Jenny's Diary

A resource to support conversations about dementia with people who have an intellectual disability

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Jenny's Diary

A resource to support conversations about dementia with people who have a learning disability

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Jenny's Diary is available as a free download at www.uws.ac.uk/jennysdiary

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How to use the booklet and postcards

Booklet

This booklet is in three parts:

Part 1: Jenny's Diary

Pages 7–30 are for staff or family supporting a person with an intellectual disability. You will see photographs of a typical week for Jenny who has dementia. The aim is to support conversations with people with an intellectual disability about why Jenny is behaving differently, and how she can be supported to live as well as possible with dementia. This will also help staff and family members to answer any questions they may be asked.

Part 2: Talking to Jenny about her diagnosis of dementia

Pages 31–37 suggests how to have a conversation with a person who has an intellectual disability about their diagnosis of dementia.

Part 3: Talking to friends about dementia

Pages 39–43 contains guidance for staff or family to explain dementia to friends of the person with a diagnosis.

Although primarily aimed at staff and family members, Jenny's Diary has been written using words that can be used in conversation with people who have an intellectual disability.

We recommend that you read all of this booklet before you use it as part of your conversation.

This version of Jenny's Diary uses the term intellectual disability instead of learning disability. Both versions are available as a free download from www.uws.ac.uk/jennysdiary

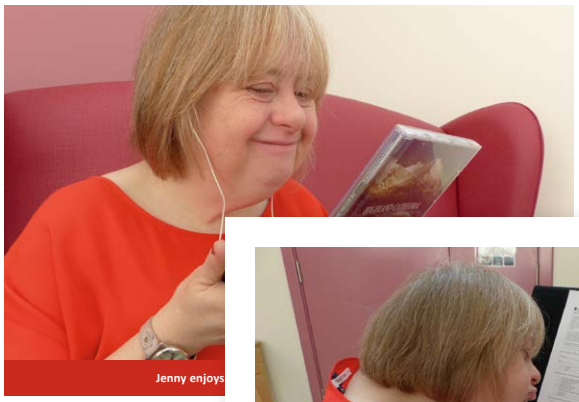
Postcards

The postcards are examples of activities that Jenny does in a typical week. They can be passed around, held closer to look at if needed, viewed on a computer screen, or stuck on a wall at home.

Jenny and Anna

Jenny likes growing flowers and wants to keep volunteering at the garden centre.

Jenny likes to wear n



Jenny enjoys

Jenny and Linda are looking at a screening tool. This is to find out what has changed for Jenny since her baseline assessment.

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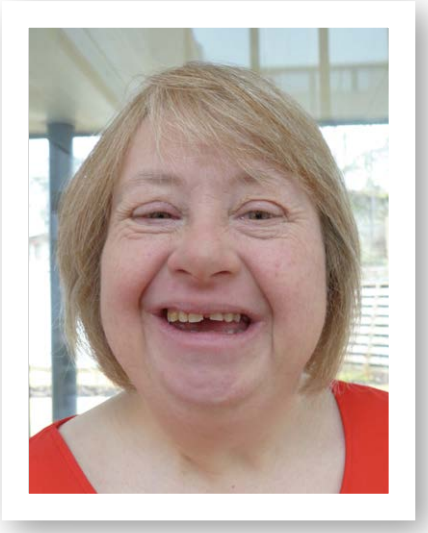
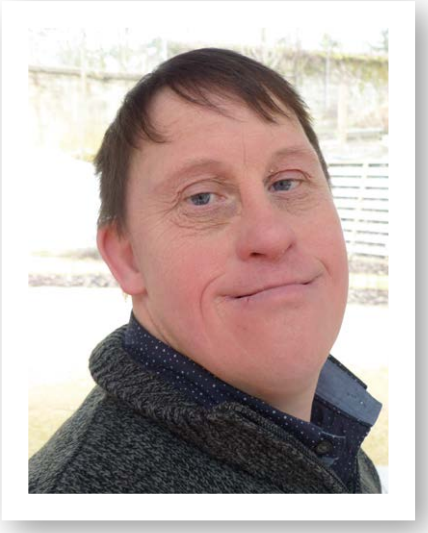
Meet the actors

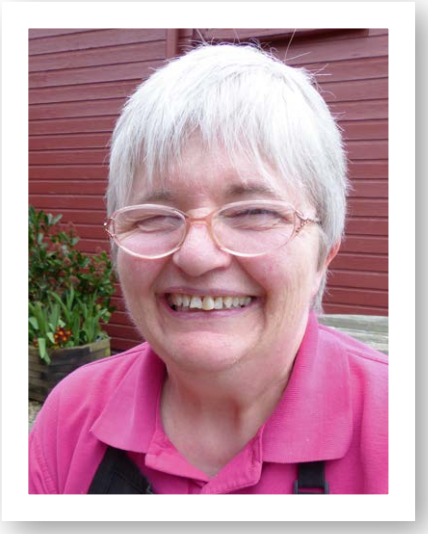


Jenny



George is Jenny's boyfriend

Linda is Jenny's sister



Anna is Jenny's friend

Part 1

Jenny's Diary

Monday

Jenny and Anna work at the café.

On Monday Jenny works at a café.

She usually enjoys talking to people and serving customers, especially her boyfriend George.

Anna is Jenny's friend.

She works at the café with Jenny.

Jenny enjoys serving customers, especially her boyfriend George.

Recently Jenny has been quiet at work.

Anna said that Jenny doesn't like working at the café anymore because she can't always find the toilet.

This makes Jenny feel upset.

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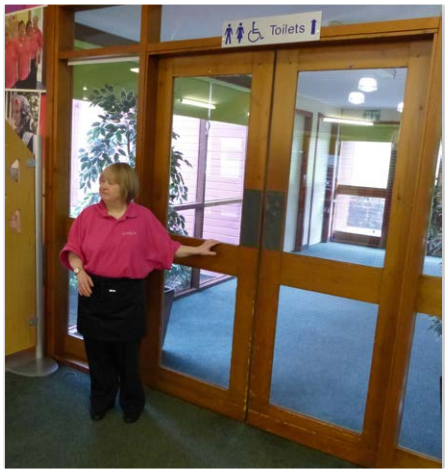
Monday

Jenny gets upset if she can't remember how to get to the toilet.



Jenny doesn't sleep very well on a Monday night after she has been to work at the café.

Sometimes she wakes up at night and cannot remember why she has got up.

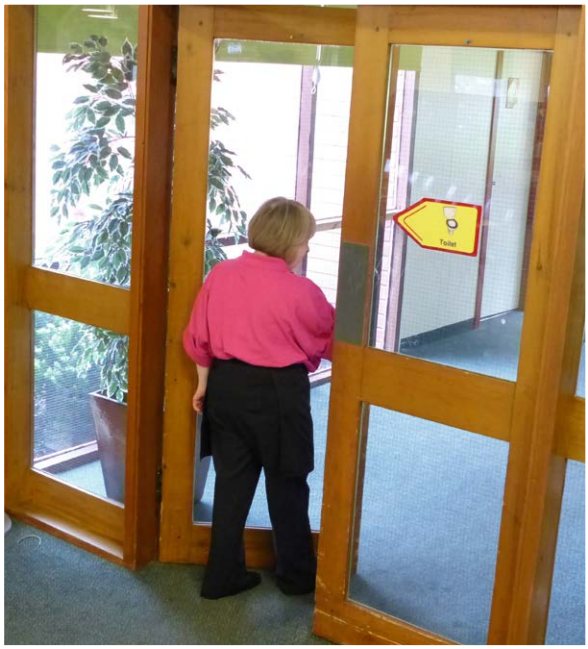
This may be because she is upset or agitated after working at the café.

It may be that she is mixing up day and night.

We can help:

- Having dementia makes it harder for Jenny to understand rooms or buildings that she used to know very well. We can make it easier for her at the café by using photographs, pictures and signs.
- Staff or family can talk to the café owner about putting up different signs at an appropriate (low) height to show how to find the toilet. This will help a lot of people, not just people with dementia.
- Way Out signs should be on the inside of the toilet door at an appropriate height to help Jenny find her way back to the café.
- A dark coloured toilet seat on a white toilet can make it easier to see. This is because the colours contrast with each other.
- Developing a regular routine for going to the toilet and allowing enough time can help people with dementia.
- At home a bathroom light can be left on so Jenny can find the toilet when she gets up at night.
- Going to work every week has been an important part of Jenny's routine. She should be encouraged to keep going for as long as possible. There may come a time when she wants to stop.
- If Jenny stops working at the café she may still like to go as a customer so that she can see Anna and other friends.

Monday



Signs at the right height for Jenny can help her find her way to the toilet.

Jenny is not very tall. Signs need to be at her eye level showing the way in and out of the toilet.

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Tuesday

On Tuesday Jenny goes to a resource centre but she is always tired.

Sometimes she is late for the minibus because she takes a long time to get dressed.

Jenny doesn't always remember which clothes to put on first.

She doesn't always remember how many clothes she should be wearing.

Jenny finds it harder to get dressed. She takes a long time to get ready on a Tuesday morning.

The minibus waits for her, but Jenny finds it harder to climb up the steps.

George sometimes gets annoyed waiting for her and tells her to hurry up.

When she gets to the resource centre, Jenny doesn't like the noise.

George sometimes gets annoyed when Jenny takes a long time to get into the minibus. She is finding it harder to climb the steps.

Tuesday

We can help:

- Brighter lighting, or more natural light, in her bedroom can help Jenny to see her clothes. Giving Jenny fewer choices of outfit will help her to make decisions.
- Staff or family can put Jenny's clothes out for her in the right order each morning.
- Staff or family may need to spend more time with Jenny to help with personal care.
- It may be possible for Jenny to get the minibus to the resource centre later in the day and arrive when it is a bit quieter.
- Jenny may not like moving between rooms or activities at the resource centre. She may prefer to sit in a quiet area and do something that she likes.
- Eventually Jenny may stop going to the resource centre. When this happens, friends can be supported to visit her.
- Jenny can talk to her friends on the telephone, or on the computer or iPad.

Jenny may prefer to sit quietly doing something that she enjoys.

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Tuesday

It is important for Jenny and her friends to keep in touch with each other, even if she stops going out as much.

With support, Jenny can use different kinds of technology or social media to keep in touch with friends.

Tuesday

Jenny can continue to talk to her friends and family using a laptop with a webcam and microphone.

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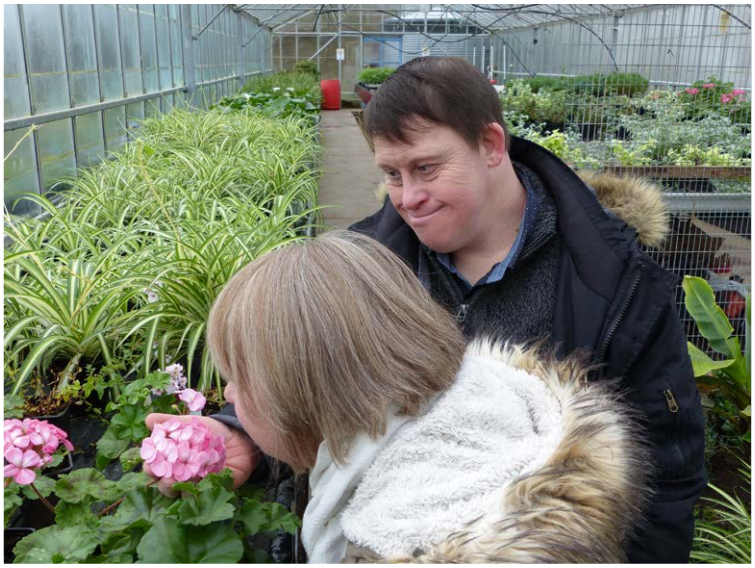
Wednesday

On Wednesday morning Jenny and George volunteer at a garden centre. Jenny enjoys working in the gardens and in the greenhouse.

Jenny and George enjoy working together at the garden centre.

Being outdoors in sunlight or natural light can help people with dementia sleep at night.

Jenny likes growing flowers and wants to keep volunteering at the garden centre.



Wednesday

Jenny finds it hard to go up and down the steps to the greenhouse and this makes her upset.

Sometimes she shouts at friends when they try to help her.

This happens at home too.

She stands at the top or bottom of the stairs but doesn't move.

Jenny finds it hard to go up or down steps and stairs.

Jenny is more confident going up or down steps if George holds her hand to help her.

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Wednesday

We can help:

- Encourage Jenny to keep doing things she enjoys.
- People with dementia can find it harder to go up and down steps or stairs because their depth perception has changed. This means that Jenny can't tell if a step goes up or down. She doesn't want to move because she is afraid she will fall.
- Jenny might feel more confident if George or someone else holds her hand.
- It will help Jenny if there are contrasting colour strips (paint or tape) on the edge of each individual step or stair. This will highlight the change from flat surface to step.
- At home a handrail that is a different colour to the wall is more visible. Contrasting coloured wall switches are also more visible and easier to locate.
- Improve the lighting indoors and at home. Jenny may avoid dark areas in corridors and rooms. She may be more confused as it gets darker. Lightning should be even to minimise shadows and free from glare.

Thursday

On Thursday evening Jenny likes to play games or look at magazines.

Jenny likes to sit quietly and look at magazines.

Sometimes she says the same thing over and over again.
She doesn't always remember how to play games that she used to enjoy.
Jenny gets confused and upset when it is too noisy.

Jenny doesn't remember how to play games that she used to enjoy.

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Thursday

Sometimes Jenny holds her stomach.
Linda and George don't know why.

Sometimes Jenny can't tell us if she is in pain. We might know by looking at her.

Thursday

We can help:

- Playing games or watching television might be too noisy. Jenny might like to do something quieter. She likes wearing nail polish and enjoys painting nails with Linda.
- Jenny may prefer to listen to her favourite music, but not all the time as this might cause agitation or distress.
- Many of us enjoy collecting our own pictures, photographs or personal items in a memory box or photo album. Jenny likes to look at her memory box with Linda.
- Not all changes are because of dementia. If Jenny gets more confused very quickly this is probably caused by an infection, or not drinking enough water. It is not likely to be because she has dementia.
- Jenny may shout because she is in pain. She may have stomach ache for example but is not sure how to tell us. She may not be taking medicine that can help her.
- Jenny's face can sometimes tell us if she is happy, sad or in pain, even if she is not able to talk about how she is feeling.
- Jenny needs us to pay attention to all of the ways she communicates, not just what she says.
- It might take Jenny longer to find the right words. She may mix up her words. It is ok to sit and wait quietly with her while she thinks about what to say.
- Using headphones will allow Jenny to focus on her favourite music and can cut out any distraction.
- If friends are upset or angry with Jenny, it is important to talk to staff or family.
- Try not to argue with Jenny. Just like all of us, Jenny has good days and bad days.

Jenny likes to wear nail polish and to paint her sister Linda's nails.

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Thursday

It is important for Jenny to keep doing things that she enjoys.

Jenny likes listening to music and singing along to her favourite songs or playlist.

Friday

On Friday Jenny likes to have lunch at the café with George.
Jenny is getting more confused about how to order food.

Jenny enjoys going to the cafe with George when she is not working.

She has started to cough more when she eats.
George is worried because it looks as if Jenny is choking.

Eating and drinking are getting harder. Jenny may cough more when she eats to stop food and drink going down the wrong way.

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Friday

We can help:

- Having dementia means that Jenny might find it harder to eat, drink and swallow.
- Jenny may prefer to go to the cafe at a quieter time of day when it is not noisy.
- Smaller meals eaten more often are better than one or two large meals a day. This is due to difficulty in concentration, poor appetite and changes in how food tastes.
- Remind Jenny to sit upright when she is eating and drinking. This means that she won't cough or choke as much on her food or drink.
- Jenny might forget how to use a knife and fork. She can be reminded to eat by putting cutlery in her hand. We can put our hand over hers as she uses the cutlery to act as a guide.
- Jenny may be confused by what we are doing or saying. Using short sentences when we talk can help.
- Having dementia means that it may get harder for Jenny to chew and swallow food and drink. The muscles that control swallowing in her mouth and throat do not work so well.
- Jenny may cough more to stop food 'going down the wrong way'. She may be short of breath after eating or drinking. She may keep food in her mouth instead of chewing and swallowing it. All of this means that Jenny is at risk of getting aspiration pneumonia and losing weight.
- Jenny might need to see a Speech and Language Therapist if she has a lot of difficulty with eating, drinking and swallowing. They will tell Jenny what food and drink is safe for her. She might need thickener in her drink. It may also help to have food cut up small or pureed.
- There are different types of thickened food and drink. Some are a little bit thicker, others are very thick and need to be eaten with a spoon.
- People with dementia can forget to eat or drink. Food with a strong smell or taste can be more appealing as it may stimulate appetite.
- A dietitian will make sure that Jenny has enough food and drink each day and is getting the vitamins she needs.
- Jenny and George can still enjoy spending time together. Part 3 of this booklet will support staff and family to talk to George about what is happening to Jenny.

Friday

Soup might be easier for Jenny to eat. Small meals eaten more often are better than a large meal.

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Saturday

On Saturday Jenny walks to the shops.

She goes into the same shop and buys a magazine every week.

Lately she has been taking a long time.

Sometimes Jenny gets lost when she is walking home.

She has started saying that she doesn't want to go to the shops anymore.

She stands at the side of the road and doesn't like to step down onto the road.

Crossing the road is getting harder. Jenny is not sure if this is a step up or down.

Saturday

This happens at home when Jenny steps between rooms.
She sometimes looks as if she is scared to walk through doorways.

Stepping through doorways is getting harder. If the flooring is a different colour Jenny thinks that there is a step.

Jenny keeps asking her sister Linda, 'What's wrong with me?'
She knows that something is wrong but doesn't know what it is.

Jenny knows there is something wrong but she doesn't know what it is. She can talk to her sister Linda about it.

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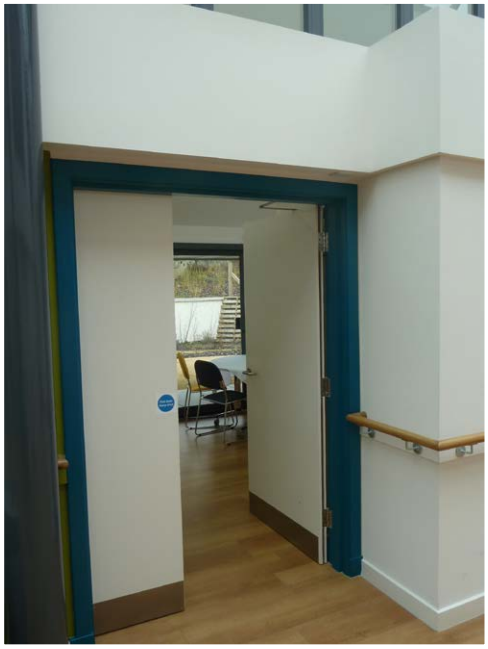
Saturday

We can help:

- Poor eyesight, loss of vision in one eye or reduced lighting can also make it hard for Jenny to walk up or down stairs or steps. This might not be caused by dementia.
- Changing some of the furniture or flooring at home can help Jenny to cope altered with depth perception. For example it can be easier to walk between rooms if the floor and carpets are the same colour.
- Door frames in a different colour can make an entrance or exit more visible.
- Staff, family or friends can go with Jenny to the shop.
- Some people with dementia use a tracking system to let staff or family know if they are late or lost. An example of this is a watch or mobile phone that has GPS (Global Positioning System). Jenny can put this in her pocket or bag when she goes out. She will need reminding to take it with her.
- Eventually Jenny may need to get the magazine delivered to her house so that she can still enjoy looking at it.
- Walking in a safe area, such as a garden, is still important if Jenny stops walking to the shop.
- Part 2 of this booklet will help staff and family talk to Jenny about what is happening to her.



The same flooring in different rooms makes it easier to walk through doorways. Door frames in a different colour make an entrance or exit more visible.

Saturday

Jenny can get her magazine delivered if she finds it hard to walk to the shops.

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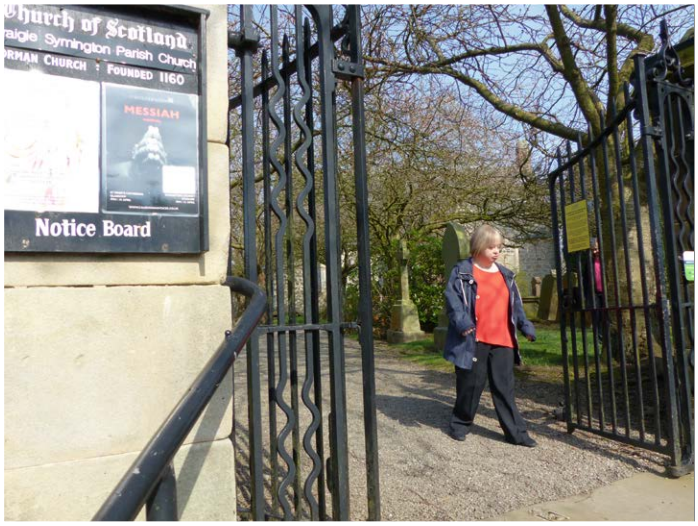
Sunday

On Sunday Jenny goes to church.

She enjoys singing and helping with social events.

Now she says that the service takes too long and she sometimes goes home early.



Jenny does not enjoy going to church. Sometimes she leaves church early because the service takes too long.

We can help:

- Find out if the service can sometimes be shorter or plan for Jenny to leave when there is a natural break.
- Jenny can still be given a role at social events so that she feels valued.
- Sing hymns at home.
- Staff or family can find out if someone from the church can visit Jenny at home. This applies to a synagogue, mosque or Gurudwara as well as a parish or congregation.
- Watch religious programmes on television with Jenny or listen to music.
- Jenny may want to go to church at different times during the week when it is quieter.
- Dementia awareness training may be welcomed by all faiths.
- Recognise that spiritual needs are not only met through religion, but as part of wider holistic care.

Sunday

Jenny enjoys listening to religious music at home.

Jenny may prefer to go to church at different times during the week when it is quieter.

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Part 2

Talking to Jenny about her diagnosis of dementia

This part of the booklet suggests a 4 step approach to help a person who has an intellectual disability understand their diagnosis of dementia. We recommend that every organisation has a policy on how to talk to people with an intellectual disability about a health diagnosis.

In the photographs and postcards, Jenny is talking to her sister Linda about the changes she has been experiencing.

Step 1: Find out about Jenny's current framework of knowledge

New information will only make sense to Jenny if it fits with her current framework of knowledge. You will need to find out as much as you can about how much she remembers about her past, the extent to which she understands what is happening today and how far she can plan ahead.

Separate this into Jenny's understanding and experience of the following:

- background knowledge
- what she thinks is happening to her right now
- what she thinks will happen in the future

You could start by writing down what you know. Discuss this with Jenny, and with as many people as possible who know her.

This can be part of building up Jenny's life story. Life story work can help to understand Jenny's past experiences, significant relationships and previous changes or loss in her life. This can be shared, as appropriate, between Jenny, Linda and other family members and her current or future carers.

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Here is a simplified example of how awareness of Jenny's life history can contribute to an understanding of her current framework of knowledge.

Step 2: Decide which small, separate pieces of information will be simplified for Jenny at the current time.

A seemingly simple statement such as, 'You have dementia' is actually very complex and may not be the most appropriate way to share information about the diagnosis. Here are some examples of how it can be simplified:

- Build on the background knowledge that Jenny has. For example, if a family member or friend has dementia she may know that it is an illness of the brain
- Focus on knowledge about the immediate implications on a day to day basis and anything she is worried about, for example, 'I can't find the toilet and it scares me'
- Decide if Jenny is able to cope with discussion of future changes, for example, 'Dementia is likely to get worse, not better'

Jenny is learning that she has an illness.

You need to decide with Jenny:

- What is the most important information for her right now on a day to day basis?
- What parts of Jenny's background knowledge do we need to build upon?
- What parts of her experience of the present does she need help to understand?
- How much does Jenny need to understand about the future?

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Step 3: Give Jenny the new pieces of information one by one, fitting in with her current framework of knowledge.

Often, the most important thing is for the person to make sense of the current changes in their life. For example, not understanding why she can't find the toilet or why she is struggling with the stairs is frightening for Jenny. She has indicated this by asking, 'What is wrong with me?'

At this stage, it will help Jenny to understand that these changes and difficulties are caused by dementia, or because she is ill. She can probably understand this with careful explanations.

How small the chunks of information need to be will depend on the individual. If Jenny has friends or relatives who have, or had, dementia, then saying, 'You have dementia' will have some meaning. The focus can then be on the implication of the diagnosis and what it means for her. Jenny needs help to build up her background knowledge about dementia. It will reassure her to know that getting things wrong is not her fault, and that family, friends and staff will help her. She may have her own ideas about what this help should be.

Use words that Jenny can understand and relate to. This may be, 'Your brain isn't working' or, 'Your brain is broken'.

If Jenny cannot grasp the concept of her brain making her ill, then it is unlikely to be helpful to convey this information. You may need to simplify it to, 'You are not well' and, 'It is not your fault'. Stick with words that Jenny knows and understands.

You will need to decide whether it is important for Jenny to address her perceptions of the future, some of which may be wrong. This is important as there may be choices to be made, including staying in employment, voluntary work, attending the day service or a change in accommodation, such as moving to a downstairs bedroom.

If Jenny is supported to think about such issues soon after a diagnosis of dementia, then you will have helped her to understand her future situation. This way, she can be involved in her future care planning.

If Jenny finds it hard to talk about how she is feeling, a communication tool such as Talking Mats ™ can help.

Looking at pictures, such as the ones in this booklet, can help. George can be encouraged to help too. For example when she is struggling with the stairs he can say: 'Never mind Jenny, that's your brain not working. Shall I hold your hand?'

It is important that others in the café, the resource centre and the garden centre are all aware of what Jenny knows and understands.

Everyone should use the same words to describe her illness and to talk about the chunks of information she has been given. The words used should be written down and shared for consistency.

Everyone can help Jenny to build her framework of knowledge although what is 'current' for Jenny will change as dementia progresses.

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Step 4: Check and reassess

Keep checking with Jenny if she still understands what she has been told, whether she needs to understand more, or if something different is needed.

Things change all the time and even more so when someone has dementia. You are trying to build up Jenny's framework of knowledge, but dementia is breaking it down. Rather than Jenny's knowledge and understanding growing, it will start shrinking. You will need to re-write Jenny's framework often. This is what might happen:

- **Jenny's grasp of the future will gradually fade.**

You will need to keep assessing how much of the future she understands, and how much she wants or needs to understand. She may only need to understand what is happening today or this week, perhaps with the help of a pictorial diary. Eventually Jenny's experience of life will shift completely to the present moment.

- **The boundaries between 'background knowledge' and 'what is happening right now' may become blurred.**

A particular feature of dementia is that older memories can become an experience of the present day. Jenny's memory, ('I used to make tea for my dad') can become a reality right now for her, ('I need to make a cup of tea for my dad'). If this happens, there is no need to put that piece of knowledge back into her past, by saying, 'No, your dad has died; you don't need to make him tea' as this doesn't fit in with her new framework of knowledge. Jenny will keep forgetting that her dad has died, so correcting her can cause unnecessary confusion and distress. Instead, you can affirm her experience, 'Yes, your dad always liked his tea. It's nice you are thinking of him' and then change the subject, 'Perhaps George would like a cup of tea?'

Part 3

Talking to friends about dementia

This part of the booklet is about George, Jenny's boyfriend. The aim is to enable staff or family to talk to a person with an intellectual disability about what it means when their friend, partner or relative has dementia.

In the photographs and postcards, Linda, Jenny's sister, is talking to George.

Understanding Dementia

George wants to understand why Jenny is behaving differently.

Jenny may not be able to learn many new things. George, and other friends such as Anna at the café, can help Jenny to keep doing the things she enjoys. Having dementia means that Jenny may:

- forget things
- find it hard to understand what George is saying
- not concentrate as much
- not always use the right words
- behave differently

We all forget things sometimes. If George forgets something it is important for him to know that this does not mean he has, or will get, dementia.

Our brain helps our body to work properly. It helps us to move and speak. Our brain tells us what to do even if we don't realise it. Dementia is an illness of the brain. The brain gets muddled and doesn't give our body the right messages.

Watchman, K. Tuffrey-Wijne, I. & Quinn, S. (2015) *Jenny's Diary: A resource to support conversations about dementia with people who have a learning disability*. London, Alzheimer's Society.

When Jenny forgets George's name she isn't doing it on purpose. It is her brain sending her the wrong messages. This can sometimes make Jenny confused, upset or angry. It can also make George upset.

It is hard for George to hear that Jenny is ill. Linda is talking to him about how they can both help.

Knowing what dementia is can help George to understand why Jenny does some things differently. Jenny will still be his girlfriend.

Jenny and George are still boyfriend and girlfriend.

When Linda talks to George, she uses the same words she used when she talked to Jenny. Just as Jenny needs increased support as dementia progresses, so too will George, and others who care for and about Jenny.

George is learning that dementia is an illness of the brain, in the head.

How do we know if a friend might have dementia?

Jenny had a baseline assessment a few years ago. This means that someone who knows Jenny well filled in a form about her preferred activities, routines, accommodation, sleep pattern, weight and general health. A baseline assessment is not a test and does not hurt. It is a way of helping to understand changes over time.

Every year the same questions can be asked again. If possible the same person who knows Jenny well will help to answer the questions with her. This is called screening and is to find out about any changes. The changes may not be related to dementia. Screening can identify other, treatable, health-related changes.

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Jenny and Linda are looking at a screening tool. This is to find out what has changed for Jenny since her baseline assessment.

Not all changes mean that Jenny is ill. Some changes happen to us all when we get older. For example, our hearing or eyesight can change. Often, this can easily be helped. We may need to talk to a doctor or nurse, or get new glasses. Most changes as we get older are not due to dementia.

The most important thing is for Jenny to feel safe and supported. Your first question should always be:

'What can we do to help Jenny to be less confused and less frightened?'

Often, she will simply need help and support with managing her life. The practical tips in this booklet can help. In addition, Jenny needs help to understand the changes and to make sense of them. This is an approach that family, friends and staff can, and should, take proactively and consistently.

Thank you to our actors:

Sara Watt who plays the part of Jenny, Margo McConchie who plays the part of Anna, Colin Johnstone who plays the part of George and Kay Bell who plays the part of Linda.

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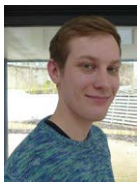

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Further information

- Watchman, K. (2014) *Intellectual Disability and Dementia: Research into Practice*. London, Jessica Kingsley Publishers.
- Tuffrey-Wijne, I. (2012) *Breaking Bad News*, London, Jessica Kingsley Publishers.
- Watchman, K., Kerr, D & Wilkinson, H. (2010) *Supporting Derek: a practice development guide to support staff working with people who have a learning disability and dementia*. London, Joseph Rowntree Foundation/University of Edinburgh

Online information:

- Alzheimer's Society learning disability and dementia factsheet www.alzheimers.org.uk/factsheet/430
- National Task Group Early Detection Screen for Dementia http://aadmd.org/ntg/screening
- Talking Mats™ communication tool http://www.talkingmats.com/
- Website about breaking bad news to people with learning disabilities: http://www.breakingbadnews.org/
- Website about learning (intellectual) disability and dementia: www.learningdisabilityanddementia.org

Jenny's Diary was developed in collaboration with Hansel, Ayrshire, Scotland, UK. Hansel is proud to have been innovatively supporting the rights and choices of people with learning disabilities in Scotland since 1963. With a strong commitment to the values and principles of the person-centred approach Hansel offers around 700 people each year the opportunity to co-design personally tailored community-centred lifestyle supports, including offering a specialist small group living environment for the older person living with a learning disability and dementia. For more information please visit www.hansel.org.uk

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Available online at www.uws.ac.uk/jennysdiary

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