



Scottish
Social Services
Council



Promoting excellence in supporting people through a diagnosis of dementia

Enhanced practice resource



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Welcome!

Welcome to Promoting excellence in supporting people through a diagnosis of dementia: Enhanced practice resource

We have developed the resource to help health and social services staff further develop their ability to support people with dementia and their families before, during and after receiving a diagnosis of dementia. It forms part of a broader range of learning resources produced by NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC) to support implementation of the 'Promoting Excellence' framework (Scottish Government, 2011a) and the *Standards of Care for Dementia in Scotland* (Scottish Government, 2011b).

People can be reluctant to go to the doctor when they are worried that they may have dementia. The benefits of diagnosis are not clear to them. But appropriate support in the early stages can have a very significant impact on the degree to which someone will be able to manage the condition over time and live independently.

Timely diagnosis enables people to plan ahead while they still have capacity to do so. It means they can get early and effective access to interventions and support to sustain their well-being and quality of life. Good post-diagnostic support helps them to adjust to the diagnosis and its likely impact, both practically and emotionally, and enables them to plan for future care and support. It can also help services work better with people's 'natural' family supports during this important stage of the illness and contributes to people with dementia having a better quality of life, living independently and as part of their community for as long as possible.

The learning resource focuses on the key knowledge and skills needed to use a personal outcomes-focused approach to support people with dementia and their families and covers a range of issues – we will outline these later.

What is the background to this resource?

The Scottish Government has had a strategic focus on increasing dementia diagnosis rates for a number of years, recognising that it presents a gateway to improved services and support for people. Supporting people with dementia and their families following diagnosis (commonly known as post-diagnostic support) was one of the key change areas in Scotland's first dementia strategy. The second *National Dementia Strategy: 2013–2016* (Scottish Government, 2013), launched in 2013, set out a new Health Improvement, Efficiency, Access to Services and Treatment (HEAT) target and commitment to:

“... deliver expected rates of dementia diagnosis and by 2015/16, all people newly diagnosed with dementia will have a minimum of a year's worth of post-diagnostic support coordinated by a Link Worker, including the building of a person-centred support plan.”

The post-diagnostic target is designed to give people time and space to access services and receive high-quality support in a way that meets their individual needs over the course of a year. It recognises that a diagnosis of dementia can have a huge impact on people and their families and that coming to terms with a diagnosis and what it will mean for the person and the family takes time and requires skilled support. It is a three-year target, with services expected to be delivering the commitment to everyone newly diagnosed by March 2016.

While the target is primarily designed to support people in the earlier stages of the illness, it applies equally to everyone diagnosed from 1 April 2013 and in every setting, including the person's own home, care homes and hospitals.

The post-diagnostic support target is informed by Alzheimer Scotland's Five Pillars of Post-diagnostic Support (Figure 1).

Figure 1
Alzheimer Scotland's Five Pillars of Post-diagnostic Support



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We will refer throughout this resource to how the knowledge and skills described support the delivery of the five-pillars model.

The *National Dementia Strategy: 2013–2016* states that each person's support needs will be assessed at the end of the 12-month period. It is expected that people in the earlier stages of the illness will be able to move to self-management, drawing on support when needed; others may need more time-limited support, while some with more complex needs may require longer-term support and treatment.

Who is this learning resource for?

The resource has been developed for health and social services staff who will be working directly with people with dementia and their families in providing support before, during and following a diagnosis, including those who are fulfilling the role of link worker. The strategy describes how the link worker will:

“ ... work flexibly with each person with dementia, and with the person's family and natural support networks, introducing each of the five pillars in a personalised and holistic way and at the appropriate time for the person. Recognising the key roles of carers and families is essential in helping design and implement a person-centred support plan.”

The knowledge and skills described in the resource reflect the 'Enhanced' level on the 'Promoting Excellence' framework (Scottish Government, 2011a) at the 'Keeping well, prevention, and finding out it's dementia' and 'Living well with dementia' stages of the dementia journey. We presume that most people using the resource will already be experienced in dementia care and support and have the knowledge and skills set out at the previous levels of the 'Promoting Excellence' framework.

How should this resource be used?

We want you to use the resource in the way that best suits you, your team and your organisation. The activities that appear throughout the modules play a key part in helping you further develop the knowledge, skills and attitudes that are central to using personal outcomes-focused approaches to supporting people prior to and following a diagnosis of dementia. The focus is on practical applications of the learning, reflective practice and putting your learning into action. Suggested responses and key learning points related to activities are provided in Appendix 1.

The resource can be used for individual learning, learning as a group or team, in a facilitated learning event, or in a mixture of all of these approaches.

You can use it:

- to discuss your thoughts and responses with your colleagues in, for example, team meetings, workshops or study sessions
- for individual study, reflecting on the activities in your own time
- with a facilitator in dedicated learning sessions
- to build a portfolio of evidence that may support you to gain qualifications and provide proof of your professional development
- to check out links to other resources to enhance your development
- to involve colleagues from a range of disciplines or agencies in joint learning
- as part of your supervision.

Whichever approach you favour, we recommend that you take part in some group discussions to help you put individual experiences into a broader context and enhance your learning.

Before starting this resource

Before you start the resource, we suggest you undertake the following activity either individually or within a team.

Learning activity I.1. Learning needs analysis



Access the 'Promoting Excellence' framework [<http://www.scotland.gov.uk/Publications/2011/05/31085332/12>].



Consider your own or the team's learning needs against the knowledge and skills set out at '**Enhanced practice level**' at the following stages of the dementia journey:

- Keeping well, prevention, and finding out it's dementia
- Living well with dementia.

Record the key strengths you or your team already have in relation to the knowledge and skills set out in the framework.



Record the key learning needs you or your team have identified in relation to the knowledge and skills set out in the framework.



If you and your team are supporting people who receive their diagnosis at more progressed levels of their dementia journey, you should include assessment against the 'Enhanced' level of knowledge and skills set out in the 'Living well with increasing help and support' stage of the framework.

Links to other resources



We make links to a number of other resources throughout – **it is important that you use these alongside this resource.** Any areas for development identified by your learning needs analysis may be supported by completing the learning in these resources:

- *Dementia Skilled – Improving Practice Learning Resource* [http://www.nes.scot.nhs.uk/media/857092/dementia_skilled_final.pdf]
- *Promoting Psychological Wellbeing for People with Dementia and their Carers: an enhanced practice resource* [www.knowledge.scot.nhs.uk/home/portals-and-topics/dementia-promoting-excellence/framework/enhanced-level/learning-resources.aspx]
- *Enhanced Dementia Practice Resource for Social Workers and other Professionals* [www.cactusidclients.com/sssc/dementia/resource_new/index.html]
- *The ACE-III trainer* [<https://www.fom.gla.ac.uk/aceiiitrainer/>]
- *Pharmacological Care of People with Dementia* [www.nes.scot.nhs.uk/media/2565054/05-03-2014_dementia_web_version.pdf].

How is the resource structured?

The resource has four modules and this introduction. It is important that you work through the modules in sequence. Each includes links to further learning for people who choose to explore issues in greater depth.

The modules are:

- **Module 1.** Introducing a personal outcomes-focused approach
- **Module 2.** Before diagnosis
- **Module 3.** Receiving a diagnosis
- **Module 4.** Living well with dementia.



Module 1

**Introducing a personal
outcomes-focused approach**

1.1 Introduction

A number of initiatives within the policy context in Scotland aim to drive the shift in health and social care towards a focus on the outcomes that are important to people who use services and their families, rather than a service-led model.

This emphasis on **personal outcomes-focused approaches** aims to ensure that people are supported to live the best lives possible, while also ensuring effective use of resources. The shift has been welcomed by people using, providing and planning services and fits with initiatives seeking to:

- personalise public services
- maximise a person's independence
- support rehabilitation, recovery and strengths- and asset-based approaches, well-being and quality of life.

“By engaging with people about their desired outcomes as a starting point for decision-making, the approach is seen to focus on possibilities rather than on problems and as such, to be professionally rewarding.”

Leading for outcomes: a guide (IRISS, 2010)
[www.iriss.org.uk]

This module introduces personal outcomes-focused approaches to working alongside people to support their health, well-being and quality of life and will enable you to refresh or develop your knowledge in this area.

It sets the tone for some of the issues we will explore in later modules, where a personal outcomes-focused approach to working is applied to supporting people with dementia and their families before, during and following a diagnosis of dementia.

The module will enable you to:

- explore the concept of personal outcomes-focused approaches
- begin to consider how personal outcomes-focused conversations can be used to establish what is important to individuals (this will be further developed in the later modules)
- reflect on how personal outcomes-focused approaches can enable the delivery of person-centred support to people before, during and after a diagnosis of dementia.

1.2 What is a personal outcomes-focused approach?

A personal outcomes-focused approach:

- aims to shift engagement with people who use services away from service-led, input-orientated approaches by working towards specific outcomes identified by the person
- is used in assessment, planning, review and evaluation
- involves everyone working together to support the person to have the best quality of life possible
- involves the person in identifying and working towards his or her outcomes, which is critical to the approach and will support and promote individuals' independence, quality of life and well-being.

Box 1.1 sets out the core features of a personal outcomes-focused approach.

Box 1.1

Core features of a personal outcomes-focused approach

A focus on outcomes often goes **back to the 'basics'** of core training and professional skills and values for health and social services staff.

Adopting a **conversational** approach to assessment, support planning and review allows for meaningful engagement with people and their families and carers, as compared to more prescriptive, tick-box question and answer approaches.

The value of a **relationship** is central to the approach.

Early engagement and **good listening** and other **interpersonal skills** are key.

The continuing relevance of services and supports and the extent to which people's personal outcomes are being achieved are constantly reviewed with the person as **creative alternatives** are sought.

A personal outcomes-focused approach should support staff and organisations to be honest with people using services about what can and cannot be achieved with existing supports and resources and promote **creative alternative pathways as required**.

The approach **relies on, and restores the importance of, the analytical skills of staff** in bringing together information from diverse sources, **most importantly the person**, who should retain ownership of the outcome.

Health and social services staff have indicated that adopting a personal outcomes-focused approach requires a significant 'culture shift' away from service-driven assessment and support.

Learning activity 1.1



Look at the definition of personal outcomes below:

"The definition of outcomes is the impact or end results of services on a person's life. Outcome-focused services and support therefore aim to achieve the aspirations, goals and priorities identified by service users (and carers) – in contrast to services whose content and/or form of delivery are standardised or determined solely by those who deliver them."

Glendinning et al., (2006)

Reflect on the service in which you work. Describe to what extent the purpose and goals of your service are concerned with achieving the aspirations, goals and priorities identified by the people who use the services and their families and carers.



1.3 Personal outcomes and quality of life indicators for people with dementia

The *Standards of Care for Dementia in Scotland* (Scottish Government, 2011b) were developed to help people with dementia, their families and carers understand their rights and recognise how they can help to ensure they are supported and listened to. The 'Promoting Excellence' framework was designed to ensure staff have the knowledge and skills to work in a human-rights and outcomes-focused way.

The main sources underpinning the standards and the 'Promoting Excellence' framework are:

- the *Charter of Rights for People with Dementia and their Carers in Scotland* (Alzheimer Scotland, 2009)
- what people with dementia and their carers in Scotland have identified as being important to them and what they want from services
- quality of life outcome indicators for people with dementia.

Learning activity 1.2



Consider the 'Promoting Excellence' framework quality of life indicators below.

'Promoting Excellence' quality of life outcome indicators

People with dementia:

- have access to a timely and accurate diagnosis of dementia
- feel empowered and enabled to exercise rights and choice, maintain their identity and be treated with dignity and equity
- maintain their best level of physical, mental, social and emotional well-being
- have access to individuals, groups and organisations that can support their spiritual or personal beliefs and reflect their cultural wishes
- have access to quality services and can continue to participate in community life and valued activities
- feel safe and secure and are able to be as independent as possible
- are able to maintain valued relationships and networks and have the opportunity to develop new ones, both personal and professional
- (and their family and friends) have access to information, education and support that enhances the well-being of the person with dementia and those who support him or her.

Imagine you have a long-term health problem. Which of the quality of life indicators would you consider to be of particular importance to you in your care and treatment, and why?



Reflect on a person with dementia you are working with. To what extent are the quality of life outcome indicators being applied to inform the support you provide?

What are the successes in applying quality of life outcome indicators in your team or service?

What are the barriers to applying the quality of life outcome indicators in your team or service?

What could you do to influence this?

1.4 Assessment using a personal outcomes-focused approach

Table 1.1 outlines the main differences between service-led approaches to assessment and personal outcomes-focused assessment.

Table 1.1. Main differences between service-led approaches to assessment and personal outcomes-focused assessment

	Service-led assessment	Outcomes-focused assessment
Endpoint	Delivery of service	Impact of the plan
Format	Pre-determined question and answer formats	Semi-structured conversation = open questions
Approach	Obtaining information required for form filling = filtering information	Skilled interaction including active listening and reflecting back
Person	Client, service user or patient who receives services	Person in his or her own right with skills, ability and a role to play in achieving his or her outcomes
Practitioner	Expert	Enabler and partner
Focus	Identify problems and deficits and match to a limited list of services	Build on capacities and strengths towards creative solution
Recording	Tick box	Building a picture towards a clear plan for achieving outcomes

Learning activity 1.3



It would be useful to complete this activity with the team you work with.

Use Table 1.1 to reflect again on the service in which you work. Consider your approach to, and your role in, assessment.



Considering all the criteria in Table 1.1, what aspects of your current assessment are service-led?

What aspects of your current assessment are outcomes focused?



What changes could you and your team make to move towards a more outcomes-focused approach to assessment?

1.5 Working with people to identify their personal outcomes

1.5.1 The importance of conversations

Conversation is at the heart of identifying personal outcomes and can be a very important intervention in its own right. Conversations provide the crucial opportunity for meaningful engagement and relationship-building.

A focus on outcomes calls for a different type of conversation. It involves active listening, which requires concentration, effort and practice. It is important to keep an open mind to ensure that what someone is actually saying is heard. Partial listening can happen when we think in terms of services and use a tick-box rather than personal-outcomes approach. This can still be the case even when staff are not using a physical checklist. As a result, there is a tendency to unconsciously fit the person's needs to existing services while the person is speaking.

We will discuss outcomes-focused conversations in the context of working alongside people with dementia before, during and after their diagnosis in later modules.

“*So it is about the openness of the conversation: you're not leading, you're not necessarily advising, but you're giving the opportunity for the carer to identify where things either can improve or possibilities of achieving.*”

Member of staff, quoted in Tsegai and Gamiz (2013)

The principles of a personal outcomes-focused approach are to focus on the following open questions.

- What is important to you in life and what is it that you want to achieve (outcomes)?
- How will you know that you have achieved these outcomes?
- What are your strengths, abilities and the resources available to you that will enable you to achieve what you want (assets)?
- What's already working and what's been changing to help you get what you want?
- What will be the next small signs of progress toward what you want?

Although there are many tools to support communication, including those that help people

with a range of communication difficulties to express their views, it is essential that the approach is right for the person and is introduced at a pace that reflects his or her needs.

Outcomes-focused assessment involves a process of exploration, working with people, their family, carers and friends to consider their stories and the outcomes identified as important to them. The next step is to work alongside people to prioritise outcomes and develop a personal support plan.

1.6 Planning to support people to achieve their personal outcomes

Personal outcomes can involve:

- changes a person is looking to achieve that will make a difference to him or her; or
- maintaining an aspect of the person’s quality of life, despite deteriorating health.

They can be explained as being the result of a series or chain of events that includes an input (resource), process (activity), output (service) and outcome (impact on the person’s life). Focusing on personal outcomes at organisational level therefore involves moving away from service priorities to what matters to the person and the difference made to people (personal outcomes).

Figure 1.1 shows an example using one of the ‘Promoting Excellence’ framework quality of life outcome indicators: ‘People with dementia have access to quality services and can continue to participate in community life and valued activities.’

Thinking about outcomes in this way can help people being supported and those supporting them to be creative in striving to achieve their outcomes. If it transpired that something was not possible at any stage of the process in the example shown in Figure 1.1, the possibility of adopting alternative means of supporting the person to achieve his or her outcome remains open. If, for example, the person:

- cannot travel to the meeting because he or she is no longer able to drive, alternative transport can be arranged
- is not able to participate in the meetings due to communication issues, alternative communication methods can be investigated
- is no longer able to contribute at the meeting, looking at the outcome (which is about feeling happy because they feel valued) may suggest other ways that he or she can contribute to the community.

Keeping a **personal support plan** converts the person’s hopes, choices and aspirations into a live plan with a series of goals, steps and outcomes. This is a key aspect of the HEAT target mentioned earlier and relates to the ‘Planning for future care’ pillar in the five-pillar model. The record of personal outcomes will describe not only the key outcomes identified, but also the actions planned to achieve the outcome – who is doing what and when. It will also include the timescale for achieving each outcome and the date when they will be reviewed. **We will explore personal support planning further in Module 4.**

Figure 1.1
Example using ‘Promoting Excellence’ framework quality of life outcome



1.7 A personal outcomes-focused approach – benefits for services, teams and staff

We have introduced the idea that working in a personal outcomes-focused way can make a significant difference to people who have received a diagnosis of dementia and their families and will continue to explore this in more depth in subsequent modules. But there are also significant benefits for staff, teams and services from this way of working. Some of these are summarised in Table 1.2.

Table 1.2 Key aspects and benefits of an outcomes-focused approach

Aspects of the approach	Key benefits
Defining anticipated outcomes	Brings clarity to mission and goals
Conversationalist approach to person-centred assessment, support planning and review approaches	Allows for more meaningful engagement with individuals and families than with more prescriptive question-and-answer approaches The approach is about ‘engaging people, rather than processing them’
Putting service user/family/carer views first and working backward to identify support options	Enables staff to gain a clearer understanding of user/family/carer needs and circumstances which in turn lead to improved support planning and more person-centred care and support packages
Involving people who receive support and their families/carers in the planning and measuring of outcomes	Provides staff with a means for being accountable to service users/families and carers It also enables users/families/carers to have more control and say over their care and support
Outcomes information collated from assessment and review methods	Enables staff to see what is working and what is not, and is potentially useful to inform planning and service developments
Approach recognises that some outcomes cannot be met within existing supports and resources	Encourages staff to promote more creative alternative pathways to outcomes It can also facilitate a more appropriate targeting of resources

Adapted from the findings of the Joint Improvement Team and documented studies of the charities evaluations services in *The Case for an Outcomes Focus* (Ellis, 2009).

Please take some time to reflect on this in relation to your role and the team and service in which you work.

1.7.1 Organisational implications

The Joint Improvement Team (JIT) has identified key principles for organisational change that support implementation of a personal outcomes-focused approach that you, your team, service and organisation may want to consider and discuss in going forward. These are shown in Box 1.2.

Box 1.2 **Principles underpinning organisational change required to support personal outcomes-focused approaches**

A personal outcomes-focused approach needs to be taken forward across the whole organisation. Communication between practitioners and strategic planning needs to be two-way.

Staff need to know not just that they have permission to practice in a different way, but also that the information they gather will influence planning and service developments.

Adopting a personal outcomes-focused approach requires significant organisational change, with a need to review financial, planning and reporting systems and how services are prioritised.

A successful personal outcomes-focused approach requires that systems for collecting and analysing data are developed around practice and should not dictate practice.

Organisations and partnerships need to ensure that aggregated information is available as a means of measuring outcomes and to shape service development and commissioning.

Qualitative and quantitative information on individual outcomes should be used to support and evidence organisational change. Information can be used by partner organisations to identify whether and how they are delivering good outcomes and to understand and further improve performance.

Joint planning and joint commissioning approaches underpinned by effective communication among partner organisations is required to support the development of a shared vision and goals.

Miller et al., (2009)

1.8 Module summary

This module has introduced you to personal outcomes-focused approaches to working alongside people to support their health, well-being and quality of life and has hopefully enabled you to refresh or develop your knowledge in this area.

It has set the tone for some of the issues we will now explore in more depth, examining how a personal outcomes-focused approach is applied to supporting people with dementia and their families before, during and following a diagnosis of dementia.

Additional sources of information and learning are available at the end of the resource.

Module 2

Before diagnosis

2.1 Introduction

For many people, taking the first step in approaching services to find out if they have dementia is extremely stressful. They experience anxiety and uncertainty about what will happen to them and what their future might look like if they receive a diagnosis of dementia. It is important to understand that the way in which health and social services staff respond in this initial contact will have a lasting impact on the person's social and emotional well-being and on his or her ongoing quality of life after diagnosis.

People and their families may be better prepared to adjust to ongoing changes if they can access personal outcomes-focused assessment and support in advance of receiving a diagnosis. We will explore some of the reasons for people being reluctant to approach services in this module, considering the assessment process, how a diagnosis is reached and how you can support the person to have a more positive experience through your own attitudes, behaviour and actions.

The module will enable you to:

- critically understand the complex issues that need to be addressed and explored by people, their families and carers facing a potential diagnosis of dementia
- understand the range of professional skills and approaches needed to support people to explore the benefits and implications of receiving a diagnosis of dementia, including options for assessment
- critically explore the benefits of personal outcomes-focused approaches in supporting a person and his or her family to prepare for a potential diagnosis of dementia
- appreciate how to discuss findings of assessments sensitively and empathically and promote access to appropriate services and specialists for further advice and support.

2.2. Approaching services

People may have been aware of memory or other difficulties for some time and experienced changes in many aspects of their daily life. They are likely to be conscious that something is wrong and may even suspect dementia, but feel reluctant to approach services. Family and friends may have noticed changes or just sense that the person is 'not their usual self'. They will commonly rationalise that life events may explain the changes – a recent bereavement, perhaps, or a change in circumstances such as retirement. It might require a significant incident to occur before the person or family seek support and advice.

Current evidence suggests that the main reasons people and their families delay approaching services are:

- being unsure of what is going on
- not knowing how to raise concerns
- fear of stigma and of others 'finding out'
- fear of embarrassment
- fear of long-term dependence
- a sense of not being listened to
- a perception that there is nothing that can be done to help.

The stigma associated with dementia is caused by lack of understanding about dementia, the negative images it portrays and a focus on deterioration of abilities. Society's stereotypical perspectives of people with dementia can enhance the fear experienced around diagnosis. A person with a stereotypical view of dementia who notices changes may be fearful of how others will view him or her. These stereotypical views can be reinforced by what we read, hear and see in the media (Box 2.1).

Box 2.1

“Dementia’s a curse on modern living”

Consider what main messages people might receive from reading the following news article.

Dementia’s a curse on modern living

With all of us living longer, the number of people with dementia will inevitably rise, putting a much greater burden on families and the NHS.

What do you do when the person you have loved and lived with for a great chunk of your life suddenly, for no apparent reason, becomes a totally different person?

From being attentive, kind, caring, thoughtful, joyous and witty, a change comes over them. They descend into bad temper, irritability, abusiveness, self-centredness, anti-social behaviour. They become a stranger. This is how dementia can change the personality.

True, dementia takes many forms, as many as there are sufferers, but this personality change isn’t uncommon and presents well-nigh impossible difficulties for a victim’s partner and their family.

Sometimes, an upright pillar of the community, a totally dependable, highly reasonable, conscientious person can become the opposite: driving recklessly, drinking heavily, ignoring demands from the bank, failing to fill in tax returns.

That turns everybody’s life upside down and if it happens before retirement age, it can result in job dismissal.

Mirror online, accessed 18 February 2014
[www.mirror.co.uk/lifestyle/health/dementia-is-a-curse-on-modern-living-1315444#ixzz2tffhsKoE]

Language can be extremely powerful and can influence how people are viewed and treated. Negative language such as that expressed in the article reinforces inaccurate stereotypes and heightens the fear and stigma surrounding dementia. This can make it more difficult for the person and his or her family to come to terms with what is happening.

The common reaction is to try to hide the changes, excuse lapses in memory and adopt changes in lifestyle in an attempt to prevent others noticing. Many older people may believe it is a normal part of the ageing process and will reaffirm this by pointing out that they maintain many functional abilities.

These reactions may be related to the person’s beliefs about dementia and the expectation of a rapid decline in physical and mental ability with age. He or she may be fearful about becoming a burden on family and friends and may have a strong sense of needing to maintain his or her roles in social relationships. It may be difficult to acknowledge or discuss changes being experienced because of the desire to remain a valued person. He or she may resist the threat to self and social identity brought about by a diagnosis of dementia: as public awareness grows and attitudes change, however, we are more likely to see people approaching services at an earlier point.

It is not always the case that the person resists seeking help. Changes that develop gradually over a long time may go unnoticed, particularly early signs. In some instances, the person may not realise there is anything wrong due to the brain changes of dementia interfering with his or her ability to recognise memory lapses. What we have assumed to be a ‘lack of awareness’ in the past could nevertheless be a defensive reaction to the person’s experience.

2.3 Early changes in dementia

In this learning resource, we do not discuss different types of dementia; if you wish to refresh your understanding of dementia, you should access *Dementia Skilled – Improving Practice Learning Resource* [www.nes.scot.nhs.uk/education-and-training/by-theme-initiative/mental-health-and-learning-disabilities/publications-and-resources/publications-repository/] *Module 1 – Promoting psychological wellbeing for people with dementia and their carers: an enhanced practice resource* [www.nes.scot.nhs.uk/education-and-training/by-discipline/psychology/multiprofessional-psychology/psychology-and-psychological-interventions-in-dementia/enhanced-practice-resource.aspx] (Section 2).

Early changes in dementia can be very subtle and vague and may not be immediately obvious. They will vary from person to person, but often the individual or family and friends will first notice memory lapses, particularly in remembering recent events, and problems finding the right words.

Early changes can nevertheless appear with no obvious signs of memory loss. The person's personality and mood may alter. He or she can become more fearful, apathetic and withdrawn, or anxious and easily frustrated. Confidence in negotiating familiar environments and carrying out usual activities may be lost, or the person may become depressed. He or she might begin to experience difficulties with talking, reading and writing, all of which may be attributed to age-related changes or other life events.

So identifying possible early changes in dementia can be difficult. The following list of signs that may indicate a need to seek further assessment is adapted from the Alzheimer Society's *Know the 10 signs* resource [www.alz.org/alzheimers_disease_know_the_10_signs.asp].

Recent memory loss that affects job skills

Anyone can forget appointments, names they are familiar with, or to pay a bill occasionally, but remember them later.

A person with dementia may forget these type of things more frequently and not remember them later.

Difficulty performing familiar tasks

Anyone who is busy or stressed can be so distracted that they may burn food if a timer is not used or forget to serve part of a meal and only discover it later.

A person with dementia might prepare a meal but forget to cook and serve it.

Problems with language

Everyone has trouble finding the right word sometimes.

A person with dementia may forget simple words or substitute with inappropriate words.

Disorientation of time and place

Anyone can forget the day of the week or their destination for a moment.

People with dementia can become lost on their own street, not know where they are, how they got there or how to get back home.

Poor or decreased judgement

While a number of physical health problems and drugs can impair judgement, these are usually detectable from blood tests.

Dementia affects a person's memory and concentration and this in turn affects judgement. Many activities, such as driving, require good judgement: when this ability is affected, the person will be a risk not only to him or herself, but also to others on the road.

Problems with abstract thinking

It is not unusual to forget passwords and bank personal identification numbers momentarily and recall them later.

Someone with dementia could forget the numbers completely and what needs to be done with them.

Misplacing things

Anyone can temporarily misplace a wallet or keys.

A person with dementia may repeatedly put things in inappropriate places.

Changes in mood or behaviour

Everyone can feel sad or moody from time to time.

Someone with dementia can have rapid mood swings from being calm to tearful or angry, for no apparent reason.

Changes in personality

People's personalities can change a little with age.

A person with dementia can become suspicious or fearful, or just apathetic and uncommunicative. They may also become disinhibited, over-familiar or more outgoing than previously.

Loss of initiative

It is common for people to become disinterested in housework, business activities or social obligations.

A person with dementia may become very passive and require cues prompting them to become involved or withdraw from social activity.

“I knew very little about the ways in which a person with dementia's behaviour can change as dementia progresses. The first inklings I had were when mum began to make inappropriate comments in public.”

(Family member)

Source: www.dementiachallengers.com/when-behaviour-changes.html

2.4 Personal outcomes-focused approach to assessment

Personal outcomes-focused approaches should inform the initial contact through to assessment, future planning and review.

We saw in Module 1 that good conversations can support meaningful engagement and are at the heart of personal-outcomes approaches. Effective communication is needed to begin to identify personal outcomes, so it is important that you adopt a conversational approach in your initial contact with the person and family rather than using an assessment tool or question-and-answer format.

This involves actively listening to what the person is saying and asking the right questions.

You will already be aware that active listening is essential to good communication and is key to building a relationship and rapport with the person and family and will use these skills in your practice, but you might find it helpful to refresh your understanding in the context of working with people who approach your services with concerns about their memory.

The main difference between active and passive listening is that the goal of:

- **active listening** is to **understand** what is being said
- **passive listening** is to basically **hear the words** that are being used.

An active listener is totally focused on what the person is saying, ignoring any distractions and irrelevant mental activity to truly engage and carefully analyse and digest what he or she is hearing.

By contrast, a passive listener may appear to be superficially focused on what the person is saying while his or her mind is elsewhere. A passive listener is not trying to understand what is being said, but is hearing it without additional thought and may be thinking instead of how all appointments can be completed on time, services the person can be offered or issues in his or her personal life.

A key element of active listening is reacting to what is being said by asking the right questions. Questions may be open or closed and will be determined by the type of answer you want. You need to ask open questions, such as “Tell me a bit more about the changes you have been experiencing” and “How are you feeling about what has been happening?” when you want to find out more about the person and encourage him or her to share thoughts and feelings. Closed questions, on the other hand, are helpful when you want specific information or facts, like “Are you worried about the changes?” and “Have you spoken to your family about the changes?”

Active listening and open questions will enable you to get to know the person and gain insight into his or her personal background, strengths, abilities and successes in life. It will help you understand the person and what he or she is trying to communicate and allow you to explore strategies used in the past when faced with major life events. You will be able to identify what the person is feeling, as well as hear the words spoken, and pick up cues, such as when the person has fears that he or she is not openly expressing. It might sound straightforward to ask open questions, but we are more inclined to use closed questions unconsciously when engaging in conversations with people with dementia and their families.

Learning activity 2.1



Take a few moments to look at the list of questions below and identify which are open and which are closed questions.

1. What kind of information do you need to help you make a decision?
2. Would you like to speak to the doctor or the nurse?
3. Are you making plans for the future?
4. What worries you about going to see the doctor?
5. Have you been managing to focus at work?

Having identified the closed questions, try to think of a way to re-phrase them to make them open.



2.5 First conversation

The person may not be ready to engage, but your approach can play a decisive influence. You can support him or her in the first conversation by actively listening, acknowledging his or her feelings and providing factual information. A calm, caring, empathic attitude at this time can help overcome the person's very real worries and fears.

Adequate time needs to be allocated to the first meeting. If this is not available, initial information should be sought and a further appointment made for soon after to ensure the person does not feel his or her concerns are being dismissed, consequently dissuading him or her from accessing further assessment until the situation has deteriorated or reached crisis point.

It is also important to engage with the person's family, as they may have a different perspective on what is happening. The rest of this learning resource explores how you can work with the person and family to support them in negotiating and agreeing outcomes across a range of different situations.

2.5.1 What are the benefits of using an outcomes-focused approach at initial contact?

An outcomes-focused conversation conveys to the person and family that their views and feelings are important and that they have choices, control and a sense of hope about their future.

Conversations and information-gathering are fundamental elements in the assessment process and in the development of your relationships with people and their families. The way this is conducted, and the nature of the questions asked, will determine how people will view your understanding of their situations and convey your beliefs about what is happening to them. If you, for example, use cognitive tests without providing adequate explanation of the process and purpose, you risk demoralising people by emphasising their areas of weakness. It is then likely that they too will focus on these areas rather than recognising strengths highlighted by the tests, potentially confirming their fears about dementia and leading to further social isolation and withdrawal. This may also have

a longer-term impact on social and emotional well-being, which we will explore in Module 4.

Taking time to explain the reasons for tests and describing the process is therefore extremely important. Cognitive tests should only be conducted at the appropriate time during the full assessment process.

Imagine how it feels for a person who has noticed early changes in dementia, such as those we have described above. The person will be worried and anxious and may only have agreed (reluctantly) to approach services. He or she is then asked to undertake a General Practitioner Assessment of Cognition (GP Cog) [www.gpcog.com.au/info.php] or ACE-III Assessment Training Tool [www.fom.gla.ac.uk/acelltrainer/] test. Not surprisingly, people with dementia who have not been prepared for the test will often describe the experience as arduous, stressful and confusing; they are in a strange environment and are being questioned by someone they do not know.

Ultimately, the distress of the experience will often negatively influence the person's willingness to engage in further assessment. While ACE-III will be a necessary element of neuropsychological assessment (and is discussed later in this module), it is important to prepare the person and family in advance: also, it should not be conducted during the first conversation.

“She was so embarrassed; she didn't want to go through some of the tests. She just felt that they were treating her like a child and then she refused to do any more. They need to make the process for diagnosis more amenable.”

Family member

Learning activity 2.2



What would be your priorities be for the first conversation you engaged in with a person and family?



“You're not going to get every bit of information straight away, there may be trust needing to be built up and also it might be the fact that they're identifying things during the third conversation that they can either trust you with or identify that you can help with, that they may not have identified at first.”

Tsegai and Gamiz (2013)

We should not assume that someone has dementia just because some of the key changes are present. Strokes, depression, excessive alcohol use, infections, hormone disorders, nutritional deficiencies and brain tumours can all cause dementia-like symptoms. Many of these conditions can be treated. You should make people aware of this.

You should provide details of the assessment process and the expected timescale and establish people's preferences on where and how they might want to undertake an assessment and be informed about findings. A person may wish to undertake elements

of the assessment in a primary care setting or at home, for example, rather than attend a memory clinic or other mental health facility.

It is important to provide information about dementia that will be helpful to the person at this stage, when a diagnosis has not been confirmed. You should provide information, leaflets and resources about dementia: Health Scotland, for example, have produced a useful leaflet, *Worried about your Memory?* [www.healthscotland.com/documents/3250.aspx], that can help with this.

A number of appointments, in places and at times of the person and families' choosing, may be necessary before assessment focusing on diagnosis can begin. You should have an understanding of people's anxieties and uncertainties and establish priorities. You should also agree with them their specific outcomes in relation to the assessment process and discover what support they need to enable them to continue with all aspects of their life during the process.

2.6 Potential benefits and implications of early diagnosis

Working with, and providing support for, people to help them prepare and make choices about assessment involves discussing the potential benefits and implications of receiving an early diagnosis of dementia. Perceptions of benefits and implications will be specific to each person and family, but may include enabling them to:

- access help in understanding, and adjusting to, the diagnosis
- prepare for the future appropriately
- take an active role in decision-making and planning for the future
- choose the best supports to enhance quality of life for longer
- access memory-enhancing medications promptly
- reduce uncertainty and experience relief from fears and anxieties
- understand the cognitive changes and learn about dementia

- access advice on health promotion and treatment for other medical conditions
- access relevant welfare benefits.

The potential implications of early diagnosis include:

- complexity raised by the diagnosis: for instance, a diagnosis of mild cognitive impairment can cause increased distress and uncertainty for some people, while it may provide reassurance for others
- the person losing his or her driving licence
- impacts on the person's relationships with family and friends
- impacts on the person's ability to work
- financial implications for the person and family.

Peter's story

Peter is a 48-year-old accountant who works for a private company. He is married with two children, a girl aged 10 and a boy of 14. His parents live close by and his wife works full time as head teacher of a primary school. Peter has a keen interest in science and technology and enjoys wind surfing and scuba diving.

Peter's wife has recently noticed that he has difficulty finding words and has told her the same story on more than one occasion. He is usually a happy, sociable person, but over the past few months has become more irritable and less interested in meeting up with friends.

Peter went for a walk while on a family holiday two months ago, but had to phone his wife to collect him, saying that he did not feel well. He refused to see a doctor and claimed he felt better after resting for a couple of hours. Since their return from holidays, Peter's employer has brought to his attention the fact that he has not authorised monthly payments on behalf of the company for two months.

Learning activity 2.3



Consider Peter's story. What are the potential implications of early diagnosis for Peter as a younger person?

Early changes in dementia may be similar regardless of a person's age, but younger people may have different needs and require different supports. We cannot cover all of these in depth in this learning resource, but Health Scotland has produced an information booklet, *Younger people with Dementia: living well with your diagnosis* [www.healthscotland.com/documents/3884.aspx] – you should make yourself familiar with this booklet (if you have not already done so) and ensure that younger people you are working alongside have access to it.

Getting an accurate diagnosis of dementia can take a very long time for younger people. They are often referred to neurological rather than mental health services, which affects the level of support available to prepare for assessment and diagnosis. This is often because of a lack of awareness that dementia can happen to younger people. They may consequently be misdiagnosed as being depressed, experiencing relationship difficulties, suffering from the effects of stress or, for women, going through the onset of the menopause.

Young people are more likely to:

- be in work at the time of diagnosis
- have a partner who still works
- have dependent children
- have ageing parents who may need support
- be more physically fit and active
- have heavy financial commitments, such as a mortgage
- have a rarer form of dementia.

Having a diagnosis of dementia does not mean the person has to stop working – this will depend entirely on the effects of the dementia – but they may need to do so before reaching normal retirement age and will need to seek employment advice. They need to consider if they want to tell their employer: doing so will enable them to access specific employment rights and entitlements, as dementia is recognised as a disability under the Equality Act 2010. Full details of rights are outlined in Health Scotland's *Younger people with Dementia: living well with your diagnosis* booklet [www.healthscotland.com/documents/3884.aspx].

By law, an employer must:

- make reasonable adjustments to support the person to remain in work
- assess the workplace risks the person faces because of the health issue
- put all necessary measures in place to mitigate the risks identified.

There are many benefits to telling the employer, but in some instances the person may choose not to do so. You have a key role in supporting people through this process and, where necessary, working with employers to raise awareness of dementia.

It is important to acknowledge that while telling employers about a diagnosis of dementia is a personal choice for many, some occupations carry a legal obligation for the person to do so. These include the armed forces, jobs on aeroplanes and ships and those involving dangerous machinery.

Driving is also of concern, particularly among younger people. Driving can be part of a person's way of maintaining independence and following an

active lifestyle. Again, no one needs to stop driving because of their dementia diagnosis, but it is a legal requirement to inform the Driver and Vehicle Licensing Agency (DVLA) and insurance company when a diagnosis is confirmed.

The basic skill of driving becomes almost automatic for most drivers and people with dementia may retain these skills for a considerable time after diagnosis, but dementia affects reaction speed, judgement and decision-making. People with dementia may be slower to react, especially under stress. There is no single cognitive test to specifically determine driving ability, but the person will need to undertake an assessment or an appraisal via the driving standards agency to determine their safety to drive following a diagnosis. If the person is declared safe to drive, he or she will be issued with a new licence that will be reviewed annually.

2.7 Co-morbidities

Dementia can develop at any age but the incidence grows **exponentially** as the person gets older.

People over the age of 80 are at highest risk and may also be affected by any number of other long-term conditions, such as diabetes, Parkinson’s disease, chronic obstructive airways disease, heart disease and arthritis. If the person with dementia has multiple health problems, this can complicate the situation and be exacerbated by problems such as dehydration, malnutrition, constipation and infection. Consequently, post-diagnostic support needs to reflect all of the person’s physical health care needs, as well as the dementia. This may require greater input from primary care and long-term condition services, depending on the complexity of the person’s condition.

Elsie’s story

Elsie is 84 years old and lives in a care home. She has no family, but her close friend Mary visits regularly and takes her out in the car. They like to visit the fishing village in which Elsie lived as a young evacuee during World War II. She enjoys watching the boats come and go and having afternoon tea in a nearby hotel.

Elsie has a number of long-term physical conditions and is very frail. Mary notices that she has become more drowsy, lethargic and forgetful over the past week. She mentions this to the care home manager, who contacts you to assess Elsie.

Learning activity 2.4



What will be a key consideration in your assessment?

Why would you need to respond with some urgency?

What would help you determine if Elsie has dementia or delirium?



What action would you take if you suspect Elsie has delirium?

2.8 Supporting people during assessment

Being assessed and undergoing health checks will be stressful for anyone, but the impact of a test that highlights cognitive deficits can be distressing. Assessment should be a positive experience that promotes inclusiveness, collaboration and empowerment for all involved, with the rights, choices and wishes of the person being assessed being paramount.

As we discussed earlier, the personal outcomes-focused approach adopted in pre-assessment contacts should ensure the person and family are able to choose their assessment rather than going through the traditional process of GP referral to psychiatry and subsequent visit to hospital.

The first step in reaching a diagnosis is to assess symptoms through a thorough medical history, physical examination and evaluation of memory and thinking abilities. Other causes of dementia-like symptoms must be ruled out through laboratory tests and, in some cases, brain scans. The decision to undertake further assessment should be discussed with the person, based on pre-assessment information and evidence of early changes we outlined earlier.

Before continuing with assessment, you will have established that the person:

- understands that he or she is having an assessment and its purpose
- understands the range of assessments that may be necessary and that it can be a lengthy process
- has defined the information he or she wants as part of feedback

- wishes to know of a diagnosis of dementia: this is his or her right and should only be withheld when he or she has expressed a wish not to know, or in unique circumstances
- has agreed how the diagnosis should be shared with him or her and who will be present.

You should be familiar with, and be able to discuss with the person and family, the range of potential assessments that may be offered in advance of a diagnosis being reached. Assessment may involve the following.

Medical assessment

Blood or urine tests are carried out to exclude other causes of dementia symptoms such as infections, vitamin and nutrient deficiency and kidney, liver and thyroid disorders.

Brain scans can be used to detect brain tumours, strokes or brain haemorrhages, brain shrinkage and increased pressure of fluid in the brain. Routine brain scans include computerised tomography (CT) scans and magnetic resonance imaging (MRI). These procedures produce an image of the brain, allowing the identification of abnormal changes: they are relatively non-invasive and are only used for diagnosis in certain cases.

CT scanning involves use of specialised X-rays to generate a 3-D image of brain structure and is useful to rule out other causes of symptoms. MRI uses a strong magnetic field and radio waves instead of X-rays to produce a 3-D image. MRI can be used to rule out other causes, find characteristic patterns of brain damage and differentiate between types of dementia.

Brain scans do not always show abnormalities in people diagnosed with dementia, as there may be no visible changes in the brain, but they can be used to indicate the type of dementia. A person with vascular dementia, for example, might show evidence of strokes or other vascular changes, while someone with Alzheimer's disease may show brain shrinkage or no changes at all.

Other types of brain scans are used primarily in research studies. SPECT (single proton emission computed tomography) is a brain scanning technique used primarily in research studies to show functional changes in brain activity. fMRI (functional magnetic resonance imaging) also provides information about brain function and structure. PET (positron emission tomography) is another type of functional brain imaging typically used in a research setting.

Genetic testing is only performed in rare cases where there is a family history of younger-onset dementia and is currently not common practice in diagnosis.

Neuropsychological assessment

These tests aim to determine the extent of any memory or thinking problems and can be used to track progression over time. It is generally recommended that they be conducted by a specialist service, such as a memory clinic or memory assessment service, but may be carried out by the GP.

The first point of contact in many instances is the person's GP, who will review the medical history and conduct a physical examination. He or she may perform a brief screening of the person's cognitive function using the GP Cog [<http://gpcog.com.au/info.php>], but it is important to consider the limitations of such tools. To find out more about this, revisit the NES *Promoting Psychological Wellbeing for People with Dementia and their Carers: an enhanced practice resource*, Section 3.

Many of the tools available have either limited validity or present copyright issues. The neuropsychological assessment tool recommended for use in Scotland, and which is freely available, is Addenbrooke's Cognitive Examination ACE-III [www.fom.gla.ac.uk/acelltrainer/]. If you have not already completed the online training in using this assessment tool, you will need to do so before

conducting an assessment. The test examines different areas of function such as memory, language, reasoning, calculation and attention. As such, it can distinguish between patterns of decline and help to identify the type of dementia. Results can sometimes seem unclear, in which case the person may be referred to a specialist (such as a clinical psychologist) for further in-depth neuropsychological assessment.

The training tool is aimed at professionals working at 'Enhanced' and 'Expertise' level, as outlined in the 'Promoting Excellence' framework. Training allows individuals to develop skills and knowledge in cognitive screening, specifically in relation to accurate administration and scoring of the ACE-III. It takes approximately two hours to complete and includes case vignettes, video clips of health professionals administering the ACE-III and opportunities to practice scoring the test live.

All health professionals must have completed this training prior to using the ACE-III screening tool in clinical practice. It does not enable them to diagnose dementia.

Mental health assessment

The person may be referred to a mental health specialist to evaluate whether depression or other mental health problem may be causing the changes. In most cases, this will be conducted as part of the assessment at the memory clinic or memory assessment service.

A feedback session that takes account of the person's expressed wishes should be arranged following assessment and details of diagnosis discussed.

2.9 Module summary

We have explored how you can support people and their families in preparing for a diagnosis and looked at the range of assessments that may be offered. We highlighted the importance of effective communication during this time in reducing anxiety and distress and building a trusting relationship. We will continue to build on these approaches and demonstrate how effective preparation and the development of a trusting relationship can have a positive impact on the person and family when receiving a dementia diagnosis.

Module 3

Receiving a diagnosis

3.1 Introduction

Receiving a diagnosis of dementia can be devastating for the person, family and friends, but the outcomes-focused approach taken in preparing the person and family in advance of receiving a diagnosis can positively influence their response and adjustment to ongoing changes. In this module, we will explore how you can effectively communicate a diagnosis of dementia to the person and family and guide them towards a more positive outcome.

The module will enable you to:

- understand how to sensitively and empathically communicate a diagnosis of dementia to the person and family
- understand the level of preparation needed to communicate a diagnosis of dementia
- appreciate the range of emotional responses to a diagnosis
- appreciate the importance of providing the person and family with timely and accessible information
- recognise how promoting hope can contribute to a person's positive adjustment to a dementia diagnosis.

3.2 Confirmation of diagnosis

There is currently no definitive test for diagnosing dementia. It requires a pooling of information and findings from a range of sources and tests, as we have already outlined. The process can be complex, time-consuming, take several months and involve different professionals and repeat assessments to monitor whether changes are taking place. Uncertainty may persist even after extensive tests and assessments; the diagnosis is often conveyed as 'possible' or 'probable', although it is accurate in around 90% of cases. The impact of not getting a diagnosis confirmed or being left undiagnosed can have serious consequences for the person and family.

A diagnosis of mild cognitive impairment (MCI) may be given if dementia cannot be confirmed, reflecting the person's memory and cognitive difficulties but acknowledging that the impairment is not affecting his or her everyday life sufficiently to confirm a diagnosis of dementia. This raises some concerns about 'early' versus 'timely' diagnosis. The identification of MCI suggests that the person is at risk of developing dementia, with 50% going on to develop dementia within five years and 20% in the first year. The dilemma is that we have no way of predicting who will go on to do so.

A diagnosis of MCI means people will be unable to access benefits, supports and services, but will continue to have the same uncertainties, memory difficulties and other impairments affecting their lives. This needs to be explained from the outset, with people's preferred supports being in place throughout the process despite the absence of a dementia diagnosis.

If Peter, for instance, is given a diagnosis of MCI, it will be essential that he has access to ongoing support and monitoring. The lack of a confirmed diagnosis will not only mean that he is unable to access benefits, but may also lead to continued uncertainty and distress that could prevent him from understanding his difficulties and adjusting to the changes in his cognition. This is likely to have a negative impact on his ongoing health and well-being, which we will explore in more detail in Module 4.

Learning activity 3.1



This activity is entirely optional.

Imagine you have been undergoing tests for a potentially serious and life-threatening illness.

Who would you want present?



Where and how would you like to receive this diagnosis?

How much would you want to know?

How would you feel if the doctor spoke to your family separate from you?

How would you feel during the time you were waiting to hear the diagnosis?

3.3 Communicating a diagnosis of dementia

Communicating the diagnosis is never easy, but the timing of the discussion and the way it is conducted will influence the person's response, adjustment to the diagnosis and longer-term outcomes for him or her and the family.

The **5 key steps** to effectively communicating a diagnosis of dementia and supporting and guiding the person and family towards a positive outcome are:

- prepare for the discussion about diagnosis
- provide timely and accessible information
- respond to emotions
- promote hope
- arrange follow-up discussion.

3.3.1 Prepare for the discussion about diagnosis

Communicating a diagnosis is an ongoing process rather than a one-off conversation. In working alongside the person in the time before diagnosis, you should take the following steps.

- Discuss with the person how the early changes he or she has experienced may have many causes, including dementia.
- As investigations continue, you should sensitively and empathically convey to the person and family that reversible causes were not found, and that dementia is a possibility.
- When sufficient information is available, you should arrange to meet with the person and family to discuss the diagnosis, anticipated future changes and support and treatment options. It can be helpful to desensitise people (and yourself) to the word 'dementia' early in that discussion by, for instance, reminding them that when they first came to see you, the plan was to carry out this assessment to help understand the reason for their reported difficulties and that there were many possible causes, including dementia.

- You will have already established who the person wants to attend the meeting and where it will take place. Additional arrangements may need to be made if the person is not accompanied by a preferred companion, such as providing an opportunity for further discussion and questions later the same day. This should be a face-to-face discussion and should build on information given earlier.
- Find a location with adequate privacy and minimise noise and distractions.
- Arrange sufficient time for the discussion.

It is important that the person communicating the diagnosis is confident and comfortable in his or her ability to do so effectively. Many clinicians report experiencing intense emotion and anticipatory stress before conveying a diagnosis. This may result in a diagnosis being portrayed in an overly positive light, or negative information being omitted. The main factors influencing this include:

- lack of training in this area
- fear of not being able to manage or cope with the person's emotional reaction
- fear of their own emotional reaction
- fear of being blamed
- concern about a potential long-term negative impact on the person
- fear of a negative impact on their future relationship with the person and family.

Practitioners should recognise this and take time to explore and address their own feelings, opinions and anxieties in advance of the meeting. You also need to be aware of the potential personal impact of working with people who are expressing intense emotion: you should have access to clinical supervision on an ongoing basis to preserve and enhance your own well-being.

3.3.2 Provide timely and accessible information

People with dementia and their families tell us that the right information is vital in their adjustment to a diagnosis of dementia, living well with the condition and developing long-term coping strategies. The information provided needs to be timely, accessible and provided sufficiently in advance of the process or change in the person's life to have a positive impact: information about assessment, diagnosis, symptoms and potential early support and treatment, for instance, should be offered before the diagnosis is delivered.

The information should set out clearly issues regarding the person and family's rights, supports and treatments and provide contact details for services. Terminology, language and format are important considerations, with medical details and technical language being tailored to the person's needs and wishes. This will allow the person to think about what it would mean to live with dementia before a diagnosis is confirmed and begin to deal with the emotions associated with dementia.

The person should be provided with verbal and written information and also information in any other format he or she prefers. Best practice recommends that an information pack is provided with information relating to:

- supports, services and benefits
- available cognitive-enhancing medicines and potential benefits and limitations
- emotional and psychological interventions and supports available
- how to undertake advanced planning and the benefits of doing so.

The same information should be provided to the person and the family or other supporting person(s). Inconsistent information may lead to distrust and suspicion, especially if the person already feels his or her sense of control and decision-making is being eroded or being assumed by others.

“My daughter went in and they asked her questions but of course I don't know what they asked her. I don't ask her because I think they mightn't want to talk about that so I don't ask her.”

Evelyn, in Koppel and Dallos (2007)

In summary, information-giving should include the following.

- It should be timely and accessible.
- It should be given in a step-by-step manner in response to individual need.
- The person should choose what information is given.
- Terminology, language and format should be used sensitively.
- You should recognise that different family members will have different information needs, and respond appropriately.
- Do not make assumptions about what the person and family already know.
- Check frequently that the person has understood.
- Find out the person's current understanding and perception of dementia.
- Reinforce areas where the person has perceived correctly, and gently educate in areas of misunderstanding.
- Recognise that people can 'shut down' after hearing bad news and it may take some time before they can articulate the questions they want to ask. Provide an information pack and offer contact details for when they feel able to ask.
- Answer questions fully and be clear and honest when there are no specific answers. If you are unable to answer questions, explain why this is so.

3.3.3 Respond to emotions

As you will already be aware, emotions are our natural first level of defence against threat: they act as our alarm or warning system. Emotions are automatic and trigger a reaction before the thinking brain has a chance to appraise the situation or fully understand what is happening. As a result, very intense emotions may delay or even override the cognitive response.

This can happen when a person receives a diagnosis of dementia. How the person reacts will vary from individual to individual, but it will come as a shock for most people, despite ongoing support throughout the process of assessment. The result can be an overwhelming sense of loss for the person and family, or a feeling of relief after a time of uncertainty.

When a person with dementia or his or her family reacts emotionally at the time of diagnosis, their distress may be exacerbated by poor and insensitive communication.

Common responses to emotionally challenging situations are often based on lack of confidence in knowing how to respond and include:

- avoiding discussion by changing the subject or focusing on less threatening issues
- immediately seeking a solution to make the person feel better
- feeling pressured by having to complete tasks within a tight timeframe
- trying to reassure the person, rather than responding to his or her emotions
- feeling anxious about ‘opening a can of worms’.

If you would like to refresh your understanding of key strategies to support people to express their emotions, you should access the NES learning resource *Emotions Matter* [www.knowledge.scot.nhs.uk/home/learning-and-cpd/learning-spaces/emotion-matters.aspx].

We should allow the person to express emotion, recognising it not only in conversation, which may feel as if it is going around in circles, but also in non-verbal clues. We need to let the person and family know we are trying to understand what they are going through by empathising sensitively and compassionately.

“*I think it’s compassion. They’ve got to be able to listen to what the person is saying, treat them as an individual.*”

Henry, Scottish Dementia Working Group member

Empathy is the ability to appreciate, understand, interpret and respond to another person’s emotions. It can help reduce the intensity of the emotional experience and the length of time dominant emotions persist. This will not be new to you and you will already use empathy in your practice, but some of the barriers to effectively and genuinely empathising with people with dementia who are distressed about their diagnosis may be about our own unconscious beliefs about dementia. We may make a judgement, based on stereotypes, social stigma or fear, that if we ask how the person is feeling, we cannot predict the response. Empathy is a very important interpersonal skill that takes time and practice to develop to the point where it becomes ‘second nature’. If it is not genuine, the person will see through our insincerity, which will jeopardise our relationship.

Responding to emotionally charged situations and conversations draws on key interpersonal skills, such as reflecting on what the person has said. This will help to show that you understand what has been said and gives him or her a chance to elaborate further. It is not simply repeating or paraphrasing, but conveying that you know how the person feels: “I see this is upsetting you”, or “This is hard to talk about”.

You can use a **continuer**, through open questions as described in Module 2, to enable the person to continue to express his or her feelings. Examples would be “Tell me more” and “What are your thoughts about what I have said?” But you should avoid the use of **terminators** that stop the conversation or move away from emotions before the person has finished – joking, changing the topic or moving on to facts about diagnosis, for example.

Validating the person’s emotion will convey that his or her feelings make sense. You can use expressions

such as “I can understand why you are upset”, “Anyone would have felt the same way”, or “This is a totally normal response”.

Offers of personal support let the person and family know that you care and want to help. It is not about giving advice or finding solutions, but rather asking them how you can help. Engaging in a collaborative relationship builds on your offer and creates a sense of partnership, confirming for the person that he or she has control and can be part of the solution.

Finally, always show respect for the person by focusing on positive aspects of the situation. This is similar to conveying hope and will be discussed later in this section.

3.3.4 Promote hope

There is considerable evidence that promoting hope can be very powerful in enabling people to positively adjust to a diagnosis of dementia. Hope can be defined as:

“ A combination of desires for the future, values and goals about future outcomes and action to bring about hoped-for outcomes.”

(Simpson, 2004)

To promote hope, you need to have established a relationship of trust with the person. After taking time to discuss emotions, you should check with the person and family that they are ready to discuss facts: “Would it be OK for me to talk about ...”.

When the intensity of emotion has reduced, focus discussions on positive elements of how the person can live well with dementia for a long time, ensuing this is balanced with realistic goals and providing an information pack and contact details. Many practitioners find this difficult as their beliefs about dementia are not congruent with their concept of hope or recovery.

Learning activity 3.2



Peter's story

You have been working alongside Peter and his family and supported them during his assessment. You have arranged to meet with Peter and his wife to discuss his diagnosis.

Having sensitively and empathically communicated a diagnosis of dementia to Peter and his wife and responded to their emotions, how can you promote hope for Peter and his family?



Practitioners can promote hope simply by being empathic and letting the person feel understood and supported. Hope is connected with the manner of the practitioner, who becomes an ally at a time of distress. Supporting the person and family to open up and talk is hope-inducing – discussing hope with the person and asking directly about worst fears and best hopes can be helpful. And just as some practitioners manage their own emotions by practising simple mindfulness techniques, the person might also be offered ideas about how to live in the present moment at some stage.

Being on the lookout for any future-oriented discussion, then exploring it, offers a sense of hope. The person talking about plans for Christmas or what he or she is doing between now and the next appointment provides evidence of hope that can be utilised and amplified in the conversation.

Anything that encourages the person to dare to live as normal a life as possible inspires hope. Hope is infectious (as is pessimism): a hopeful and optimistic (but realistic) practitioner can inspire hope in others.

3.3.5 Arrange follow-up discussion

We need to be aware that information-giving is not a one-off event. As we have highlighted, the person and family are unlikely to absorb all the information at the time due to their overwhelming emotions and sense of shock.

“You don’t take in a word she says. You need help with that shell shock,”
Ann, family member

As the person and family attempt to take in the diagnosis, they may have questions that can cause increased anxiety and distress if left unanswered until a future appointment. An early follow-up appointment should be organised, but a contact person to answer questions as they arise should also be identified. This will help to avoid additional anxiety and distress that may lead to the person withdrawing and failing to contact services. The contact should be the individual who has been

working with the person prior to assessment wherever possible, supporting a person-centred and outcomes-focused approach. Contact details for the Alzheimer Scotland 24-hour helpline should also be provided.

The opportunity to have follow-up discussions allows the person and family time to assimilate the dementia information they have been given, reflecting on it relative to their own perceptions and understanding and enabling them to begin to address the emotional impacts. We need to be aware that readiness to take on board, or even be prepared to listen to, explanations will vary from person to person. For this reason, follow-up contacts should be conducted face-to-face rather than by telephone. This allows the person to access information supported by discussions with a trusted practitioner at a point in time when he or she may be more open to dealing with the diagnosis. It will also better enable the practitioner to assess the person and family’s emotional state and take appropriate action.

It will be important at this point that the person and family are aware of their rights under the HEAT target to have a minimum of a year’s worth of post-diagnostic support coordinated by a link worker, including the building of a person-centred support plan.

3.4 Module summary

We have explored how you can support the person and family by sensitively and empathically communicating a diagnosis of dementia. We considered the need to respond to emotions when communicating a diagnosis and highlighted that how the person reacts when receiving a diagnosis is not necessarily indicative of how he or she will adapt in the months that follow. For this reason, follow-up discussions and ongoing support in the time after diagnosis are essential.

We will consider how you can support the person and family to live well with dementia and explore the impact of the diagnosis on their social and emotional well-being in Module 4.

Module 4

Living well with dementia

4.1 Introduction

People may only begin to take in the diagnosis in the time immediately following its delivery, and this is when they may feel an overwhelming sense of loss and hopelessness. They may experience considerable difficulty in coming to terms with this major life change, but central to early diagnosis is the idea that an opportunity exists to enable and support people to maintain their independence and ensure they have the best quality of life possible.

People who receive a diagnosis early often find that other people either doubt the diagnosis (because the person still appears to function very much as before) or expect the person's functional abilities to fail rapidly. Younger people with dementia may experience additional difficulties because dementia is commonly seen as an older person's condition.

This final module explores the impact of receiving a diagnosis on people's social and emotional well-being. We will consider how an outcomes-focused approach can enable people to continue to live well with dementia, support them to stay connected with their communities and plan for the future.

The module will enable you to:

- critically understand the potential impact of a diagnosis of dementia on people's emotions, relationships, roles and expectations and the risk of social isolation that can follow a diagnosis
- critically evaluate the processes involved in adapting to changes in sense of self, relationships and roles
- understand how to apply a range of strategies to engage people with dementia in outcomes-focused conversations to establish what is important to them, and support them to prioritise and achieve these personal outcomes
- understand how to sensitively and empathically work alongside people with dementia to support them to identify and record their priorities for the future, including their wishes for times when they have reducing capacity and end-of-life issues need to be addressed.

4.2 What contributes to a person living well with dementia?

People with dementia and their families have said that social and emotional support following a diagnosis, being able to continue with previous occupation and interests, and remaining connected to their community are crucial. As we highlighted in the introduction to this learning resource, supporting people with dementia and their families following a diagnosis was one of the key change areas in Scotland's first dementia strategy. The second *National Dementia Strategy: 2013–2016* launched in 2013 set out a new target and commitment to:

“ ... deliver expected rates of dementia diagnosis and by 2015/16, all people newly diagnosed with dementia will have a minimum of a year's worth of post-diagnostic support coordinated by a link worker, including the building of a person-centred support plan.”

This target is informed by Alzheimer Scotland's five-pillars model, which is designed to guide the support offered to people in the time following a diagnosis of dementia (Figure 4.1).

Figure 4.1 Alzheimer Scotland's Five Pillars of Post-diagnostic Support



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The five pillars are:

1. help to understand the illness and manage its symptoms
2. support to stay connected to their community
3. peer support from other people with dementia and their families and carers
4. help to plan for their future decision-making
5. support to plan the shape of their future care from their own perspective.

These pillars do not represent a linear set of actions to be completed, but rather a framework underpinning the range of supports that contribute to people with dementia and their families living well following a diagnosis. They reflect the 'Promoting Excellence' framework quality of care outcome indicators detailed in Module 1.

In essence, they are about working alongside the person and family to enable and support them to remain as independent as possible following a diagnosis by:

- enabling them to feel empowered to continue to maintain choice and control in all aspects of their life and decisions about the future

- providing accessible information and education to help them come to terms with their diagnosis
- recognising the importance to quality of life of people remaining occupied and stimulated and being able to continue activities that were meaningful to them prior to the diagnosis
- enabling them to have opportunities to speak to others, express their feelings and reduce their anxiety and depression
- facilitating them to continue to be part of, and to contribute to, their local community and social networks through ongoing engagement and activity
- promoting a physically active life to benefit physical and mental health and well-being and improved quality of life
- planning for the immediate and long-term future, enabling them to manage changes and make choices about personal care, medical treatment, end-of-life care and financial and legal decisions
- ensuring their support plans are recorded and accessible to people working with them throughout their dementia journey.

The central consideration in working alongside the person and family to enable them to live well with dementia is to recognise the social and emotional impact of the diagnosis and support them to adjust to their life with dementia.

In my case, I actually was thinking of suicide. Because I felt I'd be no use to anybody and I didn't want people to be looking after me. That was a decision my wife took on board and helped me she talked to me she said that she'd look after me. After all I've been married for 36 years, and she's my rock. She's my tower of strength. And she stopped me from actually doing that.

Henry, Scottish Dementia Working Group member

4.3 Social and emotional response following a diagnosis of dementia

Working alongside the person and family in accepting and adjusting to the diagnosis of dementia supports the pillar 'Help to understand the illness and managing its symptoms'.

Accepting, and adjusting to, a diagnosis of dementia can be a lengthy process during which the person may experience a range of emotions. These will differ from person to person, but can include fear, terror, shame, guilt, sadness, anger and despair, and sometimes result in apathy, withdrawal and depression. Feelings may be very strong, conflicting and mixed.

The notion of 'adjustment' recognises the impact of a diagnosis on a person's identity and sense of who he or she is. The person needs time to process what is happening, consider what it means for his or her life and make necessary changes or 'adjustments'. This involves moving from a life without dementia to incorporating the changes it brings, while also

holding on to who they were before diagnosis. The person's emotional response and ability to make these changes will be influenced by several factors, such as his or her personality, social situation and previous life experiences, and the strength of support through the assessment and diagnostic process.

A significant influence will be the person's perception and understanding of dementia and expectations for the future. Another important influence will be how others respond to the diagnosis, as well as the person's perception of how others might respond. You should read *Promoting Psychological Wellbeing for People with Dementia and their Carers: an enhanced practice resource* Section 1 (What makes us who we are?) to refresh your understanding of this.

Recognising where the person is in relation to coming to terms with, and accepting, the diagnosis is important in supporting him or her through the adjustment process. Where someone is having difficulty moving on, it is important to provide support appropriate to the stage of adjustment he or she is currently experiencing to enable them to continue through the process.

The influence of other people, including family, friends and health and social care professionals, on the adjustment process and outcomes for the person with dementia is significant. Other people may make assumptions that the person will be 'different' and no longer able to participate in his or her usual social and daily life activities. The person's sense of identity is at risk when people might advise a cessation of activities and interests or the relinquishing of family or work life roles. A potential consequence of this may be that the person becomes socially isolated, withdrawn and depressed.

People may not adjust to their diagnosis for other reasons. Some may get 'stuck' with finding a meaning for the changes, particularly if a full explanation is not offered during the course of the diagnosis or if they have not understood what they have been told. They may question why they have dementia and even blame themselves because of their lifestyle choices. Alternatively, they may underplay the significance of the diagnosis

and relate their declining cognitive abilities to a longstanding difficulty: perhaps their current lack of ability to concentrate and listen is not new, because it was constantly referred to during their school years. They may also be angry: they have been very active and have led a healthy lifestyle, so shouldn't this have prevented dementia?

Building positive networks and supports is essential to enable people to adapt to the changes that dementia brings over time. You will be able to support them through this process with sensitive, empathic engagement and the ongoing adoption of a personal outcomes-focused approach. This will enable the person and family to mobilise their resources and assets to build resilience and put in place necessary changes to live well with dementia.


Learning activity 4.1



You should complete this activity with a colleague.

Take a few moments to think about a particular stressful event or traumatic time in your life and share the answers to the following questions with your colleague.

Can you recall how you got through this stressful time?



What things helped you through?

What things restricted you in this process?

The ability to 'bounce back' from such experiences is called 'resilience'. We all experience stressful times or traumatic events of varying degrees in our lives. While some people recover quickly and feel a sense of personal growth, others become trapped and consumed by their experience. Resilience is not about eliminating the stress: it is about using strengths to tackle the problem. This may seem to come naturally to some people, but it is important to recognise that it is a skill that can be learned; we can therefore support people with dementia and their families to build resilience.

Our resilience comes from our inner strength, key relationships or the beliefs we hold. As we highlighted earlier, each person's process of adjustment to a diagnosis of dementia will be different and is influenced by several factors, such as personality, previous life experience, beliefs about dementia, being able to remain connected to significant people and activities and feeling they still have a role and a sense of worth. These same factors determine resilience.

In working alongside people with dementia, we need to think about how the difficulties they face fit with their resources and assets – their own strengths and resources and those available from others close to them and their community. Adopting a personal outcomes-focused approach will support this process.

4.4 Personal outcomes-focused approaches to supporting people with dementia following a diagnosis

Module 1 introduced the concept of outcomes-focused approaches and how to engage in personal outcomes-focused conversations. You should continue to adopt this approach in your engagement with the person and his or her family in the identification of personal outcomes following a diagnosis. The agreement of priority outcomes and actions needed to achieve these will form the basis of the person's personal support plan.

We have already highlighted that focusing on outcomes requires a different type of conversation. We need to actively listen, which requires concentration, effort and practice. We may believe

we are listening to the person, but our mind may not be open to what her or she is saying. Partial listening is more likely to occur when we approach the discussions with a set agenda, thinking, for example, in terms of whether the person meets the criteria for particular services. This can result in a service-led, rather than an outcomes-based, approach.

Ian's story

Ian is 74 years old and a retired electrician. He has rarely had any contact with health services, apart from visits to his GP for minor ailments. He has lived in the same house since marrying his wife Kathy some 52 years ago. Kathy died five years ago but he lives in a very supportive neighbourhood with many friends who moved in around the same time. He is also a keen hill-walker, although he has not managed to get out for a walk for some time. He visits his sister, who lives in a nearby town, every fortnight. Although he lives alone, he has two sons, one who lives at the other end of the country and one about 10 miles away.

Ian has been having memory problems for about two years and received a diagnosis of dementia three weeks ago. This came as a shock to him and he is feeling hopeless and devastated. He is avoiding contact with neighbours and has not left the house since receiving his diagnosis.


Let us consider our approach to personal outcome conversations with Ian.

Learning activity 4.2



Ian is feeling hopeless and devastated. You have been asked to support him following his diagnosis, and this is your first agreed contact.

What would be your priority in your first meeting with Ian?



How would you approach a personal outcomes-focused conversation with him?

The following is an example of how your first conversation with Ian may progress.

Example of dialogue with Ian

You introduce yourself and remind Ian that you arranged this visit with him at the memory clinic three weeks ago. You explain that you are meeting him to see how he is feeling since his diagnosis and to talk to him about what he wants to happen next.

Worker How did you feel after the last appointment?

[Silence]

Worker Have any questions arisen for you since that meeting?

Ian There is no point. I'm finished, I'm no good anymore.

Worker You feel like you're no good anymore?

Ian Yes, I'm no good anymore.

Worker What do you mean when you say I'm no good anymore?

Ian I can't believe I got this Alzheimer's thing.

Worker It sounds like what you are saying is that your diagnosis came as a shock – have I got this right?

Ian I didn't expect this, but what does it matter, I will be dead within a year.

Worker Is that what you expect – that you will be dead within the year?

Ian It's no use, I'm finished.

Worker Where have these thoughts come from, that you will be dead within a year?

Ian This Alzheimer's – I've seen what it does.

Worker Can you say a bit more about that?

Ian My grandmother – terrible, terrible.

Worker Your grandmother had Alzheimer's?

Ian [Nods head] I don't want them to see me like that.

Worker It must have been really hard to see your grandmother with Alzheimer's. It can affect people very differently.

[Short pause/silence]

Worker So although I can see how this experience makes you worry about what the future looks like for you, there is nothing to suggest that you will experience the disease in the same way as your grandmother.

[Short pause/silence]

Worker There are lots of things we now know about how to live well with Alzheimer's that perhaps were not available in your grandmother's day.

Ian [No response, just shakes his head.]

Worker What things about Alzheimer's would it help you to know more about?

[Short pause/silence]

Ian [No response, just shakes his head.]

Worker Thank you, Ian, for being open about some really difficult feelings. When we next meet, we will continue to explore how you feel about your diagnosis and what it means to you. We will also work together to start identifying the strengths and skills that you have that will help you continue to do all the things that are important to you.

As you read through the example, you will have noticed how the worker asked questions to better understand what Ian was saying. He or she used clarification to ensure he or she had accurately interpreted what Ian meant and to validate his feelings. You will also have noticed the use of therapeutic silence.

It is important to emphasise that this is just an example. Every conversation is individual and depends on the interactions between the two people.

4.5 Impact on family and relationships

Some people will have family, partners and children or grandchildren, while others may be alone or have close friends and neighbours. Everyone involved can react differently.

Family members may be more devastated by the diagnosis than the people diagnosed. The sense of loss can sometimes be even greater than if they had experienced bereavement. Interpersonal dynamics with partners are highly likely to change.

Even though the diagnosis has been made early, the family will have been living with changes for some time previously. This may have led to tensions and friction, even before diagnosis. The family may have seen the changes as lack of consideration by the person, who may seem uncooperative or annoying.

If we consider Peter withdrawing and refusing to meet with friends, this will have had an impact on any previous arrangements made and may have left his wife having to make excuses. This could have resulted in increasing resentment, especially when repeated time and time again.

The person may have become irritable, moody or lethargic and his or her loving and caring side may have disappeared during this time. In some instances, it can even leave partners questioning the validity of a lifelong happy relationship. There may also be a physical impact on sexual feelings, desires and needs of the person with dementia and partner. By the time a diagnosis is made, the couple may be living in the same house but not communicating and there is a risk that this could continue following diagnosis. If families are not supported to express their feelings openly, antagonisms that have built up within the relationship will persist and leave families in a draining cycle of conflict.

People with dementia, or family members, may have to give up work if they are still in employment. If they are retired, they will have to take a different perspective on future plans. Many people will tend to focus on what is going to happen as the person's

dementia advances rather than focus on the here and now.

Family and partners may struggle to adapt to the diagnosis. They may feel:

- guilty about not being more patient with the person, for feeling embarrassed about dementia and for not wanting to take on extra responsibilities
- a sense of potential grief and loss for the person they knew
- resentful because of the potential impact on plans they have made for the future or for retirement
- anxiety about the potential loss of income, having to give up work or having to be a carer.

It is well documented that as dementia progresses, it has a negative impact on the health and well-being of the family. When the family are given support at this early stage, many of these negative experiences can be averted. It is important to take the same outcomes-focused approach to identifying what is important to families. As we have already highlighted, they may have their own perspective and priorities. It is often best to organise to meet with the partner or family member alone to establish their feelings, fears and concerns: they may not be comfortable discussing these with the person with dementia present. This will require sensitivity to ensure that the person with dementia does not feel excluded or that decisions are being made about them.

Similarly, you should organise one-to-one meetings with the person with dementia as he or she may also have concerns that would not be shared if the family member was present. It is crucial, however, to also work with the family as a whole to support them in finding ways of discussing difficult issues openly together.

You will be in a position to act as mediator or facilitator so that all parties have a voice and are heard by others involved. Working with the family in this way and identifying personal outcomes can enable them to appreciate that the person continues to have many strengths and abilities. If you do not feel confident in undertaking this role, you should encourage the family to agree to a referral to specialist psychological therapy services.

It is crucial to appreciate and respond to the particular needs of children and young people when a parent has been diagnosed with dementia. Children will respond to the parent's diagnosis in different ways. Families may tend to avoid talking about dementia as a means of protecting them, but regardless of age, children will be aware of changes, tensions and stresses. The level of information they receive will need to be age-appropriate and ongoing support will be required for the family to adjust as a whole.

A coping strategy many families find useful in supporting children is to use humour to deal with difficulties or when the person does not successfully manage a task or activity. They focus the blame on the dementia rather than the person, which helps reduce tension.

The Health Scotland booklet *Younger People with Dementia: living well with your diagnosis* is a very useful source of information to help families support children. The Mental Health Foundation booklet *The Milk's in the Oven* has been specifically designed to help children to understand dementia.

Learning activity 4.3



You will recall that Peter is a younger person who has just received a diagnosis of dementia. He has young children, a girl aged 10 and a boy of 14.

During one of your visits to Peter's family following his diagnosis, Peter's wife becomes tearful and upset. She tells you that they have reports from the school that their son is not doing his homework and he refuses to speak about it, spending most of his time in his room. She is exhausted and cannot cope with all the responsibility.

What could you do to support the children?



Many families also find that friends withdraw, leaving them with a limited social network. This may be linked to the friends' understanding of dementia, stigma, embarrassment and not knowing how to talk to the person. It may also be that the family have not been open about the diagnosis: in that instance, it may be appropriate to encourage them to share the information and resources provided about dementia with friends.

4.6 Supports, intervention and activities to live well with dementia

Supporting people with dementia to remain socially active, access specific interventions and health promoting activities links to the following pillars: 'Support to stay connected to their community', 'Peer support from other people with dementia and their families and carers', and 'Understanding the illness and managing symptoms'.

A wide range of supports, specific interventions and health and well-being activities can enable people to live well with dementia. The person may want to use a combination of these, based on preferences and changes he or she is experiencing. Your role is to be familiar with the range available and provide sufficient information to enable the person and family to make decisions about preferred options.

4.6.1 Social networks and peer support

Being able to create and develop relationships with others is essential for all of us. A wide circle of friends and networks is important for some, while a small number of close friends and family is preferable for others. A diagnosis of dementia does not change this. The person should be encouraged and supported to continue with existing friendships and develop new ones. Many people with dementia find they establish new or previously lost interests

and friendships as part of their adjustment once a diagnosis is confirmed.

Many people with dementia also value the opportunity to meet, socialise and share experiences with other people with dementia. You should be aware of, and provide information about, opportunities in your area and support people to access them. Examples of peer support include the Scottish Dementia Working Group (SDWG) and dementia cafés.

It is important to remember that some people with dementia would not wish to engage in peer support.

It is equally important for families to feel supported, be able to share experiences and engage with others through, for example, the National Dementia Carers Action Network (NDCAN).

4.6.2 Health promoting activity

Encouraging people to improve their overall well-being will enable them to be more physically and emotionally resilient. There is considerable evidence to suggest that physical activity has a positive effect on cognitive function, increases physical well-being, improves mood and heightens opportunities for social engagement, especially if the person enjoys the activity.

A healthy diet can help reduce the risk of developing co-morbid conditions such as coronary heart disease, cancers, diabetes and stroke. People can continue to enjoy alcohol but should be advised to follow Scottish Government guidance on recommended limits set out in Health Scotland's Drinks Calculator [www.healthscotland.com/documents/5843.aspx]. People with Korsakoff's syndrome should abstain from alcohol, and medical advice on intake may be necessary when the person is taking medication. The general health risks from smoking, including

increased risk of stroke (which is particularly important for people with vascular dementia), also apply to people with dementia.

Stress management is an important consideration for people with dementia and their families, as stress may only become obvious through physical symptoms. A range of relaxation techniques has been designed to help to manage stress, including mindfulness and reflective writing exercises. If you have concerns about the person, you should discuss the idea of referral for specialist psychological therapy with them. Spirituality is important for some people, who can reduce their stress through practising their faith, spending time with family and friends, enjoying nature or meditating.

4.6.3 Cognitive-enhancing medicines

There are currently no drug treatments that can provide a cure for dementia, but drug treatments can improve symptoms or temporarily slow down their progression in some people.

There are two classes of medication licensed to treat Alzheimer's disease in the UK – acetylcholinesterase inhibitors (AChEIs) and N-methyl-D-aspartic acid (NMDA) receptor antagonists, which work in different ways. Acetylcholinesterase inhibitors include donepezil hydrochloride, rivastigmine and galantamine. The NMDA receptor antagonist is memantine. You can enhance your knowledge of these medicines by accessing the NES Pharmacy learning resource, *The Pharmaceutical Care of People with Dementia* [www.nes.scot.nhs.uk/media/2565054/05-03-2014_dementia_web_version.pdf].

4.6.4 Cognitive rehabilitation

The evidence base for the effectiveness of cognitive rehabilitation for people with dementia, particularly those who receive an early diagnosis, is growing. They have been found to be particularly effective in maximizing independence and allowing people to participate in everyday tasks that are important to them.

The main goal of this type of therapy is to help people with dementia manage or compensate for cognitive difficulties by maximizing remaining

cognitive skills. Specific techniques include memory aids (such as diaries or wall charts), errorless learning, paired association and repetition. It is an individualized approach in which the person with dementia works with a therapist (usually an occupational therapist, clinical psychologist or member of nursing staff) to agree specific realistic goals and consider the most appropriate technique to meet them, based on the person's profile of cognitive ability. For more details, see the *Cochrane Review (2013) on Cognitive training and cognitive rehabilitation for mild to moderate Alzheimer's disease and vascular dementia*.

NES is currently developing learning resources to support staff to deliver cognitive rehabilitation.

4.6.5 Cognitive stimulation therapy

Cognitive stimulation can occur informally through recreational activity or formally through a cognitive stimulation therapy (CST) group programme.

CST was developed by Aimme Spector and colleagues from University College London and represents a combination of the most effective non-pharmacological interventions for dementia. Extensive evaluations have shown that it significantly improves cognitive function and quality of life for people with mild-to-moderate dementia. People with dementia, their families and staff describe involvement in CST groups as a positive experience.

The CST programme consists of 14 sessions delivered over a seven-week period, although weekly sessions running over a longer period have been found to be as effective. The sessions involve themed activities designed to actively engage and stimulate the person. CST can be delivered by a wide range of people working in dementia care, such as care assistants, nursing staff or occupational therapists. A number of people in Scotland have undertaken training in CST. You may wish to establish the availability of the intervention in your local area.

Self-directed support

Self-directed support (SDS) is an important consideration in future planning conversations. SDS allows people to choose how their support is

provided by giving them as much ongoing choice and control as they want over the individual budget spent on their support. People may not meet the criteria to receive SDS immediately following a diagnosis, but it would be appropriate to ensure they have information about it and can detail their wishes in their personal care plan. For further information on SDS, access the website [www.selfdirectedsupportscotland.org.uk/directing-your-own-support/].

While enabling the person to live well with dementia, these supports, interventions and activities can also facilitate risk enablement.

4.6.6 Risk enablement

Life is never risk-free. Risk is part of all our lives, but assumptions about the diminished capacity of people with dementia to make decisions about risk can result in their quality of life being restricted.

Awareness of the potential impact of risk aversion on the rights and freedoms of people with dementia led to the Department of Health in England producing guidance on 'risk enablement' in 2010 (Department of Health, 2010). *Nothing Ventured, Nothing Gained – risk guidance for people with dementia* shifts the focus to recognising the many positive benefits of supporting people with dementia to take risks. It is based on the idea that the process of measuring risk involves balancing the positive benefits from taking risks against the negative effects of attempting to avoid risk altogether. It takes a tailored approach to risk by acknowledging that dementia affects different people in different ways. People's perception of risk will have been built up over the course of their life and by the impact of changes that can be attributed to dementia.

Some issues may arise because of conflict between the outcomes the person with dementia wants and those family and carers want. Differences in views often focus on what the person with dementia is able to continue to do and the risks involved. The family will need support to enable the person to take risks, as they will naturally tend to want to protect the person without realising the impact of restrictions on his or her quality of life.

Interventions to support risk enablement should aim to cause the least disruption or change in the circumstances of people with dementia and maximise independence, with due attention to the safety of others. The innovative use of telecare and assistive technology can enable people with dementia to remain independent and minimise risk. All new technology should be in place before it is required: this will give people the opportunity to adjust to using it and develop a routine. You should have detailed up-to-date knowledge of the range of telecare and assistive technology supports available and be able to work with people to establish what is going to be of greatest help to them.

Learning activity 4.4



Ian's story

Ian has many interests and was socially active before receiving his diagnosis. He was a keen hill-walker, although he has not been on a hill for a couple of years. More recently, he enjoyed going to his local pub and occasionally placed a bet on the horses. He travelled by bus to visit his sister in a nearby town every fortnight and was actively engaged in his local Neighbourhood Watch group. Following his diagnosis with dementia, Ian's sons suggested that one of them take him to visit his sister once a month, rather than Ian travelling by bus.

Ian has been going to the pub and placing bets every day. His son has contacted you because he is concerned that Ian is spending all his money and he wants you to facilitate a conversation with him about granting power of attorney.

What issues would you consider?



4.7 Supporting future planning

Supporting future planning links to the pillar 'Help to plan for their future decision-making'.

Planning for the immediate and long-term future can ensure the experience of living with dementia is less stressful. It is important as a means of supporting people to prioritise and plan for the future as the dementia progresses, enabling them to manage changes and choose who they wish to make decisions on their behalf when they are no longer able to do so. People can record their preferences in relation to personal care, medical treatment, end-of-life care and financial and legal decisions. It is therefore important to encourage people to work through this process as soon as possible after diagnosis, particularly identifying proxy decision-makers.

The process needs to progress, however, at the person's pace and at his or her choosing. There is a risk that the mention of issues such as power of attorney at a point when the person is not ready to consider them may threaten his or her sense of control and negatively impact on his or her engagement at a later date.

4.7.1 Identifying when the person is ready to discuss future plans

Some people may be ready to discuss advance plans soon after diagnosis and will be likely to initiate this conversation. Others may need an opportunity to adjust to their diagnosis first, as advance planning can create a sense of relinquishing control and looking at a future in which the person is no longer able to make decisions. While the HEAT target aspires that people develop a personal plan within one year, it is important to recognise that some people may not be ready for this. The key thing is to respect people's wishes and work alongside them at their pace.

Many families will look to health and social services professionals to support them to engage the person in conversations about the future. It can be challenging for professionals to initiate what can be seen as difficult conversations where the outcome is unpredictable and there are heightened and intense

emotions. It is understandable that as professionals we are anxious about starting conversations we feel may have a negative impact on the person.

A conversation using a personal outcomes-focused approach, such as the one we described earlier, will enable people to express their feelings and make you aware of the extent to which they have adjusted to their diagnosis and their personal outcomes. You will pick up on verbal and non-verbal cues that the person may be ready, or there may be natural points to think and talk about the future. This can in some instances mean seizing the opportunity to discuss when you get an indication that the person wants to begin, rather than waiting for a planned meeting.

Generally, however, you will need to initiate the conversation rather than leaving it to the person with dementia and the family to do so. Some tips for planning and engaging in conversation are shown in Box 4.1.

Box 4.1 Tips for planning and engaging in conversation

Arrange a time to meet the person in a familiar non-threatening environment.

Focus the conversation and do not gloss over it.

Be clear in your own mind about the purpose of the conversation.

Do not make assumptions about the outcome, but do have some knowledge about the person's views and perceptions of future planning.

Recognise that your attitude toward the conversation influences your perception of it and will impact on the outcome. Do not let your own fears get in the way of the conversation.

Be supportive and honest.

Ask the person for his or her view on the subject. Use open cues such as: "I'd like to talk about ... with you, but first I'd like to get your point of view".

Acknowledge that you have heard and understood.

Explain the positive benefits of future planning, such as the person experiencing reduced stress and anxiety, knowing what to expect and how to respond.

Do not assume that the person will see things from your point of view.

Acknowledge emotions and allow the person to express his or her feelings.

Sensitively bring the person back to the discussion, remembering your purpose at these difficult points.

Remember it is a process and an ongoing conversation, not a once-off.

Learning activity 4.5a**Hilary's story**

Hilary is a 67-year-old retired history professor. She lives with her partner, Susan, who is 55. Susan is an administrator and continues to work at the university where they met.

Hilary was diagnosed with dementia six months ago. She has been having memory difficulties for a couple of years but refused to seek advice, despite support from Susan. Hilary resigned from her post at the university a year ago when her employer launched disciplinary action because of her poor performance.

Hilary is nevertheless a very good teacher, with many of her students over the years commenting on how inspiring she is. She has been a prolific collector of history and art books, loving nothing better than sharing them and her wide knowledge with others. She enjoys combining her love of art, photography, history and museums, visiting many interesting places around the world: and she has the photographs to prove it.

The house they have been living in for the past five years belongs to Hilary and is in her name. Her sister has a negative view of the relationship and believes Susan is only interested in Hilary's money and the house. She contacts you with her concerns because she has witnessed an argument between Hilary and Susan and feels action needs to be taken to protect Hilary's property and finances. She feels that as a family member, she should take over the management of Hilary's affairs.

What are your key considerations, given the information you have received?



Learning activity 4.5b



Hilary's psychiatrist has determined that Hilary is capable of managing her property and financial affairs. What action should you take to support her?

Learning activity 4.5c



Susan's story

You arrange to meet with Susan to establish her personal outcomes and perspective. When you meet her, she is tearful and describes how her relationship with Hilary has changed.

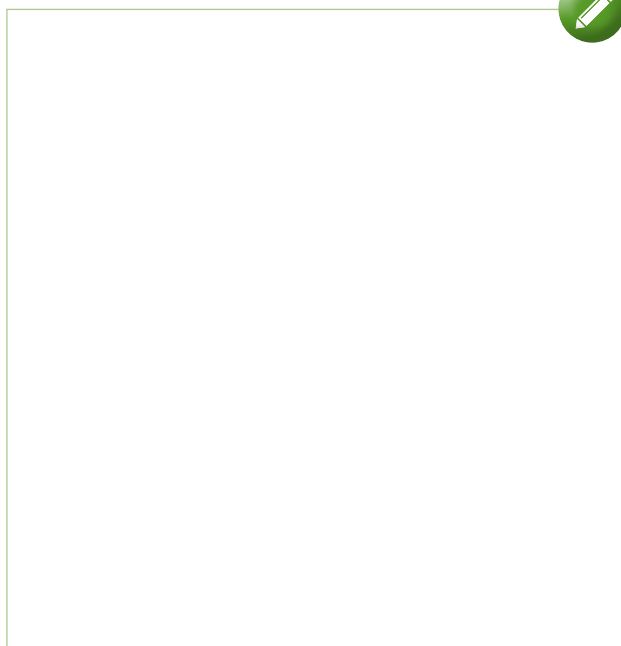
They had a very happy relationship, sharing many interests and hobbies – chess, quiz games and photography. They took their holidays in areas of great natural beauty where they could indulge their love of photography.

Susan remarked that she had begun to notice changes in Hilary more than three years earlier. She had initially put her outbursts of anger and refusal to play chess or quiz games down to pressure of work, as she had always said she felt pressured. She kept losing things and accusing Susan of hiding them, particularly her car keys. Hilary decided to give up driving immediately after retiring almost a year ago. Susan hoped things would improve in their relationship with less pressure, but Hilary now spends a lot of her time sitting at home watching TV and will not engage in joint interests.

It was a relief for both of them when Hilary got the diagnosis of dementia, but their relationship has not improved. Hilary now spends most days in pyjamas watching TV and is constantly angry, rude and belittling. She will not participate in conversation with visitors and often asks them to leave.

Susan's attempts to discuss their relationship have resulted in Hilary suggesting that she can leave if that is what she wants. Susan now feels that Hilary is a 'stranger': she is no longer the caring and loving person she was and perhaps they would be better to part, although she still loves Hilary.

How would you support Susan?



4.8 Developing a support plan

Developing a personal support plan is a key aspect of the HEAT target mentioned earlier and relates to the ‘Support to plan the shape of their future care from their own perspective’ pillar.

We introduced the concept of outcomes-focused approaches in Module 1. The approach expands the scope of our engagement with people with dementia and their families. Rather than beginning by establishing what people have difficulty with, the starting point for an outcomes-focused approach is an understanding of what is going on in their life and what they want to achieve. We can then go on to identify barriers to people achieving their outcomes and how they can be overcome, building on their abilities, assets and strengths.

Developing a personal support plan is a key aspect of this process. There is no single ‘best’ way of developing one, but the process will involve all of the skills that have been discussed throughout this learning resource, particularly those around outcomes-focused conversation. A personal outcomes-focused assessment, as described in Module 1, is an important source of information in the development of a plan, and there is a range of person-centred planning approaches that staff can use to facilitate its development (Box 4.2).

Box 4.2 Examples of person-centred planning approaches

Essential lifestyle planning (ELP)

ELP is a tool that lets you know how someone wants to live. It reveals what is important to people and the support they need (from their perspective) to remain healthy and safe. A good plan reflects the perceptions of the person and those who love and care about them.

ELP looks at:

- what people like and admire about the person
- what is important to the person
- communication
- how to provide support
- identification of successful methods
- how to solve problems.

ELP is a good approach to starting to get to know people and working out what they feel is needed to support them on a day-to-day basis. It does not focus on ‘dreams’, unlike some of the other methods.

Planning alternate tomorrows with hope (PATH)

PATH is a fast-moving tool that is usually graphically presented and has a powerful impact on those involved. It focuses mostly on the process of change and helps a group of people who are committed to the person to understand the plan and how it will progress. This is not so much about gathering information, but centres on planning action. It focuses on the ‘dream’ and works its way back from there, mapping actions required along the way (*Forest et al, 1993*).

Making action plans (MAPS)

MAPS is similar to PATH in that it focuses on desirable futures or dreams and how service users might try to achieve these. It covers people’s history and identifies their gifts.

Source: *Realising Recovery Learning Materials* (NES, 2007) [http://www.nes.scot.nhs.uk/media/376420/13875-nes-mental_health-all_modules.pdf]

You can find out more about these approaches in NES *Realising Recovery Learning Materials* [www.nes.scot.nhs.uk/media/376420/13875-nes-mental_health-all_modules.pdf], Module 4.

4.8.1 Recording a personal support plan

The record of someone's personal outcomes will include the key outcomes identified, actions planned to achieve the outcome, who is responsible for the actions, and by when. It will also include the timescale for achieving each outcome and the date they will be reviewed. This, in essence, is their personal support plan. It is not about having a specific recording tool, as people will choose what format they want to use to record their outcomes.

The recording format could include, for example, a straightforward written plan or a video or audio recording. It may be a photograph of the MAP or PATH used during the planning process. The language should reflect the person's own language and the words they would naturally use. Outcomes can be written/spoken in the first person depending on the person's preference.

4.8.2 Some key considerations in recording personal outcomes

Good personal support plans require clarity on how outcomes should be recorded. We have listed below some common mistakes staff make when recording personal outcomes.

Outcomes too high-level/general

Staff sometimes record outcomes in a very general way, referring, for example, to the person wanting to 'feel healthier'. A meaningful outcome is expressed in a way that means something to the person. It needs to reflect what is important to the person and what he or she is hoping for or would like to change.

Outputs, not outcomes

Staff can sometime link the person's circumstances to a fixed set of service solutions. For instance, 'John Smith is being referred to the memory clinic': this raises the question, is this what John Smith really wants? It is important to identify what is important **to the person**, and then work backwards to identify how everyone can work towards achieving that outcome, which may or may not involve a service.

Outcomes reflect organisational rather than personal priorities

It should be clear whose views are being expressed in the plan. For example, 'John Smith will attend the memory clinic': in fact, the personal outcome for John Smith is more likely to relate to something personal to him to enable him to live well with dementia.

Unachievable outputs recorded as outcomes

Identifying and recording personal individual outcomes can sometimes involve a process of negotiation. For example: 'John Smith will be able to continue to drive': when staff are aware that the ideal expressed by the person is unlikely to be realised, they can support the person to discover what it is about the activity/output that is desirable. John Smith's desire to continue to drive may relate to his desire 'to feel independent'. It may be possible to identify an alternative course of action that might help to achieve this outcome.

A number of principles can guide people who are facilitating the development and recording of a personal support plan (Box 4.3).

Box 4.3 Principles to guide development of a personal support plan

The person is at the centre of the plan and has as much input and control over the planning process as possible.

Families, carers and friends are partners in the planning.

The plan includes how the person will have control in his or her life and how he or she will be supported.

The process of making the plan is organised in a way that suits the person and supports him or her to be involved.

The plan includes what is important to the person, relationships, networks and connections, strengths and abilities.

The plan has specific goals (outcomes) and actions and activities (outputs) to achieve them.

The plan is clear about who is responsible for undertaking the actions and activities, including the person, family, carers and friends, staff and volunteers.

The plan is recorded in a format that makes sense to the person.

The plan is a living document: the person can change his or her mind about what is in it.

The plan is regularly reviewed to establish what is working or not working and what needs to change.

Facilitators have a positive 'can-do', person-centred approach.

The plan belongs to the person and family but a copy will be given to other key individuals and the main service providing support.

An outcomes-focused personal support plan provides a useful means of tracking progress over time, as long as it is reviewed. Review should take place on a regular basis, comprising discussion with the person to discover whether and to what extent he or she has achieved the relevant outcomes. All the person's outcomes should be discussed, not only those recorded in the support plan. This ensures that new issues are not missed and also helps to assess the impact of any supports implemented to identify if the plan is helping.

Learning activity 4.7



You can undertake this activity alone or as part of a team.

Look back at the principles to guide development of a personal support plan (Box 4.3). Record your thoughts and discussions below.

Reflect on how your service records the personal outcomes of people with dementia you work with.



Examine some of the personal support plans of the people with dementia you work alongside. Do you think they reflect the principles described?



What are the key challenges for your team in implementing this approach to recording?

Thinking about the 'cultural shift' required, what do think might support you and your team to ensure that this happens?

What do you think you could do to overcome the challenges to implementing this approach?

4.8.3 Tensions in recording personal outcomes

Recording personal outcomes can sometimes be viewed as onerous by staff, and it is important to acknowledge the challenges it presents. These often relate to tensions between the various functions of recording, which we highlight below.

- **Value demands:** professional values, respecting individual views and person-centred and outcomes-focused values have to be reconciled with statutory responsibilities, duty of care and consideration of risk.
- **Functional demands:** how information is shared with other colleagues, eligibility for services and support, over-specification for providers and standardisation versus consistency while ensuring the flexibility required for an inclusive approach.
- **Accountability demands** for scrutiny and legal purposes: a focus on evaluation of the service can lead to defensive recording. Performance management demands are seen as dominant by practitioners. Within health services, the Quality Measurement Framework developed to support the *Healthcare Quality Strategy for NHSScotland* (Scottish Government, 2010) interprets outcomes as the impacts that an intervention or service has on pre-defined aspects of people's lives and is based on effectiveness and quantitative measurement. This may appear to be in conflict with personal outcomes-focused approaches, which centre on shared decision-making and what matters to each person in the context of his or her life.

For an in-depth exploration of these issues, you can read *We've Got To Talk About Outcomes – reconciling patient reported outcome measures and personal outcomes* [www.alliance-scotland.org.uk/what-we-do/projects/personal-outcomes-and-quality-measures-project/].

The recording of personal outcomes in a support plan is the tangible manifestation of successful outcomes-focused approaches. Implementing personal outcomes-focused approaches supports everyone involved to focus on what matters to the people with dementia you work alongside. You may wish to return to Module 1 to remind yourself of the benefits of personal outcomes-focused approaches for staff and organisations.

4.9 Module summary

We have considered the social and emotional impact of a diagnosis of dementia on the person and family, exploring how you can support them in adjusting to the diagnosis and highlighting the range of supports, interventions and activities that can enable the person and family to live well with dementia. The underpinning framework outlined in Alzheimer Scotland's five-pillars model was threaded throughout: this will enable you to better support people with dementia and their families following a diagnosis.

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Appendix 1

**Suggested responses
and key learning points
related to activities**

Suggested responses and key learning points related to activities

The suggested responses to selected learning activities provided in this appendix set out examples of what learners may be expected to include in their answers to the activities.

Module 2

Learning activity 2.1

Take a few moments to look at the list of questions below and identify which are open and which are closed questions.

1. What kind of information do you need to help you make a decision?
2. Would you like to speak to the doctor or the nurse?
3. Are you making plans for the future?
4. What worries you about going to see the doctor?
5. Have you been managing to focus at work?

1. Open

2. Closed

3. Closed

4. Open

5. Closed

Having identified the closed questions, try to think of a way to re-phrase them to make them open.

2. Who do you think would be the most helpful to speak to about this?
3. What are the things that are important to you for the future?
5. Tell me about what has helped you to focus at work?

Learning activity 2.2

What would be your priorities be for the first conversation you engaged in with a person and family?

Using a personal outcomes-focused conversation, you should seek to explore the following global issues:

- what changes has the person been experiencing
- when did he or she first notice the changes
- have these changes been continuous or occasional
- what is the person still able to do
- what, if anything, seems to improve things
- what, if anything, makes things worse
- are there any activities that the person has had to stop because of the changes
- what might he or she want to know at this stage of the process
- is there a family history of dementia
- their medical history.

Learning activity 2.3

What are the potential implications of early diagnosis for Peter as a younger person?

A younger person may be misdiagnosed as being depressed, experiencing relationship difficulties, suffering from the effects of stress or, for women, going through the onset of the menopause.

As we have seen with Peter, younger people with dementia are more likely to:

- be in work at the time of diagnosis
- have a partner who still works
- have dependent children
- have ageing parents who may need support
- be more physically fit and active
- have heavy financial commitments, such as a mortgage
- have a rarer form of dementia.

A key concern for Peter may be about being able to continue to work as this will have an impact on all other areas of his life and on his longer-term health and well-being. With appropriate support, a diagnosis could enable him to continue to have a role and responsibility, make a contribution and feel valued. Having dementia does not mean people have to stop working: this will depend on how the dementia affects them. They may need to stop, however, before reaching normal retirement age and will require employment advice. Depending on what is happening at work, Peter may want to tell his employer that he is undergoing tests relating to his memory. He should be made aware that if he gets a diagnosis and informs his employer, he is entitled to specific employment rights, as dementia is recognised as a disability under the Equality Act 2010. Full details of rights are outlined in Health Scotland's *Younger People with Dementia: living well with your diagnosis* [www.healthscotland.com/documents/3884.aspx] publication.

Learning activity 2.4

Elsie's story

What will be a key consideration in your assessment?

A key consideration will be delirium, as the risk of developing delirium is increased when a person is older and a combination of multiple precipitating and/or predisposing factors exists, such as frailty, physical health problems and cognitive impairment.

Why would you need to respond with some urgency?

Delirium is a medical emergency that can be prevented and treated if dealt with urgently. If delirium persists, it can result in serious consequences and poor outcomes for the person.

What would help you determine if Elsie has dementia or delirium?

Some of the key distinguishing features between dementia and delirium are as follows.

Onset and progression

Dementia tends to develop gradually, while delirium develops rapidly within hours or days and presents in a fluctuating pattern. Vascular dementia, however, can present with sudden deterioration and dementia with Lewy bodies also has a fluctuating course similar to delirium.

Attention

The person's attention span will vary in both dementia and delirium, but in the latter the person will not be able to focus even for a limited time.

Thinking

In dementia, the person may have difficulty with abstraction, thoughts and finding words. A person with delirium will have disorganised, distorted, incoherent and either slow or accelerated thinking.

The changes in Elsie have developed quite suddenly and the fact that she is drowsy and lethargic could suggest hypoactive delirium. This type of delirium is frequently missed because the person is quiet and can easily go unnoticed in a busy environment. It is also important to be aware that when a person is known to have dementia, a superimposed delirium is frequently attributed to dementia and left untreated. As a guide you should think delirium if there is: acute onset and fluctuating course **and** inattention **and either** disordered thinking or altered level of consciousness.

It is always safest to assume delirium and seek medical advice and treatment.

What action would you take if you suspect Elsie has delirium?

Depending on Elsie's level of consciousness, you may need to organise an emergency admission to hospital for further investigation and treatment. If delirium is detected early, you should contact her GP to enable her to be treated in the care home with input from a prevention of admissions team.

The consequences of persistent delirium and being admitted to hospital are that the person may:

- have a longer stay in hospital than necessary
- have an increased risk of developing dementia
- be at greater risk of falls and pressure sores
- have a permanent deterioration in physical function
- be more likely to go into long-term care sooner than necessary
- be more likely to die (NICE, 2012).

To enhance your knowledge and understanding of delirium, you should complete the NES *Introduction to Delirium* and *CPD Delirium Module* available on Learnpro.

Module 3

Learning activity 3.2

Peter's story

You have been working alongside Peter and his family and supported them during his assessment. You have arranged to meet with Peter and his wife to discuss his diagnosis.

Having sensitively and empathically communicated a diagnosis of dementia to Peter and his wife and responded to their emotions, how can you promote hope for Peter and his family?

Before being able to convey hope to Peter you need to explore your own values and beliefs about dementia to enable you to believe in his abilities. Working alongside Peter and his family in a personal outcomes-focused way during his assessment will have allowed you to build a trusting relationship with him, which is the first step in promoting hope. As a result, if Peter feels you are supporting him and care about him, he will begin to believe in positive possibilities for the future. You may be able to remind him of successes in overcoming changes experienced during the assessment process. As well as showing empathy and respect for Peter, you should intentionally highlight his strengths and resources: for example, the fact that he is good with technology will enable him to use these skills to make best use of telecare and assistive technology for some time. You should also use words and phrases that convey a message of hope to Peter, such as "living well with dementia", "when you go scuba diving" and "I believe you can".

It will be important to focus on the things that will strengthen hope, such as support from family and friends and remaining socially active and engaged in activities that were meaningful before his diagnosis.

Module 4

Learning activity 4.1

Take a few moments to think about a particular stressful event or traumatic time in your life and share the answers to the following questions with your colleague.

Can you recall how you got through this stressful time?

What things helped you through?

What things restricted you in this process?

You may have identified practical and emotional support. This may be someone helping you out with things such as child care, food or transport, but may also include people sitting with you, allowing you to talk through what is happening or sending you good wishes.

The things that may have restricted you could include others telling you what you need to do to move on or your own belief that you could not cope with what was happening. You may also have found that you responded in a similar way to earlier stressful experiences.

Learning activity 4.2

Ian is feeling hopeless and devastated. You have been asked to support him following his diagnosis, and this is your first agreed contact.

What would be your priority in your first meeting with Ian?

How would you approach a personal outcomes-focused conversation with him?

In your first meeting, you will be connecting with Ian and beginning to build a rapport. You will be empathically conveying to him that you are there to let him talk about what is happening and how he feels about it. You need to remember that Ian is feeling very low and despondent and has not yet made sense of what is happening. It is important to recognise the skill of just being with Ian.

Ian is not ready to consider personal outcomes and it would not be appropriate to begin with any discussion about aspirations or what matters to him for the future.

In your first meeting, you will allow him to express his feelings and actively listen to identify his depth of feelings, fears and anxieties. At this stage, it is about acknowledging and validating his experiences and using opportunities to reflect back what he has expressed during the session to show that you are listening to his story. This will give Ian the opportunity to vent his feelings and clarify his thinking and will encourage the development of a positive therapeutic relationship with you.

You will use a range of techniques to enable Ian to express his feelings. You will:

- **check your understanding** of what is being said to ensure you have listened properly
- use **clarification** to help you find out what Ian really means, as opposed to just the words being used
- be picking up on **non-verbal cues**
- use **validation** when you feed back to Ian to show you understand what he has been through and how he is responding.

Ian may have difficulties expressing his feelings, but you should sensitively pay attention to non-verbal signs of emotion. Help him to identify his emotions by commenting (at an appropriate time) on how you think he may be feeling, using comments such as “You seem worried” or “You look sad” and allowing time for the comment to sink in and for him to answer. If the response confirms your impression, acknowledge the feeling.

In some situations it can be useful to get a person to begin a conversation by talking about something removed or neutral from the diagnosis, such as interests or hobbies. Given Ian’s level of hopelessness and despair, however, this would be too difficult at this point, especially as it is the first meeting.

The most important thing about this first meeting is building a therapeutic rapport: part of this will be to not overly encourage Ian to open up about his feelings when he is not ready. As the meeting progresses, you can move to more neutral subjects that may put him at ease and help him open up.

When a person with dementia shows strong emotions, it can make us feel uncomfortable and we tend to attempt to stop the person as quickly as possible. As a result, there may be a desire to discount the feelings, give advice or not respond at all. Your response would not be to reassure Ian, as this can convey a message that his feelings are wrong in some way. To suggest there is nothing to worry about will make him think you do not understand what he is going through or that he is responding to his situation inappropriately.

The use of therapeutic silence may also be important. Practitioners can often feel awkward about silences, but it allows people to process and speak about their emotions without us jumping in too quickly to direct the conversation. Similarly, when the person’s emotions are strong

and there are conflicting feelings, giving a neutral response such as “You are angry because you have dementia” will undermine the depth of feeling and may cause him to withdraw from further discussion. You should acknowledge the person’s feelings and let him know that you understand why he feels this way and that these feelings make sense.

As you continue to meet with Ian and get to know his life experience, you will begin to recognise the source of his feelings, which will be partly due to current circumstances and partly due to past experiences. Although it is difficult to determine the full source of each feeling, as a guide, the present holds an understandable trigger and the past may account for the degree and intensity of feeling. It is crucially important that you do **not** suggest to Ian the relative influences of past or present on his feelings as this may be perceived as implying that they are inappropriate. Your simple validation that his feelings are understandable in his present situation will support Ian to spontaneously begin to explore how their intensity may also be due to past events. By the end of your first meeting, a successful outcome will have been achieved if Ian agrees to you visiting again, even though he is still likely to be suggesting it is pointless.

You should organise further early visits and, through this continued exploration, Ian will be able to identify the source of his feelings with you using probing questions to find out if he has had to deal with similar situations in the past. This will enable Ian to reflect on how he acted in response to past situations, which can help him adopt similar strategies now. It will also enable him to identify his strengths and continued capabilities, begin to engage in positive conversations and ask more focused questions around the issues that he highlights as important.

Learning activity 4.3

What could you do to support the children?

In addition to helping the family understand the impact of the diagnosis on the children, you need to ensure they have access to information and resources specifically for younger people. You should also encourage them to raise awareness with the school and ensure they are supported to access student counselling, or you may support them directly if they accept this.

A key to helping children is for everyone to have a part in supporting the person through continued engagement with him in fun and enjoyable activities and in conversation. It may be helpful to get them engaged in helping Peter to write his life story.

The following Alzheimer Scotland factsheet provides details of the potential impact of dementia on children.

Young people may need to talk about their feelings as changes occur. These feelings may include:

- **grief and sadness at what is happening to someone they love**
- **anxiety about what will happen to the person in the future**
- **fear, irritation or embarrassment, for example at unusual behaviour in front of other people**

- **frustration, for example with hearing the same stories and questions over and over again**
- **guilt for feeling some of the emotions listed above**
- **confusion about 'role reversal': having to be responsible for someone who used to be responsible for them**
- **a sense of loss if their relative doesn't seem to be the same person that they were, or because it isn't possible to communicate with them in the same way anymore**
- **a sense of uselessness or rejection**
- **anger**
- **less time for them.**

They may react in different ways and distress may show in different ways such as:

- **anxiety-related symptoms of sleep difficulties, unexplained aches and pains or a change in behaviour – more attention-seeking**
- **school work is neglected**
- **the young person seems unaffected – bottling up**
- **sad and weepy**
- **retreat from situation**
- **getting overly involved in care to detriment of own development.**

Learning activity 4.4**Ian's story****What issues would you consider?**

The key issue is that Ian is going to the pub and bookies more often because he is no longer engaged in meaningful activities that were part of his life before dementia. For example, Ian should be encouraged and supported to continue with his Neighbourhood Watch group as this will enable him to make a valued contribution to his community. His neighbours are supportive and could ensure he is reminded when meetings are being held and accompany him or phone to remind him an hour before meetings.

You could work alongside Ian to find out what walking groups are in the area and encourage and support him to join. He may also be able to continue using the bus to visit his sister with the use of assistive technology: he could be given phone reminders about bus times, for example, and support from family and friends so that they know what time he leaves and someone can check when he is home.

It may also be the case that Ian is forgetting how many drinks he had or how many bets he has placed. With Ian's agreement, you could find out who Ian's friends are in the pub and bookie's and encourage him to make an arrangement with them about how often he wants to be there and how much he spends.

It may help to discuss the dementia diagnosis so that people in the community are aware of how they can offer support, but this should only be done with Ian's agreement and permission. It will be important to discuss the risks Ian wishes to take with his sons and support them in understanding the impact of restricting his activities.

The approach Ian wishes to take with regard to managing his finances and power of attorney can be discussed at an appropriate time as part of his future planning.

Learning activity 4.5a**Hilary's story****What are your key considerations, given the information you have received?**

The first consideration is to establish if Hilary is an 'adult at risk' under the Adult Support and Protection (Scotland) Act 2007. To be so, Hilary would need to meet the three-point test, which is that the person is:

1. unable to safeguard well-being, property, rights or other interests
2. at risk of harm
3. is more vulnerable to being harmed because he or she is affected by disability, mental or physical ill health.

A person is not considered an 'adult at risk' if he or she meets only one or two elements of the three-point test. Just because Hilary has a diagnosis of dementia, it does not mean she cannot safeguard her property. We also do not know if she is at risk of harm: while her sister has expressed concern, she does not suggest there is an immediate risk. You should never dismiss any information as being unimportant, however, as it may be a crucial part of the full picture. If you think a person is an adult at risk and you have cause for concern, you should consult your multi-agency procedures for action under the Adult Support and Protection (Scotland) Act 2007.

It will be important to establish Hilary's ability to give informed and empowered consent to the situation she finds herself in. Her GP or psychiatrist should carry out an assessment of capacity, but given that there is no immediate risk, it would be important to organise to meet Hilary, adopting the personal outcomes-focused approach described in earlier modules. This will help inform her assessment of capacity, during which a number of factors will be taken into consideration, including the following.

- Has Hilary been given information appropriate to her level of comprehension?
- Can she consider choices available to her and can she reach a decision?
- Is she able to express her views in a way that will enable her to communicate a decision?
- Has she been put under undue pressure from others?
- Is her decision-making consistent?

Learning activity 4.5b

Hilary's psychiatrist has determined that Hilary is capable of managing her property and financial affairs. What action should you take to support her?

You should sensitively and empathically engage Hilary in a conversation about future planning, particularly discussing the appointment of a continuing power of attorney and making a will. In the case of the will, Hilary's sister may make allegations of lack of knowledge and undue influence, meaning testamentary capacity will need to be determined as part of the assessment. You should complete the *Respecting and Protecting Adults at Risk in Scotland* learning resource [www.nes.scot.nhs.uk/education-and-training/by-theme-initiative/mental-health-and-learning-disabilities/publications-and-resources.aspx] to refresh your knowledge and understanding of adult protection legislation in Scotland.

Learning activity 4.5c**Susan's story****How would you support Susan?**

It will be essential to work alongside Susan in raising her awareness and understanding of dementia and support to build her personal resilience.

A framework that may help is Susan McCurry's *When a Family Member has Dementia: steps to becoming a resilient carer* (McCurry, 2006), which uses the acronym DANCE to outline the core principles for resilience in caring:

- D: don't argue
- A: accept the distress
- N: nurture your physical and emotional health
- C: use creative problem-solving
- E: enjoy the moment with your loved one.

This is not to suggest that family are aware of, or intentionally triggering, an argument with the person with dementia. They may be trying to help the person understand things 'logically' and persist in getting them to grasp an alternative viewpoint. This verbal persuasion can result in frustration, arguments and upset for both.

Family members may not be aware of the tone they use when stressed or that they have a confrontational manner. People with dementia may feel embarrassed in such situations because it highlights their difficulties, or may feel they are being 'bossed around' and are not in control of their life. As a result, they may act in a manner or use a tone that is upsetting to their family or appear as if they are intentionally trying to make life difficult.

If this is something that is happening between Hilary and Susan, you can support Susan to develop strategies to avoid and manage stressful situations. For example, suggesting to Susan to **stop and think**: "Will what I say help in any way?"; "Is there something else I could say instead?" You could also suggest she take time out, taking a moment in another room or perhaps taking some slow deep breaths to compose herself before communicating with Hilary. As already highlighted, it will be important for Susan to ensure she actively engages in a health promoting lifestyle. While not suggesting people compromise standards that are important to them, finding creative solutions and reviewing priorities can enable families to re-establish relationships.

It is crucial to facilitate a joint discussion between Hilary and Susan, having previously agreed this with each of them, and agree a way forward. This may lead to you supporting Hilary in her adjustment to her diagnosis. She could, for example, become involved in a local history group, or take up art. She and Susan could set time aside to share their interest in photography. In this way, they will be able to enjoy time together and time apart, which can enhance their relationship and reduce stress for both of them.

Ultimately, it may be that some people simply cannot cope with the person with dementia because of their own previous emotional health or the quality of their relationship, which has been brought into focus by the diagnosis of dementia. It will be essential that you are able to engage with both of them in a supportive, empathic and non-judgemental manner.



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