



Early diagnosis of dementia in Southampton

This leaflet is for the public, carers, health professionals, housing support workers and city council workers.

Take the next steps

For more information contact:



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www.solinked.org.uk

Supported by:





The Big "D" Dementia.

Let's talk about it.

Benefits of Early Diagnosis of Dementia

- Be yourself and look after yourself
- Plan for the future
- Remain as active and connected as you can
- Understand what is happening
- Challenge denial in a compassionate way

- Learn and understand about dementia and the journey you will tread with your family and loved ones
- Have better health and healthcare to optimise quality of life
- Organise care and support
- Involve the whole family, no shame, it's an illness

Challenges of Early Diagnosis

- Denial of a problem
- Family resistance
- Signs of dementia are gradual onset and are present for several years before diagnosis is made
- Social Stigma
- Fear of the future
- Relationship problems because of dementia get to breaking point



What is Dementia?

Dementia is a brain condition where the brain function is damaged for various reasons and works less well.

It is progressive, without a cure and you can die with or of dementia. But you can live well with it if there is understanding, support and practical help.

Memory loss, especially for recent events.

Seeing things, hallucination, delusions, believing things that are not true.

Difficulty with language and communication, repetition.

Getting lost and not knowing what time or day it is.



Difficulty planning and solving a problem.

Being moody, anxious, sad or frightened.

Reduced ability to cope with everyday tasks.

Slow and muddled thinking.

Dementia is not:

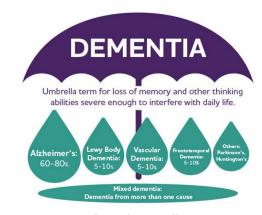
- Normal aging changes
- Attention seeking behaviour
- New headache or funny turns
- To be ashamed of

- To be hidden away in the family
- A reason to allow your physical health to deteriorate

Types of Dementia

About 40% of cases of dementia are undiagnosed and are recognised very late once they are moderately or severely affected. By then, insight is lost, and medications may be less effective.

Receiving a dementia diagnosis can be life-changing, and lead to feelings of grief, loss, anger or helplessness.



But a diagnosis is essential in supporting people to live well, even in the absence of a cure or drugs to slow the progression. It opens the door to emotional, practical, legal and financial advice and support.

Alzheimer's Dementia: 50 -75% of cases

Affects memory, thinking, language or perception. Person can't do everyday tasks.

Caused by inflammation and a build up of proteins in the brain.

Vascular Dementia: up to 20% of cases

Slow thinking, problems with planning or organising, making decisions or solving problems.

At risk of vascular problems, eg raised blood pressure or stroke etc. Caused by reduced blood supply to the brain.

Lewy Body Dementia: 10 to 15% of cases

Difficulty staying focussed, hallucinations and delusions, movement problems and poor sleep.

In a spectrum with Parkinson's Disease dementia.

Frontotemporal dementia: 2% of cases

Changes in personality and behaviour, language and communication problems.

Colin and Janet's story



"You don't realise what is going to happen in the future" said Janet when talking about her husband Colin's diagnosis of dementia.

"Colin started to develop some memory issues and they visited the GP a few times. Colin learnt the MMSE memory test and was able to "blag" the answers to this series of questions so diagnosis came a bit later than would have been helpful. I had insisted that it was essential that a doctor should see him as a whole person rather than talk about different symptoms.

This was agreed and he had a half hour appointment, one of the most thorough ever, addressing all his problems. The doctor was very insightful and so helpful. The GP arranged a brain scan and the Memory Clinic gave us the diagnosis.

Since diagnosis we have had much support from the GP, the Community Wellbeing Nurse and the memory clinic. We were referred to other services such as the OYSTA tracker system so Colin can go out for walks alone.

A physiotherapist did a home visit and recommended some aids and advised us about a variety of social and functional services. She was brilliant.

I also have the support of the Admiral nurses, who have been invaluable to us. Marvellous!

We enjoy the friendship and advice we have experienced at the memory cafes and would recommend these to others."



The Southampton Dementia **Diagnosis Journey**

1. See your GP. Tell them the problem.

"I will listen well to your story, test your memory and thinking and look for the best plan to help. I will order some blood and urine tests, and if concerned it is dementia will refer to the Southampton Memory Clinic."

Screening tests first to rule out other physical causes.

2. What happens at the Memory Clinic at Moorgreen Hospital, the Western Community Hospital or at your home.

This is the Older Persons Mental Health Team (OPMHT)

"I will listen fully to the concerns, do more memory and visuospatial tests and look at the test results so far. You will be referred for a brain scan if necessary. We will consider all possible causes of memory difficulties."

A scan will rule out a brain tumour and inform about the type of dementia if





3. Who will tell me the diagnosis?

Memory Clinic Clinician: "I will explain the diagnosis and its implications. If medication is indicated, this will be discussed and started if appropriate.

If necessary, follow up appointments will be arranged."

A personal treatment plan will be made.

4. What happens next?

Memory Clinic: "Mostly you will be discharged back to your GP for follow up, and you will be offered a referral to a Dementia Navigator who will listen to your situation and advise what might be helpful. This might include tracking and security devices, community wellbeing, financial and benefits advice, home adjustments and planning, social clubs and adult Social Care as appropriate.

Find out about support and help for the dementia community in Southampton.

5. As time goes on

Admiral Nurses support carers of people living with dementia. They give one to one support at first and again if there is a need or a crisis. They attend memory cafes where you can meet other carers. You will be signposted to a local course to learn more about dementia.

Help with the decisions and challenges, so you can face the future with more confidence and less fear.





Dementia can be confused with:

Delirium

A sudden change, reversible

Delirium or confusion is when a person becomes confused in time and where they are, often see hallucinations, and act out of character, but with a sudden onset. It is often caused by an infection, medication or stress. It can mean that the person is more likely to develop dementia. Delirium means the person is very unwell and needs to be medically assessed.

May be overactive: confused, hallucinating, agitated and think everyone is against them.

Or may be underactive: sleepy confused, tired and withdrawn.

1 in 3 people born in the UK this year will develop dementia in their lifetime

Depression

Sad, hopeless and slow, reversible

A depressed person can become withdrawn, with slow speech, slow thinking and even paranoid feelings and hallucinations.

They are eating and sleeping poorly, feel life is not worth living and may be caused by major life events such as a bereavement and needs urgent mental health assessment.

Dementia

Slow onset, progressive

It is not recognised by the person, who may not believe they are deteriorating. They deny there is a problem.

Dementia has many types, but all show difficulty thinking, and loss of memory and communication problems.

Early medical assessment, and accurate diagnosis really help!

Things that can get in the way...

Denial by the person who has a memory problem.
"I don't need to see a doctor, leave me alone!"



Fear.
"I am so
scared of the
future."

Family resistance.

"Leave Mum alone, she is just forgetful."

Situation whole so complex understand what what was going what



Stigma.
"I fear to go
out as I will
others as being
stupid."

We are alone.
"Society doesn't
want to know
about dementia
and what it
really is."

What you can do to stay feeling well, and have the best quality of life possible.



Look after your heart



Exercise daily



Stop smoking



Keep talking to others



Do fun things



Reduce or stop



Eat a healthy diet



Keep your brain busy



Are you safe to drive?



Care for your teeth and gums





What people say

Natasha, I had to push all the way to get a diagnosis sunil, Now
everyone knows
I have dementia
I can go to the
I can go to the
shops alone and
they will look out
for me.

Lee, On reflection, the dementia had been coming on for 10 years or more, we just didn't want to accept it.

Lesley, Our children believed me at last and started to help us not fight us.

Peter, I have made new friends at the memory café

Local sources of help:

Solent NHS Admiral Nurses Southampton

https://tinyurl.com/46pvs3cf

Tel: 0300 1234 026

Dementia Navigators

https://www.solinked.org.uk/community-navigation

Tel: 0238 0610 159

Southampton City Council Adult Social Care

https://tinyurl.com/mdzyntcr

Tel: 023 8083 3003

Southampton City Council Information Directory

https://tinyurl.com/47hd5vet

Carers in Southampton

www.carersinsouthampton.co.uk

Tel: 023 8058 2387

Memory cafes

Caraway provides Memory Cafes and Anna Chaplains for older people.

https://www.carawav.uk.com/resources/memory-cafes

Email: caraway@caraway.uk.com

Portswood Dementia Action Group

A fundraising and support group providing social activities.

Sends a weekly activities email Email: portswooddag@gmail.com

Communicare

Can arrange help with practical tasks and befriending.

https://communicareinsouthampton.org.uk/

Tel: 023 8250 0050

Next Steps

A great website to inform and advise you on a wide range of aspects of having dementia in the family.

www.nextsteps.org.uk

Living with Dementia Toolkit

https://livingwithdementiatoolkit.org.uk/

Our Sponsors:



Portswood Dementia Friendly **Action Group**

