

# The Dementia Journey - where to start

**Wisdom from people affected by  
dementia in Nottinghamshire**



Part of the Dementia Notes from Notts Project

## **What is The Dementia Journey?**

The Dementia Journey is a short booklet. It aims to describe the dementia journey, from pre-diagnosis to finding support.

The Dementia Journey has been written in collaboration with people living with and affected by dementia in Nottinghamshire.

The Dementia Journey includes hints and tips about what might be helpful at different stages of the journey.

The Dementia Journey includes suggestions of where to find help in Nottingham and Nottinghamshire.

**“It’s a sad, lonely but interesting journey”**  
- partner of person living with dementia

## Things to remember

Everyone's journey with dementia will be different.

What happens after a diagnosis will be different for everyone.

The information and support you need will change over time.

You are not alone. There are other people in the same situation as you. There are other people who are further on in their dementia journey.

“Timing of support is important. I attended a short course for carers five years after my partner was diagnosed. It was useful but it would have been even more useful five years earlier”

- partner of person living with dementia

“Have you got dementia? No. Then how can you know what I need?”

- person living with dementia

## **Pre-diagnosis**

For most people, it will take some time from noticing that something isn't right to being diagnosed with dementia.

“As a carer, I found it a lonely journey, because we struggled with diagnosis for a lot of years.”

- partner of a person living with dementia

## **Post-diagnosis**

Receiving a dementia diagnosis can be overwhelming. You may feel frightened and unsure about what the future will be like.

“I was in denial. You need to accept it, come to terms with it.”

- person living with dementia

## **Finding out more about dementia**

You might want to find out more about dementia. Lots of charities produce information leaflets. Your local library can help too.

**Notts Tip** - your local library can help you find out more about dementia from books and the internet. For more information and help, contact your local library -

### **Nottingham City Libraries**

**Telephone:** 0115 915 5555 option 4

**Email:** [enquiryline@nottinghamcity.gov.uk](mailto:enquiryline@nottinghamcity.gov.uk)

**Website:** [www.nottinghamcitylibraries.co.uk](http://www.nottinghamcitylibraries.co.uk)

### **Inspire Culture - libraries in Nottinghamshire**

**Telephone:** 01623 677200

**Email:** [ask@inspireculture.org.uk](mailto:ask@inspireculture.org.uk)

**Website:** [www.inspireculture.org.uk](http://www.inspireculture.org.uk)

## **Family and friends**

Family and friends may find it hard to come to terms with a dementia diagnosis too.

It is hard to predict how dementia will impact someone. This is hard to live with but others are having similar experiences. This is where support groups can be helpful.

## Finding support

People affected by dementia are often the best source of information about local support.

Going to a dementia support group or memory café in your area will connect you to other people in the same situation as you.

**Notts Tip** - many dementia support groups and memory cafes advertise in local free magazines like the NG magazines.

Your healthcare professionals may know of groups local to you.

You can also find details of groups on the internet or ask at your local library.

“It’s no good sitting back, It won’t come to you. ... That’s why it’s important to join the groups, because they share information in the groups.”

- partner of a person living with dementia

You might have to try a few different groups before you find one that suits you, your personality and life style.

Persevere though as when you find the right group, it can make a real difference to your life.

“A lady from the Alzheimer’s Society put us on to the Woodthorpe Memory Café. They gave me good information”

- partner of a person living with dementia

“Support groups are a lifesaver ... there’s a shared understanding ... and people there know of other groups and services that might help you”

- partner of a person living with dementia

## **Research projects**

Some people affected by dementia like to get involved in research projects. These can cover all sorts of issues related to living with dementia.

Contact Trent Dementia to find out about research projects you may be able to get involved with. Trent Dementia’s contact details are on the back of this leaflet.

## **Who has produced The Dementia Journey?**

The Dementia Journey has been produced by Trent Dementia in collaboration with people and families living with dementia in Nottinghamshire.

## **Who has funded The Dementia Journey?**

The Dementia Journey is part of Trent Dementia's Dementia Notes from Notts project. This project is funded by Boots.

Trent Dementia Services Development Centre  
Institute of Mental Health  
University of Nottingham Innovation Park  
Jubilee Campus, Triumph Road  
Nottingham, NG7 2TU

**Telephone:** 0115 74 84220

**Email:** [contact@trentdementia.org.uk](mailto:contact@trentdementia.org.uk)

**Website:** [www.trentdementia.org.uk](http://www.trentdementia.org.uk)

Registered Charity No. 1109855

Printed August 2022