

“If you have only two pennies, spend  
the first on bread, and the other  
on hyacinths for your soul”

– Arab proverb



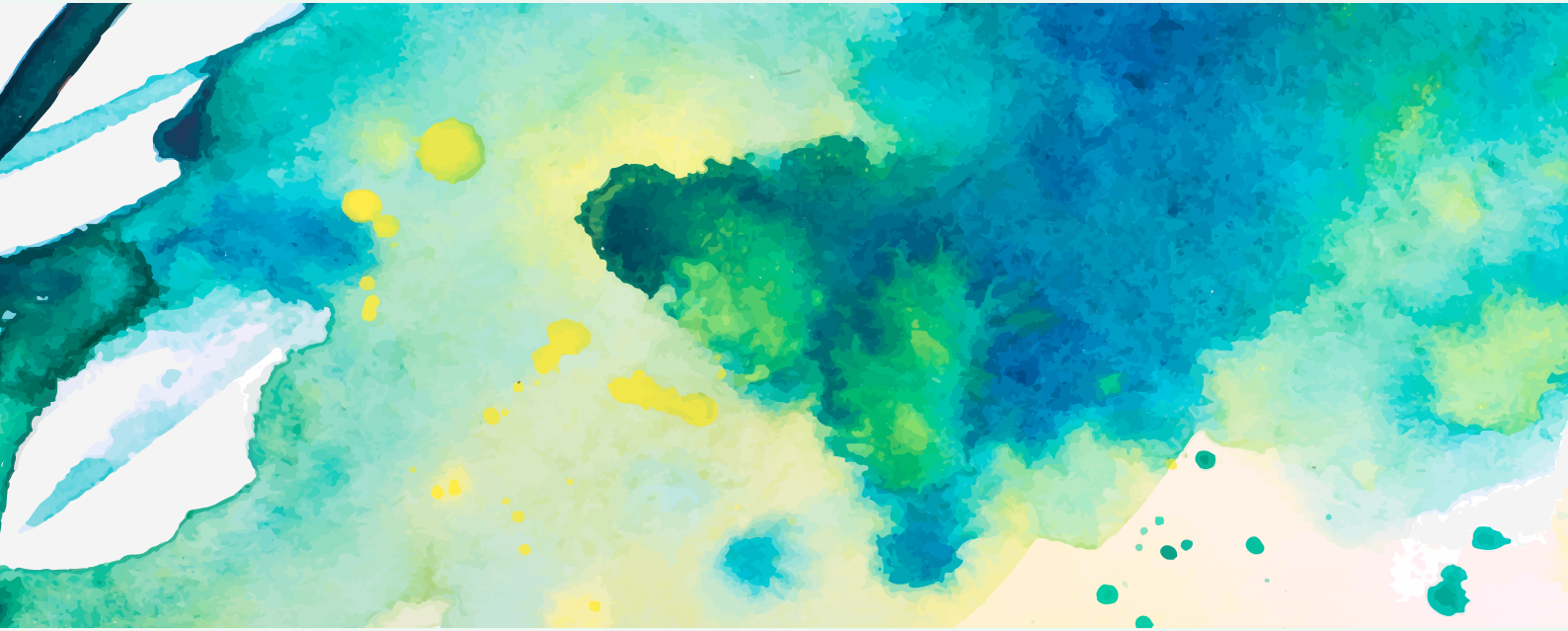
# A guide to supporting people with dementia through the arts



Dementia Services  
Development Trust

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## A guide to supporting people with dementia through the arts – travelling in hope

The numbers of people with dementia in our communities are increasing. As a result, many families and individuals are struggling to cope. While there are momentous improvements in dementia awareness, diagnosis and care, there are still significant gaps in the spiritual and cultural support of people with dementia. Working on art projects with communities is challenging enough when they are active and engaged. But what can we do when dementia is part of the issue? Most people with dementia are old, or very old, and their numbers are increasing as our population ages. Working age people and children with dementia, though fewer, have a particularly difficult time.

There is a growing popular consensus that support from artists, art activity and experiencing great art benefits people with dementia. There is some

scientific support for this idea. Even if the formal research base for dementia-specific benefits is still relatively slight, based on small studies and anecdote, the possibilities are endless. If we extrapolate from the human need that we all have for artistic expression, beauty and challenge, we know that people with dementia have this same need. They just have a problem in meeting it, and that is where this guide comes in.

Produced by the Dementia Services Development Trust after seminars and workshops over two years with artists, carers, professional workers, volunteers and people with dementia, this is designed to help when you are considering using art in the context of this complex but well researched and defined condition. The project leaders Prof June Andrews and Mark Butler express their gratitude to all those who helped.

Further copies of this resource can be downloaded from the website of the Dementia Services Development Trust at:

[www.dementiatrust.org.uk](http://www.dementiatrust.org.uk)

A film of the artists reflecting on their experience is here:

<http://dementia.stir.ac.uk/ideas-and-innovation/reframing-dementia>



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# What is dementia?

'Dementia' is the word given for a diverse set of symptoms that affect people who have an underlying disease such as Alzheimer's disease, or vascular disease. It is called dementia when the person has difficulty in thinking, and working things out. It might be hard to get their words out and their behaviour becomes difficult to understand. The person will become more dependent over time. Artists frequently think of it fundamentally as a memory problem, but people with dementia and their carers will tell you that the memory issue is often the least troublesome. Research supports this.<sup>1</sup>

## Why is art important in dementia?

Art is an important element of civilised society at every age. As we are all going to live much longer the incidence of dementia in all our communities will grow. Dementia is too big an issue and too important to be left solely to health and social care or to Government. The specific role of art and culture in supporting people with dementia is crucial and must be addressed. This is important for the art community as well as the care community and families.

We believe in the dignity of every person, but people with dementia and their carers can have their dignity undone by others, particularly if they are treated in an undignified way or are denied the benefits that art can bring. We believe that families of all kinds are the foundation of community, and people who are old or in care may have no family except those directly involved in their care. Giving access to artistic expression

and experiences is hard for families and carers to manage. We believe that artists have a crucial role to play, but people with dementia may be very difficult to work with, and at times beyond the skill and knowledge of lay people. People with dementia must be protected from being perturbed by well-intentioned but patronising or pointless interventions or where artistic merit or the individual need of the person have become secondary to the process or the aims of the project funders.

These seem very difficult problems, but with a positive attitude and some practical interventions, art can work wonders for people with dementia and their families, and for the professional care workers among us.

## In making art and art activity available to people with dementia and their carers we have an active role

- when someone might have dementia
- when someone has been diagnosed
- when the person is trying to live the best life possible
- when care becomes hard
- when the person must go into care
- at the end of life

## Who is this guide for?

This guide is to support artists of any kind in any medium, craft workers, dementia care workers, families and anyone who wants to help people affected by dementia through the arts.



# Overview of the guide

This guide is divided into 6 sections followed by some concluding remarks.

## 1. When someone might have dementia

It is hard to know what to do when someone's behaviour is giving rise to worry. People are afraid and hide their symptoms. You may be shy about offering help because of fear of causing offence. This section gives some ideas for action when wondering if someone has dementia.

## 2. When someone has been diagnosed

Being diagnosed is not something that just happens to the 'patient'. It is a significant blow for the whole family, adjusting to a new way of living. How to support the person affected and those around them who have a new role of 'caregiving' is important knowledge for those working in the arts field.

## 3. When the person is trying to live the best life possible

Because diagnosis is coming earlier all the time, people discover that they have dementia when there is still a lot of good living to do. This time can be extended and made more dignified and happy by the actions of those around them. What can art and artists do to help with this?

## 4. When life becomes too hard

With the best care, and the best environment, things can still go wrong. The person may respond in ways that are hard to understand. The care system may not seem to be responding as it should. The response of the artist is to protect the dignity of others...but how can we do this?

## 5. When the person must go into care

When they go to a care home, you might think the person can relax and breathe a sigh of relief. But it is not always like that. Every waking moment may be spent in idleness and boredom punctuated with incidents of animated routine interventions. How can art help now?

## 6. At the end of life

How can art be used to comfort and support people at such a time? And what comfort is there for ourselves?

*"The beneficial impact of participatory art in terms of mental and physical wellbeing is evident at the individual, community and societal levels. Although the evidence base is relatively weak, it suggests that there is tremendous potential for participatory art to improve the quality of life of older people in general as well as those older people who are most excluded including those with dementia"*

*An evidence Review of the Impact of Participatory Arts on Older People, Mental Health Foundation, 2011*



# 1. When someone you are working with might have dementia

This section raises issues for artists, musicians and others working with people who possibly have dementia. The first and most important thing is to find out as much as you can about dementia so that you know what you are looking out for and how you might help. A better understanding of dementia will allow the artist to interpret and adapt to the person's responses. As is emphasised later, basic awareness will not be sufficient.

Research demonstrates that up to 90% of the people in a care home have dementia even if they don't have a diagnosis. In any community setting where there are older people it's a matter of fact that the older the group, the more likely it is that someone is affected. Don't forget that working age people can also have dementia, but especially if you work with older frailer people, the things that would help a person with dementia may help those people.

## Is it unkind or rude to ask if someone has dementia?

How confident you are to do this depends on your relationship, your work, and how much you know about dementia yourself. If it is regarded as 'clinical information' you won't be told, but if you are working in a dementia unit or on a dementia project, then it can perhaps be assumed. But don't think that everyone with dementia has the same problems. You will have to make unique adjustments for each.

There are some things that you can do without asking which will benefit people you work with whether they have dementia or not

- undertake 'dementia friends' training which offers some basic awareness of dementia
- read around the subject<sup>1</sup> and learn to sift through myths and sensational headlines to reach the facts
- consider a formal educational programme<sup>2</sup>
- make sure you understand the safeguarding policies for vulnerable adults for the organisation sponsoring your work
- offer opportunities for shorter interventions and make sure to mix old experiences with the new ones in your offerings

The environment, including noise and light, makes a huge difference to people with dementia. Always prepare your environment.<sup>3</sup>

## Activities

- in a group, see how much knowledge you already have about dementia and what is already there to help in your community
- pull together an information file about local resources for people with dementia and their carers (this might include the Alzheimer's Society, a dementia café, dementia specialist nurses, a day hospital, care homes and day centres)
- don't forget the wisdom of experienced family carers but be aware that their experience may be limited to one or two people they've helped
- take every chance to talk to people with dementia

1 Andrews J 2015 Dementia the One Stop Guide Profile, London

2 Free eLearning modules here <http://www.scie.org.uk/dementia/e-learning/>

3 Good Practice in Design for Dementia and Sight Loss <http://www.dsdc.stir.ac.uk/design/good-practice-design-dementia-and-sight-loss>



## 2. When someone has been diagnosed

Being diagnosed is a shock and over time the person will have to adjust to a new way of living. Supporting the person affected and those around them who have a new role of “caregiver” is a skill. Sometimes friends have no idea what to do and say and may back off. At this stage art can be a great comfort and distraction. Diagnosis is happening earlier all the time, and this means that the person you work with may be only slightly different from how they were last year, or last month. They may still be driving, working and volunteering for a long time. Encouragement to keep on enjoying art and artistic activities may be needed, and adjustment in how this is supported.

### What is happening?

Dementia happens because of structural changes in the brain. There is no cure, but there are things that can be done to stay as well as possible for as long as possible. Exercise, hydration, diet, medication, social activity...any of these might play their part. The real enemy in dementia is stress, which makes all aspects of dementia worse. Anything that artists could do to reduce stress is worth trying. Being happy and occupied is extremely important.

### What families go through

To begin with there may be denial, as they try to pretend nothing happened, and anger follows behind. That is understandable, as is the grief that people feel when they realise what they are losing – time, memories, social contacts. The financial loss is very worrying. Even if they are resilient people and try to think positively, there is

a great risk of isolation and depression. Research indicates that a significant element of the value of art activity is the companionship and respite for the family or carer. Keeping caregivers well is a vital part of the picture.

### Memories

Remember that seeing dementia as primarily ‘a memory problem’ is a very narrow and restricted way of looking at it. Think wider and focus on what bothers the individual, not on this oversimplified tag.

### Activities

What can you do to get alongside people who are going through this? In a group, list the ways you can help with

- keeping in touch and supporting the person to get out and about
- making sure that they can still get along to galleries and places of entertainment such as theatres, cinemas and dancing as before
- offering exploration of new artistic experiences
- listening to what they are going through and not judging their anger and grief, or falling into that sorrow along with them, but staying strong
- giving practical support including reminders and transport because personal organisation becomes harder
- creating in advance a playlist of favourite music, images, films, radio plays, poetry etc. to be used in case the person is eventually unable to express their preferences





## 3. When the person is trying to live the best life possible

Because diagnosis is being given at much earlier stages of the illness, some people discover that they have dementia when there is still a lot of good living to do. This time can be extended and made more dignified and happy by the actions of those around them. Even though research shows that most of us fear dementia more than cancer, it can be a relief for the person to finally have a name to put to the symptoms that have been afflicting them. Early diagnosis is a good thing, because it increases the time to put your affairs in order, and complete a wish list of things to do before it is too late. What can artists do to help with this?

### **“What is good for your heart, is good for your head.” How to stay well**

There is strong evidence for exercise, stopping smoking and reducing alcohol. Socialising is vital, and keeping up as much as possible with fun things. Any underlying illnesses must be managed, such as diabetes, blood pressure or depression. Craft activities are good for reducing stress if they are fun and interesting, but what makes a difference in dementia is hard to research and there is a lack of strong evidence in this area. This means that claims about what makes a difference are sometimes elevated beyond their merit.

Even though they have dementia, someone might still be able to decorate cakes, sew or paint, with encouragement. Food and conversation is an important part of life. Laughter while helping in the kitchen is life enhancing. If these activities can help the person to feel alive and well they are valuable even if they are not what some would describe as ‘Art’. We hold to a very broad definition. But we recognise that much of what is described as art therapy is arguably not art or therapy. At times that is uncomfortable.

### **Preparing the environment is vital whatever you are doing**

Look up some of the information about ‘dementia friendly design’ and audit. Can you make some inexpensive and simple changes in the immediate environment? Make sure everyone knows why you are making the changes. You might consider:

- a noise audit (noise is as disabling for a person with dementia as a stair is for a person in a wheelchair)
- increasing the light level (old people need light many times brighter than the young, and seeing reduces confusion)
- a dedicated room for art activities so that materials and instruments are not disturbed and never need to be shifted, and visits can be made at any time in the 24 hours when the person is wakeful and interested
- consider practical issues such as access to toilets and helpers to assist if needed and check if venues have quiet and reserved times
- dehydration is a big problem, so make sure drinking water is available

Be aware of the difference (without obsessing about the terms) between:

- art therapy (a form of psychoanalysis)
- art activity (covering anything from simple general craftwork to the performance or activity of an artist or musician with dementia)
- art appreciation (where the person can consume public or private art works, as in a recording, book, live concert or gallery)





## 4. When life becomes too hard

Preparation is key. Find out as much as possible about the difficult symptoms, so activities aren't disrupted by things that can be avoided such as agitation, anxiety, aggression, wandering, or other psychological symptoms. Knowing the individual and their own pattern of behaviour is crucial.

With the best care, and the best environment, things still go wrong. The person may show behaviour that is hard to manage<sup>1</sup>. The care system may not be responding well. It would be wrong to abandon them and deny them the right to access art. The artist's response is to protect the dignity of the client...but how?

People who are visiting a person with dementia can give the greatest gift, which is time. Time to listen, time to go for a walk, time to keep company with the person who has dementia, time to free the carer for an hour or two. We know that the person may be soothed by a familiar song. It may give a sense of security to take part in a dance or look at pictures. The difference from an ordinary intervention, and the support given by an artist or art activity is the focus on creativity, skill and imagination. It's a question of appreciation, satisfaction and emotional power.

Art offers an opportunity to demonstrate skills that others did not know the person has latent within them. However, it may also work to underline their loss of skills. The emotional response to not being able to paint or play as one once did might be disturbing for everyone. Be prepared for an agitated or angry response. At such times, it becomes very clear why we

should avoid spurious or over-inflated claims about the effectiveness of art interventions when reporting on or bidding for arts funding.

### Activities

The practical elements – can you do any of these?

- limit the length of an activity to 20 minutes
- keep the singing focused on old familiar songs, but individualise, and avoid the assumption that one decade or genre is appropriate for everyone
- read or tell short stories or poems with just a few short words
- make sure that carers and people with dementia know that they cannot ever embarrass themselves, because the focus is not on 'being proper' but on their need to take part and our overwhelming desire to support that
- work up a good flyer/poster to let people know about it
- have a reading group or painting class that allows people with dementia to sit in, and just be there

There is great added value if you can contribute a hot lunch.

Disrupting moments provide opportunities to demonstrate patience and gentleness. The fine nuances between discouragement, distraction, disruption, and danger need to be read by the artist. Be aware of what would count as dangerous behaviour.

<sup>1</sup> How to manage disturbing behaviour: further reading from Alzheimer Europe: <http://www.alzheimer-europe.org/Living-with-dementia/Caring-for-someone-with-dementia/Changes-in-behaviour/Embarrassing-and-odd-behaviour?#fragment3>





## 5. When the person must go into care

### The care home

Although many care home workers understand the need to appreciate and experience art, some don't or may just lack confidence or training to support it. The care home design may not offer a quiet place for activities such as painting, or listening to music. You can offer to take the resident out of the home, to a venue or gallery, if they would find that comforting. Always be flexible on any occasion about whether it's going to work.

### Art 'work'

- when you are working in a care home, be prepared for resistance or resentment from staff who think you get to offer fun and they must do the heavy work. Could you volunteer for 'non-art' duties to demonstrate you're not 'too posh to wash' and forge a long-term relationship?
- when someone goes into a care home, they might spend a long time without activities. Can you devise activities that can be continued by them alone, or with care staff, volunteers and family visitors when you're not there? Can you support the care staff to do this?
- visiting someone who does not speak a lot and seems not to understand can be hard work. Can you take images to look at, or show them on your iPad? Could you read out loud from a book, or just sit together? Would they let you rub in some hand cream while singing or listening to music to offer distraction and relaxation?
- in a short-term project, with limited funding, reflect on the ethics of entering the life of

the people with dementia and how you will manage your exit and any consequent loss experienced by them

- be prepared for staff using your activity as a 'minding' exercise by abandoning residents to your care to 'get on with work'. Involve the staff and keep them in the room. Educate them in the value of art, or help them to find ways of using it
- don't undertake work with people who have dementia without prior learning – more than just awareness. The most fundamental knowledge is how to communicate with cognitively impaired people and this should be a priority for your own development

Even though art may seem at least harmless, removing the person's choice about participating is manipulation. The artist must not collaborate in the exploitation of people with dementia. Provision of "art" is sometimes used as a marketing tool by care organisations or presented as evidence that art organisations are doing work of social worth.

Whether the goal is artistic merit may vary. Social worth may be a justification for interfering in the lives of people who are ill, but you have to have evidence, and claims that you have 'reduced dementia' or 'improved memory' require rigorous clinical evidence. Don't leave work of limited artistic merit as a memorial to your project. Even those who remember taking part may well be gone within a year or eighteen months, and it may mean nothing to those coming after and add little to the quality of their environment. It isn't 'better than nothing'.





## 6. At the end of life

You may have heard people say about someone with dementia “This is not our mum. She died a year ago when she stopped knowing who we all are.” What a sad end to a lifelong story of love. How can art comfort and support people at that time? And what comfort is there for ourselves?

### What brings the end

Towards the end of their life a person with dementia will be more vulnerable to infections and have difficulty moving about independently. Swallowing and eating become difficult, and it will be hard to sit up without help. They will be dependent of others for everything. Communicating with words will come to an end, and even facial expressions fade away making it hard to know how they feel. They might be at home, or in a care home, in a hospice or taken to hospital at the end. They may seem like a completely different person. It is impossible to know how much the person sees, hears or feels, but it is best to assume that they are acutely aware of everything round them, and take that into consideration in what you say and do in their presence.

### Preparation

Some families may not have discussed the end of life in advance or experienced the death of someone they love who has dementia.

Grief is natural and healthy. There is no short cut, and we must let people know they are not alone. If families feel the person they love has died because they stopped recognising their family, they may be comforted by remembering that this is just the disease, and the person is always there. Using the person’s favourite music, whether religious or secular, can help reinforce this positive view. Singing together or playing favourite music in the room, even after the person does not join in, can comfort everyone.<sup>1</sup> Reading a poem or a story both gives the family something to do, comforts them, and possibly comforts the dying person. An artist friend can make sure that a solitary person does not die alone.

### Activities

- think about how music might be used to create a peaceful and relaxed environment around the time of death
- a memory box with photos of good times such as visits to galleries and preserving any work done is a good object to focus reflection and memories for families and friends, and reminds carers of the life of the person now passing away
- take time to consider how you would design a celebration of the life or service of remembrance for someone who died with dementia
- through your art, you may explore how the experience of supporting a dying person influences your own view of life and death

<sup>1</sup> See TAnDem at the Nottingham-Worcester Universities Doctoral training centre <https://www.worcester.ac.uk/discover/claire-garabedian.html>



# Project practicalities for artists

- a written **project start-up agreement** will reduce possible confusion. An agreement with the people with dementia, their families or attorneys and staff should set out what the project will involve for everyone
- are there legal or regulatory requirements or policies of the institution about **protection of vulnerable adults?**
- relatives and staff have a role in protecting the person, but among themselves may have differing views about **what 'art' is**. Be clear and consistent about how and when it is right to engage with different perceptions of what is 'appropriate' activity for people with dementia
- get agreement from the start about **use of facilities and costs** at the end of the project – for example about on-site printing or drawing/painting materials
- **ownership and intellectual property**. Who will the work “belong to” and have control of its use, exhibition and display? Especially if the resulting art is challenging or even a matter of concern to relatives, the professionals or the person with dementia, anticipate this
- a clear written agreement on a route to **exhibition and publication** is good, even if the artist needs to be sensitive and be guided by ethical judgement if there is concern
- nominate a **mentor or a mediator** to help resolve disputes and problems should they arise
- check **insurance cover** and practical arrangements to protect all concerned. Consider different scenarios and possibilities through a risk assessment even if the workspace does not require this
- what times are key to the project and how can the residents and staff be **protected from other activities** and demands? Are the staff genuinely happy with the proposed pattern of access?
- **awkward situations**. Some people living with dementia become confused and even aggressive (though most do not) both with the artist and others. It is important to establish clarity about triggering alarms, including an understanding with staff about them staying with you in the space or ‘checking in’
- choice of venue plays a positive role in creating **the right, safe environment** for the artist, the people living with dementia and the staff. Time spent creating an environment with as few distractions as possible pays dividends
- keep one or two **staff close to the project**. The project may change shape and evolve as it develops. Good communication has practical value in ensuring lines are not stepped over and expectations are managed actively on all sides and they can facilitate this



# Knowledge or awareness

Artists need to be self-aware and sensitive when practicing in health and care settings. It is important not to presume. Local staff and relatives with responsibility for care know the person. An artist may seem to have a privileged and personal relationship with someone with dementia. It is important to keep this in perspective and for the artist to be careful if they have concerns and feel they need to act as an advocate or champion for them. Where concerns do need to be raised, this should be done as something separate from the art work. Organisations should have processes for raising concerns and you should ask about them in advance of projects.

If a person with dementia, a carer or care worker confides in the artist it presents ethical and personal challenges. Ask yourself:

- what do I do with information shared with me? This might be private and potentially awkward – perhaps about staff or relatives and accusations about abuse, theft, competence and other issues
- what if someone asks me to help them – to escape, to get food, to protect them from abuse? Blurring access to people in the name of art and acting as an agent for them is a complex practical and ethical matter
- how do I keep the integrity of the art but also respect everyone involved?

- how can I be aware of and account for my own bias, preconceptions and political sensibilities in the setting and in the work?
- where do I seek a proper level of advice and support if it is needed on dementia or the care environment?

Artists need to be confident in their level of dementia knowledge. It is disrespectful to underestimate the importance of this before starting. Working with people with dementia is not the same as working with other disabilities. Your life experience offers insight, but superficial awareness may reduce the sensitivity of the artist to what knowledge is needed. It is good practice to have a mentor in place to help gauge the right level of knowledge for the specific project. It helps if this mentor is independent of the specific space and has knowledge of what success looks like.

Some feel daunted by the need to acquire a specific understanding of dementia for their project. This can also be dangerous as it can disable the artist from following their intuition and reduce their creative freedom. So, a balance needs to be struck where the artist feels sufficiently able to practice their art and yet remain independent of the slant or even misrepresentations of others, including health and social care staff or relatives. If these questions seem challenging to an artist they should consider not proceeding with a dementia project.





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