



# Guidance for film-makers working with people with dementia

## Key messages

- Film is a powerful medium that when used positively can make a huge contribution to increasing understanding about dementia.
- Done badly, the process of making a film and the end result can be disempowering and increase stigma.
- Involving people with dementia at every stage in the film-making process will ensure that the film reflects the messages that people with dementia want others to hear.

## Why make films about people with dementia?

People want to make films about people with dementia for a variety of reasons:

- To raise awareness of dementia, generally or for targeted audiences
- To challenge stigma and misunderstandings about dementia
- To show what people with dementia can do
- To highlight a particular piece of work that people with dementia have been involved in
- To raise a particular issue of concern to people living with dementia.

In our first film project, we wanted to make films about dementia by people with dementia to show what people with dementia can do and to challenge stigma. But we changed our focus after being told by one man: 'Lovely idea but can't it be more interesting? I am so bored of dementia.' So in the end we made films about topics that people were passionate about. We still challenged stigma but in a different and I suspect much more powerful way.

*Steve Milton, Innovations in Dementia*

## **Planning is key – give lots of time for planning and preparation**

Film-makers should involve participants as much as possible and listen to people's ideas. The more people with dementia are involved in the planning for a film, the more likely they are to:

- Understand the process
- Be able to give informed consent.
- Have a sense of ownership of the finished product: ideally, people with dementia should see themselves as collaborators in the film-making process, not passive contributors.

Film-makers should be clear about the outcomes they want – and the messages the film should communicate – and discuss these with people with dementia during the recruitment process.

People with dementia will also need to know how filming will work and what is expected of them.

To enable good planning and preparation, film-makers should take time to get to know the participants.

## **Recruitment**

People with dementia might want to get involved for a variety of reasons:

- They have experience of film-making already.
- They see it as an interesting thing to get involved in.
- They have a message they want to get across. This might be about dementia or about some other topic or issue they feel strongly about.

When contacting a group of people with dementia, be clear about:

- Who you are
- Why you are making the film
- What messages you want to the film to have
- Who is funding the film
- Where it will be shown – and who the target audience is
- What roles in the film-making process you are looking for people to fill
- What kind of support is available to people who want to get involved
- How people with dementia will be portrayed.

## The consent process

Getting consent to be filmed is not a tick-box exercise. You will need plenty of time to talk through the issues and make sure everyone understands the purpose of the film and how it will be made.

For the film-makers and organisations commissioning the film, not having a good consent process in place means that showing the film may not be possible.

People with dementia may change their minds about giving consent – or forget they gave consent. The consent process is continuous. Be aware of people's behaviour and what they say about being filmed. If you get the impression during the course of filming that a person is not understanding what is going on or is unhappy, you should stop filming and check. Some people might need to be reminded of the message and the purpose of filming. Bear in mind that people's capacity can vary from day to day; a person might understand something tomorrow they struggled to grasp today.

Any consent process should keep bureaucracy to a minimum.

People being filmed need to understand the nature of the film and how it will be used. Don't forget that there is still a lot of stigma about dementia. Being seen in a film about dementia is a public declaration that you have the condition.

In particular, people need to understand that:

- There is little control over how a film is used a film once it has been distributed (especially over the internet).
- It may still be being shown in many years' time.

## Involving family and friends

- Don't forget that dementia can have a huge impact on family members, who may have concerns about:
  - The way a person might be portrayed on film
  - Whether they want such a public declaration
  - Whether the person truly has capacity to consent to the process
  - Whether the film should be shown if the person gets very ill or dies.

Family and friends often appear in films alongside people with dementia or get involved in other aspects of the film-making process.

This can help carers feel that the film and the process of making it are as 'safe' as possible for the person with dementia.

The carer can also act as a backup to explain the process and ensure that the person has understood the consequences of getting involved.

## Message, tone and content

There is no denying that dementia is a condition that has a profound effect on those with a diagnosis and those around them.

Some people will be happy to get involved in a film that explores the darker sides of dementia. They will feel that it is important to raise awareness of the problems and difficulties they are facing.

However, this has been the 'story' that has been told about dementia for many years. Others will be keen to support a new story which offers a more positive portrayal of people with dementia living well with their condition.

You must be upfront with people about the message – and how people with dementia will be portrayed.

One group we work with had been asked to appear in a film being made by their local council. The group is well known for its positive approach to living with dementia. On being shown the rough edit, they were horrified to find that text captions about dementia had been overlaid onto gravestones and the whole film was set to a doom soundtrack in a minor key. Needless to say, the group withdrew their consent and the whole thing had to be re-edited.

*Steve Milton, Innovations in Dementia*

## The filming process

Make sure that people with dementia are enjoying themselves.

- Allow enough time for filming – it may take longer than you expect.
- Don't be in a rush – take your time and give people with dementia plenty of time to speak.
- Create a calm, comfortable and relaxed atmosphere.
- Reduce noise and avoid lots of conversations happening at once.
- Remove distractions and avoid being interrupted.
- Consider the role of professionals and families in supporting people with dementia during the process.
- If the film-making is boring or confusing, people may withdraw from the process.

All filming sessions were limited to half-days.

Dementia can make it harder for people to maintain focus and they become tired more easily. Working in short bursts enabled us to give people the best chance of keeping engaged with the task in hand.

Building relationships and encouraging people themselves to engage with the camera and sound equipment from the first meeting on made it easier for people to relax during the filming process.

*Steve Milton, Innovations in Dementia*

We had encouraged participants to view footage as we were filming, which meant that when it came to the first screening people were accustomed to seeing and hearing themselves on film.

This may have made it easier for people to focus on the task of editing, rather than being preoccupied with the novelty of their own image on screen.

*Steve Milton, Innovations in dementia*

During film-making, some people with dementia may get emotional. Consider how you will support people through their emotions. Ensure that you have the person's consent to use footage of emotions in the film.

## **The editing process and final sign-off**

Where possible, people in the film should have a way of contributing to the editing process or give feedback.

How much people can be involved in the editing process will depend on timeframes and the interests and abilities of the participants.

It is important to explain that not all footage will appear in the final film. People may have a particular interest in a piece of filming that is not used in the final film. Misunderstandings and upset can be avoided by involving participants as much as possible.

In an ideal situation, the people with dementia who have contributed to the film should give approval to the final version of the film.

Consider showing the film to as many participants and supporting family, friends and professionals as possible to obtain final consent for release.

We were anxious to ensure that decisions about what was left in and what was taken out were driven by participants. Thus the first 20-minute edit was done to ensure that the content was representative of the entire footage.

For example, we deliberately left in scenes where people were clearly struggling with the effects of dementia.

It would have been easy, and was sometimes, tempting to edit in such a way as to give the impression that people were less affected by their dementia than they really were.

In every case, participants were keen that these scenes were kept in and the representations on screen were authentic and honest.

*Steve Milton, Innovations in Dementia*

## See also...

*Telling our stories: a guide to film-making with people with dementia.* Available at [www.innovationsindementia.org.uk/Telling%20our%20stories.pdf](http://www.innovationsindementia.org.uk/Telling%20our%20stories.pdf)

This guide was created  
with the help of people  
with dementia from the  
JRF Sounding Board

DEEP guides aim to support the involvement of people with dementia. Some are aimed at DEEP groups, others at organisations wanting to work well with people with dementia. They have all been co-produced with people with dementia and will be updated regularly throughout the project. Suggestions for new guides are welcome – contact Rachael Litherland at Innovations in Dementia: email [rachael@myid.org.uk](mailto:rachael@myid.org.uk) or telephone 01392 420076.

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