



Sandwell Dementia Care and Support Planning Toolkit





# **Sandwell Dementia Care and Support Planning Toolkit**

## Introduction

Personalised Care Planning is crucial in delivering improved care for all people living with dementia, their families and carers.

This toolkit aims to support Health and Social Care to provide personalised dementia support and annual reviews in a meaningful way to enable people to continue to live well and independently for as long as possible.

It is a live document and the information and resources it contains will be reviewed on a regular basis to ensure they are as up to date as possible.

## **Toolkit Dashboard**

Teeth

panning

#### **Assessing Needs and Support Planning Eating and Drinking** <u>Alcohol</u> **Behaviours Driving Eyesight** Independence and Falls and feet Incontinence Finance and legal Hearing staying safe Pain Medication My Future Care <u>Memory</u> Mood Sex and Sandwell Dementia Pets, hobbies Sandwell resources **Physical Activity** relationships and interests support Services <u>Supporting</u> Social, spiritual and **Smoking** Sleep **Staying Warm** Family/Carer cultural Templates: care **Toolkits: DiADeM** <u>Transport</u>

# Assessing needs and support planning

When undertaking a needs assessment, support planning or annual review its important to encourage the client / patient to prepare in advance of the appointment. It's advisable to check if the following two documents have already been completed, if not please see the resources in this section.

Sandwell promote the use of "<u>This is me"</u> which is a simple leaflet for anyone receiving professional care who is living with dementia.

'This is me' helps health and social care professionals better understand who the person really is, which can help them deliver / arrange care that is tailored to the person's needs.



www.alzheimers.org.uk



www.murrayhall.co.uk/scds

#### **Sandwell Community Dementia Service**

provide everyone referred into the service with a copy of "My Future Care Handbook". It is packed with information to make, record and share decisions about what the individual wants in the future.



A one-stop shop for all things related to later life and beyond, from compiling a bucket list to writing a Will, from creating a music play list to considering where they want to live and/or be cared for if they need support, and much, much more. There are also links provided to further online resources for those wishing to use the internet. Sandwell Community Dementia Service support people to complete the handbook.

## **Alcohol**

It's important to balance the person with dementia's right to enjoy a pleasurable activity such as drinking alcohol, against the risk it may pose.

Excessive alcohol consumption over a lengthy time period can lead to brain damage, and may increase the risk of developing dementia.

Having a drink in company can be a pleasant way to relax. However:

- •People with dementia can become more confused after a drink, so may need to limit the amount they have.
- ·Alcohol doesn't mix well with certain medicines.
- •People who have dementia secondary to alcohol abuse should not drink alcohol.
- •People with alcoholic dementia should have high thiamine diets and/or thiamine supplements.

# Tips to support people to reduce drinking alcohol

- •Keep alcohol out of reach and out of sight.
- •Provide low alcohol or non-alcoholic substitutes.
- Provide watered down alcoholic drinks.
- •Consider support from local alcohol cessation services.
- •Avoid drinking alcohol in front of the person with dementia.



#### Alcohol and dementia



Alcohol related brain damage and dementia

## **Behaviour**

# Tips to support people who repeat the same question or activity

- Try to be patient and keep your tone level and calm.
- If the person keeps asking about the time or date, consider putting a calendar or clock somewhere they can easily see it.
- Think about what need might be behind the behaviour. For example, if the person keeps asking if they've been to the supermarket, they may be worried about running out of food.
- If the person keeps looking for a particular item, have an allocated place for it that is easy to see and access.
- Look at what may be triggering the behaviour for example, does this happen the same time of day or around the same people? See our information on identifying triggers.
- Distracting the person or engaging them in an activity they enjoy can help to shift their focus onto something else.
- If the behaviour is not harmful or causing a problem, accept that the person finds it comforting and reassuring and let it be.

#### Tips to support people who are agitated

Rule out or treat underlying cause:

- -Uncontrolled pain
- -Untreated depression
- -Infection, e.g UTI
- -Medication side effects

If the person behaves in an aggressive way, try to stay calm and avoid confrontation. Call for assistance if not they are not settling.

#### Tips to support people who are restless

- Make sure the person has plenty to eat and drink.
- Have a daily routine, including daily walks.
- Accompany them on a walk to shops or consider tracking devices and alarm systems (telecare).
- Give them something to occupy their hands if they fidget a lot, such as worry beads or a box of items that mean something to them.



#### **Coping with Dementia Behaviour**



Find out more about behaviour changes

# **Driving**

### Safe driving with dementia –tips for clinicians

People with mild dementia may still drive if they are safe, although they must inform the DVLA of their diagnosis.

#### Questions to assess whether safe to drive:

- ☐ Would family be happy for the person with dementia to drive with their
- ☐ grandchild alone? Have they had any accidents or near misses?
- ☐ Have they got lost driving in a familiar area, or lost their car?

Consider using objective tools to assess safety:

- ☐ Black box/tracking device
- ☐ Consider a safe driving assessment (local councils)

#### When someone is considered unfit to drive

- Inform the person they must tell the DVLA they are no longer able to
- drive.
- Send a letter to the patient (as a written prompt) and/or inform family. Family members/carers can help by supporting the DVLA notification, removing the car from the drive, safe holding the car keys, etc.



#### **Driving and DementiaPDF**

#### Alternative to driving ideas

- ·Book a taxi to go to the supermarket once a month.
- •Set up an account with a taxi firm to order taxis in advance.
- •Local voluntary organisations may offer community transport services.
- ·Hospital transport for hospital appointment.
- •Pay bills by direct debit so need to visit the bank or post office less often.
- •Getting a shoppers' bus to the supermarket.
- •Order shopping online (if possible) and have it delivered to the house.
- •The Council may be able to offer <u>Transport support.</u>



**Applying for a Blue Badge** 

# **Eating and Drinking**

#### Tips to promote eating well

- Create an appetite encourage activities and walking.
- Make the environment calm, relaxing and as appealing to the person as possible. If the person feels comfortable, it can affect how much they enjoy eating and the amount they eat.
- Keep the table free from clutter. Avoid patterned items that can cause confusion.
- Consider playing soothing music to help create a relaxing environment. Switch off background noise and avoid distracting movement.
- Be led by the person with dementia on where they would like to sit and eat. Ensure that they are comfortable.
- Try not to worry about mess it's more important for the person to eat than to be tidy.
- If you or others are eating at the same time as the person, it may help encourage them to eat.



Keeping a person with dementia

safe during hot weather

**Dementia**UK

#### Tips to promote good hydration

- Provide drinks rather than ask if the individual would like one, ensure not too hot or too cold.
- Encourage individuals to take each tablet of medication separately with fluid to maximise intake.
- Leave glasses or jugs of water within easy reach.
- Make drinking easier. Use a glass so the person can see what's inside or use a brightly coloured cup to draw attention). Straws can help.
- Make drinking a social occasion. Have a cup of tea or an ice lolly with the person.
- Leave reminders. Prompt by leaving notes out for them or notices around the house. You could also set up a phone reminder or set an alarm clock.
- Supplement drinks with food that has high water content.

# **Eyesight**

## **Tips for clinicians**

There is a high prevalence of visual impairment in people with dementia.

Visual impairment is much higher for people with dementia living in care homes.

- Poor eyesight can increase confusion for people with dementia, and can make it harder for them to recognise people or objects.
- 80% of people with dementia are still able to complete a routine eye test.
- Optometrists have special techniques for assessing sight, even for people in the later stages of dementia.

## **Tips for carers**

- Opticians can also check for cataracts and glaucoma pressure, diabetes.
- Optometrists can mark-up spectacles with people's names.
- Home assessments for eye checks can be arranged if people are frail or housebound.
- Someone with dementia may need to be tactfully reminded to wear their glasses and check that their lenses are clean.



Sight, perception and hallucinationsPDF



**Dementia and Sight Loss** 

## **Falls and Feet**

People withdementiashave a higher risk of falling. They are more than three times more likely to fracture their hip when they fall, which leads to surgery and immobility, and increased mortality.



<u>Fabulous Footcare Sandwell</u> (specialising in Dementia friendly footcare)



**Falls** 



Falls and dementia



Fitter Feet-Healthy feet are essential to remain mobile and active

## Tips to help prevent falls

Consider providing the person with a personal falls alarm: these are usually worn around the neck and can alert a family member or help centre if the person falls. Find out more about Sandwell's Community Alarms service and how they can help. Think about where you could place items like phone handsets, blankets and bottles of water around the home in case the person falls and cannot get up.

The person may be able to ask an Alexa device, Siri or other voice-activated device/system to call a family member, neighbour or emergency services if they fall.

Consider how the emergency services can access the property and contact you if the person falls, for example by installing a key safe; nominating a trusted person such as a neighbour to keep a spare key; and placing contact information in a prominent position (eg a hallway table) so it is easy to find.

# **Finance and Legal**

## Tips to help people manage their money more easily

- •Set up standing orders or direct debits.
- ·Have all income, including pension and benefits, paid directly into bank or building society accounts.
- ·Consider getting a chip and signature card a signature is required rather than a personal identification number (PIN).
- ·Set up a third party mandate -to allow someone you trust access to your bank account and specify how much access to give (for example, a set amount for the weekly shop).
- ·Consider appointing a Lasting Power of Attorney (LPA).

#### **Finance**



**Benefits for carers** 









**Council TaxPDF** 



**Benefits and entitlements** 



Expanding support for carers of DementiaUK **Veterans** 



How we support veterans with dementia



**Managing MoneyPDF** 

# Legal

Advance decisions, advance statements and living wills managing difficult situationsPDF

Managing legal affairs for someone with dementia

Legal and financial

# Hearing

# People with hearing loss are more likely to develop dementia

Telling the difference between dementia and hearing loss

People who develop hearing problems during mid-life (aged 40-65) have an increased risk of developing dementia. It may also be one of the early symptoms of dementia.

People with hearing problems may be more likely to withdraw from social situations and become more socially isolated over time- a risk factor for dementia. Hearing loss may also mean that the areas of the brain that help us understand sounds and speech have to work harder to understand what sounds are. This additional effort may lead to changes in the brain that affects our memory and thinking abilities.



Dementia and difficulty with soundsPDF



Sight and hearing loss



**Hearing Loss: What Works GuidePDF** 



The Deaf Dementia Experience



**Sensory Support Team** 

## Incontinence

It's common for people to have more difficulties using the toilet as they get older, particularly if they have dementia. Accidents and incontinence can cause problems, especially as a person's condition progresses. This can be upsetting for the person with dementia and difficult when you're supporting them.



## **Practical tips**

Encourage the person to drink throughout the day. The recommended amount is six to eight glasses of liquids each day – more if the person has hard poo. Not drinking enough liquids can cause constipation.

Support the person to eat a balanced diet with plenty of fruit and vegetables, and enough fibre to help regular bowel movements. Fibre can be found in cereals, brown rice and potatoes, for example.

Keep active. Walking every day (if the person is able to) helps with regular bowel movements.

Try to build going to the toilet into the person's routine, and allow enough time for the person to empty their bowels.

**Continence Service for Adults in Sandwell** 



Continence and dementiaPDF



Continence and using the toiletPDF

# **Independence and Keeping Safe**

## National Dementia Helpline: Call 0300 222 11 22

#### Resources



Living with dementia -living alone



Using equipment and making adaptations at home



Making the home dementia friendly and safe



NHS healthcheck Dementia Leaflet

#### **Tips for carers**

#### **Personal Care**

- •Involve the person in decisions around washing and dressing.
- •Offer tactful reminders e.g. change clothes regularly.
- •Consider easy to wear clothing (i.e. to easily access the toilet).
- •Offer practical help but encourage independence.
- •Give lots of encouragement and try not to dwell on things that do not go well.

#### **Technology**



Assistive technology -devices to help with everyday livingPDF



Living aids and assistive tech

## **Medication**



Drug treatment for Alzheimer's Disease

## **Antipsychotic prescribing**

- A person living with dementia should only try an antipsychotic if they are at risk of harming themselves or others, or if they are severely distressed.
- •The antipsychotic should be tried alongside other activities to try to help their distress.



Drugs for behavioural and psychological symptoms in dementiaPDF

### Drugs to avoid in people with dementia

	Antipsychotics	Antidepressants	Anticholinergic (Bladder incontinence)	Antihistamines
Drugs to AVOID in dementia	Olanzapine Chlorpromazine	Tricyclics e.g. amitriptyline imipramine	Oxybutynin Solfenacin Tolterodine	Chlorpheniramine Hyoscine Promethazine Cyclizine
Drugs to use with CAUTION in dementia	Haloperidol Quetiapine Prochloperazine Risperidone	Fluoxetine Mirtazapine Paroxetine Venlafaxine Duloxetine		
PREFERRED drugs to use in dementia		Sertraline Citalopram		Cetirizine Loratadine

## **Memory**

# Tips to help cope with memory loss

- •Keep a regular routine.
- •Put a weekly timetable on the kitchen wall.
- •Schedule activities for when feeling better (for example, in the mornings).
- •Put keys in an obvious place.
- •Keep a list of helpful numbers (put regular bills on direct debits).
- •Use a pill organiser box (dosette box).
- •Use signs and labels.
- •Use telehealth gadgets to prompt and keep safe.
- •Use your brain -crosswords, Suduko, etc.
- •Healthy lifestyle to prevention further deterioration –stop smoking, exercise, etc.



#### **Dementia guidePDF**



**Coping with memory lossPDF** 



How to make your home dementia friendly

## Mood

- At least one in five people in the UK will experience depression at some time in their lives.
- It is more common among people with dementia

dementia (20-40% of whom may have depression), particularly those who have vascular dementia or Parkinson's disease dementia.

- Identifying anxiety and depression means the person with dementia can be treated and supported in the correct way.
- Untreated, either condition can become more severe, resulting in further distress or deterioration in their health.



Apathy, depression and anxietyPDF



**Managing Anxiety and depression** 



**Anxiety and Depression - Tips for carers** 



Talking therapiesPDF

## **My Future Care**

Advance Care Planning is a process to help plan and record future wishes and priorities of care with family and friends. This means there is a record of wishes when the person may no longer be able to make or communicate such decisions.



**Lasting Power of AttorneyPDF** 



This Is Me templatePDF



**Understanding Dying** 



Planning for the future



**Advanced Care PlanPDF** 



Moving to a Care Home-check listPDF



Deprivation of Liberty Safeguards



FAST test to assess stage of dementia (for professionals)PDF

### **Pain**





#### Pain and dementiaPDF



Wong-Baker pain scale

Abbey et al, Medical Research Foundation, 1998-2002 Abbey pain scorePDF

# Clinical tips to recognise when people with dementia are in pain

- •Change in behaviour, such as fidgeting, restlessness, or distress during personal care.
- ·Calling out, groaning or shouting.
- •Sleeping more or less than usual.
- •Body language, such as, bracing or guarding, or repetitive movements.
- ·Facial expressions, such as grimacing, or frowning.
- •Mood, withdrawal or uncharacteristic quietness, low mood.
- •Increased pulse, sweating, flushing or appearing pale.
- Poor appetite.

## Pets, Hobbies and Interests



**Activities for those with dementia** 



Caring for a pet help those with dementia



For terminally ill, elderly and their pets



**Dementia Dog Programme** 



**Musical Map for dementia** 

## **Tips for carers**

- •Having dementia doesn't mean stopping doing the things people enjoy.
- •There are all sorts of activities –physical, mental, social and creative that help people with dementia to live well and improve wellbeing.
- •A shared activity can make both people happier and able to enjoy quality time together.

# **Physical Activity**

# Benefits of exercise and physical activity for people with dementia

- •Reduces the risk of high blood pressure and heart disease.
- •Reduces the risk of some types of cancer (particularly breast and colon cancer)
- •Reduces risk of stroke and Type 2 diabetes.
- ·Improves physical fitness and balance.
- •Maintains strong muscles and flexible joints to maintain independence.
- •Improves the ability to dress, clean, cook and perform other daily activities.
- •Helps to keep bones strong and reduces the risk of osteoporosis.
- ·Improves cognition -activity can improve memory and slow down mental decline.
- ·Improves sleep patterns.
- Reduces isolation
- •Reduce the risk of falls by improving strength and balance
- •Improves confidence and self-esteem.
- •Improves mood.



Physical activity and exercisePDF



Physical Activity in care homes



Sandwell Living well with dementia



Prescribing movement for dementia

## **Sandwell Dementia Support Services**

Sandwell Community Dementia Service (SCDS) is a partnership of 8 local voluntary sector organisations working together to provide advice, information and support to people worried about their memory and those with a dementia diagnosis in Sandwell.



www.murrayhall.co.uk/scds

#### Make a Referral:

To make a referral, you can contact the Single Point of Access by phone or email. You can also **download a Referral Form.** 

#### **Contact:**



01902 826 655



bcicb.dementiasupport@nhs.net

**Read the latest newsletter from SCDS** 



The service provides support at each stage of the dementia pathway and helps to facilitate Dementia Friendly Communities in Sandwell.

They engage with schools and community groups to raise awareness and run Dementia Friends sessions

#### Who can access the service?

It is free for people living in Sandwell who are registered with a Sandwell GP practice and are:

- at any stage of memory loss and/or other cognitive symptoms.
- diagnosed with dementia.
- a carer/family member of someone living with dementia.

<u>Download SDCS Support for Dementia resource</u>

<u>Practical tips for supporting people with Dementia</u>

## **Sandwell Resources**

Carers Services in Sandwell - browse Sandwell's Information point Directory's list of carer support service providers.

**Advocacy Services in Sandwell** - information on Advocacy support.

<u>Sandwell Dementia Road Map</u> - helping primary care to support people with Dementia.

<u>Older Adults Treatment Teams</u> - community support for Older Adults.

**<u>Admiral Nurse Service Sandwell</u>** - tailored support for people living with Dementia.





## **Sex and Relationships**



Dementia can cause relationships to change. It can be difficult to adjust, and may take some time.

Intimacy is important and can be physical, e.g. touching, cuddling or sex or spending time with loved ones.

# Sleep

Sleep disturbance can affect the quality of life of a person with dementia and anyone caring for them.

It can have impact on a person's wellbeing, and can lead both the person with dementia and those caring for them to become more fatigued and stressed.



Good habits at BedtimePDF



Sleep and night time disturbance

# Tips to support good sleep for people with dementia

- ·Limit daytime naps.
- •Ensure a range of stimulating activities –someone is more likely to doze off during the day if they are bored.
- Avoid caffeinated drinks such as tea and coffee.
- •Exercise during the day.
- •Finding relaxing ways to encourage the person to sleep, such as giving them a warm milky drink at bedtime and listening to music.
- ·Consider using black out curtains.
- •Use a clock indicating day and night times.
- •Ensure the person is not thirsty/hungry/in pain.

# **Smoking**

Smoking increases the risk of vascular dementia, and toxins in cigarettes increase inflammation causing Alzheimer's.

Some researchers estimate that 14% of dementia worldwide may be attributable to smoking.



**Smoking and dementia** 

# Tips to helping people with dementia stop smoking

- •Refer to a local smoking cessation clinic.
- •NHS SmokefreeHelpline is free to call on 0300 123 1044.
- •Carer to reduce cigarettes given to person and gradually wean off.
- ·Consider e-cigarettes as an alternative.
- •Patches can be helpful in people with dementia.
- •If carer is a smoker, to consider stopping too as "quit buddy".
- •Remove ashtrays out of sight as person may then forget to smoke.
- •Remove fire risks -replace matches with disposable lighters.

# Social, Spiritual and Cultural



Building dementia friendly faith communitiesPDF



Dementia friendly faith groups



LGBT living with dementiaPDF



**BME** communities and dementia

## Tips to keep connected

- •Dementia-friendly swimming, gym and walking sessions.
- •Arts-based activities -drawing or painting classes, drama groups and book clubs.
- •Reminiscence –share life experiences and stories from the past with photos, objects, video and music clips.
- •Dementia café –meet other people with dementia and their carers in an informal setting.
- •Singing for the brain groups.



**Supporting veterans** 

# **Staying Healthy**

For someone with dementia, it's important to remain as fit and healthy as possible. The better they feel, the better life will be for them and those around them.



Staying healthy to support your memory



Reducing your risk of dementia



Helping your brain stay healthyPDF



**Keeping Healthy** 

# What's good for the heart is good for the brain

·Don't smoke.

Keep cholesterol and blood pressure under control.

- •Be active and exercise regularly.
- Maintain a healthy weight.
- •Eat a healthy balanced diet.
- •Drink fewer than 14 units of alcohol per week.

Remember the annual <u>flu vaccination</u> for both the person with dementia and their carer.

# **Staying Warm**

## Tips to keep warm

Someone with dementia may not realise they are cold or may be unable to tell someone.

- Stay active when indoors, avoid sitting still for too long;
- Heat your home to at least 18 C (65 F);
- Wear several layers of light clothing to trap warmth.
- Check your heating and cooking appliances are safe. Visit the Gas Safer Register website

If you are concerned someone may have hypothermia, call NHS 111.

For more tips on staying well, including eating a healthy, balanced diet, go to the **NHS Live Well website**.

You may be able to claim financial and practical help to make your home more energy efficient, improve your heating or help with bills. Visit the **GOV.UK improve energy efficiency webpage** or call 0800 444 202 to speak to an adviser.

Warmer Homes West Midlands offers personalised energy advice to households if you are struggling to heat your home. Visit the **Warmer Homes website** or call 0800 988 2881 or 0808 196 8298 and press option 2.



**Keeping Warm with dementia** 



Top Tips for keeping warm and wellPDF

# **Supporting Family and Carers**

The Care Act (2014) mandates that every carer should have an assessment of needs – regardless of financial status.



#### **Assessment for care and supportPDF**



The carers assessment



Getting help and advice



Paying for care and supportPDF



Getting care and support for dementia

## **Tips to support carers**

Any family member or friends who regularly cares for someone with dementia should also get the help they need.

- Ensure carers are registered with local Carers Support organisations (e.g. Carers UK, Carers Bucks, etc.)
- Local Authorities provide an annual Carers' Assessment.
  - Respite care of financial support may be provided
- following a carers' assessment.

### **Teeth**

It's important to support people with dementia to keep good dental hygiene and well-fitting dentures if they are worn, to enable them to eat well, reduce infections (and therefore reduce confusion) and reduce pain.

It is recommended that a person diagnosed with dementia who has their own natural teeth is seen by a dentist every six months.

#### Resources



Mouth care for people with dementia



Dental care and oral healthPDF



Find an NHS Dentist



**Keep smiling** 

## **Tips for carers**

f you are helping someone to brush their teeth, there are things you can do make it easier for both of you.

#### Establish a routine

The most important part of mouth care is brushing teeth twice a day, including just before going to sleep to help prevent dental problems developing. It is also a good chance to check the rest of the mouth for any concerns.

#### Encourage the person to do the task themselves

Where possible, try to encourage a person with dementia to brush their teeth themselves. Some people may find this difficult because of their dementia symptoms or other health problems, such as arthritis.

If the person is struggling, assist them, but it's best not to take over completely. Instead, try gently prompting them or only helping when they get stuck. If you need to brush their teeth for them, see tips below.

#### Information about dental and mouth care for carers

# **Templates: Care and Support Planning**

## **Templates**



**Dementia Annual Review Invite** 



What Could Make a Difference



My Dementia Review Care Plan



**Your Care and Support Plan Summary** 

Download the set of four templates from here.

# **Toolkits (DiADeM)**

#### **DiADeM**

#### **Diagnosing Advanced Dementia Mandate**

This protocol aims to support GPs to diagnose dementia for people living with advanced dementia in a care home setting.

DiADeM is designed to be used only with those patients living with advanced dementia within a care home setting for whom a trip to memory services is unlikely to be feasible and/or make a difference to ongoing management.

- •Reports suggest that 70% and 80% of care home residents have dementia & that many do not have a formal diagnosis
- •Often residents with advanced dementia &/or frailty, are denied a diagnosis due to difficulty attending a memory service clinic even though formal referral to memory services is rarely desirable & often distressing.
- •A Diagnosis enables access to appropriate support, care planning & in some cases, treatment & gives the opportunity for the patient with dementia to share their preferences for future care with family &carers

There are different versions of the tool available.

You can find out more, register and download them here:

diadem.apperta.org



## **Transport**

#### **Blue Badge information in Sandwell**

#### **Community Transport services**

Provides accessible transport services to local supermarkets

#### **Ring and Ride WestMidlands**

#### **Transport for West Midlands**

Disabled persons travel pass – free travel during off peak times

