

# Talking Together

Facilitating peer support activities to help people with learning disabilities understand about growing older and living with dementia



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foundation for  
people with  
learning disabilities

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# Introduction

## Background

The fact that people with learning disabilities are living longer raises many questions about how they can be supported to have a good life with opportunities to be involved and connected with others into old age.

One challenge posed by this increased longevity is that they are more likely to develop illnesses associated with ageing, including dementia, and potentially become more isolated and lonely. People with a learning disability are at greater risk of developing dementia compared to the rest of the population and the risk is significantly higher for people with Down's syndrome.

More needs to be done to help them understand the changes associated with the ageing process and dementia. This is particularly important because, with the move from residential care to supported living, more people are living in shared houses in the community and will need support to cope with dementia if they or one of their housemates develop the disease.

## Purpose of the handbook

The overall purpose of the handbook is to help people with learning disabilities experience a greater sense of well-being as they grow older. An important aspect of this is looking at positive ways of supporting people who develop dementia as well as those whose friends or housemates are living with dementia. The handbook describes how to run facilitated peer support groups where people use their understanding and experiences to help each other.

There are 20 participative activities that will engage people to think and talk about the changes that may occur as they get older, including developing dementia, thus increasing their understanding of the process and providing the opportunity for peer support. They help to explain that someone with dementia cannot help their behaviour and also provide strategies to make life easier.

### The benefits of a peer support approach are:

- People who have lived with a learning disability and have experience of being excluded and judged often feel empathy with others in the same position and a willingness to understand about developing dementia.
- It provides an opportunity for people with learning disabilities to positively contribute to others' lives rather than solely being the recipients of support.
- Participants can shape the group and gather and share useful information from their peers. This enables them to have some choice and control over their life, which in turn encourages them to maintain as much independence as they can and want to have.
- People with learning disabilities often rely on paid supporters rather than a mixed network of formal and informal support; peer support has the potential to increase social interaction and therefore reduce isolation.

### The benefits of an activity-based approach are:

- Activities create opportunities to gather information in many different ways – this is important as people differ in the way they receive and remember information.
- Activities provide an opportunity for people in the group to socialise together and form relationships that can be built on outside of the meetings, thereby reducing potential feelings of loneliness.
- People are more likely to feel empathy if they participate in an activity than if they are simply told something (for example what it is like to live with dementia).

The peer support activities aim to promote discussion and understanding. They should provide an opportunity for thoughts and feelings to be acknowledged and explored, and generate ideas for practical ways to help people cope with any changes as they grow older. They may also have the additional benefits of aiding earlier diagnosis of dementia and of improving staff understanding about growing older and living with dementia.

## Who is the handbook for?

The activities in the handbook can be used and adapted by anyone wanting to support people with learning disabilities as they grow older but key people are likely to be:

- Staff working in supported living, residential care services or extra care housing
- Staff providing daytime activities or working in day centres
- Health practitioners in Community Teams for People with Learning Disabilities
- Staff working in community centres providing activities for older people who are aiming to be inclusive of those with learning disabilities
- Personal assistants (who may adapt the activities to facilitate conversations about growing older)

## Piloting the activities

This project involved running group sessions in two places: a shared house for six people with learning disabilities where one of the housemates had developed dementia and a small day centre for older people with learning disabilities where one person had dementia.

The groups evolved in different ways in response to the experiences and concerns of the people taking part; the activities that we introduced aimed to address the specific issues that people were experiencing. They were also influenced by the level of understanding people had and how well they knew and related to each other.

When talking to people about joining the groups we didn't emphasise the need to be over a certain age but rather the fact that we were going to be thinking about growing older; people's interest in taking part was what mattered most.

The tenants in the shared house had only been living together for just over a year but had a sense of caring and thinking about each other. They were mostly in their 50s and 60s. One of the tenants had developed dementia, which had become apparent only after he moved into the house, and the others were, at times, finding it difficult to understand the nature of his illness and the changes in his behaviour.

The people in the second group were more diverse in their experience and understanding: some were living at home with family and others in residential and supported living services. Their common experience was going to the day centre a number of days a week. They had a variety of needs around growing older: problems of ill health, dementia, caring for an elderly parent and feeling stressed in noisy environments. In both groups, support staff were involved in the sessions, and sometimes followed up ideas between the meetings.

The groups were co-facilitated by Cindy Glover and Christine Towers. Cindy had previously led a project at the Mental Health Foundation on self-help groups for people with dementia living in sheltered accommodation. Christine Towers was leading on a number of projects about people growing older at the Foundation for People with Learning Disabilities and was aware that more and more people with learning disabilities were living with others who were developing dementia.

# Running a peer support group

## Facilitation

It is preferable to have two people co-facilitating a peer support group as this enables shared responsibility for listening, recording and adapting the planned activities during a session, and helps when evaluating it afterwards. If co-facilitation is not feasible, it would be useful for the facilitator to have someone external with whom to debrief, discuss the group and share ideas.

It is important to facilitate a group in a manner that gives people choice and control over what happens when they meet, thus providing them with a sense of ownership of the group.

Flexibility is key to the success of the group. Listening to people's experiences, worries and ideas and adapting the activity according to their needs will help everyone to be engaged and get as much as they can or want from the sessions.

## Starting a group

The process for starting a group will depend on your role in relation to the potential members. You may already know the people you are asking to be part of it or you may be approaching people you have not met before. It is important to spend time with them before setting up a group to find out about their experiences and what they would like to get from meeting.

They should not feel it is something they have to take part in because they have reached a certain age. They may like the opportunity to try a 'taster' session to see whether they like it. Initial discussions should emphasise the peer support aspect of the group; i.e. that the people who are part of it will help to shape it and learn together rather than the facilitators coming in with answers.

**Once you have a number of people interested in meeting together there are some practical issues to address:**

- How many people should ideally be involved in the group to allow discussion but still enable everyone to feel involved?
- How do people like to communicate and what would help them to feel comfortable?
- What would work best in terms of time and place?
- This information can be gathered from possible participants as well as support staff and managers.

## Planning a session

There is a template in Appendix 3 to assist you with the planning of a session. However, your plan should remain flexible so that it responds to what people want to talk about and the time you have available. This structure worked well:

- An introductory section that included saying hello and checking out how people are, recapping on the last session and explaining the plan for the current one
- A main activity lasting approximately 40-50 minutes
- A break with refreshments and a chance to chat
- A short activity
- A reflection on the session

Alternatively, the short activity could take place first and you could have a break during the main activity. You may want to have two breaks depending on people's needs and the time available. The above structure takes approximately two hours.

It is important that each session has an element of enjoyment or laughter and that the types of activity vary (discursive, creative, using different learning approaches and appealing to different senses).

Food and drink contribute to the social feel of the group and provide an opportunity for people to talk about their favourite cakes, fruit or snacks.

When arranging a session it is helpful to let others in the building know the timing in advance so that there are as few disruptions as possible.

## At the start of each session

- Check that people understand a little about the reason for meeting up and are happy to be involved in the session.
- Ensure the room is set up correctly with everyone able to see and hear each other and feel comfortable.
- Check that people attending have all the necessary equipment with them in order to fully participate: hearing aids, glasses, magnifiers etc.
- Ask for mobile phones to be switched to silent.
- Begin with a welcome and check out how everyone is (is anyone feeling unwell, had a bad week, done something special...); one person's worries can affect the mood of the whole group.
- Recap on the purpose of the group and what you have already talked about together.

## Ideas to help people feel engaged

- Address people by their names when you ask them a question.
- Remember that people often need time to process information so keep sentences short and clear.
- Some people will take longer to reply – make sure those who need more time are given it.
- Questions can be rephrased so that people have more than one opportunity to understand what is being asked.
- Keep the atmosphere of the group relaxed and supportive.
- Provide plenty of opportunities for people to offer ideas and comments using questions like 'what

do you think about what we have just talked about?'; 'would you like to talk about this a bit more next week?'; 'how do you feel about that?'

- Use visual prompts, such as photographs and objects, as much as possible and look for opportunities to use other sensory prompts.
- Be prepared to be flexible and adapt the session according to people's engagement.

## After each session

Use the last 10-15 minutes of each session to reflect with the group on how the session has gone and to plan for the next one. This is important because it ensures people feel that they can shape the group to work for them and because the experiences of the group members can help to improve future sessions.

- Talk about what people enjoyed.
- Ask people what they found helpful and/or unhelpful.
- Check whether they would like to change anything, for example the timing or venue.
- Check whether people would like to talk about anything touched on in the session again.
- Ask the group what they would like to plan for the next time and make suggestions or give options.
- Ask what refreshments people would like to choose for the following session.

It is a good idea for facilitator(s) to spend some time reflecting on what they felt worked well or didn't work well in the session. They should keep notes about what was covered, how it went and information gathered from group members so that it can be referred to in the future.

## Ideas for activities

The activities described in this handbook provide ideas for initiating conversations about growing older. Some also look at living with dementia. Some of the activities help people to get to know each other (useful even if they have known each other for a long time); others help them to understand the

changes they are experiencing or provide practical ideas and strategies for them to try.

Each activity includes a summary, a list of aims, preparation details and ideas about how to facilitate the session. The length of the activity will depend on how many people are in the group and how much time they would like to think and talk about things, so the time given is only for guidance.

The activities can be done more than once; we found that people enjoyed returning to them through recapping and adding new ideas and comments. This gives people an opportunity to think about a topic between sessions and develop their ideas and knowledge.

Many of the activities can be extended according to the interests of the group; for example the activity on relaxation (16) could be extended to design a card or sign that indicates to others that they want to be left to relax.

## Issues that may emerge

### Concerns about early stages of dementia

Being part of the group may lead people with learning disabilities, a member of staff or a facilitator to be aware that a person is showing signs of the early stages of dementia; for example they may talk about feelings of confusion or how they find it more difficult to do familiar things.

Changes like these may be caused by health problems other than dementia, such as a thyroid condition, a urinary tract infection or depression. However, if there are any concerns it is important for the person to visit their GP or to speak to someone in the Community Learning Disability Team.

### Concerns about poor practice or abuse

While running the group you may see or hear things that raise concerns about abuse or poor practice in the way a person is being supported. Depending on the nature of your concerns, you should speak to an appropriate manager or look online to find out how to report your concerns according to the local safeguarding adults process.

# Activity 1:

## Agreeing how to support each other in the group

### Summary

This is an activity to use at the beginning of the first session to create a discussion among group members about how they would like the group to run so that it is supportive and everyone feels comfortable. It helps people to feel they can shape the group. The activity can be returned to at the beginning of subsequent sessions.

### Aims:

- For the people in the group to develop a shared understanding of how they would like to support each other
- For the people to take responsibility for how they would like to behave with each other

**Preparation time:** 15 minutes

**Length of activity:** approximately 20 minutes

### You will need:

- Two cards for each member of the group: a red one with a cross and a green one with a tick (preferably on a stick – see tips below)
- A list of suggestions about how people would like to support each other in the group (ideas in point 4 below)

### Method:

1. Let the group know that it is their group and that it is important it works well for them. Explain that it is important that everyone in the group feels comfortable and safe to talk. Also, that everyone has space to talk and will be listened to. Explain that in order for this to happen, the group is going to think about how they would like to behave with each other.
2. Give each person a green tick and a red cross and explain that the green tick means you agree and red cross that you don't agree.
3. Explain that you are going to suggest different ways of behaving with each other in the group and would like people to say whether or not they agree with them. Point out that there is no right or wrong answer.

4. Use the list below to go through different ways of behaving with each other. Read out one point at a time and check people understand what it means. Ask them to hold up the green tick if they agree with the suggestion or the red cross if they don't agree with the suggestion. Explain again that it is okay to agree or not agree. Prompt each person if necessary to make their choice.

### Suggested points to talk about:

- Do people need to be kind?
  - Do people need to try to understand each other?
  - Should people be given time to speak?
  - Should people listen as well as talk?
  - Should people speak one at a time?
  - Is it okay to be late?
  - Is it okay to have different feelings in the group, for example, to be sad or happy?
  - Is it okay to say you don't like doing something?
  - Is it okay to get up and move around?
  - Is it okay to be quiet?
  - Is it okay to shout (it may be if someone is deaf)?
  - Is it okay to look at or use your phone?
5. Ask at the end if there is anything that has not been said that people would like to add.
  6. Summarise the decisions made by the group.

### Tips

The design of the ticks and crosses was worked out over a few weeks to suit the group. Initially they were on cards but these were not easy to handle: a group member living with dementia thought it was an envelope and was keen to look inside and another person was possibly colour blind. The group therefore chose to have them circular in shape and on sticks but it is important to work out what would work best for your group.

# Activity 2:

## The meaning of names

### Summary

This is a relaxing and fun activity involving talking about people's names by looking at what they mean. It is a good introductory activity that can be returned to, and developed, during other sessions.

### Aims:

- For the group to get to know each other, relax and possibly find out something new and different about themselves or each other
- To build a sense of individuality that can get lost as people get older

**Preparation time:** 10 minutes to research the names of people in the group

**Length of activity:** approximately 20 minutes

### You will need:

- Access to a book of babies' names, or the internet, to search for the meaning of names (suggested site: [www.babynames.com](http://www.babynames.com))

### Method:

1. Explain that names usually have a meaning and are often chosen by parents because of their meaning. An example is that the name Philip means 'friend of horses' and Sidika means 'truthful'.
2. Look up the meaning of each person's name in turn. Talk about the meaning of their name; some words may need explaining. Ask the group whether the name matches what they know about the person. Be positive and affirmative about the qualities of the person in relation to their name and look for examples that show how their name reflects them as a person.

### Tips

You may be able to get a names book from the library or in a second-hand book shop. Ensure that you are able to provide meanings for all the names including unusual ones; if it is not in the book then search for the meaning beforehand to make sure the person does not feel left out. In future sessions you can return to what was learnt in this activity, particularly if someone does something that reflects their name.

# Activity 3:

## Why do I have my name?

### Summary

This is a short extension to Activity 2 that gives people an opportunity to talk about their family life. It could be used as a warm-up activity at the beginning of a session once Activity 2 has been done.

### Aims:

- For people to have an opportunity to talk about their personal history
- For people to learn more about each other, particularly about their families and early life

**Preparation time:** none

**Length of activity:** 15 minutes

### Method:

1. Remind the group about the activity looking at the meanings of their names and ask people if they remember what their name means.
2. Ask each person in turn whether they know who chose their name and whether there was a reason for choosing it. People may talk about relatives or film stars they were called after or disagreements between parents over choosing a name.
3. Encourage people in the group to ask each other questions or comment on what each other says.

# Activity 4:

## If I could change my name

### Summary

A short, relaxing extension to Activity 2 that gives people an opportunity to talk about whether they like or dislike their names and whether they wish they had a different name.

### Aims:

- For people to relax at the start of a session or after a more intense activity
- For people to learn more about each other
- To encourage people to talk to each other about what is important to them

**Preparation time:** none

**Length of activity:** 15 minutes

### You will need:

- A book of names

### Method:

1. Explain that something we all have is the name we are called by. Some people like their names but others do not.
2. Ask each member of the group in turn if they like their name and, if they could change it, what they would choose to be called.
3. Encourage group members to chat with each other about what they have heard and ask each other questions.

# Activity 5:

## Losing things

### Summary

This is a main activity for a session. It looks at the problem of being forgetful and losing things as we get older and provides some practical solutions.

### Aims:

- To give an opportunity to discuss losing things as one of the symptoms of growing older and particularly for people who develop dementia
- To give an opportunity to discuss the feelings that can occur when we lose things
- To help understand the feelings of someone who lives with dementia and who possibly loses things more frequently
- To look at practical tips for remembering where things are

**Preparation time:** 20 minutes

**Length of activity:** 30-40 minutes

### You will need:

Six drawstring bags each containing one of the following items:

- A bunch of keys (or a key)
- A travel card
- A pair of glasses
- A glove
- A small folding umbrella
- A wallet/purse

### Method:

1. Explain that you are going to give a bag to each person (or two people to share) in turn for them to guess what is inside. Give a bag to one person and ask them not to open it but to feel through the material and guess what it contains. Once they have guessed, ask them to open the bag to see if they are right. If they cannot guess they can ask the person next to them to help.
2. Continue with each of the six bags.

3. Once all the bags have been opened, place all the objects on a tray or table where everyone can see them. Ask the group to think about what all these things have in common. The answer you are looking for is that they are all items that are easy to lose. However, you may also get other answers; people often suggest that they are all found in a handbag.
4. Ask people if they tend to lose the things that were in the bags. Find out what other things they tend to lose. Find out what causes them the most problems when they lose it.
5. Explain that with dementia people often lose things or forget where they have put them, particularly everyday things that we have to move around as we use them and put in bags, pockets or drawers. This is because it is harder to remember things that have happened recently. This activity can lead to a variety of discussions which can be adapted depending on the level of ability within the group:
  - The feelings that occur when they themselves lose something (for example anxiety, upset, worry, depression, frustration, anger) and how they might feel if this happened every day. Help them to understand that this is how someone with dementia might feel
  - Ask people what helps most when they lose something (for example someone reassuring them, helping them look or helping to think back to where they last had it)
  - Ask whether they feel there are things that they could do to help each other
  - If a member of the group has dementia, try to find out what they would find helpful and ask others whether they would be able to help with that

6. Summarise the ideas that are suggested and use the list below to suggest any that have not been mentioned:

- Remember to take things with you by having a checklist of pictures by the front door of a key, travel card, etc.
- Have a special bowl or place where important items are always kept
- Have a spare set of items, for example spare glasses kept somewhere safe
- Help the person to think back to when they last had the item or the last activities they were doing and where they had been
- Give reassurance and try to avoid getting cross
- Help someone to look for an item

### Tips

You may find this activity easier to do if there is a coffee table in the centre of the group. If the group is large you could ask people to work in pairs to guess what is in a bag. If anyone has a visual impairment, pass the objects around once they are out of their bag and before putting them on the tray.

At the end of the session make sure you make a note of the points that people find most helpful so that you can use the information gathered in future activities/sessions. You may wish to split this activity over two sessions to give people enough time to talk; if you do this, start the second session by showing the items that were in the bags.

# Activity 6:

## The visible and invisible signs of growing older

### Summary

This is an activity that works well as a main session and helps people to begin to think about some of the changes that take place as we age. It introduces the idea that some changes are physically visible while others, such as dementia, are invisible.

### Aims:

- To help people understand that a number of changes occur as we age: they may not happen to everyone and will happen to different degrees
- To help people understand that some of the signs of ageing are visible while others, such as dementia, can't be seen

**Preparation time:** 10 minutes

**Length of activity:** approximately 40 minutes

### You will need:

- Photocopied sheets of each of the relevant pictures in Appendix 4 (preferably one for each person – this was found to work better than showing one picture to the group)
- Visual prompts such as a pair of glasses, a walking stick, a hearing aid, a toothbrush, handcream, a Post-it note

### Method:

1. Explain that the group is going to look at the changes that happen to our bodies as we get older.
2. Ask the group what they have noticed happening to their bodies or to those of people they know as they have grown older: what are the changes that they can see? People may talk about how their parents have aged and this can be a useful reference point for those whose parents are still alive. You can look at each other's hands and chat about wrinkles or find out whether anyone has started to wear glasses as they have got older.

3. Use the pictures one at a time to talk about changes that may happen to some people:

- Their eyesight gets worse and they may need glasses
- They find it more difficult to move around and may need a walking stick
- They have problems with their teeth and may have difficulty eating
- Their hearing is not very good and they may need to wear a hearing aid or ask people to shout

As you look at each picture discuss what things could help, for example a hearing aid or a magnifying glass, and use the objects as visual prompts. You could also discuss as a group how you might help that person.

4. Show the picture of the person who looks fine and ask people whether they notice anything is wrong. Explain that he is finding it harder to remember things as he has dementia. Ask people what else he might be finding difficult because of his dementia.

### Tips

Give out one set of pictures at a time and gather each set in at the end of the discussion about each change to avoid confusion. If this activity is too long you could talk about the physical changes in one session and the invisible changes, i.e. the person with dementia, in the following one. If you do this it would be necessary to recap on the discussion about physical changes first.

# Activity 7:

## Good things about growing older

### Summary

This activity provides a contrast to the ones that focus on changes that can make life more difficult as people grow older. It explores instead the good things that can happen and identifies whether there are new things that people would like to try.

### Aims:

- To help people understand that there are opportunities to have a good life as they get older
- To identify the things people would like to do more of or have a go at doing

**Preparation time:** 15 minutes

**Length of activity:** 40 minutes

### You will need:

- Some photographs of older people being busy or relaxing doing a variety of activities (you could use pictures from magazines that you think people would relate to). These could include activities such as sitting in a chair watching TV, going for a walk with friends, gardening, going on a bus ride, having a cup of tea with a friend, doing a gentle exercise class, having a lie-in in the morning, a lunch club for older people, knitting, bird-watching, looking after a pet
- Objects that could be used to do the activities in the photos, such as knitting needles and wool, a TV remote, gardening gloves, a pillow

### Method:

1. Remind people that they looked at the changes that sometimes happen as people grow older and ask if they remember some of them (Activity 6).
2. Ask people what they think has got better in their lives as they have got older (for example do they have more time to themselves, have they got new interests, have they made new friends, can they get up later in the morning).
3. Ask people whether there are things they have that their parents (or older people in the past) might not have had that make their life easier or more enjoyable, such as mobile phones, computer games or going on holidays abroad.
4. Give each person in the group in turn an object and ask them to say whether they do anything that uses this object. If they don't you can ask whether anyone else in the group does. That person can then hold the object and talk about what they do.
5. Show the photograph of someone doing the related activity and ask people whether this is something they would like to have a go at doing or do more of. If you are able to follow it up, you could ask people whether they would like to find out about any local groups where they could do the activity or meet people who share the interest.
6. Make a list of what people say they would like to do as you go through the different activities (you could use a grid that you have prepared beforehand) and summarise at the end what people have said.

# Activity 8:

## Understanding what it is like to live with dementia

### Summary

This is an activity that follows on from Activity 6, using a video clip (from the Supporting Derek pack) which shows Derek's experience of living with dementia (an actor playing the part of someone who is living in a shared house and is struggling to cope). It brings to life the day-to-day difficulties that a person living with dementia has to face.

### Aims:

- To gain a better understanding of what it can be like for someone living with dementia and a learning disability
- To reduce some of the feelings of annoyance that may be felt by friends and housemates
- To develop an understanding about how the environment can make it more difficult for someone living with dementia and come up with ideas to make their life easier

**Preparation time:** 20 minutes (to watch Supporting Derek and become familiar with the sections you want to use)

**Length of activity:** 30-45 minutes

### You will need:

- Supporting Derek DVD or shorter version on YouTube (details in Appendix 1)
- TV and DVD player

### Method:

1. Explain that you are going to watch a film clip in which an actor with Down's syndrome is playing the part of someone living with dementia.
2. Play the section of the DVD that you think would work for the group or play the video clip.
3. Ask people in the group how they felt when they were watching the clip. Make sure that everyone has a chance to speak and share your own thoughts as well. Acknowledge that it can be upsetting to see Derek struggling with his dementia (repeat that Derek is played by

an actor). Check that everyone is feeling okay before continuing with the activity.

4. One by one, discuss some of the different points that the DVD raises:
  - How did all the noise make Derek feel? (this links to Activity 17: Music and relaxation)
  - Why did Derek eat someone else's food? (this links to Activity 10: Choosing a plate)
  - Why did Derek wave to the reflection that he saw?
  - Why did Derek want to go 'home'? (this links to Activity 11: Mother and child)
  - What things could have been done differently to help Derek?
5. You may then want to introduce the idea that changes can be made to the environment (where someone lives, places they go to) that would make life easier. You could ask people whether they ever feel a bit bombarded by things that are going on around them, for example a lot of noise or toing and froing. Ask people if, in a future session, they would like to look at how changes can be made to the environment to make life calmer and easier (you could do Activities 16 and 20).

### Tips

Be aware of the feelings that can be evoked by watching the film clip: most of the people said they had found it hard to watch and some looked and felt sad. After the discussion, the people who shared a house said how helpful it had been to watch the clip as they had a better understanding of how it was for their housemate who was living with dementia.

# Activity 9:

## Understanding the brain

### Summary

This activity follows on from Activity 6 and helps people to understand more about dementia being a hidden disability.

### Aims:

- For the group to understand that there are hidden disabilities that might develop as we grow older, i.e. things we might not see but might cause us to behave differently
- To help people without dementia to understand how different kinds of dementia affect people in different ways
- To help people feel less annoyed by the behaviour of someone with dementia through realising they cannot control what is happening to them and how this makes them behave

**Preparation time:** 10 minutes

**Length of activity:** 30-40 minutes

### You will need:

- Pictures of a normal brain – a copy for everyone or one to share between two people (Appendix 4)
- Pictures of a brain affected by dementia – a copy for everyone or one to share between two people (Appendix 4)
- Photograph of a man with dementia (Appendix 4)

### Method:

1. Show the picture of the man with dementia used in Activity 6 and ask people what they remember about him. Have a recap of the discussion about dementia being a hidden change that happens to some people.
2. Explain that the group is going to be thinking a bit more about what happens to the brain when people get dementia and how changes to the brain affect the way people behave.
3. Show the picture of the complete brain (Appendix 4) and ask people to identify what the picture might be. Explain that all our brains look like this but that some people's brains change as they grow older. This is something we can't see on the outside (like wrinkles) so it can be harder to understand it is happening.
4. Depending on people's ability to understand, you could talk a bit about the brain and explain how different areas control different parts of our bodies.
5. Show the picture of the brain that has blank spaces. Explain that in this picture:
  - There are blank spaces where the brain is not working properly
  - There are different kinds of dementia that affect different parts of the brain – the parts of the brain that are affected will show as blank spaces
  - The problems that someone with dementia experiences will depend on which part of their brain has the blank spaces
  - You can go on to explain that if the blank spaces are at the side, the person might have more problems with their memory and remembering things; if they are at the top, the person may have a problem with speech; and if they are at the front, the person might seem thoughtless or do something you don't expect them to do. Give people time to talk about this.
6. Discuss how it might feel to forget what you are doing or what you are saying, or not remembering things. How would you feel if that was happening to you?
7. Ask people what they think would not be helpful to someone who couldn't remember something or was repeating themselves. Discuss how you might be able to help that person. Explain that it will not help the person to remember by getting cross or shouting at them; the part of the brain that helped them do that is no longer there. You could explain this by comparing it with asking someone to climb a ladder if they no longer have the use of their legs.

## Tips

A useful bookshelf analogy about the loss of memory is used by Dementia Friends and the Alzheimer's Association. This analogy could be used with pictures to help people understand about the loss of memory.

It should be told as a story using the bullet points as a guide.

- The books on the shelves are full of memories.
- The books/memories are arranged in time order on the shelves.
- The oldest memories from childhood (i.e. long-term memory) are on the bottom shelf.
- The newest memories, such as where you have put something or someone you have recently met (i.e. the short-term memory), are on the top shelf.
- In the shelves between there are memories from the years between childhood and the present day.
- When you don't have dementia it is easy to find the right book to find the memory you are looking for.
- Dementia makes the bookshelf shake and books begin to fall off; the books that fall first are on the top shelf. Those memories are lost.
- To begin with only some of the books on the top shelf will fall but over time they will all fall.
- As dementia progresses the next shelf down will lose some of the books.
- This may keep on happening until the only memories that will be left are from when someone was young.

# Activity 10:

## Choosing a plate

### Summary

This activity gets people thinking about the difficulties of day-to-day life for a person with dementia. It highlights one of the challenges shown in Activity 7 in a hands-on way by looking at food on a plate.

### Aims:

- To develop an understanding of how dementia can affect everyday life
- To give simple ideas about how to make it easier for someone living with dementia

**Preparation time:** 10 minutes

**Length of activity:** 20 minutes

### You will need:

- Food that is white or cream in colour, for example mashed potato, rice or macaroni cheese (available in a tin)
- A spoon and tin opener (if needed)
- A white plate
- A non-patterned red or blue plate
- A white tablemat (or sheet of A4 paper to resemble a tablemat)

### Method:

1. Have half of the pale-coloured food ready on the white plate and the other half on the red or blue plate.
2. Introduce the activity by asking people how they like their food to look on a plate; for example do they have a favourite plate or do they like certain colours of food?
3. Show people the food on the white plate placed on the white mat and ask how they think it looks, how easy it is to see and whether it makes them feel hungry. Give everyone the opportunity to express their thoughts (people usually have fun expressing how unappetising it looks).

4. Explain that someone living with dementia may not see there is food on their plate or might not find it appealing to eat. This is because they cannot see its shape or colour as there is no contrast in colour between the food and plate. This may cause the person to stop eating and over time they may become very thin or unwell.
5. Show people the food on the red or blue plate and ask how they think it looks.
6. Look at both plates together and ask people which they would prefer; make sure anyone with dementia in the group has the chance to talk about what they see and what they find helpful.
7. You could go on to discuss other ways in which people living with dementia might perceive things differently (there are further examples in Supporting Derek so the clip could be watched again or people reminded of his experiences):
  - They might not recognise their own reflection in a mirror and might think it is someone else
  - A threshold between rooms might be seen as a step
  - Patterns on a carpet might look like things lying on the floor that need to be avoided
  - A dark rug on a wooden floor might look like a hole
  - A toilet bowl might not be recognised if there is no contrast between the bowl, the seat and the flooring
  - Patterns in wallpaper might look like monsters.

### Tips

You can expand this activity by doing a session walking around and looking at the environment and discussing how it might be changed to be more dementia-friendly (see Activity 20).

# Activity 11:

## Mother and child

### Summary

This is a short but fairly intense activity that helps people to think about their relationships with their mothers and understand why people with dementia sometimes talk a lot about their mothers.

### Aims:

- For people in the group to understand why a person living with dementia might ask for their mother
- To give people ideas about how to respond to someone with dementia who often talks about their mother
- To remind people what happens to the brain when someone has dementia

**Preparation time:** 10 minutes

**Length of activity:** 20 minutes

### You will need:

- A4 pictures of a mother and child – one for each person or one to share between two people (Appendix 4)

### Method:

1. Distribute pictures of a mother and child and ask people what memories they bring up for them.
2. Ask people if they know anyone with dementia who asks for their mother or talks as though their mother were still alive.
3. Explain that the person is probably thinking about their mother because they have a memory of feeling safe and comfortable when their mother was around and that they are probably not feeling safe and comfortable at that moment. If their mother has died recently they may have forgotten because the short-term memory part of their brain is no longer working (you can refer back to the bookshelf analogy).
4. Talk about how they might respond. It probably won't help to say that their mother is not around (or that she is no longer alive).
  - They could say 'You seem a bit sad – is there something upsetting you?' or 'I am here, I'm happy to sit with you' or 'Is there anything I can do for you?'
  - They could talk to the person about their mother and talk about the good things they did together (having a photograph or a memory box could help to facilitate these conversations – see Activity 16)
  - They could sit quietly with them and, for example, hold their hand.

### Tips

Remember some people may not have had a good relationship with their mother or may not have known her so this activity needs to be approached with sensitivity. Some people may have the strong feelings described above for another adult they felt close to in their childhood.

# Activity 12:

## Helping others as they grow older

### Summary

This activity looks at the things people in the group already do, or could start to do, to help other people. It gives them the opportunity to think about what they contribute to other people's lives in a fun way and may be particularly relevant for someone living with elderly parents or a housemate who is less active or has developed dementia.

### Aims:

- For the group to think about the day-to-day things they can do to help their friends or family members as they grow older, more frail or develop dementia
- To help people realise they are making an important contribution to the lives of people they help with day-to-day tasks.
- To find out whether anyone in the group is giving a significant level of care and/or needs to be better supported in their caring role

**Preparation time:** approximately 30 minutes

**Length of activity:** 30-40 minutes

### You will need:

- Objects that relate to the activities that the group are able to do. Using six of the following, in two groups of three, works well:
  - Some clothes pegs (laundry)
  - A packet of tea bags (making cups of tea)
  - A duster (cleaning)
  - Door keys (opening the door and making people welcome)
  - A shopping list and some loose change (shopping)
  - A washing-up brush (washing up)
  - A knife and fork (setting the table)
- Relevant photographs from Appendix 4

### Method:

1. Explain that you are going to be thinking about the things we do for other people. Often, we do

more for others as they grow older or develop dementia, whether a parent, a friend we live with or a partner.

2. Put three of the items suggested above on the table and hand out three of the pictures that relate to the items.
3. Ask the group to match an item to each picture.
4. Ask people if they do that task at home (and whether for themselves or for someone else).
5. If anyone does one of the activities to help another person, give them the object and ask them to talk about what they do. Get them to talk a bit more about the activity: do they like doing it or does it feel like a chore? Have they always done it or have they started to do it more recently to help someone else? Find out if they have been doing it more as their parent (s) have grown older. You can support other people in the group to ask these and other questions.
6. Put another three items and photographs on the table and follow points 3-5 above.
7. Discuss other ways in which we might help someone, particularly if they have dementia; for example looking after items such as door keys when they are out, helping them with money, giving them time to answer questions, reassuring them and being kind. Also discuss the importance of letting people do things for themselves when they feel able to.
8. You can finish this activity by asking whether the group would like to watch a film clip about people with learning disabilities supporting their elderly parents (Activity 13). This would be more relevant to people living at home with their families rather than in supported living.

### Tips

Only use three items and photographs at a time as too many pictures caused confusion. Appreciate and acknowledge the help that they give to one another and their families.

# Activity 13:

## Caring for someone

### Summary

This activity follows on from Activity 12 and is relevant if there is someone in the group who seems to be providing a significant amount of care for a relative, partner or friend (or may do in the future). It uses a film clip about mutual caring that focuses on people with a learning disability caring for an elderly relative but also raises more general issues about being a carer. This activity was developed as a response to one of the group members who was caring for his elderly mother.

### Aims

- To support people to identify themselves as a carer for someone else
- To help people to understand that they may need support as a carer and could, for example, ask for a carer's assessment
- For people with a learning disability who live with parents who are growing older to understand how their roles may start to change

**Preparation time:** 20 minutes to watch the third section of the Mutual Caring DVD called 'Carers' Assessments'

**Length of activity:** 30-40 minutes

### You will need:

- Mutual Caring video clip on [www.youtube.com/watch?v=bJXsvpMxUX4](http://www.youtube.com/watch?v=bJXsvpMxUX4)

### Method:

1. Recap on Activity 12 and the discussion about how people usually need more help as they grow older.
2. Introduce the film clip by explaining that it is about Michael who has a learning disability and is doing lots of things at home for his mother who is 90 years old and has dementia. You may want to say that at the end of the film we are told that Michael's mother has since died. This can make people feel emotional so it is a good idea to prepare them.
3. Watch the video clip.

4. Ask people what they thought after watching it. How did they feel hearing Michael talk about his mother and how he cares for her? Did they think Michael enjoyed his role as a carer? What did they think helped Michael in his role as a carer? (You can discuss things such as the easy-read carer's assessment, Michael being worried about his mother having another fall, the loneliness you can feel as a carer, the importance of getting support as a carer.)
5. You can also ask whether anyone feels they are doing similar things to Michael for a parent, other relative or a friend. If they are, how do they feel about it? If they are not doing this themselves they may know someone else who is. You could also ask whether anyone feels they would like to be doing more to help a parent, other relative or friend.
6. If people are interested in talking about this further you could ask them how it feels to help someone who has previously been caring for them (such as a parent) or someone who is a friend but for whom they now provide care and support.
7. If someone in the group seems to have caring responsibilities for a parent/relative, find out if they are being supported in this role. Do they have someone they can talk to about any worries they might have? Have they had an assessment as a carer? (See 'Being a Carer and Having a Carer's Assessment' [www.learningdisabilities.org.uk/publications/being-a-carer/](http://www.learningdisabilities.org.uk/publications/being-a-carer/).) Do they receive support to have a break from their caring role (as Michael does)?
8. At the end of the discussion, check how everyone is feeling and offer to talk to anyone afterwards.

### Tips

Although the main focus of the clip is people with a learning disability being carers, it also touches on topics that can be painful, for example bereavement, parents growing older and possibly dying. At the end of the clip it says that Michael's mother has since died. People in the group may have already lost their parents or cared for a parent in the past. Some may be living with a relative who has dementia, like Michael's mother.

# Activity 14:

## Things going missing

### Summary

This short activity looks at some of the difficulties of living with dementia but also taps into the potentially funny side of things going missing. This is a very helpful activity for people sharing a house with someone with dementia who may be accusing others of using or taking their things.

### Aims:

- To help people understand how difficult and frustrating it is to be forgetful
- To help people understand why it is not a personal attack when they are accused by someone with dementia of taking something of theirs
- To give people ideas about how to help someone who can't find their belongings

**Preparation time:** 10 minutes

**Length of activity:** 15 minutes

### You will need:

- A picture of an older person that is full of character (you could use the one in Appendix 4)
- An ability to tell a story!

### Method:

1. Show the photo and say this is a picture of John (or whatever name you choose) and ask people what they think John might be like.
2. Once people have had a chance to talk about John, explain that although John looks like many other older people he finds it difficult to remember things as he has dementia. This means that sometimes he forgets where he has put things and accuses other people of taking them.

3. Explain that you are going to tell a story about something that happened to John.

*'One day John lost his wallet, he looked everywhere for it and became very angry with his friend Mary and said she must have stolen it. Mary was very upset about this and got cross with John but then remembered that John had dementia and was often losing things. So she stopped being cross and talked to John about what he had been doing that morning. She reminded him that he had done the shopping and put the things away in the kitchen. Together, they looked in the places where he had put the things away. When they looked in the fridge they found John's wallet as he had put it away in the fridge along with the milk.'*

4. Ask people what they think of this story (it often causes a lot of laughter). Ask how they think Mary must have felt when John accused her of stealing the wallet and how John might have felt when he found his wallet.
5. Ask people if they have been accused of doing something that they haven't; if someone has, encourage them to tell the story and how it made them feel.

### Tips

If the group responds well to hearing this story about John and Mary, the activity can be expanded to talk about lots of different scenarios that might arise, for example John wetting the toilet floor because he cannot see the white toilet seat against the white floor, or thinking there is a man in his bedroom at night when it is his coat hanging up.

You can create scenarios that address issues that people have brought up. The stories can help people to understand the confusion someone might be experiencing.

# Activity 15:

## Time

### Summary

This activity is useful for people sharing a house with someone who is having problems with understanding what time of day it is and therefore doing things at unusual times. It also provides them with an opportunity to talk about the importance of routine.

### Aims:

- To help people understand how someone might have problems understanding time and the frustration this can cause for themselves and others
- To come up with ideas about what might help

**Preparation time:** 15 minutes

**Length of activity:** 40 minutes

### You will need:

- A set of photos that includes someone sleeping, getting dressed, eating lunch, doing the shopping, eating supper and going to bed
- Photos of the sun and moon
- An ordinary clock and a clock that identifies night and day (optional – see Appendix 1)
- The picture of the brain in Appendix 4

### Method:

1. Discuss as a group the importance of routines. You could start by talking about daily routines such as what time people get up, make breakfast, have lunch, watch television, have a shower.
2. Hold the photos up, one by one, and ask the group what the person in the picture is doing and what time of day they think it might be. Put the photos in a logical sequence (people could hold them if you don't have a table to lay them on where everyone can see them). People's routines will probably differ, for example what time they choose to have a shower or go shopping, but activities such as eating and sleeping will probably be similar.
3. Explain that sometimes people with dementia have problems knowing what time it is: they may go out at four in the morning to do the shopping when others are asleep or even go back in time and think that they are living somewhere else. This happens because of changes to the brain: show people the photo of the brain they looked at before.
4. Put the photos in a different order and ask people what it might be like to do things in this way; for example what might happen if you tried to cook a meal in the middle of the night? (You might disturb and annoy people who are sleeping in the house.) Or what might happen if you ate your lunch and then had supper half an hour later?
5. Tell the story of John who woke up when it was summer and light outside and thought it was time to get up to make breakfast before going out to the day centre. He went to the bathroom and got washed, got dressed and went downstairs to make breakfast. The problem was that it was only four o'clock in the morning and John had stopped going to the day centre about 10 years before. Luckily for John, a housemate was woken by the noise of him making breakfast and came down to see what was going on. He explained that it was very early in the morning and everyone else was asleep.
6. Talk about how others could help John. This might include:
  - Making sure that the room stays dark in sleeping hours even in the summer by using a black-out blind
  - Using a day/night clock (show the example) which has pictures of the sun and moon to help John understand whether it is day or night
  - Having a photo of the moon beside John's bed and/or on his bathroom mirror which gets changed to a sun in the daytime (use the photos of the moon and sun)

- Helping John to be busy in the day so that he is tired at night and less likely to wake up
- Not getting cross as it is not John's fault but a problem with his brain
- Not arguing with John about the time of day as this may upset him and make things worse
- Taking time to be with John and having a cup of tea with him if he has woken up
- Making sure John is safe by having an alarm on his front door to alert you if he goes out at night.

7. You could finish by asking people how they feel when their routines are changed or interrupted and ask what helps them when this happens. They may have experienced this type of disruption if they have been let down by someone who supports them.

### Tips

People with dementia commonly get confused about time at the end of the day when they are tired and want to go 'home'. Having a cup of tea, listening to calm music, going for a short walk, or a bit of reassurance can help.

# Activity 16:

## Relaxation

### Summary

This short activity shows how to use relaxation techniques when things feel a bit hectic or noisy.

### Aims:

- To help people realise that they may need times of calm and quiet, particularly as they get older
- To give people techniques to deal with stress

**Preparation time:** none

**Length of activity:** 15 minutes

**You will need:** nothing required

### Method:

1. Explain that some situations, or lots of noise and activity, can make people feel worried or tense. It is important to recognise when they feel like this and do something about it.
2. Ask the group what they do when they feel stressed, anxious or angry. For example, at home do they find a quiet space in their room or in the garden? Find out from each person where they go when they need to relax or have some quiet time. Ask whether other people leave them in peace when they go somewhere quiet to try to relax.
3. You could ask people whether they have a way of indicating to others that they are trying to relax and would like not to be disturbed. You could suggest ideas such as having a sign on their bedroom door, or a photo of them relaxing to put on a table by their chair, having headphones on or closing their eyes. A separate activity to make a personal sign could be created.

4. Move on to discuss ways of managing stress through breathing. Ask people to:

- Sit comfortably, relax their body and close their eyes
- Put one hand on the top half of their chest and feel themselves breathing in and out for a few minutes
- After this, put their hand on their lower chest and try to take deeper/bigger breaths so that they can feel their hand moving
- Continue to take deep slow breaths for a few minutes

If people find this deep breathing difficult, you could suggest instead that they focus on where their feet or hands are resting and just relax thinking about this.

5. Afterwards ask how it felt to do the breathing or focusing on their hands/feet. Explain that it usually gets easier to relax the more often you do it, i.e. it is something you gradually learn. Find out whether they would like to do this relaxation activity again.

### Tips

This session was developed in a busy day centre that was fairly noisy at times. If you are running the group in a place you are not familiar with, find out if there is a quiet area where people can go or look at how a space can be created for times when people need to have some peace and quiet.

# Activity 17:

## Music and relaxation

### Summary

This gentle activity follows on from Activity 16 by looking at how music can help people to relax and find some peace and quiet.

### Aims:

- To help people develop a strategy for relaxing (whether at home or in a noisy place such as a day centre)
- To help people with dementia find out whether music has a calming (or stimulating) affect on them

**Preparation time:** 20-30 minutes

**Length of activity:** 20-30 minutes

### You will need:

- A few pieces of music that are calming or soothing downloaded on to an MP3 player (the music used was Enya singing 'Pilgrim', Norah Jones singing 'Come Away with Me', Beethoven's 'Moonlight Sonata' and Vaughan Williams' 'The Lark Ascending', but you could use any music you know that could be relaxing, or sounds of waves, birdsong etc.)
- A docking station with sufficient amplification for people to hear

### Method:

1. Ask people what music they like and whether they like different pieces of music depending on their mood. Is there music they listen to when they want to relax?
2. Explain how music can change people's mood and that you are going to play a few pieces of music so they can see how it makes them feel.
3. Ask people to sit comfortably, relax their bodies (as they did in Activity 16) and close their eyes when pieces of music are playing.
4. Play each piece of music in turn and after each piece discuss how the music makes people feel – do they feel relaxed or calmer? Ask them if they would like to listen to it again as sometimes it can be hard to know on the first listen.

### Tips

Keep a record of which pieces of music received a positive response and add it to a playlist for people to listen to at other times. This could be especially helpful at the end of the day if someone with dementia often becomes agitated at this time. Research has shown that music can have a calming (and stimulating) effect on people living with dementia.

# Activity 18:

## Favourite music

### Summary

This is an enjoyable and relaxing activity that gives people the opportunity to share the music they enjoy and reminisce about why it is important to them. You will need to prepare for the activity in a previous session by asking people whether they have favourite pieces of music.

### Aims:

- To help build a sense of individuality: this is sometimes lost as people get older
- To identify shared interests in music
- To make a playlist of favourite music that can be enjoyed outside of the group

**Preparation time:** 30 minutes (to download the music)

**Length of activity:** 30 minutes

### You will need:

- Different types of music (approximately 10 pieces) downloaded
- A docking station or suitable way to play the music so that everyone can hear
- Photos of people singing solo, choirs, bands, someone playing the piano, popular singing competitions etc. (these could reflect the pieces of music that you are going to play)
- A grid with the pieces of music on one axis and the names of group members on the other for your own use to note the music that each person likes or dislikes
- Tick and cross cards as used in Activity 1

### Method:

1. Show people the photos and ask them what sort of music the images make them think about. Alternatively, you could ask people what kind of music they like: do they like musicals, classical music, pop?
2. Explain that you are going to play pieces of music and after each piece people can say whether they like it or not by holding up the green tick or the red cross card.

3. Play a piece of music and then ask people to hold up their tick or cross. If everyone holds up a green card you could play the music for a bit longer so it can be enjoyed before going on to the next one. Fill in the grid as you go along.
4. After playing all the music, find out if people have a favourite piece. You can also use the grid to talk about the different kinds of music people like and look at shared likes and dislikes.
5. Ask people whether they would like to have their own playlist based on the music they have said they like. Depending on your role, this may be something you could do outside of the sessions or ask support staff or family to help with this.

### Tips

Playing music is a good way to start the session while you are waiting for everyone to gather for the group and choosing an individual's favourite tunes can help to create a warm and welcoming atmosphere. The number of activities that people can enjoy in the later stages of dementia is often limited, and music is frequently one of them: having a playlist of favourite music can contribute greatly to someone's sense of well-being.

Creative skills, such as singing, dancing, poetry and reading, are often the last ones to be lost (and people may enjoy these activities even if they didn't before developing dementia). The bookshelf analogy in Activity 9 can be further developed to describe this:

- There are two bookshelves: one made of flimsy wood and the other of a strong wood.
- The bookshelf made of flimsy wood represents the hippocampus where facts are stored: it falls apart before the other bookshelf.
- The bookshelf made of stronger wood represents the amygdala where feelings and emotions are stored: this bookshelf lasts longer so people can keep using those memories.

# Activity 19:

## Memory boxes

### Summary

This is an extended activity that involves discussions about important people, places, events and objects in group members' lives. It can lead to the development of a memory box for those who would like to have one. The box can help them to talk about their past, engage others to talk with them and conjure up memories.

### Aims:

- To help people retain a sense of their own identity and what is important to them and to share this, if they wish, with others
- To help people in the group get to know more about each other and encourage conversations about significant things in their lives and common interests
- To encourage people to think about either family belongings or their own that they would like to keep (families often need prompting to understand the importance of giving/leaving things to their relative and support staff sometimes clear up people's rooms without checking what is important)
- To help people create a memory box that can be shared with friends, family and support staff; if people develop dementia it can be a useful tool to aid reminiscence and meaningful conversations

**Preparation time:** approximately 30-45 minutes if you need to make a sample memory box

**Length of activity:** 30-40 minutes to talk about memory boxes and possible contents: this would be enough for an initial discussion about memory boxes but actually putting one together would take more time.

People could either do this during a group session or they could be supported to make one outside of the group. If they do it outside of the sessions, you could arrange a time for members to meet and talk about what they have been doing and/or to bring their box along and talk about their items.

### You will need:

- A demonstration box: this could be a box you make to reflect your own memories or one that you make beforehand with a member of the group (alternatively, someone in the group may already have a memory box that they would be happy to be used). If you are making one you could use a decorated shoe box or a box from a stationery shop; the outside of the box could be decorated to reflect the personality or interests of the person
- Various items to put inside the box. These may be items that reflect the person's history and interests, for example photos, travel tickets, an ornament that belonged to their parents, programmes from shows, postcards from people. Alternatively, people may not have actual items they could use but they could be supported to find objects that evoke memories of favourite people, places and times, perhaps including things that stimulate memories in a sensory way such as perfume, aftershave, scents of flowers, sweets or a scarf
- Material or tissue paper in which items can be arranged (if necessary)

### Method:

1. Show the box to the group and explain why some people like to create and look at a memory box or items that remind them of the past.
2. Ask people if they have some special items that remind them of their parents/grandparents or other family members and friends, or from holidays or special events in their life. Also, ask if there are certain things that remind them of a special person or place (give an example, such as chocolate peppermint creams make me think of my mother or the smell of roses makes me think of a lovely holiday we had in a cottage in Yorkshire) and find out more about that memory.
3. Ask people if they would like to make up their own boxes. Discuss what they might put in their

box and write this down. If you are able to make memory boxes as part of the sessions you could do it over several weeks, selecting different items to discuss, for example favourite places, holidays, smells, food, family photographs.

4. It is helpful to write an explanation of the box contents to facilitate conversations with someone who doesn't know the person or to help the person reminisce when they no longer remember the significance of the objects.
5. An alternative or addition to a memory box is a Talking Photo album in which a message or further information can be recorded to accompany a photograph or picture (see Appendix 1).

### Tips

Some people might not have any belongings to reflect their memories but they can still make a memory box, for example by buying postcards of places or items that remind people of the memory. Items that were important to someone with a learning disability may have been thrown away without their permission, and they may be upset if this has happened. The items that people say are important should be valued.



# Activity 20:

## Creating a friendly environment

### Summary

This is an activity that engages people with thinking about the environment where they live or places they go to. The design of the built environment is important for someone with a learning disability and becomes even more critical if the person develops dementia.

Depending on your role, you may need to discuss this activity beforehand with someone responsible for the building as it is important that suggested changes can be considered and implemented where possible. Also, talk to people in the group before planning this activity to find out whether they would like to go around the building and which rooms they would like to look at.

### Aims:

- To ensure that the environment is as easy to manage as possible for people as they get older, in particular, people living with dementia
- To give people a sense of choice and control over their living environment

**Preparation time:** 15 minutes

**Length of activity:** 20-30 minutes

### You will need:

- A list of different aspects of the home to think about (see Dementia Care's guide to making a home more dementia-friendly with a room-by-room checklist [www.dementiacare.org.uk/living-well-with-dementia/i-am-a-carer-or-friend/supporting-someone-in-their-home/making-your-home-more-dementia-friendly/kitchen](http://www.dementiacare.org.uk/living-well-with-dementia/i-am-a-carer-or-friend/supporting-someone-in-their-home/making-your-home-more-dementia-friendly/kitchen))
- A grid to record what you find out

### Method:

1. You may need to plan the tour beforehand to check that people in the group will be able to get around and look at the different spaces.

2. Explain that you are going to look together at the building and the rooms to see how well they work for people in the group. Refer back to the film clip of Derek in Activity 8. You should explain that it may not be possible for all the changes to be made, as it will depend on who owns the building, the costs involved etc.
3. Ask people what difficulties they have had and make a note of these. You could also ask them to think of any other problems that might arise.
4. If the group is mobile enough, walk around the building. Start at the front door and ask questions such as:
  - Would it be easy for someone to find their way to the kitchen or toilet from here?
  - Is there clear signposting or arrows, for example is there a cupboard for coats with a coat sign on it?
  - Is the lighting good?
  - What is the flooring like, for example is it slippery?
  - Is there an obvious place to put the door keys?
  - Is there a threshold between the rooms that might look like a step?
5. Make a list of things that can be changed and decide with the group how important they are and how soon they need to be done. You could use a table like the one overleaf.

### Tips

You might find it helpful to have a checklist with pictures for the group to refer to as you walk around; for example keys: is there a key hook?

Area looked at	Things to consider	Suggested change	How important (high, medium, low)
Front door	Steps	Paint trim of contrasting colour	High
	Numbering/name Lighting Keys/locks Letter box	Put a 'letter catcher' on the inside	Low
	Front doormat Front door bell/ knocker	Needs to be louder	Medium

# Appendices

# Appendix 1:

## Resources for running the group sessions

### Template for planning a group session

Name of group:

Date and time:

Session number:

Theme or objective for the week:

People attending:

Any specific needs:

Time	Activity	Points to cover	Resources needed

## Activity 2: The meaning of names

Babies' names website:  
[www.babynames.com](http://www.babynames.com)

## Activity 5: Losing things

Drawstring bags available from Amazon at approximately 99p each.

## Activity 8: Understanding what it is like to live with dementia

*Supporting Derek: learning difficulties and dementia practice development pack* by Karen Watchman, Diana Kerr and Heather Wilkinson (Joseph Rowntree Foundation, 2010). A DVD and training materials about diagnosis and responding to people's needs, available for £15 from [www.jrf.org.uk/publications/supporting-derek](http://www.jrf.org.uk/publications/supporting-derek) or a short extract from Part 1 of the DVD is available at [www.youtube.com/watch?v=O3ekO4QdKXU](http://www.youtube.com/watch?v=O3ekO4QdKXU).

The first five minutes of the DVD in this pack were used to aid a discussion about understanding what it might feel like to have dementia.

## Activity 9: Understanding the brain

Dementia and the brain, an information sheet produced by the Alzheimer's Society that explains the different effects on the brain

[www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=114](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=114)

## Activity 13: Caring for someone

Foundation for People with Learning Disabilities' video clip on mutual caring  
[www.youtube.com/watch?v=bJXsvPMxUX4](http://www.youtube.com/watch?v=bJXsvPMxUX4)

## Activity 15: Time

Clairmont produces four clocks designed to help people with dementia including one with pictures of day and night and others with yellow faces with black hands for high contrast:

[www.clairmontplc.co.uk/product-category/clocks/](http://www.clairmontplc.co.uk/product-category/clocks/)

## Activity 19: Memory boxes

Talking Photo Albums available from [www.TalkingProducts.com](http://www.TalkingProducts.com) at approximately £28

Telephone: 01794 278327

Email: [info@talkingproducts.com](mailto:info@talkingproducts.com)

For further information on activities see: National Activity Providers Association (NAPA)

[www.napa-activities.co.uk](http://www.napa-activities.co.uk)

Daily Sparkle, a reminiscence activity newspaper available on subscription (a free trial is available)

[www.dailysparkle.co.uk](http://www.dailysparkle.co.uk)

Dementia Care's guide to making a home more dementia-friendly with a room-by-room checklist

[www.dementiacare.org.uk/living-well-with-dementia/i-am-a-carer-or-friend/supporting-someone-in-their-home/making-your-home-more-dementia-friendly/kitchen](http://www.dementiacare.org.uk/living-well-with-dementia/i-am-a-carer-or-friend/supporting-someone-in-their-home/making-your-home-more-dementia-friendly/kitchen)

# Appendix 2:

## Further reading and resources on growing older and dementia

*About My Friend: for friends of people with Down's syndrome and dementia* by Karen Dodd, Vicky Turk and Michelle Christmas (BILD). Available for £12 from [www.bild.org.uk](http://www.bild.org.uk)

A booklet to help people with learning disabilities understand what happens when a friend gets dementia.

*Ann Has Dementia* by Sheila Hollins, Noelle Blackman and Ruth Eley (Books Beyond Words, 2011).

*Being a Carer and Having a Carer's Assessment: a resource pack for people with learning disabilities* (Foundation for People with Learning Disabilities, 2009). Free to download from [www.learningdisabilities.org.uk/publications/being-a-carer/](http://www.learningdisabilities.org.uk/publications/being-a-carer/)

Dementia Friends, an information-sharing initiative to change people's perceptions of dementia  
[www.dementiafriends.org.uk/](http://www.dementiafriends.org.uk/)

*Down's Syndrome and Dementia Workbook for Staff* by Karen Dodd, Diana Kerr and Scott Fern (Down's Syndrome Association, 2007).

*Growing Older Evaluation Toolkit for Providers: an assessment tool and action plan for organisations to improve the quality of life for people with learning disabilities as they grow older* (Foundation for People with Learning Disabilities, 2014). Free to download from [www.learningdisabilities.org.uk/our-work/changing-service-delivery/improving-support-older/](http://www.learningdisabilities.org.uk/our-work/changing-service-delivery/improving-support-older/) (and accompanying Real Change Challenge produced by Association for Real Change: free to download from [www.arcuk.org.uk/realchangechallenges/real-change-challenge-older-people/](http://www.arcuk.org.uk/realchangechallenges/real-change-challenge-older-people/))

*How to Break Bad News to People with Intellectual Disabilities: a guide for carers and professionals* by Irene Tuffrey-Wijne (Jessica Kingsley, 2012).

*Intellectual Disability and Dementia: Research into Practice* edited by Karen Watchman (Jessica Kingsley, 2014).

*Is your housing dementia friendly? An assessment tool for assisted living and extra care housing* (The King's Fund, 2014). Free to download from [www.housinglin.org.uk/Topics/browse/HousingandDementia/Design/?&msg=0&parent=5091&child=9379](http://www.housinglin.org.uk/Topics/browse/HousingandDementia/Design/?&msg=0&parent=5091&child=9379)

Learning disabilities and dementia, an information sheet produced by the Alzheimer's Society  
[www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=103](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=103)

Mutual Caring resources, including *Supporting You and Your Family as you Grow Older, a booklet for people with learning disabilities who live at home with an older family carer* (Foundation for People with Learning Disabilities, 2010). Free to download from [www.learningdisabilities.org.uk/our-work/family-friends-community/mutual-caring/](http://www.learningdisabilities.org.uk/our-work/family-friends-community/mutual-caring/)

*Perspectives on Ageing with a Learning Disability* by Cally Ward (Joseph Rowntree Foundation, 2012). Free to download from [www.jrf.org.uk/publications/perspectives-ageing-learning-disability](http://www.jrf.org.uk/publications/perspectives-ageing-learning-disability)

*Running self-help groups in sheltered and extra care accommodation for people who live with dementia* by Cindy Glover (Mental Health Foundation, 2014). Free to download from [www.mentalhealth.org.uk/publications/](http://www.mentalhealth.org.uk/publications/) (search for Dementia Self-Help Group Guide).

*Thinking Ahead: a planning guide for families* by Christine Towers (Foundation for People with Learning Disabilities, 2013). Free to download from [www.learningdisabilities.org.uk/our-work/family-friends-community/thinking-ahead/](http://www.learningdisabilities.org.uk/our-work/family-friends-community/thinking-ahead/) (contains relevant information about talking about difficult subjects, memory boxes and supporting people to be involved in decision making).

# Appendix 3:

## Further information about dementia

Dementia is an umbrella term used to describe a variety of disorders of the brain which lead to a decline in cognitive ability and memory. These include Alzheimer's disease, vascular dementia, frontal lobe dementia, alcohol-related dementia and Lewy body dementia. These diseases are progressive so people's symptoms will get worse but the pattern and speed at which they do so will vary.

### The signs and symptoms of dementia include:

#### Changes in remembering things

This is commonly the loss of memory about recent events (short-term memory); for example people may have difficulty in remembering where they have put things or what they have recently eaten. In most forms of dementia, it is the short-term memory that is affected first. Long-term memory, such as of things that happened in childhood, tends to be less affected; however, in the later stages this may also be lost. Memories with strong emotional content tend to be better preserved and remembered, even if they are memories of recent events. The person may not recall the details but they will remember the emotions; for example remembering they feel happy or cross after someone has been to visit them yet not remembering who has been to visit.

#### Changes in organising and sequencing tasks

In the earlier stages of dementia, difficulty with organising and sequencing is likely to be in relation to new or less familiar tasks, such as changing a light bulb. With the progression of the disease, people may have problems doing routine things that they have done all their life: they may put tea bags into the electric kettle, put the electric kettle on the stove, or have difficulty in sorting coins for change in a shop.

#### Changes in speech

People may not be able to recall the right word, or may say the wrong word (for example 'knife' instead of 'biscuit') or say words the wrong way round.

#### Disinhibited or inappropriate behaviour

This can occur when the frontal lobe of the brain is affected as it is the part that controls the ability to regulate impulses. The person may say or do things that are not socially acceptable in relation to the environment they are in or the people they are with. For example in a shop they may take something they want and eat it without having paid for it or they may touch someone in an inappropriate way.

#### Vision and perception problems

Various types of mistakes can occur but include illusions, misperceptions and misidentifications. Illusions may occur when an object has characteristics that make it look like something else; for example someone might see a round black rug on the floor as a deep hole, or a threshold of a door as a step. This can be frightening.

#### Hallucinations

An hallucination is the perception of something that is not there. The most common hallucinations are visual but people can also experience smells and sounds that don't exist. They can make people feel very wary, afraid and anxious, and can occasionally cause them to be aggressive.

#### Disorientation

People can feel disorientated regarding time, place or in recognising people. For example they may think it is morning when it is night or that their son is their husband. This again can be very distressing or frightening, and upsetting for the people who are close to them.

#### Changes in behaviour

Behaviour changes vary from person to person. People may become more withdrawn, less able to initiate tasks, more agitated, frustrated or depressed. The changes may be a result of knowing something is wrong, a reaction to the way they are being treated by others, or due to frustration at not being able to express themselves. It is important to rule out other potential reasons for behaviour changes such as pain or undiagnosed health problems. A person with a learning disability and dementia will have other health care needs associated with ageing. Older people with learning disabilities have higher rates of arthritis and other problems that impair mobility. Respiratory disorders are common. The person may have hypertension which in turn is associated with cerebrovascular disease. People with Down's syndrome are more prone to thyroid disorders and hearing problems.

# Appendix 4: Photographs

Activity 6



Activity 6



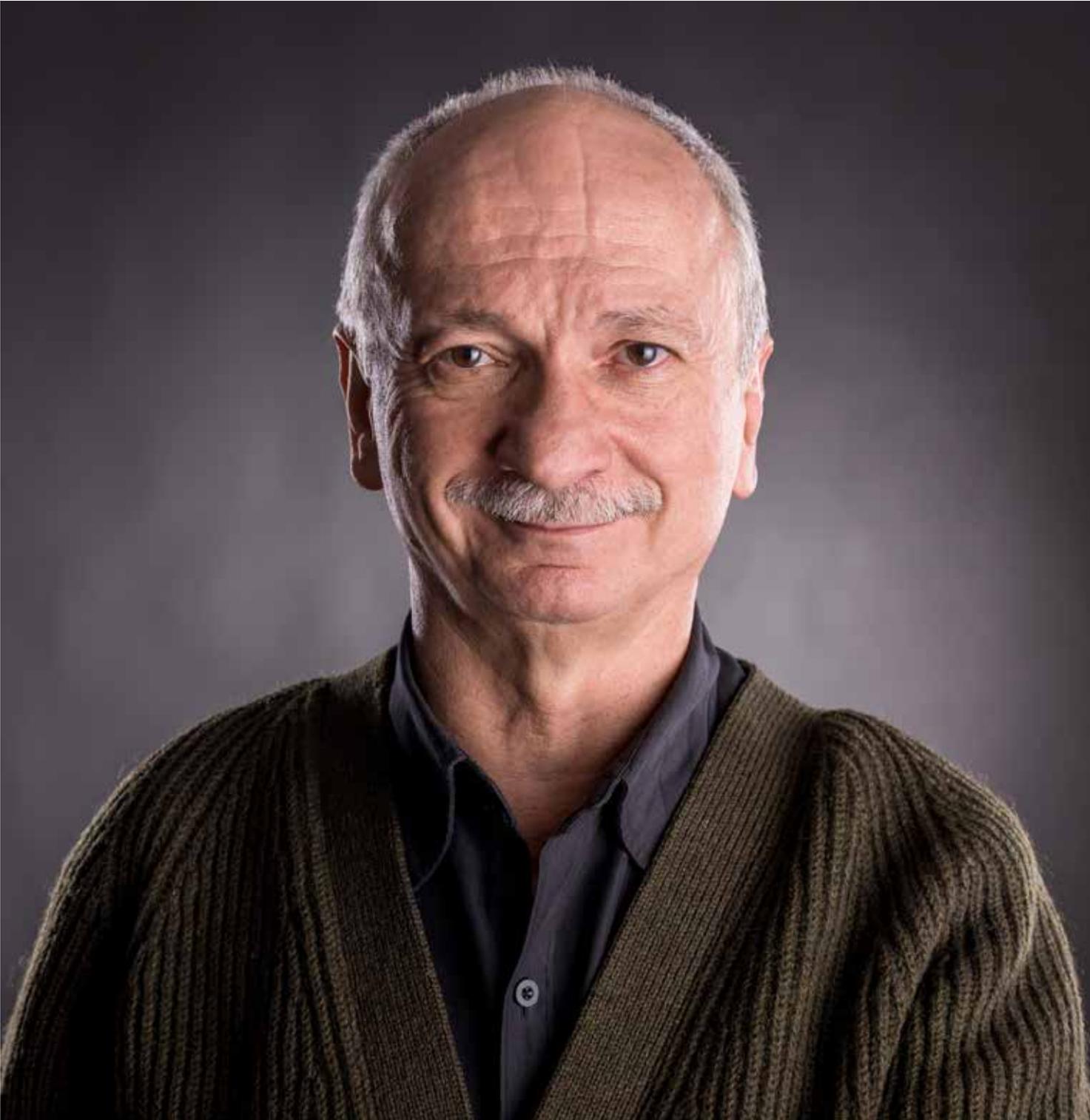
Activity 6



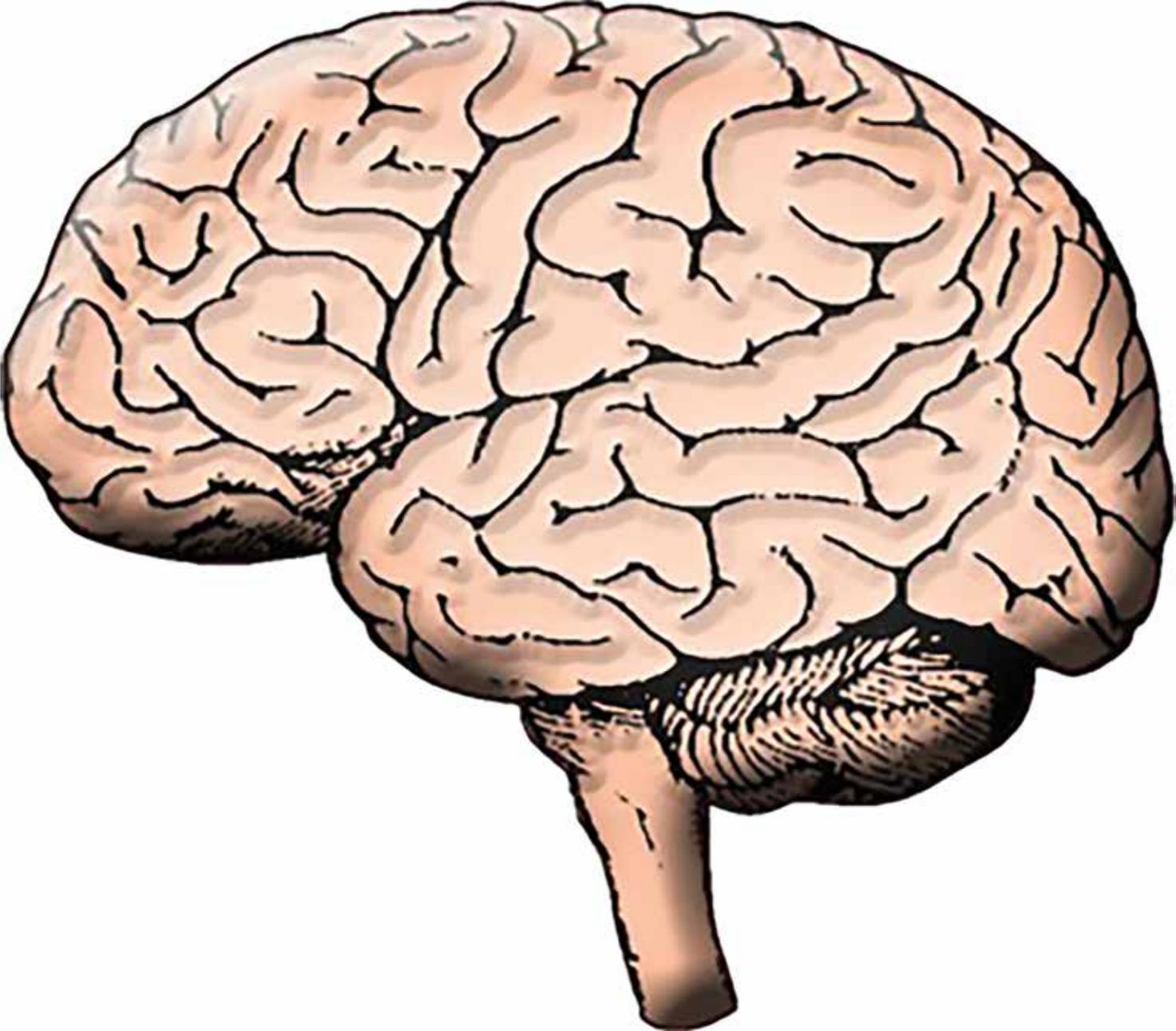
## Activity 6



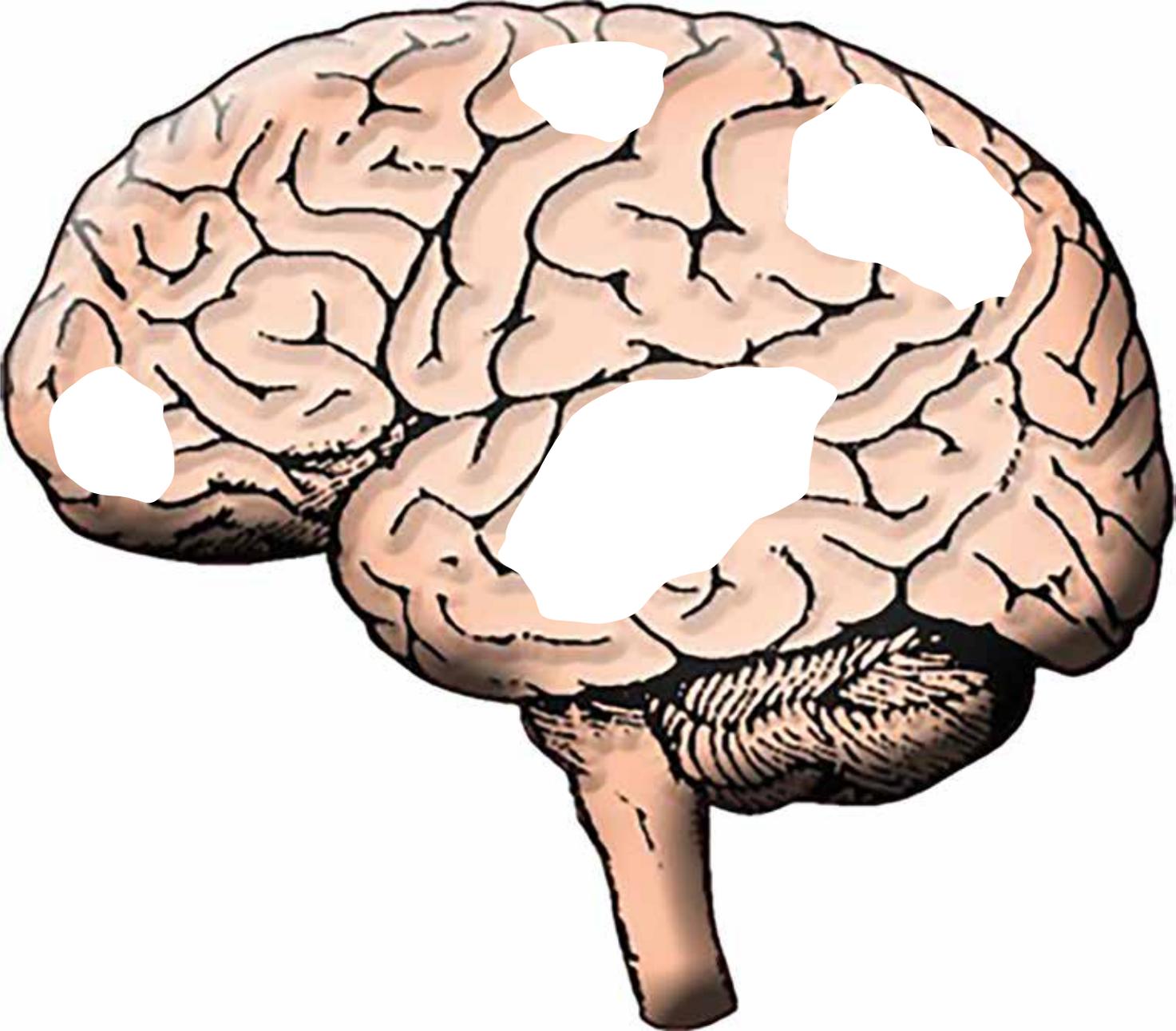
Activities 6, 9 and 14



Activity 9



Activities 9 and 15



Activity 11



## Activity 12



Activity 12



Activity 12



Activity 12



## Activity 12



Activity 12



## Activity 12





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