

Lighting Up

ARTISTS WORKING WITH PEOPLE LIVING WITH DEMENTIA

Joining Pack for new artists

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1. Introduction

Welcome to the documentation for artists interested in joining *Lighting Up*, which we call our Joining Pack. Thank you for being interested in joining us – we hope that what you read will encourage you to join this exciting project.

The Pack starts with some information about dementia, and outlines our approach to working with people who are living with dementia. This is followed by some general guidance on working with participants.

After sections on evaluation and about *Lighting Up* as an organisation, it moves on to describe how the actual process of joining us works.

The Pack aims to give you an overall view, and help you to decide whether you would like to move on to the joining process. At the stage of reading this Pack nearly all artists express doubts about whether they will be suitable, but once they have been to one of the *Lighting Up* sessions (this happens as part of the joining process) they realise, almost inevitably, that it is right for them, and right for *Lighting Up* too!

Please see also the *Lighting Up* website www.lightingup.org.uk for:

- information about *Lighting Up* on the Home Page
- information about joining us, which includes the combined 'job description' and 'person specification', on the page *Like to be a Lighting Up Artist?*
- our Mission Statement and Aims, which are on the *Aims Page*.

If anything in this Pack is not clear, or if you would like to talk more about joining us, please contact the person you initially talked with, or the *Lighting Up* trustee responsible for artist recruitment, Jo Matthews, whose phone number is on the contact section at the end of this Pack.

2. About dementia

Some facts about the condition

This section gives some information about dementia. The focus is mainly on medical-based information. The next section refers to approaches to working with people who have dementia, which focus more on the social effects of dementia rather than the condition and the disabilities it causes.

- ◆ Dementia can seriously affect a person's ability to manage daily living activities – the most significant impairment is memory, but all aspects of living can be affected.
- ◆ These impairments are caused by damage to the person's brain, which in turn is caused by one or more of a number of conditions that are known collectively as 'dementia'. The best known, and most common of these conditions or causes is Alzheimer's disease – other fairly common causes include vascular dementia, dementia with Lewy bodies and Pick's disease, and there are many less well-known causes.
- ◆ Different parts of people's brains can be affected to different extents, so some parts can be working fairly well while other parts are seriously impaired. The way that each part of the brain performs can change over time. While variations from one day to the next are fairly common, some forms of dementia can lead to unpredictable changes.
- ◆ The reason why people get most kinds of dementia is still not understood. Generally it is not a condition that can be inherited.
- ◆ About 750,000 people in the UK have dementia. The likelihood of a person getting dementia increases as they get older - about one third of people aged over 90 have dementia. A small number of people start dementia when they are significantly younger (*source: Alzheimer's Society*).
- ◆ For most people the dementia is fairly mild when it is detected but it is a condition that progresses over time. It can pass through a number of stages and can lead to total disablement. However, many people's lives end through other causes before this stage is reached.

- ◆ When it is thought that a person may have dementia they are normally referred by their GP to specialist medical services for diagnosis, but there are no physical tests (eg blood tests or scans) that can give an absolute diagnosis.
- ◆ Some drugs can slow down the progress of some types of dementia.
- ◆ There is no known cure at present.
- ◆ There is also a condition called 'mild cognitive impairment' – this is when an older person becomes mildly forgetful or mildly confused – this is one of the many normal processes of ageing that affect some but not all older people, and is not the same as dementia.

Living with dementia

The information above tells about the *effects* of dementia and its associated *disabilities*. In common with views about physical and other disabilities, approaches to dementia are shifting away from this disability-based model.

The alternative approach, known as *living with dementia*, recognises that every person who has dementia remains an individual, and retains abilities, likes and dislikes etc., even though these may not be easy to detect. Thus the emphasis moves away from *disabilities* to focus on the *lives* of people with dementia and their carers. Instead, the emphasis is on helping people affected by dementia to retain some sense of meaning and dignity at a time when they may be feeling that their lives are falling apart.

In *Lighting Up* we have made our approach to dementia clear by adopting the logo *Artists working with people living with dementia*.

Further information about dementia

If you are interested in finding out more about dementia, we suggest The Alzheimer's Society website www.alzheimers.org.uk as a valuable and readable source, especially the section headed *About dementia*. A free e-learning course about dementia can be accessed at www.scie.org.uk/publications/elearning/dementia.

3. *Lighting Up* sessions in practice

We work at several venues across Bristol some of which are organised in conjunction with Alzheimer's Society. We also work with some people living in extra-care housing.

The number of participants can vary from around 6 to up to say 25. The number of artists varies too, but we aim for a ratio of about one artist to 2 participants.

Much consideration is put into the nature of the activities offered to the participants. The artists have a short meeting at the end of each session to plan the activity for the forthcoming session. The highest value is given to the opportunity for the individual participants to express themselves creatively and the activities are designed to provide a stimulus that would fully engage all of the participants whatever their ability. The artists sit alongside participants and engage in dialogue with the aim of allowing them the freedom to express their preferences as their work progresses through a process of exploration and development. The input of the artists varies according to the specific needs of the individual person with dementia and/or the carer they are working with.

A very wide range of activities is available and these are reappraised and added to all the time. The *Lighting Up* coordinator at each venue ensures that the tools and materials are of a high quality and in excellent condition.

Towards the end of the 2-hour session there is often a pause when all participants enjoy sharing what they have done, usually a time of satisfaction and some humour.

4. Participants

People who have dementia

A person's dementia is not always obvious when we first meet them. This can be because they have good social skills or their memory is reasonably intact; other elements of their dementia can be less obvious. But we soon begin to recognise the areas where the person has difficulty (sometimes the person or their carer tells us), and this guides our response.

Some *Lighting Up* sessions are quiet and calm, while participants and artists concentrate on what they are doing, but at other times there is a lively interaction that can involve the whole group. But what stands out is that we do not need to know any of the formal details of a person's dementia (for example what kind of dementia they have) because we are responding to the person as we meet them on that particular day.

But we can't claim that everything is easy, for example:

- A person may become withdrawn, in which case it would be so easy to leave them alone. If we did so we would be letting them (and ourselves) down.
- A person who is participating may begin (say) to splash paint around. But instead of holding the person's arms so they can't splash, the skill is to find the reason behind their actions. Perhaps they don't want to paint today? Perhaps the image that people are painting reminds them of something painful? Perhaps they are in pain?
- A person might begin calling out or making loud noises. It is likely that this person is distressed and this is the only way they can express it. Listening and understanding can be quite a challenge while other participants are disturbed by the noise.

We don't have many experiences like this, but what matters is that we try not to be distracted by the actual behaviour and concentrate on understanding the message it gives us. We listen (again through words or facial expression and other body language), aiming to find out what the person needs and wants, which can lead us to knowing how to respond. Above all, wherever we are working, and whoever we are working with, we see each person as an individual and we concentrate on what they *can* do rather than on what they *can't*.

Carers

Carers are usually family members, most often the partner of the person with dementia. They too are *living with dementia*. Many carers have seen major changes in their lives – two people have been together for many years and what was expected to be a peaceful later life has been disrupted by dementia. Relationships change. The carer has to take on full responsibility. Any leisure time may be interrupted by the partner who, for example, continues to ask the same questions, or who may do something that is unsafe if they aren't watched all the time. Although family carers

come with a smile and may give the impression that all is well, some of them are sad, or may be feeling guilty because they can't meet all their partner's needs. Above all they may be exhausted.

Carers can help us enormously to get to know the person they care for, what they like and don't like, what upsets them and so on. But *Lighting Up* also offers something special to the family carer. Some need a bit of time on their own and may want to take part but to work apart from the person they care for. Others enjoy sharing time with their partner, an event that does not happen often in their disordered lives.

The term carer can also refer to a paid carer who brings a person with dementia to *Lighting Up*. In this case it is to be hoped that they too can help us to know how to work with the person they care for. It is normally part of their carer role to participate with the person they bring.

5. Some general points about practice

This section outlines some general issues for practice arising from our approach to dementia and people living with it, as outlined in Section 2.

Working with participants

- See each participant as an individual who is different from every other person.
- Avoid making assumptions about people who have dementia.
- Work to find the positives in each person who has dementia, regardless of their disabilities.
- Listen carefully to carers.

Communicating with people who have dementia

- Work alongside the person and make eye contact where appropriate.
- Listen to all their communication – even if a person seems to be talking 'nonsense'. Make the assumption that they are expressing *something*, and work to understand what it is.
- Use any form of communication that works well – while you are talking or listening to a person who has difficulty communicating, look for the best way to develop understanding – sometimes signs, body language, pictures, song or even noises can be more effective than words.
- Have confidence in your own ability and in the approach that we support. If something seems 'difficult', persevere quietly and you can expect to stay in control of the situation.
- If you are worried or don't know what to do, share it with a colleague artist.

Terminology

To express our focus on individual people rather than on the disabilities of dementia, we use some terms in preference to others:

we use these terms.....	in preference to these terms
dementia	Alzheimer's (or any other specific type of dementia)
person with dementia, <i>or</i> person who has dementia	sufferer <i>or</i> patient
participant (to refer to carers as well as to people who have dementia)	client <i>or</i> user

6. Relationships

Lighting Up's Practice Documentation gives guidance on a number of issues to do with the relationship between artists and participants. This section gives a brief outline of these issues.

Working with people who have dementia

Artists bring their own considerable talents to *Lighting Up* but are not expected to give personal care.

Confidentiality

Artists sometimes hear about the private lives of participants: it is important that this is treated as confidential, and guidance is given during training as to when this should be shared with others.

Boundaries

Lighting Up participants recognise that artists are volunteers, and may see them as friends, but only in the context of *Lighting Up*. There is guidance about avoiding confusion about personal relationships.

Gifts

Artists cannot accept presents from participants – though sometimes it may be appropriate to accept a very small token gift.

7. Does it work?

We find that people who have significant levels of dementia can:

- be helped to choose what to do
- participate and concentrate for up to 2 hours
- express pleasure
- create a piece of work while working individually or at times in a group
- remember what they have done from one month to the next.

Carers have found that they can:

- get pleasure from seeing the person they care for enjoying themselves and getting a sense of achievement
- have some quality time sharing something with the person they care for, which may not happen often in their troubled lives
- gain some sense that the person they care for is less disabled than they had previously believed.

Carers have written:

- “I had no idea my wife was so artistic, I wish we’d discovered this earlier.”
- “I haven’t seen my husband so engrossed in years, he really looks forward to the sessions, it’s a delight.”
- “After the session where we made beads, I found my husband showing our granddaughter how to do it, I never thought I’d see that, it was wonderful.”

These are some of the indicators that our approach to working with people living with dementia is helping us to meet our aims. You can read a fuller outline of how we evaluate ourselves on the *Lighting Up* website, on the page ‘How we work’.

8. *Lighting Up* as an organisation

Lighting Up was formed in 2007. It started as an idea, and when it worked we gave ourselves the name *Lighting Up*. In October 2011, with around 30 artists and three active venues, we created a small charity in the name of *Lighting Up*. As our annual income is less than £5,000, we are not required to register with the Charities Commission, so we do not have a charity number, but we are bound by the same legislation as larger charities.

The charity trustees, some of whom are practising artists, form the management group that coordinates the working of *Lighting Up*. All other practising artists (and some other supporters) are members of the charity, and have the right to vote at annual general meetings (this includes voting for trustees).

Each venue has its own coordinator who is the link between the venue and the *Lighting Up* management group. Some venues share the role of coordinator and other artists share responsibility for planning activities, ensuring the right materials are available etc.

Funding

Lighting Up income comes from donations and fund-raising. This funds materials, training etc. including an element for artists’ expenses. Participants do not pay for attending *Lighting Up* sessions.

9. The joining process

Commitments

Lighting Up commits to:
Ensuring that volunteers:

- find their involvement satisfying
- feel at ease with *Lighting Up*, and that any concerns are heard and responded to
- are offered appropriate induction and ongoing training

Volunteers commit to:

- regularly attending LU sessions (this commitment is subject to normal events such as holidays, illness etc.) - giving a minimum commitment of one year
- participating in induction and relevant ongoing training
- supporting venue coordinators

Involvement is unpaid though there is a budget for individual expenses.

The joining process

This process is described as it applies to volunteer artists, and may be adapted when the potential volunteer is being considered for a different role in *Lighting Up*.

Sometimes artists find it is difficult to be sure that working with *Lighting Up* is right for them until they have actually seen it in action. To overcome this, the following process is designed to integrate as far as possible the informal aspects of familiarisation and the formalities of recruitment.

Stage 1: the initial stage is likely to be a conversation between the artist and a trustee, during which volunteer roles will be discussed, and the artist is helped to clarify whether they wish to progress to the formal recruitment process. They will be asked to read information for potential volunteers on the *Lighting Up* website and especially in this Joining Pack, before proceeding to the next stage. The formal recruitment process is as follows:

Stage 2: the artist will meet two trustees. This will be an information-sharing session. It will confirm the artist's understanding of the commitment they will be making and will provide the opportunity to appreciate the practice and ethos of *Lighting Up*. It will also be the main opportunity to establish suitability on both sides.

Stage 3: the artist will be invited to go to, and participate in a *Lighting Up* session – an artist from that venue will act as their helper for this introductory session

Stage 4: the artist will complete a form giving personal data, which also gives the names of two people (who are not trustees) who have consented to act as personal referees

Stage 5: when satisfactory references have been received and suitability has been agreed, the coordinating trustee will inform the potential volunteer and discuss arrangements for their joining a specific venue. At this stage the artist will be asked to complete a second form giving details of their skills and interests, and details of a person to be contacted in case of emergency.

Notes

- the process will normally be coordinated by the trustee involved at Stage 1. At least one of the trustees involved will be a venue coordinator
- Stage 2 will normally take the form of a meeting between the artist and the two trustees, but in exceptional circumstances this stage could be covered fully in separate conversations
- the venue chosen for the artist to visit at Stage 3 will be selected in response to the convenience/preference of the artist and the needs of *Lighting Up*
- paperwork at Stages 4 and 5 will be arranged by the *Lighting Up* coordinator (or his/her nominee).
- there is an informal review after three months.

10. Contacting *Lighting Up*

This is how to contact us:

Email address: info@lightingup.org.uk

Telephone: Jo Matthews on 0117 968 3510

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