

Lighting Up

ARTISTS WORKING WITH PEOPLE LIVING WITH DEMENTIA

Joining Pack for new artists

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1. Introduction

Welcome to our Joining Pack for artists interested in joining *Lighting Up*. The Pack aims to give you an overall view of how *Lighting Up* works and help you to decide whether you would like to move on to the joining process.

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* Coordinator, Jo Matthews, whose phone number is in the contact section at the end of this Pack.

2. About dementia

Some facts about the condition

- 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.
- Dementia is a collective term for a number of conditions which cause damage to a person's brain. The best known, and most common of these is Alzheimer's disease. Other 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 well while others are seriously impaired. The way that each part of the brain performs can change over time, often gradually but sometimes suddenly and unpredictably.
- The reason people get most kinds of dementia is still not understood.
- The likelihood of a person getting dementia increases as they get older; about one third of people aged over 90 have dementia.
- For most people the dementia is fairly mild when it is detected but the condition progresses over time. It can pass through several stages and can lead to total disablement.
- 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', where an older person becomes mildly forgetful or mildly confused. This is one of the normal processes of ageing and is not the same as dementia.

Living with dementia

Living with dementia is an approach to dementia which moves the emphasis away from the disabilities attendant on the condition to focus instead on the lives of people with dementia and their carers. It recognises that every person with dementia remains an individual, and retains abilities, likes and dislikes etc. even though these may not be easy to detect. The emphasis is on helping people affected by dementia to retain a sense of meaning and dignity in their lives.

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

The Alzheimer's Society website www.alzheimers.org.uk is a valuable and readable source, especially the section headed *About dementia*.

3. *Lighting Up* sessions in practice

We work at venues in Bristol which are organised in partnership with Alzheimer's Society.

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. We use art as a means of contributing to the quality of life of participants and not as an end in itself, so the highest value is given to the opportunity for participants to express themselves creatively. The activities are designed to provide a stimulus that will engage all the participants whatever their ability. The artists sit alongside participants and engage in dialogue, allowing everyone the freedom to express their preferences as their work progresses. The input of the artists varies according to the specific needs of the person with dementia or the carer they are working with.

The artists have a short meeting at the end of each session to plan the activity for the next session. A wide range of activities is offered, 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.

Some *Lighting Up* sessions are quiet and calm, while participants and artists concentrate on what they are doing. At other times there is a lively interaction that can involve the whole group. Towards the end of the 2-hour session there is a pause when all participants enjoy sharing and celebrating what they have done.

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 may be less apparent, but we soon begin to recognise the areas where the person has difficulty, and this guides our response. We do not need to know the details of a person's dementia because we respond to the person as we meet them on that day.

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

- A person may become withdrawn, requiring a gentle response aimed at engaging them in the activity without putting pressure on them.
- A person may begin (say) to splash paint around. Instead of holding their 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 they are distressed, and this is the only way they can express it. Listening and

understanding can be 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 behaviour and concentrate on understanding the message it gives us. We listen, aiming to find out what the person needs and wants, which can lead us to knowing how to respond. Above all, 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*. They may have seen major changes in their lives and their relationships. They will have been forced to take on new responsibilities. Sleep and leisure time may be interrupted by the needs of the partner. 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 work apart from the person they care for. Others enjoy sharing time with their partner in a sociable and relaxed setting.

The term carer can also refer to a paid carer who brings a person with dementia to *Lighting Up*. 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.

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'. Assume that they are expressing *something*, and work to understand what it is.
- Use any form of communication that works well – while 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 several 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 are not expected to give personal care. Responsibility for this rests with the carer or, if the carer is not available, with the representative of the host agency,

Confidentiality

Artists sometimes hear about the private lives of participants: it is important that this is treated as confidential. *Lighting Up's* safeguarding policy documentation gives guidance on the particular circumstances in which 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*. Likewise, artists recognise that their relationship with participants does not extend beyond their role in *Lighting Up*.

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 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.
- 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.”

8. *Lighting Up* as an organisation

Lighting Up was formed in 2007 and established as a small charity in 2011. As our annual income is less than £5,000, we are not required to register with the Charities Commission, but we are bound by the same legislation as larger charities.

The charity’s trustees, some of whom are practising artists, form the management group that coordinates the working of *Lighting Up*. All other practising artists are members of the charity, and have the right to vote at annual general meetings.

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

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

9. The joining process

Commitments

Volunteer artists commit to:

- regularly attending LU sessions, one session per month (subject to normal events such as holidays, illness etc.) with a minimum commitment of one year
- participating in induction and relevant ongoing training
- contributing to the working group of artists at their particular venue.

Lighting Up commits to ensuring that volunteer artists:

- find their involvement satisfying.
- feel at ease with *Lighting Up*, especially that they can contribute to how it is run and that any concerns are heard and responded to
- are offered appropriate induction and ongoing training.

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

The joining process.

Lighting Up welcomes visual artists/crafts-persons in any medium, regardless of whether they have formal training in the arts.
Experience of being with people with dementia may be helpful but is not essential.

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

Stage 1: This 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.

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. The venue chosen will be selected in response to the convenience/preference of the artist and the needs of *Lighting Up*

Stage 4: the artist will complete a form giving personal data and provide the names of two people (who are not trustees) who have agreed to act as personal referees.

Stage 5: when satisfactory references have been received and suitability has been agreed, the *Lighting Up* Coordinator will inform the potential volunteer and discuss arrangements for their joining a specific venue. 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.

There will be an informal review after three months.

10. Contacting *Lighting Up*

Email address: info@lightingup.org.uk

Telephone: Jo Matthews, *Lighting Up* Coordinator, 0117 968 3510

Website www.lightingup.org.uk

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