

Telling our stories: using film to hear the voices of people with dementia

This booklet is based on our experiences of a filming workshop at the Club for younger people with dementia at Age Concern Woodley in October 2011.

The workshop was run by filmmakers from Be Inspired Films who filmed, edited and created our film during the two-day workshop.

The project was funded by Big Lottery 'Awards for All'.

The film – called My Life, My Dementia, My Club - can be seen at www.myid.org.uk/films



We want to encourage services for people with dementia and other groups to use film as a powerful way to ensure that people's voices are heard

Why use film?

Film is an incredibly powerful medium – through film people who are not usually heard can be seen telling their stories in their own words.

While dementia does have an effect on communication, many people with dementia retain the ability to communicate even if their dementia is quite progressed. Many people with dementia have a story to tell, or something they want to say. Their voices are a powerful tool for challenging stigma and negative stereotypes. Some people with dementia who engage in public speaking tell us that because they can often be unsure on a day-to-day basis how they will feel, they can become very worried about their ability to “perform” on the day. By using film, we can enable a wider range of people with dementia to have a say, in comfort, and in their own time, and in a form that allows their voice to be heard forever.



For example, people looking for information online are increasingly using sites like YouTube. Having a film available enables you to reach a wider audience.

Ways you can use film

- A film can be used to promote your service or activity to a wider audience.
- A film about your service can be used to encourage and reassure people with dementia who are unsure about coming along to your group.
- Film can be used to challenge the stigma, myths and stereotypes that surround dementia.
- The process of making a film can be highly enjoyable, and be a meaningful and creative activity for people with dementia.
- Most importantly ... a film can be used to allow people with dementia to tell their own stories and have a say.



How to get started?

Editing lots of footage is time consuming and can be expensive. If you plan what you want to film, you will have a lot less editing to do.

You can do some or all of the filming yourselves with relatively cheap cameras. This will not look as good as something done with professional help, but is an option if you are on a really tight budget.

Tip: Plan, plan, plan – decide what message you want from the film and how you are going to portray this.

How long will it take?

If you spend a bit of time planning and introducing the idea to the group, filming need not take too long – maybe just a day.

The process of editing the film will take longer – and you need to allow time for showing the footage to the group, and listening to their comments and suggestions.

Tip: Don't aim to high – aim for a film of about 5 minutes at the most. Remember that the time limit for YouTube is 10 minutes.

Tip: We recommend some training for staff, finding a gifted volunteer or working with a friendly professional filmmaker. If you are very lucky you may even have some people with dementia with experience of film making within your group.

Involving people with dementia

Any group of people with dementia will include a variety of people with different views, skills, abilities and experiences.

Everyone in the group can be involved in some way.

People can:

- Help decide what the film is to be about.
- Help decide what the key messages are.
- Help decide what will be filmed, and how, and where.
- Help with scripting.
- Talk on film.
- Record their stories or message as a voiceover (ie just as sound)
- Be filmed doing things.
- Do the filming.
- Help to make editing decisions.
- Help to decide on titles.



Consent

Getting consent when making a film is very important.

Be aware that films can have a life of their own once placed on the internet - they can be copied and used by many people. DVDs will be distributed widely and used for many years to come. This is one of the powerful things about film – but it is also something to think about when getting consent from people who appear in the film. For these reasons, involving families and friends in the consent process is wise.

Where possible, get written consent. You will need to ask people who are appearing in the film to sign a form indicating that they understand the process and they understand how and where the film may be shown.

Filming is a very interactive process. While filming it will probably become obvious if people don't want to appear on film. Showing the footage back to people ensures that they understand and remember that a film is being made.

Tip: Even people who do not want to appear on the film can be involved in the process. Alternatively, they may be happy for their voice to be heard without their face.

Obscuring the identity of people who appear in your film, even if they are in the background, is very difficult. People should be made aware and reminded that they can withdraw consent up to the point at which the film is released. Remember that once it is online – it is there forever.

Ways in which you can involve professionals

Tip: Get professional advice early on. Even the best editor can't make a wonderful film from bad footage.

Depending on the quality of the film you want to make, and the experience and skills of staff, volunteers, or the group itself, it is a good idea to engage the services of a professional filmmaker.

As well as bringing professional expertise, they will also be able to bring professional equipment, which can make a huge difference to the look of your film.

Try to find someone approachable and friendly. Ask around for information about local filmmakers who are used to working at community level – your local arts centre would be a good place to start.



If you are on a really tight budget but still feel you need some more knowledgeable input, you might also consider your local college or university which might run film making courses.

Think about which tasks you want them to do:

- Do you want them to do the filming, or just the editing?
- Do you just want them to help you plan your film?
- Do you just want them to advise you on filming or editing?

Choosing the right people to work with

It is likely that you will need some professional (or gifted amateur) help. In particular a skilled editor will know how to produce an engaging film.

Things to think about when working with professionals:

- Make sure they are genuinely interested in making your film – not making the film they think you need.
- Make sure that they understand about dementia and how different people will want to contribute to the film making process.
- Make sure they have the time to get to know people – and that people know and trust them
- Make sure they are happy for you to have the final say about what goes into the film.
- Have a look at some of the other films they have made and talk to them about the process.



Equipment

Depending on the quality of the final film you are after, you can do some or all of the filming yourselves – there are good quality and relatively inexpensive video cameras on the market.

Sound: The voice of people with dementia is very important.

Having a good microphone and recording sound in a quiet place are key. Watch out for background noise, which can not only distract or mask what the speaker is saying, but can also make editing very difficult. Make sure the camera you use has an input for an external microphone – this makes a huge difference to the finished product.

If you are filming a group activity, where the clarity of individual voices against background sound is relatively unimportant, you can use the camera's microphone. But if you want to catch individual voices use an external microphone.

Tip: For more information on the best equipment to get on a budget and for further tips and guidance on creating your own films you can visit www.learntocreatevideo.co.uk



You can buy very inexpensive microphones that clip on to clothing of the person who is talking. This is ideal if one person is talking to camera. Slightly more expensive, but important if you want to film a group in conversation, is a shotgun microphone that you hold in your hand and point at the person who is talking.

Tripod: A tripod can make a big difference to the stability of your film. Shaking images can be very distracting to the viewer.

Lighting: Think about lighting – natural light is fine, but hard to control and can be quite harsh. There are relatively inexpensive lights for filming available if you need to film away from a sufficient source of natural light, and sometimes domestic or office lamps can do a good job too!

Tip: We learnt that many people find it easier to talk naturally without a camera. Consider recording people's stories and using it as a narrative over still photos or film of activities.

Still photos: Still photos can be just as effective as moving ones. If you are starting out on your own, linking still photos together with software can be very attractive. People with dementia can be involved in taking the photos, choosing which ones to include, and adding captions.

Software: There are a variety of software packages that help you edit your film. These will vary in price and functionality.