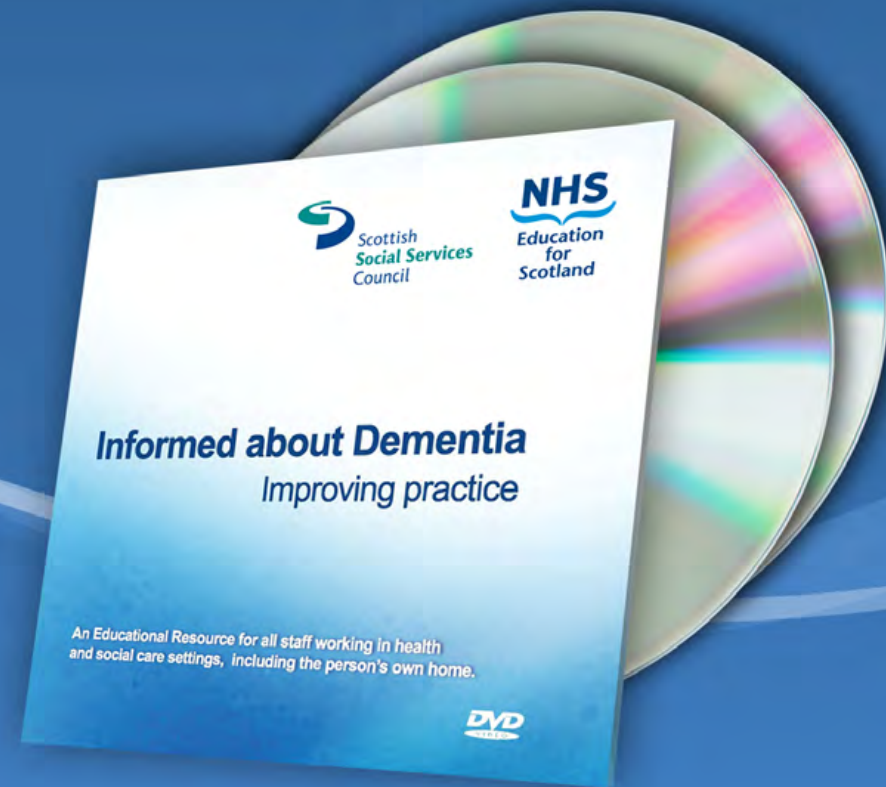


*Informed about dementia: Improving Practice*

## **Workshop Facilitator's Guide**

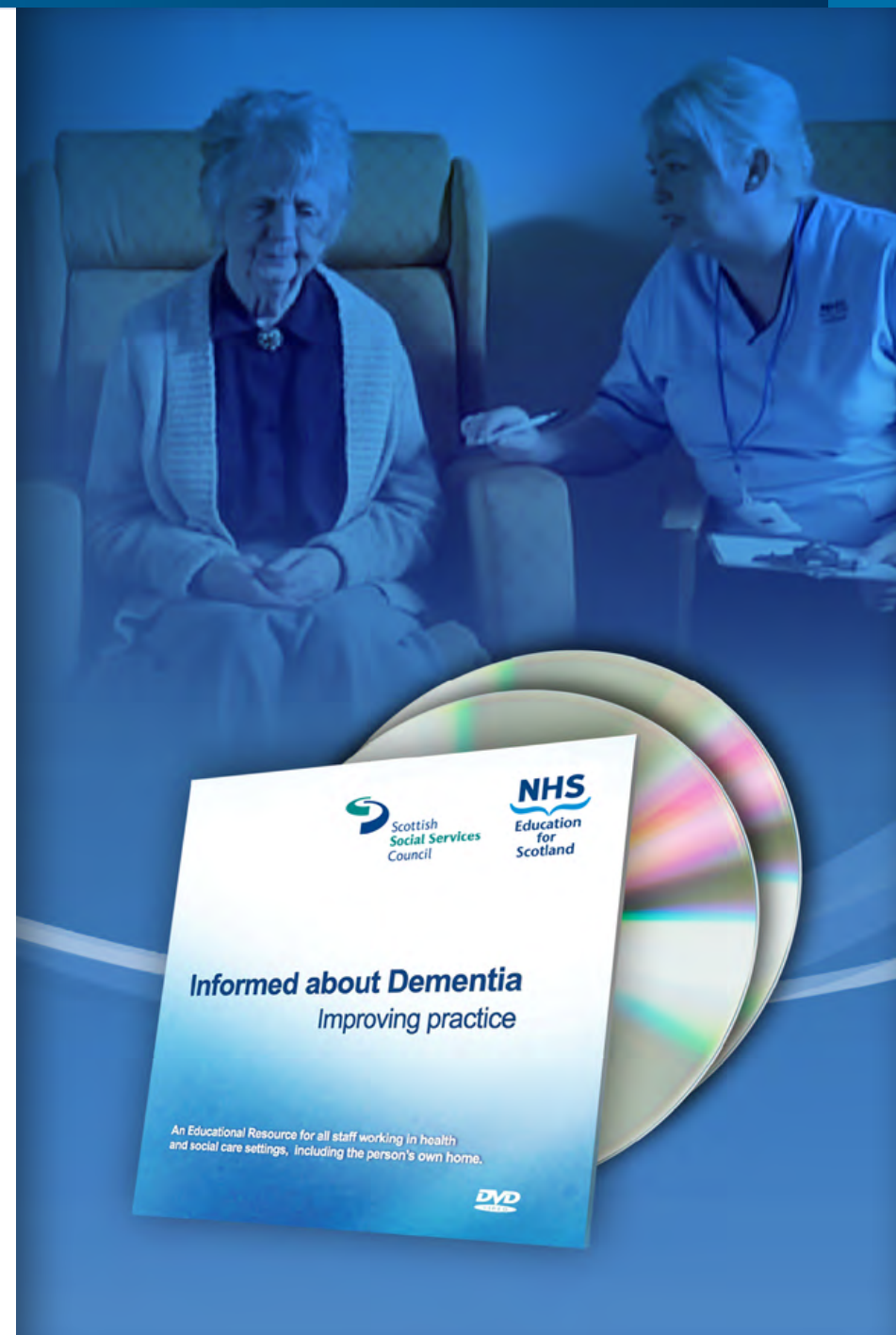




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## Contents



## Introduction

In June 2010, the Scottish Government launched Scotland's National Dementia Strategy. In order to support delivery of the aspirations and change actions outlined in the strategy, two key publications were launched in June 2011.

### Standards of Care for Dementia in Scotland:

Action to support the change programme, Scotland's National Dementia Strategy



### Promoting Excellence:

A framework for all health and social care staff working with people with Dementia, their families and carers



NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC) developed Promoting Excellence: A framework for all health and social services staff working with people with dementia, their families and carers. It details the knowledge and skills all health and social services staff should aspire to achieve in relation to the role they play in supporting people with a diagnosis of dementia, and their families, and carers.

The framework has been designed in a way that recognises the existence of various sector (and professional group) specific standards and frameworks, for example: the NHS Knowledge and Skills Framework; the Social Services Continuous Learning Framework and the National Occupational Standards for Health and Social Care. This framework supplements these existing frameworks.



### Levels of knowledge and skills

The framework outlines 4 levels. Each level defines the knowledge, skills and behaviours specific to the worker's role in relation to dementia. The levels are:

- **Dementia Informed Practice Level**
- **Dementia Skilled Practice Level**
- **Dementia Enhanced Practice Level**
- **Dementia Expertise Practice Level**

Rather than being hierarchical, the levels are concerned with levels of responsibility in relation to working with people with dementia which will vary greatly across organisations and sectors. Each level defines the knowledge and skills, specific to their role in relation to dementia, that a worker must have, rather than in relation to their seniority within the organisation or their profession.

## Dementia Informed Practice Level

The **Dementia Informed Practice Level** provides the baseline knowledge and skills required by **all** workers in health and social services settings including a person's own home.

The DVD Informed about Dementia - Improving Practice has been produced to support staff and students who require the knowledge and skills described in Promoting Excellence for the Dementia Informed Practice Level. It was developed in partnership by NES, SSSC, Alzheimer Scotland and The Scottish Dementia Working Group.

The DVD is available online at:

<http://www.knowledge.scot.nhs.uk/home/portals-and-topics/dementia-promoting-excellence/framework/informed-level/learning-resources.aspx>

It should be emphasised that Informed about Dementia - Improving Practice is the **only** recommended educational resource for staff to use to gain the knowledge and skills required at Dementia Informed Practice Level.

“

This testimonial from an Alzheimer Scotland Volunteer gives a flavour of what can be achieved through viewing the DVD.

*The DVD won't fail to enlighten people who will have no knowledge of the condition and it even has much to offer those with considerable experience of dementia and all the associated problems that can arise... The approach to my mind stimulates the viewer by encouraging them to think for themselves and as a result enables them to see each situation from both sides... allowing them to arrive at conclusions and discover alternative ways to deal with problems posed.*”

*This DVD may be aimed primarily at those working in the health sector but due to the relaxed and straightforward manner in which the information is presented the connection is easily made with the ordinary person in wider society who may know little or nothing about dementia.*”



## The Dementia Informed Workshop

This Dementia Informed Workshop utilises the DVD, is designed to take 2 hours and covers all chapters. However, this can be adapted to meet time, organisation and group needs. For example you may cover only one chapter at a time and meet 4 times for 30 minutes.

It may be that you are using the video clips directly from the **Promoting Excellence** website rather than the separate DVD however, for brevity, throughout this plan DVD means video clips too.

The optimum number of participants for the workshop is 10-12, however it is possible to run the workshop with up to 14 people.

**NB:** This workshop format and content is offered as a viable option to achieve the learning outcomes for staff in a supportive way. It has been used by a range of Health and Social Services staff to support training in the workplace. However, it is recognised that this is only one example and is not the only way to use the DVD or to organise training for staff.



## Workshop Plan

Dementia Informed Workshop: Workshop Plan			
Time 120 Minutes			Number of Participants 8- 14
	Time	Activity	Facilitator and Materials
		<p><b>For session</b></p> <p>It is recommended that:</p> <ul style="list-style-type: none"> <li>• At least one of the facilitators should be very familiar with the content of the Dementia Skilled - Improving Practice learning resource as participants often ask questions about dementia beyond the remit of the content of the DVD</li> <li>• Both facilitators should be familiar with the content of the DVD</li> <li>• It is important to be aware that some participants may have personal experience of friends or family who are living with dementia. It is vital that facilitators are sensitive to this possibility (please see <b>“Health warning”</b> in Section 1). One facilitator should be identified to support anyone who may experience distress.</li> </ul>	<ul style="list-style-type: none"> <li>• 2 Facilitators</li> <li>• Access to DVD Player/computer/ PC</li> <li>• DVD Informed about Dementia or video clips on PE website</li> <li>• Projector and Screen/Blank Wall</li> <li>• Transcriptions of chapters for facilitators (Appendix I)</li> <li>• Handouts ( Appendix II)</li> </ul>
<b>Section 1 Introduction</b>	15 mins	<ul style="list-style-type: none"> <li>• Ice breaker/ introductions including facilitators</li> <li>• Housekeeping/lunch plan</li> <li>• Ask participants to write their expectations on post it – notes</li> <li>• Find out about the prior knowledge/experience of participants</li> <li>• <b>Key Point - Health warning</b> – Inform participants that should they find anything in the workshop/ DVD causes any distress they should inform the facilitators or leave the room. Identify which facilitator will support any individual who requires it.</li> </ul>	<ul style="list-style-type: none"> <li>• Sign in Sheet</li> <li>• Post it notes</li> <li>• A3 Sheet - <b>Expectations about the workshop today?</b></li> <li>• Blutac</li> </ul>

Dementia Informed Workshop: Workshop Plan (continued...)			
	Time	Activity	Facilitator and Materials
<b>Section 2</b> <b>Chapter one</b> <i>Running time:</i> 6 mins	15 mins	<b>Chapter one</b> <b>Introduction to DVD</b> <b>View chapter one</b> <ul style="list-style-type: none"> <li>• Content</li> <li>• Background Information               <ul style="list-style-type: none"> <li>• <i>Legislation</i></li> <li>• <i>Policy</i></li> <li>• <i>Framework etc</i></li> </ul> </li> <li>• Short discussion and questions</li> </ul>	<b>Handout</b> <b>Chapter one sheet</b> <ul style="list-style-type: none"> <li>• Key learning points</li> </ul>
<b>Section 3</b> <b>Chapter two</b> <i>Running time:</i> 12 mins	25 mins	<b>Chapter two</b> <b>Learning Outcomes</b> <ul style="list-style-type: none"> <li>• Recognise the common signs and symptoms of dementia</li> <li>• Communicate with people with dementia in a way that takes account of their difficulties</li> <li>• Recognise individual needs and diversity of people with dementia</li> <li>• Understand the effect of stigma on people with dementia and address this wherever possible</li> </ul> <b>View section 1 and 2 of chapter two</b> <b>Scenario a - George at the GP surgery</b> <b>Activity</b> How would you feel coming in to this situation? Take time to consider the following: <ul style="list-style-type: none"> <li>• How do you think George is feeling at this point?</li> <li>• How else could this have been handled to make sure that George feels respected and valued?</li> <li>• What is suggested by the neighbour's response?</li> <li>• How do you think this scenario could have been changed to make sure that there was a better outcome for George?</li> </ul> <b>View section 3 of chapter two</b> <b>Scenario b – George's alternative experience</b> <ul style="list-style-type: none"> <li>• Short discussion and questions</li> <li>• Hand out chapter two sheet</li> </ul>	<b>Handout</b> <b>Chapter two sheet</b> <ul style="list-style-type: none"> <li>• Learning outcomes</li> <li>• Key learning points</li> </ul>



Dementia Informed Workshop: Workshop Plan (continued...)			
	Time	Activity	Facilitator and Materials
<b>Section 4</b> <b>Chapter three</b> <i>Running time: 10 mins</i>	20 mins	<b>Chapter three</b> <b>Learning Outcomes</b> <ul style="list-style-type: none"> <li>• Recognise the impact of the symptoms of dementia on feelings and behaviour</li> <li>• Recognise the impact of the environment on the person with dementia</li> <li>• Respond appropriately to distress, confusion and frustration</li> </ul>	<b>Handout</b> <b>Chapter three sheet</b> <ul style="list-style-type: none"> <li>• Learning outcomes</li> <li>• Key learning points</li> </ul>
		<b>View section 1 and 2 of chapter three</b> <b>Scenario a - Ellen getting ready for the day centre</b>	
		<b>Activity</b> Take time to consider the following: <ul style="list-style-type: none"> <li>• How would you feel coming in to this situation?</li> <li>• What else could be contributing to Ellen's distress?</li> </ul>	
		<b>View section 3 of chapter three</b> <b>Scenario b - Leanne (Worker) seeks advice from manager</b>	
		<b>Scenario b – George's alternative experience</b> <ul style="list-style-type: none"> <li>• Short discussion and questions</li> <li>• Hand out chapter three sheet</li> </ul>	

Dementia Informed Workshop: Workshop Plan (continued...)			
	Time	Activity	Facilitator and Materials
<b>Section 5</b> <b>Chapter four</b> <i>Running time:</i> <i>8.5 mins</i>	20 mins	<b>Chapter four</b> <b>Learning Outcomes</b> <ul style="list-style-type: none"> <li>• Appreciate that people with dementia have the right to a quality of life that reflects their priorities, wishes and interests</li> <li>• Understand what is meant by the term person centred support in relation to people with dementia</li> <li>• Understand the importance of recognising, enhancing and supporting the strengths and abilities of people with dementia</li> <li>• Support people with dementia to remain engaged in life's roles and relationships</li> </ul>	<b>Handout</b> <b>Chapter four sheet</b> <ul style="list-style-type: none"> <li>• Learning outcomes</li> <li>• Key learning points</li> </ul>
		<b>View section 1 and 2</b> <b>Scenario a - Jim sitting inactive in the care home</b>	
		<b>Activity</b> How would you feel coming in to this situation? Take time to consider the following: <ul style="list-style-type: none"> <li>• Do you think Jim is experiencing a quality of life that takes account of his interests?</li> <li>• What are the difficulties for staff in providing person centred care for Jim?</li> <li>• Can you think of any way that Jim's situation could be improved?</li> </ul>	
		<b>View section 3</b> <b>Scenario b: Jim engaging in activities he enjoys</b> <ul style="list-style-type: none"> <li>• Short discussion and questions</li> <li>• Hand out chapter four sheet?</li> </ul>	

Dementia Informed Workshop: Workshop Plan (continued...)			
	Time	Activity	Facilitator and Materials
Section 6 Chapter five	20 mins	<b>Chapter five</b> <b>Learning Outcomes</b> <ul style="list-style-type: none"> <li>• Understand that people with dementia have the right to take risks within the context of their own lives</li> <li>• Understand how people with dementia may be harmed</li> <li>• Have an awareness of legislation and local policy and any actions you need to take</li> </ul>	<b>Handout</b> <b>Chapter five sheet</b> <ul style="list-style-type: none"> <li>• Learning outcomes</li> <li>• Key learning points</li> </ul>
		<b>View section 1 and 2</b> <b>Scenario a- Margaret in the community hospital</b>	
		<b>Activity</b> How would you feel coming in to this situation? Take time to consider the following: <ul style="list-style-type: none"> <li>• Why might Margaret want to get up?</li> <li>• What is the difficulty for the staff in this situation?</li> <li>• How do you think Margaret's situation might be resolved?</li> </ul>	
		<b>View section 3</b> <b>Scenario b- Using risk enablement approaches to support Margaret</b> <ul style="list-style-type: none"> <li>• Short discussion and questions</li> <li>• Hand out chapter five sheet?</li> </ul>	
Section 7	20 mins	<b>Summary and discussion</b> <ul style="list-style-type: none"> <li>• Discussion and questions</li> <li>• Show participants any additional resources provided</li> <li>• It can be useful here to inform people about their local Alzheimer Scotland Branch</li> <li>• Revisit expectations</li> </ul> <b>Evaluation</b> Ask participants to write their views on post-it notes in response to the following questions. They can make as many points as they wish. <b>Evaluation questions</b> <ul style="list-style-type: none"> <li>• <i>What was the main thing that you learned at the workshop today?</i></li> <li>• <i>What was the best thing about the workshop today?</i></li> <li>• <i>How would you improve the workshop today?</i></li> </ul>	Resource table- a range of resources available from Alzheimer Scotland Website and Promoting Excellence Website <ul style="list-style-type: none"> <li>• Previously completed 'Expectations' post it notes</li> <li>• Three A3 sheets headed with evaluation questions</li> <li>• Blutac</li> </ul>

## Further Information and Resources

To view the full 'Promoting Excellence: A framework for all health and social care staff working with people with Dementia, their families and carers' and for additional information and resources, visit:

<http://www.knowledge.scot.nhs.uk/home/portals-and-topics/dementia-promoting-excellence.aspx>

An additional source of information is the Dementia Managed Knowledge Network (Dementia MKN) the MKN is an open, community site which contains pertinent information and links to raise awareness of the wide range of resources available.

<http://www.knowledge.scot.nhs.uk/dementia.aspx>

Alzheimer Scotland is an organisation which helps people with dementia, their carers and families. You will find a range of useful and user friendly resources on the Alzheimer Scotland website

<http://www.alzscot.org/pages/info/pubslisforinfosheets.htm>

The Scottish Dementia Working Group (SDWG) is a national campaigning group, run by people who have dementia.

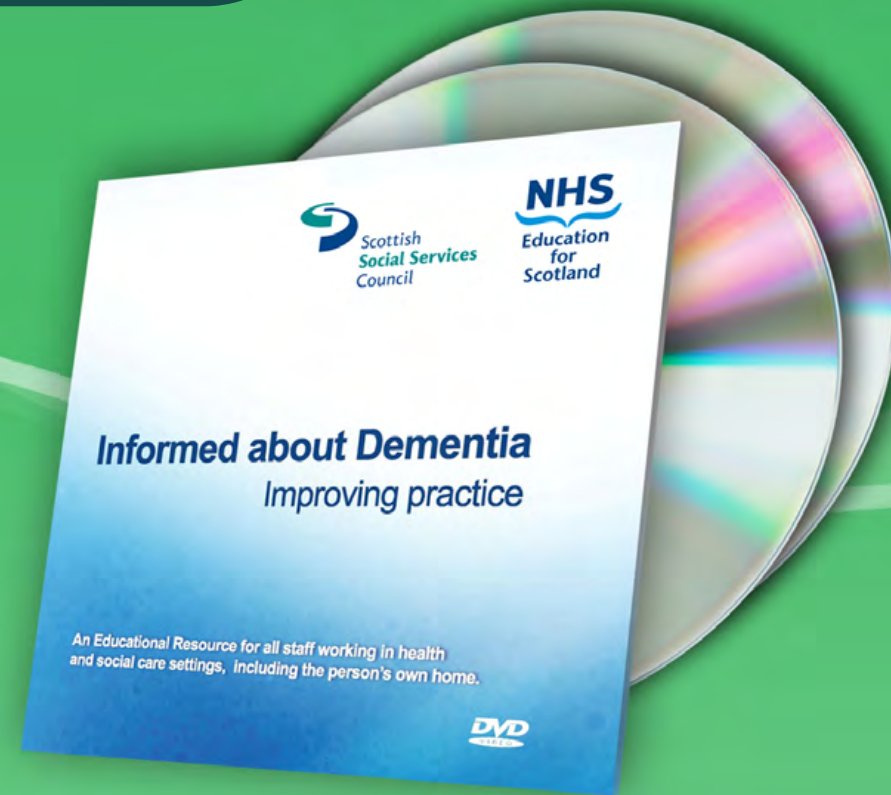
<http://www.sdwg.org.uk/>



*Informed about dementia*

## Appendix I

### Transcriptions of DVD chapters for facilitators





## DVD Contents: Chapter One



**This resource will help all of you to:**

- Recognise and develop the skills and values you need to support people with dementia and their families and carers
- Understand more about dementia
- Think differently about people with dementia

It might be while they are attending an appointment, living in a care home, in their own home or in a hospital ward. People with dementia have rights and abilities, rich histories and experiences. All of these must be recognised as we care for and support the people we meet in our different roles.

As people live longer there are more and more people living with dementia in Scotland.

**Dementia affects about:**

- 2% of people aged 65 to 70
- 5% of people aged 70 to 80 and
- 20% of people over 80
- And currently (2011) around 82,000 people in Scotland.

**That figure is expected to double over the next 25 years.**



Dementia is not only a condition affecting older people. It can affect people in their 40s and 50s or even younger. It is sometimes only one of a range of conditions that people may be living with, for example

- Dementia and depression
- Dementia and learning disability
- Dementia and heart disease.

We need to develop new approaches to the way we offer information, care and support and that goes for the families' friends and neighbours of people with dementia too. They need support to help people with dementia to have the best quality of life as they journey through their illness.

Wider communities also have a role in keeping people connected to the life and activities they value.

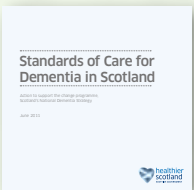
We are all part of communities and our lives will be increasingly affected by dementia, at a personal level, in our work settings and among our families and communities



In June 2010 the Scottish government launched *Scotland's National Dementia Strategy* which set out a range of commitments in relation to dementia, care, support and education.



One year later in June 2011 the Scottish government launched *Promoting Excellence: A framework for all health and social services staff working with people with dementia and their families and carers.*



At the same time they launched *Standards of Care for Dementia in Scotland.*

The Standards outline what people can expect from the services they receive. So together these documents represent a means of making sure that improving quality of life for people with dementia is at the heart of what we do.

### How can we use this resource (*Informed about dementia: improving practice DVD*)?

- We want you to use this resource in the way that best suits your preferred way of learning.
- You can use the resource as an individual, as a team, or as an organisation. You can focus on one chapter at a time, discussing the questions posed, with your colleagues, or reflect on them in your own time.
- You can confirm your progress against the key learning points at the end of each chapter and you can check out the links to other resources to enhance your development.

The scenarios throughout this resource show people who are working in situations you might recognise from your own experience.

Although we have not based the scenarios on the experiences of any real individual, we think they illustrate practice that does exist.

We want to show you how these situations can be dramatically transformed for people with dementia, often with little change in our behaviour.

All of us can do our work just a bit better if we think about what we are doing, develop our knowledge and skills and focus on who we are actually working for.

Promoting Excellence describes the minimum knowledge and skills required for all health and social services staff whether you work in a care home as a cook or a gardener, whether you are a receptionist in a clinic or whether you work in someone's own home.

Some staff such as social workers or nurses working in the community or on acute hospital wards will need more detailed knowledge and skills. Others such as pharmacists, consultant psychiatrists and mental health officers will need very detailed knowledge in relation to their specialist areas of work. But all their training and learning will build from the information, aspiration and principles outlined in this resource (*Promoting Excellence*).

We are working together to improve quality of life for people with dementia.

Dementia is a journey and it is a journey you can influence. We are all able to make a difference.

***People living with dementia can best describe how important our work is:***

Here is what someone living with dementia has to tell us.

*“What I would say to the professionals is that-you can pull me back, give me my life back and pull me into the light. And by the same token, ignorance, arrogance, couldn’t care less, you can shove me down into the darkness and just cast me away. I can’t do it. I need your help to do it”*

## Key Learning Points

- Dementia affects a large and increasing number of people in Scotland
- Dementia affects a range of age groups and can occur alongside other health problems
- Dementia is everyone’s responsibility in health, social services and communities



***Running Time:***  
**6 minutes 03 seconds**

## DVD Contents: Chapter Two



This chapter will help all of you to:

- Recognise the common signs and symptoms of dementia
- Communicate with people with dementia in a way that takes account of their difficulties
- Recognise individual needs and diversity of people with dementia
- Understand the effect of stigma on people with dementia and address this wherever possible

Dementia is a condition that affects the brain and the way people behave, act and think. No two people will have the same experience of dementia. It will not progress at the same rate or have the same impact.

Dementia can be described as a journey and although everyone's journey is unique it may start with a diagnosis:

- Finding out it's dementia

And follow a route through

- Living with dementia
- Living with increasing help and support
- End of life and dying well



Dementia is a condition that affects the brain. Brain cells die at a faster rate than normal and this creates a number of challenges for daily living. People with dementia can begin to find normal activities more difficult. They can, however, expect to have a good quality of life, to retain their relationships and interests and to feel good about themselves and the people closest to them.

We all have a role in contributing to that quality of life and being able to recognise some of the ways dementia can affect people, will help us to be sensitive and responsive in the way we work with people with dementia.

There are a number of common signs and symptoms that you may recognise as you meet people in your work or home life.

### People with dementia:

- ✓ May have problems remembering a range of things from the day of the week, to where they are or what they have said.
- ✓ They can repeat things or get lost.
- ✓ Visiting unfamiliar places can be challenging, particularly if they are noisy or busy.
- ✓ Need to be allowed time to think and to process information
- ✓ Need to feel our understanding and support
- ✓ Can feel confused, uncertain, anxious and distressed as a result of their symptoms.

Their families and carers may feel bewildered and afraid or sad and overwhelmed. They too, need our support.

Gradually people with dementia may lose the ability to do everyday things such as budget, cook or play games. Doing things in the right order, or following normal patterns can be can start to become a challenge and this may have an impact on doing things such as caring for their appearance.

People with dementia may stop doing things that they have enjoyed, things that are part of their daily routine.

With support and encouragement many interests and activities can be continued for much longer and continue to provide satisfaction and a sense of achievement.

We take communication for granted. We think nothing of finding the right words to use as we do things like write messages or speak to friends, families or colleagues.

For a people with dementia their may be difficulties in finding words as language starts to need more thought and effort.

- If we use jargon, we are likely to alienate the very people we want to support
- Keeping sentences short and using everyday words will keep us connected
- Following up verbal information with written or visual material will also help us to understand each other
- A gesture a smile or a touch can also convey encouragement and connection.

Dementia is progressive and the person will gradually become less and less able. This usually happens very slowly. Little by little the person may need more help. Eventually someone with dementia will be unable to manage even basic tasks, like eating, drinking and going to the toilet, but this won't happen suddenly.

The illness can last many years. At present there is no cure BUT there is a lot that we can all do to support quality of life for people with dementia as well as that of their families and carers.



We have mentioned that dementia affects a range of ages not just older people.

It is also found in cultures across the world, in men, in women, those from a range of faith groups and with different sexual orientation. It can occur along with other conditions and in all economic groups.

Sadly, people with dementia can be exposed to stigma and negative stereotypes, for example some newspaper headlines talk about dementia as a

***“LIFE SENTENCE”***  
**or**  
***“Suffering from dementia”***

which gives us a different picture from “living with dementia”.

It is easy to dismiss and belittle people with dementia if we listen to these messages. It is very important that we support and encourage positive attitudes and behaviour towards people with dementia.

We want Scotland to be ***Dementia Friendly***.

**Video clip of people with dementia describing the impact that dementia has on their lives.**

Exploring the experiences of people with dementia shows us ways to provide the best possible care and support.

We want to illustrate how small changes in our thinking and behaviour and our communication can make a big difference.

An appointment at a Dr's surgery is something that we are all familiar with and yet the quality of the experience can have significant consequences for person with dementia.

## Scenario a: George's experience

No one in this scenario is trying to make life difficult for George but the outcome for him is confusion and distress.

### *How would you feel coming in to this situation?*

*Take time to consider the following:*

- How do you think George is feeling at this point?
- How else could this been handled to make sure that George feels respected and valued?
- What is suggested by the neighbour's response?
- How do you think this scenario could have been changed to make sure that there was a better outcome for George?

### *Key Learning Points*

- A person with dementia commonly presents with memory problems and confusion
- Communication must take into account the person and their needs
- It is important that we do not assume that dementia only affects older people –in fact early onset dementia is not uncommon and there is growing evidence of people with learning disabilities developing dementia at a younger age as they are living longer
- Stigma can be associated with people with dementia and can take a variety of forms

**How else could this have been handled to make sure George feels respected and valued?**

## Scenario b: George's alternative experience

### *Key Learning Points*



- Recognising the person and responding respectfully can change the experience for people with dementia
- Good communication is critical- it is important to speak clearly and simply
- Present one question at a time and allow time for responses
- By doing this we can support a sense of working together
- We can all contribute to finding feasible and creative solutions to the difficulties encountered by people with dementia

## DVD Contents: Chapter Three



### Section 1

**This chapter will help all of you to:**

- **Recognise the impact of the symptoms of dementia on feelings and behaviour**
- **Recognise the impact of the environment on the person with dementia**
- **Respond appropriately to distress confusion and frustration**

We have already looked at communication in Chapter two and we want to build on this information in relation to feelings, emotions and behaviour. As dementia develops the person will, at different times, experience changes in their feelings, emotions and behaviours.

It is important that we remember that every person is an individual and will react to circumstances in their own way. It is essential that we understand what is causing the changes to allow us to best help and support that person. There are many possible reasons for changes in feelings, emotions and behaviour. It may be the result of changes in the brain that affect the person's memory, concentration or perception of their surroundings. The person may understand less of what is happening around them and become anxious or restless but be unable to say what is wrong.

A task which was previously familiar may become too complicated. The person may try to complete a task and fail or they may feel under pressure and worry about doing something incorrectly, leaving them feeling frustrated, angry or embarrassed.

These feelings may even lead to the person becoming distressed or withdraw. In many instances it is other factors in the environment that trigger changes, such as entering a place which is noisy, busy, cluttered or poorly lit. All of these can increase the risk of confusion for the person with dementia.

The person will also sense impatience, tension and negative feelings in others and in situations around them and e.g. if they feel rushed or if you show annoyance, distressed behaviour may be the only way that the person can communicate with you. It is easy to assume that a person is being uncooperative when in fact they might be ill, in pain or unable to communicate. They may know what they want but because of language difficulties they are unable to tell you.

Now we will hear from people with dementia as they discuss the impact of these changes on their lives.

**Video clip of the personal experiences of people with dementia**



## Section 2

We are now going to meet Ellen who is an 80 year old woman living at home with the support of her family, homecare and other community supports. Leanne is coming to take her to the lunch club and Ellen's daughter Carolyn has come to help her to get organised as she has not answered the phone this morning.

### Scenario a: Ellen getting ready for the lunch club

#### *Take time to consider the following:*

- How would you feel coming in to this situation?
- What else could be contributing to Ellen's distress?

#### *Key Learning Points*

- We cannot make assumptions about what is causing a person with dementia to be distressed
- Knowing the person and paying attention to their non-verbal communication, and listening to those around them can help us to understand what the person with dementia may be experiencing
- Remaining calm and unhurried helps to create a less pressurised environment and helps minimise distress

## Section 3

### Scenario b: Leanne (Worker) seeks advice from manager

#### *Key Learning Points*

- It is important to seek help and advice when you are uncertain about the best approach to use
- Small simple adaptations to the environment, including appropriate signage, can make a significant improvement in quality of life for the person with dementia and their families
- There are also a wide range of assistive technologies and tele-care solutions that can be used to allow a person with dementia to perform tasks that they may otherwise struggle with e.g.
  - ✓ Automatic lighting and tele-care solutions to alert a family member or carer if the person leaves the house
  - ✓ Tracking systems that can be used to enable the person to get out while ensuring that their carer or family member always knows where they are
  - ✓ The range includes devices to assist with speaking, hearing, eyesight, memory and getting out and about

However, all of these helpful resources must meet the needs of the person or they can be ineffective or even cause additional confusion and distress.

## DVD Contents: Chapter Four



### Section 1

**This chapter will help all of you to:**

- **Appreciate that people with dementia have the right to a quality of life that reflects their priorities wishes and interests**
- **Understand what is meant by the term person centred support in relation to people with dementia**
- **Understand the importance of recognising, enhancing and supporting the strengths and abilities of people with dementia**
- **Support people with dementia to remain engaged in life's roles and relationships**

Maintaining a good quality of life is perfectly possible following a diagnosis of dementia. Even when a person requires increasing help and support we should not make the assumption that the attempts to improve a person life are pointless.

There are many factors other than a person's dementia that affects their quality of life. It is important to value their life style, environment, relationships, culture and experience. People with dementia should be able to participate in activities that are meaningful to them, enjoyable, bring happiness and make life worth living.

Sometimes it is not obvious how we can do this but staff, carers, friends and communities can all contribute to helping a person live well with dementia, and we should never forget the contribution of the person themselves. After all, each person comes with a life time of experience of their own interests, skills and abilities.

### Section 2

Next we will meet Jim. Jim is 85 and lives in a care home but his situation could easily occur in a hospital ward or in his own home.

#### Scenario a: Jim sitting inactive in the care home

*Take time to consider the following:*



**How would you feel coming in to this situation?**

- **Do you think Jim is experiencing a quality of life that takes account of his interests?**
- **What are the difficulties for staff in providing person centred care for Jim?**
- **Can you think of anyway that Jim's situation could be improved?**

Jim is not experiencing a good quality of life and staffing and resources can often be stretched to the limit. This can seem like a hopeless situation. It appears that, given the stage of the dementia journey that Jim is at, there is very little that can be done about improving his quality of life.



### Key Learning Points



- No matter what stage someone is at in their dementia journey they are entitled to the best quality of life possible.
- It is important to recognise that whatever our job we can all make a difference to the life of someone with dementia
- It is important to use all the information at our disposal and to think of different ways to use it to help people with dementia to make the most of their abilities and remain engaged as much as possible.

## Section 3

Susan (housekeeping services assistant) had found out from her son that the art group that Jim used to help run, was indeed, still going and many of the members remembered him well. She informed the staff about this and they got in touch with the group organiser. Jim began to have regular visits from a volunteer and together they would look at art books. Although Jim could not communicate much the volunteer would reminisce about the group and talk to Jim about art. As we see from Jim's actions and behaviour his quality of life was enriched and enhanced by staff recognising his interests and responding to them.

### Scenario b: Jim engaging in activities he enjoys

#### Key Learning Points



- Whatever stage people are at in their dementia journey they are entitled to the best quality of life possible
- Using all of the information that we have available about a persons life can help us to provide person centred care and this can make a big difference to how they experience their world
- Sometimes thinking about things in a different way can make all the difference for someone with dementia
- It doesn't only need to be health and social services staff who help people with dementia have a good quality of life
- Using a persons own networks, relationships and communities can have a big impact on their lives

## DVD Contents: Chapter Five



### Section 1

#### This chapter will help all of you to:

- Understand that people with dementia have the right to take risks within the context of their own lives
- Understand how people with dementia may be harmed
- Have an awareness of legislation and local policy and any actions you need to take

We tend to assume that people with dementia are not able to think, process information and make sound decisions. This makes it more likely that we are over cautious in how we work with them. And the safety first approach is the biggest barrier to enabling people with dementia to have control over their own lives.

In 2010 the Department of Health in England issued guidance which moves this negative approach to a much more positive one of *risk enablement*.

This is based on the idea that measuring risk involves balancing the positive benefits from taking risks against the negative effects of attempting to avoid risk altogether.

For example the risk of getting lost if a person with dementia goes out unaccompanied needs to be set against the consequences of boredom and frustration from remaining inside. It recognises the strengths a person has and builds on their abilities. It also encourages us to find creative ways to enable them to take risks. Central to this approach is the person with dementia deciding the level of risk they want to take.

A person with dementia is similar to many other groups in society who may be at risk of harm from other people. This may be people close to them, or working with them.

#### This may include:

- Physical abuse – being hit or injured on purpose
- Financial or material abuse – such as theft, or misuse of money, property or personal possessions
- Emotional abuse – intimidation, threats or humiliation, verbal or psychological abuse
- Sexual abuse – the involvement in sexual activity that is unwanted or not understood
- Neglect – from not providing the basics such as food, clothing, attention or care to the failure to provide appropriate access to health and social care
- Discrimination – treating people negatively because they are older, more frail or confused
- Misuse of medication – giving medication inappropriately, overdosing or withholding medication

### Signs and symptoms of abuse may include:

- Injuries
- Bruises
- Weight loss
- Behaviour changes such as being withdrawn or depressed
- Self harm
- Dishevelled or unkempt appearance

We can help to protect people with dementia and enable them to express their wishes. We can support them to give particular individuals the power to make decisions on their behalf when they are no longer able to do so.

### How is this possible?

The Scottish government has put in place a range of legal measures which enable us to take action to protect the person with dementia.

You don't need to know the detail of these pieces of legislation but it is important that you know they exist and that you report concerns you may have to your manager. You need to act when you suspect when someone is being abused or neglected even if you are not certain it is happening.

The following legislation applies;

- **The Adults with Incapacity (Scotland) Act 2000**
- **Mental Health (Care and Treatment) (Scotland) Act 2003**
- **Human Rights Act 1998**
- **Adult Support and Protection (Scotland) Act 2007**

We will now hear from people with dementia about how important taking risk is to them

**Video clip of people with dementia talking about risk enablement.**



## Section 2

Next we will meet Margaret. Margaret is 90 and was recently admitted in to a community hospital. But this situation could easily occur in a nursing home, a hospital ward or in the person's own home.

### Scenario a: Margaret in the community hospital

*How would you feel coming in to this situation?*



**Take time to consider the following:**

- **Why might Margaret want to get up?**
- **What is the difficulty for the staff in this situation?**
- **How do you think Margaret's situation might be resolved?**

### *Key Learning Points*



- **Workers have a duty to ensure that people they are working with are safe**
- **In protecting people with dementia from harm it sometimes feels like the only option is to prevent them from taking any risks**
- **Preventing people with dementia from doing things they want to because they are considered too risky can result in the person feeling distressed or frustrated**
- **Restricting a person's movements can also be viewed as restraint**

## **Section 3**

In our second visit to Margaret, we can see that small changes in our approach and a more positive approach to Margaret's abilities can make a big difference. These changes develop Margaret's sense of confidence and independence, and the ethos of the environment she lives in.

### **Scenario b:**

### **Using risk enablement approaches to support Margaret**

### *Key Learning Points*

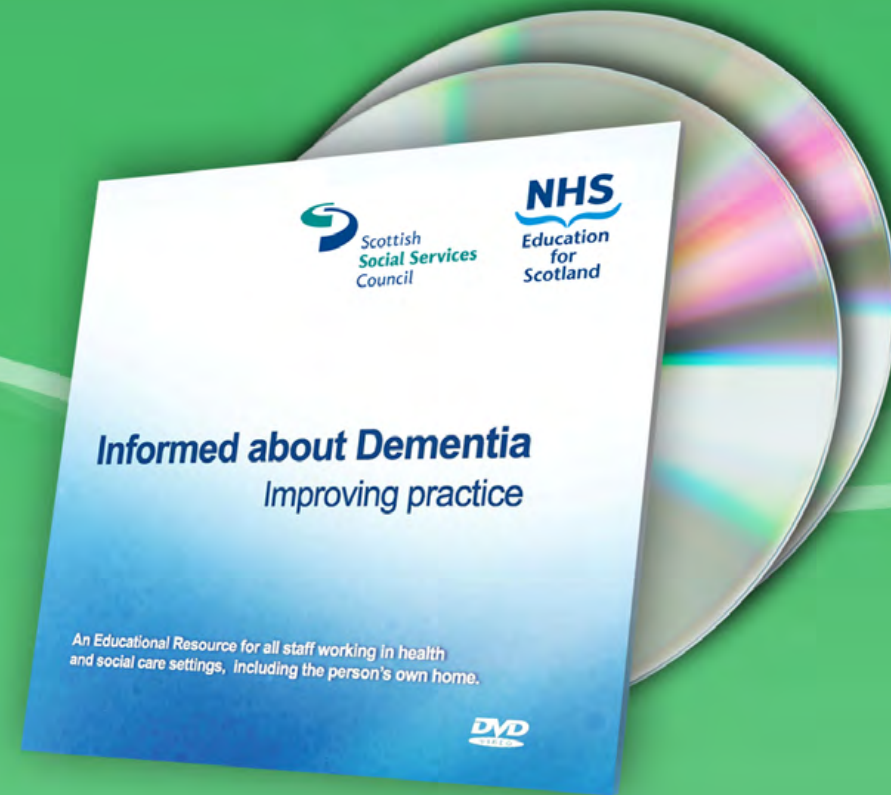


- **Risk enablement – it is important to balance the risks to a person with dementia against their current capabilities and their rights to engage in activities they enjoy.**
- **It is sometimes the case the staff and others involved with the person with dementia can be so protective that they cannot see ways to balance rights and risks.**
- **There is often a way around these apparently impossible situations and this can contribute a great deal to the quality of life for somebody with dementia.**

*Informed about dementia*

## Appendix II

### Handouts for Chapters one to five





## Handout: Chapter One



This resource will help you to:

- Recognise and develop the skills and values you need to support people with dementia and their families and carers
- Understand more about dementia
- Think differently about people with dementia

*People living with dementia can best describe how important our work is:*

Here is what someone living with dementia has to tell us.

*“What I would say to the professionals is that - you can pull me back, give me my life back and pull me into the light. And by the same token, ignorance, arrogance, couldn’t care less, you can shove me down into the darkness and just cast me away. I can’t do it. I need your help to do it”*



### Key Learning Points



- Dementia affects a large and increasing number of people in Scotland
- Dementia affects a range of age groups and can occur alongside other health problems
- Dementia is everyone’s responsibility in health, social service and communities

## Handout: Chapter Two



This resource will help you to:

- Recognise the common signs and symptoms of dementia
- Communicate with people who have dementia in a way that takes account of their difficulties
- Recognise individual needs and diversity of people with dementia
- Understand the effect of stigma on people with dementia and address this wherever possible

### Key Learning Points



- A person with dementia commonly presents with memory problems and confusion
- Communication must take into account the person and their needs
- It is important that we do not assume that dementia only affects older people –in fact early onset dementia is not uncommon and, in particular, there is growing evidence of people with learning disabilities developing dementia at a younger age as they are living longer
- Stigma and discrimination can be associated with people with dementia and can take a variety of forms



### Key Learning Points



- Recognising the person and responding respectfully can change the experience for people with dementia
- Good communication is critical- it is important to speak clearly and simply
- Present one question at a time and allow time for responses
- By doing this we can support a sense of working together
- We can all contribute to finding feasible and creative solutions to the difficulties encountered by people with dementia

## Handout: Chapter Three



This resource will help you to:

- Recognise the impact of the symptoms of dementia on feelings and behaviour
- Recognise the impact of the environment on the person with dementia
- Respond appropriately to distress, confusion and frustration

### Key Learning Points



- We cannot make assumptions about what is causing a person with dementia to be distressed
- Knowing the person and paying attention to their non-verbal communication, and listening to those around them can help us to understand what the person with dementia may be experiencing and respond appropriately
- Remaining calm and unhurried helps to create a less pressurised environment and helps minimise distress

### Key Learning Points



- It is important to seek help and advice when you are uncertain about the best approach to use
- Small simple adaptations to the environment, including appropriate signage, can make a significant improvement in quality of life for the person with dementia and their families
- There is also a wide range of assistive technologies and tele-care solutions that can be used to allow a person with dementia to perform tasks that they may otherwise struggle with e.g.
- Automatic lighting and tele-care solutions to alert a family member or carer if the person leaves the house
- Tracking systems that can be used to enable the person to get out while ensuring that their carer or family member always knows where they are
- The range includes devices to assist with speaking, hearing, eyesight, memory and getting out and about.

However, all of these helpful resources must meet the needs of the person or they can be ineffective or even cause additional confusion and distress.

## Handout: Chapter Four



This resource will help you to:

- Appreciate that people with dementia have the right to a quality of life that reflects their priorities, wishes and interests
- Understand what is meant by the term 'person centred support' in relation to people with dementia
- Understand the importance of recognising, enhancing and supporting the strengths and abilities of people with dementia
- Support people with dementia to remain engaged in life's roles and relationships

### Key Learning Points



- No matter what stage someone is at in their dementia journey they are entitled to the best quality of life possible.
- It is important to recognise that, whatever our job, we can all make a difference to the life of someone with dementia
- It is important to use all the information at our disposal and to think of different ways to use it to help people with dementia to make the most of their abilities and remain engaged as far as possible.



### Key Learning Points



- Whatever stage people are at in their dementia journey they are entitled to the best quality of life possible
- Using all of the information that we have available about a persons life can help us to provide person centred care and this can make a big difference to how they experience their world
- Sometimes thinking about things in a different way can make all the difference for someone with dementia
- It doesn't only need to be health and social services staff who help people with dementia have a good quality of life
- Using a persons own networks, relationships and communities can have a big impact on their lives to the difficulties encountered by people with dementia.

## Handout: Chapter Five



This resource will help you to:

- Understand that people with dementia have the right to take risks within the context of their own lives
- Understand how people with dementia may be harmed
- Have an awareness of legislation and local policy and any actions you need to take

### Key Learning Points



- Workers have a duty to ensure that people they are working with are safe
- In protecting people with dementia from harm it sometimes feels like the only option is to prevent them from taking any risks
- Preventing people with dementia from doing things they want to because they are considered too risky can result in the person feeling distressed or frustrated
- Restricting a person's movements can also be viewed as restraint which is not good practice

### Key Learning Points



- Risk enablement – it is important to balance the risks to a person with dementia against their current capabilities and their rights to engage in activities they enjoy.
- It is sometimes the case the staff and others involved with the person with dementia can be so protective that they cannot see ways to balance rights and risks.
- There is often a way around these apparently impossible situations and this can contribute a great deal to the quality of life for somebody with dementia.

## Notes



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