



For Healthcare professionals:

# DIABETES AND DEMENTIA: GUIDANCE ON PRACTICAL MANAGEMENT

Endorsed by:



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## RATIONALE AND REMIT

Diabetes and dementia are both common complex conditions which affect people in different ways. The successful management of diabetes requires the person to have a good understanding of the condition, to follow a regular healthy eating and physical activity plan, to monitor glucose levels, attend clinic reviews and to take medication as prescribed. The presence of dementia, with increasing problems with memory and communication, can make these tasks difficult to follow. Diabetes can also have a negative impact on memory and confusion.

This guidance has been developed to highlight the importance of recognising the relationship between diabetes and dementia, the impact one condition has on the other, and maximising the benefits and safety of diabetes treatments while minimising the risk of hypoglycaemia. It is intended to serve as a helpful resource for care workers and health care professionals working in nursing and residential homes, care workers and community nurses working with older people living in their own homes, and for commissioners, managers and designers of services in both primary and secondary care.

Healthcare professionals have an individual responsibility of care to make decisions appropriate to the circumstances of the individual person with diabetes and dementia. Decisions should be informed by the person with diabetes and dementia where possible, and/or his or her carer/family, taking full account of their medical condition and treatment.

When implementing this guidance, full account should be taken of the local context and any action taken should be in line with statutory obligations required of the organisation and individual. No part of this guidance should be interpreted in a way that would knowingly put any person at risk.





# ABOUT THIS GUIDANCE

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## Authors

**Debbie Hicks:** Nurse Consultant-Diabetes, Enfield Health, B.E.H-MHT, TREND-UK

**Jill Hill:** Independent Nurse Consultant, TREND-UK

**June James:** Nurse Consultant-Diabetes, University Hospitals of Leicester NHS Trust, and Associate Professor University of Leicester, TREND-UK

## Document reference group

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We would also like to thank Amar Puttana, Consultant Diabetologist, for reviewing this 2nd edition of the document.

## About TREND-UK

TREND-UK is a working group of diabetes nurses with different skills and backgrounds, set up in 2009 in response to a request by the diabetes tsar at that time for a collective voice that represented all diabetes nursing groups. The original founding co-chairs of TREND-UK were experienced nurse consultants, working in a variety of settings and closely involved with most of the organisations representing nurses working with people with diabetes. TREND-UK has produced a number of resources for nurses and people with diabetes, available on [www.trend-uk.org](http://www.trend-uk.org). Registration to access these is free of charge and available to anyone interested in caring for people with diabetes as well as those with the condition.

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## FOREWORD

There is increasing recognition that diabetes and neurodegenerative disease including Alzheimer's dementia are linked and whilst further studies are necessary to elucidate cause and effect in this area, clinicians are facing the challenges of managing rising numbers of people with both conditions.

Care of individuals with dementia raises moral, ethical and clinical issues. In the setting of diabetes this may become a complex illness model. This will require health or social care professionals to focus a great deal more on the thinking, behaviour, and the ability of an individual to perform everyday routine tasks, including diabetes self-care actions. As a consequence, these individuals are highly vulnerable and significantly more resources are needed in primary care to manage these cases effectively.

This 2018 revision of the earlier document on practical management in diabetes & dementia has been led by a distinguished team of authors at TREND-UK who should be congratulated for producing a comprehensive set of chapters dealing with more than six key aspects of care. These include diagnosis of both index conditions, hypoglycaemia, communication issues, and end of life scenarios. The algorithm for managing 'hypos' and the competency framework for nurses and care workers is particularly helpful. The illustrations and drawings are really eye-catching and remarkably easy to interpret. There is no other comparable guidance available at this time.

### Professor Alan Sinclair MSc MD FRCP

Director, Foundation for Diabetes Research in Older People at Diabetes Frail,  
and Honorary Professor of Metabolic Medicine, University of Aston, UK

The number of people living with both diabetes and dementia is increasing as the UK population ages and it is important for healthcare professionals to understand the relationship between the two conditions. Dementia can adversely affect a person's ability to manage their diabetes. These guidelines provide practical advice on how to support people with both conditions, how to optimise diabetes management while keeping the individual safe and how to maintain independence as much as possible.

### Libby Dowling

Senior Clinical Advisor  
Diabetes UK



# INTRODUCTION

The population world-wide is ageing, and by 2040, it is predicted that nearly 1 in 4 people in the UK will be aged 65 years or older. Currently, 11.8 million people living in the UK are aged 65 years or older, and 1.6 million are aged over 85 years (AGE UK, 2018). The prevalence of Type 2 diabetes and dementia increases in older people so it is unsurprising that both conditions are significantly increasing in numbers, with over 850,000 people with dementia (Dementia UK, 2017) and almost 3.7 million people with diabetes (Diabetes UK, 2018a) in the UK.

Both are progressive, complex long-term conditions which consume a considerable amount of health and social care resources. Therefore as the population gets older, this is likely to become an increasing problem. By 2025, the number of people with dementia is predicted to rise to over 1 million and to 2 million by 2050 (Prince et al, 2014), and the number of people with diabetes to rise to over 5 million by 2025 (Diabetes UK, 2018a).

There is a close association between Type 2 diabetes and dementia, in particular Alzheimers disease and vascular dementia, with Type 2 diabetes associated with a 60% increase in risk for all-cause dementia (Gudala et al, 2013). The association with vascular dementia is perhaps unsurprising given that Type 2 diabetes is a known risk factor for cardiovascular and cerebrovascular disease. Those individuals with a longer duration and earlier age of onset of diabetes have the highest risk. Interestingly, women with Type 2 diabetes had a 19% greater chance of developing vascular dementia than men (Cholderton et al, 2016). There is a 56% increased risk of developing Alzheimers disease in individuals with Type 2 diabetes (van de Vorst et al, 2016) but also people with Alzheimers have an increased risk of developing Type 2 diabetes (35% vs 18% people without dementia) and impaired glucose tolerance (46% vs 24%) (Janson et al, 2004).



Cognitive decline in older people with Type 2 diabetes is double that of older people without diabetes. In addition, slowing down of general cognitive function (which is a marker for accelerated brain ageing and dementia risk) is related to middle-aged adults with Type 2 diabetes (Cholderton et al, 2016).

Due to the nature of the condition and age at diagnosis, most people with dementia and diabetes will have Type 2 diabetes. However, as life expectancy increases, more people with Type 1 diabetes will also need to be considered. In fact, recent studies in people with Type 1 diabetes have noted the association between blood glucose control and the increased risk of dementia (Zheng et al, 2018).

Insulin has an important role in the healthy functioning of the central nervous system. The brain is rich in insulin receptors but the hyper-insulinaemia associated with insulin resistance (a key feature of Type 2 diabetes) reduces the sensitivity of these insulin receptors and so reduces the passage of insulin into the brain. Metabolic disturbances and vascular complications are additional factors which may contribute to dementia risk (Cholderton et al, 2016)

An NHS Mandate published by the Department of Health in 2012, updated in 2015 (DH, 2015) aimed to ensure that the diagnosis, treatment and care of people with dementia in England would be the best in Europe. This would be achieved by improving early diagnosis through raising awareness, access to memory assessment and diagnostic clinics, access to the right information at the right time, and improving the experience for people seeking help for memory problems. There are similar processes to improve the early diagnosis of diabetes and ensure that people with the condition receive the recommended checks and treatments (NICE 2015a, 2015b).

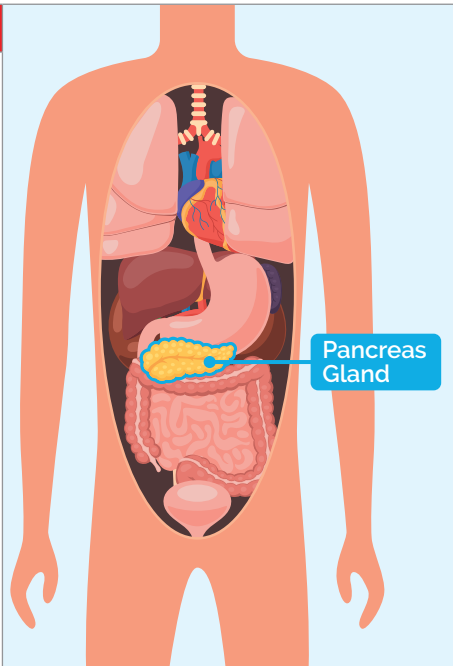
The successful management of diabetes requires the person to have a good understanding of the condition, to follow a regular and healthy eating and physical activity plan, to monitor glucose levels, attend clinic reviews and to take medication as prescribed. The presence of dementia, with increasing problems with memory and communication, can make these tasks difficult to follow. Diabetes can also have an impact on memory and confusion. The combination of diabetes and dementia will influence treatment choices, treatment targets, and type of care with the main aim of success being the safety of the individual, the avoidance of hypoglycaemia and unplanned hospital admission and a good quality of life. This document describes the basic features and management of diabetes and dementia, and aims to identify the issues to consider when caring for someone who has both conditions. It is meant to complement other national guidance developed by a multidisciplinary collaborative initiative of a national expert group – see references.

# RECOGNISING DIABETES AND DEMENTIA

## What is diabetes?

Diabetes is a condition in which the amount of glucose in the blood is too high due to defects in insulin secretion, insulin action or both (Diabetes UK, 2017). Insulin is a hormone produced by the pancreas gland which controls glucose levels in the blood. If diabetes is not well-controlled, or is diagnosed late, people with the condition can develop a number of disabling complications including blindness, kidney failure, foot ulcers, heart attacks and stroke. There are two main types of diabetes. Table 1 outlines the differences between Type 1 and Type 2 diabetes.

Table 1: The two main types of diabetes

TYPE 1 DIABETES		TYPE 2 DIABETES
<ul style="list-style-type: none"> <li>• Develops when the insulin-producing cells in the pancreas have been destroyed and the body cannot produce any insulin</li> <li>• Is usually diagnosed in children or adults under 30 but can occur at any age</li> <li>• Usually presents with significant weight loss, marked thirst and passing large amounts of urine frequently</li> <li>• Affects 5 to 15% of people with diabetes</li> <li>• Is always treated with insulin injections, a healthy eating plan and regular physical activity</li> </ul>		<ul style="list-style-type: none"> <li>• Develops when the pancreas can still make some insulin, but not enough, or when the body is unresponsive to the effects of insulin so it does not control blood glucose very well</li> <li>• Is usually diagnosed in older people but can occur in people aged 30 or less, and even children, especially if they are very overweight</li> <li>• People may present with thirst, tiredness and passing large amounts of urine frequently but often may have no symptoms</li> <li>• Affects 85 to 95% of people with diabetes</li> <li>• It is treated by normalising weight where appropriate, eating healthily, taking regular physical activity. It is usually progressive and tablets, injection therapy and/or insulin are often required as time passes</li> </ul>

People with dementia may be unable to recognise the symptoms associated with hyperglycaemia. The presence of infections such as thrush or urinary tract infections may be the only sign that the person has diabetes. Repeated requests for drinks or to be taken to the toilet may be mis-interpreted by carers as forgetfulness in the person with dementia. The likelihood of having co-morbid conditions may add to the complexity of managing such individuals and can increase the risk of hospitalisation.

Diabetes is always diagnosed by testing the glucose level in blood taken from a vein. This may be a fasting venous blood glucose sample (taken in the morning when the person has not eaten since the previous night) or an HbA1c test. The HbA1c blood test can be taken at anytime without the need to fast, and measures how high the blood glucose level has been for the previous 2-3 months. People who do not have symptoms will need two positive results to confirm they have diabetes. Table 2 summarises the test results. Urine tests should not be used to diagnose diabetes.





Table 2: Diagnosing diabetes with venous blood sample

Fasting venous blood glucose	HbA1c venous sample
7.0 mmol/l or greater	48 mmol/mol or greater (42 to 47 mmol/mol is classed as high risk for developing Type 2 diabetes)

Available at [www.diabetes.org.uk/professionals/position-statements-reports/diagnosis-ongoing-management-monitoring/new\\_diagnostic\\_criteria\\_for\\_diabetes](http://www.diabetes.org.uk/professionals/position-statements-reports/diagnosis-ongoing-management-monitoring/new_diagnostic_criteria_for_diabetes)

## Dementia:

Dementia is a progressive, irreversible condition of the brain causing widespread impairment of mental function. The presentation of dementia varies from person to person but generally results in a range of cognitive and behavioural symptoms including memory loss, problems with reasoning and communication, changes in personality and a reduction in ability to carry out daily activities of living (NICE, 2018). As the dementia process worsens, it leads to restlessness, wandering, eating problems, incontinence, delusions, hallucinations, mobility difficulties leading to falls and fractures and increasing dependence on others as well as morbidity and mortality (NICE 2018).

There are over 200 different types of dementia, usually diagnosed in people over 65 years old. The most common types are Alzheimer's, vascular dementia, dementia with Lewy bodies, fronto-temporal dementia and mixed dementia (Dementia UK, 2017). One in 14 people over the age of 65 has dementia and one in 6 in those aged over 80 years old. However, more than 42,000 people aged under 65 years have the condition. It is more common in women than men (Alzheimers Society, 2017)



Investigations should include taking a history of signs and symptoms, cognitive and mental state examination, a physical examination including blood tests, and a medication review (to exclude any drugs which may affect cognitive functioning). A validated brief structured cognitive instrument should be used to assess mental function such as the 10-point Cognitive Screener (10-CS), the 6 item Cognitive Impairment Test (6CIT), the memory impairment Screen (MIS) or the Mini-Cog (NICE, 2018). These assess abilities in attention and concentration, orientation, short and long-term memory, praxis and language function. It is important that factors which may affect the result of these tests are taken into account such as prior educational level, usual spoken language, presence of any psychiatric illness and sensory impairments. Examination of brain structure and vascular changes by Magnetic Resonance Imaging (MRI) or Computed Tomography (CT) scans may also be performed to exclude other cerebral disorders (such as a tumour).

## Why early diagnosis of dementia and diabetes is important:

People with diabetes are encouraged to manage the condition themselves so the diagnosis of dementia in people who already have diabetes will lead to difficulties with self-management and adherence with medication, including giving themselves insulin injections safely. Having both conditions may mean agreeing higher targets for blood glucose and blood pressure to keep people safe, and help the person and their family to make sensible decisions about the future.

Diagnosing diabetes early in people who already have dementia will ensure they receive regular review and management of the risk factors that can lead to developing damage due to complications of diabetes. Complications can be identified early and treated as required. If necessary, medications can be started to relieve the symptoms of high blood glucose which will improve quality of life (e.g. reduce tiredness, frequency of urination, thirst) and avoid hospital admissions for very high blood glucose levels, and the associated effects and complications.

***Diagnosing diabetes early in people who already have dementia will ensure they receive regular review and management of the risk factors that can lead to developing damage due to complications of diabetes.***



# TREATMENTS FOR DIABETES

Treating blood glucose levels to maintain a target which minimizes risk of hypoglycaemia but avoids unpleasant symptoms of hyperglycaemia and risk of developing long-term complications is challenging in the individual with diabetes but is even more difficult if the condition is in combination with dementia. Glycated haemoglobin (HbA1c) targets in the general diabetes population are:

- Type 1 diabetes: 48 mmol/mol (NICE, 2015a)
- Type 2 diabetes: 48-53 mmol/mol (NICE, 2015b)

In the frail person (defined as dependent on others, with multiple co-morbidities, dementia and living in a care home), a more relaxed HbA1c target of 59-69 mmol/mol is appropriate (Sinclair, 2017)

## A nutritionally sound diet:

There is no need for a special "diabetic" diet. Sugary foods as well as sugar added to hot drinks, non-diet drink and Lucozade should usually be avoided, but it is not necessary to exclude sugar completely from the diet, especially if this causes distress and increased confusion in the person with dementia. Small portions of sugary foods such as cake and sweets are acceptable. Regular consumption of small portions of carbohydrate foods (e.g. bread, potatoes, pasta) is essential for people using insulin or sulphonylurea tablets so cake, ice-cream, or milky drinks may be needed if other healthier carbohydrate foods are refused. Food supplements such as Fortisip or Complan may be necessary in people with dementia who are unable to eat meals or are unable to consume sufficient calories by other means. If blood glucose levels rise after these are consumed, they should not be stopped but diabetes tablets or insulin injections may be needed to manage high blood glucose levels. Advice from a dietitian is required for people who need nutritional support.

As dementia advances, nutritional intake may vary or reduce. Therefore, medication and regimes will need closer review with particular focus on safety and hypoglycaemia risk reduction (especially for those on insulin and/or sulphonylureas).



## Medications:

There are a number of different tablets which can be used to treat high blood glucose levels in people with Type 2 diabetes. They have different modes of action and varying side effects. Tablets have a pharmaceutical name and a brand name so check with the pharmacist or GP if you are not sure if the person with dementia is taking one of these tablets. Also, some tablets may be in combination with metformin and have a different name.

The table below gives a brief overview of the different tablets, how they work and what side effects to be aware of.

Table 3: Different types of Diabetes tablets and their side effects

Proper name	Brand name	How they work	Main side effect
• Metformin	• Glucophage • Sukkato	Helps the liver to store excess glucose from the blood	Diarrhoea, nausea, can affect nutritional intake in the person with dementia
• Gliclazide • Glipizide • Glimepiride • Tolbutamide (Sulphonylureas)	• Diamicon • Minodiab • Amaryl	Makes the pancreas produce more insulin	Low blood glucose levels (hypoglycaemia)
• Nataglinide • Repaglinide (Prandial glucose regulators)	• Starlix • Prandin	Helps the pancreas produce more insulin for 2 to 3 hours (Shorter duration of action compared to sulphonylureas)	Low blood glucose levels (hypoglycaemia) especially in those with an erratic eating pattern
• Pioglitazone	• Actos	Helps the body to use its insulin more efficiently	Fluid retention
• Sitagliptin • Vildagliptin • Linagliptin • Saxagliptin • Alogliptin	• Januvia • Galvus • Trajenta • Onglyza • Vipidia	Helps a gut hormone to work more efficiently	Pancreatitis (very rarely)
• Dapagliflozin • Canagliflozin • Empagliflozin	• Forxiga • Invokana • Jardiance	Makes the kidney excrete glucose from the body into the urine	Urinary tract and genital infections, dehydration. Should be avoided in people with vascular concerns in the foot

## Injectable therapies:

Type 2 diabetes may become more difficult to manage as time passes. Eventually diabetes tablets will not control the blood glucose levels sufficiently so injectable therapy will be needed. Injections may be insulin, or another type of therapy reserved for people who are very overweight called GLP-1 receptor agonists.

### GLP-1 receptor agonists:

These injectable therapies can reduce appetite and aid weight reduction as well as improving blood glucose levels. Nausea is the main side effect. However, this and the effects on appetite may have further consequences on food intake in those with dementia.

Table 4: Common injectable (non-insulin) therapies for treating Diabetes

Proper name	Brand name
• Exenatide	• Byetta
• Liraglutide	• Victoza
• Lixisenatide	• Lyxumia
• Extended action Exenatide	• Bydureon
• Dulaglutide	• Trulicity
• Semaglutide	• Ozempic

## Insulin:

Insulin is available in short-acting form (working from 4 to 8 hours and usually given with meals) or long-acting (from 12 to 24 hours given once or twice a day). It is also available as a mixture of both short and long-acting insulin which is usually given with breakfast and evening meal but these are fixed rigid regimes that may have a higher risk of hypoglycaemia in those with variable eating habits or intake. For someone with dementia who needs help with giving their insulin therapy, a simple once-daily insulin injection with or without diabetes tablets is preferable. Insulin injections are essential for someone with Type 1 diabetes so should **never** be omitted though insulin dose may be reduced if appropriate. The diabetes specialist nurse should be involved early, to advise on a suitable insulin regime. The main side effect of insulin is low blood glucose levels (hypoglycaemia) and weight gain, especially (in those with Type 2 diabetes) if also taking a sulphonylurea.



# HYPOGLYCAEMIA

Dementia is an important risk factor for hypoglycaemia.

## What is it?

Hypoglycaemia (“hypos”) is more likely to occur when people with diabetes are treated with tablets such as sulphonylureas, prandial glucose regulators (meglitinides) (see table 3) or insulin (TREND-UK, 2018). Hypoglycaemia is the medical term for a blood glucose level of less than 3.5 mmol/L. However, in the interests of safety, Diabetes UK states that “4 is the floor” and recommends that a blood glucose reading of less than 4 mmol/L should always be treated ([www.diabetes.org.uk](http://www.diabetes.org.uk)).

In someone with dementia taking medications with a risk of hypoglycaemia, low blood glucose must be avoided and so the diabetes team may define a higher level at which treatment should be given, especially in someone who refuses food on occasions or is agitated and pacing up and down. (Activity can reduce the level of glucose in the blood).



## When may hypoglycaemia occur?

Anyone taking sulphonylureas or insulin is at risk of hypos especially if they miss their usual meals or snacks, or these are delayed or the portion of starchy carbohydrate is smaller than usual. Being more active than usual can be a cause (e.g. wandering, being restless or agitated). People with renal impairment (failing kidneys) are at risk due to prolonged action or build up of insulin or sulphonylureas.

## Signs and symptoms of hypoglycaemia (TREND-UK, 2018)

Examples of EARLY signs and symptoms of hypoglycaemia include:	The LATE signs and symptoms of hypoglycaemia are:
<ul style="list-style-type: none"> <li>• Sweating</li> <li>• Palpitations</li> <li>• Shaking</li> <li>• Hunger</li> <li>• Anxiety</li> <li>• Paraesthesia</li> <li>• General malaise: headache and nausea.</li> </ul>	<ul style="list-style-type: none"> <li>• Confusion (or rapidly worsening confusion in someone with dementia)</li> <li>• Drowsiness</li> <li>• Unusual behaviour</li> <li>• Speech difficulties</li> <li>• Lack of co-ordination</li> <li>• Coma</li> </ul>

People with dementia may not be able to recognise symptoms of hypoglycaemia, so carers and HCPs need to be vigilant for the late signs described below. As it may present as uncharacteristic behaviour, hypoglycaemia may mistakenly be interpreted as declining mental status.

## How do you treat it?

If hypoglycaemia is not treated, the person may fall, lose consciousness, choke and it can trigger a stroke or heart attack. Appendix 1 describes how to treat hypoglycaemia, depending on how quickly it is identified. Carers need to have appropriate treatments readily available and know how to treat appropriately.



## Reducing risk of hypoglycaemia

Agree safe blood glucose targets which aim to avoid symptomatic high blood glucose levels (hyperglycaemia) but avoid low blood glucose levels (hypoglycaemia). If possible, tablets that cause hypoglycaemia (sulphonylureas and prandial glucose regulators) should be avoided, especially where medication is delivered in a Dossett box. If the person with diabetes takes this tablet but then forgets to eat, they are at high risk of hypoglycaemia. Ensure regular meals and snacks containing starchy carbohydrate are available for people who use insulin. Many hypos occur overnight or early morning. Therefore, considerations such as bedtime snacks or modification of certain regimes (such as giving long-acting insulin in the morning rather than at night) may be beneficial.



# GOOD CARE FOR PEOPLE WHO HAVE DIABETES & DEMENTIA

People who have had diabetes for many years may have been very skilled at managing their own injections and blood tests, but the onset of dementia will mean they become increasingly less competent at these skills. People with dementia who develop diabetes may appear to have a worsening of their dementia because of the diabetes symptoms. (See table 5).

Table 5: Issues for people with dementia/diabetes who develop diabetes/dementia


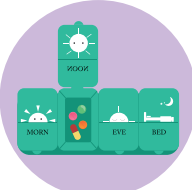




Issues for people with <b>DEMENTIA</b> who develop <b>DIABETES</b>	Issues for people with <b>DIABETES</b> who develop <b>DEMENTIA</b>
<ul style="list-style-type: none"> <li>• Developing incontinence if they need to pass urine more often but are not able to find the toilet</li> <li>• Increased risk of falls due to more frequent visits to the toilet</li> <li>• Increased confusion if blood glucose levels are high and causing tiredness and dehydration</li> <li>• Distress if usual diet is changed significantly</li> <li>• Distress, wandering, rocking movements, crying if they have pain and are unable to put this into words</li> <li>• Increased risk of infections</li> </ul>	<ul style="list-style-type: none"> <li>• Forgetting to take medications regularly</li> <li>• Forgetting they have taken medication so at risk of double dosing</li> <li>• Forgetting how to do injections</li> <li>• Unable to make decisions about interpreting blood glucose results such as adjusting insulin doses or treating hypoglycaemia</li> <li>• Missing meals and drinks so at risk of low blood glucose levels and dehydration</li> <li>• Forgetting they have eaten and at risk of high glucose levels if they eat again</li> </ul>



## Support plans:

These documents help people to see the person with dementia as an individual with distinct health and social needs. They are useful to pass on to other people involved in caring for that person such as hospital staff, agency staff, or dentist. They should be reviewed and updated regularly as the dementia progresses. Things to consider when completing a plan for someone who has both diabetes and dementia are listed in table 6.

Table 6: Points to consider when developing support plans for people with diabetes/dementia

Keeping me safe	
	<ul style="list-style-type: none"><li>• Agree appropriate blood glucose levels with the person's diabetes team. This should avoid the risk of low blood glucose levels (hypoglycaemia) but also avoid glucose levels being so high that symptoms of high blood glucose affect day to day living (such as tiredness, thirst, frequency of urination)</li><li>• Be observant for signs of low blood glucose in people taking insulin or tablets with a risk of hypoglycaemia. Know how to treat it, and ensure appropriate treatments are always readily available</li><li>• If the individual is still able to inject insulin but is forgetful, the carer can keep it in a locked box until it is needed</li></ul>
Cognitive ability (What can I still do, what do I find difficult?)	
	<ul style="list-style-type: none"><li>• Support self-care (or care given by their partner) as long as possible (e.g. testing blood glucose, injecting insulin). Review self-care ability regularly</li><li>• Ask the GP to simplify medication regimes and tablet load, preferably to once daily. Review the need for medications known to increase risk of hypoglycaemia</li><li>• Ask the pharmacist about tools to support self-medication such as blister packs and timed 'dosset' boxes (NICE, 2017). However, these are not helpful in people who have no awareness of time or day</li></ul>
Biography (life story)	
	<ul style="list-style-type: none"><li>• Some people may have had diabetes for a long time and may become distressed or angry if they are prevented from continuing familiar tasks like injecting insulin, or their regular diabetes management routine is changed</li><li>• If the individual has had diabetes for a long time it is useful to know their life story so the care elements and routines the individual is used to, and can manage themselves, can be included in their care plan</li></ul>
Personality	
	<ul style="list-style-type: none"><li>• Symptoms of diabetes or the complications of diabetes may be ignored and assumed as personality traits. Loud aggression may be a symptom of low blood glucose for example, in people taking insulin or tablets with a risk of hypoglycaemia, or a sign the person is in pain from diabetes damage to nerves</li></ul>
Physical health	
	<ul style="list-style-type: none"><li>• Toilet training is a skill learnt at an early age and so is not lost initially but the person may have difficulty in completing the tasks with going to the toilet. Increased urination and trips to the toilet may increase the risk of incontinence as well as falls and dehydration</li></ul>
Environment	
	<ul style="list-style-type: none"><li>• Meals should be provided in a calm and distraction free environment</li><li>• Encourage a nourishing diet that provides sufficient calories to maintain ideal weight and fits the person's usual meal pattern. Smaller portions of items in a familiar diet may be easier to achieve than completely removing items or making big changes to eating patterns</li><li>• Verbal and non-verbal communication: use calm tone when speaking, use short sentences with small amounts of information, make time for person to answer, maintain eye contact</li></ul>

## Communication:

Dementia can make it difficult to pronounce words, or find the right words for the individual to express themselves. They may find it difficult to concentrate on what is being said to them or find it difficult to remember what has been said. This can be frustrating and cause anxiety, especially when being given instructions or information about their diabetes, or asking for information. Dementia UK gives some useful tips on communicating with people with dementia:

- 🗨 Stop what you are doing and focus on the person
- 🗨 Say their name when talking to them
- 🗨 Listen carefully with empathy and understanding
- 🗨 Maintain appropriate eye contact
- 🗨 Speak clearly and slowly, using short sentences
- 🗨 Pictures and hand gestures can be helpful in getting messages across (miming drinking a cup of water or giving an injection)
- 🗨 Give the individual time to reply to questions so they do not feel rushed
- 🗨 Distractions like background noise from the television should be reduced
- 🗨 Use simple straight-forward language
- 🗨 Avoid using too many open questions at once
- 🗨 People with dementia may find that difficulty with concentration and confusion is worse in the early evening, probably because they are tired. It may be easier for them to take in information, answer questions and make decisions earlier in the day

(Adapted from "Tips for better communication" Dementia UK, 2017)

Changes in behaviour, increasing agitation and anxiety, worsening confusion and a feeling of being in the wrong place is more common at dusk, a phenomenon described as "sun-downing" by Dementia UK (2017) in their leaflet "Sun-downing (Changes in behaviour at dusk)". Tiredness, thirst, hunger or pain may be the cause of this. Risk of hypoglycaemia (due to pacing, shouting, agitation) may be more pronounced because of this. Concordance with medication or agreement to blood glucose monitoring at this time of the day may be challenging. It may be difficult to distinguish between "sun-downing" behaviour and the signs of hypoglycaemia.

## Nutrition:

People with diabetes should eat a healthy balanced diet which includes some carbohydrate food at each meal. Sugars do not need to be completely excluded from the diet but large amounts of sugary drinks and sweets should be avoided. As the majority of people with dementia are older, poorly-fitting dentures and gum disease may cause difficulties with ingesting a nutritionally-sound diet. Other barriers to healthy eating in people with diabetes and dementia include the following:

Table 7: Nutrition barriers

<b>Memory problems</b>	Forget to eat meals or forget that they have already eaten
<b>Agnosia</b>	May not recognise food, cutlery, or even those caring for them
<b>Dysphasia</b>	Unable to say they are hungry or feel "hypo" (have low blood glucose)
<b>Dysphagia</b>	Problems chewing and swallowing
<b>Dyspraxia</b>	Can impair people's ability to prepare food and to use utensils
<b>Executive Dysfunction</b>	Impacts on the ability to plan the preparation of food and/or drinks





## END OF LIFE

As dementia progresses, there is a slow decline in health status, decrease in appetite and nutritional intake, reduced ability to follow the usual diabetes regimen, increased risk of frailty, and vulnerability to infections. Becoming bed-bound or developing urinary and faecal incontinence are signs of advanced dementia and nearing the end of life (Diabetes UK, 2018b). Further relaxing of clinical targets, minimising invasive monitoring and stopping all but essential medications is a reasonable process, with the focus being on avoiding hypoglycaemia, safety of the individual, and maintaining the best possible quality of life. Insulin dose and frequency of injections may be reduced but should never be completely stopped in someone with Type 1 diabetes.



## COMPETENCY TO CARE FOR PEOPLE WITH DIABETES & DEMENTIA

Diabetes and dementia are both common conditions and the person who has both will have increasingly complex needs. Over 280,000 people living in residential care in the UK have dementia or significant memory problems (Alzheimer's Society, 2016) and many will have diabetes too. Carers (both formal and informal) require particular skills to provide safe and appropriate care for these individuals. Care and support providers should provide all staff with training in person-centred and outcome-focused care for people living with dementia, including understanding the needs of the person and their family members or carers (NICE, 2018). Appendix 2 describes the competencies required for care workers and managers working in community and residential care homes who are supporting people with both diabetes and dementia.



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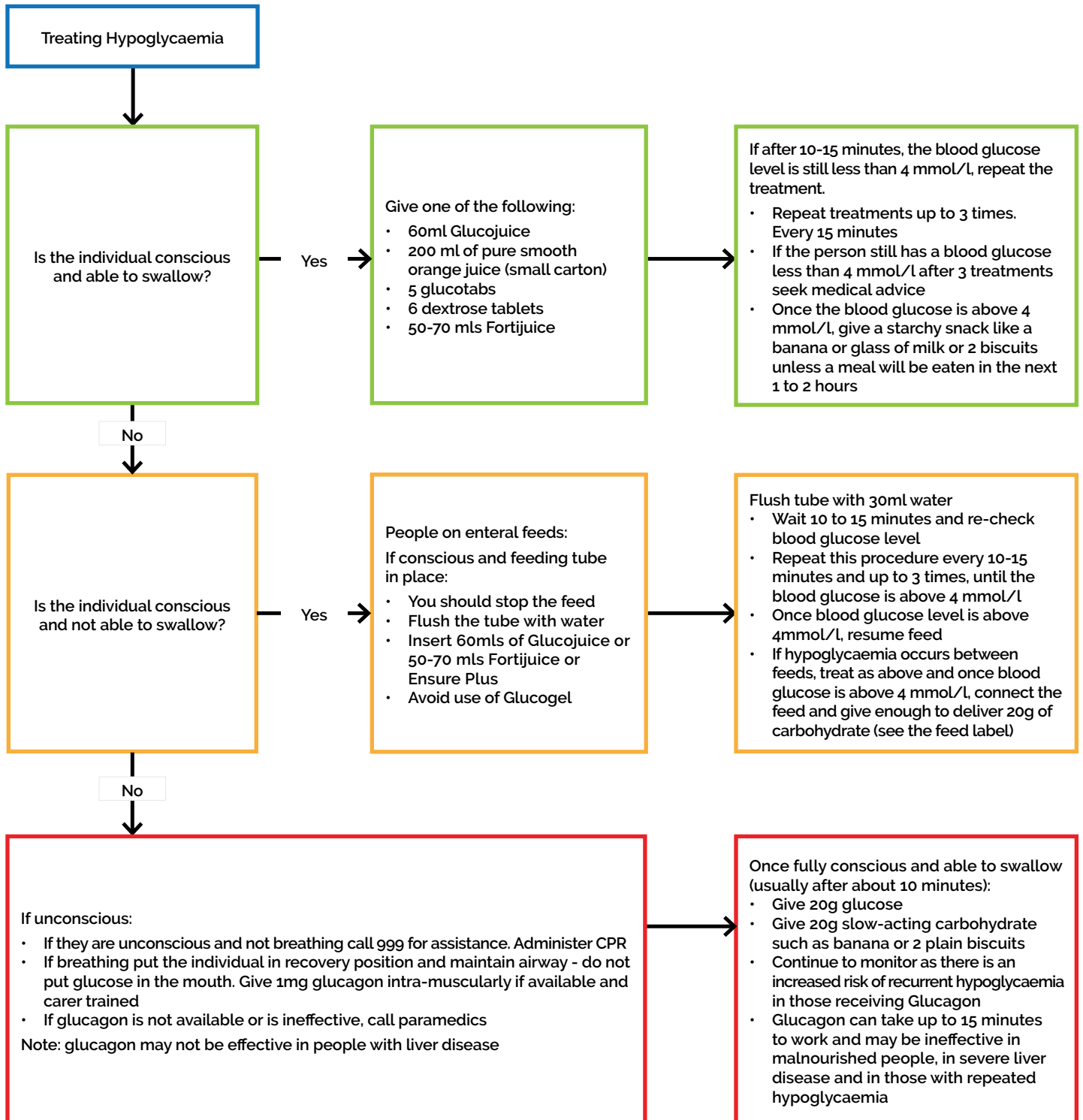
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## USEFUL RESOURCES:

- Alzheimer's Society: [www.alzheimers.org.uk](http://www.alzheimers.org.uk)
  - Carers UK: [www.carersuk.org](http://www.carersuk.org)
  - Dementia UK: [www.dementiauk.org](http://www.dementiauk.org)
  - Diabetes UK: [www.diabetes.org.uk](http://www.diabetes.org.uk)
  - TREND-UK: [www.trend-uk.org/resources](http://www.trend-uk.org/resources)
- Leaflets and guidelines: hypoglycaemia, management of illness, steroids, End of Life, insulin safety

# APPENDIX 1

## Hypoglycaemia treatment flowchart:



⚠ Always review medication following an episode of hypoglycaemia : If hypo episode more than once within same time frame with unknown cause consider reducing insulin and/or sulphonylurea doses

Adapted from Diabetes UK (2018) Diabetes and End of Life Care: Clinical Care Recommendations



## APPENDIX 2

### Competency framework for people caring for individuals with diabetes and dementia

1: Promoting self-care for people with diabetes and dementia	
<b>Unregistered practitioner</b>	<ul style="list-style-type: none"> <li>support the person to develop self-care skills with guidance from a registered nurse where appropriate</li> <li>observe and report any concerns that might affect the ability of the person with diabetes to self-care due to dementia</li> <li>encourage people to use their personalised care plans where appropriate if there is mental capacity to do so</li> <li>support the person with diabetes &amp; dementia to carry out activities of daily living where there is mental capacity to do it for themselves</li> </ul>
<b>Competent nurse</b>	<p>As 1, and:</p> <ul style="list-style-type: none"> <li>assess ability to self-care and work with the person with diabetes &amp; dementia &amp; significant others to optimise self-care skills</li> <li>direct people to information and support to encourage informed decision- making about living with diabetes and dementia to managing life events</li> <li>support them in realistic goal setting and achievement of those goals through care planning recognising the cognitive abilities of the person with diabetes and dementia</li> <li>refer to the GP or diabetes specialist team for support when necessary</li> </ul>
<b>Care/Service Manager</b>	<ul style="list-style-type: none"> <li>identify service shortfalls and develop a strategic action plan for the diabetes &amp; dementia service to address these</li> <li>work with stakeholders to develop a culture of client centered approach for people with diabetes &amp; dementia</li> <li>ensure that national guidance specifically related to diabetes and dementia is implemented and monitored in the care setting</li> </ul>
2. Nutrition: To meet the patient's individual nutritional needs you should be able to:	
<b>Unregistered practitioner</b>	<ul style="list-style-type: none"> <li>follow the nutritional plan and report any related problems</li> <li>recognise foods and drinks that are high in sugar</li> <li>be able to measure and record weight accurately</li> </ul>
<b>Competent nurse</b>	<ul style="list-style-type: none"> <li>list the principles of a healthy balanced diet</li> <li>be able to calculate and interpret Body Mass Index (BMI)</li> <li>recognize which foods contain carbohydrate and how these affect blood glucose level</li> <li>ensure clients with diabetes and dementia are supported to have a healthy balanced diet</li> <li>identify people at risk of malnutrition and situations where healthy eating advice is inappropriate</li> <li>refer the person with diabetes &amp; dementia to a diabetes dietitian when appropriate</li> <li>refer the client with diabetes and dementia to the GP or diabetes specialist team if glycaemic control is suboptimal</li> <li>work in partnership with the person with diabetes and dementia and their carers to identify realistic and achievable dietary changes</li> <li>know the dietary factors that affect blood pressure and lipid control</li> </ul>
<b>Care/Service Manager</b>	<ul style="list-style-type: none"> <li>identify service shortfalls and develop strategic plan for the service to address these</li> <li>work with stakeholders to develop/implement local guidelines and interventions, promoting evidence-based practice and cost effectiveness</li> </ul>
3. Blood glucose monitoring: For the safe use of blood glucose monitoring and associated equipment	
<b>Unregistered practitioner</b>	<ul style="list-style-type: none"> <li>perform the test according to manufacturer's instructions and local guidelines</li> <li>perform the test unsupervised as required</li> <li>document and report the result according to local guidelines</li> <li>recognise and follow local quality assurance procedures, including disposal of sharps.</li> <li>recognise hypoglycaemia and be able to give glucose</li> <li>understand the normal range of glycaemia and report readings outside this range to appropriate person</li> </ul>
<b>Competent nurse</b>	<p>As 1, and:</p> <ul style="list-style-type: none"> <li>interpret the result and report to appropriate person if outside the expected range for the individual</li> <li>teach procedure to person with diabetes/carer</li> <li>identify situations where testing for ketones is appropriate</li> <li>refer to the GP or diabetes specialist team to support &amp; guide the interpretation of results</li> <li>teach clients with diabetes and dementia to interpret results and take appropriate action if they are capable</li> </ul>
<b>Care/Service Manager</b>	<ul style="list-style-type: none"> <li>identify service shortfalls and develop strategic plan for the service to address these</li> <li>work with stakeholders to develop/implement local guidelines for use, promoting evidence-based practice and cost effectiveness</li> </ul>

#### 4. Intercurrent illness: To manage intercurrent illness, you should be able to:

<b>Unregistered practitioner</b>	<ul style="list-style-type: none"> <li>• identify common signs of intercurrent illness and report to a registered nurse</li> <li>• document and report any abnormal findings from observations</li> <li>• be aware of the impact of intercurrent illness on glycaemic control</li> </ul>
<b>Competent nurse</b>	<p>As 1, and:</p> <ul style="list-style-type: none"> <li>• take a comprehensive assessment and patient history</li> <li>• initiate appropriate preliminary investigations</li> <li>• know how and when to refer for specialist treatment</li> <li>• administer baseline treatment</li> <li>• give advice regarding continuance of treatment for diabetes</li> <li>• refer to the GP or diabetes specialist team for support with the following: <ul style="list-style-type: none"> <li>- interpret results and initiate appropriate action</li> <li>- support the person with diabetes and/or carers in managing diabetes during intercurrent illness</li> <li>- give advice about sick day management including ketone testing where appropriate according to local policy</li> <li>- educate nurses / carers about sick day management</li> </ul> </li> <li>• recognise when treatment may need adjusting</li> </ul>
<b>Care/Service Manager</b>	<ul style="list-style-type: none"> <li>• identify service shortfalls and develop strategic plan for the service to address these</li> <li>• monitor trends on hospital admissions for illness-induced diabetes emergencies and work with relevant agencies to reduce these</li> </ul>

#### 5. Hypoglycaemia: For the identification and treatment of hypoglycaemia you should be able to:

<b>Unregistered practitioner</b>	<ul style="list-style-type: none"> <li>• state the normal range of blood glucose level</li> <li>• describe signs and symptoms of hypoglycaemia</li> <li>• demonstrate competent use of blood glucose monitoring equipment to confirm hypoglycaemia</li> <li>• offer appropriate treatment as per local guidelines</li> <li>• give reassurance and comfort to the person with diabetes/significant others</li> <li>• document and report to registered nurse</li> <li>• if patient is unresponsive, ensure clear airway and call emergency services</li> </ul>
<b>Competent nurse</b>	<p>As 1, and:</p> <ul style="list-style-type: none"> <li>• list possible causes of hypoglycaemia including physical activity</li> <li>• ensure appropriate hypoglycaemia treatments are available &amp; in date</li> <li>• identify patients at high risk of hypoglycaemia and recognise when treatment may need to be adjusted</li> <li>• recognise and discuss possible reasons for hypoglycaemia with the person with diabetes including hypo unawareness and frequent hypoglycaemia</li> <li>• participate in educating other professionals and carers in identification, treatment and prevention of hypoglycaemia</li> </ul>
<b>Care/Service Manager</b>	<ul style="list-style-type: none"> <li>• ensure/develop standard operating procedures are in place to treat hypoglycaemia</li> <li>• identify service shortfalls and develop strategic plan for the service to address these</li> <li>• work with stakeholders to ensure systems &amp; processes are in place to reduce attendance to A&amp;E, ambulance callouts and admission to hospital for episodes of severe hypoglycaemia</li> </ul>

#### 6. Hyperglycaemia: For the identification and treatment of hyperglycaemia

<b>Unregistered practitioner</b>	<ul style="list-style-type: none"> <li>• state the normal range of blood glucose levels</li> <li>• describe signs and symptoms of hyperglycaemia</li> <li>• perform blood /urine ketone test according to local guidelines</li> <li>• correctly document results and report those out of accepted range</li> </ul>
<b>Competent nurse</b>	<p>As 1, and:</p> <ul style="list-style-type: none"> <li>• document and report signs &amp; symptoms of hyperglycaemia</li> <li>• recognise and provide appropriate treatment for the different levels of hyperglycaemia</li> <li>• list possible causes of hyperglycaemia including concordance with current medication, excessive carbohydrate intake and intercurrent illness</li> <li>• make appropriate referral to the GP</li> <li>• administer/advise treatment to resolve hyperglycaemia in accordance with individual management plan</li> </ul>
<b>Care/Service Manager</b>	<ul style="list-style-type: none"> <li>• ensure there are standardised operating procedures in place to manage hyperglycaemia/DKA/ HHS</li> <li>• identify service shortfalls and develop strategic plan for the service to address these</li> <li>• work with stakeholders to ensure systems &amp; processes are in place to reduce attendance to A&amp;E Ambulance callouts and admission to hospital for episodes of DKA, HHS and severe hyperglycaemia</li> </ul>



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[info@trend-uk.org](mailto:info@trend-uk.org)

[www.trend-uk.org](http://www.trend-uk.org)

[@\\_trenduk](https://twitter.com/_trenduk)