



Dementia Diaries: Information for Diarists

What is Dementia Diaries?

Dementia Diaries is a UK project funded by Comic Relief and The National Lottery Community Fund. It is co-ordinated by Innovations in Dementia and closely aligned with DEEP (the UK Network of Dementia Voices).

Dementia Diaries enables you (people who are living with dementia) to record your day-to-day reflections and experiences as short recordings ('audio diaries').

The audio diaries are then posted on:

- Soundcloud – www.soundcloud.com (search Dementia Diaries)
- The Dementia Diaries website - www.dementiadiaries.org
- Twitter @DementiaTweets

Recordings are available to the public as soon as they have been published. But, at your request, they can be removed from the website at any time (though they will still be put on social media).

Why is the project important?

By talking about your lives to the public, we hope to improve understanding of the diverse experiences of living with dementia. Communities, individuals, professionals, and services can become more aware, and have a better understanding, of day-to-day life experiences.

Recordings can be used to help others affected by dementia or publicly by professionals in training, media, meetings, or conferences.

How does the project work?

You can make a recording whenever you want over a landline or mobile phone to a dedicated phone number. If there is any cost involved you will be reimbursed (ask us for details). We will provide you with the phone number (for your use only) on a membership card. You could save it on your 'Favourites' in your phone. We will also give you a fridge magnet with the number on it.

The phone number is linked to a dedicated voicemail. As soon as a diary entry is recorded, it is automatically privately stored. No-one but the project team can listen to it at this point.

If you do not feel able to make a recording but you are able to send us a written diary entry, we can either record it on your behalf or you can ask someone you know to record it on for you.

Or you can record your Diary on your phone using a recording app (such as Voice Memo) – and email us the file.

One of the team will listen to your recording (this is usually done once a week). We have agreed (with a working group) certain conditions of your recording being published and made public. Mainly we want to ensure nothing has been shared that might compromise your safety or dignity. We may need to edit slightly if necessary. See our **full guidance checklist** for further information.

We aim to get the diaries transcribed by volunteers online, so that people can see a written record of your recording - this will also be published on the website www.dementiadiaries.org. Some diarists choose to write notes for themselves before they record, which they then email to us.

Your information:

When you become a diarist, we will ask you to complete a personal profile consent form, including your preferred details and those of your nominated person (who we can contact if we have any concerns about you).

Your recordings:

You have the right at any time to withdraw your consent for a recording and transcript and ask for it to be removed (though it can't be removed from social media).

You can make as many or as few Diaries as you like.

You can stop whenever you like.

What we publish:

We want to publish Diaries which are:

- raw
- honest
- critical where necessary of services, attitudes, and policies
- and which illustrate the challenges - and joys - of every-day life with dementia.

In some cases, we have to think very hard about whether or not to publish a specific Diary. This is because we have a duty to safeguard those who are going through a very difficult time – and also a responsibility not to publish Diaries which will be unnecessarily offensive to individuals and even groups. So, we will **not** publish a Diary which:

- the diarist may, in our judgment, regret later (for example, if they are in a very emotional state)
- is personally offensive to their friends, partner or carer – or to any individual
- uses offensive language

We may need to edit a Diary to overcome any of these issues. And we may contact you (or your nominated person – see form below) if we have any particular concerns.

Now that we have more diarists, we also have to be very careful to be balanced in what we publish, so that the listeners hear a wide range of voices. We cannot usually publish more than a couple of Diaries a week from the same diarist (sometimes it may be less). Because we are only funded to work for a few days a month on the project,

we simply don't have the capacity to do this. If there are a lot on the same theme we will choose one which we judge to be representative – or we may put two together.

What support do Diarists receive?

You'll receive training, support, and information as necessary. You may want to discuss the kinds of stories and experiences you'd like to share or talk about a recording you have made.

You can access ongoing support via a call or email to us. We cannot promise to have personal contact every week or month. But please know that we are here as needed. We will try and be in touch regularly, but it depends on how many recordings are made!

You might contact us to say you have just made a recording you aren't happy with and you would like it removed or want to check with us that it is okay. Or that you have made a recording which you feel should be published and promoted sooner than the following week (because it is a particularly newsworthy and timely issue).

What do current Diarists say about the project?

“Dementia Diaries is one of the best projects that I as a person living with dementia have had the privilege of taking part in. It gives people with dementia a platform to express what is good and bad regarding dementia and things that affect our wellbeing. Being able to instantly say what's on your mind is vital to us with dementia, as a pen and paper are not always to hand and the moment may well pass and vital thoughts are lost forever. The good thing is I can see and hear what my peers are reporting about, which is very important to me, as it helps you understand that you are not alone, and that is very reassuring.”

Tommy Dunne, Liverpool

‘Dementia Diaries is a wonderful tool that enables us lot who have to cope with dementia to express ourselves with our thoughts or memories either now or

long ago. It gives an insight to those who read our stories those difficulties that perhaps to them is quite normal, whereas for us is a nightmare.'

Steve Clifford, Stockport

How you can help promote Dementia Diaries

You can:

- encourage other people with dementia who you know to become Diarists
- use Twitter to share reports
- volunteer for media interviews
- talk about the project at events
- send reports from events or at the end of meetings or trips
- try to integrate Dementia Diaries into other projects you might be involved in
- attend conferences and events to talk about Dementia Diaries
- transcribe other people's recordings

Suggested themes for your recordings:

- Everyday life and experiences
- Comment on news and campaigns
- Your activities
- How dementia affects you on a day to basis
- Peer support
- Your rights
- Share your memories and how they make you feel
- Sharing your adapting and coping strategies
- Examples of good and bad experiences
- Sharing your creativity e.g. if you are a poet!
- What you are doing – speaking at a meeting, attending a group or having a quiet day
- Some people talk about their children, their pets, their partners
- Others talk about how important remaining active is to living well
- Challenging assumptions
- Above all – it's about having your voice heard!

Here is a transcript form a diary recording by Shelagh Robinson.

“This is Shelagh Robinson. Yesterday, I was introduced to someone who has a recent diagnosis of dementia, and is very, very frightened and very, very negative – as I guess we all are in those first weeks of dementia. She said, when we were introduced, “I don’t want to talk to you; I can’t be like you.” Of course, you can’t; we all deal with dementia in our own, different ways.

But I suggested to her that she went online and had a look at some Dementia Diaries. I saw her again this afternoon, and she gave me a big hug, and said, “That was the best thing you could have ever given to me to do. They were all so different; it was like entering a world that I could be in – I could be positive in.” Well done, Dementia Diaries”

Contact:

Steve Milton Steve@myid.org.uk or by phone/text on **07549 944795**

Philly Hare, Innovations in Dementia Director and lead for Dementia Diaries
Philly@myid.org.uk or by phone/text on **07932 995620**

Making a Diary – Your checklist

- Make sure you have as little background noise as possible
- You may want to read from something you have written, write down a couple of prompts, or just speak freely – whatever works for you
- You can talk about your personal story and/or thoughts or about a theme/cause/campaign
- Try and speak slowly – (but don't worry too much about that). Don't worry if you pause or repeat yourself.
- If you are unable to speak, you can ask a family member/supporter to do so on your behalf
- If you are unable to use a phone, you can email or even post your report to us and we will record it for you
- Phone: **xxxxxxxxxxxx** - call either from your mobile or landline
- You will hear a message and then a beep (like an answerphone)
- Please say your name at the beginning of the recording (don't worry if you forget to!)
- You can then speak into the phone and it will be recorded
- Try not to make the recording too long – a couple of minutes is about right
- When you have finished talking, just hang up
- We may not hear your message immediately, but if you want us to listen to it and publish it as soon as possible contact us.

Please try to:

- Avoid offensive language - be respectful
- Avoid saying anything which is, or could be, illegal e.g. discriminatory
- Be as clear and logical as possible about what you are saying
- Follow DEEP language guidelines visit the DEEP Website www.dementaivoices.org.uk - we can send you a copy of this guide about language if you are not able to look on the website.
- Avoid using the number as a helpline. We are not set up for this.

We agreed that:

- We will keep the reports as 'raw' and unedited as possible
- The recordings will be confidential until they go live
- If we have any concerns about your recording or your wellbeing, we will be in touch with you and/or a person nominated by you

Dementia Diaries - Personal Profile & Consent Information

- It is important that we provide the right support to enable you to have the best possible experience of being a diarist.
- It also means that we run our work in the safest way for everyone.
- We will keep this information safe. We will not share your personal details with anyone else.
- You can make changes to your personal profile at any time.

About you

Name	
The name you want to be public i.e. first name or both or nickname	
Address	
Landline number	
Mobile number	
Email	
Do you have a Twitter or Facebook account? Are you happy to use this for Dementia Diaries? If so, please let us know your user-name	
Preferred method of communication and keeping in touch	
Do you have a preferred photo you would like us to use? (if so please send – must be hi-res) Or are you happy for us to use photos from our resources?	
Do you need any special support to do your recordings?	

Contact details of a nominated contact person (in case of concern)

Name	
Address	
Telephone number	
Mobile number	
Email	

I confirm that I understand this information and that I wish to become a Dementia Diarist.

Name:	
Signed:	
Date:	

**Please return this form to:
Dementia Diaries PO Box EX1 9JB**

For office use: Review Date for information provided (12 months): Telephone reimbursement cost:
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