding to their needs. By using communication strategies like narrative-based care, you can increase the wellbeing of the person/carer, improve physical and mental state, promote a better adjustment to illness and increase an individual’s sense of control.

Activities: brief outline answers

Activity 2.1 Communication (page 33)

To help Peter prepare for his consultation, you could assist him to identify his main concerns, to write these down and to identify any specific questions he has that he would like answered. These may relate to his medication and the likely progression of his Alzheimer’s disease. You could encourage Peter to share how he is feeling, especially in relation to talking about ‘assisted suicide’. It could be that Peter is depressed and would benefit from some treatment, either pharmacological, therapeutic or both. Help Peter to write down his questions and remind him to take some paper and a pen, or a dictaphone, with him so that he can write down the answers or

record them for Sarah. Remind Peter that this is his consultation and that before he leaves he should review with his consultant what has been said.

Activity 2.4 Decision-making (page 48)

Medication and pain management – access information from the GP in relation to Mary’s medication, it may be that a medicines review needs to take place with Mary to ensure that she understands her medication, what she is taking and why. Undertake a pain assessment using a recognised pain assessment tool to assess Mary’s baseline level of pain (if any). Use this information to inform any further treatment/referrals.

Personal hygiene – discuss with Mary the importance of keeping her skin clean and dry. You may need to meet with Mary’s carer to go over the care of Mary’s skin tear and grade 2 pressure sore to ensure effective healing. Ensuring that Mary’s skin is kept moist can reduce skin tears, so applying moisturiser would be appropriate.

Nutrition – provide Mary with information about the importance of a healthy, balanced diet; this information may also have to be provided to both her carer and daughters. Due to her age and possible reduced appetite, it may be more appropriate for Mary to have six small meals a day rather than three larger ones.

Management of symptoms – Mary has a history of falls, therefore referral to occupational therapy and physiotherapy may be relevant.

Emergency situation – discuss with Mary the importance of wearing her pendant alarm and using it; it may also be relevant to discuss the signs of infection with Mary, her carer and daughters.

Further reading

Crawford, T, Roger, P & Candlin, S (2017) Tracing the discursive development of rapport in intercultural nurse–patient interactions. *International Journal of Applied Linguistics*, 27 (3): 636–50.

Davis, N (2011) Reflection, in Davis, N, Clark, AC, O’Brien, M, Sumpton, K, Plaice, C and Waugh, S (eds) *Learning Skills for Nursing Students*. Exeter: Learning Matters, pp. 173–92.

Edward, K (2013) Chronic illness and wellbeing: using nursing practice to foster resilience as resistance. *British Journal of Nursing*, 22 (13): 741–46.

An article exploring co-morbid LTCs with mental illness and the role that nurses have in developing resilience to promote self-management.

Grant, A and Goodman, B (2019) *Communication and Interpersonal Skills in Nursing* (4th edn). London: Sage/Learning Matters.

A useful introduction for nursing learners to the complexities of communication skills.

Useful websites

www.autism.org.uk/advice-and-guidance/topics/autism-friendly-guide/accessible-information

Information on communication and other challenges facing those with autism.

www.carersuk.org

Provides a gateway to all carer UK sites – e.g. Scotland, Northern Ireland and Wales; offers advice and information for carers.

www.patientvoices.org.uk

Using digital storytelling, Patient Voices provides insight into the experiences of patients, carers and staff to promote change, both individual and organisational.