Resources

Resource 1.1: Self-evaluation tool

In order to ensure that learning objectives are met by the training, **at the start of the day** rate your ability on a competence scale of 1-5 as follows in the PRE column:

1. No knowledge/skill.
2. A little knowledge/skill but considerable development required.
3. Some knowledge/skill but development required.
4. Good level of knowledge/skill, with a little development required.
5. Highly competent – no/very little development required.

Write your numerical rating in the 1st column (PRE).

At the end of the day: Repeat the exercise, writing your new rating, in the 2nd column (POST).

COMPETENCE	PRE (1-5)	POST (1-5)
Knowledge I have an awareness of how dementia can affect people with a learning disability.		
I am aware of strategies to support people who have a learning disability and dementia.		
Skill I am able to develop an action plan to implement my learning into practice.		
I am able to work in an outcome-focused way.		
Confidence I feel confident in introducing small changes to my own practice and the practice of others		
I feel confident in talking about dementia to people with a learning disability		
Total		

Please return this form to the trainer before you leave, thank you.

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Resource 1.2: Action plan

Please add action points to your list throughout the day. This may be a topic that you want to find out more information about, something you would like to try in practice or a change that you would like to make. At the end of the day we will discuss your key actions and priorities.

Action	By when?	What will I need to do to help me achieve this?	Priority 1-5 (1=high, 5= low)

Resource 1.3: Down's syndrome quiz

Statement	True	False
There are two different types of Down's syndrome.		
Screening for dementia in people with Down's syndrome typically starts at age 45.		
Down's syndrome runs in families.		
The average age of onset of dementia in people with Down's syndrome is 59.		
People with Down's syndrome have a high pain threshold.		
Women with Down's syndrome experience an earlier menopause.		
People with Down's syndrome may develop Korsakoff's syndrome (alcohol related brain damage).		
People with Down's syndrome only develop one type of dementia – Alzheimer's disease.		
People with Down's syndrome are typically musical and enjoy singing.		
Women with Down's syndrome cannot have children.		
Men with Down's syndrome cannot father a child.		
Most babies with Down's syndrome are born to older women.		
People with Down's syndrome are typically cheerful.		
People with Down's syndrome are prone to hypothyroidism (underactive thyroid).		

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Resource 1.4: Down's syndrome quiz with answers

Statement	True	False
There are two different types of Down's syndrome. *There are 3 different types:* ***Trisomy 21*** *accounts for 95% of people with Down's syndrome. A child with Trisomy 21 has three copies of chromosome 21, rather than the normal pair.* ***Translocation Down's syndrome*** *accounts for just 3-4% of people with Down's syndrome. Translocation is what people are referring to if they say that the condition is inherited, because usually one parent is a carrier. The extra #21 chromosome is present, but attached to a different chromosome in the egg or sperm.* ***Mosaic Down syndrome*** *accounts for less than 1% of all people with Down's syndrome. Children born with Mosaic Down's syndrome have some cells with three copies of chromosome 21 and some cells that have the usual pair which may result in fewer characteristics of Down's syndrome in some cases and a lesser degree of learning disability.*		✘
Screening for dementia in people with Down's syndrome typically starts at age 45. *A baseline should be carried out by the age of 30 in the UK, this needs to be before changes begin – or it is not a 'baseline' of functioning. Some areas screen for dementia from age 30 (recommended by British Psychological Society), some from age 40.*		✘
Down's syndrome runs in families. *The broad statement of saying all cases of Down's syndrome are hereditary is a myth, but 3-4% of Down syndrome diagnoses are hereditary (see translocation Down's Syndrome above)*		✘
The average age of onset of dementia in people with Down's syndrome is 59. *Average is 54.2 in men, slightly younger in women (but not significantly).*		✘
People with Down's syndrome have a high pain threshold. *This is a myth, although it is commonly believed. Pain may be difficult to describe or explain but this does not mean it is not there. 'As required' pain relief is not recommended for this reason in people with dementia. 'Just in case' is preferred.*		✘

Resource 1.4: Down's syndrome quiz with answers

Statement	True	False
Women with Down's syndrome experience an earlier menopause. *Women with Down's syndrome have an earlier onset of menopause compared to women in the general population; average age is 44 years for women with Down's syndrome compared with 52 years of age in the general population. Also there is a strong relationship between the age of menopause onset and the age at which dementia is diagnosed (also earlier).*	✘	
People with Down's syndrome may develop Korsakoff's syndrome (alcohol related brain damage). *Yes, the risk factor is the same as for anyone else, and perhaps increasing as a result of community and independent living/choice.*	✘	
People with Down's syndrome only develop one type of dementia – Alzheimer's disease. *People with Down's syndrome are more likely to develop Alzheimer's disease but may also develop other types; there are cases of Lewy body and vascular, for example. There is also increasing evidence of early frontotemporal changes in people with Down's syndrome as an early indicator of Alzheimer's disease. Just as in the population without learning disabilities, people may also have more than one type of dementia at the same time.*		✘
People with Down's syndrome are typically musical and enjoy singing. *This is a myth but again is commonly believed. A group of people with Down's syndrome are as individual as any other group.*		✘
Women with Down's syndrome cannot have children. *Where one parent has Down's syndrome, there is a 35% to 50% chance that the child would inherit the syndrome. This chance is even higher where both parents have Down's syndrome. There is also a high chance that pregnancy would end in miscarriage. Women with Down's syndrome are also more likely than other women to have a premature baby, or to need a caesarean section.*		✘

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Resource 1.4: Down's syndrome quiz with answers

Statement	True	False
Men with Down's syndrome cannot father a child. *Men with Down's syndrome are reported as having a very low sperm count. It has been recorded that only two men with Down's syndrome have been fathers. However, information about fertility in people with Down's syndrome is considered outdated and based on research in institutions where men and women with learning disabilities were kept apart.*		✘
Most babies with Down's syndrome are born to older women. *The chance of having a baby with Down's syndrome increases to 1 in 400 for women who become pregnant at age 35. The likelihood of Down's syndrome continues to increase as a woman ages, so that by age 42, the chance is one in 60, and by age 49, the chance is one in 12.* *However this answer is false because most babies who have Down's Syndrome (about 75%) are born to mothers who are 35 or younger. This is because older mothers tend to have fewer babies. In the UK the average age for women having their first baby is 28 years so this is when most babies with Down's syndrome are born.*		✘
People with Down's syndrome are prone to hypothyroidism (underactive thyroid). *Hypothyroidism occurs in up to 40% of people with Down's syndrome. It is particularly important to identify this condition as it can be misdiagnosed as dementia because of similar symptoms such as lethargy, lack of concentration, weight gain, dry skin, memory impairment and intolerance to cold. People with Down's syndrome also have a slightly higher incidence of hyperthyroidism than the general population (overactive thyroid)*	✘	

Resource 1.5: Dementia quiz

Statement	True	False
1. Approximately 4.5 million people in the US have dementia (aged 65 and over).		
2. Alzheimer's disease only affects older people.		
3. Dementia is a progressive condition.		
4. There are factors which may decrease the risk of dementia.		
5. You should not tell someone that they have dementia, as they will be devastated.		
6. Once a person has been diagnosed with dementia, it is important that decisions about their care are made by someone else.		
7. People with dementia may also have depression.		
8. People with vascular dementia are not aware of their difficulties.		
9. People with dementia with Lewy Bodies may experience Parkinsonian symptoms.		
10. Damage in the frontal lobe of the brain may lead to a lack of inhibition.		
11. Inability to remember recent events is associated with damage to the occipital lobe.		
12. The parietal lobe of the brain makes sense of visual information.		
13. When a person with dementia has trouble communicating it is unhelpful to complete their sentences for them.		
14. If you talk about a person with dementia when they are there, they won't understand.		
15. If a person with dementia has an unpleasant experience, the feeling will go away once they have forgotten what happened.		
16. Physical, social and cultural factors can have a profound effect on the well-being, morale and self-confidence of a person with dementia.		
17. It's safe to assume that everyone from the same country will have the same cultural and religious beliefs.		
18. People with delirium need immediate medical attention.		

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Resource 1.6: Dementia quiz answers

Statement	True	False
1. **Approximately 4.5 million people in the US have dementia (aged 65 and over).** *False, as of March 2018, an estimated 5.5 million people age 65 and older have dementia and approximately 200,000 individuals under age 65 have younger-onset Alzheimer's. One in 10 people age 65 and older (10 percent) has Alzheimer's dementia. Almost two-thirds of Americans with Alzheimer's are women.*		✘
2. **Alzheimer's disease only affects older people.** *False. Approximately 98% of people with Alzheimer's disease are over the age of 65, and the risk increases with advancing age. However, Alzheimer's disease can and does develop in younger people, affecting approximately 5,000 people under the age of 65 in the UK.*		✘
3. **Dementia is a progressive condition.** *True. However, while there are many similarities experienced by people with different types of dementia, no two people will experience dementia in exactly the same way, and the rate of progression varies greatly between people.*	✘	
4. **There are factors which may decrease the risk of dementia.** *True. Dementia can affect anyone and there is nothing we can do to provide total protection against dementia. However, there are some things that might decrease the risk of developing it. These are known as 'protective factors' and include taking regular exercise and eating fresh fruit, vegetables and foods high in polyunsaturated fatty acids such as oily fish. There are also factors that could increase our risk of dementia, known as 'risk factors', such as smoking, drinking alcohol to excess and having high blood pressure. Growing old and/or having Down's syndrome increase the risk of dementia.*	✘	

Resource 1.6: Dementia quiz answers

Statement	True	False
5. **You should not tell someone that they have dementia, as they will be devastated.** *False. It is true that a diagnosis of dementia can have a huge impact on the individual and their family, depending on the individual's personality, background and circumstances. For some it may come as shock, while for others it may confirm what they have suspected and provide relief in receiving confirmation regarding what is happening. There is considerable evidence to show that a diagnosis can be helpful for a number of reasons, such as providing more time for the person with dementia and their families to come to terms with and adjust to the diagnosis, consider and provide care and treatment options and improve functioning and quality of life. It can mean more time to make future plans and arrangements, especially regarding financial and legal matters before the condition becomes more severe.*		✘
6. **Once a person has been diagnosed with dementia, it is important that decisions about their care are made by someone else.** *False. There are many ways to live well with dementia, and no two people will experience the same journey in the same way or have the same support needs. During their journey, they should be fully involved in any decisions about their care for as long as possible. It is important that people remain as active, independent and in-control as their abilities allow, and are fully enabled to exercise their rights.*		✘
7. **People with dementia may also have depression.** *True. Depression is common among people at all stages of the dementia journey, but the two should not be confused.*	✘	
8. **People with vascular dementia are not aware of their difficulties.** *False. People with vascular dementia often have good awareness of their difficulties. They may have problems with concentration and verbal communication, memory problems (although this may not be the first symptom), periods of acute confusion and epileptic seizures. People with vascular dementia may experience physical symptoms of stroke, such as physical weakness or paralysis. Partly due to their awareness of their difficulties, depression can be quite common.*		✘

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Resource 1.6: Dementia quiz answers

Statement	True	False
9. **People with dementia with Lewy Bodies may experience Parkinsonian symptoms.** *True. In common with most other dementias, typical symptoms of dementia with Lewy bodies (DLB) include memory loss, shortened attention span, disorientation and communication difficulties. Additionally, people with DLB will often experience Parkinsonian symptoms such as tremor and muscle stiffness. They may experience visual hallucinations and fluctuations in symptoms from day-to-day or within the same day. People with DLB may also be prone to fainting or unexplained falls.*	✘	
10. **Damage in the frontal lobe of the brain may lead to a lack of inhibition.** *True. Early on in this condition, it is typical for the memory to remain intact, but personality and behaviour tends to change. People may lack insight, lose the capacity to empathise with others, behave in inappropriate, disinhibited and occasionally aggressive ways, or become withdrawn and lack motivation. Additionally, people will also experience verbal communication difficulties, spatial disorientation and a shortened attention span. They may also develop compulsive behaviour, such as overeating.*	✘	
11. **Inability to remember recent events is associated with damage to the occipital lobe.** *False. The occipital lobe makes sense of visual information. It is the temporal lobe that helps people store new information. Damage in this area of the brain can cause problems in understanding and producing speech, and remembering recent events, while memories from the past may remain intact. It means people may experience a short attention span.*		✘
12. **The parietal lobe of the brain makes sense of visual information.** *True. Damage to this part of the brain may lead to people having problems processing visual information, such as recognising faces and objects. It may lead to people having problems carrying out a sequence of actions, such as getting dressed. It can affect people's body sense – knowing which part of your body is where. It can also affect spatial awareness – knowing where objects are relative to your own body.*	✘	

Resource 1.6: Dementia quiz answers

Statement	True	False
13. **When a person with dementia has trouble communicating it is unhelpful to complete their sentences for them.** *True. Communication can become difficult for a person with dementia. The person may struggle to find the right word or may use the wrong word with increasing frequency. Holding conversations may be difficult as they struggle find the right words to express their thoughts and feelings. We should not assume we know what the person is trying to communicate but should allow them sufficient time to express themselves.*	✘	
14. **If you talk about a person with dementia when they are there, they won't understand.** *False. We may wrongly think that the person with dementia does not understand and will forget in five minutes anyway. However, our body language and gestures are likely to be understood, and the person with dementia could be aware they are being talked about even if they do not fully grasp the meaning of what is being said. This can be upsetting, and they can continue to feel upset long after they have forgotten why.*		✘
15. **If a person with dementia has an unpleasant experience, the feeling will go away once they have forgotten what happened.** *False. People with dementia often have difficulty remembering recent events but are more likely to retain memories with strong emotional connections. If they become upset in a particular situation, they are likely to retain this feeling even after they have forgotten what happened. Similarly, if they have had a pleasurable experience, they are likely to forget what they have done but remember the pleasant memories.*		✘
16. **Physical, social and cultural factors can have a profound effect on the well-being, morale and self-confidence of a person with dementia.** *True. It is crucial that the physical environment is enabling and is not a barrier for a person with dementia. Use of colours and furnishings, signage, lighting, noise levels, stimulation, exercise and activity, private and communal spaces and use of assistive technology can help create a safe, relaxing and calm area to reduce stress levels and maximise independence for as long as possible. Factors such as participation in carrying out activities and self-care, personalised care and attention, activities meaningful to the individual, social interaction and attitude of staff can all impact on the social and cultural environment.*	✘	

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Resource 1.6: Dementia quiz answers

Statement	True	False
17. **It's safe to assume that everyone from the same country will have the same cultural and religious beliefs.** *False. Equality and diversity are an integral part of a person's well-being and are key to person-centred care. Equality is about treating people fairly according to their needs. Diversity is about respecting differences, including spiritual, cultural and religious beliefs. An individual's experience of dementia may be informed by their cultural background, and care provided should be culturally sensitive. However, it is important to identify individual needs and preferences and not make assumptions. Not all who speak the same language will follow the same religion, and not all people sharing the same religion will practice the same rituals or share the same beliefs.*		✘
18. **People with delirium need immediate medical attention.** *True. Older people and people with dementia are more at risk of delirium. Delirium develops quickly, often in a matter of hours. There is a sudden onset of agitation, hallucinations and rapid changes in a person's level of consciousness. It is usually a sign that something important and potentially very damaging is occurring. Delirium can result from an infection or other physical problems. Once the problem is treated, the delirium usually passes.*	✘	

Resource 2.1: Is this INSIDE public space dementia-inclusive?

Is this INSIDE public space dementia-inclusive?

A checklist for use by dementia groups

Has your dementia group been invited to walk round and comment on an inside public space? For example, a theatre, museum, cafe, leisure centre or airport.

Here are 10 key questions to think about.

Funded by the ESRC and HammondCare

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Suggestions for use

- You can use the checklist while you walk round and/or afterwards to focus discussion.
- Some groups choose one (or more) people to carry the checklist and make notes.
- Or everyone might want to have a copy of the checklist as they walk round.
- It may help to bring clipboards and pens.
- Some people may prefer this printed on yellow paper.

Feedback

You can feed back to the staff at the end, using your checklist as a reminder.

And/or, if they walk round with you, they could fill in a checklist themselves, recording the group's comments.

And/or you could send them a tidied-up version following the visit.

Keep a copy for yourselves so that you can refer to it later.

Venue being checked ....

Date ....

Produced in April 2017 by Innovations in Dementia CIC, ECRED (University of Edinburgh) and Dementia Centre HammondCare.

Tested by member groups of the UK DEEP network (dementiavoices.org.uk)

Question 1 Is coming into the building easy?

This is how it should be:	Yes/No	Our comments
Easy to find from main street		
Disabled parking bay nearby		
Purpose of building obvious		
Entrance clearly signed		
Entrance feels welcoming		
Obvious & easy disabled access		
Easy to find reception, information desk, check-out, or ticket desk		

Question 2 Is it easy to find your way around inside?

This is how it should be:	Yes/No	Our comments
Good signage should:		
• Stand out well in its setting		
• Not be too high or low - easily visible for all		
• Be easy to read		
• Not be reflective		
• Have an understandable picture as well as words		
• Have both picture and words that contrast well with the background		
There should be clear signs to show:		
• Restricted areas		
• Fire routes and exits		

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	Yes/No	Our comments
• How to open doors (pull/ push/ automatic)		
• Cupboards (and maybe contents)		
• Way out of rooms		
• Easy to find someone official who can help (wearing badge/ uniform?)		

Question 3 **Is it easy to find and use a toilet?**

This is how it should be:	Yes/No	Our comments
Clear signs into and back out of toilet		
Signs should:		
• Stand out well in their setting		
• Be at a height that is easily visible for all		
• Be large and clear		
• Have an understandable picture as well as words		
• Have picture and words which contrast well with the background		
Inside, everything you need to use should have good contrast, including:		
• The pan against the floor		
• The seat against the pan		
• The basin against the wall		
• The grab rails against the wall		

	Yes/No	Our comments
• The soap dispenser against the wall		
• The towel dispenser against the wall		
• Taps and other fittings are easy to understand and use		
• Hand dryer is not too noisy (choice of paper towels?)		

Question 4 Does the floor cause any problems?

This is how it should be:	Yes/No	Our comments
Not too much contrast and pattern		
Not too much change in tone in adjoining flooring		
Patterns or joints not too obvious		
Flooring repairs not too obvious		
No tricky slopes		
Not too shiny		
No dark black mats		

Question 5 Is the place calm or confusing?

This is how it should be:	Yes/No	Our comments
There are not too many distractions, such as:		
• Advertising		
• Display items		

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	Yes/No	Our comments
• Clutter at checkouts		
• Signage that is not relevant		
• Mirrors that can cause confusing images		
There is not too much noise such as:		
• Loud music (or it can be turned down)		
• Café clatter (e.g. noisy coffee machine)		
• Noise from cleaning machines		
• Echoes		
• Any ‘quiet times’ advertised?		
• Enough places to sit?		
Note: If you can measure sound levels, it needs to be less than 65 decibels		

Question 6 Is the lighting good?

This is how it should be:	Yes/No	Our comments
Enough lighting for you to see where you are going, and to read		
Lighting does not form confusing shadows or patterns on the floor		
Lighting evenly spread		
No glare or flickering		
Mirrors placed where they do not cause confusing reflections		
Switches easy to find (or sensors)		

Question 7 Is the place safe, especially for people with disabilities?

This is how it should be:	Yes/No	Our comments
Easy-to-see handrails on all ramps and stairs		
Ramps as well as steps to enter public buildings		
Easy to find accessible toilet		
Signage to first aid, defibrillator and help if sick		
Choice of high and low seats		

Question 8 Is the lift easy to use for everyone?

This is how it should be:	Yes/No	Our comments
Floor inside lift same tone as floor outside		
Threshold similar tone to both floor surfaces		
Small, rather than large, mirror		
Buttons: big, clear and with good signs		
Hand-rail		
Enough space		

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Question 9 Does everything you need to use contrast well?

This is how it should be:	Yes/No	Our comments
Good contrast so you can see:		
• Tables against the floor		
• Chairs against the floor		
• Cups and plates against the table		
• Mirrors or picture frames against the background		

Question 10 How is the general atmosphere?

This is how it should be:	Yes/No	Our comments
Gives a sense of security		
Feels easy to ask for help		
Staff seem friendly		
Staff helpful in conducting the audit		

Our overall assessment

Main things we like:

Main things we think could be improved:

Please contact the dementia centre with any ideas and suggestions for future versions of this tool. Email: dementia@hammondcare.com

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Resource 2.2: Is this OUTSIDE public space dementia-inclusive?

Is this OUTSIDE public space dementia-inclusive?

A checklist for use by dementia groups

Has your dementia group been invited to walk round and comment on an outside public space? For example, a shopping centre, park, station or the approach to a public building

Here are 9 key questions to think about.

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Suggestions for use

- You can use the checklist while you walk round and/or afterwards to focus discussion.
- Some groups choose one (or more) people to carry the checklist and make notes.
- Or everyone might want to have a copy of the checklist as they walk round.
- It may help to bring clipboards and pens.
- Some people may prefer this printed on yellow paper.

Feedback

You can feed back to the staff at the end, using your checklist as a reminder.

And/or, if they walk round with you, they could fill in a checklist themselves, recording the group's comments.

And/or you could send them a tidied-up version following the visit.

Keep a copy for yourselves so that you can refer to it later.

Venue being checked ....

Date ....

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Tested by member groups of the UK DEEP network (dementiavoices.org.uk)

Question 1 Is it easy to find your way around?

This is how it should be:	Yes/No	Our comments
Good signage should:		
• Stand out well in its setting		
• Be easily visible, not too high or low		
• Be easy to read		
• Not be reflective		
• Have an understandable picture as well as words		
• Have both picture and words that contrast well with the background		
There should be clear signs to show:		
• Restricted areas		
• Fire routes and exits		
• How to open doors (pull/ push/ automatic)		
• Way out		
• Easy to find someone official who can help (wearing badge/ uniform?)		

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Question 2 **Is it easy to find and use a toilet?**

This is how it should be:	Yes/No	Our comments
Would you have to find a café or shop if you needed a toilet?		
Clear signs to a toilet should:		
• Stand out well in their setting		
• Be at a height that is easily visible for all		
• Be easy to read		
• Have an understandable picture as well as words		
• Have picture and words which contrast well with the background		
Inside the toilet, everything you need to use should have good contrast, including:		
• The pan against the floor		
• The seat against the pan		
• The basin against the wall		
• The grab rails against the wall		
• The soap dispenser against the wall		
• The towel dispenser against the wall		

Question 3 Does the surface cause any problems?

This is how it should be:	Yes/No	Our comments
Not too much change in tone in adjoining flooring		
Patterns or joints are not too obvious		
Paving repairs are not too obvious		
Paving is non-slip and has an even surface		
No tricky slopes		

Question 4 Is the place calm or confusing?

This is how it should be:	Yes/No	Our comments
Nothing blocks your way such as:		
• Sign posts		
• Lamp posts		
• Litter bins		
• Café pavement boards		
• Bollards		
• There are not too many distractions, which can make it hard to find your way		
There is not too much noise such as:		
• Music coming out of shops		
• Very heavy traffic nearby		
Note: If you can measure sound levels, it needs to be less than 65 decibels		

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Question 5 **Is the lighting good?**

This is how it should be:	Yes/No	Our comments
Enough lighting for you to see where you are going, and to read		
Lighting does not form confusing shadows or patterns on the floor		
Lighting evenly spread		

Question 6 **Is the place safe, especially for people with disabilities?**

This is how it should be:	Yes/No	Our comments
• Easy to understand road crossings		
• Clearly defined edges of steps and kerbs		
• Ramps as well as steps to enter buildings		
• Easy-to-see handrails on all ramps and stairs		

Question 7 **Are there public open spaces nearby to sit, rest and relax?**

This is how it should be:	Yes/No	Our comments
• Attractive nearby areas e.g. garden, park, courtyard, paved area		
• Good signage to these		
• Easy access		

	Yes/No	Our comments
Benches:		
• Lots		
• Easy to see and use		
• Recognisable as seating		

Question 8 Does everything you need to use contrast well?

This is how it should be:	Yes/No	Our comments
Good contrast so you can see:		
• Seats and benches against the pavements		
• Litter bins against the pavements		

Question 9 How is the general atmosphere?

This is how it should be:	Yes/No	Our comments
Gives a sense of security		
Feels easy to ask for help		
Staff seem friendly		
Staff helpful in conducting the audit		

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Our overall assessment

Main things we like:

Main things we think could be improved:

Please contact the dementia centre with any ideas and suggestions for future versions of this tool. Email: dementia@hammondcare.com

Resource 2.3: Developing a supportive environment

Tool 3: Developing a supportive environment

Person's name ______________________________

What would make their environment ...

Calm

What are the barriers to this?

____

How can these be overcome?

____

Predictable

What are the barriers to this?

____

How can these be overcome?

____

Familiar

What are the barriers to this?

____

How might these be overcome?

____

Suitably stimulating

What are the barriers to this?

____

How can these be overcome?

____

Make sense

What are the barriers to this?

____

How can these be overcome?

____

Action to be taken

____

Person(s) responsible ______________________________

Date for next review ______________________________

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Resource 3.1: Verbal and non-verbal cues

Tool 5: Verbal and non-verbal cues	
Verbal and non-verbal changes in communication that may occur	**Suggestions for verbal and non-verbal communication**
▶ Difficulty in finding the right word ▶ Unusual speech pattern ▶ Repeating words ▶ Changing pronunciation of words ▶ Increase in shouting ▶ May forget recently learned ▶ Makaton signs ▶ Becoming flustered ▶ Picking at skin ▶ Becoming more upset ▶ Losing track of a conversation ▶ Constantly talking more or less ▶ Wringing of hands	▶ Make eye contact ▶ Smile while speaking ▶ Use a friendly tone of voice ▶ Use short sentences ▶ Speak in the same language as the person with dementia ▶ Do not be afraid of silence, this can be thinking time ▶ Do not give too many messages at the same time ▶ Do not use defensive or aggressive body language ▶ Talk to someone at their eye level ▶ Make sure the room is quiet ▶ Do not speak to anyone else at the same time ▶ Do not touch the person from behind
People with dementia still want and need to communicate. To support this we must pick up on and return their cues. Remember, a large part of our communication is non-verbal.	

Resource 4.1: Case studies

Case study 1: Claire

Claire is 61 and has a learning disability (not Down's syndrome).

Living situation

At home with her 89-year-old mum. Until recently no additional support had been sought or accepted from health or social care services.

Claire has always enjoyed watching television – Disney films and soaps – but lately hasn't wanted to do anything else.

Changes observed

It has become apparent that Claire has been caring for her mum for a number of years but has now become ill herself.

Claire is believed to have sleep apnoea and has been diagnosed with cataracts and keratoconus (coning of the cornea which affects her vision).

Diagnosis

Claire received a diagnosis of Alzheimer's disease just after her mum was also diagnosed. Her Dad had dementia before he died, she knows of her diagnosis.

Current supports

Community Learning Disability Nurse visits Claire and a homecare worker supports her mum twice a day.

Questions

- What outcomes might you be working towards in the next six months?
- What outcomes might you be working towards beyond 12 months?
- What challenges may be faced?
- What and who can help to overcome the challenges?

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Case study 2: Louise

Louise is 49 and has Down's syndrome.

Living situation

Louise lives in a care home for older people. She moved there 18 months ago after her dad died suddenly.

Louise loves animals and misses her neighbour's dog that she used to play with in the garden.

Changes observed

Louise does not engage with the other residents. Staff find it difficult to understand what she is trying to say. They think that she is in pain but are not sure.

Recently Louise has recently started having seizures.

Diagnosis

It was only after Louise moved to the care home that a diagnosis was suspected. Staff reported that she became withdrawn very quickly and at times aggressive. Her sister used to visit and take her out every weekend but Louise is refusing to go with her now.

Louise is not aware of her diagnosis.

Current supports

Care home staff, Louise's sister and nieces visit monthly.

Questions

- What outcomes might you be working towards in the next six months?
- What outcomes might you be working towards beyond 12 months?
- What challenges may be faced?
- What and who can help to overcome the challenges?

Case study 3: Alina

Living situation

Alina lives with her sister and brother-in-law. Her sister works part-time when Catherine is at a resource centre.

Alina has always been very sociable but lately has been much louder than usual and her friends are becoming embarrassed by her behaviour.

Changes observed

Alina has become obsessed with her brother-in-law. Resource centre staff have noted that this is taking over her whole day. She is fixated with him and talks only of marrying him. She becomes verbally abusive if anyone corrects her.

Alina has glasses but staff report that she rarely wears them. It is noticeable that she avoids bright lights.

Diagnosis

Alina was diagnosed with dementia three months ago. She has experienced rapid changes in behaviour and personality. She is not aware that she has dementia.

Current supports

Attendance at the resource centre.

Questions

- What outcomes might you be working towards in the next six months?
- What outcomes might you be working towards beyond 12 months?
- What challenges may be faced?
- What and who can help to overcome the challenges?

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Case study 4: Jamie

Jamie is 39 and has Down's syndrome.

Living situation

Jamie lives alone with outreach support from a service provider (voluntary sector).

Changes observed

Jamie has been arriving late at college and staff there report that his personal care skills appear to be deteriorating – he doesn't shave or shower as often as he used to.

Diagnosis

Jamie had a baseline assessment at age 30 and has had screening approximately every couple of years, although not always with the same person. He hasn't yet had a diagnosis but has been referred to his GP and Community Learning Disability Nurse. He is worried that something is wrong.

Jamie has difficulty hearing and staff think this may be getting worse. He also frequently bumps into furniture.

Current supports

Jamie enjoys going bowling with friends and watching football.

Questions

- What outcomes might you be working towards in the next six months?
- What outcomes might you be working towards beyond 12 months?
- What challenges may be faced?
- What and who can help to overcome the challenges?

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Case study 5: Angus

Angus is 59 and has Down's syndrome.

Living situation

Shared house for people with a learning disability and dementia with 24-hour staffing, including waking night staff.

Angus has lived here for five months, the other two tenants have advanced dementia and have lived there for over a year. Angus previously lived in a different house with the same service provider until he became unable to go upstairs to his room. He grew up in a long-stay institution.

Changes observed

Angus was initially settled when he moved but has grown increasingly restless at night and has stomach pain. He will only eat certain foods and has started choking and coughing when he eats.

Diagnosis

Angus had regular screening and received a diagnosis of dementia 18 months ago, although had been experiencing changed behaviour for over two years. He has been prescribed Aricept, which he knows is to 'help his head'.

Current supports

Staff at the shared home and visiting family.

Questions:

- ▶ What outcomes might you be working towards in the next six months?
- ▶ What outcomes might you be working towards beyond 12 months?
- ▶ What challenges may be faced?
- ▶ What and who can help to overcome the challenges?

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Resource 4.2: Learning disability and dementia training evaluation form

Which part(s) of the day did you find most useful?				
Which part(s) of the day did you find least useful?				
How would you rate the venue?				
1 Not good	2	3	4	5 Very good
How far did the training meet your needs?				
1 Not well	2	3	4	5 Very well
Any additional comments				

Thank you for completing this form.