Enabling People with Dementia: Understanding and Implementing Person-Centred Care

Pat Hobson

Third Edition

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I would like to dedicate this book to my grandmother, Pauline. Like most people with dementia, she was never diagnosed with this disorder. She had a history of hypertension, transient ischaemic attacks (TIA) and behaviours associated with vascular-type dementia. Despite her experiences with dementia, which affected us all, my grandmother remained a unique individual, dearly loved and respected by everyone who knew and cared for her.
I would also like to dedicate this book to:
My grandfather, Solomon
My father, Albert
My mother, Phildah
My mother-in-law, Marcella
My father-in-law, Fred
My aunt, Noanah
My aunt, Petronella
A selfless generation that is irreplaceable.

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I would like to thank my husband, Mark, for his unconditional love, support, patience and belief as I endeavoured to write this book. I would also like to extend a special thanks to all the acute medical wards, specialist dementia units and organisations I have worked with and continue to work with in my consultancy work. These establishments demonstrate some of the wonderful work not recognised within health and social care sector, which makes a world of difference to people with dementia. I would also like to extend a special thanks to all the people with dementia and their carers whom I have had the pleasure to meet, work with and support.

About This Book

The main focus of this book is to explore dementia from a person-centred perspective. Understanding dementia can help health and social care staff understand how simple everyday tasks we take for granted can be a challenge for people with dementia.

This book is for health and social care staff at all levels, and the term 'staff' will be used throughout to refer to these key individuals working with people with dementia in various specialist units. It examines the main theory relating to dementia care and provides an overview of other person-centred models that allude to this theory. It also explores the different types of dementia and the issues relating to person-centred communication that help to create the right environment to enable and promote meaningful activities for people with dementia and emphasises the importance of seeing the world from the perspective of the person with dementia. The key message here is that despite the disability, the person remains unique, and it should be our aim to promote that uniqueness.

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About the Author

Pat Hobson is a dual-qualified registered nurse in Mental Health and Adult Nursing. She also has an MSc in Gerontology; a Postgraduate Certificate in Academic Practice and in Clinical Governance, Clinical Leadership and Change Management; and a BSc (Hon) in Nursing. She has worked as a nurse and manager in the public and private sector and has over 20 years of experience in older people and dementia care nursing.

Pat currently works as an independent nurse consultant, lecturer in nursing and adult safeguarding and dementia specialist. She supports organisations, managers and their teams in the care sector on issues relating to nursing, adult safeguarding, workforce development and dementia care as well as provides support in leadership and management issues and continued professional development.

Introduction

Advances in modern medicine will see the ageing population treble over the next few decades. This increase will have implications on how older people are cared for, and supported, in general. Illnesses and disorders associated with age will also increase. Dementia is one of those disorders that will have implications on society as a whole.

People are now living longer, and advanced age results in failing physical health and an increase in the illnesses and disorders associated with this. This will have an impact on how care is delivered within organisations. Nearly 80% of older people in organisations are said to have some form of dementia, and a third of people supported on acute medical wards are said to have dementia. Therefore, the specialist care and expertise required to support people with dementia remains an issue that needs to be addressed. There is evidence to demonstrate that the health and social care organisations are not equipped to deal with the specialist support that people with dementia require, which in turn has implications for the state of future care.

For years, the care of people with dementia has received little attention in comparison to other services. Furthermore, dementia care has still not been recognised as a key speciality within the general services for older people, which means that the needs of people with dementia are not always effectively met.

The need to develop services in which staff are equipped with the relevant knowledge and skills to enable them to reflect the needs of a more effective workforce remains paramount. Staff form a large component of this workforce, and hence, the need to focus on how they can develop their knowledge and skills in relation to dementia care is crucial. Education, training and the changing role of health and social care staff will be central to organisational requirements. Therefore, they need to be fully supported to achieve best practice.

Chapter 1
Background to Person-Centred Care Theory

Person-Centred Theory

Person-centred theory is not new. The original theory dates back as far as the 1950s and is associated with the work of Carl Rogers who applied it to psychotherapy and counselling [1]. The main focus was on the person, and how the care delivered should centre around them, with the emphasis being on empowering rather than disempowering the person. Professor Kitwood explored person-centredness from the perspective of people with dementia. His work focused on viewing each person as a unique individual, challenging past medical perspectives to dementia care [2, 3]. Kitwood further reinforces this by alluding to evidence from different studies indicated dementia as being unique to the person [2, 3]. This included staff developing high interpersonal skills that promoted dignity, respect and trust, to underpin dementia care, and begins with love, being at the centre, surrounded by comfort, attachment, inclusion, occupation and identity [3].

Kitwood identified dementia as a disability and argues that it has a complex interaction of five defining attributes that have implications for the person with dementia. These attributes are the pivotal components governing person-centred theory for dementia care. They are identified as personality, biography, neurological impairment, social psychology and physical health status [2]. Each of these is said to interact with the others and affect the person with dementia in different ways. The main priority should be on maximising the environment and the person's abilities by adapting the way in which staff interact with them. To enable better dementia support, organisations need to adopt a more holistic approach in order to explore the implications that Kitwood's attributes have on the person with dementia.

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Personhood

The term *Personhood* is used to emphasise his person-centred theory. *Personhood* is about recognising the 'sense of self' and focuses on the role of individuals in the care setting [2].

Personhood is a crucial component of person-centred care and aims to promote a more positive interaction with the person and everyone around them. The aim is to encourage well-being and a sense of belonging that is unique to each person, as everyone needs to feel they have a sense of purpose in life [2, 3]. This is further explained within the five fundamental attributes of *Personhood* as in the following equation:

$$\mathbf{D = P = B = H = NI = SP}$$

D: Dementia Presentation

The disease process and how it leads to memory problems, personality changes and impaired reasoning. However, this is unique to each person with dementia [2].

P: Personality

Everyone has a unique personality and the main emphasis should be on maintaining this. Dementia may affect the person and change their personality, but their uniqueness remains [2].

B: Biography

The person's biography can affect how they interact with others, the words or phrases they may use, and even their behaviour. Therefore, an understanding of the biography enables staff to gain some insight into the person based on their background, which is unique to them [2].

H: Health Status

People with dementia not only have to cope with the general deterioration in their cognitive abilities, but also the physical deterioration, which can result in illnesses and disorders that can greatly influence their health and well-being [2].

N: Neurological Impairment

This refers to the form of dementia the person has, and the impact this can have on them. Many staff state that very little is known about the diagnosis of dementia a person may have. Some may argue that knowing and having a diagnosis can lead to stigmatisation and labelling of the person. However, knowledge and understanding of how dementia affects the needs of the person is essential, as no two people with dementia are the same [2].

S: Social Psychology

The person with dementia will be affected by the world around them. This includes the environment in which they are looked after, which may or may not accommodate their needs [2].

Conclusion

There are other issues to consider when exploring the person-centred theory. One of these is enabling the person with dementia to maximise their abilities. Some staff may focus more on what the person with dementia cannot do, rather than on what they can achieve. In promoting person-centred care, the emphasis should be on empowering rather than disempowering the person.

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Chapter 2
Malignant Social Psychology (MSP): Behaviours That Threaten Dignity and Respect

Kitwood's Malignant Social Psychology

Kitwood's terminology is useful for highlighting the seriousness of malpractice in dementia care. Kitwood purposefully used the term 'malignant', normally associated with a disease process, which if not treated, can spread to healthy areas of the body. The term 'social' is more indicative of everyday interactions with everyone around, which includes people with dementia. The term 'psychology' relates more to what people believe, their behaviours, attitudes and perceptions. When relating this to practice, the term 'malignant social psychology' would indicate 'bad practice' that can infiltrate organisations, which if not stopped, can 'spread', and is likely to influence the behaviours and attitudes of members of the team, without them realising this. One individual can instigate poor practice (the malignant), particularly if they are in an influential position where everyone follows suit (social), and staff can start to believe that this is how people with dementia should be treated (psychology). In most cases, behaviours that staff display may not be intentional, but more embedded within the culture of the team, which has not been challenged for years. This lack of challenge results in these behaviours continuing to the extent that staff will start to consider them as 'normal' [1].

Examples of Kitwood's MSP That Threaten Dignity in Organisations

Treachery

Lying to the person, telling the person false stories, justifying that this will make the person feel better. For example, a person with dementia may ask for their mother or children; staff may respond by telling the person that their mother or children will

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be coming later, knowing full well that this is not true. Other examples include staff telling the person with dementia that they will be back to assist with care needs, and not coming back to fulfil the promise.

Some staff may rationalise ‘lying’ as being better than telling the person the truth. However, the key focus should be about addressing the emotional needs of the person.

Disempowerment

This may include doing everything for the person, taking over tasks when the person is attempting to do these themselves, not allowing the person to make choices, and taking their rights to always be an individual. This results in the person losing confidence in their abilities, and therefore, becoming more dependent on staff when they are still able to do things for themselves.

Infantilisation

This involves referring to the person with dementia as a ‘boy’ or ‘girl’, talking to them in a condescending manner, using words such as feeding, feeds (for people that need assistance to eat), cot sides (to refer to bedrails), bibs (to refer to protective clothing at meal times) or using oversize bib-like protective clothing. This may also include: talking or answering for the person when they are able to do this themselves, using terms such as toileting (to refer to when they need assistance to use the toilet), using cutlery that are used for children and babies, or colours that are mainly found in children’s centres, and giving people with dementia colouring books or dolls (unless this is part of an individualised activity programme identified in the person’s care plan, based on their unique needs and abilities).

Labelling

Use of words such as ‘double’ to refer to a person that needs assistance of two staff, or a ‘single’ to refer to a person that requires the assistance of one staff member. Other examples include words, such as demanding, difficult, challenging, nightmare, feeding, feeds, feeders, toileting, wandering or wanderers.

Banishment

Putting the person with dementia in an isolated place when they are displaying certain behaviours that staff may find challenging, rather than finding out what the problem is. Leaving the person for long periods of time without any interaction at all.

Objectification

Staff assisting a person with care needs, whilst talking to each other. There is no interaction at all with the person. Instead, the person becomes a 'task', or 'chore' that staff need to 'complete' rather than a person that requires support with care needs. Referring to a person as a number rather than using their name. This depersonalises the person.

Withholding

Telling the person with dementia that they can only have refreshments, or food, at specified times; leaving the person waiting for a long time to have personal care; taking their call bell away, because they keep ringing this. This can also involve cutting services for people with dementia to save money, resulting in them going without essential equipment and resources.

Accusation

Accusing the person of things they are unable to change. For example, calling the person 'lazy', when they are unable to do things, or stating that they are 'attention seeking'.

Invalidation

The person is looking for their mother or loved one, and again staff do not acknowledge the emotional needs and feelings of the person, but merely ignore this. Not responding when the person is visibly upset and needs comfort.

Outpacing

Rushing the person during activities of daily living tasks, or talking at a rate that the person cannot keep up with.

Imposition

Making people with dementia engage in activities and tasks that are not person centred, but indicated by staff. Imposition takes away the right for the person to make choices about what they want to do and achieve.

Disparagement

Continuously telling the person what they cannot do, rather than focusing on what they can do. Saying things that may belittle the person, making it obvious that they have made or are making mistakes, which can make the person feel worthless.

Disruption

Entering a person's personal space without being invited. For example, going into a bedroom, whilst the person is in there (without asking for permission), and start undertaking tasks such as cleaning/hoovering, or tidying laundry.

Mockery

Mockery is where staff will laugh at the behaviours of the person with dementia and will even joke about the person's failures and inabilities to undertake everyday tasks.

Stigmatisation

This involves treating the person like a disease, where the person with dementia is alienated. Some organisations have designated dementia units, where people with dementia are looked after, away from other residents. Although there may be a rationale for this, it is how people with dementia are perceived, that makes the difference as to whether they are stigmatised or not.

Ignoring

Ignoring is when the person is not acknowledged. Staff may be talking among themselves, and the person may attempt to interact with staff but is ignored. The person's feelings and emotions are not recognised.

Reference

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Chapter 3
Positive Person Work (PPW): Behaviours That Promote Dignity

Positive Person Work (PPW) Behaviours

Celebration

Celebration enables individuals to retain control over their lives. It is about celebrating the person's life, accepting them for who they are, and encouraging them to maintain their personhood or self-control. To maintain this within organisations, staff need to implement empowering values and person-centred care, where individuals are allowed to dictate the care implemented, and their unique values are promoted [1, 2].

Kitwood [1] used this term to reinforce the collaboration between staff and people with dementia, which is indicative of a joint partnership that allows people with dementia to develop skills, confidence and empowerment. There is no 'them and us' culture, as staff work alongside people with dementia. Within the care setting this involves not doing everything for the person, but allowing them to complete tasks for themselves (wherever possible), and when they attempt to fulfil these tasks, ensuring they are encouraged to do so, rather than staff taking over. The emphasis is on allowing people with dementia to make choices, promoting their individual rights [1, 2].

Creation

Kitwood [1] reinforces the need to seek activities that are therapeutic for people with dementia. Wherever possible, people with dementia should be encouraged to undertake activities that are initiated by the people themselves, rather than staff continuously introducing activities that may have little meaning to people with

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dementia. Activities include singing, dancing, walking, talking, reading, listening and engaging. Creation enables people with dementia to use their own creativity in terms of what they wish to do, rather than what staff believe they need to do. This concept is designed to be empowering and respectful, treating people with dementia with dignity by allowing them to identify what is meaningful to them [1].

Facilitation

This focuses on understanding the simple things that a person may convey. Facilitation allows staff to help to make things easier for people with dementia, and to find ways to reach an agreement with the person on what they want using the person's unique way of communicating. Staff should facilitate care and activities that are based on the person's preferences and interests, which allows the person to be directly involved in the process, therefore, enabling them to find a resolution to any issues affecting the person [1].

Holding

This involves supporting people with dementia in times of distress, or when they are unwell. Staff can allow a person to express negative feelings and emotions based on past experiences or as a result of a physical illness, and therefore identify ways to acknowledge and address this. This enables people with dementia to recognise that staff do not merely ignore their feelings, but validate these and provide support and reassurance in times of distress [1].

Negotiation

This focuses on interacting with the person with dementia in a way that is based on listening to their needs and requests. This involves consulting with them and also looking at behaviour in a way that enables staff to learn the meaning of those behaviours, and the implications this has with regard to the person's needs and preferences. For example, it may mean helping a person choose what they wish to wear or eat, and negotiating with the person so they can make choices that promote dignity, without having decisions made for that person. The decision-making process is about putting the person at the centre, and limiting institutionalised behaviour that can have implications on the person's dignity [1, 3]. The relationship between people with dementia and staff is built on mutual respect and trust [4, 5].

Play

Play enables staff to allow people with dementia to spontaneously undertake activities that are meaningful to them, and enables staff to join in with jokes, in which interaction is positive. The atmosphere created is one which does not alienate people with dementia from staff and other people within the care setting. People with dementia should not be in a care setting where they feel disempowered or appear to be 'dying' of boredom, with little evidence of meaningful activities [1].

Recognition

This relates to interacting with people with dementia in a way that makes them feel valued. A person needs to feel listened to, and to be recognised. People with dementia should not be treated as stereotypes, and should be able to communicate with staff in a way that they feel comfortable, based on their own preferences and needs. The different aspects of a person's life must be accepted and recognised, and this includes accepting their family. Staff should also recognise and respect the person's unique cultural abilities and needs [1].

Relaxation

This promotes an environment where people with dementia can freely walk around and interact with staff, feel relaxed and there is no tension. This is an environment where care is carried out in a calm, informal way. Music is allowed but is appropriate, allowing times for rest, and engaging people with dementia in activities that promote relaxation [1].

Timelation

This refers to activities that allow people with dementia to focus on different senses, which include music or aromatherapy, where appropriate. Care settings should be able to identify activities that are person centred, reflecting the needs of each individual [1].

Validation

This is an important aspect of empowering people with dementia and is about being sensitive and sympathetic to their feelings and emotions. Validation can be fulfilled in the following ways: by accepting and acknowledging a person's reality; by being aware of the different behaviours that people with dementia can display, triggered by mental health needs or other factors; by listening to and responding to a person's distress or behaviours that challenge, such as paranoia or other mental health conditions. Validation is a word that means acknowledging a wide range of emotions and feelings, and being able to sensitively listen and respond, taking the time to support the person [1, 6].

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Chapter 4
Person-Centred Models in Dementia

The VIPS Framework in Dementia Care

The VIPS framework is based on the person-centred theory, which promotes the key principles of valuing individuals as unique. Professor Brooker, a contemporary of Kitwood, explored person-centred care from a different perspective. However, the key components allude to the work of Kitwood [1, 2].

Similar to Kitwood, the VIPS framework focuses on the need to identify and establish the concept of personhood and seeks to acknowledge the rights and values of a person. This enables staff to enter the world of the person with dementia and provide support that will promote the individual abilities of the person [1–4]. By implementing and promoting person-centred approaches to dementia care, staff can prevent the deterioration in people with dementia, which is attributed to negative interactions and experiences [5]. Staff need to understand and appreciate the impact dementia can have on the person, and that 'the person's character is not lost, but rather concealed' [6].

The VIPS framework is used widely within many organisations today. Key government departments, such as the Department of Health, in the United Kingdom, have also embraced the VIPS framework within guidelines relating to dementia care.

Key Elements of the VIPS Framework

V = Valuing People

The aim of this is to focus on the person, as they have value, irrespective of who they are. To provide effective dementia care, the following questions need to be addressed:

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Vision—does the organisation have a person-centred vision and mission statement in relation to the care provided for people with dementia?

Human resource management—does the organisation have systems in place that empower and value staff?

Management ethos (belief system)—does the management and practice reflect staff empowerment and support in delivering person-centred care?

Training and staff's development—Are there systems within the organisation that reflect a commitment to the development of an effective workforce, that promote person-centred care?

Service environment—does the environment enable people with dementia rather than disable them?

Quality assurance—are there continuous systems in place that monitor quality improvement, which are acted upon when issues identified threaten person-centred care?

I = Individualised Care

This promotes the uniqueness and individuality of the person.

Care planning—do care plans reflect individuality and identify key strengths of the person and not their weaknesses?

Regular reviews—are regular reviews completed, and the needs of the person addressed immediately, if any changes occur?

Personal possessions—does the organisation ensure that all individuals have their personal possessions that they require for everyday use?

Individual preferences—do staff promote the individual needs and preferences of the person that enables them to maintain their normal routine?

Life history—do all staff have an awareness of the person's unique life history that reflects some of their significant memories and events? If so, are these referred to regularly?

P = Personal Perspectives

Personal perspectives enable staff to understand and see the world from the person with dementia's perspective.

Communication with service providers—is there carer involvement that enables them to identify any issues regarding the person with dementia's needs and opinions, as well as allowing them to consent to care?

Empathy and acceptable risk—do staff respect the person with dementia and ensure that decisions reflect their individual perspective and point of view?

Physical environment—are staff aware of the impact the environment can have on the person with dementia? This includes environmental factors, such as noise, colour and temperature. Are comfort levels maintained?

Physical health—do staff have knowledge and understanding of the impact physical health needs can have on the person with dementia?

Behaviours of concern as communication—do staff regard behaviour as a form of communication, in which the person is viewed, not as a problem, but in the light of how their behaviour can be a symptom of an underlying need that should be addressed?

Advocacy—do staff respect individual needs of people with dementia and ensure that the care given does not compromise their rights, whilst ensuring safety is maintained?

S = Social Environment

Social environment provides a community setting that meets the psychological needs of people with dementia.

Inclusion—do staff actively support people with dementia to ensure they are included in conversations with others around them, including staff?

Respect—do staff treat each person with dementia with respect, refraining from language or terminologies that are labelling or demeaning?

Warmth—do staff promote an atmosphere that reflects warmth and acceptance of people with dementia, without an atmosphere of fear, neglect and intimidation?

Validation—do staff acknowledge and validate the feelings of people with dementia, where a more feelings-based approach is advocated that meets their emotional needs and does not leave them on their own for long periods of time?

Enabling—do staff engage with people with dementia and ensure activities undertaken are not governed by routines, but are initiated and led by people with dementia? Do staff treat them with dignity in the way they communicate with them, engaging them with meaningful activities?

Community—do staff encourage people with dementia to engage with the community, and are people with dementia able to visit areas of local interest? [2].

The ‘Feelings Matter Most’ Model

The model advocated by Dr. David Sheard also alludes to Kitwood’s original theory of person-centredness and draws from the model of neuro-linguistic programming [1, 7, 8]. Similar to Kitwood and Brooker [1, 2], this theory focuses on enabling staff to experience the world from the perspective of a person with dementia, but advocates the need to develop emotional connections and intelligence. The model has eight key attributes.

The Eight Key Attributes

Being—this enables staff to focus more on person-centred care by moving away from doing 'tasks', but by connecting and reaching people with dementia [9].

Enabling—this helps staff to see, feel and hear the lived experiences of people with dementia, thus being able to capture and measure the minute-by-minute experiences of the person to help improve the moment [10].

Inspiring—this focuses on what Sheard refers to as attached leadership, which enables managers to develop management and leadership styles that are more involved, more 'hands on', where they lead from the heart, and are less detached [11].

Nurturing—by developing an emotion-led organisational strategy, which enables the team to build and foster more positive relationships [12].

Growing—this focuses on the type of training that moves away from *tick box* exercises and competency-based awareness training. The training seeks to develop emotional intelligence and uses key concepts, such as reflection coaching and modelling [13].

Achieving—this focuses on outcome-based strategies that balance the need to ensure that policies, procedures and systems are maintained, with the need to ensure that quality of life and service remain central to the process [14].

Supporting—this aspect focuses on the need to develop skills that promote culture change, where best practice is central, and staff can demonstrate leadership and implementation of person-centred care [15].

Mattering—this enables staff to develop the core skills of feel, look, connect and occupy. These skills are balanced with the need to develop culture change, which enable them to promote the community-based attributes of sharing, reaching, relaxing and mattering [16, 17].

Behavioural Stages Model of Care

The behaviour stages model of care was development by Gemma Jones in the early 1990s in which she adapted the concept of validation therapy model based on Naomi Feil [18]. Feil [18] in her earlier work identified dementia as a gradual progression in which individual will display specific characteristics and symptoms which begin from stage 1 (early diagnosis) to a continuum through to end of life (stage 4). Jones [19] alludes to Feil [18] by enhancing the staging process of the progression of dementia and advocates that dementia consists of a gradual progression and changes in the person's needs which can last over a period of time. As such the stages make reference to the different experiences of the person at various stages of their life and the impact dementia can have on them. Therefore, to understanding the person's needs and abilities is better achieved within a much wider context of the person and their experiences of dementia. Person-centred strategies are developed for each stage to support the person with dementia and their carers [19].

Stage One: Malorientation, Mild Confusion

- The person may appear orientated, although attention span may be reduced. The person is more aware of mistakes and forgetting or misplacing things and may become frightened as they think they may be 'losing their mind'. Loss of independence and control may be evident, as well as challenges in finding the right words may be defensive, tense and anxious [19].

Stage Two: Time Confusion, Moderate Confusion

- The person may be visibly disorientated and there is evidence of a loss of time, day and season. They may refer to significant memories relating to parents and will refer to them as being alive or revert to more happy memories of their life. In some cases, the person may start to become more disinhibited in their behaviour and will say what they are thinking. There may be marked differences in the communication and language, as well as difficulties in finding the right words. The person's attention span may now be limited and will appear to misplace things more [19].

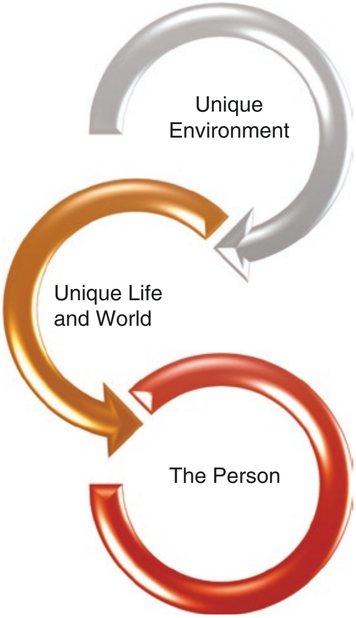
Stage Three: Repetitive Motion, Severe Confusion

- The experiences for the person in this stage will involve abilities being limited and the person may still communicate using short phrases. This may include specific words such as mum, dad, names of children, or call out the word 'help' or 'nurse' constantly. Other behaviours may include the person singing and whistling and there may be minimal efforts to verbally communicate. Also evident will be poor visual and sensory perception. The person may also have repeated behaviours such as patting, tapping, rocking and rolling up clothing. Often the person may recognise the faces of family members, but will struggle to recall their names, or who they are [19].

Stage Four: Vegetation

- The last stage may see the person lose most of their abilities and will not be able to recognise their loved ones. However, they may still respond to external stimuli, music, engage in specific activities such as massage, respond to a friendly voice and enjoy their favourite food. The person may spend most of their day sleeping [19].

Unique Life-World-Environment: Model of Dementia Care



Background of the Model

This model was developed by the author and draws from the person-centred theories and models explored in this book, and from experiences of working with people with dementia. The model known as the ‘Unique Life and World. Environment: Model of Dementia Care’ provides a way in which organisations can implement dementia care, which focuses on what is important to people with dementia. It emphasises the importance of achieving the best outcome or end goal for the person.

Person-Centred Care Versus Outcome-Based Care

Terms such as needs led or outcome-based service or care have been cited and used extensively within health and social organisations. The emphasis is about making dementia personal by ensuring that the needs and aspirations of the person are examined within the context of person-centred theories. Outcomes or needs led are merely an extension of person-centred care and more associated with frameworks and models that have been used to support care delivery. These are based on pulling together the key components of person-centred theories, which are outlined within a core framework or model, with a focus on the end result of the person and how they wish to achieve this. Whilst the organisation delivers the service to enable the person to achieve their ultimate goal, the person does not fit in within this process, but that the process fits in within the needs and aspirations of the person wherever possible. If a clinical pathway is used by the organisation to support in meeting the needs of the person, the person is given the opportunity to make decisions with regards when they wish to engage with the key components of the pathway and decide at what point they may wish to do this. In each case, they remain in control and at the centre of their care throughout. The role of staff within this is to ensure that the person does not 'fall through the net', but that staff in all different roles, specialties and responsibilities are there to support the person from when they are diagnosed with dementia to end of life.

The model addresses key aspects that promote person-centred care. It is about recognising that life is a 'journey' that each person embarks on and they will use their own unique means of transport to achieve their desired goal. However, during this life 'journey' they will encounter a range of experiences that will have a significant impact on their life.

Dementia should not overshadow the person's present life, as the experiences of the disorder should not be regarded as a 'journey' in itself, but that some people will have and experience dementia as part of their life 'journey'. Although it does affect a person's abilities, the key emphasis should be to enable the person to retain control throughout this experience and to remain in the 'driving seat'.

Staff are merely 'passengers' that the person with dementia will encounter at different times in their life. Human beings' lives are intertwined and influenced by their past, present, physical, psychological, social and environmental factors. Therefore, it is about ensuring that each aspect of these key factors is fulfilled, wherever possible, but most importantly by recognising the uniqueness of the person.

The Person's Unique Life and World

The section in the model alludes to Kitwood's biography, personality and who the person is in which the person's life story can be explored in more detail. In addition to this, the significant memories and how this may have an impact on the person [1]. This will also include the type of dementia, accurate diagnosis and the implications this can have on the person and family. The life section explores what was meaningful to the person in the past and how this fits in within the context of what is important to them now. It examines the person's own reality and their unique communication in which staff will support the person.

This section explores the world of the person with dementia and to ensure that care centres upon the person with dementia's perspective. This will enable staff to use the life story work to explore person-centred communication, based on the unique significant memories of the person. It shows the importance of meeting the emotional needs of people with dementia, as being equally important to that of meeting their physical needs. This requires staff to 'enter' the world of someone with dementia, make sense of what is unique to the person and understand their significant memories. As the dementia progresses, the person's abilities and what they may relate to in their past will change. Therefore, staff have to learn to adapt the way they communicate and interact with the person with dementia, rather than expecting the person with dementia to do so. This will enable them to continue to relate to what is important to the person with dementia at that moment in time, and being able to address the person's emotional needs. It will include the person's behaviour, where the care is managed using a psychosocial approaches that advocates the need to address the underlying causes of the behaviour, what may contribute to behaviour changes and that behaviour is a form of communication, in which the personality and the impact of physical and mental health needs will have on the person with dementia's health and well-being. It alludes to the work of Verity, Jones, Kitwood, Brooker and Sheard with a key emphasis on feelings-based approaches [1, 2, 9, 19, 20]. This is further explored in detail in Chaps. 8 and 9.

The Person's Unique Environment

The section builds on from my Unique Life and Unique World, by outlining the importance of creating an environment that enables, not disables people with dementia, where meaningful activities are paramount and at the centre of everyday care. This section alludes to Kitwood's [1] social psychology elements and draws from the VIPS framework and the work of [9]. It focuses on the environment and how staff's interaction with people with dementia can have an impact on health and well-being [2, 17]. Staff need to learn to recognise the unique footsteps of the person with dementia and even 'walk' in those footsteps. This will enable people with dementia to have a sense of purpose in life, raise their self-esteem and give them a sense of belonging [21–23]. This is examined in detail in Chaps. 10 and 11.

Summary of the Person-Centred Care Theory

Although there are several person-centred theories and models in dementia care today, the key focus should be on how these are incorporated within care settings to make a difference to people with dementia. Kitwood's theory remains revolutionary within dementia care as he challenged medical perceptions of how people with dementia were viewed and treated. Most theories, frameworks and models evident today are based on Kitwood's person-centred theory and organisations have been able to adapt and utilise these within care settings. What remains unique with regard to Kitwood's theory is how he was able to demonstrate the different forms of interactions that staff can have with people with dementia. He highlighted how malignant social psychology behaviours are a form of abuse that erodes at the fabric of personhood and results in harm and neglect of people with dementia. In comparison, his positive person work provides positive interactions with people with dementia, which safeguards them from this form of abuse.

Many countries, including the United Kingdom, now have adult safeguarding at the same legal footing as that of children, therefore, safeguarding is now everybody's business. Staff should focus on protecting the rights of people with dementia to ensure that they have a positive outcome which promotes dignity, respect and personhood.

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Chapter 5
Experiences of the Person with Dementia and How It Affects Them

Enable the person to maintain their skills wherever possible

Key Areas That Are Affected in Dementia

The main area of the brain that supports these functions is the cerebral cortex. The cerebral cortex consists of two hemispheres, right and left, both having specific roles to play. The right hemisphere mainly deals with how to put things together and is more visual [1]. For example, an individual may look at a house and recognise that it is a house. Thus the ability to achieve this task is governed by the right side, enabling them to put this visual information together. The left side then helps the individual to analyse that information, where, instead of identifying that this is a house, they will reason who the house belongs to. Each of the hemispheres has areas

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identified as lobes. In total, there are four main lobes consisting of the temporal, frontal, parietal and occipital. Individuals have both left and right lobes that perform specific tasks, enabling them to function more effectively [1].

Temporal lobes enable people to remember how to cook a meal

The Temporal Lobes

The temporal lobes are responsible for two main types of memory: episodic and semantic. The episodic memory deals with our memory of events [1]. This enables people to remember things, such as how to cook a meal, or where they have left their wallet or purse. The semantic memory is what is referred to as the encyclopaedia of facts, enabling people to remember things, such as that a wallet or purse is an item where people put money and cards to keep them safe. The temporal lobes also have other functions, such as enabling people to hear, their memory acquisition, visual perception and ability to categorise objects. They help to tell the difference between smells and sounds, to sort out information and aid the function of the short-term memory. The area responsible for consolidating and transforming short-term memory into long term is located in this area. This is known as the hippocampus.

Experiences of the Person with Dementia

Associated problems with the temporal lobes will involve difficulties in recognising faces (a term known as prosopagnosia) and understanding spoken words (known as Wernicke aphasia) [1]. Also evident is the inability to verbalise and identify objects. Short-term memory is also affected, along with some interference with long-term memory. Problems with the right side of the temporal lobe may lead to persistent talking. The behaviour of the person may be affected, and in some cases, this might result in increased aggression.

The episodic memory appears to be the most affected in dementia. As a result, a person with dementia may remember simple things, such as the detailed process involved in cooking a beef and dumpling stew, but in the next sentence, they may ask who staff are or have problems identifying their environment. As the person with dementia loses the ability to perform rapid movement, they will be unable to perform tasks quickly, and may become frustrated if rushed by staff. Therefore, staff should allow people with dementia time to achieve things, thereby reducing anxiety.

Frontal Lobes

The frontal lobes are located just behind the forehead. They are the emotional centre, controlling emotional responses and enabling people to know what they are doing, and to make judgments about things. The frontal lobes also control the ability to express language, helping to assign meaning to the words people choose. They help with word association, memory of habits and their motor activities. They are also the personality centre [1].

Experiences of the Person with Dementia

Associated problems with the frontal lobes may involve the loss of simple movements, or an inability to plan a sequence of complex movements. As the frontal lobes are the motivation centres, the person may become withdrawn and appear to lack motivation, which can affect their social behaviour, mood and cause problems when interacting with others. Concentration might also be a challenge, as the person might have problems focusing on tasks and have difficulties with problem-solving [1]. The person might have problems expressing language, sometimes known as expressive dysphasia: the person knows what they want to say but fail to do so. A person with dementia might appear to do the same thing over and over again, such as folding items of clothing, or repeatedly touching things. In other cases, they may display behaviours that staff might find difficult to deal with, such as what would be perceived as inappropriate use of the toilet, language that others may find offensive, or perhaps drinking or eating items that are not considered food. The person is not responsible for such behaviours, as these actions are as a result of what is happening in this part of the brain. The frontal lobes are also the personality centre, so relatives might express that the person is no longer the person they knew, their father, mother, husband or wife, as the personality may change due to the deterioration occurring in this area.

Parietal Lobes

The parietal lobes enable people to utilise the use of language, speech, reading, writing and cognition. This is the responsibility of the left side, which is the most dominant side. The non-dominant side involves receiving information from the occipital lobes, which then enables people to make some sense of what they see around them. The ability to find the way around familiar spaces is governed by the parietal lobes and to feel different sensations, such as touch and taste [1].

Experiences of the Person with Dementia

The associated problems with the parietal lobes will result in difficulties in attending to one task at a time, which is why complex tasks can be frustrating for a person with dementia. They might also have problems naming objects (anomia), locating words when writing (agraphia), reading (alexia), drawing objects, distinguishing from left to right, mathematics (dyscalculia), being aware of certain parts of the body or space, visual attention difficulties and eye and hand coordination [1]. People with dementia often have problems finding their way around new or even some familiar places, a term known as spatial orientation. Or they might recognise the voice of a loved one, but not the face.

Occipital Lobes

The occipital lobes located at the back of the head enable people to utilise their vision. These lobes help to identify what people see, and to receive and process information. They also help to identify colours and shapes. These contain the map of the visual world and are the last to help process information and understand what the eyes see [1].

Experiences of the Person with Dementia

The associated problems with the occipital lobes will involve visual defects, difficulties locating objects and the environment. There are other evident problems, such as identifying colours, seeing objects accurately, recognising and drawing objects, the inability to recognise the movement of objects, and difficulties with reading and writing [1]. The person will have difficulties understanding the use of things, such as not knowing what to do with clothing, how to use the toilet or bath. For example, staff might take a person with dementia to the toilet and ask them to use it; the person might recognise it as a toilet, but does not understand what it is used for, and therefore, have problems performing the task.

The Brain Stem

The brain stem is located deep within the brain. This area is responsible for breathing, heart rate, swallowing, and reflexes for seeing and hearing. It also controls sweating, blood pressure, digestion, temperature, levels of alertness, the ability to sleep and the sense of balance. The brain stem controls the messages between the rest of the body and the brain [1].

Experiences of the Person with Dementia

Associated problems in this area may result in difficulties with the capacity for breathing, swallowing (dysphagia), problems with organisation and perception of the environment, dizziness, vertigo and problems with sleeping [1]. As the dementia progresses, a problem with swallowing difficulties and choking often arises. Furthermore, with the brain stem affecting breathing, an increased risk of chest infections and pneumonia become more common.

The Cerebellum

The cerebellum is located at the base of the skull and is responsible for the coordination of voluntary movements and balance [1].

Experiences of the Person with Dementia

Associated problems with the cerebellum will involve difficulties with coordination, mobility, tremors, dizziness and vertigo, and slurred speech. As the dementia progresses, it becomes increasingly difficult to undertake tasks such as reaching and clasping things [1]. The coordination deteriorates, and balance and mobility become an issue. As a result, incidents of falls increase. Therefore, staff might find that a person might attempt to stand and walk, but falls or stumbles, which can be frustrating for them.

Summary of How Dementia Affects the Person

This section focuses on the neurological impairment aspect of dementia, which staff need to have knowledge of to enable them to understand some of the behaviours they may see in people with dementia. This will also enable them to appreciate why allowing time to undertake tasks is important, and that rushing the person may lead to distress. Every behaviour that is displayed by a person with dementia has a meaning, when examined within the context of what is happening to the person. The key focus should be on enhancing what the person with dementia is still able to do and not attempt to get them to do aspects of their care that they may no longer be able to achieve. Staff have to adapt the way they work with people with dementia, rather than expect people with dementia to change their behaviour. Most importantly, the person-centred theory advocates the need to see the person first, then the dementia, and not the other way round.

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Chapter 6

Different Stages and Types of Dementia

See the person first, not the dementia

Different Stages in Dementia

Mild Dementia

Mild dementia may involve episodes of forgetfulness where the person may show some subtle changes in behaviour, and may have some insight into what is happening, therefore, they might attempt to hide this. In an attempt to deal with what is happening, the person may start to develop coping mechanisms. For example, the person may appear to 'confabulate' in an attempt to cover up any shortcomings. Those close to the person may start to see and report changes in the person's behaviour. Many people at this stage of dementia will go undiagnosed. Communication skills and other abilities remain intact during the early stages of dementia. Depression

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is common at this stage, as the person starts to realise that something is wrong. However, the person will still be able to maintain activities of daily living. During the early stages of dementia, the person can continue to live an active life with little impact on most of their skills. Therefore, the key issue here is to ensure that the person has the support they require to maximise their skills and abilities.

Moderate Dementia

In moderate dementia, the person's condition deteriorates further, and cognitive impairment may be more noticeable. The person will require assistance with maintaining activities of daily living. Self-neglect may become more frequent. Communication abilities start to deteriorate and may become more of a challenge. The person with dementia may have problems finding words, leading to frustration. Behaviours that challenge may also become more evident in some people with dementia.

Advanced Dementia

As the dementia progresses, the person becomes more and more dependent on others for all care needs. Verbal communication becomes almost non-existent, and other forms of communication become more evident, such as body language. Behaviours that challenge become more frequent. The person will require full assistance with all activities of daily living. The person may be confined to bed and unable to move or change position without assistance. Mobility may be reduced as the dementia progresses. The signs and symptoms highlighted above focus on the skills and abilities that the person is no longer able to do, and there is a danger that they may become 'lost' in this world, where staff regard them as 'helpless'. There is evidence to suggest that people with advanced stage dementia can still have episodes of insight. In this case, the key issue is to maximise their abilities by focusing on their main strengths, which should be maintained, as long as the person is able to cope with this.

Different Types of Dementia

Dementia is an umbrella term used to encompass a range of disorders, some of which will now be explored. A person might experience various symptoms associated with dementia. However, each of these may be specific to the type of dementia involved.

The most common types of dementia identified are:

- Alzheimer’s type dementia
- Vascular dementia
- Dementia of Lewy bodies
- Frontal-temporal lobe dementia
- AIDS-related dementia
- Creutzfeldt–Jacob Disease (CJD)
- Alcohol-related dementia

The diagnosis of dementia will depend on the symptoms present. However, this is sometimes difficult, as the symptoms may be interchangeable.

Alzheimer’s Type Dementia

This is the most common type of dementia, which accounts for about 50–80% of most cases. Originally identified by Alois Alzheimer in 1906, the main symptoms are a general progression and deterioration of the person. The reason for this deterioration is attributed to changes within the brain, particularly in the cerebral hemispheres, which involve the frontal, parietal and temporal lobes.

The cerebral hemispheres are said to actually ‘shrink’, resulting in cell damage caused by protein deposits known as amyloid plaques. The main protein in plaques is called beta amyloid. These are found outside the neurones. The neurones are the nerve cells in our brains that help to transform messages around the brain. They are also affected by neurofibrillary tangles that are caused by another type of protein called tau, and a loss of neurotransmitters, such as acetylcholine (ACh). The tangles can be found inside the neurones. This in time causes damage to the microtubules that start to disintegrate and results in impairment of the cells. Alzheimer’s type dementia is difficult to give a definite diagnosis. It is a progressive disorder, therefore, over time more areas within the brain are affected. The symptoms eventually become more severe.

Experiences of People with Alzheimer’s Type Dementia

The person may experience the following symptoms:

- Lapses in memory (particularly in the early stages of the disorder).
- Confusion and problems recognising people.
- Problems remembering things, such as recent events or how to do things they were able to do previously.
- Mood may vary; the person may appear sad at times or frustrated and angry.

- May appear withdrawn, as communication difficulties appear more significant as the dementia progresses.
- May have difficulties in finding the right words.
- The person will require more support to enable them to cope with the changes occurring in their life. This can be a frightening experience for them.

The key issue to remember is that no two people are the same despite the same diagnosis.

Vascular Dementia

Vascular dementia is caused by evidence of vascular disease, such as heart disease, high blood pressure and circulation problems. It accounts for about 30% of people with dementia and occurs due to repeated small strokes or cerebral problems. There are two types of vascular dementia:

- **Multi-infarct dementia** is caused by a series of small strokes, known as mini strokes or transient ischemic attacks (TIA). Multi-infarct dementia is the most common type of vascular dementia.
- **Binswanger's disease** (sometimes called subcortical vascular dementia) is related to changes in the brain as a result of a stroke. Atherosclerosis is the main cause, which results in the thickening of the arteries and poor blood supply.

In vascular dementia, the presentation may be similar to Alzheimer's disease but the deterioration is usually followed by a period of some recovery when the person may appear to be back to their 'old self'.

The person may experience the following symptoms:

- Sudden onset and difficulties in doing everyday tasks.
- Communication is affected.
- Problems with balance and coordination.
- Episodes of aggression.
- Confusion.
- The occurrence of strokes.

Dementia of Lewy bodies (DLB)

Dementia of Lewy bodies occurs when cells are present in the brain stem of people with Parkinson's disease. The cells appear in the cerebral cortex. Dementia of Lewy bodies may initially have a similar presentation to Alzheimer's disease, and misdiagnosis can occur. However, there are differences in the symptoms. This was originally identified by Dr. Lewy in 1912. The person may experience the following symptoms:

- Problems with language and memory.
- Problems judging distances and space.

- May have a similar presentation to Parkinson's disease, which is why there is a link between the two diseases.
- Movement may be slow.
- Tremors and stiffness.
- Fluctuation in mood throughout the day.
- Delusions and hallucinations may be present.
- The disease is progressive and the symptoms worsen over a period of time.

People with DLB are sensitive to neuroleptic medication and can result in Parkinson type side effects, such as rigidity or immobility. This medication can potentially cause sudden death.

Frontal-Temporal Lobe Dementia

This type of dementia affects the frontal-temporal lobe and includes disorders such as Pick's disease. The frontal lobes deal with the function of our personality, behaviour and emotional centres. The person may experience the following symptoms:

- Insight may be impaired.
- Extrovert or inappropriate behaviour may occur.
- A person may appear to be rude.
- A person might lose their inhibitions, for example, exhibiting sexual inappropriate behaviour in public.
- Aggression may be evident.
- Problems with concentration and conversation may occur.
- A tendency to develop compulsive rituals.
- Language problems may be evident and difficulties finding the right words are apparent.

AIDS-Related Dementia

Cognitive impairment can occur in people with AIDS, especially toward the later stages of the illness. AIDS is caused by a human immunodeficiency virus (HIV). The virus attacks the immune system, making the person more susceptible to infection. The person may experience the following symptoms:

- Hallucinations.
- Loss of appetite.
- Short-term memory.
- Unsteadiness and changes in personality.
- Changes in mood.
- Problems with communication.

Creutzfeldt–Jacob Disease (CJD)

CJD is a rare but fatal brain disorder that is caused by a particular protein called a prion. The protein results in what is known as spongiform encephalopathy (the appearance of the brain is that of a sponge when examined under a microscope). The most common prion-related disease is CJD, with two other rare, but inherited diseases, called Gerstmann–Straussler–Scheinker syndrome and fatal familial insomnia. CJD was identified by two German doctors Creutzfeldt and Jacob in 1920.

The person may experience the following symptoms:

- Lapses in memory.
- Changes in mood.
- There may be problems with movement (jerky), shakiness and stiffness of limbs.
- Incontinence may occur.
- Difficulty undertaking activities of daily living, therefore, requiring full nursing care.
- Rapid deterioration and death occurs within 6 months, although some patients may live longer.

Types of CJD

There are four types of CJD:

- **Sporadic CJD—**this mainly affects people over 50 years old, and the cause is unknown. The onset of dementia is rapid.
- **Familial CJD—**this type is inherited, and the person develops this at an early age. The course of the illness tends to be longer.
- **Iatrogenic CJD—**this stems from contaminated tissue from an infected person. If medical procedures are carried out, such as grafts and corneal transplants, the infection can be passed on.
- **Variant CJD** (linked to BSE)—in the last decade, this type of CJD has received much media attention and is generally linked to BSE, which is caused by bovine spongiform encephalopathy (BSE). This is a form of prion disease that affects cattle. These are also found in some animal species, such as sheep, cats and deer. The consumption of infected products is said to lead to the development of BSE in people. Variant CJD was reported in 1996 and appeared to affect younger people with the average age of death being 29. The number of people with variant CJD has now declined although the length of incubation is still uncertain.

Alcohol-Related Dementia

This type of dementia is associated with heavy drinking. The cause of alcohol-related dementia is a deficiency in vitamin B1 called thiamine. Many heavy drinkers appear to have poor nutritional intake lacking in essential vitamins. Alcohol also results in poor absorption of nutrients as damage to the lining of the stomach can occur. This disorder is part of the Wernicke–Korsakoff syndrome.

The person may experience the following symptoms:

- Poor insight.
- Apathy.
- Confusion.
- Problems with short-term memory.

Chapter 7
Implementing Person-Centred Communication

Focus on the person's unique way of communicating and engaging

Communication is an essential aspect of human interaction and a necessity that enables individuals to express their feelings, their thoughts and desires. When people communicate with each other, they may expect some form of response from the other person, which can be either verbal or non-verbal.

Statistically, the majority of communication is attributed to body language, with a quarter, being the tone of voice and only a fraction attributed to the words spoken. Dementia affects the areas of the brain that enable people to verbalise or identify the right words, to receive information and to understand what is being said. The person with dementia might have problems expressing language, known as expressive aphasia (when the person knows what they want to say, but fail to do so) or receptive aphasia (where they are unable to take in the information that is being said to them).

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This can prove frustrating for the person with dementia, and when staff attempt to rush them during communication, this can lead to agitation and distress.

Dementia also affects short-term memory, with some interference with long-term memory [1]. This can result in the person asking the same question over and over again, and some staff may find the repetition challenging and frustrating. The key issue here is for staff to remember that they need to adapt the way they speak to the person with dementia, rather than expect the person with dementia to adapt to them. Dementia also affects a person's ability to reason. Therefore, as the dementia progresses, attempting to reason or argue with the person will be of no benefit and can result in the person being frustrated and angry. Staff may also attempt to bring the person back to reality, which no longer has any significance for them, and will result in distress. In addition to this, dementia also affects a person's ability to relate to their environment, which can evoke feelings of fear, anxiety and loss. As the verbal skills deteriorate, other forms of communication become more significant. In this case, person-centred communication can be defined as communicating with the person using their preferred communication method, which is based on their unique significant memories. In other words, staff need to take these significant memories into consideration when communicating with people with dementia.

Behaviour as a Form of Communication

The use of body language is a key factor in the person's ability to convey how they feel. Body language becomes more significant as verbal abilities deteriorate. Therefore, behaviours that challenge may be more indicative of how the person is feeling. Sloane et al. [2] identify agitation as indicative of a desire to communicate needs, and associate it with the loss of control and discomfort such as pain. Manfredi et al. [3] support this by stating that people with dementia use body language as a way of communicating needs, particularly within the advanced stages of dementia. Therefore, behaviour should be seen as the most important indicator to aid in communication.

Similarly, Kovach et al. [4] argue that body language expresses a desire to communicate unmet needs, and found that behaviours such as facial expressions and verbal outbursts are major communication indicators. Dementia can evoke feelings of fear, anxiety and uncertainty, which can result in the person constantly searching and seeking comfort and solace from staff. The need to fulfil these emotional needs by alleviating the negative symptoms becomes significant.

Meeting the Emotional Needs of People with Dementia

Staff may appear to meet the physical needs of people with dementia well. However, the everyday emotional needs are what many staff struggle to fulfil, due to a number of key factors, such as organisational cultures, time limitations and unsuitable environments [5]. However, meeting the emotional needs of people with dementia should have equal importance to that of meeting their physical needs. Therefore, organisations should have systems and processes in place that advocate this to ensure that this is clearly outlined in the person's care plan and on how the emotional needs are unique to them.

The Importance of Focusing on Emotional Needs

Theories relating to meeting the emotional needs of people with dementia are now used with a key emphasis on 'feelings'-based approaches [6]. As the dementia progresses, people with dementia may struggle to find the right words to express their needs. Therefore, feelings become significant as the person attempts to convey how they feel [6–9]. Emotional need 'centres on such basic feelings as love, fear, anger, sorrow, anxiety, frustration and depression, and involves the understanding, empathy and support of one person for another. Such needs normally occur in everyone but usually increase during periods of excessive stress or physical and mental illness and during various stages of life, such as infancy, early childhood and old age' [10]. Verity [11] summarises the importance of feelings and emotions by identifying five key universal emotional human needs (Table 7.1). These are significant at each stage of a person's life. Often overlooked in dementia care, understanding emotional needs can provide a useful way in which staff can identify the significance of emotions and feelings to better understand the complex world of people with dementia.

Emotional Needs and Significant Memories

People with dementia may use words that relate more to significant memories, which may be indicative of deeper emotional needs. The most significant memories that can fulfil emotional needs of most people are those associated with key individuals, places, special items or pets [12]. These include mother, father, children, wife, husband, pets, grandparents, grandchildren, siblings, home, work and even

Table 7.1 Universal emotional human needs

1.	The need to have a sense of belonging where people can love and be loved
2.	Self-esteem needs to be boosted in different ways
3.	The need to have the opportunity to care, not just for others, but for oneself
4.	The need to have a sense of purpose in life, where people feel useful and needed
5.	The need to have choice, be respected and treated with dignity

Adapted from Verity [9, 11]

places. These give people an identity, a sense of belonging and a purpose in life [11]. The person may not necessarily have had a positive relationship with these key people or places, but it is the significance of them and what they represent that can evoke an emotional response or need. Therefore, when people find themselves in situations that are frightening, uncertain, or that do not make sense to them because where they have little control over their lives, it is what is familiar to them that then helps to reassure themselves that they are safe. (Tables 7.2 and 7.3 outlines some examples of what is significant to many people and the possible emotional need they may associate with this significant memory. This is a generalisation as each significant memory and emotional need will be unique to each person.)

Table 7.2 Significant memories that involve key people in a person's life and the possible emotional meaning

Children—the need to feel useful and needed, to love and be loved, opportunity to care, boost self-esteem, feeling valued, inclusion, self-worth, acceptance, acknowledgement, admiration, appreciation, being believed in, competence, confidence, being in control, listened to, reassurance, recognition, being respected, feeling safe and secure, support, trust and understanding. Children give people a sense of purpose. Many people with dementia were and are still parents and grandparents

Mother and wife—the opportunity to care, to love and be loved, feel useful and needed, boost self-esteem, control, belonging, intimacy, provider of physical needs, such as food, alleviate physical discomfort such as pain, fear, feeling valued, inclusion, self-worth, acceptance, acknowledgement, admiration, appreciation, being believed in, competence, confidence, listened to, reassurance, recognition, being respected, feeling safe and secure, support, trust and understanding

Father and husband—the opportunity to care, to love and be loved, feel useful and needed, boost self-esteem, control, comfort, security, stability, protector, provider of physical needs such as food, alleviate physical pain and discomfort, feeling valued, inclusion, self-worth, acceptance, acknowledgement, admiration, appreciation, being believed in, competence, confidence, being in control, listened to, reassurance, recognition, being respected, feeling safe and secure, support, trust and understanding

Reference—Taken from Hobson [13]

Table 7.3 Significant memories that involve key places/roles/belongings in people's lives and the possible emotional need that needs to be fulfilled

Home—a place of comfort, opportunity to care, love, privacy, belonging, feeling useful and needed, alleviate fear, feel valued, safe and secure, support and trust

Pets—the opportunity to care, to love and be loved, useful and needed, boost self-esteem and control. Pets are also a significant source of comfort for many people with dementia. If someone had a pet for a long time, he or she would relate to this at times when they may need to fulfil an emotional need

Work—the opportunity to care, feel useful and needed, boost self-esteem, control, a sense of purpose and belonging, feeling valued, inclusion, self-worth, acceptance, acknowledgement, admiration, appreciation, being believed in, competence, confidence, listened to, reassurance, recognition, being respected, feeling safe and secure, support, trust and understanding

Reference—Taken from Hobson [13]

Communicating with the person by exploring significant memories to meet their emotional needs

People with dementia, like everyone else, may relate to the significant memories identified above and, when they feel frightened and lost, will search for what is familiar to them. Listening to the words they may say enables staff to communicate and interact with them based on the person's unique significant memories. The example in Table 7.4 is based on one staff member's experience, and how she was able to respond to the unmet need of the person with dementia.

Table 7.4 Example

'Mary' was a nurse in a dementia care unit. She observed one of the people with dementia, called 'Joan' walking around the unit. Joan had been walking around for most of the morning. What drew Mary to Joan was the fact that her eyes were tearful and red, and she appeared visibly upset. Mary approached Joan and asked her how she was. The following account is how the conversation progressed

Mary: Hello Joan
Joan: Hello dear
Mary: Are you okay?
Joan: No dear, I'm not. I'm looking for my mother.
Mary: You are looking for your mother. What would mother bring you, Joan?
Joan: Everything (Joan bursts into tears). I do not know who I am, where I am going, where I have come from. I feel lost; nobody has spoken to me at all; you are the only person who has spoken to me today, no one talks to me here, dear

The Response of Staff

Mary might have responded by focusing more on the word 'mother', stating 'She is not here', or by telling Joan, 'She will be coming later', or even worse, she could have attempted to bring Joan back to reality, which might have distressed her even more. These responses may not necessarily address the unmet emotional need that the person is attempting to convey [13].

Communication That Focuses on Feelings and Emotions

By focusing on the feelings and emotions of the person with dementia, their tone of voice and body language, staff may begin to realise that the person in their care is asking for something other than their literal 'mother'. As the dementia progresses, the person may struggle to find the right words to express how they feel, therefore, the use of significant memories becomes a way to express their needs and desires. It could be argued that Joan in this case may not be literally asking for her 'mother', but the significance of 'mother', which indicates a more complex and deeper emotional or physical need, such as they are hungry, upset, need the toilet, need to be loved, or someone has upset them, means they are looking to staff for comfort and reassurance [13, 14].

By developing the ability to focus more on the tone of voice and body language, staff can become more skilled in identifying the complex emotions and feelings evoked through spoken words, and the significance of these in relation to fulfilling emotional or physical needs. For Mary, asking 'what would mother bring you' is a way of enabling her to explore feelings and emotions behind the word 'mother', thus empowering Joan to state what it is that would take away those feelings of fear, loss, emptiness and sadness. Joan is asking for her emotional needs to be fulfilled:

the need to feel useful and needed, to love and be loved, to have self-esteem boosted and to have a choice. Having these needs met enables individuals to feel a sense of purpose and belonging.

In addition to this, when people with dementia are asking staff if they can go home, it is important to think of the significance of home and observe the person's body language and tone of voice. The 93% of communication that is body language and tone of voice will be telling staff how the person with dementia is feeling when asking to go home. They may be distressed, upset, appear lost, or be standing by the main door or attempting to open it, indicating a desire to leave, particularly if they are distressed. The person may feel trapped and lost, therefore, responding by telling them that they now live in the care home, may exacerbate the feelings of anxiety and distress, as the person is no longer able to relate to this or respond to reasoning.

Equally so, wanting children, partners or even significant places and pets are all key communication factors that people with dementia will use to express emotional needs [13]. Unfamiliar places can constantly evoke negative feelings of loss, and if these continue, people with dementia may well display behaviours that challenge. Therefore, staff will need to identify ways in which they can meet the emotional needs of people with dementia more effectively by focusing on communication based on the person's unique significant memories [12].

As a person with dementia attempts to make sense of the world around them, communication becomes central to their understanding of what is happening to them. The need for staff to adapt their approach becomes an important factor in communicating with people with dementia. The person with dementia may forget what has been said to them by staff, but they may not forget how staff might have made them feel, even if they may not necessarily understand the significance of this. Therefore, even if both negative and positive interactions may be forgotten by the person, the feelings that have been evoked by such interactions will linger for hours. These feelings have a significant impact on the person, therefore, staff need to ensure that each interaction is one that will evoke positive, and not negative feelings.

Summary on Communication

The role of staff is to facilitate the process of communication to enable the person to convey their feelings and emotions. However, each person will be unique in the manner in which they will communicate and respond. Therefore, staff need to take this into consideration and ensure that they continue to adapt the way they communicate with each person with dementia and enable them to explore and relate to their significant memories. This will enable staff to promote quality person-centred communication that reduces distress, and above all preserves the dignity, rights and uniqueness of the person [14]. Staff can be a driving force in achieving this.

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Chapter 8
Managing Behaviours That Challenge

Definition of Behaviours That Challenge

Behaviours that challenge is any behaviour that staff find difficult to deal with, as such the focus is on the person and why they are displaying the behaviour, rather than the person being perceived as the issue. As such the term behaviours that challenge was introduced by the National Collaborating Centre for Mental Health [1] which reinforced the need to move away from seeing the behaviour, but more about the person and the significance of the behaviour. However, the term BPSD is often cited in relation to this and is defined as any behaviour that is identified as putting the individual at risk to themselves or others and can result in harm and poor outcomes and quality of life [2]. This is said to be relatively common in people with dementia with as many as 90% experiencing this at some point in their life, and aggression being cited in almost a third of people with dementia. However, there is growing evidence to suggest that these behaviours are attributed to other factors, other than the experiences of dementia itself [3, 4]. The challenge for staff within health and social care settings is that too often the person is seen as the issue or problem, as such the support provided is often based more on reactive and crisis intervention approaches and 'dealing' with the behaviour, rather than more proactive and preventative strategies to minimise the risks to the person and others.

Five Main Categories of Causes of Behaviours That Challenge

Establishing the causes of behaviours that challenge can be an issue for health and social care professionals and it requires in-depth assessment and reviews of the person whether they are in a care home, own homes or an acute hospital. In most cases, what results in admission to an acute hospital is when there is evidence of physical health deterioration that is as a result of some acute illness, which then

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affects the person's behaviour to the extent that this becomes a risk to themselves or others. As such the main causes that may result in the change in behaviours are attributed to the following: physical, physiological, psychological, environmental and social factors. These need to be considered when supporting the person to identify what else could be causing the behaviour and to ensure that the person is supported to manage this in the first instance. Kitwood advocates that each of these factors has to be considered within the context of personhood and the impact these have on people with dementia [5]. As such he cites attributes such as the person's personality being a factor in their behaviour, as well as their experiences of dementia, their mental and physical health status, their social psychology (that is the environment and social factors) and their biography. The biography is based on significant memories and life story, which will also support in establishing whether the behaviour is based on other factors that may be from the person's past. In other words, the behaviour that challenges may be attributed to the person's past occupation or where they are in their reality and experiences of their significant memories and how they may relate to the here and now, as such understanding the significance of this will be important in supporting the person.

Physical and Physiological Factors

Behaviours that challenge can be exacerbated by physical and physiological factors. These include urinary tract infection, constipation, chest infection, pain, electrolyte imbalance caused by poor fluid intake, medication, heart failure, kidney problems, endocrine problems, such as high and low sugar levels, thyroid problems such as high and low levels of hormones and side effects medication.

Psychological and Emotional

The psychological and emotional factors will include unmet emotional needs, loss of identity, sense of purpose and belonging. Loss of loved ones, family, things that are significant, a clash of reality (the person's reality versus staff's reality), mental illness such as anxiety disorder and distress, depression, schizophrenia, mood disorders and drug and alcohol abuse.

Environmental and Social Factors

These include staff approaches (not understanding what the person wants, a clash of realities), noise, external stimuli such as nursing intervention, which involves bathing, eating, dressing and grooming and support to use the toilet. Other factors such as temperature being hot or cold, frequent changes or restriction in the environment, not having enough space, other people/patients within the unit, lack of stimulation or boredom are all significant factors to consider.

Examples of Behaviours That Challenge

The following are some of the behaviours that staff find a challenge within care settings. These include hallucinations, delusion, paranoia, behaviours of a sexual nature perceived as inappropriate, sleep disturbances, repetitive behaviours, resistive to intervention, self-injurious behaviour, moving property and furniture around in a manner that may cause damage, use of language that may not be perceived as appropriate by others, altered eating habits and all forms of harassment.

'See the Person First, Not the Behaviour' Approach

Kitwood refers to behaviours that threaten dignity and respect of people with dementia. Examples such as these are seclusion, isolation, disempowering, infantilising, institutionalised practice, withholding of services and support, restraint, depersonalising and labelling. Terms that may be used to describe the person such as challenging, problematic, wandering, awkward, difficult, nightmare, attention seeking, demanding and disruptive are best avoided, as these focus on the person as the problem. Kitwood further explores the impact of seeing the behaviour and not the person by referring to the behaviours that challenge identified above as malignant social psychology behaviours and how staff may start to view behaviours evident in people with dementia as a problem. As a result of this, these labelling terms can all become part of everyday language and staff may not necessarily see the implications of this to the person with dementia and in practice [5].

On the other hand, Kitwood advocates the need to replace these malignant social psychology behaviours with positive person work behaviours, which advocate the following: inclusion, life story work, understanding the experiences of dementia and the person's own reality, validation, meeting emotional needs, significant memories and occupation, meaningful activities, positive engagement, respect, dignity, empowerment, behaviours as significant and as a way to communicate, sensory stimulation. Psychosocial approaches to supporting the people allude to positive person work, which promotes respect, empowerment, dignity and least restrictive practice [5].

Behaviour as a Form of Communication

Behaviours that challenge are the person's way of attempting to communicate how they are feeling. The use of body language becomes a key factor as the person's communication abilities start to deteriorate. Sloane et al. [6] identified behaviours such as agitation as indicative of the person's need to communicate unmet needs, and is as a result of experiences of pain. The use of body language is also cited as a way to communicate needs, as such behaviours that challenge become essential communication factors particularly in the advanced stages of dementia [7, 8]. Therefore, behaviours that challenge should not be seen as a challenge, but as key indicators in which the person can express their feeling.

The person's experiences of dementia may result in feelings that can result in uncertainty, fear and anxiety, and often can result in the person seeking solace from staff as a way to deal with negative experiences and the need to fulfil unmet emotional needs.

As such behaviour becomes a form of communication, in which unmet needs are expressed and it is as a result of a combination of factors [5, 9–11]. Theories and models advocate that certain factors are attributed to sudden and gradual changes in the behaviours of people with dementia. All human beings have the five following fundamental psychological needs that have to be met at all times. These are comfort, which centres on the provision of warmth and strength. The need for attachment, which relates to the forming of specific bonds, inclusion, which involves being part of a group, occupation, thus being involved in the process of life and identity which is about a sense and feeling of who one is [5]. As such our human needs are said to drive our behaviour, and if these are not met, the result will be behaviours that challenge, particularly aggression and agitation.

What happens if these needs are not met?

Using Psychosocial Approaches to Deal with Behaviours That Challenge

Research advocates that to address behaviours that challenge in dementia care requires staff to utilise psychosocial approaches in the first instance which involve less restrictive interventions based on identifying the underlying causes and establishing how best to address these using individualised strategies [12–17].

There are two main psychosocial approaches to managing behaviours that challenge. These are behavioural and non-pharmacological (the use of psychosocial approaches and person-centred communication). There is a third approach, used in conjunction with these above and that is pharmacological, which focuses on the use of medication [18]. The key focus should be on using the first two approaches in the first instance, and then the use of medication should be as a last report when all else have failed. In some instances, if the person's behaviour places them at risk of harm to themselves of others, the use of medication may be advocated in conjunction with the more psychosocial models of care.

Psychosocial models in dementia advocate that dementia is a complex interaction of key defining attributes, in which the person's biography, personality, physical and mental health status, the person's environment, meaningful activities, and the impact of dementia on the person become significant in behavioural changes in people with dementia [5]. As each of these is said to contribute to behaviours that challenge, the focus should be on reducing the impacts of these on the person. It is about moving away for seeing the person as having some form of illness that needs to be treated, but more about promoting greater acceptance of the behaviour and its significance to the person. As such the focus should be addressing the unmet needs of the person [19].

Assessing and Addressing Unmet Needs

Finding out about the person—the need to find out about the person is important before establishing the individual approaches to be used to support the person. The following are considered as part of the detailed assessment of the behaviours and the underlying issues relating to this [4, 20, 21].

Life Story and Significant Memories

The person significant memories and the impact this has on how they relate to the 'here and now'. This will also include examples where there may be 'clash or reality', which is where staff may attempt to bring the person back to reality when the person is no longer able to relate to this, as they can only relate to their own reality [10].

Life story work and significant memories can support in identifying behaviours that are attributed to the person's emotional needs, sense of loss, attachment, occupation family and their ability to cope with an uncertain world resulting in frustration and aggression [5, 9, 10, 19–21].

The Person's Personality

Behaviours that challenge may be attributed to the person's personality, and as such finding out about this will enable staff to establish key aspects relating to the person's personality. Staff will need to recognise the challenges associated with attempting to change a behaviour attributed to the person's personality, which will be an unrealistic expectation to attempt to address this [4, 5, 9, 20].

The Environment and Impact on the Person

The environment can have a significant impact in contributing to the changes in the person's behaviour. The key issues to consider will be the impact of the surroundings on the person. This will include colour, noise levels, visual confusion, how restrictive the environment is, how the person is able to relate to this, whether the environment enables or disables the person abilities [4, 5, 9, 20].

Impact of the Person's Physical Health Needs

The physical health needs of the person will be a significant impact on the person. This will include assessing for pain levels and undertaking a series of medical investigations and examinations to rule out any physical and physiological factors that may be contributing to the changes in the person's behaviour [4, 5, 9, 20, 21].

The Person's Experience of Dementia

Each person with dementia is unique and as such it will be important to establish the person's experience of this. The need to identify factors at each stage of the progression of dementia will indicate different behaviours and their significance of this. There are behaviours that may be indicative in the early stage of dementia as such understand how to provide the right support for the person which will be best suited to meet their needs [5, 11].

Assessment of the Person's General Appearance

This will involve understating as assessment of the person and their general appearance and what the behaviour may be indicating. Staff would assess what the person may be indicating by the way they may be presenting themselves, whether they look depressed, frightened, anxious, angry, and the extent to which this may not be consistent with what staff are used to seeing when the person is happy and relaxed [4, 20].

Impact of Mental Health Needs

The assessment of the person's mood, anxiety levels and any evidence of delusion or hallucinations, depression, emotional needs.

Medication and Side Effects

This will include any medication the person is prescribed, the side effects and how they may impact on the person's behaviours.

What the Person May Be Saying

Any evidence of behaviours such as constantly calling out, crying or screaming continuously and the significance of this [4, 10, 20, 22].

Assessment of the Person's Behaviour

This will involve undertaking a detailed and comprehensive assessment and obtaining information about the behaviour. Two types of behaviour charts can be used for this. These consist of one that will include monitoring the person's behaviour on a daily basis over a specified period of time. Initially, it will be useful to record the person's behaviour on an hourly basis within the acute phase to obtain a detailed assessment of this. In addition to this, each time a behaviour that challenge occurs which requires recording as an incident, further recording of the specific episode will also be required in conjunction with hourly observations. Recording each incident to identify the significance of the behaviour will be achieved using a behaviour chart that will be based on the antecedent, behaviour and consequence approach, which provides details of the frequency and intensity of the behaviour as follows [22].

Antecedent

Before the incident—what happened before the incident, what was the persons doing, who was with them, what time did the incident happen, where were they, what did they say prior to the behaviour, how did staff response initially?

Antecedents are any of the factors that will have been identified in the assessment process, which includes physical, physiological, psychological, social and environmental factors.

Behaviour

During the incident—what was the actual behaviour, how did it happen, who was there, what did staff do, what did the person say or do during the behaviour, what words did they use, what actions did they use?

After the incident—what happened after the behaviour, was anyone injured, what happened to the person, what did staff learn from the behaviour, what could have been done differently to avoid the incident, what debrief tool place, was the care plan and the person reviewed? [4, 19, 20, 23, 24].

Example of a Simple Behaviour Chart to Be Used After an Incident

Date and time	Antecedent	Behaviour	Consequence
	.		

Implementing the Psychosocial Model

Implementing a psychosocial model to supporting the person will involve using the evidence that would have been obtained as part of the detailed assessment and then identify how this information can be used to develop a person-centred strategy [13, 19, 22, 25, 26].

The following case studies outline how people with dementia can be supported to manage the experiences of the behaviour in different care settings. This can be achieved using a systematic approach to care using a process that will clearly assist staff working with them to undertake a differential diagnosis.

Example 1: Managing Behaviour Within an Acute Ward

Molly was admitted in an acute medical assessment unit with a suspected urine infection. When she arrived on the ward she was agitated and distressed, and staff were not able to undertake any observations on her as she would refuse. Molly started to call out requesting to go home and asking for her mother constantly. The ward was really busy, as such no one took much notice of what was happening and she continued to call out and did not settle. Molly's behaviour began to be escalated and she warned staff that if she was not able to leave, she would do something that people would regret. After an hour, the behaviour continues and she got up from her bed and walked across the ward where she picked up a chair and threw this across the ward. It was at this moment that everyone on ward started to take notice and one member of staff attempted to engage with her, which resulted in her hitting them. She then walked out of the ward and no attempts from staff could deescalate the behaviour. She then left the hospital only to be retuned back by security guards as she left the hospital and was handing toward the main road. When she returned back on the ward, she was given rapid tranquillisation using the protocol for the hospital, which resulted in her being sedated for several hours. During this time, staff were able to take her blood and other observations required.

Supporting Molly with the Behaviour

Supporting people on an acute medical assessment unit does have many challenges for staff as unlike purpose build dementia unit, the unit is not equipped to support the need of people with dementia within an acute care environment. When Molly was first admitted, there should have been someone with her to support her needs on a one to one basis initially as Molly's behaviour was indicative that she was frightened and had an underlying physical health need that may have been exacerbating the behaviour. Preferably Molly should have been supported in a side room that was equipped to support people with dementia. Having specialist rooms and areas that are dementia-friendly within acute care settings is essential as part of promoting dementia-friendly environment that is equipped to support people with dementia. Molly was agitated and distressed and there is evidence that her behaviour escalated gradually to the extent that the time staff become more involved, the behaviour had reached crisis point and no amount of attempts to deescalate could work at this stage. She had been communicating her needs to staff about how she was feeling.

On admission Molly should have been admitted with details of her life story and all the key essential information that would have enabled ward staff to provide the initial assessment for her. As well as having this information, Molly should have been immediately referred to a team of specialist dementia and delirium nurses based within the AE and Medical Assessment Unit, who would have this specialist role of supporting the ward staff to make the initial differential diagnosis of Molly using the psychological approach to assess the behaviour and the underlying causes. These nurses would support the person with ensuring that she had all the initial screening which included taking important blood, and physical examinations were done and to diagnose acute delirium and dementia to enable the team to establish and treat the underlying illnesses exacerbating the behaviour. As part of the assessment, pain would also be monitored and a chart commenced, along with prophylactic pain relief, which Molly requires to help to reduce the temperature evident as a result of the urine infection, as well as the pain associated with this. This is what should be advocated within the first few hours of Molly being admitted on the unit. All the other information pertaining to Molly's life story, mental health, usual behaviour, medication and side effects will already be known to the specialist dementia and delirium nurses, and they will be able to utilise this to complete an initial 72 h emergency care plan to help manage the behaviour, whilst Molly was being treated for the acute infection. This care plan would then be used by all key individuals within the unit and any other wards that Molly would be transferred to during the period in hospital. As part for this process, the team would already be undertaking a discharge process and liaising with the care home to see if Molly could return to there as soon as she was well enough and to avoid her remaining in the hospital where she would be at risk of developing further complications associated with prolonged hospital stay. A clear coordinated multi-agency approach would ensure that Molly was supported during the acute phase of her illness and hospital staff would support her with the discharge process to enable her to return home as soon as possible [21].

Example: Managing Behaviour Within a Care Home

Alfred is an 87-year-old man admitted to a care home. He was living at home with his wife who was no longer able to cope with his behaviour. The behaviour was described as complex as it included what was perceived as 'property' destruction, constantly moving furniture around, agitated, restless, verbal and physical aggression to staff when they attempt to stop him. He would spend several times a day moving furniture around and attempting to place them in a pile in the corner of the dining room. When Alfred was admitted, he was agitated, restless, distressed and would not stop walking around the unit. He struggled to sleep at night and would refuse to take his medication.

Supporting Alfred with Managing the Behaviour

To support Alfred and to establish the main causes of his behaviour, staff had to start undertaking a differential diagnosis within the first 72 hours, which included ensuring that the General Practitioner (GP) was informed and bloods were arranged to be taken. This also included him being seen by the GP and a physical examination completed to establish if he had any medical and physical health needs that would impact on his behaviour. The staff also undertook a urinalysis to rule out a urine infection and a sample was sent and the team also checked with his wife to establish when he last had a bowel movement to rule out constipation.

The staff commenced a pain monitoring chart and checked with the GP to commence a prophylactic pain relief using paracetamol and would monitor his behaviour prior to administrating the pain relief and then record this again after a few hours to see if this had reduced. The nursing staff would continue with this throughout the day and monitor the behaviour over a period of 24 hours and also after each incident using the ABC chart.

Following an examination of his physical and physiological needs, the staff then assessed his mental health needs, and the fact that he was very distressed and kept calling out for his wife. His life story work was completed by staff in conjunction with his wife and all the medication and potential side effects were recorded. The staff then discussed what his past occupation was, which was that he was a removal man and had spent 40 years working in this role. As the staff continued to monitor his behaviour, it become more and more evident that he would move furniture and appear to take things apart as part of this process and that him placing the furniture in a pile in the corner was that that he was preparing for the removal team to come and start work. The staff were able to differentiate between what behaviour was indicative of his past occupation and those that were attributed to his experiences of dementia based on an underlying factor. Once the staff had gathered all these key factors, they were able to devise a person centred plan to manage the behaviour. This included staff working with him on a one to one basis during the times he was displaying the behaviour and would allow him to participate in moving the furniture around safely. This would be for a period of about 2 hours twice a day and in between he would settle and have a cup of tea, interact with other service user and staff. The staff realised that this behaviour was not going to stop as Alfred was displaying behaviours that were consistent with his significant memories and past occupation and that by managing this, they were able to work with him safely. The staff recognised that it would be unrealistic to attempt to stop the behaviour, but what they were able to achieve was reduce the intensity of this. They were able to achieve this by implementing more positive risk strategies that allowed and provided Alfred with a sense of identity, purpose, belonging, self-esteem and meaningful activities, occupation, dignity and respect. As a result of this, the behaviour was managed well in conjunction with his wife and with the support of all staff involved.

Example: Managing Behaviours Within Person's Own Home

Mary is 75 years old and lives with her husband, who is her main carer. Mary spends most of her time following her husband everywhere and becomes frightened each time she is not able to find. Mary will search continuously for her husband and her behaviour has started to become a challenge to her husband and she will become distressed. She is not sleeping at night and her husband had reported that he is struggling to support her as he is not in good health himself. She is also not eating and will use the toilet inappropriately and has hit her husband on several occasions. Professionals were alerted of the concerns with her behaviour when a safeguarding was raised as she had been found walking on her own in the street wearing only her nightdress. Mary's husband does not want her to be admitted to hospital or residential care and feels that this is not something she would want, and he also expresses a wish to have further support and help for her to remain at home with him.

Supporting Mary with Managing the Behaviour

Mary was referred to a team of nurses who specialise in crisis intervention to support people with dementia who may have behaviours that are a challenge within the community. When the team visited, they reviewed the care and support for Mary by undertaking a comprehensive assessment of her immediate needs which they did in conjunction with the GP. The initial physical health assessment was completed by the GP and the nurses, to include taking blood and completing a full physical examination to rule out any factors that may have affected her behaviour. Mary was also commenced on prophylactic paracetamol and a pain monitoring chart to see if there was any evidence of a reduction in behaviour following the administration of pain relief, as her husband had reported that she may have been in some discomfort. The nurses with the support of her husband started to monitor her behaviour very closely over a period of a few weeks, and extra support was provided for her husband to help him to cope with the behaviour and to provide him with some relief whilst comprehensive assessments were being undertaken as part of a differential diagnosis. The urinalysis and urine sample were taken, which indicated that Mary had a urine infection and on further observation, it was also established that she had not had her bowel open for over a week, and her diet and fluid intake was very poor. The specialist nurses worked in conjunction with the GP to initiate a plan to address her urine infection and constipation as it was also evident that this had been the source of the pain and discomfort; the husband had indicated that this was as a result of the urine infection and constipation. When Mary was given the paracetamol and the pain was monitored and recorded on the chart; there was evidence that her behaviour would reduce during the times she was given the pain relief. The nurses also undertook a complete assessment of the home and the environment to establish what else could be done to improve the environment to ensure that this was enabling by providing her with the appropriate recourses to enable her to find her way around. Mary was now referring to her husband as her father, as such causing further distress when her husband continued to attempt to use reality orientation, as such the nurses provided him with the strategies to help him to address her emotional needs, and how-to response when she called him father instead of his name. The staff also provided guidance on how to support Mary with her food and fluid intake and how the husband with the support of carers now coming in could record what she was eating and drinking. Over a period of a few weeks Mary's behaviour reduced significantly when the urine infection and constipation were addressed, and her diet and fluid intake also improved, which meant that she was no longer dehydrated. Her pain levels reduced, and the GP was able to reduce the pain relief from regular to as and when required. The nurses also provided her husband with support to engage with carers that provided support for people with dementia and their families. Mary was able to remain with her husband with regular support from the specialist nurses. This was in conjunction with other members of the third section who all worked and coordinated with the husband to support Mary, as such they were able to utilise a range of resources available, thus supporting in managing the behaviour that was a challenge.

Summary on Managing Behaviours That Challenge

The three case studies highlighted the challenges for staff in each of the care settings and the person's home. However, despite this, the key focus was to demonstrate how people with dementia should be supported to manage behaviours that challenge. This requires the support of individuals who have the right skills, knowledge and competencies to support people with dementia. The case studies outlined the importance of detailed assessments as key to supporting people with dementia when required. The need for staff to examine the underlying causes of what could be contributing to the behaviour was a key factor. In each of the cases, what was demonstrated was that with the right support people with dementia do not necessarily require the use of restrictive interventions or the use of medication, but an understanding of what the person's wishes are and how they can be supported to live well wherever possible with dementia. The need for staff to undertake close behaviour monitoring, in which for the first week, the behaviour was monitored on an hourly basis, over a 24-hours period was crucial. In addition to this, every incident that occurred was recorded on the ABC charts and the details were used to review the person, and as such the antecedence, behaviour and consequences would enable staff to establish what the triggers to the behaviour were, who was there, what the person was doing, who were they with, what impact the environment or other people have on the person, whether there was any evidence of any restriction in the environment, lack of space to move around, noise and poor light and an environment that disabled the person's abilities.

This detailed assessment would enable staff to develop a person-centred plan to mitigate the risks associated with the behaviour. This would include person-centred ways to support them in managing the behaviour without resorting to restrictive interventions that would result in further distress unless there was evidence that the person was at risk to themselves or others.

Psychosocial approaches to managing behaviours that challenge promote dignity, respect, autonomy, empowerment, positive risk taking and an acceptance that behaviours that challenge are normal, as such staff should recognise this and see the person first and not the behaviour, but above all recognise that behaviour is a form of communication which enables people with dementia, just like everyone else to communicate their unmet needs.

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Chapter 9
Designing Environments That Enable

Designing environments for people with dementia is an important aspect of maintaining well-being within organisations [1]. There has been much debate relating to what constitutes a dementia care environment, and whether current dementia organisations adequately reflect the needs of people with dementia [2, 3]. Issues in relation to dementia care environments will be explored, which will highlight the importance of how the environment should enable, rather than disable people with dementia. Human beings have a relationship with their environment, and how they relate to this is dependant on where or who they are with. People spend the majority of time engaging with what is in their environment, and this includes other people, the amount of space they may have, and any objects or tasks at hand. The everyday environment gives people a sense of belonging and helps them to relate and make sense of what is happening around them.

People with dementia are no different; the very same feelings and emotions that are created by the environment are also evident among people with dementia. The only difference is many people have, to some extent, chosen to live in their environment. However, most people with dementia are living in organisations because they may no longer be able to remain in their own homes.

Experiences of People with Dementia and the Environment

Dementia affects a person's cognitive abilities, which has an impact on the way in which they relate to the world around them, their perception and sense of time [4]. Since dementia is a progressive disorder, the environment needs to be reviewed regularly to ensure that it meets the changing needs of people with dementia. As such, the need to adapt the environment can aid in alleviating many of the feelings and emotions evoked as the person struggles to make sense of where they are, who they are with and why they are in this environment [5]. The environment

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cannot realistically meet the needs of all the people living within the care setting, but it should provide an opportunity for people with dementia to feel a sense of belonging [6].

An organisation needs to understand the impact dementia can have on the person before designing the environment. According to Victoria State Government [7], as dementia affects memory and perception, many people with dementia may:

- Forget where they have put things, hence the need to search for items that are significant to them.
- Forget what they have just done recently, hence the need to repeat things, even if they have just completed that task seconds before.
- Forget the names and faces of people who are close to them, and this includes staff.
- Relate more to their unique significant memories and struggle with the most recent aspects, which is why some people with dementia struggle to understand when staff attempt to bring them back to reality. This can lead to distress as the person may struggle to relate to this.
- Affect the person's ability to reason. They may struggle to relate to actions that are in the future, and understanding patterns and abstract things leading to misinterpretation.
- Affect the person's ability to learn new things. Therefore, changes in the environment can be confusing and disorientating.
- Affect the way in which the person can find their way around. As a result, they can forget where the toilet, bedroom, or dining room are, even though they may have lived in this environment for a long time [7].

Key Issues to Consider When Designing a Dementia Care Environment

Dementia care environments should take into consideration the importance of both the physical structure of the building design and the social aspects required to meet the emotional needs of people with dementia [1]. To maintain the quality of life for people with dementia, an environment should have fewer restrictions in relation to the physical design of the building. At the same time, it should provide opportunities for people with dementia to engage in social aspects that enrich and fulfil their lives. This should be achieved at the initial design phase; however, for some organisations that are already established, this may not be possible. Therefore, the key focus should be on how the current environment can be enhanced as much as possible to meet the needs of people with dementia. The following can be embedded within any organisations that advocate person-centred dementia care environments irrespective of the structural design.

The Environment Needs Fewer Restrictions

Many people with dementia experience a sense of loss, the constant searching for loved ones and what is familiar to them, which can result in anxiety and distress [8]. Having people with dementia confined to one particular area in the care setting is common in larger establishments. This can create a restrictive environment, where the person may constantly request to leave. Confining people with dementia to only one area of the care setting, with the occasional outdoor activity, may not in anyway promote comfort or empowerment if the person cannot go out when they choose to do so. Some organisations may rationalise this as being in the person's best interest; however, there needs to be a balance struck between protecting the person from harm and organisational and design issues, rather than the person being perceived as the problem [9].

Provide a Sense of Belonging

This is an important aspect for people with dementia. As the person starts to struggle to relate to the world around them, the need to connect with the here and now becomes crucial. The person may not feel a sense of belonging, and no amount of reassurance from staff can alleviate feelings of anxiety, fear and distress [6]. It is about seeking what is meaningful to them, making sense of their environment and what is happening to them, and above all, feeling a sense of belonging [3, 10].

Provide the Need for Inclusion

There has been much debate as to whether people with dementia should be supported alongside people without dementia, or at different stages of the disorder. Inclusion is important for people with dementia, and when supported in separate units or feeling isolated, it may create distressing experiences of rejection, where they are not able to feel part of what is happening [11].

Person-centred care should seek to identify this, and find ways in which people with dementia can feel included in everyday life and encouraged to engage in various tasks with others living in the care setting and staff [12]. A dementia care environment should not have a 'them and us' culture between staff and people with dementia, where staff only sit in their designated rooms, using separate utensils and utilities [12]. If it is not good enough for staff to use, then it is not good enough for people with dementia either. It is best to encourage an environment where staff can eat and drink with people with dementia, wherever possible.

Provide a Sense of Purpose

Although the person may have dementia, it does not mean that they suddenly stop being a nurse, teacher, housewife, parent, partner or grandparent. People with dementia revert back to their past, which has significant memories, and they need to relate to these more as the dementia progresses, finding the present more difficult to understand [13]. Providing opportunities to support people with dementia in everyday tasks will enable them to alleviate anxieties, as everyday tasks create a sense of normality that many of us take for granted [4]. This will also draw from the person's life experiences, strengths and abilities, thus providing them with activities that are meaningful, and give them a sense of purpose in life [6].

Provide the Need for a Unique Identity

The person with dementia is unique, and as such, their uniqueness should be advocated based on their life story. The care setting may not be able to design each person's unique environment based on their life story, but their own bedroom provides the opportunity to promote their uniqueness [11, 13]. Therefore, if the person wishes to change their own environment, this opportunity should be respected. Their life story should be incorporated in the person's day to day life, and any interactions that staff have with them should reflect this, and be maintained at all times [11].

Dementia care environments should avoid adopting the medical approach that sees dementia in terms of a general decline of the person's abilities, where there is little or no attempt to advocate positive interaction or create an enabling environment [14]. The person-centred theory advocates the need to focus on promoting personhood and sees dementia as a complex interaction of five attributes, of which a person's unique identity and the environment are some of these. When viewing the environment from a person-centred perspective, the key focus should be on adapting this to reflect the person's unique identity [11].

Designing the Environment: The Initial Phase

When designing environments to support people with dementia, many organisations often overlook the initial design stage [2]. The responsibility for those designing the environment should focus on how the health and social care needs will be viewed from the perspective of people with dementia [7]. The designer should have some knowledge of dementia and the impact this can have on a person's perception of the world around them. This will allow the designers to focus on designs, features and fittings, furnishings and colours that reflect a dementia-friendly environment [15, 16].

Physical Environment and Social Interaction

For many people with dementia, it is difficult to separate the physical environment from social interaction; therefore, these two aspects tend to be interlinked [2]. Having a physical environment that appears dementia-friendly is not adequate in itself, as staff and others in this environment need to support people with dementia to deal with the changes and stresses encountered on a daily basis [12].

It is, therefore, important that people with dementia are supported to engage in their environment; some may be able to do this spontaneously, whilst others may require support [12]. It is about creating an environment that has meaning for people with dementia. Every person with dementia is unique, and their interpretation and experience of the environment will also be unique, hence the need to find ways to interact with them on an individual basis, wherever possible [13].

What Does a Home-Like Environment Involve?

The design of a dementia care environment can contribute to the deterioration of people with dementia and can have a significant impact on their well-being [2]. The environment can also ‘enforce’ dependency, where the people with dementia may feel powerless and helpless as a result of the layout, particularly if they may be required to remain in one particular area of the care setting for most of the time. Although organisations may need to consider health and safety requirements, there needs to be a balance between what is required to maintain health and safety, and providing a home-like environment that allows people with dementia to move freely with fewer restrictions around them [17].

For a care setting to reflect a home-like environment, it needs to consider what is important to people with dementia and what is meant by this term [4]. However, the broad nature of the term ‘home-like’ can lead to various interpretations. For example, making references to corridors may appear to relate more to an institutional setting rather than a home, as many homes do not have corridors, but have hallways or halls. Organisations also need to avoid having designated activity rooms, where people are taken to engage in different activities [4]. Activities should be undertaken in any part of the care setting as these should be regarded as part of people with dementia’s day to day living. It is also important to avoid fake environments, such as referring to a wallpaper of books as a library, when staff know that this is not the case. It would be better to provide an actual library room with real books, which people with dementia can touch and feel, as well as read.

The need to have a designated nurse’s station perched along a ‘corridor’ may not be consistent with a home-like environment, but a hospital. For most people, a home-like environment is about having what is familiar, having normality, doing everyday tasks and things, and having continued family involvement and interaction [4, 18]. According to Calkins [19], people with dementia need to:

- Feel as if they have personal control and are able to have a choice and make decisions for themselves.
- Feel as if they are receiving person-centred care based on their own unique significant memories.
- Feel that the relationships they have with staff and people around them are meaningful.
- Have smaller living arrangements that reflect a more home-like feel, rather than being made to sit in large sitting rooms with chairs laid out in rows.
- Have an environment that enables people with dementia to engage with the different senses. This provides opportunities for people with dementia to have a stimulating environment.

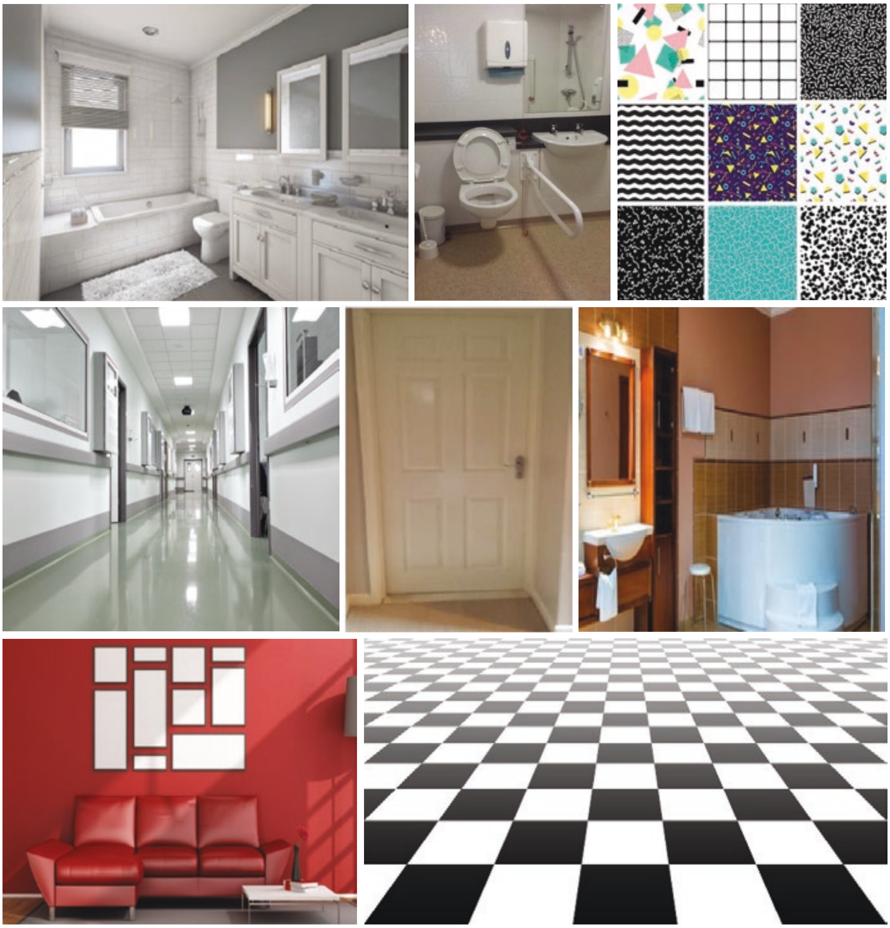
The factors above highlight important issues to consider when designing environments for people with dementia. Although this can be a challenge for many care providers, it is important to ensure that the perception of what constitutes a home-like environment is based more on what would be suitable for people with dementia, rather than what the organisation feels should be regarded as a dementia care environment. The home-like environment should also seek to alleviate feelings and emotions of anxiety, fear and distress that can be created by an unfamiliar environment. This can be achieved by having a dementia-friendly home-life environment that has features, fittings, colours that enable people with dementia to find their way around the care setting.

Physical Environments That Disable

Doors, Corridors, Bathrooms, Flooring, Textures

Many organisations make the mistake of having everything in plain white or the same as the colour of the walls, features and textures. If a person with dementia was to try and find their way around, they may struggle to see doors, door handles, handrails, floor, toilet seats, taps or chairs. This is because everything will blend in with the same colour background and flooring. This colour scheme camouflages the significant areas, equipment, furnishings and features within the environment. Physical environments that disable also have too much clutter, lacking enabling stimulating resources, which staff can use to support people with dementia to engage in activities that should appeal to the senses. Also the signs to help orientate people with dementia are normally very poor, either in the same colour as the doors or too small to see and not at the right eye level. The following images show examples of an environment and colour schemes that should be avoided.

Examples of Colour Schemes and Textures to Avoid



Shiny flooring creates an illusion that there is water on the floor, whilst complex abstract textures can be confusing and overwhelming. Also, avoid having flooring with different textures, such as carpet in one section, followed by laminated flooring, which can create an illusion that there is a step. This could potentially lead to falls.

Environments That Enable with Good Colour Contrast

A good colour contrast is best to use on chairs, toilet seats and equipment, as this will enable the person to find their way around. There should be no matching colours between the floors, walls and equipment so as to make it easier for people with dementia to see areas that are of significance. For doors to stand out, they should be painted on both sides and have a sign indicating what the room is, and this should be at the right level to enable people with dementia to see this. If the person's pictures are to be used to help orientate the person to their room, it is best to use images of the person when they were younger, not as they are in the present. This is because the person may no longer recognise themselves. However, this will depend on the stage of the person's dementia and where they are in their own reality. It is also best to limit colours used and to avoid colours that are too intense and can be overwhelming.

Examples of Door Colours That Can Be Used

Examples of Good Colour Contrast in Significant Areas

Environments That Meet Emotional and Social Needs

The environment should create comfort and acceptance—this helps alleviate negative feelings and emotions evoked by unfamiliar environments. The use of smaller units can help create this.

The environment should promote social interaction—this helps people with dementia to feel less isolated and lonely.

The environment should create a home-life atmosphere—this helps provide what is familiar and associated with comfort and safety.

Should create the need for a unique identity—this helps to retain personhood and individuality, control, dignity, choice and respect.

Promote the need for occupation—this helps to provide a sense of purpose in life, self respect and dignity. It is also about what is meaningful to the person and draws from their life experiences associated with everyday life.

Promote inclusion—an environment should provide an opportunity for people with dementia to engage, eat and drink with staff. There is no 'them and us' culture that alienates staff and people with dementia.

Summary on Designing Environments That Enable

Providing an environment that enables people with dementia to maximise their abilities is important within organisations. Negative emotions and feelings evoked by unfamiliar surroundings can have an impact on people with dementia, and behaviours that challenge can also intensify. Therefore, the environment should seek to alleviate these feelings and emotions of anxiety, fear and distress.

Providing meaningful everyday opportunities to engage in different tasks gives people with dementia a sense of belonging and normality, and should be central in supporting people with dementia. Finally, a dementia care setting should provide opportunities that empower and enable, rather than disempower and disable. That is what organisations should seek to achieve when designing an environment that will meet the needs of people with dementia.

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Chapter 10
Maintaining Meaningful Activities

Activities Within Care Settings

Activities are some of the most important aspects within care settings and if done effectively can enhance the well-being of people with dementia. Staff need to promote and maintain a supportive environment that enables people with dementia to utilise their skills and abilities [1–3]. However, the subjective nature in which the term activity is interpreted by many organisations leads to variations in the manner in which this is implemented. The benefits of activities within dementia organisations will be explored, as evidence suggests that this can reduce behaviours that challenge and depression [4–7]. For people with dementia, it is about being supported in an environment that enables them to gain a sense of belonging, whilst for staff, the focus should be on providing person-centred activities that promote well-being [6, 8, 9].

Activities is a term used by many organisations to demonstrate that they are providing a service within care settings that enable them to meet the recreational needs of people with dementia. When entering care settings, organisations pride themselves on promoting person-centred activities and often display evidence of this (sometimes through having an activity board) in an attempt to justify that activities are a part of everyday lives for people with dementia. However, having an activity board does not in any way demonstrate that the health and social care is supporting people with dementia to engage in what would be regarded as meaningful activities.

In reality, this process may not be as straightforward as it appears, as evidence demonstrates that many people with dementia are indeed 'dying of boredom' [10, 11]. They are often seen sitting in chairs in lounges, with the occasional interaction from staff, who through no fault of their own may not have any option, but to prioritise what appears to be the more essential tasks that only fulfil the physical needs of people with dementia. Some organisations may appear to achieve this, even with only the minimal number of staff required to meet the physical needs of people with

P. Hobson, *Enabling People with Dementia: Understanding and Implementing Person-Centred Care*, https://doi.org/10.1007/978-3-030-20479-2_10

dementia [10]. However, the emotional needs of people with dementia are often overlooked and may fade into insignificance.

This imbalance is due to a combination of factors, which includes the complex needs of people with dementia and the environment that they are supported in. Each person with dementia is unique, and as such, person-centred activities will require in-depth knowledge of the person to determine what best suits their individual needs and abilities [12]. The process is also complicated by the fact that providing activities has now become more of a requirement within some care settings. This ranges from meeting compliance requirements imposed by various local authorities to legislative stipulations as outlined by the regulatory bodies.

The implications for organisations has resulted in the need to adopt a more structured, 'tick box' exercise approach, which for many organisations is about fulfilling these requirements, rather than providing what would be regarded as everyday meaningful activities [13]. Activities should include three key elements: those based on occupation, those that are leisure related, and those that relate to self-care needs. Organisations should enable people with dementia to have a balance between each of these three elements. For people with dementia, this will depend on their abilities, they will rely on staff to enable them to meet some of the basic needs in life that most people take for granted.

The Purpose of Activities

The purpose of activities is to enable the person with dementia to maximise their abilities and to enhance emotional well-being and self-esteem, as well as providing the opportunity for the person to interact with staff and those around them [5–7, 9, 13]. It should focus on the needs and abilities of the person, rather than focusing on what the person cannot do. In addition to this, activities should also be culturally sensitive, and staff need to adapt to achieve this more effectively. People with dementia, like everyone else, will only engage in activities they find beneficial or that they are interested in; if activities are imposed upon them, they may be less likely to engage in them. Therefore, activities should:

- Be regarded as meaningful, and that means enabling the person with dementia to 'come alive'. If an activity does not allow a person with dementia to achieve this, it cannot be regarded as a meaningful activity [5, 13].
- Be age appropriate, not infantilising, making people with dementia feel like children. This includes the colours and resources used. Items such as colouring books and dolls are often seen within care settings. However, doll therapy has been found beneficial, but only if used as part of a person-centred approach activity programme [14].
- Not be imposed on people with dementia, as they are likely to disengage. For example, if a person is walking around a care setting, staff should avoid the need to try and get the person to sit down and engage with them in an activity that they feel would be appropriate for the person. Instead, staff should focus on what the

person is doing, and may even join the person as they walk around. This provides an opportunity for them not only to accept that it is the person's choice of activity, but also to engage with them. This also enables the person to feel a sense of acceptance, as walking around is a purposeful activity and should not be regarded as a behaviour that challenges, unless it has been identified as such. Therefore, staff should be documenting this as an activity that is going to benefit the person with dementia, as long as they are not distressed.

The Activity Coordinator: Myths Surrounding This Role

Organisations sometimes employ specific individuals, known as activity coordinators, whose role is to provide and deliver activities to people with dementia. The role of the activity coordinator is poorly understood by some organisations, and the coordinators are often regarded as being the only key individuals responsible for providing all of the activities in the care setting. There is also the belief within some organisations that the activity coordinator should be solely responsible for devising and maintaining the relevant sections relating to the activities in a person's care plan, which can be difficult to achieve.

Activity coordinators are often isolated and overwhelmed by what is required from this role. The perception that activities are solely the responsibility of the activity coordinator may be unrealistic, bearing in mind that the ratio of activity coordinators to people with dementia is very low. Therefore, it is impossible to meet the person-centred activity needs of a significant number of people with dementia in a care setting. Providing activities in organisation should be the responsibility of everyone, not just activity coordinators. Activity coordinators enhance what staff are already achieving in maintaining the activity-based needs of people with dementia. In most organisations, activity coordinators undertake the more structured activities that are planned well in advance, whilst staff undertake the unstructured day to day activities that also incorporate care needs. When staff in one care setting were asked about activities for people with dementia they were looking after, they remarked that this question should be directed at the activity coordinator, whilst others commented that activities only took place between the hours of 9 a.m. and 4 p.m., when the activity coordinator was on duty. This approach to activities in dementia should be avoided as this promotes a more institutionalised task-oriented method of maintaining activities. Therefore, activities should not only be carried out at specific times of the day when the activity coordinator is around, or immediately stop when the person goes home. Provision for activities starts from the moment a person with dementia wakes up in the morning, to when they go to bed. For people with dementia who may have more complex needs, the basic everyday activities we take for granted, such as eating, drinking, washing, dressing and even walking, can lead to a significant improvement if the person was not able to do this before.

Although the use of activity coordinators is important in organisations, this can lead to complacency on the part of staff and could be perceived just as another task to be completed. As activities provide an opportunity for staff to integrate and engage with people with dementia, they should be regarded as an integral part of care that promotes mental health and well-being.

Structured Versus Unstructured Activities

Structured activities are those that are initiated by activity coordinators and some staff, where there is a plan in place with a date and time, and tend to be displayed on various activity boards within the care setting or in the person's care plan. They are mainly activity coordinator driven, and if the activity coordinator is not available, they may not always go ahead.

Structured activities can either be individually based and planned, or can be offered to a group. These include activities, such as board games, bingo, exercise groups, art groups, reminiscence groups, cognitive stimulation therapy, sensory sessions, taking the person out for a walk, cooking, gardening, massage sessions, aromatherapy groups, music and sing along group sessions. Organisations also provide equipment and resources that can range from memorabilia on the walls, photographs of different key historical individuals and places that are designed to aid in reminiscence.

In addition to this, other organisations may purchase sensory equipment to provide themed rooms and corridors, all designed to create an environment that should enable people with dementia to engage. Care settings may claim to provide these facilities, throughout the environment, but these can be costly and have little significance if people with dementia are not supported and encouraged to engage with them. Reminiscence rooms provide areas that are designed to enable a person to explore significant events from their past. For example, memory cafes have been designed to enable people with dementia to explore key events of a time period in their life.

The use of reminiscence resources is the most widely structured activity used in the UK, with evidence to suggest that it has therapeutic value in maintaining well-being for people with dementia. However, there is also research to indicate that the evidence in relation to its effectiveness is poor, and therefore, reminiscence therapy should only be offered as part of an individual assessment [15]. Each person with dementia is unique; some people with dementia may spontaneously engage and use reminiscence resources around them, whilst others may require the support of staff to make sense of these different activities aids.

On the other hand, unstructured activities are those that are driven and instigated by the person, which are often overlooked by staff. These include the person walking around the care setting, engaging in spontaneous conversation with others or staff, or engaging in everyday tasks around the care setting, such as cleaning, serving food, moving things and putting them back again, or rearranging things, such as items in cupboards or drawers.

Other unstructured activities include sitting down and having a cup of tea with others. People with dementia will initiate their own activities, and it is important for staff to ensure that they build the activities on the person's individualised needs based on what they can do, rather than what staff feel is best for them.

Impact of Dementia on Activities

Dementia has an impact on the person and affects the way in which they can relate to and communicate with the world around them [16]. As the dementia progresses, the person will start to have difficulties recognising certain things, such as objects or even being able to verbalise this. There may be some interference with memory, which can mean that undertaking some structured activities and tasks may prove frustrating. If the activity is too complex, this can lead to frustration, confusion and difficulties following and engaging with the tasks. Other areas affected can involve problems with reading, writing or even naming objects. Therefore, when undertaking a structured activity, the person may appear disinterested, disengaged or unwilling to take part in the activity.

Staff should be made aware of how dementia affects the person's abilities, and therefore, focus on activities based on the person's strengths. Knowledge of a person's life story will provide an opportunity for staff to identify what the person may wish to engage in. Although it may not be possible to meet each individual's unique needs, organisations should ensure that the provision of activities reflects key aspects of how dementia may impact on the person's ability to engage in activities [10, 12]. Therefore, ensure that activities are adapted if the person appears agitated or distressed [16].

The Environment and Activities

The environment should be designed to provide everyday tasks that enable people with dementia to focus on their previous roles [16]. Just because the person has dementia does not mean that they no longer have a role in life. As many people with dementia revert back to their previous roles, opportunities that provide a sense of normality should be advocated wherever possible [16]. This means activities, such as washing, cooking, buttering of bread, cleaning and looking after loved ones, and outdoor tasks should be encouraged.

The environment should provide activities that enable people with dementia to have a sense of relaxation and to minimise distress. Many staff make the assumption that because people with dementia have a compromised short-term memory, they will forget what they have done.

Although this may be true, emotions and feelings do not necessarily go away. Therefore, it is important that staff create an environment that promotes continuous positive interactions and activities with people with dementia. Each time staff interact or engage in an activity with a person with dementia, they need to ensure that the feelings left behind are positive and the activity has been meaningful. The care setting should also ensure that time is provided for activities, and that these should never be hurried, as it will only lead to frustration and disengagement. The abilities of people with dementia fluctuate; it is, therefore, important to ensure that activities are based on how the person is feeling at that moment in time. It is also important to remember that both over stimulation and under stimulation can have adverse effects on people with dementia. The environment should seek to provide a skillful balance to ensure that the activities meet the different needs of people with dementia.

The person with dementia may become withdrawn when the environment no longer makes sense, and can start to feel isolated. Therefore, staff need to recognise the impact this can have on people with dementia and the distress that may result in being in an unfamiliar place [17]. As a result of this, there are times when the environment may evoke feelings and emotions that are negative, triggered by the uncertainty of the environment as the person no longer recognises where they are. Therefore, it is important to enable the person to engage in an activity that will help to alleviate and reduce the stress associated with this and to provide the opportunity for an emotional outlet. As the life experiences of people with dementia can sometimes be relived, the person's own environment (their bedroom) should have what is meaningful, with activities designed to assuage negative feelings unique to the person [12, 18]. The person's unique environment should provide these individual activities that are simple and not complicated, but help to reduce distress.

The Power of Human Interaction

Human interaction is an invaluable activity and enables people with dementia to engage with others around them, and that includes staff. Evidence suggests that the need to feel a sense of belonging is central to people with dementia, and human interaction promotes the need for inclusion and becomes crucial in maintaining well-being [8].

There is no cost associated with human interaction. However, some staff may not always recognise the importance and significance of this behaviour. This is because it is often associated with not 'doing any work', and in some organisations, staff may be reprimanded if seen not undertaking any tasks or chores. Human interaction is an unstructured activity, which is invaluable for people with dementia, therefore, should be encouraged and advocated as part of day to day living. Human interaction activities that are often overlooked include:

- Staff sitting down and talking to people with dementia.
- Staff sitting down and having a cup of tea with people with dementia.
- People with dementia assisting staff with day to day tasks around the care setting.
- People with dementia meeting their own care needs, such as personal care and even walking, when they may not have been able to walk.

- People with dementia watching and commenting on the TV.
- People with dementia going around the care setting tidying things, rummaging in memory boxes, singing, using different sensory items to see, feel, taste and smell.

Activities Should Meet the Emotional Needs of People with Dementia

Staff need to appreciate that tasks that fulfil emotional needs include enabling a person to get washed and dressed, eat, drink, relax, watching television, resting and communicating/interacting with others. These are some of the day to day activities that provide the person with a sense of purpose [8]. Therefore, staff should be incorporating these activities as part of an integrated activity plan and people with dementia should be supported to achieve these wherever possible. The relationship between activities and fulfilling emotional needs is well documented within dementia care [12, 17, 18].

Verity [17] explores the importance of meeting the emotional needs of people with dementia and how this includes the need to feel love, and to extend that love to others, along with the need to care for oneself and others. Care settings should provide opportunities for this, and not see the actions of a person with dementia who appears to want to support and assist others, as a problem. Therefore, they should seek to recognise this behaviour as significant, and find activities that support fulfilment of this emotional need.

People with dementia need to engage in activities of their choosing wherever possible. They can sometimes experience feelings of loss and worthlessness [19]. These feelings can impact on a person's ability to engage in various activities, hence the need to focus on supported actions that will fulfil the emotional needs of the person and alleviate those feelings of loss and worthlessness [20]. Therefore, activities should focus on raising self-esteem, independence and confidence, make the person feel useful and needed. Even if the person repeats the tasks over and over again, it is about giving the person a sense of purpose, which is what fulfills an emotional need. Although feelings of wanting to go home or seeking loved ones may never entirely go away, the intensity of these feelings and emotions can be reduced in an environment that creates opportunities for people with dementia to engage in day to day activities that provide a sense of normality and certainty [18]. The need for people with dementia to have normality and certainty in their lives is sometimes overlooked by staff. People with dementia, just like everyone else, need to have and feel a sense of belonging.

Therefore, they should be provided with the opportunity to engage in meaningful activities and tasks that are not only person centred but help alleviate emotional distress. Some staff may allude to the lack of time and resources for undertaking meaningful activities. However, Sheard [18] argues that a lack of activities should not always be attributed to time restrictions. This is because meaningful activities are not necessarily about how much time staff have, but should focus on identifying opportunities that capture unique moments that are special to people with dementia [18]. These moments may be brief, but if done frequently by all staff throughout the day, they can provide opportunities for staff to continuously engage with people with dementia in unstructured activities.

Therefore, providing activities should not be about trying to find the right time to undertake these; but to focus on capturing special moments with people with dementia that are meaningful and fulfilling to their emotional needs [18].

Activities Led by the Person with Dementia

The need to focus on activities that are led by the person with dementia can be a challenge for staff. There may be a tendency for staff to choose and identify what they may feel is the best activities for people with dementia.

However, there may be a reluctance for people with dementia to engage in activities that have been 'imposed' on them. Moreover, many people do not engage in activities that have been 'imposed' and decided by others, even if they are deemed to be beneficial for them. Therefore, staff need to recognise that people with dementia may not necessarily engage in activities that have been chosen for them and that they have every right to say no. Moreover, when staff complete care plans, they should ensure that they record the activities that may have been led by people with dementia, which may often be overlooked. Person-centred activities focus on what is unique to the person and to some extent can be led by the person. However, in many situations, staff may have to assist and prompt the person to partake in the activity based on their needs.

Example

Betty's care plan states that staff must ask her to attend a reminiscence group every morning to enable her to engage and explore the past. Betty says no to this every morning. However, Betty will then walk around the care setting engaging and talking to other people with dementia in the unit. She then goes into the office and interacts with staff, before sitting down for a cup of tea and a chat with other people with dementia.

Therefore, in Betty's activities plan, staff may record that she refused to join the reminiscence group when asked, but fail to document the activity initiated by Betty, which is unstructured and more meaningful to her. This activity was walking around the care setting, engaging with staff and sitting down with others to have a cup of tea. It is important to allow the person with dementia to guide staff on what they feel are meaningful activities for them. Organisations need to move away from always documenting structured activities but to also include unstructured activities initiated by people with dementia. In other words, if a person with dementia chooses to walk around the care settings all day, staff should seek to engage with the person in the walking, rather than attempt to get them to sit down when they are less likely to. Remember, the person with dementia is no longer able to adapt. It is, therefore, staff that need to adapt to the needs of the person. Staff need to 'enter' the world of people with dementia and attempt to make sense of it, providing a more meaningful environment based on activities that fulfil the individual needs of people with dementia.

The Importance of Everyday Activities

For most people with dementia, meaningful activities may involve everyday tasks. These include leisure activities, household chores, work-related activities based on previous occupational roles, and social interactions with those around them. Other examples include the following: relaxation, gardening, going out for a meal or coffee/afternoon tea, going to the cinema, pub, museum, theatre, for a drive, or taking part in family gatherings. Therefore, these everyday activities provide normality and enable people with dementia to have a purpose in life, and above all, give them a sense of belonging. In fact, recognising the things that the person used to enjoy are all important aspects of these everyday activities, where autonomy, inclusion, connection and personal identity are central to maintaining meaningful activities.

Example: How Activities Can Meet Emotional Needs

Pauline is supported in a side room on a ward in bed all the time. Staff member Holly hears Pauline calling for help. When Holly goes into Pauline's room, Pauline is visibly upset and appears frightened.

When Holly asks Pauline if she is okay, Pauline responds that she feels sad, lonely, frightened and wants her mother. Holly gives Pauline a reassuring hug, holds her hand and remains with her for a while. Although Pauline remains agitated, she continues to relate to Holly and the intensity of her negative feelings and emotions reduce. Holly knows that she cannot take away those feelings and emotions of fear, sadness and loneliness, but she is able to capture special moments that Pauline responds to and meets the emotional needs of Pauline, even if these are only brief. All staff continue to interact with Pauline at different times throughout the day and capture these positive moments that relieve the intensity of Pauline's negative feelings and emotions.

Example: How Activities Can Be Unstructured

Linda sees Joan sitting on her own in the lounge in a care home and she goes and tells her that she is going to have a cup of tea, and asks her if she would like one too. Joan agrees and Linda asks Joan to come with her to make the cup of tea. Afterwards they both sit down and enjoy the cup of tea, whilst they chat about Joan's life. Other residents come in the lounge and join Linda and Joan as they too make their own cups of tea with the assistance of Linda, and then all engage in conversation with Linda. Activities that involve human interaction are invaluable in that they do not involve any resources or equipment to achieve this. They only require staff's time, and yet the impact can be significant for people with dementia.

Example: How Activities Can Be Individualised

Molly is in her room in a residential home with an ipad that her grandchildren bought for her. The activity coordinator asks Molly if she would like to partake in a reminiscence group. Molly declines this offer and remains in her room all morning using her ipad. The activity coordinator later records in Molly's activity profile that she declined to take part in the reminiscence group. What is not made clear is that Molly was engaged in an activity led by her, and one that was meaningful to her. This is what should be recorded in her activity profile, rather than focusing on what she has not done as determined by an activity programme.

Example: How Activities Can Be Meaningful

Fred and Albert are in the lounge of a care home talking and laughing loudly and staff do not appear to know what they are talking about, but both Fred and Albert appear to come alive as they engage in conversation. A staff member then asks them if they would like to join the card game in the next room, and they both decline and continue talking and laughing. The manager later asks the staff member what activity Fred and Albert had done and the staff member states that they refused when asked, and this is also documented in their activity profiles. However, what should be recorded in both their activity profiles is that Fred and Albert were sitting in the lounge all morning chatting and laughing and how this made Fred and Albert feel, and above all, how this activity was meaningful, and made them both come alive.

Summary on Maintaining Activities

Activities are essential within organisations. However, they are only effective when they enable people with dementia to have a choice. Activities should start from the minute the person wakes up in the morning to when they go to bed. People with dementia require environments that provide an opportunity for them to engage in activities that not only give them a sense of purpose, but that have a meaning, enabling people with dementia to come alive. Staff are the key in enabling people with dementia to achieve this.

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Chapter 11
Conclusion

This book has explored some of the key issues in relation to dementia care, including the implications of person-centred theories. Examining different theories relating to dementia care highlighted that no one theory has a greater authority over another, other than the need to promote a suitable environment that promotes the individuality of people with dementia. The book explored how theorists, such as Rogers and Kitwood, provide an invaluable background for the importance of person-centred care. Kitwood highlights different forms of interactions, both positive and negative. Kitwood's malignant social psychology focused on how dignity can still be threatened in care settings and positive person work remains of great significance today in relation to ensuring that dignity remains central to the key philosophies within organisations.

The book also explored the definition of dementia and the implications for those who have it. Although it is important to identify the type of dementia a person has, the key message should always be to see the person first, then the dementia. Dementia is unique to the person and no two people with dementia are the same.

This book has also explored the importance of communication in dementia care, the right environment and activities that are meaningful. Person-centred communication is based on exploring the individual's own way of communicating, based on their unique significant memories. Therefore, staff should aim to achieve this by adapting the way they communicate with each person.

Providing the right environment focuses on promoting meaningful activities, where staff can continually interact and provide resources that positively engage people with dementia.

Although the experience of these actions may be forgotten by the person, it is important to remember that both positive and negative feelings and emotions evoked will linger for much longer. Staff should, therefore, seek to ensure that the last interaction they have with the person is a positive experience, and not one that leaves the person distressed.

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Organisations need to realise that dementia care is not merely about providing for the physical needs of people with dementia. The culture of organisations needs to change to encompass a more holistic approach that embraces the individual emotional needs of people with dementia. A dementia health and social care should seek to create an environment that not only provides positive interactions among people with dementia and staff, but one that enables people with dementia to retain some autonomy to express and fulfil their particular needs wherever possible. Above all, each person should be seen as a unique individual, where dignity and respect remain central in making a difference to their life.