



Changed Days
Notes on how to use the film to gain a better understanding of the way dementia can affect the individual and the carer



May 2011

The film should be used sensitively!



Caring about people with dementia and their carers

Foreword

I have been working with people who have dementia and their carers for over 30 years, both initially as a General Practitioner in primary care and for the past 14 years as a consultant in Old Age psychiatry. It is of course sometimes very sad to deal with people who have dementia and their families, but we all can and do make a difference. Particularly in the past 5 years or so there has been a lot more public awareness, and interest in, dementia, including at Government level. The film *Changed Days* deserves to be seen by everyone who might deal with people who have dementia - and that means everyone in society. I find it a very moving piece of film, even after viewing it several times.

To me, it gives two main messages, that dementia is everyone's business, and that people with dementia like all the rest of us have had a previous life too, and we should not lose respect for people as people simply because they have an illness.

I hope like me you enjoy the film, and that you can get a lot out of it.

Dr Graham A Jackson

M.B., ChB; FRCPsych; MRCPGP

Associate Medical Director

for Old Age Psychiatry

Greater Glasgow and Clyde Health Board.

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The North Dementia Forum

The Forum is a network of professionals, carers and individuals in North Glasgow who strive to improve the quality of care for people with dementia and their carers. For “Dementia Awareness Week” and “Carers Week” in 2009, the Forum commissioned a 35 minute play to tour around community venues.

The play, ***Changed Days***, aimed to show in a thought provoking and entertaining way, how local people can support someone with dementia and their carers . It showed scenes from a family where a daughter and grandson are struggling to cope with the father/grandfather who has moderate vascular dementia e.g. scenes within the family home, local corner shop, doctor’s surgery, a bus, hospital A&E and a local bowling club. It also provided some insight into how the person with dementia struggles to make sense of what is happening to them.

Due to the play’s success, it was decided to make a film version to take the message to a wider audience. At the launch of the DVD, ***Changed Days***, at the Glasgow Film Theatre on 25 November 2010, there was a request for guidance on how it could be used for training purposes.

Creation of the film

Alison Couston, who wrote the original script, spent a considerable amount of time with members of the North Dementia Forum and with a group of carers of people with dementia as well as consulting a wide range of dementia related material produced by Alzheimer Scotland. Her writing skills combined with those of David Goodall as a film director have

produced a very moving, realistic and powerful insight into the impact of dementia in everyday life.

General Awareness Raising

The aim of the DVD is to raise awareness among the general public about the implications of dementia for those who have the illness and for their carers, and to show how family, friends and neighbours can all provide much needed support. It also has a strong message for those in the care sector who have the responsibility for providing high quality services whether it be in hospital or in the community and for those in the private and public sectors whether it be a shop keeper or a bus driver.

During the course of the illness, both the person with dementia and their carer(s) will come into contact with a wide range of people and it is all too easy to forget they are individuals going through a very traumatic experience.

What is dementia?

Dementia is the generic term covering a number of brain related illnesses some of which are:

Alzheimer’s disease (causes more than half of dementia cases)

Vascular dementia (second most common)

Lewy body dementia

Alcohol related dementia (includes Korsakoff’s syndrome)

Frontotemporal Dementia and Pick’s disease and others

We tend to think of dementia as a condition affecting people over the age of 65 but it can occur earlier in many cases: then it is referred to as ***Early Onset Dementia***

These illnesses cause brain cells to die off far more rapidly than is normal. How the illness

affects someone will depend on which area of the brain is damaged, how the person reacts as an individual and the local and physical environment. It is a progressive illness for which there is currently no cure; unlike damaged skin, brain cells cannot re-grow. Nevertheless, a great deal of medical research is ongoing into causes and cures. You may notice many features, one of the main ones being memory loss.

Short-term memory loss

The most common type of memory loss will be *short-term memory* loss, where people sometimes literally cannot remember things from one hour or minute to the next. For example, you may find the person you are working with or caring for does not remember that they have just eaten, wonders where they are, or perhaps does not remember where the toilet is. You may be asked the same question repeatedly as the person might not remember asking the question in the first place or hearing the answer. All of this is caused by damage to the temporal lobes of the brain: located at each side of the temples, these lobes are responsible for short-term memory.

Long-term memory loss

The person may surprise you by having no recollection of something that happened a moment ago yet can talk at great length about things that happened as far back as childhood. This *long-term memory* usually lasts much longer than short-term memory as it is held in a different part of the brain and may not be affected until the later stages of the illness. Memory is not only about remembering events, it is also about being able to remember how to

do things for **yourself**, remembering that you need to get up in the morning, wash and dress, eat and drink, keep cool/warm, go to the toilet. It is about everyday tasks, like cleaning the house, shopping and cooking. Memory also forms an important aspect of your identity - remembering your family, your role within it, your likes and dislikes, your attitudes, hobbies or fears. It encompasses everything that makes you a **unique** individual. All of this makes dementia a very individual experience.



Using the film for Learning and Training

The film breaks down into 10 key scenes:

1. **The Shop** Davie finds his own way to the local corner shop but forgets what he needs.
2. **The Flat** Davie's daughter and grandson try to engage with him.
3. **The Buttons** Davie struggles to button up his jacket.
4. **The Bus** Linda tries to cope with both the bus driver and her father who has lost his bus pass.
5. **At the GP's (First Visit)** Father and daughter in confrontation.
6. **At the Hospital** Davie found by Police wandering out during the night in his pyjamas.

- 7. **Visit from Marie** Neighbour pops in for a quick visit.
- 8. **At the GP's (Second Visit)** Diagnosis.
- 9. **The Bowling Club and a Break from Caring** Davie visits an old haunt.
- 10. **Marie's second visit** Relaxation all round.

The Three Zones for looking at each scene.



Observation Zone
Suggested comments with key words *italicised* to highlight their importance and to encourage you to reflect on their significance.



Thinking Zone
Questions to explore key themes around dementia.



Learning Zone
Points to encourage participants to reflect on.

User Notes

The ten sections can be used as one continuous learning programme or individually to meet local or personal requirements: they are designed so that you can simply follow each scene as it is in the film or you can focus on one or two scenes which reflect your own area of interest, whether you are a carer, a family member, a friend or a professional worker.

Remember to always see each person as an individual i.e. the person with dementia and their carer, and take into consideration all aspects of their life – health, family, friends and interests.

Practical suggestions may work well for one person and not for another. Dementia can affect anyone and does not discriminate.



Scene 1 The Shop



1. Davie is able to find his own way to the shop as he has **a daily routine** which is important as it allows him to be independent as well as giving him a sense of security.
2. Despite the above, Davie has difficulty in **recognising faces**, even those he has known for many years, and **remembering lists** (shopping). This is why it is helpful when you meet someone who has dementia to say who you are and avoid causing embarrassment. Marie's advice to **write things down** is a practical suggestion.
3. When Marie sees that Davie is struggling, she tries to assist in a patient and friendly manner, giving him simple clues to aid his memory.
4. The Shop Assistant demonstrates a lack of **respect and dignity** especially in referring to Davie as a "Weirdo". She makes **assumptions** without knowing the facts, showing astonishment that Davie has not had his breakfast despite it being the afternoon. It can be very difficult for someone with dementia to have any **realistic sense of time**: they may not recognise many of the key time indicators we all take for granted – morning sun, the rush hour, clocks, street lights ...
5. On his way back home, Davie passes a Swing Park which triggers his memory. People with dementia tend to depend on their long term memory more than the short term: hence the importance of **reminiscence (memories)**.



1. What impact do signing, facial expressions and body language have in communicating with someone who has dementia?
2. How do *you* feel when you cannot communicate in a foreign country?
3. What might Davie be feeling?



1. The nature of the illness means people with dementia can routinely experience stigma and discrimination in daily living. Look at the person, not the illness, by challenging perceived attitudes towards dementia and avoiding stigma.

2. By developing your knowledge of dementia you can gain insight into how the world presents itself to the person with dementia.
3. Learning how to communicate with someone diagnosed with dementia can overcome barriers to effective communication (see “12 Helpful Hints”, Page 15).

Scene 2 *The Flat*



1. Davie just sits there with a blank face, the clock ticking away. He does not have the **stimuli** to motivate himself into wanting to do something.
2. Even the arrival of Gordon does not prompt him to have a normal **conversation** and Gordon finds it a challenge to decide how to interact with his grandfather.
3. Davie happily accepts the offer of a game of Snap but becomes **frustrated** when he realises he is **not in control**. Gordon **assumed** his grandfather remembered how to play the game, not appreciating that it requires the use of **short term memory** which has been impaired.
4. When Davie vents his **frustration and annoyance**, Gordon does not challenge him or argue but quietly **withdraws**, leaving the room.
5. Linda finds her father settled again but he has become **confused**, mistaking Linda for his wife, Mary, who had died some years ago and thinking Gordon was a competitor for Mary's favours.
6. **Mood swings, annoyance and frustration** are all key indicators of how the person with dementia is struggling to make sense of reality or to communicate how they are feeling.
7. It is common for someone with dementia to lose all **facial recognition**, not recognising someone they have been living with for many, many Years.
8. When Linda tells Davie that his wife, Mary, had passed away, he reacts as if **hearing the news for the first time**.



1. Why does the game of Snap break down? Was it an appropriate activity to suggest?
2. Why does Gordon leave the room?
3. How do you react when you are frightened or vulnerable?
4. Why did Davie react as he did on hearing about his wife's death?



1. Consider how you would encourage someone with dementia to take part in activities.
2. Think about how *you* would like to be treated when frightened and vulnerable.
3. Someone with dementia can relive events held in their long-term memory such as the death of a loved one.
4. Appreciate that the person with dementia's perception of reality may not be the same as yours.
5. Think about how difficult and stressful it must be for carers when the person they care for may not recognise them, can be challenging or behave aggressively.

Scene 3 *The Buttons*



1. Davie vents his frustration by swearing and losing his temper at not being able to button his jacket – a simple, **automatic function** for him before his illness. Don't assume that someone with dementia will remember simple, routine tasks such as how to put a jumper on or tie shoe laces.
2. People with dementia can even forget that they have just eaten or **forget to eat** which can be detrimental to their general health.
3. Linda reminds Davie that he didn't used to swear like that. There are times when people lose some inhibitions and swearing is not uncommon, even when such behaviour would have been totally unacceptable to them before the onset of dementia. Linda feels for her father, shows compassion and love for him.
4. For carers, the person's loss of short term memory adds to the challenge of looking after someone who is unaware of their illness.

5. Back in the room, Davie has **completely forgotten what has just occurred** and readily accepts another invitation for a walk in the park which Linda accepts with quiet resignation.



1. How has Davie's illness affected simple daily tasks?
2. What feelings does Linda have and what influences them?



1. It is important to try and maintain a daily routine. Social interaction and physical activity like walking in the park all help to maintain skill levels. How would you do this?
2. Dementia can significantly affect a person's mood or decision making. The person may act irrationally or out of character which can be difficult for carers to come to terms with or manage.
3. It is important to recognise that carers can feel they have *already lost* their loved one.

Scene 4 *The Bus*



1. Davie is **confused** about the request to show his bus pass and Linda suggests he looks in his wallet but he produces his hanky.
2. The bus driver does not **understand** the situation and becomes annoyed.
3. Davie wanders off and has already **forgotten** the incident, **reminiscing** and leaving Linda **struggling** to cope, feeling **embarrassed** and **at her wits' end**.
4. A person with dementia does not always understand **routine questions** or **everyday social skills which we all take for granted**.



1. If Linda carried her Dad's bus pass for him, might this disempower him, taking away his ability to do things for himself?
2. How would the driver have reacted if Davie had been on crutches or in a wheelchair?

3. Why did no-one on the bus support Linda or Davie?
4. What do you think is the impact of the incident on the person with dementia and on the carer?



1. Dementia is an invisible illness. People tend to see it as a condition associated with old age but it can affect *any* age.
2. Think about how giving too much information can be confusing.
3. People with dementia can find it difficult to process information quickly (see “12 Helpful Hints”, Page 15).
4. It is important to enable people with dementia to do as much for themselves as possible to maintain maximum independence. However, it is also important to protect people with dementia to ensure they are treated with dignity and respect.
5. Providing ongoing support and achieving the balancing act of rights and protection for someone with dementia can be stressful for carers.

Scene 5 *At the GP's (First Visit)*



1. Davie sits in the Waiting Area ***indifferent to and unaware of his surroundings*** while Linda ***appears to have switched off*** and is reading a magazine.
2. Again Davie is unable to remember anything about the incident on the bus and ***disagrees quite strongly that he has a memory problem*** or that there are times when things are amiss (this is quite a common feature).
3. Although Davie is ***stumped*** by some of the GP's questions he is able to ***avoid*** directly answering some of them.
4. Davie demonstrates ***a lack of awareness*** of the time of the year and is unable to see the contradiction in that he thinks it is winter, yet he is dressed for the summer.
5. Both Linda and her father ***display deep feelings of frustration and annoyance***. It can be very difficult for both carers and professionals to determine how the person with dementia is actually thinking and whether they are in the present or back in the past.

6. The GP advises *Linda* that she ***must look after herself***.



1. What is your response when you've forgotten something and are put on the spot?
2. If a person does not accept they have a *memory problem*, what challenges could it throw up?
3. Who could Linda speak to?
4. Is there a conflict of confidentiality?
5. Try to understand how the person with dementia and the carer feel in such situations.



1. There are people with dementia living in the community with no formal diagnosis.

Scene 6 *At the Hospital*



1. While Davie ***lacks awareness of his situation***, Linda shows signs of ***acute embarrassment*** and being ***physically and emotionally drained***.
2. The busy hospital staff did not seem to acknowledge their predicament.
3. It is quite a common occurrence for someone with dementia to go off ***“wandering” with a purpose*** - Davie just thought he was off to work as usual!



1. Could the hospital staff have acted/behaved differently?
2. Why do people with dementia *“wander”*?
3. Is there anything that can be done to prevent someone ***“wandering”*** off? Does this scenario demonstrate possible ethical issues?



1. Think about the restrictions facing professional staff, such as the hospital staff and the policeman, due to red tape e.g. the issue of confidentiality.

Scene 7 *Visit from Marie*



1. When Marie pops in for a visit, Davie has **a moment of insight** when he remembers what has happened in the shop. Levels of insight may never be lost.
2. It should not be assumed that someone with dementia will never recall a face or a memory.
3. He also shows his appreciation for Marie's visit by observing that Linda **does not have many visitors**.



1. Why do you think people stop visiting someone with dementia?
2. How does Marie's visit help both Davie and Linda?



1. Consider what *you* could do to maintain social contact.

Scene 8 *At the GP's (Second Visit)*



1. Davie is told he has **vascular dementia** and the GP explains what that is.
2. The GP also explains what **services** may be available after a **comprehensive assessment** and encourages maintaining the current routines and social activities.
3. The GP suggests that other family members should **help shoulder some of the caring role** by, for example, taking Davie out.



1. What other types of dementia are there?
2. What do you think is going through Linda's mind at this stage?
3. What could be the advantages and disadvantages of the person with dementia being present at the point of the diagnosis being given?
4. How can family, friends and neighbours provide support?



1. Why do you think the GP has recommended that Davie maintains routine and social activities?
2. Where can you find information on dementia and local support services?

Scene 9 *The Bowling Club and a Break from Caring*



1. Linda encourages Gordon to invite Davie to the Bowling Club. While she appreciates this will give her some time to herself, she is also anxious as to whether it will work or not.
2. Davie, however, is in his element at the Bowling Club.
3. Previously, the bus driver did not understand dementia whereas the bar maid does and changes her attitude accordingly.
4. Marie **shares her feelings** with Linda and refers to her experience with her own mother who had dementia when on occasions *she “just wanted to choke her”*.
5. Marie also points out **sources of help**.



1. What is it that Davie finds so enjoyable at the Bowling Club?
2. Did you notice any difference in body language and behaviour in relation to both Linda (at home) and Davie (in the Bowling Club)?
3. What do you think about Marie’s confession about “*wanting to choke*” her mother? Would you see this as a cry for help or, in some instances, a sign of risk?
4. How easy do you think it is for carers to *get a break from caring*?



1. People with dementia are more likely to feel safe in an environment which has long term significance for them i.e. familiar faces and memories.
2. Supporting a person with dementia can be extremely stressful. Carers need information and support at the time of diagnosis to be able to provide care and stay well.

4. Carers will feel valued and properly supported in their role if they know where to find help which can be provided by local services or through friends and family.

Scene 10 *Marie's Second Visit*



1. When Marie comes round to let Linda out for the night, everyone is relaxed and enjoying the friendly banter and jokes.
2. Davie is at his best when talking about the old days, demonstrating again the **importance of reminiscence (memories)**.
3. Linda looks more relaxed when she leaves the house.



1. Why do you think Davie feels more relaxed talking about his past?
2. What is it about Marie's approach and communication that helps Davie to relax?
3. Who benefits from Marie's visit?



1. Reminiscence encourages people with dementia to interact with others and build friendships.
2. Coming to terms with a dementia diagnosis can make it difficult for carers to accept help.
3. A short break from caring can improve the quality of life for the carer and the person with dementia.

And Finally



1. What are the three most important things **you** have learned from watching this film?
2. What three things could **you** do as an individual or an organisation to support people with dementia and their carers?



(Above can be downloaded in leaflet or poster format from www.goodmorning.org.uk)

1. Be calm and patient.
2. Face the person, speak clearly and slowly.
3. Make sure that you have their attention by gently touching their arm and saying their name.
4. Use short, simple sentences and say exactly what you mean.
5. Try to get one idea across at a time.
6. Allow plenty of time for the person to take in what you are saying and to reply.
7. Try not to confuse or embarrass the person by correcting them bluntly.
8. Use questions which ask for a simple answer.
9. Don't ask questions which test their memory, e.g. "who am I?" or "what did you do yesterday?"
10. Talk about familiar people, places and ideas.
11. Use the names of the people you are talking about instead of "he" or "she". It will remind the person of who you are talking about.
12. Use facial expressions and hand gestures to make yourself understood.

Some General Advice

If you notice someone is having difficulties in remembering, be patient and think what you might be able to do to help.

Give people with dementia time to think.

Use short, familiar words and simple sentences. Dementia isn't infectious! Stay in touch with friends and neighbours who develop the illness.

Don't be embarrassed and avoid someone because you can't think of the right thing to say. Don't be put off by what seems to be odd behaviour.

Treat the person with dementia as you've always done – they are still the same person.

Actions speak louder than words!

A smile, touch or gesture can be just as important in getting the message across and showing that you care.

Sometimes simply holding the person's hand when you talk to them can be very reassuring.

A partnership approach

Family, carers and friends should be seen as **partners in care** who not only know the person but can assist with helping someone to eat, to accompany the person with dementia for consultations or even to stay overnight when one to one attention may be needed.



For further information, please contact:

Julia McCrum Tel: 0141 531 8858 Email: julia.mccrum@ggc.scot.nhs.uk

John P Kelly Tel: 0141 931 5423 Email: john.kelly2@ntlworld.com

The User Notes are available to download in A4 size (PDF) from: www.goodmorning.org.uk

The North Dementia Forum welcomes your views on the film and the User Notes as well as any suggestions for improvements.



*Caring about people with dementia
and their carers*

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The North Dementia Forum would like to see this document used as widely as possible but asks that it be acknowledged as the author should it or any of part of it be used by a third party.