

For Healthcare Professionals:

# **DIABETES AND DEMENTIA:**

# **GUIDANCE ON PRACTICAL MANAGEMENT**

Endorsed by:

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## **CONTENTS**

Rationale and remit	Page 3
About this guidance	Page 2
Foreword	Page 5
Introduction	Page 6
Recognising diabetes and dementia	Page 7
Table 1: The two main types of diabetes	Page 7
Table 3: Stages of dementia life expectancy	Page g
Table 4: Stages of dementia	Page 10
Best practice care for diabetes and dementia	Page 11
Table 5: Different types of Diabetes tablets and their side effects	Page 12
Table 6: Common injectable (non-insulin) therapies for treating diabetes	Page 12
Hypoglycaemia	Page 13
Good care for people who have diabetes & dementia	Page 14
Table 7: Issues for people with dementia/diabetes who develop diabetes/dementia	Page 14
Table 8: Points to consider when developing support plans for people with diabetes/dementia	Page 15
Table 9: Nutrition barriers	Page 16
End of life	Page 17
Competency to care for people with diabetes & dementia	Page 17
Summary	Page 17
References	Page 18
Useful resources	Page 18
Appendix 1: Hypoglycaemia treatment flowchart	Page 19
Appendix 2: Competency framework for people caring for individuals with diabetes and dementia	Page 20

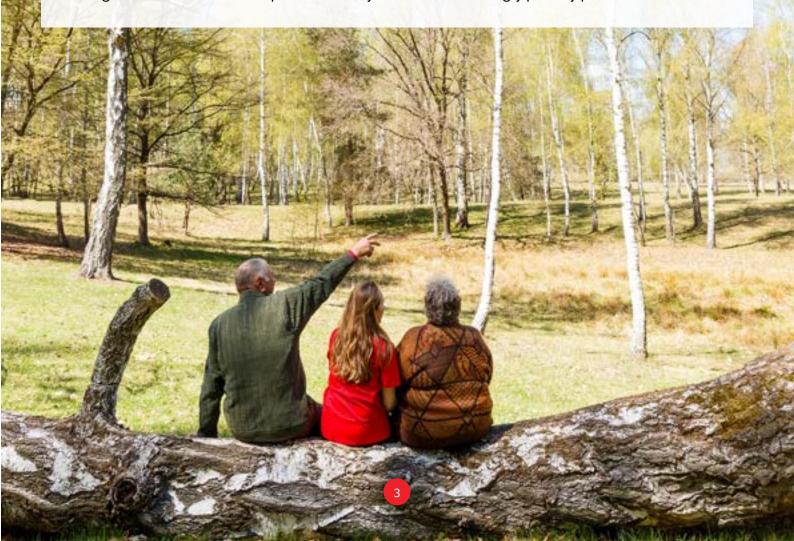
## **RATIONALE AND REMIT**

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, 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 their 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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This document is available at www.trenddiabetes.online. Access to these resources is free of charge to anyone registering as a member of Trend Diabetes. Any replication of these materials must be referenced to the source document.

## **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 and social care professionals to focus a great deal more on the thinking, behaviour, and on the individual's behaviour and their ability to think logically and 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 2020 revision of the earlier document on practical management in diabetes & dementia has been led by a distinguished team of authors at Trend Diabetes 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 fDROP and ABCD

Director, Foundation for Diabetes Research in Older People (FDROP) and Visiting Chair, King's College, London

Diabetes UK both welcomes and supports this practical guidance which will benefit people caring for individuals with diabetes and dementia. Both are complex conditions, which in combination makes successful management a challenge

#### Natasha Marsland

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## INTRODUCTION

The older population in the UK is increasing as is life expectancy. People aged 65 are predicted to make up 24% of the population by 2043 (17.4 million people). Those over the age of 75 is projected to rise from 8% in 2018 to 13% in 2043. During the same time period the proportion of those individuals aged 85 and over is projected to rise from 2% to 4% (Lewis A. 2021). The prevalence of type 2 diabetes and dementia increases in older people so it is unsurprising that both conditions are significantly increasing in numbers (Budson 2021, Amidei et al 2021). There are 944,000 people with dementia in the UK. It is predicted that this number will increase to over one million by 2030 and over 1.6 million by 2050 (Alzheimers Research UK. 2023a). One in two people will develop dementia in their lifetime. It is therefore important that healthcare professionals understand the impact that one of the conditions mare have on the management of the other.

Diabetes and dementia 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. 65% of the almost 1 million people in the UK who have dementia are women (Alzheimers Research UK. 2023b).

There is a close association between type 2 diabetes and dementia (Srikanth et al. 2020; Celis-Morales et al. 2022), in particular the association with vascular dementia is perhaps unsurprising given that insulin resistant type 2 diabetes is a known risk factor for cardiovascular and cerebro-vascular disease. Those individuals with a longer duration and earlier age of onset of diabetes have the highest risk (Celis-Morales et al. 2022).

Both diabetes and dementia consume a considerable amount of health and social care resources. As the population gets older, this is likely to become an increasingly significant problem. In England dementia and Alzheimer's disease was the leading cause of death in 2022. This is not reflected in data from Wales where the leading cause of death was ischaemic heart disease (ONS. 2022).

There are 944,000 people known to have dementia in the United Kingdom (UK) and 1 in 2 people will develop dementia in their lifetime. It is predicted that the number of individuals with dementia will increase to over 1.6 million by 2050 (Alzheimers Statistics. 2023).

The number of individuals living with diabetes is now predicted to be 5 million, considering the proportion not yet diagnosed with the condition (Diabetes UK. 2023). Individuals with type 1 diabetes are at increased risk of developing dementia compared with those do not have diabetes (Whitmer et al. 2021). There is a close link between type 2 diabetes and dementia (Srikanth et al. 2020), Individuals considered at risk of diabetes and those with a longer duration and earlier age of onset of diabetes have the highest risk of developing dementia (Barbiellini et al. 2021). 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 may also be affected.

Suboptimal glycaemic control of diabetes over time can lead to the development of dementia as reported by Celis Morales and colleagues (Celis-Morales et al. 2022). 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.

In 2017 and 2018 guidance was issued for commissioners; including care pathways, an implementation guide and resource information (NHS England. 2018). The guide is shaped by the framework set by the NHS Mandate (DH. 2015) and has two clear requirements to enhance dementia care, through:

- ▲ Increasing the number of people being diagnosed with dementia, and starting treatment, within six weeks from referral; and
- ▲ Improving the quality of post-diagnostic treatment and support for people with dementia and their carer (NHS England. 2023).

A recent mandate recommends research funding streams aimed at reducing the numbers of individuals a developing dementia was published in 2022 (Gov.UK. 2022). These processes are designed to improve 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
- · to take medication as prescribed.

The presence of dementia, with increasing problems such as memory and communication, can make these tasks difficult to follow. The combination of diabetes and dementia will influence:

- treatment choices
- treatment targets
- type of care offered and availability

The main aim of success is 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 to the management of diabetes and dementia, and aims to identify the issues to consider when caring for someone who has both conditions.

## **RECOGNISING DIABETES AND DEMENTIA**

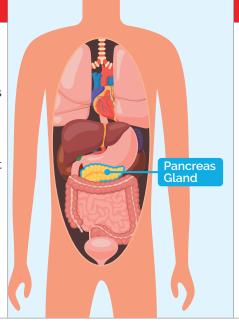
#### What is diabetes?

Diabetes is a serious condition where the glucose level is too high. It can happen when the body doesn't produce enough insulin, or when you can't produce any at all. (Diabetes UK. 2023a) 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**

- Develops when the insulin-producing cells in the pancreas have been destroyed and the body cannot produce any insulin
- Is usually diagnosed in children or adults under 30 but can occur at any age
- A recent study (Thomas et al, 2018) suggested that 42% of people diagnosed are between the ages of 31 and 60
- Usually presents with significant weight loss, marked thirst and passing large amounts of urine frequently
- Affects around 8-10% of people with diabetes
- Is always treated with insulin injections
- A healthy eating plan and regular physical activity is always recommended as an adjunct to treatment



#### **TYPE 2 DIABETES**

- 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 glucose very well
- Is usually diagnosed in older people but can occur in people aged 30 or less, and even children, especially if they are very overweight
- People may present with thirst, tiredness and passing large amounts of urine frequently but often may have no symptoms
- Affects 90% of people with diabetes
- 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

People with dementia may be unable to recognise the symptoms associated with hyperglycaemia. The presence of infections such as thrush or urinary tract infections or an unexplained fall 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 can only be diagnosed using a laboratory tested sample of venous blood. 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 glucose level has been for the previous 2-3 months. HbA1c should not be used to diagnose type 1 diabetes. People who do not have symptoms will need two positive results to confirm they have diabetes. Table 3 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 (HbA1c taken on 2 seperate occasions two weeks apart if asymptomatic)
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)

 $A vailable \ at \ www.diabetes.org.uk/professionals/position-statements-reports/\ diagnosis-ongoing-management-monitoring/new\_diagnostic\_criteria\_for\_diabetes. NICE \ (2020)$ 

#### 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, 2022). 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). Life expectancy and stages of dementia are shown in tables 3 and 4.

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, mixed dementia, alcohol related dementia (Dementia UK, 2023a). 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, 2023)



Investigations should include taking a history of signs and symptoms, cognitive and mental state examination, a physical examination including blood tests Coordination/ gait assessment, sensory assessment, motor sysmptoms assessment (NICE update 2022), 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), IQCODE (NICE update 2022) 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 may 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 glucose and blood pressure to keep people safe, and help the person and their family to make sensible decisions about the future (ADA. 2020).

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 the development of complications associated with diabetes. If these complications are identified early they could be mitigated. If necessary, medications can be started to relieve the symptoms of high glucose levels which will improve quality of life (e.g. reduce tiredness, frequency of urination, thirst) and should reduce the need for hospital admissions for very high glucose levels, and the associated effects and complications.

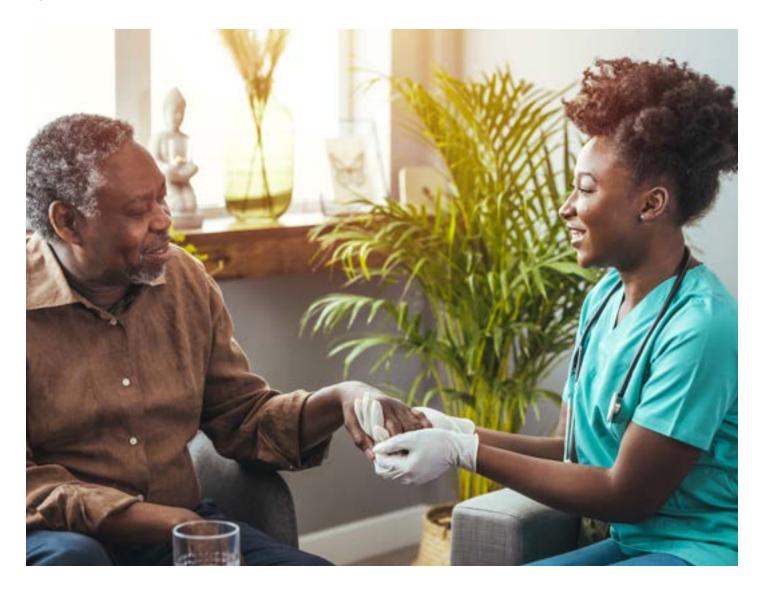
Diagnosing diabetes early in people who already have dementia will ensure they receive regular review and management of the risk factors that can lead to developing damage due to complications of diabetes.

Life expectancy is aligned with stages of dementia will be determined by several factors such as the age, and type and stage of dementia on diagnosis.

Table 3: Stages of dementia life expectancy

Stage	Expected Duration of Stage	Expected Life Expectancy (years remaining)
Stage 1: No cognitive decline	N/A	N/A
Stage 2: Very mild cognitive decline	Unknown	More than 10 years
Stage 3: Mild cognitive decline	2-7 years	10 years
Stage 4: Moderate cognitive decline	2 years	3 to 8 years
Stage 5: Moderately severe cognitive decline	1.5 years	1.5 to 6.5 years
Stage 6: Severe cognitive decline	2.5 years	4 years or less
Stage 7: Very Severe cognitive decline	1.5 to 2.5 years	2.5 years or less

(Agespace, 2023)



#### Table 4: Stages of dementia

#### 1. Normal Behaviour

3. Mild Decline

No symptoms are apparent, though change in the brain might already be occurring - these can happen several years before symptoms emerge.

Loved ones may begin to notice subtle changes and signs that something 'isn't quite right. They might be frequently losing their purse, or keys or forgetting appointments. Experts believe this

stage can last up to seven years.

5. Moderately Severe Decline

Loved ones may need more help with dav-to-dav living during this stage. Whilst they can probably still take care of other personal needs on their own (such as using the toilet), they could find it difficult to dress appropriately or be unable to remember simple facts about themselves, such

as their address or phone number. However, they usually recognise family and friends and

can recall events from decades ago (especially

their childhood) with great clarity. On average this

#### 2. Forgetfulness

They forget things easily and constantly lose things around the house, although not to the point where the memory loss can easily be distinguished from normal age related memory.

#### 4. Moderate Decline

Symptoms become clearer to everyone. They find it difficult to manage money or pay bills, or remember what they had for breakfast. If they visit their doctor at this point, and undergo a Mini Mental State Examination (MMSE) it's likely they will be diagnosed with dementia. The average length of this stage is around two years.

#### 6. Severe Decline

This is the stage when constant supervision is needed at home. They may need help with washing and dressing and may also become incontinent. You could notice changes in their personality and behaviour - such as anger and aggression - which can be upsetting and difficult to cope with. However, although they might be very confused, they often still know and recognise the people closest to them - which can be some comfort. Experts believe this stage can last, on average 2.5 years.

#### 7. Very Severe Decline

stage can last around 1.5 ears.

Many of those with dementia pass away before they reach this stage, often as a result of other health conditions. At this stage, they'll experience severe loss of speech, need assistance with day-to-day living, feeding, need round-the-clock care and the support of professional Carers (if they haven't already got this). It's important to remember that the person with dementia no longer really understands what's happening.

Adapted from Dementia Care TLC (2023)

## BEST PRACTICE CARE FOR DIABETES AND DEMENTIA

Treating glucose levels to maintain a target which minimise risk of hypoglycaemia but avoids unpleasant symptoms of hyperglycaemia and risk of developing long-term complications is challenging in the individual with diabetes. This is more challenging 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 2015, updated 2022)
- Type 2 diabetes: 48-53 mmol/mol (NICE. 2015a, 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 (ADA, 2020)

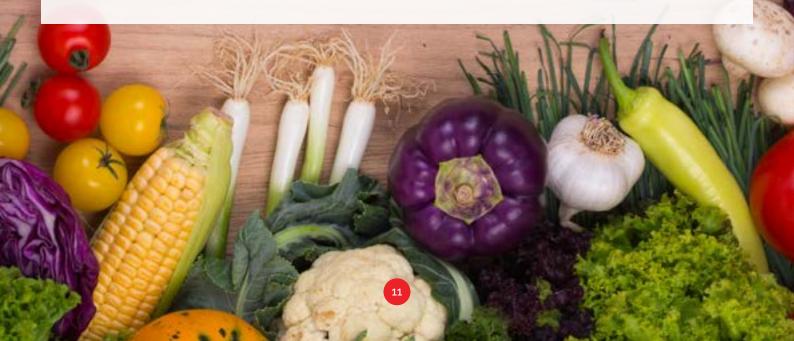
#### Glucose monitoring:

Glucose monitoring (GM) is recommended for people at risk from hypoglycaemia, in those taking insulin or sulphonyureas. Regular testing is required at initiation and during adjustment of medication. Frequency may be reduced when glycaemic targets are reached. Increased testing may be required during intercurrent illness and when there is risk of hypoglycaemia. Some people benefit from glucose testing for short periods of time, e.g. when oral medication is changed or adjusted or if the individual is on a course of steroid therapy. Older people, living independently, recently introduced to monitoring may need initial support from district nursing teams. In some instances, the use new glucose sensor technology may prove beneficial as this removes the need for more invasive "finger prick" capillary testing and bed-side testing. NICE guidance now recommend CGM for those with a condition or disability that means they can not self monitor BG levels or require input from carers (DUK, 2020).

#### 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 glucose levels rise after these are consumed, they should not be stopped but diabetes oral hypoglycaemic agents (OHA's) or insulin injections may be needed to manage high glucose levels. Dietetic advice is suggested for those people requiring nutritional support.

As dementia advances, nutritional intake may vary or reduce. Medication and regimen will therefore 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 oral therapies which can be used to treat hyperglycaemia in people with type 2 diabetes. They have different modes of action and varying side effects. OHAs 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 oral therapies. The table below gives a brief overview of the different tablets, how they work and what side effects to be aware of.

The use of continual glucose monitoring systems or or flash glucose monitoring may assist with the identification of hypoglycaemia. For more information see Monitoring in adult diabetes: Glucose and ketones: https://bit.ly/3sKcOoo

Table 5: Different types of diabetes tablets and their side effects

Pharmaceutical name	Brand name	How they work	Main side effect
Biguanide: • Metformin	<ul><li>Glucophage</li><li>Sukkato</li></ul>	Helps the liver to store excess glucose from the blood	Diarrhoea, nausea, can affect nutritional intake in the person with dementia
Sulphonylureas:     Gliclazide     Glipizide     Glimepiride     Tolbutamide	<ul><li>Diamicron</li><li>Minodiab</li><li>Amaryl</li></ul>	Makes the pancreas produce more insulin	Hypoglycaemia and weight gain
Prandial glucose regulators: <ul><li>Nateglinide</li><li>Repaglinide</li></ul>	<ul><li>Starlix</li><li>Prandin</li></ul>	Helps the pancreas produce more insulin for 2 to 3 hours (Shorter duration of action compared to sulphonylureas)	Hypoglycaemia especially in those with an erratic eating pattern. Present as confusion in older people, can be chronic rather than acute hypoglycaemia
Thiazolidiones: Pioglitazone	· Actos	Helps the body to use its insulin more efficiently	Fluid retention
DPPIV-i:	<ul><li>Januvia</li><li>Galvus</li><li>Trajenta</li><li>Onglyza</li><li>Vipidia</li></ul>	Helps a gut hormone to work more efficiently	Pancreatitis (very rarely). Heart Failure and/or fracture.
SGLT2-i: Dapagliflozin Canagliflozin Empagliflozin Ertugliflozin	<ul><li>Forxiga</li><li>Invokana</li><li>Jardiance</li><li>Steglatro</li></ul>	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 or foot ulceration Postural hypotension and/or falls
Oral Semaglutide:	Rybelsus	Can reduce appetite and aid weight reduction as well as improving glucose levels.	Nausea is the main side effect; this and their effects on appetite may impact on food intake in those with dementia.

#### Injectable regimens:

Type 2 diabetes may become more difficult to manage as time passes. Eventually OHAs will not control the glucose sufficiently so injectable therapy may 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 (RA):

These injectable therapies can be given once daily or once weekly depending on the specific drug prescribed. This type of medication can reduce appetite and aid weight reduction as well as improving glucose control. 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 6: Common injectable (non-insulin) therapies for treating diabetes

Pharmaceutical name	Brand name
<ul> <li>Exenatide</li> <li>Liraglutide</li> <li>Lixisenatide</li> <li>Extended action Exenatide</li> <li>Dulaglutide</li> <li>Semaglutide</li> <li>Tirzepatide</li> </ul>	<ul> <li>Byetta</li> <li>Victoza</li> <li>Lyxumia</li> <li>Bydureon</li> <li>Trulicity</li> <li>Ozempic</li> <li>Mounjaro</li> </ul>

#### 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 42 hours. Depending on the preparation these insulin therapies may be given once or twice daily). They are 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 regimens 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 OHAs should be considered. 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 regimen. The main side effect of insulin is low glucose levels (hypoglycaemia) and weight gain, especially (in those with type 2 diabetes) if also taking a sulphonylurea.

▲ In type 2 diabetes as the dementia progresses and the person entered the last year of life medications may need to be de-escalated in order to reduce the risk of hypoglycaemia (Strain, 2021).

## **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 (see table 4) or insulin. Hypoglycaemia is the medical term for a 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 glucose reading of less than 4 mmol/L should always be treated (Diabetes UK, 2023b).

In someone with dementia taking medications with a risk of hypoglycaemia must be avoided so the diabetes team may define a higher level at which treatment should be given.



#### 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 also 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 Diabetes, 2023a)

#### **Examples of EARLY** (Adrenergic) signs & symptoms of hypoglycaemia include:

- Sweating
- **Palpitations**
- Shaking
- Hunger
- Anxiety
- Paraesthesia
- General malaise:

headache and nausea.

#### **Examples of LATER** (Neuroglycopenic) signs and symptoms of hypoglycaemia are:

- Confusion (or rapidly worsening confusion in someone with dementia)
- **Drowsiness**
- Unusual behaviour
- Speech difficulties
- Lack of co-ordination
- Coma

Many older people lose their adrenergic symptoms so may not experience the 'early' warning signs in the table (this is irrespective of whether they have retained the ability to recognise them). The glucose levels at which adrenergic symptoms occur falls to around 3mmol /L in older people so there is no time to react before neuroglycopenic symptoms begin. Older people are

more likely to present with symptoms suggestive of CVA (Stroke) (which can reverse on restoration for normal glucose levels) - it is important to check the glucose level if someone has signs of CVA (Stroke). A hypo can precipitate an actual stroke, cause arrhythmias and falls, so again important to check the glucose level if either of these occurs. Older people can also have chronic hypoglycaemia (particularly if on sulphonylurea) and this can be interpreted as cognitive decline but is reversible if the recurrent hypoglycaemia is corrected (Abdelhafiz AH et al 2015).

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 hypoglycaemia may present as uncharacteristic behaviour, It may also be misinterpreted as declining mental status.

#### How do you treat it?

If hypoglycaemia is not treated, the person may fall, lose consciousness or choke and this could trigger other complications such as a CVA (Stroke) or a cardiac event. 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 glucose targets which aim to avoid symptomatic hyperglycaemia but avoid 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 daily regimens (or use of super long acting insulins with flatter insulin profiles) may be beneficial.

For further information visit: www.trenddiabetes.online/ portfolio/hypoglycaemia-in-adults-in-the-communityrecognition-management-and-prevention/

### 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 7).

Table 7: Issues for people with dementia/diabetes who develop diabetes/dementia

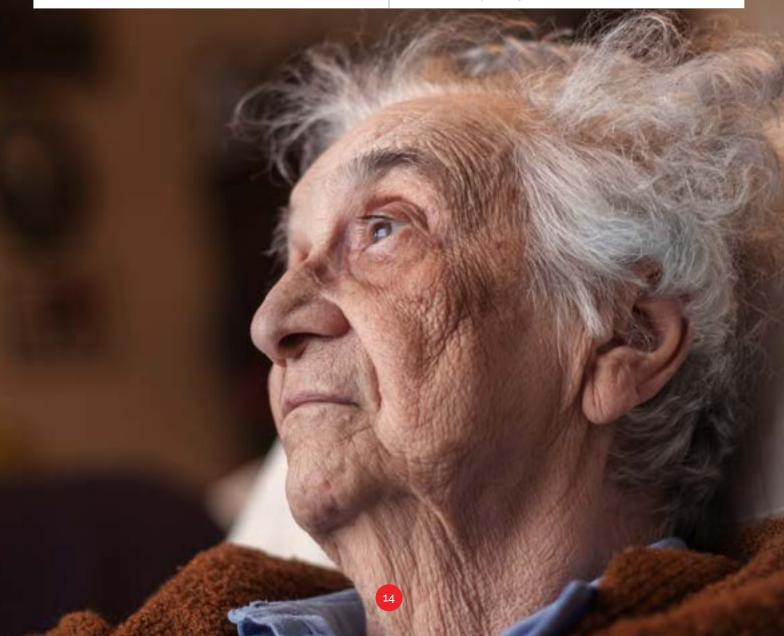
#### Issues for people with **DEMENTIA** who develop **DIABETES**

#### Developing incontinence if they need to pass urine more often but are not able to find the toilet

- Increased risk of falls due to more frequent visits to the toilet
- Increased confusion if glucose levels are high and causing tiredness and dehydration
- · Distress if usual diet is changed significantly
- Distress, wandering, rocking movements, crying if they have pain and are unable to put this into words
- Increased risk of infections (Trend Diabetes. 2020)

#### Issues for people with DIABETES who develop DEMENTIA

- Forgetting to take medications regularly
- Forgetting they have taken medication so at risk of double dosing
- Forgetting how to do injections
- Unable to make decisions about interpreting glucose results such as adjusting insulin doses or treating hypoglycaemia
- Missing meals and drinks so at risk of low glucose levels and dehydration
- Forgetting they have eaten and at risk of high glucose levels if they eat again



#### 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 8.

Table 8: Points to consider when developing support plans for people with diabetes/dementia

#### Keeping me safe



- Agree appropriate glucose levels with the person's diabetes team. This should avoid the risk of low glucose levels (hypoglycaemia) but also avoid glucose levels being so high that symptoms of high glucose affect day to day living (such as tiredness, thirst, frequency of urination)
- Be observant for signs of hyperglycaemia in people taking insulin or tablets with a risk of hypoglycaemia. Know how to treat it, and ensure appropriate treatments are always readily available
- 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

#### Cognitive ability (What can I still do, what do I find difficult?)



- · Support self-care (or care given by their partner) as long as possible (e.g. testing glucose, injecting insulin).
- Sulphonylureas should be avoided in people with memory issues or when appetite is variable. as there is a danger of double doses and or hypoglycaemia
- Review self-care ability regularly
- Ask the GP to simplify medication regimen and tablet load, consider once daily preparations. Review the need for medications known to increase risk of hypoglycaemia
- Ask the pharmacist about tools to support self-medication such as blister packs and timed 'dosset' boxes (NICE, 2017). However, these are not helpful for people on sulphonyurea agents or those who have no awareness of the time of day

#### Biography (life story)



- 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
- 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

#### Personality



Symptoms of diabetes or the complications of diabetes may be ignored and assumed as personality traits. Loud aggression may be a symptom of low 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

#### Physical health



- HCPs should consider the comprehensive frailty assessment in assessing the person's level of frailty to understanding their functional ability to enable a person-centred care for people living with diabetes and dementia. (Sinclair et al, 2018)
- For example 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

#### **Environment**



- Meals should be provided in a calm and distraction free environment
- 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
- 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

(Trend Diabetes, 2021)

#### 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, 2019b)

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 "sundowning" by Dementia UK (2019c) 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 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. (Dementia UK, 2019)

#### Mental Capacity Act and Deprivation of Liberty

People living with dementia and diabetes can be placed on deprived of liberty (DOLs) in best interest decisions .DOLs is an aspect of mental capacity act to protect the health of those in the hospital or care homes who lack mental capacity to make decisions about their care e.g diabetes care . A mental capacity assessment is always performed by a trained health care professional to establish that the individual is either able or not able to make decisions regarding their dementia and diabetes care (Alzheimer's Society, 2021).

Diabetes and dementia care would be managed in best interest meetings using the least restrictive option (Jackson,2018). This involves the family and a group of relevant health care professionals e.g mental health professional, diabetes specialist nurse. These meetings are to ensure that all aspects and wishes of the individual have been considered (Jackson, 2018).

#### 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 eating a nutritionally-sound diet. Other barriers to healthy eating in people with diabetes and dementia include the following:

#### Table 9: Nutrition barriers

Memory problems	Forget to eat meals or forget that they have already eaten
Agnosia	May not recognise food, cutlery, or even those caring for them
Dysphasia	Unable to say they are hungry or feel "hypo" (have low glucose)
Dysphagia	Problems chewing and swallowing
Dyspraxia	Can impair people's ability to prepare food and to use utensils
Executive Dysfunction	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 (Trend Diabetes, 2021). 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. It is estimated that 80% of people living in care homes have either dementia or severe memory problem (SCIE, 2023) 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.



## **SUMMARY**

Dementia is recognised as a long-term vascular complication of diabetes and the numbers of individuals living with both diabetes and dementia is increasing. Each of these specific conditions requires complex management, but when an individual lives with both conditions care can be more problematic both for the individual, their families, and carers. It is important that healthcare professionals involved in the care of these vulnerable people are equipped with the knowledge, skills and competence to manage both conditions safely and appropriately. This document has offered practical recommendations to support HCPs working in any healthcare setting



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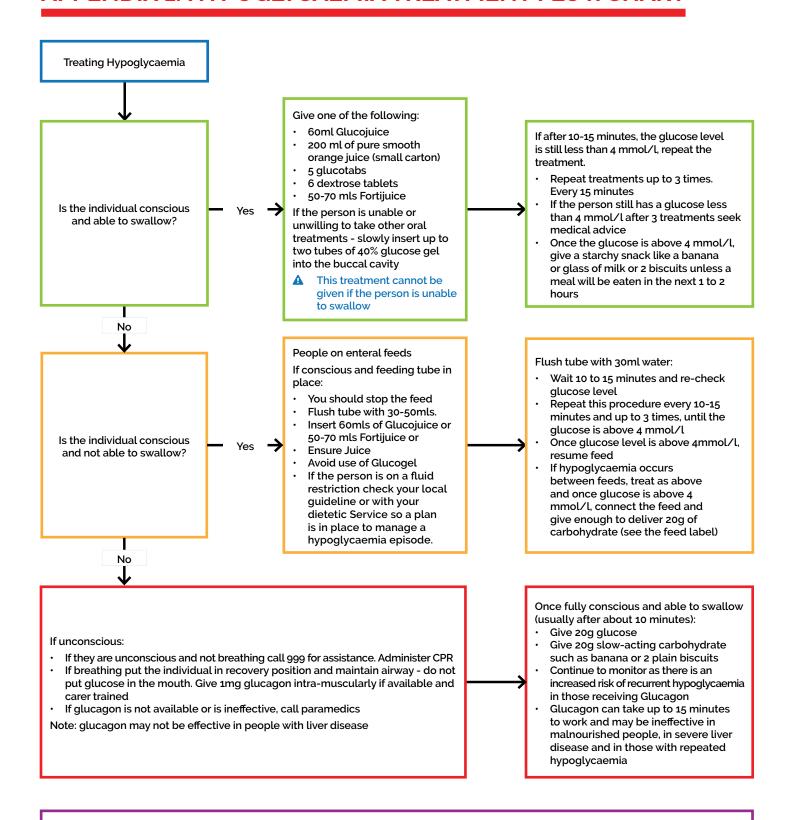
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## **USEFUL RESOURCES**

- 6 Alzheimer's Society: www.alzheimers.org.uk
- Carers UK: www.carersuk.org
- Dementia UK: www.dementiauk.org
- Diabetes UK: www.diabetes.org.uk

Trend Diabetes: 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 more than once within same time frame with unknown cause consider reducing insulin and/or sulphonylurea doses

 $Adapted \ from \ Trend \ Diabetes \ (2023) \ Hypogly caemia \ In \ Adults \ In \ The \ Community: \ Recognition, \ Management \ And \ Prevention$ 

# APPENDIX 2: COMPETENCY FRAMEWORK FOR PEOPLE CARING FOR INDIVIDUALS WITH DIABETES AND DEMENTIA

1: Promoting self-care	e for people with diabetes and dementia
Unregistered practitioner	<ul> <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>
Competent nurse	As 1, and:
	<ul> <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>
Care/Service Manager	<ul> <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 t	he patient's individual nutritional needs you should be able to:
Unregistered practitioner	<ul> <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>
Competent nurse	<ul> <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 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>
Care/Service Manager	<ul> <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. Glucose monitoring	: For the safe use of glucose monitoring and associated equipment
Unregistered practitioner	<ul> <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>
Competent nurse	As 1, and:  interpret the result and report to appropriate person if outside the expected range for the individual  teach procedure to person with diabetes/carer  identify situations where testing for ketones is appropriate  refer to the GP or diabetes specialist team to support & guide the interpretation of results  teach clients with diabetes and dementia to interpret results and take appropriate action if they are capable
Care/Service Manager	<ul> <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:
Unregistered practitioner	<ul> <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>
Competent nurse	As 1, and:  take a comprehensive assessment and patient history  initiate appropriate preliminary investigations  know how and when to refer for specialist treatment  administer baseline treatment  give advice regarding continuance of treatment for diabetes  refer to the GP or diabetes specialist team for support with the following:  interpret results and initiate appropriate action  support the person with diabetes and/or carers in managing diabetes during intercurrent illness  give advice about sick day management including ketone testing where appropriate according to local policy  educate nurses / carers about sick day management  recognise when treatment may need adjusting
Care/Service Manager	<ul> <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:
Unregistered practitioner	<ul> <li>state the normal range of glucose levels</li> <li>describe signs and symptoms of hypoglycaemia</li> <li>demonstrate competent use of 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>
Competent nurse	<ul> <li>As 1, and:</li> <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>
Care/Service Manager	<ul> <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: Fo	r the identification and treatment of hyperglycaemia
Unregistered practitioner	<ul> <li>state the normal range of 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>
Competent nurse	As 1, and:  document and report signs & symptoms of hyperglycaemia recognise and provide appropriate treatment for the different levels of hyperglycaemia list possible causes of hyperglycaemia including concordance with current medication, excessive carbohydrate intake and intercurrent illness make appropriate referral to the GP administer/advise treatment to resolve hyperglycaemia in accordance with individual management plan
Care/Service Manager	<ul> <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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