

**An Educational Resource
to Support Early Interventions
for People receiving a
Diagnosis of Dementia**



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1 Introduction

In December 2008 NHS Education for Scotland (NES) commissioned the Dementia Services Development Centre to develop and deliver an educational programme to support early interventions for people receiving a diagnosis of Dementia. This educational resource is based on the content of that programme. It is relevant to all staff working with people in the period immediately following a diagnosis of dementia, regardless of discipline or practice area. However some staff groups will already have a good understanding of dementia and will not need to complete section 2.

Early dementia diagnosis and post-diagnosis support is increasingly a key element in service provision. As people with dementia receive an earlier diagnosis this presents challenges for the person and their carer about how they cope and the type of help they require.

There is no single model of support. It begins with understanding the individual, their circumstances, hopes, beliefs and fears. Early intervention activity crucially has to see the person first and then recognise the impact of receiving a diagnosis of dementia. The key emphasis of this resource is to demonstrate that many positive things can be done to help a person with dementia as well as their families, friends and others significant to them.

Using this educational resource

This educational resource has been written for use by NHS staff, community based staff and allied health professionals working in the field of dementia care. It can be used by teams to reflect on their practice through the use of discussion points throughout this resource.

It consists of 6 sections including this introduction and the suggested study time is shown at the beginning of each section.

The Overall Learning outcomes

On completing this educational resource participants will be able to:

- Describe different and effective responses to people with dementia their family, friends and others significant to them in the period following diagnosis.
- Confidently plan and deliver appropriate early interventions and support.
- Understand the importance and affect of the assessment process both on the person with dementia their family, friends and others significant to them.
- Understand the importance of working with family, friends and others significant to the person with dementia.
- Consider ways to change practice in early interventions to provide effective support.

Dementia is a very personal journey, with no two people experiencing the condition in the same way. Help and support can begin pre-diagnosis when crucial groundwork can be done to establish expectations, fears and perceptions and to gain an insight and understanding into the person's circumstances and relationships. Assessment is crucial. The need to understand what changes are occurring and their cause have to be considered alongside a person's concerns about being 'labelled' with a diagnosis and the effects this will have on their life.

At the time of diagnosis, a life-changing transition is taking place. Important relationships have to be developed between the person with the diagnosis, their family, friends and others significant to them as well as health care staff. This period can be characterised by a sense of loss and bewilderment about the future. The need for information and support at this time is paramount.

A person with dementia frequently enters into a long 'flat' period after diagnosis because of the belief that little will – or can be done – for them in these early stages. In fact, the potential for help through early intervention is high.

Early intervention – including providing good information, support and care – is designed to help a person with dementia deal with the challenges of their diagnosis and to aspire to a meaningful and positive life.

There is a clear and prolonged window of opportunity for health and social care professionals, third sector and other support services to play an important role in making early intervention a reality.

2 Understanding dementia

(allow 2 hours to complete this section)

Learning Outcomes

On completing this section participants will be able to:

- Identify core concepts that underpin different understandings of dementia
- Compare and contrast different understandings of dementia
- Understand how varying perspectives may inform subsequent care practices
- Recognise how such understandings impact on the lived experience of the people with dementia
- Analyse how professional approaches are in themselves influenced by particular models

Knowledge about dementia

Dementia is the general term for a gradual progressive decline in a person's memory and other mental abilities. There are many different illnesses which can cause dementia, but **Alzheimer's disease** is the most common, affecting 55% of people with dementia in Scotland. Most people with Alzheimer's disease are over 70 years old. It is uncommon for people to develop it under 60 and it is very rare under the age of 50. The onset of Alzheimer's disease is slow, and the decline is gradual over many years. In this disease the chemistry and structure of the brain is altered and brain cells die.

Vascular dementia is the second most common cause of dementia and recently its incidence has been found to be higher than previously expected. It accounts for almost 20% of all cases of dementia, with at least another 20% of people having both Alzheimer's disease and Vascular dementia. It usually affects people between the ages of 60-75 years and is slightly more common in men than women. The most common type of Vascular dementia is **Multi-infarct dementia (MID)** where the brain has been damaged by repeated **small strokes**. However, Vascular dementia can be caused by a number of other conditions including:

- high blood pressure (hypertension)
- irregular heart rhythms (arrhythmias)
- diseases which cause damage to the arteries in the brain

The person's condition gets worse in steps, sometimes dropping suddenly after a period of stability. The person will usually deteriorate at the point that they have a stroke, but they may improve or remain stable for a while before the next stroke occurs, when they will again deteriorate. It is often difficult to decide with certainty whether a person has Alzheimer's disease or Vascular dementia and often a person will have both types of dementia

Dementia of Lewy Body is thought to be the third most common cause of dementia, accounting for 15% to 20% of people with dementia which start after the age of 65. People who have dementia of lewy body have microscopic changes called Lewy bodies in the nerve cells of the brain caused by tiny protein deposits in the brain, which disrupt its functioning. The progress may be confusing because the person affected may have hallucinations and see things that are not there. This means their abilities fluctuate. The first descriptions of this were made by Frederich Lewy in 1912. He looked at the brains of people with Parkinson's disease, where Lewy bodies are mostly in one tiny area of the brain called the substantia nigra. In people with dementia of lewy body they are much more widely spread throughout the brain.

Fronto-temporal dementia is rarer, and the person may have personality changes before their memory is affected. They sometimes seem dramatically more selfish or unfeeling.

What causes dementia?

The different diseases that cause dementia tend to affect particular regions of the brain and different cognitive syndromes emerge which reflect the particular region of the brain that is affected. The underlying cause for brain cell death is explained in terms of chemical and structural damage caused by amyloid and tau protein aggregation.

Research is going on all the time into what causes these brain changes. These differ for each kind of dementia, but there is growing consideration of genetic factors.

What is currently known about the genetic factors associated with Alzheimer's disease and other forms of dementia can be summarised as follows:

- There is no single gene responsible for all cases of dementia
- Genetic factors only directly cause the disease in a very small number of families with dementia
- Among cases without a family link, there is often a genetic component to the disease; however, inherited factors alone do not explain why some people develop it and others do not

Key point

The number of people in Scotland with dementia is expected to increase by 75% by 2031.

Dementia facts

- Over 750,000 people in the United Kingdom have dementia
- Dementia affects one in 20 people over the age of 65
- There are 18,500 people in the UK under 65 with dementia
- There were about 58,000 to 65,000 people with dementia in Scotland in 2007, between 1,350 and 1,650 of whom were under 65
- By 2031, it is projected that there will be about 102,000 to 114,000 people with dementia in Scotland, a 75% increase
- 6% of people with dementia are independent and do not need care, 11% of people with dementia need care at some time during the week, 48% need care daily and 34% need constant care or supervision
- Around 60% of people with dementia live in the community and 40% live in care homes or hospitals
- An estimated 4,722 deaths of people over 65 in Scotland were theoretically attributable to dementia in 2005.

Team Discussion

What do you think will be the likely impact of a substantial increase in the number of people with dementia in the next 20 years or so?

Do you think our communities will cope with the increase? Will the NHS and care organisations be in a position to provide the support needed? Will early diagnosis – and early intervention – make enough of an impact?

Individual Activity

Answer the following questions

- 1 Is dementia a disease only found in old age?
- 2 Under the umbrella term of dementia, list the common types
- 3 What percentage of people with dementia live in the community?
- 4 What percentage increase in dementia is predicted by 2031 in Scotland

(Activity 1a – answers at end of section)

Four approaches to understanding dementia

This section explores four broad approaches to understanding dementia. How we use these different approaches in practice will influence the experiences of people with dementia.

A **biomedical approach** (*ie biological factors applied to understanding a medical condition*) puts the emphasis on diagnosis and treatment for the individual. It focuses on individual symptoms and behaviour and looks to minimise these through interventions such as drug treatments. Through the biomedical approach, dementia is seen as a progressive condition with little hope for the future.

A **psychological approach** will take more account of an individual's particular life history and how it impacts on experiences of dementia. When a psychosocial (*ie the relationship between a personal environment and the wider social world*) approach is followed we begin, as practitioners, to reflect on how our behaviour and interactions with people with dementia impact on their symptoms, behaviour and experiences.

A **gerontological approach** (*ie the study of ageing and old age*) encourages a broader view of how societal (*ie human society*) and structural factors influence the lives of people with dementia.

Social approaches allow us the opportunity to take a step back and look at how dementia is constructed in social and cultural terms.

Particular negative behaviours are frequently described as symptoms of dementia and these include:

- Wandering,
- Restlessness,
- Aggression,
- Apathy
- Incontinence
- (Forstl 2005)

However, while some of these symptoms may relate directly to the brain damage described above in many cases they are caused and/or exacerbated by the psychosocial environment of the individual.

Moniz-Cook et al (2003) describe a 'multiple aetiology' (*cause or origin*) of dementia. They stress that many of the symptoms of dementia are caused by factors other than the actual brain damage an individual may experience. Psychological, social and environmental aspects can exacerbate and may cause symptoms.

Key point

The use of biomedical, psychological, gerontological and social approaches will influence the experiences of people with dementia.

Team Discussion

Going to a doctors' practice or hospital is a daunting experience for most people. For those with dementia the many changes in the environment, social interactions and their own fears and apprehensions can change their behaviour and reactions.

Reflect on the team experience and observations, and consider how you could help.

Biomedical approaches

Taking a biomedical perspective means that the cause of symptoms and behaviours is assumed to be the individual involved. Brain damage leads to observed symptoms and behaviour. A biomedical understanding of dementia can be important in ensuring the individual has a proper diagnosis, can access support and treatment from memory clinics and other services, and have access to the latest and most appropriate drug treatments.

Two key thoughts to consider about the biomedical approach:

- Essentially, the person is viewed as a condition or disease. Illness is understood in terms of the physical malfunction of parts. The determinants of health and illness are viewed as primarily physical

- The way medicine views the issue of 'cause' places physical causes ahead of psychological and social factors. This invites treatment of the mind and body as separate entities, and neglects the role of social and environmental issues in the causation of disease

The biomedical approach is only one way of understanding dementia. But it is the approach which still dominates understanding and treatment of dementia.

Key point

Dementia is usually defined and understood as a biomedical condition.

Individual Activity

Think about some of your observations and experiences of a person going through the process of being diagnosed with dementia. Discuss the effect of the diagnostic process.

Consider

- What behaviour they exhibit
- How they interact with you or their family, friends and others significant to them
- What questions or information they seek answers to

Remember that the following discussions on alternative approaches to care do not exclude a biomedical understanding of dementia but emphasise the need for a broader understanding. It is also important to note that biomedical approaches are 'theories' for understanding dementia, not descriptions of the practice of medical staff. Few people draw on just one approach in understanding dementia.

Psychological approach

Reminiscence, life history work, validation therapy (*developed by Naomi Feil for older people with cognitive impairments and dementia*), reality orientation (*psychological treatment designed to help make people with dementia aware of time, where they are and the world around them*) and cognitive stimulation therapy (*CST – a brief treatment for people with mild to moderate dementia*), are all examples of psychological therapeutic approaches.

One name that stands out among psychologists in the field of dementia is Tom Kitwood, a social psychologist who challenged the accepted biomedical definition of dementia and who viewed the symptoms of dementia as a result of more than the brain damage an individual may have suffered. He suggested a more holistic approach defining dementia as dialectic (*ie a system of reasoning to arrive at the truth through logic*) interplay between neurological damage and the psychosocial environment. He expanded on the ideas that the effect of the

psychosocial environment can be negative or positive, either increasing the negative impact of the neurological damage or reducing its impact on the individual's cognitive and social abilities.

Kitwood's work led to his formulation of the experience of dementia having five key components:

D (dementia) = P + B + H + NI + SP

P represents the person's personality or resources for action

B their biography

H their physical health

NI their neurological impairment

SP the social psychology that surrounds the person from day to day

(Kitwood 1997)

The experience of dementia is described as being unique to the individual and dependent on the interaction of these various components *(Kitwood 1997)*. The central concept in Kitwood's work is that of 'personhood'. This is defined as: 'A standing or a status that is bestowed upon one human being, by others, in the context of a relationship and social being. It implies recognition, respect and trust.' *(Kitwood 1997)*

Key point

Psychological approaches recognise that dementia is due to more than just brain damage and that an individual's personality and life experience are also influential.

Individual Activity

A helpful way to see the person behind the disease of dementia is to think about the various things that make us different, individual, and unique.

Take a moment and consider the combination of things that make you who you are.

To help you get started, here a few pointers:

Personality: Outgoing/caring/scatty/dull/shy/jolly?

Life story: Place of birth/family/your work/where you have lived/proudest moment?

Relationships: Family/friends/neighbours/work colleagues?

Pastimes/hobbies: Sport/gardening/TV/radio?

Exercise

Coping with change

You have just started a new job, in a new area. You had been in your previous job for over 10 years, in the town you grew up in. It's your first day, you have just walked through the door and everyone seems very busy. How would you feel?

You may feel

Anxious, frightened, apprehensive, nervous or even intimidated.

You may think

'I hope these people are as friendly as my last work mates.'

'Have I made a terrible mistake?'

'I'm not sure I want to be here.'

This exercise highlights a time when we can feel vulnerable, insecure and anxious. These feelings may be as a result of the environment that we find ourselves in, but also may be as a response to people's reaction, or lack of reaction, to us.

It is important to remember that the response of a person with dementia is no different from ours.

Gerontological approaches

Most people with dementia are 65 or older. With the number of pensioners increasing, older people are seen to be the cause of a 'crisis' in terms of costs for pensions and care (*Innes 2002*) and the dominant view in the UK is they are a burden on society. This promotes negative images of older people and supports and reflects a culture of ageism (*Bytheway 2005*).

Ageism and stigma towards people with mental health problems including dementia act at all levels in our society. Ageism includes both prejudice through 'labelling' and negative stereotypes and discrimination through denial of opportunities and resources (*Bytheway 2005*). The way that older people are perceived by others can be an important indicator of care-giving, and the range and quality of care they receive.

Older people are often subjected to negative stereotypes, characterising them as incompetent and dependant and devaluing them as people. This has led to discrimination in all parts of society. Clinical and care practitioners and providers are not exempt from this.

Key point

Gerontology is a multi-disciplinary field that focuses on the views and experiences of older people and the ways in which these are affected by the ageing process.

Exercise

Which of the following phrases sound familiar?

- What are you doing out here? Don't you know it's cold?
- Let me do that for you or we will never get to the shops today?
- Shall I make everyone a cup of tea? No mum, you just sit there.
- Are you having a nice day, pet? I bet you don't remember this place, do you?
- Hello Fred. Now then, why don't you just take a seat over there and I will give you a shout when the doctor's ready.
- You can't seriously want to go on a safari at your age. What are you thinking about?

Consider how these phrases portray a negative view of older people and how alternative phrases would be more respectful.

Older people have a wealth of experience and knowledge that they can share and we can learn from, if only we give them time and listen.

Team Discussion

What common ideas exist about how older people should behave?

Stereotypical notions of how older people should behave are that:

- They are expected to slow down and take things easy
- They will become slightly muddled and eccentric
- They should 'grow old gracefully'
- They will adopt a less stressful lifestyle

If the person has dementia, what common ideas exist about how they will behave?

Stereotypical notions of how older people with dementia are likely to behave are that:

- They will wander around
- They will become forgetful and lose their memory
- They will have rapid mood swings
- They will be unable to understand what people are saying and what's going on

Exercise

Think about ageism and stigma regarding dementia in your workplace.

Is it evident in day-to-day practice?

List some of the words and phrases used when talking about older people and people with dementia.

Reflect on whether these words support positive images of older people and people with dementia.

Social approaches

To counteract the impact of negative social and cultural influences, there has been a move to regard dementia as a disability and people with dementia as citizens. Conceiving dementia as a disability takes the focus away from individual deficits to ideas such as rights, social inclusion and citizenship. The citizen approach to dementia is based on reciprocity (*Marshall and Tibbs, 2006*) and asks: 'What can people with dementia give to us?' Rather than: 'What can we do for people with dementia?'

The disability movement has been instrumental in raising awareness of the denial of citizenship that people with disabilities have experienced because of social and structural marginalisation and discrimination. It calls for a shift in thinking from an individual to a social model of disability whereby the difficulties faced by a disabled person are seen as a product of society rather than due to an individual's deficits.

In the same way, the symptoms of dementia can be understood as resulting from poor social and physical environments rather than the organic brain damage (*injury caused by natural event*) an individual develops.

Key point

Moves to look at dementia as a disability shifts the focus away from individual deficits to ideas such as rights and social inclusion.

The Environment

The physical environment can play an important role in improving the lives of people with dementia. A few simple changes in a care setting can have a significant, positive impact. Here are a few examples:

- Colour plays an important part in helping with recognition. Use the same colour for toilet doors throughout the building. Choose a bright colour that contrasts well with the door frame (*ie a yellow door with red door frame*)
- Place a sign on every toilet door (not the wall next to the door) at eye level. Consider using a picture as well as the word
- Lighting plays an important part in helping people with dementia make sense – and the most of – their environment. Ageing eyes need twice as much light as young eyes – and people with dementia need even more

- Try not to make rooms an obstacle course. Have clear pathways allowing easy movement around the room
- Noisy environments can create problems for people with dementia. Try to reduce/remove unnecessary background noise from TVs, radios and high levels of chattering

(Reference: Pollock R(2007) Designing Interiors for people with Dementia Stirling DSDC)

Key point

Ageing eyes need twice as much light as young eyes – and people with dementia need even more.

Individual Activity

How does your work environment currently help or cause problems for people with dementia?
What things could you change that would help?

Labelling theory

A label of 'dementia' will influence how other people behave towards an individual and how their behaviour is interpreted. This is the essence of the 'labelling' theory. The label can determine future perceptions that others hold of the person with dementia and can influence the actions of others. For example, when people with dementia misinterpret a situation by becoming aggressive, the misinterpretation is often attributed to their dementia when it might equally be attributable to the context of the situation. Labelling someone as aggressive puts the blame squarely on their shoulders – and results in a failure to understand and take into account what was happening at the time.

Be aware of the dangers and impact of labelling. People with dementia already have one label. They don't need to carry around a collection of others.

Labelling impacts differently on different groups:

- Family friends and others significant to the person often look to diagnosis and subsequent labelling of a person to explain behaviour that they don't understand
- For the person being labelled, the impact is less positive as their actions often become attributed to the label attached to them. We in turn then react to that label
- Remember that behaviour, rather than being a symptom of dementia, should also be seen as a way of communicating

Key point

Any label attached to a person will influence how that person responds and other people's reactions.

Exercise

Imagine that you are walking into a room and you think that someone is about to harm you and you are unable to communicate verbally. How would you react? What might your behaviour be?

Reflect on the things that you have written and ask yourself what types of label you would have given to this person?

Cultural differences and ethnicity

We live in a multicultural society and so we need to be aware of cultural and ethnic differences which might impede good communication with a person with dementia. For example, a person with dementia may not be fluent in the English language or may have strong religious or cultural beliefs which care staff need to be aware of.

We also need to appreciate how people from different regions and countries may hold differing understandings of ageing and dementia. Within a care environment, such cultural differences may inadvertently contribute to misunderstandings, confusion and communication difficulties.

Some issues to consider when providing support to people with dementia from a different culture or black and ethnic minority group:

- Language barriers and low education can lead to diagnostic errors and misinterpretation. Ensure that the first language and dialect of the person with dementia their family, friends and others significant to them are identified and correct translations are given. In some cases, the use of translators is often beneficial and appropriate.
- Cultural beliefs about dementia may create a barrier for acceptance and support in the diagnosis. Changes in memory function are may be regarded as a natural part of the ageing process and the diagnosis of dementia may be seen as bringing shame on the family.
- Older people from black and minority ethnic groups may not feel services meet their needs. This can lead to a lack of knowledge about assessment centres, support services and formal care. Promoting awareness via culturally sensitive leaflets and access to information in the appropriate places and alternative languages can help overcome this problem
- Some families, friends and others significant to the person may be reluctant to admit to the stress and problems of caring for a person with dementia for cultural reasons.

Key point

In a multicultural society, it is important to consider and understand the implications of providing support for people with dementia from different backgrounds and with different beliefs.

Individual Activity

Think about how many people with dementia from black and ethnic minority groups you care for.

What differences in their approach have you observed?

What difficulties has this presented? And how have you overcome them?

Identify areas and practice in your place of work that could improve the service that you can offer to people with dementia from black and ethnic minority groups?

Person centred approach

We have discussed the importance of seeing the person first and the dementia second. All of the above approaches have their place in providing support to the person with dementia their family, friends and others significant to them.

Person centred care and person centred approaches are terms that are widely used in practice by both policy makers and practitioners. However, there is a lack of consistency in how these terms are used and their definition.

Brooker (2004) proposes that 'in person centred care the relationships between all the people in the care environment should be nurtured'. Similarly, *McCormack (2004)* proposes that relationships, environmental conditions and individual values epitomise person centred gerontological nursing.

Brooker (2004) proposed four elements that must be included to produce person centred care:

- Valuing people with dementia and those who care for them
- Treating people as individuals
- Looking at the world from the perspective of the person with dementia
- A positive social environment to enable the person with dementia to experience relative well-being

McCormack (2004) argues that person centred nursing (or care) has four aspects:

- Being in relation (social relationships)
- Being in a social world (biography and relationships)
- Being in place (environmental conditions)
- Being with self (individual values)

Key point

Valuing people with dementia, treating them as individuals and looking at the world from their perspective are regarded as important elements of providing person centred care.

Exercise

Drawing on your previous experience, identify areas where you have applied some of the elements mentioned above to provide person centred care.

Consider how you could change your practice to embrace more of the principles of person centred care.

Think about the benefits to the person with dementia if these changes were implemented.

Discussion point

Taking one of the broad approaches discussed in this section, consider the implications in providing early intervention for people with dementia.

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Further reading

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Activity answers

1a

- 1 Is dementia a disease only found in old age?

Answer: No

- 2 Under the umbrella term of dementia, list the common types.

Answer: Alzheimer's disease, vascular dementia, Lewy body dementia, frontotemporal dementia

- 3 What percentage of people with dementia live in the community?

Answer: 60%

- 4 What percentage increase in dementia is predicted by 2031 in Scotland

Answer: 75%

3 Engagement and assessment in early stage dementia

(allow 2 hours to complete this section)

Learning outcomes

On completing this section participants will be able to :

- Outline and evaluate best practice in the engagement and subsequent assessment of people living with dementia
- Demonstrate sensitivity and awareness in the process of engaging with people living with dementia
- Understand and apply person centred principles of assessment within a multidisciplinary context
- Demonstrate awareness of the potential application of participation principles to promote the involvement of people with dementia in the assessment and management of their care

Introduction

An assessment is critical in producing an effective care plan for a person with dementia. It is essential not only for making a diagnosis, but also in identifying and meeting future needs of a person with dementia their family, friends and others significant to them.

An assessment means different things to different people. In this section, we will explore some of these meanings, as they apply to dementia, and try to understand the act of assessment from the perspective of a person with dementia.

Key point

An assessment is vital in identifying and meeting the future needs of a person with dementia their family, friends and others significant to them.

What is an assessment?

It is normally viewed as a task and a formal process that is based upon a series of observations and investigations. It occurs once an individual, or someone close to them, makes a decision to seek help, and is often an acknowledgement that a threat to their health and well-being is both real and present.

The purpose of an assessment is:

- To gain a comprehensive understanding of the person, their situation and the interaction between these two complex things
- To act as a 'baseline' for future comparison
- To ensure that any intervention is based upon the evidence gained during the assessment process
- To do something positive that will contribute towards the quality of life for a person with dementia their family, friends and others significant to them.

The aim for those key people involved in an assessment is to recognise and acknowledge areas of unmet need.

Traditionally, assessment, as a process, follows a set of rules and adopts certain roles, *ie*:

- The 'assessor' who controls the assessment and
- The 'assessed' who is expected to comply with the process

In cases of dementia, this traditional model is inadequate. In fact, many people with dementia do not always want assessment.

In primary care, it is not uncommon for people found to have cognitive impairment to subsequently refuse assessment aimed at identifying their dementia. A recent study in the USA showed that half of people in this situation elected not to pursue assessment (*Boustani et al, 2006*).

Two common features emerged:

- They tended to be older than those who accepted assessment
- They perceived themselves to have no significant cognitive impairment

The researchers recommended that health care professionals had to improve their understanding of the individual's decision-making process.

Team Discussion

A diagnosis of dementia can be devastating for the individual involved – their family, friends and others significant to them. A diagnosis, and cognitive impairment, may be hard to accept. Do you think that early diagnosis and better advice and information on, and awareness of, dementia will make a difference?

Beliefs and behaviours associated with being assessed

Older people with a cognitive impairment which is measurable but not affecting their 'functioning level' can maintain the belief that this is just part of the ageing process. So, they often seek to portray it as 'normal'.

Current evidence consistently shows that people generally know very little about dementia. They frequently misunderstand – or form stereotypical images – of symptoms until they or someone close to them are personally affected by it.

The stigma associated with the word dementia and the images that maintain it are powerful symbols of the fear that we as a society feel about illnesses that have the ability to strip away the very essence of a person's self identity.

Key point

People generally know very little about dementia. Older people with cognitive impairment often believe that it is part of the 'normal' ageing process.

The Health Belief Model

The Health Belief Model (*Rosenstock, 1974*) is a psychological model that aims to understand and predict decision making around health behaviours by focusing on the attitudes and beliefs of the individual. The model incorporates a number of influencing factors that lead the person to make a decision whether to take action or not in relation to their health.

The model is based around four core beliefs held by individuals based on perceptions of:

- 1 **Susceptibility** or risk of getting the condition
- 2 **Severity** or the seriousness of the condition, and its potential consequences
- 3 **Barriers** to taking advice based upon the individual's assessment of the influences that encourage or discourage adoption of the suggested behaviour
- 4 **Benefits** of adopting the suggested behaviour or taking the offered advice

Each individual, when faced with a choice related to their health, will enter into a complex decision making process. It will be shaped around consideration of the relevance of the advice offered based on their beliefs, perceptions, level of understanding and knowledge, and an intuitive assessment of risk.

Perceptions of dementia that affect the assessment process

The fear of dementia – in the person themselves, or in their family – is the most significant barrier to seeking a diagnosis (*National Audit Office 2008*).

It is not unusual to see avoidance behaviour producing skewed thought processes (*ie* 'If I don't have an assessment, I won't be diagnosed with dementia and, if I'm not diagnosed with dementia then I don't have it').

This perception and desire not to have a confirmation of dementia may well be the biggest hurdle to overcome.

Other barriers may be:

- Not wanting to be seen by a psychiatrist
- Having to go to a hospital
- Taking tests that highlight their cognitive deficit.

Many people believe that a dementia 'label' will have serious implications for them – in the workplace, in their social lives, in daily routines and how they will be viewed by family, friends and other people.

Individual Activity

Think about a time when you went to your GP and were concerned about possible tests that may have to be undertaken, and the implications of the possible diagnosis.

Consider how you approached the appointment, what changes you experienced in your behaviour and what your feelings were.

Team Discussion

In your place of work, what changes in people's behaviour have you observed during an assessment process? How could you help people during this process?

Things you could consider

- Having a selection of relevant information in the form of leaflets, booklets and guidance sheets to answer some of their concerns
- Referring them to a specialist dementia help line, website or support group such as Alzheimer Scotland
- Allowing the person their family, friends and others significant to them some time to discuss or express their concerns and offer reassurance

Read the following passage and describe what this horrendous image means for people thinking about an assessment.

'The stigma of this disease is to put you in a bed having to be turned every three hours by on-duty nurses, or sitting in a chair waiting to be fed and to wipe the drools from your mouth. Having to be carried from the bed to the chair because you can no longer walk. Being told when it is time to get up or go to bed, being told when it is time to eat or go to the bathroom.'

Mobley (2007,P2)

Early dementia and stages of adjustment

People appear to go through a number of experiences before they reach the point of diagnosis.

In the very early days of dementia, the person affected gradually becomes aware that there is some kind of change taking place. This **initial awareness** may be nothing more than an 'intuitive feeling', a sense that 'something is not quite right'. It is not uncommon at this stage for people to try to minimise or excuse lapses in memory.

As time passes there is often increasing **suspicion** that all is not well, particularly when they experience difficulties in everyday activities (possibly noticed by family, friends and others significant to them). They may start to show signs of frustration, uncertainty, fear, stress and often watch or compare themselves to others.

When people realise that something significant is happening to them, fear and psychological stresses often prevent them from being able to admit to these problems and open up to others. A common reaction is to try to hide these changes, to work apart from even those closest to them and to **suffer in silence**.

However, it is often the concerns or frustrations of family, friends and others significant to them that can bring things to a head.

It is only after people find the psychological strength to end their silent suffering and to seek help that they are perhaps able to engage with the assessment process.

If the assessment comes too early, or if people are not sensitively supported through the process, they may well resist it or become detached from it.

Key point

Many people are only able to engage with the assessment process once they find the psychological strength to stop 'suffering in silence' and to seek help.

Awareness and insight

People with dementia are often assumed to lack awareness and insight into what is happening to them (*Clare et al, 2005*). This has often been viewed as symptomatic of a dementia.

People with early stage dementia often adopt specific ways of coping with things that are happening to them. Coping is either based on self-maintaining responses aimed towards self protection and preservation or, self-adjusting responses aimed at 'integrating new experiences into a changing self concept' (*Clare et al 2005 p489*).

Self maintaining responses: You will see the person believing that assessment is a threat and will attempt to resist or become removed from the process.

Self adjusting responses: You will see the person regarding assessment with a degree of caution, but they will usually become involved with the process.

Individual Activity

Think about people who you have met that are in the early stages of dementia. What behaviour have you observed? How do they express themselves? What kind of concerns do people close to them raise?

Individual Activity

Many dementia patients will already have lost insight in the early stages of the disease process and therefore will be unaware of problems and indeed resistant to the idea that there might be a problem' (Svanberg 1997)

Compare the inherent belief contained within this quote and consider the findings of *Clare et al (2005)*. Think about the main ways in which the two belief systems differ.

Exercise

Think about people that you have met in the early stages of diagnosis. List some of the ways that they have coped. Put some thought as to how you may be able to help someone who is in denial to engage in the assessment process.

You might like to consider giving them time to discuss why they feel threatened by the process.

Do they have a fear of tests (perhaps having not done well at school)? Are they concerned about the changes that it will make to their life and relationships? Are any problems related to their identity, who they are and the role they have within the workplace or family?

Key points

Some people may wish to avoid assessment that may lead to a diagnosis of dementia. Others may wish to undermine the assessment process itself. Further assessment may be perceived as a risk to the individual.

It is important to consider why people, diagnosed with dementia, may disengage from further assessment. To do this, it is imperative to look at the act of assessment itself and then consider it from the perspective of people with dementia who have been assessed.

The traditional model of assessment

The traditional model of assessment is usually based on one or some of the following:

- Identifying things that are not working, that represent a change from the person's norm
- A search for signs and symptoms that signal the presence of a possible dementia
- A way of measuring the impact that the dementia has upon the person affected and others
- An opportunity to evaluate the benefit of some form of intervention or treatment

The model may appear neutral, but is often very ritualistic. The way in which it is applied can make it a positive or negative experience. The traditional roles – with the assessor as an authority figure and the person being assessed expected to comply – can lead to the relationship being viewed as unfair.

The person with dementia will often describe this procedure as arduous, confusing and geared to enhancing the role of the assessor.

DeBaggio (2002) offers an insight into the often subtle processes that occur for someone with the label of Alzheimer's disease:

'The doctor stood up and walked over to the examining table and picked up a white hospital gown that lay there. He handed me the garment and asked me to undress and put on the gown... I changed into the hospital gown, a piece of clothing with which I was totally

unfamiliar. It was style-less and not cut for warmth; the back was open...garments like hospital gowns were undoubtedly designed to humble any person wearing them.'

Key point

A traditional model of assessment can be very ritualistic. The way it is carried out can make it a positive or negative experience.

Strategic resistance

Strategic resistance in assessments can be a coping mechanism for a person with dementia. It affects the person being assessed their family, friends and others significant to them. For some, the impact of assessment can be so distressing their aim is to get it over with as soon as possible. Resistance is often perceived by others as uncooperative or unhelpful. *Keady J, Gilliard j (2002)* found that, 'in relationships where strategic resistance was the over-riding coping style for the person with Alzheimer's disease, the seeds were sown for a culture of recrimination to grow and germinate.'

When encountering strategic resistance, it is important to know that it is happening and to be able to reduce its impact upon the reliability of the information gathered. The primary strategy is rooted in the concept that 'prevention is better than cure'. Therefore, adapting your behaviour and preparing for the assessment is crucial.

Individual Activity

Imagine that you are going to a hospital appointment, where a traditional model of assessment is being adopted. Describe how you would feel.

How would you react to an assessor adopting a role of authority? What likely effects would this have on the outcome of the assessment?

Person centred assessment – and the importance of relationships

Introduction

Assessment is both a task and a process: the two can never be divorced from each other. A task relates to the purpose of the assessment whilst the process relates to how we go about undertaking an assessment. Adopting a person centred approach to assessment places greater value and emphasis on the process than upon the task.

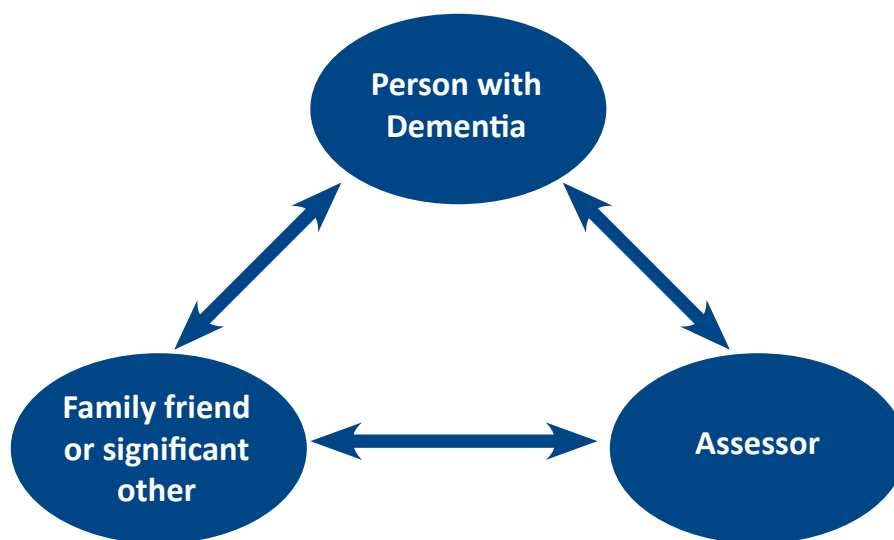
An assessment usually involves a three-way (or triadic) relationship – between the person with dementia, the family, friend or others significant to the person and an assessor. The role playing within this relationship can lead to misunderstandings and threaten positive interaction.

Within this interactive or interpersonal relationship, each of the three characters (**see Fig. 1**) play out roles and, in a competitive manner, they form, break and re-form alliances with each other. Usually two characters form alliances that disadvantage the third.

Key point

A doctor and family, friend or other significant person alliance (versus the person) in a three-way assessment process is the most common in dementia care. This often leads to the person with dementia becoming isolated, marginalised or dismissed altogether.

Fig. 1: The triadic relationship



Roscow (1981) identifies these potential alliances as being:

- Person with dementia and family, friend or other significant person versus the doctor (assessor)
- Doctor and family, friend or other significant person versus the person with dementia
- Doctor and person with dementia versus the family, friend or other significant person

The second of the alliances is the most common one found in dementia care. This often means the person with dementia may become isolated, marginalised or dismissed altogether, with a feeling that their wishes are not important.

Case Scenario

Mr and Mrs Jacob are attending an appointment with their local GP. Mrs Jacob is concerned about her husband's change in behaviour. Mr Jacob thinks he is just getting a bit forgetful, but that it's due to old age.

Place the following phrases next to the correct alliances

Alliances

- 1 Person with dementia and family, friend or other significant person versus the doctor
- 2 Doctor and family, friend or other significant person versus the person with dementia
- 3 Doctor and person with dementia versus the family, friend or other significant person

Phrases

- a *Doctor:* I have known Mr Jacob for a number of years. I think that the changes that you have described are just part of you both getting a bit older and perhaps rubbing each other up the wrong way.
- b *Mr and Mrs Jacob:* We have been married for 45 years; we both know that this is more than just part of the ageing process.
- c *Doctor:* I think that it would be fair to say that your wife has known you for longer than me and I would agree with her that there appears to be cause for concern.
- d *Doctor:* Some of the things that your wife is describing are more than just being forgetful. I think you may have some problems with your memory that we should investigate further.
- e *Doctor:* Mr Jacob, could you explain why you don't agree with your wife when she is expressing concern about some of the changes she is seeing on a daily basis.
- f *Mr Jacob:* I trust my wife. If she says my behaviour has changed then it must be true. She never lies.

(Activity 1a – answers at end of section)

Individual Activity

Drawing on your own experience, explore an example of a three-way relationship. This may be in the family, at school or in the workplace.

How did each of the people in the 'triad' react? Was there a dominant person? Who aligned with whom? What effect did individual behaviour have on the group?

Using the knowledge that you have gained what would you do to improve the outcome for the group?

Making the assessment process a positive experience

By changing the assessment process to achieve inclusiveness, collaboration and empowerment for all those involved, it becomes a matter for negotiation and the role of the 'assessed' will become much more dynamic.

Responsibility for achieving a satisfactory outcome is shared by all those involved rather than resting exclusively upon individual members. The emphasis is placed upon equality, resulting in a significant shift of power away from the assessor.

There is general recognition that the person being assessed has the capacity and natural or moral right to make any decision or choice, even if it is unwise, until it is proved otherwise.

Key point

The aim of the assessment process should be to achieve inclusiveness, collaboration and empowerment for all involved.

Person centred assessment

Kitwood (1997) views people with dementia as essentially honest individuals who will try as far as possible to provide the best information that they can. Too often the three-way relationship breaks down because the person with dementia is assumed to be unable to offer valid or reliable information or is being evasive or uncooperative. Attention shifts towards the family, friend or other significant person and away from the person with dementia.

A person centred assessment encompasses the following values:

- A respect for the person's biography
- A belief in the validity of the emotional context surrounding the actual experience of dementia
- Understanding that a person with dementia can make a valuable contribution to the assessment process

A number of positive outcomes emerge when time is taken to show interest in the person.

There is:

- An opportunity to utilise more preserved long term memory
- A reduced anxiety related to more challenging aspects of assessment
- A potential lift in self esteem as aspects are identified that the person values about themselves
- An insight gained into how the person has managed up to this point
- A heightened awareness of different backgrounds, cultures, values and beliefs (preventing an assessor from imposing a view of what is a 'normal' or desirable standard)

The use of some of the standard recognised assessment tools or questionnaires can be seen by the person undergoing an assessment as too easy, childish, intrusive or embarrassing. Through discussion and involvement, it is possible to improve on the negative aspects of the process.

Team Discussion

Consider within your workplace opportunities for making the assessment process a more positive experience.

Key point

An assessment means different things to different people, but the way the assessment is undertaken can be viewed as a positive or negative experience. Feelings of anxiety, uncertainty and apprehension can be caused by the delay between referral and assessment. The experience of being assessed leads some people to deliberately use strategies that are aimed at slowing down or resisting the assessment.

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Further reading

Read the following paper – *Clare et al, 2005 'Perceptions of change over time in early-stage Alzheimer's disease'* *Dementia* 4(4) 487-520.

Website: To explore further issues around consenting to an assessment, visit the Office of the Public Guardian in Scotland website <http://www.publicguardian-scotland.gov.uk/awi/index.asp>

Activity answers

1a

A-3/B-1/C- 2/D-2/E-2/F-1

4 Early interventions: addressing needs

(allow 4 hours to complete this section)

Learning outcomes

On completion of this section participants will be able to :

- Explore and evaluate evidence underpinning interventions for people in the early stages of dementia
- Determine effective interventions in response to the assessment and identification of need which takes into account the environment in which care is to be delivered.
- Recognise where current practice requires modification and adaptation in the light of new learning
- Utilise support and supervisory mechanisms to consider change strategies

Introduction

In section one we noted that the term 'early intervention' is used broadly to encapsulate a range of options. Specific 'therapies' were given as examples but there are 'service issues' that relate to signposting and referral to other services. The core needs of people in the early stages of dementia have been summarised as: information, emotional support and therapeutic intervention, including drug treatments, rehabilitative assistance and other therapies (Lingard & Milne 2004). Alzheimer's Scotland (2003) provides a helpful summary of the range of needs that might be addressed:

- health care needs, including diagnosis, assessment and treatment
- information on the illness, coping techniques, financial and legal issues, services available and planning ahead
- advocacy support to assist in accessing services
- practical support including rehabilitative approaches to managing memory loss, disorientation or difficulties with daily living skills
- emotional support including one-to-one support and support groups
- social support to combat isolation and stigma, and to ensure that they can continue their usual level and range of activities or even develop new initiatives
- financial support to offset income loss for younger people with dementia or relatives who give up work

Later in the section we explore other processes such as one to one support and groups by which this can be achieved.

Interventions: pre-diagnosis

In section 3 we identified consensus about how a person copes with memory impairment from diagnosis to the person's attempts to integrate the impairment into everyday life. Keady and Gillard (2001) articulate a helpful model comprising a number of distinct phases: **'Slipping', 'Suspecting', Covering Up' and 'Revealing'**.

- **Slipping** is when the person becomes aware of lapses in their performance which are discounted and/or normalised.
- **Suspecting** describes a subsequent period wherein problems become more pronounced, and the person is no longer able to rationalise or ignore these problems but their fears are kept private.
- **'Covering Up'** is a conscious and deliberate compensation phase.
- **'Revealing'** is when the problems are recognised and addressed either through a conscious decision to do so or following confrontation from others who have begun to recognise the impact of cognitive impairment on daily functioning.

Steeman et al (2006) also report on a general consensus regarding this pre-diagnostic phase. They note the increased awareness that something is wrong, related emotional distress, development of strategies of vigilance and avoidance, shared awareness with others (family) which may eventually lead to seeking professional help. The important element in this is that such models go on to describe potential for people living with dementia to enter into a phase of their existence in which they address the relevant issues and 'move on'.

Harris & Durkin (2002) promote the notion that people with dementia are able to utilise strategies which allow them 'take on their diagnosis' and 'work it through' emphasising the aspiration of reaching a point, and life, beyond diagnosis. This aligns with the 'living with dementia' philosophy that seeks to help people reach a point, and life as a re-framing of one's world view into one of rehabilitation, of 'making the best of it'. Bryden (2002)

Key point

The journey can become 'blocked' for many people who receive a diagnosis. Some have a negative experience of the assessment and diagnostic process, denial of the diagnosis or a lack of subsequent provision.

Individual Activity

Access the Lecouturier et al (2008) paper on appropriate disclosure of a diagnosis of dementia <http://www.biomedcentral.com/1472-6963/8/95>. Familiarise yourself with the approach taken and the findings. Follow the link to 'Additional file 1'. Consider the behaviours and how they are grouped and note responses to the two questions

- 1 Given the included elements is there any difference from your own practice?
- 2 What is the implication for practice if the cited behaviour has been identified by people living with dementia but not professionals?

Team Discussion

Discuss whether your current practice area aligns with the behaviours identified in Lecoutuner's paper or to what extent do these reflect aspirations?

Addressing Informational Needs

A general consensus is that information needs to be timely and accessible. The Scottish Intercollegiate Guidelines Network (SIGN 2006) recommends that information should be offered to patients (and carers) in advance of the next stage of the illness. Similarly, the Alzheimer Society (2008) argue that 'relatives and people with dementia want clear unambiguous information about diagnosis, symptoms, treatments, the illness trajectory and services, and more opportunity to discuss concerns with staff'. p82

Once someone is diagnosed, support, information and referral on to wider services will follow, although evidence shows that this is not always the case (Bowes and Wilkinson 2003). Crucially, when this does not happen people living with dementia have reported feeling 'abandoned' (Bass et al 2003).

Why might information not be conveyed? SIGN (2006) points out that the literature does not provide a clear consensus regarding the type of information people with dementia need at different stages of their journey as well as highlighting the multiple methods by which information can be conveyed. We do not need to start from the beginning in generating information packs and there are a range of good quality resources available to you (see table)

Examples of information about dementia available from Alzheimer Scotland web site.
About dementia
Treatment
Getting help from your doctor
Money and legal issues section
Research
Services provided by Alzheimer Scotland
Support services available within individual local authorities
Other dementia organisations

Key point

There is an important differentiation between information and education. Some material seeks to explain and some relates to sources of advice

Individual Activity

Reflect upon and consider the kind of material you have at hand now when it comes to helping people with dementia understand their situation. The following questions serve as a mini audit and you could consider your local provision, assess suitability and identify gaps.

What information do you have available?

What format is it in – are large text versions available?

Does it deal with different kinds of dementia?

Is it available in different languages?

Does it provide sources of additional reading?

Does it direct people to other modes of support?

Do you think it is up to date?

Does it reflect a biopsychosocial approach to dementia?

Does it convey a positive ethos about living with dementia?

Is there specific material such as on driving and benefits?

Any analysis of the provision of information can not proceed without consideration of the manner in which it is conveyed. Terminology, language and format are important considerations. Generally, people benefit from an opportunity to be able to read about information that they have been given verbally and require time to process such information. As a consequence one needs to think about what written materials are available, in what format and what opportunities people have to consider and clarify information. Too often information giving is a one off event.

A note of caution needs to be sounded at this juncture as there is a danger that the imparting of information might be viewed too simplistically. Health and social care staff need to be cognisant of the fact that they are operating from generally common belief systems about the nature of the illness and its consequences. The belief systems of those they seek to assist may or may not align with these. As a result it is recommended that an integrative approach is taken. An integrative approach assumes that people develop their own subjective models of illness in order to make sense of ill health and that these will influence how new information is assimilated. The aim then is to gain a clear idea about what the person with dementia currently understands of their situation as well as exploring what they perceive to be causative and influencing factors.

It may not be the case that a biological understanding of the illness is reflected in responses and wide ranging explanations regarding aetiology can be encountered. One common example is that it is ascribed to 'punishment' for some prior activity. It is important to acknowledge the logic that underpins the persons understanding even if it is erroneous so that you are better able to provide an accessible alternative. The information you are imparting is arguably more likely to be absorbed if based on real world examples relating to the person with dementia's current understanding rather than coming from an abstract academic base.

Integrative approaches to education have a longer pedigree in the carer support literature and examples are referred to in subsequent sections. However, principles from these approaches can be helpful in directing our activity with the person with dementia. Consequently it seems reasonable to ascertain what the person knows about their diagnosis and what they understand by it; what do they perceive as symptoms or behaviours caused by the diagnosis; what do they think is the cause of their problems; what is their understanding of the importance of medical treatment; what factors do they think may effect the course of the illness and what do they think would be helpful or unhelpful in the future.

A further consideration regarding the imparting of information is the process of assimilation. People need time and space to examine and address the material as well as begin to address its emotional impact. To this end, the notion of a process and the journey metaphor again enter our consciousness as a helpful guiding principle with the incumbent need to provide opportunities for people to check out their understanding and clarify issues. People prefer to use information alongside discussions with a trusted professional (DH 2009).

Team Discussion

Are there processes and systems within your own service which overtly facilitate a process of clarification? – how and when are opportunities built into the care pathway for people living with dementia to clarify their understanding of the information received? Similarly, when and how do you as a care professional ascertain the persons' understanding of the information they have received?

The foregoing section has proceeded from the assumption that there exist clear communication pathways between you as the care professional and the people living with dementia. In reality, of course this may not always be the case. The magnitude of the diagnosis and the implications of it are enormous. As is the case in other fields of healthcare, we must realize that peoples' readiness to take on board or even be prepared to listen to explanations is variable. To this end we should remind ourselves of the self-maintaining and self-adjusting stances as articulated by Clare (2003). A self-maintaining stance consists of attempts to normalize the situation and minimise difficulties (suggested as a way in which people attempt to maintain continuity with their prior sense of self). Consequently, where a person adopts such a response it can be misunderstood as reflecting a degree of unawareness or denial on that person's behalf whereas it can also be viewed as an effective coping mechanism in the face of increased stressors.

What this all means is that there are very good reasons why the people you encounter might not be ready and able at a particular point in time to receive, understand and act on the information you might wish to impart. To this end you need to become what might be described as a 'clinical chameleon' – adaptive and responsive to the background information you will constantly be receiving and analyzing. Through gentle probing and sensitivity to the persons lived experience you need to decide whether this is a viable option at this point in time. Alongside this approach is the subsequent need to identify when a 'window of opportunity' might present itself when the person might be more receptive. It is perhaps not surprising given the additional layers of complexity that have been revealed regarding

education and information provision that the process appears to have evolved away from a separate activity to one that is increasingly integrated into and alongside other support mechanisms such as support groups which we consider later. In the interim, a useful reference point is the Lecouturier et al (2008) paper cited earlier which helpfully identifies a number of behaviours associated with checking understanding and tailoring information to the person's needs as well as eliciting and addressing questions and concerns. The table below has been collated to capture some of the relevant issues.

Table * - Examples of behaviours that might be adopted during the information giving process (adapted from Lecouturier et al 2008)

- Give information step by step according to the person's ability to cope with it
- Allow the person to choose when they have heard enough
- Use terminology carefully as a way of getting information across without telling the person what they don't want to hear
- Recognise that different family members will have different information needs
- Avoid making assumptions about what the person with dementia their family, friends and others significant to them already know (e.g. based on job or previous experience)
- Check understanding frequently
- Reinforce areas that the person perceive correctly & gently educate in areas of misunderstanding
- Ask the person to summarise what s/he understands
- Draw on the person's experiences, those of acquaintances or knowledge from the media, to gauge understanding
- Look for a window on denial to give the person a chance to review the situation without forcing them to accept reality when they are not ready to do so
- Find out the person's knowledge level about the disease
- Ask the person what other information would be helpful
- Discuss the persons questions on the same day
- Recognise that the person may shut down after hearing bad news & it may take some time before they can articulate the questions that are buzzing around in their head
- Since people may not know the appropriate questions or be hesitant to ask, anticipate critical unanswered questions & suggest discussing them
- Answer questions fully
- If unable to answer questions, explain why not

Key Points

- 1 Good quality information is valued by people with dementia as an aid to decision-making and should come in a variety of formats
- 2 The combination of centrally developed resources with locally applied information is recommended.
- 3 Access to a comprehensive directory of resources is valued
- 4 An integrative model of information giving over time is beneficial

Addressing Emotional and Psychological Needs

A prime consideration in making an effective response to meeting an individual's needs after diagnosis is to address the emotional and psychological consequences of the dementia and the impact of receiving the diagnosis.

Support for the person with dementia should begin at diagnosis to help them acknowledge and understand their situation. Beyond diagnosis, psychological support and the opportunity to engage in some form of counselling or psychotherapeutic relationship is an important factor.

Psychological therapy aims to:

- Increase awareness of factors that contribute to distress
- Help make sense of experiences
- Find more adaptive ways of coping
- Improve psychological and emotional well-being

Until relatively recently, psychological therapy was rarely used in the field of dementia care. Inspired by the shift towards person centred care, it is increasingly recognised as valuable in alleviating distress.

A person's identity is seen to be threatened by the onset of dementia, directly through the loss of skills and indirectly through the loss of social roles and through the threat of future changes. Consequently, intervention should be designed to 'increase emotional security and to create and maintain self worth and a sense of identity'. (*Cheston & Bender, 1999*)

Key point

Psychological therapy can play a key role in increasing emotional security and in creating and maintaining self worth and a sense of identity.

Sense of 'self'

A recurring theme in the literature is the need to help the person with dementia maintain their identity and sense of self. For Cheston & Bender (1999) this is 'compromised by both a reduced cognitive capacity and the changes in their social world which restrict the opportunities to receive emotional support' (p186). Identity is seen to be threatened by the onset of dementia directly through the loss of skills, indirectly through the loss of social roles and through the threat of future changes. As a consequence, they argue that the goals of intervention should be to 'increase emotional security and to create and maintain self worth and a sense of identity' (p192)

Bryden (2002) refers to the immediate and continuing threat to self that is presented by a diagnosis of dementia whilst Lipinska (2009) says the need to help people build their sense of 'self' is a constant and recurring theme in her work as a person centred counsellor. Here, she offers an insight into what it might be like to live with dementia:

'The person...begins to dwell in a place of paradox. On the one hand, she has the ability to still be the person and do many of the things she used to...on the other hand, she has the encroaching awareness that all is not as it seems and that there are many "parts" to the once known self that are newly emerging and causing trouble, an unwelcome or unruly guest at a family gathering. Sometimes aspects of self that once seemed so vital, so important are let go as they recede into the mists of the unremembered. In order to proceed as "normally" as possible, the person will cover up and rationalise the new feelings and behaviours, will blame others for those feelings and behaviours in an effort to save face.'

Discussion point

From your experience, do you think what Lipinska says has something to say about how we need to view the person with dementia?

Many people with dementia say they receive little help or advice at the point of diagnosis. In your opinion, should psychological therapy be available to everyone at this point? What would need to be done to make this possible?

A review of approaches

A review of the literature on psychotherapy and counselling reveals a range of approaches available to us. A significant differentiating factor between approaches is the extent to which they promote an exploratory or directive stance with a client. A glance at the contents page of any related handbook reveals a plethora of theories and approaches that guide us. These include but are not limited to psychodynamic, cognitive behavioural, humanistic-existential and eclectic- integrative approaches. It is also possible to detect a continuum reflecting the extent to which such approaches are integrated into day to day practice and the level of training required, although this is very much weighted towards formal and distinct theory driven approaches, of which there are many versions.

It is important to make a distinction between the work that a practitioner who is professionally qualified or trained in such approaches might undertake and the extent to which the theoretical and practical underpinnings of these approaches can guide us in our attempts to engage therapeutically with people living with dementia. This aligns with Cheston's appeal for the need to be 'psychotherapeutic rather than doing psychotherapy' (Cheston, 1998, p. 214) and McLeod's (2007) distinction between offering counselling as opposed to being a counsellor.

Key point

There is considerable overlap between respective approaches and indeed some might argue that it is the core principles that are applicable in this instance.

It is not possible to do justice to the full range of methods available to us in this section and you are encouraged to pursue your own interests further. The following methods are considered as they appear to hold particular value for working with people with dementia:

Counselling

What does counselling mean? The British Association for Counselling and Psychotherapy (BACP) offers the following as guidance:

'Counselling takes place when a counsellor sees a client in a private and confidential setting to explore a client's difficulty, distress they may be experiencing, their dissatisfaction with life, or loss of a sense of direction and purpose. Counselling is about listening attentively and patiently and looking at the difficulties from the client's point of view. Counselling is a way of enabling choice or change or of reducing confusion. It is a relationship that develops between the counsellor and the client based on trust and acceptance, which can enable the client to examine their behaviour or areas of concern in detail and explore options to improve their situation. It is always at the request of the client as no one can properly be 'sent' for counselling. It does not involve giving advice or directing a client to take a particular course of action. Counsellors do not judge or exploit their clients in any way.'

McLeod (2007) suggests counselling can be viewed as 'making a space to talk it through', and *crucially* argues that *the* 'space' needs to have boundaries. The word 'talk' reinforces the importance of dialogue around the topic ('it'). Terry Pratchett famously commented: 'If we are to tame the beast we must first name it'. The word 'through' suggests 'a sense of movement to arrive at another place'.

The 'problems in living' perspective

McLeod (2007) articulates a three-stage framework to assist in understanding the counselling process and for effective working in a focused manner – goals, tasks and methods. Based on collaboration, the worker seeks to arrive at an understanding of what people want or need. He promotes a 'problems in living' perspective, whereby the demands being placed on an individual are seen to outweigh the resources that the person has available.

McLeod highlights that 'goal' is not the same as a 'problem'. The latter emphasises negatives whereas the former is phrased in an active and positive way. Tasks are defined as 'a sequence of actions carried out by a person, in collaboration with a counsellor, in order to be able to get on with their life'. Methods are found within conversation, structured problem-focused approaches; expressive arts based methods, cultural resources, and the personal resources of the practitioner.

Weaks et al (2006) have articulated nine therapeutic tasks following a dementia diagnosis. They are:

- 1 Exploring the possibility of life as normal
- 2 Evaluating the usefulness of different sources of information
- 3 Understanding changing roles and relationships
- 4 Understanding the emotional process
- 5 Addressing deep philosophical questions around personal identity
- 6 Facing up to dealing with and challenging stigma
- 7 Creating a modified personal and social identity
- 8 Telling and retelling their story
- 9 Finding a way through the health system

These tasks provide us with clear direction and guidance as to the possible nature and content of our discussions. Central to this is the opportunity to express emotions about their diagnosis and regain a sense of control.

Methods overlap but essentially can be located within the five domains of Conversation; Structured problem-focused approaches; Expressive arts based methods; Cultural resources, and the Personal resources of the practitioner.

Person centred counselling

Of the options available, person-centred counselling receives particular attention in the field of dementia care. Also known as client-centred or non-directive counselling (Merry & Tudor 2006) person-centred counselling places the client at the centre of the process. It holds that an individual has the resources within themselves for change and this potential is facilitated by provision of the right conditions. Means & Thorne (1999) suggest the aim of person centred counselling is to help the person 'unravel the personal theory which he has constructed around his own experience' (p5). The nature of relationships the person has with others is crucial. There are 3 core conditions of genuineness, unconditional positive regard and empathic understanding.

- Genuineness refers to the extent to which the therapist avoids presenting a facade or professional front. This requires one to be aware of one's own feelings and to be transparent.
- Unconditional positive regard refers to a non-judgmental, accepting attitude of understanding.

- Empathic understanding relates to ‘the capacity of one person to tune in to the reality of another person.... to see the world from that other person’s perspective’ (McLeod 2007 p138). Roger’s (1961) highlighted the importance of this element in the counselling relationship when he wrote ‘very rarely do we listen with real understanding, true empathy. Yet listening, of this very special kind, is one of the most potent forces for change that I know’.

Carl Roger’s work is cited by Kitwood. In particular he draws attention to the concept of ‘congruence’ the correspondence between what a person undergoes experiences and communicates to others. Where people have a high degree of reliance on the evaluation of others for their sense of self worth, they are prone to internalising such perspectives and in the case of someone with dementia these are often characterised by their negative tone Merry & Tudor (2006). Lipinska (2009) places particular importance on this process and describes the views that people with dementia have presented to her.

‘They speak of being stupid, an embarrassment, useless, worthless, an impostor, pathetic, disgusting, vile, hateful, a burden, a drag and a drudge’ (p58)

Person-centred counselling is, in essence, the communication of an empathic, understanding, non-judgemental acceptance which validates and values the person’s experiences. Within the context of this relationship we allow space and time for the person to tell it as it is – to tell their story without fear of judgment or reprisal. A person centred approach doesn’t ask the ‘therapist’ to take on a role of expert but recognizes that the person with dementia will direct the content, time and frequency of contact. The appropriateness of this approach for people with dementia seems apparent yet the availability of such resources is low.

Exercise

Read chapters 5 from Lipinska (2009) – ‘What is the counselling experience like’ and summarise how the application of person-centred counselling can be adapted for people with dementia.

(Exercise 1a-suggested answer at end of section)

Supportive psychotherapy

Supportive psychotherapy is a practical means of helping people with dementia to adjust to the effects of their illness. As Junaid & Hedge (2007) point out, support is a component of all psychotherapy but in what is an evolving concept, supportive psychotherapy is seen as the application of techniques such as ‘inspiration, reassurance, suggestion, persuasion, counselling and re-education’ within a one to one, conversation based, dyadic treatment.

Its aims have been summarised by Bloch (1979):

- To promote the person’s best possible psychological and social adaptation by restoring and reinforcing their abilities to cope with the challenges of life
- To bolster self-esteem and self-confidence by highlighting assets and achievements
- To make the person aware of the reality of their life situation (*ie* their own limitations and those of treatment, and of what can and cannot be achieved)

- To delay a relapse of their clinical condition
- To enable the person to require only the degree of professional support that will result in their best possible adaptation, and so prevent undue dependency
- To transfer the source of support from professionals to relatives or friends

Key point

Supportive psychotherapy can play a key role in helping a person with dementia to cope with the challenges of life.

Cognitive-behavioural therapy

Cognitive and behavioural therapies, (CBT) are a range of therapies based on principles and concepts from psychological models of human emotion and behaviour (Grazebrook & Garland, 2005).

Our 'cognitive processes' are our thoughts (our ideas, mental images, beliefs and attitudes). Cognitive therapy is based on the principle that certain ways of thinking can trigger, or 'fuel' problems. Behaviour therapy aims to change any behaviour that may be harmful or not helpful.

CBT is a combination of the two. It starts from the point that psychological distress is a fault in the process by which experiences are interpreted and evaluated, and thoughts or their processing (cognitions) can become distorted and unhelpful.

CBT aims to help individuals understand how their thoughts and behaviour are interlinked. The therapy is based on helping the person to regain a sense of control through problem solving, coping strategies and through challenging negative thoughts and assumptions.

A helpful model for understanding these underlying principles is the ABC-E Model of Emotion (Briddon, Baguley & Webber, 2008), which has been influenced by Lang's work (1979). It focuses on:

- Physical symptoms (*ie* lethargy, poor concentration, loss of appetite, poor memory and disturbed sleep)
- Behaviours (*ie* anxiety, restless, fretful, wandering)
- Changes in thoughts (*ie* 'I can't cope', 'I'm a failure' or 'I'm hopeless')

Equally, the person's social and economic or environmental factors can also impact on how the person might behave, think or feel. It is important to understand the inter-relationships between thoughts (including beliefs, images and memories), moods, behaviours, physical reactions and the environment (past and present).

Each of these aspects of a person's life in turn influences all of the others. For example, changes in our behaviour can influence how we feel emotionally and physically and also how we think about ourselves or others. Similarly, changes in our thinking can affect our behaviour, how we feel physically as well as emotionally in terms of our mood.

Key point

Cognitive and behavioural therapies are designed to help individuals understand how their thoughts and behaviour are interlinked.

CBT outcomes

Using a person's own words to describe how they are feeling allows them and the therapist to work collaboratively by:

- Identifying and agreeing what the problem is, when it occurs, who or what makes it better or worse and clarifying what aspect of their life the person wants to change
- Identifying person centred and jointly agreed problems and establishing agreed SMART (Specific, Measured, Accurate, Relevant and Realistic and Timed) goals
- Attempting to understand the relationship between thoughts, feelings and behaviour and how each of these impact on the person's understanding of their situation
- Experimenting with new learning. This might be an agreed behavioural experiment in order to confirm or disconfirm that a perceived fear is justified
- Working with the person's cognitions (thoughts and processing). For example, if working with a person who thinks they are a failure, you would ask them to explore any evidence in their life to the contrary (*ie* when they had succeeded), then build that into their current situation to change their thinking
- Keeping a diary of evidence to challenge Negative Automatic thoughts (NATs)

Clearly this list is not exhaustive, but it illustrates how a structured approach can help the person to gain control of their situation, rather than only talking about their problems. Although the techniques can vary, generally the focus is on helping the person develop an understanding of why and how their thoughts, feelings and actions are related.

Some examples of common thinking errors that may be seen during this process include:

- Catastrophising – anticipating disaster as the only outcome
- Black-and-white thinking – seeing everything in 'all or nothing' terms
- Exaggerating – magnifying the negative or frightening aspects of one's experiences
- Ignoring the positive – mentally filtering out positive and reassuring facts and events
- Scanning – searching for whatever we fear will prolong anxiety when it results in unnecessary fear
(*Kennerley, 1997*)

Key point

Unless people are helped to recognise and then challenge these forms of thinking they are likely to perpetuate negative beliefs which in turn perpetuate the anxious or depressive cycle of feelings and symptoms.

CBT and people with dementia

The application of CBT principles to older people generally, and people with early stage dementia specifically, is in its infancy. However, it has the potential to be helpful with a wide range of applications. An area where it would benefit a person with dementia would be in helping them to deal with any negative thoughts, fears or stereotypes associated with dementia. They would be encouraged to share their information with others and identify approaches that could help them to see a more realistic and positive journey ahead.

Individual Activity

Explore how our thoughts and behaviour are interlinked by thinking about a situation where you over-reacted. What were the influencing factors that caused this over-reaction?

Team Discussion

Case Scenario: Jane Smith believes that her manager secretly dislikes her and is trying to undermine her job. Because of this she becomes anxious, depressed and doesn't sleep well. This has an effect on her work, and she begins to make mistakes. Her manager notices the change and points out the mistakes, and suggests ways that she could avoid making them again. Unfortunately, this reinforces her belief that he doesn't like her. She shares her fears with a friend and convinces herself that she is going to be fired, her work suffers and more mistakes are made. Finally, after a period of time, her manager loses patience and fires her.

Discuss what is happening for Jane. Discuss what is happening with her manager. How could you help Jane change her negative thoughts?

Practical application of methods for psychological and emotional support

Thus far we have considered principles of three approaches that might be used in helping to address the emotional and psychological needs of people with dementia. The provision of a safe psychological space seems to be a prerequisite for successful intervention, there being a clear need to establish and maintain a therapeutic relationship which allows the person with dementia to ventilate their feelings, concerns and fears in a safe environment. There also appears to be consensus that the goal of therapy should not be to confront the individual with their diagnosis but rather to establish current understanding of their situation and to work with that understanding for beneficial goals. The extent to which such goals are overt is dependent on the approach taken but these tend to be stated in terms of assisting the individual reconfigure their conception of the situation in such a way as to emphasize the positive and assist the person to live with dementia.

It is apparent that whatever approach is taken, all require time and resources and this can be a crucial stumbling block for their application in practice. It may be the case that you are able to locate such resource within your own service and are able to ring fence time and space. Where this is not the case the model of embedded counselling "where the provision of counselling is embedded within other roles and tasks" (McLeod 2007 p17) might prove useful. McLeod (2007) points out that many of the skills required for a counselling exchange

are inherent in a professional practice and life. In essence they are not something we need to relearn. Instead he prefers the term competence for its wider utility pointing out that the user wants a professional who is competent in facilitating exploration of meaning as opposed to a mechanical application of specific skills. In this regard it perhaps requires more of a conscious drive to integrate such approaches into our day to day practice.

For Cheston & Bender (1999) a pre-requisite for any talking therapy with people with dementia is to reduce anxiety (turn off the alarm system) by maximising emotional security. As previously stated they suggest routine, familiarity and a confiding and supportive relationship are component parts. It is from this firm foundation that one can begin to listen to the person's experience and story and this is crucial.

Lipinska (2009) acknowledges that counselling for people with dementia is in its infancy but that we need to expand the 'parameters of our expectations' (p90) inline with the changing profile of the client group as the drive to earlier diagnosis takes root. It would be wrong though to assume that such adaptation needs to be radical for people in the early stage of dementia. McLeod (2007) argues that the 'importance of 'just talking' can not be overemphasised' and draws out attention to the fact that we need to think in terms of an activity that is more and deeper than social discourse.

However, as implied above there is a danger that we can begin to see such activity as distinct and different from working with any other group and we shouldn't loose sight of the fact that skills and techniques can be transferable.

Individual Activity

Read Chapter 8 - McLeod (2007) Counselling Skill "Having a useful conversation: 'just talking'" and summarise the ways in which you can deepen the level of conversation with a person with dementia

Key point

Allowing space for someone to tell their story appears to be fundamental and therapeutic and helps people to 'begin to make sense of something that has happened' (McLeod 2007).

Empathic engagement

Empathic engagement involves understanding and engaging with a person, taking their emotions into consideration. It is not enough to empathise silently. Empathy is a verbal skill – so needs to be communicated.

Barrat-Lennard's (1981, 1993) model (below) of empathic engagement is seen as a practical aid in achieving this goal.

	The person seeking help	The counsellor
Step 1	Is aware of an issue they wish to explore	Open and attentive – signalling a readiness to hear what the person has to say
Step 2	Talks about the issue or concern	Actively listens and allows the emotional meaning of what the person is talking about to 'resonate' in them
Step 3	Pauses to hear what the counsellor has to say	Expresses their understanding of what the person has said, usually in the form of a summary
Step 4	Receives what the counsellor has said and conveys their sense of the extent to which the summary was accurate and helpful.	Observes the person response to their attempt to summarise and convey understanding
Step 5	Resumes talking – the cycle continues	Resumes attentive listening – the cycle continues

Ensuring understanding

When using methods of psychological support, it is important to ensure that information given is understood. This can be achieved by asking the person to repeat key information or to make notes.

People with dementia can have a conversation where they appear to understand everything and afterwards can't recall key aspects. This can cause stress and anxiety because they know they have forgotten something and they fear it may be important.

Many forms of psychological support involve intense one-to-one situations in which people can explore their feelings and emotions. This can be distressing for both the practitioner and the person with dementia. Those offering psychological support should look to set clear boundaries, work within the realms of their own capability but be open to referring people to other more experienced or qualified professional support.

Key points

- 1 The provision of psychological support aligns closely with the goals of early interventions for people with dementia
- 2 A number of theoretical models are available to guide practice
- 3 It is not necessary to be a qualified counsellor or psychotherapist to provide psychological and emotional support
- 4 As health and social care professionals you are equipped with many competencies that enable you to provide psychological and emotional support
- 5 Practical application of psychological and emotional support for people with dementia is in its infancy and adaptations may be required
- 6 Not everyone will engage in this manner, and it may not be suitable for some

Individual Activity

Read the following statement and answer the question.

During a discussion with Bob about his experience of living with his dementia, he says: 'I feel like I am on a rowing boat that has been cut adrift'.

What might be the message that Bob is conveying here and how could you respond to this?

Post-diagnosis support groups

After diagnosis, many people with dementia greatly appreciate access to other people with dementia and their families – and information on the options available to them. Post-diagnostic support groups (sometimes called post-diagnostic counselling groups) are one way of providing this support.

Feedback on the level of support offered in support groups is consistently positive. They help to instil hope, reduce levels of anxiety, assist people in coming to terms with the future and cope with dementia – and provide good social and educational support.

Key point

Post-diagnostic support groups help people to come to terms with their dementia – and provide invaluable access to other people with dementia and their families.

Structured /Unstructured groups

Group sessions may be structured, unstructured or a combination of both. They provide the opportunity for conversation and offer useful advice and practical tips on how to cope with everyday life.

Things to consider when running a group:

- Membership – who can join?
- Do you begin and run the group with the same people – or allow others to join over time?
- When and for how long should the group meet? (This can range from 8-15 weeks, depending on resources)

People with dementia often feel that not enough time is devoted to group sessions. A two-stage process may help resolve this:

- Stage one: time limited and focused on education and empowerment
- Stage two: less time sensitive and focused on longer term support

Selection criteria

When setting up and running a group, it is important to consider who can join so that members can gain maximum benefit. Areas to look at may include age, gender and size of the group (6-8 members is common). It may also be possible to consider MMSE (Mini Mental State Examination) tests designed to assist with the diagnosis of dementia.

You will also need to think about where you would meet, what facilities would be required and how many people would be needed to run the group. A second person, or assistant, may be valuable in helping with practical issues like helping people to find the toilet or making tea. This assistant may also be involved with the content, discussion and communication and help with observing the responses of group members.

Influences of the group dynamics

What do people with dementia get out of support groups? Research and group feedback suggest that groups are useful in providing people with dementia with:

- A sense of support and a social network
- The ability to offer help and advice to one another with a positive impact on their own self esteem
- Helpful and meaningful conversation
- The ability to maintain a sense of identity

The role of the group facilitator is seen as key in the success of the group. Specifically in facilitating, encouraging and providing opportunities for all members of the group to contribute, keeping the group well informed on subjects covered (particularly when there are problems with speech or other memory issues), and in offering feedback and recollection from previous meetings.

Difficulties may be encountered when running groups. Initial participation can be seen as threatening and anxiety producing. Time must be given for individuals in the group to overcome any initial fears and perceptions. Some topics may prove uncomfortable for individuals to discuss. The behaviour of some people in the group may cause concern, particularly if a person is coming to terms with their diagnosis and they feel they are potentially looking at themselves in the future. This is where consideration needs to be given to group selection.

Self help groups

A notable development has been the empowerment of people with dementia to establish self help groups and increasingly to take on a mutually supportive role. The role of professionally led support groups is consequently under continual review. An example of how one such group operates is that inclusion in the group is not dependent on a diagnosis of dementia. It is an open, self selecting group which allows individuals to participate and receive support as and when they want it. The role of the professional is to organise practical arrangements and co-facilitate meetings. The partnership with the voluntary sector and the informal nature and flexibility of the group seems to be appreciated and beneficial.

In setting up and running any group, the support mechanisms which provide vital security for people with dementia need to be considered. For example:

- The availability of professional staff to support a group
- Establishing lines of access so the person knows how to make contact with someone they know, who is aware of their circumstances, and who is available at the end of a telephone
- Arrangements to make contact with other professional support should it be required

Key point

Groups offer substantial potential for assisting people with early dementia. The added value of peer support is highly valued by users of services notably in reducing feelings of isolation and for promoting the perception of a shared experience.

Team Discussion

Identify the benefits of groups and some of the challenges in setting up and running them. Consider the ways in which they can support people recently diagnosed with dementia.

Addressing instrumental needs

The final element that we will consider relates to functional ability and activities of daily living. Charlesworth (2008) uses the term 'instrumental' to describe this category of support. Clearly in early stage dementia issues around loss of memory are a significant cause of concern and distress and it is unsurprising that a host of activities have been developed to try and assist people in the early stages maximise, supplement and/or improve their memory. Steeman et al (2006) provide a useful summary of the nature of experiences commonly encountered with cognitive loss. They are;

- Loss of thinking ability
 - Decision-making difficulties
 - Problem-solving difficulties
 - Loss of practical skills
 - Needing more time to think to accomplish tasks
 - Difficulty using objects or devices
 - Unable to perform or finish taken-for-granted tasks (without difficulty)
 - Difficulties with new situations and activities
 - Forgetting/unable to recall names and events
 - Getting lost
 - Losing things and spending time searching for them
 - Misperception or doubts about date or time that results in difficulty in keeping appointments
 - Losing track of conversations and having problems expressing oneself coherently
- Steeman et al (2006)*

A central concern in this area relates to how best to compensate or address the cognitive losses as well as how best to sustain function. Three specific areas can be discerned - namely Cognitive Training, Cognitive Rehabilitation and Cognitive Stimulation. These terms are sometimes used interchangeably but Clare & Woods (2004) offer the following definitions:

Cognitive training

Guided practice on a set of standard tasks designed to reflect particular cognitive functions. A range of difficulty levels may be available within the standard set of tasks to suit the individual's level of ability. Cognitive training may be offered in individual or group sessions.

Cognitive rehabilitation

An individual approach putting the emphasis on improving performance in everyday life, building on the person's strengths and developing ways of compensating for impairment. The therapist works with the person and his/her family to devise strategies to address these issues.

Cognitive stimulation

Engagement in a range of activities and discussions (usually in a group) aimed at general enhancement of cognitive and social functioning. These sessions can be very simple. For example, discussing topics in a newspaper can help with current affairs or orientating the person to the day. Staying socially and mentally active is a helpful coping strategy and cognitive stimulation is an important element of this.

Key point

Cognitive stimulation, training and rehabilitation have been developed to improve the memory of a person with dementia. Loss of memory is a significant cause of concern and distress in the early stages of dementia.

Restorative and compensatory approaches

Cognitive training and cognitive rehabilitation have two common threads in restorative and compensatory approaches.

Restorative approaches focus on attempting to improve memory functions that remain intact. For instance:

- Spaced-retrieval (developed to facilitate the recall of information by people with dementia)
- Vanishing cues (in which information is repeatedly presented with diminishing intensity)
- Errorless learning (which involves preventing mistakes during recall)

Sitzer et al (2006)

Compensatory approaches aim to teach new ways of working and learning to compensate for the loss (*ie* through memory aids).

Memory groups

The aim of a memory group is to help people with memory problems overcome difficulties by teaching strategies and techniques that help them to continue with their activities of daily living. The groups are important to family, friends and others significant to the person with dementia, who feel involved in a practical way. And they have been instrumental in boosting the confidence of people with dementia.

Key techniques used in memory groups, in which family, friends and others significant to the person with dementia are included, focus on the importance of routine and repetition, and the use of rhymes and alliteration and mnemonics (rhyming phrases that help people to remember).

Assistive technology

Many devices are available that can provide useful support for people with dementia. There are two main types of assistive technology – those that are used to monitor and control and those that compensate for disability. In the early stages of dementia, aids that prompt and assist memory can be particularly useful. They can include clocks that have the day, date and time, labels on doors to indicate what's behind or inside, notice boards with reminders and prompts and check lists in important places.

Individual Activity

Log on to <http://www.atdementia.org.uk/> and explore the prompts and reminders section for ideas about how assistive technology can be used. What resources would be of particular assistance to your care group?

Physical health

The focus so far has been on the emotional and psychological wellbeing of the person with dementia. It is equally important to maintain their physical health and wellbeing. An Alzheimer's Society campaign (*What is good for your Heart is good for your Head*) sums this up very well. The positive effects of exercise on the cognitive functioning of older adults are well documented. *Heyn et al (2004)* suggest that 'exercise training increases fitness, physical function, cognitive function, and positive behaviour in people with dementia and related cognitive impairments'.

The effects of diet, smoking, reducing stress levels and monitoring cholesterol levels are crucial factors in maintaining health and wellbeing. Stress management for both the person with dementia their family, friends and others significant to them is an important consideration. Stress can manifest itself as a physical symptom and can affect behaviour. Understanding activities and relaxation techniques designed to help manage stress is critical.

Key point

Exercise and the effects of diet, smoking and reducing stress levels can be critical to the physical health and wellbeing of a person with dementia.

Individual Activity

Think about activities that could be incorporated into everyday life that would improve the physical wellbeing of a person with dementia. Consider:

- Walks (they offer the opportunity for observing and identifying surroundings)
- Gardening (it offers an opportunity to stimulate the senses)
- Housework (it provides an opportunity for increasing exercise and movement)

Multi-modal interventions

Multi-modal interventions are where a range of activities are combined to create a different form of intervention. Examples include:

- A combination of physical exercise, cognitive therapies and support groups
- A combination of counselling, support groups, education, telephone outreach and log books to create an intensive model of intervention
- A combination of activity planning, self-assertiveness training, relaxation exercise, stress management techniques, information and advice on memory aids, memory training and physical exercise

The benefits of multi-modal interventions to a person with dementia will depend on the individual and where they are on their journey of dementia. By utilising skills already raised in this resource you can produce a personalised package of interventions to address the individual's needs. However, the benefits of group participation in helping with improving self esteem, socialising and in developing coping strategies should not be overlooked.

Key point

A personalised package of interventions – focusing on physical exercise, cognitive therapies, stress management techniques and support groups – can be produced to address individual needs.

Involving others

The focus so far has been on activities that a health or social care professional might reasonably be expected to undertake or integrate into their practice. However, it would be remiss of us not to locate such work within the context of multidisciplinary working in the practice. We all experience limitations in terms of resources and finding sufficient time to develop meaningful interventions. Which makes integrating your activity with others vitally important. Moniz-Cook & Manthorpe (2009) suggest that this in fact represents one domain of intervention – the activity of signposting.

Moniz-Cook & Manthorpe (2009) highlight the importance of interventions being both early and timely and describe three broad categories of help:

- Support at the time of diagnosis
- Interventions to enhance cognition and memory
- Interventions to enhance psychological and social adjustment

Moniz- Cook & Manthorpe offer a simple four-step approach to decision-making about the nature and type of appropriate psychosocial interventions:

- **Step one:** Interventions should use the time of diagnosis as an opportunity to address stigmatised attitudes and provide methods of promoting health and wellbeing of the person with dementia. The general principle would be to promote in-home cognitive rehabilitation or training, to provide technologies to enhance the sense of control over memory, to reinforce usual family and social support networks and associated activities and to involve, where possible, both the person their family, friends and others significant to them.
- **Step two:** Interventions include evidence based groups that are preventative in nature in that they do not target those that are already distressed. They will best suit people with early dementia and their families who do not have adequate opportunity for mental stimulation and social activity and valued friendships in their natural environment
- **Step three:** Interventions of those described under the social inclusion umbrella, where a strong focus on opportunity for social engagement and voluntary sector support in communities is the norm. These interventions tend not to be time limited and offer the opportunity for the shared experience of having dementia to reinforce a social identity. Alternatively, where social relationships have been undermined by the effects of dementia, structured support to engage in services for people with dementia or internet-based social support may be considered
- **Step four:** Interventions include individual and group therapy for the person with dementia who may be distressed and require support to adjust to the knowledge of having dementia or to recover their sense of self identity

Key point

Any decision taken in relation to early intervention needs to be based on a careful assessment of the individual's preferences as well as being aware of prior interests, hobbies and motivation.

The area of early intervention is not simple, and you will need to think carefully about the range and types of options offered.

Discussion point

From your study and personal experience, what activities or approaches do you think you might be able to bring to your own practice?

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Further reading

Chapter 8 – McLeod (2007). *Counselling Skill: Having a useful conversation: just talking.*

Chapter 5 – Lipinska (2009). *What is the counselling experience like? ’*

Chapter 7 - Burnham M (2009). *Memory Groups for people with early dementia* in Moniz-Cook E. and Manthorpe J. (eds). *Early psychosocial interventions in dementia evidence based practice.* Jessica Kingsley. London. p106-114

Read the following section which is adapted from the BACP website at <http://www.bacp.co.uk/education/whatiscounselling.html>

Exercise answers

1a

You might have identified some of the following elements;

- There is still a need to outline the parameters of the session but consent to participate is monitored using principles of process consent. This means that indicators of ill-being can become highly relevant.
- The added importance of clarity of communication – use of concrete, short sentences and checking understanding
- Conscious attention to facilitating choice
- The helpfulness of summarising or reminding about issues – a ‘keeper of memories’ role.
- The absence of any inter session requirements
- Involving others in future plans
- Use of closed questions to limit responses
- The use and importance of metaphor
- Repetition may not just be a memory issue

[Balasubramanyam et al \(2007\)](#) suggest focusing on only one or two themes per session, and presenting new concepts as concretely as possible. To ensure understanding they suggest that the person be asked to repeat key information as well as using written material

5 Working with Family, Friends and Others Significant to the Person with Dementia

(allow 2 hours to complete this Section)

Learning Outcomes

On completion of this part participants will be able to :

- Formulate and justify a plan of evidence based intervention for a person with dementia their family friends and others significant to them.

Introduction

The role of family friends and others significant to the person with dementia in helping them adjust to and live with dementia is gaining increasing recognition. This includes partner, relative carer, friend or neighbour who has an important regular contact and relationship with the person with dementia.

The impact of dementia on such relationships and the importance of the role of family friends and others significant is recognised in policy guidance issued in 2005 by the Care Services Improvement Partnership (CSIP). It maintains that if older person's mental health services are to be 'fit for purpose' they should provide 'the practical advice and information service users their family friends and others significant to them need as well as developing a consistently high quality, comprehensive package of care and support.'

The Scottish Intercollegiate Guidelines Network (SIGN), in their updated guidance of the management of dementia in 2006, say that 'carers should receive comprehensive training on interventions that are effective for people with dementia'.

Individual Activity

What is your experience of working with family friends and others significant to the person with dementia? Do you believe they receive the recognition – and support – they deserve?

What frustrations do they experience? For instance:

- Are family friends and others significant to the person that you know are struggling to cope?
- Do they believe they have no one to turn to?
- Are they offered support – but fail to receive it?

What changes do you believe would improve support for family friends and others significant to the person – and make their lives easier?

The complexity of caregiving

Imagine finding yourself in an unpredictable new world where you have to deal with an ever changing relationship that is hard to make sense of and cope with. Having to develop new knowledge and skills almost immediately – and facing constant changes in their life.

Welcome to the world of the family friends and others significant to a person with dementia. The unpredictability, caused by the symptoms of dementia and the impact on the person with the diagnosis, creates stress for the family friends and others significant to them. The constant redirection and re-organisation of their life causes further anxiety and uncertainty.

Those who help care and support people with dementia come from a variety of backgrounds and may be of any age, culture and health status. During the initial period after diagnosis, family friends and others significant to them may have a role which is more supportive and less hands-on caring.

Caring has been described as a 'career' by *Aneschensel et al (1995)*. The role may last for a very long time and share similarities with a workplace career, such as learning and development and reflection. Even when someone stops being a carer (*ie* when a person with dementia moves into long-term care or dies) the carer's life continues to be affected.

Caring requires a breadth and range of knowledge and skill that family friends and others significant to them may not possess. Equipping them to support a person with dementia – and cope with their own adjustment to the changes in the person, their relationship and lifestyle – is vital to a positive experience of life with dementia.

Key point

Enabling family friends and others significant to them to support a person with dementia – and to cope with changes in their own life – is critical to creating a positive experience of life with dementia.

Exercise

Reflect on what support, knowledge and skills you needed when you first worked with people with dementia.

How might your situation compare with family friends and others significant to them who have suddenly found themselves in a caring role with no easy access to support?

Who are the carers?

The Government defines a carer gives as 'someone who spends a significant proportion of their life providing unpaid support to family or potentially friends. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems'.

Caring can be a 24-hour, seven day a week role with interrupted sleep and feelings of helplessness and hopelessness. They can be of any age or relationship. A younger person, perhaps a daughter or a son, may have their own life to balance with demands from work, relationships, children and friends. An older person may have overwhelming demands placed upon them, with little or no break away from the role. They may have their own health problems.

Team Discussion

What steps could be taken to ease the burden placed on family friends and others significant to the person with dementia?

The impact of caregiving

It is difficult not to be aware of the losses a person experiences through the negative impact of caring, and the strains and distress caused by care-giving. Less obvious, but very important in achieving a balanced view of life with dementia, is the satisfaction of caring. Being more aware of the idea of satisfaction can help family friends and others significant to the person focus on positive experiences – and aid your understanding of how to assess and intervene.

Caring is not done in isolation of other life events. Our lives are influenced by a complex set of inter-related events and relationships and many factors can potentially impact upon family friends and others significant to the person with dementia. Understanding the effects of these is especially important when considering what support is needed. Sometimes it is not the direct caring that causes strain but the indirect pressures associated with caring.

Family friends and others significant to the person with dementia react and respond in different ways when a diagnosis of dementia is given. Many think memory loss is inevitable in older age and this attitude can delay the start of the journey towards assessment and diagnosis. Those with an initial appreciation that all is not well may still find this does not cushion them from the upset of a diagnosis and they may be reeling from the shock for days, weeks or months. Some may not have any appreciation of what a diagnosis of dementia actually means and its impact on them.

Key point

The satisfaction of caring is vital in achieving a balanced view of living with dementia. Awareness of the satisfaction of caring can be pivotal in providing the right help at the right time.

Exercise

From your observation of family friends and others significant to the person list the losses, anxieties and areas of satisfaction they have experienced . Does your list tend to be biased towards one particular area?

Team Discussion

Read the following case scenario and discuss

How you might as a team respond to each and what support would you consider might help family friends and others significant to the person adapt, adjust and cope?

Case Scenario

Read the following three scenarios of pressures that family friends and others significant to the person with dementia may face.

- Mrs J finds that caring is a strain and causes her depression. This is not because she finds the direct care difficult but because they are worried about another family member who has problems with being deprived of helping with the caring role.
- Miss P finds that she is happy to take on new roles in the home such as managing the bills but has become anxious and stressed because she cannot maintain friendships and attend her local community group. She feels guilty about leaving her sister with dementia at home alone.
- Mr S feels that it is best to give as much time as possible to his mother who has dementia and moves her into the family home. His mother enjoys being with the family but demands a lot of their time. He and his wife find it hard to support their son who is sitting school exams. Mr S mother in law is also ill and she needs their support. Both Mr and Mrs S feel a sense of overwhelming guilt that they do not have enough time for everyone.

Potential losses for family friends and others significant to the person with dementia

Supporting someone with an early diagnosis of dementia may at first only require family friends and others significant to them to help with things such as money management or in making everyday decisions. If a diagnosis has been made late, some may find themselves already helping with activities of daily living and personal care. In either situation, they are likely to experience some sense of loss. For instance, in:

- **Intimacy and relationship** – Many feel that they lose a sense of intimacy and closeness with the person with dementia
- **Finance** –The person with dementia may have been the main earner in the home and income may be significantly reduced. Financial hardship can be faced
- **Social opportunity** – Many family friends and others significant to them along with the person with dementia, find that they become socially isolated. After diagnosis, they may avoid family and friends because they do not know how or want to tell others. They may feel trapped, with little opportunity to have time to themselves
- **Relationships with family and friends** – There may be conflict within a family or circle of friends. Family and friends may stop calling by phone or visiting because they do not acknowledge or understand changes in the person with dementia. Leading to the loss of a vital support network
- **Confidence and motivation** – Some family friends and others significant to the person with dementia lose confidence as they try to take on a role for which there has been little preparation. This can lead to other problems such as depression or anxiety. Even after relinquishing their role they complain about a lack of confidence

- **Mental health:** Those caring for people with dementia experience higher rates of depression and poorer physical health.

Key point

A ‘loss’ for family friends and others significant to the person with dementia – particularly in intimacy and relationship – can feel like grief. Many talk of the concept of ‘living bereavement’ or ‘living grief’.

Satisfactions in care

Promoting the positive nature of care-giving can have a positive effect on family friends and others significant to the person with dementia. When they achieve some satisfaction in their role they may feel less stressed. Work by *Nolan et al (1996)* identified sources of satisfaction:

- Giving good care
- Maintaining the dignity of the cared for
- Doing things that make the person happy
- Maintaining the dignity of the person being cared for
- An ability to express love
- A closer relationship to the person being cared for
- Seeing small improvements
- Feeling closer to family
- Knowing that they have done their best
- Appreciation from the person/others
- Meeting a new challenge
- Developing wider interests
- Gaining a sense of purpose in life

In supporting people with dementia their family friends and others significant to them it is important to attempt to foster a sense of empowerment and achievement of a positive and healthy life.

Key point

A key objective is to promote a better quality of life for people with dementia and those who support them – and move away from the negative, hopeless attitudes that persist in dementia care.

Discussion point

Look at the sources of satisfaction identified by *Nolan et al* and identify the ones that, in your opinion, are easiest to achieve – and those that present the greatest challenge. Using your experience, discuss how you could help a carer achieve satisfaction in their role.

Assessing the needs of family friends and others significant to the person with dementia

The individuality and uniqueness of family friends and others significant to the person with dementia is as important as the person with dementia, but they will have differing needs. It is vital not to make the assumption that, by meeting the needs of the person with dementia, the needs of family friends and others significant to them are also met. For many people, care giving will be only one part of their life. If this is not recognised and supported it can ultimately lead to conflict or resentment. It is equally crucial not to assume that the consequences of caring are the same for everyone.

Each person's experience of caring will be unique and depend on a number of factors. For example:

- The relationship with the person with dementia and other family members
- The personality of the care giver
- Past life experiences
- Current life strains which may be unrelated to caring
- Coping mechanisms
- Their own health status

It is essential that they receive an assessment to identify whether they feel they want to care, and what support they would need. It is important to hear what they are trying to say. The aims of the assessment would be to help family members communicate difficulties associated with the illness and to highlight the family's particular strengths and resources.

Key point

It is vital not to make the assumption that, by meeting the needs of the person with dementia, the needs of family friends and others significant to them are also met.

Assessing the needs

A useful starting point in assessing the needs of family friends and others significant to the person with dementia may be to ask them to relate the events prior to the point of seeking professional help. Using assessment tools mapping out their level of knowledge and burden may be a helpful way to structure an interview and to help identify areas of need.

The Knowledge and Dementia Interview (*KADI*) covers six broad areas of knowledge that prompt the following questions:

- **Diagnosis:** Do they know about the person's diagnosis. Who told them and what do they understand by it?
- **Symptomatology:** Do they recognise the symptoms of the illness as they are manifested in the person's behaviour? Do they think the person can control them?
- **Aetiology:** What do they think was the cause of the person's problems?
- **Medication:** What is their understanding of the importance of medical treatment?
- **Course and prognosis:** What factors do they think may affect the course of the illness?
- **Management:** What do they think is helpful/unhelpful to the person?
- Another assessment framework is provided by *Mittelman et al (2003)*. In this, the focus is put on demographic characteristics, the relationship of the care giver to the person, information, the care giving role, the physical and emotional health of the care giver, their understanding of and response to illness, the quality of life and clinical impressions.

Working with the person

Goals for intervention should emerge from caregivers themselves. Beginning at the point they are coping with dementia can allow an opportunity to discuss alternative explanations and strategies. Positive attitudes can be helpful in devising effective management strategies that are most likely to have a beneficial effect and can be enhanced.

Issues which can emerge include:

- Incorrect understanding about the cause of the illness (sometimes characterised by guilt or blaming the person with dementia for their condition)
- Failing to recognise some behaviours as part of the illness (often expressed by statements such as 'he/she is doing something deliberately to make me angry')
- Assessment might reveal that the caregiver is being unduly protective of the person with dementia (trying to protect them from any form of stress)
- Age inappropriate or intrusive behaviour may be detected
- Self sacrificing behaviour on the part of the caregiver impacting on their own quality of life

Marriott (2003) suggests that the information gathered from assessment can be categorised under six headings:

- Understanding of the illness
- Distress and situations triggering distress
- Coping strategies
- Restrictions to lifestyle
- Dissatisfaction with the person's behaviour
- Strengths of the family unit

Key point

All the interventions covered in section 4 apply equally in supporting family friends and others significant to the person with dementia

Exercise

Below is a list of useful questions that you might ask to help to identify their situation. Using the information supplied in this section, identify weaknesses and strengths in assessments you may have carried out in the past.

- Do they want to care, do they feel they have a choice in whether they care or not?
- What is their motivation to care, what drives them to get up every day to care?
- What do they find the most pleasurable thing about caring?
- What is the most difficult thing that they face?
- What do they know about the diagnosis, what do they understand it to mean?
- Do they understand the relationship between the symptoms and dementia?
- What was the past relationship like with the person with dementia and what is it like now?
- How is their own health, do they need support to maintain their own health?
- Do they have any fears about caring or fears about the future?
- Do they wish to discuss the future?
- What can we do to help them to care, and to look after themselves?

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Websites

<http://www.crossroads.org.uk> (carers stories)

<http://www.carersuk.org/Home> (policy documents)

<http://www.carerscotland.org/Policyandpractice>

<http://www.networks.nhs.uk/networks/page/792>. Log on and access 'Carers Chronicles: The way it is and signposts for the future'. The final section of the report is a list of questions, to help reflect on how the experience of these families can help you to deliver or plan effective support.

Further reading

One example of good practice is cited in the booklet 'Coping with dementia – a practical handbook for carers', published by NHS Health Scotland.

6 Changing Practice

(allow 1 hour to complete this section)

Learning outcomes

On completion of this part participants will be able to:

- Evaluate change theories and strategies within organisations and apply these to the development of early intervention services
- Identify and analyse potential developments within early intervention services that address national and local policy directives for service development and change, identifying barriers to their implementation and critically appraising potential solutions to overcome them
- Contribute to the development and implementation of strategies for service development, change and innovation through the use of effective leadership and change management skills and the engagement of key stakeholders including service users and their carers

Introduction

Putting principles into practice is the challenge facing health workers, community based staff and allied health professionals operating in the field of dementia care. The emphasis of this educational resource has been on how best to intervene to help those living with dementia improve their quality of life.

In this final section, we consider aspects of putting change into practice and highlight crucial learning points.

Key point

The challenge facing all those operating in the field of dementia care is how to put principles into practice.

Putting things into practice

Putting principles into practice can be complicated. The following need to be taken into consideration:

- How to work with people (one-to-one or in groups)
- The resources available in terms of time, budget and space
- How to integrate family members
- How to mix and match approaches to generate a multi-modal approach
- What kind of support is required and how it is supplied

It has been identified that the caring role is not straightforward. It has to be considered that:

- Family friends and others significant to the person with dementia are likely to need support to adjust and adapt their lives to living with and supporting someone with dementia at the beginning of the journey
- They need support to understand the diagnosis and its symptoms, to express their thoughts and feelings and to realise some satisfactions in care
- They may feel a sense of burden for which they require appropriate support

- Caring is complex and family friends and others significant to the person with dementia should not be expected to be able to cope unless they have the right education and emotional support in place

Change and the organisation

Most of us will have worked in organisations where major change has been implemented and will have seen or experienced the distress this can cause.

Burnes (2000) describes change as either planned or resulting from a change in circumstances. Both require an organisational approach, and need to take account of how people feel when confronted by change, whatever position they hold.

Common feelings expressed are:

- Stress caused by the necessity for change
- A lack of skill for the new role
- The sudden 'loss' of skills they were previously confident in

Change needs to be planned and managed. Stability or 'comfort zones' can be introduced by maintaining routines that do not need to be changed. This then provides the opportunity to experience and understand new ways of working.

Away days, in which new groups can meet and explore changes and the implications, can prove beneficial. Regular breaks can ease the stress generated by periods of change – and provide staff with an opportunity to recharge their energies.

Key point

Stability or 'comfort zones' – to maintain routines that do not need to be altered – can be critical in planning and managing change.

Implementing change

Lewin (1951) devised a simple but long-lasting framework for the stages involved in the management of change. He suggested a three-stage approach:

- 'Unfreezing' from the current situation (based on information identifying the need for change)
- Moving to new methods or approaches which will involve practitioners and managers developing new behaviours
- 'Refreezing' (focusing on embedding the new practices being integrated into everyday working)

Individual Activity

How does your organisation create stability or 'comfort zones'? What impact does this have on staff morale and the work environment?

Being a change agent

You are enthused, motivated, have good new ideas and intentions but are met with a lukewarm response from colleagues when changing practice. Why do people resist change? *Kanter (1989)* suggests the following reasons:

- Loss of control
- Personal uncertainty
- Shock or surprise
- Loss of face or identity
- De-skilling or fears about competence
- Ripples into other areas
- More work
- Past resentments
- Real threats

Key point

Resistance is an inevitable consequence of change. With this knowledge, it is important to develop strategies to deal with it.

Strategies for change

Six strategies for helping people through a period of change, based on the assumption that there will be resistance, have been established by *Kotter and Schlesinger (1979)*:

- **Education and communication:** Communication may need to happen in a variety of ways to be sure of reaching and influencing the widest range of staff. By helping people to see the need for change and the benefits it will bring, you will help them overcome resistance
- **Participation and involvement:** The best way to deal with resistance is to involve and gain the participation of the people undergoing the change
- **Facilitation and support:** Can be used to minimise the de-skilling effect of change by providing training and development opportunities as a way into the new practice. Emotional support is invaluable in helping colleagues come to terms with the changes and to deal with the inevitable stress that change brings

- **Negotiation and agreement:** Offer incentives for colleagues to accept and participate in the changes. Incentives do not need to be monetary – new kinds of work, development opportunities, new career paths etc, all offer incentives that will enable staff to feel valued and appreciated
- **Manipulation and co-option:** Strategies that managers may need to use to help overcome resistance. There are times when it is helpful to hold on to some information until the timing is better or to solicit the support of particularly influential people in order to get an idea progressed. Co-option involves giving individuals who are respected a particular role in the design, planning or implementation of change
- **Explicit and implicit coercion.** In a situation where speed is important, change is forced through using managers' authority and power. This approach may be necessary, but it is a risky process and not one to be used as a strategy of choice. In situations where coercion is used, resistance is usually high and therefore much work will be needed to mitigate the effects of such a potentially harmful method

Individual Activity

Imagine that you are a manager that is planning a change within your organisation. Think about the barriers that you might encounter and ask yourself:

- How you might avoid adding to the problem
- What support and guidance you can access
- Who do you know who is already engaged in making change?
- How can you learn from him/her?
- How you can use what you have already learned to address certain problems

Change and the learning organisation

According to *Senge (1990)*, learning organisations are 'where people continually expand capacity to create the results they truly desire, where new and expansive patterns of thinking are nurtured. The basic rationale for such organisations is that they need to discover how to tap people's commitment and capacity to learn at all levels'.

Learning is not a discreet activity or something to be fitted in when time permits. It should be seen as a productive part of everyday work which is embedded in the culture, relationships and processes of the workplace. Essentially, there are three demands of leadership in a learning organisation:

- As a designer of learning processes so that workers develop their skills and knowledge
- As the manager of commitment and responsibility to be involved with others in developing a shared vision
- As a teacher, encouraging learning for everyone

Key point

It is important to introduce and support change in a way that is helpful to people who will have to implement it. The outcome of change should be improved services.

Individual Activity

In your workplace, identify a change in your practice that will support early intervention for people with dementia their family, friends and others significant to them. Write a brief report of what the change will involve.

Team Discussion

Consider changes that could be made in your team practice to support people with dementia their family friends and others significant to them.

- Understand dementia
- Provide pre-diagnostic support
- Provide support through the assessment process
- Address the emotional and psychological impact of dementia and receiving the diagnosis
- Provide post-diagnostic support

Summary

An understanding of dementia and its perspectives is crucial in producing a response – and support – that values the person. Adopting a holistic approach to support puts the emphasis on what the person can still do and helps them retain their abilities.

Acknowledging ‘quality of life’ aspects and focusing on personalisation and potential ethical dilemmas is vital in providing early intervention and support. For many people the period between referral and assessment can be marked by anxiety, uncertainty and apprehension. They continue to believe they have lives of value and purpose, but a ‘shadow of the future’ (or the prospect of a life with dementia) hangs over their lives

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(This is a link to the publications section and not a direct link to the booklet)

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