



This resource was created by the East Kent Forget Me Nots.

The Forget Me Nots are a service user group that aims to raise the standards of dementia services nationally and battle the stigma against dementia.

The group is supported by NHS staff, and meet monthly.

If you wish to get involved or know more about the Forget Me Nots, the details can be found online using the QR code:



[kmpt.forgetmenots@nhs.net](mailto:kmpt.forgetmenots@nhs.net)

# Telling Your Friends and Family about Living with Dementia

Advice from people living with dementia on how to tell the important people in your life about your dementia diagnosis

# About this booklet

We understand that informing your loved ones and colleagues about your dementia diagnosis can be a challenge, and there is often a lack of guidance on how to navigate this conversation. This brochure provides valuable advice on how to approach this situation, drawing from the experiences of individuals living with dementia who are a part of the service user group Forget Me Nots. They have offered personal insights and general tips to help you share your diagnosis with those who are important to you. Additionally, this resource emphasises the significance of informing your friends, family, and colleagues to receive the necessary support.

## Resource Recommendations

### East Kent Forget Me Nots

[www.kmpt.nhs.uk/get-involved/participation-and-involvement/living-with-dementia/forget-me-nots](http://www.kmpt.nhs.uk/get-involved/participation-and-involvement/living-with-dementia/forget-me-nots)

### Dementia Tool Kit

<https://livingwithdementiatoolkit.org.uk>

### 3 Nations Dementia Working Group

[www.3ndementiawg.org/living-with-dementia](http://www.3ndementiawg.org/living-with-dementia)

### Alzheimer's Society

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

### Age UK

[www.ageuk.org.uk/services/in-your-area/dementia-support/](http://www.ageuk.org.uk/services/in-your-area/dementia-support/)

### My Life, My Goals

[www.alzheimers.org.uk/blog/life-after-dementia-diagnosis-guide-setting-reaching-goals](http://www.alzheimers.org.uk/blog/life-after-dementia-diagnosis-guide-setting-reaching-goals)

# Living with Dementia

## Closing thoughts

As individuals living with dementia, we believe it is important to not let dementia limit you. At Forget Me Nots, we are constantly pursuing new creative projects and making the most out of life with dementia.

To get you started, we have included some resources and contacts that we have found helpful on the next page.

We hope you found this resource helpful and wish you all the best going forward.

**“We are all individuals with dementia—it is not one size fits all.”**

## Why tell your friends and family?

Telling your friends and family about your dementia diagnosis is important in ensuring a support system around you when living with dementia. Family and friends can support you in your life with dementia by helping you to develop new habits and strategies to help cope with the symptoms of dementia. Knowing about your diagnosis can also help family and friends be supportive and understanding of you going forward.

Informing family members about dementia also opens the space for important conversations such as future care plans and preferences, legal decisions such as power of attorney, and creating a supportive network around you.



# How to tell your friends and family

Opening the conversation about dementia can be tricky and it can be hard to find the right time to bring the topic up.

For some, it is easier to tell loved ones straight away after diagnosis. This can help ensure that you have the support you need from family as soon as possible.

For other people, it might be harder to find the appropriate time to talk to friends and family about their diagnosis.

“I let people know very early in the conversation that I am living with dementia. That way they will realise why I am having trouble understanding or following a conversation. Lets face it, if you were deaf, you would very early on let people know you have that hidden disability.”

## Local Authorities and Organisations

We think it's important to inform the local authorities and organisations about your diagnosis, as it could lead to a discount or exemption from council tax. Additionally, you may qualify for a blue disabilities badge, which provides access to more convenient parking spaces. The council may also give you a bus pass to help you get around.

You can find more advice and guidance at:

[alzheimers.org.uk/get-support/legal-financial/](https://www.alzheimers.org.uk/get-support/legal-financial/)

# Who else should I tell?

## Work and Colleagues

You might want to let a few trusted people in the workplace know about your diagnosis. This could help them to understand your difficulties, and adopt strategies to help you at work. Many people are reluctant to share their diagnosis with employers as they fear that it could lead to financial instability. Our advice would be:

- Review your contract of employment
- Seek advice on employment rights from Age UK and Alzheimer's Society.
- Consider taking an advocate with you to any employment meetings.

“Every person with a diagnosis and every situation is unique, you are the person who knows best when, how and who to share this information with.”



# Dawn's Story

“Shortly after I was diagnosed I stood up in front of my church of about 100 people and told them. I have Alzheimer's. When I was told that I thought my life was over with no hope. But shortly after I was told of my Dementia, I had a phone call asking me to go on a panel to change a questionnaire to make it suitable for people with Dementia to understand (it has taken two years) but in the moment of being asked, I realised one life was over but a new one was beginning, and there were things I could still do. I am still doing things to help change things for people with Dementia.”



## What to tell your friends and family

**When sharing your dementia diagnosis, be mindful how much information your loved ones would wish to have.**

Some may want to know everything, while others may need time to process and may not be ready to discuss it yet. Give them space and revisit the topic later when they are more open to talking about it. Sometimes this may be the other way round: you may not feel ready to talk about some aspects of your dementia. This is normal, and you should open this conversation when you feel ready.

Often, family members are happy to be involved and assist you when living with dementia.

We think that it is essential for you to be involved in conversations regarding your care and future.

It may also be hard for your family to understand the difficulties you are having: they do not have the experience of living with dementia. We think it is important to acknowledge that although you are the one with the condition, it is a tough experience for your friends and family members too. However, make sure that your family understand that your condition should not be minimised.

## Chris' Story

“I’m still the same person today as I was yesterday. Its not the end of my life—it will just be a different life. There is a beginning , middle and an end. I will not suddenly change over night.

**Please remember that it is the condition that is governing behaviour and challenges. It is nothing to be ashamed of. You are not to blame, it can affect anyone.”**

