

# 5 Steps to Embedding a new service in the YPWD care pathway – charity begins at work!

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making a difference community  
understanding specialist local  
together

## Why are younger people with dementia different?

Often working at time of diagnosis

Partner often employed

Dependent children

Financial commitments

More physically fit

More likely to have a rarer form of dementia

Behaviour and psychological symptoms can be more challenging

# Background

**Over 17,000 people under 65 have dementia**

**How many  
in Thames  
Valley?**

**Almost  
all have a  
family carer**

**50% of  
young  
carers give  
up work**

**75% of  
children  
develop  
psychological  
illness**

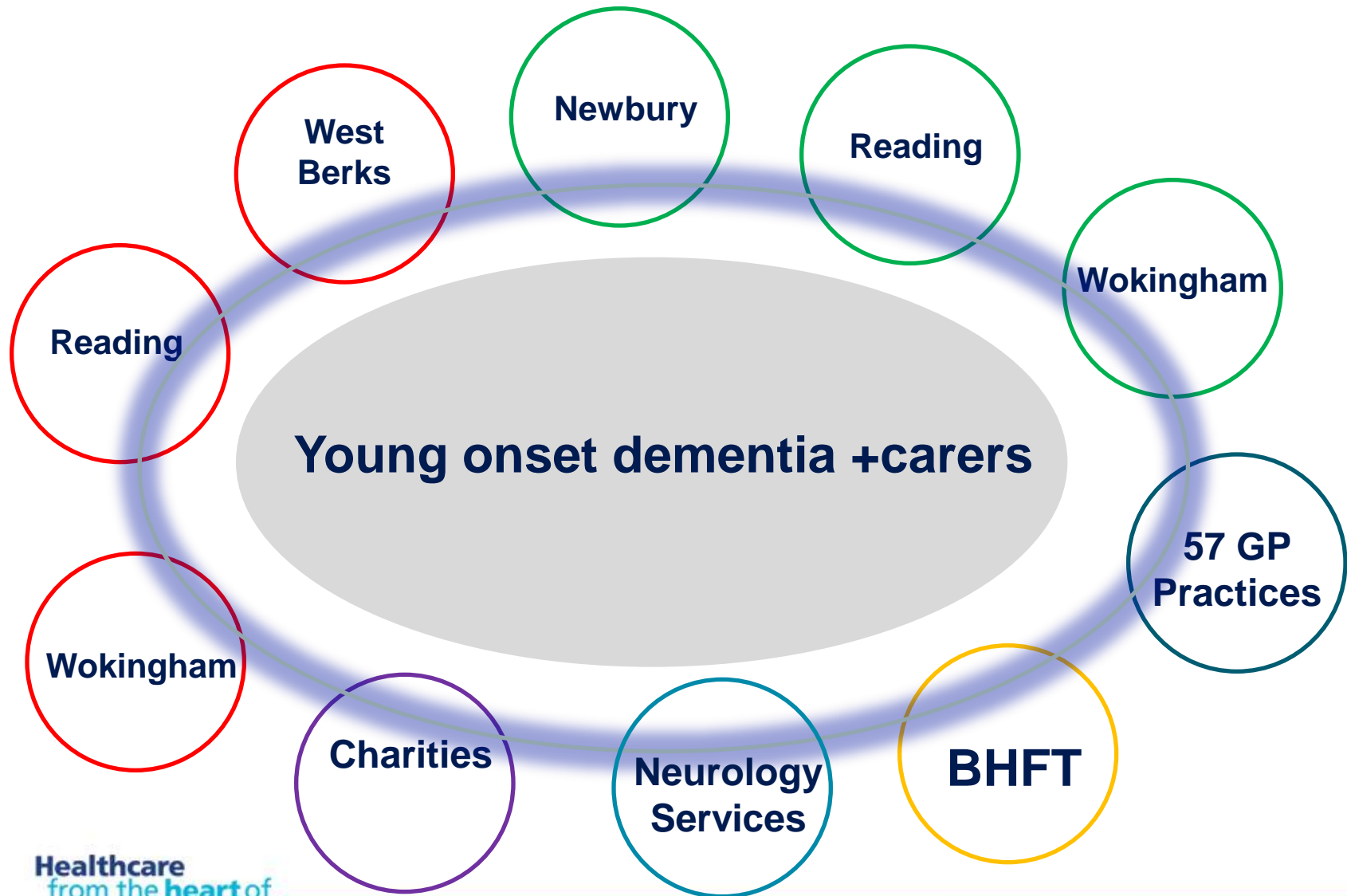
**Cost to the  
economy of  
2 people not  
working**

**Even less for  
younger  
people**

**Under 50% of people with dementia receive a diagnosis**

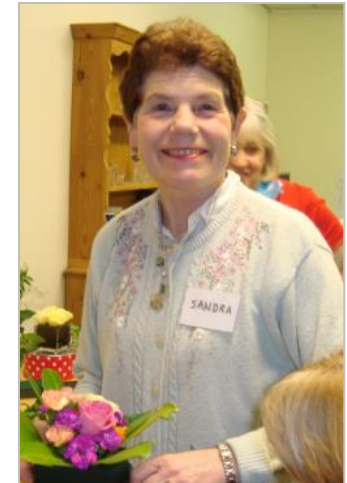
# What is possible?

**How we developed services for younger people with dementia, their families and carers – in 5 steps**



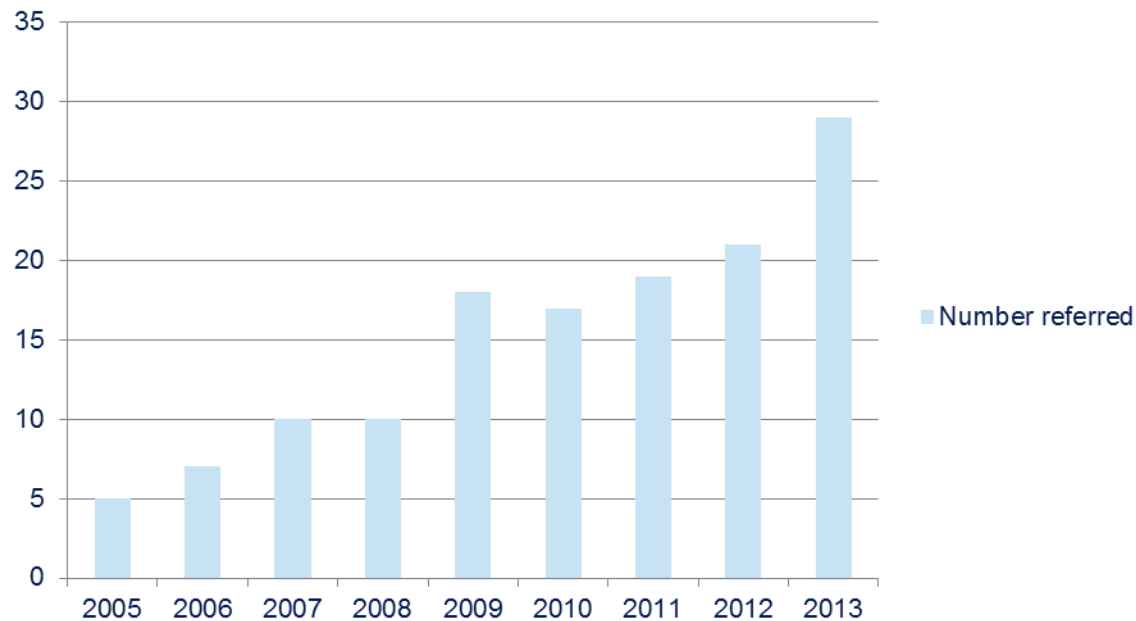


- **250 people with young onset dementia in Berkshire West**
- **35 new cases each year**
- **Diagnosis rate in Wokingham**  
**90 – 100%**



# The Wokingham service - 2013

## Number referred



# Expected numbers of YPWD in Wokingham

<b>Population 30-64 years</b>	<b>80,150</b>	
Expected number YPWD	54	
Actual number on case register	59	



# So how have we done it?

## 5 steps to a YPWD service

- **Step 1:** early diagnosis pathway
- **Step 2:** partners
- **Step 3:** staff skill mix
- **Step 4:** engage carers + people with dementia
- **Step 5:** expand the model? Thames Valley?

# Step 1: Diagnosis

- **GPs often don't recognise dementia in younger people**
- **Younger people are treated by Old Age Services, yet referred to General Adult Psychiatry & Neurology**

**Step 1 – befriend your local Neurologists!  
Care Pathway**

# Step 2: Engaging Partners

YPWD Forum

Website

Business plan but small numbers

Look within services!

# Step 3: Staffing

Initially – low numbers, staff were reluctant, lacked confidence and felt un-skilled.

**Now** – passionate, involved and taking on new things

# Step 3: How?

YPWD education courses for carers  
& patients. A catalyst!

Re-designated roles

# Step 4: Carers + people with dementia

Charity begins at work!



# What we are working to achieve

**People with dementia treated as full members of the community**

**Carers able to stay in work longer**

**Delivery of services & support appropriate to the needs of younger people**

**Education & activity programmes for younger sufferers & their carers**

**Greater awareness**



**More Funding**



**More research**

# Gardening





# Art & Furniture Restoration



# Sports & Outdoor Activities



# The Harmony Choir



Neil Sedaka

The Carpenters

The Beatles

The Bee Gees

Louis Armstrong

RedCape  
Theatre

Turtle Key Arts



## Open mic nights

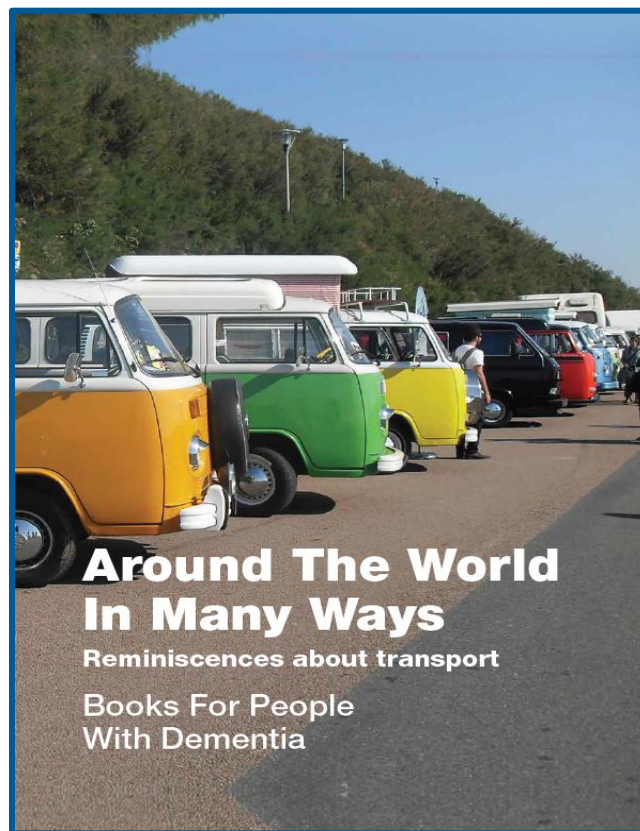
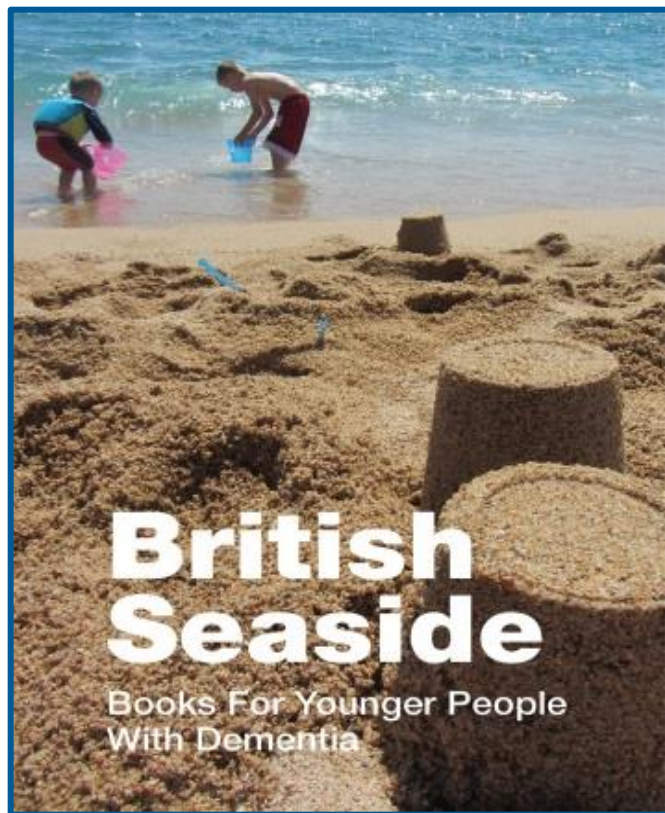


## Salsa



## Zumba





# Additionally:

- **Al's Place**
- **Carer's Drop-in**
- **Admiral Nurse**
- **Dementia Care Adviser ( LA)**



## All of these activities provide:

- Respite opportunities

**BUT** respite must engage the person with dementia in meaningful activities

- Safe opportunities for people with dementia & carers to enjoy activities together

# How is this achieved?

- £60000 from Carers Respite grant = 2 respite workers
- £40,000 from People's Health Lottery (18months)
- Fundraising

## Joint Working

### Honorary contracts with BHFT

(Use NHS electronic notes)

BHFT staff work for or  
volunteer with charity

Work closely with Memory  
Clinics

Jointly run education courses

Joint supervision & training

## Benefits

**Advantages of monitoring people in  
non-clinical settings**

**Carers find us accessible**

**Patient choice**

**Staff confidence and skills increase**

**“All in it together”**

**Seamless service**

**Cost effective**

# Step 5:

## Sustainability & expanding the model

### Opportunities & AHSN:

- Health & social care funding & voluntary sector
- Outcomes
- Model could be reproducible within Thames Valley

# Thank you

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