





Diabetes and Dementia

Guidance on Practical Management

CONTENTS

Rationale and Remit

ntroduction	5
Recognising Diabetes And Dementia	6
reatments For Diabetes	8
Hypoglycaemia	10
Good Care For People Who Have Diabetes And Dementia	11
Caring For People With Diabetes And Dementia	13
References	14
Jseful Resources	15
Appendices	16

RATIONALE AND REMIT

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 risks. It is intended to serve as a helpful resource for carers and health care professionals working in nursing and residential homes, carers and community nurses working with elderly people living in their own homes, and for commissioners and designers of services.

This guidance was written by Training, Research and Education for Nurses in Diabetes (TREND UK) in partnership with the Institute of Diabetes for Older People (IDOP). Other organisations representing people with diabetes and people with diabetes have been involved in the development of the guidance via a process of consultation and review.

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 anybody at risk.

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INTRODUCTION

Diabetes and dementia are both increasing in numbers, with **800,000** people with dementia in UK in 2012 (Alzheimer's Society, 2012) and **3 million** people with diabetes (Diabetes UK, 2012).

Both are progressive, long-term conditions affecting the same group (older people, although 8% people of people with dementia are under the age of 65 (Alzheimer's Society 2013). As people in the UK are living longer, this means these conditions will become an increasing problem. By 2021, the number of people with dementia is predicted to rise to over 1 million (Alzheimer's Society, 2012), and the number of people with diabetes to rise to 5 million by 2025 (Diabetes UK, 2012).

People with type 2 diabetes may have twice the risk of developing dementia compared with people without diabetes. In combination, dementia makes management of diabetes difficult, but poorly controlled diabetes can also impact on the safety and well-being of people with dementia (Biessels et al, 2006).

An NHS Mandate published by the Department of Health in 2012 (DH, 2012) aims to ensure that the diagnosis, treatment and care of people with dementia in England should be the best in Europe. This will 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 2012).

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, action or both (American Diabetes Association, 2009). 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
Develops when the insulin-producing cells in the pancreas have been destroyed and the body cannot produce any insulin	Develops when the pancreas can still make some insulin, but not enough, or when the body is insensitive to the effect s of insulin so it does not control blood glucose very well
 Is usually diagnosed in children or adults under 30 but can occur at any age 	 Is usually diagnosed in older people but can occur in people aged 30 or even children, especially if they are very overweight
Usually presents with significant weight loss, marked thirst and passing large amounts of urine frequently	People may present with thirst, tiredness and passing large amounts of urine frequently but often may have no symptoms
Affects 5 to 15% of people with diabetes	Affects 85 to 95% of people with diabetes
 Is always treated with insulin injections, a healthy eating plan and regular physical activity 	It is treated by normalising weight where appropriate, eating healthily, taking regular physical activity and tablets. It is usually progressive and insulin is often needed 6 years or so after diagnosis.

People with dementia may be unable to recognise symptoms. The presence of infections such as thrush or urinary tract infections may be the only sign that the person has diabetes.

Diabetes is 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 are not 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)

Dementia:

There are over 100 different types of dementia. The most common type is Alzheimer's, but the list also includes vascular dementia, Lewy body dementia, Parkinson's, CJD, Pick's disease, and alcohol-related dementia. Early symptoms include forgetfulness, repetitiveness, short-term memory loss, and difficulty in finding the right words.

The condition gradually worsens and the person may start becoming disorientated and getting lost, have difficulty in managing social situations and daily living skills, have impaired reasoning, and struggle with making decisions and managing their money and finances. When they reach the later stages of dementia, they lose skills learned at an early age involving bodily functions such as continence, feeding themselves, and so become completely dependent on others. There are several simple screening tests for dementia including the **Mini Cog** test (fig 1) which has 83% accuracy and takes about three minutes to perform (*Sinclair et al, 2013*). It is important to check hearing and sight is intact when assessing for dementia. However, a formal comprehensive assessment by a specialist memory assessment service is always required to diagnose dementia, with other investigations such as blood tests for thyroid function, brain scan and EEG.

Fig 1: The Mini Cog Test for Screening for Dementia



Why early diagnosis is important:

People with diabetes are encouraged to manage the condition themselves so diagnosing 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. Less than 44% of people with dementia in the UK have a formal diagnosis (Alzheimer's Society, 2013) but improving diagnosis rate is a target for the NHS. (NHS Commissioning Board, 2012).

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 diabetes damage. Complications are identified quickly 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.

TREATMENTS FOR DIABETES

A nutritionally sound diet:

There is no need for a special diabetic diet. Sugary foods such as sugar added to hot drinks, non-diet pop 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 carbohydrate foods (e.g. bread, potatoes, pasta) is essential for people using insulin or sulphonylurea tablets so cake, ice-cream, milky drinks, may be needed if other healthier carbohydrate foods are refused. Food supplements such as Fortisip, 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 control blood glucose levels. Advice from a dietitian is required for people who need nutritional support.

Medications:

There are a number of different tablets which can be used to treat high blood glucose levels. They have different modes of action and varying side effects. Tablets have a proper 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	Helps the liver to store excess glucose from the blood	Diarrhoea, upset stomach
Gliclazide Glipzide Glimepiride Tolbutamide (Sulphonylureas)	Diamicron Minodiab Amaryl	Makes the pancreas produce more insulin	Low blood glucose levels (hypoglycaemia)
Pioglitazone	Actos	Helps the body to use its insulin more efficiently	Fluid retention
Sitagliptin Vildagliptin Linagliptin Saxagliptin	Januvia Galvus Trajenta Onglyza	Helps a gut hormone to work more efficiently	Pancreatitis (very rarely)
Dapagliflozin	Forxiga	Makes the kidney excrete glucose from the body	Urinary tract and genital infections

(BNF 2013)

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 can 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 improving blood glucose levels. Nausea is the main side effect.

Table 4: Common injectable therapies for treating Diabetes

Proper name	Brand name
Exenatide	Byetta
Liraglutide	Victoza
Lixisenatide	Lyxumia
Extended action Exenatide	Bydureon

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, and is usually given with breakfast and evening meal. 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 should never be omitted in someone who has type 1 diabetes. Involve the diabetes specialist nurse early, to advise on a suitable insulin regime. The main side effect of insulin is low blood glucose levels (hypoglycaemia) and weight gain.

HYPOGLYCAEMIA

What is it?

Hypoglycaemia is the medical term for low blood glucose and is defined as a blood glucose level of less than 4 mmol/l. Hypoglycaemia ("hypos") may occur when people with diabetes are treated with tablets such as sulphonylureas (see table 3) or insulin.

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 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.

What does hypoglycaemia look like?

Examples of **early** signs and symptoms of hypoglycaemia include:

- Sweating
- Palpitations
- Shaking
- Hunger

The **late** signs of hypoglycaemia are:

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

People with dementia may not be able to recognise symptoms of hypoglycaemia, so carers need to be vigilant for the late signs described above.

How do you treat it?

If hypoglycaemia is not treated, the person may fall, lose consciousness, choke and can trigger a stroke or heart attack. Appendix 1 describes how to treat hypoglycaemia, depending how quickly it is identified. Carers need to have appropriate treatments 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). Tablets that cause hypoglycaemia (sulphonylureas) should be avoided. Ensure regular meals and snacks are available for people who use insulin.

GOOD CARE FOR PEOPLE WHO HAVE DIABETES AND DEMENTIA

People who have had diabetes for many years may have been very skilled at managing their own injections, 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 dementia who develop diabetes	Issues for people with diabetes who develop dementia
 Developing incontinence as they need to pass urine more often but not able to find the toilet Increased risk of falls due to more frequent visit to the toilet Increased confusion if blood glucose levels are high and causing dehydration Distress if usual diet changed significantly Distress, wandering, rocking movements, crying if they have pain and are unable to put this into words 	 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 blood glucose results such as adjusting insulin doses or treating hypoglycaemia Missing meals and drinks so at risk of low blood 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, 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	
	 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) 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 available If they are still able to inject insulin but are forgetful, the carer can keep it in a locked box until it is needed
Cognitive ability (Wha	t 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 blood glucose, injecting insulin). Review self-care ability regularly Ask the GP to simplify medication regimes and tablet load, preferably once daily. Ask the pharmacist about tools to support self-medication such as blister packs and timed 'dosset' boxes. However, these are not helpful in people who have no awareness of time or day
Biography (life story)	
	Some people may have had diabetes for a long time
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 blood glucose for example
Physical health	
	 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, resulting in apparent incontinence
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

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. Barriers to healthy eating in people with diabetes and dementia include the following:

Table 7: 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 blood 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	

CARING FOR PEOPLE WITH DIABETES AND DEMENTIA

Diabetes and dementia are both common conditions and the person who has both will have increasingly complex needs. 80% of people living in residential care in the UK have dementia or significant memory problems (Alzheimer's Society, 2013) and many will have diabetes too. Carers (both formal and informal) require particular skills to provide safe and appropriate care for these people. Appendix 2 describes the competencies required for carers and managers working in community and residential care homes.

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USEFUL RESOURCES

Alzheimer's Society

www.alzheimers.org.uk

Help-line: 0300 222 1122 (Monday to Friday 9am-5pm,

weekends 10am-4pm)

The Alzheimer's Society is the leading care and research charity for people with Alzheimer's disease and other forms of dementia, their families and carers. The Society has expertise in information and education, and produces fact sheets and other publications. They also have branches which run local services.

e-LfH is a Department of Health Programme which provides free-of-charge training materials for the NHS workforce across the UK. This is an interactive e-learning resource to support the training of all health and social care staff in recognising, assessing and managing dementia, and in providing high-quality dementia care. It consists of ten sessions covering a wide range of issues relevant to dementia. To access the resource in full you will need to register with an NHS or equivalent email

Dementia UK

www.dementiauk.org

Patient Help line 0845257 9406 (Tues/Thursday/ Saturday)

Dementia UK is a national charity, committed to improving quality of life for all people affected by dementia. A key part of their work is the promotion and development of Admiral Nursing. Admiral nurses help support the needs of family carers and people with dementia. The charity has also established 'Uniting Carers' a national network of carers, family members and friends of people with dementia.

Institute of Diabetes for Older People (IDOP)

Available at www.instituteofdiabetes.org

Wide range of resources and information on the special issues of managing diabetes in older people

Carers UK

www.carersuk.org

Help-line 0808 808 7777

Support for people caring for people with long-term conditions

Diabetes UK

E learning

e-LfH: e-Dementia

www.diabetes.org.uk

Careline: 0845 120 2960 (Monday to Friday 9am-5pm)

Diabetes UK provides information about all aspects of living with diabetes for healthcare professionals and people living with the condition

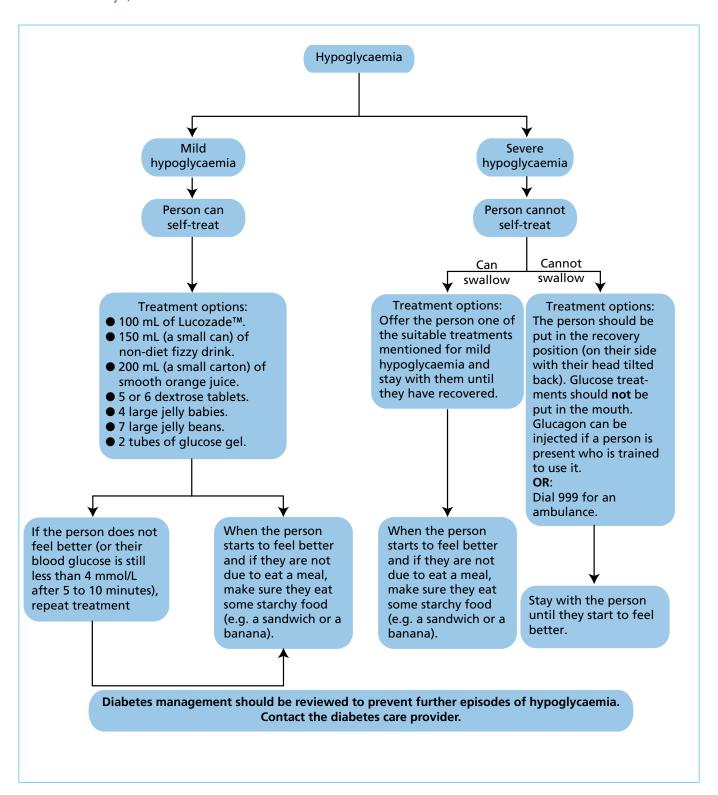
Hypoglycaemia

Available at www.trend-uk.org

Recognition, treatment and prevention of hypoglycaemia in the community

APPENDIX 1

(Hypoglycaemia management algorithm taken from "Recognition, treatment and prevention of hypoglycaemia in the community")



APPENDIX 2

Competency framework for people caring for people with diabetes and dementia in care homes

1: Promoting self-care for people with diabetes and dementia		
Unregistered practitioner	 support the person to develop self-care skills with guidance from a registered nurse where appropriate observe and report any concerns that might affect the ability of the person with diabetes to self-care due to dementia encourage people to use their personalised care plans where appropriate if there is mental capacity to do so support the person with diabetes & dementia to carry out activities of daily living where there is no mental capacity to do it for themselves 	
Competent nurse	 As 1, and: assess ability to self-care and work with the person with diabetes & dementia & significant others to optimise self-care skills direct people to information and support to encourage informed decision-making about living with diabetes and dementia to managing life events 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 refer to the GP or diabetes specialist team for support when necessary 	
Care /Service Manager	 identify service shortfalls and develop a strategic action plan for the diabetes & dementia service to address these work with stakeholders to develop a culture of client centered approach for patients with diabetes & dementia ensure that national guidance specifically related to diabetes and dementia is implemented and monitored in the care setting 	

2. Nutrition: To meet the patient's indi	vidual nutritional needs you should be able to:
Unregistered practitioner	 follow the nutritional plan and report any related problems recognise foods and drinks that are high in sugar be able to measure and record weight accurately
Competent nurse	 list the principles of a healthy balanced diet be able to calculate and interpret Body Mass Index (BMI) recognize which foods contain carbohydrate and how these affect blood glucose level ensure clients with diabetes and dementia are supported to have a healthy balanced diet identify people at risk of malnutrition and situations where healthy eating advice is inappropriate refer the person with diabetes & dementia to a diabetes dietitian when appropriate refer the client with diabetes and dementia to the GP or diabetes specialist team if glycaemic control is suboptimal work in partnership with the person with diabetes and dementia and their carers to identify realistic and achievable dietary changes know the dietary factors that affect blood pressure and lipid control
Care /Service Manager	 identify service shortfalls and develop strategic plan for the service to address these work with stakeholders to develop/implement local guidelines and interventions, promoting evidence-based practice and cost effectiveness

This competence links with the NHS Skills for Health HA5 & HA6.

3. Blood glucose monitoring: For the s	afe use of blood glucose monitoring and associated equipment
Unregistered practitioner	 perform the test according to manufacturer's instructions and local guidelines perform the test unsupervised as required document and report the result according to local guidelines recognise and follow local quality assurance procedures, including disposal of sharps. recognise hypoglycaemia and be able to give glucose understand the normal range of glycaemia and report readings outside this range to appropriate person
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	 identify service shortfalls and develop strategic plan for the service to address these work with stakeholders to develop/implement local guidelines for use, promoting evidence-based practice and cost effectiveness

This competence links with the NHS Skills for Health HA8 & HA9.

4. Intercurrent illness: To manage intercurrent illness, you should be able to:					
Unregistered practitioner	 identify common signs of intercurrent illness and report to a registered nurse document and report any abnormal findings from observations be aware of the impact of intercurrent illness on glycaemic control 				
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	 identify service shortfalls and develop strategic plan for the service to address these monitor trends on hospital admissions for illness-induced diabetes emergencies and work with relevant agencies to reduce these 				

5. Hypoglycaemia: For the identification and treatment of hypoglycaemia you should be able to:					
Unregistered Practitioner	 state the normal range of blood glucose level describe signs and symptoms of hypoglycaemia demonstrate competent use of blood glucose monitoring equipment to confirm hypoglycaemia offer appropriate treatment as per local guidelines give reassurance and comfort to the person with diabetes/significant others document and report to registered nurse if patient unresponsive, ensure clear airway and call emergency services 				
Competent Nurse	 As 1, and: list possible causes of hypoglycaemia including physical activity ensure appropriate hypoglycaemia treatments are available & in date identify patients at high risk of hypoglycaemia and recognise when treatment may need to be adjusted recognise and discuss possible reasons for hypoglycaemia with the person with diabetes including hypo unawareness and frequent hypoglycaemia participate in educating other professionals and carers in identification, treatment and prevention of hypoglycaemia 				
Care/ service manager	 ensure/develop standard operating procedures are in place to treat hypoglycaemia identify service shortfalls and develop strategic plan for the service to address these work with stakeholders to ensure systems & processes are in place to reduce attendance to A&E, ambulance callouts and admission to hospital for episodes of severe hypoglycaemia 				

6. Hyperglycaemia: For the identification and treatment of hyperglycaemia					
Unregistered Practitioner	 state the normal range of blood glucose levels describe signs and symptoms of hyperglycaemia perform blood /urine ketone test according to local guidelines correctly document results and report those out of accepted range 				
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	 ensure there are standardised operating procedures in place to manage hyperglycaemia/DKA/ HHS identify service shortfalls and develop strategic plan for the service to address these work with stakeholders to ensure systems & processes are in place to reduce attendance to A&E Ambulance callouts and admission to hospital for episodes of DKA, HHS and severe hyperglycaemia 				



TREND-UK - Trend-uk.org
Institute of Diabetes for Older People IDOP - instituteofdiabetes.org